JMIR Aging

Journal Impact Factor (JIF) (2023): 5.0
Volume 4 (2021), Issue 3 ISSN 2561-7605 Editor in Chief: Yun Jiang, PhD, MS, RN, FAMIA; Jinjiao Wang, PhD, RN, MPhil

Contents

Original Papers

Smart Home Sensing and Monitoring in Households With Dementia: User-Centered Design Approach (e27047)
Federico Tiersen, Philippa Batey, Matthew Harrison, Lenny Naar, Alina-Irina Serban, Sarah Daniels, Rafael Calvo. 2

Satisfaction, Usability, and Compliance With the Use of Smartwatches for Ecological Momentary Assessment of Knee Osteoarthritis Symptoms in Older Adults: Usability Study (e24553)
Charlotte Rouzaud Laborde, Erta Cenko, Mamoun Mardini, Subhash Nerella, Matin Kheirkhahan, Sanjay Ranka, Roger Fillingim, Duane Corbett, Eric Weber, Parisa Rashidi, Todd Manini. 22

Ecological Momentary Assessment of Depression in People With Advanced Dementia: Longitudinal Pilot Study (e29021)
Iulia Niculescu, Hannah Quirt, Twinkle Arora, Terry Borsook, Robin Green, Brett Ford, Andrea Iaboni. 52

A Sociodemographic Profile of Mask Use During the COVID-19 Outbreak Among Young and Elderly Individuals in Brazil: Online Survey Study (e28989)
Rodrigo Vancini, Luiz Camargo-Neto, Marilia Andrade, Claudio de Lira, Rafaela dos Santos, Pantelis Nikolaidis, Beat Knechtle, Luiz Piacezzi, Maria Teixeira-Lopes, Ruth Assayag-Batista, Meiry Pinto-Okuno, Cássia Vancini-Campanharo. 71

Review

Using Living Labs to Explore Needs and Solutions for Older Adults With Dementia: Scoping Review (e29031)
Henk Verloo, Adrien Lorette, Joëlle Rosselet Amoussou, Estelle Gillès de Pélichy, Alcina Matos Queirós, Armin von Gunten, Elodie Perruchoud.
3 5

Viewpoint

Decreasing COVID-19 Risk Factors for Older Adults by Using Digital Technology to Implement a Plant-Based-Diet: An Opinion (e25327)
Heidi Benavides, Christiane Meireles, Viola Benavente, Mary Mays, Jing Wang. 65

XSL•FO
RenderX

Original Paper

Smart Home Sensing and Monitoring in Households With Dementia: User-Centered Design Approach

Federico Tiersen[1], MEng; Philippa Batey[2], BA, MRes; Matthew J C Harrison[2], MEng, MA; Lenny Naar[2,3], BFA; Alina-Irina Serban[2], BEng, MSc; Sarah J C Daniels[2,4], BSc, MSc; Rafael A Calvo[1], PhD

[1]Dyson School of Design Engineering, Imperial College London, London, United Kingdom

[2]Care Research and Technology Centre, UK Dementia Research Institute, Imperial College London, London, United Kingdom

[3]Institute of Global Health Innovation, Imperial College London, London, United Kingdom

[4]Department of Brain Sciences, Imperial College London, London, United Kingdom

Corresponding Author:
Federico Tiersen, MEng
Dyson School of Design Engineering
Imperial College London
25 Exhibition Road
South Kensington
London, SW7 2DB
United Kingdom
Phone: 44 (0)20 7594 8888
Email: federico.tiersen16@imperial.ac.uk

Abstract

Background: As life expectancy grows, so do the challenges of caring for an aging population. Older adults, including people with dementia, want to live independently and feel in control of their lives for as long as possible. Assistive technologies powered by artificial intelligence and internet of things devices are being proposed to provide living environments that support the users' safety, psychological, and medical needs through remote monitoring and interventions.

Objective: This study investigates the functional, psychosocial, and environmental needs of people living with dementia, their caregivers, clinicians, and health and social care service providers toward the design and implementation of smart home systems.

Methods: We used an iterative user-centered design approach comprising 9 substudies. First, semistructured interviews (9 people with dementia, 9 caregivers, and 10 academic and clinical staff) and workshops (35 pairs of people with dementia and caregivers, and 12 health and social care clinicians) were conducted to define the needs of people with dementia, home caregivers, and professional stakeholders in both daily activities and technology-specific interactions. Then, the spectrum of needs identified was represented via patient–caregiver personas and discussed with stakeholders in a workshop (14 occupational therapists; 4 National Health Service pathway directors; and 6 researchers in occupational therapy, neuropsychiatry, and engineering) and 2 focus groups with managers of health care services (n=8), eliciting opportunities for innovative care technologies and public health strategies. Finally, these design opportunities were discussed in semistructured interviews with participants of a smart home trial involving environmental sensors, physiological measurement devices, smartwatches, and tablet-based chatbots and cognitive assessment puzzles (10 caregivers and 2 people with dementia). A thematic analysis revealed factors that motivate household members to use these technologies.

Results: Outcomes of these activities include a qualitative and quantitative analysis of patient, caregiver, and clinician needs and the identification of challenges and opportunities for the design and implementation of remote monitoring systems in public health pathways.

Conclusions: Participatory design methods supported the triangulation of stakeholder perspectives to aid the development of more patient-centered interventions and their translation to clinical practice and public health strategy. We discuss the implications and limitations of our findings, the value and the applicability of our methodology, and directions for future research.

(JMIR Aging 2021;4(3):e27047) doi:10.2196/27047

XSL•FO
RenderX

KEYWORDS

assistive technology; independent living; internet of things; remote monitoring; dementia; human centered design; user-centered design; patient-centered care; smart home; digital health

Introduction

Background

Dementia is a syndrome that accounts for the ongoing decline of brain functioning including problems such as memory loss, thinking speed, mental sharpness, language, understanding, judgment, mood, movement, and difficulty in carrying out daily activities [1]. Around 50 million people have dementia, with 10 million new cases reported each year [1]. The psychological and physical impacts on patients, caregivers, and families can be devastating and life-limiting. The economic cost is also significant, costing over £30,000 (US $41,628) annually per person with dementia in the UK [2]. Because of the wide-ranging consequences of the illness, interventions need to address health, safety, and psychological concerns.

Understanding the needs of people living with dementia is critical and finding ways to support patient and caregiver autonomy and well-being is an ethical imperative. During the early stages of the illness most people with dementia want to remain living in their own home as independently as possible. In the advanced stages of the disease, psychiatric and behavioral disturbances are common, and patients often require professional medical care. Patients may suffer significant personality changes, hallucinations, paranoid ideas, aggression, wandering, and incontinence, so care is often provided in special facilities. In this study we focus on care in the home environment.

It is generally agreed that participatory approaches to research and development are essential for the design of products and services that satisfy patients' health and psychological needs. Designers agree that user-centeredness helps create products that are more useful and engaging. Interventions should be designed based on a holistic understanding of the patient's values, goals, functional abilities as well contextual factors such as living situation, relationships, and daily habits [3]. Including all stakeholders, not only people living with dementia and caregivers, can enrich participatory design activities.

This user research is particularly important when developing artificial intelligence (AI) and the internet of things (IoT) systems. On the one hand, they offer unprecedented opportunities to build environments that are safe for patients and caregivers and support autonomy and well-being. At the UK Dementia Research Institute (UK DRI), Care Research and Technology Centre (CR&T), advances in these technologies enable our smart home system to interpret the broad range of data input from devices and sensors in the home to infer behavioral, physiological, and cognitive markers and create alerts for human intervention (clinical or casual) through a cloud-based program [4-6].

On the other, AI, sensing, and monitoring also pose major potential threats. If they are taken as an unmitigated good and not carefully designed, they can have a significant negative impact on a disadvantaged community. This can go beyond basic requirements such as safety and accessibility. They can, for example, reduce the privacy and individual autonomy of patients and their families; they can be demeaning, unfair, or biased. Ethical and social risks are a significant barrier to a more widespread adoption of intelligent assistive technologies (ATs) for dementia. While concerns about autonomy are the most prevalent in literature, issues surrounding beneficence, justice, interdependence, and privacy have been identified [7]. A systematic review of the ethics of ambient assistive living technologies for people with dementia identified the involvement of patients in product development, informed consent, social isolation, and cybersecurity as sources of ethical risks [8].

More specifically, there is evidence that smart home technologies can be included in a pattern of elderly abuse (see, eg, [9]). This risk becomes particularly relevant for people with dementia as they may inherently be in a position where smart homes are used *on* them rather than *by* them. Moreover, their cognitive impairments may make them unable to provide informed consent to alterations of their privacy and agency [10]. Older adults have identified privacy issues surrounding smart homes [11], and the psychosocial impact of feeling under surveillance has privacy-related implications [12] that cannot be overlooked.

These factors must be investigated through the perspectives of end users (people with dementia and elderly caregivers) who may have very different expectations of these technologies due to their cognitive impairments or their cultural beliefs to those of the designers, engineers, and health care providers developing and implementing these technologies (eg, [13]). Such a multitude of perspectives can only be captured through participatory activities with the people directly involved (people with dementia and caregivers) and with clinicians who are experts at understanding the medical, psychosocial, and contextual needs of the people they care for. Moreover, older adults who have never tried smart home systems may have very different understandings of these technologies than people who have used them. People who have lived in smart homes express fewer concerns regarding intrusion, privacy, trust, and usability and more concerns about their utility [14]. Participatory activities should therefore investigate both actual use and anticipated use by involving current smart home users as well as members of the wider community.

This study aims to explore the development and translation of such opportunities while preventing such risks through participatory and user-centered design methods. We iteratively define and evaluate opportunities and challenges with end users (people with dementia and caregivers) and a wide range of stakeholders.

This study explores opportunities for care research and innovation enabled by the remote monitoring of data captured by the sensors illustrated in Figure 1. These include tablet-based cognitive assessment puzzles and chat interfaces, smartwatches, passive environmental sensors (appliances, bed, hallways,

XSL•FO
RenderX

doors), and physiological measurement devices (blood pressure, blood oxygen saturation, temperature). These devices are used in households that are part of larger research program at the UK DRI CR&T. This paper describes design research studies conducted with the UK DRI CR&T cohort investigating their experiences of these technologies as well as studies with stakeholders from the wider public investigating needs in daily activities and health and social care.

Figure 1. The internet of things technologies implemented in this study.



The UK DRI CR&T at Imperial College London and the University of Surrey, London

The CR&T aims "To empower people with dementia and their caregivers by using friendly 'Healthy Homes' - intelligent environments that transform and personalize care" [15]. To achieve this the CR&T is developing novel devices (including biosensors, point-of-care diagnostics, AI interfaces, sleep monitoring) which are monitored by a team of researchers and clinicians. The design and development team is highly interdisciplinary including dementia researchers, scientists, clinicians, interaction designers, and electronic, software, and design engineers at Imperial College London.

In this study researchers collaborated with end users and stakeholders including (1) trial participants of the wider UK DRI study [16] that had smart home systems installed in participants' households collecting, analyzing, and intervening on behavioral and physiological data [4-6] (participants were originally recruited from local communities and associations to be representative of the dementia population and able to give informed consent); (2) patients, caregivers, and medics at the Imperial Memory Unit, Imperial College Healthcare National Health Service (NHS) Trust, Charing Cross Hospital; (3) the clinical monitoring team at the Surrey and Borders Partnership NHS Foundation Trust (SABP); (4) UK DRI CR&T members (clinicians and researchers); (5) clinical steering groups (clinicians and social workers); (6) people with dementia and caregivers who are members of the Alzheimer's Society; (7) managers of the West London Frailty Services; and (8) service managers, neuropsychiatrists, clinical psychologists, and AT managers at the Hammersmith & Fulham Cognitive Impairment and Dementia Services, West London NHS Trust.

First, this study explores the needs of people living with dementia, home caregivers, and professional stakeholders (clinicians, researchers, and health care service providers) in both daily activities and technology-specific interactions. Based on those needs, we identify opportunities for care innovation in the broad design space enabled by emerging remote monitoring technologies. The final substudy then explores how to effectively translate some of these opportunities to clinical practice through user-centered design. We review existing literature in participatory design research for dementia care and provisions for research in this section. The design research methods used in this study are described in the "Methods" section. The "Results" section outlines the study findings, and the "Discussion" section discusses implications and concludes.

Literature Review

Challenges in Designing Support Systems for Individuals With Dementia

Designing to support people with dementia is very challenging. First, there are declining cognitive and physical abilities that need to be addressed to reduce risks of illness and accidents. For example, preventable causes such as disease of the urinary system, pneumonia, and lower respiratory infections account for 20% of admissions to hospitals for patients with dementia, and another 16% is accounted by injury and poisoning [17]. But designers also need to consider other stakeholders such as the patients' caregivers. This includes paid staff (eg, occupational therapists [OTs] and clinical teams) who are in short supply, and family members who are generally untrained, often find it difficult to deal with the strain of caring, and are at high risk of mental illness [18].

Designing for People With Dementia

Concerns about designing for people with dementia have been addressed in different ways. Some attempt to address the behavioral needs of people with dementia as defined by the literature as comprehensively as possible. For example, early studies on designing environments for people with dementia recommended that dementia-specific residential facilities should compensate for disability, maximize autonomy, and support personal identity, enhancing self-esteem [19]. A more recent study [20] takes a top–down system design approach and identifies stakeholders and use scenarios (eg, risk of dehydration, isolation, night-time wandering) from dementia care literature before defining opportunities for smart home touchpoints (eg, *inviting awareness* to drink, *performing* communication with acquaintances, *urging caregivers* to react to wandering episodes). The authors then involve caregivers and clinicians to qualitatively evaluate their use cases and to refine the system's requirements.

Alternatively, involving people with dementia and caregivers in the design process can reveal more nuanced experiential factors. Orpwood and colleagues [21] discussed potential smart home features with caregivers and concluded that such systems should have familiar appearances and affordances, could incorporate verbal prompts and reminders, and should emulate

XSL•FO
RenderX

caregivers when intervening to respect the person with dementia's autonomy. For example, automated interventions should encourage the person with dementia to resolve the issue they forgot about (eg, "remember, you left the tap open") before doing things for them to support autonomy rather than conveying helplessness [22]. However, notifying people with dementia, caregivers, or clinicians about every opening or closing of doors, taps, and appliances (eg, [23]) can be overwhelming. Machine learning can increase the precision of activity detection and help prioritize urgent medical and functional alerts [4].

Besides environmental sensors, passive sensing through ubiquitous devices such as smartphones and wearables can provide objective, rich, and granular data on clinically robust measures [24]. For example, a variety of daily activities (eg, boarding transport vehicles, washing dishes, or talking) of a person with dementia can be inferred from data sensed by his/her smartphones' microphone and accelerometer [25]. Ubiquitous devices can achieve a context-bounded understanding of human activity, capture users' attention when an intervention is needed, and otherwise "calmly" remain in the periphery of their attention [26]. It follows that, to maximize their benefits, such care systems should be designed focusing on the contextual experiences of patients rather than on the condition. The person with dementia should be considered "an active participant in everyday life rather than a passive recipient of care" [27].

Participatory Design Approaches

More recently, the call for attending to experience and researching and designing *with* rather than *for* users and stakeholders of health and social care services [28,29] received further attention in the human–computer interaction community. For example, Morrissey et al [30] explored the potential of collaborative, explorative, experience-centered design to more finely understand long-stay residential care experiences and design products that are more useful in that context. This new approach has prompted workshops with researchers, industry stakeholders, and communities of people with dementia [31] to further develop co-design processes for dementia-friendly ATs. They highlight the need for higher patient and clinician involvement in design research as both participants and leaders. Patients and stakeholders should also be involved in translating findings to industry to commercialize less "one-size-fits-all," more personalized technologies, and to consider the impact and consequences of AT on how people with dementia engage with their communities [31].

Dementia-specific participatory design approaches are increasingly common. Topics covered include the design of long-term care environments (reviewed by Fleming and Purandare [32]) as well as interventions with context-specific purposes. For example, Houben and colleagues [33] explored therapeutic sounds with people with dementia and Jayatilaka and colleagues [34] investigated the challenges around people with dementia's eating behaviors with care workers. Conducting co-design activities with a more comprehensive set of stakeholder groups can help design more user-centered care *services* in addition to single touchpoints or products. For example, Goeman and colleagues [35] involved people with dementia, care partners, aged-care service experts, policymakers, and academics to define the role for a new "key worker" in community settings. Moreover, investigations can be conducted in multiple stages to use optimal methods for each phase of iterative design processes. For example, while co-designing a novel IoT assistive product, focus groups may be used for scoping, workshops for product ideation, and interviews for prototype development and evaluation [36]. This approach led Robinson and colleagues [36] to identify tracking devices as stigmatizing, intrusive, and coercive before designing a smart armband that guides people with dementia home during wandering episodes without sharing their location with anyone else.

Personas can be co-developed with people with dementia to enable them to synthesize their needs and empathize with other potential users without directly confronting their personal relationship with their condition [37]. While developing a self-management smart home system for people with dementia and Parkinson disease, Bourazeri and Stumpf [37] used persona-based workshops to (1) explore the background, technology use, activities, and goals of users; (2) explore the use of sensors and gain input to the computational model; (3) design the user interface using low-fidelity prototyping; and (4) evaluate the interface design via cognitive walkthroughs. For example, a floorplan of a hypothetical home was used to allow workshop participants to envision possible uses of smart home sensors without being constrained by their personal living situations [37]. Furthermore, the input of other stakeholders from health and social care can complement patient co-design activities to ensure personas are representative of the spectrum of demographics, disease symptoms, needs, behaviors, and attitudes of their service users.

Achieving confidence and compliance with technological platforms that may be unfamiliar to an elderly population (eg, smartphones, tablets, IoT devices) requires designers to ensure accessibility, perceived privacy, and trust in both adoption and use [38]. For example, older adults may be especially wary about sharing personal information or obeying automated instructions, or they may perceive such devices as stigmatizing. Collaborative investigation therefore needs to reveal personal and social emotional aspects (eg, perceived confidence, dignity, independence) in addition to physical and cognitive impairments. Focusing on smart homes for elderly adults without dementia, Curumsing et al [39] advocated the need to include human, social, and organizational factors into smart home engineering. They systematically related the emotions experienced during use of a system (eg, anger, disgust, joy) to users' underlying emotional *expectations* when adopting the system (eg, the elderly feeling cared for and independent, and caregivers feeling reassured). Capturing, representing, and evaluating both functional and emotional goals of elderly adults, caregivers, and relatives across all touchpoints and use cases resulted in a smart home system that alleviates health concerns and loneliness and is perceived by end users as empowering, caring, safe, and neither controlling, stigmatizing, nor intrusive.

Collaborating with older adults can be particularly beneficial for designers, as they "often challenge simplistic technological solutions to complex problems and help us question and critique the values and ethics embedded in the technologies we set out

XSL•FO
RenderX

to design" [40]. For example, Ghorayeb and colleagues [14] qualitatively evaluated smart home systems both with older adults living independently in their communities and with participants who had been living in smart homes for 8-12 months. Anticipating the use of a technology that may be of future rather than current value to them led the first group to express concerns about the technology being intrusive, noticeable, and increasing the household's vulnerability. Reflecting on actual use led the second group to be more critical about smart homes' utility but less weary about privacy, trust, and usability. Both groups suggested making functionality customizable and shared concerns about smart homes' affordability, their impact on relationships, and about the engagement and competencies of those monitoring their data. To capture this variety in perspectives, this study's sampling strategy should include both members of the public and people who have *decided* to have a smart home installed and have experience living in it.

Designing for Patient-Centered Care

Designing *with* rather than *for* patients with dementia maximizes the benefits of specific technologies [28] as well as of programs of clinical care [41]. A shift in philosophy from traditional medical models of care that focus on processes, schedules, and staff and organizational needs to *person-centered care* was pioneered by Kitwood [42]. He conceptualized dementia as the interplay between neurological impairment and psychosocial factors including the individual's health, psychology, environment, and social context.

Operationalizing person-centered care requires establishing interpersonal relationships with people with dementia and caregivers to identify and address the needs of individuals, as well as commitment from everyone within care organizations, especially leadership [41]. Similarly, creating technologies that support person-centered health care requires designers to personally empathize with patients to understand the experience of living with specific conditions and the concerns and emotions of vulnerable participants [43].

However, when designing for a variety of stakeholders and analyzing data in which one group speaks for another group, care must be taken to verify whether the second group actually disagrees. This phenomenon has been discussed by Cajander and Grünloh [44] and can be mitigated by a careful triangulation of data sources [45]. We achieved this through *value-sensitive design*, a theoretical and experimental framework comprising techniques to investigate stakeholders' values and relationships around a common phenomenon to uncover innovation opportunities and manage value tensions through design [46]. In this study, the phenomena being investigated include interactions with remote monitoring technologies as well as, more broadly, life and care with dementia.

Designing *with* rather than *for* users becomes particularly important when creating products and services for people with dementia [28] because they inherently have very different experiences and abilities from those of the designers, engineers, clinicians, and researchers who develop such clinical tools [47]. Capturing these differences in mental models, however, comes with significant ethical and logistical challenges. The work by Waycott and Vines [40] on research ethics with older adults addresses issues around beneficence, justice, respect, and research merit and integrity [48].

The integrity of the research could be compromised, for example, if an episode of cognitive decline leads a participant with dementia to misinterpret the researcher as a loved one and thus affects their ability to provide informed consent and alters power balances. Ethnographic activities and interviews involving people with dementia in this study therefore always involved the accompaniment of their principal caregiver.

In addition to providing insight into their personal needs as stakeholders of smart home systems, working with caregivers and clinicians with expertise in the needs of people with dementia as "surrogates" for patients can enable researchers to bypass some of these logistical and ethical challenges and to achieve an understanding of people with dementia's needs more efficiently. The involvement of stakeholders in this study should nevertheless *complement*, not *replace*, that of people with dementia. Bartels and colleagues [49] found that people with mild dementia retain the ability and insight to accurately reflect on their own ability to use everyday technologies. Complementing self-reports on the use of technologies in an individual's everyday life with the observation of specific interactions with technology and the consideration of underlying psychological determinants thus leads to a more thorough understanding of patients as individual technology users. The perspectives of other stakeholders can therefore add value in interpreting self-reported and observed needs to build a more thorough understanding of the complex, dynamic, and comorbid needs of people with dementia. This becomes especially valuable when the disease's progression may impair the cognitive abilities required to perceive, recognize, and express such needs.

Envisioning intangible concepts, maintaining structure in meetings, and preventing stigmatization are common challenges in designing with older adults [50] or vulnerable people [51]. Prolonged discussions about abstract concepts are particularly challenging to people with dementia due to their cognitive impairments [52] and possibly distressing due to the confrontation with their disabilities [53]. Self-expression should be encouraged by focusing on the abilities of the person with dementia (eg, interacting with tangible objects, creating, sharing) rather than on their deficits [54]. Cocreation activities that are aligned to all participants' abilities and that allow them to express their individuality can be beneficial to people with dementia as well as designers. Successful activities can help recently diagnosed patients to build their self-esteem, identity, and dignity and can help keep them connected to their community [55].

Methods

Overview

Functional and psychological human needs, and social and organizational factors, should be addressed through human-centered design approaches that create empathy with users (people with dementia and their principal caregivers) and stakeholders (clinicians, researchers, and health care service

XSL•FO
RenderX

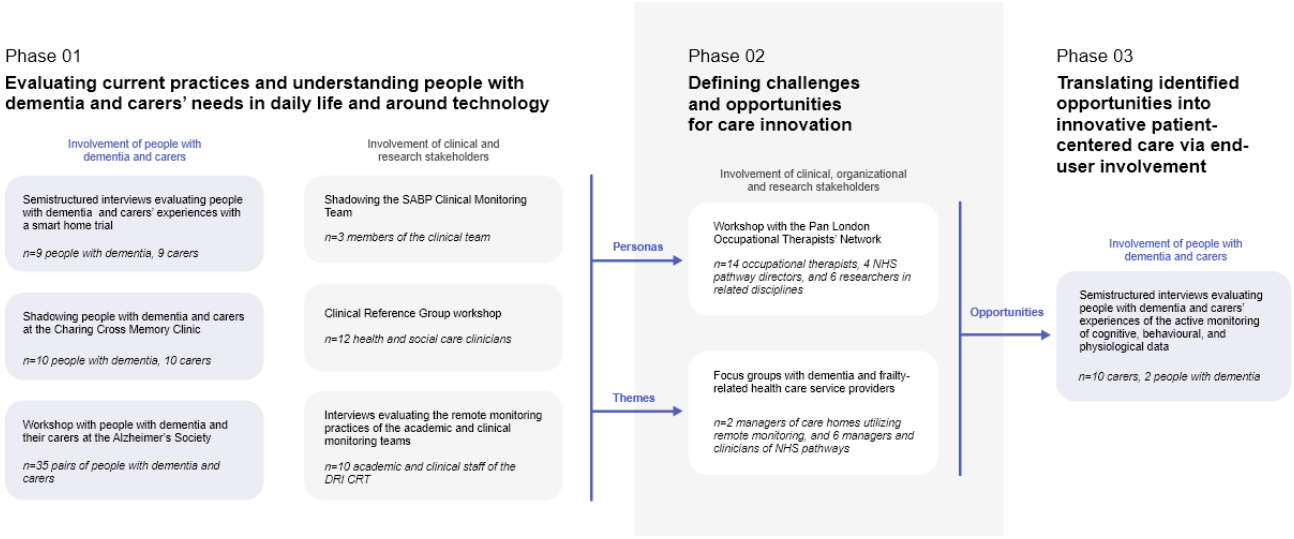
managers). Our approach to user research, and building such empathy, is through home visits, shadowing and observation, workshops, and in-depth interviews with a diverse range of representative users and stakeholders. Participants included people with dementia, home caregivers, clinicians (OTs, clinical psychologists, nurses), social workers, managers of cognitive impairment and frailty-related public health care services, and researchers in health and technology.

Such research activities informed the creation of personas that represent the spectrum of needs and aspirations of the intended users. A thematic analysis revealed factors affecting acceptance of and engagement with AT as well as challenges and opportunities related to their implementation.

We used a mixed methods approach including semistructured interviews, focus groups, workshops, and ethnographic observation (shadowing). The latter informed the process but is not reported due to incomplete documentation. Each of the methods was applied to end users (caregivers and people with dementia) and stakeholders (clinical, research, and health care service management teams). Interviews, visits, and workshops were carried out by researchers at the Helix Centre, the UK DRI CR&T, and the Dyson School of Design Engineering and approved by the Human Research Ethics Committee of Imperial College London.

Having different researchers (1 to 3 of the authors ran each substudy) conducting a variety of methods to gain input from various users and stakeholders resulted in the triangulation of investigators, methods, and data sources [45] to develop a more comprehensive understanding of the phenomena being studied. The diversity of methods and stakeholders involved in this study allowed researchers to alternate divergent and convergent investigations. The tripartite approach illustrated in Figure 2 enabled researchers to iteratively develop a thorough understanding of the design space surrounding dementia life and care and, more specifically, interventions enabled by remote-monitoring technologies.

Figure 2. Purpose and activities of each of the three phases of this study. CR&T: Care Research and Technology Centre; DRI: Dementia Research Institute; NHS: National Health Service; SABP: Surrey and Borders Partnership.



Generally, the first phase of this study focused on evaluating people with dementia and caregivers' experiences of daily activities, clinical visits, and a smart home system. Additionally, this phase investigated clinicians' experiences of supporting such daily activities through such clinical and social care appointments and pathways as well as smart homes. The generalization of these findings informed the definition of a rich set of personas that not only include the person with dementia but also his/her principal caregiver.

In a more generative second phase, these personas were used as case studies to elicit a more comprehensive set of needs, frustrations, and opportunities from the perspective of OTs, health care managers, and researchers. Focus groups with dementia and frailty-related health care service providers explored related topics from the perspective of a wider range of stakeholders. This phase resulted in the definition of a set of challenges and opportunities for innovation.

Finally, more focused interviews with users (people with dementia and home caregivers) around their experiences of a more intensive remote monitoring system enabled a deeper validation and exploration of some of the challenges and opportunities defined in the second phase from the perspectives of people with dementia and caregivers. Namely, this smart home system involved (1) implementing remote cognitive assessments; (2) educating patients and caregivers to use proposed technologies; (3) identifying and addressing causes of psychological disturbances related to interventions; (4) collecting objective behavioral and physiological data; and (5) providing reliable clinical oversight to manage false alarms and prevent anxiety. This third user-centered design phase enables opportunities that were defined by clinicians in *Phase 02* based on *Phase 01*'s findings to be developed into accessible, usable, useful, and desirable products that can be successfully translated in clinical practice.

Semistructured Interviews

Three sets of semistructured interviews were performed.

XSL•FO
RenderX

Evaluating People With Dementia and Caregivers' Experiences With a Smart Home Trial

First, we visited 9 homes of participants who had experienced the smart home technologies as part of the UK DRI trial. The interviews occurred during visits (1-2 hours long) and included semistructured conversations around themes within the larger project with 9 people with dementia and 9 caregivers. Discussions include guided observations of people with dementia and their caregivers within their home environment to help the design process by getting feedback on future design solutions.

Participants were then invited to the Helix Centre to evaluate proposed features that were being considered for the center's smart home system. The Helix team used rapid cycles of "provocative prototyping" with multiple low-fidelity concepts of smart home interactions. This elicited end user needs specific to particular technologies and allowed to steer the focus of technological development at regular intervals to promote creative problem solving. Figure 3 illustrates this activity.

Figure 3. Exploring the needs surrounding proposed smart home touchpoints with a home caregiver.



Evaluating the Current Remote Monitoring Practices of the Academic and Clinical Monitoring Teams

In the second set of semistructured interviews, 2 design researchers interviewed 10 academic and clinical staff from the UK DRI CR&T. Interviews were intended to provide a different perspective to that of users. Their academic training, their expertise with methods aimed at improving people's health, and their experience caring for others could frequently allow them to find patterns of problems and solutions. People with dementia and caregivers had highlighted that an important factor of patient engagement is the connection they make with this team.

Evaluating Persons Living With Dementia and Caregivers' Experiences of the Active Monitoring of Cognitive, Behavioral, and Physiological Data

The third set of semistructured interviews (10 caregivers, 2 people with dementia; 20-50 minutes per interview) was conducted in 10 households with patients and caregivers who trialed a remote monitoring device and cognitive test battery comprising a smartwatch, a tablet, a pulse oximeter, and a thermometer for 2 weeks. Restrictions imposed by the COVID-19 situation led researchers to conduct these interviews via phone calls. Contrary to home visits observing and discussing in situ interactions with technologies, this medium relies on memory, self-reporting, and abstraction, and thus excluded 8 moderate and advanced patients with dementia from being active participants in these interviews. This substudy explored some of the opportunities elicited in Phase 02. A thematic analysis revealed factors that can motivate or disengage users when adding more active or intrusive products into a passive smart home configuration.

Focus Groups With Health Care Service Providers

Two group discussions were held through online videoconferencing software with stakeholders of 2 health care services. First, 2 managers of the West London Frailty Services discussed their experiences with remote physiological and activity monitoring in care homes. Discussions covered relevant topics including patient compliance with wearables, assigning responsibility for out-of-hours clinical monitoring, and information sharing between support services. Second, 6 stakeholders from the Hammersmith & Fulham Cognitive

XSL•FO
RenderX

Impairment and Dementia Services, West London NHS Trust discussed opportunities and challenges in designing remote cognitive assessment products and ways to collaborate to design more inclusive services.

Workshops

Three workshops were carried out with different groups to understand the needs of stakeholders within the smart home trial and the wider dementia context.

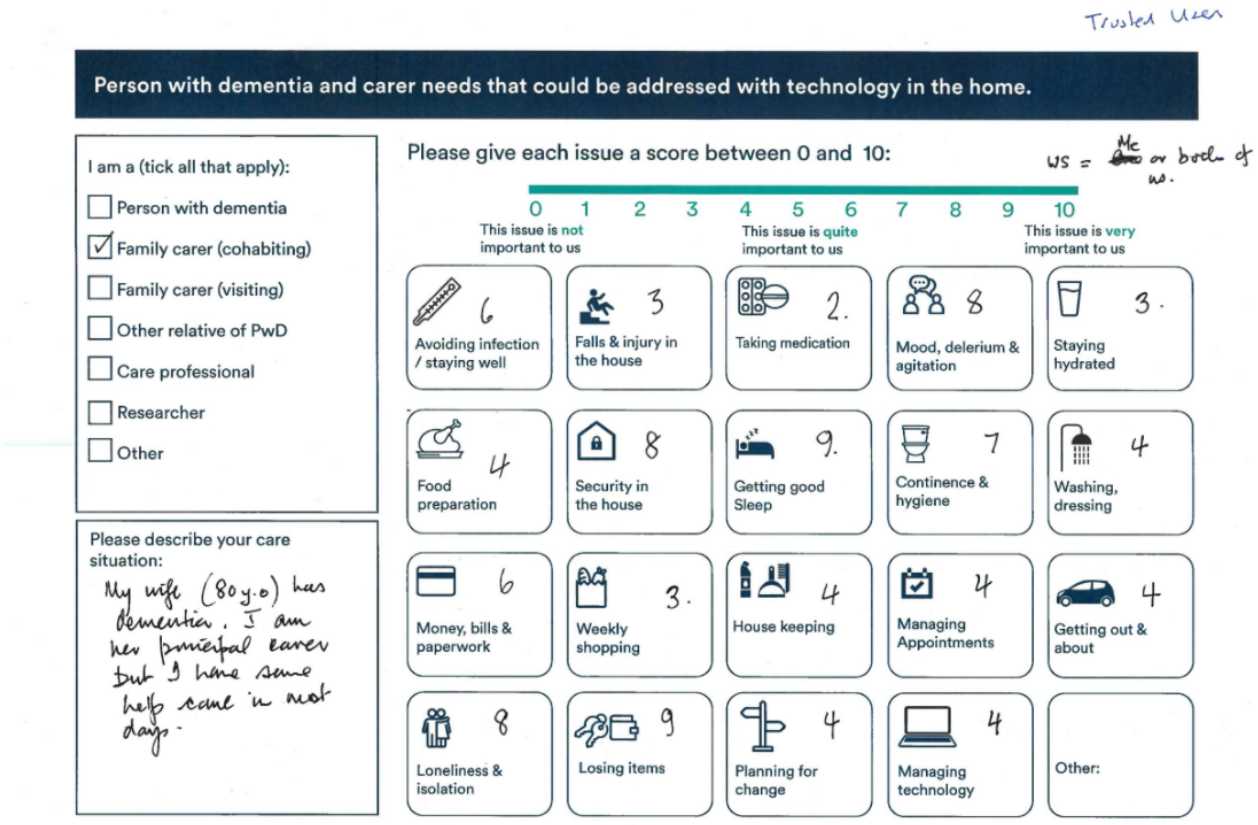
Clinical Reference Group Workshop

A group was set up to ensure the researchers gain insight from a range of clinicians within health and social care (n=12). Throughout the workshop, the group collaboratively generated a map of 19 needs that are common to people with dementia from different perspectives, then went on to plot 3 contrasting dementia journeys (from diagnosis to end of life care) to show how a person with dementia and his/her principal caregiver would navigate through the UK's health and social care system.

Workshop With People With Dementia and Their Caregivers at the Alzheimer's Society

A sample of people with dementia and caregivers that does not comprise early adopters of the CR&T's remote monitoring systems and is therefore more representative of the general population was selected to investigate the prevalence of needs in activities of daily living (ADLs) in dementia households. As part of a workshop at the Alzheimer's Society in London, pairs of people with dementia and caregivers were asked to complete a worksheet scoring their needs (Figure 4) on parameters defined in the previous workshop with the *Clinical Reference Group*, and 35 responses were received. The worksheets identified and prioritized the perceived needs of individuals in various aspects of daily life affected by dementia to help ensure that the interventions of the smart home system would address the most pressing concerns of people with dementia and caregivers.

Figure 4. Needs map ranking worksheet.



Workshop With the Pan London Occupational Therapists' Network

OTs' clinical roles and the similarities between user-centered design and occupational screening [3] make OTs suitable for participatory design activities aimed at (1) understanding the needs of clinical monitoring teams as service providers and users of remote monitoring technologies; (2) defining the spectrum of care needs of their patients and their caregivers; and (3) making the scenarios (personas) ideated by design researchers more clinically relevant and comprehensive.

A workshop with 24 participants (14 OT; 4 NHS pathway directors; 6 researchers in occupational therapy, neuropsychiatry, and engineering) was hosted online through Zoom, Miro, and Qualtrics at a conference held by the UK DRI CR&T for the *Pan London Occupational Therapists' Network*. Because of the nature of their roles, multiple members of the same multidisciplinary teams cannot take half days off to participate

XSL•FO
RenderX

in an in-depth workshop synchronously. Alternating between group calls and 8 breakout rooms in Zoom allowed for parallel discussions and contributions to maximize efficiency and limit the workshop to under an hour. Qualtrics was used to record asynchronous inputs around discussed topics both before and after the session. Subjects covered include challenges and frustrations when delivering their services, use cases of specific ATs, service changes imposed by COVID, factors affecting the deployment of assistive products, and wished-for technology developments.

The patient–caregiver personas described in this paper were used as case studies to systematically elicit specific desires and concerns while assessing, treating, evaluating, and discharging patients. Wearables, remote physiological and behavioral monitoring, and virtual communication technologies were explored as solutions. For each case study, participants were separated into groups of 3 in their breakout rooms to contribute their desires (eg, answers to "if technology could let you see or do anything about this person, what would you like to see or do? Why?") and concerns (eg, answers to "do you foresee any problems or barriers to implementation? Why?") to the aforementioned categories in the Miro board. Breakout rooms increased the number of contributions by enabling 8 parallel conversations where all attendees are prompted to actively participate. All participants regrouped at the end of each case study to share inputs and triangulate results. The "Patient–Caregiver Personas" section illustrates these case studies, while the "Current Challenges in Delivering Professional Care Identified by Clinicians, Researchers, and Health Care Managers" and "Technology and Service Development Opportunities Identified by Clinicians, Researchers, and Health Care Managers" sections illustrate this workshop's outputs.

Results

Overview of Outcomes from Different Activities

The interviews, focus groups, and workshops produced useful insights about the users and their needs that we summarize here. The outputs of Phase 01 activities that preceded the definition of patient–caregiver personas were analyzed by transcribing key themes arising from interviews, observations, and workshops. Themes were organized into affinity diagrams in collaborative design workshops at the Helix Centre to identify patterns of end-user or stakeholder needs across all use cases. Together with *needs mapping*, these activities elicited a comprehensive understanding of personal experiences that helped define personas for use in further studies to design products and services that better address these needs. Moreover, the interactions that were observed between users and the monitoring team pointed to many of the design and usability issues within the current configuration of the UK DRI CR&T's smart home system.

The second and third phases of this study build on findings of the first phase through their communication as personas and themes. Phases 02 and 03 were aimed at further exploring and defining challenges and opportunities in delivering technology-enabled care through the OT workshop, the 2 focus groups, and the last set of semi-structured interviews.

The audio from interviews and focus groups was recorded and fully transcribed using Descript (Descript, Inc.) and workshop outputs were exported from Miro and Qualtrics. A thematic analysis of all transcripts and workshop contributions was conducted by researchers using the coding and referencing software NVivo (QSR International). An *inductive* analysis as described by Elo and Kyngäs [56] was conducted to derive concepts from the data. The analysis investigated everyday living and interactions with technology from a phenomenological perspective, focusing on participant's subjective experiences of trialed or proposed technologies. The coding process involved 3 stages but was iterative in nature. First, researchers read the entire body of texts and defined a codebook of all the themes that emerged while coding the evidence with the newly defined themes in NVivo. Instances in which the theme being discussed could encapsulate other themes that had emerged prompted researchers to define layers of subthemes and reflect this architecture in NVivo. For example, the need to "establish duty of care" in public health services' strategy contained "clinician stress," "determining the appropriateness of episodic or continuous monitoring," "understaffing," and "handling urgent out-of-hours data" among its subthemes. Layers of meta-themes were also established to organize and communicate findings. The subthemes above were assigned to "lack of resources, infrastructures or information" under "current challenges in delivering professional care." Findings from this thematic analysis were communicated both in prose for qualitative insights or in a table containing the number of instances in which a theme was mentioned toward a more quantitative understanding of the prevalence of different needs.

Patient Needs as Mapped by Clinicians and Researchers and Prioritized by People With Dementia and Caregivers

Table 1 presents the breakdown of user responses from a mapping exercise held at an event for people with dementia and caregivers hosted by the Alzheimer's Society. The categories of patient needs had been defined by the Clinical Reference Group workshop and their relative importance scored by people with dementia and their caregivers in the subsequent Alzheimer's Society workshop. The sample included 35 people with dementia at various stages of disease progression and 35 principal caregivers. Each pair of people with dementia and their caregivers provided 1 set of responses via the needs mapping worksheet illustrated in Figure 4.

This analysis of patient needs suggests that preventing illness and injury is the most salient concern. Sleep, hydration, continence, hygiene, and psychological states are relevant targets for interventions. Medication compliance is also worthy of consideration.

This activity enabled researchers to start identifying and prioritizing areas of opportunity for intervention and to communicate a comprehensive spectrum of patient needs in the personas that were being defined. The clustering of needs (eg,

XSL•FO
RenderX

correlations between infection and hydration, or between security and losing items) informed the definition of personas described below. Future needs mapping activities can analyze the impact of the patient' stage of disease progression on prioritized needs.

Table 1. Needs of people with dementia as scored by 35 pairs of people with dementia and caregivers.

Needs map item	Cumulative score	Average[a] (SD)	Completion
Avoiding infection, staying well	280	8.0 (3.0)	35
Falls and injury at home	269	7.9 (3.1)	34
Getting good sleep	269	7.9 (2.7)	34
Staying hydrated	269	7.7 (3.1)	35
Continence and hygiene	268	7.7 (3.1)	35
Mood, delirium, agitation	254	7.7 (3.2)	33
Taking medication	244	7.4 (3.6)	33
Washing and dressing	231	7.0 (3.0)	33
Loneliness and isolation	223	6.6 (3.6)	34
Losing items	218	6.2 (2.9)	35
Security in the house	207	6.3 (3.9)	33
Food preparation	185	5.8 (3.6)	32
Managing appointments	185	5.6 (3.6)	33
Getting out and about	177	5.7 (3.9)	31
Planning for change	175	5.6 (3.3)	31
Money, bills, paperwork	155	5.0 (4.1)	31
House keeping	136	4.0 (2.9)	34
Managing technology	117	3.9 (3.0)	30
Weekly shopping	114	3.8 (3.2)	30

[a]Blanks ignored.

Patient–Caregiver Personas

Brief Overview of Personas

Personas (fictionalized representations of observed people) are a tool commonly used within human–computer interaction. Concepts and ideas can be tested against the expected requirements of each persona as an aid to ensuring the ideas are accessible to as many people as possible. The use of personas does not replace subsequent user testing, but they can be used in the early stages of product development as part of the creative process, and to communicate the breadth of user requirements to other collaborators within the technology development teams or in participatory design activities with service providers such as this study's OT workshop.

The personas defined below comprise the spectrum of daily activity needs outlined in the previous section as well as psychosocial and contextual factors identified in *Phase 01* of this study. Researchers analyzed patterns and clusters in qualitative findings and generated affinity diagrams to define the personas. Furthermore, our engagement with a range of different stakeholders supported not only the prima facie content of a persona but also what elements are included within the persona. In the context of this project, we found that describing personas as a combined unit of patient and caregiver was more valuable in representing a meaningful situation. We also described a situation where there is no family caregiver as one of the personas. The description of each persona includes (1) engagement—how much the patients and caregivers interact with the technology, data, and the clinical monitoring team and why; (2) support needs—clinical and social care needs; (3) socioeconomic factors; (4) living situation; (5) support network; (6) habitual use of technology; (7) hobbies and daily activities; (8) main issues and challenges—the main health needs and the barriers to interacting with care providers and the smart home.

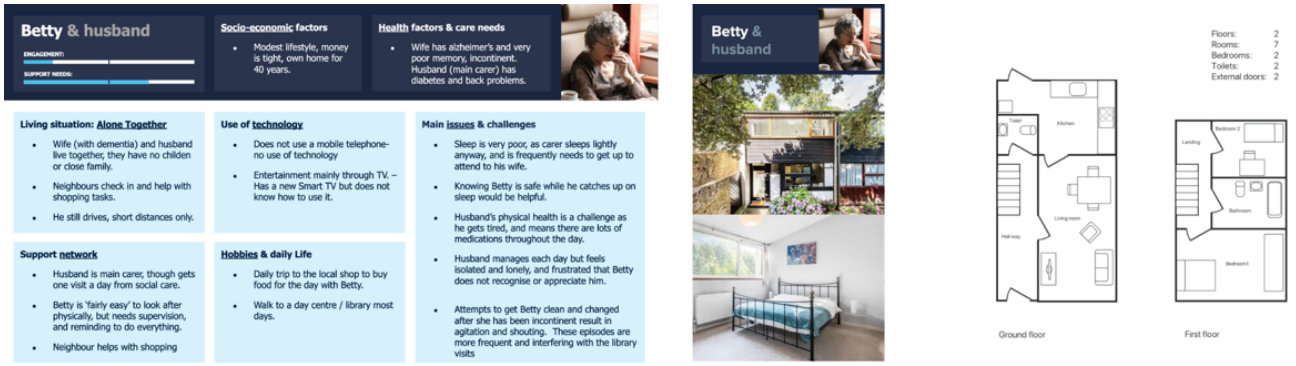
The authors identified 6 personas that combined traits of the people interviewed and their context but deliberately omitted the wide range of clinical and social care services that are delivered to patients. Focusing only on environments, patients and caregivers at this stage allowed researchers to use personas as open frameworks to guide workshops with the complex network of clinical and social care stakeholders. Pain points and desires were defined systematically and comprehensively to make technologies and interventions inclusive to all patients and use cases. Interviewees described requirements in ways that can be interpreted as needs for autonomy, competence, and relatedness. This is an area for further exploration. The 6 personas with fictitious names and homes identified are described and displayed below.

XSL•FO
RenderX

Alone Together (Betty and Husband)

Betty and her husband (Figure 5) live in a quiet house and have a large amount of time available to participate in the smart home trial. They both suffer from declining physical health which results in high care needs. Betty's husband feels socially isolated which puts a strain on their relationship.

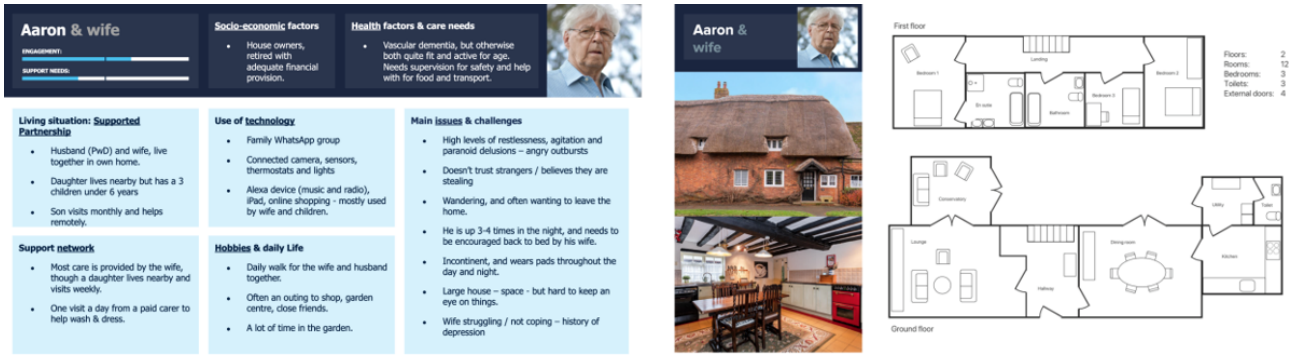
Figure 5. Persona A: Alone together.



Supported Partnership (Aaron and Wife)

Aaron (Figure 6) has high levels of support from his wife, neighbors, and community, lives in an affluent area, and has plenty of time available to engage with technology. Their big house raises challenges with device implementation. His technical skills mean he may be slower in learning to use devices and take measurements.

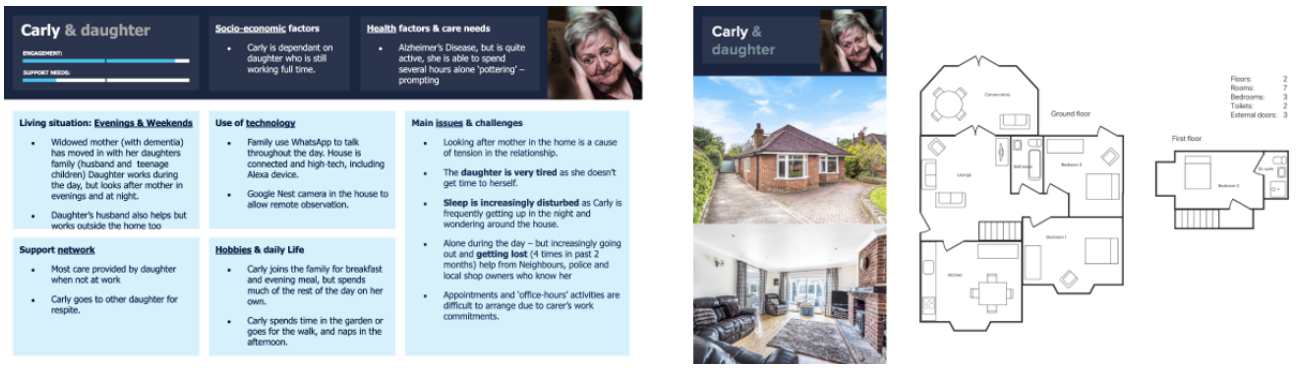
Figure 6. Persona B: Supported partnership.



Evenings and Weekend (Carly and Daughter)

Carly (Figure 7) has recently moved in with her daughter who looks after her in evenings and at night. Carly's daughter and family are very tech savvy and can easily engage in the technology. Because of the nature of their living situation, Carly has restricted hours of support which causes her family to worry. Her families sleep is increasingly disturbed as Carly is frequently getting up in the night and wondering around the house.

Figure 7. Persona C: Evenings & weekend.



Remote Relative (David and Son)

David (Figure 8) is a single father who lives alone. His son lives 40 minutes away and visits every 2-3 days. Being a single occupant in the house makes it easier for the technology to monitor behavior. David suffers from agitation and is reluctant to receive help from technology or other people. His son is only partially engaged.

XSL•FO
RenderX

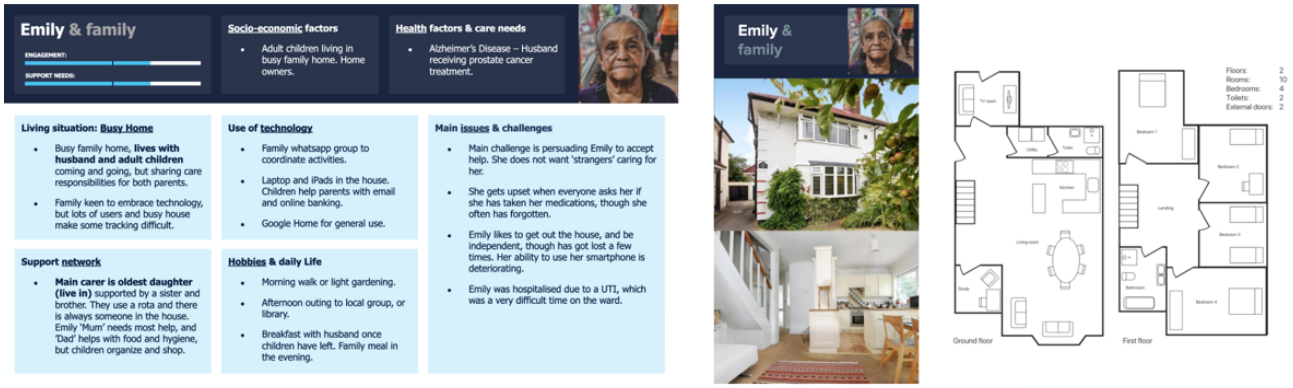
Figure 8. Persona D: Remote relative.



Busy Home (Emily and Family)

Emily (Figure 9) lives in a busy home with her family who share the care responsibilities. The family is very keen to embrace technology and engage in the trail; however, lots of users and a busy house make monitoring behavior and managing care difficult.

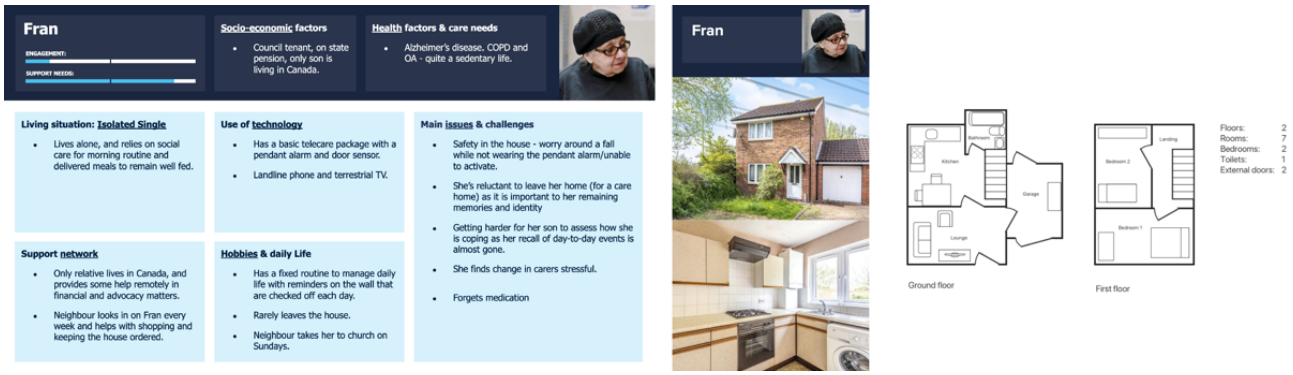
Figure 9. Persona E: Busy home.



Isolated Single (Fran)

Fran (Figure 10) lives alone and relies on social care and delivered meals to remain well fed. She has many different paid caregivers for quick visits, which means she suffers from isolation. She has low technology engagement and worries about her safety in the house (eg, a fall that remains undetected).

Figure 10. Persona F: Isolated single.



Personas were later used in the *Pan London OT Network* workshop to communicate the needs of people with dementia and caregivers to health care stakeholders to prompt them to consider a more comprehensive set of situations while defining the problems faced in clinical privacy and the ways technology can support their care.

Current Challenges in Delivering Professional Care Identified by Clinicians, Researchers, and Health Care Managers

Overview of Challenges

This section summarizes the pain points highlighted by clinicians, researchers in related fields, and managers of health care services in semistructured interviews, focus groups, and the *Pan-London OT Network* workshop. Although these challenges have been defined by stakeholders rather than end

XSL•FO
RenderX

users (people with dementia and caregivers), these 3 substudies included the communication of end-user needs to said stakeholders via the *themes* and *personas* the authors defined in previous substudies. Moreover, involving this variety of stakeholders revealed factors that are representative of general public health scenarios and not limited to the CR&T's early adopters of smart home systems.

Lack of Resources, Infrastructures, or Information

Access to ATs is not uniform across London services due to limited funding, availability, or misalignment with their patients' needs. Information about latest innovations is not always readily available. It is common for IT systems to be unreliable and for data to not be accessible across support services. Limited staffing often forces teams to reduce focus on occupational performance to work on generic assessments and provide basic care. Continuous clinical monitoring is particularly challenging and raises ethical questions: round-the-clock monitoring is resource-intensive and can be detrimental to clinicians' stress, while episodic monitoring may not be the best option for certain scenarios. There are ethical questions around duty of care and data being generated out of hours that could indicate an urgent clinical need. Some of our clinical participants opted to turn monitoring devices off at night.

Usability, Acceptance, and Consent

The lack of internet connection in patient homes and of funding for caregivers and family member to purchase assistive or communication devices are frequently coupled with skepticism or low abilities to engage with digital products. Similarly, it is common for patients to be reluctant to respond to automated alerts or notifications or to be monitored by sensors. If the perceived value of being monitored does not exceed the burden of participation, then alert fatigue and frustrations with devices may cause the participants to disengage. Many that could benefit from remote monitoring are isolated and lack mental capacity to understand its usefulness or to consent, and disengaged families may not agree with what clinicians suggest as the patient's best interest.

COVID-19 Lockdown-Related Challenges

Building therapeutic rapport and completing functional assessment are more challenging without face-to-face contact, and increased isolation has led to the deconditioning and deterioration of many patients. By contrast, this context increases the importance and the rate of implementation of remote monitoring. Despite the heightened need, social distancing has also enhanced the challenges of providing technical support to install and maintain devices and of providing in-person training.

Technology and Service Development Opportunities Identified by Clinicians, Researchers, and Health Care Managers

Opportunities for the design and integration of assisting technologies were identified and prioritized in Phase 02's workshop and focus groups by OTs, neuroscience researchers, clinical psychologists, health care service leaders, and care home managers through open questions (eg, "what advances in technology would you like to see in the next five years?", "what would you like to know or do [in this case study] if technology could let you know or do anything?"). Although no end users were involved in the definition of these opportunity areas, prompting stakeholders' ideation with the themes and personas the authors defined in previous substudies has elicited great variety of ideas based on a more comprehensive consideration of end-users' needs. Table 2 outlines the different categories and the number of instances in which they were mentioned.

Table 2. Technology and service development opportunities identified in a workshop with clinicians, researchers, and service managers and 2 focus groups with health care service providers.

Technology and service development opportunity	Mentions
Efficient, accurate remote cognitive assessments which are validated against standard tests despite learning, language, education, and cultural variations in patients	23
Objective covert behavioral and physiological data (eg, falls risk)	22
Measuring and managing caregiver strain through peer and professional support regarding dealing with situations, knowing what to expect, and planning for emergencies	16
Improving access to the wider network of casual and professional care and social services	15
Alternating between continuous and episodic measurements for optimal use of resources	8
Increased on-demand communication for practical, clinical, and emotional support	7
Informal monitoring products (eg, trackers) for caregivers	7
Educating patients and caregivers to use proposed technologies	6
Proactive medical interventions (eg, UTI prediction) to prevent further deterioration	6
Identifying and treating causes of psychological disturbances (eg, surveillance paranoia) before implementing intervention	5
Automated reminders and interventions supporting activities of daily living	5
Providing reliable clinical oversight to manage false alarms and prevent anxiety	5
Dynamic adjustment of medication administration enabled by granular monitoring of its effects	3

XSL•FO
RenderX

The most frequently mentioned desired technology development opportunities are related to unearthing novel, more accurate, objective data about cognitive, behavioral, and physiological parameters to enable clinicians to perform more informed assessments and distinguish between subtly different conditions (eg, between memory, language, visual-spatial, and sensory-motor deficiencies) in their diagnostics. Improving the availability and the quality of support and reassurance to caregivers through clinical, professional, and casual services and through informal care products and automated interventions is another priority. Having a platform over which to conduct intensive monitoring on an episodic basis can help treat acute conditions, counteract deterioration of preventable infections, and titrate drug prescriptions. Educating patients and caregivers about their prospective products and treating potential causes of rejection can improve compliance.

Factors Affecting Compliance and Engagement With Active, Passive, and Intrusive Devices Identified by Exploring Phase 02's Challenges and Opportunities With People With Dementia and Caregivers

Phase 03 Findings

Our Phase 03 interviews investigated 5 opportunities identified in the "Technology and Service Development Opportunities Identified by Clinicians, Researchers, and Health Care Managers" section from the perspectives of end users: (1) implementing remote cognitive assessments; (2) educating patients and caregivers to use proposed technologies; (3) identifying and addressing causes of psychological disturbances related to interventions; (4) collecting objective behavioral and physiological data; and (5) providing reliable clinical oversight to manage false alarms and prevent anxiety.

A thematic analysis of discussions with people with dementia and their home caregivers regarding the addition of pulse oximeters, thermometers, tablet-based cognitive testing puzzles, and smartwatches into the homes of selected study participants revealed factors that can motivate or disengage users. Achieving a deep understanding of such factors is crucial toward translating these technology-enabled opportunities into clinical practice.

Preventing Anxiety and Frustration

When dealing with sensitive data such as physiological readings and cognitive assessment results, any misunderstanding or technical problems may cause anxiety or helplessness in patients and caregivers. Strategies to mitigate this effect may include providing clear feedback when a task has been completed or a reading has been taken, avoiding time-pressured tasks, increasing task complexity gradually and within comfort, and using friendly, reassuring vocabulary. Moreover, systems could be designed to fulfill caregivers' wishes to monitor the person with dementia's location, physiological data and sleep while preventing the anxiety that could result from 'abnormal normal' and false readings, both of which can be common in elderly populations and in busy households.

Frustration and demotivation may also result from discrepancies between the expected function of an AT and its perceived usefulness (eg, caregivers not understanding why their smartwatch, adapted for the study, does not display the patient's location). Fluctuating cognition can be a significant barrier to the remote monitoring of isolated patients as forgetting about one's motivations to be monitored can lead to anxiety and agitation for being watched and, consequently, the disablement or destruction of equipment.

Aligning Tasks to the Patient's Routine

Allowing patients to perform tasks or take readings at their own pace and in their preferred time prevents feelings of being forced into a routine. Completing short, finite tasks motivates people with dementia more than partial progress toward a complex goal, and short but frequent engagement forms both habit and skill. Patients with advanced dementia, however, may not have the patience, ability, or motivation to draw satisfaction from completing tasks. They may be more compliant to sporadic, in-depth, episodic checks than to daily routines that demand their sustained engagement. Moreover, it is advisable to introduce ATs that are in line with the patient's existing habits and entertainment activities for higher engagement.

Discussion

Principal Findings

We explored functional and psychological needs of people with dementia using participatory user-centered design methods that produced a rich understanding of their experiences. These were expressed as design personas that help develop the empathy required for design and identify the challenges and opportunities of assistive remote monitoring technologies. Specific opportunities can subsequently be translated into technological innovation, public health strategy, and clinical practice through more focused user-centered design activities.

Supporting the Translation of Stakeholder's Experiences Into Public Health Strategy and Clinical Practice

Public health research and innovation processes benefit from involving patients and the public [41,57]. Our triangulation of findings with clinical, research, and organizational stakeholders enabled the definition and prioritization of care objectives, challenges, and both wide-ranging and solution-specific opportunities.

Moreover, the triangulation of findings with numerous stakeholders can significantly deepen researchers' knowledge of relevant themes and reveal new opportunities, especially when stakeholders (eg, clinicians) are specialized in understanding patients' needs. There are commonalities between the needs identified by patients and caregivers and the priorities identified by professional stakeholders (OT, health care service directors, clinical psychologists, and researchers in neuropsychiatry, behavior, and engineering). Thoroughly investigating these perspectives through 9 substudies elicited a wide variety of themes. The needs described by patients and caregivers mostly referred to physical health and independence in ADLs and started to reveal underlying values including autonomy, dignity, competence, relatedness, and reassurance. By contrast, clinicians identified more technology-specific (eg,

XSL•FO
RenderX

"filtering 'abnormal normal' readings before alerting caregivers") or medical (eg, "validated cognitive assessment tools") needs and value-aligned ways to address the challenges that prevent the satisfaction of people with dementia and caregivers' ADL needs. For example, "educating older adults to use the proposed technology" or "diagnosing and treating paranoia *before* prescribing a smart home system."

The *personas* and the *needs map* helped highlight the range of needs within the dementia population. Personas emphasize that the ways users receive care and interact with smart home systems depend heavily on their socioeconomic status, health factors, care needs, technology usage, daily life routine, family dynamics, and support network within the community. All these factors impact how engaged they are with the technology, and therefore how much users value the system. It is hence important for participatory activities to investigate not only the prima facie content of personas, but also what elements or traits should be included within personas. The patient–caregiver personas also highlight the technical challenge of designing for a range of different home environments, for example, determining how many sensing devices are needed in each home.

Harnessing personas as case studies successfully elicited a wide range of responses from the clinicians, service managers, and researchers participating in this study's final workshop. In our focus groups, some NHS service providers suggested refining these personas into a clinically accurate, quantitative, and validated spectrum of traits, contexts, health conditions, and stages of disease progression as an opportunity for further studies. This may be of value for researchers, designers, and engineers in a field where variables such as technology literacy, language, ethical and cultural differences, education, and the types of cognitive impairment (which may be related to memory, language, special acuity, sensory-motor, executive functioning, etc.) have an active impact not only on patient's technology acceptance but also on the results of the cognitive and functional assessments upon which care plans are based. These variables can be investigated in further participatory activities involving people with dementia, caregivers, and clinicians. More precise clinical information can be identified by health care providers and through a review of the literature. However, the generalization of personas into a detailed characterization of social groups has been criticized [58]. While communicating fictional user archetypes can support empathy in design workshops, personas' inherent risks of stereotyping, stigmatization, and limited diversity make them unsuitable as accurate representations of a population.

Our strategy of involving both participants who are early adopters of remote monitoring technologies and stakeholders more representative of the general population helped investigate both technology-specific considerations and more general needs and objectives in ADLs. We recommend that future studies replicate this strategy of combining evaluations of the technology-related experiences of early adopters (selected patients) with bottom–up investigations of the ADLs and care needs of the general population (members of the public and arbitrarily selected patients).

Conducting substudies in 3 phases and structuring Phases 02 and 03 around themes and personas identified in previous substudies allowed researchers to generalize insights elicited by investigating specific interactions with technology into widely relevant ADL needs and psychological factors. Conversely, conducting generative research and ideation activities based on previously defined patient and caregiver needs enabled researchers to guide stakeholders and people with dementia and caregivers to explore a wider design space and converge into more comprehensive and relevant service design and technology development opportunities.

Future studies continuing to combine results from a variety of stakeholders should ensure to evaluate findings across relevant groups of stakeholders to account for the potential limitations of one group speaking for another group, which may in fact disagree (eg, [44]). Therefore, to build on our findings, future studies can evaluate and explore each technology and service development opportunity identified by clinicians, researchers, and managers through the perspectives of a range of people with dementia and caregivers. Moreover, future studies may investigate how the prioritization of needs of people with dementia outlined in Table 1 and in the personas is dependent on the stage of dementia and on who is describing the problems.

Methodological Limitations

Methodological limitations of this study should be addressed in future activities of research and development of "Healthy Homes." While findings of ethnographic observations informed all the substudies, their documentation was incomplete due to operational constraints. Moreover, interviewing patients before and after they experience smart home interventions may reveal different insights than the sample of early adopters interviewed in this study. Comparisons would result in a more comprehensive understanding of how users' preconceived ideas affect adoption and engagement with the technology. Quantifying the occurrence of each persona's traits, conditions, and environments will require further studies. Although sample numbers were small, they are considered sufficient for qualitative analyses.

Our sampling strategy for the substudies of Phases 01 and 02 was to include both (1) end users and stakeholders who are early adopters of the CR&T's smart home systems; and (2) patients, caregivers, clinicians, researchers, and managers that are representative of the wider public health "users," services, and organizational processes. Phase 03's substudy of the implementation of a more intensive monitoring system, however, could only be conducted under the current UK DRI CR&T's research ethics approval and within suited recruitment timeframes with a cohort of self-selected UK DRI smart home trial users. Although this cohort was representative of the general dementia population when recruited through communities and social care channels for the UK DRI trial, participants may now be familiar with smart home technologies devices and inclined to support research. The samples might not be reflective of the common situations of disengaged, isolated people with dementia we identified in Phase 01 substudies and communicated in the "Patient–Caregiver Personas" section. Future qualitative studies investigating such intensive cognitive testing, smart home

XSL•FO
RenderX

systems, and wearable-based monitoring may benefit from allocating sufficient time and resources to receive ethical approval to recruit a sample that comprises the needs of our personas. This would enable the analysis of their needs both before and after the implementation of smart home systems. Capturing the values and emotional expectations of people with dementia and caregivers who are living independently but anticipate they may need such monitoring systems in the future can aid researchers to address these factors through design. This could prevent the perceived utility of such systems from decreasing with actual use [14].

Despite this potential sampling bias, the cognitive testing tablets and the activity tracking smartwatches we introduced for Phase 03 were very unfamiliar for 8 of the 10 households. This unsurprisingly resulted in generally low acceptance and compliance, as may be expected in the general dementia population. Moreover, as the sample (10 caregivers and 2 people with dementia) was too small for quantitative analysis, the richness of insight resulting from the interviews' thematic analysis was satisfactory for the purpose of our substudy. Interviews with this sample, however, had to be conducted via telephone due to the pandemic. This excluded 8 people with moderate and advanced dementia to be able to directly express their experiences. When in-person participatory design session return to be a possibility, creative and interactive activities during home visits can be more inclusive to people with dementia. The presence, sounds, aesthetics, and materials of prototypes can be used as props for creating and sharing concepts (eg, [54]).

Limitations of Findings

Our strategy of recruiting early adopters of smart home systems for our substudies evaluating specific interactions with such technologies may have resulted in the underrepresentation of disengaged, nontechnology-savvy people with dementia and caregivers. Disengaged attitudes toward technology-based care are common in the general population of people with dementia and elderly caregivers, as identified in Phase 01 substudies and communicated in our personas. The challenges that the constant surveillance of smart home technologies poses around privacy [12] and agency [9] were not emphasized in our evaluative substudies as much expected [11]. Such themes were only touched on superficially by 2 nontech-savvy participants of Phase 03 interviews and by clinicians in our persona-based *Pan London OT Network* workshop.

Recruiting participants that represent the variety of attitudes toward care and technology outlined in our personas (including, for example, weariness toward devices, reluctance to obey automated alerts, reluctance for anyone to "know my business," and isolated living situations) should be a priority of future sampling strategies. Best practices in conducting research with socially isolated older adults [46] should be followed. Understanding the human values (eg, dignity, autonomy) that underlie people's attitudes toward smart homes can enable researchers to address tensions that may arise within a person or between stakeholders. For example, much of our cohort of early adopter caregivers inherently values "supporting research" and is inclined to data sharing, while our compliant people with dementia likely value "pleasing my caregiver." The motivations of the general population should be understood in more detail for the translation of such products into public health pathways to be successful. In a context where products are often used *on* people, particular care must be taken in supporting end-users' values to prevent undesirable but plausible consequences such as elderly abuse, loss of perceived autonomy or dignity, and increased isolation.

Direct Implications of This Study's Findings

Patient needs mapping results and personas are being used as a tool to communicate to the wider UK DRI research community the issues and challenges of creating environments that support independent living in an empathetic and realistic way. By improving such communication, this project aims to influence research and development on new AI and IoT technologies.

The challenges in delivering professional care and the technology development opportunities identified in this study are currently being addressed and prioritized by local and nation-wide public health care partners through the deployment of surveys. In parallel, our findings regarding intensive remote monitoring have directly informed the design of a new substudy by the CR&T and resulted in incremental improvements in the center's cognitive testing app and its underlying clinical services. For example, the difficulty of puzzles now gradually increases, participants can pause tasks and repeat instructions, and feedback about tasks being completed is more explicit. Additionally, some of the insights that emerged from Phase 03 have been translated into improvements in the interface and user experience of the CR&T's novel traumatic brain injury assessment app for in-person clinical use.

Conclusions

Enabling communication between designers, technologists, and public health care providers (the UK DRI's stakeholders) via participatory design processes and artifacts can foster more effective, inclusive, and rapid innovation in public health sectors. We aim to design and deploy remote monitoring and intervention systems that are fully integrated into a complex network of services, pathways, and stakeholders. Ensuring these systems are widely accessible yet tailored to the individual needs, technological knowledge, and level of engagement of individual patients and caregivers is a substantial task. Today's pandemic-affected context has made it urgent to streamline innovation in this space through participatory, user-centered, and value-sensitive design.

Although this study focused on living with dementia, the iterative application of qualitative research methods involving patients, caregivers, and various stakeholders is applicable to other medical fields. This paper exemplifies how this methodology can reveal nuanced but critical psychosocial and contextual factors and support the development and translation of more patient-centered interventions.

XSL•FO
RenderX

Acknowledgments

A-IS is supported by the UKRI CDT in AI for Healthcare (Grant No. P/S023283/1). Human Research was approved by UK DRI trial ID - IRAS ID: 25756. This project is partially funded by the UK Dementia Research Institute Care Research & Technology Centre.

Authors' Contributions

FT, PB, and MH conducted the studies and analyzed the data. All authors contributed to the conception, design, writing, and editing of the manuscript.

Conflicts of Interest

None declared.

References

1. World Health Organization. Dementia. Geneva, Switzerland: World Health Organization; 2020. URL: https://www.who.int/news-room/fact-sheets/detail/dementia [accessed 2021-02-27]
2. Alzheimer's Society. Dementia UK (2nd Edition). London, UK: Alzheimer's Society; 2014. URL: https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf [accessed 2021-06-28]
3. Parkinson S, Forsyth K, Kielhofner G. User's Manual for Model of Human Occupation Screening Tool (MOHOST). 2004. URL: https://moho.uic.edu/pdf/MohostManual.pdf [accessed 2021-06-28]
4. Enshaeifar S, Zoha A, Skillman S, Markides A, Acton ST, Elsaleh T, et al. Machine learning methods for detecting urinary tract infection and analysing daily living activities in people with dementia. PLoS One 2019;14(1):e0209909 [FREE Full text] [doi: 10.1371/journal.pone.0209909] [Medline: 30645599]
5. Enshaeifar S, Zoha A, Markides A, Skillman S, Acton ST, Elsaleh T, et al. Health management and pattern analysis of daily living activities of people with dementia using in-home sensors and machine learning techniques. PLoS One 2018;13(5):e0195605 [FREE Full text] [doi: 10.1371/journal.pone.0195605] [Medline: 29723236]
6. Enshaeifar S, Barnaghi P, Skillman S, Sharp D, Nilforooshan R, Rostill H. A Digital Platform for Remote Healthcare Monitoring. New York, NY: Association for Computing Machinery; 2020 Presented at: Companion Proceedings of the Web Conference 2020; April 2020; Taipei, Taiwan. [doi: 10.1145/3366424.3383541]
7. Ienca M, Wangmo T, Jotterand F, Kressig RW, Elger B. Ethical Design of Intelligent Assistive Technologies for Dementia: A Descriptive Review. Sci Eng Ethics 2018 Dec;24(4):1035-1055. [doi: 10.1007/s11948-017-9976-1] [Medline: 28940133]
8. Novitzky P, Smeaton AF, Chen C, Irving K, Jacquemard T, O'Brolcháin F, et al. A review of contemporary work on the ethics of ambient assisted living technologies for people with dementia. Sci Eng Ethics 2015 Jun;21(3):707-765. [doi: 10.1007/s11948-014-9552-x] [Medline: 24942810]
9. Brandl B, Dyer CB, Heisler CJ, Otto MJ, Stiegel LA, Thomas RW. Elder Abuse Detection and Intervention: A Collaborative Approach (1st edition). Berlin, Germany: Springer; 2006.
10. O'Brolcháin F, Gordijn B. Privacy challenges in smart homes for people with dementia and people with intellectual disabilities. Ethics Inf Technol 2019 Jul 12;21(3):253-265. [doi: 10.1007/s10676-019-09507-0]
11. Alkhatib S, Waycott J, Buchanan G, Bosua R. Privacy and the Internet of Things (IoT) Monitoring Solutions for Older Adults: A Review. Stud Health Technol Inform 2018;252:8-14. [Medline: 30040675]
12. Geeng C, Roesner F. Who's In Control? Interactions In Multi-User Smart Homes. Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems. New York, NY: Association for Computing Machinery; 2019. URL: https://www.franziroesner.com/pdf/geeng-smarthomes-chi19.pdf [accessed 2021-07-12]
13. Alkhatib S, Waycott J, Buchanan G. Privacy in Aged Care Monitoring Devices (ACMD): The Developers' Perspective. 2019. URL: https://www.hisa.org.au/slides/hic19/mon/SamiAlkhatib.pdf?x44177 [accessed 2021-07-12]
14. Ghorayeb A, Comber R, Gooberman-Hill R. Older adults' perspectives of smart home technology: Are we developing the technology that older people want? International Journal of Human-Computer Studies 2021 Mar;147:102571. [doi: 10.1016/j.ijhcs.2020.102571]
15. Sharpe D. UK DRI Care Research & Technology Centre. London, UK: UK Dementia Research Institute; 2020. URL: https://ukdri.ac.uk/centres/care-research-technology [accessed 2021-07-12]
16. Rostill H, Nilforooshan R, Morgan A, Barnaghi P, Ream E, Chrysanthaki T. Technology integrated health management for dementia. Br J Community Nurs 2018 Oct 02;23(10):502-508. [doi: 10.12968/bjcn.2018.23.10.502] [Medline: 30290728]
17. Public HE. National Dementia Intelligence Network Briefing: Reasons Why People With Dementia Are Admitted to a General hospital in an Emergency. London, UK: Public Health England; 2015. URL: http://www.swscn.org.uk/wp/wp-content/uploads/2015/12/ReasonswhypeoplewithdementiaareadmittedtoagenerA.pdf [accessed 2021-07-12]
18. Brodaty H, Donkin M. Family caregivers of people with dementia. Dialogues Clin Neurosci 2009;11(2):217-228 [FREE Full text] [Medline: 19585957]
19. Marshall M. The challenge of looking after people with dementia. BMJ 2001 Aug 25;323(7310):410-411 [FREE Full text] [doi: 10.1136/bmj.323.7310.410] [Medline: 11520820]

XSL•FO
RenderX

20. Amiribesheli M, Bouchachia H. A tailored smart home for dementia care. J Ambient Intell Human Comput 2017 Dec 6;9(6):1755-1782. [doi: 10.1007/s12652-017-0645-7]
21. Orpwood R, Gibbs C, Adlam T, Faulkner R, Meegahawatte D. The design of smart homes for people with dementia—user-interface aspects. Univ Access Inf Soc 2005 Jul 2;4(2):156-164. [doi: 10.1007/s10209-005-0120-7]
22. Amiribesheli M, Bouchachia H. Towards Dementia-Friendly Smart Homes. New York, NY: IEEE; 2016 Presented at: 2016 IEEE 40th Annual Computer Software and Applications Conference (COMPSAC); June 10-14, 2016; Atlanta, GA p. 638-647. [doi: 10.1109/COMPSAC.2016.211]
23. Demir E, Köseoğlu E, Sokullu R, Şeker B. Smart Home Assistant for Ambient Assisted Living of Elderly People with Dementia. Procedia Computer Science 2017;113:609-614 [FREE Full text] [doi: 10.1016/j.procs.2017.08.302]
24. Taylor KI, Staunton H, Lipsmeier F, Nobbs D, Lindemann M. Outcome measures based on digital health technology sensor data: data- and patient-centric approaches. NPJ Digit Med 2020 Jul 23;3(1):97 [FREE Full text] [doi: 10.1038/s41746-020-0305-8] [Medline: 32715091]
25. Ouchi K, Doi M. Smartphone-based monitoring system for activities of daily living for elderly people and their relatives etc. In: Proceedings of the 2013 ACM Conference on Pervasive and Ubiquitous Computing Adjunct Publication. New York, NY: Association for Computing Machinery; 2013 Presented at: 2013 ACM Conference on Pervasive and Ubiquitous Computing; July 17–21, 2011; Zurich, Switzerland p. 103-106. [doi: 10.1145/2494091.2494120]
26. Rogers Y. Moving on from Weiser's vision of calm computing: engaging ubicomp experiences. In: UbiComp'06: Proceedings of the 8th International Conference on Ubiquitous Computing. Berlin, Germany: Springer; 2006 Presented at: 8th International Conference on Ubiquitous Computing; September 2006; Orange County, CA p. 404-421. [doi: 10.1007/11853565_24]
27. Davis S, Byers S, Nay R, Koch S. Guiding design of dementia friendly environments in residential care settings: Considering the living experiences. Dementia 2009 Apr 22;8(2):185-203. [doi: 10.1177/1471301209103250]
28. Wang R, Viswanathan P, Czarnuch S, Boger J, Nejat G, Mihailidis A. Developing Advanced Assistive Technology for Older Adults With Dementia: Lessons Learned. 2013. URL: https://www.academia.edu/28178544/Developing_advanced_assistive_technology_for_older_adults_with_dementia_Lessons_learned [accessed 2021-07-12]
29. Greenhalgh T, Jackson C, Shaw S, Janamian T. Achieving Research Impact Through Co-creation in Community-Based Health Services: Literature Review and Case Study. Milbank Q 2016 Jun 06;94(2):392-429 [FREE Full text] [doi: 10.1111/1468-0009.12197] [Medline: 27265562]
30. Morrissey K, McCarthy J, Pantidi N. The Value of Experience-Centred Design Approaches in Dementia Research Contexts. In: CHI '17: Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems. New York, NY: Association for Computing Machinery; 2017 May Presented at: 2017 CHI Conference on Human Factors in Computing Systems (CHI '17); May 2017; Denver, CO p. 1326-1338. [doi: 10.1145/3025453.3025527]
31. Lazar A, Toombs A, Morrissey K, Kenning G, Boger J, Brankaert R. HCIxDementia Workshop: Engaging People Living with Dementia. In: Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems. New York, NY: Association for Computing Machinery; 2018 Presented at: 2018 CHI Conference on Human Factors in Computing Systems; April 21-26, 2018; Montreal QC. [doi: 10.1145/3170427.3170613]
32. Fleming R, Purandare N. Long-term care for people with dementia: environmental design guidelines. Int. Psychogeriatr 2010 May 18;22(7):1084-1096. [doi: 10.1017/s1041610210000438]
33. Houben M, Brankaert R, Bakker S, Kenning G, Bongers I, Eggen B. Foregrounding Everyday Sounds in Dementia. In: Proceedings of the 2019 on Designing Interactive Systems Conference. New York, NY: Association for Computing Machinery; 2019 Presented at: DIS '19: Designing Interactive Systems Conference 2019; June 23-28, 2019; San Diego, CA. [doi: 10.1145/3322276.3322287]
34. Jayatilaka A, Ranasinghe DC, Falkner K, Visvanathan R, Wilson A. Care workers' voices in designing assistive technologies for preventing malnutrition in older people with dementia: Innovative Practice. Dementia (London) 2020 Feb 04;19(2):505-511. [doi: 10.1177/1471301217722852] [Medline: 28776410]
35. Goeman DP, Corlis M, Swaffer K, Jenner V, Thompson JF, Renehan E, et al. Partnering with people with dementia and their care partners, aged care service experts, policymakers and academics: A co-design process. Australas J Ageing 2019 Sep;38 Suppl 2:53-58. [doi: 10.1111/ajag.12635] [Medline: 31496067]
36. Robinson L, Brittain K, Lindsay S, Jackson D, Olivier P. Keeping In Touch Everyday (KITE) project: developing assistive technologies with people with dementia and their carers to promote independence. IPG 2009 Feb 5;21(03):494. [doi: 10.1017/s1041610209008448]
37. Bourazeri A, Stumpf S. Co-designing smart home technology with people with dementia or Parkinson's disease. In: Proceedings of the 10th Nordic Conference on Human-Computer Interaction - NordiCHI '18. New York, NY: Association for Computing Machinery; 2018 Jan 1 Presented at: NordiCHI '18: 10th Nordic Conference on Human-Computer Interaction; September 29, 2018-October 3, 2018; Oslo, Norway p. 2018. [doi: 10.1145/3240167.3240197]
38. Little L, Briggs P. Pervasive healthcare: the elderly perspective. In: PETRA '09: Proceedings of the 2nd International Conference on PErvasive Technologies Related to Assistive Environments. New York, NY: Association for Computing Machinery; 2009 Jun Presented at: PETRA '09 2nd International Conference on PErvasive Technologies Related to Assistive Environments; June 9-13, 2009; Corfu, Greece p. 1-5. [doi: 10.1145/1579114.1579185]

XSL•FO
RenderX

39. Curumsing MK, Fernando N, Abdelrazek M, Vasa R, Mouzakis K, Grundy J. Emotion-oriented requirements engineering: A case study in developing a smart home system for the elderly. Journal of Systems and Software 2019 Jan;147:215-229. [doi: 10.1016/j.jss.2018.06.077]
40. Waycott J, Vines J. Designing Technologies with Older Adults: Ethical Tensions and Opportunities: Designing and Evaluating Emerging Technologies for Older Adults. Ageing and Digital Technology. In: Ageing and Digital Technology. Berlin, Germany: Springer; 2019:173-187.
41. Fazio S, Pace D, Flinner J, Kallmyer B. The Fundamentals of Person-Centered Care for Individuals With Dementia. Gerontologist 2018 Jan 18;58(suppl_1):S10-S19. [doi: 10.1093/geront/gnx122] [Medline: 29361064]
42. Kitwood T. Toward a theory of dementia care: ethics and interaction. J Clin Ethics 1998;9(1):23-34. [Medline: 9598430]
43. Thieme A, Vines J, Wallace J, Clarke R, Slovák P, McCarthy J. Enabling empathy in health and care: design methods and challenges. New York, NY: Association for Computing Machinery; 2014 Presented at: CHI EA '14: CHI '14 Extended Abstracts on Human Factors in Computing Systems; April 26, 2014 to May 1, 2014; Toronto, ON p. 139-142. [doi: 10.1145/2559206.2559237]
44. Cajander Å, Grünloh C. Electronic Health Records Are More Than a Work Tool: Conflicting Needs of Direct and Indirect Stakeholders. Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems: Association for Computing Machinery; 2019 Presented at: Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems; May 4-9, 2019; Glasgow, Scotland p. 635. [doi: 10.1145/3290605.3300865]
45. Carter N, Bryant-Lukosius D, DiCenso A, Blythe J, Neville AJ. The use of triangulation in qualitative research. Oncol Nurs Forum 2014 Sep;41(5):545-547. [doi: 10.1188/14.ONF.545-547] [Medline: 25158659]
46. Friedman B, Hendry DG. Value Sensitive Design: Shaping Technology with Moral Imagination. Cambridge, MA: The MIT Press; 2019.
47. Malinowsky C, Fallahpour M, Lund ML, Nygård L, Kottorp A. Skill clusters of ability to manage everyday technology among people with and without cognitive impairment, dementia and acquired brain injury. Scand J Occup Ther 2018 Mar 02;25(2):99-107. [doi: 10.1080/11038128.2017.1298665] [Medline: 28276961]
48. Waycott J, Morgans A, Pedell S, Ozanne E, Vetere F, Kulik L, et al. Ethics in Evaluating a Sociotechnical Intervention With Socially Isolated Older Adults. Qual Health Res 2015 Nov 02;25(11):1518-1528. [doi: 10.1177/1049732315570136] [Medline: 25646003]
49. Bartels SL, Assander S, Patomella A, Jamnadas-Khoda J, Malinowsky C. Do you observe what I perceive? The relationship between two perspectives on the ability of people with cognitive impairments to use everyday technology. Aging Ment Health 2020 Aug;24(8):1295-1305. [doi: 10.1080/13607863.2019.1609902] [Medline: 31056927]
50. Lindsay S, Jackson D, Schofield G, Olivierditors. Engaging older people using participatory design. New York, NY: Association for Computing Machinery; 2012 May Presented at: Proceedings of the 2012 ACM annual conference on Human Factors in Computing Systems - CHI '12; May 2012; Austin, TX p. 1199-1208. [doi: 10.1145/2207676.2208570]
51. Vines J, Mcnaney R, Clarke R, Lindsay S, Mccarthy J, Howard S. Designing for- and with- vulnerable people. In: CHI EA '13: CHI '13 Extended Abstracts on Human Factors in Computing Systems. 2013 Apr Presented at: CHI Conference on Human Factors in Computing Systems; April 27, 2013-May 2, 2013; Paris, France p. 3231-3234. [doi: 10.1145/2468356.2479654]
52. Hendriks N, Truyen F, Duval E. Designing with Dementia: Guidelines for Participatory Design together with Persons with Dementia. In: Kotzé P, Marsden G, Lindgaard G, Wesson J, Winckler M, editors. Human-Computer Interaction – INTERACT 2013. INTERACT 2013. Lecture Notes in Computer Science (Vol 8117). Berlin, Germany: Springer; 2013.
53. Moltu C, Stefansen J, Svisdahl M, Veseth M. Negotiating the coresearcher mandate - service users' experiences of doing collaborative research on mental health. Disabil Rehabil 2012;34(19):1608-1616. [doi: 10.3109/09638288.2012.656792] [Medline: 22489612]
54. Lazar A, Cornejo R, Edasis C, Piper A. Designing for the Third Hand: Empowering Older Adults With Cognitive Impairments Through Creating and Sharing. 2016. URL: https://www.ics.uci.edu/~ampiper/papers/pn0431-lazar.pdf [accessed 2021-07-12]
55. Rodgers PA. Co-designing with people living with dementia. CoDesign 2017 Feb 15;14(3):188-202. [doi: 10.1080/15710882.2017.1282527]
56. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs 2008 Apr;62(1):107-115. [doi: 10.1111/j.1365-2648.2007.04569.x] [Medline: 18352969]
57. Hayes H, Buckland S, Tarpey M. riefing notes for researchers: public involvement in NHS, public health and social care research. 2012. URL: https://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf [accessed 2021-06-27]
58. Marsden N, Haag M. Stereotypes and Politics: Reflections on Personas. New York, NY: ACM; 2016 Presented at: Proceedings of the CHI Conference on Human Factors in Computing Systems (CHI '16); May 7, 2016; San Jose, CA. [doi: 10.1145/2858036.2858151]

Abbreviations

ADLs: activities of daily living

XSL•FO
RenderX

AI: artificial intelligence
AT: assistive technologies
CR&T: Care Research and Technology Centre
DRI: Dementia Research Institute
IoT: internet of things
NHS: National Health Service
OT: occupational therapist
SABP: Surrey and Borders Partnership

Edited by R Kukafka, G Eysenbach; submitted 08.01.21; peer-reviewed by C Kunze; comments to author 08.02.21; revised version received 01.05.21; accepted 16.05.21; published 11.08.21.

Please cite as:
Tiersen F, Batey P, Harrison MJC, Naar L, Serban AI, Daniels SJC, Calvo RA
Smart Home Sensing and Monitoring in Households With Dementia: User-Centered Design Approach
JMIR Aging 2021;4(3):e27047
URL: https://aging.jmir.org/2021/3/e27047
doi:10.2196/27047
PMID:34383672

©Federico Tiersen, Philippa Batey, Matthew J C Harrison, Lenny Naar, Alina-Irina Serban, Sarah J C Daniels, Rafael A Calvo. Originally published in JMIR Aging (https://aging.jmir.org), 11.08.2021. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Aging, is properly cited. The complete bibliographic information, a link to the original publication on https://aging.jmir.org, as well as this copyright and license information must be included.

XSL•FO
RenderX

Original Paper

Satisfaction, Usability, and Compliance With the Use of Smartwatches for Ecological Momentary Assessment of Knee Osteoarthritis Symptoms in Older Adults: Usability Study

Charlotte Rouzaud Laborde[1,2*], PharmD, PhD; Erta Cenko[3*], MSPH; Mamoun T Mardini[2,4*], PhD; Subhash Nerella[4*], MSc; Matin Kheirkhahan[5*], BE; Sanjay Ranka[6*], PhD, Prof Dr; Roger B Fillingim[7*], PhD; Duane B Corbett[2*], PhD; Eric Weber[7*], PhD; Parisa Rashidi[4*], PhD; Todd Manini[2*], MD, PhD, Prof Dr

[1]Department of Pharmacy, University of Toulouse, Toulouse, France

[2]Department of Aging and Geriatric research, University of Florida, Gainesville, FL, United States

[3]Department of Epidemiology, University of Florida, Gainesville, FL, United States

[4]Department of Biomedical Engineering, University of Florida, Gainesville, FL, United States

[5]Google, Mountain View, California, CA, United States

[6]Department of Computer and Information Science and Engineering, University of Florida, Gainesville, FL, United States

[7]Department of Community Dentistry and Behavioral Science, University of Florida, Gainesville, FL, United States

[*]all authors contributed equally

Corresponding Author:
Charlotte Rouzaud Laborde, PharmD, PhD
Department of Pharmacy
University of Toulouse
Hopital Paule de Viguier
330 Avenue de Grande Bretagne, TSA 70034
Toulouse, 31059
France
Phone: 33 625088692
Fax: 33 561771055
Email: charlotte.laborde@yahoo.fr

Abstract

Background: Smartwatches enable physicians to monitor symptoms in patients with knee osteoarthritis, their behavior, and their environment. Older adults experience fluctuations in their pain and related symptoms (mood, fatigue, and sleep quality) that smartwatches are ideally suited to capture remotely in a convenient manner.

Objective: The aim of this study was to evaluate satisfaction, usability, and compliance using the real-time, online assessment and mobility monitoring (ROAMM) mobile app designed for smartwatches for individuals with knee osteoarthritis.

Methods: Participants (N=28; mean age 73.2, SD 5.5 years; 70% female) with reported knee osteoarthritis were asked to wear a smartwatch with the ROAMM app installed. They were prompted to report their prior night's sleep quality in the morning, followed by ecological momentary assessments (EMAs) of their pain, fatigue, mood, and activity in the morning, afternoon, and evening. Satisfaction, comfort, and usability were evaluated using a standardized questionnaire. Compliance with regard to answering EMAs was calculated after excluding time when the watch was not being worn for technical reasons (eg, while charging).

Results: A majority of participants reported that the text displayed was large enough to read (22/26, 85%), and all participants found it easy to enter ratings using the smartwatch. Approximately half of the participants found the smartwatch to be comfortable (14/26, 54%) and would consider wearing it as their personal watch (11/24, 46%). Most participants were satisfied with its battery charging system (20/26, 77%). A majority of participants (19/26, 73%) expressed their willingness to use the ROAMM app for a 1-year research study. The overall EMA compliance rate was 83% (2505/3036 responses). The compliance rate was lower among those not regularly wearing a wristwatch (10/26, 88% vs 16/26, 71%) and among those who found the text too small to read (4/26, 86% vs 22/26, 60%).

XSL•FO
RenderX

Conclusions: Older adults with knee osteoarthritis positively rated the ROAMM smartwatch app and were generally satisfied with the device. The high compliance rates coupled with the willingness to participate in a long-term study suggest that the ROAMM app is a viable approach to remotely collecting health symptoms and behaviors for both research and clinical endeavors.

(JMIR Aging 2021;4(3):e24553) doi:10.2196/24553

KEYWORDS

ehealth; mobile health; ecological momentary assessment; real-time online assessment and mobility monitor; ROAMM; older adults; compliance; personal satisfaction; usability; smartwatch; knee osteoarthritis; pain; fatigue; wearable electronic device; mobile application

Introduction

Mobile devices are becoming commonplace in patient-based research [1]. Their ability to capture sensor data and enable interaction with participants in both observational and interventional studies makes mobile devices a powerful tool to augment traditional data collection approaches [2]. For example, these devices passively record activity with an accelerometer and location via GPS sensors to track physical activity and mobility. This information could be useful in understanding patients' symptoms in the free-living environment. Such knowledge would be ideal for patients with osteoarthritis who exhibit variable pain experiences that may also interact with their mood and fatigue levels [3,4]. Coupled with sensor-based mobility data, smart devices offer a rich portrait of the interplay between symptoms and mobility levels.

Osteoarthritis is a degenerative and progressive disease affecting approximately 250 million patients worldwide [5]. Pain experiences greatly differ between patients and are often irregular within the same patient [6]. The complexity of symptoms is partly due to the site (knee, hip, or hand), genetic predisposition, initial cause of damage (ie, injury), obesity status, level of inflammation, and environmental factors [5,7]. Traditionally, patients receive treatment after reporting pain complaints and a physical examination along with optional imaging (eg, radiographs) [8,9]. Physical activity patterns, mobility function, and symptoms are used by clinical practitioners to inform treatment decisions [8,10,11]. However, difficulty in retrospective assessment of complex experiences like pain and the recall bias of self-assessing activity patterns present obstacles for care management of patients with osteoarthritis [12]. As a result, there has been considerable interest in using smart mobile devices—phones and wearables—for ascertaining symptoms and objective activity measures for informing practitioners [13]. In 2019, approximately 30 to 40 apps were designed for logging pain symptoms, but only one-fifth of those apps engaged the patients for which they were designed [14]. Moreover, none were solely designed for a smartwatch interface. Mobile devices and smart wearables have the potential to better characterize symptoms in the free-living world, but involvement of end-users (eg, patients) are necessary for appropriate design and long-term adoption.

New tools are needed to collect symptoms, experiences, and patterns of mobility and activity in real time in the free-living environment. Ecological momentary assessment (EMA) is a method based on data collection originally developed by Larson and Csikszentmihalyi in 1983 [15] for the psychological assessment of what activities people engage in, how they feel, and what they are thinking during their daily lives. It was developed because people are poor at reconstructing psychological experiences after they have occurred [16,17]. Rather, EMA considers experiences in the moment in a real-world environment and is potentially more representative of reality [18]. EMAs were first collected using paper diaries, followed by dedicated electronic diaries [19]. Recently, however, smartphone and smartwatch apps are becoming a pervasive means of assessing medical symptoms [20,21]. Work by Murphy and Smith demonstrated that tracking activity patterns with daily EMA fatigue reports yielded insights into the manifestation of activity-induced fatigue in participants with knee or hip osteoarthritis [22]. Another recent report used a custom-designed smartwatch app to prompt older adults with knee osteoarthritis to report their pain 4 to 5 times per day for approximately 3 months. Results demonstrated that older adults wore the watch for 75% of the study duration and answered 50% to 60% of the twice-daily prompts to rate their pain. Despite some drawbacks, including battery drain and technical issues, participants generally thought the watch was convenient and acceptable [23]. Although this previous work is encouraging, additional research is clearly needed to document smartwatch satisfaction, usability, and compliance for knee osteoarthritis symptoms.

The large increase in mobile medical apps has prompted the US Food and Drug Administration (FDA) to release a guidance statement [24]. The FDA is clearly supportive of evaluating patient-reported outcomes [25]; however, the framework for regulating medical mobile apps is still in its infancy [24]. Moreover, FDA guidance documents state that any patient-based software should undergo evaluation for overall design, usability, and acceptability for use in clinical care and research settings [26]. In that regard, the objective of our study was to evaluate satisfaction, usability, and compliance using the real-time and online assessment and mobility monitoring (ROAMM) mobile app designed for smartwatches. This study builds on initial input from interviews about the ROAMM app interface and usability in both patients and practitioners [27,28]. We hypothesized that older adults with knee osteoarthritis would provide positive satisfaction and usability ratings while being compliant with wearing the smartwatch and answering EMA prompts over an approximately 2-week evaluation period.

XSL•FO
RenderX

Methods

Participant Recruitment and Visit Design

Community-dwelling older adults aged 65 years and above with symptomatic unilateral or bilateral knee osteoarthritis were enrolled in the study. Recruitment sources included community advertisements and participant-based registries. Exclusion criteria included significant cognitive impairment, neurological conditions that severely inhibited mobility, inability to communicate because of severe hearing loss or speech disorder, terminal illness with life expectancy less than 12 months, severe pulmonary disease, renal failure with hemodialysis, severe psychiatric disorder (eg, bipolar, schizophrenia), excessive alcohol use (>14 drinks per week), drug addiction, or treatment for cancer (radiation or chemotherapy) within the past 1 year. All participants provided written informed consent, and the protocol was approved by the University of Florida Institutional Review Board.

Participants were asked to attend 2 clinic visits: one at baseline and another approximately 2 weeks later. After providing written informed consent, participants were administered the Mini-Mental Status Examination and then instructed on how to use the ROAMM app as previously described [27,29]. Participants were provided a simple user guide on how to use the wireless charging station and USB cable. They were also provided with a demographic questionnaire and an "exit" questionnaire that asked about their satisfaction with watch functionality and usability (see Multimedia Appendix 1) to be completed at the end of the second week. At the second visit, participants were asked to return the smartwatch and completed questionnaires.

ROAMM App and EMA

The ROAMM app was developed at the University of Florida to enable real-time capture of patient-generated information. The smartwatch app collects wearable sensor (accelerometer and GPS) data simultaneously with symptom EMAs, as described previously [27]. Briefly, the ROAMM app is composed of a server and smartwatch app that are remotely connected through a secure https protocol. This integrated framework is designed and developed to perform several tasks, including remote data collection, storage, retrieval, and analysis. The primary goal of this project was to evaluate usability, satisfaction, and compliance of wearing the smartwatch and responding to EMA prompts in free-living conditions. Participants were asked to wear and charge the smartwatch every day for approximately 2 weeks during waking hours. The ROAMM app was programed to prompt the participant three times a day in a stratified random manner at prespecified windows: 8:00-11:59, 12:00-15:59, and 16:00-19:59.

While wearing the watch, participants were prompted in the morning to report their prior night's sleep quality. Thereafter, EMA pain, fatigue, mood, and activity were assessed throughout the day. Participants used the rotating bezel on the Samsung Gear S3 to dial in responses and then saved their responses by pressing a button located on top of the bezel. Rating scales were chosen based on the previous literature and the ability to scale down the content for the watch interface [30-34]. In the morning, participants rated their previous night's sleep quality on a scale of 0 to 10 [35,36], with the following anchors: 0 to 1, "very poor"; 2, "poor"; 3 to 4, "OK"; 5 to 8, "well"; and 9 to 10, "very well". EMA pain was evaluated using a valid and reliable numerical rating scale—the 11-point Box Scale (BS-11) of pain intensity that ranges from 0 to 10 [37,38]. There is a wide variety of versions of this scale and its inclusion of text anchors [39]. Because of the small watch face, we preferred to include more anchors than the traditional numeric scales. The following text anchors were shown as the participant rotated the dial: 0, "none"; 1 to 3, "mild"; 4 to 5, "moderate"; 6 to 7, "severe"; 8 to 9, "very severe"; and 10, "worst possible." A depiction of the interface is shown in Figure 1 and in our previous publications [27,28].

Figure 1. Depiction of watch face with visual analog scale used to rate pain intensity.



Fatigue severity was also assessed using a scale of 0 to 10, using the abovementioned anchors, according to other similar validated scales previously reported [40-42]. Mood ratings were scaled slightly differently to more closely follow previously validated visual analogue scales [43,44]. By default, the zero value for "neutral" was placed at the bottom of the screen; rotation to the right reported negative mood ratings, with text anchors "negative" for –1 to –3 and "very negative" for –4 to –5. Rotation to the left reported positive mood ratings. Finally, participants rotated the bezel to choose an icon representing one

XSL•FO
RenderX

of the following activity categories that they were presently engaged in: lying down, standing, walking, sitting, and other activities (representing other possible activities such as gardening and exercise). Thus, participants were prompted to report pain, fatigue, mood, and activity three times per day. To reduce burden, prompts were delivered in a contiguous manner—one after another. The total time to answer a set of prompts was very short, typically <30 seconds.

ROAMM Exit Questionnaire to Evaluate Satisfaction and Usability

A 13-item exit questionnaire was administered at the end of the second week of the study (see questionnaire in Multimedia Appendix 1). The questions dealt with wearing comfort (eg, size, weight, wristband material), usability of the ROAMM app (eg, responding to prompts, font size, battery life), ease of using the inductive charger, and willingness to participate in future research studies. Participants were also asked to provide feedback to improve the app and its usability. Questions that used a 4-point Likert scale were reduced to two categories for statistical analysis (eg “very satisfied and satisfied” vs “somewhat satisfied and not satisfied”). Some questions asked participants to select as many options as possible that apply. Participants were also asked to provide any additional opinions of the ROAMM app and the smartwatch. Responses to this question were categorized into 4 major areas: technical issue; usability or functionality issue; size, weight, or display issue; and no issue (ie, positive opinion).

ROAMM EMA Compliance

Compliance with each ROAMM app prompt was calculated in two ways. First, a raw compliance rate was calculated as the number of actual responses divided by the total number of possible responses assuming the watch was delivering the EMAs during programmed times:

(Total responses / Total number of possible responses) × 100.

Second, it was important to adjust the compliance rate to not *penalize* participants for potential technical issues or for when the watch was not being worn (ie, when charging). For this calculation, time windows with <3 hours of sensor data (ie, the watch was turned off during a time when an EMA could be delivered) or if the watch was charging for >30 minutes were flagged. Flagged time windows were not counted *against* the participant for nonresponsiveness (ie, they were not included in the denominator of the compliance rate). We considered this form of ”adjusted“ compliance in the stratified analysis described below. Only days where there were >3 hours of data, signifying a sufficient time to judge compliance, were considered in the analysis.

Data Analysis

Comparisons of dichotomous responses on the patient satisfaction surveys were described as proportions and analyzed using Fisher exact test. Questions that contained multiple answers or free text were tallied, but formal statistical comparisons were not performed owing to the low number of responses. Adjusted compliances were compared using the Student *t* test between two groups and one-way analysis of variance with posthoc tests for more than two comparisons. Differences and associations were considered statistically significant at an α level <.05.

Results

Characteristics of the Study Population

Table 1 provides demographic characteristics of 27 of the 28 participants who completed the demographic questionnaire. Their mean age was 73.2 (SD 5.5) years, with a total of 19 (70%) female participants, 21 (78%) White participants, and 24 (89%) participants with a college-level education. Participants were moderately active, and most were overweight (n=10, 37%) or obese (n=9, 33%).

XSL•FO
RenderX

Table 1. Characteristics of study participants (N=27).

Characteristic	Participants
Age (years), mean (SD)	73.2 (5.5)
Sex, female, n (%)	19 (70)
Race, n (%)	
White	21 (78)
Other	6 (22)
Education level, n (%)	
College education	24 (89)
Other	3 (11)
Living status, n (%)	
Lives alone	6 (22)
Other	21 (78)
Housing, n (%)	
Single-family home	22 (82)
Other	5 (19)
Morphology	
Height (m), mean (SD)	1.7 (0.1)
Weight (kg), mean (SD)	80 (21.4)
BMI (kg/m^2), mean (SD)	28.3 (5.5)
Obese (BMI ≥30 kg/m^2), n (%)	9 (33)
Overweight (BMI 25-30 kg/m^2), n (%)	10 (37)
Normal (BMI 18.5-25 kg/m^2), n (%)	8 (30)
Physical activity, n (%)	
No regular leisure-time physical activity	4 (15)
Some leisure-time physical activity	13 (48)
Regular leisure-time physical activity	9 (33)
Bill Payment, n (%)	
Somewhat difficult or very difficult time paying bills	13 (48)
Not very difficult	14 (52)

ROAMM Exit Questionnaire to Evaluate Satisfaction and Usability

Of the 26 participants, 81% (21) reported that they would be willing to wear the smartwatch while sleeping, and 85% (22) reported the text was large enough to read (Table 2). Moreover, all 26 participants reported it was easy to enter ratings using the smartwatch. About 77% (20/26) of the participants reported that the smartwatch's battery life ended while they were wearing it. A similar proportion of participants regularly wore a wristwatch (16/26, 62% vs 10/26, 38%; *P*=.16) and answered that they would wear the smartwatch as their personal watch (11/24, 46% vs 13/24, 54%; *P*=.77).

Approximately half of the participants (14/26, 54%) reported the smartwatch was "very comfortable" or "comfortable" (Table 3). A follow-up question asking participants how the smartwatch comfort could be improved received the following responses: no changes (n=7), reduce weight of the watch (n=11), improve wristband clasp function (n=7), reduce display size (n=6), change the material of wrist band (n=6), reduce wrist band size (n=5), and other (size, weight, display and motion detection) (n=8). Despite these criticisms, a majority of the participants reported that they were satisfied with the function of the watch (19/26, 73%; *P*=.002) and charging the battery (20/26, 77; *P*<.001; Table 3).

XSL•FO
RenderX

Table 2. Real-time, online assessment and mobility monitoring exit questionnaire.

Question	Participants,[a] n (%)		*P* value[b]
	Response: yes	Response: no	
Do you regularly wear a wristwatch?	16 (62)	10 (38)	.16
Would you wear the Samsung smartwatch as your personal watch? (n=24)	11 (46)	13 (54)	.77
For research purposes, would you occasionally wear the watch while sleeping?	21 (81)	5 (19)	<.001
Was the text large enough to read?	22 (85)	4 (16)	<.001
Was it easy to enter the ratings using the smartwatch?	26 (100)	0 (0)	N/A[c]
Did you charge it every night?	26 (100)	0 (0)	N/A
Did the watch ever run out of battery (ie, battery died) while you were wearing it?	20 (77)	6 (23)	<.001

[a]Total number of participants is 26, unless otherwise noted in the row header.

[b]Fisher exact test.

[c]N/A: not applicable.

Table 3. Real-time, online assessment and mobility monitoring exit questionnaire (continued).

Question	Participants (N=26), n (%)	*P* value[a]
How satisfied were you with the function of the watch (ie, you were able to tell date/time easily)?		.002
Very satisfied and satisfied, n (%)	19 (73)	
Somewhat satisfied and not satisfied, n (%)	7 (27)	
How satisfied were you with the charging of the battery of the Samsung smartwatch?		<.001
Very satisfied and satisfied, n (%)	20 (78)	
Somewhat satisfied and not satisfied, n (%)	6 (22)	
How comfortable was the Samsung smartwatch to wear on a daily basis?		.78
Very comfortable and comfortable	14 (54)	
Somewhat or not comfortable	12 (46)	
How likely are you to participate in a 1-year research study asking you to wear the Samsung smartwatch daily?		.002
Very likely, likely or somewhat likely	19 (73)	
Not likely	7 (27)	

[a]Fisher exact test.

Furthermore, a majority of the participants (19/26, 73%; *P*=.002) expressed their willingness to use the ROAMM app for a 1-year research study. In a follow-up question that asked the participants the reasons for responding ”not likely“ or ”somewhat likely“ (n=11), participants cited lack of comfort (n=5), (the watch was) not stylish (n=3), gets in the way (n=4), screen was hard to read (n=3), screen was unresponsive (n=4), privacy issue (n=1), technical issue (n=5), and size or weight issues (n=1). However, some of these participants were willing to wear the smartwatch for 1 month (n=5) or 3 months (n=1). Only 3 participants reported not willing to wear the watch at all.

All participants were asked to provide additional comments on the ROAMM app and the smartwatch. Those who opted to respond commented on technical issues (battery charging: n=10; temperature of the watch being too hot: n=2) and usability issues (resetting the watch: n=5; unresponsive screen: n=1; and size, weight, or display issues: n=7). There were positive opinions about the health monitoring aspects (n=4) and the ability to use the device as a phone or for email and calendar use (n=2).

ROAMM EMA Compliance Rates

Twenty-eight participants wore the smartwatch for a mean of 13.9 (SD 0.4) days. When considering only those days with >3 hours of wear-time, participants wore the watch for a mean of 11.3 (SD 0.6) days. The accumulated total was 316 days recorded along with a total of 2505 smartwatch responses. The raw compliance rate was 61% (2505/4108) and the adjusted compliance rate was 83% (2505/3036). Specific to different windows throughout the day, the adjusted compliance rate was 86% (1004/1161) in the morning, 79% (800/1016) in the afternoon, and 77% (701/908) in the evening; details of adjusted compliance rate according to EMA responses in each window are shown in Table 4.

XSL•FO
RenderX

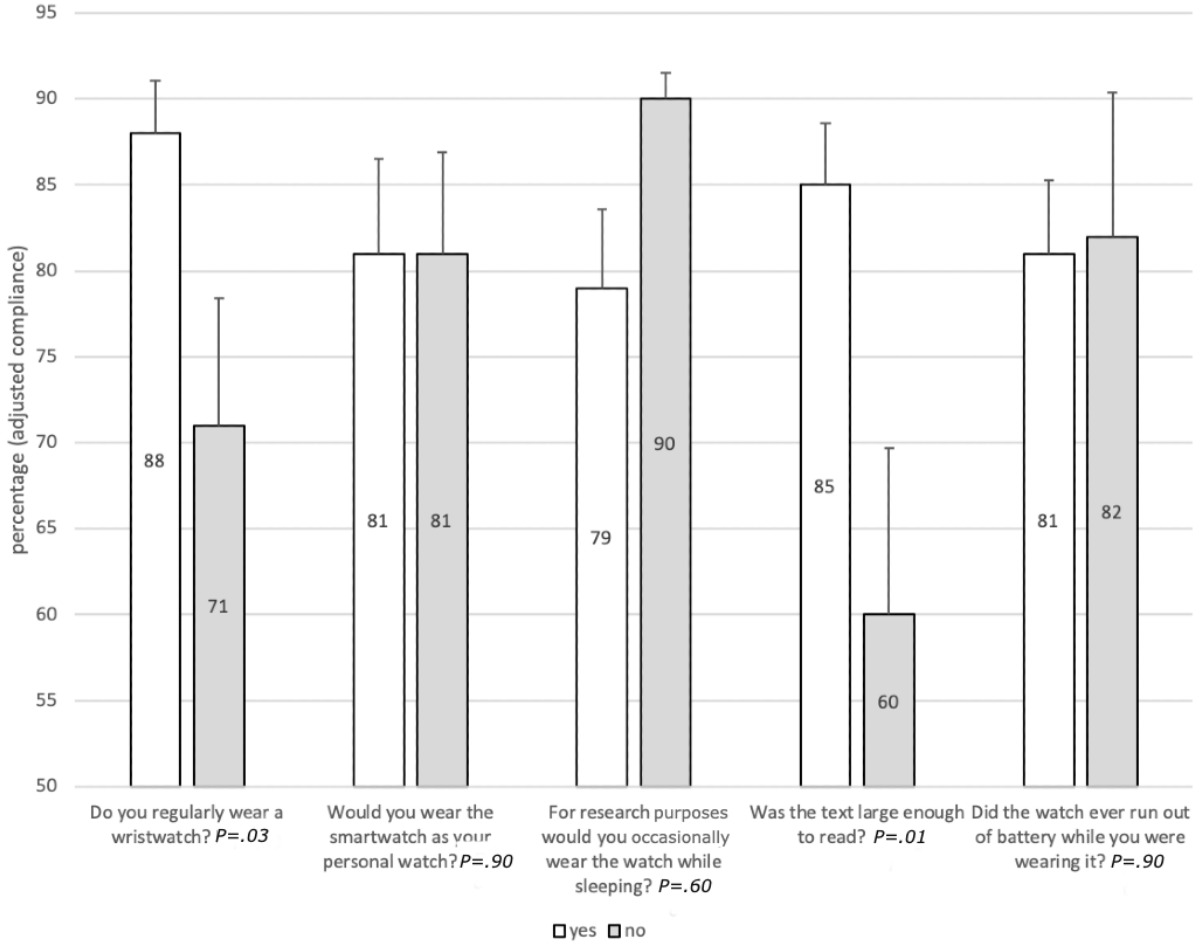
Table 4. Adjusted compliance rates according to ecological momentary assessment responses across the three evaluation windows.

Evaluation window	Sleep	Pain	Mood	Fatigue	Activity
Morning	.93	.875	.873	.87	.82
Afternoon	N/A[a]	.84	.823	.83	.71
Evening	N/A	.815	.795	.81	.71

[a]N/A: not applicable.

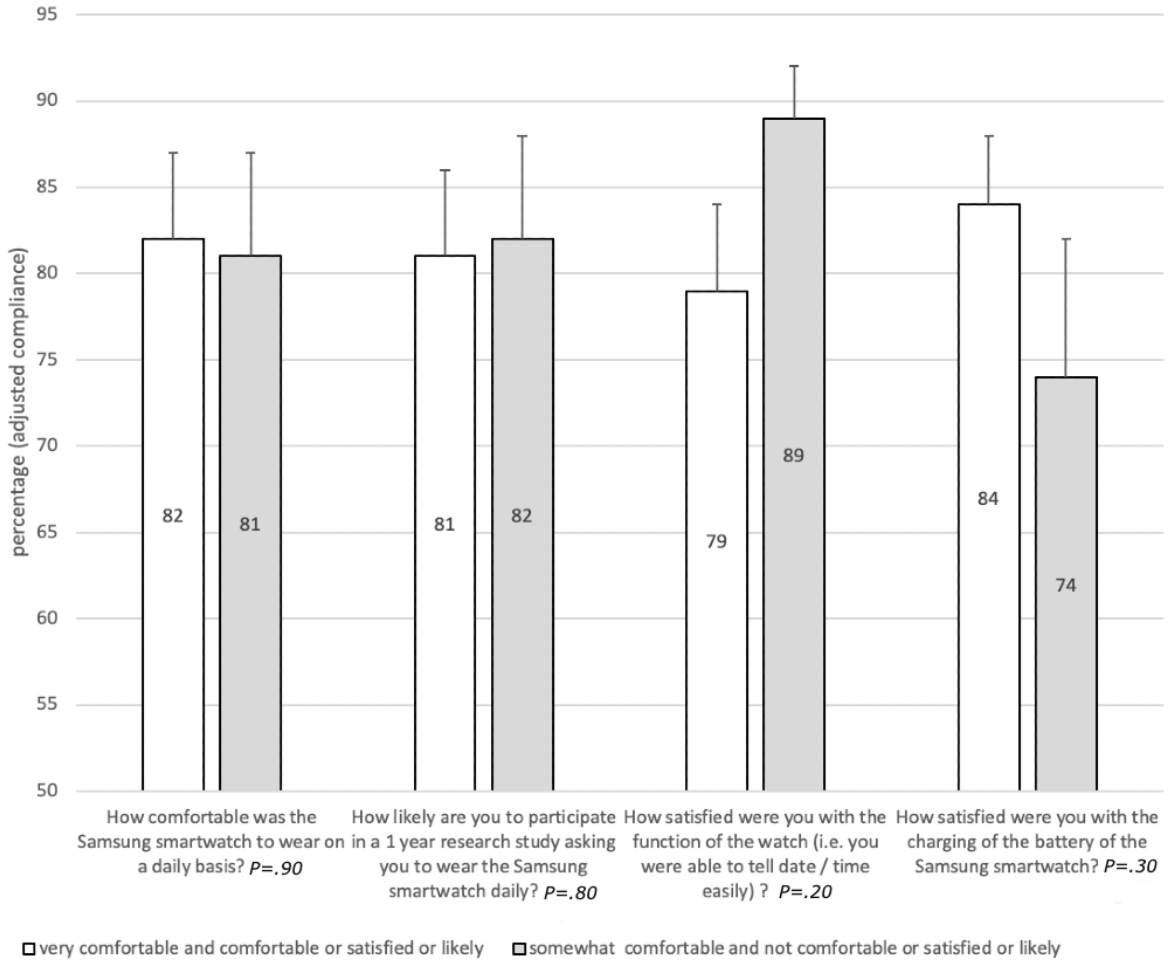
Average adjusted compliance for EMA prompts were similar for pain, mood, fatigue, activity, and sleep (*P*=.14), although compliance was consistently lowest for reporting activity, which was the final question of the bundle. Moreover, average adjusted compliance rates were similar across the three time windows (*P*=.92). We explored potential reasons for compliance differences in a stratified analysis. Adjusted compliance was lower among those who do not regularly wear a wristwatch (88% vs 71%; *P*=.03) and was better among those who thought the text was large enough to read (86% vs 60%; *P*=.01) (Figure 2). No differences in adjusted compliance rates were observed for participants who reported higher satisfaction levels, those who were more likely to wear the watch for a 1-year study, those who would wear the smartwatch as a personal watch, and those who reported the smartwatch did run out of battery (Figures 2 and 3).

Figure 2. Adjusted compliance average according to responses from the real-time online assessment and mobility monitoring app exit questionnaire for Yes and No responses.



XSL•FO
RenderX

Figure 3. Adjusted compliance average according to responses from the real-time online assessment and mobility monitoring app exit questionnaire for Likert's responses.



Discussion

Gerontechnology is a relatively new concept that aims to promote health and well-being through technology that considers older adults' needs and preferences [45]. The ROAMM app was developed based on these guiding principles and was designed to capture information about gerontological symptoms in the free-living environment. To ensure the technology is appropriate for this population, our research team and others have conducted focus groups to gather feedback about *gero-friendly* visualization (eg, display size) and functionality [27,46-49]. In the next phase of this study, we evaluated the technology in a small target sample. In this context, the purpose of this study was to evaluate the ROAMM smartwatch app for usability, satisfaction, and compliance in a patient population of older adults with knee osteoarthritis. Subsequent paragraphs interpret the results within the framework of gerontechnology and compare the current results to the existing literature. Based on our exit questionnaire, a majority of participants positively rated the ROAMM app display and functionality (eg, rotating dial). About half of the participants felt the smartwatch was uncomfortable, but almost three-fourths were likely to participate in a long-term study asking them to wear the smartwatch. Additionally, EMA compliance rates reported here were similar to a recent meta-analysis that pooled data from 701 participants across 12 EMA studies [50]. The high EMA compliance rates also indicate that older adults were able to use the app in free-living conditions. Participants also responded that it was easy to enter information using the rotating bezel, the text was sufficiently large, and they were satisfied with charging the smartwatch and effectively charging it every night. These responses culminated in a high likelihood of participating in research asking them to wear the smartwatch in a 1-year study—a goal for research related to health monitoring. However, it should be noted that willingness to participate in a long-duration study might not transfer to long-term compliance. Overall, our results suggest that older adults with knee osteoarthritis were generally satisfied with the ROAMM app and smartwatch, but the next intervention requires improved comfort and wearability for planning long-term studies.

Battery drain was a consistent issue observed during the study. The ROAMM app collects sensor data simultaneously with EMA data. We previously reported that the battery is most susceptible to the GPS sensor, with approximately 1% battery drain per collected sample [29]. This drain is exponentially increased when all sensors are collected simultaneously and further affected when the screen is activated during EMA responses. In a similar study, investigators from the KOALAP (Knee Osteoarthritis, Linking Activity and Pain) study also struggled to ensure the smartwatch battery lasted during the day—about 15 hours. They also found that the lack of battery life significantly impacted engagement with the smartwatch

XSL•FO
RenderX

[51]. Additional innovation is needed on battery technology, smart sensor triggering (eg, activate accelerometer during movement only, activate GPS outside a geofence), and energy efficiency to ensure that apps like ROAMM are capable of health monitoring for an entire waking day. Advances in sensor technology and EMA tools for health monitoring are only effective if sufficient compliance is demonstrated [52]. The compliance rates reached in this study were consistent with systematic reviews of EMA for assessing chronic pain in adults (eg, 83% [53] and 86% [54]). However, achieving good compliance is a multifactorial challenge, as it involves the type of behavioral coaching, perceived burden, demographics of the population, and the usability of the technology [55]. Regarding the demographics, older adults tend to have higher compliance (88%-90% at 75 years old) than younger adults (72%-74% at 25 years old) even in technology-based evaluations, as reported in a chronic pain study [50]. In fact, an EMA-based study in older African American adults reported over a 90% compliance rate when rating their activity and stress, four times per day, on a smartphone [56]. There was also some evidence that fewer questions yielded higher compliance. We observed that a single sleep quality question in the morning yielded the highest compliance. In prior work, microinteraction EMAs—where people are prompted with fast, glanceable questions that could be answered in a few seconds similar to ROAMM—were developed on smartwatches and compared to less-frequent EMA prompts on smartphones. Researchers found that although prompts on the smartwatch were eight times more frequent than those on the smartphone, participants were 35% more compliant to short microinteraction EMAs on the smartwatch [57]. Participants also responded to EMAs in less time and reported the EMAs to be less distracting on the smartwatch than on the smartphone [58]. Therefore, EMAs on a smartwatch might serve as an excellent approach for longitudinal studies, which was also conveyed by a majority of older adults in our study who were willing to participate in a 1-year research study.

Stratified analysis of compliance rates yielded important information for practice and for planning future research. In general, compliance was similar between participants with different opinions of the comfort and satisfaction with the function of the smartwatch and ROAMM app. Unexpectedly, compliance was similar among participants not likely to wear the smartwatch as their own personal watch and those who would not volunteer for a 1-year research study. Participants regularly wearing a wristwatch had significantly higher compliance than nonwearers. Furthermore, individuals who had difficulty reading the text on the watch had lower compliance than those who did not experience difficulties. In the focus group study, approximately 80% of the respondents reported the display text size was adequate [27]. In the current study the same results were found (24/28, 79%) and participants reported the text was large enough. To be more inclusive and generalize to the population as a whole, future studies will need to consider whether people regularly wear watches and ensure text size or fonts are optimized for compliance.

There are strengths and weaknesses of this study that will aid in conducting future research using smartwatch devices for monitoring health. One of the weaknesses is that this study was performed on a relatively small, homogenous sample of older adults with knee osteoarthritis. In particular, this was a well-educated sample, and the results may not be generalizable to individuals with lower levels of education. Furthermore, we did not employ a commonly used ”usability“ scale for assessing the ROAMM app, which makes comparisons to the literature difficult. At the time of data collection, existing scales were not appropriate for assessing both the software and hardware of wearable devices. Moreover, despite internal pilot testing, rapid battery drainage found during wear in the free-living environment remained to be an issue. These weaknesses are balanced with some strengths such as the thorough investigation of usability and user compliance following an extended use of the ROAMM app in real-world settings.

In conclusion, older adults with knee osteoarthritis positively rated and were generally satisfied with the ROAMM app on the Samsung smart watch. Battery life remains a concern and will need to be carefully considered in future studies. Compliance rates were generally high but were impacted by personal experiences wearing a watch and text readability. After using the ROAMM app for about 2 weeks, a majority of older adults were willing to participate in a 1-year study requiring them to wear the smartwatch. Overall, the results support new opportunities to monitor health symptoms while capturing objective sensor information from a smartwatch in older adults with knee osteoarthritis.

Acknowledgments

This study was funded by the Data Science and Applied Technology (DSAT); Core of the Claude D. Pepper Older Americans Independence Center at the University of Florida (UF) (P30 AG028740). The UF Informatics Institute and the UF Clinical and Translational Science Institute contributed for partial funding (R21 AG059207) supporting staff and faculty during the project.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Exit questionnaire to be filled in by the participants after 2 weeks.
[PDF File (Adobe PDF File), 110 KB - aging_v4i3e24553_app1.pdf]

XSL•FO
RenderX

References

1. Sama PR, Eapen ZJ, Weinfurt KP, Shah BR, Schulman KA. An evaluation of mobile health application tools. JMIR Mhealth Uhealth 2014 May 01;2(2):e19 [FREE Full text] [doi: 10.2196/mhealth.3088] [Medline: 25099179]
2. Peart DJ, Balsalobre-Fernández C, Shaw MP. Use of mobile applications to collect data in sport, health, and exercise science: a narrative review. J Strength Cond Res 2019 Apr;33(4):1167-1177. [doi: 10.1519/JSC.0000000000002344] [Medline: 29176384]
3. Allen KD, Coffman CJ, Golightly YM, Stechuchak KM, Keefe FJ. Daily pain variations among patients with hand, hip, and knee osteoarthritis. Osteoarthritis Cartilage 2009 Oct;17(10):1275-1282 [FREE Full text] [doi: 10.1016/j.joca.2009.03.021] [Medline: 19410670]
4. Murphy SL, Kratz AL, Williams DA, Geisser ME. The association between symptoms, pain coping strategies, and physical activity among people with symptomatic knee and hip osteoarthritis. Front Psychol 2012;3:326 [FREE Full text] [doi: 10.3389/fpsyg.2012.00326] [Medline: 22969747]
5. Lim SS, Vos T, Flaxman AD, Danaei G, Shibuya K, Adair-Rohani H, et al. A comparative risk assessment of burden of disease and injury attributable to 67 risk factors and risk factor clusters in 21 regions, 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010. Lancet 2012 Dec 15;380(9859):2224-2260 [FREE Full text] [doi: 10.1016/S0140-6736(12)61766-8] [Medline: 23245609]
6. Bartley EJ, Palit S, Staud R. Predictors of osteoarthritis pain: the importance of resilience. Curr Rheumatol Rep 2017 Sep;19(9):57 [FREE Full text] [doi: 10.1007/s11926-017-0683-3] [Medline: 28752491]
7. Hunter DJ, Guermazi A, Roemer F, Zhang Y, Neogi T. Structural correlates of pain in joints with osteoarthritis. Osteoarthritis Cartilage 2013 Sep;21(9):1170-1178 [FREE Full text] [doi: 10.1016/j.joca.2013.05.017] [Medline: 23973127]
8. Kolasinski SL, Neogi T, Hochberg MC, Oatis C, Guyatt G, Block J, et al. 2019 American College of Rheumatology/Arthritis Foundation Guideline for the Management of Osteoarthritis of the Hand, Hip, and Knee. Arthritis Rheumatol 2020 Feb;72(2):220-233 [FREE Full text] [doi: 10.1002/art.41142] [Medline: 31908163]
9. Hunter DJ, Bierma-Zeinstra S. Osteoarthritis. Lancet 2019 Apr 27;393(10182):1745-1759. [doi: 10.1016/S0140-6736(19)30417-9] [Medline: 31034380]
10. Juhl C, Lund H, Roos EM, Zhang W, Christensen R. A hierarchy of patient-reported outcomes for meta-analysis of knee osteoarthritis trials: empirical evidence from a survey of high impact journals. Arthritis 2012;2012:136245 [FREE Full text] [doi: 10.1155/2012/136245] [Medline: 22792458]
11. Dobson F, Hinman RS, Hall M, Marshall CJ, Sayer T, Anderson C, et al. Reliability and measurement error of the Osteoarthritis Research Society International (OARSI) recommended performance-based tests of physical function in people with hip and knee osteoarthritis. Osteoarthritis Cartilage 2017 Nov;25(11):1792-1796 [FREE Full text] [doi: 10.1016/j.joca.2017.06.006] [Medline: 28647467]
12. Daoust R, Sirois M, Lee JS, Perry JJ, Griffith LE, Worster A, et al. Painful memories: reliability of pain intensity recall at 3 months in senior patients. Pain Res Manag 2017;2017:5983721 [FREE Full text] [doi: 10.1155/2017/5983721] [Medline: 28260963]
13. Sim I. Mobile devices and health. N Engl J Med 2019 Sep 05;381(10):956-968. [doi: 10.1056/nejmra1806949]
14. Zhao P, Yoo I, Lancey R, Varghese E. Mobile applications for pain management: an app analysis for clinical usage. BMC Med Inform Decis Mak 2019 May 30;19(1):106 [FREE Full text] [doi: 10.1186/s12911-019-0827-7] [Medline: 31146739]
15. Larson R, Csikszentmihalyi M. The Experience Sampling Method. In: Flow and the Foundations of Positive Psychology. Dordrecht: Springer; 2014:21-34.
16. Bradburn NM, Rips LJ, Shevell SK. Answering autobiographical questions: the impact of memory and inference on surveys. Science 1987 Apr 10;236(4798):157-161. [doi: 10.1126/science.3563494] [Medline: 3563494]
17. Schwarz N. Self-reports: How the questions shape the answers. Am Psychol 1999;54(2):93-105. [doi: 10.1037/0003-066X.54.2.93]
18. Smyth JM, Smyth JM. Ecological momentary assessment research in behavioral medicine. J Happiness Stud 2003;4(1):35-52. [doi: 10.1023/A:1023657221954]
19. Shiffman S, Stone AA, Hufford MR. Ecological momentary assessment. Annu Rev Clin Psychol 2008;4:1-32. [doi: 10.1146/annurev.clinpsy.3.022806.091415] [Medline: 18509902]
20. Boulos MNK, Brewer AC, Karimkhani C, Buller DB, Dellavalle RP. Mobile medical and health apps: state of the art, concerns, regulatory control and certification. Online J Public Health Inform 2014;5(3):229 [FREE Full text] [doi: 10.5210/ojphi.v5i3.4814] [Medline: 24683442]
21. McManus DD, Trinquart L, Benjamin EJ, Manders ES, Fusco K, Jung LS, et al. Design and preliminary findings from a new electronic cohort embedded in the Framingham heart study. J Med Internet Res 2019 Mar 01;21(3):e12143 [FREE Full text] [doi: 10.2196/12143] [Medline: 30821691]
22. Murphy SL, Smith DM. Ecological measurement of fatigue and fatigability in older adults with osteoarthritis. J Gerontol A Biol Sci Med Sci 2010 Feb;65(2):184-189 [FREE Full text] [doi: 10.1093/gerona/glp137] [Medline: 19776216]
23. Beukenhorst AL, Howells K, Cook L, McBeth J, O'Neill TW, Parkes MJ, et al. Engagement and participant experiences with consumer smartwatches for health research: longitudinal, observational feasibility study. JMIR Mhealth Uhealth 2020 Jan 29;8(1):e14368 [FREE Full text] [doi: 10.2196/14368] [Medline: 32012078]

XSL•FO
RenderX

24. Policy for Device Software Functions and Mobile Medical Applications. U.S. Food and Drug Administration (FDA). 2019 Sep 27. URL: https://www.fda.gov/regulatory-information/search-fda-guidance-documents/policy-device-software-functions-and-mobile-medical-applications [accessed 2021-06-25]
25. Patient-reported outcome measures: use in medical product development to support labeling claims. U.S. Food and Drug Administration (FDA). 2019 Dec. URL: http://www.fda.gov/regulatory-information/search-fda-guidance-documents/patient-reported-outcome-measures-use-medical-product-development-support-labeling-claims [accessed 2020-07-01]
26. Quality System (QS) Regulation/Medical Device Good Manufacturing Practices Internet. U.S. Food and Drug Administration (FDA). URL: https://www.fda.gov/medical-devices/postmarket-requirements-devices/quality-system-qs-regulationmedical-device-good-manufacturing-practices [accessed 2020-04-28]
27. Manini TM, Mendoza T, Battula M, Davoudi A, Kheirkhahan M, Young ME, et al. Perception of older adults toward smartwatch technology for assessing pain and related patient-reported outcomes: pilot study. JMIR Mhealth Uhealth 2019 Mar 26;7(3):e10044 [FREE Full text] [doi: 10.2196/10044] [Medline: 30912756]
28. Alpert JM, Manini T, Roberts M, Kota NSP, Mendoza TV, Solberg LM, et al. Secondary care provider attitudes towards patient generated health data from smartwatches. NPJ Digit Med 2020;3:27 [FREE Full text] [doi: 10.1038/s41746-020-0236-4] [Medline: 32140569]
29. Kheirkhahan M, Nair S, Davoudi A, Rashidi P, Wanigatunga AA, Corbett DB, et al. A smartwatch-based framework for real-time and online assessment and mobility monitoring. J Biomed Inform 2019 Jan;89:29-40 [FREE Full text] [doi: 10.1016/j.jbi.2018.11.003] [Medline: 30414474]
30. Gould D, Kelly D, Goldstone L, Gammon J. Examining the validity of pressure ulcer risk assessment scales: developing and using illustrated patient simulations to collect the data. Information point: visual analogue scale. J Clin Nurs 2001 Sep;10(5):697-706. [doi: 10.1046/j.1365-2702.2001.00525.x] [Medline: 11822520]
31. Paul-Dauphin A, Guillemin F, Virion JM, Briançon S. Bias and precision in visual analogue scales: a randomized controlled trial. Am J Epidemiol 1999 Nov 15;150(10):1117-1127. [doi: 10.1093/oxfordjournals.aje.a009937] [Medline: 10568628]
32. McCormack HM, Horne DJ, Sheather S. Clinical applications of visual analogue scales: a critical review. Psychol Med 1988 Nov;18(4):1007-1019. [doi: 10.1017/s0033291700009934] [Medline: 3078045]
33. Huskisson EC. Measurement of pain. Lancet 1974 Nov 09;2(7889):1127-1131. [doi: 10.1016/s0140-6736(74)90884-8] [Medline: 4139420]
34. Downie WW, Leatham PA, Rhind VM, Wright V, Branco JA, Anderson JA. Studies with pain rating scales. Ann Rheum Dis 1978 Aug;37(4):378-381 [FREE Full text] [doi: 10.1136/ard.37.4.378] [Medline: 686873]
35. Monk T, Reynolds C, Kupfer D, Buysse D, Coble P, Hayes A, et al. The Pittsburgh Sleep Diary. J Sleep Res 1994;3(2):120. [doi: 10.1111/j.1365-2869.1994.tb00114.x]
36. Smith MT, Wegener ST. Measures of sleep: The Insomnia Severity Index, Medical Outcomes Study (MOS) Sleep Scale, Pittsburgh Sleep Diary (PSD), and Pittsburgh Sleep Quality Index (PSQI). Arthritis & Rheumatism 2003 Oct 15;49(S5):S184-S196. [doi: 10.1002/art.11409]
37. Jamison RN, Gracely RH, Raymond SA, Levine JG, Marino B, Herrmann TJ, et al. Comparative study of electronic vs. paper VAS ratings: a randomized, crossover trial using healthy volunteers. Pain 2002 Sep;99(1-2):341-347. [doi: 10.1016/s0304-3959(02)00178-1] [Medline: 12237213]
38. Farrar JT, Young JP, LaMoreaux L, Werth JL, Poole RM. Clinical importance of changes in chronic pain intensity measured on an 11-point numerical pain rating scale. Pain 2001 Nov;94(2):149-158. [doi: 10.1016/S0304-3959(01)00349-9] [Medline: 11690728]
39. Hjermstad M, Fayers P, Haugen D, Caraceni A, Hanks G, Loge J, European Palliative Care Research Collaborative (EPCRC). Studies comparing Numerical Rating Scales, Verbal Rating Scales, and Visual Analogue Scales for assessment of pain intensity in adults: a systematic literature review. J Pain Symptom Manage 2011 Jun;41(6):1073-1093 [FREE Full text] [doi: 10.1016/j.jpainsymman.2010.08.016] [Medline: 21621130]
40. Hacker ED, Ferrans CE. Ecological momentary assessment of fatigue in patients receiving intensive cancer therapy. J Pain Symptom Manage 2007 Mar;33(3):267-275 [FREE Full text] [doi: 10.1016/j.jpainsymman.2006.08.007] [Medline: 17349496]
41. Piper BF, Borneman T, Sun VC, Koczywas M, Uman G, Ferrell B, et al. Cancer-related fatigue: role of oncology nurses in translating National Comprehensive Cancer Network assessment guidelines into practice. Clin J Oncol Nurs 2008 Oct;12(5 Suppl):37-47 [FREE Full text] [doi: 10.1188/08.CJON.S2.37-47] [Medline: 18842523]
42. Curran SL, Beacham AO, Andrykowski MA. Ecological momentary assessment of fatigue following breast cancer treatment. J Behav Med 2004 Oct;27(5):425-444. [doi: 10.1023/b:jobm.0000047608.03692.0c]
43. Cella DF, Perry SW. Reliability and concurrent validity of three visual-analogue mood scales. Psychol Rep 1986 Oct;59(2 Pt 2):827-833. [doi: 10.2466/pr0.1986.59.2.827] [Medline: 3809343]
44. Folstein MF, Luria R. Reliability, validity, and clinical application of the Visual Analogue Mood Scale. Psychol Med 1973 Nov;3(4):479-486. [doi: 10.1017/s0033291700054283] [Medline: 4762224]
45. Özsungur F. Gerontechnological factors affecting successful aging of elderly. Aging Male 2020 Dec;23(5):520-532. [doi: 10.1080/13685538.2018.1539963] [Medline: 30741066]
46. Mitzner TL, Savla J, Boot WR, Sharit J, Charness N, Czaja SJ, et al. Technology adoption by older adults: findings from the PRISM trial. Gerontologist 2019 Jan 09;59(1):34-44 [FREE Full text] [doi: 10.1093/geront/gny113] [Medline: 30265294]

XSL•FO
RenderX

47. Bergschöld JM, Neven L, Peine A. DIY gerontechnology: circumventing mismatched technologies and bureaucratic procedure by creating care technologies of one's own. Sociol Health Illn 2020 Feb;42(2):232-246. [doi: 10.1111/1467-9566.13012] [Medline: 31663618]
48. Chen K, Chan AHS. Gerontechnology acceptance by elderly Hong Kong Chinese: a senior technology acceptance model (STAM). Ergonomics 2014;57(5):635-652. [doi: 10.1080/00140139.2014.895855] [Medline: 24655221]
49. Peek STM, Luijkx KG, Vrijhoef HJM, Nieboer ME, Aarts S, van der Voort CS, et al. Understanding changes and stability in the long-term use of technologies by seniors who are aging in place: a dynamical framework. BMC Geriatr 2019 Aug 28;19(1):236 [FREE Full text] [doi: 10.1186/s12877-019-1241-9] [Medline: 31462214]
50. Ono M, Schneider S, Junghaenel DU, Stone AA. What affects the completion of ecological momentary assessments in chronic pain research? an individual patient data meta-analysis. J Med Internet Res 2019 Feb 05;21(2):e11398 [FREE Full text] [doi: 10.2196/11398] [Medline: 30720437]
51. Beukenhorst AL, Parkes MJ, Cook L, Barnard R, van der Veer SN, Little MA, et al. Collecting symptoms and sensor data with consumer smartwatches (the Knee OsteoArthritis, Linking Activity and Pain Study): Protocol for a Longitudinal, Observational Feasibility Study. JMIR Res Protoc 2019 Jan 23;8(1):e10238 [FREE Full text] [doi: 10.2196/10238] [Medline: 30672745]
52. NA. Ecological momentary assessments and the science of behavior change. Exerc Sport Sci Rev 2017 Jan;45(1):3. [doi: 10.1249/JES.0000000000000091] [Medline: 27741024]
53. Morren M, van Dulmen S, Ouwerkerk J, Bensing J. Compliance with momentary pain measurement using electronic diaries: a systematic review. Eur J Pain 2009 Apr;13(4):354-365. [doi: 10.1016/j.ejpain.2008.05.010] [Medline: 18603458]
54. May M, Junghaenel DU, Ono M, Stone AA, Schneider S. Ecological momentary assessment methodology in chronic pain research: a systematic review. J Pain 2018 Jul;19(7):699-716 [FREE Full text] [doi: 10.1016/j.jpain.2018.01.006] [Medline: 29371113]
55. Hekler EB, Klasnja P, Traver V, Hendriks M. Realizing effective behavioral management of health: the metamorphosis of behavioral science methods. IEEE Pulse 2013 Sep;4(5):29-34. [doi: 10.1109/MPUL.2013.2271681] [Medline: 24056791]
56. Fritz H, Tarraf W, Saleh DJ, Cutchin MP. Using a smartphone-based ecological momentary assessment protocol with community dwelling older African Americans. J Gerontol B Psychol Sci Soc Sci 2017 Sep 01;72(5):876-887 [FREE Full text] [doi: 10.1093/geronb/gbw166] [Medline: 28057696]
57. Intille S, Haynes C, Maniar D, Ponnada A, Manjourides J. µEMA: microinteraction-based ecological momentary assessment (EMA) using a smartwatch. In: Proc ACM Int Conf Ubiquitous Comput. Proc 2016 ACM Int Jt Conf Pervasive Ubiquitous Comput Internet Heidelberg Germany: ACM; 2016 Sep Presented at: proceedings acm international conference ubiquitous computing; 2016 september; Germany Heidelberg p. 1124-1128 URL: http://europepmc.org/abstract/MED/30238088 [doi: 10.1145/2971648.2971717]
58. Ponnada A, Haynes C, Maniar D, Manjourides J, Intille S. Microinteraction ecological momentary assessment response rates: effect of microinteractions or the smartwatch? Proc ACM Interact Mob Wearable Ubiquitous Technol 2017 Sep;1(3):92 [FREE Full text] [doi: 10.1145/3130957] [Medline: 30198012]

Abbreviations

DSAT: Data Science and Applied Technology
EMA: ecological momentary assessment
FDA: Food and Drug Administration
KOALAP: Knee Osteoarthritis, Linking Activity and Pain
ROAMM: real-time, online assessment and mobility monitoring
UF: University of Florida

Edited by J Wang; submitted 24.09.20; peer-reviewed by D Bychkov, F Lamers; comments to author 24.11.20; revised version received 12.01.21; accepted 22.04.21; published 14.07.21.

Please cite as:
Rouzaud Laborde C, Cenko E, Mardini MT, Nerella S, Kheirkhahan M, Ranka S, Fillingim RB, Corbett DB, Weber E, Rashidi P, Manini T
Satisfaction, Usability, and Compliance With the Use of Smartwatches for Ecological Momentary Assessment of Knee Osteoarthritis Symptoms in Older Adults: Usability Study
JMIR Aging 2021;4(3):e24553
URL: https://aging.jmir.org/2021/3/e24553
doi:10.2196/24553
PMID:34259638

XSL•FO
RenderX

©Charlotte Rouzaud Laborde, Erta Cenko, Mamoun T Mardini, Subhash Nerella, Matin Kheirkhahan, Sanjay Ranka, Roger B Fillingim, Duane B Corbett, Eric Weber, Parisa Rashidi, Todd Manini. Originally published in JMIR Aging (https://aging.jmir.org), 14.07.2021. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Aging, is properly cited. The complete bibliographic information, a link to the original publication on https://aging.jmir.org, as well as this copyright and license information must be included.

XSL•FO
RenderX

Review

Using Living Labs to Explore Needs and Solutions for Older Adults With Dementia: Scoping Review

Henk Verloo[1,2], PhD; Adrien Lorette[2], MD; Joëlle Rosselet Amoussou[3], MSc; Estelle Gillès de Pélichy[4], MD; Alcina Matos Queirós[5,6], MSc; Armin von Gunten[7], MD; Elodie Perruchoud[1], MSc

[1]School of Health Sciences HES-SO Valais and Department of Nursing Sciences, University of Applied Sciences and Arts Western Switzerland, Sion, Switzerland

[2]Service of Old Age Psychiatry, Lausanne University Hospital, Prilly-Lausanne, Switzerland

[3]Psychiatry Library, Education and Research Department, Lausanne University Hospital and University of Lausanne, Prilly-Lausanne, Switzerland

[4]Service of Old Age Psychiatry, Sector West, Prangins Hospital, Lausanne University Hospital, Prangins, Switzerland

[5]Department of Health and Social Welfare, Lausanne, Switzerland

[6]Institute of Biomedical Sciences Abel Salazar, University of Porto, Porto, Portugal

[7]Head of the Service of Old Age Psychiatry, Lausanne University Hospital, Prilly-Lausanne, Switzerland

Corresponding Author:
Henk Verloo, PhD
School of Health Sciences HES-SO Valais and Department of Nursing Sciences
University of Applied Sciences and Arts Western Switzerland
Chemin de l'Agasse 5
Sion, 1950
Switzerland
Phone: 41 78 769 8990
Fax: 41 21 606 8400
Email: henk.verloo@hevs.ch

Abstract

Background: Numerous living labs have established a new approach for studying the health, independent living, and well-being of older adults with dementia. Living labs interact with a broad set of stakeholders, including students, academic institutions, private companies, health care organizations, and patient representative bodies and even with other living labs. Hence, it is crucial to identify the types of cocreations that should be attempted and how they can be facilitated through living labs.

Objective: This study aims to scope publications that examine all types of living lab activities, exploring the needs and expectations of older adults with dementia and seeking solutions, whether they live in the community or long-term health care facilities (LTHFs).

Methods: This scoping review was reported according to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) recommendations for the extension of scoping reviews. We searched six bibliographic databases for publications up to March 2020, and a forward-backward citation chasing was performed. Additional searches were conducted using Google Scholar. The quality of the selected papers was assessed.

Results: Of the 5609 articles identified, we read 58 (1.03%) articles and retained 12 (0.21%) articles for inclusion and final analysis. All 12 articles presented an innovative product, developed in 4 main living labs, to assist older adults with cognitive disorders or dementia living in the community or LTHFs. The objectives of these studies were to optimize health, quality of life, independent living, home care, and safety of older adults with cognitive disorders or dementia, as well as to support professional and family caregivers or reduce their burdens. The overall methodological quality of the studies ranged from poor to moderate.

Conclusions: This scoping review identified several living labs playing a pivotal role in research aimed at older adults with dementia living in the community or LTHFs. However, it also revealed that living labs should conduct more better-quality interventional research to prove the effectiveness of their technological products or service solutions.

International Registered Report Identifier (IRRID): RR2-10.2147/SHTT.S233130

(JMIR Aging 2021;4(3):e29031) doi:10.2196/29031

XSL•FO
RenderX

KEYWORDS

living lab; aged; dementia; cognitive dysfunction; long-term care; primary health care; technology; mobile phone

Introduction

Background

The world's population of people aged >65 years is growing rapidly. In Europe, their proportion has increased from 14% in 2010 to 28% in 2020 [1]. According to the World Health Organization, approximately 20% of people aged ≥65 years have difficulties performing some of the activities of daily living (ADL) or instrumental ADL, often due to reduced mobility, weakened muscular strength, and disorders linked to cognitive disorders [2]. Innovative technologies or services are being used more frequently to provide responses to health problems, particularly for those affected by dementia [3]. In parallel, health care professionals and individual citizens want to participate in relevant, innovative, and implementable solutions that challenge the mainstream conceptions of the targets of health innovation [4]. Recent years have seen numerous studies reporting the advantages of adopting user-centered design approaches for developing innovative solutions. These approaches question users about their needs or observe their behavior with respect to a product, technology, or piece of equipment [5]. More recently, design research has evolved from a user-centered approach, wherein users are considered experimental subjects, to a more participatory approach, wherein users are considered partners [6]. This perspective points to the utility of design methods oriented toward increasing user and stakeholder participation, whether they are nonspecialists or professionals [7,8]. The emergence of living lab (LL) approaches has enabled researchers to go beyond the user-centered vision by adopting a *user-driven* perspective supported by other stakeholders [6]. LLs can turn the main beneficiary of a problem's resolution into an actor with a key role in a scientific process [9].

There are many different definitions of an LL depending on the domain and the author's research field; therefore, a widely recognized definition is lacking [10]. Depending on the definition, LLs are considered as a methodology for user-driven innovation; a user-driven, open-innovation ecosystem; a focus group involving users and stakeholders; or even an experiment in the environment [6]. This scoping review retained the definition presented by Bergvall-Kåreborn and Ståhlbröst [11]: "a living lab is a user-centric innovation environment built on every-day practice and research, with an approach that facilitates user influence in open and distributed innovation processes engaging all relevant partners in real-life contexts, aiming to create sustainable values." With regard to older adults with dementia in different health care settings, Bergvall-Kåreborn and Ståhlbröst [11] also stated that an LL could be "a pragmatic research environment, which openly engages all relevant partners with an emphasis on improving the real-life care of people living with dementia through the use of economically viable and sustainable innovation" [12]. LLs can be viewed as settings for open innovation that provide collaborative platforms for research, development, and experimentation in real-life contexts using specific methodologies and tools [13]. Følstad [14] described nine characteristics of LLs, four of which are discovery, evaluation, familiar contexts, and a focus on the medium to long term. The other five contribute to the variety of LLs as they may or may not be displayed: the investigation of the context, active roles for the users, technical testing, real-world contexts, and multiple settings [14]. In the context of ever-increasing worldwide economic competition, it is becoming necessary for industries and companies to innovate incessantly. However, it has been estimated that 70% of the innovative products and services they develop cannot find a market because they do not meet the real-world user needs [15]. Given that LL solutions are developed under conditions that are designed to be closer to reality and that they can produce more effective solutions to the needs of end users, LLs represent a considerable advantage in many industrial and economic sectors [16]. By using LL platforms and methodologies, companies and health care institutions can reach beyond their own boundaries, follow an open-innovation model [17], and integrate outsiders into the cocreation of products [18], experiences, designs, quality implementation strategies, and service development [17]. LLs often act as intermediaries or innovation facilitators for the cocreation process by providing structure and governance [19,20]. The key components of LLs include information and communication technology (ICT), management, stakeholders, research, and methods of cocreation and product testing [12]. The ICT and infrastructure component reflects the role that new and existing ICT can play in facilitating new means of cooperating and cocreating innovations among stakeholders. The research symbolizes the collective learning and thinking that occurs in an LL and should contribute to both theory and practice. Technological research partners can also provide direct access to the panels of older adult testers of new products, which can benefit the development of technological innovation with regard to criteria such as ease of use [12].

LLs for Older Adults With Dementia

Dementia is a progressive, disabling, chronic disease affecting 5% of all people aged >65 years and >40% of people aged >90 years [21]. Older adults with dementia need a great deal of support and assistance, and this need increases with the progression of the disease [22]. Nevertheless, most older adults prefer to live in their own homes for as long as possible, even if they risk falls, are disabled, or are physically and mentally impaired [23]. Although this decreases the pressure on nursing homes and other long-term health care facilities (LTHFs), it increases pressure on both informal family caregivers and community health professionals [24]. Some research and development has been conducted on cognitive prosthetic devices; however, there are few relevant tools, solutions, or technologies specifically for people with dementia [25].

To the best of our knowledge, there are no clear overviews of the research conducted by LLs either using modern assistive technology specifically designed for older adults with cognitive impairment or dementia or based on their observed and expressed needs. Numerous studies have addressed the areas of concern for aging populations in general rather than specifically for those with dementia [26]. Some studies have

XSL•FO
RenderX

reported on the use of general memory aids that can be used by those affected by memory problems and other cognitive impairments [27]. These studies were often conducted in traditional laboratory settings and did not include older adults in their natural environments. Although laboratory studies are easier to control, their ecological validity is limited [28]. Considering the needs of older adults with dementia in conjunction with relevant technologies has led to the identification of potentially innovative solutions for cognitive reinforcement. The increasing drive to develop innovative, cost-effective dementia care strategies will only work effectively if innovative technologies meet the real needs of people living with dementia. These processes are often only discussed with their informal or professional caregivers, yet there is evidence that people with dementia are very capable of participating [29]. Involving them in the studies of their day-to-day life is challenging; however, because of their impaired cognitive abilities, studies that do not include them will face difficulty demonstrating the potential effects of implementation in real life [29]. LLs can involve people in their natural environments, thus providing more environmentally valid evaluations in the context of innovations for dementia [30].

The literature already contains attempts to explain and analyze the effects of LLs on technology and communication [31,32]. However, the many different and separate needs of older adults with dementia and their respective solutions remain underresearched [33]. This study aims to scope publications examining all the types of LL activities, exploring the needs and expectations of older adults with dementia, and suggesting solutions for them, whether they live in the community or in LTHFs. The following research question defined our search: "What does the literature say about living labs whose activities are dedicated to older adults with dementia living in the community or in LTHFs?" The overall outcomes of this scoping review will provide useful insights into existing activities and identify any remaining gaps in the services provided and the research conducted by LLs [34]. It will summarize knowledge on the contributions of (old age) LLs exploring needs, testing technology, and applying user-based approaches for improving the lives of older adults with dementia living in the community and LTHFs. The specific objectives are identifying LL activities linked to older adults with dementia; describing the fields of action of LLs dedicated to older adults with dementia and the types of research they conduct, investigating the technologies cocreated in LLs to improve the independence and quality of life of older adults with dementia, considering the impact of such solutions with regard to how effectively they reduce burdens on informal and formal caregivers, and addressing how LLs involve various stakeholders in identifying needs and finding solutions for older adults with dementia so that they can live more independently and with a better quality of life.

Methods

Overview

This scoping review was based on the guidelines published by Tricco et al [35]. The research protocol for this scoping review has been documented elsewhere [34]. Studies were included if they provided a description of the cocreation process; research methodology or design; the stakeholders involved; the impact or effects on independence or quality of life; or the impact or effects on health status, as defined by the authors. Studies were included if they were conducted within LLs or by researchers and managers (eg, health care professionals, ICT experts, and engineers) attached to an LL and working with older adults with dementia living in the community or LTHFs.

Outcomes

The primary outcomes were information on the nature, number, and assessment of studies conducted with older adults with dementia performed by or in collaboration with LLs. Secondary outcomes were information on the documentation produced by different types of LLs, their objectives, the location of their interventions, and the types and methods of cocreation used for developing technologies and services for older adults and other stakeholders.

Search Strategy

The search was conducted by a medical librarian (JRA) in March 2020. Six bibliographic databases—were searched—Embase.com, MEDLINE Ovid, PubMed (not MEDLINE[sb]), CINAHL EBSCO, APA PsycINFO Ovid, and the Web of Science Core Collection—with no language or date restrictions. The detailed search strategies are available in Multimedia Appendix 1. Additional searches were conducted in Google Scholar in French and English, and the *Journal of Engineering and Technology Management* (ISSN 0923-4748), *Technology Innovation Management Review* (ISSN 1927-0321), and the *Journal for Virtual Organization and Networks* (ISSN 1741-5225) were manually searched. A forward citation search based on key articles was conducted in the Web of Science Core Collection and Google Scholar in January 2021. Two members of the research team (HV and EP) performed reference screening and reviewed the bibliographies of the selected studies.

Study Screening, Data Collection Process, and Data Items

Two reviewers (HV and EP) independently reviewed the abstracts and full text papers. In cases of disagreement, a consensus was reached through discussions and consultations with the coauthors. The research team developed Microsoft Excel spreadsheets to tabulate data on the studies and interventions and on their study quality assessments. The following information was extracted from each relevant study included and put into an appropriate usable form: (1) study authors, year of publication, and country where the study was conducted; (2) study characteristics (including research questions, study setting and design, sample size, instruments used, duration of follow-up, and stakeholders involved); (3) participants' characteristics (including age, sex, health status, and place of living); and (4) types of outcome measures [36].

Methodological Quality

The quality assessment of the selected papers was conducted using the Joanna Briggs Institute's critical appraisal tools for quantitative, qualitative, and mixed methods studies [37]. Studies were not excluded based on their quality assessment as

XSL•FO
RenderX

we wanted to provide an overview of the available information and its extent.

Data Synthesis

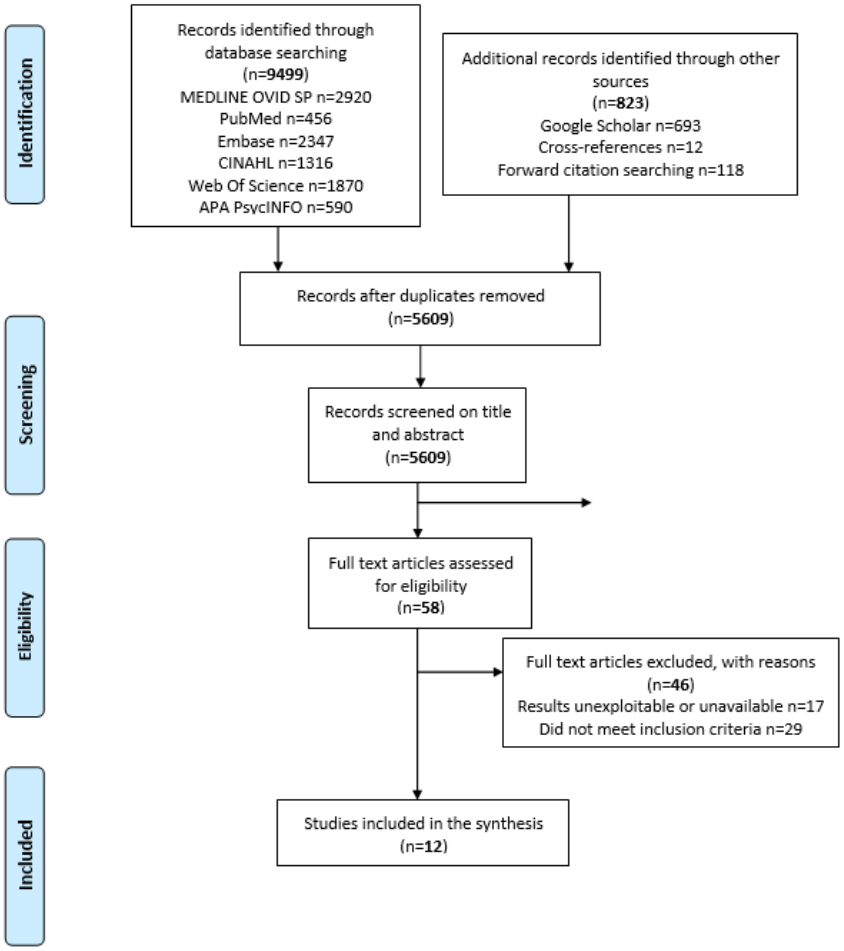
The results are summarized using descriptive narrative synthesis. All data on LLs were integrated into a table.

Results

Search Strategy

Our strategy of searching bibliographic databases retrieved 5609 articles after eliminating duplicates. On the basis of their titles and abstracts, 58 articles were retained as potentially eligible, and their entire texts were evaluated. A total of 12 studies satisfied the selection criteria and were included (Figure 1 [38]).

Figure 1. Flow diagram summarizing the results of the search strategy based on the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) recommendations [38].



Characteristics of Studies and Participants

The 12 included studies were conducted in Canada, France, and the Netherlands and were published between 2009 and 2020 (Tables 1-3; Multimedia Appendix 2 [39-50]). These included 4 case studies, 3 mixed methods studies, 3 qualitative studies, 1 quasi-experimental study, and 1 quantitative, iterative pilot usability study. All these studies presented an innovative product to assist older adults with cognitive disorders or dementia.

XSL•FO
RenderX

Table 1. Characteristics of the included study from the Médéric Alzheimer Foundation living lab in France.

Study	Product	Design	Setting and sample	Method	Results	Quality of life; independence; caregivers

Charras et al [44]	"Dance intervention": a modern and classical dance teacher with a nursing background led a 50-minute dance intervention	Mixed methods study	• Day-care center:
			  • n=23 older adults with Alzheimer disease (12 women and 11 men)
			  • Mean age 83.47 (SD 5.4) years
				• Quantitative data:
				  • Get-Up and Go test; Stop Walking when Talking test; one-leg balance test
				  • Balance Confidence Scale
				  • Quality of Life in Alzheimer Disease
				  • Well-being: participant's feedback
				• Qualitative data: verbalization, behaviors, and attitudes noted in a logbook
					Immediately enhanced well-being of 86% of participants, shorter execution time in the Get-Up and Go test for 66% of participants, variations in participants' social behaviors	Strengthened physical condition and well-being

XSL•FO
RenderX

Table 2. Characteristics of the included studies from the Innovate Dementia living labs in four regions of northwest Europe (Belgium, Germany, the Netherlands, and the United Kingdom).

Study	Product	Design	Setting and sample	Method	Results	Quality of life; independence; caregivers

Brankaert and den Ouden [45]	• "Qwiek Play": a media system that creates an ambient experience through visual projection and sounds	Case study	• Long-term care units:
			  • Study 1: n=14 residents with advanced dementia; n=6 care staff in care home for 29 days
			  • Study 2: n=11 residents with advanced dementia; n=4 care staff in a care home for 33 days
			  • Study 3: n=28 residents with moderate dementia; n=3 care staff in day-care center for 35 days
				• Sequence of activities:
				  • System and research method explained to staff
				  • Staff members invited to use and experiment with the system during the study period and record their experience on an evaluation form
				  • After the study period, additional insights collected during the focus group discussions with care professionals
					• The system had a considerable potential for people with dementia: could reduce need for medication and could help with better sleep. The system increased the efficiency of care provision by giving nurses more time to engage in care practices.	• Reduction of agitation and aggression
						• Improvement of quality of care and reduction of burden on formal caregivers

Suijkerbuijk et al [46]	• "Aangenaam": personal evaluation game with question cards
	• "Vitaallicht": dynamic light system that positively influences the sleep and wake cycle
		Qualitative study	• Community: 12 households; 5 women and 7 men with dementia, and their partners
			• Mean age 74.92 years (SD 6.17; range 66-87 years)
				• Aangenaam: two methods—8 households received personal evaluation game and 4 received a tablet-based questionnaire
				  • Semistructured reflection and questionnaire administered at start and after first and second week
				• Participants used Vitaallicht for 3 weeks
				  • Questionnaire to assess sleep quality
					• Aangenaam results: helped to capture first-person perspectives; a more appropriate research tool for people with dementia; enabled detailed capture of participants' daily lives due to the diverse types of input
					• Vitaallicht results: slight increase of mean subjective sleep quality over 2 weeks
						• Improved sleep quality

XSL•FO
RenderX

Study	Product	Design	Setting and sample	Method	Results	Quality of life; independence; caregivers
Brankaert et al [47]	• "GoLivePhone": smartphone app for communication, personal navigation, and sending out an emergency signal to caregivers	Qualitative study	• Community: n=10 older adults with dementia and their informal caregivers	• 3 home visits over 3 weeks • GPS data: activity levels data to see how often the phone was used • Questionnaire: evaluate experiences and perspectives of participants or caregivers • Reflection sessions: on technology and study	• Device data: phones were used very irregularly • Questionnaire: half of participants had positive experiences • Reflection session: most comments pertained to positive experiences; some difficulties related to technological errors	• Strengthened personal safety and independent walking • Helped to reassure informal caregivers
Brankaert and den Ouden, [48]	• "PhysiCAL": activity reminder calendar to improve day's structure and independence	Case study	• Community: n=4 couples (1 older adult with dementia and 1 informal caregiver)	• For 1 week, 4 couples used PhysiCAL at home. Perceptions collected through interviews	• All the older adults with dementia said they did not need the device, but half of the caregivers noted that it was valuable	• Stimulation of independence • Reduction of informal caregiver's burden

XSL•FO
RenderX

Table 3. Characteristics of the included studies from DOMUS (Laboratoire de Domotique et informatique Mobile à l'Université de Sherbrooke) in Canada.

Study	Product	Design	Setting and sample	Method	Results	Quality of life; independence; caregivers
Imbeault et al [49]	"AP@LZ": electronic organizer to support day-to-day activities and help people to compensate for memory problems	Quasi-experimental study	Community: 3 older adults with Alzheimer disease (aged 71 years, 58 years, and 78 years)	• Measures at 0, 3, 6, and 12 months • Impact on daily living: Multifactorial Memory Questionnaire and Prospective and Retrospective Memory Questionnaire; personalized observation journals • Impact on psychological components: Geriatric Depression Scale and Caregiver Burden Inventory	• Postintervention: participants continued to use the system for managing appointments and making phone calls. • Depressive symptoms did not significantly change in intensity. Decrease in perceived caregiver burden observed for one participant	• Stimulated independence • Reduced informal caregiver's burden
Bier et al [50]	"SemAssist": a computer program to assist people with semantic aphasia perform different steps of an activity	Case study	Community: one 68-year-old woman with semantic dementia	• Therapy comprised preparing a target recipe. The participant was asked to generate semantic attributes of ingredients found in one target, one control, and two no-therapy recipes. The study took place over a 1-year period	• Generated semantic attributes of ingredients pertaining to the target, and control recipes increased significantly (P<.001) as compared with no-therapy recipes (P=.79). The proportion of cooked meals was increased significantly (P=.02)	• Stimulated independence

Of the 147 older adults who participated in these studies, 28 (19%) presented with mild cognitive impairment (MCI), 39 (26.5%) had Alzheimer disease, 12 (8.2%) presented with early-stage dementia, 42 (28.6%) presented with moderate dementia, 25 (17%) presented with advanced dementia, and 1 (0.7%) presented with semantic dementia. The participants' ages ranged from 66 to 96 years. All studies included men and women. There were eight studies that were conducted in community settings, three in LTHFs, and one in a day-care center. Finally, 27 family caregivers—the partners of older adults affected by cognitive disorders or dementia—and 13 health care professionals were also included in these studies.

Methodological Quality of the Studies

Measured using the Joanna Briggs Institute's critical appraisal tools, the overall methodological quality of the studies included in this review was poor to moderate [37]. Only the study by Bier et al [50] was evaluated as having high methodological quality (Table 4).

XSL•FO
RenderX

Table 4. Critical appraisal results for included studies using the Joanna Briggs Institute's Critical Appraisal Checklists.

Study design	Appraisal questions									
	Question 1	Question 2	Question 3	Question 4	Question 5	Question 6	Question 7	Question 8	Question 9	Question 10
Mixed methods study										
Quantitative analysis[a]										
Charras et al [44]	Yes	Yes	Yes	Yes	No	No	Yes	Yes	__[b]	—
Wu et al [39]	Unclear	Yes	Yes	Yes	No	No	Yes	Yes	—	—
de Sant'Anna et al [43]	Yes	Unclear	Yes	Yes	No	No	Yes	Yes	—	—
Qualitative analysis[c]										
Charras et al [44]	N/A[d]	Yes	Yes	Yes	Yes	No	No	No	Yes	Unclear
Wu et al [39]	N/A	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
de Sant'Anna et al [43]	N/A	Unclear	Unclear	Unclear	No	No	No	No	Unclear	Yes
Quasi-experimental study[e]										
Imbeault et al [49]	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	—
Quantitative study[f]										
Boulay et al [42]	No	Yes	Yes	Unclear	No	No	Unclear	Unclear	—	—
Qualitative study[g]										
Suijkerbuijk et al [46]	N/A	Yes	Yes	Yes	Yes	No	No	Yes	No	Unclear
Brankaert et al [47]	N/A	Yes	Yes	Yes	Yes	No	No	Yes	No	Unclear
Wu et al [40]	N/A	Yes	Yes	Unclear	Unclear	No	No	No	Yes	Unclear
Case study[h]										
Brankaert and den Ouden [45]	Unclear	No	Unclear	Yes	Yes	N/A	Yes	Yes	—	—
Brankaert and den Ouden [48]	No	No	No	Unclear	Yes	N/A	Yes	Yes	—	—
Bier et al [50]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	—	—
Faucounau et al [41]	Yes	No	Yes	Unclear	Yes	N/A	Yes	Yes	—	—

[a]Joanna Briggs Institute's Critical Appraisal Checklist for analytical cross-sectional studies [37].

[b]No appraisal question.

[c]Joanna Briggs Institute's Critical Appraisal Checklist for qualitative research [37].

[d]N/A: not applicable.

[e]Joanna Briggs Institute's Critical Appraisal Checklist for quasi-experimental studies [37].

[f]Joanna Briggs Institute's Critical Appraisal Checklist for analytical cross-sectional studies [37].

[g]Joanna Briggs Institute's Critical Appraisal Checklist for qualitative research [37].

[h]Joanna Briggs Institute's Critical Appraisal Checklist for case reports [37].

XSL•FO
RenderX

Description of the Included Studies

The studies included in our evaluation were conducted in four LLs playing pivotal roles in developing innovations aimed at older adults with MCI or dementia and at their family or professional caregivers. These projects all aimed to contribute to optimizing the health, quality of life, independence, home care, and safety of older adults with MCI or dementia and to support their family and professional caregivers or reduce their burdens (Tables 1-3; Multimedia Appendix 2).

The LUSAGE (Laboratoire d'analyse des Usages en Gerontechnologies) LL, affiliated with the Geriatrics Department of the Broca Hospital and Paris Descartes University in France, specializes in the design, development, and supply of products and services providing assistive technologies to older adults with cognitive impairment (eg, MCI, Alzheimer disease, and related dementias) as well as their family and professional caregivers (Multimedia Appendix 2) [51]. LUSAGE is a partner laboratory of the National Expert Center in Cognitive Stimulation, launched by the National Solidarity Fund for Autonomy, whose main objective is to promote the development and use of innovative cognitive interventions. The European Network of Living Labs (ENoLL) certified LUSAGE in 2012, which has a flexible architectural configuration that can be adapted to conduct in situ observations (eg, home-like settings) according to each project's requirements. LUSAGE develops solutions in assistive technologies in collaboration with their primary end users and stakeholders, which represents a multidisciplinary team comprising specialists from numerous fields such as researchers in geriatrics, technology, cognitive sciences, public health, law, and ethics, in addition to psychologists, physicians, engineers, designers, sociologists, and health economists. LUSAGE's primary end users are older adults with cognitive disorders (recruited from the Broca Memory Clinic, Centers for Local Information and Coordination, and local Alzheimer associations), healthy older individuals, their families, and their informal and professional caregivers. These end users are involved in every stage of the product development cycle (eg, needs gathering, usability testing, monitoring studies, evaluation of technology acceptance, and ethical issues) [51].

One of LUSAGE's primary activities is to test the utility and acceptability of personal assistance robots in older adults' everyday lives (Multimedia Appendix 2). In 2014, Wu et al [39] simulated participants' homes and compared how using the *Kompai* robot (Kompaï Robotics, Robosoft) to complete daily tasks affected the lives of 6 older adults with MCI and 5 others in good cognitive health. Participants with MCI were able to use *Kompai* just as well as those with good cognitive health. However, despite the robot's positive attributes, such as its ease of use and playful dimension, participants reported that they had no intention of using a personal assistance robot in their daily life as they had negative perceptions about this type of device, associated with negative representations of dependence linked to aging [39]. With the aim of improving the acceptability of personal assistance robots for the homes of older adults with MCI, LUSAGE subsequently ran the Robadom project [40]. The objective of Robadom was to define an ideal robot, in appearance and functionality, that would meet the expectations of older adults with MCI. The most appreciated functions were cognitive stimulation, object finding, and diary reminders about upcoming events, such as the need to take medication or go to an appointment. Most of the participants had negative perceptions of robots with human characteristics and preferred short robots with stylized, rounded, discrete, and yet familiar shapes [40].

Another innovation developed by LUSAGE was using GPS to improve the independence, quality of life, and safety of home-dwelling older adults with dementia and to help their family caregivers [41]. A mobile telephone attached to the older adult's belt provided standard telephone functionalities, but it also transmitted geolocation data to the family caregiver by SMS text messages and could send numerous alarms. Faucounau et al [41] tested this device for a month in the daily life of an 84-year-old man with Alzheimer disease and his wife. The couple's general impressions were that the device was too bulky, sometimes gave imprecise location coordinates, and had a poor battery life [41].

Finally, LUSAGE has also been used to develop and test innovations in LTHF settings [42,43]. In 2011, Boulay et al [42] tested their MINWii device with 7 older adults with Alzheimer disease institutionalized in a nursing home. MINWii mixes music therapy and cognitive stimulation by allowing players to improvise or play songs of their choice by pointing at a virtual keyboard with a Wii remote control. Numerous benefits of the MINWii, such as positive stimulation of cognitive function, participants' ability to reminisce, and easier interactions with the care team, have been reported [42]. Sant'Anna et al [43] evaluated the impact of using a seal-shaped robot named Paro on the capacity to communicate and the behaviors of 5 nursing home residents with severe Alzheimer disease. Quantitative results indicated that using Paro led to a significant reduction in *disturbed behaviors* (P=.04), especially anxiety, aggressivity, irritability, and sleep disorders. A positive change in communication skills and abilities was also noted in 4 of the 5 patients. Thus, Paro seemed to be an excellent facilitator of communication for older adults with Alzheimer disease, inciting verbal and tactile communication as well as the expression and transfer of feelings by voice and touch [43].

A second French LL working on projects aimed at older adults with dementia was set up in Versailles in 2017 by the Médéric Alzheimer Foundation (Table 1). It focuses on developing and evaluating innovative responses in this field to improve the integration and quality of life of older adults with Alzheimer disease or related illnesses [52]. This LL collaborates in a coparticipative manner with older adults and their family caregivers, treating them as both actors and experts in their disease. It also works with health care professionals, researchers, and entrepreneurs. The central focus of the Foundation's LL is evaluating the impact of various psychosocial interventions, such as cognitive stimulation, art therapy, music therapy, or reminiscence, on the quality of life of older adults with Alzheimer disease.

In 2020, Charras et al [44] evaluated the impact of a dance therapy intervention on 23 older adults with Alzheimer disease who regularly attended a day-care center. The study's results

XSL•FO
RenderX

revealed that 86% of participants (P<.001) experienced a significant increase in well-being immediately after a dance session, and 66% of them (P=.04) also showed a tendency toward faster times in a balance test [44].

A third European grouping of LLs focuses on developing innovative solutions for older adults with dementia. The Innovate Dementia Project comprises ten partners in four regions of Northwestern Europe (Belgium, Germany, the Netherlands, and the United Kingdom), and they collaborate via more than 25 LLs to explore, develop, test, and evaluate innovative, sustainable solutions that consider the socioeconomic challenges linked to aging and dementia (Table 2) [53]. Their goal is to improve the quality of life and independence of older adults with dementia and to facilitate the support given to them by their close family caregivers. This project began in 2012 and became a member of the ENoLL network in 2014, concentrating on four issues: intelligent lighting systems, nutrition and physical exercise, living environments, and models of assistance. The Innovate Dementia Project allows end users (persons living with dementia and their family caregivers), whose role is central, to collaborate with different stakeholders (care professionals, businesses, academic and knowledge institutes, and local governments) to develop and test innovative products in real-life conditions, notably in the homes of older adults with dementia. To date, this project has involved 500 end users, more than 200 health care professionals, and more than 25 business partners, and these partnerships have allowed them to bring more than 15 innovative solutions to the market.

In 2013, Brankaert and den Ouden [48] presented the results of the first product to be tested at the Eindhoven LL: PhysiCAL, a personal activity reminder calendar that promotes older adults' independence. All of the participating older adults with dementia stated that they did not need such a device, whereas 3 of the 4 family caregivers thought that it had helped [48]. In 2014, Brankaert et al [47] trialed a second product, GoLivePhon*e*, in the homes of 10 older adults with dementia and their family caregivers. The phone had three main functions: communicating with other people, providing support when out in the community via a personal navigation system, and sending an emergency signal to a family caregiver. Family caregivers were able to monitor and consult their partners' smartphones via a web-based app, *GoLiveAssist*. Although the app was used irregularly and several technical errors occurred during the trial period, slightly more than half of the participants reported having had a very positive experience and that the device had been helpful. Family caregivers reported that they were reassured by the device as it improved their partner's support and safety [47]. A 2016 study by Suijkerbuijk et al [46], conducted in the homes of 12 couples where one of the pairs had dementia, managed to test two innovative products at the same time: the Aangenaam personal evaluation game and the Vitaallicht dynamic light system. The Aangenaam system enables informal data collection on the daily lives of older adults with dementia, and as it takes the form of a game, it has a minimal risk of disturbing their ADLs. The older adult picks a card from a deck and can answer the question in different ways, by writing in a notebook, by answering orally to make an audio recording, or by taking photographs with the camera provided. The questions explored four categories of data: experiences linked to the ADLs, the participant's social and physical context, their personal objectives and significant life events, and a category adaptable to the product or device being tested. As compared with using a questionnaire on a tablet computer, the findings revealed that the Aangenaam system was better suited and more appreciated by participants; however, thanks to the different potential means of response, it also allowed the researchers to gather more details about their daily lives [46]. The Vitaallicht product, for its part, is a dynamic lighting system that uses blue light to positively influence sleep-wake cycles by suppressing melatonin production during the day. After only 2 weeks of use, this system induced a subjective increase in the quality of the participants' sleep [46]. One of the latest products developed by the Innovate Dementia Project is the Qwiek Play media system, which creates a calming ambient experience in a room by projecting images and sound (a walk through the woods, looking up at a starry sky, visiting a farm, or viewing a custom slideshow of family photos accompanied by music). This product was used in 2017 by Brankaert and den Ouden [45], with 25 patients with severe dementia living in nursing homes and 28 older adults with moderate dementia attending a day-care center. The impressions of the 13 health care professionals were also explored. The results reported very positive perceptions about the product, mentioning its potential for use in nonmedicated interventions to reduce stress and agitation in older adults with moderate to severe dementia, thus giving care staff more time to engage in their care practices [45].

Our scoping review identified a final LL aimed at helping older adults with dementia: DOMUS (Laboratoire de Domotique et informatique Mobile à l'Université de Sherbrooke) in Canada (Table 3) [54]. Set up in 2014, this LL represented the first project of its type in Canada, and it is equipped with a rich, multipurpose infrastructure for the design, implementation, and evaluation of different types of cognitive orthotics. The resulting set of orthotics support a wide variety of ADLs (eg, medication, meal preparation, or budgeting), fostering greater independence at home for people with cognitive impairments (Alzheimer disease, mental retardation, schizophrenia, or traumatic brain injury). DOMUS operates three variants of the LL concept: a smart apartment on its campus that is controlled by a home automation system enabling short-term studies in technology-rich simulated housing; an LL in an alternative housing unit for people with traumatic brain injury, enabling long-term ecological studies in a technology-rich real house; and the LL *at home* that can be installed in older adults' places of residence (apartments and houses), enabling long-term ecological studies in a mobile, agile-technology environment. From the beginning of each project, developing cognitive orthoses involves implicating end users (older adults with cognitive disorders and people with traumatic brain injury) with other stakeholders (clinical researchers, engineers, health care professionals, gerontologists, occupational therapists, neuropsychologists, and researchers in ergonomics and design) to ensure that assistive technologies are focused on users and fully satisfy their needs [54].

In 2011, Bier et al [50] tested a cognitive assistance product named SemAssist with a 68-year-old woman living alone and

XSL•FO
RenderX

who had semantic dementia. This device helps people with semantic aphasia in performing different stages of an activity. Findings showed that this therapy, involving following the same targeted recipe several times over a year, helped this woman reduce the number of errors she made while preparing that recipe. The intervention stimulated her memory function as food preparation developed new episodic memories surrounding the following recipes. Thanks to SemAssist, the participant's self-confidence in being able to cook also grew, which encouraged her to do so more often. The proportion of meals that she cooked for herself increased significantly (P=.02) [50]. Finally, in 2018, Imbeault et al [49] tested the AP@LZ smartphone app in the homes of 3 older adults with Alzheimer disease. The goals were to optimize their independence in ADLs by compensating for their memory problems, further supporting family caregivers and alleviating their burdens. The AP@LZ works like a personal assistant or organizer and has five main functions, namely appointment reminders, a personal database, a medical database, a list of contacts, and a notepad for jotting down shopping lists. The 3 participants had different profiles with respect to age, cognitive status, and social status. Participant 1 was a 71-year-old married man diagnosed with Alzheimer disease 1 year earlier, who had language problems and both verbal and visual memory deficits. Participant 2 was a 58-year-old married man diagnosed with atypical Alzheimer disease 1 year earlier, dominated by dysexecutive syndrome and constructive and ideomotor apraxia. Participant 3 was a 78-year-old single woman living alone in sheltered housing and diagnosed with Alzheimer disease 1 year earlier, which mainly manifested a memory disorder. The findings underlined that all 3 participants, despite their different profiles, could use the app in their everyday lives. Indeed, they all continued to use it after the study ended as they found that the system helped them, and they especially appreciated the appointment reminder function. Using AP@LZ also reduced the burden on family caregivers. The authors concluded that the app might have long-term utility, despite Alzheimer disease being a progressive disease and that it could be used by people with different profiles and degrees of cognitive impairment [49].

Discussion

Principal Findings

This review aimed to identify publications examining all types of LL activities, exploring the needs and expectations of older adults with dementia and looking for solutions, whether they were living in the community or in LTHFs. We discovered 12 studies that met our inclusion criteria (quantitative, qualitative, or mixed methods) involving 147 older adults with MCI or dementia, 27 informal caregivers, and 13 formal caregivers. These studies originated from three European LLs and one Canadian LL playing key roles in research in this field. Their work has allowed the development, testing, and evaluation of a series of innovative products aimed not only at optimizing the health, quality of life, independence, home care, and safety of older adults with MCI or dementia but also at supporting formal and informal caregivers and reducing their levels of burden. Most of the studies in this scoping review reported promising findings, and the LL approach highlighted both positive and negative points in all the devices, products, and services, which will be open to improvements through future testing.

Limitations

This scoping review has some limitations. Our literature search strategy may have omitted some studies as they did not meet all our inclusion criteria or as researchers failed to identify them in the study selection process. Some bias might have also been present in the reporting of findings by the investigators in the analysis of the selected studies. It is impossible to exclude some bias in the selection of studies as all the included studies had very limited sample sizes. Indeed, only one of the studies was evaluated as having a high methodological quality. The limited number of participants and the overrepresentation of European LLs means that generalizing these findings to a broader population or other countries should be done with great care. Finally, the limited number of recent studies revealed by this scoping review raises questions about whether any LL activities are ongoing and whether LLs are sustainable.

To the best of our knowledge, there are no previous, clear overviews of the research conducted by LLs with respect to older adults with cognitive impairment or dementia. Our scoping review has allowed us to understand the services, research, and clinical activities developed in different LL settings for older adults with dementia. Therefore, it provides valuable information to nurses, general practitioners, policy makers, and other stakeholders involved in LLs dedicated to older adults. Furthermore, the diversity of the research projects that we included managed to test the innovative solutions using a variety of methodologies.

Comparison With Previous Work

LLs represent a promising approach for developing innovative solutions to the numerous challenges of an increasingly older population [3]. Indeed, it can offer an ideal, pragmatic framework for research involving a realistic, real-life setting, multiple stakeholder participation, multi-method approaches, and cocreation [55].

To the best of our knowledge, there are no best practices for design-driven LLs. The lack of consensus on the practices, methods, tools, and boundaries of LLs raises several obstacles to the adoption of this approach as well as creating confusion about the definition and components of an LL [56]. Thus, some research groups claim to be using an LL approach, although they really are not. In contrast, some research groups using LL approaches are not labeled as such. For example, the ENoLL label is so new that it has not yet been classified as an LL [15]. Furthermore, the complexity and diversity of what is going on within an LL can blur the boundaries among research, industry, and other economic market sectors [15]. Multifactorial difficulties in finding financing for LLs are another frequently reported problem (instability over the medium to long term, problems balancing representativity between stakeholders in decision-making, and investors' different expectations with regard to returns on investment, and the absence of social capital). Managing intellectual property is also problematic because of the lack of a consensus model for doing this and the ad hoc nature of contractual dealings and agreements [15,56].

XSL•FO
RenderX

Finally, several difficulties have been reported concerning the sustainability of LLs [57]. Primarily because of the notable lack of sustainable financing or nondiversified financing (whether from private or public sources), it is common for LLs not to survive beyond the time needed to conduct their first financed research project [57]. Thus, it seems essential that to have sustainable LLs, they should be developed within solid, dynamic, long-term, strategic frameworks that continuously evaluate financing, new target audiences, and potential revenue streams. They should involve multiple stakeholders and have the capacity to evolve over time, moving from one innovation category to another [57].

With regard to projects aimed at older adults, numerous studies conducted in LLs aim to find solutions to the pressing problems facing older populations in general [26]. However, there are still few innovative tools, solutions, or technologies that are especially adapted for older adults with dementia [25]. It will be essential to promote more research and experiments in LLs aimed at populations with dementia as these approaches are promising and encourage the cocreation of innovative solutions to maintain or improve their health, quality of life, and independence [58,59]. Although integrating older adults with dementia into the LL process—from product design to evaluation—is also essential, it remains sporadic, unfortunately, because of the inherent difficulties of collaborating with individuals with an impaired cognitive function and the ethical issues that this raises [29]. LL approaches too often only include formal and informal caregivers when older adults are still capable of participating, and innovative solutions will never be optimally effective if they fail to fully meet their needs and expectations [29]. Several studies have reported that older adults with dementia would be happy to actively participate in the development processes seeking innovative solutions that would benefit them in the future. They are enthusiastic about the idea of contributing to these solutions by bringing their unique and precious experiential knowledge [60]. The LL approach represents an ideal research and experimental framework for older adults with dementia as studies that fail to include them as coparticipants will not be able to meet their real-world needs and reliably show the effects of innovative solutions on this population's daily lives [29]. There are numerous strategies to ensure the voluntary participation of older adults with dementia and overcome the challenges of cognitive impairments and ethics, such as the concepts of fluctuating consent, process consent, or rolling consent. These strategies promote effective communication between all stakeholders involved so that the vulnerable person's willingness to participate can be monitored continuously [61]. A complete LL approach must necessarily involve formal and informal caregivers as innovative solutions must meet the needs and expectations of end users and those who look after them [54]. The LL approach also requires the points of view, expertise, and collaborations of all the involved stakeholders (eg, students, academic institutions, private companies, health care organizations, and patient representative bodies) [62]. Given that most LLs focusing on older adults with dementia appear to be in Europe, this approach requires development on other continents [63]. We do not know of any best practices for design-driven LLs, and it may be necessary to develop guidelines on the LL approach to direct and support the establishment and sustainability of innovative solutions, and to facilitate relationships and engagement with stakeholders and end users [45].

Conclusions

To the best of our knowledge, there are no clear views of the research conducted by LLs with respect to older adults with cognitive impairments or dementia. This scoping review enabled us to draw together the few but varied existing research findings and contributed to consolidating knowledge in this field. This allowed us to identify 4 LLs that play a central role in research testing and evaluating innovative products to optimize the health, quality of life, independence, home care, and safety of older adults with dementia, whether they live in their homes or in LTHFs. This research also supports and reduces the burden on formal and informal family caregivers. Furthermore, this scoping review could be used as a reference for anybody interested in using LLs with older adults with cognitive impairments or dementia. It provides valuable information to nurses, general practitioners, policy makers, and other stakeholders involved in LLs dedicated to older adults on the practices, methods, and tools that can be used with older adults with cognitive impairment or dementia. To date, very few studies using the LL approach have focused on older adult populations with dementia, notably because of the difficulties associated with their lower cognitive abilities and the ethical challenges this raises. By allowing older adults with dementia to experience cocreation within a well-defined environment and influence a potential product's design, ease of use, or acceptability, the other stakeholders should be better able to address their needs and expectations. Therefore, it is essential that more LL experiments integrate both older adults with dementia, their formal and informal caregivers, and all other pertinent stakeholders. This will assist in the development of more appropriate, better adapted, sustainable, innovative interventions, services, and products to meet the growing societal challenges brought on by dementia.

Authors' Contributions

All authors contributed to the design and development of this scoping review and to the drafting of the manuscript, and approved the final version and agreed to be held accountable for all aspects of the work.

Conflicts of Interest

None declared.

XSL•FO
RenderX

Multimedia Appendix 1
Bibliographic database search strategies.
[DOCX File , 24 KB - aging_v4i3e29031_app1.docx]

Multimedia Appendix 2
Characteristics of the included studies from the LUSAGE (Laboratoire d'analyse des Usages en Gerontechnologies) living lab in France.
[DOCX File , 26 KB - aging_v4i3e29031_app2.docx]

References

1. People in the EU: Who Are We and How Do We Live? Publications Office of the European Union. Eurostat. 2019. URL: https://ec.europa.eu/eurostat/documents/3217494/7089681/KS-04-15-567-EN-N.pdf/8b2459fe-0e4e-4bb7-bca7-7522999c3bfd [accessed 2021-07-28]
2. Global Strategy and Action Plan on Ageing and Health. World-Health-Organization. 2017. URL: https://www.who.int/ageing/GSAP-Summary-EN.pdf [accessed 2021-07-28]
3. Lapointe D, Guimont D. Open Innovation Practices Adopted by Private Stakeholders: Perspectives for Living Labs. Emerald Group Publishing Limited. 2015. URL: https://www.emerald.com/insight/content/doi/10.1108/info-01-2015-0003/full/html [accessed 2021-07-28]
4. Bächle M, Daurer S, Judt A, Mettler T. Assistive technology for independent living with dementia: Stylized facts and research gaps. Health Pol Technol 2018 Mar;7(1):98-111. [doi: 10.1016/j.hlpt.2017.12.002]
5. Vredenburg K, Isensee S, Righi C. User-Centered Design: An Integrated Approach. Upper Saddle River, NJ: Prentice Hall; 2002.
6. Dell'Era C, Landoni P. Living Lab: A Methodology between User-Centred Design and Participatory Design. Inov Manag 2014 Mar 18;23(2):137-154. [doi: 10.1111/caim.12061]
7. Bergvall-Kareborn B, Hoist M, Stahlbrost A. Concept Design With a Living Lab Approach. In: 42nd Hawaii International Conference on System Sciences. 2009 Presented at: CSS'09; May 17-19, 2009; Hawaii. [doi: 10.1109/hicss.2009.123]
8. Coignard P, Joseph P, Busnel M, Fattal C, Picard R, Laffont I. Living Labs Health and Autonomy: what place for users and clinicians? The example of the French APPROCHE Association. Annals of Physical and Rehabilitation Medicine 2015 Sep;58:e54-e55. [doi: 10.1016/j.rehab.2015.07.134]
9. Sauer S. Faculty of Behavioural, Management and Social Sciences. New York, USA: Universiteit Twente; 2013.
10. Hossain M, Leminen S, Westerlund M. A systematic review of living lab literature. J Clea Produc 2019 Mar;213:976-988 [FREE Full text] [doi: 10.1016/j.jclepro.2018.12.257]
11. Kareborn BB, Stahlbrost A. Living lab: an open and citizen-centric approach for innovation. Int J Innco 2009;1(4):356. [doi: 10.1504/ijird.2009.022727]
12. Bergvall-Kåreborn B, Eriksson C, Ståhlbröst A, Svensson J. A Milieu for Innovation: Defining Living Labs. In: The 2nd Ispim Innovation Symposium: Simulating Recovery - the Role of Innovation Management. In: Huizingh KRE, Conn S, Torkkeli M, Bitran I. editors. ISPIM Innovation Symposium /12/2009 - 09/12/2009; 2009 Presented at: ISPIM'09; December 6-9, 2009; New York. [doi: 10.22215/timreview/951]
13. Schaffers H, Turkama P. Living labs for cross-border systemic innovation. Technol Manag Innov Rev 2012:30. [doi: 10.22215/timreview/605]
14. Følstad A. Living Labs for innovation and development of information and communication technology: a literature review. The Electronic Journal of Virtual Organizations and Networks 2008;10.
15. Picard R, Poilpot L. Pertinence et valeur du concept de « Laboratoire vivant » (Living Lab) en santé et autonomie. Ministère de l'économie des finances et de l'industrie 2011:68-72.
16. Living Labs EN. European Network of Living Labs. BrusselsNoLL. 2019. URL: https://enoll.org/newsroom/ [accessed 2020-12-15]
17. Westerlund M, Leminen S. Managing the challenges of becoming an open innovation companyxperiences from living labs. Technology Innovation Management Review 2011;10:25. [doi: 10.22215/timreview/489]
18. Payne A, Storbacka K, Frow P, Knox S. Co-creating brands: Diagnosing and designing the relationship experience. Journal of Business Research 2009 Mar;62(3):379-389. [doi: 10.1016/j.jbusres.2008.05.013]
19. Almirall E, Wareham J. Living labs and open innovation: Roles and applicability. The Electronic Journal for Virtual Organization and Networks 2008;10(3):46.
20. Cleland B. Innovation of eParticipation strategies using living labs as intermediaries. Electronic Journal of e-Government 2012;10(2):32.
21. Lethin C, Rahm Hallberg I, Renom Guiteras A, Verbeek H, Saks K, Stolt M, et al. Prevalence of dementia diagnoses not otherwise specified in eight European countries: a cross-sectional cohort study. BMC Geriatr 2019 Jun 24;19(1):1-10. [doi: 10.1186/s12877-019-1174-3]

XSL•FO
RenderX

22. Topo P. Technology Studies to Meet the Needs of People With Dementia and Their Caregivers: A Literature Review. Journal of Applied Gerontology 2008 Oct 01;28(1):5-37. [doi: 10.1177/0733464808324019]
23. Boldy D, Grenade L, Lewin G, Karol E, Burton E. Older people's decisions regarding 'ageing in place': a Western Australian case study. Australas J Ageing 2011 Sep;30(3):136-142. [doi: 10.1111/j.1741-6612.2010.00469.x] [Medline: 21923707]
24. North MS, Fiske ST. Modern Attitudes Toward Older Adults in the Aging World: A Cross-Cultural Meta-Analysis. Psychol Bull 2015 Sep;141(5):993-1021. [doi: 10.1037/a0039469] [Medline: 26191955]
25. Petonito G, Muschert G. Silver Alert: Societal Aging, Dementia, and Framing a Social Problem. Critical Gerontology Comes of Age: Routledge. 2018; 2018:146-162.
26. Meiland F, Innes A, Mountain G, Robinson L, van der Roest H, García-Casal JA, et al. Technologies to Support Community-Dwelling Persons With Dementia: A Position Paper on Issues Regarding Development, Usability, Effectiveness and Cost-Effectiveness, Deployment, and Ethics. JMIR Rehabil Assist Technol 2017 Jan 16;4(1):e1 [FREE Full text] [doi: 10.2196/rehab.6376] [Medline: 28582262]
27. Van der Roest HG, Wenborn J, Pastink C, Dröes RM, Orrell M. Assistive technology for memory support in dementia. Cochrane Database Syst Rev 2017 Dec 11;6:CD009627. [doi: 10.1002/14651858.CD009627.pub2] [Medline: 28602027]
28. Koskinen I, Zimmerman J, Binder T, Redström J, Wensveen S. Design Research Through Practice From the Lab, Field, and Showroom. Waltham, MA: Morgan Kaufmann; 2011.
29. Astell AJ, Ellis MP, Bernardi L, Alm N, Dye R, Gowans G, et al. Using a touch screen computer to support relationships between people with dementia and caregivers. Interacting with Computers 2010 Jul;22(4):267-275. [doi: 10.1016/j.intcom.2010.03.003]
30. Payne A, Ballantyne D, Christopher M. A stakeholder approach to relationship marketing strategy. European Journal of Marketing 2005 Jul;39(7/8):855-871. [doi: 10.1108/03090560510601806]
31. Følstad A. Living Labs for innovation and development of information and communication technology: A literature review. The Electronic Journal of Virtual Organizations and Networks 2008;10(8):131.
32. Leminen S, Westerlund M, Nyström A. Living labs as open-innovation networks. Technology Innovation Management Review 2012;2:11. [doi: 10.22215/timreview/602]
33. Ballon P, Schuurman D. Living labs: concepts, tools and cases. Info 2015;4:11. [doi: 10.1108/info-04-2015-0024]
34. Verloo H, Lorette A, Gomes DRC, Rosselet AJ, Gillès DPE, Matos QA. A Comprehensive Scoping Review Protocol of Using Living Labs to Explore Needs and Solutions for Older Adults with Dementia. Smart Homecare Technology and TeleHealth. URL: https://doi.org/10.2147/SHTT.S233130 [accessed 2020-12-15]
35. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, Tunçalp, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med 2018 Oct 02;169(7):467-473. [doi: 10.7326/M18-0850] [Medline: 30178033]
36. Aguayo-Albasini JL, Flores-Pastor B, Soria-Aledo V. [GRADE system: classification of quality of evidence and strength of recommendation]. Cir Esp 2014 Feb;92(2):82-88 [FREE Full text] [doi: 10.1016/j.ciresp.2013.08.002] [Medline: 24361098]
37. Aromataris E, Munn Z, editors. JBI Manual for Evidence Synthesis. USA: JBI; 2020.
38. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med 2009 Jul 21;6(7):e1000097 [FREE Full text] [doi: 10.1371/journal.pmed.1000097] [Medline: 19621072]
39. Wu Y, Wrobel J, Cornuet M, Kerhervé H, Damnée S, Rigaud A. Acceptance of an assistive robot in older adults: a mixed-method study of human-robot interaction over a 1-month period in the Living Lab setting. Clin Interv Aging 2014;9:801-811 [FREE Full text] [doi: 10.2147/CIA.S56435] [Medline: 24855349]
40. Wu Y, Wrobel J, Cristancho-Lacroix V, Kerhervé H, Chetouani M. Le projet Robadom : conception d'un robot d'assistance pour les personnes âgées. Revue de Gériatrie 2013;38(5):349.
41. Faucounau V, Riguet M, Orvoen G, Lacombe A, Rialle V, Extra J, et al. Electronic tracking system and wandering in Alzheimer's disease: a case study. Ann Phys Rehabil Med 2009;52(7-8):579-587 [FREE Full text] [doi: 10.1016/j.rehab.2009.07.034] [Medline: 19744906]
42. Boulay M, Benveniste S, Boespflug S, Jouvelot P, Rigaud A. A pilot usability study of MINWii, a music therapy game for demented patients. Technol Health Care 2011;19(4):233-246. [doi: 10.3233/THC-2011-0628] [Medline: 21849735]
43. de Sant'Anna M, Morat B, Rigaud A. Adaptabilité du robot Paro dans la prise en charge de la maladie d'Alzheimer sévère de patients institutionnalisés. NPG Neurologie - Psychiatrie - Gériatrie 2012 Feb;12(67):43-48. [doi: 10.1016/j.npg.2011.10.002]
44. Charras K, Mabire J, Bouaziz N, Deschamps P, Froget B, de MA. Dance intervention for people with dementia: Lessons learned from a smallsample crossover explorative study. The Arts in Psychotherapy. URL: https://doi.org/10.1016/j.aip.2020.101676 [accessed 2020-12-15]
45. Brankaert R, den Ouden E. The Design-Driven Living Lab: A New Approach to Exploring Solutions to Complex Societal Challenges. Technology Innovation Management Review;Volume 7, Issue 2017:1. [doi: 10.22215/timreview/1049]

XSL•FO
RenderX

46. Suijkerbuijk S, Brankaert R, de Kort YAW, Snaphaan LJAE, den Ouden E. Seeing the first-person perspective in dementia : a qualitative personal evaluation game to evaluate assistive technology for people affected by dementia in the home context. Interacting with Computers. URL: https://doi.org/10.1093/iwc/iwu038 [accessed 2020-12-15]
47. Brankaert R, Snaphaan L, den Ouden E. Stay in Touch: An in Context Evaluation of a Smartphone Interface Designed for People with Dementia. Springer, Cham. URL: https://doi.org/10.1007/978-3-319-13105-4_42 [accessed 2020-12-15]
48. Brankaert R, den Ouden E. Setting up a LivingLab for innovation in the dementia care chain, a case study of the PhysiCAL. In: Lappeenranta University of Technology Press. 2013 Presented at: the XXIV ISPIM Conference on Innovating in Global Markets : Challenges for Sustainable Growth; 2013; Lappeenranta University of Technology Press p. 16-19.
49. Imbeault H, Gagnon L, Pigot H, Giroux S, Marcotte N, Cribier-Delande P, et al. Impact of AP@LZ in the daily life of three persons with Alzheimer's disease: long-term use and further exploration of its effectiveness. Neuropsychol Rehabil 2016 Apr 28:1-24. [doi: 10.1080/09602011.2016.1172491] [Medline: 27126266]
50. Bier N, Macoir J, Joubert S, Bottari C, Chayer C, Pigot H, SemAssist Team. Cooking "shrimp à la créole": a pilot study of an ecological rehabilitation in semantic dementia. Neuropsychol Rehabil 2011 Aug;21(4):455-483. [doi: 10.1080/09602011.2011.580614] [Medline: 21714761]
51. Pino M, Benveniste S, Kerhervé H, Rigaud A. Contribution of the Living Lab approach to the development, assessment and provision of assistive technologies for supporting older adults with cognitive disorders. Studia Informatica Universalis 2014:34-62.
52. Le Living Lab 2020. Fondation-Médéric-Alzheimer. URL: https://www.fondation-mederic-alzheimer.org/living-lab [accessed 2020-12-15]
53. Brankaert R, den Ouden E, Brombacher A. Innovate dementia: the development of a living lab protocol to evaluate interventions in context. Emerald Group Publishing Limited;Volume 17 NO. 4 2015:2015. [doi: 10.1108/info-01-2015-0010]
54. Pigot H, Giroux S. Living labs for designing assistive technologies. 2015 Oct 17 Presented at: IEEE 17th International Conference on e-Health Networking, ApplicationsServices (Healthcom); Oct. ; Boston, MA. USA; 2015; Boston p. 14-17. [doi: 10.1109/healthcom.2015.7454493]
55. Ballon P, Schuurman D. Living labs: concepts, tools and cases. Info 2015;4:11. [doi: 10.1108/info-04-2015-0024]
56. Dubé P, Sarrailh J, Grillet C, Billebaud C, Zingraff V, Kostecki I. Le livre blanc des Living Labs. UMWELT, editor 2014:2014.
57. Mastelic J, Pieter BM, Sahakian M, Bonazzi R. How to keep a living lab alive? Info 2015;17(4):12-25. [doi: 10.1108/info-01-2015-0012]
58. Schuurman D. Bridging the gap between Open and User Innovation: exploring the value of Living Labs as a means to structure user contribution and manage distributed innovation. Ghent: Ghent University; 2015.
59. Leminen S, Nyström A, Westerlund M. A typology of creative consumers in living labs. Journal of Engineering and Technology Management 2015 Jul;37:6-20. [doi: 10.1016/j.jengtecman.2015.08.008]
60. Gove D, Diaz-Ponce A, Georges J, Moniz-Cook E, Mountain G, Chattat R, European Working Group of People with Dementia. Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). Aging Ment Health 2018 Jun;22(6):723-729. [doi: 10.1080/13607863.2017.1317334] [Medline: 28513210]
61. Novitzky P, Smeaton AF, Chen C, Irving K, Jacquemard T, O'Brolcháin F, et al. A review of contemporary work on the ethics of ambient assisted living technologies for people with dementia. Sci Eng Ethics 2015 Jun;21(3):707-765. [doi: 10.1007/s11948-014-9552-x] [Medline: 24942810]
62. Dutilleul B, Birrer F, Mensink W. Unpacking European Living Labs: Analysing Innovation's Social Dimensions. Central European Journal of Public Policy 2010;4(1):60.
63. Kim J, Kim YL, Jang H, Cho M, Lee M, Kim J, et al. Living labs for health: an integrative literature review. Eur J Public Health 2019 Jun 06:55-63. [doi: 10.1093/eurpub/ckz105] [Medline: 31169898]

Abbreviations

ADL: activities of daily living
DOMUS: Laboratoire de Domotique et informatique Mobile à l'Université de Sherbrooke
ENoLL: European Network of Living Labs
ICT: information and communication technology
LL: living lab
LTHF: long-term health care facility
LUSAGE: Laboratoire d'analyse des Usages en Gerontechnologies
MCI: mild cognitive impairment

XSL•FO
RenderX

Edited by J Wang; submitted 23.03.21; peer-reviewed by T Dening, I Ahmed, L Robinson; comments to author 29.04.21; revised version received 27.05.21; accepted 01.06.21; published 19.08.21.

Please cite as:
Verloo H, Lorette A, Rosselet Amoussou J, Gillès de Pélichy E, Matos Queirós A, von Gunten A, Perruchoud E
Using Living Labs to Explore Needs and Solutions for Older Adults With Dementia: Scoping Review
JMIR Aging 2021;4(3):e29031
URL: https://aging.jmir.org/2021/3/e29031
doi:10.2196/29031
PMID:34420916

©Henk Verloo, Adrien Lorette, Joëlle Rosselet Amoussou, Estelle Gillès de Pélichy, Alcina Matos Queirós, Armin von Gunten, Elodie Perruchoud. Originally published in JMIR Aging (https://aging.jmir.org), 19.08.2021. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Aging, is properly cited. The complete bibliographic information, a link to the original publication on https://aging.jmir.org, as well as this copyright and license information must be included.

XSL•FO
RenderX

Original Paper

Ecological Momentary Assessment of Depression in People With Advanced Dementia: Longitudinal Pilot Study

Iulia Niculescu[1,2], MSc; Hannah Quirt[2], RPN; Twinkle Arora[2], MA; Terry Borsook[2], PhD; Robin Green[1,2,3], PhD; Brett Ford[4], PhD; Andrea Iaboni[1,2,3], MD, DPhil

[1]Department of Rehabilitation Sciences, University of Toronto, Toronto, ON, Canada
[2]KITE, Toronto Rehabilitation Institute, University Health Network, Toronto, ON, Canada
[3]Department of Psychiatry, University of Toronto, Toronto, ON, Canada
[4]Department of Psychology, University of Toronto, Toronto, ON, Canada

Corresponding Author:
Andrea Iaboni, MD, DPhil
KITE
Toronto Rehabilitation Institute
University Health Network
550 University Avenue
Toronto, ON, M5G 2A2
Canada
Phone: 1 (416) 597 3422 ext 3027
Email: andrea.iaboni@uhn.ca

Abstract

Background: Barriers to assessing depression in advanced dementia include the presence of informant and patient recall biases. Ecological momentary assessment provides an improved approach for mood assessment by collecting observations in intervals throughout the day, decreasing recall bias, and increasing ecological validity.

Objective: This study aims to evaluate the feasibility, reliability, and validity of the modified 4-item Cornell Scale for Depression in Dementia for Momentary Assessment (mCSDD4-MA) tool to assess depression in patients with advanced dementia.

Methods: A intensive longitudinal pilot study design was used. A total of 12 participants with advanced dementia were enrolled from an inpatient psychogeriatric unit. Participants were assessed using clinical depression assessments at admission and discharge. Research staff recorded observations four times a day for 6 weeks on phones with access to the mCSDD4-MA tool. Descriptive data related to feasibility were reported (ie, completion rates). Statistical models were used to examine the interrater reliability and construct and predictive validity of the data.

Results: Overall, 1923 observations were completed, representing 55.06% (1923/3496) of all rating opportunities with 2 raters and 66.01% (1923/2913) with at least one rater. Moderate interrater reliability was demonstrated for all items, except for *lack of interest*. Moderate correlations were observed between observers and patient-reported outcomes, where observers reported fewer symptoms relative to participants' self-reports. Several items were associated with and able to predict depression.

Conclusions: The mCSDD4-MA tool was feasible to use, and most items in the tool showed moderate reliability and validity for assessing depression in dementia. Repeated and real-time depression assessment in advanced dementia holds promise for the identification of clinical depression and depressive symptoms.

(JMIR Aging 2021;4(3):e29021) doi:10.2196/29021

KEYWORDS

dementia; depression; ecological momentary assessment; tool performance

XSL•FO
RenderX

Introduction

Background

Dementia and Depression

Dementia and depression are the most common psychiatric conditions in aging, and there is considerable overlap between them, with the prevalence of depression between 5% and 77% in people with dementia and between 7% and 54% in people at the advanced stage of dementia [1-3]. This wide range demonstrates the challenge in identifying depression in individuals with dementia, including individuals with advanced dementia, a group frequently excluded from studies [3]. The overlap between symptoms of depression and symptoms of dementia (eg, concentration difficulties and apathy) can also confound the diagnosis of depression, making it difficult to assess [4,5]. Many clinical interviews and assessments for depression in dementia include both informant reports and self-reports, and informant reports can be affected by confounding depressive symptoms for symptoms of dementia, mood-congruent biases (eg, related to caregiver burden projected onto the person with dementia), and recall biases [6,7]. Self-reports of people with dementia are limited by memory impairment, poor insight, and language impairment [8-10]. Although validated criteria and tools exist, such as the 19-item Cornell Scale for Depression in Dementia-19 (CSDD-19) [4-11], there is an opportunity to improve the detection and assessment of depression in people with advanced dementia [12,13]. People with dementia and comorbid depression are at risk for negative outcomes, such as hastened cognitive decline and higher rates of morbidities and mortality [14,15]. Detecting depression where it might otherwise be missed provides an opportunity for greatly enhanced patient care in this vulnerable population.

Ecological Momentary Assessment

Novel data collection methodologies provide promising opportunities for improving the measurement of depression in people with dementia. Ecological momentary assessment (EMA) encompasses a range of longitudinal data collection methods that capture momentary symptoms repeatedly over time and are typically registered on mobile devices [9]. Real-time and repeated measurements of behaviors and emotions can provide valuable information related to an individual's dynamic internal state and fluctuations in the expression of symptoms. EMA helps to address various methodological limitations of conventional tools, such as reducing recall bias and enhancing the ecological validity of the data collected [9]. EMA studies in older adults have demonstrated its feasibility, enhanced precision of outcome measurement, and the ability to identify clinically significant depressive symptoms, although most studies exclude people with dementia and are typically self-reported [16-18]. Informant-rated EMA studies are less common than self-reported EMA studies but have been used in the population of people with dementia. For example, daily self-reports of emotional well-being in people with dementia have been compared with informant reports, and internal consistency was found between the two data sources [19]. The use of an observational affect scale was examined in individuals with dementia using EMA. The scale demonstrated excellent reliability among activity therapists as well as family members and nursing assistants and good validity [20]. EMA has thus been used to monitor daily life behaviors and well-being in people with dementia, and these studies have demonstrated the validity of informant ratings and the ability to capture individual differences over time [20-23]. However, no EMA depression screening tools have been developed for people with advanced dementia.

Objective

This study seeks to address these gaps in a pilot intensive longitudinal EMA study of people with advanced dementia in an inpatient psychogeriatric unit. The aim of this study is to evaluate the psychometric performance of an EMA tool for assessing depression in people with advanced dementia. The first objective is to test the preliminary feasibility outcomes of an observer-rated EMA tool by examining the completion rates and observations of participant acceptability. The second objective is to test the reliability of an observer-rated EMA tool in advanced dementia by examining the reliability of within-person changes and interrater reliability. The third objective is to explore the construct validity and ability of the tool to predict clinical depression and depressive symptoms in patients with advanced dementia. To address these objectives, we conducted a pilot intensive longitudinal study using a modified 4-item Cornell Scale for Depression in Dementia for Momentary Assessment (mCSDD4-MA) tool.

Methods

Participants and Sample Size

Participants were patients admitted to the Specialized Dementia Unit at the Toronto Rehabilitation Institute. For study inclusion, participants should be aged ≥65 years and have a diagnosis of moderate-to-severe dementia based on a Mini-Mental State Examination [24] score of <20 [3]. Substitute decision makers provided informed consent, and participants were excluded if they showed signs of dissent to the study procedures, had a previous history of bipolar disorder or schizophrenia, were receiving palliative care, or were unable to understand and speak English (ie, required to self-report).

In keeping with previous pilot EMA studies [16,25,26], the sample comprised 12 participants. Recommendations for determining sample size in intensive longitudinal designs are based on the power of both the within- and between-person sample sizes [27,28]. Despite our smaller between-person sample size (n=12), the within-person sample size (ie, number of repeated observations) is important in detecting the reliability of the random effects and within-person variability and typically requires >50 observations per individual and >1000 observations in total [29-31]. With our study design, we aim to achieve a large number of observations well above this cutoff (ie, eight observations per day for 6 weeks, totaling approximately 336 observations per participant), providing sufficient power for our primary within-person analysis [32]. Our third objective, which involved a between-person analysis, was exploratory in nature and no sample size calculation was completed.

XSL•FO
RenderX

Design and Setting

We used a pilot observational study design. Observers consisted of 4 trained research staff members. The study was set on the Specialized Dementia Unit at the Toronto Rehabilitation Institute, a psychogeriatric unit caring for people with behavioral and psychological symptoms of dementia. This study was approved by the research ethics board of the University Health Network (Coordinated Approval Process for Clinical Research ID: 19-5132).

Measures

Participant Characterization

At baseline, demographic data collected included sex, age, and dementia diagnosis. The Mini-Mental State Examination was completed by a research assistant to assess cognition [24].

Outcome Variables

mCSDD4-MA Tool

The mCSDD4-MA tool (Table 1 and Textbox 1) was used as the primary data collection tool. The tool measures depressive symptoms collected by observers, modified for the purposes of this study from the 4-item CSDD (CSDD-4) [13]. Modifications included changing the retrospective language in the CSDD-4 tool to refer to the present, as is necessary for momentary assessments. The final tool consisted of five observational items: *sadness, anxiety, irritability,* and *lack of interest* (ie, from the original tool). *Negativity* was added as it is common in other assessments, including the CSDD-19 tool, and has good specificity in distinguishing between individuals with and without depression in dementia (Table 1) [1,11,33]. In addition to the observational component, a patient-reported component was added, which was unique to the tool (Textbox 1). Patient-reported outcomes included sadness and anxiety as they were central symptoms of depression in older adults [34], were relatively simple concepts to communicate [35], and have shown to be discordant between informants and patients [7].

Table 1. Developed observational items in the modified 4-item Cornell Scale for Depression in Dementia for Momentary Assessment tool for people with advanced dementia.

Original CSDD[a] item	Question	mCSDD4-MA[b] tool items	Response scale
Introduction	I am going to ask you questions about how your relative has been feeling during the past week.	Looking at the person right now and reflecting on their mood today	N/A[c]
Sadness	Has your relative been feeling down, *sad, or blue*[d] this past week? Has she/he been crying at all? How many days out of the past week has she been feeling like this?	Does the person seem sad or blue?	• No sadness • Some sadness • A lot of sadness • Unable to evaluate
Lack of interest	If a pleasant event were to occur today (ie, going out with spouse, friends, or seeing grandchildren), would your relative be able to enjoy it fully, or might his/her mood get in the way of his/her interest in the event or activity? Does your relative's mood affect any of the following: his/her ability to *enjoy* activities that used to give him/her *pleasure*, his/her surroundings, his/her feelings for family and friends?	Is the person showing enjoyment or pleasure in what is going on around them?	• No lack of interest • Some lack of interest • Lacking a lot of interest • Unable to evaluate
Anxiety	Has your relative been feeling *anxious* this past week? Has she/he been *worrying* about things she/he may not ordinarily worry about or ruminating over things that may not be that important? Has your relative had an anxious, tense, distressed, or apprehensive expression?	Does the person seem anxious or worried?	• No anxiety • Some anxiety • A lot of anxiety • Unable to evaluate
Irritability	Has your relative felt short-tempered or easily *annoyed* this past week? Has she/he been feeling *irritable*, impatient, or *angry* this week?	Does the person seem irritable, annoyed, or angry?	• No irritability • Some irritability • A lot of irritability • Unable to evaluate
Negativity	Has your relative felt *pessimistic or discouraged* about his/her future this past week? Can your relative see his/her situation improving? Can your relative be reassured by others that things will be okay or that his/her situation will improve?	Is the person discouraged or expressing pessimistic or negative thoughts?	• No negativity • Some negativity • A lot of negativity • Unable to evaluate

[a]CSDD: Cornell Scale for Depression in Dementia.

[b]mCSDD4-MA: 4-item Cornell Scale for Depression in Dementia for Momentary Assessment.

[c]N/A: not applicable.

[d]Italicization indicates the words that were taken from the original tool and used directly in the 4-item Cornell Scale for Depression in Dementia for Momentary Assessment tool.

XSL•FO
RenderX

Textbox 1. Developed self-reported items in the modified 4-item Cornell Scale for Depression in Dementia for Momentary Assessment tool for people with advanced dementia.

4-Item Cornell Scale for Depression in Dementia for Momentary Assessment Tool Patient-Reported Items and Scoring

- Self-reported sadness
  - Are you feeling sad?
    - Yes
    - No
    - Unable to evaluate
- Self-reported anxiety
  - Are you feeling worried?
    - Yes
    - No
    - Unable to evaluate

Observational items were scored on a 3-point scale where *no*=0, *some*=1, and *a lot*=2. Originally, the CSDD-4 tool included *none*=0, *mild/intermittent*=1, and *extreme*=2 [11,13]. Patient-reported items were scored as yes or no. For the self-report items, raters were encouraged to take time to engage with the participants with the intention of asking these items naturally. Where there would be any inclination toward a yes (ie, including maybe), yes would be chosen, whereas only a clear no was scored as a no in the tool. If participants were asleep or receiving care, raters would select *unable to evaluate* for each item. A total score was generated for items that formed part of the CSDD-4 tool. As the other items were novel in the tool, it was not yet known if these could be included in the total score.

Provisional Diagnostic Criteria for Depression of Alzheimer's Disease

The Provisional Diagnostic Criteria for Depression of Alzheimer's Disease (PDC-dAD) [4] was used to diagnose clinical depression based on the presence of at least three core symptoms (one of which must be depressed mood or decreased positive affect) within a 2-week period that represented a change from previous functioning. These criteria have been validated in people with dementia. Overall, the findings support the criterion, content, and convergent validity of the PDC-dAD [36]. Specifically, the PDC-dAD has shown greater sensitivity to depression in dementia compared with other common clinical interviews, such as the Diagnostic and Statistical Manual of Mental Disorders [3,4,37]. The PDC-dAD was also able to discriminate group differences on the Hamilton Depression Rating Scale and the Neuropsychiatric Inventory (NPI), highlighting its convergent validity [36].

The Improved Clinical Global Impressions Scale

The Improved Clinical Global Impressions (iCGI) scale [38] comprises the 7-item (*normal, not ill at all*=1 to *among the most extremely ill patients*=7) Severity subscale and the 13-item (*ideal improvement*=6 to *maximum deterioration*=−6) Improvement subscale. The iCGI has demonstrated good to excellent interrater reliability (ie, intraclass correlations [ICCs] ranging from 0.62-0.94) and large effect sizes in measuring sensitivity to change (ie, Cohen *d* values of 0.76-1.02) and has been validated in people with depression [38,39].

NPI Dysphoria Subscale

The NPI dysphoria item was rated on a 3-item severity scale (*mild*=1, *moderate*=2, and *marked*=3) and a 4-item frequency scale (*occasionally*=1, *often*=2, *frequently*=3, *very frequently*=4). The dysphoria subscale has been shown to correlate significantly with the Hamilton Depression Rating Scale and has shown strength as a stand-alone measure, demonstrating good interrater reliability and strong convergent validity with the CSDD-19 [40]. ICCs by items ranged from 0.54-0.89 [40,41]. The NPI has also been validated in people with dementia and was chosen as it was familiar to clinical staff [42,43].

Procedures

At baseline and at 6 weeks, diagnostic assessments for depression were completed by a geriatric psychiatrist using the PDC-dAD scale [4], the iCGI scale [38], and the NPI dysphoria subscale [42]. Participants were observed by trained research staff for up to four times a day, 7 days a week, over a 6-week period, and their symptoms were recorded using the mCSDD4-MA tool on a mobile phone.

Before the commencement of data collection, observer training for the research staff was undertaken. This consisted of guidance related to detecting and interpreting depressive symptoms based on affective and behavioral cues and explaining the technical aspects of the mCSDD4-MA tool [20]. Preliminary trial ratings were completed and discussed with raters to ensure that the tool was being used correctly and to improve rater consistency. Four raters recorded depressive symptoms exhibited by participants in pairs on a rotating basis, four times a day (ie, 10-11 AM, 1-2 PM, 4-5 PM, and 7-8 PM) using the tool. The pairs of raters responsible for observing participants on any given day observed all of the enrolled participants within the 1-hour observation period at each timeslot. The raters were blinded to the depression

XSL•FO
RenderX

diagnosis for all participants and their co-rater's depressive symptom ratings.

Statistical Analyses

A large number of observations (approximately 4 observations × 12 participants × 2 raters × approximately 7 days × approximately 6 weeks) were undertaken. Descriptive analyses were completed for the demographic and EMA data, including feasibility data (ie, completion rates, *unable to evaluate* ratings, and observations of participant acceptability). Completion rates included *unable to evaluate* ratings as completed observations, whereas missing data were defined as the absence of a reported observation during the assigned timeslot. Having reported a participant as unable to be evaluated was thus not classified as a missed observation and instead indicated feasibility data related to observing participants.

Separate cross-classified mixed effects ordinal logistic regression models (ie, cumulative link mixed models) were fit for each item of the mCSDD4-MA tool as the dependent variable, with day and hour variables as fixed effects, participant and observer variables as crossed random effects, and a fixed interaction between day and participant [44]. These models provided estimates of the variances of the random intercepts for participants and observers. The ICC values were generated from these variances [45]. A higher participant ICC would suggest that the variability of the random intercepts was accounted for largely by mood changes in the participants and less because of the sources of error related to the observers [44].

Polychoric correlations (r) were generated to examine the interrater reliability between pairs of raters for each item [46]. Krippendorff α values were also generated for each item, given that they evaluate the agreement between multiple raters and multiple time periods and have shown to handle missing data well [47]. Consistent with previous literature, a value of $\alpha>.67$ is used to denote moderate agreement and $\alpha>.80$ for excellent agreement [48]. Pairwise polychoric correlations and the level of incongruency between observers and self-reports were generated to examine the relationship between groups of ratings.

To establish construct validity, participants were categorized into clinically depressed and nondepressed groups at baseline, as determined by the PDC-dAD. Total scores for each mCSDD4-MA item and a total score for the baseline week were generated by averaging each participant's first week data. Wilcoxon rank-sum tests between the 2 groups were run for each item and for the total score, and Cohen d effect sizes were generated for each item.

Additional ordinal logistic regression models were fit (ie, cumulative link models) to establish if EMA data could predict clinical depression at the start and end of the study. These models were generated for each item individually, with the mCSDD-4MA symptom ratings and the interaction of the mCSDD-4MA symptom ratings and day inserted as fixed effects. A model was also generated using the total score at each time point and the interaction of the total score and day as fixed effects. The presence of clinical depression on the PDC-dAD admission and discharge assessments was the dependent variable for all models. This process was repeated for the iCGI admission and discharge as dependent variables. All statistical tests were analyzed with $P>.05$.

Results

Feasibility and Completion Rates

The demographic characteristics of the participants are presented in Table 2. A total of 1923 observations were completed. This represented a 55.06% (1923/3496) completion rate across the 6-month study, based on 2 raters present at each timeslot, 7 days a week. When excluding weekends and the 7 PM timeslot, the completion rate was 92.01% (1923/2090), with 2 raters present. If at least one rater was present at any point in time, the rate was 66.01% (1923/2913) for 7 days a week. Once weekends and evenings were excluded, the completion rate increased to 98.01% (1923/1962), with at least one rater present. Across the day, 29.02% (558/1923), 31.98% (615/1923), 30.99% (596/1923), and 8.01% (154/1923) of all reported observations occurred at the 10 AM, 1 PM, 4 PM, and 7 PM timeslots, respectively. The majority of the data were skewed toward reporting the absence of symptoms. The most to least frequent items reported were *lack of interest*, *sadness*, *anxiety*, *irritability*, and *negativity* (Multimedia Appendices 1 and 2).

Overall, the rating *unable to evaluate* was selected at 26.99% (519/1923) of the observations, 41.03% (789/1923) of the self-reported sadness, and 43.52% (837/1923) of the self-reported anxiety items. The 7 PM-8 PM timeslot resulted in the greatest inability to evaluate participants where more than half of all observations (83/154, 53.9%) and self-reports during this time were reported as unable to be evaluated, usually because the participants were already asleep. The 10 AM-11 AM timeslot was next, where 32.9% (184/558) of each observational rating could not be evaluated during that time (Multimedia Appendix 3). Overall, participants' experiences with being assessed were positive, and many expressed appreciations for visits from the observers.

On the basis of the random intercept variances of the participant and the observer, the participant ICCs ranged from 0.13-0.48 for the different symptoms, whereas the observer ICC ranged from 0.00-0.06. Thus, the variability in random intercepts was accounted for primarily by the participants, rather than the rater for most symptoms (Multimedia Appendix 4).

XSL•FO
RenderX

Table 2. Demographic characteristics of patient participants (N=12).

Characteristics	Total sample (N=12)	Depressive symptoms (n=4)[a]	No depressive symptoms (n=8)
Age (years), mean (SD)	77.4 (8.2)	81.3 (9.3)	75.5 (6.7)
Dementia type, n (%)			
Alzheimer	9 (75)	3 (75)	6 (75)
Vascular	2 (17)	0 (0)	2 (25)
Parkinson dementia	1 (8)	1 (25)	0 (0)
MMSE[b], median (IQR)	0 (2.5)	0 (4.8)	0 (2.5)
Sex (female), n (%)	5 (42)	3 (75)	2 (25)
Duration in study (days), mean (SD)	38.1 (8.3)	35.5 (11.9)	39.4 (6.4)
NPI[c] admission, mean (SD)	42.3 (22.3)	51.5 (13.6)	37.6 (25.1)
NPI dysphoria admission	2.83 (4.7)	8.50 (4.1)	0 (0)
NPI discharge, mean (SD)	18.9 (15.3)	24.8 (6.6)	16.0 (18.0)
NPI dysphoria discharge	2.00 (3.6)	4.00 (4.6)	1.00 (2.8)
PDC-dAD[d] depressed admission, n (%)	2 (17)	2 (50)	0 (0)
PDC-dAD depressed discharge, n (%)	1 (8.3)	1 (25)	0 (0)
iCGI[e] admission, mean (SD)	2.92 (1.4)	4.25 (1.7)	2.25 (0.7)
iCGI discharge, mean (SD)	2.08 (1.2)	2.75 (1.3)	1.75 (1.0)
iCGI improvement score, mean (SD)	1.00 (2.0)	1.50 (3.1)	0.75 (1.4)

[a]Defined by a Neuropsychiatric Inventory cutoff >4.

[b]MMSE: Mini-Mental State Examination.

[c]NPI: Neuropsychiatric Inventory.

[d]PDC-dAD: Provisional Diagnostic Criteria for Depression of Alzheimer's Disease.

[e]iCGI: Improved Clinical Global Impressions.

Interrater Reliability

For all pairs of raters, interrater reliability ranged from 0.67-0.92 for *sadness*, 0.57-0.83 for *anxiety*, 0.41-0.90 for *irritability*, −0.07 to 0.82 for *negativity*, and 0.24-0.79 for *lack of interest* (Table 3). These analyses identified that the fourth rater was consistently less reliable, given the differences in their scores. Thus, separate reliability analyses were conducted using all raters and only raters 1-3.

Krippendorff α values across all raters were generated and showed moderate reliability for *sadness* (α=.74) and *irritability* (α=.67) but lower reliability for *negativity* (α=.62), *anxiety* (α=.61), and *lack of interest* (α=.45). Once the fourth rater was excluded, the α values increased, but the trends remained the same (Table 4).

XSL•FO
RenderX

Table 3. Polychoric correlations (*r*) of the observational data comparing pairs of the 4 researchers for each of the items.

Raters	1	2	3
Sadness			
2	0.91	—[a]	—
3	0.86	0.67	—
4	0.75	0.59	0.57
Irritability			
2	0.87	—	—
3	0.90	0.72	—
4	0.66	0.50	0.41
Negativity			
2	0.75	—	—
3	0.82	0.62	—
4	0.28	−0.07	0.71
Anxiety			
2	0.82	—	—
3	0.83	0.71	—
4	0.75	0.59	0.57
Lack of interest			
2	0.69	—	—
3	0.79	0.50	—
4	0.34	0.27	0.24

[a]N/A: not applicable.

Table 4. Krippendorff α values for ecological momentary assessment item data by research staff.

Item	Krippendorff α
Raters 1-4	
Sadness	.74
Anxiety	.61
Irritability	.67
Lack of interest	.45
Negativity	.62
Raters 1-3	
Sadness	.78
Anxiety	.65
Irritability	.77
Lack of interest	.54
Negativity	.62

Concordance Between Observational and Self-reported Items

Patient–self-reported symptoms were moderately correlated with observer-rated sadness (r=0.68) and anxiety (r=0.57). When participants reported feeling sad or anxious, raters would observe sadness 88.1% (730/829) of the time and would observe anxiety 78.9 % (601/761) of the time. When raters reported observed depressive symptoms, participants would confirm feeling sad in 90.97% (968/1064) of the cases and would confirm feeling worried in 93.83% (1081/1152) of the cases. Overall, 72.95% (1403/1923) of the ratings showed agreement between observers and self-reports of sadness and anxiety (Multimedia Appendix 5).

XSL•FO
RenderX

Construct Validity

Observer-rated *sadness*, *anxiety*, and total symptom score in the first week of assessment were significantly associated with the presence of clinical depression at baseline, as determined by the PDC-dAD (Wilcoxon-rank sum, W=20, *P*=.04, Cohen *d*=1.00 for *sadness*; W=20, *P*=.04, Cohen *d*=0.49 for *anxiety*; and W=20, *P*=.03, Cohen *d*=1.00 for the total score).

Observational and self-reported measures of *sadness* and *anxiety* over the course of the study were associated with clinical depression diagnosis over time, as determined by the PDC-dAD at baseline and at 6 weeks. Scoring at least *some* (vs no) observational *sadness* and *anxiety* increased the log odds of clinical depression diagnosis by 2.74 and 1.51, respectively. Likewise, scoring *a lot* (vs *no*) of observational *sadness* and *anxiety* increased the log odds of clinical depression diagnosis by 5.37 and 3.13, respectively. Finally, answering *yes* (vs *no*) on the sadness and anxiety self-reports increased the log odds of clinical depression diagnosis by 2.20 and 2.58, respectively (Table 5).

Table 5. Association between items in the modified 4-item Cornell Scale for Depression in Dementia for Momentary Assessment tool and clinical depression, as determined by the Provisional Diagnostic Criteria for Depression and Dementia, over the course of the study.

Items and item score	Estimate (SE)	*P* value	95% CI
Sadness			
2	2.74 (0.62)	<.001[a]	1.52 to 3.95
3	5.37 (0.73)	<.001[a]	3.93 to 6.80
Anxiety			
2	1.51 (0.32)	<.001[a]	0.87 to 2.15
3	3.13 (0.58)	<.001[a]	2.00 to 4.26
Irritability			
2	0.44 (0.62)	.47	−0.77 to 1.67
3	0.61 (0.79)	.44	−0.95 to 2.17
Lack of interest			
2	−0.46 (0.54)	.40	−1.52 to 0.60
3	0.74 (0.85)	.86	−0.94 to 2.42
Negativity			
2	0.74 (0.58)	.20	−0.39 to 1.88
3	1.61 (1.93)	.40	−2.16 to 5.40
Self-reported sadness			
2	2.20 (0.47)	<.001[a]	1.07 to 2.94
Self-reported anxiety			
2	2.58 (0.51)	<.001[a]	1.59 to 3.58

[a]*P*=.04.

In addition to *sadness*, *anxiety*, and self-reported anxiety, *negativity* over the course of the study also predicted depressive symptom severity, as measured by the iCGI Severity scale. Scoring *a lot* of *sadness* and *anxiety* relative to *no* increased the log odds of severe depressive symptoms by 4.49 and 4.81, respectively. Scoring *some anxiety* and *negativity* compared with *no* increased the log odds of severe depressive symptoms by 1.93 and 1.13, respectively. Finally, answering *yes* compared with *no* for the anxiety self-report decreased the log odds of severe depressive symptoms by 0.63 (Multimedia Appendix 6).

The total CSDD-4 score generated at each observation point did not predict clinical depression diagnosis or depressive symptoms as determined by the PDC-dAD or iCGI over the course of the study.

Discussion

Principal Findings

Our study evaluated the performance of the mCSDD4-MA tool for assessing depression in people with advanced dementia. EMA ratings of depressive symptoms show potential for identifying clinical depression and can contribute to a wider understanding of depression assessment in this population. EMA approach showed preliminary feasibility, and the items demonstrated moderate reliability, with the exception of *lack of interest*. Moderate correlations were observed between the observational and patient-reported items. In addition, the tool showed construct validity across several items and for the total score and promising predictive validity for several items.

XSL•FO
RenderX

The mCSDD4-MA tool was feasible and acceptable to the participants, with the participants enjoying engagement by the research staff. Overall, 7 PM-8 PM and 10 AM-11 AM timeslots accounted for the lowest proportion of observations based on both observer completion rates and their ability to observe participants. In terms of observing participants, these times may occur when participants are sleeping or receiving personal care. From a feasibility perspective, it may be appropriate to cut down to 2 observations per day in the afternoon. However, the next steps require comparing the sensitivity of the tool when observing participants two times versus four times a day to conclude if two observations are sufficient.

Capturing observational ratings of depressive symptoms repeatedly in real time was found to be a reliable method for assessment. Item-level analyses demonstrated that *sadness* and *irritability* were the most reliable and that *anxiety* and *negativity* were less reliable. This is consistent with previous research in which observers who repeatedly rated effect in people with dementia in real time found high interrater reliabilities for sadness and irritability [20]. Sadness and irritability may be easily recognizable because of their intensity and are thought to be biologically hard-wired emotions [20,49]. Ratings of *anxiety* were less reliable between raters, which may be related to their high heterogeneity in the presence of emotional disorders [20].

Although four out of five items demonstrated good psychometric properties, *lack of interest* displayed clear psychometric problems for which there are several possible explanations. These relate to the time taken to assess the item, the definition of the item, and the overlap of *lack of interest* with apathy. First, it is possible that insufficient time was spent observing participants to properly assess their degree of interest. The evaluation of interest requires both the presence of engaging activities to stimulate interest as well as the time to observe whether an individual is deriving any enjoyment from the activity [20]. Even in a well-resourced inpatient unit, there may still be moments throughout the day of low activity or understimulation for participants. Second, the adaptation of the *lack of interest* item for real-time assessment was: "Is the person showing *enjoyment* or *pleasure* in what is going on around them?" with options, "No lack of interest," "Some lack of *interest*," and "Lacking a lot of *interest*." Studies have shown that although pleasure and interest are highly correlated, there is heterogeneity in the definition of anhedonia [50]. As pleasure and enjoyment were included in the question, and interest was used in the response, this may have affected the understanding of the item. Finally, symptom overlap with apathy (ie, loss of interest and motivation, fatigue, and low social engagement) may have confounded the item [51]. Overall, there is a need to develop a more reliable *lack of interest* item for real-time assessment. This would require modifications such as wording the item to be more closely related to the concept of anhedonia and more distinct from apathy, recommending longer observation periods for evaluating the presence of symptoms, and improving rater training [20,52].

Using EMA to measure depressive symptoms in advanced dementia also shows construct and predictive validity, as demonstrated by its association with depression at baseline and over time. Our analyses confirmed the validity of several items, including observed sad and anxious affect, which have been previously reported to predict and correlate with depression and depressive symptoms in people with dementia [19,20]. In this study, we were also able to demonstrate a relationship between patient-reported symptoms in a population with advanced dementia and clinical depression and symptoms. This is a unique finding, as self-reporting is not typically included in observer-rated depression assessments. This lends some support to the inclusion of patient self-reports, in keeping with patient-centered care approaches. *Negativity* was also shown to be associated with depressive symptoms; however, the rating of *negativity* was contingent on the participants' ability to communicate negative cognitions. Although *negativity* is a highly specific depressive symptom in advanced dementia, it has poor sensitivity given its low frequency. Overall, several items in the mCSDD4-MA tool demonstrated a promising ability to detect clinically significant depression and depressive symptoms.

Discrepancies between informant and patient-reported symptoms are well documented in the literature and were found in this study, illustrating the importance of collecting both types of reports. Low patient-proxy agreement in mood can be attributed to subjectivity in observing these items and raters attributing depressive symptoms to dementia or vice versa [10,53,54]. In this study, the majority of ratings (1403/1923, 72.95%) completed by participants and observers were concordant. In 57% (12/21) and 78% (21/27) of the discordant ratings, the participants self-reported the presence of sad and anxious mood, respectively, whereas observers rated the symptoms as absent. This differs from the literature in which people with dementia have reported *fewer* symptoms than their informants, although some studies have shown similar results [7,8]. Again, this underscores the importance of including patient-reported ratings, although it is important to ensure the reliability of these self-reports. In this study, the severity of cognitive impairment may have affected the reliability of patient-reported outcomes. Some participants agreed to feeling sad or anxious, despite not showing any outward sign of negative affect, leading the observers to doubt whether the participants had understood the question. Thus, there is a need to improve the reliability of self-reports, which could be done by combining some neutral and positively worded questions, in addition to the questions about symptoms to ascertain the consistency of the responses [35].

This study had several limitations. As this was a pilot study, the between-person sample size affected the power and generalizability of the results to a larger population of people with advanced dementia. However, we aimed to compensate for this by achieving a large within-person sample size. In addition, although intensive longitudinal designs are limited in their generalizability to other individuals, they are strengthened by their ability to generalize across situations within individuals [32]. Although certain patient-related (ie, cognitive impairment and level of awareness) and observer-related (ie, quality of training and internal mood states) factors can have an impact on the interpretation of mood, our study did not specifically examine these effects on depression ratings. Future studies can

XSL•FO
RenderX

address the psychometric issues with the assessment of interest in people with dementia in real time and develop EMA protocols to improve the overall psychometric properties of the tool. Given the previous findings on caregiver biases, it is important to note that research staff ratings may differ from caregiver ratings, which may limit the generalizability of these findings [6,7]. Therefore, future studies should also examine the performance across different categories of observers.

Conclusions

A modified CSDD4-MA tool for momentary assessment of depression in people with advanced dementia is feasible and has moderate reliability and validity. Repeated and real-time assessment of mood in these individuals holds promise to monitor depressive symptoms and clinical depression.

Acknowledgments

This work was generously funded by the Walter & Maria Schroeder Institute for Brain Innovation and Recovery. The authors would also like to acknowledge Steven Stewart for his helpful contributions to statistical analyses.

Authors' Contributions

IN wrote the manuscript with support and supervision from AI, RG, and BF. IN, TA, and HQ collected data. TB contributed to statistical analyses and interpretation.

Conflicts of Interest

AI has received research grants from the Alzheimer Association, Canadian Institutes for Health Research, AGE-WELL, and the Centre for Aging and Brain Health Innovation. She is on the scientific advisory panel for Winterlight LLC. The other authors have no conflicts of interest or financial disclosures.

Multimedia Appendix 1
Frequency of research staff observations for the observational 4-item Cornell Scale for Depression in Dementia for Momentary Assessment items.
[PNG File , 45 KB - aging_v4i3e29021_app1.png]

Multimedia Appendix 2
Frequency of the self-reported 4-item Cornell Scale for Depression in Dementia for Momentary Assessment items.
[PNG File , 35 KB - aging_v4i3e29021_app2.png]

Multimedia Appendix 3
Percentage of data (%) that was rated as unable to be evaluated at each observation period.
[DOCX File , 13 KB - aging_v4i3e29021_app3.docx]

Multimedia Appendix 4
Ratios of variance components of the participant and observer variables in the 4-item Cornell Scale for Depression in Dementia for Momentary Assessment items.
[DOCX File , 14 KB - aging_v4i3e29021_app4.docx]

Multimedia Appendix 5
The level of congruence between observational sadness and anxiety and self-reported sadness and anxiety.
[PNG File , 50 KB - aging_v4i3e29021_app5.png]

Multimedia Appendix 6
Association between items in the 4-item Cornell Scale for Depression in Dementia for Momentary Assessment tool and clinical depressive symptoms, as measured by the Improved Clinical Global Impressions scale over the course of the study.
[DOCX File , 15 KB - aging_v4i3e29021_app6.docx]

References

1. Engedal K, Barca ML, Laks J, Selbaek G. Depression in Alzheimer's disease: specificity of depressive symptoms using three different clinical criteria. Int J Geriatr Psychiatry 2011 Sep 07;26(9):944-951. [doi: 10.1002/gps.2631] [Medline: 21845597]
2. Starkstein SE, Jorge R, Mizrahi R, Robinson RG. The construct of minor and major depression in Alzheimer's disease. Am J Psychiatry 2005 Nov;162(11):2086-2093. [doi: 10.1176/appi.ajp.162.11.2086]

XSL•FO
RenderX

3. Goodarzi ZS, Mele BS, Roberts DJ, Holroyd-Leduc J. Depression case finding in individuals with dementia: a systematic review and meta-analysis. J Am Geriatr Soc 2017 May 02;65(5):937-948. [doi: 10.1111/jgs.14713] [Medline: 28152174]
4. Olin JT, Schneider LS, Katz IR, Meyers BS, Alexopoulos GS, Breitner JC, et al. Provisional diagnostic criteria for depression of Alzheimer disease. Am J Geriatr Psychiatry 2002 Mar;10(2):125-128. [doi: 10.1097/00019442-200203000-00003]
5. Starkstein SE, Mizrahi R, Power BD. Depression in Alzheimer's disease: phenomenology, clinical correlates and treatment. Int Rev Psychiatry 2008 Aug 11;20(4):382-388. [doi: 10.1080/09540260802094480] [Medline: 18925487]
6. Snow A, Kunik M, Molinari V, Orengo CA, Doody R, Graham DP, et al. Accuracy of self-reported depression in persons with dementia. J Am Geriatr Soc 2005 Mar;53(3):389-396. [doi: 10.1111/j.1532-5415.2005.53154.x] [Medline: 15743279]
7. Chemerinski E, Petracca G, Sabe L, Kremer J, Starkstein SE. The specificity of depressive symptoms in patients with Alzheimer's disease. Am J Psychiatry 2001 Jan;158(1):68-72. [doi: 10.1176/appi.ajp.158.1.68] [Medline: 11136635]
8. Teri L, Wagner AW. Assessment of depression in patients with Alzheimer's disease: concordance among informants. Psychol Aging 1991;6(2):280-285. [doi: 10.1037/0882-7974.6.2.280]
9. Shiffman S, Stone AA, Hufford MR. Ecological momentary assessment. Annu Rev Clin Psychol 2008 Apr;4(1):1-32. [doi: 10.1146/annurev.clinpsy.3.022806.091415] [Medline: 18509902]
10. Towsley G, Neradilek MB, Snow AL, Ersek M. Evaluating the Cornell scale for depression in dementia as a proxy measure in nursing home residents with and without dementia. Aging Ment Health 2012 Sep;16(7):892-901 [FREE Full text] [doi: 10.1080/13607863.2012.667785] [Medline: 22486638]
11. Alexopoulos GS, Abrams RC, Young RC, Shamoian CA. Cornell scale for depression in dementia. Biol Psychiatry 1988 Feb;23(3):271-284. [doi: 10.1016/0006-3223(88)90038-8]
12. Jeon Y, Li Z, Low L, Chenoweth L, O'Connor D, Beattie E, et al. The clinical utility of the Cornell Scale for Depression in Dementia as a routine assessment in nursing homes. Am J Geriatr Psychiatry 2015 Aug;23(8):784-793. [doi: 10.1016/j.jagp.2014.08.013] [Medline: 25256214]
13. Jeon Y, Liu Z, Li Z, Low L, Chenoweth L, O'Connor D, et al. Development and validation of a short version of the Cornell Scale for Depression in Dementia for screening residents in nursing homes. Am J Geriatr Psychiatry 2016 Nov;24(11):1007-1016. [doi: 10.1016/j.jagp.2016.05.012] [Medline: 27538349]
14. Mehta KM, Yaffe K, Langa KM, Sands L, Whooley MA, Covinsky KE. Additive effects of cognitive function and depressive symptoms on mortality in elderly community-living adults. J Gerontol A Biol Sci Med Sci 2003 May 01;58(5):461-467 [FREE Full text] [doi: 10.1093/gerona/58.5.m461] [Medline: 12730257]
15. Enache D, Winblad B, Aarsland D. Depression in dementia : epidemiology, mechanisms, and treatment. Curr Opin Psychiatry 2011;24(6):461-472. [doi: 10.1097/yco.0b013e32834bb9d4]
16. Moore RC, Depp CA, Wetherell JL, Lenze EJ. Ecological momentary assessment versus standard assessment instruments for measuring mindfulness, depressed mood, and anxiety among older adults. J Psychiatr Res 2016 Apr;75:116-123. [doi: 10.1016/j.jpsychires.2016.01.011] [Medline: 26851494]
17. Kim H, Lee S, Lee S, Hong S, Kang H, Kim N. Depression prediction by using ecological momentary assessment, actiwatch data, and machine learning: observational study on older adults living alone. JMIR Mhealth Uhealth 2019 Oct 16;7(10):e14149 [FREE Full text] [doi: 10.2196/14149] [Medline: 31621642]
18. Kim H, Kim S, Kong S, Jeong Y, Kim H, Kim N. Possible application of ecological momentary assessment to older adults' daily depressive mood: integrative literature review. JMIR Ment Health 2020 Jun 02;7(6):e13247 [FREE Full text] [doi: 10.2196/13247] [Medline: 32484442]
19. Kolanowski A, Hoffman L, Hofer SM. Concordance of self-report and informant assessment of emotional well-being in nursing home residents with dementia. J Gerontol B Psychol Sci Soc Sci 2007 Jan 01;62(1):20-27. [doi: 10.1093/geronb/62.1.p20] [Medline: 17284553]
20. Lawton MP, Van Haitsma K, Klapper J. Observed affect in nursing home residents with Alzheimer's disease. J Gerontol B Psychol Sci Soc Sci 1996 Jan 01;51(1):3-14. [doi: 10.1093/geronb/51b.1.p3] [Medline: 8548515]
21. de Boer B, Beerens H, Zwakhalen S, Tan F, Hamers J, Verbeek H. Daily lives of residents with dementia in nursing homes: development of the Maastricht electronic daily life observation tool. Int Psychogeriatr 2016 Mar 23;28(8):1333-1343. [doi: 10.1017/s1041610216000478]
22. Rullier L, Atzeni T, Husky M, Bouisson J, Dartigues J, Swendsen J, et al. Daily life functioning of community-dwelling elderly couples: an investigation of the feasibility and validity of Ecological Momentary Assessment. Int J Methods Psychiatr Res 2014 Jun;23(2):208-216. [doi: 10.1002/mpr.1425] [Medline: 24375556]
23. Junge S, Gellert P, O'Sullivan JL, Möller S, Voigt-Antons J, Kuhlmey A, et al. Quality of life in people with dementia living in nursing homes: validation of an eight-item version of the QUALIDEM for intensive longitudinal assessment. Qual Life Res 2020 Jun 18;29(6):1721-1730 [FREE Full text] [doi: 10.1007/s11136-020-02418-4] [Medline: 31955375]
24. Folstein MF, Robins LN, Helzer JE. The mini-mental state examination. Arch Gen Psychiatry 1983 Jul 01;40(7):812. [doi: 10.1001/archpsyc.1983.01790060110016] [Medline: 6860082]
25. Cain AE, Depp CA, Jeste DV. Ecological momentary assessment in aging research: a critical review. J Psychiatr Res 2009 Jul;43(11):987-996. [doi: 10.1016/j.jpsychires.2009.01.014] [Medline: 19272611]

XSL•FO
RenderX

26. Paterson C, Jones M, Rattray J, Lauder W, Nabi G. What is the mechanism effect that links social support to coping and psychological outcome within individuals affected by prostate cancer? Real time data collection using mobile technology. Eur J Oncol Nurs 2016 Apr;21:126-133. [doi: 10.1016/j.ejon.2015.09.002] [Medline: 26440544]
27. Astivia OL, Gadermann A, Guhn M. The relationship between statistical power and predictor distribution in multilevel logistic regression: a simulation-based approach. BMC Med Res Methodol 2019 May 9;19(1):97. [doi: 10.1186/s12874-019-0742-8]
28. Kerkhoff D, Nussbeck FW. The influence of sample size on parameter estimates in three-level random-effects models. Front Psychol 2019 May 21;10:1067 [FREE Full text] [doi: 10.3389/fpsyg.2019.01067] [Medline: 31164847]
29. Sadikaj G, Wright A, Dunkley D, Zuroff D, Moskowitz D. Multilevel structural equation modeling for intensive longitudinal data: a practical guide for personality researchers. In: The Handbook of Personality Dynamics and Processes. Cambridge, Massachusetts, United States: Academic Press; 2021:855-885.
30. Lafit G, Adolf J, Dejonckheere E, Myin-Germeys I, Viechtbauer W, Ceulemans E. Selection of the number of participants in intensive longitudinal studies: a user-friendly Shiny App and tutorial for performing power analysis in multilevel regression models that account for temporal dependencies. Adv Methods Pract Psychol Sci 2021 Mar 23;4(1):1-24. [doi: 10.1177/2515245920978738]
31. Maas CJ, Hox JJ. Sufficient sample sizes for multilevel modeling. Methodology 2005 Jan;1(3):86-92. [doi: 10.1027/1614-2241.1.3.86]
32. Conner TS, Tennen H, Fleeson W, Barrett LF. Experience sampling methods: a modern idiographic approach to personality research. Soc Personal Psychol Compass 2009 May 1;3(3):292-313 [FREE Full text] [doi: 10.1111/j.1751-9004.2009.00170.x] [Medline: 19898679]
33. Alexopoulos GS. Depression in the elderly. Lancet 2005 Jun;365(9475):1961-1970. [doi: 10.1016/s0140-6736(05)66665-2]
34. Gallo JJ, Rabins PV. Depression without sadness: alternative presentations of depression in late life. Am Fam Physician 1999 Sep 01;60(3):820-826 [FREE Full text] [Medline: 10498109]
35. Tappen RM, Barry C. Assessment of affect in advanced Alzheimer's disease: the Dementia Mood Picture Test. J Gerontol Nurs 1995 Mar 01;21(3):44-46. [doi: 10.3928/0098-9134-19950301-09] [Medline: 7706649]
36. Sepehry A, Lee P, Hsiung G, Beattie B, Feldman H, Jacova C. The 2002 NIMH Provisional Diagnostic Criteria for Depression of Alzheimer's Disease (PDC-dAD): gauging their validity over a decade later. J Alzheimer's Dis 2017 May 11;58(2):449-462. [doi: 10.3233/jad-161061]
37. Asmer MS, Kirkham J, Newton H, Ismail Z, Elbayoumi H, Leung RH, et al. Meta-analysis of the prevalence of Major Depressive Disorder among older adults with dementia. J Clin Psychiatry 2018 Jul 31;79(5):r11772. [doi: 10.4088/jcp.17r11772]
38. Kadouri A, Corruble E, Falissard B. The improved Clinical Global Impression Scale (iCGI): development and validation in depression. BMC Psychiatry 2007 Feb 06;7(1):7. [doi: 10.1186/1471-244x-7-7]
39. Romijn AR, Rucklidge JJ, Kuijer RG, Frampton C. A double-blind, randomized, placebo-controlled trial of Lactobacillus helveticus and Bifidobacterium longum for the symptoms of depression. Aust N Z J Psychiatry 2017 Aug 10;51(8):810-821 [FREE Full text] [doi: 10.1177/0004867416686694] [Medline: 28068788]
40. de Medeiros K, Robert P, Gauthier S, Stella F, Politis A, Leoutsakos J, et al. The Neuropsychiatric Inventory-Clinician rating scale (NPI-C): reliability and validity of a revised assessment of neuropsychiatric symptoms in dementia. Int Psychogeriatr 2010 Sep;22(6):984-994 [FREE Full text] [doi: 10.1017/S1041610210000876] [Medline: 20594384]
41. Wood S, Cummings JL, Hsu M, Barclay T, Wheatley MV, Yarema KT, et al. The use of the neuropsychiatric inventory in nursing home residents. Characterization and measurement. Am J Geriatr Psychiatry 2000 Dec;8(1):75-83. [doi: 10.1097/00019442-200002000-00010] [Medline: 10648298]
42. Cummings JL. The Neuropsychiatric Inventory: assessing psychopathology in dementia patients. Neurology 1997 May 01;48(5 Suppl 6):10-16. [doi: 10.1212/wnl.48.5_suppl_6.10s] [Medline: 9153155]
43. Cummings JL, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, Gornbein J. The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. Neurology 1994 Dec 01;44(12):2308-2314. [doi: 10.1212/wnl.44.12.2308] [Medline: 7991117]
44. Bolger N, Laurenceau J. Introduction to intensive methods. In: Intensive Longitudinal Methods: An Introduction to Diary Experience Sampling Research. New York, United States: The Guilford Press; 2013:1-256.
45. Hedeker D. Multilevel models for ordinal and nominal variables. In: Leeuw J, Meijer E, editors. Handbook of Multilevel Analysis. New York: Springer; 2008:237-274.
46. Mukaka MM. Statistics corner: a guide to appropriate use of correlation coefficient in medical research. Malawi Med J 2012 Sep;24(3):69-71 [FREE Full text] [Medline: 23638278]
47. Krippendorff K. Estimating the reliability, systematic error and random error of interval data. Educ Psychol Meas 2016 Jul 02;30(1):61-70. [doi: 10.1177/001316447003000105]
48. Shelley M, Krippendorff K. Content Analysis: an introduction to its methodology. J Am Stat Assoc 1984 Mar;79(385):240. [doi: 10.2307/2288384]
49. Kätsyri J, Sams M. The effect of dynamics on identifying basic emotions from synthetic and natural faces. Int J Hum Comput Stud 2008 Apr;66(4):233-242. [doi: 10.1016/j.ijhcs.2007.10.001]

XSL•FO
RenderX

50. Rizvi SJ, Pizzagalli DA, Sproule BA, Kennedy SH. Assessing anhedonia in depression: potentials and pitfalls. Neurosci Biobehav Rev 2016 Jun;65:21-35 [FREE Full text] [doi: 10.1016/j.neubiorev.2016.03.004] [Medline: 26959336]
51. Marin RS, Firinciogullari S, Biedrzycki RC. The sources of convergence between measures of apathy and depression. J Affect Disord 1993 May;28(1):7-14. [doi: 10.1016/0165-0327(93)90072-r]
52. Landes AM, Sperry SD, Strauss ME, Geldmacher DS. Apathy in Alzheimer's disease. J Am Geriatr Soc 2001 Dec;49(12):1700-1707. [doi: 10.1046/j.1532-5415.2001.49282.x] [Medline: 11844006]
53. Snow AL, Cook KF, Lin P, Morgan RO, Magaziner J. Proxies and other external raters: methodological considerations. Health Serv Res 2005 Oct;40(5 Pt 2):1676-1693 [FREE Full text] [doi: 10.1111/j.1475-6773.2005.00447.x] [Medline: 16179002]
54. Lachner C, Armstrong MJ, Gruber-Baldini AL, Rezvani Z, Reich SG, Fishman PS, et al. Discordance between physician assessment and patient-reported depressive symptoms in Parkinson Disease. J Geriatr Psychiatry Neurol 2017 Jul 24;30(4):191-195. [doi: 10.1177/0891988717710335] [Medline: 28535723]

Abbreviations

CSDD: Cornell Scale for Depression in Dementia
CSDD-4: 4-item Cornell Scale for Depression in Dementia
EMA: ecological momentary assessment
ICC: intraclass correlation
iCGI: Improved Clinical Global Impressions
mCSDD4-MA: 4-item Cornell Scale for Depression in Dementia for Momentary Assessment
NPI: Neuropsychiatric Inventory
PDC-dAD: Provisional Diagnostic Criteria for Depression of Alzheimer's Disease

Edited by J Wang; submitted 23.03.21; peer-reviewed by S Schneider, S Victor; comments to author 27.04.21; revised version received 28.05.21; accepted 01.06.21; published 04.08.21.

Please cite as:
Niculescu I, Quirt H, Arora T, Borsook T, Green R, Ford B, Iaboni A
Ecological Momentary Assessment of Depression in People With Advanced Dementia: Longitudinal Pilot Study
JMIR Aging 2021;4(3):e29021
URL: https://aging.jmir.org/2021/3/e29021
doi:10.2196/29021
PMID:34346884

©Iulia Niculescu, Hannah Quirt, Twinkle Arora, Terry Borsook, Robin Green, Brett Ford, Andrea Iaboni. Originally published in JMIR Aging (https://aging.jmir.org), 04.08.2021. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Aging, is properly cited. The complete bibliographic information, a link to the original publication on https://aging.jmir.org, as well as this copyright and license information must be included.

XSL•FO
RenderX

Viewpoint

Decreasing COVID-19 Risk Factors for Older Adults by Using Digital Technology to Implement a Plant-Based-Diet: An Opinion

Heidi Lynn Benavides[1], RN, AAH, ADN, MSN; Christiane Lumachi Meireles[1], RD, PhD; Viola Benavente[1], RN, BSN, MSN, PhD; Mary Helen Mays[2], RD, MBA, MPH, MSHI, PhD; Jing Wang[1], RN, MPH, PhD, FAAN

[1]School of Nursing, UT Health San Antonio, San Antonio, TX, United States

[2]Office of Faculty Excellence, UT Health San Antonio, San Antonio, TX, United States

Corresponding Author:
Heidi Lynn Benavides, RN, AAH, ADN, MSN
School of Nursing
UT Health San Antonio
7703 Floyd Curl Drive
San Antonio, TX, 78229
United States
Phone: 1 2103232289
Email: benavidesh@uthscsa.edu

Abstract

A disproportionate number of COVID-19 cases affect older, minority populations. Obese older adults are at higher risk of developing severe COVID-19 complications and lower survival rates, and minority older adults often experience higher rates of obesity. A plant-based diet intervention may improve COVID-19-related modifiable risk factors for obesity. Encouraging the consumption of plant-based diets comprising vegetables, fruits, whole grains, legumes, seeds, and nuts by utilizing community outreach strategies and digital technology can contribute to improving COVID-19 risk factors among this population.

(JMIR Aging 2021;4(3):e25327) doi:10.2196/25327

KEYWORDS

COVID-19; coronavirus; older adult; plant-based diet; eating patterns; whole foods; Mediterranean diet; obesity; pandemic; ethnic minorities; telehealth; digital technology; racial disparities; aging

Introduction

The risk of severe illness with COVID-19 increases with age, with older adults at the highest risk of hospitalization or death [1]. Certain underlying medical conditions increase these risks, including hypertension, heart disease, cancer, type 2 diabetes, chronic kidney disease, and obesity [2]. Minority populations are at higher risk for developing these chronic diseases, thereby increasing their risk of contracting COVID-19 and consequent death. Many factors place minority individuals at risk of contracting the virus, including health care access, socioeconomic status, and frontline worker occupational exposure [3].

The Centers for Disease Control and Prevention reports COVID-19 cases, hospitalizations, and deaths of people of various ethnicities in comparison to White, non-Hispanic persons [3]. American Indian or Alaska Native non-Hispanic persons are high-risk groups for COVID-19, with 1.6 times higher cases, 3.5 times higher hospitalization rates, and 2.4 times higher death rates reported. Black, non-Hispanic individuals are also disproportionately affected by the pandemic, with 1.1 times higher likelihood of contracting COVID-19, 2.8 times higher hospitalization rates, and 1.9 times higher death rates reported. For example, in the District of Columbia, Black individuals constitute 47% of the population, yet they accounted for 74% of COVID-19–related deaths [4]. Hispanic or Latino individuals were 2 times more likely to contract COVID-19, had 3 times higher hospitalization deaths, and were 2.3 times more likely to die [3]. Moreover, Hispanic individuals living in the District of Columbia make up 11% of the population but accounted for 29% of all COVID-19–related deaths [4]. In Texas as well, disparities were noted, as 39% of the population is Hispanic but accounted for a higher COVID-19 death rate of 54%.

The United States is plagued with an obesity epidemic, which has worsened over the recent decades [5]. Obesity and severe obesity are defined as a BMI of 30 kg/m^2 and ≥40 kg/m^2, respectively. The rate of obesity in the period from 1999 to 2000 was 30.5%; during 2017-2018, this rate had increased to 42.4%. The trend for severe obesity nearly doubled in 10 years,

XSL•FO
RenderX

increasing from 4.7% in 1999-2000 to 9.2% in 2017-2018. Obesity and severe obesity rates have increased, placing a disproportionate burden among communities of color. Non-Hispanic black individuals had the highest prevalence rates of obesity (49.6%), followed by Hispanic individuals (44.8%). By gender, US-born Hispanic or Latino men have the highest obesity rate compared to men of other ethnicities, including those who are foreign-born [6].

Age is also a risk factor known to increase the development of severe illness related to COVID-19, including increasing rates of hospitalization and lowered prognosis of survival [1]. Individuals 65 years and older with a positive COVID-19 laboratory test were noted to have higher hospitalization rates (13.8%) than younger individuals, and those 85 years and older were at even greater risk, with a hospitalization rate of 17.2% [7]. The COVID-19 crisis has highlighted how the cumulative impact of multiple risk factors, such as being older, obese, and a member of a minority group, dramatically increases the probability of hospitalization and death due to COVID-19. For example, older, minority men who smoke and have a BMI ≥35 kg/m^2 require increased oxygenation while hospitalized [1].

Support for Plant-Based Diets: Role in Managing Obesity and Related Risk Factors

Reducing obesity and severe obesity is a complex process, including behavior change, diet modifications, and increased in physical activity. Dietary changes that reduce the amount of trans and saturated fat consumed, as well as refined or simple carbohydrates, support healthy weight loss.

Although only 2.4% of the general US population has adopted a plant-based diet, there is a growing interest toward incorporating a more plant-based diet for different reasons, including a healthy lifestyle [8]. Dietary modification is an accessible, measurable, and translatable health behavior. Identifying achievable self-management behaviors that promote and maintain a plant-based diet has been shown to decrease adiposity, BMI, and hemoglobin A_{1C} levels in certain minority groups and older adults [9,10].

A plant-based diet refers to a pattern of food intake that emphasizes consumption of vegetables, fruits, whole grains, legumes, seeds, and nuts, excluding the intake of all animal products or including some animal-based foods such as milk, dairy products, and eggs. Cumulative evidence shows the benefits increasing consumption of plant-based diets has on several chronic diseases such as obesity [11-13]. Healthy plant-based dietary patterns include consumption of foods low in total saturated fat and high in fiber, antioxidants, and phytochemicals [14]. As a result, a number of health and nutrition organizations, as well as evidence-based weight loss programs, recommend foods that are more plant-based. The American Institute for Cancer Research recommends that two-thirds of the total dietary intake include vegetables, fruits, whole grains, and beans [15]. The Academy of Nutrition and Dietetics states that “appropriately planned vegetarian, including vegan diets are healthful, nutritionally adequate, and may provide health benefits for the prevention and treatment of certain diseases” [14]. These diets, the Academy notes, can be appropriate for older adults when balanced to meet recommended daily requirements. A concern with plant-based diets is the lack of vitamin B_{12}, which is only available in animal foods. Older adults can have decreased absorption of vitamin B_{12} and may require vitamin B_{12} supplementation, regardless of their overall eating patterns.

Additional support for plant-based diets can be found in the Dietary Guidelines for Americans, 2020-2025, which reports that increasing consumption of vegetables, fruits, and whole grains and adopting vegetarian and Mediterranean eating patterns is healthful for all ages [16]. The Mediterranean Diet and the DASH (Dietary Approach to Stop Hypertension) diet have been linked to healthy dietary patterns focusing on higher consumption of plant-based foods. These dietary plans also recommend a moderate intake of milk and dairy, decreased consumption of red and processed meat, and increased consumption of fish [17,18].

The PREDIMED (Prevención con Dieta Mediterránea) study, comprising a prospective cohort with more than 7000 older participants, associated a preference for plant-derived foods with reduced mortality among older adults with high cardiovascular risk [19]. Although the PREDIMED study shows the benefits of shifting food patterns to a more vegetarian diet in an older population, adherence to the diet, especially in this population, may pose a challenge.

Transition to a plant-based diet may be easier when the foods are consistent with the individual’s culture, religious beliefs, and food preferences. In a study of middle-aged to older South Asian participants in the United States, those who had strong traditional South Asian cultural beliefs maintained their vegetarian diet [20]. In a previous study by Ramal et al [10], Latino patients with type 2 diabetes living in medically underserved areas were educated on the benefits of foods rich in fiber, low in fat, and derived from mostly plant-based sources. Group sessions were used to help participants shift their dietary patterns to a more plant-based one, also helping them to implement and comply with the dietary recommendations. The intervention had a significant impact on the participants’ hemoglobin A_{1C} levels, a reduction in fat intake, and hip circumference. This study showed plant-based foods can be successfully implemented in the Hispanic culture when the individuals and families are aware of the benefits and are supported by their families, community, and health care professionals. Research has shown that Latino or Hispanic participants who followed a more plant-based dietary approach had lower adiposity rates, BMIs, and hemoglobin A_{1C} values with reduced cardiovascular risk [9,10]. Given the growth of and high prevalence of obesity among US Hispanic or Latino populations, especially in older adults with underlying cardiometabolic conditions, a change in dietary patterns has the potential to make a great public health impact and reduce COVID-19 risk and mortality rate [10,21].

The Adventist Health Study 2 sampled members of the Seventh-day Adventist church [22]. A large sampling of

XSL•FO
RenderX

non-Hispanic Black adults showed that the absence of obesity improved life expectancy and that a plant-based diet promoted healthy weight, which was associated with increasing longevity. Such positive study findings indicate that this type of nutritional approach is a healthy lifestyle behavior in underserved racial or ethnic subpopulations [23,24].

Increasing Adoption of Plant-Based Diets

Plant-based nutrition education programs in the United States are scarce. However, there is enough scientific evidence supporting plant-based diets to help combat obesity and associated diseases [11-13], and such programs should be considered for large-scale implementation and effectiveness testing. Community outreach programs and other strategies can help minority older adults adopt plant-based diets to increase consumption of vegetables, fruits, whole grains, and legumes.

Nutrition education is often effective when delivered through the grocery shopping process. Yet, this routine activity may constitute a burden and barrier for older people, especially older adults living in food deserts and poverty-stricken areas. During the COVID-19 pandemic, there has been an increased use of online and curbside pickup for grocery shopping. Nutrition education tips and recommendations can be included in grocery store websites that support increasing plant-based food consumption. This may include highlighting weekly sales items that fit into a plant-based diet as well as simple recipes for preparing these foods, where local cultures and food preferences are considered. Moreover, in situations where the older adult may get assistance from family members with grocery shopping, this information may not only influence the dietary intake of the older adult but may also positively influence the nutritional intake of the family in general.

Community gardens are effective outreach programs implemented in neighborhood community centers and can be tailored to local cultural preferences [25,26]. These programs often increase access to a variety of affordable and healthy foods to older adults, as well as the community at large [27-30]. This concept represents a "farm-to-table" resource for fresh produce, which may be at lower cost or no cost to older adults. Social distancing restrictions during the COVID-19 pandemic have limited opportunities for social interaction at community gardens, as well as contributions to garden development. As more people are immunized against COVID-19, and these opportunities open up, it is likely that participation in community gardens may increase followed by improved vegetable consumption, increased physical activity, and reduced obesity rates [31].

In 2001, the US Department of Agriculture began a Seniors Farmers' Market Nutrition Program (SFMNP) [32]. The program serves low-income older adults, generally defined as individuals who are at least 60 years old and who have household incomes of not more than 185% of the federal poverty income guidelines with sites located typically at centers and housing locations for older adults. In fiscal year 2017, the SFMNP assisted 811,809 low-income older adults with benefits. SFMNP awards grants to US states, US territories, and Indian Tribal Organizations to provide fresh, nutritious, unprepared, and locally grown fruits, vegetables, herbs, and honey through farmer's markets, roadside stands, and community-supported agriculture programs [32]. Older adults who qualify for the program should be encouraged to utilize the coupons to help increase their consumption of eligible foods. Transportation may be a barrier for some older adults, thereby decreasing their ability to utilize SFMNP coupons in their community. If available, ride-share programs (eg, Uber and Lyft) may be an option.

The Older American's Act (OAA) funds 39% of the Meals on Wheels program and is the primary federal legislation supporting social and nutritional needs of vulnerable persons who are 60 years and older [33]. Meals on Wheels America supports over 5000 community nutrition centers for older adults and the delivery of meals to homebound older adults [34]. One myth about the program is that meal choices are not allowed; however, in 2016, Meals on Wheels provided an executive summary that dispelled this myth. The OAA allows food choices and should be promoted among the older adult population. However, each US state develops their own policies and procedures based on the OAA, making interpretations difficult. Older adults should be encouraged to make menu choices to accommodate personal preferences, and plant-based options could be included, especially in forms that are in harmony with the participant's culture, beliefs, and religion. Encouraging older adults to eat fruits and vegetables through outreach programs such as Meals on Wheels can improve their adoption of a plant-based diet.

Leveraging Digital Technologies to Promote Plant-Based Diet Intake

The COVID-19 pandemic has significantly increased the use of technology in a broad range of activities such as health care (eg, telemedicine and telehealth); sourcing foods, both ready-to-eat as well as to be prepared (eg, restaurant delivery, curbside grocery pickup); and social and work interactions through platforms such as Zoom and Microsoft Teams. Advances in digital health technologies, telehealth, and internet access can facilitate the delivery of effective plant-based diets and behavioral programs safely to minority, aging populations. These types of modalities decrease the risk of COVID-19 exposure, provide ways to deliver education, and enhance local and community support.

When considering the use of eHealth and technology by older adults, including minority older adults, in general, it is important to realize that many may lack or have low levels of eHealth literacy [35]. Norman and Skinner [36] defined eHealth literacy as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem." eHealth literacy is a combination of six core skills (or literacies): traditional literacy, health literacy, information literacy, scientific literacy, media literacy, and computer literacy. Although proficiency is not needed in all six skill areas, a minimum competency across all skills is considered essential to promote eHealth literacy.

XSL•FO
RenderX

Reducing barriers to technology use among older adults, including those representing minorities, is important to improve uptake and use of available resources. Many older adults face low vision challenges; therefore, understanding how to enlarge text or images on a computer screen can help address this barrier. For those older adults who have less experience in basic computer or smartphone use (eg, how to access the internet, how to access or download an app), having a trusted friend or family member provide a "guided tutorial" on how to complete these steps can help build both knowledge and confidence in the ability to use available technology. Instruction via distance (such as Zoom or Facetime on smartphones) makes this instruction possible even when physically separated. Those older minority adults who are not comfortable with or fluent in English, may find apps and sites that are available in different languages. Although multilanguage websites and applications are more frequently available, some minorities may still find barriers resulting from cultural variations in spelling or word usage. In these cases, a family member, friend, or local public librarian who can navigate these idiomatic challenges may be needed.

Telehealth can enhance digitally delivered education through behavioral coaching with a remote health care provider, dietitian, and/or nurse either individually or by utilizing a shared medical appointment (SMA) approach. SMA is a group patient visit and may last 120 minutes long. An SMA can provide group education by the health care team to help reduce costs and allow more time with the health care team; it has been overwhelmingly supported by the patient [37]. For instance, a group of 10 patients with the same medical diagnoses could have an appointment at the same time with the health care provider, a nurse, and a dietitian, thus allowing more time to be spent with the patient than a typical one-on-one appointment tailoring to each specific condition.

User-friendly, low-literacy apps and online community support platforms are available in various languages to support nutrition behavior modification. These apps typically allow food tracking through capturing pictures and easy access to lifestyle coaches. Such apps can help track calorie-counting, provide information on plant-based meal preparation, and calculate macro and micronutrients. In addition, there are apps to help search for local plant-based diet restaurants, stores, and markets, thus aiding the individual in achieving healthy decision-making. These types of apps are becoming more popular to support the adoption of plant-based diets.

Conclusions

Promoting plant-based diets by using technology can be beneficial in decreasing modifiable COVID-19 risk factors for minority older adults. Consumption of a mostly plant-based dietary pattern promotes healthier BMI and hemoglobin A_{1C} levels. Community outreach programs such as Meals on Wheels, community gardens, Seniors Farmers' Market Nutrition Program and other strategies are critically important to help improve obesity and related health considerations. Implementing technology into patient treatment plans by using low-literacy apps and either individual or group virtual health visits could significantly improve health disparities among vulnerable populations and benefit future generations. Emphasizing plant-based diet consumption is promising and needs to be further explored, which may reduce COVID-19–related health disparities and promote healthier weights in minority older adults.

Conflicts of Interest

None declared.

References

1. Palaiodimos L, Kokkinidis DG, Li W, Karamanis D, Ognibene J, Arora S, et al. Severe obesity, increasing age and male sex are independently associated with worse in-hospital outcomes, and higher in-hospital mortality, in a cohort of patients with COVID-19 in the Bronx, New York. Metabolism 2020 Jul;108:154262 [FREE Full text] [doi: 10.1016/j.metabol.2020.154262] [Medline: 32422233]
2. Malavazos AE, Corsi Romanelli MM, Bandera F, Iacobellis G. Targeting the adipose tissue in COVID-19. Obesity (Silver Spring) 2020 Jul;28(7):1178-1179 [FREE Full text] [doi: 10.1002/oby.22844] [Medline: 32314871]
3. Risk for COVID-19 Infection, Hospitalization, and Death By Race/Ethnicity. Centers for Disease Control and Prevention. URL: https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html [accessed 2020-08-20]
4. Racial Data Dashboard. The COVID Tracking Project - The Atlantic Monthly Group. URL: https://covidtracking.com/race/dashboard [accessed 2020-08-10]
5. Hales CM, Carroll MD, Fryar CD, Ogden CL. Prevalence of obesity and severe obesity among adults: United States, 2017-2018. NCHS Data Brief 2020 Feb(360):1-8 [FREE Full text] [Medline: 32487284]
6. Hill SE, Bell C, Bowie JV, Kelley E, Furr-Holden D, LaVeist TA, et al. Differences in obesity among men of diverse racial and ethnic background. Am J Mens Health 2017 Jul;11(4):984-989 [FREE Full text] [doi: 10.1177/1557988315580348] [Medline: 25862694]
7. Garg S, Kim L, Whitaker M, O'Halloran A, Cummings C, Holstein R, et al. Hospitalization rates and characteristics of patients hospitalized with laboratory-confirmed coronavirus disease 2019 - COVID-NET, 14 States, March 1-30, 2020. MMWR Morb Mortal Wkly Rep 2020 Apr 17;69(15):458-464 [FREE Full text] [doi: 10.15585/mmwr.mm6915e3] [Medline: 32298251]

XSL•FO
RenderX

8. Jaacks LM, Kapoor D, Singh K, Narayan KV, Ali MK, Kadir MM, et al. Vegetarianism and cardiometabolic disease risk factors: differences between South Asian and US adults. Nutrition 2016 Sep;32(9):975-984 [FREE Full text] [doi: 10.1016/j.nut.2016.02.011] [Medline: 27155957]
9. Singh PN, Clark RW, Herring P, Sabaté J, Shavlik D, Fraser GE. Obesity and life expectancy among long-lived Black adults. J Gerontol A Biol Sci Med Sci 2014 Jan;69(1):63-72 [FREE Full text] [doi: 10.1093/gerona/glt049] [Medline: 23682156]
10. Ramal E, Champlin A, Bahjri K. Impact of a plant-based diet and support on mitigating type 2 diabetes mellitus in Latinos living in medically underserved areas. Am J Health Promot 2018 Mar;32(3):753-762. [doi: 10.1177/0890117117706793] [Medline: 28503930]
11. Harland J, Garton L. An update of the evidence relating to plant-based diets and cardiovascular disease, type 2 diabetes and overweight. Nutr Bull 2016 Nov 15;41(4):323-338 [FREE Full text] [doi: 10.1111/nbu.12235]
12. Satija A, Bhupathiraju SN, Rimm EB, Spiegelman D, Chiuve SE, Borgi L, et al. Plant-based dietary patterns and incidence of type 2 diabetes in US men and women: results from three prospective cohort studies. PLoS Med 2016 Jun;13(6):e1002039 [FREE Full text] [doi: 10.1371/journal.pmed.1002039] [Medline: 27299701]
13. Wright N, Wilson L, Smith M, Duncan B, McHugh P. The BROAD study: a randomised controlled trial using a whole food plant-based diet in the community for obesity, ischaemic heart disease or diabetes. Nutr Diabetes 2017 Mar 20;7(3):e256 [FREE Full text] [doi: 10.1038/nutd.2017.3] [Medline: 28319109]
14. Melina V, Craig W, Levin S. Position of the Academy of Nutrition and Dietetics: vegetarian diets. J Acad Nutr Diet 2016 Dec;116(12):1970-1980. [doi: 10.1016/j.jand.2016.09.025] [Medline: 27886704]
15. Recommendation - Eat a Diet Rich in Whole Grains, Vegetables, Fruits, and Beans. American Institute for Cancer Research. URL: https://www.aicr.org/cancer-prevention/recommendations/eat-a-diet-rich-in-whole-grains-vegetables-fruits-and-beans/ [accessed 2020-08-20]
16. Dietary Guidelines for Americans 2020-2025, Ninth Edition. DietaryGuidelines.gov. URL: https://www.dietaryguidelines.gov/sites/default/files/2021-03/Dietary_Guidelines_for_Americans-2020-2025.pdf [accessed 2021-04-17]
17. D'Innocenzo S, Biagi C, Lanari M. Obesity and the Mediterranean diet: a review of evidence of the role and sustainability of the Mediterranean diet. Nutrients 2019 Jun 09;11(6):1306 [FREE Full text] [doi: 10.3390/nu11061306] [Medline: 31181836]
18. Locke A, Schneiderhan J, Zick SM. Diets for health: goals and guidelines. Am Fam Physician 2018 Jun 01;97(11):721-728 [FREE Full text] [Medline: 30215930]
19. Martínez-González MA, Sánchez-Tainta A, Corella D, Salas-Salvadó J, Ros E, Arós F, PREDIMED Group. A provegetarian food pattern and reduction in total mortality in the Prevención con Dieta Mediterránea (PREDIMED) study. Am J Clin Nutr 2014 Jul;100 Suppl 1:320S-328S. [doi: 10.3945/ajcn.113.071431] [Medline: 24871477]
20. Jin Y, Kanaya A, Kandula N, Rodriguez L, Talegawkar S. Vegetarian diets are associated with selected cardiometabolic risk factors among middle-older aged South Asians in the United States. J Nutr 2018 Dec 01;148(12):1954-1960 [FREE Full text] [doi: 10.1093/jn/nxy217] [Medline: 30418560]
21. Commodore-Mensah Y, Selvin E, Aboagye J, Turkson-Ocran R, Li X, Himmelfarb C, et al. Hypertension, overweight/obesity, and diabetes among immigrants in the United States: an analysis of the 2010-2016 National Health Interview Survey. BMC Public Health 2018 Jun 20;18(1):773 [FREE Full text] [doi: 10.1186/s12889-018-5683-3] [Medline: 29925352]
22. Singh P, Jaceldo-Siegl K, Shih W, Collado N, Le L, Silguero K, et al. Plant-based diets are associated with lower adiposity levels among Hispanic/Latino adults in the Adventist Multi-Ethnic Nutrition (AMEN) study. Front Nutr 2019 Apr 9;6:34 [FREE Full text] [doi: 10.3389/fnut.2019.00034]
23. Tonstad S, Stewart K, Oda K, Batech M, Herring RP, Fraser GE. Vegetarian diets and incidence of diabetes in the Adventist Health Study-2. Nutr Metab Cardiovasc Dis 2013 Apr;23(4):292-299 [FREE Full text] [doi: 10.1016/j.numecd.2011.07.004] [Medline: 21983060]
24. Sterling S, Bowen S. The potential for plant-based diets to promote health among Blacks living in the United States. Nutrients 2019 Dec 02;11(12):2915 [FREE Full text] [doi: 10.3390/nu11122915] [Medline: 31810250]
25. Malberg Dyg P, Christensen S, Peterson C. Community gardens and wellbeing amongst vulnerable populations: a thematic review. Health Promot Int 2020 Aug 01;35(4):790-803. [doi: 10.1093/heapro/daz067] [Medline: 31369084]
26. Palar K, Lemus Hufstedler E, Hernandez K, Chang A, Ferguson L, Lozano R, et al. Nutrition and health improvements after participation in an urban home garden program. J Nutr Educ Behav 2019 Oct;51(9):1037-1046 [FREE Full text] [doi: 10.1016/j.jneb.2019.06.028] [Medline: 31601420]
27. Twiss J, Dickinson J, Duma S, Kleinman T, Paulsen H, Rilveria L. Community gardens: lessons learned from California Healthy Cities and Communities. Am J Public Health 2003 Sep;93(9):1435-1438. [doi: 10.2105/ajph.93.9.1435] [Medline: 12948958]
28. Wakefield S, Yeudall F, Taron C, Reynolds J, Skinner A. Growing urban health: community gardening in South-East Toronto. Health Promot Int 2007 Jun;22(2):92-101. [doi: 10.1093/heapro/dam001] [Medline: 17324956]
29. Lombard KA, Forster-Cox S, Smeal D, O'Neill MK. Diabetes on the Navajo nation: what role can gardening and agriculture extension play to reduce it? Rural Remote Health 2006;6(4):640 [FREE Full text] [Medline: 17044752]

XSL•FO
RenderX

30. Alaimo K, Packnett E, Miles RA, Kruger DJ. Fruit and vegetable intake among urban community gardeners. J Nutr Educ Behav 2008;40(2):94-101. [doi: 10.1016/j.jneb.2006.12.003] [Medline: 18314085]
31. Burges DL, Moore HJ. Community gardening and obesity. Perspect Public Health 2011 Jul;131(4):163-164. [doi: 10.1177/1757913911412475] [Medline: 21888117]
32. Seniors Farmers' Market Nutrition Program. United States Department of Agriculture. 2018. URL: https://fns-prod.azureedge.net/sites/default/files/sfmnp/SFMNPFactSheet.pdf [accessed 2020-08-10]
33. How Meals on Wheels is funded. Meals on Wheels America. 2020 Sep. URL: https://www.mealsonwheelsamerica.org/docs/default-source/fact-sheets/2020/2020-national/mowa_2020factsheet_funding.pdf?sfvrsn=25a8b53b [accessed 2021-06-24]
34. Dispelling myths: supporting public policy for greater impact and sustainability. Meals on Wheels America. 2016. URL: https://www.mealsonwheelsamerica.org/docs/default-source/membership/executive-summary-2016-final.pdf?sfvrsn=2 [accessed 2021-06-24]
35. Anderson MA, Perrin A. Tech adoption climbs among older adults. Pew Research Center. 2017 May 17. URL: https://www.pewresearch.org/internet/2017/05/17/tech-adoption-climbs-among-older-adults/ [accessed 2021-04-22]
36. Norman CH, Skinner HA. eHealth literacy: essential skills for consumer health in a networked world. J Med Internet Res 2006 Jun 16;8(2):e9 [FREE Full text] [doi: 10.2196/jmir.8.2.e9] [Medline: 16867972]
37. Ludlow M, Clairmont E. Shared medical appointment: role of clinical dietitian. J Acad Nutr Diet 2019 Sep;119(9):A14 [FREE Full text] [doi: 10.1016/j.jand.2019.06.062]

Abbreviations

DASH: Dietary Approach to Stop Hypertension
OAA: Older American's Act
PREDIMED: Prevención con Dieta Mediterránea
SMA: shared medical appointment
SFMNP: Seniors Farmers' Market Nutrition Program

Edited by G Eysenbach; submitted 27.10.20; peer-reviewed by J op den Buijs, CY Lin; comments to author 04.02.21; revised version received 28.04.21; accepted 31.05.21; published 05.07.21.

Please cite as:
Benavides HL, Meireles CL, Benavente V, Mays MH, Wang J
Decreasing COVID-19 Risk Factors for Older Adults by Using Digital Technology to Implement a Plant-Based-Diet: An Opinion
JMIR Aging 2021;4(3):e25327
URL: https://aging.jmir.org/2021/3/e25327
doi:10.2196/25327
PMID:34081595

©Heidi Lynn Benavides, Christiane Lumachi Meireles, Viola Benavente, Mary Helen Mays, Jing Wang. Originally published in JMIR Aging (https://aging.jmir.org), 05.07.2021. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Aging, is properly cited. The complete bibliographic information, a link to the original publication on https://aging.jmir.org, as well as this copyright and license information must be included.

XSL•FO
RenderX

Original Paper

A Sociodemographic Profile of Mask Use During the COVID-19 Outbreak Among Young and Elderly Individuals in Brazil: Online Survey Study

Rodrigo L Vancini[1], PhD; Luiz Camargo-Neto[2], PhD; Marilia S Andrade[3], PhD; Claudio A de Lira[4], PhD; Rafaela G dos Santos[5], PhD; Pantelis T Nikolaidis[6], PhD; Beat Knechtle[7,8], MD; Luiz HV Piacezzi[2], PhD; Maria CB Teixeira-Lopes[2], PhD; Ruth E Assayag-Batista[2], PhD; Meiry F Pinto-Okuno[2], PhD; Cássia R Vancini-Campanharo[2], PhD

[1]Universidade Federal do Espírito Santo, Espírito Santo, Brazil

[2]Escola Paulista de Enfermagem, Universidade Federal de São Paulo, São Paulo, Brazil

[3]Departamento de Fisiologia, Universidade Federal de São Paulo, São Paulo, Brazil

[4]Setor de Fisiologia Humana e do Exercício, Faculdade de Educação Física e Dança, Universidade Federal de Goiás, Goiânia, Brazil

[5]Campus X, Teixeira de Freitas, Universidade do Estado da Bahia, Bahia, Brazil

[6]School of Health and Caring Sciences, University of West Attica, Athens, Greece

[7]Institute of Primary Care, University of Zurich, Zürich, Switzerland

[8]Medbase St. Gallen Am Vadianplat, St. Gallen, Switzerland

Corresponding Author:
Beat Knechtle, MD
Institute of Primary Care
University of Zurich
Pestalozzistrasse 24
Zürich, 8091
Switzerland
Phone: 41 44 255 98 55
Fax: 41 44 255 90 97
Email: beat.knechtle@hispeed.ch

Abstract

Background: Sociodemographic variables may impact decision making regarding safety measures. The use and selection of adequate face masks is a safety and health measure that could help minimize the spread of COVID-19 infection.

Objective: This study aims to examine sociodemographic variables and factors relating to COVID-19 that could impact decision making or the choice to use or not use face masks in the prevention and care of a possible COVID-19 infection among a large sample of younger and older Brazilian people.

Methods: An online survey composed of 14 closed-ended questions about sociodemographic variables and COVID-19 was used. A total of 2673 participants consisted of Brazilian people (aged ≥18 years) from different states of Brazil and were grouped according to age (≤59 years and ≥60 years). To compare the variables of interest (associated with wearing a face mask or not), chi-square and likelihood ratio tests were used (with P<.05 being significant).

Results: Most of the participants in both groups were women from the southeast region who had postgraduate degrees. Approximately 61% (1452/2378) of individuals aged ≤59 years and 67.8% (200/295) of those aged ≥60 years were not health professionals. In the group aged ≤59 years, 83.4% (1983/2378) did not show COVID-19 signs and symptoms, and 97.3% (2314/2378) were not diagnosed with COVID-19. In the older adult group, 92.5% (273/295) did not show signs and symptoms of COVID-19, and 98.3% (290/295) were not diagnosed with the disease. The majority of the participants in both groups reported using face masks, and their decision to use face masks was influenced by the level of education and their occupation as a health professional.

Conclusions: Younger and older adults have worn face masks during the COVID-19 outbreak. It is difficult to measure how much of a positive impact this attitude, habit, and behavior could have on the degree of infection and spread of the disease. However, it can be a positive indicator of adherence to the population's security and safety measures during the pandemic.

XSL•FO
RenderX

(JMIR Aging 2021;4(3):e28989) doi:10.2196/28989

KEYWORDS

aging; older adults; COVID-19; pandemic; sociodemographic profile; face mask; social media; online media; adolescents

Introduction

COVID-19 is an infectious disease caused by SARS-CoV-2, which mainly affects the functioning of the pulmonary system [1]. Current evidence shows that the COVID-19 pandemic has a much higher mortality rate in older adults due to morbidities and bad lifestyle (poor diet and physical inactivity) associated with aging [2]. Factors associated with increased risk of mortality in COVID-19 include comorbidities related to aging, such as obesity, insulin resistance, and cardiovascular disorders, and individuals, especially older adults, are at risk of having lower functional capacity and physical activity levels [3-5], which makes them more vulnerable to the infection [2,4].

During periods of social isolation and physical distancing for a pandemic, coping strategies (physical activity and adequate diet) and safety measures (use of face masks) that promote well-being and improve or maintain the general state of health should be performed and encouraged among the general population to mitigate the negative impacts of the disease [6].

The COVID-19 pandemic has had an unprecedented impact on the global health, economy, and functioning of societies [7]. Latin American countries with a high level of social and economic inequality have experienced worse effects of the pandemic. For example, São Paulo, Brazil has a high population density and great disparity in demographic and epidemiological profiles, social and economic levels, and accessibility to health services and protection and safety measures, such as the use of face masks [8].

Therefore, understanding the sociodemographic variables and adherence to mask use is essential to auxiliary health decisions by public and health authorities to minimize the effects and negative consequences of the COVID-19 pandemic on public health [9]. The assessment of sociodemographic variables determines the impact of population diversity on the effects of the pandemic [10] and how choices regarding safety, security measures, and adherence could affect the consequences and outcomes in the field of public health.

It is known that a population's profile and social characteristics can impact safety measures, hygiene, social distance, outcomes, and possible changes in timing of pandemics [11]. Due to the risk and characteristics of the professional practice and health literacy, it is quite plausible that health professionals, because of their frequent contact with the public, are more sensitive regarding adherence to safety measures [12]. Moreover, the physical and social distancing, use of face masks, and eye protection devices in public and health care facilities are needed for the public and health professionals to control COVID-19 transmission [13].

However, in low-income countries like Brazil, the lack of literacy and access to health care, the spread of fake news among the general population, and the lack of proper management by the government can make a difference in the results and outcomes of such complex health scenarios [14]. Unfortunately, this is what we observed in Brazil during the COVID-19 pandemic. Brazil has been one of the countries with the worst management of the public health crisis; it is on the brink of a progressive social and economic collapse. Thus, studies that aim to check the population's sociodemographic profile and the choices related to security and protective measures during a pandemic are essential to make more precise decisions based on technical and scientific knowledge.

An online-based cross-sectional study involving 12 Bangladeshi residents 64 years of age recruited via social media investigated the influence of factors related to perception, knowledge, attitudes, and practices regarding COVID-19 and found that the factors that impact perception and choices were female sex, older age, higher education, higher family income, and urban area residence [15]. A cross-sectional survey conducted by telephone or mobile phone with older individuals living in the state of Minas Gerais, Brazil showed that older individuals were knowledgeable and had good health literacy regarding COVID-19, but those that did not implement all the preventive measures were older adult male individuals living by themselves with a low educational level, and they are more vulnerable to COVID-19 [16].

Importantly, individuals 60 years and older are more vulnerable to COVID-19, and the use of face masks is a protective, safety, and health care measure to decrease the risk and spread of infection [13]. In addition, older people have a higher peak viral load and, especially those with comorbidities, have higher mortality rates related to COVID-19 than young people. This would be associated with chronic inflammation present in older people who are frail, which could allow a "more effective" action from SARS-CoV-2 leading to serious infection-related complications [17].

Currently, epidemiologists emphasize that the use of face masks covering the mouth and nose effectively stops airborne infections. In general, health and government officials followed the World Health Organization recommendations and, in some cases, forced the population to wear face masks in public places. However, in some countries like Brazil, there is a low rate of health literacy among government officials at all levels. Research shows that using the right type of face mask, according to location and profession, protects and reduces the infection risk [18]. Our aim is to present the sociodemographic and economic profile and health features (about COVID-19) and compare the individual determinants of face mask use during the COVID-19 outbreak among younger and older Brazilian people.

XSL•FO
RenderX

Methods

Study Design

This online and cross-sectional survey was conducted between May 1, 2020, and May 31, 2020, and was approved by the Research Ethics Committee of the Federal University of São Paulo (Certificate of Presentation of Ethical Appreciation - CAAE: 31540620.9.0000.5505). The study was conducted according to the guidelines of the Declaration of Helsinki. We enrolled Brazilian citizens living in Brazil who were 18 years or older (to compose the groups ≤59 years vs ≥60 years), and the consent to participate was obtained from all participants. Participants who did not answer all the research questions were excluded to minimize discrepancies in the number of answers. However, the exclusion of unanswered questionnaires was low, as all the questions on the Google Forms were mandatory. Furthermore, minors were excluded because the aims and procedures were designed for adults.

Participants

The sample was selected using a nonrandom method and comprised of 2673 participants (mean age 40.0, SD 13.8 years). These participants were divided into two age groups: ≤59 years (n=2378, 89%) and ≥60 years (n=295, 11%).

Procedures

Participants were invited to answer the questionnaire voluntarily through posts made on social media (Facebook and Instagram) and WhatsApp using a standard text that publicized the study and drew attention to the importance of understanding the behavior of the population in relation to COVID-19, which could provide subsidies to implement awareness actions, reducing the spread of the disease.

A link to the informed consent form was provided to each participant. Upon consent and agreement to voluntary participation, the participants were directed to the mandatory study questions. The questionnaire was developed by the researchers; corrected and adjusted by a panel of health experts, including a professional statistician; made available on the online platform Google Forms; and disseminated through social networks. The online questionnaire [19] was composed of 14 closed-ended questions about the following variables: age, sex, origin, marital status, religion, family income, education, presence of signs or symptoms or confirmed diagnosis of COVID-19, and occupation as a health professional (yes or no). In addition, multiple-choice questions about COVID-19 included the following: knowledge about the forms of transmission of COVID-19; risk groups, signs and symptoms, and what to do if they were present; preventive measures (hand hygiene, use of masks, and cleaning of surfaces) to be taken in case of traveling; and information on popular beliefs regarding the prevention, transmission, and treatment of COVID-19.

Statistical Analysis

For the descriptive analysis of categorical variables, frequency and percentage were calculated. For continuous variables, mean, SD, median, minimum, and maximum were calculated. To compare the variables of interest (associated with mask use), chi-square and likelihood ratio test (only for comparisons regarding the level of education) were used. A significance level of 5% (P value<.05) was used. The data were analyzed using SPSS, version 19 (IBM Corp).

Results

Our sample consisted of the adult Brazilian population from different states of Brazil: Acre (n=1), Alagoas (n=3), Amapá (n=3), Amazonas (n=1), Bahia (n=23), Ceará (n=36), Distrito Federal (n=22), Espírito Santo (n=32), Goiás (n=31), Maranhão (n=23), Mato Grosso (n=31), Mato Grosso do Sul (n=13), Minas Gerais (n=109), Pará (n=13), Paraíba (n=12), Paraná (n=52), Pernambuco (n=2), Piauí (n=2), Rio de Janeiro (n=73), Rio Grande do Norte (n=8), Rio Grande do Sul (n=24), Rondônia (n=1), Roraima (n=5), Santa Catarina (n=30), São Paulo (n=2117; in the state of São Paulo, the use of facial masks became mandatory on May 7, 2020), Sergipe (n=2), and Tocantins (n=4). The majority of participants were from São Paulo.

Table 1 shows that most of the 2673 individuals in the study were aged ≤59 years (n=2378, 88.9%), were female (n=2039, 76.3%), were from the city of São Paulo (n=2331, 87.2%), were married (n=1261, 47.2%), were Catholic (n=1241, 46.4%), had a monthly family income of 4 to 7 minimum wages in R$ (n=813, 30.4%), and had completed or were currently doing postgraduate studies (n=1181, 44.2%). In addition, 61.8% (n=1652) were not health workers, 84.4% (n=2256) did not show symptoms of COVID-19, and 97.4% (n=2604) had no confirmed diagnosis of the disease. The studied age groups (≤59 years and ≥60 years) were not homogeneous regarding the following variables: sex, Brazil region, marital status, religion, total family income, professional type, and health characteristics and status (Table 1).

Table 2 compares the profiles of participants with regard to the use of masks between the groups in terms of sex (male vs female), education level, occupation as a health worker (yes vs no), and presence of signs and symptoms or a confirmed diagnosis of COVID-19 (yes vs no).

On the use of masks, there were significant differences in sex (female vs male; P<.001), level of education (P<.001), and occupation as a health professional (P=.001). Females, health professionals, and those with a higher level of education adhered to the use of masks more than others.

XSL•FO
RenderX

Table 1. Characteristics of sociodemographic variables of younger and older people during the COVID-19 outbreak.

Variables	Age group (years)		Total (N=2673), n (%)
	≤59 (n=2378), n (%)	≥60 (n=295), n (%)	
Sex			
Women	*1833 (77.1)*[a]	*206 (69.8)*	2039 (76.3)
Men	545 (22.9)	89 (30.2)	634 (23.7)
Brazil region			
North	22 (0.9)	6 (2)	28 (1)
Northeast	108 (4.5)	3 (1)	111 (4.2)
Midwest	93 (3.9)	4 (1.4)	97 (3.6)
Southeast (São Paulo is located)	*2060 (86.6)*	*271 (91.9)*	2331 (87.2)
South	95 (4)	11 (3.7)	106 (4)
Marital status			
Married	*1093 (46)*	*168 (56.9)*	1261 (47.2)
Divorced	153 (6.4)	49 (16.6)	202 (7.6)
Single	894 (37.6)	23 (7.8)	917 (34.3)
Stable union	225 (9.5)	24 (8.1)	249 (9.3)
Widowed	13 (0.5)	31 (10.5)	44 (1.6)
Religion			
Catholic	*1080 (45.4)*	*161 (54.6)*	1241 (46.4)
Evangelical	401 (16.9)	17 (5.8)	418 (15.6)
Spiritism	386 (16.2)	60 (20.3)	446 (16.7)
Agnostic and atheist	274 (11.5)	21 (7.1)	295 (11)
Others	237 (10)	36 (12.2)	273 (10.2)
Total family income in minimum wages (R$ monthly)			
<1	99 (4.2)	1 (0.3)	100 (3.7)
1-3	620 (26.1)	56 (19)	676 (25.3)
4-7	*730 (30.7)*	83 (28.1)	813 (30.4)
8-10	339 (14.3)	50 (16.9)	389 (14.6)
>10	590 (24.8)	*105 (35.6)*	695 (26)
Education level according to the Brazilian standard			
Incomplete elementary school	5 (0.2)	1 (0.3)	6 (0.2)
Complete primary education	15 (0.6)	2 (0.7)	17 (0.6)
Incomplete high school	26 (1.1)	5 (1.7)	31 (1.2)
Complete high school	245 (10.3)	47 (15.9)	292 (10.9)
Higher education (or studying)	1025 (43.1)	*121 (41)*	1146 (42.9)
Postgraduate studies	*1062 (44.7)*	119 (40.3)	1181 (44.2)
Are you a health professional?			
No	*1452 (61.1)*	*200 (67.8)*	1652 (61.8)
Yes	926 (38.9)	95 (32.2)	1021 (38.2)
Have you experienced symptoms of COVID-19?			
No	*1983 (83.4)*	*273 (92.5)*	2256 (84.4)
Yes	395 (16.6)	22 (7.5)	417 (15.6)
Did you have a confirmed diagnosis for COVID-19?			

XSL•FO
RenderX

Variables	Age group (years)		Total (N=2673), n (%)
	≤59 (n=2378), n (%)	≥60 (n=295), n (%)	
No	*2314 (97.3)*	*290 (98.3)*	2604 (97.4)
Yes	64 (2.7)	5 (1.7)	69 (2.6)

[a]Data in italics were the most frequent.

Table 2. Characteristics of mask use according to the variables of interest during the COVID-19 outbreak.

Variables	Mask use, n (%)		Total, n (%)	*P* value
	No	Yes		
Age (years)				.80
≤59	121 (5.1)	*2257 (94.9)*[a]	2378 (100)	
≥60	14 (4.7)	*281 (95.3)*	295 (100)	
Total	135 (5.1)	2538 (94.9)	2673 (100)	
Gender				<.001[b]
Female	87 (4.3)	*1952 (95.7)*	2039 (100)	
Male	48 (7.6)	*586 (92.4)*	634 (100)	
Total	135 (5.1)	2538 (94.9)	2673 (100)	
Level of education				<.001[c]
Incomplete elementary school	0 (0)	*6 (100)*	6 (100)	
Complete primary education	3 (17.6)	*14 (82.4)*	17 (100)	
Incomplete high school	7 (22.6)	*24 (77.4)*	31 (100)	
Complete high school	32 (11)	*260 (89)*	292 (100)	
Higher education (or studying)	51 (4.5)	*1095 (95.5)*	1146 (100)	
Postgraduate studies	42 (3.6)	*1139 (96.4)*	1181 (100)	
Total	135 (5.1)	2538 (94.9)	2673 (100)	
Are you a health professional?				.001[b]
No	101 (6.1)	*1551 (93.9)*	1652 (100)	
Yes	34 (3.3)	*987 (96.7)*	1021 (100)	
Total	135 (5.1)	2538 (94.9)	2673 (100)	
Have you experienced symptoms of COVID-19?				.99
No	114 (5.1)	*2142 (94.9)*	2256 (100)	
Yes	21 (5)	*396 (95)*	417 (100)	
Total	135 (5.1)	2538 (94.9)	2673 (100)	
Did you have a confirmed diagnosis for COVID-19?				.77
No	131 (5)	*2473 (95)*	2604 (100)	
Yes	4 (5.8)	*65 (94.2)*	69 (100)	
Total	135 (5.1)	2538 (94.9)	2673 (100)	

[a]Data in italics were the most frequent.

[b]Found to be statistically significant by the chi-square test.

[c]Found to be statistically significant by the likelihood ratio test.

XSL•FO
RenderX

Discussion

Principal Findings

The main aims of this study were to describe the sociodemographic variables, determine the profiles of individuals compliant to the use of face masks, and compare them between younger and older people. The majority of the 2378 participants in the group aged ≤59 years were women (n=1833, 77.1%), were living in the southeast region (n=2060, 86.6%), and had postgraduate degrees (n=1062, 44.7%). In the case of the 295 individuals aged ≥60 years, the majority were women (n=206, 69.8%), were living in the southeast region (n=271, 91.9%), and had completed or were still completing higher education (n=121, 41%). In addition, the majority of participants in both groups have been using face masks; this was significantly influenced by sex, level of education, and whether the participant was a health professional or not.

This study has two major findings. Nearly 30% to 40% of the participants were health professionals, and 80% to 90% were from São Paulo, that is, people who have good health literacy and educational level and those who are living in regions with the highest socioeconomic level in Brazil. Bambra et al [20] reported that social, economic, demographic differences and inequalities, and lack of access to health care have implications in any pandemic recorded in history, including COVID-19. Dowd et al [9] pointed out that understanding the profile of sociodemographic variables are important for all governments to rapidly make policies to mitigate the negative effects of the COVID-19 pandemic. Through sociodemographic studies, it was possible to verify that the most serious cases and deaths were prevalent among older adults and those with comorbidities. This is important information for health care systems worldwide.

Hence, tracing the sociodemographic profile of different populations worldwide to outline short-, medium-, and long-term positive coping strategies (eg, focused on improving physical and mental health) to help mitigate the COVID-19 pandemic will help decrease inequalities in access to social and health services for future generations. It is interesting to note that hospitalizations and mortality are higher in men than in women and that men are more inclined to smoke and thus have the potential for poorer respiratory outcomes in COVID-19 infection [21].

Regarding the use of face masks, in general, the majority of the participants in this study, both the general population and health professionals, reported adherence to this measure during the course of the COVID-19 pandemic. The factors that significantly influenced this relevant control measure were sex, level of education, and whether the participant is a health professional or not. We highlight three clinical trials, but only one of them is directly related to the use of facial masks as a central measure to control the spread of COVID-19 infection. Bundgaard et al [22] conducted a nonblind, randomized, controlled trial to investigate whether the use of facial masks could reduce the risk of SARS-CoV-2 infection. They included adults (aged >18 years, n=6000) without previously confirmed COVID-19 or symptoms suggestive of COVID-19 who spent more than 3 hours a day outside the home with exposure to other people. The authors concluded that the use of a face mask could be a protective factor for the user against SARS-CoV-2 infection. However, more evidence is needed through robust clinical trials to provide consistent scientific evidence for recommendations from health authorities worldwide and in the future. Liang et al [23] through a meta-analysis concluded that the use of masks is an auxiliary method and measure of health and prevention in relation to the outbreak of COVID-19 and highlighted that these protective health measures are impacted by the level of knowledge and health literacy, [24] and different beliefs, moral values, and even conditions of access to health.

Final Considerations

In this study, women (P<.001), health workers (P=.001), and people with a higher level of education (P<.001) had greater adherence in relation to the use of masks. A potential correlation was found between gender, where there was a higher incidence of disease in men, and there has been a globally observed shorter life expectancy in men as compared to women [25].

Determining sociodemographic profiles and identifying the factors that favored the use of face masks, especially in São Paulo, does not reflect the actual scenario in Brazil, which is a country with many social inequalities, but provides subsidies to study other regions from the same point of view, which can assist in facing the current scenario and future health crises.

Study Limitations and Practical Applications

This study has limitations. Using social media to collect the data may have influenced the study sample, as many participants are health workers and living in the state of São Paulo, the most economically developed region in Brazil. Nevertheless, we were able to gather an expressive sample. In view of the results of our study, we believe that the implementation of health care policies aimed at certain age groups, such as older adults, and populations, for example, men and people who are not health professionals, can increase the compliance to disease prevention measures, for example, the use of face masks, since these populations are heterogeneous from the health care point of view.

Other limitations were the absence of some items in our questionnaire regarding family size (number of people living in the same house), the type of mask used (which can be difficult information to access for those people who are not health professionals), evaluation of the proportion of infected men and women, and a larger sample of people 60 years or older. One of the difficulties of our study was to obtain a larger sample of older participants. Our expectation was to have a more equalized sample size between younger and older groups, which was not possible. It is necessary to understand why older adults tend to answer questionnaires less than younger people despite the massive dissemination of the instrument to this audience. Finally, we did not include questions regarding the smoking habits and alcohol consumption (and other health habits) of younger and older people. These are factors that can impact the general health status and outcome of a COVID-19 infection in cases of abuse and excessive or constant use. Despite this, these are areas of study that need to be further explored and may be the focus of future studies.

XSL•FO
RenderX

Finally, education actions, carried out by health workers, for health promotion and disease prevention can be stimulated and carried out increasing the health literacy of the population, which will provide individualized and effective actions.

Acknowledgments

RLV has a productivity fellowship at the Fundação de Amparo à Pesquisa e Inovação do Espírito Santo Agency (Edital No. 18/2018-Bolsa Pesquisador Capixaba-FAPES). CABL is a productivity fellowship at the Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq) (grant number 305276/2020-4).

Authors' Contributions

RLV, LCN, and CRVC conceptualized the study. RLV, LCN, CABL, MSA, RGS, PTN, BK, LHVP, MCBTL, REAB, and CRVC designed the methodology. The formal analysis was done by RLV, LCN, and CRVC, the investigation was done by RLV, LCN, CABL, MSA, RGS, PTN, BK, LHVP, MCBTL, REAB, and CRVC. The data was curated by RLV, LCN, and CRVC. The original draft was prepared by RLV, LCN, CABL, MSA, RGS, PTN, BK, LHVP, MCBTL, REAB, and CRVC. RLV, LCN, CABL, MSA, RGS, PTN, BK, LHVP, MCBTL, REAB, and CRVC reviewed and edited the paper. RLV, LCN, CABL, MSA, RGS, PTN, BK, LHVP, MCBTL, REAB, and CRVC contributed toward visualization. CRVC supervised the study. RLV, LCN, and CRVC contributed toward project administration. All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

None declared.

References

1. Guan W, Ni Z, Hu Y, Liang W, Ou C, He J, China Medical Treatment Expert Group for Covid-19. Clinical characteristics of coronavirus disease 2019 in China. N Engl J Med 2020 Apr 30;382(18):1708-1720 [FREE Full text] [doi: 10.1056/NEJMoa2002032] [Medline: 32109013]
2. Shahid Z, Kalayanamitra R, McClafferty B, Kepko D, Ramgobin D, Patel R, et al. COVID-19 and older adults: what we know. J Am Geriatr Soc 2020 May;68(5):926-929 [FREE Full text] [doi: 10.1111/jgs.16472] [Medline: 32255507]
3. Brooks SK, Webster RK, Smith LE, Woodland L, Wessely S, Greenberg N, et al. The psychological impact of quarantine and how to reduce it: rapid review of the evidence. Lancet 2020 Mar 14;395(10227):912-920 [FREE Full text] [doi: 10.1016/S0140-6736(20)30460-8] [Medline: 32112714]
4. Jiménez-Pavón D, Carbonell-Baeza A, Lavie CJ. Physical exercise as therapy to fight against the mental and physical consequences of COVID-19 quarantine: special focus in older people. Prog Cardiovasc Dis 2020;63(3):386-388 [FREE Full text] [doi: 10.1016/j.pcad.2020.03.009] [Medline: 32220590]
5. Zbinden-Foncea H, Francaux M, Deldicque L, Hawley JA. Does high cardiorespiratory fitness confer some protection against proinflammatory responses after infection by SARS-CoV-2? Obesity (Silver Spring) 2020 Aug;28(8):1378-1381 [FREE Full text] [doi: 10.1002/oby.22849] [Medline: 32324968]
6. Antunes R, Frontini R, Amaro N, Salvador R, Matos R, Morouço P, et al. Exploring lifestyle habits, physical activity, anxiety and basic psychological needs in a sample of Portuguese adults during COVID-19. Int J Environ Res Public Health 2020 Jun 18;17(12):4360 [FREE Full text] [doi: 10.3390/ijerph17124360] [Medline: 32570737]
7. Coronavirus disease (COVID-2019) situation reports. World Health Organization. 2020. URL: https://www.who.int/emergencies/diseases/novel-coronavirus-2019/situation-reports [accessed 2020-03-17]
8. Fortaleza CMCB, Guimarães RB, de Almeida GB, Pronunciate M, Ferreira CP. Taking the inner route: spatial and demographic factors affecting vulnerability to COVID-19 among 604 cities from inner São Paulo State, Brazil. Epidemiol Infect 2020 Jun 19;148:e118 [FREE Full text] [doi: 10.1017/S095026882000134X] [Medline: 32594926]
9. Dowd JB, Andriano L, Brazel DM, Rotondi V, Block P, Ding X, et al. Demographic science aids in understanding the spread and fatality rates of COVID-19. Proc Natl Acad Sci U S A 2020 May 05;117(18):9696-9698 [FREE Full text] [doi: 10.1073/pnas.2004911117] [Medline: 32300018]
10. Renzaho A. The need for the right socio-economic and cultural fit in the COVID-19 response in sub-Saharan Africa: examining demographic, economic political, health, and socio-cultural differentials in COVID-19 morbidity and mortality. Int J Environ Res Public Health 2020 May 15;17(10):3445 [FREE Full text] [doi: 10.3390/ijerph17103445] [Medline: 32429123]
11. Wang J, Pan L, Tang S, Ji JS, Shi X. Mask use during COVID-19: a risk adjusted strategy. Environ Pollut 2020 Nov;266(Pt 1):115099 [FREE Full text] [doi: 10.1016/j.envpol.2020.115099] [Medline: 32623270]
12. Tirupathi R, Bharathidasan K, Palabindala V, Salim SA, Al-Tawfiq JA. Comprehensive review of mask utility and challenges during the COVID-19 pandemic. Infez Med 2020 Jun 01;28(suppl 1):57-63 [FREE Full text] [Medline: 32532940]
13. Chu DK, Akl EA, Duda S, Solo K, Yaacoub S, Schünemann HJ, COVID-19 Systematic Urgent Review Group Effort (SURGE) study authors. Physical distancing, face masks, and eye protection to prevent person-to-person transmission of

XSL•FO
RenderX

SARS-CoV-2 and COVID-19: a systematic review and meta-analysis. Lancet 2020 Jun 27;395(10242):1973-1987 [FREE Full text] [doi: 10.1016/S0140-6736(20)31142-9] [Medline: 32497510]
14. Nutbeam D, McGill B, Premkumar P. Improving health literacy in community populations: a review of progress. Health Promot Int 2018 Oct 01;33(5):901-911. [doi: 10.1093/heapro/dax015] [Medline: 28369557]
15. Ferdous MZ, Islam MS, Sikder MT, Mosaddek ASM, Zegarra-Valdivia JA, Gozal D. Knowledge, attitude, and practice regarding COVID-19 outbreak in Bangladesh: an online-based cross-sectional study. PLoS One 2020;15(10):e0239254 [FREE Full text] [doi: 10.1371/journal.pone.0239254] [Medline: 33035219]
16. Tavares DMDS, Oliveira NGN, Marchiori GF, Guimarães MSF, Santana LPM. Elderly individuals living by themselves: knowledge and measures to prevent the novel coronavirus. Rev Lat Am Enfermagem 2020;28:e3383 [FREE Full text] [doi: 10.1590/1518-8345.4675.3383] [Medline: 33174993]
17. Vellas C, Delobel P, de Souto Barreto P, Izopet J. COVID-19, virology and geroscience: a perspective. J Nutr Health Aging 2020;24(7):685-691 [FREE Full text] [doi: 10.1007/s12603-020-1416-2] [Medline: 32744561]
18. Matuschek C, Moll F, Fangerau H, Fischer JC, Zänker K, van Griensven M, et al. Face masks: benefits and risks during the COVID-19 crisis. Eur J Med Res 2020 Aug 12;25(1):32 [FREE Full text] [doi: 10.1186/s40001-020-00430-5] [Medline: 32787926]
19. Avaliação do conhecimento da população brasileira sobre a COVID-19 através de uma pesquisa online. Google Forms. URL: https://forms.gle/vzWqCCJ5dD4UYFVDA [accessed 2020-05-01]
20. Bambra C, Riordan R, Ford J, Matthews F. The COVID-19 pandemic and health inequalities. J Epidemiol Community Health 2020 Nov;74(11):964-968 [FREE Full text] [doi: 10.1136/jech-2020-214401] [Medline: 32535550]
21. Ahmed SB, Dumanski SM. Sex, gender and COVID-19: a call to action. Can J Public Health 2020 Dec;111(6):980-983 [FREE Full text] [doi: 10.17269/s41997-020-00417-z] [Medline: 32990927]
22. Bundgaard H, Bundgaard JS, Raaschou-Pedersen DET, Mariager AF, Schytte N, von Buchwald C, et al. Face masks for the prevention of COVID-19 - rationale and design of the randomised controlled trial DANMASK-19. Dan Med J 2020 Aug 18;67(9):A05200363. [Medline: 32829745]
23. Liang M, Gao L, Cheng C, Zhou Q, Uy JP, Heiner K, et al. Efficacy of face mask in preventing respiratory virus transmission: a systematic review and meta-analysis. Travel Med Infect Dis 2020;36:101751. [doi: 10.1016/j.tmaid.2020.101751] [Medline: 32473312]
24. Elsborg L, Krossdal F, Kayser L. Health literacy among Danish university students enrolled in health-related study programmes. Scand J Public Health 2017 Dec;45(8):831-838. [doi: 10.1177/1403494817733356] [Medline: 29052485]
25. Jin J, Bai P, He W, Wu F, Liu X, Han D, et al. Gender differences in patients with COVID-19: focus on severity and mortality. Front Public Health 2020;8:152. [doi: 10.3389/fpubh.2020.00152] [Medline: 32411652]

Edited by J Wang; submitted 21.03.21; peer-reviewed by N Nazari, M Ahmed Kamal, MA Bahrami, M Sehgal, YL Leung, R Sauvayre; comments to author 03.04.21; revised version received 16.05.21; accepted 19.06.21; published 14.09.21.

Please cite as:
Vancini RL, Camargo-Neto L, Andrade MS, de Lira CA, dos Santos RG, Nikolaidis PT, Knechtle B, Piacezzi LHV, Teixeira-Lopes MCB, Assayag-Batista RE, Pinto-Okuno MF, Vancini-Campanharo CR
A Sociodemographic Profile of Mask Use During the COVID-19 Outbreak Among Young and Elderly Individuals in Brazil: Online Survey Study
JMIR Aging 2021;4(3):e28989
URL: https://aging.jmir.org/2021/3/e28989
doi:10.2196/28989
PMID:34253508

©Rodrigo L Vancini, Luiz Camargo-Neto, Marilia S Andrade, Claudio A de Lira, Rafaela G dos Santos, Pantelis T Nikolaidis, Beat Knechtle, Luiz HV Piacezzi, Maria CB Teixeira-Lopes, Ruth E Assayag-Batista, Meiry F Pinto-Okuno, Cássia R Vancini-Campanharo. Originally published in JMIR Aging (https://aging.jmir.org), 14.09.2021. This is an open-access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Aging, is properly cited. The complete bibliographic information, a link to the original publication on https://aging.jmir.org, as well as this copyright and license information must be included.

XSL•FO
RenderX

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org

XSL•FO
RenderX