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Original Paper

Health Impacts of the Stay-at-Home Order on Community-Dwelling Older Adults and How Technologies May Help: Focus Group Study

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Abstract

Background: As of March 2021, in the USA, the COVID-19 pandemic has resulted in over 500,000 deaths, with a majority being people over 65 years of age. Since the start of the pandemic in March 2020, preventive measures, including lockdowns, social isolation, quarantine, and social distancing, have been implemented to reduce viral spread. These measures, while effective for risk prevention, may contribute to increased social isolation and loneliness among older adults and negatively impact their mental and physical health.

Objective: This study aimed to assess the impact of the COVID-19 pandemic and the resulting “Stay-at-Home” order on the mental and physical health of older adults and to explore ways to safely increase social connectedness among them.

Methods: This qualitative study involved older adults living in a Continued Care Senior Housing Community (CCSHC) in southern California, USA. Four 90-minute focus groups were convened using the Zoom Video Communications platform during May 2020, involving 21 CCSHC residents. Participants were asked to describe how they were managing during the “stay-at-home” mandate that was implemented in March 2020, including its impact on their physical and mental health. Transcripts of each focus group were analyzed using qualitative methods.

Results: Four themes emerged from the qualitative data: (1) impact of the quarantine on health and well-being, (2) communication innovation and technology use, (3) effective ways of coping with the quarantine, and (4) improving access to technology and training. Participants reported a threat to their mental and physical health directly tied to the quarantine and exacerbated by social isolation and decreased physical activity. Technology was identified as a lifeline for many who are socially isolated from their friends and family.

Conclusions: Our study findings suggest that technology access, connectivity, and literacy are potential game-changers to supporting the mental and physical health of older adults and must be prioritized for future research.

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KEYWORDS

aging; quarantine; mental health; physical health; social isolation; COVID-19 pandemic; continued care senior housing community; CCSHC; qualitative research; videoconferencing; older adults; gerontechnology; loneliness; housing for the elderly; independent living

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Introduction

Social isolation and loneliness affect human health, well-being, and overall quality of life [1] and are known risk factors for poor mental and physical health across an individual's lifespan, particularly among adults aged over 65 years [2-4]. Social isolation is defined as "the objective lack or limited extent of social contacts with others," whereas loneliness is defined as "the perception of social isolation or the subjective feeling of being lonely" [5]. Research has documented the relationship between social isolation and loneliness and mental health contributing to suicides and opioid-related deaths [6]; poor physical health, including cardiovascular disease and stroke [7]; and premature mortality [8].

The serious societal and public health concerns around social isolation and loneliness prompted the American Association for Retired Persons to commission the National Academies to convene a working group to address social isolation and loneliness among older adults. The resulting report, which included recommendations for improving our health care system, was published in February 2020, just around the time when the COVID-19 pandemic was beginning to grip the United States. The COVID-19 pandemic and related social distancing guidelines are expected to exacerbate social isolation and loneliness, particularly among older adults [9]. In fact, the "double pandemic" of social isolation and COVID-19 has received increasing attention, as the balance of survival against the sacrifices of social connectedness are clearly at odds [8]. An important consideration is how long preventive measures can be kept in place, while considering the consequences of such measures on the public's health and well-being.

In March 2020, "Stay-at-Home" quarantine orders were imposed across the USA to mitigate the spread of COVID-19. As Continued Care Senior Housing Community (CCSHC) residents were considered at high risk of infection, conservative protocols were implemented to prevent the escalation of infection and deaths among older adult residents. The Centers for Disease Control and Prevention issued guidance for CCSHCs to increase protections for residents and workers and advised administrators to work with their local health officials to develop safe and feasible guidelines [10]. Recommendations included risk reduction practices to limit exposure by closing access to common areas (eg, gyms and restaurants) and encouraged workers and residents to refrain from visiting other individuals' living spaces. In addition, those residing or permitted to work within the facility were asked to maintain at least six-feet physical distance, complete daily health screens, and wear face coverings. In many cases, nonessential workers and visitors were not permitted within the facilities.

As COVID-19 continued to spread, it was clear that older adults were at significant risk, particularly those living in CCSHCs where outbreaks were concentrated and associated with community spread and a higher death rate. In the United States, there are nearly 2000 CCSHCs offering long-term care options for older adults [11]. We selected a CCSHC in southern California for our qualitative study designed to assess the impact of quarantine on resident's physical and mental health. This CCSHC was selected because many of its residents are currently involved as participants in an ongoing longitudinal research study. This larger parent study is designed to learn about cognitive, physical, and mental health and factors that influence healthy aging among older adults living independently in a CCSHC [12]. The community-based longitudinal study involves 112 participants (about one-third of all the CCSHC residents) aged 65-100 years and living independently. For our qualitative study, we invited residents, including participants of the longitudinal study, to participate in one of four virtual 90-minute focus group meetings scheduled for May 2020. The aim of the study was to assess the impact of the COVID-19 pandemic and resulting quarantine on the residents' mental and physical health and to explore ways to safely increase social connectedness among them.

Methods

Inclusion Criteria

Four focus groups were conducted in May 2020 using the Zoom videoconferencing platform; the focus groups comprised residents from a CCSHC in southern California aged 65 years and above. Residents were considered eligible for this study if they were an independent-living resident at the CCSHC; willing to participate in a 90-minute group discussion using the Zoom videoconferencing platform; had access to the Zoom platform using a phone, tablet, or computer; and had a general understanding of how to use the platform.

Recruitment and Scheduling

The study was reviewed and verified as exempt by the institutional review board. An informational flyer was circulated electronically and physically to residents. The research staff also contacted participants of the ongoing longitudinal study to share study information and gauge their interest. Interested residents were provided with details of the focus group (eg, date and time) and asked to indicate their availability. A research assistant confirmed the selected date/time along with instructions for joining the meeting via the Zoom platform. Two email reminders were sent prior to the focus group sessions with the meeting link and a message that technical support was available for 30 minutes prior to the meeting.

Data Collection: Focus Group Semi-Structured Interview Guide

Participants joined the Zoom focus group via a phone, tablet, or computer device, and any technical difficulties they experienced were addressed by the research staff. Each 90-minute session was led by a trained focus group facilitator (CN or JD), with both facilitators attending all four sessions.

Focus groups began with an introduction to the study purpose, confidentiality expectations, and ground rules. All focus group attendees gave verbal consent to participate and the meeting to be recorded. The first focus group took place on May 5, 2020, that is, 47 days after the stay-at-home order was issued in California. The fourth or the last focus group was held on May 27, 2020, that is, 22 days after the first group and 69 days after the stay-at-home mandate was imposed.

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The focus group protocol items (see Table 1) included two forced choice and several open-ended prompts to gauge participants' responses to the quarantine measures. The polling feature of the Zoom platform was used early in the session to have participants anonymously respond to two questions that asked how the social distancing requirement had impacted their mental health and physical health. The facilitator also asked open-ended questions to explore how the quarantine was affecting participants' mental and physical health, thoughts about what other residents might be experiencing, strategies to manage stress and isolation, the use of technology to increase social connectedness, and potential solutions that would mitigate health consequences due to quarantine.

Table 1. Focus group protocol items.

Category	Question
Zoom polling feature	• The impact of the corona virus pandemic social distancing requirement has impacted my mental health: 1. Not at all 2. Somewhat 3. A lot • The impact of the corona virus pandemic social distancing requirement has impacted my physical health: 1. Not at all 2. Somewhat 3. A lot
Social distancing	How would you describe the impact of social distancing on your (a) mental health and (b) physical health? What about the people around you?
Strategies	What strategies have you found helpful to manage your anxiety and reduce stress? What strategies have your family or friends used?
Activities	Have you engaged in new activities to help cope with the coronavirus pandemic?
Technology	How are you using technology differently than pre-COVID?
Intervention	We are planning to conduct a program that, we hope, will reduce loneliness in senior housing communities. What are your thoughts about this type of program, and would you be interested?

Community Validation

Two additional group meetings were held in September 2020 with a subset of participants who reviewed a summary presentation of the study results. One of the objectives of this meeting was to check in with the participants, also called "member checking," to validate that what they learned from the focus group meetings was consistent with their recollection and to confirm the trustworthiness of findings [13]. The participants also provided an update on how their circumstances had changed in the 3 months since participating in the focus groups.

Data Analysis

Group discussions were digitally recorded and professionally transcribed. Transcripts were deidentified by redacting identifiable information. Two researchers (CN and JD) manually coded and analyzed the transcripts to identify distinct themes and patterns. The analysis followed a traditional content analysis process whereby text was reviewed, codes were developed, and themes and patterns were identified [14]. The inductive coding framework was developed from the interview guide and research questions. Both researchers (CN and JD) reviewed notes taken during each focus group, along with all transcripts, and independently coded two transcripts that were then compared and analyzed to verify intercoder consistency. Codes were then grouped into categories, and emerging themes were identified. The resulting codebook was used to guide the analysis of the remaining focus groups' transcripts carried out by JD.

Results

CCSHC Campus Management Response to COVID-19

When the California stay-at-home order went into effect on March 19, 2020, the CCSHC management effected the following changes: (1) closed the restaurant and initiated delivery of meals directly to each resident's apartment; (2) closed the gym and suspended organized social gatherings (eg, bingo, trivia, and exercise classes); and (3) closed the campus to all external visitors except for deliveries.

Focus Groups

Twenty-one residents participated in one of four 90-minute focus group meetings. Demographic information was available for 20 of the 21 participants who were also enrolled in the parent study. Participants were predominately Caucasian (20/21, 95%) and female (14/21, 67%) with a mean age of 80 (SD 5.5) years. A majority of the participants (17/21, 81%) had attained an associate degree or higher, with 86% (18/21) reporting an annual household income over US $50,000.

Poll Results

Impact of social distancing on participants' mental and physical health was quantified from poll responses (see Table 1). Of the 21 participants, 17 (81%) confirmed they experienced a negative impact on their mental health and 12 (57%) indicated they experienced a negative impact on their physical health.

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Results of the Thematic Analysis

Four themes were identified from the qualitative analysis and labeled as follows: (1) impact of the quarantine on health and well-being, (2) communication innovation and technology use, (3) effective ways of coping with the quarantine, and (4) improving access to technology and training. Qualitative responses attest to the effects of quarantine on the participants' mental and physical health, which were attributed to restricted social routines, including limited access to family and friends, and reduced physical activity.

Impact of the Quarantine on Health and Well-Being

A common frustration expressed across all focus groups was the negative impact of the quarantine on participants' physical and mental health. Negative effects most frequently mentioned included weight gain, decreased mobility, worsening of existing health conditions, and/or development of new conditions due to decreased physical activity.

> *I miss the gym a lot. I was there almost every day, and my mobility has suffered from not being able to use the machines down there. I'm limited in the distance that I can walk due to neuropathy and things like that, arthritis, so it's really taken a toll.*
>
> *The not being able to use the equipment down in the gym has really been detrimental to my physical health because I have these stents in my legs, and the one thing that my doctors told me I needed to do was to be on a treadmill or on an exercise bike several times a week for an hour a day and I haven't been able to...*

Participants expressed a consistently strong preference for the gym to reopen and provided ideas for how the management could reopen the facility safely. Some suggested that gym visits could be scheduled and a sanitation protocol could be included, which they felt was feasible since the facility was not open to the public. To mitigate the reduced access to the gym, the management organized 15-minute group workout classes that were conducted by a health educator in the parking lot. Participants could join from their balconies or using a web-based platform. Although many appreciated the opportunity to participate, it did not replace their desire to return to the in-house gym facility.

From a mental health perspective, limited opportunity to engage with others was taking a toll. Participants expressed their desire to interact with friends and family and hoped for a return to the routines and activities that originally connected them as a community. Many emphasized a longing for physical touch (eg, hugging) and social connection without a mask, so they could interact with smiles and other facial expressions. Additionally, participants expressed how much they missed celebrations, and some felt diminished joy for life. Participants who had lost their partner prior to the quarantine spoke about increased feelings of grief associated with being alone. Several participants described short bouts of anxiety and depression. Some managed these low moods by going for a drive, working on a hobby, or enjoying the company of their partner or pet. Others worried that the impact of the quarantine on their mental health may be long lasting.

> *I don't normally get real [sic] depressed. But, for about 2 days, I just really thought this is it, that we're never gonna get out of here. Because I wanna keep things closed down 'til it's really safe. I don't feel good about going out and doing things...*
>
> *It's all of these quarantine fears that have cast question over my capability to handle myself, which has been an ever-present piece of fear in my mind...It's all causing a fearful mentality of what could happen.*

For many participants, social connectivity and group activities were key reasons for relocating to the CCSHC; however, the lockdown requirements were met with frustration, despite understanding the need to stay safe during the pandemic.

> *I lost human connection and I'm the type of person that wants to be with a group of people and do fun things together. We lost our family connection, family celebration, family hugging, joking around, and sometimes I feel lost.*

In addition to physical distancing requirements, the use of face masks contributed to the loss of connection. One participant noted that some older adults rely on reading lips to follow a conversation, particularly when experiencing hearing loss. With masks, they have fewer social and emotional signals, making conversing in person more difficult. The inability to see a smile or other forms of expression proved challenging when physically near one another, as depicted by this participant.

> *I'm kind of a touchy-feely person and enjoy looking at people's faces and expressions and the tone of their voice, so it's been a big loss.*

Communication Innovation and Technology Use

Communication innovation reflects creative strategies for social engagement, including technology use, that participants developed to mitigate the social isolation stemming from the quarantine. Most participants used a smartphone, and some used a videoconferencing platform.

> *We use a lot of texting and phone calls to get back and forth and sending pictures back and forth, so it helps a lot. It makes a big difference.*

Video communication platforms (eg, Zoom and Skype) were identified as an ideal solution for connecting with family and friends while in quarantine. Several participants mentioned using these tools for virtual book clubs and social groups. They also enjoyed the idea of leveraging technology to support access to discussion groups with specific topics, interactive group games, and/or support groups.

> *I think that there needs to be some appreciation and recognition that Zoom is a tool that can be very beneficial for this community on an ongoing basis.*
>
> *There's so much to be said in a face and an expression and the quality of voice [sic]. It just communicates so much, while safely using videoconferencing* [to connect]

One participant coordinated web access to her church for Sunday services, and another continued participating in her women's group via Zoom. The use of digital medicine was also mentioned

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as an advantage of the quarantine, making it possible to speak with a clinician without having to travel to the clinic themselves.

> *My women's group that I belonged to for 25 years is scheduled for this afternoon and is supposed to be on Zoom. We have sort of grown up together and it's a support group and a friendship group…*

Many participants were concerned about the shy or reclusive residents who may not have well-established relationships within the community and felt that community videoconference meetings could help to connect these individuals with the rest of the community and reduce the effects of social isolation and loneliness.

> *I was thinking that Zoom is a way for introverts to reach out from the safety of their own home and sometimes having an anchorage available gives courage to movement. And that being safe in your own apartment and reaching out is a little step that is safer to take than putting your whole self out there.*

Although technology was seen as an ideal intermediary resource, participants preferred interacting with other residents while physically distancing, for example, meeting for a meal in the parlor or walking around the campus grounds.

> *There are 6 to 8 of us that sit in one of the parlors and have dinner together, although we're all at our own tables and we're all at least 6 feet apart...*

Effective Ways of Coping with the Quarantine

The two most common ways that the participants coped with the quarantine was by maintaining a positive attitude and finding support and companionship within the community. As previously mentioned, technology was also used as a coping mechanism to provide social connection and access to certain activities (eg, church).

With respect to attitude, many participants recognized that they had some control in how they perceived the quarantine as either an opportunity or a threat. One participant stressed that her framing of the situation made a big difference in her perspective of the pandemic and reduced its negative impact.

> *It's all about attitude, I think. I saw something recently that said we can look at ourselves as being stuck at home or we can look at ourselves as being safe at home. So, to me, a lot of it is just in how you look at it. We are safe, we're healthy, and this will end.*

Similarly, another participant noted that in addition to recognizing how you can control your own narrative, you can also let others know that they have the ability to change their attitude and, subsequently, their reality.

Finding safe community support was another tool that participants mentioned. Within the CCSHC, each building or floor is considered an individual neighborhood. Participants described different ways that their "neighborhoods" supported one another. For instance, singing or reciting the pledge of allegiance every day at noon was becoming a custom.

> *Most of our residents come out every day at noon, and we say the Pledge of Allegiance and sing a song. And then we spend just a few minutes making sure everybody is okay and talking about any problems they might have come up with...everybody says it's really good for their mental health to see each other.*

Another neighborhood held a fundraiser by selling ice cream bars down the hallways, while distancing and wearing proper protective equipment. Other neighborhoods posted artwork near the elevators for their fellow residents to enjoy. Many found happiness in celebrating uncommon holidays, such as National Pretzel Day on April 26, 2020. Residents left bags of pretzels at their neighbor's doorsteps with small notes attached, hoping that this would bring some celebration back into their lives.

> *On the positive side, it seems to me that floors have become little neighborhoods and are beginning to look out for each other more than they used to.*

Participants who had a pet expressed gratitude for the companionship and the additional motivation to walk outside, which supported their physical activity.

> *But if you have a dog or a cat...there is company in that too. That helps a lot. But I think it would be very hard if you're by yourself in your apartment.*

Improving Access to Technology and Training

Despite mentioning technology as a communication coping strategy to mitigate the effects of social isolation and loneliness, participants emphasized that technological barriers existed. For those with access, the cost of an internet service was potentially prohibitive. For those with both a device and connection, training was needed to learn how to use technology.

> *In our meeting earlier today, they [management] said that only about 50% of the residents here are computer literate.*

Participants suggested that a peer-educator model, whereby participants taught each other, would be desirable. This approach could facilitate a safe and enjoyable environment that would enable them to interact and learn how to use their devices.

> *I like the idea of more Zoom activities for meetings and things like that. The one thing that is needed, though, is a concerted effort to educate people and help them set their computers up.*

Debriefing Meetings

Two additional meetings held in September 2020 included a subset of participants to validate the findings. Participants confirmed our study results and, similar to the findings in May 2020, they remained frustrated, and negative impacts of the quarantine on their mental and physical health persisted. Many appreciated that restrictions were loosening and felt encouraged by the reopening of the community gym and local restaurant, yet the monotony of day-to-day reality was taking a toll on their mental health. Social activities had not resumed and community facilities where people gathered (eg, dining rooms and clubs) remained closed. Participants expressed concern that the gym may be closed again if the county community outbreak numbers increased, which would be detrimental to their physical health and mental well-being.

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> *They [management] failed to weigh the effects that the re-closing of the gym would have on the residents, you know. It's getting to the point where not having a gym is just as bad as the risk of contracting the virus, so there has to be a trade.*

Participants continued to use technology (eg, Zoom, videoconferencing, and texting) as a communication coping strategy but reiterated their need for physical contact, emphasizing the negative effects of diminished social contact with friends and family. Participants generally agreed that the primary source of frustration came from the quarantine having "no end in sight."

Additionally, they felt the standards and guidelines within their community lacked detail, and it was unclear what activities were allowed. Despite these frustrations, participants continued to focus on potential solutions, and again expressed the need for simple and straightforward technology training, emphasizing the peer-educator model, and the potential for videoconferencing to aid social connection.

Discussion

Principal Findings

This focus group study of CCSHC residents informs our understanding of the impact that the COVID-19 pandemic and the resulting quarantine and increased social isolation has had on older adults' physical and mental health. Additionally, the role of technology emerged as being key to preserving social connectedness for many within these communities; however, unfortunately, the technology was not accessible by all participants. Below, we discuss the major findings of the focus groups with recommendations for next steps.

Impact on Physical and Mental Health

Prior to COVID-19, older adults already represented the least physically active age group in the United States [15]. Greater self-reported physical activity has been associated with better self-reported and objectively measured physical health of older adults living in a retirement community [16]. Reduced physical activity may also have negative implications for other aspects of health such as cognitive trajectories; older adults that spend less time in physical activities of moderate-to-vigorous intensity may have a greater long-term risk for cognitive impairment [17]. It was mentioned multiple times by participants that physical and mental health were directly tied to one another and when one declined, the other did as well. These assertions are supported by recent literature demonstrating that even light physical activity during the COVID-19 pandemic may help alleviate the negative impact on the mental health of older adults who are socially isolated [18]. Furthermore, studies have reported that decreased physical activity may increase susceptibility of at-risk groups to infections and exacerbate existing chronic medical conditions such as cardiovascular disease and cancer [19]. Alternative exercise and social activities are clearly necessary to maintain the physical and mental health and well-being of socially isolated older adults.

Prior studies have associated social isolation and loneliness itself with poor physical and mental health outcomes. Specifically, social isolation and loneliness have been associated with unhealthy lifestyle behaviors, including increased smoking, alcohol consumption, and malnutrition [20-23]. Moreover, social isolation and loneliness are independent predictors of depression, anxiety, and cognitive impairments among older adults [24-26]. The duration of social isolation and loneliness is also of concern, particularly in conjunction with quarantine, as recent findings suggest that social disengagement and fewer subjectively meaningful interpersonal interactions are related to decreased physical performance over time [27]. Evidently, more research is needed to assess the impact of quarantine-induced social isolation and loneliness, with an emphasis on how technology may be useful in reducing health risks.

Technology Solutions

Participants highlighted technology as critical to maintaining social connectedness, by using Zoom and other media to reduce social isolation and loneliness throughout quarantine. The barriers to adoption of technology reported by the participants were consistent with those reported in prior research among older adults, including attitudes, cognitive ability, prior experience, product design, cost, and access [28,29]. An issue with the design of health technologies (eg, monitors and sensors, communication systems, and artificial intelligence), is that older adults are rarely involved in the design process or are engaged too late in the development cycle. For example, older adults are the likely major users of telehealth, yet little attention is given to their end-user perspectives [30]. Older adults may therefore have a lack of confidence that they can learn to use these technologies, or they may have limited interest [28,31]. Prior research has shown that older adults want to assist with co-designing health technologies and can help technology developers understand how to design, considering their physical and cognitive limitations as well as privacy concerns [32].

Importance of Attitude

Aging is associated with heterogeneity, with some older adults having increased emotional responses to naturally occurring daily stressors and others being more resilient [33]. Increased resilience has been associated with better cognitive function and self-perceived health, reduced depression, and greater optimism for older adults [34]. Negative stereotypes associated with aging, particularly negative self-perception of aging, may play an additional role in the varying severity levels of the effects of quarantine on the mental health of older adults [35]. Research has shown that negative attitudes towards aging can increase emotional response to daily stressors [36]. Our study found that maintaining a positive attitude during quarantine was a key coping factor. The combined effects of varying resiliency and attitudes towards aging among older adults are likely responsible for the diverse findings in recently published studies evaluating the impact of the COVID-19 pandemic on senior persons [37].

Participants demonstrated compassion for other residents in many ways (eg, regular check-ins). This compassion for others may relate to the community prioritizing supportive actions, where neighbors were "beginning to look out for each other more than they used to." These findings support the role of compassion in battling potential loneliness caused by social

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isolation [3,38,39] and reinforce the need for interventions to reduce loneliness by promoting compassion [40,41]. Once technology barriers have been addressed, web-based platforms could be used as a resource for these types of interventions.

A final and concerning observation was that the fear of exposure to COVID-19 infection among the participants appeared to diminish over time, while feelings of quarantine frustrations increased. Being "safe at home" comes with frustrations that could undermine the ability to persist with behaviors that support infection prevention; subsequently, the behaviors enacted due to these frustrations may have contributed to the second COVID-19 wave in the USA that occurred in fall 2020.

Recommendations for Addressing Social Isolation During COVID-19

The COVID-19 pandemic will continue to exacerbate social isolation and loneliness and related health issues for older adults. There are actions that individuals and organizations, including CCSHCs, can undertake to mitigate quarantine harms and related social and physical implications. Due to the current quarantine restrictions, technology emerged as a clear and viable solution for supporting older adult's mental and physical health while practicing social distancing. The key areas that must be prioritized for future research are described below.

Communication Platforms

Recognizing the prevalence of and predictors for loneliness in older adult populations is important. A grim statistic in a survey of older adults (N=6,786) revealed that 39% suffered from loneliness, with 5% of the total population reporting loneliness often or always [42]. Given that loneliness is linked to social isolation, could loneliness be prevented through proactive interventions? One suggestion from the study participants was to schedule more frequent and consistent virtual gatherings using communication platforms (eg, Zoom and Google Hangouts). These gatherings could bring the community together for physical activity, educational lectures, book clubs, and other social opportunities. Participants suggested that access to these virtual opportunities may encourage access by people who normally do not attend social activities, as they would be able to attend without the pressure to participate. Online group gatherings may hold promise for older adults, as current research shows that by implementing a group intervention reduced social isolation and loneliness and health care costs, whereas it increased feelings of well-being [43]. Access to resources that facilitate physical activity were prioritized by participants to support their physical and mental health, which is known to alleviate the negative consequences of quarantine [18]. Increased efforts to provide older adults with consistent and easily accessible workouts, either via web-based platforms or by observing social distancing within the community, are essential to support their overall well-being.

Access and Connectivity

Access to technologies, including communication platforms and social robots, may mitigate frustrations associated with social distancing and isolation. Presently, little is known about the extent to which campus residents have access to or own personal technologies. Assessing interest among the participants as well as facilitators and barriers to access are the first steps for research in this direction. Results could inform interventions to connect with and use technologies. If technology is a key to the short- and long-term health and well-being of older adults, efforts should be made by programs of all levels to identify needs and bridge gaps so that participants are able to access and use technologies that support social connection with friends, family, and the community. Additionally, when information is communicated by the management using a technology platform that not all can access, the leadership is encouraged to explore all avenues necessary to reach residents, as communication is a lifeline for many during these uncertain times.

Technology Literacy

Once challenges pertaining to access and connectivity are addressed, which is an issue of digital equity and beyond the scope of this paper, training to use the technology is necessary. In this study, participants expressed a lack of confidence that may be addressed through education; however, with the pandemic raging, it is challenging to match appropriate education to promote technology literacy. Participants suggested that the development of a peer-led education program would be a desirable method, as it would increase community capacity safely. The peer-educator model suggested by participants has been used successfully in programs designed for older adults [44,45]. Although this is a starting point, these resources will need to be evaluated, augmented, and implemented to support older adults, particularly those with limited technology experience.

Limitations

There are several limitations to this study. Focus groups were conducted using the Zoom videoconferencing platform, rather than in person, due to the quarantine restrictions. Participants represented a select subset of CCSHC residents who had technology access, connectivity, and some knowledge of how to navigate the technology. The majority of participants were highly educated, financially stable, Caucasian, and represented a single CCSHC in southern California. For these reasons, the results of this study may not be generalizable to other locations and more socioeconomically diverse older adult populations.

Conclusions

This study engaged residents of a CCSHC to learn how the COVID-19 pandemic and the resulting quarantine has impacted the mental and physical health of older adults. The preventive measures to reduce the spread of infection has revealed that technology access, connectivity, and literacy are potential game-changers in supporting the mental and physical health of older adults and must be prioritized for future research. CCSHC residents reported the impact of the quarantine on their mental and physical health was directly tied to the stay-at-home mandate due to social isolation and reduced physical activity. Technology was identified as a lifeline for many participants who were socially isolated from their friends and family. The digital divide is more prevalent among older adults than other populations and will exacerbate health disparities if not prioritized and addressed.

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Conflicts of Interest

None declared.

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Abbreviations

CCSHC: Continued Care Senior Housing Community

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Original Paper

Web-Based Cognitive Testing of Older Adults in Person Versus at Home: Within-Subjects Comparison Study

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Abstract

Background: Web-based research allows cognitive psychologists to collect high-quality data from a diverse pool of participants with fewer resources. However, web-based testing presents unique challenges for researchers and clinicians working with aging populations. Older adults may be less familiar with computer usage than their younger peers, leading to differences in performance when completing web-based tasks in their home versus in the laboratory under the supervision of an experimenter.

Objective: This study aimed to use a within-subjects design to compare the performance of healthy older adults on computerized cognitive tasks completed at home and in the laboratory. Familiarity and attitudes surrounding computer use were also examined.

Methods: In total, 32 community-dwelling healthy adults aged above 65 years completed computerized versions of the word-color Stroop task, paired associates learning, and verbal and matrix reasoning in 2 testing environments: at home (unsupervised) and in the laboratory (supervised). The paper-and-pencil neuropsychological versions of these tasks were also administered, along with questionnaires examining computer attitudes and familiarity. The order of testing environments was counterbalanced across participants.

Results: Analyses of variance conducted on scores from the computerized cognitive tasks revealed no significant effect of the testing environment and no correlation with computer familiarity or attitudes. These null effects were confirmed with follow-up Bayesian analyses. Moreover, performance on the computerized tasks correlated positively with performance on their paper-and-pencil equivalents.

Conclusions: Our findings show comparable performance on computerized cognitive tasks in at-home and laboratory testing environments. These findings have implications for researchers and clinicians wishing to harness web-based testing to collect meaningful data from older adult populations.

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KEYWORDS

web-based testing; aging; cognition; neuropsychology; mobile phone

Introduction

Background

The internet is an increasingly popular medium for running behavioral experiments in psychology [1-4]. In 2017, approximately a quarter of research papers in 4 top cognitive psychology journals featured at least one web-based study, up by 5% from the past 5 years [5]. This is an exciting paradigm shift for researchers given that web-based methods allow for the cost-effective collection of larger data sets from broader geographical regions and more diverse participants [6-10]. A growing number of studies have validated the use of web-based

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behavioral research by reproducing benchmark findings in cognitive psychology among web-based samples (eg, attentional blink, Flanker, Simon) [7] or finding equivalent performance between web-based and laboratory-tested samples on memory, perception, and attention tasks [8,11-15].

Cognitive aging research especially stands to reap the benefits of web-based testing: Participation among older adults may be hindered by restricted mobility and access to testing sites. As a result, many studies rely on convenience sampling where participants are self-selected due to the ease of recruitment and willingness to participate [16]. This is problematic as convenience samples of cognitively normal older adults tend to be younger and better educated than those recruited via population-based sampling [16-19] and more likely to have a family history of Alzheimer disease [17], all factors that can skew research findings. A similar issue exists in research on neurodegenerative diseases, where the research samples are overwhelmingly White, well-educated, and have a high socioeconomic status, limiting the generalizability of clinical research to the population at large [20].

An obstacle to web-based aging research is that adults aged above 65 years have lower rates of technology adoption than their younger peers [21] and unfamiliarity with computers may affect performance on computerized tasks. Moreover, Mechanical Turk by Amazon, the most popular crowdsourcing platform for psychology researchers, has a population of workers that tends to be younger than the overall population [22]. Nonetheless, some studies have examined cognitive abilities in large web-based samples with ages ranging from 10 to 70 years [23,24] and 10 to 85 years [25]. Web-based data collection has also been used to investigate age-related changes in prospective memory [26] as well as working memory and visuospatial processing [27]. More commonly, however, web-based research among older cohorts is often used to test the validity and reliability of web-based neuropsychological batteries for clinical purposes of cognitive screening [28] or tele-neuropsychology [29]. A small body of work in tele-neuropsychology has explored the use of web-based cognitive screens for self-monitoring of cognitive impairment [30-32]. There are promising avenues for better detection and monitoring of cognitive impairment using well-established cognitive tasks [33-35]. Nevertheless, most clinicians (ie, neurologists, neuropsychologists) continue to rely on paper-and-pencil testing conducted during in-office visits, using technology only sparingly in their assessments [36,37].

Given the ongoing effects of COVID-19 on health care delivery and behavioral research, there is a pressing need to establish and validate protocols for remote cognitive testing among older adults. A chief concern, however, is whether performance within a standard testing situation is comparable with testing done in an unsupervised web-based format [38]. Using a within-subjects design, Assman et al [39] found that a self-administered web-based cognitive battery (NutriCog) provided similar information to a version supervised by a neuropsychologist. However, they found learning effects such that performance was better on the second completion of the battery, independent of the mode of administration. A recent study by Backx et al [40] also used a within-subjects design to examine the effects of testing environment (supervised in the laboratory vs unsupervised at home) on performance on the Cambridge Neuropsychological Test Automated Battery. They found comparable performance across contexts, although reaction times (RTs) were slower in the web-based version. Although the results of these studies are encouraging, they did not examine older adults specifically. An advantage of supervised testing is that the neuropsychologist or experimenter can clarify instructions, provide encouragement, and ensure that the setting is free of distractions for participants—this may be especially important with older participants who are likely to be less fluent with technology. However, older adults may also be more stressed in such situations: novel testing locations have been shown to disproportionately stress older adults relative to younger adults, leading to greater age differences in memory [41].

Objectives

The aim of this study is to investigate using a within-subjects design whether performance on computerized cognitive tasks differs as a function of the testing environment in a group of community-dwelling older adults aged above 65 years. We selected cognitive tasks that are well established in both experimental research and neuropsychology, have low susceptibility to practice effects, and are known to be sensitive to age-related changes. The word-color Stroop task [42] (response inhibition and processing speed) is a widely used test in both experimental psychology and clinical neuropsychology, with a large body of work demonstrating declines in Stroop performance due to normative aging [43] and age-related neurodegenerative disease [44]. Similarly, paired associates learning (PAL) has long been used as a measure of the associative nature of episodic memory, which is well-known to be affected during normative aging [45] and is strongly implicated in Alzheimer disease [46-48]. Participants completed computerized versions of these tasks in 2 testing sessions spaced 24 hours apart: unsupervised in their own home using their personal computer as well as supervised by an experimenter in the laboratory. If the testing environment does indeed affect performance on these web-based measures, we would predict a significant difference between scores across the 2 conditions: given the paucity of previous findings using these particular measures, we did not have any strong a priori hypothesis with respect to the directionality of effects of testing environment on performance (ie, performance would be better or worse in person vs on the web). In addition, we explored the extent to which scores on computerized cognitive tests correlated with their gold standard neuropsychological test equivalents and the extent to which performance on computerized tests is associated with technology use and familiarity.

Methods

Participant Recruitment

This study was powered to detect moderate effect sizes (Cohen d=0.50) at a power >0.80 (two-tailed α at .05). To date, no studies have compared these experimental measures across testing conditions among older adults; however, a handful of studies have compared performance on web-based

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neuropsychological tests as a function of testing location [28,39,40] and found moderate effects of testing location. A power analysis using G*Power 3 [49] determined that a sample size of 34 would be required to detect moderate effects (Cohen *d*=0.50) with a power >0.80 (two-tailed distribution with an =.5). A total of 38 adults age above 65 years were recruited via the York Research Participant Pool and agreed to participate in the study. The data of 6 participants were excluded: 3 due to computer-related issues and 3 due to participant error. The analyses included 32 participants (20 females). Participants were screened to ensure that they were diagnosed with any medical, neurological, or psychiatric condition known to impact cognition.

Measures

Web-Based Cognitive Tasks

In total, 3 experimental tasks were completed on a computer. For the in-person testing session, the tasks were presented on a 23.8" Dell monitor and responses were provided on a QWERTY keyboard. The specifications of the computer used in the web-based testing session are unknown as participants used their personal devices. However, participants were told before being enrolled into the study that a QWERTY keyboard was required.

1. *Word-color Stroop task*: 36 congruent (eg, *blue* in blue ink) and 36 incongruent (eg, *blue* in yellow ink) stimuli were randomly presented to participants using PsyToolKit [31,32]. Participants were instructed to press the *r*, *y*, *g*, and *b* keys on the keyboard in response to words presented in red, yellow, green, and blue, respectively. If they did not respond within 4500 milliseconds, the following stimulus was presented. Participants first completed a practice trial with 6 trials before beginning the main task. Key outcome measures were raw RTs to respond to the congruent and incongruent trials, Stroop effects (calculated by subtracting RT to incongruent trials from RT to congruent trials), and errors (eg, pressing on the key corresponding to red when the ink was blue).
2. *PAL task*: 32 unrelated word pairs (eg, *baker-wagon*) were selected from the study by Connor et al [50] and divided into 2 sets of 16 pairs (set A and set B). There were no differences in word frequency or concreteness between sets, $F_{1,30}$ <1. Stimuli were presented using Qualtrics. In total, 16 unrelated word pairs (eg, tool-coast) were randomly presented, one at a time, for 4 seconds followed by a 1-second interstimulus interval (study 1). Immediately after, participants completed a self-paced cued recall (eg, tool-?) for the word pairs they had just studied (immediate recall 1) using the keyboard to type their responses. The same study-test cycle was then repeated (study 2 followed by immediate recall 2). After a 15-min delay, they completed the delayed cued recall portion of the PAL task (eg, tool-?) at their own pace. Key outcome measures were a PAL learning score calculated by adding the number of correctly recalled words during immediate recall 1 and 2 as well as a PAL delayed memory score defined as the number of words recalled during the delayed cued recall.
3. *International Cognitive Ability Resource (ICAR)*: The ICAR is a public-domain cognitive assessment tool [51] that includes 4 item types measuring reasoning: three-dimensional rotation presents cube renderings and asks participants to identify which of the response choices is a rotation of the target stimulus. The letter and number items show participants a short digit or letter sequence and ask them to identify the next position in the sequence from among 6 choices. The matrix reasoning items present 3×3 arrays of geometric shapes with one of the 9 shapes missing, and participants are instructed to identify which of the 6 geometric shapes best complete the stimulus. Finally, the verbal reasoning items include logic questions. We created 2 sets of problems each with 4 items from each item type for a total of 16 questions per set (set A and set B). Stimuli were presented using Qualtrics. Participants were given 7.5 min to complete 4 verbal reasoning and 4 letter and number problems, followed by 7.5 min to complete 4 matrix reasoning and 4 three-dimensional rotation problems from the ICAR. All questions were in a multiple-choice format, and participants used the mouse to select their answer. The key outcome was total accuracy across verbal and matrix questions (score from 0 to 16).

Standardized Neuropsychological Tasks

The following neuropsychological tasks were administered in person by a research assistant. All testing was performed under the supervision of a licensed neuropsychologist (KR). The verbal Paired Associates subtest of the Weschler Memory Scale -IV (WMS-IV) and Color Word Interference test of the Delis-Kaplan Executive Function System (D-KEFS) were included so that we could compare performance with their computerized analogs (PAL and Stroop task, respectively). The Montreal Cognitive Assessment (MoCA), Patient Health Questionnaire-9 (PHQ-9), and Shipley Verbal subtest were included for the purposes of describing our sample and ensuring that participants did not exceed clinical cut-offs for cognitive impairment or depression.

1. Verbal Paired Associates subtest (WMS-IV) [52]: this test assesses the ability of an individual to learn unrelated word pairs. Participants were given the task according to standard instructions. Specifically, they were presented with 14 pairs of unrelated words at a rate of 1 pair every 3 seconds. They were then given the first word of each pair and asked to recall the second word. This was repeated for 4 trials using the same list of word pairs. After a delay of 15-min, participants were again given the first word of each pair and asked to recall the second word. Key outcomes include the total number of correctly recalled word pairs across the immediate recall trials (learning score) and the total number of words recalled after the delay (delayed score). These raw scores were then converted to age-corrected scaled scores.
2. Color Word Interference test (D-KEFS) [53]: participants were administered the color naming and interference conditions of this task according to standardized instructions. In the color naming condition, participants were shown a page of colored patches and had to name them one by one as fast as possible, without making mistakes. In the interference subtest, participants were shown a page with names of colors printed in various colors

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and were instructed for each word to name the color the word was printed in, rather than read the word itself. Participants were told to complete the task as quickly as possible without making mistakes. Key outcomes for both subtests were the time to completion (in seconds). These raw scores were then converted to age-corrected scaled scores.

3. MoCA [54]: this is a brief administered screening tool used to detect cognitive impairment. It assesses cognitive domains including short-term memory, visuospatial processing, executive functioning, attention, and orientation in time and space. The key outcome was the total score out of 30 (for geriatric samples, scores >26 are considered normal, whereas scores 18-25 indicate mild cognitive impairment, 10-17 indicate moderate cognitive impairment, and less than 10 indicate severe cognitive impairment).
4. PHQ-9 [55]: this is a self-administered 9-item measure of depression severity. The key outcome was the total score out of 27, with higher scores indicating greater depression severity.
5. The Shipley Verbal subtest (from the Shipley Institute of Living Scale) [56] was included as a brief measure of verbal abilities (scores range from 0-40, with higher scores reflecting greater ability). This test requires participants to identify synonyms for stimulus words presented in a multiple-choice format.

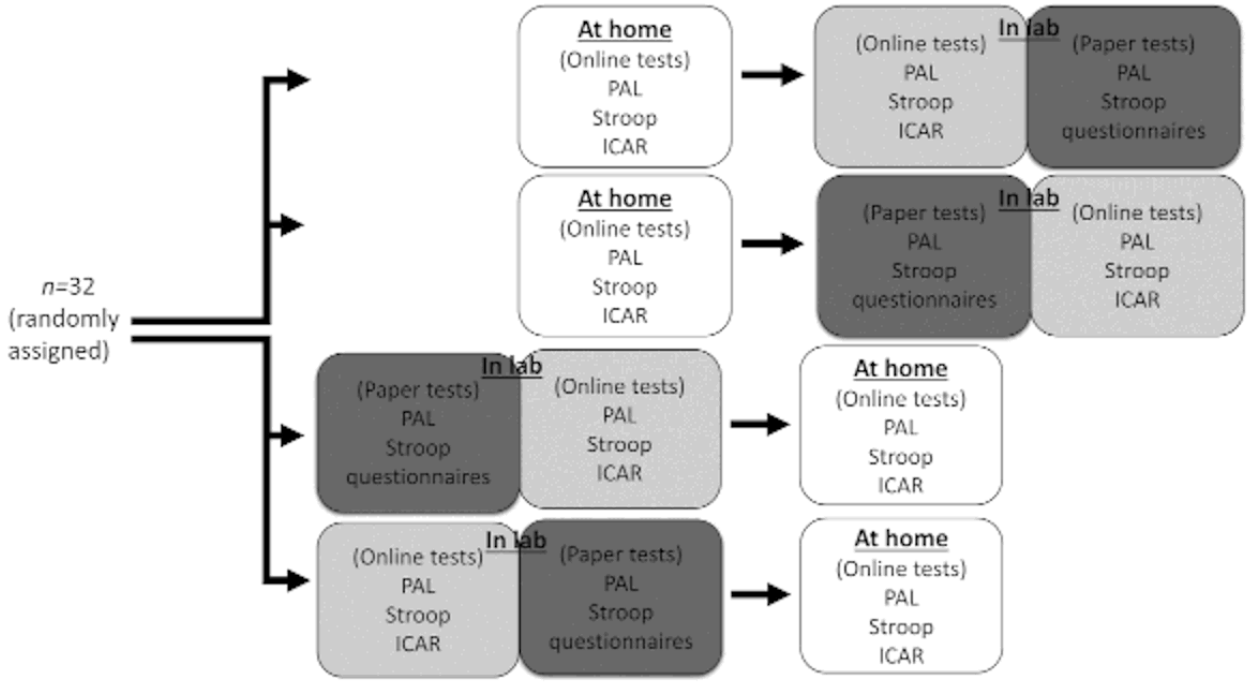
Computer Questionnaires

The 20-item Computer Anxiety Scale [57] and the 19-item Computer Anxiety Rating Scale [58] are questionnaires asking individuals to indicate their level of agreement (1: *strongly disagree* to 5: *strongly agree*) with statements pertaining to attitudes toward computer use (eg, *I feel apprehensive about using computers*). The Computer Aversion, Attitudes, and Familiarity Index [59] is a 40-item questionnaire that prompts participants to indicate the extent to which statements about computer use and feelings surrounding computers apply to them (−3: *absolutely false* to +3: *absolutely true*; eg, *I enjoy using computers*).

Procedure

All participants completed both an in-person testing session at the laboratory and a web-based testing session at their home, 24 hours apart. Whether participants completed the first testing session on the web (home first) or in-person (laboratory first) was counterbalanced across participants (Figure 1). The assignment of participants to order of testing (home first vs laboratory first) and order of test administration in the laboratory setting (web-based tests first vs paper-and-pencil tests first) was determined using a Latin square design. Upon recruitment, a participant was assigned to the next row in the Latin square, which determined their testing orders.

Figure 1. Flowchart of counterbalancing participant assignment to conditions in the experiment. ICAR: International Cognitive Ability Resource; PAL: paired associates learning.



Web-Based Testing Session

Participants were sent a link to the study on the Qualtrics platform via email. After providing consent, they first completed the PAL task using stimuli from set A or B (set used was counterbalanced across participants). Finally, participants were redirected to the PsycToolkit site [60,61] to complete the word-color Stroop task. Participants were prompted to enter a 3-digit identifier before each task.

In-Person Testing Session

Participants completed 2 blocks of testing during the in-person session: an experimental testing block and a neuropsychological testing block. The order of the testing blocks was

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counterbalanced across participants. The experimental testing block was identical to the web-based testing session, with the exception that the PAL stimuli and the ICAR problems were different. For example, if a participant studied set A during the web-based testing session's PAL task, they studied set B during the in-person testing session. Importantly, both the web-based testing and the in-person testing were completed on the PsycToolkit website, ensuring that the only difference between conditions was the testing location. In the neuropsychological testing block, participants completed the immediate and delayed recall conditions from the WMS-IV VPA (Verbal Paired Associates) test: the color naming condition and the interference condition from the D-KEFS Color Word Interference Test, MoCA, and the Shipley vocabulary test. In the 15-min interval between the VPA learning trials and the delayed cued recall, the following questionnaires were administered: PHQ-9, Computer Attitude Scale, Computer Anxiety Rating Scale, and Computer Familiarity Scale.

Statistical Analyses

All analyses were conducted in Jamovi (version 1.2.27) using R statistical language, and an alpha level of .05 was used throughout.

To avoid the undue influence of extreme outliers on the Stroop task, trials where the participants responded under 200 milliseconds or over 4000 milliseconds were excluded. This led to 1.5% of total trials being excluded in the laboratory condition and 2% being excluded in the home condition. The Stroop data of 1 participant were removed in the home condition due to the fact that they missed all trials (RTs >4500 milliseconds).

Mixed analyses of variance were conducted to examine how performance on the outcome measures of our computerized experimental tasks (Stroop, PAL, and ICAR) varied as a function of testing environment (home vs laboratory) and testing order (home first vs laboratory first). In addition, Bayesian inferential testing was performed to provide a more comprehensive perspective on the equivalence of the test data across testing environments. This approach allows us to assign a probability of the null hypothesis or alternative hypothesis being true, given our obtained data [62]. Specifically, we conducted paired *t* tests and calculated corresponding Bayes factors for each *t* test using the BayesFactor R package [63] implemented in Jamovi to investigate the PAL total scores in both conditions (learning and delayed recall), mean RTs for Stroop (congruent, incongruent, and inhibition), and total scores on the ICAR reasoning task using testing environments as the paired conditions. The null hypothesis was defined as no meaningful difference in performance on these measures across testing environments, whereas the alternative hypothesis would be defined as a significant (nondirectional) difference in test scores between tasks done in the laboratory and on the web. As there are no prior studies on paired associate learning and Stroop task performance across in-laboratory and web-based settings, we did not have a strong a priori hypothesis regarding the presence or directionality of any effects of testing environment, other than a general alternative hypothesis of nonequivalence across testing conditions. In addition, given the lack of previous studies, we had no scientific knowledge to inform the most appropriate prior distribution. Thus, we used a Cauchy distribution centered around 0 (ie, the null) and specified a width parameter of 0.707. Results are presented in terms of a Bayes factor (BF01), which denotes the probability of the observed data, given the null hypothesis. Bayes factors were interpreted using the guidelines by Lee and Wagenmakers [64], which are as follows: Bayes factors below 1 are seen as evidence for the alternative hypothesis (0.33-1: anecdotal evidence, 0.1-0.33: moderate evidence; and <0.1 strong evidence), and Bayes factors above 1 are seen as evidence for the null hypothesis (1-3: anecdotal evidence, 3-10: moderate evidence; and >10 strong evidence).

To explore the validity of these experimental measures, Pearson correlations were conducted to explore the association between performance on the computerized experimental tasks and their pencil-and-paper analogs currently used in clinical practice. Specifically, we examined the relationship between performance on the computerized Stroop and the D-KEFS Color Word Interference Test as well as performance on the PAL task and the WMS-IV Verbal Paired Associates test. In addition, Pearson correlations were conducted to investigate the association between scores on the questionnaires querying computer attitudes, familiarity, and outcome measures on the computerized experimental tasks and the neuropsychological tests.

Results

Participant Characteristics

Demographic variables and neuropsychological scores as a function of testing session order are shown in Table 1.

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Table 1. Mean demographic and neuropsychological scores as a function of order of testing environments.

Participant characteristics and neuropsychological variables	Order of testing environments, mean (SD)	
	Home first[a]	Laboratory first[b]
Age (years)	70.50 (6.87)	70.90 (7.30)
Years of education	17.90 (3.12)	17.90 (2.72)
PHQ-9[c]	2.56 (2.73)	1.00 (1.46)
MoCA[d]	27.70 (1.89)	27.30 (1.85)
Shipley	36.10 (3.90)	37.20 (1.47)
WMS-IV[e]-Verbal Paired Associates		
Learning score (scaled score)	11.94 (2.46)	11.75 (2.96)
Delayed score (scaled score)	11.81 (3.27)	11.19 (3.15)
D-KEFS[f]-Color-Word Interference test (Stroop)		
Color naming (scaled score)	11.06 (2.46)	12.13 (2.36)
Inhibition score (scaled score)	11.81 (3.10)	11.81 (1.72)

[a]Home testing session on day 1 and laboratory testing session on day 2.

[b]Laboratory testing session on day 1 and home testing session on day 2.

[c]PHQ-9: Patient Health Questionnaire-9.

[d]MoCA: Montreal Cognitive Assessment.

[e]WMS-IV: Wechsler Memory Scale-IV.

[f]D-KEFS: Delis-Kaplan Executive Functioning System Test.

The years of education of the 2 participants could not be confirmed. There were no significant differences in age (t_{30}=0.15; P=.88) or years of education (t_{28}=0.01; P=.99) as a function of session order. Participants assigned to the home-first testing order had marginally higher scores on the (PHQ-9) than those assigned to the laboratory-first testing order (t_{30}=2.02; P=.05); however, none of the participants exceeded the clinical cut-off for major depressive disorder on the PHQ-9 (total score ≥10). There were no group differences in the MoCA (t_{30}=0.57; P=.58) nor the Shipley vocabulary test (t_{30}=1.02; P=.32).

Performance on Experimental Tasks Across Testing Environments: Frequentist Analyses

Stroop Task

We first conducted a 2 (Stroop condition: congruent vs incongruent)×2 (testing environment: home vs laboratory) repeated measures ANOVA with raw RTs as the dependent variable. RTs were significantly faster in congruent trials than incongruent trials ($F_{1,30}$=54.54; P<.001; η^2_p=0.65), and there were no group differences in RTs across testing environments ($F_{1,30}$=1.15; P=.29; η^2_p=0.04). The Stroop condition×testing environment interaction was not significant ($F_{1,30}$<1; P=.77; η^2_p=<0.01). Next, we wanted to examine whether first being administered the Stroop test at home or in the laboratory would affect Stroop performance. A 2 (Stroop condition: congruent vs incongruent)×2 (order of testing environment: home first vs laboratory first) mixed ANOVA with reaction time on the Stroop test completed at home revealed a significant effect of condition ($F_{1,30}$=81.33; P<.001; η^2_p=0.73) and no order effect ($F_{1,30}$=1.46; P=.24; η^2_p=0.05). The interaction was insignificant ($F_{1,30}$<1; P=.43; η^2_p=0.02). The same analysis as above was conducted but with RT on the Stroop test completed in the laboratory. Participants were faster on congruent trials than incongruent trials ($F_{1,30}$=30.40; P<.001; η^2_p=0.51), and there was no order effect ($F_{1,30}$<1; P=.52; η^2_p=0.01). The interaction was insignificant ($F_{1,30}$<1; P=.59; η^2_p=0.01).

We repeated the set of analyses above to examine Stroop errors as a function of testing environments and testing order. A 2 (Stroop condition: congruent vs incongruent)×2 (testing environment: home vs laboratory) repeated measures ANOVA with errors on the Stroop test as the dependent variable revealed that participants made more errors on the incongruent compared with congruent trials ($F_{1,30}$=11.33; P=.002; η^2_p=0.27). There was no significant main effect of the testing environment ($F_{1,30}$<1; P=.55; η^2_p=0.01), and the Stroop condition×testing environment interaction was insignificant ($F_{1,30}$=2.41; P=.13; η^2_p=0.07). A 2 (Stroop condition: congruent vs incongruent) ×2 (order of testing environment: home first vs laboratory first) mixed ANOVA with errors on the Stroop test completed at home revealed a significant effect of condition ($F_{1,30}$=90.94; P=.004; η^2_p=0.25) and no order effect ($F_{1,30}$=1.99; P=.17; η^2_p=0.06). The interaction was insignificant ($F_{1,30}$=1.29; P=.27; η^2_p=0.04). The same analysis as above was conducted but with errors committed on the Stroop test completed in the laboratory. Errors were equivalent across conditions ($F_{1,30}$=1.45; P=.24; η^2_p=0.05) and the order of testing environment main effect was

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insignificant ($F_{1,30}$=2.28; P=.14; η^2_p=0.07). The interaction was insignificant ($F_{1,30}$<1; P=.87; η^2_p<0.01).

Finally, Stroop effects were calculated for each participant by subtracting the RT for congruent trials from the RT for incongruent trials. We then conducted a 2 (testing environment: home vs laboratory)×2 (order of testing environment: home first vs laboratory first) mixed ANOVA with these Stroop effect scores as the dependent variable. The results showed no significant main effect of the testing environment ($F_{1,29}$<1; P=.78; η^2_p<0.01) or order of testing environment ($F_{1,29}$<1; P=.45; η^2_p=0.02). The testing environment×order of testing environment interaction was insignificant ($F_{1,29}$<1; P=.89; η^2_p<0.01).

PAL

We conducted a 2 (testing environment: home vs laboratory)×2 (order of testing environment: home first vs laboratory first) mixed ANOVA with PAL learning scores as the dependent variable (Table 2).

Table 2. Mean performance on experimental tasks as a function of testing environment and order of testing environment (SDs in parentheses).

Variables	Home testing session, mean (SD)		Laboratory testing session[a], mean (SD)	
	Home first[b]	Laboratory first[c]	Home first	Laboratory first
Word-color Stroop				
Congruent—RT[d] (ms)	1415.63 (289.03)	1317.13 (253.14)	1276.61 (317.03)	1374.46 (315.87)
Incongruent—RT (ms)	1661.52 (320.55)	1522.54 (280.04)	1510.95 (461.22)	1566.58 (257.71)
Interference scores (ms)	245.89 (168.18)	205.41 (108.55)	234.34 (216.48)	192.12 (213.85)
Congruent—errors	0.43 (1.32)	0 (0)	0.50 (2.00)	0.13 (0.34)
Incongruent—errors	1.50 (2.63)	0.50 (1.27)	0.44 (1.09)	0.63 (0.89)
Paired associates learning				
Learning scores	18.13 (8.28)	17.25 (8.56)	15.75 (8.41)	15.06 (9.73)
Delayed cued recall	10.68 (4.54)	9.94 (4.72)	9.88 (4.80)	9.13 (5.24)
ICAR[e] scores	5.75 (3.21)	6.88 (2.31)	5.69 (1.96)	5.75 (2.54)

[a]Laboratory testing session on day 2.

[b]Home testing session on day 1 and laboratory testing session on day 2.

[c]Laboratory testing session on day 1 and home testing session on day 2.

[d]RT: reaction time.

[e]ICAR: International Cognitive Ability Resource.

Results showed no significant difference in cued recall learning scores across testing environments ($F_{1,30}$=3.57; P=.07; η^2_p=0.106) or as a function of the order of testing environment ($F_{1,30}$<1; P=.79; η^2_p<0.01). The testing environment×order of testing environment interaction was insignificant ($F_{1,30}$<1; P=.94; η^2_p<0.01).

Next, we conducted the same analysis as above, with delayed cued recall scores as the dependent variable. There was no effect of testing environment ($F_{1,30}$=1.66; P=.21; η^2_p=0.05) or order of testing environment ($F_{1,30}$<1; P=.64; η^2_p<0.01). The interaction was insignificant ($F_{1,30}$<1; P=.99; η^2_p<0.01).

ICAR

We ran a 2 (testing environment: home vs laboratory)×2 (order of testing environment: home first vs laboratory first) mixed ANOVA with ICAR scores as the dependent variable (Table 2). This showed insignificant main effects of testing environment ($F_{1,30}$=1.55; P=.22; η^2_p=0.05) and order of testing environment ($F_{1,30}$<1; P=.44; η^2_p=0.04). The interaction was insignificant ($F_{1,30}$=1.24; P=.28; η^2_p=0.04).

Performance on Computerized Tasks Across Testing Environments: Bayesian Analyses

The Bayesian paired samples t test of PAL learning scores yielded a Bayes factor of 1.04, indicating that the data could be consistent with either the null hypothesis or the alternative hypothesis. However, on PAL delayed recall, there was a Bayes factor of 2.44, providing anecdotal evidence that data were 2.44 times more likely under the null hypothesis (ie, the groups of test scores were equivalent across testing environments). In terms of Stroop RT performance, results from the paired t test for the congruent condition indicated that the data were 3.4 times more likely under the null hypothesis than the alternative hypothesis (BF01=3.40). Similarly, RTs from the incongruent condition and the Stroop effects (incongruent RT-congruent RT) also provided moderate evidence that the null hypothesis was more likely than the alternative hypothesis (BF01=3.12 and 4.34, respectively). Finally, the Bayesian paired t test on the ICAR reasoning total scores yielded a Bayes factor of 2.63, providing anecdotal evidence that the data were more likely

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under the null hypothesis than the alternative hypothesis. Collectively, these results bolster the notion that there was no meaningful difference in performance on computerized PAL, Stroop, and ICAR reasoning tasks when done in a laboratory or on the web. Prior and posterior distribution plots and Bayes factor robustness checks are provided in Multimedia Appendix 1.

Correlations Between Computerized Tasks and Standard Neuropsychological Tests

Regarding Stroop performance, we found no significant correlation between mean RT for the congruent condition and color naming on the D-KEFS Color Word Interference Test (r=0.13; P=.47; 95% CI −0.23 to 0.46). However, we did find a significant positive association between mean RT in the incongruent condition and the inhibition subtest (r=0.69; P<.001; 95% CI 0.46 to 0.84). We found a similar significant positive association between PAL total learning scores across 2 trials and the total learning score on the WMS-IV Verbal Paired Associates test (r=0.67; P<.001; 95% CI 0.42 to 0.83). In terms of delayed recall, there was also a significant positive association (r=0.67; P<.001; 95% CI 0.41 to 0.82). Collectively, these findings suggest a robust association between performance on web-based computerized tests and standard neuropsychological tests completed in person.

Test-Retest Reliability of Web-Based Cognitive Measures

We also conducted intraclass correlations between PAL and Stroop scores obtained at home and in the laboratory to obtain an estimate of the reliability of these measures over time. Regarding the Stroop test, there were adequate ICC (intraclass correlations) values between scores obtained in the laboratory and on the web for the congruent (r=0.72; P<.001; 95% CI 0.49 to 0.85) and incongruent (r=0.75; P<.001; 95% CI 0.53 to 0.87) conditions. The ICC for the interference condition was modest (r=0.61; 95% CI 0.34 to 0.79). For PAL, there were adequate ICC values between scores obtained in the laboratory and on the web for the total learning score (r=0.70; P<.001; 95% CI 0.46 to 0.84) and delayed recall score (r=0.73; P<.001; 95% CI 0.51 to 0.86) conditions.

Correlations Between Computerized Tasks and Computer Questionnaires

Scores on the 3 questionnaires (ie, Computer Anxiety Scale [CAS], Computer Anxiety Rating Scale [CARS], and Computer Aversion, Attitudes, and Familiarity Index [CAAFI]) were scored for each participant. The mean scores and correlations among the questionnaires are shown in Table 3.

Table 3. Pearson correlations among questionnaires.

Questionnaires	Mean (SD)	1		2	
		Correlation coefficient	*P* value	Correlation coefficient	*P* value
1. CAAFI[a,b]	−11.20 (13.30)	—[c]	—	—	—
2. CARS[d,e]	40.30 (14.00)	−0.649	<.001	—	—
3. CAS[e]	70.10 (10.10)	0.487	.005	−0.584	<.001

[a]CAAFI: Computer Aversion, Attitudes, and Familiarity Index.

[b]Higher scores on the CAAFI reflect greater familiarity and more positive attitudes toward computers.

[c]Correlation scores not applicable.

[d]CARS: Computer Anxiety Rating Scale.

[e]Higher scores on CARS and the Computer Anxiety Scale (CAS) reflect lesser and greater computer-related anxiety, respectively.

Questionnaire scores did not differ as a function of the order of the testing environment for the CAS ($F_{1,30}$=3.31; P=.08), CARS ($F_{1,30}$=1.80; P=.20), or CAAFI ($F_{1,30}$<1; P=.77). There were significant correlations between CAS and CARS scores and ICAR scores completed at home (r=0.50, P=.004 and r=−0.45, P=.01, respectively). However, there were no significant correlations between these measures when completed in the laboratory nor were there any other significant correlations between scores on any of the questionnaires and performance on the computerized tasks (Multimedia Appendix 1).

Discussion

Principal Findings

The primary aim of this study is to examine whether performance on computerized versions of well-known cognitive tasks (ie, word-color Stroop, PAL, and matrix and verbal reasoning) would vary as a function of the testing environment (supervised in the laboratory vs unsupervised at home) among healthy older adults. Our results align with other studies that found comparable results across testing environments using a within-subjects design [39,40] and extend them to older adults. Our findings are encouraging for researchers and clinicians looking to harness web-based testing among older adult populations. We found no significant differences in performance on any of the computerized tasks across testing environments, a pattern of results supported by complementary Bayesian analyses. Crucially, there were no order effects, that is, whether participants completed the at-home or in-person testing session first had no influence on performance. There was no consistent correlation between the measures of computer familiarity or attitudes and performance on any of the computerized tasks. This is congruent with past research finding that computer familiarity did not mediate benefits derived from web-based memory training [65]. There is some evidence, however, that the total learning score on PAL may not be equivalent across

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contexts, given the *P* value approached significance and the Bayesian analysis indicated that the data were not more consistent with either the null hypothesis or alternative hypothesis. Further studies are required to replicate this finding and establish a more precise estimate of any putative differences due to the testing location. It is interesting to note that the scores obtained during web-based testing (ie, in the participant's home) were higher on average than those obtained in the laboratory, which is counterintuitive to the idea that performance should suffer in an uncontrolled environment with more potential distractors. Nevertheless, the results indicate that older adults can produce equivalent results on tests tapping into various cognitive domains, regardless of whether they are done at home or in the laboratory.

Our findings are reassuring for experimental researchers seeking to extend their web-based research program to older adult populations. Our findings support the viability of testing older adults in their homes, which is likely a lower stress environment than a laboratory or office [41]. Past studies have found that older adults report preferring computerized over traditional assessments [66] and that they value being able to choose the timing [67] and circumstances [68] of at-home assessments. Our findings also have relevance for clinical neuropsychology, a field that has been slow to integrate technology into practice [36]. Although our study was among cognitively healthy adults, the fact that we found equivalent task performance on several cognitive tests across testing environments supports the further investigation and validation of computerized measures in geriatric patients, which can open new avenues for the diagnosis and monitoring of cognitive functioning. Adapting experimental paradigms into clinical assessment protocols may prove useful for increasing precision in measuring underlying cognitive constructs (ie, validity) and in drawing brain-behavior associations [69]. Important next steps would be to validate web-based testing as an appropriate means to measure cognition to support diagnosis and also as an appropriate assay of everyday functioning in key cognitive domains such as memory [70], given that age differences in memory tend to be minimized in the real world relative to laboratory settings [71].

The need for further research into the utility of remote testing has been brought to the forefront by the ongoing COVID-19 pandemic. Much of the extant work has focused on administering existing cognitive screens and neuropsychological tests via tele-conferencing [29,39,66,72,73] rather than exploring updated options, such as using well-validated experimental tasks in a clinical context. Looking into the future, incorporating data collected from wearables, smartphone apps, and/or other sensors may also provide a rich source of data for better detection and monitoring of cognitive [37,74] and mood symptoms in neurodegenerative diseases [75]. For example, if some cognitive domains can be reliably measured using web-based cognitive tasks with acceptable psychometric properties [28,76-78], clinical practice can shift toward more remote monitoring of cognitive changes in memory or executive functioning, given that these domains are key factors in the loss of functional independence in neurodegenerative diseases [79].

An additional, encouraging finding regarding the validity of these computerized measures is that participants' performance on web-based computerized cognitive tasks was significantly associated with performance on analogous standard neuropsychological tests, with correlations in the order of 0.6, and CIs showing a lower-bound correlation of approximately 0.4. These findings suggest that across a sample of healthy older adults, the rank order of their performance on standard neuropsychological tests is generally preserved when examining web-based test scores. However, unlike the Stroop and the PAL tasks, we did not include a paper-and-pencil analog for our computerized ICAR task, so we could not estimate its validity with current clinical tools. Although subsequent research is needed with more robust samples, these preliminary results are consistent with a recent study [75] showing that normative data from web-based measures can be used for individual differences research and eventually to guide decision making about individual patients.

Strengths and Limitations

Our study examined cognitive task performance across at-home and in-laboratory settings within the same group of older adults. A limitation of our study is that participants were recruited via a university participant pool. As discussed above, it is likely that participants recruited via population-based sampling would be lower in education and higher in age, which would likely yield lower familiarity with computer usage. However, it is important to note that over time, older cohorts will be increasingly technology savvy, so this will not be an enduring issue: 67% of adults aged above 65 years report going on the internet, up from 13% in the early 2000s, and the figure increases to 82% when we look at the youngest-old between the ages of 65 and 69 years [21]. Our study also had participants performing the web-based tasks on different devices as the at-home computer was their own. Although this was not an issue for our purposes, future research should consider using the same devices, especially for screening and diagnosis. Finally, it should be noted that 3 participants (9% of our sample) had to be excluded due to user problems. Our study required individuals to navigate to 2 different platforms to complete the tasks, which may have added confusion. Improving the design of computerized tasks continues to be an important goal for bringing cognitive testing on the web.

Conclusions

In summary, we provide evidence that healthy older adults who conduct computerized cognitive tests on a web-based platform can produce results comparable with those obtained in a laboratory environment. Moreover, performance on these web-based measures was correlated with standard neuropsychological test performance but was not correlated with technology familiarity. The results serve as a starting point for future studies on the validity of web-based platforms for measuring cognition in healthy and unhealthy aging populations.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary correlational matrix and output of Bayesian analyses.
[DOCX File , 285 KB - aging_v4i1e23384_app1.docx]

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Abbreviations

CAAFI: Computer Aversion, Attitudes, and Familiarity Index
CARS: Computer Anxiety Rating Scale
CAS: Computer Anxiety Scale
D-KEFS: Delis-Kaplan Executive Function System
ICAR: International Cognitive Ability Resource
ICC: intraclass correlations
MoCA: Montreal Cognitive Assessment
PAL: paired associates learning
PHQ-9: Patient Hospital Questionnaire 9
RT: reaction time
VPA: Verbal Paired Associates
WMS-IV: Weschler Memory Scale -IV

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Original Paper

A Multipurpose Platform for Ambient Assisted Living (ActiveAdvice): Usability Study

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Abstract

Background: Aging of the global population is slowly paving the way for new markets for care products and services. The desire of older people to maintain their independence while remaining at home is boosting the development of ambient assisted living (AAL) solutions. Lack of user awareness of AAL solutions paired with an insufficient use of user-centered and participatory design approaches in the development of these products has hindered the uptake of these solutions by end users.

Objective: This study aims to describe the usability and users' experiences within a novel platform, ActiveAdvice, aimed at offering advice and a holistic market overview of AAL products and services.

Methods: Usability tests were performed on the developed platform among identified prospective end users, with 32 older adults and informal carers from 4 European countries being part of the user tests. The usability and appeal of the web interface design, information flow, and information architecture were analyzed by collecting both objective and subjective measures. These would include pretest and posttest surveys, along with a series of think-aloud tasks to be performed within the platform.

Results: The outcomes suggest that the ActiveAdvice platform's objectives and functionalities are mostly aligned with the needs and expectations of end users, who demonstrated interest in using it, stressing its purpose along with its simple and intuitive interaction. Task completion rates were high, and participants had good satisfaction rates when navigating the platform. However, the tests still advocate for an improved design at some points and better disclosure of information.

Conclusions: Our findings shed light on a few peculiarities of interface design, information architecture, user needs, and preferred functionalities, which should be applied to future developments of similar platforms with related services. The AAL field could benefit from tools supporting the dissemination of available AAL solutions and how they can improve one's quality of life. These tools may benefit not only older adults but also caregivers, business owners, and governmental employees.

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KEYWORDS

aging; ambient assisted living; elderly; usability testing; user-centered design

Introduction

Background

The world's population is aging. Several countries are now experiencing a demographic shift, which translates into a rising proportion of older people among their inhabitants. According to data from the United Nations' World Population Prospects [1], the number of older persons (aged 60 years or older) is expected to more than double by 2050 and more than triple by 2100, rising from 962 million globally in 2017 to 2.1 billion in 2050 and 3.1 billion in 2100. We should also consider a decrease in physical and mental abilities and the impact of age-related or chronic diseases such as Alzheimer disease and Parkinson

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disease. In response, new markets for care products and services are aiming to provide older people with a higher level of autonomy and quality of life [2]. As reported by a number of studies [3-5], older people would prefer to spend time in their home or a familiar environment, prioritizing their independence rather than being taken care of, especially in institutional settings. A variety of new possibilities allowing older adults to retain a degree of autonomy at home is now being offered by the progressive use of information and communication technologies, which can also help fend off issues such as isolation and loneliness, both linked to physical and mental decline [6]. These technologies are based on the ambient intelligence paradigm, along with the concept of ambient assisted living (AAL), and address the struggles that arise from this demographic shift [7,8]. The development of most AAL systems is based on the implementation of pervasive and unobtrusive devices, which is meant to increase autonomy and quality of life [9]. These AAL tools can assist in a variety of ways and can be divided into 3 categories, in line with people's needs as they grow older: devices for everyday activities, home safety equipment, and technology for social participation [10-12].

Researchers in the field of aging and human factors have been investigating a number of pre- and postimplementation elements that can hinder the adoption of and influence the attitudes toward technology for aging in place. The barriers were identified as the characteristics of older persons (perceived needs, technological skills, and medical conditions), their environment (social support for technology use, living environment), and technology features (hardware, interface design, usability testing, and accessibility) [13-16]. The design of systems that are intended to be used by older people is often highly technology-oriented instead of user-oriented, being mostly defined from the ground up by the analysis of available technologies rather than by the users' needs. The image the system delivers and the mental models that come with it should be carefully studied by designers to avoid producing something that presents the older users with a metaphor they do not understand at a fundamental level [17,18]. As the need to pay special attention to user research and usability testing was recognized, better approaches for conceiving new technological developments came to be in demand. Getting the end users involved has been shown to be among the most successful strategies in fomenting engagement and trust with those technologies [19]. It is widely agreed that both user-centered design (UCD) and participatory design (PD) are meaningful approaches when designing AAL solutions, and their importance is shown in a variety of different studies, despite failing to prevail in technological developments [18,20,21]. This issue also seems to contribute to a well-identified challenge in the uptake of AAL solutions by end users [18,22,23], paired with the low level of general public awareness of AAL solutions [22-24].

Efforts to raise awareness among potential users of AAL technologies are currently undertaken by publishing informative websites on the internet, but they often focus on comprehensive information for older adults on topics such as nutrition, leisure and sports, and events, falling short in dedicating a bigger part to AAL. When the topic is mentioned, the most commonly presented information only explains the AAL concept and its implications, hardly delivering any comprehensive and well-structured overview of existing technologies or solution providers. There are no thoroughly tested, trustworthy, reliable, and established platforms that gather information about AAL and related products in a clear and understandable way, while providing options to know more or acquire them online. Although existing websites [25,26] could be considered as projects that started to fill the gap on the matter, they lack particular key elements deemed necessary to solidify and disseminate the concept. Building an online product catalog without tending to and validating other issues such as feasibility, functionality, or usability can be proven unproductive or fruitless, hence the scope to improve.

The ActiveAdvice [27] project, a European AAL-funded project carried out in 6 countries (Austria, Belgium, the Netherlands, Portugal, Switzerland, and the United Kingdom), was developed to address these gaps by delivering a web platform directed to older adults and their relatives, AAL business representatives, as well as governmental organizations involved in aging issues across Europe. The platform offers a holistic market overview, presenting a directory of AAL products and services while combining it with a group of advisory functionalities that can inform and guide users in the process of finding a product suited to their needs.

This study aims to evaluate the level of interest, feasibility, and usability of the ActiveAdvice platform among its prospective primary and secondary end users. Primary end users are, as defined by the AAL program [28], individuals using a product or service for a direct benefit of their quality of life—here, the older adults—while secondary end users—here, the informal carers (ICs)—are individuals who may benefit from products and services indirectly providing the reduction of primary end users' care needs. Informal caregivers may also enable older adults to search for and use AAL solutions. We recruited older adults and informal caregivers to enroll in a number of test sessions to test a prototype of the ActiveAdvice platform and presented and discussed the findings and takeaways produced from a variety of challenges. To frame the prototype under study, the next section presents the development process and outcomes of the ActiveAdvice platform. The following sections describe the usability study, along with a presentation and discussion of the results. All study procedures were approved by the ethics committee of the University Hospital Center of S. João/Faculty of Medicine of the University of Porto (CE-305-2020).

The ActiveAdvice Platform

The ActiveAdvice platform originated from a European Union or AAL program–funded project intended to set up a European-wide advisory and decision support platform that brings together a broad range of available AAL products, services, and experts. As stressed by Nedopil et al [29], although AAL projects are substantially diverse, they all share a basic innovation process consisting of 3 basic stages: (1) understanding the users, including their characteristics, necessities, and requirements; (2) conceptualizing the solution,

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namely use cases, technology elements, and implications for users; and (3) testing the full solution or parts, as well as its benefits. Although this paper delves into the third phase (testing), we briefly discuss the previous stages, with a greater emphasis on the conceptualized solution to better frame the testing procedures.

Understanding the Users: Requirement Analysis

A user-centered requirements engineering methodology puts the intended user at the center. Stakeholder needs, interests, and expectations need to be transferred into requirements and subsequently into measurable qualities, assisting the creation of a better layout of the platforms' representation and functionality. It also helps create a common vision for the developers, free of implicit assumptions and technological constraints. For the ActiveAdvice platform development, the integration of stakeholders at a very early stage of the project was a precondition, and thus, several stakeholder groups were integrated in a requirement analysis stage. This allowed for a better understanding of their perspectives, insights, motivations, and concerns, clarifying what could help, as well as hinder the development and implementation of the ActiveAdvice platform. The process featured a total of 38 semistructured interviews with stakeholders (12 end users, 14 business representatives in the AAL market, and 12 government representatives engaged in aging issues) in 5 European countries (Austria, Belgium, the Netherlands, Portugal, Switzerland, and the United Kingdom), with the results fully described by Teles et al [30], supporting the subsequent development of the platform.

Conceptualizing the Solution and Building the Platform

The ActiveAdvice platform was envisioned to be a product-advising, awareness hub on AAL solutions across Europe, with an emphasis on the premises of UCD and PD, drawing from the feedback of all interested parties (Figure 1). It would also feature a blog branch with assorted information on the AAL subject, including funding and support measures for the purchase of products and services, tips on community resources, articles from experts, personal stories, and other news (Figure 2).

Figure 1. The ActiveAdvice project main index with tile-based navigation. AAL: ambient assisted living.

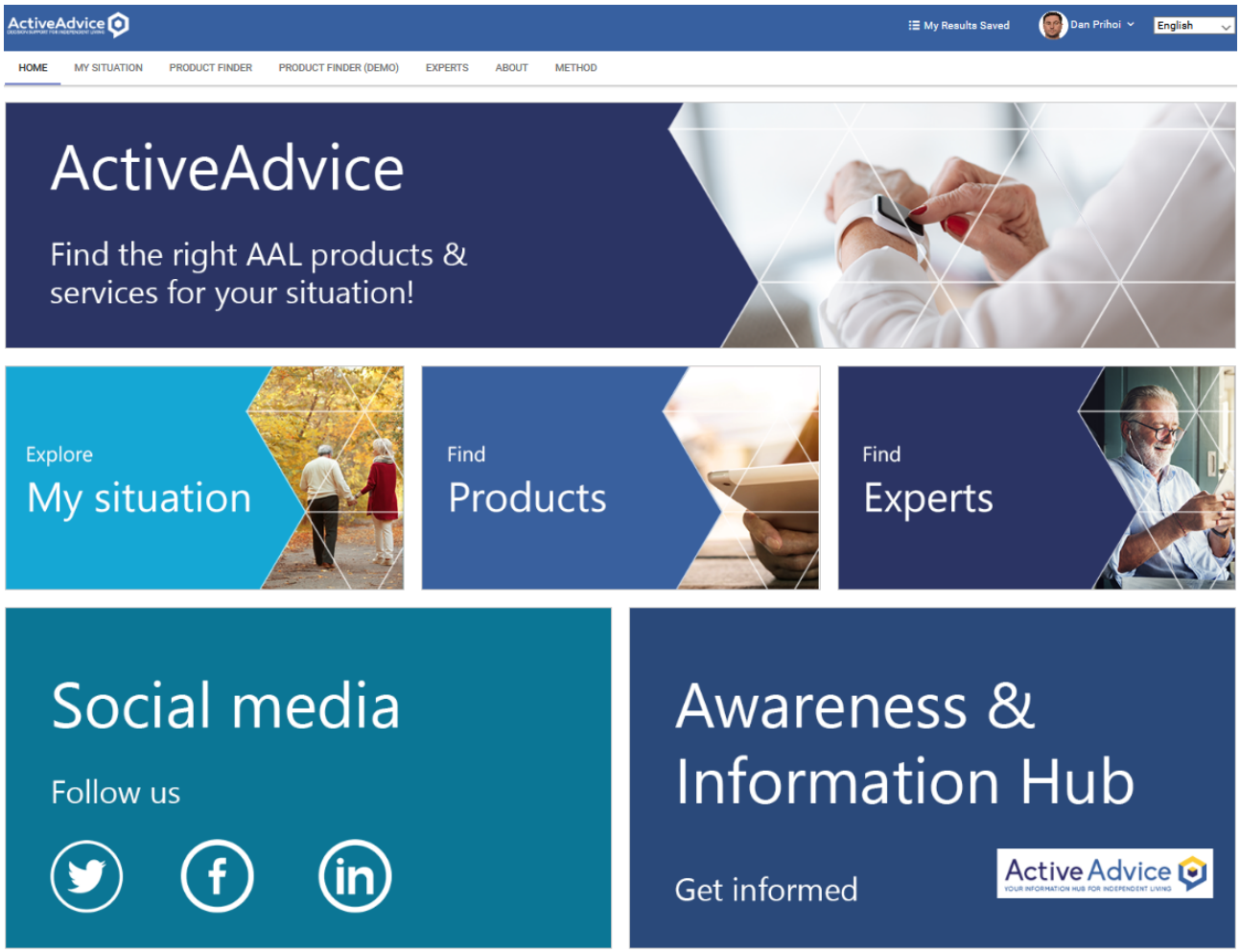

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Figure 2. The ActiveAdvice awareness hub.

With functionalities being defined based on structured feedback from the requirement analysis, product cataloging was proposed following the TAALXONOMY classification system, which takes into account international definitions (eg, World Health Organization, Organisation for Economic Co-operation and Development), initiatives (eg, Building, Recruiting, And Inclusion for Diversity [BRAID], European Innovation Partnership on Active and Healthy Ageing [EIP-AHA]), and standards (eg, ISO [International Organization for Standardization] 9999) [31]. This was supported by a comprehensive information and communications technology (ICT)–based environment, presenting a broad and state-of-the art library on available AAL products and services offered at regional, national, and international levels and stored in a cloud database. For testing purposes, all available products on the platform were added by the research team. At a later stage, the catalog is populated by companies that could benefit from the dissemination of a strong and established platform by means of a service module developed for their business profiles (Figure 3).

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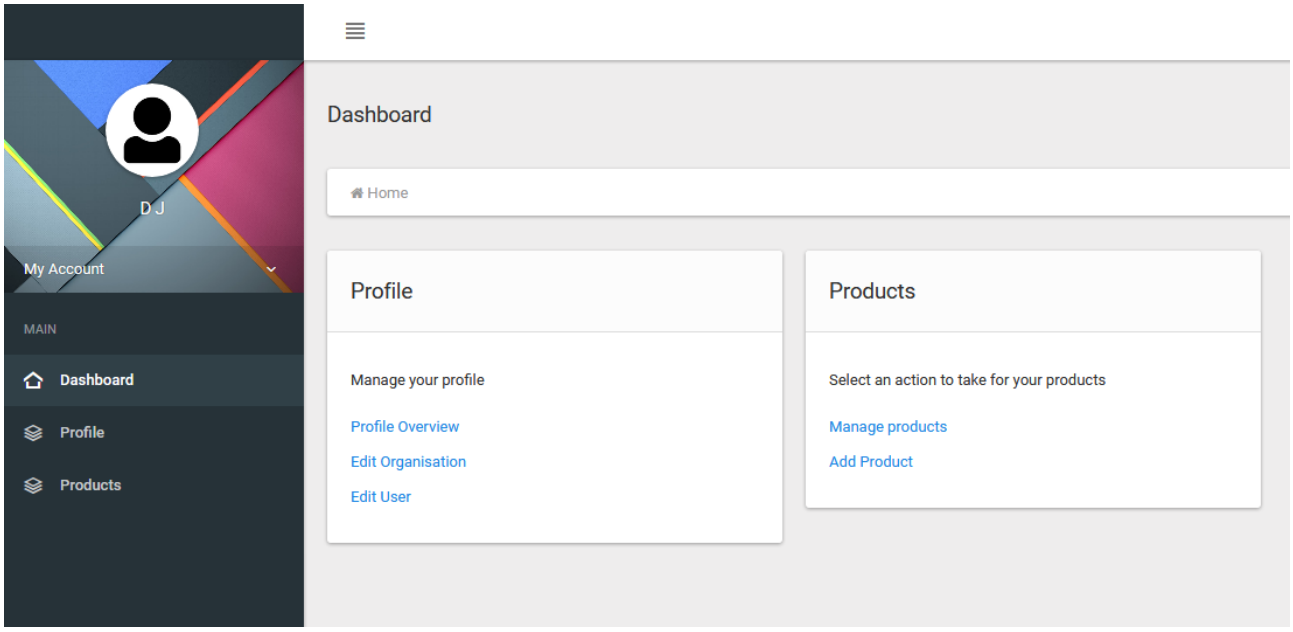
Figure 3. Dashboard of the business profile service module.



Adding a product requires filling several attributes, such as name, description, price, related features, and subfeatures (Figures 4 and 5). In this way, products are tagged with their specific characteristics, which fit them into a certain category (or categories; Figures 6-8), where they can be reached by a simple keyword search or by resorting to an advisory feature. The latter can guide the users by asking or exemplifying common or personal situations (issues, problems, conditions, and statuses) and then posing a series of questions and filters to either find a product suited to their needs and wishes or be given a suggestion for the next best option, given the availability (Figure 9).

Businesses are required to specify the type and amount of expertise they have, know-how, and technical support needed to install, upgrade, or maintain the indicated services and products, described with concise and honest data. Ideally, information should be provided not only on where to buy products or services (online or offline) but also on who can or will install them if needed. The more thorough they are in this process, the better the chance that their product will stand out among others.

With the launch of a viable prototype, the researchers set out to test how prospective end users of the ActiveAdvice solution—older adults and ICs—would interact with it. Future plans include the evaluation of not only the service module but also the general user platform interface with business profiles, along with the inclusion of government representatives, both for usability and feasibility analysis.

Figure 4. List of added products on the business module.

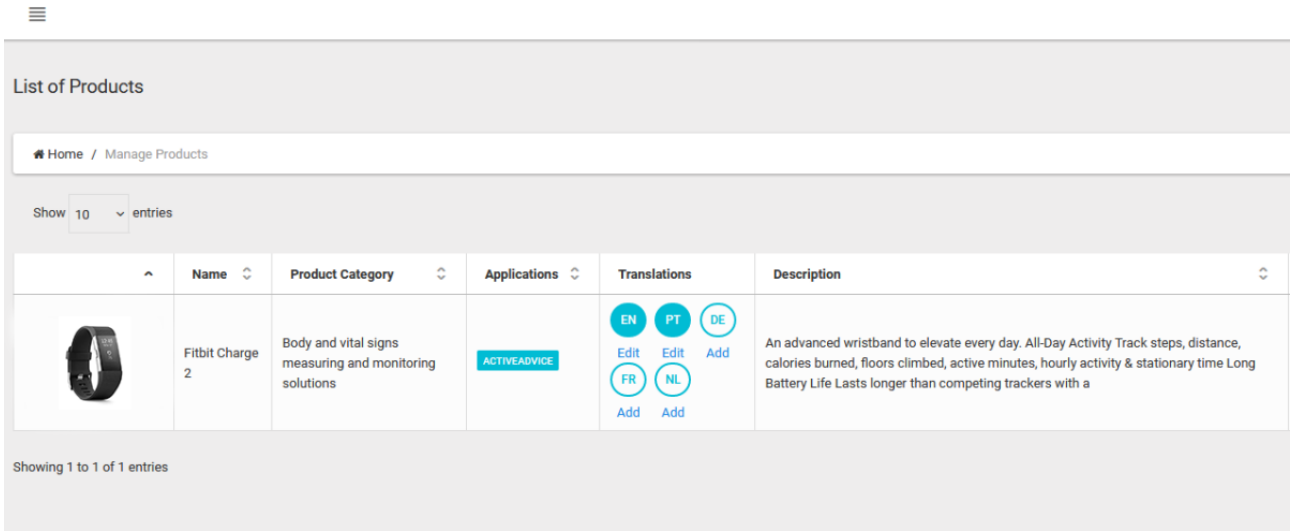


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Figure 5. Adding a product to the database from the business module.

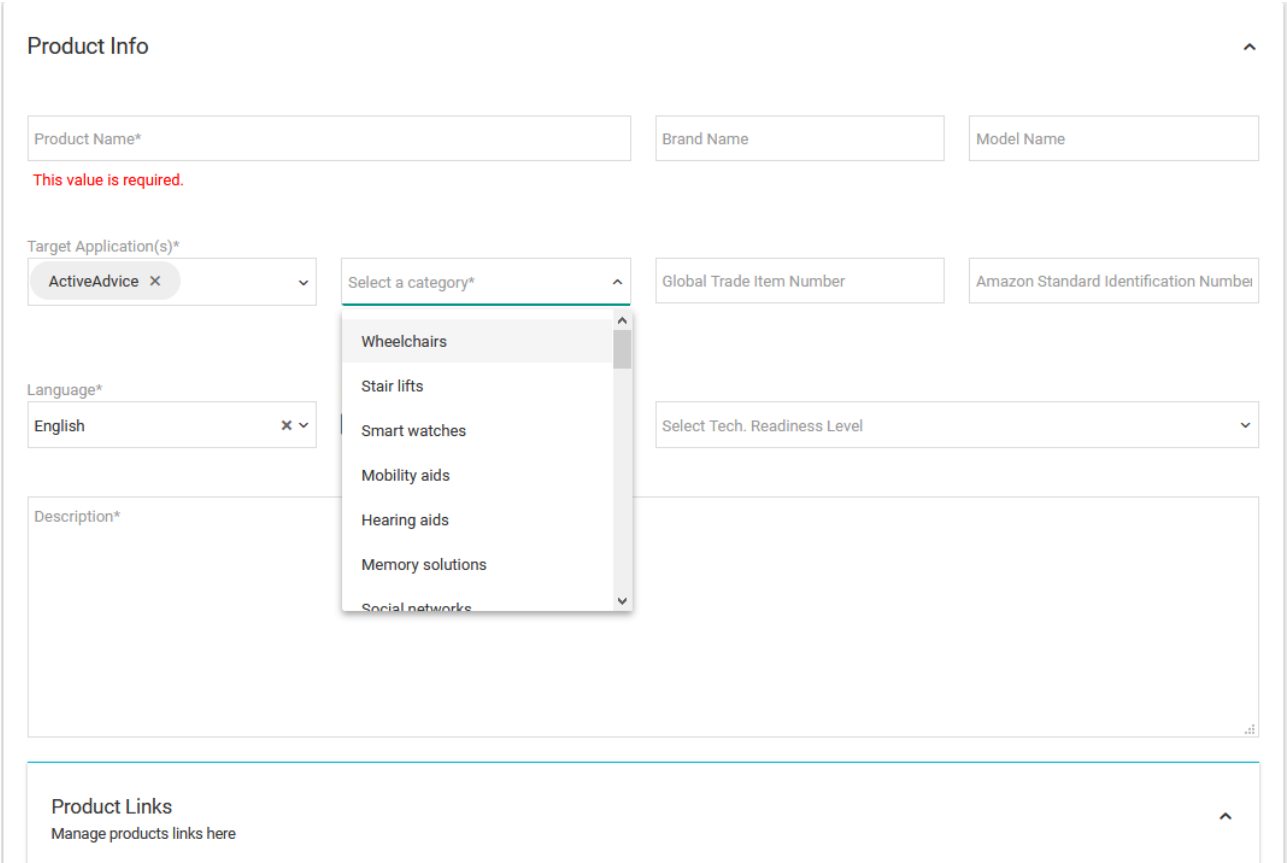

Figure 6. Available master categories with search bar.

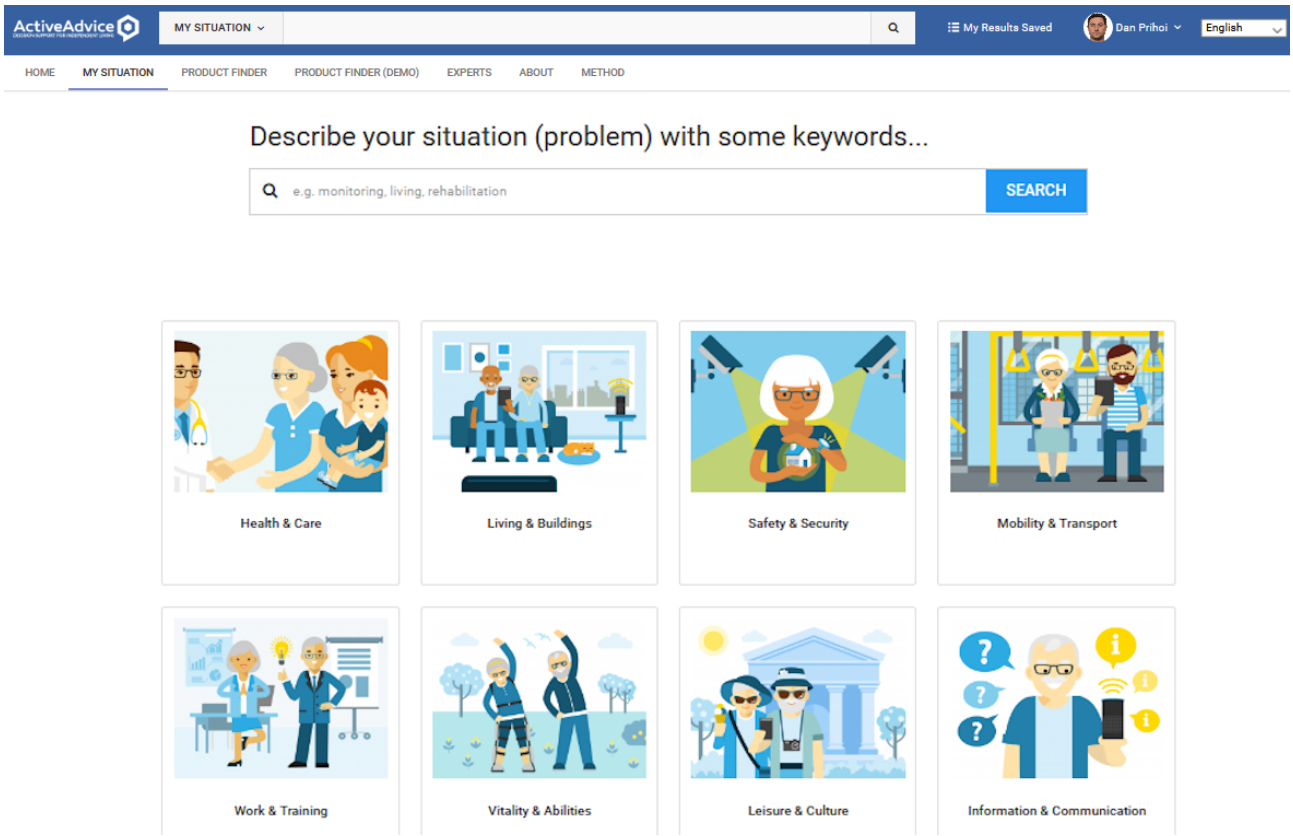

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Figure 7. Available subcategories inside the main ones.

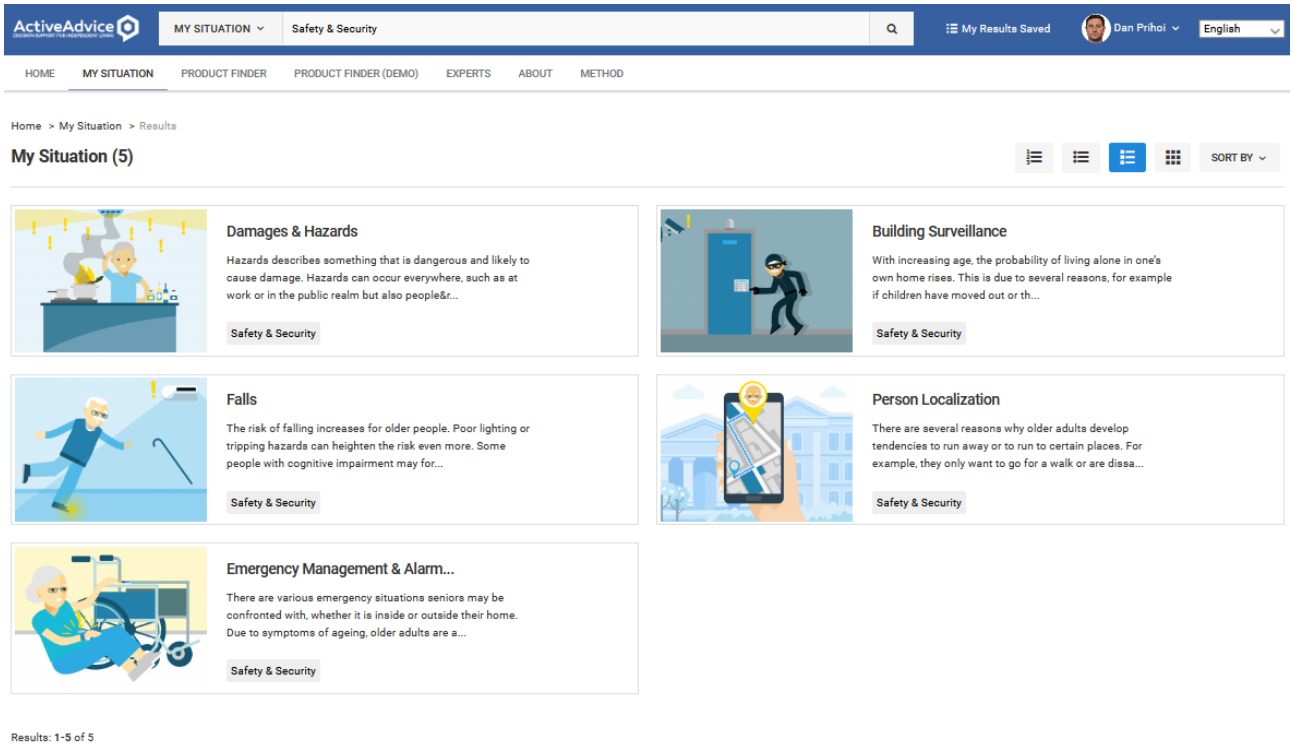

Figure 8. Detailed subcategory together with description and relevant products.

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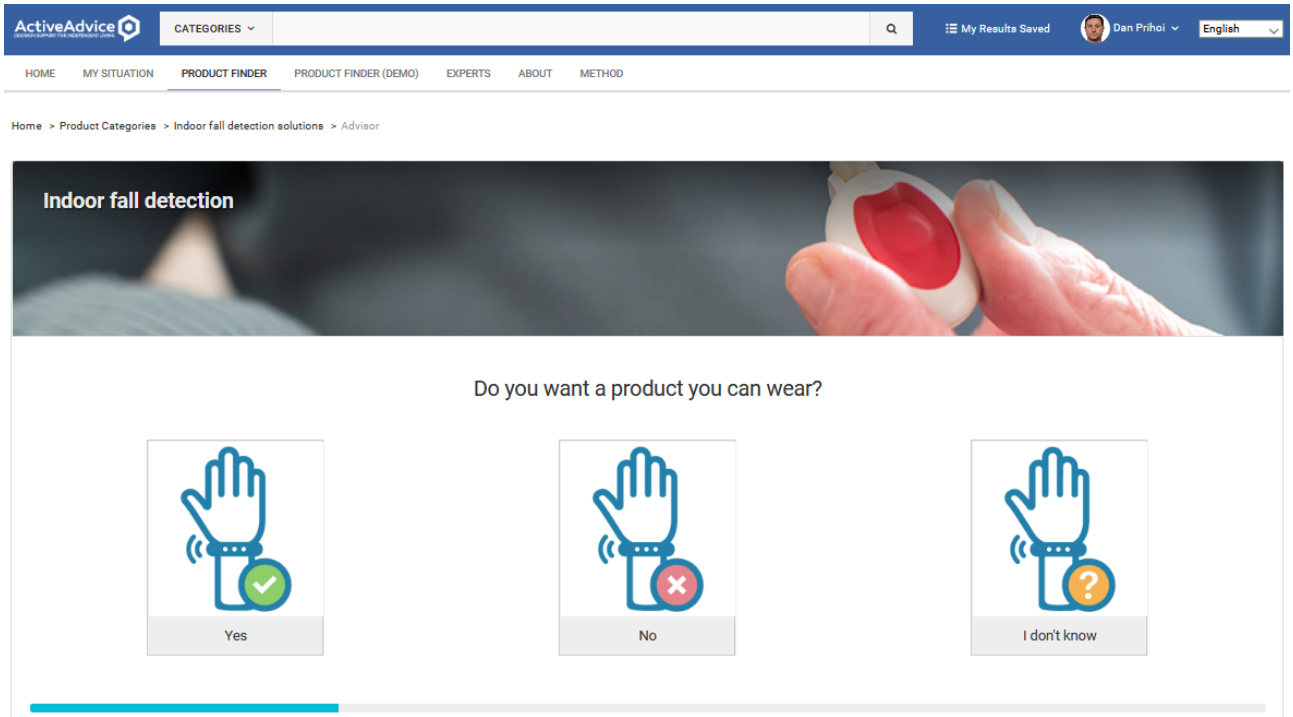
Figure 9. Product advisor wizard filtering product properties from user choices.



Methods

Main Approach

The development of the ActiveAdvice platform went through several internal feedback cycles and end user usability testing. The general goal for usability tests was ultimately to identify the extent to which the interface facilitated a user's ability and motivation to navigate the platform. The usability and appeal of the design, information flow, and architecture were also analyzed based on the collection of both objective and subjective measures. These would include pre- and posttest surveys, along with a series of tasks performed by the users within the platform, while following a think-aloud protocol. Outcomes would clarify if the platform's functionalities were aligned with the needs and expectations of end users, while presenting a high level of usability to the point where potential customers showed interest in using it. In accordance with the systematic review by Martins et al [32] on usability evaluation methods that have been used during the last few years, empirical methods are the most frequently used, which confirms the recognition of the end users' roles as a source of knowledge for usability evaluations. In addition, a very comprehensive guideline from Nedopil et al [29] also reassured that the test procedures and methodology used in this study are in conformity with a successful process of user integration and product evaluation.

Participants

Primary data were collected from a nonprobabilistic sample. Prospective end users of the ActiveAdvice platform were recruited by convenience and resorting to advertising or snowball sampling in Belgium, the Netherlands, Portugal, and the United Kingdom. All information collected from users was gathered exclusively for testing and improving the prototype. An informative, jargon-free sheet was provided to all participants at the time of recruitment, including a description of the study's aims, conditions to participate, and eligibility. Participants who agreed to cooperate signed an informed consent according to the Declaration of Helsinki, with their personal data being pseudonymized, codified, and stored in secured servers to safeguard the right to privacy. Participants were free to withdraw from the project and request the deletion of their data at any time without the need for justification or incurring penalties.

Eligible individuals participating in this study were older adults living in the community (not in institutional care) and informal or nonpaid caregivers or relatives of older adults living in the community. We considered not only individuals aged 65 years or older but also young older adults (aged 55 years and older) to capture a profile of individuals who are preparing their aging process and thinking ahead. With respect to older adults, we selected individuals matching 2 distinct profiles: (1) autonomous older adults with no perceived or apparent relevant functional loss, who wish to live longer at home and think ahead to prepare for a potential loss of autonomy or upcoming chronic illnesses; and (2) older adults presently facing some degree of functional loss with implications for the autonomous performance of basic and/or instrumental activities of daily living (as self-declared), who wish to live longer at home while avoiding institutional care. Moreover, we also aimed to include informal caregivers of older adults living in the community who provide nonpaid and ongoing assistance with basic and/or instrumental activities of daily living.

Efforts were made to gather heterogeneous participants across those profiles regarding demographics (eg, age, including older and younger older adults; sex; living arrangements including older adults living in rural or urban settings) and ICT skills, in particular internet usage (including more or less ICT-savvy users). To appraise this diversity, a screening tool (described

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in Data Collection Tools) was used by the research team for the recruitment process.

Data Collection Tools

The researchers conducting the usability tests were provided with a toolkit developed by the consortium, highlighting systematic instructions for recruitment, testing, and reporting as a means to guarantee consistency across countries or testers.

Regarding the user eligibility section, the toolkit included the following:

A *screening tool* to administer at the first contact with the potential participant to check for eligibility criteria and pursue a diverse sample. It included the following:

1. Questions on basic sociodemographic characteristics of potential participants (age, sex, living arrangements, years spent in education, and country of origin)
2. Questions to appraise the autonomy profile: Potential participants were asked to classify their degree of independent living and daily task accomplishment without assistance. Participants selecting "very easy" and "somewhat easy" fitted the profile of autonomous older adults. Others reporting "somewhat difficult," "very difficult," or "cannot accomplish daily tasks without assistance" matched the profile of older adults with autonomy loss. This question was also asked to informal caregivers about the care receiver.
3. Questions to appraise the intent or actual use of products or services to support their own everyday activities or those of the person being cared for. The participants indicated whether they need, or the person they care for, is in need of assistance from products, services, or both. In the case of a positive answer, they indicated if they were already using them, considering a purchase, actively looking, or thinking about doing so. In case there is no recognized need for products or services, participants indicated if at least they had ever thought about it preventively.
4. Questions to appraise the intent of aging in place (applied to older adults only), which included asking about the intention to continue living in their current home in a 10-year time frame, as well as about the plans to make home modifications to support aging in place.

Regarding the usability test session, the toolkit included:

1. A questionnaire featuring questions on ICT usage, including (1) a question to appraise the frequency of internet usage as daily, at least once a week, at least once a month, less than once a month, and never; (2) devices used to access internet and activities performed online; and (3) attitudes toward technology, using 9 items gathered from the Media and Technology Usage and Attitudes Scale. Only 2 attitude subscales were selected—positive and negative attitudes subscales—as the authors state that subscales can be used in isolation [33]. Items in this scale are rated from 1 (strongly disagree) to 5 (strongly agree). All questions were aimed at understanding the skills and mindsets of the participants, which could be useful in framing the findings.
2. A list of scenarios and subsequent tasks to be performed in the prototype, featuring hypothetical real-world scenarios involving needs that could be addressed by AAL solutions [34]. These scenarios and tasks were provided to participants in printed forms to facilitate immersion and provide context for the participant to engage with the interface.
3. Posttest debrief, which included open questions concerning the participant's feedback on key features of the platform, such as the amenity of color schemes, clarity of language, the content's level of readability, perceived usefulness, and perceived ease of use. These also included overall impressions and missing features that they would expect to see. Participants were also asked to position themselves about their overall experience with the platform on a Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree), along 9 statements, using an adapted version of the System Usability Scale (SUS) [35]. The need of adapting the items on the scale created on the basis of a previous pilot experience of the usability testing protocol where the researchers concluded that some items of the original scale were not understandable by older adults (eg, "I thought there was too much inconsistency in this system," or "I found the various functions in this system were well integrated").

Procedures

Tests were carried out in 4 countries: Belgium, the Netherlands, Portugal, and England. The research team in Austria was responsible for the internal testing and development. To allow testing in multiple countries and cultural contexts or groups, the platform prototype was translated into Portuguese, English, German, Dutch, and French.

Sessions were implemented in realistic but controlled environments, addressing first the core functionalities of the platform and lasting from 30 to 50 minutes. Each test session included 2 test administrators, one having the role of moderator and the other being the observer and note taker. Regarding the session schedule, the participants were first briefed about the process and asked to fill out a consent form and the ICT usage and attitudes questionnaire (section Data Collection Tools). Subsequently, they were given access to the platform and asked to engage with the proposed tasks while thinking aloud when trying to solve them.

Three different tasks were proposed, each referencing a different scenario, with the respective goals being built to understand if users could find specific products, allowing the researchers to learn how they behave. The first task asked the user to find an alarm watch—a specific product-based on the following hypothetical scenario:

> *Last Summer you fell down and broke your hip. You were alone, and it was very painful. Being fully recovered took you some time and you wish to prevent situations like that from happening again. You want to find a watch that works like an alarm in case of a fall. Knowing that if you fall down at home, there might be a chance that in case no one is there to help you, someone will assist you in time.*

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The second task asked the user to find a suitable product, using a specific functionality of the platform—a product filtering wizard-based on the hypothetical scenario:

> *A close friend of yours went to the doctor and was told he was starting to show some signs of Alzheimer's, which means that he might start to become forgetful in the near future. He lives alone and still shops for groceries and likes his morning walks. Your friends' children would feel more comfortable if he would carry some type of localization device that would allow them to know where he is, so he asked you for help to find a solution. This will help him to stay independent while giving his children some peace of mind. He would like to spend no more than 150€, and it should have an alarm function.*

The third task asked the user to use the platform as they would see fit to find a generic suitable product based on the hypothetical scenario:

> *During a conversation with your neighbor she tells you about her heart condition, as over time it has worsened, hospitalizing her a few times. Her doctor advises her to keep track of her heart rhythm. In order to prevent risks she needs to be aware when the heart rate is spiking. The neighbor asks you to help her find a suitable product that could keep track of her heart rhythm and warns her in case it rises above a certain level. She would like to spend no more than 200€ on a solution.*

Provided with these contexts, the participants would look for a way to obtain the aforementioned product while navigating the platform. The process itself, along with their verbalizations, would provide the researchers with an idea of the difficulty level as well as other inherent parameters regarding layout and organization. The level of success regarding task completion (the moment when the user finds the targeted product) was registered by the researchers according to a 3-point classification: 0=not completed; 1=completed with difficulty or acceptable prompts; and 2=easily completed. The *stop* criterion for task performance was applied when 1 of 3 conditions occurred: (1) the users completed the task successfully; (2) the users said they completed the task, even if they did not; or (3) the users decided to give up. During task performance, the users' navigational choices, verbalizations, and nonverbal reactions (eg, facial expressions) were registered and recorded *verbatim* by resorting to written notes, video screen capture, or audio capture.

All researchers were provided with a list of all possible pathways to successfully complete each task to facilitate the recording. Finally, after task completion, the posttest debrief (*Data Collection Tools*) was administered to gather participants' perceptions of the platform and satisfaction. The audio recordings of the posttest interviews were transcribed by researchers from each country performing the tests and collecting the data.

Data Analysis

Descriptive statistics were used to characterize the participants in this study as well as to describe quantitative usability indicators (eg, ratings on scales). Absolute and relative frequencies, central tendency, and dispersion measures were used as appropriate. When reporting median values, the IQR was the measure of statistical dispersion selected to be reported. The administered scales were analyzed itemwise. In particular, for the adapted version of the SUS, a composite score for the 9 items was not computed, as we could not assume unmeasured psychometric properties of the scale (eg, factorial structure).

After transcription, text data, both from relevant user verbalizations when performing the tasks (think-aloud protocol) and from the interviews on the posttest debrief were analyzed by performing a thematic analysis [36]. The themes were defined deductively, meaning that they were guided by a structured analysis matrix [37]. The matrix corresponded with the main topics approached in the posttest interview guide (refer to *Data Collection Tools*). The deductive or top-down approach in data analysis was selected as the most suitable and feasible approach to guarantee a common ground among researchers from different nationalities. A researcher from each country performing the tests performed this analysis; thus, 4 researchers performed the tests. Next, the contents categorized in each theme were translated from the source language to English by researchers from each country. All excerpts organized in their respective categories were sent to the Portuguese project team, who created a common data file. The entire corpus was inspected by a researcher of this team to find any inconsistencies among categories and correct them if necessary, under the agreement of the researchers who first analyzed the data. This is a validation process for a deductive approach to data analysis [37]. A researcher from the Portuguese team then identified, if any, the trends, or most common opinions within each theme, inspected for potential different trends per group (eg, trends per country, per type of participants—older adult or IC) and reported the overall findings. In the *Results* section of this paper, relevant text excerpts are used to illustrate themes and trends.

Results

Sociodemographic Characteristics of the Participants

A total of 32 participants matching any of the described profiles were recruited. Of these 32 participants, 21 were older adults, and 11 were informal caregivers or relatives of older adults. The former group was composed of 13 female and 8 male participants, and the latter by 4 female and 7 male participants. Overall, the sample was well balanced with regard to sex (17 female and 15 male), although within the groups of older adults and caregivers, the sex distribution was less balanced with more female than male participants in the former group and the opposite trend in the latter. Regarding age groups, participants were distributed from a 25-29 years range to an 80 years or older range; most older adults were aged between 65 and 79 years (12/21, 57%) and most caregivers were aged between 55 and 64 years (6/11, 55%). The participants' education level was rather high, with a median of 15 years of formal education, either for the group of older adults (IQR 6.5) and for informal

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caregivers (IQR 4; median of 15 years for the entire sample, IQR 5.75). Most users (20/32, 63%), regardless of being older adults or caregivers, lived in a household of 2; 12 (12/21, 57%) of them were older adults, whereas 8 (8/11, 73%) were caregivers. Regarding the 2 profiles of older adults we aimed to recruit (see *Participants* section), most of them were autonomous, who wished to prepare for a future functional decline. When older adults (n=21) assessed the extent to which it was easy or difficult for them to live independently and accomplish daily tasks without assistance, most classified it as "very easy" (14/21, 67%), 3 as "somewhat easy" (3/21, 14%), 2 as "somewhat difficult" (2/21, 10%), 1 as "very difficult" (1/21, 5%) with 1 older adult reporting to "not being able to accomplish daily tasks without assistance" (1/21, 5%). Caregiver-wise (n=11), 3 reported that the older person they support "cannot accomplish daily activities without assistance" (3/11, 27%), the same number reported a *very difficult* accomplishment of such activities (3/11, 27%), and 2 caregivers reported "some difficulty" (2/11, 18%). In contrast, 2 caregivers (2/11, 18%) classified as "very easy" and 1 as "easy" (1/11, 9%) for the autonomous completion of daily activities by the person they support. The country mostly contributing to the recruitment of older adults was the Netherlands (13/21, 62%), as it is a country with good digital literacy among older adults [38]. Portugal contributed the most to the recruitment of informal caregivers (6/11, 55%), as it is a country characterized by a familialistic approach to care provision (the so-called Mediterranean care model [39,40]). Further details are presented in Table 1.

Table 1. Demographic data from the study participants (N=32).

Variable	Older adults (n=21)	Informal caregivers (n=11)
Age group, n (%)		
<55	0 (0)	1 (9)
55-64	8 (38)	6 (55)
65-79	12 (57)	1 (9)
≥80	1 (5)	3 (27)
Sex, n (%)		
Male	8 (38)	7 (64)
Female	13 (62)	4 (36)
Years spent in education, median (IQR)	15 (7)	15 (4)
Autonomy profile, n (%)		
Autonomous or no relevant functional decline	17 (81)	8 (73)[a]
Loss of autonomy or relevant functional decline	4 (19)	3 (27)[a]
Living arrangements, n (%)		
Living alone	7 (33)	1 (9)
Household of 2	12 (57)	8 (73)
Household of 3 or more	2 (10)	2 (18)
Country of origin, n (%)		
Belgium	5 (24)	2 (18)
The Netherlands	13 (62)	2 (18)
Portugal	2 (10)	6 (55)
United Kingdom	1 (5)	1 (9)

[a]The autonomy profile in the column of informal caregivers refers to how they appraised the person they care for, thus referring to the autonomy profile of the person they care for.

Plans to Age in Place

Regarding plans to age in place, the great majority of older adults in this study (17/21, 81%) declared their intention to continue living in their current home in the next decade, with 14 (14/21, 82%) of them contemplating the modification of their current houses to achieve that. Participants planning to move (4/21, 19%) were all autonomous older adults at the time of data collection. More than half of all participants (56%, n=18) reported a need to use products, services, or both to support the performance of their own daily activities or the activities of the person they care for. Curiously, among those, one-third (n=6) reported an "easy" or "very easy" completion of daily activities (their own or of the person receiving support) without help, suggesting a *think-ahead* mindset. Among those recognizing the need for supportive products and/or services (n=18), 8 (8/18, 44%) reported that they had already used these types of solutions, 11% (2/18) already found what they needed and were

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considering a purchase; 22% (4/18) were actively looking for the most suitable solution, and 22% (4/18) had yet to take any action to look for solutions. Among the participants currently using, having found, or actively looking for supportive services (n=14), only 4 (4/14, 29%) had resorted to ICT-supported products and/or services. From the participants who did not report a need of using products and/or services to support their own or their care receivers' daily activities (14/32, 44%), more than half (8/14, 57%) showed a preventive mindset, having thought about using such products or services to facilitate aging in place.

ICT Usage and Attitudes Toward Technology

The majority of participants (29/32, 91%) stated that they used the internet on a daily basis, with the remaining participants (3/32, 9%) using it at least once a week. The tablet was the most used device to access the internet (24/32, 75%), followed by the smartphone (20/32, 63%) and the laptop (18/32, 56%), with the desktop being the lesser used device (15/32, 47%). As for online activities, consulting news and weather reports (30/32, 94%), email and online messaging (29/32, 91%), and looking for products and services information (24/32, 75%) comprised the top 3, whereas online banking (20/32, 63%) and social media (20/32, 63%) fell on the sparser habits.

Concerning attitudes toward technology (Table 2), there were some paradoxical findings with users showing both overall positive (items 1, 2, 3, 4, and 5; median rates from 4 to 5) and negative attitudes toward technology (items 7, 8, and 9; median rates of 4). A substantial share of the users (28/32, 88%) agreed with the importance of having access to the internet at any time and to information offered online (median of 5). More than half of the participants believed that technology offers a solution to many problems (26/32, 81%), stated that they like to keep up with technological trends (23/32, 72%), and feel more accomplished with the use of technology (20/32, 63%; all median of 4). Less than half of the participants believed that technology complicates life (15/32, 47%), but a relevant share believed that technology makes people waste too much time (20/32, 63%) or that it might contribute to increased personal isolation (20/32, 62%, all median 4).

Table 2. Participant's attitudes toward technology (N=32).[a]

Item	Participants, n (%)			Participants, median
	(Strongly) disagree	Neutral	(Strongly) agree	
1. Important to find information online	0 (0)	4 (12)	28 (88)	5[b]
2. Important to access internet at any time	4 (12)	0 (0)	28 (88)	5[b]
3. Important to keep up with technological trends	4 (12)	5 (16)	23 (72)	4[b]
4. Technology is a solution to many problems	2 (6)	4 (12)	26 (81)	4[b]
5. Technology makes anything possible	3 (10)	20 (63)	9 (29)	3[b]
6. Technology helps to feel accomplished	6 (19)	6 (19)	20 (63)	4[b]
7. Technology makes people waste time	6 (19)	6 (19)	20 (63)	4[c]
8. Technology complicates life	6 (19)	11 (34)	15 (47)	4[c]
9. Technology increases isolation	5 (15)	7 (22)	20 (63)	4[c]

[a]The description of the items is abbreviated and rephrased for presentation purposes. To learn about the scale from where these items were gathered (Media and Technology Usage and Attitudes Scale, positive and negative attitudes subscales, please consult Rosen et al, 2015 [33]).

[b]Scale ranges from 1 to 5, with higher median values indicating more positive attitudes.

[c]Scale ranges from 1 to 5, with higher median values indicating more negative attitudes.

Usability and User Impressions

Task Analysis

Regarding successful tasks with no input from the researchers (Table 3), task 3 had the best results (15/32, 47% success rate), followed closely by task 1 (14/32, 44% success rate). However, if we refer to the completion of the task at hand, be it by the user alone or with acceptable prompts from the researcher, the most successful was task 2 (26/32, 81% full and partial success rates). Accordingly, task 3 also had a higher rate of unsuccessful completion (10/32, 31% no success rate), followed by task 1 (8/32, 25% no success rate).

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Table 3. Task completion rates and illustrative verbalizations on task (N=32).

Task	Participants, n (%)			User verbalizations
	Full success	Partial success	No success	
Task 1: use the platform to find an alarm watch	14 (44)	10 (31)	8 (25)	"I'm not sure that it is what I'm looking for, I'm not sure of being in the right section"; "There is a lot of overlap between the various categories"; "I would search for the name of the device on the bar, but I don't know the term, so I'm trying to find a relatable category"
Task 2: use the product finder to find a device that allows you to locate a person	12 (38)	14 (44)	6 (19)	"It is not clear for me how to deal with the filtering questions and the price drag bar"; "The problem should be discussed first, and then it would present you with choices"
Task 3: use the platform to find a product that suits the need of your neighbor	15 (47)	7 (22)	10 (31)	"This demands a lot of knowledge on these products to find the desired product"; "It is hard to come up with keywords"; "I don't really think that some people would know what some of these options/functions actually mean"

Posttest Debrief

Overall, participants' ratings of their experience with the ActiveAdvice prototype with regard to usability were fairly positive (Table 4). The usefulness of the platform was by far its best appraised characteristic, with the great majority of participants considering the ActiveAdvice platform to be a useful resource (29/32, 91%). More than half of the participants considered that the platform was easy to use (19/32, 59%) and well organized (21/32, 66%) and that information on the platform could be easily retrieved (19/32, 59%) and navigating on the platform was a pleasurable experience (21/32, 66%). Most participants also considered that navigating on the platform could be done with no support from others (20/32, 62%) and that it was easy to keep track of their location within the platform (19/32, 59%). However, participants assumed an overall neutral position when judging how easy it would be for other people to use the platform, with less than half agreeing that most people would quickly learn how to use the website (15/32, 47%). Despite the overall good appraisal of ActiveAdvice usability, less than half of the participants reported that they would like to use the platform frequently (13/32, 41%).

Table 4. Ratings of the users' experiences with the ActiveAdvice interface (N=32).

Item	Participants, n (%)			Participants, median
	(Strongly) disagree	Neutral	(Strongly) agree	
1. I think the website was easy to use.	4 (13)	9 (28)	19 (59)	4[a]
2. I think I would need support to be able to use this website.	20 (62)	3 (9)	9 (28)	2[b]
3. I think the website is well organized.	8 (25)	3 (9)	21 (66)	4[a]
4. I could get the information quickly.	8 (25)	5 (16)	19 (59)	4[a]
5. I found it difficult to keep track of where I was on the website.	19 (59)	4 (13)	9 (28)	2[b]
6. I think that most people would learn to use this system very quickly.	11 (34)	6 (19)	15 (47)	3[a]
7. I think that I would like to use this website frequently.	9 (28)	10 (31)	13 (41)	3[a]
8. I think the website is useful.	3 (9)	0 (0)	29 (91)	4[a]
9. I found the website pleasant to use.	7 (22)	4 (13)	21 (66)	4[a]

[a]Scale ranges from 1 to 5, with higher median values indicating a more positive assessment of usability.

[b]Scale ranges from 1 to 5, with higher median values indicating a more negative assessment of usability.

The quantitative assessment of users' experiences (ratings) was further explored by collecting qualitative data from a posttest debrief or interview. We provide a qualitative synthesis of the content produced by the participants with respect to each specific dimension of the platform. The debriefing was conducted in a semistructured style, thus not all participants contributed to each unique topic under the analysis below. We did not distinguish between quotes from older adults or caregivers, as no different patterns emerged from their answers to the posttest interview.

Layout (General Impressions)

Overall, the ActiveAdvice layout was well accepted by most participants (17 of 23) and considered to have an organized and clear structure:

> *Clear structure and well organized.* [User (U)7]
>
> *I think it's pretty and well organized.* [U18]
>
> *It's very clear and neat.* [U10]

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A total of 6 participants perceived negative aspects of the layout, considering the platform complex or confusing, while also including too many product categories:

> *Could be better, I had to think where I was a lot of times.* [U17]
>
> *It's neat and low-key. There are a lot of categories though.* [U11]
>
> *Stick to simple things.* [U16]

Amenity of Color Schemes and Use of Images

Most participants were pleased with the esthetics of the platform (23 of 27):

> *Not flashy, creates serenity.* [U9]
>
> *The use of colour is soothing.* [U14]
>
> *I found the colours very appealing.* [U20]

Four participants found the platform "a bit too bland" [U3] or "not contrasting enough" [U4]. Images were considered attractive, conveying a nondiscriminatory image of older adults or disabled or ill people:

> *the platform is developed not only for elderly people and it does not feed stereotypes about elderly people, this could be for anyone, a family with elderly or someone with some disability who wants to live independently (...) the appearance makes me think that.* [U24]
>
> *[images are] not offensive.* [U22]

Readability

This parameter allows participants to appraise how easy it is for them to read and understand the text on the platform, depending both on the presentation of text (eg, font size, spacing) and the actual text content (ie, use of understandable words and sentences). Regarding text presentation, participants were divided into those who appraised this parameter positively (14 of 23):

> *...easily readable.* [U3]
>
> *...style is professional and easy to read.* [U7]

Some participants who did not appraised this parameter positively (9 of 23). Participants with negative comments mostly focused on font size, and 1 participant mentioned the amount of text:

> *...text size in some areas is too small.* [U5]
>
> *...too much text.* [U21]

Regarding textual content, most participants considered them easily understandable (19 of 25):

> *...good, sentences were written in short and plain language.* [U22]
>
> *...terminology is fine.* [U14]
>
> *...very perceivable.* [U7]

Negative comments (6 of 25) relied on difficulties in understanding some of the terms used to describe the solutions:

> *...some words are difficult to understand.* [U15]
>
> *...for people with lower education one should be careful in using no professional terms.* [U23]

Missing Features

When requested to point out any missing functionality or feature in the ActiveAdvice platform that would be expected, users were divided into those who reported not missing anything in particular (12 of 25) and those stressing a number of different expectations, which include more feedback, more support, and more product information:

> *I would like to get more feedback on my actions and be able to really access the products.* [U12]
>
> *...product information should be much better.* [U9]
>
> *...there should be a number you can call if you need help figuring out how the website works.*
>
> *...people who use the website would be able to ask questions or exchange information, that would be very interesting.* [U19]

Most and Least Liked Features

When questioned about the pluses and the most liked features of the platform, participants stressed the usefulness and purpose of the platform (13 of 27) and its ease of use (8 of 27), nice layout, and overall appearance (11 of 27):

> *Good for older people who start to have trouble living at home.* [U5]
>
> *The concept is very interesting and could be useful.* [U10]
>
> *It's faster than go to a physical store and compare.* [U12]
>
> *I think the overall impression is that it looks good. I like the pictures.* [U13]
>
> *It's a site of easy access and lets people know about what is available.* [U19]
>
> *Intuitive, if you get to know it a little bit then suddenly it becomes very easy to use.* [U23]

In contrast, platform minuses almost exclusively focused on missing a more effective product search and more complete product information (10 of 27):

> *The filtering comes too late in the process of searching. Should be earlier in the process.* [U6]
>
> *The filter questions I think. You should be able to filter on your problem.* [U8]
>
> *More information about categories without having to click on them.* [U11]
>
> *Lacks keywords so you can use the search function. Can't see the difference between scenarios and categories.* [U22]

Discussion

Principal Findings

Our study presents an innovative platform in the AAL field, ActiveAdvice, and provides observations on the usability and users' experiences within the prototype. Studies on innovative

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platforms, such as ActiveAdvice, are often missing in the literature; thus, this work contributes not only to improving the prototype but also to populating the literature in this field. The main insights from this study are derived from both its results and the process, which are discussed below in a series of comments and takeaways over 2 critical sections of this work: the usability tests and the process as a whole, which translates our thoughts from the gathered data. The first section rests on dissecting the participants' attitudes and achievements while using the platform and how those observations lead to changes in the interface or information architecture. These insights are the core of knowing how to build something for a specific audience with different needs and ways to interpret digital media. Impressions on the experiences are also of crucial importance, as the reception, interpretation, usefulness, and perceived user satisfaction and engagement are effectively and ultimately the make-it-or-break-it of what we set out to develop. The second section discusses every limitation and interesting findings regarding the entire process and the characteristics of the recruited users, along with possible explanations for the obtained outcomes. Both sections also aim to discern important aspects such as difficulties, remarks, and other perceptions that are structured to help others not only to replicate the process but also to take special precautions and careful considerations regarding the specified elements.

Usability Testing

The usability testing protocol established for this study included a task analysis methodology as a means to understand users by observing them interacting with the platform while trying to achieve an intended goal. The three main tasks assigned to the participants revolved around searching products while using the existing functionalities of the ActiveAdvice platform, as these are considered the core tasks that the website must support.

We saw that task success *with ease* and *with help* were sometimes on par with each other, meaning that although the functionality was there, a fair number of users would struggle to complete the task because of confusion or lack of a clear direction. Each scenario was described in a way that allowed a very spontaneous search to look for natural patterns of interaction or provided the user with more structure to incentivize the use of specific components (eg, asked to use a certain search functionality) or named the solution being searched (eg, task 1, a smartwatch). When less detailed scenarios were provided (eg, task 3), the chances of failure were higher. Users showed a substantial lack of knowledge on AAL products or services, thereby increasing the difficulty in thinking about keywords or categories to which they could resort to for finding a solution to their needs. This observation is well illustrated by the participants' verbalizations in Table 3. This finding is particularly relevant to the AAL field, provided the considerable lack of public awareness of such solutions, and the complexity characterizing most AAL solutions (commonly requiring integration of products and services, frequently from different providers). Thus, the challenges faced in building a platform such as ActiveAdvice, where the user should be able to find a suitable solution to their problem, are more pronounced than in similar service platforms for other markets. The resource to typical search and filtering methods (eg, keywords, categories, list of product or service features) is not sufficient in terms of efficacy, as users frequently do not possess a sufficient understanding of ICT or ICT-enabled solutions to choose keywords, decide on search categories, or whether a technical feature on a device is or is not relevant for them. This observation has implications for not only the design of the ActiveAdvice platform but also initiatives aimed at informing older adults on AAL solutions and promoting their uptake. From these observations, we not only introduced improvements in the interface but also identified a need to integrate digital and human advisory services to tackle complexity and improve the user's experience (see the concept of the Authorized Active Advisor [41]). Process-wise, one should stress that when evaluating tasks, failures and successes could be somewhat misleading, as task success or failure will rest on the evaluator's interpretation of the user's actions. We aimed to minimize this by providing structured guidance to test carriers, but variability in these judgments cannot be ruled out. Some evaluators are more lenient and others stricter, as a *barely* could be a *fail* and an *easy* by other standards could be a *difficult*. In addition, when evaluating task completion rates, one should also not completely rely on success percentage fluctuations, as these might also be explained by concatenated success (or failure), where a user who eventually spends more time on the previous task learns how to perform better on the next one. It is not easy to avoid this type of bias because tasks are ultimately not independent. Nevertheless, the overall high task completion rates suggested that tasks were permissive in terms of global interaction.

Subjective user impressions of the prototype have been favorable overall with regard to its usability. The most encouraging finding from both ratings and verbalizations was the recognition of the usefulness of a platform such as ActiveAdvice, proving its concept. Design-wise, the platform was well assessed with regard to its layout and pleasurable navigation. However, when considering room for improvement, we should not neglect that about one-third of the users have found problems in the organization of the platform, on finding the information quickly, and on keeping track of their position on the website. Moreover, about one-third believed that support would be required to use the platform and that most people would need some time to learn how to use the system. Overall, with regard to the main quality components of a system usability, most encouraging results were found on user satisfaction; ultimately, participants had a satisfying experience when navigating the platform, mostly brought by the recognition of a *sense of purpose*. The platform was rated as appealing to the eye, whereas the scope was reported as interesting, educative, and useful, with a broad range of content. In contrast, the tests advocated a need for improvements, mainly in terms of learnability and effectiveness. Issues with general visualization or organization can contribute significantly to this subject if the interface fails to conduct the intended interaction. This is hinged on two aspects: a strong information architecture, which is tricky when talking about a higher range of product categorization and self-explanatory elements. Some products might be difficult to place, even when using a tested taxonomy, as they might span more than 1 category. That being said, the integration of a wide range of recognizable keywords takes a big share of the process when it comes to finding them quickly. Keywords that spring to mind

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should have immediate (and accurate) correspondence in a search bar, as the user's mental model is a crucial part of a search method. In this case, knowing and learning the most common issues the users are experiencing or will experience helps when associating those loose keywords with frequently asked questions (or frequently posed statements) in the process of finding a solution. In addition, a clear and usable design can be achieved through familiarity, consistency, guidance, and direct feedback. The participants preferred a center-focused interface, tile-based navigation, hinting at an *over-the-belt* experience, while objecting to the need to scroll down to access content. A lack of previous domain or product information knowledge makes it difficult for the user to even know what to look for or search, so a short presentation statement along with a direct visualization of what is important would help to minimize those feelings. Taking, for example, the product advisor, using a wizard, was especially handy as it simplified the task into a sequence of chunks, while dropping the learning curve, making the users follow a step-by-step path to accomplish their goal. Using polished visual cues, such as coherent images with associated labels and recognizable icons with expected placements helped to simplify the navigation. Although the use of plain terms was praised by users and accomplished in most navigational settings, it can be difficult to manage in some sections that will have to get technical to deliver the correct information across. In that case, it would be better to be explicit and true to the description than risking an oversimplified explanation that will not be up to par.

Despite a good overall satisfaction with the platform, only 42% (13/32) reported that they would use the platform frequently. However, this result may be related to sample features: first, there was a percentage of users who reported not having a real need to use products and/or services to support their own or their care receivers' daily activities (14/32, 44%), which meant that the benefits of AAL were not sufficiently exposed to the point that peaks general interest in discovering them. Moreover, most of the older adults' sample was composed of individuals with no functional loss and autonomous in their daily activities, meaning that they might recognize, as a double standard, the ActiveAdvice platform as useful for older adults but not for themselves. In contrast, we also have to link the fact that the platform was at an early stage of development, meaning that its interface and functionalities were not optimized at the time of testing. It was expected that failures within tasks and other inabilities to interact with the platform would cause some disappointments in some users, influencing their intention to return. The purpose of testing is to evaluate user interaction, so it is also expected that all aspects would be corrected and refined according to the participant's usage, to the point where user-friendliness would subsequently become a positive decisive factor. A pleasant experience could be what, together with an actual need, might keep users interested and susceptible to make some effort (both time and persistence wise) while using technology that they might not be at ease with, hoping that ultimately it will help increase their quality of life.

About the Process

The interesting findings of this study must be considered within the context of some limitations. One of them concerns the selection and inclusion of only primary and secondary end users when testing the platform. Interested parties in the AAL field have been mainly identified as 3 diverse groups [42-44], with the first and biggest target of technologies and services being the consumers. The other 2 groups are governments, such as city administrations who define policies and provide services in the field of health and care, and the businesses that develop, exploit, or market products and services. In previous stages of the ActiveAdvice research and platform development (eg, requirement analysis; see the *ActiveAdvice Platform* section), representatives of all these groups were included, and the authors have argued for this multiperspective approach on AAL research [30]. For this usability study, however, although older adults and caregivers' requirements previously gathered were mostly addressed and implemented in the tested prototype, requirements from business and government representatives (eg, specific modules and functionalities) were still in progress. Future research on the ActiveAdvice platform must enroll multiple interested parties in such a solution. Indeed, a platform that benefits more than one party needs to take into account that, apart from the common interest in the area, each group has different ways of expressing wants and needs. For example, from a budgetary perspective, governments are concerned about ensuring the successful adoption of these technologies, as full-time home or institutional health care could become very expensive. Accordingly, the promulgation and growth of the area provides businesses with a better sense of the market's wants and needs, thus boosting research and manufacturing of products, as well as supporting a broader supply of services [30,42,43]. Another limitation was the education level of the participants, which was high (median of 15 years of schooling), causing the sample to lack diversity in this aspect. Older adults and informal caregivers were comparable in terms of education, which might have influenced the analysis, but the researchers qualitatively looked for different patterns of responses between both groups and found none. Education is a well-known determinant of internet usage, so an educated sample was expected, and the so-called education bias is common in internet- and technology-related research [44]. Our participants were frequent internet users, comfortable with a range of devices, and performed multiple online activities. They have also shown overall positive attitudes toward technology and were very open to use or already using products and/or services to support aging in place, although only a small percentage use or plan to use ICT-enabled products. Altogether, this suggests that we recruited mostly a profile of early adopters, who are not only more ICT savvy but also are more open to adopting new ideas and use innovations than their counterparts. If we consider that most participants in this sample were aged 60 years and older and attend to known statistics on ICT use by older people, this idea is further reinforced. In 2016, only 45% of users aged 65 to 74 years used the internet at least once a week, compared with 82% in the general adult population [45]. According to a survey performed in the United States [46], 34% of older internet users reported that they had little to no confidence in their ability to use electronic devices, whereas 73% revealed that they will likely need help from someone else to use an electronic device. Future work with the ActiveAdvice platform must consider the inclusion of a more diverse sample. This also applies to the

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autonomy status of older adults, as it was very challenging to recruit dependent older adults, and those were mostly represented in this sample by informal caregivers. In practical terms, however, the use of a platform such as ActiveAdvice to support dependent older adults will most likely be enabled by informal caregivers, especially when autonomy loss is propelled by cognitive impairments. In this study, we decided to include those designated by some authors as young older adults (>55 years) [47]. Although this conceptualization of older adults is not consensual, when considering testing of technological solutions that will only be in the market in a few years, including prospective users is important. Moreover, AAL technologies are not only intended to compensate for functional loss, most common in old age but also to prevent it; thus, including a group who thinks ahead about aging in place is fundamental to assess the ActiveAdvice platform.

Regarding the testing protocol, challenges emerged when performing tests in 4 different countries. Even with the provision of a package with a standardized toolset, one should definitely not assume that everything will go according to plan and that testers will have the same understanding of procedures, as discussed above with regard to judging a task failure or success. Moreover, owing to language barriers, we were not able to have the same researchers performing the analysis of the text data in the original transcriptions, which were first translated into English. It might be that some discourse details may be lost in translation. These are well-known challenges of European projects, and our experience shows that communication and a systematic registration of collected data in its *as raw as possible* state is key. In this study, we were not able to perform any comparison among countries: small numbers hinder hypothesis testing, and for qualitative analysis, no different pattern of responses per country emerged. Studies have reported cultural differences in how usability is assessed by users, suggesting that this is a multidimensional concept [48]. Future ActiveAdvice studies must look to the extent to which different attributes are equally valued across cultures.

Our experience has also shown that dealing with older adults when performing usability tests also has its peculiarities, as agreed with in other studies [49-51]: users may be uncomfortable discussing their personal circumstances and often reluctant to acknowledge what they consider their own frailties or shortcomings. This can pair up with being afraid of giving a wrong answer, which eventually translates into being less prone to explore the application and task at hand. In addition, as they usually want to please the evaluator and not be a burden (social desirability bias), they are less likely to make a negative remark about something even if they are struggling, resulting in short and uninformative responses that should be taken with a grain of salt. This can be improved by starting to involve users early in a PD process, where they can feel safe when performing tasks or sharing opinions.

Conclusions

ActiveAdvice is a type of platform in the European context providing a holistic market overview and advice on AAL products and services, and its development process was tied to good practices in UCD. This platform has the potential to support the problematic uptake of digital solutions by older adults, which may support their aging in place. ActiveAdvice's purpose is fully aligned with wider political and strategic agendas and priorities for healthy and independent aging, as illustrated by the 2020 AAL Program call for proposals (p. 5 [52]):

> *Proposed solutions should meet the needs of end-users, be it seniors, their carers, or institutions providing care. Innovative approaches to deployment and adoption of ICT services should be part of the solution development alongside the development of the new ICT/digital products, as well as their integration into the regional socio-economic context.*

To reach the full potential of the ActiveAdvice platform, we should strive to improve the usability areas that we have highlighted in this study, namely efficacy and learnability. Simultaneously, to improve the chances that such a resource is recognized as useful by end users and its concepts are not totally unfamiliar, researchers and policy makers in the AAL field must determine how to better deliver information on AAL to those who need it. Pulling and retaining a user on the ActiveAdvice platform relies on 3 things: a *real need*, *knowing better* (ie, a perception that ICT-enabled solutions might help address an issue), and a *pleasant experience*. The former builds on the fact that the initial motivation for using such a platform rests on someone being at a point where they *need* advice regarding an actual (or predicted) loss of autonomy or quality of life. Getting the information out and disseminating the area both play a huge part in this, as people can learn that there might be something in the market that helps them to address a problem they might have that is affecting their independence and well-being. *Knowing better* can direct someone toward our solution when necessity occurs or is expected to occur. For a *pleasant experience*, being able to materialize that necessity into an answer is just as important. User-friendliness and simplicity are crucial when delivering a solution to someone who is often distrustful of information technologies, usually lacks the necessary patience to deal with them, and does not feel like thinking too much about things, frequently giving in to the *learned helplessness* phenomenon. To create products or services that are successful in the long run, it is necessary to ensure that the product has a sufficiently high engagement level for all relevant stakeholders, which is especially important for web services such as this platform. Making the developed concepts of ActiveAdvice not only useful for the (primary) end user but also supported and accepted by other stakeholders such as families, caregivers, product suppliers, and governments, is quite challenging but instrumental to achieving its full potential in supporting technology adoption by European older adults and, ultimately, healthy aging in place.

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Conflicts of Interest

None declared.

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Abbreviations

AAL: ambient assisted living
FCT: Fundação para a Ciência e a Tecnologia, IP
IC: informal carer
ICT: information and communications technology
PD: participatory design
SUS: System Usability Scale
UCD: user-centered design

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Original Paper

Implementations of Evidence-Based eHealth Interventions for Caregivers of People With Dementia in Municipality Contexts (Myinlife and Partner in Balance): Evaluation Study

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Abstract

Background: Very few evidence-based eHealth interventions for caregivers of people with dementia are implemented into practice. Municipalities are one promising context in which to implement these interventions due to their available policy and innovation incentives regarding (dementia) caregiving and prevention. In this study, two evidence-based eHealth interventions for caregivers of people with dementia (Partner in Balance and Myinlife) were implemented in 8 municipalities in the Euregion Meuse-Rhine. Partner in Balance is a blended care, 8-week, self-management intervention intervention designed to aid caregivers of people with dementia in adapting to their new roles that is delivered through coaches in participating health care organizations who are trained to use it to offer online support to their clients. Myinlife is an eHealth/mHealth intervention integrated into the Dutch Alzheimer's Association website and available from the App Store or Google Play, designed to help caregivers of people with dementia use their social network to better organize care and share positive (caregiving) experiences.

Objective: This study's objectives were to evaluate the success of the implementation of Myinlife and Partner in Balance and investigate determinants of their successful implementation in the municipality context.

Methods: This study collected eHealth use data, Partner in Balance coach evaluation questionnaires, and information on implementation determinants. This was done by conducting interviews with the municipality officials based on the measurement instrument for determinants of implementation (MIDI). These data from multiple sources and perspectives were integrated and analyzed to form a total picture of the determinants (barriers and facilitators to implementation in the municipality context).

Results: The municipality implementation of Partner in Balance and Myinlife showed varying levels of success. In the end, 3 municipalities planned to continue the implementation of Partner in Balance, while none planned to continue the implementation of Myinlife. The 2 Partner in Balance municipalities that did not consider the implementation to be successful viewed the implementation as an external project. For Myinlife, it was clear that more face-to-face contact was needed to engage the implementing municipality and target groups. Successful implementations were linked to implementer self-efficacy and sense of ownership, which seemed to be absent in unsuccessful implementations.

Conclusions: The experiences of implementing these interventions suggested that this implementation context was feasible regarding the required budget and infrastructure. The need to foster sense of ownership and self-efficacy in implementers will be integrated into future implementation protocols as part of standard implementation materials for municipalities and organizations implementing Myinlife and Partner in Balance.

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KEYWORDS

eHealth; mHealth; implementation science; dementia; caregiving; municipality

Introduction

Dementia is a progressive, neurodegenerative disease accompanied by cognitive decline in multiple domains, as well as mood and behavior changes. Informal caregivers play an indispensable role in providing high-quality care for people with dementia [1]. Supporting informal carers of people with dementia is essential, as informal caregiving can potentially allow people with dementia to delay institutionalization and result in positive effects on the person with dementia's physical and mental health [2]. Given the fact that there are currently 50 million people with dementia worldwide and this number is set to triple by 2050 [3], the rising cost of dementia care and its reliance on informal care is a significant concern for many modern health care systems [4]. Informal caregiving can have both positive [5] and negative [6] effects on the informal caregivers' physical and mental well-being, and the negative consequences of caregiving can include social isolation, depressive symptoms, stress and anxiety, financial issues, and sleep problems [7,8].

eHealth interventions have been suggested as a means to meet both the demand for more cost-effective dementia health care [9,10] and the need for effective informal caregiver support [11]. Here, eHealth interventions are "treatments, typically behaviorally based, that are operationalized and transformed for delivery via the internet" [12]. Many recent systematic reviews have shown evidence of the effectiveness of eHealth interventions for caregivers of people with dementia, with intervention studies reporting improvements in a variety of caregiver outcomes including increased positive experiences with the caregiving process, self-efficacy, and confidence, in addition to the reduction of stress, experienced burden, and depressive symptoms and anxiety [13-16].

Unfortunately, previous research has shown that very few of these eHealth interventions for caregivers of people with dementia are implemented into practice [17]. Here, implementation refers to "the process of putting to use or integrating evidence-based interventions within a setting" [18]. More generally, only 3% of evidence-based psychosocial interventions for dementia are translated into practice [19]. Lack of proven effects on health care outcomes, doubts from implementing health care staff, meager implementation coordination and management, lack of information on the implementation context, and the fact that users are seldom involved in the eHealth development have been cited as important barriers to the implementation of evidence-based interventions [20-23].

This study was designed to address the lack of information on the implementation context. One potentially important and well-suited implementation context for eHealth interventions for caregivers of people with dementia in Northern Europe is the local municipality. Municipalities are districts or towns with local governments. A municipality's governing functions can vary from country to country. In general, the municipality is responsible for local services, such as health care, education, recreation, and sport. The municipality context was chosen because municipalities often have policy incentives and funds to address both dementia and caregiving challenges, as well as innovation budgets that are suitable to finance online solutions [24,25]. In this study, two evidence-based eHealth interventions for caregivers of people with dementia (Partner in Balance and Myinlife) were implemented in 8 municipalities in the Euregion Meuse-Rhine (EMR) by municipality officials and by personnel in the local, participating health care organizations. The main research question addressed barriers and facilitators to implementing evidence-based eHealth interventions for caregivers of people with dementia in a municipality context. This study's specific objectives were to evaluate the success of the implementation of Myinlife and Partner in Balance and investigate determinants of successful implementation of the interventions in the municipality context.

Methods

Study Background

This implementation study took place in the context of the euPrevent Senior Friendly Communities (SFC) project [26], which is based on the World Health Organization's Active Ageing framework [27]. This project took place between September 2016 and December 2019, and data collection continued until March 2020 (see Figure 1 for a timeline of the project). In this project, 32 municipalities signed up on a first come, first serve basis, with the aim to become more senior-friendly. After a kickoff conference with the participating municipalities and other stakeholders, the project assessed what the municipalities were already doing for their aging population and how they could improve. Informed by this assessment, municipalities selected activities from a so-called activity buffet, which consisted of 15 preexisting activities. These activities were aimed at improving the mental health of the municipality's aging population by focusing on various aspects of dementia and age-related depression. The activities included a theater production, consultations with experts on various topics, a photo exhibition, courses on relevant topics and psychoeducation, creation and organization of local groups of elderly people, outreach activities, and eHealth interventions to support caregivers of people with dementia. These activities were to be implemented before a final conference with municipalities and stakeholders. Implementation and use of the chosen interventions were included in the participation in the SFC project, meaning that all activities were free of costs for both municipality and users. Data collection took place parallel to the described activities and in 3 phases: preparatory, implementation, and evaluation.

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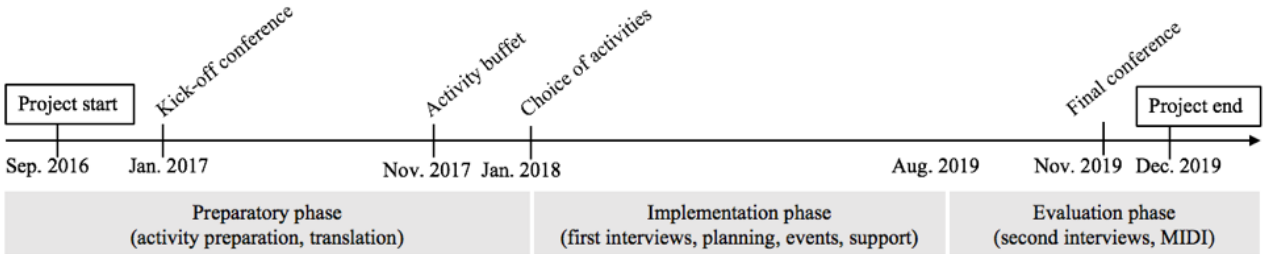
Figure 1. Timeline of eHealth implementation within a Senior Friendly Communities project.



The activity buffet included two eHealth interventions to support caregivers of people with dementia: Partner in Balance and Myinlife. These interventions were included in the activity buffet by the SFC project team due to their promising research results and local origin (they were developed with the EMR). There also was a desire to offer remote support options such as eHealth within the project, and these interventions met this need. Neither had been widely implemented previously, so there were no expectations about which intervention would be easier to implement. Six municipalities opted to implement Partner in Balance (4 in the Netherlands, 1 in Belgium, and 1 in Germany), and 3 opted for Myinlife (2 in Belgium and 1 in Germany). Table 1 depicts relevant characteristics of the SFC municipalities that chose to implement eHealth in their communities. A more detailed description of the municipalities' eHealth choice process is provided elsewhere [25].

Table 1. Characteristics of the participating municipalities[a].

Characteristics	Value, n
Number of municipalities that chose Partner in Balance	6
Number of municipalities that chose Myinlife	3
Municipality average general population	36,376
Municipality average population age >65 years	7349
Municipality average estimated dementia population	1434

[a]Population statistics sourced from the euPrevent Senior Friendly Communities project [25,26,28].

eHealth Interventions

Partner in Balance

Partner in Balance is an evidence-based eHealth intervention designed to aid caregivers of people with dementia in adapting to their new roles that is delivered through coaches in participating health care organizations who are trained to use it to offer online support to their clients. It is a blended care, 8-week, self-management intervention consisting of (1) an in-person intake session with the coach to acquaint the caregiver with Partner in Balance, select online modules, and set goals; (2) tailored online thematic modules including psychoeducation, behavioral modeling, videos of carers discussing their experiences with the chosen themes, change plans, and email feedback from the coach over 8 weeks; and (3) an in-person evaluation of the program with the coach to assess previously set goals. The in-person meetings between caregiver and coach usually take place at the coach's place of work (eg, a dementia case management organization) although some coaches choose to visit the caregiver at home. The at-home use of the chosen modules by the caregivers is asynchronous and the responsibility of the caregiver, although the coach provides encouragement and feedback via email. Partner in Balance coaches are required to have experience in health care and dementia care. All coaches take part in a 2-hour Partner in Balance training course with presentation of the intervention and exercises in coaching and self-management techniques. Detailed information about the program components and development is presented elsewhere [29]. Partner in Balance was shown to cause improvements in caregiver outcomes such as mastery, self-efficacy, and quality of life [29,30].

Myinlife

Myinlife is an eHealth intervention designed to help caregivers of people with dementia use their social network to better organize care and share positive (caregiving) experiences. Myinlife has been integrated into the Dutch Alzheimer's Association website [31] and can also be downloaded from the App Store or Google Play free of charge. In previous research, Myinlife has shown potential to make caregiving easier and help caregivers gain more control over their schedules [32,33]. Myinlife has the following functionalities: Profile, Circles, Timeline, Calendar, Helping, Personal Messages, Care Book, and Compass. Caregivers use these functionalities independently (with no help from a coach) to facilitate the organization of care for the person with dementia. Although Myinlife does not make use of a coach, it still requires local health care organizations to facilitate the dissemination and implementation of the intervention by promoting its use among the local population.

Measures

Use Data

Implementation use data was collected for the following measures: number of municipalities choosing one of the interventions, number of research team implementation hours (both face-to-face and remote), number of information

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technology support hours, and number of accounts (caregivers and coaches). No data were collected on the effect of the intervention or the caregivers' experiences with the program, as this was assessed in previous research [30].

Partner in Balance Coach Evaluation Questionnaire

Because Partner in Balance (but not Myinlife) makes use of a coach as part of its blended approach, evaluation questionnaires were sent to all Partner in Balance coaches who took part in the coach training as part of the SFC project. An English translation of the coach evaluation questionnaire can be found in Multimedia Appendix 1. The questionnaire asked the participants of the training to rate the usability and relevance of Partner in Balance for caregivers and coaches. It consisted of 11 multiple-choice items rated on a 5-point scale (1=completely disagree to 5=completely agree) and 5 open-ended items. A version of this questionnaire had previously been used in the Partner in Balance process evaluation [34].

Determinants of Implementation

The measurement instrument for determinants of innovation (MIDI) is designed to assess which determinants may affect implementation, and it can be applied before or after the introduction of an innovation [35]. The MIDI groups determinants into 4 categories: determinants associated with the innovation, adopting person (user), organization, and sociopolitical context. The MIDI was developed to be used in a research context to explore the experiences of intermediary users ("professionals whose actions determine the degree of exposure of end users to the innovation") of the innovation [36]. To construct the MIDI, determinants were extracted from the results of 8 empirical studies on the implementation of evidence-based innovations and discussed with 22 implementation experts [36]. The instrument consists of 29 questions, each designed to explore a particular determinant. Responses consist of a number on a 1- to 5-point Likert scale and an explanation of the reasoning behind the given score. However, in this study, due to the small sample size, no quantitative MIDI scores were collected, and the MIDI was used instead as a semistructured interview guide to ensure that various domains of implementation were discussed in the evaluation. Multimedia Appendix 2 contains an English version of the MIDI as it was used in these interviews.

Data Collection

Use Data

After each interaction with the municipality, implementation data were anonymously logged in a customized data collection platform with separate entries for each municipality. The interactions included emails, telephone calls, and meetings. The dates and time required for these interactions were logged, including preparations and travel time. Data were logged for all municipalities by author HLC from the start of the implementation in January 2018 until the end of implementation in December 2019.

Partner in Balance Coach Evaluation

Coaches were sent the evaluation questionnaire via email at the end of the SFC project in December 2019 and asked to reply via email. Reminders were sent after 6 and 12 weeks. Email responses were stored on the described data collection platform.

Determinants of Implementation

Interviews with the municipality representatives responsible for the intervention implementation were conducted to explore determinants of implementation. However, at the end of the project, not all municipalities had achieved the level of implementation necessary to appropriately evaluate implementation determinants using the MIDI questionnaire. The level of eHealth implementation was considered adequate to evaluate determinants if municipalities had completed the implementation activities planned in the initial interviews. These differed per municipality [25] and included a minimum implementation threshold to be considered for determinant assessment. For Myinlife, municipalities must at least have organized caregiver meetings around the intervention. For Partner in Balance, municipalities must have completed a coach training and appointed an organizational Partner in Balance administrator who oversaw the municipalities' coaches. Implementation levels were assessed prior to the interview by phone by author HLC; 5 municipalities were assessed as having completed the minimum level implementation necessary to conduct an evaluation interview using the MIDI questionnaire as a semistructured interview guide. Interviews were an average of 31 minutes long. For the remaining 3 municipalities, information was collected on the current level of implementation and what steps still needed to be taken via email for one municipality (due to municipality time restraints), via face-to-face meeting for a second, and via telephone meeting for the third.

Interviews occurred between August 2019 and March 2020 and were conducted by author HLC in Dutch, French, or English according to municipality preferences. The MIDI interviews and face-to-face and telephone meetings were recorded and later transcribed verbatim. The written email evaluation was also stored on the data collection platform.

Informed Consent and Ethical Approval

All participants (municipality interviewees, Partner in Balance coaches, and experts) had received an information letter explaining the aims of the study, which also guaranteed the anonymous processing of their data and responses, in addition to the option of discontinuing study participation at any point. All participants signed an informed consent form. Ethical approval for the study was granted by Maastricht University's Medical Ethical Oversight Commission (approval number 2018-0489).

Data Analysis

Use Data

After activities were logged in the online data collection platform by author HLC, total implementation and support hours were automatically calculated across entries and subsequently exported.

Partner in Balance Coach Evaluations

Responses were logged in the online data collection platform. Quantitative scores were calculated, and qualitative responses

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were analyzed inductively by author HLC using analysis software Atlas.ti 8.3 for Macintosh (Atlas.ti Scientific Software Development GmbH). Inductive analysis was used because there were no expectations as to what the open question replies would be. For this analysis, individual codes were independently grouped into themes and categorized by authors HLC and LMMB. Subsequently, HLC and LMMB compared these themes and categories in a consensus meeting with author MEdV to resolve any differences and confirm the final thematic analysis.

Determinants of Implementation

Authors HLC and LMMB independently coded the semistructured interviews using deductive thematic analysis [37] in Atlas.ti. In contrast to the open questions in the coach evaluations, it was expected that the interviews would reflect the thematic groups of the consolidated framework for implementation research (CFIR) and not new inductive groups. This is why deductive thematic analysis was used for the interviews. The deductive codes used were CFIR constructs (Table 2). CFIR is an established framework for mapping implementation of evidence-based interventions and can also for used for eHealth interventions [38]. CFIR comprises 5 domains (intervention characteristics, outer setting, inner setting, characteristics of individuals, and process) with 39 implementation constructs. For the analysis, authors LMMB and HLC applied the CFIR codes in Table 2 to interview transcriptions and compared interview segments with the same deductive codes across interviews. Again, HLC and LMMB compared the independently applied codes in a consensus meeting with author MEdV to resolve any differences of opinion. The focus of this analysis was to shed light on the breadth of implementation determinants (barriers and facilitators) in the municipality context.

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Table 2. Deductive consolidated framework for implementation research codes[a].

CFIR[b] domains	Deductive CFIR construct codes
Intervention characteristics	Intervention source
	Evidence strength and quality
	Relative advantage
	Adaptability
	Trialability
	Complexity
	Design quality and packaging
	Cost
Outer setting	Patient needs and resources
	Cosmopolitanism
	Peer pressure
	External policy and incentives
Inner setting	Structural characteristics
	Networks and communications
	Culture
	Implementation climate: • Tension for change • Compatibility • Relative priority • Organizational • Incentives and rewards • Goals and feedback • Learning climate
	Readiness for implementation: • Leadership engagement • Available resources • Access to knowledge and information
Characteristics of individuals	Knowledge and beliefs about the intervention
	Self-efficacy
	Individual stage of change
	Individual identification with organization
	Other personal attributes
Process	Planning
	Engaging: • Opinion leaders • Formally appointed internal implementation leaders • Champions • External change agents
	Executing
	Reflecting and evaluating

[a]Adapted from Damschoder et al [39].

[b]CFIR: consolidated framework for implementation research.

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Results

Use Data (Quantitative)

Table 3 shows the use data for Partner in Balance and Myinlife (January 2018 to December 2019). The data show that Myinlife was not chosen a single time in the Netherlands and that Partner in Balance was a more popular choice, especially in the Netherlands. One of the 6 municipalities that initially selected Partner in Balance chose to discontinue the implementation after the first meeting due to a lack of information on future financing and pricing after the project end; this is discussed in depth elsewhere [25]. This municipality is therefore not represented in the table, and averages are calculated over the 5 municipalities that sustained the Partner in Balance implementation. A total of 145 hours were spent on the implementation of Partner in Balance (average 29 hours per municipality), while 54 hours were spent on the implementation of Myinlife (average of 18 hours per municipality).

Table 3. Use data by intervention.

Measurement	Partner in Balance	Myinlife
Number of times implemented by municipalities		
Netherlands	3	0
Belgium	1	2
Germany	1	1
Total number of implementation hours (average)		
Total remote research team hours	21 (4)	3 (1)
Total in-person research team hours	124 (25)	51 (17)
Information and communication technology support hours	48	5
Number of accounts created		
Caregivers	22	29
Coaches	22	__[a]

[a]Not applicable.

Partner in Balance Coach Evaluations (Quantitative and Qualitative)

Of the 26 coaches who took part in the coach training, only 22 coaches created Partner in Balance coach accounts. An average of 5 coaches were trained per Partner in Balance municipality. Across municipalities, coaches recruited by the municipalities were dementia case managers (7/26), volunteers (3/26), nursing home personnel (6/26), municipality personnel responsible for caregiving (4/26), and dementia outreach nursing staff (6/26). Of the coaches who were sent the coach evaluation questionnaire via email, 64% (14/22) responded, with 57% (8/14) of those (6 Dutch and 2 Belgian coaches) stating they had not been able to use Partner in Balance in their work and thus did not complete the questionnaire. When asked to provide reasons they were not able to begin coaching, 75% (6/8) of those responded: lack of interest from the caregivers in their caseload (n=1), lack of digital skills in caregivers in their caseload (n=1), lack of time to implement the intervention (n=3), and lack of dementia caregivers in their current caseload (n=1), with 2 spontaneously mentioning they found Partner in Balance a very useful and worthwhile tool, despite the barriers. The remaining 43% (6/14) replied with completed questionnaires: 2 from Dutch municipalities, 2 from the German municipality, and 2 from the Belgian municipality.

The results from the completed questionnaires showed that coaches found Partner in Balance to be moderately useful (mean 3.7 [SD 0.8]) and moderately easy to integrate into their jobs (mean 3.3 [SD 0.8]). It was also perceived as a clear added value to the caregiver (mean 4.5 [SD 0.5]) and to the coach, but to a lesser degree (mean 3.5 [SD 0.8]). In general, coaches found it moderately difficult to recruit suitable caregivers (mean 3.5 [SD 1.6)], although this question was not completed by the 2 German coaches. Regarding its advantages for common practice, coaches reported an enriched contact with the caregiver (mean 4.1 [SD 1.0]). They expected the intervention to be time-efficient (mean 4.1 [SD 1.0]) but not cost-efficient (mean 2.8 [SD 1.0]) in the long run. Coaches would recommend Partner in Balance to other care professionals (mean 4.0 [SD 0.9]). Qualitative analysis of the open-ended questions resulted in 2 main findings: lack of digital literacy in the target population and lack of necessary time for the trained coaches to recruit caregivers were perceived as significant barriers.

Determinants of Implementation (Qualitative)

Characteristics of the Intervention

Complexity

In general, respondents described Myinife as easy to use. However, one municipality official thought Myinlife was too complicated, as it focused on both online care coordination and positive engagement. This respondent recommended simplifying Myinlife to just the agenda function. Similarly, Partner in Balance was perceived as clear and easy to use. Municipalities found the intervention and coach training easy to understand. However, they would have preferred a more practical, hands-on training in smaller groups, as the training was too theory-focused, and more implementation tips would have been

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welcome. Also, while Partner in Balance was easy to understand, there were a lot of tasks and organizing involved in making it work (finding coaches, advertising, coordinating, etc), which made it somewhat complex.

Design Quality and Packaging

For both interventions, it was reported that more face-to-face meetings and trainings and more advertising and promotional materials were needed. In general, it was suggested that the packaging of the interventions needed to be expanded. For instance, several respondents mentioned that they would like an implementation guidebook. In the current form, coaches receive a guidebook during the training, but the suggested implementation guidebook would help management facilitate the adoption, implementation, and maintenance of the intervention. This would contain a general implementation package, consisting of an implementation protocol and premade templates for social media posts, posters, and flyers.

> *I think it would really help if you had some kind of general promotion campaign or something, where you have flyers and messages and stuff that you can use. Because now, you really only have the information that is on the flyer on the website, which is actually very similar. And from there you have to figure out everything yourself, and think of messages... While, if you really have posters and flyers and advertising pieces for the local newspapers and such, I think you really already can reach the target group much better.* [Municipality R3 (Partner in Balance)]

Cost

For Partner in Balance, municipalities confirmed that they thought the suggested price model of payment per client was reasonable in theory. The suggested financers were municipalities and advertisers/sponsors. Regarding Myinlife, municipalities liked the idea of clients downloading from the App Store or Google Play, as this seemed to contain less liability for the municipality. In these cases, they suggested price points of €5 ($5.61) and €10 ($11.21). Some respondents also suggested the interventions be free.

Relative Advantage

At the end of the implementation, some respondents still preferred face-to-face contact for discussing dementia case management issues. They said that typing sensitive issues on the Partner in Balance platform could be hard for caregivers and coaches, as meanings could be more easily be misconstrued than in face-to-face conversations. Myinlife was considered to be expensive in terms of necessary implementation time compared with having a speaker give a lecture on the topic of dementia caregiving, especially as it is currently impossible for the municipality to see if people are actually using the Myinlife platform. They also wondered if Myinlife really posed an added value compared with other online solutions such as WhatsApp and Facebook. Nevertheless, 28% (9/32) of municipalities in the SFC project chose to implement these eHealth interventions in their communities (although only 8 continued this implementation), indicating that they perceived these interventions as having a relative advantage over the other activities on offer in this project.

Characteristics of Individuals

Self-Efficacy

Self-efficacy was a recurring topic in the interviews, especially for Partner in Balance, where more guidance of the caregivers and coaches was needed. Both coaches and organization coordinators were uncertain about whether they could fulfill their role and scared to make mistakes. These fears eased once they started the coaching and reported more confidence with increased experience. Municipality officials reported that successful coaches had confidence in the intervention and their own ability to use it to help their clients.

> *I think that first step was really a big step. But it's not about saying, "I'm not going to do this." More, "How do I go about it," "What is in here?" And from the moment it develops. That's why I also printed it, had read it, and done all of that while learning, only then did I feel like, okay, now I dare to approach someone with this.* [Municipality 4 (Partner in Balance)]

Knowledge and Beliefs About the Intervention

Municipality officials believed that the interventions would be effective at improving outcomes for caregivers, as this had been proven in previous research which they were familiar with. However, some officials wondered whether these effects would also be obtained outside the research context. For both interventions, there were significant privacy and liability concerns.

> *I think you should have it in the App Store anyway. And I think that an IT professional from a municipality is really not going to get involved in this, there is also the security issue. If we offer it, and data is lost because you no longer maintain it properly than we are responsible, because we offer it, so I will never get myself into that legal mess.* [Municipality 2 (Myinlife)]

There were also more general concerns regarding the timeliness and fit of the eHealth interventions in the current dementia health care setting. In particular, they wondered if there was sufficient digital literacy in caregivers, coaches, and in the municipality itself.

Inner Setting

Structural Characteristics and Networks and Communication

Municipality officials said that much more structural integration was needed. The implementation of the eHealth interventions was usually the sole responsibility of one person within the municipality. Municipality officials stressed that this was not enough, and that there should be a team to tackle the implementation together. As they recommended including this in the product itself, this is discussed in more detail under Characteristics of the Intervention. Municipalities added that it

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was easy to set up the necessary meetings with the Partner in Balance team.

> *Look what we can still do is try to launch it in concrete care situations, to see if people use it. But yes, if the guidance is not there, I do not know if they will manage.* [Municipality 2 (Myinlife)]

Implementation Climate

For both interventions, there was not enough goal setting and feedback, interventions had low relative priority, and there were no incentives or rewards to encourage the implementation into clinical practice. As management is primarily interested in concrete output, it is important to keep track of the output and use of the interventions. This is currently possible to track digitally for Partner in Balance but not for Myinlife.

Readiness for Implementation

Respondents indicated that there were few resources (especially in terms of available time) to spend on the implementation, as well as a lack of leadership engagement.

Outer Setting

Cosmopolitanism

Regarding how the implementing organizations are linked to other organizations, respondents stated that the interventions needed to be offered through an external party (not through the municipality) and cooperation with care providers would always be necessary, as they would have to agree to execute the interventions. Some municipalities reported that the SFC project had been a good chance to connect and strengthen their local dementia care networks.

Patient Needs and Resources

Myinlife and Partner in Balance were both perceived as fitting caregiver needs. However, for Myinlife, there was little enthusiasm from the local target population, as evidenced by the lack of attendance to the planned Myinlife caregiver meetings.

> *I think we've determined that this should work in principle... But maybe, indeed, it just doesn't fit what people here want, what they need, what they feel comfortable with. Or maybe we just didn't reach them despite all the effort... That is also possible.* [Municipality 3 (Partner in Balance)]

External Policy and Incentives

Partner in Balance was described as fitting well into initiatives around generalized services, current internal caregiver and prevention policies, and municipality innovation budgets. These budgets are facilitated by the outer setting, but their use is determined by the inner setting (municipality). The municipalities that had these innovation budgets mentioned that these budgets could potentially be used in the future to purchase licenses for the further implementation of Partner in Balance, if the experiences were positive.

> *Yes, I think it fits within the policy yes. It fits within the informal care policy, is increasingly in line with the policy of health insurers, who say if we support informal carers then it will yield results. Also for the informal caregiver and the person they care for, so that they stay better in balance, can last longer, so I think it fits within the policy.* [Municipality 1 (Partner in Balance)]

Process

Engaging

Municipalities implementing Myinlife indicated that a more hands-on demonstration and sales-pitch–like approach were needed to convince health care partners to cooperate in the dissemination of the intervention and less of an academic presentation. There was not enough engagement of the target populations (both of Partner in Balance coaches and dementia caregivers), although 2 municipalities did involve local dementia groups in their activity choice and subsequent eHealth implementation. More opinion leaders and internal implementation leaders were needed.

> *I introduced this. My supervisor, yes, but I work in my department alone. .... We have not really discussed it with anyone else. So, my supervisor is not actively pushing this now either.* [Municipality 4 (Partner in Balance)]

Executing

The plans that were made at the beginning of the implementation [25] were followed. Nevertheless, these were in many cases insufficient, and in several municipalities, implementation plans are still being made for the future.

Planning

These new plans include involving more local health care groups (for Partner in Balance), more advertising and communications, which are more direct (for both Myinlife and Partner in Balance), and more structural goal setting and feedback (for Partner in Balance, this pertains to coaching; for Myinlife, this is tracking how many people use the intervention). Reflecting and evaluating was not a big part of this implementation but was seen as important for the future implementation of both interventions.

Evaluation

Integrating the use data, coach questionnaires, and municipality interviews, it appears that the implementation of Partner in Balance and Myinlife showed varying levels of success in different municipalities. In the end, 3 municipalities planned to continue with their implementation of Partner in Balance beyond the study period, while no municipalities planned to continue with their implementation of Myinlife. What these 3 Partner in Balance municipalities had in common was that they considered the implementation of the intervention to be a success. These municipalities appeared to have a sense of internal responsibility to facilitate the implementation of Partner in Balance and devise creative solutions. The 2 Partner in Balance municipalities that did not consider the implementation to be successful seemed to see the implementation as more of an external project, where the municipality's role was more to facilitate than execute. For Myinlife, it was clear from the municipality interviews and use data that more time was needed to successfully embed the

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intervention into the local health care landscape. Despite Myinlife not necessitating the recruitment of coaches, it was clear that more face-to-face contact was needed to engage the implementing municipality and target group.

Discussion

Principal Findings

This study integrated use data, coach questionnaires, and interviews to evaluate the implementations of Partner in Balance and Myinlife. These two eHealth interventions for caregivers of people with dementia were implemented in 8 municipalities in the EMR. This study's objectives were to evaluate the success of the implementation of Myinlife and Partner in Balance and investigate determinants of the successful implementation of Myinlife and Partner in Balance in the municipality context. The analysis of the implementation determinants showed that there were unsuccessful aspects of the implementation, including the lack of goal setting and incentives, low priority, few resources, and lack of leadership. In order to successfully bring evidence-based eHealth interventions for caregivers of people with dementia into practice, a number of important improvements must be made in the implementation of these interventions.

Improvements for Partner in Balance Coaches

A main finding from the interviews with municipality officials regarding the Partner in Balance implementation was the need to increase the self-efficacy of the Partner in Balance coaches. Coaches reported that uncertainties about whether they were ready to coach and insecurities about whether they could do a good job were significant barriers to starting to coach caregivers. Hence, an important lesson from this study is that Partner in Balance cannot increase caregivers' self-efficacy without first ensuring that coaches have a minimum level of self-efficacy to start the coaching. This is supported by previous research, which has described care professional self-efficacy as a major facilitator of successful intervention implementation in a variety of contexts [40-42]. Bandura et al [43] described 4 ways to increase self-efficacy: mastery experiences, vicarious experiences, verbal persuasion, and monitoring physiological states. Subsequent research built on this by examining how self-efficacy can be enhanced through training in professional caregivers of people with dementia, which can potentially increase intervention adherence [44]. Discussing common barriers to implementation among the training participants, addressing barriers through role-playing, and providing constructive feedback on the role-play have been shown to increase dementia care professional self-efficacy [45]. In the future, Partner in Balance will incorporate these methods into coach trainings to help coaches develop the self-efficacy necessary to start coaching with Partner in Balance.

In their responses to the request to complete the Partner in Balance coach evaluation questionnaire, several coaches mentioned that they were not able to offer Partner in Balance to any caregivers, as their clients were not familiar with the use of online interventions. These clients were often older, and previous research has indicated that advanced age is a barrier to adopting eHealth due to related declines in motor, cognitive, and perceptive abilities and the difficulties accompanying the rapidly changing technological market [46-48]. In general, studies regarding older adults' attitudes toward eHealth interventions have produced mixed results [49-51]. It is also important to consider health care professionals' attitudes toward eHealth for dementia and their role as gatekeepers in deciding whether to offer eHealth interventions such as Partner in Balance to caregivers. In line with this research, a recent systematic literature review on the attitudes of health care professionals toward eHealth described workload concerns, lack of incentives, perceived threats to autonomy, liability concerns, and lack of organizational support and cooperation as important implementation barriers [52]. Here too, a possible remedy for these eHealth challenges experienced by health care professionals is the embedding of improved eHealth education in their standard training [53,54].

Improvements for Municipalities

For both Myinlife and Partner in Balance, municipality officials reported that their municipality implementation teams were often understaffed. Previous research on municipal eHealth for home care [55] and dementia care [56] has underscored the importance of municipality-specific protocols when implementing eHealth in these contexts. Based on this study, these protocols should specify how to form municipality implementation teams, including suggestions to involve at least 2 people in the team and schedule regular progress meetings within this team. These meetings should discuss new promotion ideas and opportunities using templates for the promotion and advertising of the interventions. Additionally, these meetings should monitor the success of the intervention implementation, as municipality officials reported that their management is most interested in demonstrable output. For Partner in Balance, it is possible for organizations to monitor the number of coaches and participating caregivers. However, there is currently no way to determine whether Myinlife is successfully being used in the community. Previous research on organizational learning as a method for eHealth benefit realization in a municipal health care context emphasized the importance of reviewing and evaluating results and establishing potential for further benefits [57]. This makes it possible for the implementation teams to set and achieve goals around use in the community. In this study, not doing so was counterproductive for both team motivation and acceptability of the time spent on implementation to management. For both Partner in Balance and Myinlife, future implementation packages should include protocols on setting use goals in the regularly scheduled team meetings, and the interventions should include functionalities to easily track these statistics.

Improvements for Project Management

In order to recruit external health care organizations, the municipality is required to recruit coaches (for Partner in Balance) and integrate interventions into larger health care structures that can offer it as part of their services (for Partner in Balance and Myinlife). This requires regular meetings to follow up on coaches' experiences, where coaches can learn from each other, share tips and tricks, and discuss their progress. The involvement of the management of these external health

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care organizations is crucial, as they can offer incentives for successful coaching and adapt structures to facilitate the integration of Partner in Balance into the coaches' tasks. For example, it is important that management ensures that time spent coaching can be declared to the health insurer as provided care. Previous research has reported this as a significant determinant of successful eHealth implementation for health care professionals [58]. Thus, future implementation packages should include protocols for these organizations on how to organize the suggested meetings, internal monitoring, and incentives, including the declaration of coached hours to health insurers. To facilitate this, future implementation packages should also suggest appointing an eHealth ambassador within the organization whose function is to ensure that these meetings take place, and provide a reliable and continuous level of enthusiasm for the intervention. Previous research has advocated the use of ambassadors in implementing eHealth [32,59-61].

Sustainability Measures

Despite the relative ease of setting up the infrastructural aspects of this project, implementation was only successful in just over half of the municipalities. It is clear that successful implementation depends on more than merely setting the necessary structures in place. This study's interview findings indicated that successful implementation was tied to a sense of ownership and responsibility from the municipality officials. This is in line with previous research, which has pointed to a lack of eHealth ownership at both local and national levels as a considerable implementation barrier [62,63]. Therefore, future implementation packages for Myinlife and Partner in Balance will include suggestions on how to achieve sustainability by increasing sense of ownership and end user adherence in general. An important element of this is the reflection and feedback exercises that will also be part of new measures to monitor the interventions (described above), as they have been shown to improve eHealth ownership and adoption [64]. In addition to scheduling the described reflection and role-playing exercises, previous research on increasing the adherence of end users to eHealth interventions recommends persuasive system design, which is used to aid the development of information systems to shape attitudes and behaviors [65]. This approach recommends that interventions incorporate on-the-spot reminders and feedback to increase end user adherence. Hence, future implementations will incorporate more intervention monitoring and reflection moments for implementers and end users. This new approach to training coaches is expected to reduce the uncertainties reported by coaches concerning their abilities to coach.

Finally, it is also important to consider why Partner in Balance was more often successfully implemented in this municipality context than Myinlife. Previous research has indeed shown that blended eHealth interventions for caregivers of people with dementia are more effective at improving outcomes for caregivers of people with dementia than nonblended interventions [13]. One potential explanation for the increased success of Partner in Balance in this particular context is that its blended aspect (the human contact between caregiver and coach) not only increases effectiveness through improved caregiver outcomes but also through a possible effect of increasing engagement among implementers. Here, Partner in Balance required more hours to implement in the municipality context than Myinlife. It is possible that these additional face-to-face hours required to implement Partner in Balance (but not Myinlife) increased implementers' sense of ownership of the successful implementation of the intervention. Therefore, future implementers of nonblended eHealth interventions in this context could consider incorporating this human interaction by way of face-to-face meetings about the intervention or caregiver support groups discussing the intervention to facilitate implementation by increasing the implementation hours and thus potentially the sense of ownership. Of course, this study also shows that this blended aspect is more resource intensive. Future research could investigate the comparative cost-effectiveness of these interventions in order to weigh costs and benefits.

Strengths and Limitations

This study had several important strengths. First, this study is one of few to examine the further implementation of eHealth interventions for caregivers of people with dementia after the trial phase. This study uses various measures from multiple perspectives to construct a thorough evaluation of the implementation of these interventions in a municipality context. As a result, this study is able to shed novel light on the currently underexplored organizational and contextual implementation determinants. Second, by focusing on the municipality context specifically and by taking the time to explore this context in depth, this study has successfully identified the municipality as a potential distributor with the financial means to further disseminate evidence-based eHealth interventions for caregivers of people with dementia.

This study also has several limitations. First, this study did not explore the experiences of caregivers using the Partner in Balance and Myinlife interventions. As a result, we have no information on actual eHealth use and do not know how the caregiver target group used and evaluated the interventions in this context. This is because both Partner in Balance and Myinlife were previously assessed for usability and effectiveness by caregivers in a series of trials [29,30,33,66] informed by the Medical Research Council framework [67]. The aim of this study was to gain information on their broader implementation contexts. Second, there was a moderate response rate to the request to complete the Partner in Balance coach evaluation questionnaire (64%), with only 6 coaches submitting completed questionnaires (and 8 providing details on why they had not yet started coaching). As a result, there is no information on how the nonresponders experienced Partner in Balance, causing a potentially biased sample of responses from coaches who might be more positively disposed toward the intervention. Next, this study was unable to take into account the views of the municipalities that chose not to implement Myinlife or Partner in Balance. While it was not this study's aim to generalize these qualitative findings to all municipalities, it is possible that this study represents a sample of municipalities that have more positive attitudes toward eHealth for dementia and its implementation than other municipalities. Nevertheless, it is still useful to document and learn from these (potentially more engaged) municipalities, as they can provide valuable insight

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into the feasibility of eHealth for dementia in this context and into municipality needs. Third, the focus of this study was to shed light on the breadth of implementation determinants encountered in bringing evidence-based eHealth interventions for caregivers of people with dementia from research into practice. The aim was to provide a complete overview of the encountered barriers and facilitators using data from a variety of sources. As a result, it must be acknowledged that this study lacks a more elaborate in-depth analysis of the process characteristics of the 8 municipality implementations. Future research will address this topic extensively. Finally, it must be acknowledged that all authors (with the exception of HJT) were involved in the development of Myinlife and Partner in Balance and are therefore potentially not unbiased. However, the authors were also interested in differences between the interventions and were in this sense unbiased. Moreover, it is the authors' belief that this type of implementation research is essential for evidence-based interventions, and researchers should more often conduct longer term implementation research on their own interventions.

Conclusions

This study provided a thorough exploration of the feasibility of the implementation of eHealth interventions to support caregivers of people with dementia in a municipality context. Future implementations can make use of protocols that provide municipalities and organizations with suggestions on how to tackle implementation challenges and realize improvements for the (Partner in Balance) coaches, implementation team, and external implementing organizations. In general, it is important to foster a sense of ownership of the success of the eHealth intervention in the municipality and dementia health care context, as this was seen as a main determinant of success in this implementation project. For Partner in Balance, an important finding was that the self-efficacy of coaches must be increased before they can be expected to help caregivers elevate their levels of self-efficacy regarding dementia caregiving. For Myinlife, it was necessary to involve more face-to-face contacts and integrate the intervention more into other local health services, despite it not being designed as a blended intervention. These insights will be integrated into future implementation protocols that will become a standard part of the Myinlife and Partner in Balance implementation packages for municipalities and organizations.

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Conflicts of Interest

HLC, LMMB, MEdV, and FRJV were involved in the previous development of Myinlife and Partner in Balance. All other authors have no conflicts to declare.

Multimedia Appendix 1
Partner in Balance coach evaluation questionnaire.
[DOCX File , 24 KB - aging_v4i1e21629_app1.docx]

Multimedia Appendix 2
Measurement instrument: description and operationalization of determinants.
[DOCX File , 21 KB - aging_v4i1e21629_app2.docx]

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Abbreviations

CFIR: consolidated framework for implementation research
EMR: Euregion Meuse-Rhine
MIDI: measurement instrument for determinants of innovation
SFC: Senior Friendly Communities

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Original Paper

Family Caregiver Needs and Preferences for Virtual Training to Manage Behavioral and Psychological Symptoms of Dementia: Interview Study

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Abstract

Background: Behavioral and psychological symptoms of dementia (BPSD) are associated with increased stress, burden, and depression among family caregivers of people with dementia. STAR-Caregivers Virtual Training and Follow-up (STAR-VTF) is adapted from an evidence-based, in-person program that trains family caregivers to manage BPSD. We used a human-centered design approach to obtain feedback from family caregivers about STAR-VTF. The program will be evaluated using a pragmatic randomized trial.

Objective: The objective of the study was to understand the needs of family caregivers for improving BPSD management and the extent to which caregivers perceived that STAR-VTF could address those needs.

Methods: Between July and September 2019, we conducted 15 semistructured interviews with family caregivers of people with dementia who receive care at Kaiser Permanente Washington in the Seattle metropolitan area. We identified participants from electronic health records, primarily based on a prescription for antipsychotic medication for the person with dementia (a proxy for caregivers dealing with BPSD). We showed caregivers low-fidelity prototypes of STAR-VTF online self-directed materials and verbally described potential design elements. We obtained caregiver feedback on these elements, focusing on their needs and preferences and perceived barriers to using STAR-VTF. We used a hybrid approach of inductive and deductive coding and aggregated codes to develop themes.

Results: The idea of a virtual training program for learning to manage BPSD appealed to caregivers. They said health care providers did not provide adequate education in the early disease stages about the personality and behavior symptoms that can affect people with dementia. Caregivers found it unexpected and frustrating when the person with dementia began experiencing BPSD, symptoms they felt unprepared to manage. Accordingly, caregivers expressed a strong desire for the health care organization to offer programs such as STAR-VTF much sooner. Caregivers had already put considerable effort into problem solving challenging behaviors. They anticipated deriving less value from STAR-VTF at that point. Nonetheless, many were interested in the virtual aspect of the training due to the convenience of receiving help from home and the perception that help from a virtual program would be timelier than traditional service modalities (eg, face to face). Given caregivers' limited time, they suggested dividing the STAR-VTF content into chunks to review as time permitted. Caregivers were interested in having a STAR-VTF provider for additional support in managing challenging behaviors. Caregivers reported a preference for having the same coach for the program duration.

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Conclusions: Caregivers we interviewed would likely accept a virtual training program such as STAR-VTF to obtain information about BPSD and receive help managing it. Family caregivers anticipated deriving more value if STAR-VTF was offered earlier in the disease course.

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KEYWORDS

dementia; Alzheimer disease; behavioral symptoms; caregivers; internet-based intervention; education; behavior; symptom; psychology; qualitative; caregiver; intervention; training; virtual care; digital health

Introduction

Alzheimer disease and related dementias (ADRD) are irreversible, progressive brain disorders that eventually affect a person's ability to perform basic activities, including bathing, feeding, and dressing. ADRD is the fifth leading cause of death among people 65 years and older in the United States [1]. The US prevalence of ADRD is projected to nearly triple from 5 million in 2014 to 13.9 million in 2060 [2]. People with dementia require high levels of care, most of which is provided by informal caregivers such as spouses and adult children. Up to 90% of people with dementia will experience behavioral and psychological symptoms of dementia (BPSD) over the course of their illness [3]. BPSD that can be particularly challenging to family caregivers include agitation, anxiety, irritability, depression, delusions, hallucinations, and sleep changes. BPSD are associated with increased stress, burden, and depression among family caregivers of people with dementia [4,5].

STAR-Caregivers (STAR-C) is a nonpharmacological intervention endorsed by the US Department of Health and Human Services Administration on Aging in which a coach trains family caregivers over multiple face-to-face sessions on how to manage BPSD. STAR-C is demonstrated to reduce caregiver burden, caregiver depression, and the frequency and severity of BPSD [6]. The STAR-C training is 6 sessions, covering topics such as expectations about ADRD, communication with a person with ADRD, strategies for dealing with BPSD, and coping with caregiving, including pleasant activities for caregivers and patients. In its original form, coaches conduct in-person weekly sessions with caregivers in their homes with follow-up telephone calls. Despite evidence to support its efficacy, STAR-C has not been widely disseminated across health care and community settings, in part due to the cost of providing in-person training and using printed materials [7-9].

To address these implementation barriers, a Kaiser Permanente Washington Health Research Institute pragmatic trial is testing the feasibility of STAR-C Virtual Training and Follow-up (STAR-VTF) (ClinicalTrials.gov NCT04271046) [10], which will deliver the training to family caregivers virtually. Caregivers will complete online training modules asynchronously, have 30-minute weekly telephone check-ins with a coach (social worker or mental health counselor) at Kaiser Permanente Washington (KPWA), and have ongoing support from the coach via secure email messages within the KPWA member portal. Caregivers will access the online training modules via a website hosted on the Kaiser Permanente School of Allied Health Sciences extended learning management system. Caregivers will log in to the website from their preferred web browser using their email address and a user-generated password. While caregivers will not enter personal health information or other identifiable information, the website will automatically collect their IP addresses. The KPWA technology risk review team declared caregivers' use of the website as minimal risk. Only caregivers living in Washington State that meet eligibility for the pragmatic trial will have access to the website.

While considerable evidence supports the efficacy of STAR-C, and implementation challenges from a health care system perspective could be addressed by changing the modality of program delivery from in person to virtual, family caregivers' views on participating in a virtual training program are needed. A framework for using human-centered design to improve the implementation of evidence-based interventions recommends that early phases of the design process focus on gathering information to understand the viewpoints of all stakeholders [11]. This information is then used to iteratively design, build, and test solutions that directly address the needs and preferences of all stakeholders, particularly end users such as family caregivers in STAR-VTF. Human-centered design is widely considered the key to designing tools that end users will find useful and easy to use, factors that are associated with acceptance and actual use of tools [12].

Early in STAR-VTF development, when the original in-person training was being adapted for virtual delivery, our research team used a human-centered design approach to obtain feedback from family caregivers on the idea of a virtual training program. The objective was to understand the needs of family caregivers for improving BPSD management and the extent to which they perceived that a program such as STAR-VTF could address their needs. To achieve this, we conducted and analyzed 15 semistructured interviews with family caregivers of people with ADRD who receive care at KPWA in the Seattle metropolitan area. The COVID-19 pandemic has shed light on the urgent need to design and evaluate digital health strategies that offer support virtually [13], especially for families caring for vulnerable older adults. Effective digital health strategies to support family caregivers are critically needed during the pandemic and will remain important in the post–COVID-19 era.

Methods

We conducted semistructured interviews with family caregivers of people with ADRD. The institutional review boards at Kaiser Permanente Washington Health Research Institute and the

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University of Washington approved the study. Study participants provided written informed consent.

Recruitment

To identify potential study participants, we extracted data from the KPWA electronic health record (EHR) and administrative claims system to identify patients aged 65 years or older with an ADRD diagnosis and a new prescription for an antipsychotic medication within the past 2 years. A prescription for an antipsychotic medication was a proxy for identifying caregivers who may have struggled with managing BPSD. We excluded patients with an International Classification of Diseases Ninth Revision—Clinical Modification (ICD-9-CM) or ICD-10-CM diagnosis of bipolar disorder or schizophreniform disorder and those in assisted living or skilled nursing facilities. For patients meeting our criteria, we mailed a packet to their caregiver with a cover letter describing the goals of the study and a consent form. One week after the mailing, a study staff member phoned caregivers to invite study participation. The staff member attempted up to three calls with up to two voicemail messages. Caregivers interested in participating were screened for eligibility during the phone call. Caregivers were eligible if they were 21 years or older; were an adult child, spouse or partner, or close friend of the patient; lived with the patient (or within 5 miles); provided at least 8 hours of care per week; and lived in King, Snohomish, or Pierce counties, Washington. We excluded caregivers with a diagnosis of ADRD. For eligible, interested caregivers, the staff member scheduled a date, time, and location to conduct the interview.

Data Collection

We conducted all interviews in person between July and September 2019. Interviews took place at a convenient location for caregivers, such as homes or KPWA facilities. Using a semistructured interview guide, we asked caregivers what challenging BPSD the patient experienced, how caregivers typically responded to BPSD, and how BPSD affected caregivers. Next, we used 2 storyboards to illustrate the potential experience of a caregiver using STAR-VTF to learn how to improve management of BPSD (Multimedia Appendix 1). The first storyboard depicted a caregiver struggling with behavioral symptoms in the person with dementia and learning about STAR-VTF through a health care provider. The second storyboard depicted a caregiver choosing which behavioral symptom to focus on, using STAR-VTF to learn strategies for responding to the symptom, and speaking on the phone with a coach for additional support. We asked caregivers questions to gauge their initial reactions to the idea of STAR-VTF and their interest in using the virtual program. Finally, we showed caregivers low-fidelity prototypes of the STAR-VTF online self-directed materials and verbally described potential design elements, including information content, visual and auditory presentation of information, and user interaction (Multimedia Appendix 2). We asked caregivers questions to obtain feedback on these design elements, elicit needs and preferences, and understand perceived barriers to using STAR-VTF.

We surveyed caregivers for sociodemographic and caregiving characteristics. Caregivers received US $100 for participating. All interviews were audiorecorded and transcribed verbatim by a professional transcription company. The transcripts were proofread by the interviewer. Interviews were 40 to 60 minutes.

Data Analysis

We used Dedoose version 8.1.8 (University of California, Los Angeles) to manage the coding process. The first author (MR) read all interview transcripts and developed an initial codebook containing deductive codes about the extent to which caregivers perceived STAR-VTF to align with their informational, educational, psychosocial, and accessibility needs. Two members of the research team independently coded interview transcripts using the deductive codes in the initial codebook. They applied additional inductive codes based on the content of responses that were not covered by the original deductive codes. For all 15 transcripts, after coding each transcript, we reviewed the coding as a group. During these meetings, we reconciled coding disagreements through group discussion and transcript review. We revised and expanded the initial codebook throughout the coding process. After completing coding, members of the research team met regularly to discuss the coded excerpts; identify themes representing caregivers' informational, educational, psychosocial, and accessibility needs; and identify exemplary quotes to represent each theme.

Results

Characteristics of Study Participants

From the EHR and claims data, we identified 54 potential study participants (ie, caregivers of patients who met the patient eligibility criteria) and mailed packets to them. Among these, 12 caregivers could not be reached by telephone, 17 were ineligible, and 8 declined participation. We scheduled interviews with the remaining 17 who were eligible and interested in participating. We were unable to conduct 1 interview because the patient with ADRD died before the scheduled interview. We were unable to conduct 1 second interview because the caregiver was not aware that the patient had an ADRD diagnosis, and the research team determined it would be difficult to have a meaningful conversation about the caregiver's experience caring for a person with ADRD. Therefore, we completed interviews with 15 caregivers (Table 1).

In the following sections, we present the informational, educational, psychosocial, and accessibility needs that family caregivers perceived would prompt their use of a program such as STAR-VTF. In addition, we present characteristics of STAR-VTF that caregivers perceived would address their needs (Table 2).

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Table 1. Characteristics of family caregivers and description of the caregiving situation (N=15).

Characteristic	Family caregivers
Age (years), mean (SD)	72 (10)
Female, n (%)	10 (67)
Race, n (%)	
White	13 (87)
American Indian or Alaska Native	1 (7)
Asian	1 (7)
Hispanic or Latino ethnicity, n (%)	0 (0)
Education, n (%)	
Post–high school training other than college (vocational or technical)	2 (13)
Some college	4 (27)
College graduate	8 (53)
Postgraduate	1 (7)
Occupational status, n (%)	
Employed	3 (20)
Unemployed	1 (7)
Student	1 (7)
Retired	10 (67)
Income (US $), n (%)	
$20,000 to $34,999	1 (7)
$35,000 to $49,999	1 (7)
$50,000 to $74,999	4 (27)
$75,000 to $99,999	5 (30)
$100,000 to $199,999	1 (7)
$200,000 or more	1 (7)
Prefer not to answer	2 (13)
Member of Kaiser Permanente Washington, n (%)	9 (60)
Relationship to person with dementia, n (%)	
Spouse or partner	10 (67)
Child	2 (13)
Other family member	2 (13)
Friend	1 (7)
Lives with person with dementia, n (%)	15 (100)
Duration in caregiving role (years), mean (SD)	5 (5)
Caregiving hours per week, n (%)	
15 to 20	2 (13)
21 to 24	1 (7)
35 or more	12 (80)

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Table 2. Summary of caregivers' perceptions about needs and STAR-VTF characteristics that would address them.

Family caregiver perceived needs	STAR-VTF[a] characteristics to address needs
Information and education	
What BPSD[b] to expect	Providing education earlier in disease stage (prior to symptoms) about what BPSD a person with dementia could experience
Tailored help on how to manage BPSD	Offering examples of problem-solving strategies that could work for the particular BPSD caregiver is dealing with
Psychosocial support	
Encouragement	Incorporating words of encouragement throughout training as caregiver learns to manage BPSD
Coping with BPSD	Teaching caregivers strategies for managing their own frustrations with BPSD
Supportive services	Connecting caregivers with vetted respite care and other supportive services, including caregiver support groups
Accessibility	
Timing of program	Offering STAR-VTF to caregivers earlier in their roles as caregivers
Modality of program delivery	Making STAR-VTF virtually accessible to provide convenient and timely help
Time required to participate	Breaking up content into small chunks that caregivers could review as time and space permits
Access to a designated provider	Having the same coach assigned to caregivers throughout duration of program

[a]STAR-VTF: STAR-Caregivers Virtual Training and Follow-up.

[b]BPSD: Behavioral and psychological symptoms of dementia.

Information and Education Needs

The idea of the health care organization offering a virtual training program for caregivers to learn to manage BPSD was largely appealing to caregivers. They discussed the importance of learning early what BPSD they could expect in the person with dementia as the disease progressed and receiving tailored help on how to manage BPSD.

Learning Early What BPSD to Expect

When the person with dementia was diagnosed, caregivers were only vaguely aware of BPSD that some people with dementia experience. One caregiver expressed this scenario as "going in blind." As the disease progressed, caregivers were startled to observe symptoms they did not anticipate, such as the person with dementia crying excessively. According to caregivers, health care providers did not provide sufficient warning of the personality and behavioral changes they might observe in the person with dementia. These changes became a source of deep frustration for caregivers, as they neither expected nor felt prepared to manage them. In response to the idea of STAR-VTF, one caregiver explained why it would be valuable to incorporate education earlier in the disease stage (prior to symptoms) about what BPSD a person with dementia could experience:

> *I can see where caregivers will just fall apart with some of these behaviors if you don't know what's coming. And it's not that I have anything against the doctors. They don't have time. Maybe they don't even know, but they don't have time to really prepare you for what you're taking on. But that's what caregivers need to be told from the beginning. Are you going to be caring for your husband or, you know, your parent? Here's a program to help you, to help you strategize through these difficult behaviors that might lie ahead for you. I think that really appeals to me and needs to be said in the very beginning, not when you're extremely desperate.*

Caregivers also explained that knowing BPSD could occur and worsen as the disease progressed would help them to plan medical procedures (eg, elective surgery) before it became too challenging for the person with dementia to comply. In addition, it would help caregivers plan home modifications to ensure a safe environment for the person with dementia.

Receiving Tailored Help on How to Manage BPSD

After viewing prototypes of STAR-VTF, caregivers recognized the usefulness of learning problem-solving strategies that they could then apply to any challenging symptom. However, caregivers stressed their need to also receive tailored advice for problem-solving specific BPSD. For example, one caregiver suggested adding a search feature to STAR-VTF to find targeted advice on how to solve particular symptoms:

> *Right now, it's very general, okay? So, this is how you—this is what process you go through to solve issues. And the better you get at that process, the better you are at solving the issues, right? That come up in your day-to-day lives. But if you have a specific issue that is kind of quirky or way off in right field…Is there a backup situation where you can look something up? So that could be added on to this program. Once they [caregivers] go through the basic training.*

A factor driving the suggestion to include tailored advice within STAR-VTF was caregivers' desire to quickly address a challenging symptom. Some caregivers described feeling

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"desperate" when the person with dementia was experiencing BPSD. While caregivers recognized the value of going through the trial-and-error, problem-solving process that STAR-VTF teaches, they also perceived the amount of time required to go through this process as a limitation:

> *It's not something that, okay, we can spend the next week and a half going over this and trying...It's something—you need something, like, within an hour type of deal…that's what I found more often when we had serious concerns or questions, you know, I would go online and search other people having the same exact circumstances and how did they handle it and what worked and what didn't work.*

In those difficult moments, caregivers desired to know specific strategies to try immediately to improve the situation. Thus, according to caregivers, STAR-VTF could be improved by incorporating a combination of teaching general problem solving and offering examples of strategies that could work for particular BPSD as they arise.

Psychosocial Support Needs

Caregivers discussed their psychosocial needs and how they envisioned STAR-VTF to support them. In particular, caregivers described a need to receive encouragement, learn how to cope with BPSD, and connect with supportive services.

Encouragement When Learning to Manage BPSD

Through educational materials, family members and friends, other family caregivers of people with dementia, and their own experience, some caregivers had identified successful strategies for managing particular BPSD. For example, at the suggestion of her daughter, one caregiver used a whiteboard to write answers to questions the person with dementia asked repeatedly so that the caregiver could point to the whiteboard instead of having to constantly repeat herself. Nonetheless, the process of identifying successful strategies was hard. They were discouraged when strategies that worked for other caregivers in managing a particular symptom did not work for them. They were also discouraged when strategies that had worked for them in the past were no longer effective. Consequently, caregivers underscored the importance of STAR-VTF offering encouragement during the process of learning to manage challenging symptoms:

> *Caregivers carry around a lot of guilt because they want to be perfect. We love our mates. We love whoever we're caring for. We want to do it right. What worked last week doesn't necessarily work this week. So, if a solution that worked last week doesn't work, then persevere. I would say that. Persevere for another solution…Caregivers need to be assured that no one solution is going to be perfect for everyone. But to persevere, because there is something out there that will work.*
>
> *Assuring caregivers that what worked for one isn't necessarily going to work for another. Because as a caregiver, you so often have people say to you, "oh, yeah, well, so-and-so did this and had no problem"...So, I guess caregivers need to be assured that if something doesn't work, it doesn't mean that they are a failure; it just means try—here are some other things to do.*

Caregivers expressed differences in opinion on how this type of encouragement could be embedded within STAR-VTF. Some suggested the STAR-VTF self-guided modules could display words of encouragement throughout the training and tailor these messages based on caregivers' responses to interactive exercises. Others felt that only a human could express this empathy. One caregiver stated:

> *It's that personal relationship of somebody understanding where you are and, you know, patting you on the shoulder and saying that must be really tough. And I don't know how you convey that the same way on a website.*

Coping With BPSD

Symptoms of people with dementia that caregivers described as particularly challenging were insomnia, asking repetitive questions, and having trouble getting to the toilet. Caregivers described their frustration with not understanding why the BPSD were happening and how they could handle them. When asked how they envisioned STAR-VTF would provide support, a theme that resonated with many caregivers was teaching strategies for managing their own frustrations with BPSD. One caregiver suggested that STAR-VTF put more emphasis on reducing the caregiver's frustration rather than reducing the challenging symptom in the person with dementia:

> *So, you said something about helping reduce the challenging behaviors? If you phrase it like that, it makes it sound like that's something that can be fixed. And maybe then what happens if it doesn't change? I just, you know, maybe the emphasis could be on how you deal with the challenges in a way that's less frustrating for both you and the patient as opposed to reducing the challenging behavior.*

According to caregivers, health care providers treating the person with dementia did not offer support to help caregivers cope with the frustration of BPSD. Caregivers wanted health care providers to acknowledge their challenging situation and direct them to supportive services. One caregiver said that for 4 months, a neurologist was trying different medications to treat her husband's insomnia and other behavior symptoms. Of this time, she stated:

> *Those are four months where I needed someone, and I didn't have anybody to talk to. And I think if caregivers, for instance, were told by their doctors—and we are part of Kaiser—it would be wonderful to have them say there's help for you. I needed someone to tell me this is a very challenging job. And it's not that I wasn't aware. Because I have a brother who took care of his wife with Alzheimer's, and, you know, I knew all that, but I needed a doctor to tell me this is really difficult. There's help for you. And there's this program* [STAR-VTF]

What motivated caregivers to improve their own mental health and well-being was a perception that if they felt better

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emotionally, they would be better able to provide care to the person with dementia. As one caregiver put it:

> *My goal is to keep her here at home as best I can. And if I break down, then you've got two to take care of.*

Supportive Services

Throughout the different stages of dementia, caregivers reported taking it upon themselves to seek education and supportive services. In the early stages, caregivers described a desire to gain a better understanding of dementia and its progression. One caregiver described how invaluable it had been for her to read books and academic articles on the topic. After viewing prototypes of STAR-VTF, the caregiver suggested adding more content that explained what dementia is and providing additional reading materials:

> *I thought that there ought to be definitions and some sort of information on what dementia is and Alzheimer's is, the differences. Not a great deal of difference, but just a—that sort of thing for me would be important. Books to read, you know.*

In the middle and later stages of the disease, caregivers described a need to learn what respite services were available to provide short-term breaks from caregiving. Caregivers expressed an interest in both in-home services and adult day care programs. However, according to caregivers, finding trustworthy service providers was difficult. Some caregivers talked about negative experiences with service providers they had identified online. Caregivers strongly desired for the health care organization to vet respite care programs and guide caregivers on how to choose a program that was right for their unique situation. One caregiver suggested that the role of the STAR-VTF coach include connecting caregivers with respite care and other supportive services:

> *I know one of my things coming up is that I'm going to need to have in-home assistance, and it's for short term—maybe it's just a daycare that I need to take him to but where are they, who they are, if we could have resources that we could look at. Thinking this will meet this need, this will meet that need, and at least give you someone [in STAR-VTF] to access and say, "Hi, I'm so-and-so and this is my situation. Can you help me?"*

Throughout their caregiving journey, caregivers described a desire to learn about and join a caregiver support group. Caregivers who had joined a support group stated that it was helpful to share their stories with other caregivers and get advice on various aspects of caregiving. They were interested in the health care organization helping caregivers to connect with support groups for family caregivers of people with dementia. For example, one caregiver described an online support group she participated in regularly and suggested that STAR-VTF inform caregivers about it:

> *I've been in touch with an online group…that is designed for people who are dealing with caregiving of those with Alzheimer's. And they allow you to post any kind of question you have, any kind of circumstance you found yourself in, and see what kind of feedback others can give you. And it's really an excellent resource…Sharing information of what they have experienced and how they dealt with it to give you ideas…And so, with your program [STAR-VTF], I don't know if you have a place where you're going to link to other possible resources. This [online caregiver support group] would be a strong resource to link to.*

The internet was a major source of information for most caregivers. However, they often found the amount of information online to be overwhelming. Furthermore, despite the vast amount of information online from different types of sources, caregivers desired a single source ("one-stop shop") of comprehensive and high-quality information. To that end, caregivers envisioned that STAR-VTF would consolidate educational materials and information on the availability of supportive services. Caregivers could then rely on and turn regularly to STAR-VTF as a major source of information, knowing that it came from the health care organization, which caregivers unanimously perceived as trustworthy.

Accessibility Needs

Caregivers discussed needs related to the accessibility of STAR-VTF, including the timing of offering the program to caregivers, modality of program delivery, time required to participate, and inclusion of a designated provider.

Timing of Program

When asked whether they could envision using STAR-VTF, caregivers answered affirmatively but expressed a desire for the program to be offered earlier in their role as caregivers for multiple reasons. As described above, caregivers suggested providing information about BPSD before the person with dementia begins experiencing symptoms and before caregivers begin trying their own strategies for challenging symptoms. These caregivers perceived that STAR-VTF would have been more useful to them when symptoms first began appearing:

> *This [STAR-VTF] would be key to get into people's hands at the earliest possible time. Because beyond that, then somebody—I mean, like we've already—we learned by trial and error how to do exactly what you're saying to do in this program.*

> *Having this [STAR-VTF] as something to help you adjust early on and not have to learn on your own is definitely a plus…because we have already kind of figured out some plans and realized certain things. And our own private research got us to where we are, you know. And, of course, I mean, obviously, we talked to docs a few times, but we were already on a pathway of controlling behaviors, in other words. When she got into stage 3, we had a pretty good handle on things by then—but this [STAR-VTF] would have definitely helped when we first got her five years ago.*

Another reason why caregivers suggested that STAR-VTF be offered earlier is so the STAR-VTF coach could be with them from the start. According to caregivers, the ideal scenario would

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be for the coach to get to know each caregiver and their caregiving situation over time. Caregivers could then trust the coach's advice, knowing that it was informed by an in-depth understanding of their unique situation. One caregiver indicated that she would be reluctant to trust a coach whom she had met only in the later stages of her husband's disease:

> *If I'm really going to put my trust in this program, I would probably have to start at the beginning. I don't think if I jumped in in the middle or towards the end, I would feel like, well, they [the coach] didn't know about this earlier on, and so maybe the information they're giving me now isn't considering what happened. But I think if you probably started right from the start, like he was diagnosed today and so you said go onto this online program and we could help you, I think you could grow with the program and I think develop a pretty good trust.*

Thus, while the reasons that drove preferences for the timing of the program differed among caregivers, the consensus was that STAR-VTF would be a valuable support if it were offered early in their caregiving experience.

Modality of Program Delivery

The virtual aspect of STAR-VTF was appealing to the majority of caregivers, including those who did not consider themselves to be technologically savvy. The latter group underscored their need for a user-friendly design, particularly so they could easily locate and navigate the STAR-VTF website, recover from errors, adjust the text size, and receive technical assistance. Caregivers perceived that participating in a virtual program from home would be more convenient than a program requiring in-person attendance at a health care facility. According to caregivers, the latter would necessitate finding someone to care for the person with dementia or having the person with dementia accompany them to the in-person visit. For some caregivers, neither of these options would be practical. Hiring professional care would be costly and taking the person with dementia to a health care facility would be challenging. For one caregiver, virtual participation was the most attractive aspect of STAR-VTF, given the difficulty of getting her mother to accompany her on an in-person visit:

> *That's one of the problems we have is it's almost impossible to get her out of the house, you know, she gets so upset, you know, going to the doctor…So, I can see—that's where I would see the most important part about it [STAR-VTF] being online is you can get that help at home.*

There was also a perception among caregivers that a virtual program would result in more timely help compared with the delays they sometimes experienced when seeking help from the health care team through traditional modalities. As one caregiver described, as long as a device was available to access the STAR-VTF website, caregivers would have help at their fingertips. She went on to say:

> *You wouldn't have to call a doctor to get answers…It's there when you're having those feelings and they're very frustrating feelings and you don't know what to do…If you're at the end of your rope and you don't have an answer, you can immediately sit down at your computer or your tablet or with your phone and get in there and it's like, I'm frustrated. Let's see why. Yeah, that's the behavior that he's doing. It affects me this way. Let's figure out what we can do about it. It's having this—it's right there. It's here at the house. It's not, you know, something that I have to make—I spend so much time on the phone waiting…over 35 minutes on the phone waiting to speak to the neurologist's nurse the other day.*

Caregivers hoped that STAR-VTF would enable them to access help the moment they experienced a need instead of having to wait to speak to a member of the health care team on the phone or in person. (Some caregivers reported a 2- to 3-month wait time for a clinic visit with a specialist.) All caregivers owned at least one device (eg, smartphone, tablet, laptop, desktop computer) they could use to participate in a virtual training program.

Time Required to Participate

Even with a virtual program, caregivers were concerned about the limited amount of time and space they had to devote to STAR-VTF. The vast majority of study participants provided care to the person with dementia for 35 hours or more per week (Table 1). Caregivers said the person with dementia would likely make it difficult for them to concentrate for long stretches of time on the STAR-VTF training materials. When asked to elaborate, caregivers used expressions such as "needy," "constantly interrupts me about things," and "requires a lot of attention" to describe the person with dementia. One caregiver explained what she would need to be able to fully engage with the STAR-VTF online content:

> *I would need privacy and to be away. I couldn't be in the same room with my husband [with dementia] who was giving me grief or being demanding or unpleasant or whatever. So, I think for me to use the program, I would have to be in a place where I could presume I have some privacy and some time, and it requires the concentration to be able to focus on it and not being distracted by other things, I think.*

To facilitate their use of STAR-VTF under these circumstances, caregivers suggested that the online content be broken up into small chunks that they could review as time and space permitted. Caregivers also suggested having the ability to pause a module, if needed, and then be able to pick up where they left off when they returned to it later.

Having Access to a Designated Provider

Of the aspects of STAR-VTF that we described using prototypes, of notable interest to caregivers was the availability of a coach to provide support beyond the self-directed online materials. Caregivers described an unmet need to have access to a designated health care professional they could turn to for help when they were experiencing difficulties with BPSD. According to caregivers, people with dementia receive care from multiple health care providers within the same practice area, depending on appointment availability. For example, one

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caregiver described how his wife with dementia had recently visited 3 different primary care providers, all at different health care facilities. While these providers were, “real nice, really good, and really helpful,” the caregiver desired a single provider who had direct knowledge of their clinical and caregiving situation instead of a provider who “doesn’t have any idea except what they see in the medical record.” Thus, if caregivers were to participate in STAR-VTF, it mattered considerably that the same coach be assigned to them throughout the duration of the program. Caregivers described being in extremely stressful situations that sometimes resulted in them losing their temper, becoming angry, and yelling at the person with dementia. These would be the types of situations caregivers would want to share with the STAR-VTF coach, simply to vent but also to receive help.

However, caregivers need to trust the coach to feel comfortable sharing openly and honestly about the caregiving situation. Caregivers explained that trust would develop only with time and repeated interactions with the same person. In response to a question about whether caregivers would be willing to share with the coach their responses to interactive exercises within the self-directed online materials, one answered yes but only if it were consistently the same coach with whom they had a trusting relationship:

> *Yes. Here we're talking about a coach that I've been working with on and on and on because I'm working on the program, right? So, I have developed trust with the coach. So, yes, I would talk to her about that. But, I would be a little hesitant if the coach was brand new, I didn't know her, I didn't have any experience with her, and then maybe one week this one comes, but next week she can't come so a substitute comes and, I mean, I know they're both qualified, but you don't know the second person and you don't know whether the trust is there as much as with the first person.*

In addition to having access to a designated STAR-VTF coach, caregivers discussed a desire for this person to have extensive practice experience working with people with dementia and their family caregivers. This qualification would help caregivers trust the information provided by the coach.

Discussion

Principal Findings

We found that family caregivers of people with dementia were interested in the idea of a virtual training program for learning to manage BPSD. Caregivers in our study reported that health care providers did not provide adequate education in the early stages of the disease about the types of personality and behavioral symptoms that can affect people with dementia. When the person with dementia began experiencing BPSD, it was unexpected and frustrating for caregivers, since they felt unprepared to manage the symptoms. For this reason, caregivers expressed a strong desire for the health care organization to offer programs such as STAR-VTF much sooner. When we interviewed them, many caregivers were reflecting on their extensive experience with BPSD, leading them to recommend STAR-VTF for those with less experience.

Furthermore, the virtual aspect of the training program appealed to nearly all caregivers in our study. Caregivers were interested in virtual training because of the convenience of receiving help from home and a perception that a virtual program would result in more timely help compared with traditional service modalities (eg, face-to-face visits, calling consulting nurse service). Given caregivers’ limited time and privacy for reviewing the STAR-VTF training materials, they suggested breaking up the content into small chunks that they could review as time and space permitted. Finally, caregivers desired continuity by having the same STAR-VTF coach assigned to them throughout the program duration. Collectively, our findings provide a better understanding of the type of support that caregivers need to manage BPSD. Our results indicate that caregivers perceived that features of STAR-VTF could address their needs.

Based on our findings, which were collected during the intervention design process, we improved STAR-VTF for testing in our pragmatic randomized trial [10]. We incorporated a feature in the STAR-VTF modules that enables caregivers to pause the training and continue later from that point. Multiple members of the research team iteratively reviewed the modules in a testing environment and identified usability issues to address prior to trial recruitment. During the trial, we will collect and monitor structured responses from caregivers after their completion of each module to assess perceived usability and usefulness. Furthermore, we gave each STAR-VTF coach a designated panel of caregivers to promote continuity of support. STAR-VTF coaches were trained on the importance of expressing empathy and offering encouragement during difficult times, helping caregivers to problem solve specific behavioral symptoms, referring caregivers to KPWA community resource specialists to help them find supportive services (eg, respite care), and helping caregivers learn how to use their electronic devices to access the STAR-VTF training materials. We were unable to address caregivers’ preference to offer STAR-VTF earlier. Since caregiver outcomes are not tracked within the EHR, we currently have no pragmatic alternatives to using a prescription for an antipsychotic medication as a signal for when a caregiver needs help managing behavioral symptoms and could benefit from participating in STAR-VTF. New research is needed on earlier identification of caregivers who are experiencing problem behaviors in people with ADRD.

Comparison With Previous Work

While family caregivers may not provide much assistance to people with dementia in the early stages of disease, Whitlatch and Orsulic-Jeras [14] argue that this is a critical time for family caregivers to obtain information and education about the disease, symptoms, and progression. In our study, caregivers believed they would have benefited from education about BPSD much earlier. This finding is consistent with research by Boots et al [15], which reported that retrospectively, family caregivers of patients with late-stage disease did not believe they had sufficient knowledge in the early stages about the manifestations of dementia. Furthermore, while health care providers are an important and trusted source of information for family caregivers

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of people with dementia [16], our participants reported that they did not provide sufficient information about the personality and behavior changes that people with dementia can experience. Complementary to our findings, Peterson et al [17] reported that the perception among caregivers was that health care providers offer little to no useful information about dementia and caregiving. In surveys, caregivers also report that their need for information on what to expect as dementia progresses is not met by health care providers [18,19].

STAR-VTF could be offered earlier, before the person with dementia begins experiencing changes in their behavior, as caregivers in our study suggested. For example, caregivers could learn about the activators-behaviors-consequences problem-solving strategy in advance before they need to apply it. Wald et al [20] observed that family caregivers of people with dementia requested that information about a variety of topics (including BPSD and its management) be provided at the time of diagnosis rather than when the need arose. However, in a study examining the acceptability of structured discussions about future care during the early stages of dementia, Orsulic-Jeras et al [21] found that dyads of a family caregiver and person with dementia perceived one of the major drawbacks of the program was discussing topics that did not apply to their current situation. For example, study participants stated that they did not currently have “those conditions” and were not currently experiencing problems. Thus, a compromise for STAR-VTF timing could be to first offer caregivers program components that are most relevant in the early stages of the disease (eg, realistic expectations about dementia and possible BPSD) and reserve components that are narrowly focused on problem solving for later stages when the person with dementia begins experiencing BPSD. How health care organizations can identify the optimal point at which caregiver needs for BPSD management begin to arise and thus offer the problem-solving components of STAR-VTF is a critical topic requiring future research. An important consideration is not offering the program too early, when caregivers deem the training irrelevant, but not waiting until the situation has escalated to the point of requiring antipsychotic medications.

The COVID-19 pandemic has substantially increased interest in virtual health services. We conducted interviews in the summer and fall of 2019, prior to the pandemic and the rapid shift to virtual services. At that time, most caregivers in our study perceived the virtual aspect of STAR-VTF as an attractive feature. After viewing low-fidelity protypes of STAR-VTF, caregivers noted the potential convenience of accessing support virtually and receiving timely help. We note that our study sample was predominantly White and highly educated, representing US groups with the highest internet usage. Of White adults, 92% use the internet (compared to 85% and 86% of Black and Latino adults, respectively), and 98% of college-educated adults use the internet (compared to 71% of adults with less than a high school education) [22]. All caregivers in our study had internet access at home and owned devices (eg, laptop, desktop) that would be required for participation in a virtual training program. A systematic review of internet-based interventions to support family caregivers of people with dementia reports that, among family caregivers with high digital literacy and internet access, such interventions produce beneficial impacts on caregiver depression, anxiety, and burden [23].

Limitations

Our study has limitations worth noting. First, we used a dispensed prescription for an antipsychotic medication as a proxy for identifying family caregivers dealing with BPSD in the person with dementia. This inclusion criterion likely biased our study sample toward caregivers caring for a person in the later stages of dementia when BPSD are most prevalent. Their needs for help in managing BPSD and their perception of the potential usefulness of STAR-VTF could differ from caregivers who are caring for a person in the earlier stages of dementia. However, the experiences of family caregivers in our study made them especially knowledgeable about family caregiver needs regarding BPSD management throughout the disease trajectory. Second, our sample was of KPWA members living in 3 western Washington counties that included the Seattle metropolitan area. As a qualitative study, we did not aim for generalizability [24]; however, we note that our findings represent the perspectives of a limited group. KPWA members are predominantly White and highly educated, so 13 of 15 (87%) participants were White and none were Latino. Our experience suggests that Latino KPWA members may be less likely than non-Latino White members to be prescribed antipsychotic medications. Future research needs to explore this hypothesis.

Conclusions

Our findings contribute new knowledge about family caregivers’ views on participating in a virtual training program for the management of BPSD. Family caregivers needed information about BPSD and help in managing it, and they stated that STAR-VTF had the potential to directly address these needs. Furthermore, caregivers were attracted to the convenience of accessing the training virtually. They felt that a virtual training program would be more beneficial if it were offered early in their caregiving experience. Accordingly, our findings shed light on the need for future research to identify the optimal point at which to offer STAR-VTF. Offering the program too early risks providing training that is irrelevant to caregivers’ current situation, while offering it too late risks providing training after caregivers have already spent significant effort problem solving challenging behaviors on their own. Overall, our findings provide evidence that family caregivers would likely accept a program such as STAR-VTF focused on BPSD management that is offered entirely virtually.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Storyboards used during interviews with caregivers.
[PDF File (Adobe PDF File), 416 KB - aging_v4i1e24965_app1.pdf]

Multimedia Appendix 2
An example of a low-fidelity prototype used during interviews with caregivers.
[PPTX File , 4155 KB - aging_v4i1e24965_app2.pptx]

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Abbreviations

ADRD: Alzheimer disease and related dementias
BPSD: behavioral and psychological symptoms of dementia
EHR: electronic health record
ICD-9-CM: International Classification of Diseases Ninth Revision—Clinical Modification
KPWA: Kaiser Permanente Washington
STAR-C: STAR-Caregivers
STAR-VTF: STAR-Caregivers Virtual Training and Follow-up

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Original Paper

Attitudes Toward Technology and Use of Fall Alert Wearables in Caregiving: Survey Study

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Abstract

Background: Wearable technology for fall alerts among older adult care recipients is one of the more frequently studied areas of technology, given the concerning consequences of falls among this population. Falls are quite prevalent in later life. While there is a growing amount of literature on older adults' acceptance of technology, less is known about how caregivers' attitudes toward technology can impact care recipients' use of such technology.

Objective: The objective of our study was to examine associations between caregivers' attitudes toward technology for caregiving and care recipients' use of fall alert wearables.

Methods: This study examined data collected with an online survey from 626 caregivers for adults 50 years and older. Adapted from the technology acceptance model, a structural equation model tested the following prespecified hypotheses: (1) higher perceived usefulness of technologies for caregiving would predict higher perceived value of and greater interest in technologies for caregiving; (2) higher perceived value of technologies for caregiving would predict greater interest in technologies for caregiving; and (3) greater interest in technologies for caregiving would predict greater use of fall alert wearables among care recipients. Additionally, we included demographic factors (eg, caregivers' and care recipients' ages) and caregiving context (eg, caregiver type and caregiving situation) as important predictors of care recipients' use of fall alert wearables.

Results: Of 626 total respondents, 548 (87.5%) with all valid responses were included in this study. Among care recipients, 28% used fall alert wearables. The final model had a good to fair model fit: a confirmatory factor index of 0.93, a standardized root mean square residual of 0.049, and root mean square error of approximation of 0.066. Caregivers' perceived usefulness of technology was positively associated with their attitudes toward using technology in caregiving (b=.70, $P<.001$) and interest in using technology for caregiving (b=.22, $P=.003$). Greater perceived value of using technology in caregiving predicted greater interest in using technology for caregiving (b=.65, $P<.001$). Greater interest in using technology for caregiving was associated with greater likelihood of care recipients using fall alert wearables (b=.27, $P<.001$). The caregiver type had the strongest inverse relationship with care recipients' use of fall alert wearables (unpaid vs paid caregiver) (b=–.33, $P<.001$).

Conclusions: This study underscores the importance of caregivers' attitudes in care recipients' technology use for falls management. Raising awareness and improving perception about technologies for caregiving may help caregivers and care recipients adopt and better utilize technologies that can promote independence and enhance safety.

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KEYWORDS

wearables; falls alert technology; falls; caregivers; care recipients

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Introduction

By 2035, adults 65 years and older in the United States are projected to outnumber children (under 18 years), mostly due to the continued aging of the Baby Boomer generation [1]. The proportion of older adults aged 65 years and older will increase from approximately 1 in 7 today to approximately 1 in 5 in 2030, when nearly all Baby Boomers will be of typical retirement age [2]. The majority of older adults will need long-term services and support during their lifetime [3]. The rapid growth of the oldest population (ie, those 85 years and older), individuals who tend to have more health conditions and disabilities, will compound the need for care with most requiring some level of care by either paid or unpaid caregivers [4].

According to the American Association of Retired Persons 2020 Report: Caregiving in America [4], caregivers report that the adults who receive care (care recipients) have more comorbid conditions that require care for medical and support than was reported by caregivers in 2015. Increasingly, unpaid caregivers are turning to assistive intelligent technology and wearables for assistance and support in caregiving [4]. Wearable technology is a category of electronic devices that are worn as accessories, embedded in clothing, implanted in the user's body, or even tattooed on the skin. Wearables can be powered by microprocessors to send and receive data via cellular networks and the internet [5-7]. Our review of recent literature on technology and caregiving offered multiple examples of digital technology adoption by caregivers and care recipients in the realms of education, care recipient data collection, sensors and monitoring, clinical care delivery, and social support [4,6,8-12]. While these studies [4,6,8-12] document the broad array of categories of digital and technology development, limited information is available about factors influencing care recipients' technology adoption.

Wearable technology for fall alerts among older adult care recipients is one of the more frequently studied areas of technology, given the concerning consequences of falls among this population. Falls are quite prevalent in later life; approximately 1 in 4 community-dwelling older adults fall each year, and 20% of falls result in injury [13]. The consequences of falls can trigger a downward trajectory of dependence among older adults and can result in increased health care emergency room visits and hospitalization, staggering health care costs, and premature death [13-15]. Research suggests that caregivers are increasingly interested in purchasing and using wearable and other monitoring technology to help reduce caregiver burdens and allow older adults to remain independent in their own homes [9]. A recent literature review by Stavropoulos et al [10] included reviews of systematic reviews and case studies, including studies in which the aims were to assess if the caregiver was more comfortable due to the care recipient use of the wearable and if the care recipient felt more independent [10-12,16,17].

In recent years, falls have become viewed as preventable with evidence-based programs helping older adults prevent and better manage risk factors associated with falling [18]. Concurrently, technology tools are being developed to help older adults and their caregivers predict and prevent falls [18]. Of particular interest is the growing market for fall alert systems, which are intended to help older adults reduce fear of falling and stay independent by ensuring that help will be available in the event of a fall. There is now a plethora of medical alert systems with fall detection, and while there are market comparisons and a growing amount of literature on older adults' acceptance of technology, less is known about how caregivers' attitudes toward technology can impact care recipients' use of such technology [6,8-12,16,17,19,20].

The objective of this paper is to better understand associations between caregivers' attitudes toward technology for caregiving and care recipients' use of fall alert wearables.

Based on an adapted framework of the Technology Acceptance Model (TAM) [21,22], we constructed a structural equation model to test the following hypotheses: (1) higher perceived usefulness of technologies for caregiving would predict higher perceived value of and greater interest in technologies for caregiving; (2) higher perceived value of technologies for caregiving would predict greater interest in technologies for caregiving; and (3) greater interest in technologies for caregiving would predict greater use of fall alert wearables among care recipients.

We further based our analyses on specific demographic factors and caregiving contexts available from the data in our survey. In addition, our analyses were based on the following subhypotheses, supported in the literature: (1) younger age among caregivers would predict greater perceived usefulness, perceived value, and interest in using technology; (2) more demanding caregiving situations such as longer caregiving hours and dementia among care recipients would increase caregivers' interest in technology; (3) older age among care recipients would predict greater health care needs and fall risks, hence more need for and use of fall alert–related technology [22,23]; and (4) use of or preference for using family (ie, unpaid) caregivers is most likely associated with economic status (ie, the ability to pay for caregivers) and the availability of unpaid caregivers as well as care recipients' health conditions [23,24]. Correlates that predict the use of paid versus unpaid caregivers may also influence the use of fall alert technologies. Thus, we also examined whether care recipients' use of fall alert wearables would be associated with caregiver type (paid or unpaid).

Methods

Model Construction

For this study, we adapted a validated model of technology acceptance by users in organizations, based on the TAM and an updated version (TAM2) [21,22], to guide the development of the survey instrument and data analyses to identify factors influencing caregivers' and care recipients' use and perceptions of technologies associated with caregiving. A meta-analysis of 88 studies in different fields [25] indicated that TAM is "a powerful and robust predictive model" to understand technology acceptance of users in various contexts. Davis [26] originally empirically validated TAM to explain users' willingness to use new technologies in organizations. In 2015, Marangunić and

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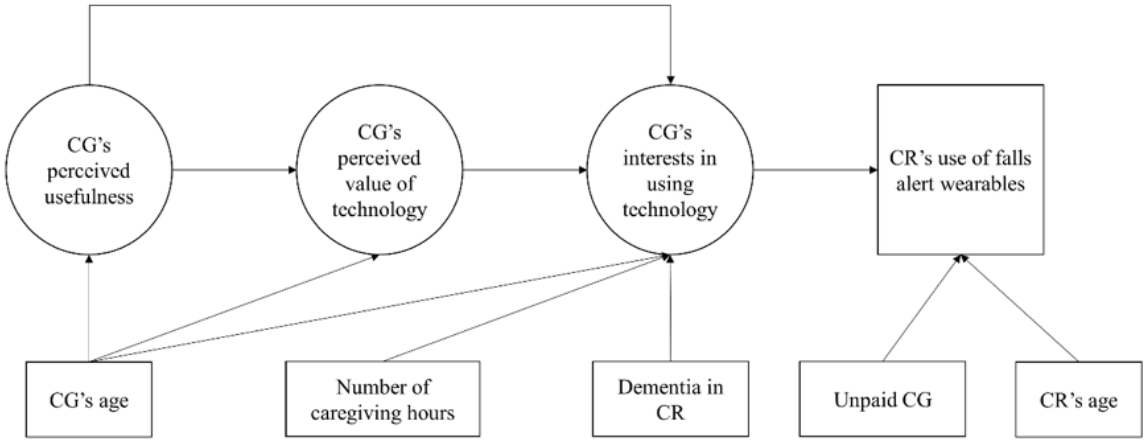
Granić [27] stated that TAM "has evolved to become the key model in understanding the predictors of human behavior toward potential acceptance or rejection of the technology."

In this study, we adapted TAM and TAM2 to build and test a framework (Figure 1) that includes factors regarding caregivers' perceptions about how useful and valuable technologies might be in their caregiving activities. The key constructs of TAM and TAM2, perceived usefulness, attitudes toward using technology, intention to use, and usage behaviors were adapted to caregivers' perceived usefulness, perceived value of technology, interests in using technology, and care recipients' use of technology, respectively. Attitudes toward a behavior consists of personal evaluation of the specified behavior [27]. In the adapted model, attitudes toward using technology was adapted to perceived value of using technology in caregiving. Figure 1 illustrates our adaptation of the TAM2 model with its 3 key constructs (caregiver's perceived usefulness, perceived value, and interest in using the technology) and other factors that potentially may directly or indirectly influence care recipients' use of fall alert wearables.

Figure 1. Initially hypothesized model predicting care recipient's use of fall alert wearables. CG: caregiver; CR: care recipient.



Data Source and Study Participants

This study used a cross-sectional online survey collected from 626 paid and unpaid caregivers for adults 50 years and older. The caregivers were recruited through an internet panel (Qualtrics XM) in November 2019. Survey respondents were eligible to be included in this study if they were aged 18 years or older, were either paid or unpaid, and provided at least 8 hours of care per week for at least one person who was over 50 years of age and who lived in a home environment. The recruited sample was targeted to resemble the population distribution across 4 US regions (eg, northwest: 17.2%; midwest: 20.9%; west: 23.8%; south: 38.1%) based on 2018 census data [28]. In addition to quotas by regions, quota sampling was predetermined for gender (approximately 75% female and 25% male), age (at least 50% of the sample 50 years and older), and race (maximum 60% White) to account for the known demographic characteristics of caregivers for middle-aged and older adults in the United States [4]. The survey design and study implementation were submitted to the Texas A&M University institutional review board and received approval for exemption (IRB2019-1128M).

Variables

Caregiver's perceived usefulness of technologies in caregiving was measured using 6 items on the extent technology helps with (1) reducing the caregiving burden in the future; (2) enabling the care recipient to live more independently; (3) enabling caregiver to have a better quality of life; (4) improving the caregiver's relationship with their care recipient; (5) improving communication with the care recipient's family and friends; and (6) improving communications with the care recipient's health care team. Each item was measured on a 0-to-100-point slider, with higher scores indicating greater perceived usefulness. For the 6 items, Cronbach α=.92. The Kaiser-Meyer-Olkin measure was 0.89, and the Bartlett test of sphericity (χ^2_{15}=2458.77, P<.001) suggested that the data were appropriate for factor analysis. Exploratory factor analysis showed that the 6 items adequately loaded onto one construct (eg, scree plot and eigenvalues). Average variance extracted was 0.67 indicating that the construct sufficiently explains the item variances.

Caregiver's attitudes toward various safety-related technology for caregiving was assessed by asking perceived value of (1) watches and wearables that enable emergency calls and provide easy to use communications with family members; (2) cameras

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and alerts to make the house safe; (3) wearable technology to track care recipient health conditions (eg, breathing, pulse, and blood pressure); (4) watches and wearable sensors to monitor and send emergency alerts about falls; (5) watches and sensors that provide care recipient's location; and (6) wearables and sensors that alert if care recipients are at risk for falls. The survey respondents rated perceived value of each technology on a 0-to-100-point slider, with higher scores indicating greater perceived value of the technology in caregiving. For the 6 items, Cronbach α was .91. The Kaiser-Meyer-Olkin was 0.90, and Bartlett test of sphericity was statistically significant (χ^2_{15}=2130.27, P<.001). Exploratory factor analysis showed that the 6 items adequately loaded onto one construct. The level of variance captured by the construct was considered acceptable with average variance extracted of 0.64.

Two items were used to measure caregiver's interest in using technology for tracking their care recipient's location and providing alerts if their care recipient is at risk for a fall. The valid response range for the 2 items was 0 to 100 points, using a slider with higher scores indicating greater interests in using the technology. The Spearman-Brown reliability estimate for the 2 items was 0.75.

The online survey collected sociodemographic characteristics of caregivers and caregiving context, as well as the caregiver's oldest care recipient's age, dementia diagnosis status, and use of fall alert wearables (eg, pendant or other wearable to alert others that a fall has occurred). Sociodemographic characteristics of caregivers included age in years, gender, race/ethnicity, place of residence (rural vs urban), education (associate degree or less education vs bachelor degree or higher education), employment status (employed for wages or self-employed vs other), previous year's household income (<US $50,000 vs ≥$50,000), and financial stress (ie, "In general, how do your finances usually work out at the end of the month? Do you find that you usually: end up with some money left over/have just enough money to make ends meet/not have enough money to make ends meet?"). Self-reported zip codes were approximated to the census tract–based rural-urban commuting area codes [29]. Caregiving-related information included caregiving type (informal or unpaid vs formal or paid) for the oldest care recipient and the number of weekly hours of caregiving for the oldest care recipient.

Statistical Analyses

Characteristics of the study's caregivers, their care recipients, and caregiving contexts, as well as caregivers' attitudes toward using technology in caregiving, were described using mean and standard deviation or frequency and percentage. Independent group comparison (eg, 2-tailed independent *t* test or chi-square test) was used to compare each described characteristic by care recipient's use of fall alert wearables. Next, a structural equation model was performed to test the hypothesized model (Figure 1). Goodness of fit was determined using confirmatory factor index (CFI), root mean square error of approximation (RMSEA), and standardized root mean square residual (SRMR)—good to fair was defined as CFI>0.90, RMSEA<0.08, and SRMR<0.08. Modification indices were also reviewed to explore potential model improvements. Figure 2 shows the final model used in this study. All statistical analyses were performed using SAS (version 9.4, SAS Institute) and with only included the caregivers who had valid data on all variables used in the structural equation model (548/626, 87.5%). Given potential differences between paid and unpaid caregivers, the independent group comparison was conducted to compare each described characteristic by caregivers' paid status (Multimedia Appendix 1), and the hypothesized model (after excluding caregiver payment status) was tested separately among the paid (116/548, 21.2%) and unpaid (432/548, 78.8%) caregivers (Multimedia Appendix 2 and Multimedia Appendix 3).

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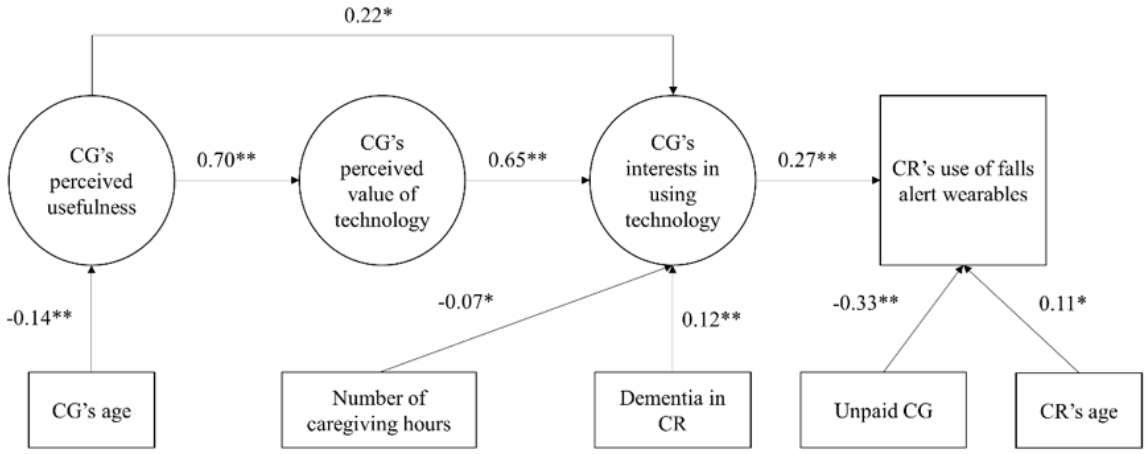
Figure 2. Revised model predicting care recipient's use of falls alert wearables. CG: caregiver; CR: care recipient. *P<.05; **P<.001.



Results

Study Population

Table 1 describes the characteristics of the caregivers and care recipients and the caregiving context. The mean age of the caregivers was 58.1 (SD 14.1) years, and the majority were females (417/547, 76.2%), non-Hispanic White (354/545, 65.0%), from an urban area (500/547, 91.4%) and had some college or higher educational attainment (420/548, 76.6%). Over 43% (237/548) were employed for wages or self-employed, and slightly more than half (279/548) had a total household income less than $50,000 in 2018. Approximately 55% (296/542) of caregivers reported some level of financial stress (ie, having just enough money to make ends meet or not having enough money to make ends meet). The mean age of care recipients was 74.5 (SD 11.93) years, and 23.4% (128/548) of caregivers reported their care recipient was diagnosed with dementia. The majority of the caregivers lived with the care recipient (311/548, 56.8%), were unpaid for the care or assistance they provided to their care recipients (432/548, 78.8%), and a reported weekly average of 37.5 (SD 28.98) hours providing care.

Fewer than 28% (153/548) of the study's care recipients used a fall alert wearable. In a bivariate analyses comparing caregivers for those who do not use fall alert wearables to those who do use fall alert wearables found that the caregivers of those who used fall alert wearables were significantly younger (P<.001), less likely to be non-Hispanic White (P=.005), and under financial stress (P=.003). They were also more likely to be employed for wages or self-employed (P<.001). Furthermore, the care recipients who used fall alert wearables were significantly older (P<.001) and more likely to have dementia (P=.01) than those not using fall alert wearables. Caregivers of those who used fall alert wearables reported fewer weekly hours of caregiving (P=.002) and were also significantly less likely to be an unpaid caregiver (P<.001) or to live with the care recipient (P<.001). Caregivers of care recipients using fall alert wearables had significantly greater perceived usefulness (P<.001), perceived value (P<.001), and interest (P<.001) in using technology in caregiving than caregivers of those not using fall alert wearables.

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Table 1. Characteristics of the study respondents and caregiving context and caregivers' attitudes toward using technology in caregiving.

Characteristic	All (N=548)	Care recipients using fall alert wearables (n=153)	Care recipients not using fall alert wearables (n=395)	*P* value[a]
Age (years), mean (SD)	58.1 (14.07)	53.2 (16.58)	59.8 (12.90)	<.001
Gender, n (%)				.71
Female	417 (76.2)	115 (75.2)	302 (76.6)	
Male	131 (23.8)	38 (24.8)	93 (23.4)	
Race/ethnicity, n (%)				.005
Non-Hispanic White	354 (65.0)	82 (53.6)	272 (69.4)	
Non-Hispanic Black	93 (17.1)	38 (24.8)	55 (14.0)	
Non-Hispanic Asian	35 (6.4)	10 (6.5)	25 (6.4)	
Non-Hispanic other races	9 (1.7)	2 (1.3)	7 (1.8)	
Hispanic	54 (9.9)	21 (13.7)	33 (8.4)	
Education level, n (%)				.87
High school or lower	128 (23.4)	35 (22.9)	93 (23.5)	
Some college or higher	420 (76.6)	118 (77.1)	302 (76.5)	
Employment status, n (%)				<.001
Employed for wages or self-employed	237 (43.2)	96 (62.7)	141 (35.7)	
Not employed for wages, not self-employed	311 (56.8)	57 (37.3)	254 (64.3)	
Household income, n (%)				.72
Less than US $50,000	279 (50.9)	76 (49.7)	203 (51.4)	
More than US $50,000	269 (49.1)	77 (50.3)	192 (48.6)	
Financial stress, n (%)				.003
End up with some money left over	246 (45.4)	79 (52.3)	167 (42.7)	
Have just enough money to make ends meet	212 (39.1)	61 (40.4)	151 (38.6)	
Not have enough money to make ends meet	84 (15.5)	11 (7.3)	73 (18.7)	
Residence, n (%)				.29
Rural	47 (8.6)	10 (6.5)	37 (9.4)	
Urban	500 (91.4)	143 (93.5)	357 (90.6)	
Care recipient				
Age (years), mean (SD)	74.5 (11.93)	77.2 (12.21)	73.5 (11.95)	<.001
Having dementia, n (%)				.01
Yes	128 (23.4)	47 (30.7)	81 (20.5)	
No	420 (76.6)	106 (69.3)	314 (79.5)	
Caregiving context				
Paid for caregiving				<.001
Paid caregiver	116 (21.2)	68 (44.4)	48 (12.2)	
Unpaid caregiver	432 (78.8)	85 (55.6)	347 (87.8)	
Weekly hours of caregiving[b], mean (SD)	37.5 (28.98)	31.3 (23.83)	39.3 (30.00)	.002
Living with the care recipient, n (%)				<.001
Yes	311 (56.8)	53 (34.6)	258 (65.3)	
No	237 (43.2)	100 (65.4)	137 (34.7)	
Caregivers' attitudes[c], mean (SD)				
Perceived usefulness	58.3 (25.57)	68.2 (21.94)	54.5 (25.86)	<.001

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Characteristic	All (N=548)	Care recipients using fall alert wearables (n=153)	Care recipients not using fall alert wearables (n=395)	*P* value[a]
Perceived value	63.5 (27.22)	73.6 (20.48)	59.5 (28.48)	<.001
Interest	59.2 (30.40)	72.6 (26.02)	54.0 (30.40)	<.001

[a]Results from unadjusted independent group comparison between the group, in which care recipients use fall alert wearables, and another group, in which care recipients do not use fall alert wearables.

[b]Total weekly hours of caregiving was capped at 100 hours.

[c]Values ranged from 0 to 100, with a higher value indicating greater perceived usefulness, greater perceived value, or more interest in using technology in caregiving.

Model Fit and Refinement

Goodness of fit, of the model shown in Figure 1, indicated good-to-fair model fit (CFI 0.93, SRMR 0.049, RMSEA 0.067). All hypothesized paths were statistically significant, except for the paths from age to perceived value (*P*=.73) and interests (*P*=.15) in technology in caregiving. Removing these 2 statistically insignificant paths did not change the direction or statistical significance of other paths in the model, and only minimal changes in the parameter estimates were observed, although the second model, shown in Figure 2, goodness-of-fit remained good-to-fair (CFI 0.93, SRMR 0.049, RMSEA 0.066).

Path Coefficients

Figure 2 presents the standardized path coefficients of the final structural equation model. Caregivers' perceived usefulness of technology was positively associated with their attitudes toward using technology in caregiving (b=.70, *P*<.001) and interests in using technology for caregiving (b=.22, *P*=.003). Greater perceived value of using technology in caregiving predicted greater interests in using technology for caregiving (b=.65, *P*<.001). Greater interests in using technology for caregiving was associated with greater likelihood of care recipients using fall alert wearables (b=.27, *P*<.001). Younger age of caregivers predicted greater perceived usefulness (b=–.14, *P*<.001). Care recipients of unpaid caregivers were less likely to use fall alert wearables (b=–.33, *P*<.001) than care recipients of paid caregivers. Fewer caregiving hours (b=–.07, *P*=.03) and presence of dementia among care recipients (b=.12, *P*<.001) predicted greater interests in using technology for caregiving. Care recipients' age was positively associated with the use of fall alert wearables (b=.11, *P*=.004).

Table 2 presents direct and indirect effects of caregivers' age and attitudes and caregiving context on care recipients' use of fall alert wearables. In terms of total effects, caregivers' interests in using technology for caregiving had the strongest positive effects on care recipients' use of fall alert wearables (b=.27, *P*<.001), followed by caregivers' perceived usefulness of technology in caregiving (b=.18, *P*<.001), and caregiver's attitudes toward using technology in caregiving (b=.17, *P*<.001). The strongest inverse relationship was with caregiver type (unpaid vs paid caregiver) (b=–.33, *P*<.001). While the observed total effects were statistically significant, the magnitudes of the relationship tended to be weaker for hours of caregiving (b=–.02, *P*=.046), caregiver's age (b=–.03, *P*=.003), and care recipient having dementia (b=.03, *P*<.001).

Table 2. Direct, indirect, and total effects of each predictor on care recipient's use of fall alert wearables.

Variable	Direct effects		Indirect effects		Total effects	
	b[a] (SE)	*P* value	b (SE)	*P* value	b (SE)	*P* value
Caregivers' perceived usefulness of technology in caregiving	0	N/A[b]	.18 (0.03)	<.001	.18 (0.03)	<.001
Caregivers' attitudes toward using technology in caregiving	0	N/A	.17 (0.03)	<.001	.17 (0.03)	<.001
Caregivers' interests in using technology in caregiving	.27 (0.04)	<.001	0	N/A	.27 (0.04)	<.001
Caregivers' age	0	N/A	–.03 (0.009)	.003	–.03 (0.009)	.003
Unpaid caregiver (vs paid caregiver)	–.33 (0.04)	<.001	0	N/A	–.33 (0.04)	<.001
Hours of caregiving	0	N/A	–.02 (0.01)	.046	–.02 (0.01)	.046
Care recipient having dementia	0	N/A	.03 (0.01)	<.001	.03 (0.01)	<.001
Care recipients' age	.11 (0.04)	.004	0	N/A	.11 (0.04)	.004

[a]Standardized estimates.

[b]N/A: not applicable.

Paid and Unpaid Caregivers

As shown in Table 1, nearly 79% (432/548) of the caregivers were unpaid. Multimedia Appendix 1 shows the comparison of caregiver and care recipient's characteristics based on caregivers' paid status. Compared to unpaid caregivers, paid caregivers were younger (48.0 years vs 60.8 years, *P*<.001); less likely to be non-Hispanic White (*P*<.001), having some college or higher educational attainment (*P*<.001), and living with the care recipients (*P*<.001); and more likely to be employed (*P*<.001). The oldest care recipients of paid caregivers were more likely to have dementia than the oldest care recipients

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of unpaid caregivers (*P*<0.001). There were statistically significant differences in the self-reported financial stress among paid and unpaid caregivers (*P*=.034). While there were 38.3% (44/115) and 49.6% (57/115) of paid caregivers having some money left over and having just enough money to make ends meet, respectively; there were 47.3% (202/427) and 36.3% (155/427) of unpaid caregivers having some money left over and having just enough money to make ends meet, respectively. Paid caregivers reported significantly greater perceived usefulness (*P*=.002) and interests (*P*=.004) in using technology in caregiving than caregivers of those not using fall alert wearables.

The model fit among paid caregiver was fair (CFI 0.93, SRMR 0.076, and RMSEA 0.062) and was comparable to the comprehensive model (CFI 0.93, SRMR 0.049, and RMSEA 0.066). The 3 prespecified hypotheses remained statistically significance, and corresponding path coefficients were comparable to the comprehensive model (Multimedia Appendix 2 shows the model among paid caregivers and Figure 2 shows the comprehensive model). Paid caregivers' perceived usefulness of technology in caregiving was positively associated with perceived value of (b=.67, *P*<.001) and interest in (b=.36, *P*=.02) technology for caregiving. Higher perceived value of technology for caregiving was predicted greater interest in technologies for caregiving (b=.65, *P*<.001); and greater interest in technologies for caregiving predicted greater use of fall alert wearables among care recipients (b=.21, *P*=.02). None of the 4 subhypotheses remained statistically significant among paid caregivers.

The model fit among unpaid caregivers was good to fair (CFI 0.93, SRMR 0.051, and RMSEA 0.069) and was comparable to that of the comprehensive model (CFI 0.93, SRMR 0.049, and RMSEA 0.066). All path coefficients remained statistically significant, and path coefficients were comparable to the comprehensive model (Multimedia Appendix 3 shows the model among unpaid caregivers and Figure 2 shows the comprehensive model). Unpaid caregivers' perceived usefulness of technology was positively associated with their attitudes toward using technology in caregiving (b=.71, *P*<.001) and interests in using technology for caregiving (b=.17, *P*=.03). Greater perceived value of using technology in caregiving predicted greater interests in using technology for caregiving (b=.67, *P*<.001). Greater interests in using technology for caregiving was associated with greater likelihood of care recipients using fall alert wearables (b=.31, *P*<.001). Younger age of unpaid caregivers predicted greater perceived usefulness (b=–.13, *P*=.005). Fewer caregiving hours (b=–.09, *P*=.02) and presence of dementia among care recipients (b=.13, *P*<.001) predicted greater interests in using technology for caregiving. Care recipients' age was positively associated with the use of fall alert wearables (b=.11, *P*=.02).

For both paid and unpaid caregivers, caregiver's interest in using technology for caregiving had the strongest positive effects on care recipient's use of fall alert wearables (b=.21, *P*=.023 in paid caregivers; and b=.31, *P*=.028 in unpaid caregivers), followed by other attitudinal variables. Estimated total effects of caregiver's perceived usefulness of technology in caregiving was b=.16 (*P*=.032) in paid caregivers and b=.20 (*P*<.001) in unpaid caregivers; and estimated total effects of caregiver's attitudes toward using technology in caregiving was b=.13 (*P*=.036) in paid caregivers and b=.21 (*P*<.001) among unpaid caregivers.

Discussion

Principal Findings

From our analyses, we have demonstrated that the adapted TAM2 concepts of caregivers provide support for our hypotheses about care recipients' use of fall alert wearables, which is reflective of previous literature [12,20-25,30]. Our model demonstrated that both high perceived usefulness and value of technology for caregiving was associated with greater interest in technologies for caregiving and that greater interest in technology for caregiving was predictive of greater use of fall alert wearables among care recipients, although only 28% (153/548) of our study's care recipients used fall alerts. While statistically significant, our results suggested that younger age among caregivers was among the less powerful predictors of perceived use, attention and interest in technology for caregiving.

Our results demonstrated that the strongest predictor of care recipients' use of fall alert wearable was the type of caregiver and that care recipients with paid caregivers were more likely to use this type of technology than care recipients with unpaid caregivers. While not expected, this may reflect the scenario where the path of caregiving for older adults typically begins with a family member or unpaid caregiver who lives in close proximity to the care recipient and provides human monitoring. Concerns for falls often results in investment in fall alert wearables for older adults living independently [9].

Our subhypothesis that more demanding caregiving situations, including longer hours of caregiving and instances of dementia among care recipients, was partially supported in this study. As hypothesized, dementia among care recipients positively predicts their use of fall alert wearables. However, contrary to our hypothesis, fewer caregiving hours was associated with care recipient's use of fall alert wearables. A potential interpretation may be that caregivers providing fewer hours of care could be more inclined to use wearables to compensate for longer durations of nonsupervised time. According to the subgroup analyses based on caregiver's payment status, the statistical significance of the subhypotheses are likely to be largely driven by unpaid care recipients, who constituted almost 79% (432/548) of the total analytic sample. While caregiver's attitude toward technology in caregiving were significantly associated with care recipient's use of fall alert wearables in both paid and unpaid caregivers, caregivers' and care recipients' age, and caregiving situations were significantly associated with care recipients' use of fall alert wearables only among unpaid caregiver participants. The smaller sample size of paid caregivers may have limited the statistical power of the model. Another potential explanation is the differential involvement of paid and unpaid caregivers in caregiving decisions [29].

There is relatively little research that examines how caregivers and their care recipients (either paid or unpaid) actually use fall alert technology in their everyday lives or how such experiences

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may affect their safety and well-being. The little research that exists is limited in scale, often focused on care recipients with dementia and on cross-sectional interview methodologies focused on the adoption of the wearable fall alert technology [12,31-38]. Limited attention is typically given to how caregivers and their care recipients use wearable fall alert technology as their care and support needs change over time. In contrast, a study by van Heek et al [39] provided an empirical examination of caregivers' acceptance of assistive technologies. However, van Heek et al [39] focused on design perspectives including gathering of data, data access, and storage duration, as well as perceived benefits and barriers, in order to integrate caregivers' perspectives into design of technologies. Our results align with those of other recent studies [38-46] showing that there is a greater likelihood for adoption and use of fall alert wearables among care recipients with dementia, which is assumedly negotiated by the caregiver as a result of care recipient incapacity.

Limitations

There were some limitations to our study. First, our caregiver population in the panel-based survey may not be representative of the caregiver population across the United States, despite our best efforts. While we have used quota sampling to match the distribution of key characteristics (eg, geographical region, age, gender, and race), this online sample excludes caregivers without access to internet and related technology (eg, computer, smartphone, or tablets). We assume that respondents were more willing to sign up to participate because they are comfortable with technology. Thus, caregivers who do have online access but are not as comfortable with technology may have elected not to participate. We also excluded caregivers who might have had online access but who had limited English proficiency. While we asked participants to self-identify as either paid or unpaid, there was no way to tell if there were subsets of unpaid caregivers who received some sort of stipend or benefit. With our cross-sectional design, it was not possible to draw conclusions about the causality between attitudes, caregiving contexts, and use of fall alert wearables. Additionally, the proposed model is limited by lack of potential factors, such as perceived ease of use for specific technology, fall history, and interpersonal relationships between caregivers and care recipients. In addition, the care recipients' use of fall alert wearables were proxy-reported by caregivers, a further study using direct observation or self-reported measure by care recipients could supplement the proxy-reported evidence. More information on the types of technology and how the specific technologies are used would help establish circumstantial data to set out recommendations for practice and policy. Future research using in-depth interviews with caregivers to explore the nuances of technology adoption would be instructive for understanding more about the context driving our quantitative research findings. Despite these limitations, we believe our data and analyses provide important new information on how caregivers' attitudes and values about technology influence adoption about the use of fall alert wearables for the protection and safety of their care recipients.

Conclusion

With this study, we have taken a small step in addressing the knowledge gap about how caregiver attitudes affect adoption of assistive intelligent technology such as wearable fall alert technologies in caregiving, but much remains to be learned. With the growth of the aging population over the forthcoming years, and the anticipated rise of the occurrence of falls and related injuries based on the increasing numbers of older Americans, the caregiving workforce will benefit from advanced and effective technologies used in caregiving. It will continue to be crucial for public health researchers to keep pace with the advances of technology and maintain an advocacy role for both caretakers and care recipients in the adoption and use of technology to support their health and wellbeing.

Acknowledgments

We thank all of the caregivers who participated in our online survey which formed the basis of this research. The caregiver survey was funded by contributions from DVD Associates LLC, Clairvoyant Networks Inc, and The Texas A&M Center for Population Health and Aging.

Conflicts of Interest

DVD was employed by DVD Associates LLC and is an editor for JMIR Cancer. SP is employed by Clairvoyant Networks Inc. The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Multimedia Appendix 1
Characteristics of the study respondents based on caregivers' paid status.
[DOCX File , 21 KB - aging_v4i1e23381_app1.docx]

Multimedia Appendix 2
Revised model predicting paid care recipient's use of fall alert wearables.
[DOCX File , 138 KB - aging_v4i1e23381_app2.docx]

Multimedia Appendix 3

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Revised model predicting unpaid care recipient's use of fall alert wearables.
[DOCX File , 138 KB - aging_v4i1e23381_app3.docx]

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Abbreviations

CFI: confirmatory factor index
RMSEA: root mean square error of approximation
SRMR: standardized root mean square residual
TAM: Technology Acceptance Model

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Review

Providing Medical Information to Older Adults in a Web-Based Environment: Systematic Review

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Abstract

Background: Cancer is a disease that predominantly affects older adults, and several organizations recommend the completion of a geriatric assessment to help with cancer treatment decision-making. Owing to a shortage of geriatric teams and the vast number of older adults diagnosed with cancer each year, a web-based geriatric assessment may improve access to geriatric assessment for older adults. We systematically reviewed the literature to obtain the latest evidence for the design of our web-based geriatric assessment tool Comprehensive Health Assessment for My Plan.

Objective: This review aimed to probe the following questions: what is the impact of providing health test results to older adults in a web-based environment without the presence of a health care provider for patient-centered outcomes, including satisfaction, perceived harm, empowerment, quality of life, and health care use (eg, hospitalization, physician visits, emergency room visits, and costs), and what recommendations do older adults and developers have for designing future apps or websites for older adults?

Methods: This systematic review was guided by the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analysis) statement. Studies were limited to publications in English that examined a web-based tool that provided test results to older adults (aged ≥65 years) without the presence of a health care provider. A health sciences librarian performed the search on November 29, 2019, on the following electronic databases: MEDLINE, Embase, CINAHL, PsycINFO, and the Cochrane Library. The quality of the included studies was assessed using the Mixed Methods Appraisal Tool Version 2018. The findings are summarized narratively and in tabular format.

Results: A total of 26,898 titles and abstracts were screened by 2 independent reviewers, of which 94 studies were selected for a full-text review, and 9 studies were included in this review. There were only 2 randomized controlled trials of high quality that explored the effects of receiving health care results on the web via eHealth tools for older adults or provided evidence-based recommendations for designing such tools. Older adults were generally satisfied with receiving screening results via eHealth tools, and several studies suggested that receiving health screening results electronically improved participants' quality of life. However, user interfaces that were not designed with older adults in mind and older adults' lack of confidence in navigating eHealth tools proved challenging to eHealth uptake and use. All 9 studies included in this systematic review made recommendations on how to design eHealth tools that are intuitive and useful for older adults.

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Conclusions: eHealth tools should incorporate specific elements to ensure usability for older adults. However, more research is required to fully elucidate the impact of receiving screening and results via eHealth tools without the presence of a health care provider for patient-centered outcomes in this target population.

(JMIR Aging 2021;4(1):e24092) doi:10.2196/24092

KEYWORDS

eHealth; systematic review; geriatric assessment; geriatric oncology

Introduction

Background

For older adults with cancer, several organizations recommend the completion of a geriatric assessment to help with cancer treatment decision-making [1,2]. A geriatric assessment consists of several questionnaires and tests that assess the medical, social, and psychological functioning of older adults to determine what interventions could be implemented to optimize their health and well-being [3]. However, owing to the shortage of geriatric teams and the large number of older adults diagnosed with cancer each year, access to a geriatric assessment remains to be limited. A web-based geriatric assessment may improve access for older adults. Although a few web-based geriatric assessment tools have been developed [4-6], these tools do not provide older adults with their test results without a health care provider being present. In addition, these tools would not increase access to a geriatric assessment because they still require the input of health care professionals, who are currently in low supply and high demand. Our overarching aim is to review the literature to develop a web-based geriatric assessment, the Comprehensive Health Assessment for My Plan (CHAMP), which will provide test results directly to older adults and help triage patients who are in greater need of geriatric consultation. To best design the CHAMP tool, we were interested in understanding the impact of receiving health test results in a web-based environment without the presence of a health care provider on older adults. We were also interested in consolidating the recommendations made by older adults and website developers for designing web-based tools for older adults. Therefore, we systematically reviewed the literature to obtain the latest evidence to inform the future design of our CHAMP tool.

As older adults with multiple comorbidities make up an increasing proportion of the population, there is a growing focus on equipping these patients with the tools needed to manage their own health. The aim is to provide patients with a sense of control over their medical conditions and decrease health care utilization [7]. Older patients particularly value the ability to manage their health independently at home, and minimizing reliance on health care resources, such as emergency rooms and inpatient units, is therefore an important outcome measure [8-10]. One strategy to meet these needs is the development of web-based health management tools that can be linked to patients' eHealth records and accessed from personal devices (such as smartphones, tablets, and laptops). A wide variety of eHealth tools have been developed [5-7,11]). For example, some enable patients to view results of laboratory and imaging tests [11], whereas others provide customized health care advice or allow patients to communicate directly with members of their health care team [12]. Web-based tools have also been developed for the management of specific medical conditions such as cardiovascular disease [13] and diabetes [14]. The adoption of these resources was found to improve patient outcomes in these studies. In a small study of 169 computer users aged 50 years and older, Zettel-Wattson and Tsukerman [15] discovered that 90% of participants found patient portals helpful for managing their health and 80% felt that portals gave them control over their health. A systematic review by Ferreira et al [16] showed that providing patients access to their electronic medical records improved patient understanding of their disease and helped break down barriers in the physician-patient relationship.

Despite the number of eHealth tools and their potential to enhance patient care, barriers exist to widespread adoption, especially among patients older than 65 years. Previous studies have cited concerns about privacy and security, lack of access to technology, low computer literacy, high computer anxiety, complex user interfaces, and concerns about losing face time with health care providers as key factors that prevent older adults from routinely using eHealth management systems [7,17-20]. Disparities in uptake have also been found based on age group, ethnicity, education level, and physical and cognitive abilities [7,18,21].

Studies have varied in their conclusions about optimal eHealth tool design, and few have offered specific recommendations to address these barriers. Some authors suggest that complete medical records, medication lists, test results, and condition-specific health advice are consistently appreciated by patients accessing web-based portals [15,17,22]. Khan et al [23] studied perceptions of a medication management system and found that participants enjoy visual representations of data but would also like accompanying text descriptions to fully understand their meaning. Furthermore, some patients desire the ability to receive appointment reminders, refill medications, or communicate with health care professionals through secure messaging. However, the impact of various designs on patient-centered outcomes remains to be fully explored [24].

Objectives

To best design the CHAMP tool to deliver geriatric assessment results to older adults with cancer, our review questions were as follows:

1. What is the impact of websites and apps providing health test results to older adults in a web-based environment without the presence of a health care provider for patient-centered outcomes such as satisfaction, empowerment, quality of life, and health care use (eg,

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hospitalization, physician visits, emergency room visits, and costs)?

2. What recommendations do older adults and developers have for designing future apps or websites for older adults?

We were most interested in understanding the impact of receiving health care screening and test results in the electronic environment on patient-centered outcomes such as satisfaction, empowerment, and quality of life compared with cancer-specific outcomes such as progression-free survival because we expect that the results of this literature review will be applicable to the care of older adults in many other fields of medicine, not just oncology. Furthermore, in geriatric oncology, factors other than progression-free survival and other cancer-specific outcomes are of substantial importance. Quality of life, overall functioning, and health care use have become increasingly important from the patient's viewpoint. Hence, it is both of service to the patients that we care for, and to other providers of care for older adults to understand the impact of receiving health results in a web-based environment from the patient perspective [25,26].

Methods

Review Methodology

We used systematic review methodology according to the Cochrane Handbook [27] and guided by the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statement [28].

Search Methods

Database searches were conducted by a health sciences librarian (MG) in Ovid MEDLINE, Ovid Embase, EBSCO CINAHL Plus with Full Text, Ovid PsycINFO, and the Cochrane Library using the Wiley interface. A combination of database-specific subject headings and text word searches was used to search for concepts included in our population intervention comparator outcomes search with publication date limits applied to identify articles published in the last 10 years. Keywords included "telehealth," "eHealth" or "mHealth" or "mobile health" or "digital health" or "telecommunications" or "electronic mail" or "cell phone" or "smartphone" or "Internet" or "Mobile Applications," "older adults," and "aged." Although a geriatric assessment is not the same as a patient portal (the former is a health assessment, whereas the latter is a web-based shared medical record), we expanded the search to include portals to identify any studies that looked at the impact of providing test results web-based on older adults' health outcomes. The results of this search were imported with other search results. Published filters were applied to limit the publication type to randomized controlled trials (RCTs) [29-32]. See Multimedia Appendix 1 for the MEDLINE search. The searches were run on November 29, 2019, and the search period was from January 1, 2009, to November 29, 2019. The search period was limited to 2009 onward to ensure that any apps and website or design recommendations would still be relevant as eHealth is a rapidly developing field. Publications in English were eligible for inclusion. Reference lists of included studies were reviewed to identify any additional relevant studies.

Papers were included if the following criteria were met:

- Included a population of older adults (aged above 65 years or the mean or median age in the study population was above 65 years, or if younger, subgroup analysis of those above 65 years was reported)
- Included an intervention in which older adults received results of health screening or tests completed in a web-based environment or eHealth (not including live chats with nurses, therapists, or doctors to go over test results)
- Compared the intervention to receiving the results of tests or screening in person from a health care provider or had no control group
- Focused on the following intervention outcomes: (1) patient-centered outcomes such as satisfaction, perceived harm, anxiety, depression, distress, empowerment, and quality of life; (2) health care use (eg, hospitalization, physician visits, emergency room visits, and costs); and (3) patient understanding of instructions of the tool used or provided recommendations on how to design eHealth tools for older adults

Study Selection

We included studies through a two-step process (see Figure 1 for our PRISMA flowchart). First, abstracts and titles were screened by two independent reviewers. Then, all potentially relevant full-text articles were reviewed for study inclusion by two independent reviewers. We used the Covidence software [33] to facilitate the study selection process. In case of disagreements, a third reviewer reviewed the abstract or full text, and a consensus decision was made whether to include or exclude the study.

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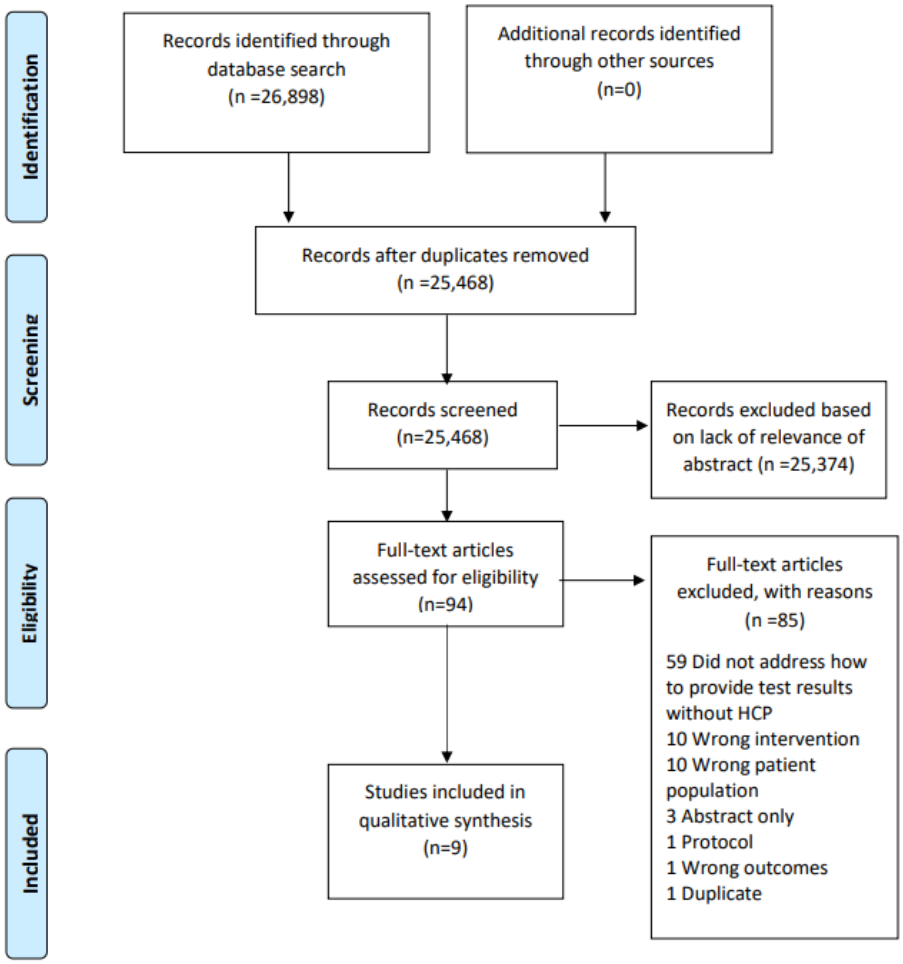
Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) flowchart for study selection.



Data Abstraction

We used standardized data collection forms developed by the research team using Excel. Data were abstracted by two reviewers independently and compared. The information that was abstracted included characteristics of the study population, study design details, details of the intervention (app or website), the methodology used to develop the app or website, details on the app or website, the impact of receiving web-based results for patients (on the aforementioned patient-centered outcomes), and details on the analyses used. For papers referring to a published study protocol, we obtained the study protocol paper to obtain the full methodological details of the study. After data abstraction, we had the missing information from all 9 studies. We contacted the authors of all the studies via email to inquire about missing information, and authors of 4 studies responded. As the studies were heterogeneous in design, intervention delivered, and outcome measures used, we summarized the abstracted data qualitatively because a meta-analysis was not possible.

Quality Assessment

We assessed the quality of the included studies using the Mixed Methods Appraisal Tool (MMAT) version 2018 [34-36]. MMAT is a quality assessment instrument that is useful for assessing qualitative, quantitative, and mixed methods studies. We noticed that several studies included a qualitative component (eg, multimethods and mixed methods studies); therefore, we chose to use MMAT over Cochrane Risk of Bias tool, which is not able to review these qualitative components. We used MMAT to review study quality, but we did not exclude any study based on the score as our aim was to understand all the evidence that was available and use that for our development of a web-based geriatric assessment.

Data Analysis

We summarized the results using a narrative descriptive synthesizing approach. A pooled analysis was not conducted because of heterogeneity in study inclusion criteria, interventions, and outcomes.

Results

Description of Included Studies

Of the 9 studies included in this review, 4 were qualitative studies [37-40], 2 were RCTs [41,42], 2 were mixed methods studies [43,44], and 1 was a quasi-experimental controlled study [45]. Overall, 8 studies were conducted in the United States [37-42,44,45], whereas 1 was a multinational study conducted in Western Europe [43]. All 9 studies included in this systematic review were published between 2015 and 2019. The sample size of the studies ranged considerably, with qualitative studies ranging from 24 to 44 participants [37-40] and the RCTs ranging from 50 to 272 participants [41-43]. The mixed methods study

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ranged from 88 (47 for the focus group and 41 for the pilot trial) [43] to 123 participants (23 for the focus group and 100 for the phone survey) [44], whereas the quasi-experimental study had 200 participants [45]. In addition, 4 studies evaluated the attitudes and experiences of older adults with patient portals [38,39,44,45], 2 studies tested web-based apps developed to deliver condition-specific (eg, cancer, cardiovascular disease) interventions [37,43], 1 study tested a user interface for a home health website [40], 1 tested a web-based decision aid [42], and 1 tested a theory-based patient portal training program [41]. A summary of the characteristics of each study included in this systematic review is shown in Table 1.

Table 1. Description of the included studies.

Study (reference)	Study design	Location	Sample size; population	Average age (years)	Female (%)	Sampling	Intervention app or tool	Analysis
Alpert et al (2016) [39]	Qualitative	United States	31 patient interviews; 2 focus groups of 13 health care professionals	Not reported (range 18-79)	58	Convenience	My preventative care patient portal	Critical incident technique
Baier et al (2015) [40]	Qualitative	United States	13 home health consumers; 28 case managers	71% ≥65 years; mean not reported	85	Convenience	Home health web-based app user interface	Content analysis
Irizarry et al (2017) [44]	Mixed methods	United States	100 older adults in phone survey, 23 in focus group	Focus group: 73; phone survey: 77	Focus group: 52.2%; phone survey: 46.2%	Convenience	Patient portal	Thematic analysis, Kruskal Wallis rank test, chi-square test
Jongstra et al (2017) [43]	Pilot RCT[a]	Western Europe	41 older adults with elevated CVD[b] risk	69	56	Random	Web-based app (HATICE) for older adults with CVD risk	Descriptive statistical analysis
Loh et al (2018) [37]	Qualitative	United States	18 older adults with malignancy; 13 caregivers	Patient: 77; caregiver: 70	Patient: 17; caregiver: 92	Convenience	TouchStream app to deliver geriatric oncology interventions	Conventional content analysis
Nahm et al (2019) [41]	RCT	United States	272 older adults with chronic disease	70	70.2	Convenience	Theory-based patient portal e-learning program	Linear mixed model, *t* test, chi-square test
Portz et al (2019) [38]	Qualitative	United States	24 older adults with chronic disease	78	71	Stratified	Kaiser permanente colorado's patient portal—my health manager	Theoretical analysis based on the technology acceptance model
Smallwood et al (2017) [42]	Pilot RCT	United States	50 older women with BMD[c] indicating osteopenia or osteoporosis	Median 79 years; mean not reported	100	Stratified	Decision aid within patient portal for osteoporosis	ANOVA, *t* test, chi-square test
Toscos et al (2016) [45]	Quasi-experimental controlled	United States	200 patients with significant CAD[d]	Average age not reported; 58% older than 66 years	27.5	Not reported	Personal health record	Linear regression, *t* test, Cochran-Mantel-Haenszel test

[a]RCT: randomized controlled trial.

[b]CVD: cardiovascular disease.

[c]BMD: bone mineral density.

[d]CAD: coronary artery disease.

Quality of Studies Included

The application of MMAT to each study included in this review is shown in Multimedia Appendix 2. Overall, there were no studies of high quality that looked at the effect of web-based screening without the presence of a health care provider on older adults or evidence-based eHealth design. Most studies that were included had small sample sizes [42-44] and used convenience sampling [37,39-41,44], thereby increasing the risk of selection bias. We were unable to determine if the outcome assessors were blinded in all RCTs [41,42], and we were unsure how randomization was performed in one of the RCTs [42]. In half

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of the qualitative studies included in this systematic review, we were unable to determine if there was coherence between the qualitative data source, analysis, and interpretation [37,40].

The results of our systematic review are stated in the order of our aims. First, we review our findings on how receiving health screening in a web-based environment affects satisfaction, perceived harm, quality of life, and health care utilization by older adults. Second, we consolidate evidence-based recommendations on how to design eHealth tools that are useful and engaging for older adults.

Objective 1: Effects of Health Screening in a Web-Based Environment

A total of 7 studies in this review evaluated the effects of receiving health screening tests or results in a web-based environment without the presence of a health care provider on older adult participants' satisfaction (n=6), perceived harm (n=5), and quality of life (n=5) [37-39,41,42,44,45]. No studies included in this review reported on the effect of eHealth tools on health care use by older adults. The main findings of these studies are shown in Table 2. Screening results from eHealth tools were generally well received by older adults, but several studies suggested that older adults felt anxious about using new technology [37,38,41,44]. In total, 63% of patients in the study by Loh et al [37] found the TouchStream health app, used to deliver geriatric interventions to older adults with cancer, enjoyable to use. A total of 20 participants (87%) in the study by Irizarry et al [44] felt that patient portals were generally useful. Five physicians (56%) in the study by Alpert et al [39] suggested that the investigated patient portal improved patient empowerment. Participants in the study by Portz et al [38] indicated that the Kaiser Permanente patient portal improved patient-provider communication and saved patients time and money. Older women with osteoporosis felt more prepared to make treatment decisions after using the web-based decision-making tool designed and studied by Smallwood et al [42]. Most participants in the same study [42] were able to complete the web-based decision aid, although 5 participants (17%) entered the information incorrectly.

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Table 2. Effects of receiving health information in web-based environment for older adults.

Study	Satisfaction	Perceived harm	Quality of life	Health care use
Alpert et al (2016) [39]	Patients found the portal useful for instantly accessing medical information. This feature accounted for more than half of the positive incidents recorded. Patients appreciated receiving laboratory test	A total of 11% of negative incidents were because of patients having difficulty interpreting laboratory test results. Patients were concerned when information was incorrect or not updated. There were more negative incidents (n=82, 72.6%) than positive incidents (n=31, 27.4%)	Physicians (n=5, 56%) suggested that the portal made patients feel empowered	NS[a]
Irizarry et al (2017) [44]	A total of 87% (n=20) of participants generally felt that the patient portal was useful. Participants with both low and high health literacy expressed interest in portal training. Participants who had experienced chronic illness praised the convenience of web-based laboratory results	57% of participants (n=13) had anxiety and frustrations about using technology because of their perceived lack of technological skills. This caused them to rely on family members to use the patient portal	NS	NS
Loh et al (2018) [37]	Most patients (n=10, 63%) and caregivers (n=8, 73%) enjoyed using the eHealth app to connect with their care providers and manage their health. Most patients or caregivers found the health app easy to use	One patient (6%) suggested that the app may be difficult for someone with less experience using technology	25% (4/16) of patients commented that the app would be most useful for patients living alone	NS
Nahm et al (2019) [41]	NS	NS	Patient portal training improved user health decision-making, patient-provider communication, and eHealth literacy. At 4 months after patient portal training, changes in self-efficacy (P=.02) and patient portal usage (P=.03) were significant	NS
Portz et al (2019) [38]	Users suggested the patient portal was useful for accessing health information and communicating with their health care providers	Users were anxious that program updates would cause the portal to become unfamiliar or too difficult to use	Users believed the patient portal saved them time and money	NS
Smallwood et al (2017) [42]	Participants were able to complete the web-based decision aid with minimal assistance. Subjects who used the decision aid compared with those who did not use it felt more prepared to make decisions about their treatment (P<.001)	Some patients (n=5, 17.2%) incorrectly entered information into the decision tool	NS	NS
Toscos et al (2016) [45]	The mean activation of participants was of the highest possible level (level 4) throughout the study	NS	Patient activation was higher in portal users, but not statistically significant. Portal users showed health improvements at 12 months in HbA_{1c}[b], LDL[c], SBP[d], and DBP[e], but only HbA_{1c} (−0.19; P=.005) was statistically significant. BMI was unchanged throughout the study	NS

[a]NS: not studied.

[b]HbA_{1c}: glycated hemoglobin A1c.

[c]LDL: low-density lipoprotein.

[d]SBP: spontaneous bacterial peritonitis.

[e]DBP: diastolic blood pressure.

Although participants were generally positive about the use of eHealth to receive screening or test results, several studies noted that older adults reported feeling anxious about using eHealth technology [38,39,44]. Participants—especially those with low health literacy—felt afraid to make mistakes because of their lack of technological experience. Many of these patients commented that computer use was not common in their working environment, which accounted for their lack of experience.

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These participants often avoided technology use altogether and preferred a family member accessing their patient portal on their behalf [44]. Participants in the study by Portz et al [38] noted specific anxiety about program updates to eHealth tools that made eHealth tools difficult to use after patients had learned and were comfortable with the tools. Difficulty in interpreting and applying laboratory results was also a concern among older eHealth users [39]. However, several studies noted that patients still enjoyed being able to view their laboratory results on the web [38,39].

Despite computer anxiety being common among this population, many older adults, including those with low health literacy, were still interested in learning how to use a patient portal [44]. Patient portal training may be an important solution to low confidence that prevents many older adults from utilizing patient portals. Nahm et al [41] conducted an RCT and found that a theory-based patient portal e-learning program resulted in statistically significant improvements in patient portal self-efficacy, health decision-making, patient-provider communication, and eHealth literacy 3 weeks after portal training. Patient portal self-efficacy remained significantly higher in the intervention group at 4 months [41]. Participants from several studies recommended providing an instructional video or detailed written instructions to aid platform navigation [40,43]. Participants with both high and low health literacy felt that task-based training programs were a valuable but underutilized tool to increase confidence and knowledge on how to navigate eHealth tools [44].

Objective 2: Designing eHealth Tools for Older Adults

All 9 studies included in this review provided recommendations on how to develop eHealth tools that are intuitive, useful, and engaging for older adults. The specific recommendations can be divided into 3 basic categories: (1) user interface (how the participant interacts with the eHealth tool), (2) functionality (what the participant wants the eHealth tool to do), and (3) information included (what the participant wants the eHealth tool to say). A summary of the recommendations can be found in Table 3.

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Table 3. Older adult and investigator recommendations for eHealth tools.

Theme and study	Older adult recommendation	Investigator recommendation
User interface		
Alpert et al (2016) [39]	• Write information as bulleted lists • Dictionary to look up challenging terminology	• Create an interactive user interface • Use images that represent the information being presented • Use motivational voice, not passive voice
Baier et al (2015) [40]	• If the page requires scrolling to view all the content, add a pop-up to remind the user to scroll down • Allow users the option to increase font size • Results and health information should be easily printed • The web-based apps should be optimized for mobile devices	• Avoid writing in all caps • Use serif fonts • Use contrasting colors to enhance readability • Provide prompts for functions • Write at a sixth-grade reading level, limit technical language • Include definitions for medical terms • Directly label graphs • Limit comparisons with 3-4 points
Jongstra et al (2017) [43]	• Use language that focuses on health rather than disease • Log-in passwords should not be complicated • Include interactive features • Health information should be easily printed	• Use large font size • Use simple and consistent layout with large buttons • Use images and distinct colors to facilitate page navigation • Include audio option
Loh et al (2018) [37]	N/A[a]	• Ensure reliable internet access • Provide stylus for touchscreen devices • Provide a list of voice options if audio included • Optimize the app for mobile phones and tablets • Ensure screen brightness, font and color are easily readable
Portz et al (2019) [38]	• Use larger font and contrasting colors	N/A
Smallwood et al (2017) [42]	N/A	• Automatic entry of patient's lab scores to decrease incorrect information
Functionality		
Alpert et al (2016) [39]	• Ability to communicate with the physician regarding information received on the portal • Seamless and intuitive password retrieval	• Ability for physician to confirm if their patient viewed or understood the information provided to them
Baier et al (2015) [40]	• Add detailed instructions at the beginning of the eHealth tool to help users learn how to navigate the tool	N/A
Irizarry et al (2017) [44]	• Include task-based training to help users understand how to navigate the different features of the patient portal	• Integrate the patient portal with in-person clinical encounters • Allow personnel to edit missing or inaccurate information in the patient portal
Jongstra et al (2017) [43]	• Provide a way for patients to ask questions about navigating the online platform • Include an instructional video to aid in platform navigation	• Include games, goal setting, automated messages among other interactive features to motivate eHealth use
Loh et al (2018) [37]	• Participants found functions including appointments, medications, nutrition, and exercise reminders helpful	• If symptom reporting is included, ensure that feedback is provided on reported symptoms • Provide digital activity tracker when exercise intervention is recommended • Incorporate nonmedical functions such as social activities, jokes, games, etc
Nahm et al (2018) [41]	N/A	• Implement patient portal training for older adults

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Theme and study	Older adult recommendation	Investigator recommendation
Portz et al (2019) [38]	• Participants were interested in using e-visits and chat functions with providers	• Portal designers should consider including functions that integrate eHealth with physical clinic visits
Information included		
Alpert et al (2016) [39]	• Include personalized, not generic health information • Patients appreciated receiving laboratory results but sometimes had difficulty interpreting them	N/A
Jongstra et al (2017) [43]	• Provide practical and reliable health information	N/A
Loh et al (2018) [37]	N/A	• Tailor interventions and activities to the individual
Toscos et al (2016) [45]	N/A	• Apply a user-centered design approach to tailor the portal to the specific population that it is designed for

[a]N/A: not applicable.

User Interface

A total of 7 studies made recommendations regarding how to design a user interface that is accommodating for older adults [37-40,42,43]. Most of the design recommendations suggested how to develop platforms that are easier to read and navigate. Recommendations included using a simple layout with large font, contrasting colors, and images that relate to the content [37-40]. Participants also wanted the technology to work seamlessly, with uncomplicated log-in, the ability to print information, and the ability to use the tool on smartphones and tablets [37,40,43]. Participants not only focused on the visuals and layout but also the tone, with recommendations for eHealth tools to use language that is motivating and positive and focuses on health rather than disease [39,43]. Finally, several studies recommended using an interface that is interactive to engage the user and encourage them to continue using the eHealth tool [39,43].

Functionality

A total of 7 studies identified functions that participants found most useful to be included in an eHealth tool [37-41,43,44]. A common suggestion among older adults was to include detailed instructions within the eHealth tool [20,40,43,44]. Several suggestions were given as to how instructions should be included. Participants in the study by Baier et al [40] recommended detailed written instructions accessible within the eHealth tool. Participants in the study by Irizarry et al [44] suggested that task-based training was most helpful for learning how to navigate the tool. Alternatively, instructional videos and communication methods that allowed participants to ask questions about navigating the platform were recommended by participants in the study by Jongstra et al [43].

Both authors and participants of 3 studies commented that the eHealth tool should be integrated with the in-person clinical environment [38,39,44]. Participants commonly cited the ability to communicate with their physician through the eHealth tool as an enjoyable and useful feature [38,39]. Physicians generally felt that the patient portal empowered patients, but they wanted the ability to confirm if their patient viewed and understood the information provided to them via the eHealth tool [39]. Portz et al [38] suggested using face to face or phone time to encourage portal use in patients.

Finally, 2 studies recommended including fun, interactive features such as games, jokes, social activities, or automated motivational messages to promote tool use and make the tool more enjoyable for older adults [37,43].

Information Included

A total of 4 studies made recommendations regarding which information older adults found most useful to include in an eHealth tool [37,39,43,45]. Two studies found that personalized health information is more useful and engaging for older adults than generic health information [37,39]. Toscos et al [45] suggested that applying a user-centered design approach to the development of eHealth tools may promote the inclusion of information that is more tailored to older adults. Participants also wanted practical and reliable health information included in the eHealth tool [43].

Discussion

Principal Findings

The aims of this systematic review were two-fold. First, we were interested in understanding how receiving health screening in a web-based environment without the presence of a health care provider affects satisfaction, perceived harm, quality of life, and health care use by older adults. Second, we were interested in consolidating evidence-based recommendations on how to design eHealth tools that are useful and engaging for older adults. We found that older adults generally had positive experiences with receiving test results via eHealth tools, and numerous features have been suggested to enhance patients' web-based experiences. Although much literature is available on the impact of eHealth tools for younger patients, older adults represent a unique subgroup of patients whose needs differ greatly [46-48]. To the best of our knowledge, there are currently no systematic reviews on the effects of receiving health screening or results via eHealth tools either on older adults' health care satisfaction, perceived harms, quality of life, or health care use or on the optimal design for eHealth tools for older adults. It is important to understand the unique experiences

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of older adults because they are often less proficient with technology than younger patients are and may require different supports [49]. As a rapidly growing population of health care consumers, older adults are positioned to benefit greatly from the use of eHealth tools if these tools are designed in ways that are attractive to older adults.

From the 9 studies included in our review, several key themes emerged. Multiple studies noted that while older adults were generally optimistic about eHealth tools, lack of technology experience and fear of failure were barriers to use [37,38,44]. Both older adults and researchers recommended detailed instructions and comprehensive training to improve older adults' confidence in using eHealth tools [40,41,43,44]. Although it is encouraging that most older adults found receiving screening tests and results via eHealth to be useful, there is currently not enough research available to draw conclusions on the impact of receiving test results in a web-based environment without the presence of health care providers on older adult satisfaction, perceived harm, and quality of life. The possible harms of providing older adults with screening results via eHealth tools are anxiety caused by technology use, confusion among older adults who may be unable to interpret their results, and disparity caused by those who are less likely to benefit from eHealth tools because of low technology or health literacy. We were unable to find any information on the effect of eHealth screening tools on older adult health care utilization and hence cannot recognize any trends or draw any conclusion on health care use.

There were substantial recommendations from the studies included in this systematic review on how to design eHealth tools for older adults. A user interface that is accessible and intuitive to older adults is imperative for promoting tool uptake and use and was the most commonly made recommendation provided by older adults. Further recommendations included ensuring that the layout and text used in the tool is accessible to users with vision or hearing impairments and is logical to those with less technological experience. Furthermore, eHealth tools should be enjoyable for older adults to use. Designing a tool that includes interactive features, uses a positive tone, and ensures a seamless technological experience creates an environment that promotes eHealth tool uptake.

To promote eHealth use among older adults, the tools must provide functions and content that are useful for older adults. Participants emphasized the importance of integrating the eHealth tools with the physical clinic environment by facilitating communication with their physicians. Older adults suggested that personalized information, interventions, and activities were more useful and engaging than generic recommendations.

How Does This Compare With the Literature?

Although there are several systematic reviews that investigate the effect of eHealth tools on healthy aging outcomes such as physical activity, diet, and psychological well-being [50-52], we were unable to find a systematic review that investigated the effects of receiving screening results without the presence of health care providers in older adults. Furthermore, we were unable to find a systematic review that consolidated evidence-based recommendations for designing eHealth tools for older adults. Kampmeijer et al [53] completed a systematic review on the use of eHealth tools in health promotion and primary prevention for older adults. Similar to our findings, Kampmeijer et al [53] found that usability and accessibility were important facilitating factors in older adults' use of eHealth tools [53]. Buyl et al [52] completed a systematic review on the effect of eHealth interventions on healthy aging outcomes such as physical activity, psychological well-being, and overall health. Similar to our study, Buyl et al [52] were unable to draw conclusions on most health-related outcomes as they also found the quality of studies to vary considerably and the certainty of evidence to be low. However, Buyl et al [52] found that eHealth tool use improved older adults' physical activity. Strengthening digital competency was a critical component of encouraging eHealth tool use among older adults, which is similar to our finding that older adults desire training programs to feel confident in using eHealth tools. However, our study differs from those by Buyl et al [52] and Kampmeijer et al [53] because both studies investigated eHealth tools that encouraged physical activity, psychological well-being, and primary prevention strategies for older adults, whereas we investigated tools that provided screening results to older adults without health care providers present. Furthermore, Narasimha et al [54] completed a systematic review of the optimal design of telemedicine for older adults. Encouragingly, the authors found that older adults were generally positive about their experience with telehealth, although a lack of confidence with technology and physical impairments (for example, hearing difficulty) proved to be a challenge. These results are similar to our findings that although older adults are optimistic and willing to use eHealth tools, designing tools that accommodate common physical impairments and include training are important for user confidence and uptake. Our systematic review is different from Narasimha et al [54] because we investigated evidence-based recommendations for developing eHealth tools, not telemedicine.

Limitations

After removing duplicate and irrelevant papers, a small number of studies were used for our final analysis, which limits the generalizability of our findings. Although many titles and abstracts were found, we applied the RCT filter as we were interested in studies that examined the intervention ideally to a comparator group. However, few studies used an RCT design, and 4 studies used a qualitative design. By applying the RCT filter, it is possible that we may have missed additional qualitative studies. However, the gold standard for evaluating interventions is the RCT design, and these studies, including quasi-experimental studies, would have been identified in our search. Furthermore, most of the studies used convenience sampling to recruit participants, which introduces significant selection bias. In addition, the studies often had small sample sizes of less than 100 patients. These limitations further constrain the applicability of the results to larger and more diverse populations. Finally, many studies did not look at the sustainability of portal use, or the duration of follow-up was not reported. Therefore, it is unclear if any benefits that were identified are sustained over a significant period.

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Implications

Our findings suggest that although older adults are generally satisfied with receiving screening tests and results via eHealth tools, improper design, and lack of confidence with technology are common barriers to use in this population. Patients and caregivers should initially receive basic training on how to use eHealth tools to mitigate patient concerns (eg, about complex user interfaces) and minimize the impact of low computer literacy. To optimize the usability of eHealth tools, they should include customizable features (such as alerts, medication reminders, and appointment scheduling) as well as easy-to-read displays (eg, with large fonts and contrasting colors). In addition, eHealth tools should be integrated with physical clinic visits to facilitate communication between patients and their health care providers. By incorporating these features routinely into the design of patient portals, older adults will be more likely to embrace technology that can potentially improve their health. However, our review demonstrates that the literature on this topic remains sparse, and there is a need to further study the effects of eHealth tools on important patient-centered outcomes such as satisfaction, perceived harm, quality of life, and health care use. Older patients highly value the ability to remain at home, and avoiding emergency room visits and hospitalizations, making this an important outcome to consider in research involving older adults [8-10].

The findings from this systematic review will aid in the design of our CHAMP tool for older adults with cancer. Notably, one aim of this systematic review was to understand the impact of receiving test results in a web-based environment without the presence of health care providers on older adults. Although older adults generally appreciated receiving their results on the web, several studies noted that older adults desired the option to review their results with a health care professional. This supports our proposed CHAMP tool in which patients will use the tool to receive health care recommendations specific to their needs. Patients who are in high need of geriatric interventions will be identified and triaged to see a geriatrician. Those who are determined to have a low need for geriatric support will receive evidence-based recommendations determined by their unique health care needs and goals. These patients may also use the findings and recommendations of the CHAMP tool in discussions with their primary practitioner or oncologist. Hence, both low- and high-risk patients have the option to review and discuss the findings from the CHAMP eHealth tool with a health care professional.

The abundance of design recommendations made by older adults in the studies included in this systematic review will aid us in designing the CHAMP tool in a way that is most intuitive for older adults. Several design recommendations such as goal setting, live chat functions, and interactive games are more suited toward eHealth tools that are meant to be used longitudinally, whereas the CHAMP tool will be a one-time eHealth screening tool. However, these recommendations are still useful for researchers designing longitudinal eHealth tools for older adults.

Recommendations for Future Research

The development and use of eHealth tools among older adults are an understudied area with an opportunity for more learning, particularly given the growing uptake of eHealth tools by older adults [55]. Currently, there is not enough research available to draw conclusions about the impact of receiving test results on the web on outcomes such as satisfaction, perceived harms, quality of life, and health care use for older adults. Future studies should investigate these outcomes in controlled trials that examine the impact of receiving test results on the web without a health care provider present. Future studies should also use random sampling methods that allow for greater generalization of the results. Finally, we were unable to find any research on the long-term implications of eHealth tools on the health and well-being of older adults or on health care use. Future studies should incorporate long-term follow-up and include health care use as an outcome to understand the extent of the benefits of eHealth tools.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
MEDLINE search.
[DOCX File , 16 KB - aging_v4i1e24092_app1.docx]

Multimedia Appendix 2
Quality assessment of included studies assessed with the Mixed Methods Appraisal Tool.
[DOCX File , 15 KB - aging_v4i1e24092_app2.docx]

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Abbreviations

CHAMP: Comprehensive Health Assessment for My Plan
mHealth: mobile health
MMAT: Mixed Methods Appraisal Tool
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-analyses
RCT: randomized controlled trial

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Original Paper

Impact of Social Media on Health-Related Outcomes Among Older Adults in Singapore: Qualitative Study

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Abstract

Background: The worldwide spread of digitalization has led to the harnessing of technology to improve health outcomes. Paying attention to older adults' social needs via social media is one way to promote healthy aging. Although 56% of older adults are smartphone users, little is known about their use patterns of social media.

Objective: This exploratory study aims to determine the experiences of social media apps' use among older adults in Singapore and understand their perceptions of its impact on health-related outcomes.

Methods: This study used a qualitative research design with an interpretative approach. Using maximum variation purposive sampling, normal aging older adults (N=16) who were aged between 60 and 80 years and experienced in the use of internet-enabled technology were recruited from an existing community study. Semistructured, in-depth interviews were conducted. Employing a thematic analysis, interviews were transcribed verbatim and analyzed for codes inductively.

Results: The following themes and subthemes were identified as key moderators of older adults' experiences on social media apps: (1) personal attitudes: participants were encouraged to use social media due to the increased accessibility, which enabled the ease of contact, but perceptions that the quality of interactions was compromised and its associated risks reduced their use; and (2) social influences: the desire to bond with co-users and the availability of support increased use. In addition, use of social media apps was perceived to positively impact health through its ability to keep older adults cognitively engaged, improve health communication, and increase social connectedness. However, opinions remained mixed on older adults' vulnerability to social media addiction.

Conclusions: Personal and social contexts determine older adults' social media use. This study's findings provide practical insights into how social media can be deployed to improve health-related outcomes in older adults.

(JMIR Aging 2021;4(1):e23826) doi:10.2196/23826

KEYWORDS

aging; social media; health; qualitative research; communication; mobile phone

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Introduction

Background

Technological advances provide opportunities to meet the social needs of older adults and to educate and empower them on health-related matters. Social media refers to internet-based platforms that use an electronic means of communication to enable social interactions via the consumption, generation, sharing, and exchange of ideas and content by users within their virtual communities [1]. It includes social messaging apps (eg, WhatsApp), social networking sites (SNSs, eg, Facebook), and media-sharing apps (eg, Instagram). These platforms yield benefits over traditional communication modalities, such as telephones and regular text messaging, as real-time updates and communications are not bound by geographical distances [2]. The audiovisual functionalities of social media permit the sharing of pictures, videos, and audio recordings, which trigger the realism of depicted activities and increase feelings of being *socially present* [3]. In addition, the level of interactivity offered on SNSs is positively associated with greater social bonding with family members [4].

The internet is a preferred source of health information for older internet users [5,6], rendering it a potential tool to improve health communications for older adults. Health blogs and online support groups on SNSs could serve as useful resources for disease management in older adults [7,8], psychological well-being [9], and cognitive functioning [10,11]. However, there is limited research investigating the potential negative health impact of social media among older adults.

The feasibility of social media as a health promotion tool depends on the acceptance of technology. The traditional view is that a digital divide exists [12], with older adults typically being slower than younger adults in adopting new technology. Although research suggests that functional limitations such as cognitive impairment limit capacities to adapt to new technology, older adults are more likely to adopt the technology if they are personally interested and willing to invest in the effort to learn and use the technology [13-15], possess beliefs in self-efficacy [16], and are socially motivated to engage in intergenerational communication with family members [4,13,17]. Fears of privacy breaches [13,14,17,18], a lack of confidence [15,19], and perceptions that web-based communication is trivial [18,19] are some barriers to social media use. These findings indicate that social media use largely hinges on older adults' own attitudes and beliefs, implying an artifactual digital divide that can potentially be overcome.

Objectives

One of the ways to access social media is the use of social media apps on smartphones. In Singapore, approximately 56% of those aged 60 years and above are smartphone users; 73% have used it to access internet-enabled platforms, including social media apps [20]. Furthermore, Singapore has actively pushed to become a *Smart Nation* with several initiatives to increase information technology literacy in seniors, including short courses to promote skills learning (eg, operating a smartphone) and becoming *social media–savvy* [21]. From a public health perspective, with the growing adoption of smartphones and Singapore's move toward a *Smart Nation*, it appears that social media apps could be tapped on as useful platforms to promote health-related outcomes among older adults. An understanding of older adults' perceptions of social media apps could also enable us to evaluate the utility of social media apps as health promotion tools in this age group.

However, despite the potential offered by social media apps, there seems to be scarce literature investigating older adults' perceptions and attitudes specifically toward social media apps. Although a previous local study examined smartphone adoption and identified generally positive attitudes toward smartphone use among older adults [22], it is unclear whether smartphone use encompasses use of social media apps. Furthermore, much of the current research focuses on attitudes toward either SNSs only (eg, Facebook) [17] or technology acceptance in general [13]. Hence, this study seeks to extend the literature by (1) exploring the experiences of older adults in Singapore in their use of social media apps in enabling interactions and (2) understanding their perceptions of how social media app use influences health-related outcomes. As this was an exploratory study, no a priori hypotheses were made.

Methods

Study Design and Sampling

This study employed a qualitative research design with an interpretative approach. The study sample was recruited from the Community Health and Intergenerational (CHI) study of community-living older adults aged 60 years and above in Singapore [23]. The CHI study is an existing 3-year cohort study that aims to comprehensively investigate health profiles of 1000 older adults by looking at the biological, psychological, and social factors associated with the aging process [23].

The following inclusion criteria were established: (1) age between 60 and 80 years, (2) normal aging (established in neuropsychological tests in the CHI study), and (3) experience with use of internet-enabled technology (determined by smartphone ownership and ability to operate it). In addition to the above, maximum variation purposive sampling was used to ensure diversity of views and opinions. To this end, key participants from different genders, age groups, language of communication, and living arrangements were selected from the list of eligible participants who met the inclusion criteria.

Procedure

Written informed consent was obtained from all participants. At the start of each interview, participants were asked to list the social media apps they used and indicate the frequency of use of each app (to quantify use patterns). Semistructured, in-depth interviews were conducted with an interview guide (Textbox 1), which was developed from a systematic review of factors found to influence technology adoption to support aging-in-place [24]. Participants also answered additional questions on their social media use and its impact on health.

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Textbox 1. Interview guide (factors and examples of interview questions).

Concerns regarding technology and benefits of technology

- "Can you give me an example of a benefit/drawback of social media?"

Need for technology

- "What made you decide to start using social media?"
- "What do you use social media for?"
- "(For low-frequency users) Why do you feel that social media is not important to you?"

Available alternatives to technology

- "What are the differences between social media apps and traditional communication platforms?"
- "If there is no social media, how do you think your communication would be like?"

Social influences

- "How do your friends/family members feel about your social media usage?"

Impact of social media use on health

- "In your opinion, do you feel that social media has any direct or indirect impact on health?"
- "Can you give me some examples of a time when you felt that social media affected your health?"

Interviews were conducted by a single trained interviewer in either English or Mandarin and were audio recorded. Participants were free to respond in colloquial speech [25]. Data analysis was conducted concurrently with the interviews, and recruitment ceased when thematic saturation was reached with 16 participants (S01 to S16). Interviews lasted approximately 1 hour and 2 minutes (SD 13.4 minutes) and were conducted between February and May 2019. Ethics approval was granted by the National University of Singapore Institutional Review Board (S-18-379).

Data Analysis

Interviews were transcribed verbatim. To mitigate reporting bias on time spent on social media, transcripts were further examined for details of older adults' use patterns before categorizing into low, average, and high. A thematic analysis with an inductive approach was used to identify and categorize codes using the QSR NVivo 12 software [26]. The transcripts were coded line by line. Two coders were involved in data coding and analysis. To increase inter-rater reliability, one coder coded 5 random transcripts, whereas another coded the rest. The coders then discussed the preliminary codes, subthemes, and key themes that emerged and resolved discrepancies to ensure coherence in the interpretation of the themes. Transcripts were reread, and coding ceased when further analyses did not produce new codes.

Two interviews conducted in Mandarin were translated directly to English by an independent research assistant proficient in both languages. These transcripts were cross-checked to ensure that there were no discrepancies and that nuances in communication were captured appropriately.

Results

Overview

A total of 16 participants participated in this study. Table 1 summarizes the sociodemographic information of the participants. All participants used multiple social media apps. Of the 16 participants, 100% (16/16) used Facebook and WhatsApp, 69% (11/16) used YouTube, 31% (5/16) used Twitter, and 25% (4/16) used Instagram. Participants were categorized into low-, average-, and high-frequency social media app users based on the time spent on social media apps per day and their use patterns. Among the 16 participants, 31% (5/16) were low-frequency users (spends <1 hour on social media apps per day and uses social media apps on the move), 44% (7/16) were average-frequency users (spends at least 1 hour on social media apps per day and uses social media apps on the move), and 25% (4/16) participants were high-frequency users (spends at least 1 hour on social media apps per day and sets aside dedicated times to use social media apps).

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Table 1. Sociodemographic data of participants (N=16) and the distribution of social media use by sociodemographic groups.

Characteristics	Total sample (N=16), n (%)	Social media use per characteristic		
		Low, n (%)	Average, n (%)	High, n (%)
Gender				
Female	8 (50)	2 (25)	3 (38)	3 (38)
Male	8 (50)	1 (13)	4 (50)	3 (38)
Age group (years)[a]				
60-69	12 (75)	4 (33)	7 (58)	1 (8)
70-79	4 (25)	1 (25)	N/A[b]	3 (75)
Language of communication[c]				
English	14 (88)	5 (36)	5 (36)	4 (29)
Mandarin	2 (13)	N/A	2 (100)	N/A
Housing type				
1-2 room public housing	3 (19)	2 (67)	N/A	1 (33)
3, 4, or 5 room public housing	4 (25)	1 (25)	2 (50)	1 (25)
Executive apartment or maisonette	2 (13)	1 (50)	N/A	1 (50)
Private housing	7 (44)	1 (14)	5 (71)	1 (14)

[a]Mean age 66.19 years (SD 5.69).

[b]N/A: not applicable.

[c]Mean schooling 15 years (SD 3.41).

The findings revealed 2 main issues related to social media apps' use among older adults. First, we found that social media apps' use among participants was moderated by personal attitudes and social influences. Second, participants perceived social media apps' use as both positive and negative influences on health-related outcomes.

Social Media Use Moderators

Two major themes were found to be key moderators of participants' social media apps' use: (1) personal attitudes and (2) social influences. Each theme was further divided into subthemes, representing factors that determined the frequency of social media apps' use (Table 2).

Table 2. Overview of themes and subthemes: older adults' experience in their use of social media apps.

Theme	Subtheme	
	Increases use	Reduces use
Personal attitudes	• Accessibility in enabling ease of contact	• Compromised quality of communication • Perceptions of risks
Social influences	• The desire to bond • Availability of support	N/A[a]

[a]N/A: not applicable.

Theme 1: Personal Attitudes

Accessibility in Enabling Ease of Contact

All 16 participants unanimously agreed that with the advent of social media, initiating contact with peers and loved ones and group communications is easier compared with the past when they only relied on traditional modes of communication, such as text messaging and phone calls:

> *In my parents' time, he (father) had to make an effort to call his friends,...somebody must organize for them to meet. Whereas now with WhatsApp, it's just a touch of the phone!* [S02]

As most social media apps have no cap on use and are free to use, it encouraged more liberal and frequent contact. Participants expressed an overt preference for them:

> *Some people call in must pay. So they tend to have the phobia there that you call me, they dare not talk long.* [S13]

Compromised Quality of Communication

Some participants (n=3), however, perceived the quality of communication over social media to be compromised. It did not afford the same kind of emotional intimacy, such as "the feeling of the other person" that face-to-face interactions provide

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(S16). Even traditional communication tools, such as phone calls, were perceived as "more personal" (S13).

Ironically, the ease of contact led participants to perceive web-based interactions as brief and superficial in nature:

> *You want to wish people, you just put a picture then "happy birthday"—there is no contact, nothing. I'd rather call the person. The sincerity is not there.* [S06]

Insofar as a willingness to share, social media provides unfiltered access to the personal moments of one's lives in real time. Some participants (n=6) perceived such communication to be trivial and excessive, noting that it "takes up a lot of the person who has to look at it, but may not be interesting enough" (S16). Describing them to be "active in a very senile way" (S12), some participants (n=3) expressed their annoyance at peers who exhibited such tendencies and actively avoided their content when surfing social media:

> *I have this friend; she would upload all her photos on her Facebook. Full 80 photos..., what is the purpose? I wouldn't bother to look through.* [S11]

Perceptions of Risks

As new adopters of digital technology, several participants (n=11) stated that they are vulnerable to risks, as social media permits unfettered access to others whose intentions remain unknown. Participants pointedly refrained from self-disclosure on social media and took precautions to avoid posting self-identifying details:

> *I always tell them not to do too much (posting of personal photos), there are people who edit and put funny things inside.* [S13]

Yet, while exercising caution in their posting habits and being selective in who they added to their networks, participants remained undeterred by security risks, as they "enjoy reading other people things on Facebook." Moreover, S11 highlighted the importance of context in allaying these fears. The knowledge that Singapore is a relatively safe and crime-free country meant that she did not perceive being *open* on social media as a threat:

> *Privacy to me, there is nothing to fear. Singapore is safe-lah. If I were in [name of country], I wouldn't dare to be so active.* [S11]

Theme 2: Social Influences

Two main social influences shape older adults' experiences on social media apps: (1) the desire to bond with co-users and (2) the availability of support from their social network.

The Desire to Bond

All participants (n=16) cited keeping up with others as the primary motivation in their social media use. Older adults saw its adoption as an opportunity to bridge the intergenerational communication gap and to bond with younger family members:

> *Because I see the children using, I just want to link with my grandchildren.* [S14]

Even for participants who were minimally active in their use by choice, they raised a caveat that despite their aversion, they valued the access granted by these platforms to be more involved in their family's lives:

> *Another motivation is like my friends say there are things that my children are doing but I don't know. I better get on to see what they are doing.* [S08]

Availability of Support

Participants reported the availability of different sources of support as motivation to use social media. These included family members (n=5) and peers (n=6). For example, when encountering difficulties with social media, participants would enlist the help of younger members of their social networks deemed to be "more knowledgeable" (S03). One participant credited her proficiency in social media use to being "lucky to have children"; she could easily learn by simply "ask(ing) them and they will tell me and teach me" (S11). The converse view was validated by S08, who cited the lack of support from her "less than encouraging" children as a reason for her lack of presence on these apps:

> *My children will only say, nobody teach me how to do it. Because of that, I'm still not on it.*

As with family, peer influence was important in shaping older adults' experiences. Digitally literate peers were usually the first point of contact for participants to learn about new social media apps:

> *Normally is friend recommend—my group of friends say, we use this app, so I will use.* [S01]

Participants exhibited greater willingness to use apps introduced by these peers and judged their recommendations as safe. As S01 explained, "Should be they (peers) won't harm you-lah." Often, these peers were the *go-to* people when participants needed help with the apps, if their children were too *impatient* or *fast* for them to follow. This support was emphasized by S07, who noted that although his own family members were "quite discouraging" when he attempted to grasp the use of Facebook, his colleagues rendered assistance to him and helped to "start (an account) for him."

Novice peers were equally important in facilitating social media use. S13 explained that the support she received from her peers while learning together in a group setting had a positive effect on her emotional well-being:

> *It helps me in that I'm not the only one that my grandchildren are not helping, I always have to go to friends, I'm not the only one. You don't feel neglected.* [S13]

Perceived Influence on Health-Related Outcomes

Participants perceived social media apps' use as both a health benefit and a health threat. Specifically, social media use was perceived to bring about positive outcomes, as it keeps older adults cognitively engaged, improves health communication, and increases social connectedness. Opinions remained mixed on whether social media addiction was perceived as a potential health threat among older adults.

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Theme 1: Cognitive Engagement

Social media use allowed older adults to remain cognitively engaged. Some participants noted that social media use provided an avenue for them to acquire new skills and keep cognitively engaged postretirement (n=11), whereas others noted that social media use helped them to maintain their language skills (n=2).

Although it was daunting to grasp new knowledge and learn to use multiple functions, participants reported being motivated to learn more and sign up for courses. They viewed these learning opportunities as helping them stay "alert" (S13), such that "they won't go senile and get dementia" (S05). Older adults perceive user-generated content on social media apps as a means to compensate for the lack of cognitive engagement as they transit into retirement. For instance, S03 described the experience of posting photos on Instagram as a way to "see your creativity" with his photography skills. Beyond developing technical expertise, the spread of fake news and misinformation on social media hones older adults' abilities to judge the credibility of its content:

> *You know how to differentiate whether good or bad. Not all news give(s) you the correct information, so you're more sharp of that.* [S03]

Other participants cited concerns over their linguistic abilities post retirement and viewed social media posting as a way to "sharpen the brain," such that "the spelling, the use of words will not be dropped off from your memory" with old age (S08).

S12 credited social media use to provide an outlet for him to articulate his opinions on news topics, which allowed him to practice his writing and thinking skills:

> *Being able to even write things every day. How you construct a sentence, how you convey an idea...it should help with your cognitive ability.*

However, S12 highlighted that those who "are the type who just forward" may not be cognitively engaged if thinking is not involved.

All participants (n=16) acknowledged that they used social media as an alternative news source. As S08 explained, social media is an additional channel to receive up-to-date news, more than what she would have been exposed to via traditional media:

> *It does get me into reading more than what I'm already reading or watching.*

Theme 2: Health Communication

Participants agreed that social media increased their accessibility to a wealth of health knowledge. This ranged from common health information on nutrition (n=4), complementary and alternative medicine (n=6), or advice that advocates engagement in behavior (eg, special exercise techniques) to prevent age-related decline (n=2):

> *They give you like what (health food) to eat more, what fruits are good, bad..., like "oh eat more ginger."* [S01]

Participants particularly appreciated the access to individuals who they saw as unofficial health experts and perceived health information from these sources to be more valuable than those from their own clinicians. As S14 remarked:

> *All doctor(s) want you to pay money one.*

However, some participants (n=2) acknowledged that with the ease of posting on social media, information circulating on social media is largely unfiltered and can be *contradictory.* The experience of trying to discern the legitimate sources of health information was *confusing* for some, and they explained the following:

> *For every information they share, the video says it's good, there's another one that says it's not good.* [S12]

A few participants (n=5) opined that as older adults, they are cognizant of this and are "mature enough not to fall into the trap." (S02). Some (n=3) attempted to cross-check with other news sources, such as other media platforms, to establish its veracity:

> *Sometimes I go YouTube to check whether true or not.* [S01]

One participant regarded traditional news media as a source of scientific authority and used it as a heuristic in deciding on what they read was believable:

> *When I see on TV the news is correct. But other news like Panadol, they say don't take because can cause what, I won't forward. Because I didn't see in the news.* [S13]

Theme 3: Social Connectedness

S02 opined that in the past when the quality of information and communications technology (ICT) was weaker, opportunities to socialize tended to diminish with age because it was difficult to sustain interactions on a regular basis. In contrast, with social media, the ease of contact meant that its frequency will consequently increase, enabling tangible opportunities for interactions and allowing relationships to withstand time:

> *Look at my mother, she retired not into social media, her world became smaller and smaller. I think when I reach 80, I would have a wider base because of social media.* [S02]

Moreover, older adults appreciated that they were able to harness the power of social media to improve or expand existing social networks (n=9). A core feature of SNSs is that they aid the discovery of lost contacts, and few participants (n=7) reported becoming reacquainted with individuals they had previously lost touch with. Recounting an episode where she reconnected with some ex-classmates from an old photo that was posted on a Facebook alumni page, S01 noted:

> *I feel good. It's just to get to know my own friends, some maybe pass away already, or they have been doing well. I just want to know their well-being only.*

Importantly, this initial contact facilitates offline interactions as well. S11 related:

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> *...through Facebook, I got connected to my school friends (from [name of country]). We managed to meet up and have a reunion!*

However, S06 felt that the increased reliance on web-mediated interactions worsened the quality of relationships in real life:

> *People get so distant. Social media doesn't help you to be a social person, it gets you more onto a machine.*

Theme 4: Addiction

Participants were divided on whether social media addiction was a consequence of its use. One participant reasoned that as older adults grew up in an era where the use of technology was less integral to everyday life, older adults would be less dependent on social media and did not perceive addiction to be a problem for their age group:

> *They don't have this habit from young. They picked up the knowledge only in the later stage. So it is something extra, rather than essential.* [S09]

Others (n=4) felt that due to their life experiences, older adults are more likely to be more "disciplined" and "aware" of the frequency of use of their smartphones as compared with youths (S02). As such, they are better able to manage the time spent on social media more effectively.

Nonetheless, with the wide variety of social media apps and the wealth of information and functions each offer, some participants (n=4) noted that new users could become deeply captivated by social media to the extent that they may be inclined to overuse it. As S05 explained:

> *Those who start to explore, go deep into it.*

Other participants (n=4) reasoned that with postretirement, the amount of leisure time at older adults' disposal significantly increased, allowing them to spend more time on other activities. These participants found themselves vulnerable to the allure of social media:

> *At one stage, I was doing this too much. Older people, especially when you are free you see. So, you tend to answer, do this.* [S13]

Discussion

Principal Findings

This study extends prior work by investigating older adults' perceptions of social media in Singapore, with a particular focus on social media apps' use. Consistent with existing literature, older adults' social media use depends on personal and social contexts [13]. Despite perceived security threats, personal contexts such as personal attitudes and accessibility to communications encouraged social media use. In addition, older adults reported the desire to bond and support from others as motivations for using social media.

Of particular interest to our study are the health-related outcomes brought about by social media use. The remainder of this discussion, thus, focuses on these outcomes and the accompanying consequences. The utility of social media in health promotion for older adults, particularly in the area of healthy aging, was also evaluated.

Social Media and Health-Related Outcomes

Cognitive Engagement

In this study, the role of cognition in influencing social media use was apparent—social media provided an avenue for older adults to remain cognitively engaged, while reducing their fears of future cognitive deficits. Other studies have also found that the acquisition of technical skills through social media use was associated with better neuropsychological test scores among novice older users [10,11]. Some have posited that an association exists between sociality and cognition, such that interacting with others improves cognitive functioning due to the multiple inferential processes involved [27,28]. The increased frequency of contact enabled by social media could be a possible mediating factor between sociality and cognition.

Improved Health Communication

Social media can be used for health communication purposes owing to its wide reach and availability of different sources of information. Interestingly, although one could obtain health information from formal sources such as physicians and health institutions, older adults appreciated the ability to acquire health information from informal sources via social media, such as individuals they deem as unofficial health experts. This highlights the importance of social relations in health communication—older adults are more likely to seek and obtain health information from individuals with whom they are socially connected (including both web-based and offline relations), compared with those who they have no connections with (eg, formal health sources). With the ability to connect to informal health sources via multiple channels, health communication is enhanced with social media use.

Although there is increased access to health information, those provided by informal sources may not be scientifically accurate, rendering the evaluation of their legitimacy challenging [29]. In addition, the sensationalism of health news [30] and the brevity of social media news increase the likelihood of readers receiving false information from them. Older adults are often vulnerable to web-based scams, and those aged above 65 years have been found to be 7 times as likely to share fake news than younger users [31]. Although older adults are aware of the need to establish the veracity of news encountered on social media, their strategies in doing so may be questionable. This suggests the need for further interventions to foster digital literacy skills among older adults to help them better evaluate health news. Different strategies, such as face-to-face classes and blended learning workshops [32,33], could be adopted to teach digital literacy skills to older adults.

Increased Social Contact and Connectedness

This study indicates that the accessibility of social media in enabling communication and its consequent increase in social contact present a means to preserve dispersed social relationships as older adults transit into retirement. Additional social contact could enrich the quality of social relationships and enhance emotional well-being, as evidenced by studies that found that SNS use was associated with perceptions of feeling valued and supported through their social networks and deriving greater satisfaction with life [34,35].

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However, an increase in social contact may not necessarily translate to social connectedness. This is dependent on the motivations behind social media use: whether engagement with others is motivated by the *reward* of prospective social ties or by the desire to avoid the negative feelings associated with social isolation [36]. For the former, social media strengthens relationships and increases social connectedness. For the latter, time spent on social media is seen as time spent away from real-life interactions, which are perceived to generate greater value [36]. Moreover, if efforts made to initiate web-based contact with other co-users are not reciprocated, the effectiveness of social media in improving social connectivity may be limited [37].

The varying views of the value of web-based social interactions suggest that social media supplements, rather than replaces the need for offline, face-to-face interactions. As can be seen from our findings, those with positive social media experiences emphasized the ease of facilitating offline interactions (eg, reunions with acquaintances or meet-ups with their social circles) as a key benefit of social media. Thus, for social media use to be meaningful, web-based interactions should be positive; rewarding; and present opportunities for fostering additional offline, face-to-face interactions. Beyond encouraging social media use, future intervention programs should also aim to provide more opportunities for older adults to connect with others through offline interactions.

Risk of Addiction

Social media addiction, characterized by its excessive use and lack of self-control over use habits, is a potential health concern. Although little has been elucidated for older adults, a Norwegian study reported that approximately 1% of those aged 60 to 74 years were found to be at risk for internet addiction [38]. The prevalence of internet and social media addiction is expected to rise with the rapid spread of digitalization today. Considering this, the findings of this study that some older adults perceive themselves as invulnerable to social media addiction and the possibility of excessive social media use due to an increase in leisure time postretirement warrant concerns.

Social Media and Healthy Aging

Potential in Reducing Social Isolation and Loneliness

Older adults are often at a high risk of social isolation, as their social networks begin to shrink. In Singapore, 73.4% of older adults are at least at a moderate risk of social isolation [39]. Furthermore, social isolation is associated with poorer health and cognitive outcomes such as increased mortality and multimorbidity risks [40] and increased risk of developing dementia [41]. Thus, social isolation is a public health concern.

Older adults with physical disabilities are at an even higher risk of social isolation. Nonambulant individuals are physically limited in the range of social activities they can engage in [42], whereas those with hearing disorders may deliberately choose to socially withdraw due to potential difficulties in verbal communication [43]. For these individuals, social media may be an effective tool to facilitate social interactions and contact, as they will not be bounded by physical spaces or abilities. Previous studies have cited the successful use of internet training and access in reducing social isolation [44-46], suggesting the possibility of tapping on digital technologies and platforms for potential interventions. Future research could explore how social media could be used to ameliorate social isolation among older adults, especially those with physical disabilities.

Although often conflated, social isolation and loneliness are 2 different states. The former is a quantitative measure of social network sizes, whereas the latter is the subjective feeling of being socially isolated. In Singapore, even among older adults deemed to be at low risk of social isolation, 44.7% were *sometimes lonely* or *mostly lonely* [39], highlighting the different social needs of these 2 groups. At present, evidence supporting the effectiveness of social media in reducing loneliness remains mixed [47,48]. Furthermore, the greater visibility into the lives of their contacts afforded by the increased access on social media may abet upward social comparison and intensify feelings of loneliness [49]. Future research could be directed toward elucidating how lonely older adults perceive social media use, to determine its utility in meeting their social needs.

Support for Learning

It is crucial to ensure a conducive learning environment (with instrumental support) for older adults. The formation of peer learning communities could prove to be beneficial, where social media literate older adults could be engaged as volunteers to support novice users in their learning on using social media. The utility of peer learning in seniors is well documented [50-52]. Specifically, in the area of ICT, even the most proficient seniors would have encountered similar experiences in their initial forays into social media and would thus be better positioned to advise new users on the knowledge of social media apps than the younger generation [53]. Venues such as senior activity centers could be tapped upon to facilitate these group sessions.

Role in Successful Aging

According to Rowe and Kahn [54], successful aging comprises 3 components: maintenance of physical and cognitive functioning, delayed onset of diseases and disability, and continued engagement in social relations and meaningful activities. Although cognitive and physiological deficits experienced in older adulthood are results of age and genetic predispositions, modifiable extrinsic factors such as lifestyle habits play a part as well. Social media use could, therefore, act as modifiable factors and potentially promote successful aging by providing older adults an avenue for cognitive engagement, while facilitating meaningful web-based and offline social interactions at the same time [54]. Moreover, as older adults value the importance of contributing back to society [55], the aforementioned recommendation allows older adults to remain engaged in meaningful activities when they volunteer to assist their peers on social media navigation.

Strengths and Limitations

One of the strengths of this study was the strong rapport the interviewer had with all participants. Consequently, participants were comfortable throughout the interviews, were forthcoming about their experiences, and did not hesitate to share their personal struggles with social media apps. This ensured the

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credibility of the data. Having a second coder outside of the study team also enhanced the confirmability of the findings. The use of maximum variation purposive sampling provided diverse views. Older adults were well represented across gender, age groups, living arrangements, and language of communication. Importantly, the study included non-novice users whose social media use was low. This was in contrast with existing qualitative research on ICT use, where they predominantly focused on novice users and the barriers faced toward technology adoption [19,56,57]. Our study, thus, allowed for a wider consideration of barriers across different user groups. Barriers faced by non-novice users are likely to be different from novice users, and both groups should not be conflated together.

The findings of our study may have limited transferability due to the inherent characteristics of the sample. Participants in this sample are more highly educated, having received 15 years of education on average. This demographic profile was to be expected, as participants had relatively high educational attainment in the original CHI study. The findings of this study should be interpreted in consideration of this limitation. Furthermore, using smartphone ownership as an inclusion criterion could limit this sample to only affluent participants, as older adults tend to view smartphone ownership as a status symbol [22]. Although this possibility was mitigated with the inclusion of participants residing in 1-and 2-room housing flats, further research could be conducted specifically on older adults with lower income and education levels.

Conclusions

The study examined the social media experiences of older adults in Singapore as well as their perceptions of social media in promoting health-related outcomes. Our findings showed that the decision to use social media is dependent on personal and social contexts, and the various socialization experiences suggest that social media benefits do not apply to everyone. Nonetheless, our findings highlight multiple health benefits that could be achieved with social media, such as cognitive engagement, improved health communications, and increase in social connectedness. Health care professionals, researchers, or nonprofit organizations interested in delivering health-related information could look into using social media as a potential psychosocial intervention for older adults. Furthermore, for older adults who express keen interest in learning to use social media, every effort should be directed toward providing the necessary infrastructure to navigate the pitfalls of social media effectively.

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Conflicts of Interest

None declared.

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Abbreviations

CHI: Community Health and Intergenerational
ICT: information and communications technology
SNS: social networking site

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Review

Technology-Assisted Home Care for People With Dementia and Their Relatives: Scoping Review

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Abstract

Background: Assistive technologies for people with dementia and their relatives have the potential to ensure, improve, and facilitate home care and thereby enhance the health of the people caring or being cared for. The number and diversity of technologies and research have continuously increased over the past few decades. As a result, the research field has become complex.

Objective: The goal of this scoping review was to provide an overview of the research on technology-assisted home care for people with dementia and their relatives in order to guide further research and technology development.

Methods: A scoping review was conducted following a published framework and by searching 4 databases (MEDLINE, CINAHL, PsycInfo, and CENTRAL) for studies published between 2013 and 2018. We included qualitative and quantitative studies in English or German focusing on technologies that support people with dementia or their informal carers in the home care setting. Studies that targeted exclusively people with mild cognitive impairment, delirium, or health professionals were excluded as well as studies that solely consisted of assessments without implication for the people with dementia or their relatives and prototype developments. We mapped the research field regarding study design, study aim, setting, sample size, technology type, and technology aim, and we report relative and absolute frequencies.

Results: From an initial 5328 records, we included 175 studies. We identified a variety of technology types including computers, telephones, smartphones, televisions, gaming consoles, monitoring devices, ambient assisted living, and robots. Assistive technologies were most commonly used by people with dementia (77/175, 44.0%), followed by relatives (68/175, 38.9%), and both target groups (30/175, 17.1%). Their most frequent goals were to enable or improve care, provide therapy, or positively influence symptoms of people with dementia (eg, disorientation). The greatest proportions of studies were case studies and case series (72/175, 41.1%) and randomized controlled trials (44/175, 25.1%). The majority of studies reported small sample sizes of between 1 and 50 participants (122/175, 69.7%). Furthermore, most of the studies analyzed the effectiveness (85/233, 36.5%) of the technology, while others targeted feasibility or usability or were explorative.

Conclusions: This review demonstrated the variety of technologies that support people with dementia and their relatives in the home care setting. Whereas this diversity provides the opportunity for needs-oriented technical solutions that fit individual care

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arrangements, it complicates the choice of the right technology. Therefore, research on the users' informational needs is required. Moreover, there is a need for larger studies on the technologies' effectiveness that could contribute to a higher acceptance and thus to a transition of technologies from research into the daily lives of people with dementia and their relatives.

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KEYWORDS

dementia; home care; assistive technologies; scoping review

Introduction

About 50 million people worldwide suffer from dementia, and there are almost 10 million new cases every year [1]. Dementia is an umbrella term that describes a syndrome, usually of a chronic nature, in which there is a disorder of several higher cortical functions: memory, thinking, orientation, language, judgment, and learning [2]. Due to the disease, people with dementia are restricted in their activities of daily life. Furthermore, the prevalence of challenging behaviors such as anxiety, hallucinations, delusions, or disinhibition is high [3-5]. Over the course of the disease, different needs for support occur. These needs range from assistance with activities of daily living (eg, personal hygiene), psychosocial support (eg, coping with the disease), and help with disorientation [6]. Nevertheless, people with dementia want to live at home as long as possible [7,8], and moving to a new environment (eg, long-term care) increases confusion, disorientation, and behavioral symptoms [9,10]. Home care is mostly provided by relatives, which can result in conflicts between the support needs and requirements of those affected and the available resources of the informal caregivers. Relatives often feel obliged [11] and have a high burden of care [12,13]. This causes tension in the family system and a feeling of being overwhelmed. As a result, the quality of care cannot be maintained, and even a move to a long-term care setting is necessary [14].

Assistive technologies can potentially maintain and support home care arrangements and consequently avoid or postpone residential care [15,16]. They have various aims, such as supporting communication [17-19], providing timely education or therapy for people with dementia and their relatives [20,21], offering assistance with daily activities (eg, cooking) [22], or reducing disease-related risks (eg, getting lost) [23]. Thereby, they encourage independence and social inclusion [15,16,24]. On the other hand, a recent study did not demonstrate a significant reduction in caregiver burden, anxiety, and depression in a large study population [25]. The evidence therefore does not seem to be clear. Barriers to the use of assistive technologies included perceptions of the high cost of formal assistive technologies; dilemmas regarding the timing and stage of technology use; and a lack of information and support from formal health and social care services about access, sources, timing, and options for use [26].

With regard to the different support domains, there is a wide diversity of assistive technologies, ranging from simple applications to complex multicomponent technologies. Assistive technologies can be defined as technological devices aimed "(…) to maintain or improve an individual's functioning and independence to facilitate participation and to enhance overall well-being" [27]. Research and development in this field has increased significantly in recent years due to technological progress, increasing demand and research funding [28]. However, the research area is very confusing due to the large number of different technologies with varying degrees of development for different target groups as well as various objectives of these technologies. We therefore conducted a scoping review to provide an overview of existing research on assistive technologies for people with dementia and their families in the home setting, guided by the research question: What types of assistive technologies are described in the current scientific literature for people with dementia and family carers to support care in the home setting?

Methods

We conducted a scoping review following the steps described by Arksey and O'Malley [29] with an extension by Levac et al [30]. The steps include (1) formulating the research question; (2) identifying relevant studies; (3) selecting relevant studies; (4) charting the data; (5) collating, summarizing, and reporting results; and (6) consultation. We did not publish a protocol for this review and used PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) for reporting of this review [31].

Eligibility Criteria

We included publications with qualitative or quantitative study designs focusing on technologies supporting people with dementia or their informal caregivers in the home care setting published between January 2013 and October 2018 in the German or English language. The time restriction of 5 years prior to the search date was chosen due to the rapid and significant changes that are made in the digital sector. We included studies conducted in day care centers and nursing homes because some of the technologies tested in these settings are also described as suitable for use in the home setting.

We excluded studies targeting people with mild cognitive impairment or delirium only as well as studies on electronic aids (eg, electric wheelchair) or technologies for the sole purpose of dementia assessment or diagnostics without any implication for the home care of people with dementia. Additionally, we excluded studies on technologies that are exclusively used by health professionals. We also excluded studies that only reported on technical aspects or parts of a technology (eg, interfaces or prototypes) as well as systematic reviews and study protocols.

Search Process

We searched the databases MEDLINE, CINAHL, PsycInfo, and CENTRAL up to October 2018. To develop the search

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strategy, the review team brainstormed potentially important search terms, scoped relevant studies for controlled vocabulary, and searched the MeSH browser for relevant MeSH terms mapped to uncontrolled vocabulary. The search strategy was reviewed internally via the Peer Review of Electronic Search Strategies (PRESS) guideline [32]. Two review authors (AS, SP) independently screened titles, abstracts, and full texts for inclusion. In cases of uncertainty, a third author (SN) was consulted.

Data Extraction and Critical Appraisal

Two study authors (AS, SP) extracted the following study characteristics using a standardized data extraction sheet and resolving differences by discussion: authors, year of publication, study design, study aim, country, setting, sample size, name of technology, type of technology, and aim of technology.

We did not perform a standardized critical appraisal of the included studies with, for example, the Cochrane Risk of Bias tool, since our goals were to give an overview and map out topics.

Synthesis

We report the results in a structured and narrative synthesis, graphically, and in tabular form. Therefore, we grouped the studies' technologies thematically and mapped out the study designs, technology groups, and goals of the studies. Additionally, we compared the settings, target groups, and sample sizes. The trends in publication numbers as well as the inclusion of the target groups were analyzed. We report the results with descriptive statistics in absolute and relative frequencies. A brief report on the nonformalized consultation process by means of expert discussions at 2 conferences is incorporated in the discussion.

Results

The database search identified 5328 titles. After abstract and full-text screening, 158 publications describing 175 studies with a total of 10,167 participants were included. See the PRISMA flowchart [33] for the illustration of the search process (Figure 1) and the multimedia appendices for the studies' references (Multimedia Appendix 1) and study details (Multimedia Appendices 2-4). The divergent number of studies and articles can be explained by the fact that several different case studies on different technologies are combined in 1 article. These studies do not meet the criteria of case series or multiple case studies. In addition, different studies, which varied in design, were described in 1 article.

In order to answer the question of existing assistive technologies to support people with dementia and their relatives, a diagram was created clustering the different types of technologies under investigation (Figure 2).

Figure 1. PRISMA flowchart.

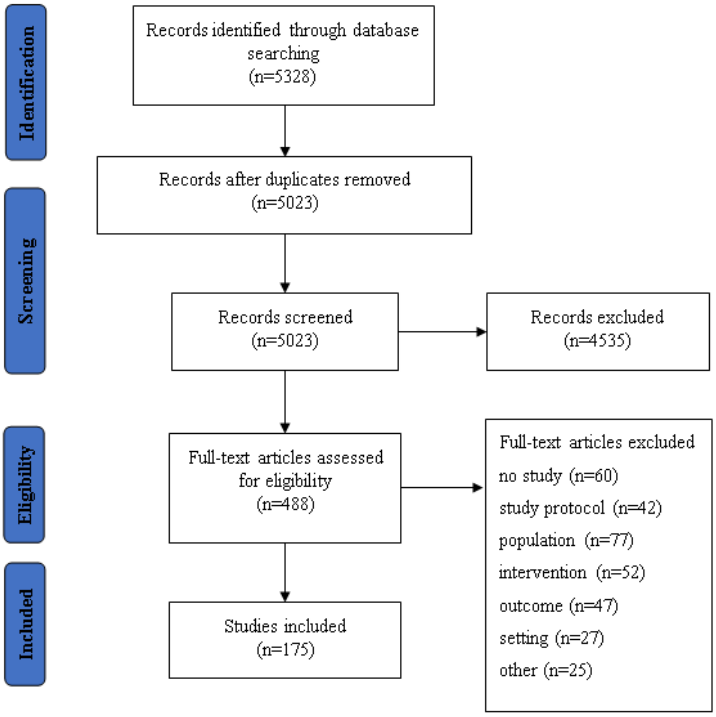

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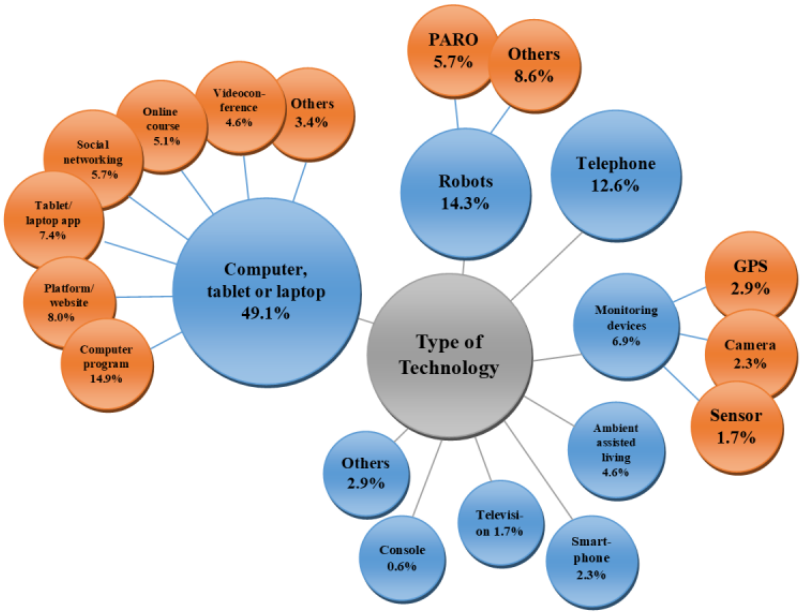
Figure 2. Relative frequencies of the types of technologies in the included studies (n=175).



About half of the studies (86/175, 49.1%) addressed different applications on computers, laptops, or tablets. Furthermore, robots (25/175, 14.3%) and telephone interventions (22/175, 12.6%) were frequently studied. Among robotic systems, PARO (PARO Robots US Inc, Itasca, IL) was the most commonly covered technology (10/175, 5.7%). Other technologies such as gaming consoles (1/175, 0.6%), apps on smartphones (4/175, 2.3%), ambient assisted living (8/175, 4.6%), and monitoring systems (12/175, 6.9%) were covered less frequently.

The studies can be classified according to different study characteristics. Focusing on the target group, technologies were primarily used by people with dementia (77/175, 44.0%), their relatives (68/175, 38.9%), or both target groups (30/175, 17.1%). With regard to the technology groups presented, most of the studies in which robots were tested were conducted with people with dementia (23/25, 92%). Computer programs (16/20, 80%) and apps on tablets (9/11, 82%) were also tested most commonly with people with dementia. Telephone-based interventions (22/22, 100%), internet courses (9/9, 100%), special websites (9/9, 100%), and online social networking or support groups (8/10, 80%) were almost exclusively related to family carers. When both target groups were addressed, monitoring (7/30, 23%) and ambient assisted living systems (5/30, 17%) were examined more frequently.

With respect to the setting, 60.0% (105/175) of the studies were conducted at home, 20.0% (35/175) in nursing homes, 11.4% (20/175) in day care centers, and 5.1% (9/175) in more than one setting. Concerning the technology groups, more than two-thirds of the studies with robots were conducted in nursing homes (17/25, 68%). Telephone interventions (22/22, 100%), apps on computers (6/6, 100%), and monitoring systems (9/12, 75%) were tested exclusively or predominantly in the home setting. Computer programs were tested more frequently in day care centers (8/18, 44%) and nursing homes (5/18, 28%) than at home (3/18, 17%). Furthermore, almost all studies that focused on the relatives took place in the home environment (66/68, 97%), and studies focusing on both target groups were more likely to take place at home (19/30, 63%) than in nursing homes (8/30, 27%). People with dementia were most often studied in nursing homes (27/77, 35%). However, a similar proportion of this target group was assessed at home (20/77, 26%) and in day care centers (19/77, 25%).

Overall, the number of included publications per year was relatively stable over time, with a mean of 26 publications per year. The number varies between a minimum of 21 publications in 2016 and a maximum of 34 publications in 2017. Table 1 shows the number of publications per year and target group of the technical intervention.

Table 1. Absolute number of publications by publication year (n=158).

Target group	Publication year					
	2013	2014	2015	2016	2017	2018
People with dementia	10	10	10	5	17	11
Caregivers	7	12	15	10	13	10
Both people with dementia and caregivers	7	5	4	6	4	2

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There is a noticeable increase in the number of publications focusing on people with dementia between 2016 (n=5) and 2017 (n=17). Additionally, it becomes clear that the number of publications with the target group of relatives increases significantly from 2013 to 2015, and they represent the largest target group from 2014 to 2016. From 2017 onwards, this trend changed, and most interventions investigated assistive technologies for people with dementia. In 2018, the number of publications of these target groups is approximately the same (caregiver n=10; people with dementia n=11). Few of the studies focused on both target groups as users of technologies.

Regarding the number of participants, the majority of studies included 1 to 50 persons (1-10: 59/175, 33.7%; 11-50: 63/175, 36.0%). Table 2 shows the number of publications by the technologies' target group and sample size. In smaller studies with a maximum of 10 participants, the proportion of publications about people with dementia (38/59, 64%) was particularly high. In studies with 51 or more participants, the majority of studies focused on caregivers (51-100: 12/19, 63%; 101-200: 11/14, 79%; ≥201: 9/16, 56%).

Table 2. Absolute number of publications by number of participants (n=175).

Target group	Number of categorized participants				
	1-10	11-50	51-100	101-200	≥201
People with dementia	38	26	5	3	5
Caregivers	10	24	12	11	9
Both people with dementia and caregivers	11	13	2	0	2

The assistive technologies were also investigated according to their study designs. Case studies represented 33.1% (58/175), 25.1% (44/175) were randomized controlled trials (RCTs), and 10.3% (18/175) were pre-post studies. Only a small proportion of the studies used case series (14/175, 8.0%), an exclusively qualitative design (14/175, 8.0%), a controlled trial (7/175, 4.0%), or a cross-sectional design (7/175, 4.0%). The remaining studies were classified as having "other" designs (13/175, 7.4%).

Grouping study designs by target groups, the largest percentage of studies focusing on patients with dementia used case studies (37/77, 48%). Subsequently, case series and RCTs represented the second largest proportion for this target group (11/77 each, 14%). Regarding the relatives, most studies used RCTs (30/68, 44%) and pre-post designs (14/68, 20.5%). When both target groups were investigated, case studies were mostly utilized (14/30, 47%). Case studies in general mainly consisted of people with dementia (37/58, 64%) or both target groups (14/58, 24%). In the qualitative studies, all target groups were examined with similar frequency (people with dementia and both groups: 5/14, 36%; relatives: 4/14, 29%).

When stratified by setting, in day care centers, mainly case studies and series were conducted (18/20, 90%). Case studies also accounted for half of the research in nursing homes (18/35, 51%). In contrast, the number of RCTs was highest in the home setting (35/105, 33.3%), followed by case studies and case series (29/105, 27.6%) as well as pre-post studies (15/105, 14.3%). In addition, most qualitative studies were conducted at home (10/14, 71%). Regarding the number of participants and study designs, 25% (11/44) of RCTs incorporated 11-50 people, and 30% (13/44) of RCTs incorporated each of 51-100 and ≥201 persons. With respect to the technology group, most of the RCTs and controlled trials were performed with testing telephone interventions (18/51, 35%), robots (8/51, 16%), and internet courses (7/51, 14%). In the case studies and case series, applications on computers, tablets, and laptops (38/72, 53%) as well as robots (10/72, 14%) were examined most frequently.

The nature of assistive technologies is particularly determined by its purpose. For better comparability, 8 categories of technology aims were formed. As some technologies had multiple functions, they were assigned to more than 1 category in order not to simplify their complexity.

The largest proportion of technologies aimed to enable or support therapeutic or caring interventions (85/308, 27.6%). Therapeutic technology–supported interventions included online therapy for people with dementia or their caregivers [34-36] or art therapeutic interventions via a technical device (n=31) [37,38]. Care interventions sought to increase the safety of people with dementia, for example by detecting the danger of falling at an early stage (n=54). A specific example was the study by Bayen et al [39], which analyzed how continuous video monitoring and review of falls of individuals with dementia can support better quality of care. Abbate et al [40] used a wireless accelerometer and electroencephalograph logger integrated in a minimally invasive monitoring sensor system with the aim of detecting possible falls and their causes. Care interventions also included online training programs for relatives with the goal of improving caring by trying to facilitate everyday life (eg, dealing with people with dementia). The European project STAR offers caregivers of people with dementia (both formal and informal) online training in order to better understand the disease and provide higher quality care [41]. Furthermore, 25.3% (78/308) of the technologies aimed to positively influence the symptoms of people with dementia such as disorientation or fear. Other technologies have been used to increase the knowledge of people with dementia or their relatives, such as through special websites (34/308, 11.0%), to enable or improve communication (29/308, 9.4%; eg, by providing an easy-to-use interface that allows people with dementia to contact their relatives) [42], or to enhance the skills of people with dementia in particular (20/308, 6.5%). Skill improvement included abilities such as remembering, orientation, and movement. This involved games that increased cognitive performance [43] or interventions to improve mobility [44]. An equal share of technologies (12/308 each, 3.9%) wanted to support activities of daily life (eg, by

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guiding people with dementia in their activities [22,45]) or improve engagement (eg through entertaining games [46]). "Other aims" were described for 12.3% (38/308) of the technologies. Overall, the objectives of the technologies were very broad. Due to the high complexity of technologies and the poor reporting, categorization of technology aims can only be based on the information provided by the studies. Therefore, the categories cannot be clearly distinguished from each other. In this context, caring tends to be a superficial main category, as many authors merely state an improvement in care provision as an aim, without describing in detail what the intervention specifically addressed in terms of needs.

A large percentage of the studies aimed to investigate the effects of the technology, either in terms of demonstrating effectiveness (85/233, 36.5%) or, more generally, by evaluating the assistive technologies (23/233, 9.9%). With regard to factors influencing intervention effects, few of the studies had the goal of measuring acceptance (16/233, 6.9%) or usability (23/233, 9.9%). In order to gain a first or deeper insight into the possible modes of action of the technologies, the minority were labelled as exploratory (22/233, 9.4%) or feasibility studies (31/233, 13.3%).

The objective of analyzing effects was similarly high in all studies regardless of the target group (people with dementia: 42/100, 42.0%; relatives: 33/84, 39%). The effectiveness was tested especially in studies in day care centers (17/26, 65%). Furthermore, many of the case studies pursued this aim (27/80, 34%). Case studies often examined the feasibility (13/80, 16%) or usability (11/80, 14%), or they were used for exploration (8/80, 10%). Feasibility, in turn, was given as the aim of the study in both target groups equally frequently (people with dementia: 13/100, 13%; relatives: 11/84, 13%). Many of these feasibility studies investigated technical interventions on computers, tablets, or laptops (21/31, 68%).

Discussion

Overall, this scoping review gives a comprehensive overview of the current literature and shows the diversity of assistive technologies for people with dementia and their family caregivers. There is a comparable amount of studies focusing on people with dementia as well as their caregivers. On the one hand, this demonstrates the increased availability of assistive technologies for informal caregivers; on the other hand, this demonstrates recognition of family members and people with dementia as consumers.

Many of the studies had the aim of demonstrating the effectiveness of the technology, although most of them were case studies with small sample sizes. This indicates that many of the technologies were rather rudimentarily tested, and only a very limited number of findings about effects or feasibility has been established, resulting in low confidence in the results. However, this seems odd, as usually a lot of financial and personal resources have to be invested in the development of a technology. Consequently, it would be reasonable to test them adequately. However, we acknowledge that it is difficult, especially for profit-oriented companies, to scientifically test the effectiveness of their developed technologies due to potential conflicts of interest. Evidence for the effectiveness of interventions through RCTs and controlled trials is more prevalent, although still limited, for telephones, robots, and internet courses. In total, a large proportion of studies was aimed at the technical evaluation, exploration, usability, or feasibility of an assistive technology. This indicates that many technologies for people with dementia and their informal carers are still in an early development stage. There is a need for larger studies of technologies' effectiveness. A broad evidence base about the benefits and risks of technologies for users is crucial to promote their acceptance and therefore achieve a transition of technologies from research into the daily lives of people with dementia and their relatives [47]. Successful technology arrangements were often characterized by pragmatic adaptation and combination of new with old equipment by the people with dementia or their caregivers [48,49].

We found heterogeneous technologies in our review. Telephone interventions have been frequently analyzed. A major advantage of telephone interventions is that there is no need to purchase expensive technologies because existing resources can be used. Furthermore, the technology is already known, used, and therefore accepted by the users. This could have the advantage, especially for people with dementia, that they could still use this technology in a later phase of the illness without being challenged with learning something new. Hence, use in everyday life seems more easily compared to other technologies. Internet courses are low-threshold interventions that can provide timely education for caregivers and reduce stress [50]. Additionally, they are relatively low-cost developments compared to, for example, a robotic system. Robots, by contrast, are complex technologies that can provide support in many ways (eg, socioemotional support, taking over household tasks, guiding actions, or recognizing and intervening in changing or dangerous situations). As we stated before, one robotic system, called PARO, has been of great interest for researchers. Studies using PARO were mostly placed in nursing homes or day care centers and evaluated its effectiveness. Reviews, which specifically analyzed robots for older people with and without dementia, found positive but not always significant effects on behavioral and emotional aspects, quality of life, and communication [51-53].

In a large number of interventions, both target groups were involved (eg, in order to individualize the interaction between the technology and people with dementia, their family chose photos, music, or videos [38]). Few of the technologies were designed to involve both target groups with the aim of supporting their interaction or communication [54]. This again shows the variety of application areas regarding assistive technologies for people with dementia and their family caregivers. To ensure that results are generalizable, we suggest that future reviews analyzing the effectiveness of assistive technologies focus on a group of technologies that are similar regarding their technical components, aims, and target groups.

Corresponding to the last step of the scoping review process model, the results of the scoping review were presented and discussed at 2 conferences in the form of a poster presentation and a lecture by experts in the field of health care research and practical care of people with dementia [55,56]. The main questions asked referred to the acceptance and adoption of the

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technologies in the household. The topic of acceptance of the technologies is hardly represented in the studies. Studies referring to the fact that the users have accepted the technologies and integrated them into their households usually provided a detailed description of how this process took place and whether there were any facilitation efforts (eg, external support by the project team) or how the acceptance was determined. Studies that explicitly investigated acceptance measured the use of the technology, user attitude, user mood (eg, relaxed or joyful), or user satisfaction [37,57,58]. Cristancho-Lacroix et al [59] reported a lack of acceptance, which was measured using qualitative data. It remains unclear which specific aspects have a negative impact on acceptance. Few of the studies explicitly reported on challenges in using the technology or barriers to use [37]. Especially with the large number of case studies, we would have expected more detailed information regarding this issue. In addition, this information could be of importance in determining whether interventions can be recommended by health care professionals or so that people with dementia and their families can decide whether to use a technology. Based on the experts' comments, we conclude that more and in-depth evidence is needed about the user acceptance of such technologies. Studies should be based on relevant theories such as the unified theory of acceptance and use of technology (UTAUT) [60], in order to gain meaningful and valid results with regard to the implementation. Specific concepts like the non-adoption, abandonment, scale-up, spread, sustainability (NASSS) framework can be helpful to evaluate factors influencing the adoption of technologies in order to plan an effective implementation [61]. It also requires industry and service providers to take a user-centric approach to design and deployment [62]. People with dementia and their caregivers identified clear information pathways for assistive technologies as essential for both service providers and service commissioners [63].

Due to the exploratory nature of the scoping review, it has to be considered that studies may have been overlooked despite the broad search because of the restrictions in databases, languages, and period of time. Because of the broad research question and heterogeneous study situation, a more in-depth analysis of specific technologies was not suitable. Furthermore, studies whose results did not demonstrate acceptance or positive outcomes may not have been published (publication bias). A particular difficulty arose in extracting data from studies and classifying technologies due to the poor reporting of the studies. This was especially prevalent for the methodological approach of the studies, description of the users, and use of the assistive technologies. In contrast, these studies focused more on technical aspects of the technologies, such as the design of an interface or data streams of systems. We still included studies with a focus on technical aspects when they reported how the technology was tested, because that was of particular interest in our review. In these cases, it was also more difficult to determine the purpose of the technology. Therefore, these were categorized based on the authors' explanations. A standardized description of the technologies using the CONSORT EHEALTH [64] or the TIDieR [65] checklist could contribute to a better understanding. In addition, the user group of people with dementia was insufficiently described in some cases. This refers to the existence of a concrete diagnosis of dementia and its testing, form of dementia, and symptoms of the disease, especially with regard to communication skills. Some participants were described as having dementia, but in the testing of cognitive abilities, they only showed limitations in the area of mild cognitive impairment. This makes it difficult to identify relevant studies and assess the transferability of study results.

Overall, there is great diversity in assistive technologies for people with dementia and their family caregivers. This becomes particularly clear when analyzing the different types of technologies and their purposes. One advantage of this diversity is that different technologies can address different problems and needs. Thus, the repertoire for the solution of these different problems is extended by technical interventions. This gives people with dementia, their relatives, and health care professionals more options for tailoring care arrangements to their needs. On the other hand, the diversity of technologies makes it more difficult for end users in particular to gain an overview of existing possibilities. This is especially true when technologies are developed for a broad group of users (eg, elderly people or people with cognitive disabilities). Here, it is even more complicated to decide on the appropriateness of the application of a specific assistive technology in a specific case. This results in the necessity of a user-oriented database to inform potential users about the available technologies. We recommend that the database includes various information of the technology, such as specific target group, aims, effectiveness, and user experiences. Therefore, an analysis of the users' informational needs would be beneficial. Furthermore, there is a major need for well-developed and tested interventions. This includes the measurement of not only (health) care outcomes but also feasibility and acceptability. Participatory design and development processes have to be implemented to fulfill the needs as well as acceptability, usability, and ethical issues of future users [23,66,67]. It is possible that case studies have remained at this level of research with no apparent follow-up projects because only low acceptance or effects have been identified. At the same time, there is a broad need for (1) technologies to assist people with dementia in several areas, (2) identification of the characteristics these technologies should have based on the users' needs, and (3) information on these technologies that is required by the users [68]. We believe that this scoping review can contribute to further guide research on assistive technologies for people with dementia and their family caregivers.

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Authors' Contributions

CD and SP conceptualized the study. SN developed the search strategy and conducted the search. AS and SP conducted the screening, data extraction, and data analysis. SN was the third rater during the screening. CD and SP interpreted the data. SP wrote the first manuscript draft. AS, CD, CK, ET, GE, SK, SN, SP, and TG revised the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategy for MEDLINE.
[DOCX File , 12 KB - aging_v4i1e25307_app1.docx]

Multimedia Appendix 2
Study details—people with dementia.
[DOCX File , 64 KB - aging_v4i1e25307_app2.docx]

Multimedia Appendix 3
Study details—informal carers.
[DOCX File , 61 KB - aging_v4i1e25307_app3.docx]

Multimedia Appendix 4
Study details—both target groups.
[DOCX File , 39 KB - aging_v4i1e25307_app4.docx]

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Abbreviations

NASSS: non-adoption, abandonment, scale-up, spread, sustainability
PRESS: Peer Review of Electronic Search Strategies
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews
RCT: randomized controlled trial
UTAUT: Unified theory of acceptance and use of technology

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Original Paper

Mobile Apps for Older Adults: Systematic Search and Evaluation Within Online Stores

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Abstract

Background: Through the increasingly aging population, the health care system is confronted with various challenges such as expanding health care costs. To manage these challenges, mobile apps may represent a cost-effective and low-threshold approach to support older adults.

Objective: This systematic review aimed to evaluate the quality, characteristics, as well as privacy and security measures of mobile apps for older adults in the European commercial app stores.

Methods: In the European Google Play and App Store, a web crawler systematically searched for mobile apps for older adults. The identified mobile apps were evaluated by two independent reviewers using the German version of the Mobile Application Rating Scale. A correlation between the user star rating and overall rating was calculated. An exploratory regression analysis was conducted to determine whether the obligation to pay fees predicted overall quality.

Results: In total, 83 of 1217 identified mobile apps were included in the analysis. Generally, the mobile apps for older adults were of moderate quality (mean 3.22 [SD 0.68]). Four mobile apps (5%) were evidence-based; 49% (41/83) had no security measures. The user star rating correlated significantly positively with the overall rating (r=.30, P=.01). Obligation to pay fees could not predict overall quality.

Conclusions: There is an extensive quality range within mobile apps for older adults, indicating deficits in terms of information quality, data protection, and security precautions, as well as a lack of evidence-based approaches. Central databases are needed to identify high-quality mobile apps.

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KEYWORDS

mHealth; MARS; MARS-G; older adults; mobile apps; apps; aging

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Introduction

Demographic change continues worldwide [1]. Globally, the proportion of older adults, those aged 65 years and older [1,2], will increase more than 60% until the year 2030 [1]. In 2050, it is estimated that 1.6 billion people (16.7% of the total world population) will be age 65 years or older [1]. The global aging population poses a variety of challenges to health care systems and their sustainability, such as increasing costs and potential medical and social undersupply to older adults due to a lack of health care professionals in the future [3,4]. Moreover, older adults are confronted with challenges such as physical and cognitive functional impairments, changes in social relationships, socioeconomic status, and loneliness [5]. These age-related changes often have far-reaching effects on overall health, preservation of independence, and ability to participate socially [5]. Some older adults might need assistance in retaining an active and independent lifestyle, sustaining physical and mental performance, preventing physical and mental disorders, and maintaining an appropriate system of social support [3,6].

Mobile and internet technologies such as mobile apps offer possible approaches to increase the empowerment of older adults, support social activities, prevent cognitive and physical decline, decrease loneliness, and provide assistance in everyday activities [7-12]. Mobile apps could be innovative solutions to help older adults maintain independence and enable them to promote their health and functioning [8,9,13,14].

Mobile apps may offer many advantages for older adults to complement traditional health care behavior, as they can be cost-effective if implemented on a large scale and used independently of time and location [15,16]. Furthermore, they have the potential to simplify social and medical care, which could contribute to the promotion of social inclusion and support living at home on a longer term [8-10,17].

Nevertheless, uptake and acceptance of mobile apps by older adults are rather low [18]. This may stem from various risks of mobile app use and barriers to uptake, including concerns about the quality and benefits of mobile technologies, accuracy of provided information, fear of misdiagnosis, worries about data misuse and insecurity regarding data transmission, costs of use, qualification of the app developers, lack of evidence, and poor usability [18-23]. Also, older adults occasionally show a lack of perceived self-efficacy regarding mobile app use, which negatively influences uptake [16,18].

Smartphones have become an integral part of everyday life, even for older adults [24,25]. In 2017, 40% of Americans aged 65 years and older were using a smartphone [24]. Two years later, in 2019, 73% of Germans aged 60 to 69 years used a smartphone [26]. Many studies imply that due to the aging of the baby boomer generation, more older adults will use smartphones [18,27]. As a result, mobile apps could reach a large number of older adults in the future [18,27].

There are many mobile apps available in the app stores [28], but the quality of publicly available mobile apps for older adults has not been systematically evaluated so far. There is only one systematic review that reports the quality of publicly available mobile apps for the promotion of balance in older adults, which concluded that mobile apps are of acceptable quality [29]. However, this review has a narrow scope as it only focused on improving balance in older adults through mobile apps, and there are presently no further systematic reviews of mobile apps for older adults available. Therefore, information about the quality, content, and data handling in mobile apps for older adults is not available to date.

Users can have problems identifying mobile apps that will effectively and safely support them in their health care [30]. This is mainly caused by the vast number of available mobile apps, opaque dynamics in the app stores, and the perceived lack of technical knowledge in older adults [30,31]. User star ratings from the app stores seem to be a questionable indicator for quality as they can originate from fictional persons and seem to be mostly determined by functionality and aesthetics [32,33].

To close this research gap, our study has systematically searched for mobile apps in the European app stores with a focus on older adults. Hence, their general characteristics, aims, methods, content, and quality were assessed using a multidimensional instrument, the German version of the Mobile Application Rating Scale (MARS-G) [34,35]. To evaluate various acceptance barriers that discourage older adults from using a mobile app, this systematic review focuses on the following characteristics of mobile apps for older adults in the European commercial app stores:

- Privacy and security features
- Quality criteria based on the MARS-G (engagement, functionality, aesthetics, information)
- Correlation between the user star rating and the MARS-G overall rating
- Prediction of overall quality due to the obligation to pay fees

Methods

Study Design

The systematic review was based on the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA statement) according to Moher and colleagues [36], with discrepancies due to the characteristics of mobile apps (for details see Multimedia Appendix 1).

Search Strategy and Inclusion Criteria

A web crawler was used to systematically screen the European Google Play and App Store for eligible mobile apps with the search terms “old,” “dementia,” “memory,” “mnemonic,” “elderly,” “senior,” “maturity,” “retiree,” “seniority,” and “aided recall.” The search string to identify mobile apps for older adults resulted from findings of self-conducted focus groups with older adults, caretakers, and physicians followed by an expert discussion (EMM, LS, HB, MD, DD, and NW). The web crawler is a search engine that systematically searches the internet and country-specific app stores such as Google Play and the App Store for eligible mobile apps [37]. The search was conducted on February 5, 2019.

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All identified mobile apps were listed in a central database, and the first results were screened by the reviewers (AP, DS, MD, MS, LS, DD, and NW). The screening was conducted via an Access (Microsoft Corp) file. Every mobile app was screened by two reviewers. Disputes were discussed with a supervisor (EMM). To be included in this review, mobile apps had to meet the following inclusion criteria: (1) designed for older adults or older adults, their caregivers, and relatives; (2) available and downloadable in the official Google Play or the App Store; (3) in German or English (in accordance with the reviewers' language skills); (4) functional to enable an assessment (eg, no device problems); and (5) usable independently of other software (eg, software on smartwatches). Duplicates were automatically and manually excluded. Nonworking links were tried several times. The reviewers excluded mobile apps that did not meet the inclusion criteria according to the title, mobile app description, given images, or comments of mobile app users in the app stores in the first step.

On May 8 and 9, 2019, an additional manual search of mobile app recommendations in the app stores took place by a reviewer (AP) to identify further relevant mobile apps. This should ensure an up-to-date and comprehensive search for mobile apps. Additionally to the previous search terms, the following German and English search terms were used: "seniors," "older adults," "Alzheimers," "memory games," "retirement," "pills," "dementia," "memory," "senior health," and "emergency call." The search terms to identify mobile apps for older adults resulted from findings of self-conducted focus groups and were developed in an expert discussion (EMM, LS, HB, MD, DD, and NW). In addition to technical terms, relevant synonyms and alternatives used by end users were added to the extracted search terms [38]. These mobile apps were also reviewed for their entitlement to be included in the analysis.

For the MARS-G analysis, the mobile apps were downloaded and checked regarding the inclusion criteria and their functionality for the review (eg, no device problems). Technical problems were validated on at least two devices. The mobile apps were downloaded and installed either on an iPad mini (Apple Corp; model MK9N2FD/A; operating system 12.1), a MediaPad X2 (Huawei Device Co; model GEM-701L; operating system 5.0.1), or an iPhone 6 (Apple Corp; model A1586; operating system 12.2).

Data Collection Process

The quality assessment of the mobile apps was conducted by two independent reviewers (AP, DS, MD, MS, LS, DD, or NW) using the MARS-G [35]. Prior to the rating, the reviewers received standardized online training, which is publicly accessible and free of charge [39]. Each mobile app had been explored and used for at least 15 to 20 minutes to examine the functionality, content, and quality. The quality rating took about 30 minutes for each mobile app and was documented via an Access file. Reviews were completed on May 28, 2019. For quality assurance, interrater reliability was calculated. Rater agreement was examined by intraclass correlation (ICC) based on a 2-way mixed-effect model with absolute agreement. When the ICC was below a minimum value of .75 [40] or when there were disputes between the reviewers, a third reviewer was consulted [34,35].

Evaluation Tool

The MARS-G evaluation tool is a reliable and valid scale for the quality assessment of mobile apps [35,41]. The MARS-G shows a good to very good internal consistency for all subdimensions (ω=.72-.90) as well as for the overall score (ω=.82, 95% CI .76-.86) and a high ICC (2-way mixed ICC .84, 95% CI .82-.85) [35]. The correlations of the corresponding dimensions of the MARS and MARS-G range from r=.92-.98 [35].

General Characteristics

The classification page of the MARS-G was used to examine mobile app characteristics. It contains descriptive and technical information about the mobile app: (1) name, (2) platform, (3) content-related subcategory, (4) store link, (5) price, (6) user star rating, (7) aims, and (8) methods [34,35].

Data Protection and Security Precautions

The assessment of privacy and security features based on MARS-G is on a descriptive level (eg, availability of privacy policy, imprint). All features were assessed based on downloaded mobile apps, and only information that was disclosed within the mobile app or its description in the app stores was investigated.

Categorization

The categorization of mobile apps for older adults according to Cunha and colleagues [42] was used for the analysis to enable a classification independent of the app stores. This classification was developed using a methodological search in Google Play and the App Store for mobile apps designed to help older adults [42]. Table 1 lists the various categories with examples of content topics.

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Table 1. Mobile app categories for older adults with exemplary topics according to Cunha et al [42].

Categories	Exemplary topics
Diagnostic	Cognitive impairments, physical and mental illnesses
History	Monitoring of vital parameters such as blood pressure, and organization of daily activities
Improve	Relaxation, speech-to-text, text-to-speech, risk assessment, magnifying glass, medication recognition, pictogram-to-speech, communication portals, and social networks
Informative	Healthy living, education, and psychoeducation about mental and physical illnesses
Interface	Mobile apps for conversion to a user-friendly interface
Measurement	Physical activity, pedometer, and GPS tracking
Protection	Drug reminder, help requests, and localization
Simulation	Simulation of diseases, impairments, or appearance
Trainer	Memory, relaxation, logical thinking, fitness, and cognitive speed
Tutorial	Accident rehabilitation, sign language, improvement of self-esteem, and improvement of communication

Quality Assessment

The multidimensional quality rating of the MARS-G includes 19 items on 4 different subdimensions, which are evaluated on a 5-point Likert scale (1=inadequate, 2=poor, 3=acceptable, 4=good, and 5=excellent): (1) engagement—5 items (entertainment, interest, individual adaptability, interactivity, target group); (2) functionality—4 items (performance, usability, navigation, motor and gestural design); (3) aesthetics—3 items (layout, graphics, visual appeal); and (4) information—7 items (accuracy of app description, goals, quality of information, quantity of information, quality of visual information, credibility, evidence base) [34,35].

Data Analyses

For the evaluation of the overall rating and quality, the total score was calculated from the 4 subdimensions [34]. The ratings of the reviewers were averaged for all calculations. Mean scores and standard deviations were calculated for the MARS-G overall rating and subdimensions.

Item 19 on the information subdimension was used to assess whether empirical studies were available for a mobile app. This item was investigated by searching the mobile app name in Google Scholar, PubMed, Google, and the developers' or providers' websites for existing efficacy and effectiveness studies [34].

Bivariate correlations between the user star rating and the MARS-G ratings were calculated. Also, bivariate correlations between the user star rating and the number of security and privacy measures were determined. The user star ratings were extracted from the app stores. The user star rating from Google Play and the App Store can be assigned on a scale of 1 to 5 stars and is displayed to mobile app seekers in the app stores as a cumulative average of individual ratings [43]. Mean score and standard deviation were calculated for the user star rating.

To examine whether the obligation to pay fees is a predictor of overall quality, an exploratory regression analysis was conducted in which the predictor was dummy coded (1=obligation to pay fees, 0=no obligation to pay fees). Mobile apps that required an initial payment for use were defined as "obligation to pay fees." Mobile apps that were not priced at the time of purchase or had a free basic version were defined as "no obligation to pay fees" [44,45].

A *t* test for independent samples was used to check whether the mobile apps from the app stores differ regarding their MARS-G overall and subdimension mean value. For all analyses, an alpha level of 5% was defined [46]. All statistical analyses were performed using SPSS Statistics 24 (IBM Corp) and R (R Foundation for Statistical Computing).

Results

Search

The web crawler identified 1154 mobile apps, of which 11.01% (127/1154) were found to be eligible by initial screening (Figure 1). Due to the unfulfilled inclusion criteria, 88.9% (1027/1154) of mobile apps were excluded. After the initial screening, 127 mobile apps were downloaded, of which 66.1% (84/127) did not meet the inclusion criteria (eg, duplicates, only for relatives and caregivers), leaving 33.9% (43/127) to be included in the MARS-G analysis. In an additional manual search, 63 mobile apps were detected, of which 37% (23/63) were excluded. In summary, 6.82% (83/1217) of mobile apps found were included in the analyses (for details on the included mobile apps see Multimedia Appendix 2).

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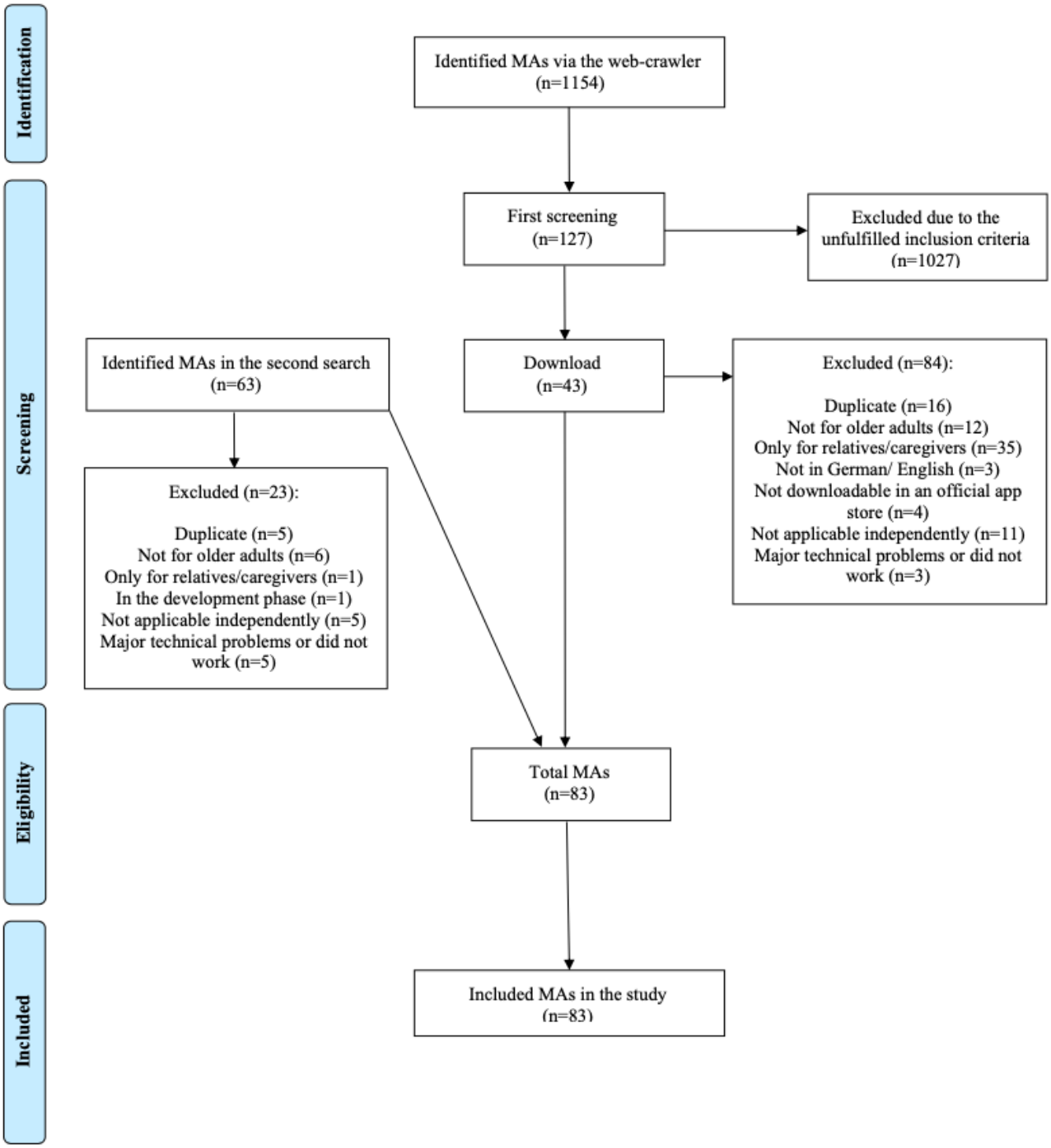
Figure 1. Flowchart of the mobile app selection process.



General Characteristics

Of the mobile apps, 64% (53/83) were from Google Play and 36% (30/83) were from the App Store. There were no significant mean differences in the MARS-G overall rating between mobile apps from different stores (t_{81}=1.399, P=.17). Furthermore, there were no significant mean differences in the individual subdimensions of the MARS-G rating for mobile apps from different app stores (for all calculations P>.05). Most of the mobile apps were free of charge (73/83, 88%); 12% (10/83) were priced. The average price was €0.75 (SD 2.76), ranging from €0 to €18.99 (US $0 to $23.32). The 69 existing user ratings from the app stores had an average score of 4.15 (SD 0.70). Of the mobile apps, 37% (31/83) were designed for prevention, 41% (34/83) for treatment, 31% (26/83) for rehabilitation, 27% (22/83) for aftercare, and 60% (50/83) for assistance in everyday life. Multiple naming of fields of application for one mobile app was possible. A total of 31% (26/83) were developed and published by a legitimate source (such as a nonprofit organization or university). None of the mobile apps were developed with the help of competitive government or research funding.

On average, the mobile apps for older adults had 3.36 (SD 1.79) aims, with a maximum of one mobile app having 8 aims. Most common aims were improvement of well-being (54/83, 65%), entertainment (39/83, 47%), reduction of stress (37/83, 45%),

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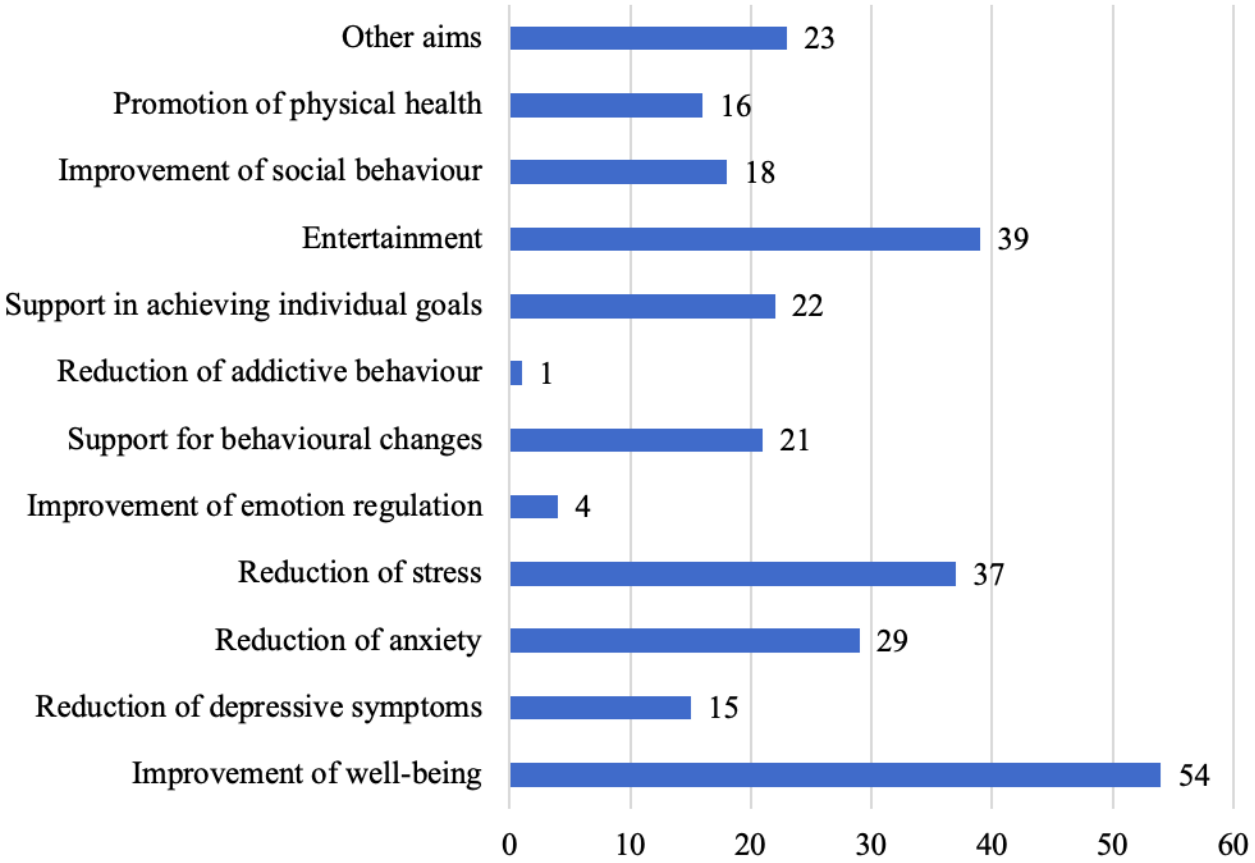
and reduction of anxiety (29/83, 35%). Aims classified under other aims (23/83, 28%) included, for example, disease education (2/83, 2%) and screening for Alzheimer disease (3/83, 4%). Figure 2 provides an overview of the frequency of aims in mobile apps for older adults.

Figure 2. Frequency of objectives of mobile apps for older adults. Multiple naming of objectives for one mobile app was possible. Data are given for n=83 mobile apps.



On average, the mobile apps used 2.88 (SD 1.81) methods. The number varied from 1 to 9 methods. The most common methods were monitoring and tracking (26/83, 31%), data collection and measurement, feedback, and gamification (each 25/83, 30%) as well as information and education and tips and advice (each 23/83, 28%). Some mobile apps included memory, reminder, amplifier (16/83, 19%), strategies, skills, training (12/83, 14%) and resource orientation (11/83, 13%). Only a few mobile apps included physical exercises (7/83, 8%), mindfulness and gratefulness, and tailored interventions (each 5/83, 6%), acceptance, pursuing own goals and relaxation exercises (each 3/83, 4%), and traditional medicine (2/83, 2%) or alternative medical intervention elements and exposition (each 1/83, 1%). Methods classified under other methods (23/83, 28%) included, for example, personalization (7/83, 8%), social networking features (4/83, 5%), and emergency button and contacts (1/83, 1%). None of the mobile apps included serious games, breathing exercises, hypnotherapy or EMDR. Figure 3 illustrates the frequencies of used methods in mobile apps for older adults.

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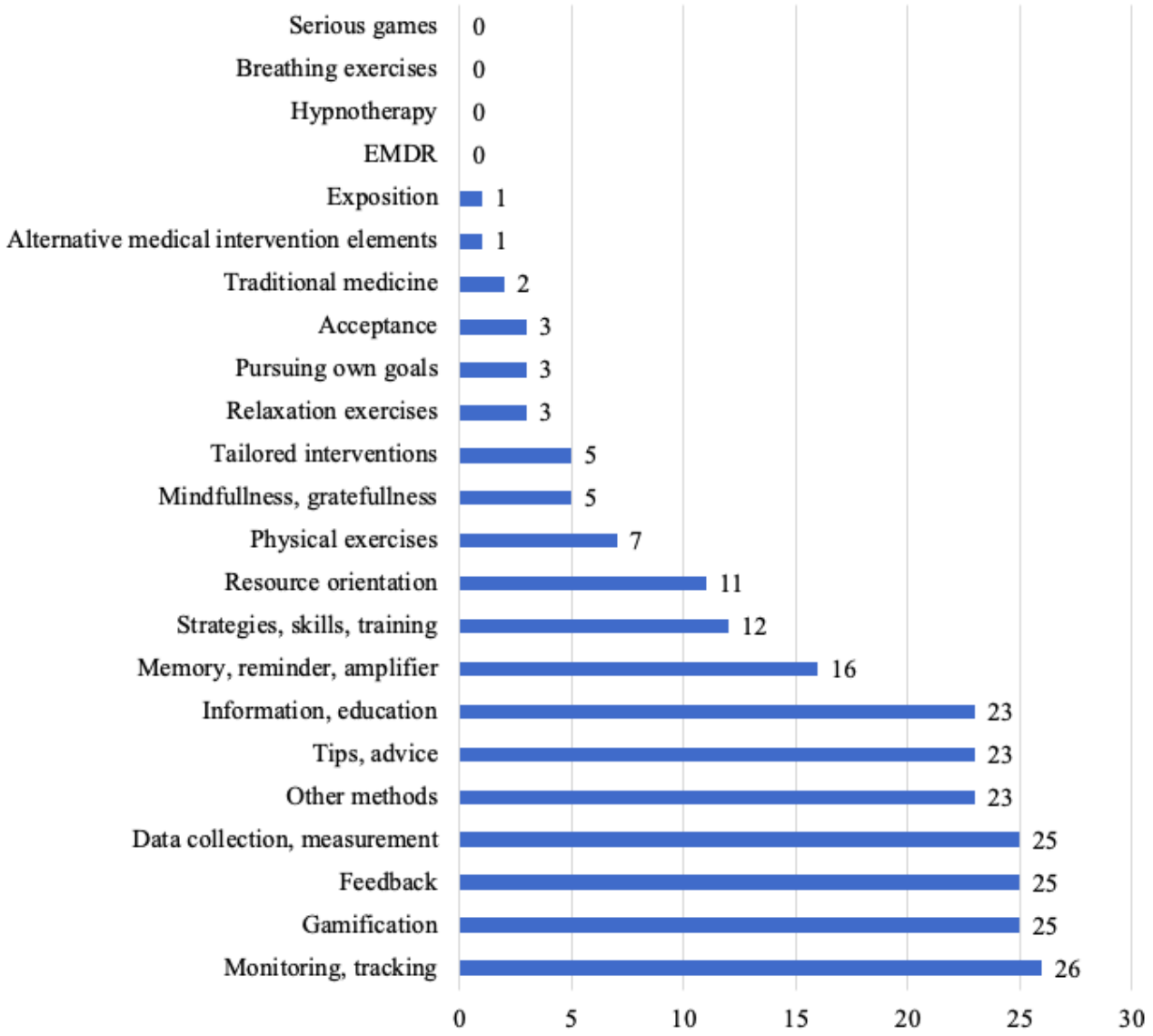
Figure 3. Frequency of methods used in mobile apps for older adults. Multiple naming of different methods in one mobile app was possible. Data are given for n=83 mobile apps.



Data Protection and Security Precautions

The average number of security and privacy measures was 2.07 (SD 2.76). Of the included mobile apps, 49% (41/83) had no data protection precautions. Most frequently (30/83, 36%), a contact, contact person, or imprint was given. Only in 7% (6/83) emergency functions were available; 5% (4/83) provided data transmission security. Table 2 provides an overview of all data protection precautions in the mobile apps.

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Table 2. Privacy and security measures found in mobile apps.

Data protection precaution	Value[a], n (%)
Allows password use	22 (27)
Requires a log-in	20 (24)
Has a privacy statement	28 (34)
Requires active confirmation of a consent form	14 (17)
Information on dealing with the data	14 (17)
Notes on financing/conflict of interest	14 (17)
Contact/contact person/imprint	30 (36)
Data transmission security	4 (5)
Emergency functions available	6 (7)
Security strategies for mobile phone loss	20 (24)
Other security strategies	0 (0)

[a]Multiple naming of different data protection precautions for one mobile app are possible.

Categorization

According to the categorization of Cunha and colleagues [42], a majority (31/83, 37%) of the mobile apps could be classified as trainer. Overall, 16% (13/83) were classified as protection, 11% (9/83) as interface, 10% (8/83) as informative, and 7% (6/83) as improve. Only a few mobile apps were found in the categories measurement (2/83, 2%), history (4/83, 5%), and diagnostic and tutorial (each 5/83, 6%). None of the mobile apps could be classified as simulation. The best overall quality was found for the categories measurement (mean 3.77 [SD 0.15]), diagnostic (mean 3.67 [SD 0.75]), and trainer (mean 3.28 [SD 0.82]). However, overall quality for categories informative (mean 3.24 [SD 0.29]), tutorial (mean 3.23 [SD 0.45]), protection (mean 3.18 [SD 0.59]), improve (mean 3.13 [SD 0.59]), interface (mean 2.86 [SD 0.44]), and history (mean 2.82 [SD 0.97]) was poor to moderate.

Quality Assessment

The overall rating showed an excellent level of interrater reliability (2-way mixed ICC .97, 95% CI .97-.98). According to Portney and Watkins [47], the interrater reliabilities of the MARS-G subdimensions were excellent (ICC .91-.99). The overall quality of the mobile apps for older adults was moderate, with a mean quality of 3.22 (SD 0.68). The subscale engagement was moderate (mean 3.25 [SD 0.82]), functionality good (mean 3.99 [SD 0.59]), aesthetics moderate to good (mean 3.60 [SD 0.85]), and information quality poor (mean 2.02 [SD 1.10]). Figure 4 shows a graphical representation of the distribution of ratings for overall quality and individual subdimensions.

Significant positive bivariate correlations were found between overall rating and subdimensions (r=.68–.85, P<.001). A correlation table is presented in Table 3.

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Figure 4. Graphical representation of the distribution of the Mobile Application Rating Scale (German version) overall rating, and the four subdimensions. The median, the interquartile distance as well as the range and outliners were given (n=83 mobile apps).

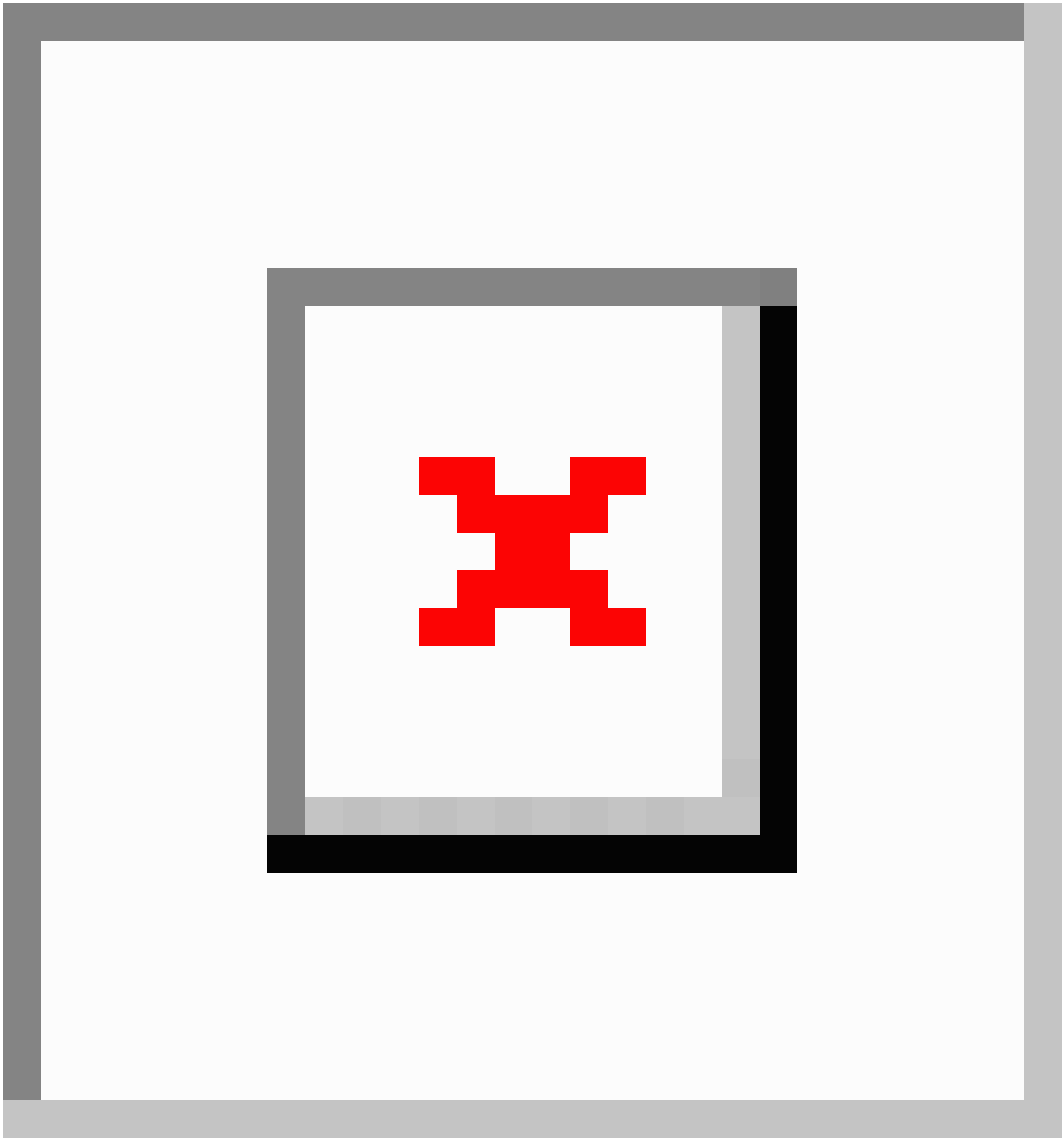

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Table 3. Correlations between the mean values of the four MARS-G subdimensions, overall rating and user star rating.

Characteristics	MARS-G[a]									
	Engagement	*P* value	Functionality	*P* value	Aesthetics	*P* value	Information	*P* value	Overall rating	*P* value
MARS-G										
Engagement	__[b]	—	—	—	—	—	—	—	—	—
Functionality	.52	<.001	—	—	—	—	—	—	—	—
Aesthetics	.62	<.001	.54	<.001	—	—	—	—	—	—
Information	.55	<.001	.33	.002	.58	<.001	—	—	—	—
Overall rating	.83	<.001	.68	<.001	.85	<.001	.83	<.001	—	—
User star rating[c]	.27	.03	.11	.38	.19	.13	.32	.01	.30	.01

[a]MARS-G: German version of the Mobile Application Rating Scale.

[b]Not applicable.

[c]Correlations were calculated with 69 mobile apps since the user star rating was missing for 14 apps.

Quality Rating on Evidence

Four (5%) mobile apps were evidence-based. For Lumosity [48,49] and NeuroNation [50], various efficacy studies, mainly for the web-based versions, in the form of randomized controlled trials with different participant groups (eg, age, health status, ethnicity) exist. These studies suggest significant improvements in different cognitive performances as processing speed or short-term memory due to training with these mobile apps. However, only a few studies met the minimal standards of a randomized controlled trial (eg, random assignment of participants) [51]. For MindMate and Constant Therapy, a significantly positive difference in therapeutic success could be shown compared with conventional or no training in older adults with cognitive impairments [52,53].

Association Between User Star Rating and Quality of Mobile Apps

The user star rating and overall rating correlated significantly positively with r=.30 (P=.01). Furthermore, there was a significant positive relationship between the user star rating and the subdimensions engagement (r=.27, P=.03) and information (r=.32, P=.01). The user star rating did not correlate significantly with the number of security and privacy measures (r=.09, P=.49). The correlations were calculated with n=69 mobile apps since the user star rating was missing for 14 apps.

Exploratory Regression Analysis

There were no bivariate correlations between the overall rating or the four subdimensions and the obligation to pay fees (P>.05). The obligation to pay fees had no predictive value for overall quality (β=.07, $F_{1,81}$=0.098, P=.75, adjusted R^2=.01%).

Discussion

Principal Findings

In this study, we systematically examined the quality of 83 mobile apps for older adults in the European commercial app stores using a reliable and valid rating instrument. Furthermore, we assessed general characteristics, aims, methods, content, and privacy and security measures of the mobile apps for older adults. In general, the mobile apps were of moderate quality with a wide range of quality ratings. This result is in line with findings from other systematic mobile app reviews using the MARS [29,54-56]. The pattern of high functionality and low information quality of the mobile apps for older adults is in accordance with other MARS studies [55,57]. However, previous research on mobile apps for older adults implies a low functionality of these [17]. This result might point out the improvement of mobile app functionality over the past years.

The generally low information quality with a wide range is also in line with the results of other systematic reviews [38,55]. The included mobile apps often did not refer to the authors or sources of information, and the actuality and correctness of the information were not guaranteed. The decreased information quality is associated with various risks for mobile app users, mainly because misinformation can result in incorrect self-diagnosis and adverse health decisions in prevention, health promotion, and treatment [58,59].

Moreover, users are confronted with data and security issues, as 49% of the mobile apps contained no security or data protection measures, and those that do exist lack clarity. The literature implies that concerns about the lack of data protection measures represent an essential usage barrier for older adults [18,21]. Sunyaev and colleagues [60] suggested that mobile apps used in health care systems contain highly sensitive data and should, therefore, be subject to particularly strict data protection guidelines. In their assessment of mobile apps that provide health advice, they found that only 30.5% of mobile apps had privacy policies, of which two-thirds did not specifically address the content of the mobile apps, but commercial rights, distribution rights, or third-party rights [60]. This indicates a lack of transparent reporting on how mobile apps handle personal and health-related data. Therefore, the risk that the data can be evaluated, merged with other data, or passed on to third parties without the mobile app users' knowledge is given [61,62]. Even if mobile apps had a privacy policy, many mobile apps transmitted data services provided by Facebook or Google [63]. In particular, mobile apps that offer interface and

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protection should guarantee the privacy and security of data transmission. However, compliance with these guidelines is currently not ensured.

Furthermore, the efficacy and effectiveness of mobile apps for older adults are poorly examined [64]. Only 5% of mobile apps had evidence for their efficacy [48-50]. This small number is in line with the results of some systematic health-related mobile app reviews [38,56,65]. The limited emergence of evidence-based mobile apps can partly be explained by the fact that the evaluation methods for health interventions, such as randomized controlled trials, are time-consuming and cost-intensive [66,67]. Also, most mobile apps in this study, as well as mobile apps for other target groups, came from private sector companies without scientific background on the specific context [55,68-70]. Many mobile apps developed by universities and research projects do not enter the mobile app market or are not included in the top rankings due to lower download rates [68,71]. Interdisciplinary cooperation between health care providers, health insurance companies, and researchers would be essential to reach older adults in need who might benefit from a high-quality mobile app.

Top-ranked mobile apps often have a high user star rating, which is discussed as an indicator of mobile app quality [72]. This study found a moderate positive correlation between user star rating and overall rating as well as the subdimensions engagement and information, which is in accordance with some systematic reviews [73] but not with others [32,57]. These results indicate that engagement and information quality might play an essential role in the rating of mobile apps by older adults. The facets of the MARS subdimension engagement, such as entertainment, individual adaptability, interactivity, and target group specificity, are cited as essential principles for the development of mobile apps for older adults and have been associated with the effectiveness of health interventions in several studies [64,74-77]. In previous studies, users were described selecting mobile apps according to the quality of the aesthetics and functionality, which could not be replicated in this study [33,78]. Mobile apps for older adults might be thoroughly checked regarding their content and quality before older adults use them. However, there was no correlation between the user star rating and the number of data security measures, which suggests that the user star rating is not an indicator of data protection and privacy and vice versa. Furthermore, user star ratings could originate from fictitious persons, and each person could apply a different focus of evaluation (eg appearance, usability) [79]. Besides, user star ratings from app stores could refer to previous versions of a mobile app, which does not guarantee that the mobile app is up to date and may cause distortions due to evaluations of different versions [43]. Therefore, the user star rating does only seem to be a limited orientation aid for the selection of a mobile app. Other strategies for selecting a mobile app should be considered.

According to our results, the obligation to pay fees did not predict mobile app quality. In previous studies, it was partly implied that paid mobile apps are more credible, trustworthy, and recommendable and are more likely to promote users' health and well-being [57,80]. Other studies could also not find an association between the obligation to pay fees and mobile app quality [32,69]. Since the cost of mobile app use represents an important barrier for the uptake of mobile technologies as mobile apps by older adults [18,21], it is beneficial that there are no significant differences in quality.

Most mobile apps could be assigned to the trainer category. Training mobile apps such as fitness and cognitive exercises for the prevention of neurodegenerative diseases as well as social media mobile apps are mostly used by older adults [18,81]. In previous studies, mobile health interventions for older adults containing preventive training and mechanisms for behavioral changes, self-management of chronic diseases, and social inclusion have had a positive effect on self-confidence, health, performance, and general well-being of older adults [10,76,82-85]. In this study, most of the mobile apps were designed to support the daily lives of older adults (eg, entertainment and family connectivity) as well as for rehabilitation and treatment of diseases (eg, symptom tracking and medication). Thereby, most of the mobile apps focused on methods such as monitoring and tracking, feedback, data collection and measurement, information and education, or gamification. Various studies implied the importance of these methods for the effectiveness of mobile apps, use behavior and adherence, interaction, and motivation in the use of mobile apps by older adults [10,68,76-78, 86-88].

Strengths and Limitations

One strength of this study is the use of traditional systematic review methodology, such as systematic search, independent screening, and quality evaluation of the included mobile apps on a reliable scale. The multidimensional MARS-G enabled an objective, reliable, and valid rating [35,41]. The categorization, according to Cunha et al [42], made it possible to classify the mobile apps specifically for older adults independently of the app stores. Also, the additional manual exploration of mobile apps in the app stores ensured an up-to-date and comprehensive search. In this way, a realistic search for mobile apps by older adults and their relatives could be simulated. The use of nonprofessional and technical terms made it possible to cover a wide range of mobile apps in the search terms.

However, due to the high frequency of new and further developments as well as the continuous technological progress of the mobile app market [58], this study shows a current snapshot of the quality of mobile apps for older adults. Some of the included mobile apps may no longer be downloadable, their content may have changed, new versions could be available, or new mobile apps may have been developed during the publication of this study, therefore reducing the actuality of this rating.

Another limitation is the country-specific search for mobile apps in the German and British app stores. Different mobile apps are offered in various countries since the selection of countries in which a mobile app is available is determined by the developers [89]. This could limit the generalizability of the results of our study [90].

Furthermore, mobile apps were not tested for a longer time, as in days or weeks. Therefore, some aspects of the mobile apps

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may not have been detected, and some errors may have remained hidden.

Additionally, we assessed privacy and security measures on a descriptive level, and the included data is based on information within the mobile apps and description in the app stores. Future studies should conduct an in-depth analysis of privacy and security measures in mobile apps for older adults (eg, analyzing if they transmit data using services provided by Facebook or Google) [63].

Scientific and Practical Implications

Since the user star rating is invalid to assess mobile app quality, publicly available expert mobile app ratings could help older adults as well as their relatives, caregivers, and health care professionals (eg, physicians) to select a high-quality mobile app. Publicly available MARS ratings by experts on a wide range of health topics on databases like Psyberguide and mHAD [71] could assist in informed health care decisions.

In the future, efficacy and effectiveness studies should be implemented for mobile apps. At present, there is a lack of high-quality studies that prove the long-term benefit, effectiveness, and safety of mobile app use for older adults [64,74]. In connection with efficacy and effectiveness studies, it could also be investigated which functions and properties of mobile apps have a particularly positive and long-term effect on the use of mobile apps by older adults. Based on this data, new evidence-based and effective mobile apps could be developed. Also, mobile apps whose effectiveness could be proven could be translated into other languages. Moreover, older adults should be involved as part of participative research in developing a new mobile app [91]. Taking end users into account increases the usability, uptake, and effectiveness of interventions [92]. After developing a new mobile app, it is essential to invest time in training tools, in-person training, user manuals, and support hotlines regarding the use of mobile app, as many older adults want to receive technical and social support for the installation, exploration, and learning of a mobile app [16,74,93-95]. Only making mobile apps available in the app stores will fail to optimize their use by older adults [96].

Promotion measures as reimbursement of costs of mobile apps with proven effectiveness through health care providers and targeted information campaigns on existing high-quality mobile apps for older adults and their relatives could help them to integrate high-quality mobile apps into their daily lives [93,97].

Conclusion

The potential inherent in mobile apps to support a healthy, active, and safe life for older adults has not yet been sufficiently explored. The study was able to indicate that currently available mobile apps for older adults are on average of moderate overall quality. In particular, deficiencies could be found in information quality, evidence-based approach, data protection, and security measures. However, some mobile apps were of high quality, were based on evidence, and had sufficient data protection, and therefore, could provide suitable support. The user star rating and the obligation to pay fees did not provide valid orientation aids. Annually conducted reviews and publicly available expert mobile app ratings could help older adults and their relatives as well as caregivers to select a high-quality mobile app.

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Authors' Contributions

EMM, YT, LS, and HB developed the study design. AP, DS, MD, LS, MS, NW, and DD collected the data. AP, EMM, and YT ran the statistical evaluations. AP and EMM wrote the first draft of the article. All authors contributed to the current version of the article and have approved the final paper.

Conflicts of Interest

EMM, YT, LS, and HB developed, and run the German Mobile Health App Database project (MHAD). The MHAD is a self-funded project at Ulm University with no commercial interests. LS, HB and EMM received payments for talks and workshops in the context of e-mental-health. LS reported receiving personal fees from Psychotherapy Training Institutes and Clinics outside the submitted work. This does not alter our adherence to JMIR policies on sharing data and materials. All other authors declare no conflicts of interest.

Multimedia Appendix 1
Preferred Reporting Items for Systematic Reviews and Meta-analyses 2009 checklist.
[PDF File (Adobe PDF File), 153 KB - aging_v4i1e23313_app1.pdf]

Multimedia Appendix 2
Included mobile apps with name, store, developer, version, price, user star rating, Mobile Application Rating Scale, German version (MARS-G), subdimensions and overall rating sorted by MARS-G overall rating.
[PDF File (Adobe PDF File), 164 KB - aging_v4i1e23313_app2.pdf]

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Abbreviations

ICC: intraclass correlation
MARS-G: Mobile Application Rating Scale, German version
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-analyses

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Original Paper

A New Tool for Detecting COVID-19 Psychological Burden Among Postacute and Long-term Care Residents (Mood-5 Scale): Observational Study

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Abstract

Background: Older adults are at high risk for developing serious somatic and psychological symptoms associated with COVID-19. Currently available instruments may not be sensitive to the concerns about COVID-19 in postacute and long-term care and their applications in telehealth remain to be clarified.

Objective: We investigated the psychometric properties of the Mood-5 Scale (M5) as a rapid self-assessment of the COVID-19 psychological burden among postacute and long-term care residents.

Methods: Residents (N=131), aged 50 years and above, from 20 postacute and long-term care facilities in Maryland, USA, were evaluated in-person or via telehealth (43/131, 32.8%) across a 4-week period (May 11 to June 5, 2020) during the COVID-19 pandemic. The COVID-19 psychological burden experienced by the residents was rated by geriatric psychologists who independently reviewed their clinical documentation. Psychometric analyses were performed on the M5 in relation to psychological tests, COVID-19 psychological burden, and diagnostic data collected during the evaluation.

Results: The M5 demonstrated acceptable internal consistency (Cronbach α=.77). M5 scores were not confounded by demographic variables or telehealth administration (P>.08). Convergent validity for the M5 was established via positive associations with anxiety (r=0.56, P<.001) and depressive (r=0.49, P<.001) symptoms. An M5 cutoff score of 3 demonstrated strong sensitivity (0.92) and adequate specificity (0.75) for identifying COVID-19 psychological distress among postacute and long-term care residents (area under the curve of 0.89, positive predictive value=0.79, negative predictive value=0.91).

Conclusions: The M5 is a reliable and valid tool for self-assessment of mood that can help identify postacute and long-term care residents with significant psychological burden associated with COVID-19. It can be completed in less than 1 minute and is appropriate for use in both in-person and virtual visits.

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KEYWORDS

nursing homes; long-term care; COVID-19; depression; stress; coping; burden; mental health; elderly; older adults; risk; telehealth; self-assessment; scale; mood

Introduction

The base rates of depression and anxiety are high among postacute and long-term care (PA/LTC) residents. Approximately one-third of all residents in PA/LTC facilities experience significant depressive symptoms [1,2], whereas an estimated 5%-10% experience anxiety-related disorders [3,4]. These numbers are significantly higher among residents referred for neurocognitive evaluations. For instance, in a sample of PA/LTC residents referred for evaluation of mood and/or cognitive symptoms, 55% met the criteria for a major depressive episode, and 36.6% met the criteria for generalized anxiety disorder [5]. Although we found no studies investigating the psychological burden associated with COVID-19 in PA/LTC settings, there is evidence suggesting that the pandemic has contributed to an increase in mental health concerns. In a

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community sample, the American Psychiatric Association found that 36% of Americans reported that COVID-19 has had a significant impact on their mental health, and 48% reported feeling anxious about potentially contracting the infection [6]. The Centers for Disease Control and Prevention has issued a warning that people over the age of 65 years, those with serious underlying medical conditions [7,8], and those living in residential care settings are at the highest risk for developing severe illness from COVID-19; therefore, it is expected that these groups experience an increased psychological burden, placing them at a considerable risk of the development or exacerbation of psychiatric symptoms.

To our knowledge, evidence supporting a rapid mood screening tool that can be used to capture psychological burden associated with COVID-19 is currently lacking. Rapid screening is especially critical in the context of COVID-19. Under normal circumstances, health care providers are highly limited for the time that they can spend on assessments, particularly for co-occurring medical conditions [9,10]. Time is even more limited when the duration and extent of face-to-face encounters is capped to prevent the spread of infection, and competition for resources restricts the duration of virtual visits. This almost rules out the use of multiple measures or instruments that require more than 2 minutes of the providers' time to administer. The measures of depression and anxiety that are most commonly used in PA/LTC settings, including the Patient Health Questionnaire (PHQ-9) [11] and the Generalized Anxiety Disorder 7-item (GAD-7) scale [12], assess depression or anxiety but not both. Moreover, formal anxiety screening is not required in PA/LTC settings. The Geriatric Depression Scale–Short Form [13] is a mood instrument developed specifically for older adults, but it has limited psychometric properties and double the number of items in the PHQ-9 [14].

In this study, we developed and validated the Mood-5 Scale (M5) to address barriers to its practical use in the context of COVID-19 by minimizing administration time, allowing for self-administration, and combining the assessment of depression and anxiety. The scale is an adapted version of the Brief Anxiety and Depression Scale (BADS), a screening tool that assesses both depressive and anxiety symptoms and is widely used by health care professionals in PA/LTC settings [5]. The M5 was designed so that it can be (1) self-administered by residents in PA/LTC settings for a variety of conditions, ranging from normal cognitive functioning to mild dementia; (2) completed in less than 1 minute; and (3) completed as part of an in-person or telehealth visit, which is particularly relevant in the context of the COVID-19 pandemic. We hypothesized that the M5 will be able to rapidly identify COVID-19–associated psychological burden, as well as clinical anxiety and depression.

Methods

Participants and Procedures

Residents (N=131) aged 50 years and above from 20 PA/LTC facilities in Maryland, USA, were evaluated by a behavioral health interdisciplinary team comprising 10 psychologists, 1 psychiatrist, and 10 nurse practitioners via in-person or telehealth visits. Data were collected across a 4-week period during the COVID-19 pandemic (ie, May 11 to June 6, 2020) to obtain a *snapshot* of the possible psychological burden during the pandemic, with the intention of sharing actionable information with the providers who care for PA/LTC residents. The relatively small sample size reflects the effort to fast-track the research process and maximize impact in the context of the current COVID-19 pandemic. Institutional approval was obtained from each PA/LTC facility, and all residents or their responsible parties completed a consent agreement. Furthermore, all residents were deidentified for the analysis. M5 items were derived from the standard evaluation procedures so that the residents experienced no additional burden through its administration. A battery of psychological tests, including the M5, BADS [5], and the Brief Cognitive Assessment Tool (BCAT) [15], was administered as part of the usual evaluation. The International Classification of Diseases 10th Revision (ICD-10) [16] and Clinical Dementia Rating Scale [17] were used to assign psychiatric diagnoses and dementia stages, respectively. Residents were excluded from the study analyses if they had incomplete M5 data, moderate-to-severe dementia, or were aged below 50 years. Demographic and clinical characteristics of the study sample are presented in Table 1.

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Table 1. Select demographics and clinical characteristics (N=131).

Variable	Value, n (%)
Age (years), mean (SD)	76.12 (11.05)
Gender	
Female	69 (52.67)
Male	62 (47.33)
Race	
White	110 (83.97)
Black	14 (10.69)
Other	4 (3.05)
Missing	3 (2.29)
Marital status	
Single	23 (17.56)
Married	14 (10.69)
Widowed	52 (39.69)
Separated	6 (4.58)
Divorced	34 (25.95)
Missing	2 (1.53)
Education (years completed)	
≤11	18 (13.74)
12	55 (41.98)
13-15	22 (16.79)
16	17 (12.98)
≥17	14 (10.69)
Missing	5 (3.82)
Facility	
Skilled nursing	87 (66.41)
Assisted living	44 (33.59)
Cognitive level	
No dementia	10 (7.63)
MCI[a]	67 (51.15)
Mild dementia	54 (41.12)
Telehealth delivery	43 (31.82)
COVID-19 distress	67 (51.15)

[a]MCI: mild cognitive impairment.

Measures

Development of the M5

The M5 was adapted from BADS, which was chosen because it measures depression and anxiety factors separately, is used widely in PA/LTC settings, and has strong psychometric properties. Two items each from the depression and anxiety factors of BADS were selected for inclusion in the M5. A fifth item was added to address somatic or cognitive features. A panel of experts comprising 3 geriatric psychologists, 1 psychiatrist, and 2 PA/LTC medical directors vetted the instrument before data collection.

For standardized administration, residents were instructed as follows: “Think about how you have been feeling during the past month as you answer the following five questions. Please answer: ‘no’=0, ‘somewhat’=1, or ‘yes’=2.” The M5 items were written as follows:

1. Have you lost interest in activities that you had found pleasurable?
2. Do you worry about things more than usual?

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3. For at least two consecutive days, have you felt depressed, hopeless, or down?
4. Are you feeling nervous, anxious, or "wound up" much of the time?
5. Are you experiencing fatigue, headaches, stomach upset, or memory problems?

Multimedia Appendix 1 presents the M5 items and standardized scoring instructions.

COVID-19 Psychological Burden

The outcome binary variable "COVID-19 psychological burden" was based on a geriatric psychologist's independent review of the behavioral health providers' clinical documentation. While completing the medical records of PA/LTC residents, health care professionals were required to directly ask the patient whether they were experiencing psychological symptoms *associated* with fear of contracting COVID-19 and/or social distancing precautions to reduce disease transmission. An affirmative score was assigned if the documentation supported that the resident was queried about the COVID-19 psychological burden and the resident made direct statements about experiencing increased anxiety or depressive symptoms associated with COVID-19 or if the health care professional observed increased anxiety or depression associated with COVID-19.

Validity Measures

The convergent and discriminant validity of the M5 were evaluated using the BADS and BCAT, respectively. The BADS is an 8-item mood questionnaire designed to identify anxiety and depression (score range 0-16) among older adults. The BCAT is a 21-item, multi-domain cognitive instrument (score range 0-21) that distinguishes among normal cognition, mild cognitive impairment, and dementia [15,18].

Statistical Analysis

Analyses were performed in R (version 3.6.1; R Core Team) [19] using RStudio (version 1.2.5019; RStudio Team) software [20]. Descriptive statistics were used to report demographics, clinical characteristics, and study measures. Pearson correlations, independent sample *t* tests, and analysis of variance were performed to investigate the relationship between these variables and the M5. Cronbach α was used to estimate internal consistency. Receiver operator characteristic curve analyses examined the ability of the M5 to identify COVID-19 psychological burden. Despite the compressed data collection period, the sample size was sufficient for preliminary reliability [21,22]. Residents with missing study measures were removed pairwise to maximize the use of available M5 data.

Results

Preanalysis

Table 2 reports descriptive statistics for the M5 and validity measures. M5 scores were not associated with gender, race, marital status, education, or provider discipline ($P>.05$). Residents in skilled nursing settings (87/131, 66.4%) reported higher M5 scores than residents in assisted living settings (diff=1.73; 95% CI 0.29-3.18; $P=.01$). Younger age was associated with higher M5 scores ($r=-0.19$, $P=.03$). M5 scores did not differ as a function of telehealth (43/131, 32.8%) or in-person evaluations (diff=0.08; 95% CI −0.97 to 1.13; $P=.88$).

Table 2. Descriptive statistics of the various study measures used.

Study measure	n (%)	Mean (SD)	Minimum	Maximum	Skewness	Kurtosis
M5[a]	131 (100)	3.60 (2.86)	0	10	0.57	−0.59
BCAT[b]	70 (53.4)	34.61 (6.38)	22	46	−0.05	−1.02
BADS[c] AF[d]	110 (83.9)	2.70 (1.78)	0	6	0.47	−0.75
BADS DF[e]	110 (83.9)	3.31 (3.01)	0	10	0.68	−0.59

[a]M5: Mood-5 Scale.
[b]BCAT: Brief Cognitive Assessment Tool.
[c]BADS: Brief Anxiety and Depression Scale.
[d]AF: Anxiety Factor of BADS.
[e]DF: Depression Factor of BADS.

Psychometric Analyses

The M5 demonstrated acceptable internal consistency (Cronbach α=.77, 95% CI 0.71-0.83). Item-level statistics for the M5 are presented in Table S1 of Multimedia Appendix 1. Convergent validity for the M5 was established via positive and moderate associations with anxiety ($r=0.56$, $P<.001$) and depressive ($r=0.49$, $P<.001$) symptoms on the BADS (Table 3). Discriminant validity was confirmed for the M5 by negligible relationship with cognitive functions on the BCAT ($r=0.17$, $P=0.15$).

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Table 3. Correlation analysis (Pearson r and two-tailed *P* values) among the study measures.

Measure	M5[a]	BCAT [b]	BADS[c] AF[d]	BADS DF[e]
M5				
r	1	0.17	0.49	0.56
P value	__[f]	.15	<.001	<.001
BCAT				
r	0.17	1	0.03	0.23
P value	.15	—	.81	.06
BADS AF				
r	0.49	0.03	1	0.52
P value	<.001	.81	—	<.001
BADS DF				
r	0.56	0.23	0.52	1
P value	<.001	.06	<.001	—

[a]M5: Mood-5 Scale.

[b]BCAT: Brief Cognitive Assessment Tool.

[c]BADS: Brief Anxiety and Depression Scale.

[d]AF: Anxiety Factor of BADS.

[e]DF: Depression Factor of BADS.

[f]Not applicable.

Residents with generalized anxiety disorder or anxiety disorder due to a known physiological condition reported significantly higher M5 scores (41/131, 31.3%) than the remaining residents without anxiety diagnoses (diff=1.94; 95% CI −0.92 to 2.95; t_{129}=3.78; *P*<.001). The effect size for this difference was medium (Cohen *d*=0.71; 95% CI 0.33-1.09).

Residents with moderate or severe recurrent major depressive disorder (without psychotic symptoms) reported significantly higher M5 scores (22/131, 16.8%) than the remaining residents without these depression diagnoses (diff=3.65; 95% CI 2.49-4.82; t_{129}=6.21; *P*<.001). The effect size for this difference was large (Cohen *d*=1.45; 95% CI 0.96-1.95).

COVID-19 Psychological Distress

An M5 cutoff score of 3 (ie, scores ≥3) maximized the product of sensitivity (0.92) and specificity (0.75) for detecting COVID-19 psychological distress among PA/LTC residents (positive predictive value=0.79, negative predictive value=0.91). Area under the curve was 0.89 (95% CI 0.83-0.95), and 16% (21/131) of the residents were incorrectly classified (16 false positive and 5 false negative). Table 4 presents the properties for alternative M5 cutoff scores. Figure 1 illustrates the M5 receiver operative characteristic curve.

Table 4. Predictive utility of several cutoff scores for the Mood-5 Scale.

Cutoff score	Value (95% CI)			
	Sensitivity	Specificity	PPV[a]	NPV[b]
2	1.00 (0.93, 1.00)	0.56 (0.43-0.68)	0.71 (0.60-0.79)	1.00 (0.88-1.00)
3	*0.93 (0.83-0.97)*[c]	*0.75 (0.62-0.85)*	*0.79 (0.69-0.87)*	*0.91 (0.79-0.96)*
4	0.78 (0.65-0.87)	0.84 (0.73-0.92)	0.84 (0.72-0.92)	0.78 (.66-0.87)

[a]PPV: positive predictive value.

[b]NPV: negative predictive value.

[c]Italicized values in the table indicate the M5 cutoff scores with the optimal product of sensitivity, specificity, positive predictive value, and negative predictive value for identifying COVID-19 psychological distress.

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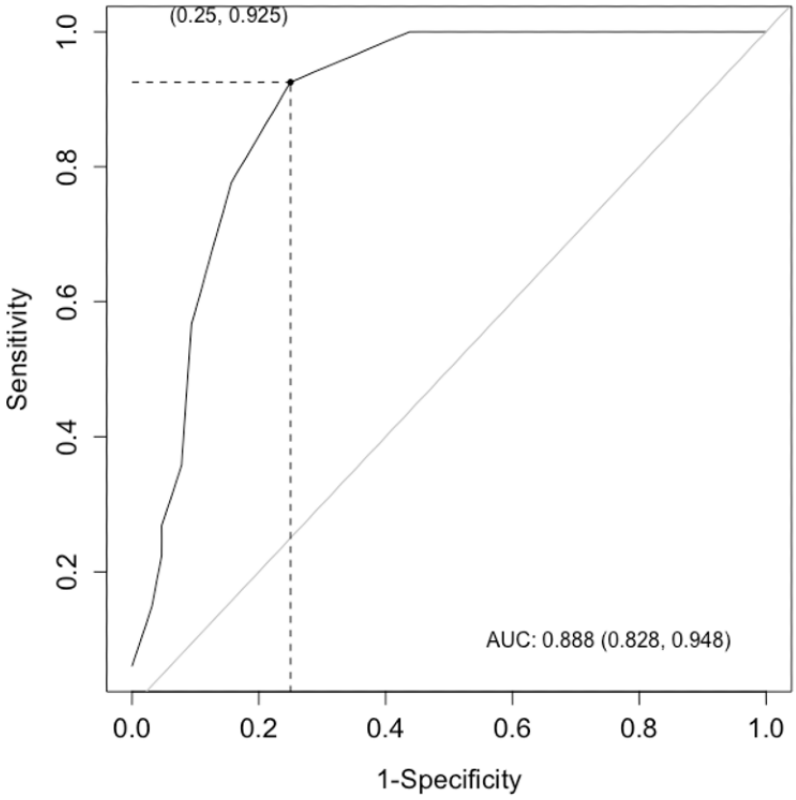
Figure 1. Receiver operating characteristics and area under the curve (AUC) were calculated from sensitivity and (1−specificity) values for the Mood-5 Scale for identifying COVID-19 psychological distress among older adults.



Discussion

Our findings support the reliability and validity of the M5 as a mood scale that can identify PA/LTC residents with COVID-19 psychological burden. The M5 is a reliable and valid mood scale that can be completed rapidly, is appropriate for in-person or virtual visits, and can be self-administered. It can be facilitated by a staff member or completed by a resident prior to or during a visit with a health care professional. Given its brevity, the M5 fits easily into an attending physician's assessment toolbox and can provide real-time information to guide the management of psychiatric medications. This may help rightsize psychotropic use, especially for PA/LTC settings wherein behavioral health specialists are lacking. We recommend a cutoff score of 3 (ie, scores ≥3) to identify those residents who are more psychologically vulnerable and may benefit from a formal mood evaluation. We selected a M5 cutoff score that emphasized sensitivity to identify residents who would benefit from specific counseling to address concerns about COVID-19. Such concerns could be associated with contracting the infection, reduced opportunities for meaningful engagement due to social distancing, and concerns about the health of loved ones.

Our study has several strengths, including (1) our use of the ICD-10 and the Clinical Dementia Rating scale for diagnoses, (2) determination of the COVID-19 psychological burden by an independent review performed by a geriatric psychologist, (3) feedback on the M5 from attending physicians and medical directors, and (4) a selection of widely used validity measures (eg, BCAT and BADS) developed specifically for PA/LTC settings. Owing to the urgency to develop a scale that could be applied to PA/LTC residents during the current COVID-19 pandemic, our sample size was relatively small. This is partly mitigated by the inclusion of residents from multiple settings. The next steps for our study should involve cross-validation, collecting additional data to investigate psychological burden over time as the prevalence of confirmed COVID-19 cases decline, and investigating the psychological burden and associated M5 scores assigned by health care professionals and staff who care for PA/LTC residents. The primary focus of this study was to establish a clinically relevant cutoff score for the M5. Future studies should compare the psychometric properties of the M5 to separate measures of anxiety and depression commonly used in PA/LTC settings, such as the GAD-7 and PHQ-9.

The most immediate implication of this study is that widespread deployment of the M5 in PA/LTC settings can identify residents who are at a higher risk for experiencing COVID-19–related psychological burden and facilitate timely intervention. However, the M5 has potential utility beyond its ability to identify residents with an increased psychological burden associated with COVID-19. For nursing homes, incorporating the M5 into standard screening practices would redress a shortcoming in the current Minimum Data Set (MDS 3.0), which mandates a depression screening but does not include an instrument sensitive to anxiety symptoms. The M5 is sensitive to *both* depressive and anxiety symptoms. The use of instruments that are sensitive to both anxiety and depression could help reduce rehospitalizations [23], thereby improving some quality measures. Finally, use of the M5 during postacute care can provide a mood baseline that can be used to track mood symptoms postdischarge, thus improving care transitions.

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Acknowledgments

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Conflicts of Interest

The corresponding author (WEM) has ownership rights of the Mood-5 Scale. RAM is partially employed by Mansbach Health Tools, LLC. The authors report no other conflicts of interest.

Multimedia Appendix 1
Item-level statistics for the M5.
[DOCX File , 15 KB - aging_v4i1e26340_app1.docx]

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Abbreviations

BADS: Brief Anxiety and Depression Scale
BCAT: Brief Cognitive Assessment Tool
GAD-7: Generalized Anxiety Disorder 7-item
ICD-10: International Classification of Diseases 10th Revision
M5: Mood-5 Scale
PA/LTC: Post-acute and long-term care
PHQ-9: Patient Health Questionnaire

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Original Paper

Understanding Technology Preferences and Requirements for Health Information Technologies Designed to Improve and Maintain the Mental Health and Well-Being of Older Adults: Participatory Design Study

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Abstract

Background: Worldwide, the population is aging rapidly; therefore, there is a growing interest in strategies to support and maintain health and well-being in later life. Although familiarity with technology and digital literacy are increasing among this group, some older adults still lack confidence in their ability to use web-based technologies. In addition, age-related changes in cognition, vision, hearing, and perception may be barriers to adoption and highlight the need for digital tools developed specifically to meet the unique needs of older adults.

Objective: The aim of this study is to understand the use of technology by older adults in general and identify the potential barriers to and facilitators of the adoption of health information technologies (HITs) to support the health and well-being of older adults to facilitate implementation and promote user uptake. In addition, this study aims to co-design and configure the InnoWell Platform, a digital tool designed to facilitate better outcomes for people seeking mental health services, to meet the needs of adults 50 years and older and their supportive others (eg, family members, caregivers) to ensure the accessibility, engagement, and appropriateness of the technology.

Methods: Participants were adults 50 years and older and those who self-identified as a supportive other (eg, family member, caregiver). Participants were invited to participate in a 3-hour participatory design workshop using a variety of methods, including prompted discussion, creation of descriptive artifacts, and group-based development of user journeys.

Results: Four participatory design workshops were conducted, including a total of 21 participants, each attending a single workshop. Technology use was prevalent, with a preference indicated for smartphones and computers. Factors facilitating the adoption of HITs included personalization of content and functionality to meet and be responsive to a consumer's needs, access to up-to-date information from reputable sources, and integration with standard care practices to support the relationship with health professionals. Concerns regarding data privacy and security were the primary barriers to the use of technology to support mental health and well-being.

Conclusions: Although HITs have the potential to improve access to cost-effective and low-intensity interventions at scale for improving and maintaining mental health and well-being, several strategies may improve the uptake and efficacy of technologies by the older adult community, including the use of co-design methodologies to ensure usability, acceptability, and appropriateness of the technology; support in using and understanding the clinical applications of the technology by a digital navigator; and ready availability of education and training materials.

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KEYWORDS

aging; mental health; technology; mobile phone; community-based participatory research; health care reform; stakeholder participation

Introduction

Strategies for Healthy Aging

The global population is aging rapidly. Within the next 40 years in Australia, for example, one-third of the population will be aged 50-65 years and a further quarter will be 65 years and older [1]. The economy will require a level of productivity from these people not previously seen. As such, there is a growing interest in strategies for supporting and maintaining health and well-being in later life to improve the social and economic participation of older adults to meet the demands of an aging society [2]. Efforts aimed at optimizing mental health and well-being are important contributors to achieving this mission.

Internet Use Among Older Adults

The international literature indicates that approximately two-thirds of adults aged 65 years and older report internet use [3,4], and these older adults also represent the fastest-growing group of internet users [5]. Thus, using health information technologies (HITs) for mental health screening, intervention delivery, and routine outcome monitoring will be an increasingly viable option for older adults globally. The increase in internet use among this population has spurred a growing interest in the development and implementation of HITs for improved health and well-being for older adults [6-8].

HITs

HITs are being developed rapidly for improving the delivery of mental health care for both consumers and health professionals and for facilitating improved self-management of care [9]. To that end, HITs have been shown to be effective for the management and treatment of symptoms in a range of mental health and medical conditions, including depression [10-12], diabetes [13], weight loss [14], problematic alcohol use [15], sleep [16], exercise [17], and social connectedness [18]. Barring some exceptions, including a diet diary app for older adults with age-related macular degeneration [19], few HITs have been designed specifically with older adults in mind. As such, this represents a largely untapped market for potential web-based tools to improve the health and well-being of older adults.

Importantly, in a study of older adults (N=221) presenting to a specialized memory clinic for concerns regarding new-onset cognitive decline and/or mood symptoms, most participants (198/209, 94.6%) reported that they would find it useful to be able to access a website designed to support healthy aging, including physical health and cognition, self-management of existing conditions, and routine tracking of changes in health outcomes over time. Similarly, most respondents also reported interest in a website designed to specifically measure mood-related concerns and changes (172/206, 83.5%) [20]. Despite having interest in and motivation to use HITs to improve their health and well-being [20,21], some older adults still lack confidence in their ability to use web-based technologies [22,23]. It has been demonstrated that older adults will only adopt new technologies when their apparent usefulness and usability outweigh concerns related to technological complexity and decreased social connection [24]. In light of these factors and age-related changes in cognition, vision, hearing, and perception, it is critical that HITs be tailored to the older adult community, taking into consideration their unique needs as users.

Participatory Design

Using strategies to enhance community and consumer acceptability, usability and engagement with HITs is a priority in the health, medical, and research sectors internationally [25,26]. To this end, co-design methodologies, including participatory design and user testing, are widely recognized as key to ensuring the quality, usability, and acceptability of HITs for specific user groups—in this case, older adults. Research has shown that the active participation of all stakeholders throughout the design of technical systems and services helps ensure that the end product meets the needs of its intended user base, improves usability, and increases engagement of all individuals [27-29]. Importantly, there is an emerging evidence base reflecting the benefits of co-design with older adults, including those with dementia, and their family and caregivers, to enable strengths-based, person-centered care [30,31]. Our research team's established co-design methodologies explicitly position users as empowered participants in all stages from design and development through to implementation and impact evaluation [28,29,32,33].

The InnoWell Platform

In 2017, the Australian Government Department of Health and InnoWell Pty Ltd (a joint venture between the University of Sydney and PwC, Australia) entered into a 3-year funding agreement to deliver Project Synergy (2017-2020), a series of collaborative research trials with the specific purpose of co-designing and implementing innovative HIT solutions, including the InnoWell Platform, to enable improved mental health service delivery in Australia, facilitating better outcomes for people with lived experience, supportive others, health professionals, and service providers [9]. As described in detail by Davenport et al [34], the co-designed InnoWell Platform was developed through Project Synergy (by InnoWell) to collect information from multiple sources to formulate a comprehensive understanding of a consumer's needs and to monitor their progress over time. These sources comprise web-based, self-reported questionnaires assessing a range of health domains (ie, psychological distress, suicidal thoughts and/or behaviors, daily functioning, depressed mood, cognition, sleep-wake cycle, social connectedness) from both consumers and their health professionals and objective behavioral data collected via third-party integrations (eg, Fitbit trackers). The multifaceted and multidimensional assessment results are designed to be understandable directly by consumers and to be reviewed in collaboration with their health professional to promote shared decision making and collaborative care and to facilitate routine

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outcome monitoring, clinical review, and coordinated care to ensure that all consumers receive the right care first time.

Objectives

We now aim to customize and configure the InnoWell Platform to meet the needs of an older age group (50 years and older) and their supportive others (eg, family members, caregivers) to ensure the accessibility, engagement, and appropriateness of the technology. We defined *older adults* as those aged 50 years and older as this aligns with our own previous work investigating technology use and preferences among this group [20]. Furthermore, the age of 50 years relates to the onset of disorders in later life [35] and the identified age range during which it is recommended to address risk factors (ie, cardiovascular disease, obesity, diabetes) known to undermine healthy aging [36]. Furthermore, we seek to understand the potential barriers and facilitators of HIT use for older adults to better identify and understand ways to promote adoption and facilitate successful implementation.

Methods

Participants

This study aimed to recruit up to 50 participants, including a combination of older adults and their supportive others. The inclusion criteria for participation in the study required participants to be aged 50 years and older or self-identify as a supportive other (eg, family member, caregiver), to be proficient in English, and to have completed the required informed consent process.

Recruitment Strategies

This study was advertised through the University of Sydney's Brain and Mind Centre, including through active research clinics working with older adults and via nongovernmental (ie, Dementia Australia) and private organizations (ie, InnoWell) associated with the Brain and Mind Centre. The recruitment strategy included the use of postcards and A3/A4 posters in both paper-based and digital forms, depending on the preference of the advertising site (eg, poster displays, postcards at reception, posting the digital advertisements on the research sites and social media pages).

To avoid any perceived coercion, recruitment was passive such that a potential participant needed to contact the senior research health professional (HL) who, only on a potential participant's request, then forwarded the study Participant Information Sheet and Consent Form. All participants were provided with detailed information about the study both before attending a participatory design workshop and again on arrival at the workshop. At the beginning of each workshop, the facilitators provided the participants with an opportunity to ask questions and clarify details of the research before providing written informed consent. Potential participants were reminded that participation was entirely voluntary and that if they agreed to participate, they could withdraw their consent at any time without being required to provide any reasons and with no impact on their relationship with the University of Sydney, the Brain and Mind Centre, InnoWell, or the participating clinics through which they were recruited.

Participatory Design Workshops

A series of 4 group-based workshops of approximately 3-hour duration, each with up to 10 participants, were conducted with older adult stakeholders to discover, evaluate, and prototype acceptable design solutions for the InnoWell Platform. These sessions involved an iterative knowledge translation process so that initially generated ideas can be further developed (and fed back on) by participants in subsequent workshops (Multimedia Appendix 1 presents a sample agenda). All workshops were coordinated by 2 facilitators (one of whom was a health professional) and a scribe was present to take detailed notes. Two facilitators were considered important; the first facilitator guided the research questions and session plan, and the second facilitator ensured that all participants' voices were heard within the workshop.

As in our previous co-design research [29], the facilitators used a variety of methods within the workshops, including prompted discussion, prototyping, creation of descriptive artifacts, and group-based development of user journeys (a series of steps illustrating how an individual might interact with the prototype). It is important to note that the InnoWell Platform is being designed and developed iteratively; therefore, although a version of the InnoWell Platform has been built, the participants were not exposed to the technology as part of the workshops to avoid bias in their thinking. As such, a *blue sky* approach (ie, brainstorming without limitations or practical constraints) was used for prototyping to ensure that the necessary features and functionality that may be unique to the older adult community were captured. On the basis of previous studies exploring the use of technology for health-related purposes by older adults [4,24,37,38], a number of critical areas were explored, including (1) preferred devices, (2) common uses of technology, (3) use of technology to support health and well-being, (4) features or functionality that promote user engagement, (5) interest in and preferences for digital health services, and (6) concerns related to data privacy and confidentiality.

Data Analysis

Interpretation of the qualitative data from the workshops, including scribe notes and artifacts, followed established thematic techniques [39]. All raw data were reviewed and checked across all participants by a senior research health professional (HL), and a coding framework outlining all key concepts was developed. Data were coded in NVivo 12 software (QSR International) using this framework. The coding followed an established iterative process of reading, coding, and exploring the pattern and content of coded data, followed by reflection and discussion. Similarities and differences in opinion were examined, and differences were dealt with through discussion to reach consensus. Coding was conducted initially by the senior research health professional (HL) and a randomly selected subsample of 10% was checked for inter-rater reliability by a research officer (AR); agreement was substantial (κ=0.631) [40]. In alignment with the topics explored in the participatory design workshops, themes were then organized as follows: (1) preferred device; (2) well-being as a concept; (3) barriers to and facilitators of technology use generally; and (4) barriers to and facilitators of technology use to support mental health and

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well-being, including a prototype of the InnoWell Platform configured for older adults. All themes were checked against each other and back to the original data to ensure that all relevant references had been collated. This process resulted in a thematic framework that was internally coherent and consistent.

Ethics

This research study was approved by the University of Sydney's Human Research Ethics Committee (Project No. 2019/172).

Results

Demographics

A total of 4 participatory design workshops (all 3 hours in duration) were held between September and November 2019. The aim of each workshop was to actively engage the older adult community in discussions about how technology may be used to promote mental health and maintain well-being. A total of 21 adults (43% female) aged 50 years and older attended the workshops, 2 of whom also identified as supportive others. All participants attended only one workshop. Although the sample size was smaller than planned, the richness of the data and the consistency of the themes indicated that we had reached saturation. To ensure participant confidentiality, further demographic details were not collected as part of this study. No participants expressed concern about or experienced any distress in any of the workshops.

Technology Preferences

When asked *What is your favorite piece of technology*, participants reported a range of preferences, including *computers, tablets, eBook readers, basic mobile phones, wearables, and televisions.* However, the *smartphone* was the most frequently referenced device (Textbox 1) for several reported reasons:

> *my phone is always on...used for a lot of functional things—news, transport, a lot of informational things.* [Workshop 1]
>
> *I read the paper on my phone.* [Workshop 2]
>
> *...to stay connected.* [Workshop 4]
>
> *I use notes a lot for writing poetry.* [Workshop 4]

Computers were also referenced frequently as a preferred device because of the diversity of available functionality, such as *"creative work...music...Photoshop," "YouTube extreme sports...puts you in places you've never been...online shopping," "use it for music composition and practice,"* and *"love using YouTube...added value for my work"* (all from Workshop 1).

Tablets were largely referenced in relation to games and ease of access to information (ie, news, politics, sports). However, there was an indication that *smartphones, tablets,* and *computers* were used interchangeably for the purpose of accessing the internet, with 1 participant noting:

> *It's all the same to me...if I'm out it's the phone, at home it's the tablet or phone.* [Workshop 4]

Participants also referenced the use of apps and e-tools both in relation to entertainment, for example, *Spotify for* "access to music…listen to podcasts" (Workshop 1) and to support health and well-being, including *"Headspace app for meditation...keeping in contact with kids through various apps"* (Workshop 3); "Lumosity…I had to wean myself off it…I was becoming competitive with it and couldn't get to sleep" (Workshop 3); and "family history and that's a real brain teaser to follow different leads…it's very complex and good for the brain" (Workshop 3).

Textbox 1. Codes related to technology preferences theme (63 references).

Preferred devices used by older adults include:

- Smartphone (18 references)
- Computer (15 references)
- Apps and e-tools (10 references)
- Tablet (9 references)
- Basic mobile phone (3 references)
- eBook readers (3 references)
- Wearables (3 references)
- Television (2 references)

Well-Being

As shown in Textbox 2, two primary themes emerged from the discussions about well-being, with *concepts* being referenced more frequently than *strategies*. In relation to the former, references to *health and functional capacity* were the most common. Participants consistently characterized well-being as a holistic combination of mental and physical health, with one stating:

> *It's not just the absence of sickness but capacity to do what you want with your body, such as reach maximum heart rate…the presence of strength…feeling good.* [Workshop 3]

There were also several references to *self-awareness and acceptance,* noting that well-being relates to *"relationship to yourself or with others"* (Workshop 1) *and "my own state of mind"* (Workshop 2*); well-being* was conceptualized as being *"personal to you...for example, someone immobile for life could still have well-being"* (Workshop 3).

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Although referenced less frequently, participants indicated that well-being also relates to *safety* (ie, *"feeling good and feeling safe"* [Workshop 3]), *social connectedness* (ie, *"connection to people"* [Workshop 1]), *and resilience or the ability to "move through" (Workshop 3) challenging events.* Although there was consensus as to the conceptualization of well-being, some participants indicated that the term had become a *buzz word (Workshop 2)* used for *marketing purposes.* In addition, it was noted that well-being can be negatively impacted by *stigma*, as 1 participant stated:

> *Those who struggle most with stigma are those with mental health issues...frustrated by telling their story over and over.* [Workshop 3]

Several strategies to promote or maintain well-being were referenced with similar frequency, including *leisure activities*, such as *a break from work (Workshop 2)* and *a massage (Workshop 3)* and *diet and exercise (Workshop 2).* Although some participants referenced the importance of *social connectedness (Workshop 2)*, others indicated a need for *self-reliance*, noting:

> *I'd manage it myself, wouldn't want to burden other people.* [Workshop 2]

Finally, there were mixed responses regarding the value of *information and tips*, with 1 participant noting:

> *A friend who worked in arthritis research used to send me information and I trusted it.* [Workshop 2]

Another stated:

> *I wouldn't be interested in daily tips.* [Workshop 2]

Textbox 2. Codes related to well-being theme (48 references).

Concepts (37 references)

- Health and functional capacity (15 references)
- Self-awareness and acceptance (10 references)
- Marketing purposes (3 references)
- Social connectedness (3 references)
- Resilience (2 references)
- Safety (2 references)

Strategies (11 references)

- Leisure activities (3 references)
- Diet and exercise (2 references)
- Information and tips (2 references)
- Self-reliance (2 references)
- Social connectedness (2 references)

Barriers to and Facilitators of Technology Use

When discussing the use and impact of technology in daily life, two primary themes emerged—*barriers and facilitators* (Textbox 3), with the latter being referenced with greater frequency. In particular, *social connectedness* was one of the primary ways in which participants were making use of technology, with participants commenting:

> *Technology is my communication...email and text are important for me to keep in touch.* [Workshop 2]
>
> *It's a huge difference to me with three children who live in the US.* [Workshop 3]
>
> *Skype/FaceTime with family makes you feel connected.* [Workshop 3]
>
> *It creates easier, less formal contact with friends.* [Workshop 3]

Interestingly, the potential for technology to drive *social disconnection and miscommunication* was noted as a potential barrier as a participant stated:

> *It worries me that young people don't know a life without a screen…they don't know how to connect without an app.* [Workshop 3]

One participant questioned:

> *Why don't you just call...there can be miscommunication with texting.* [Workshop 1]

Furthermore, it was also agreed that connecting via technology is *not equivalent to in-person*. One participant commented:

> *I know I can do it on the computer, but I enjoy the contact...it's having a human element.* [Workshop 3]

Another stated:

> *If I can do it as a video, then I can see my grandchildren...but I can't have a hug.* [Workshop 3]

Games, such as "Word with Friends...Candy Crush…Bridge" (*Workshop 4*) and "Spider Solitaire" (Workshop 4) and *information and new learning* were also frequent uses of technology, including references to websites related to news and travel and "YouTube…gives you video tutorials" (*Workshop*

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1). Although participants indicated that the *ease of access* to information was a facilitator to technology use, noting, "You can't beat Wikipedia for instant information about anything" (*Workshop 1*), it was also highlighted that this *changes the way we think*. For example, in relation to the consumption of media, one participant stated:

> *The way I read and get information now is much more snapshot rather than long form journalism.* [Workshop 1]

Another participant noted:

> *Problem-solving is lacking as you can just tap on a screen and get information...they don't question whether it's the right information.* [Workshop 3]

In relation to the latter, participants indicated that the *credibility of the source* was important when using the internet or web-based tools. Information produced by the government, reputable health organizations, universities and academics, and individuals with higher degrees or qualifications were more likely to be perceived as trustworthy and reliable. At the same time, however, the potential for *miscommunication and limited detail* was referenced, with some skepticism expressed about news sources, including:

> *We're in the age of misinformation, they don't want us to know the truth.* [Workshop 1]
>
> *If you can get someone to click on a headline, that's more valuable than relating it to the article.* [Workshop 1]

In addition, 1 participant referenced *security concerns* in relation to web-based data sharing, stating:

> *Anything on the Internet I just don't really trust, I don't want to put my information of any kind out there.* [Workshop 2]

The potential *anxiety-provoking* nature of technology was referenced, albeit infrequently, with a participant commenting:

> *My older friends get anxious if something goes wrong and they don't know how to fix it...they aren't feeling confident.* [Workshop 3]

Digital literacy was characterized as a skill:

> *You have to learn it, like anything else.* [Workshop 3]

Finally, w*ork requirements* were noted as a driver of technology use, whereas *lack of interest* was a barrier.

Textbox 3. Codes related to barriers and facilitators to technology use theme (63 references).

Barriers (28 references)

- Changes the way we think (9 references)
- Misinformation and limited detail (8 references)
- Social disconnection and miscommunication (4 references)
- Not equivalent to in-person (3 references)
- Anxiety (2 references)
- Lack of interest (1 reference)
- Security concerns (1 reference)

Facilitators (35 references)

- Social connectedness (13 references)
- Games (6 references)
- Information and new learning (6 references)
- Credibility of the source (4 references)
- Ease of access (4 references)
- Work requirements (2 references)

HIT Use

As shown in Textbox 4, *barriers* and *facilitators* again emerged as the primary themes when discussing the use of technology specifically for health-related purposes and co-designing a prototype of the InnoWell Platform for older adults. Access to *information* was the primary facilitator referenced, in relation to being able either to *read up on a problem and present that to doctors (Workshop 1)* or *to go back to the internet to take the time to review and be critical of information* discussed in an appointment with a health professional *(Workshop 1)*. Although HITs are *not equivalent to in-person care*, that is, "Need face-to-face to establish trust for subsequent phone or emails…you feel you know the person" *(Workshop 1)*, it was noted that they provide improved *access to care*. For example, the convenience, that is, "face-to-face is best, but over the phone is convenient" *(Workshop 1)* and anonymity afforded by technology may "be a good thing for people suffering mental health…if it was face-to-face or someone they knew they would be less likely to do it at all" *(Workshop 3)*. Whether the technology was *endorsed by a health professional* or *endorsed by a family member or friend* were noted facilitators of HIT adoption and engagement, with participants indicating they

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would use it if "recommended…by my doctor" *(Workshop 2)* or "a certain friend or family member" *(Workshop 2)*.

It was recognized that the ability for technologies to be *integrated with health care* increases the transparency in care:

> *...the doctor used to just have it, now you have it on your computer...you have all your health information at your fingertips.* [Workshop 4]

In addition, it affords the opportunity for *coordinated care*, allowing shared information between treating health professionals. One participant stated:

> *I see it as a total package, it's just part of your wellbeing. My different medical people should know if I have a heart issue or if I'm seeing a psychologist.* [Workshop 2]

As a caveat, *ownership and personal choice with data* provides consumers with the option "to decide who can see what and which doctors have access" *(Workshop 4)*. *Security concerns* were referenced as the primary barrier to HIT use, with concerns noted to include "once your email is connected, essentially hackers could get a lot" *(Workshop 4)*, "not getting jobs…not getting insurance" *(Workshop 3)*, and "people will target you with products based on information gathered" *(Workshop 3)*.

From a technical perspective, *user experience and customization* were referenced as facilitators of use. *Data tracking* was also an attractive feature, including the ability to track physical activity and weight loss using apps such as MyFitnessPal and via wearables (ie, *Fitbit)*. In addition, *competition* is a potential driver for technology use. For example, 1 participant commented:

> *...subscribed to Lumosity for about a year...it was lots of fun...tried to improve my score to be in the top percentile for my age group.* [Workshop 2]

However, the *potential for misuse* was also identified as "over-notifications could feel like bullying" *(Workshop 1)* or result in an "obsession with the data" by users *(Workshop 1)*. *Data entry and tracking requirements* were also viewed as a potential barrier to use, as it "might be another stressor for some people" *(Workshop 3)*, particularly "once they are unwell" *(Workshop 3)*.

Although not raised as a personal concern by any of the participants, limitations in *digital literacy* was referenced as a potential barrier as it was noted that:

> *...technology is not usable by a lot people in my generation...at the moment there is a generational cut-off.* [Workshop 4]

In addition, *lack of interest* in HITs, including how they work, may also reduce uptake.

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Textbox 4. Codes related to technology use to support health and well-being theme (308 references).

Barriers (57 references)

- Security concerns (18 references)
- Lacks credibility of health professional (10 references)
- Not equivalent to in-person care (10 references)
- Potential for data misuse (9 references)
- Data entry and tracking requirements (8 references)
- Lack of interest (7 references)
- Digital literacy (1 reference)

Facilitators (59 references)

- Information (13 references)
- Data tracking (10 references)
- Access to care (8 references)
- Endorsed by health professionals (7 references)
- Coordinated care (5 references)
- Integrated with health care (5 references)
- User experience and customization (3 references)
- Ownership and personal choice with data (3 references)
- Competition (3 references)
- Endorsed by a family member or a friend (2 references)

Prototype features and functions for a digital platform customized for older adults (192 references)

- Barriers (34 references)
  - Impersonal and social disconnection (5 references)
  - Lacks credibility of health professional (5 references)
  - Privacy and security risks (5 references)
  - Competition (4 references)
  - Limitations and potential errors (4 references)
  - Anxiety about seeking help (2 references)
  - Digital literacy (2 references)
  - Generic information (2 references)
  - Misinterpretation of information (2 references)
  - Requirements for use (2 references)
- Facilitators (158 references)
  - Personalization (32 references)
  - Information and resources (15 references)
  - Interoperability and data tracking (13 references)
  - Credible source or endorsed by health professional (12 references)
  - Interaction with health system (12 references)
  - Prevention and risk reduction (11 references)
  - Access (10 references)
  - Recommendations and interventions (10 references)
  - Anonymity (8 references)
  - Goal setting (6 references)

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- Personal data record (6 references)
- Education and training (5 references)
- Empowering (5 references)
- Social connection and support (5 references)
- Diagnosis (2 references)
- Supportive other functionality (2 references)
- User experience and design (2 references)

Prototyping the InnoWell Platform for Older Adults

Building on the foundation of their experiences with health care systems and technology generally and HITs specifically, participants co-designed a prototype of the InnoWell Platform for older adults, identifying features and functionality that would be *barriers* to and *facilitators* of adoption and implementation. Importantly, facilitators were referenced far more frequently than barriers, potentially reflecting the interest in and increasing use of technologies to support health and well-being. The primary driver for use was *personalization* (ie, a tool that is designed to meet a consumer's requirements and that responds to the data entered by a consumer to meet a consumer's needs) as participants noted:

> *I can see a clear use...someone wakes up and feels bad or experiences a new symptom…they go on this software and it give them some triage to start with.* [Workshop 1]
>
> *...questions about you and your situation...sends you off to areas of the site that could be useful.* [Workshop 3]
>
> *It could be like a referral service to send you in the right direction.* [Workshop 3]

Interoperability (ie, the ability of the digital tool to exchange information with other technologies such as apps and wearables) and *data tracking* were identified as factors that may facilitate *personalization*. For example, one participant stated they would:

> *be able to input data about my arthritis, pain levels, tracking what's happening with my fingers...I assume it would give me lots of information, things to do...take some ownership of my tracking.* [Workshop 2]

Interestingly, the need for personalization was coupled with a desire for *anonymity*. It was suggested that the user "could create a username" *(Workshop 1)*, with participants agreeing that "the information going in is so sensitive that I would only do it anonymously" *(Workshop 1)*. Furthermore, the ability to store health information in a *personal data record*, that is, "it knows all my background" (*Workshop 3*) was valued by participants. However, it is important to note that *privacy and security risks* were frequently referenced barriers as cybersecurity was characterized as "an arms race...people employed in security are constantly trying to stay in front of the hackers" *(Workshop 1)*.

The ability to find up to date *information and resources* was also referenced as a facilitator of use—a place to ask "those silly questions you just can't ask in an intimidating environment" *(Workshop 2)* and gain better understanding of "what to tell your [general practitioner] GP…teaching you the things you need to tell your specialist" *(Workshop 2)*. However, there was some concern that the *misinterpretation of information* might be a barrier, recognizing a "risk of creating a device that leads people to self-diagnosing" *(Workshop 2)* and that *generic information* may not have much benefit if it is "not personalised" *(Workshop 3)* and "only answers a silly little thing" *(Workshop 3)*.

Participants wanted there to be an *interaction with health care*, potentially as a "referral to a specialist" *(Workshop 1)*, a way to "fast track the system…direct you to service" *(Workshop 1)*, or a tool to enhance the care provided by a health professional, that is, "If I brought it in and showed it to her, she'd probably work collaboratively with me." *[Workshop 2])*. *Recommendations and interventions* were also a desired feature, with ideas including "interventions to do balance exercises" *(Workshop 1)*, "video training about how to do a guided [meditation] session" *(Workshop 3)*, and "virtual group sessions" *(Workshop 3)*. However, the *potential for error* was cited as it was recognized that there is an inherent "risk with assuming that feeding information in means the outcomes will be right" *(Workshop 1)*. Figure 1 reflects one participant's conceptualization of how he or she might use this type of tool. By inputting information about current symptoms and desired services or activities, the digital tool would then provide tailored recommendations.

Participants indicated that they would be more likely to use this type of tool if it came from *a credible source or was endorsed by health professionals*, highlighting the need for the content to be "developed by an organisation that is already trusted" *(Workshop 2)*. Similarly, a digital tool was viewed to *lack the credibility of a health professional*, thereby potentially preventing use as participants were not interested in "replacing GPs or specialists" *(Workshop 2)*. The potential for a digital tool to be *impersonal* was also referenced as a barrier, particularly for older adults who "could be more isolated…need someone that cares…the connection is still important" *(Workshop 1)*. Figure 2 presents a hypothesized user journey created by participants, highlighting the way in which they would use the prototype of the digital tool, including the information that they would input to personalize the results, the manner in which a health professional could make use of that information to coordinate care, and the support provided via the digital tool.

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Although there was minimal reference to the need for the tool to be able to provide a user with a *diagnosis*, participants reported an interest in *prevention and risk reduction* or "something that would keep me away from the doctor…preventative but also health generative…keeps you healthy and active" *(Workshop 1)*. *Goal setting* was a potential motivator of use, with participants noting that users "would establish goals after going through a level of entering information" *(Workshop 1)* and recognizing that "goals could change as you go through" *(Workshop 1)*. On the other hand, *competition* was referenced as "demotivating…don't want people to fail and say I won't look at that again" *(Workshop 1)* and "a huge problem…a goal isn't a goal unless there's a success or failure measured" (*Workshop 1)*.

It was widely recognized that a digital tool has the potential to improve *access* to health care, particularly for individuals in remote areas where "distance becomes a disability" *(Workshop 1)*, helping "people not feel isolated when they are physically isolated" *(Workshop 2)*. *Empowering* users was also referenced as an important component, with a need for a strength-based approach because "older people are told you can't do that anymore…celebrate what they are doing" *(Workshop 1)*. Although referenced infrequently, participants indicated *that they were more likely to use a digital tool that had a good user experience and design*. Furthermore, it was recommended that users would benefit from *education and training* resources, "information on how to use it – a tutorial or mind map…give people an idea of what kind of help they could get" *(Workshop 3)*. This may be particularly relevant for older adults with poor *digital literacy* as "people will always be left out if it is on a computer" *(Workshop 1)* or for those who experience *anxiety related to help seeking*, where the technology should not be "too daunting" *(Workshop 1)*. However, neither of these barriers were reported to be personal concerns for the participants.

Figure 1. App prototype of a digital tool to support health and well-being.

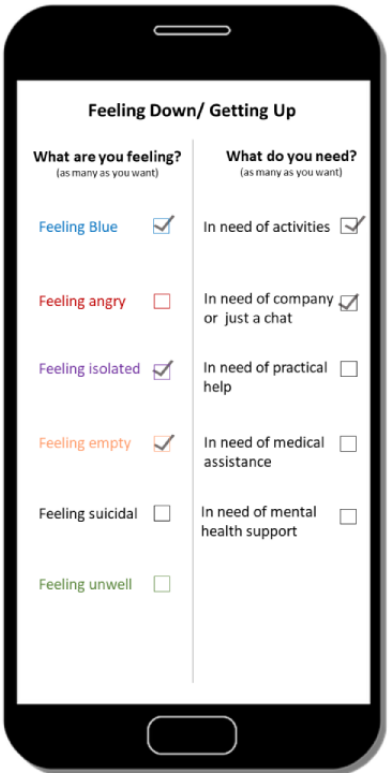

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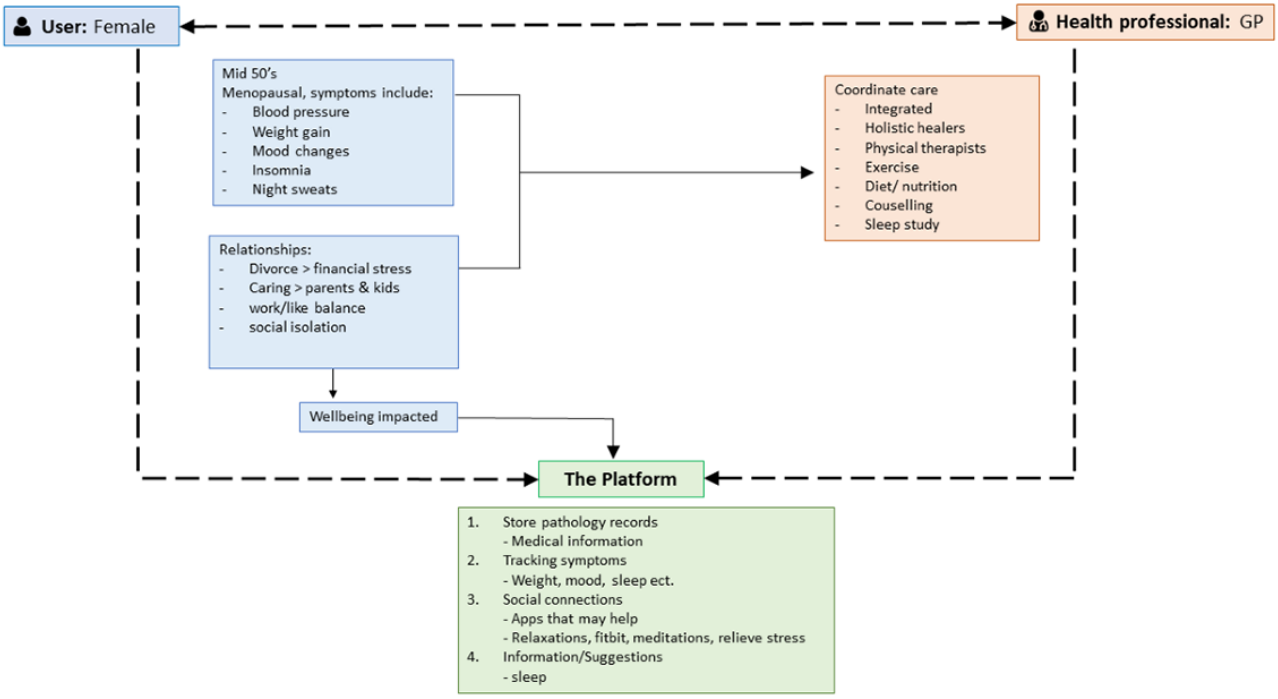
Figure 2. User journey demonstrating how a consumer might engage with the prototype.



Discussion

Technology Use by Older Adults

Our results align with previous findings that older adults routinely engage with a range of technologies, including computers, mobile phones, eBook readers, and tablets. Importantly, the preference for smartphones highlights a change in device use among older adults. Although previous studies have found that the use of home computers was nearly universal in a sample of older adults (93%), the use of smartphones was far less frequent (52%) [20]. The present results emphasize the rapid growth in smartphone ownership among older adults in recent years and the effect of aging [41], with younger people with greater digital literacy and experience with technology moving into the older age group. For example, among Americans aged 65 years and older, ownership of smartphones increased from 23% in 2013 to 42% in 2016 [4]. It is important to recognize that device adoption varies considerably with age, education, and household income. The proportion of older adults who own a smartphone or tablet is markedly higher for those aged 65 to 69 years (59% and 41%, respectively) relative to those aged 75 to 79 years (31% and 28%, respectively) [4]. Similarly, individuals with higher levels of education (a bachelor's degree or beyond) are significantly more likely to have a computer and/or smartphone [20]. As such, consideration of the *digital divide* is crucial when considering technology use among older adults, as there may be barriers to access (eg, internet, smartphone) that preclude their engagement with web-based tools, including for, but not limited to, information and entertainment purposes and for the purposes of improving and maintaining health and well-being.

Components of and Strategies to Support Well-Being

Participants generally conceptualized well-being as an absence of illness (ie, *feeling healthy*) and the capacity to fulfill one's goals and carry out activities of one's choice. However, there was also recognition that illness or disability and well-being are not mutually exclusive; rather, there is a need for personal awareness and acceptance of self. The fulfillment of basic life needs, namely, safety in one's surroundings, connection to others, and resilience (ie, the ability to bounce back in the face of stressful events) were also referenced. Importantly, participants noted that stigma can detract from well-being as it may be a barrier to seeking and accessing help for mental health problems. The factors of well-being identified by participants align with the 6 components of the Ryff model of psychological well-being [42], which includes self-acceptance, mastery of the environment, autonomy, positive relationships, personal growth, and life purpose. Our results highlight the consistency of views on psychological well-being among older adults over more than 30 years and, importantly, suggest these are key targets for health-related interventions.

Several strategies to promote and maintain well-being were referenced equally, including maintaining a healthy diet and exercising regularly, engaging in leisure activities, and making use of health-related information and tips. Consistent with the recognition that social connectedness is a key determinant of health [43,44], participants agreed that social connectedness is an important component of well-being. However, this was balanced with a need to be self-reliant in maintaining one's well-being so as not to burden others. HITs have the potential to provide low-cost intervention and prevention tools that are designed specifically to target components of well-being [42] and symptoms of mental illness, such as anxiety, depression, and problematic health behaviors (eg, alcohol, gambling, and smoking). In fact, a meta-analysis found that apps were superior

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to control conditions in improving stress levels and quality of life and depressive and generalized anxiety symptoms, with no marked difference relative to active interventions, including in-person treatment [45].

Benefits and Pitfalls of Technology Use

Although there is no doubt that technology has the potential to facilitate social connection via phone calls, videoconferencing, text messaging, group chats, and even games, participants agreed that in-person connection remains a vital part of personal relationships and interactions with health professionals. In a recent study, it was shown that when allowed to rely on a smartphone for information, participants were less likely to speak to other people and felt less socially connected than those who were not allowed to use phones [46]. As evidenced by our participants, older adults will engage with social media to stay connected to family and friends; however, previous qualitative work in this area revealed that older adults prefer deep, thoughtful, one-on-one communications as opposed to the light-touch, group-based interactions promoted through social media [47]. These findings suggest that it is important to ensure that HITs are well integrated with the health care system, enabling the therapeutic relationship between a consumer and health professional as opposed to rendering it unnecessary. This may be a particularly important consideration for older adults who tend to experience greater degrees of social isolation and loneliness, which are known risk factors for health problems, including cognitive decline and depression [48].

In addition to social connection, several participants also reported engaging with technology to play games, such as *Candy Crush* and *Words with Friends*. Interestingly, older adults aged 65 years and older are the fastest-growing segment of new digital game players in Australia [49]. Although utility as a leisure activity is important, gaming may also present an opportunity for incidental cognitive assessment, where changes in game behavior or performance may be indicative of decline at its earliest stage, thereby facilitating early intervention strategies to mitigate known modifiable risk factors such as depression, midlife hypertension, midlife obesity, and low physical activity [50]. Importantly, a systematic review of gamified cognitive assessment and training paradigms found evidence suggestive of associated improvements in engagement, intrinsic motivation, and training outcomes (when relevant) [51,52]. In addition to promoting repeated engagement, gamifying cognitive tasks can improve usability, decrease test anxiety, and increase ecological validity [51]. Further research is now required to validate the application of game design principles to cognitive assessment to improve sensitivity to the earliest signs of decline and to cognitive training to promote engagement, real-world transfer, and sustainability of outcomes.

The Potential Impact of Health Information Technologies

The disruption caused by the COVID-19 global pandemic has resulted in a greater need for and reliance on digital health care for screening, treatment, and ongoing maintenance of health. To this end, HITs offer a viable alternative for those who prefer or are required to use digital health care due to health concerns (eg, during the COVID-19 pandemic) and geographic, transport, or mobility constraints. One of the marked discrepancies between our study and others that have investigated technology use for health-related purposes by older adults relates to familiarity with and confidence in using technology. Although this was not a personal concern among our participants, a lack of familiarity with technologies has frequently been cited as a potential barrier to adoption for older adults [53], specifically in relation to web-based health care information seeking [54]. As referenced previously, consideration of the *digital divide* is crucial to ensure that those who may not have easy access to technology, or the skills required to use it, are not excluded from receiving mental health care delivered via HITs. Recommendations to bridge the digital divide include (1) technology subsidies for low-income consumers, (2) user-friendly technologies appropriate for consumers with physical disabilities and cognitive impairment; and (3) demonstrations and training opportunities for consumers who might not otherwise have the opportunity to learn how to use available technologies [55].

Furthermore, health services are also encouraged to consider the addition of a digital navigator to their care team to improve the uptake and implementation of HITs within care [56]. The role of a digital navigator is 3-fold: (1) evaluate HITs, such as apps, and make appropriate recommendations to health professionals; (2) set up technology and troubleshoot with the consumer, thereby allowing the health professional to focus on the clinical interaction with the consumer; and (3) interpret and report salient data collected by the HIT to both the consumer and the health professional in a user-friendly way to inform care and self-management. Although the current use of HITs among older adults is relatively low, this does not appear to be due to lack of interest [20] but rather due to the need for education and training in relation to the potential benefits of HITs and the practicalities of engagement with these technologies [57]. As such, a digital navigator has the potential to be particularly impactful for the older adult community, including both for consumers and their families and for health professionals.

Prototyping the InnoWell Platform for Older Adults

Importantly, many of the features and functions suggested by participants for the digital tool align with the core principles underpinning the design and development of the InnoWell Platform, which include increasing access to standardized, broad-based assessment; identifying and tracking consumer needs; matching those needs with personalized care options; and enhancing the quality of care provided to consumers [34]. Although the assessment was not discussed per se, participants recognized that the more information that was input into the digital tool, including via interoperable devices, increased the likelihood of personalized feedback and recommendations. Furthermore, the ability to track and store data over time was valued by participants as a means to better understand what information, resources, and intervention strategies were associated with positive health outcomes based on personal goals relative to those that were not effective for the consumer. It was also recognized that a personal data record, only shared with health professionals with the consumer's permission, had the potential to facilitate coordinated care across health professionals and services and to prevent the need to retell one's

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story repeatedly to new providers. Although it was noted that HITs have the potential to improve access to services, particularly for consumers in regional or remote areas, there was consensus that HITs cannot and should not replace health professionals. Even when developed and delivered by a credible source, it was believed that HITs are not comparable with in-person care and that the connection with a health professional remains a valued part of seeking and receiving care. That said, participants consistently stated that they would make use of an HIT if asked to do so by a health professional.

Despite the willingness to engage with HITs, data privacy and security concerns were frequently referenced as barriers to use, which aligns with previous user-centered work in this area [58]. This is perhaps not surprising, given the frequency of data breaches globally. For example, the United States Department of Health and Human Services' Office for Civil Rights breach portal listed 510 health care data breaches of 500 or more records in 2019, reflecting a 196% increase from 2018 [59]. Needless to say, adherence to relevant privacy policies is paramount in the development and implementation of HITs to protect consumers' health information from being disclosed for marketing purposes or, perhaps more importantly, identity theft and fraud.

Importantly, the results of this study have translated to a configuration of the InnoWell Platform specifically tailored to older adults. The broad-based assessment, for example, has been modified to reflect areas of health that are particularly relevant to older adults, including cognition and pain, and to incorporate assessment tools specifically designed for the older adult community (as opposed to tools used in configurations of the InnoWell Platform designed for young people or veterans). All informational materials provided within the InnoWell Platform are appropriate for older adults. For example, fact sheets are provided regarding the benefits of physical activity or the health impacts of excessive alcohol use for older adults. Furthermore, the care options embedded within the InnoWell Platform have been revised to reflect the needs of older adults, such as recommendations for apps for cognitive training, medication management, and cardiovascular health. The design and development of additional features and functionality of the InnoWell Platform based on the information gathered in this study are currently under consideration for inclusion in the next iteration of this innovative HIT.

Limitations

This study has some limitations that are important to note. All participants in this study were regular users of technology with high levels of digital literacy. As such, the accessibility, engagement, and appropriateness of technology for novice users or those who do not have easy access to technology could not be explored. In addition, only 2 supportive others were included in the participant sample, thereby limiting any conclusions that can be drawn about the features or functions of HITs that may be appropriate specifically for this user group. Finally, to promote patient privacy, no demographic information was collected from participants; therefore, we were unable to comment on factors such as age range, highest level of education, or occupational status (eg, retired). This also precludes the ability to investigate differences in technology preferences based on age (eg, *50-64 years vs* 65-80 years).

Conclusions

Older adults readily engage with a range of technologies in day-to-day life, with current participants endorsing a preference for smartphones and computers relative to other devices. HITs have the potential to improve access to cost-effective and low-intensity interventions at scale to improve and maintain mental health and well-being. Participants referenced personalization and the ability to access up-to-date, credible information and resources as primary facilitators of HIT adoption, with a strong desire for integration with standard care practices to preserve personal connections with health professionals. Data privacy and security risks were a primary barrier to HIT use, although this may be mitigated if the source of the digital tool is reputable. Variability in digital literacy among older adults also has the potential to limit the adoption of such tools. However, several strategies may improve uptake and efficacy, including active co-design of HITs specifically with the older adult community to ensure usability, acceptability, and appropriateness; support for HIT selection and use of clinical applications via a digital navigator; and education and training materials embedded within the HIT.

Future Directions

The configuration of the InnoWell Platform specific for older adults is now being trialed in a naturalistic 90-day user testing study. Participants aged 50 years and older are invited to engage with the InnoWell Platform for a period of 90 days and asked to complete short web-based surveys at 5 time points (baseline [or day 1], day 15, day 30, day 60, and day 90), regarding the quality, usability, and acceptability of the functionality of the prototyped InnoWell Platform. Eighteen participants have enrolled in this study to date, and results are expected to be submitted for publication in early 2021. The findings will inform the iterative redesign and development of the InnoWell Platform before the implementation within an older adult health service setting. Furthermore, participant feedback will also be used in the design and development of other HITs for the older adult community, such as gamified cognitive tests to assess and monitor cognitive functioning over time and multifaceted, interactive web-based interventions to support and maintain mental health and well-being.

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Authors' Contributions

The authors IH and TD were integral in securing funding to support this study. The study was designed by HL and TD, with subsequent contributions by AR. All data analyses were conducted by HL and AR. All authors contributed to and approved the final manuscript.

Conflicts of Interest

IH was an inaugural commissioner on Australia's National Mental Health Commission (2012-2018). He is the Co-Director, Health and Policy at the Brain and Mind Centre (BMC), University of Sydney. The BMC operates early-intervention youth services at Camperdown under contract to headspace. He is the Chief Scientific Adviser to, and an equity shareholder in, InnoWell. InnoWell was formed by the University of Sydney (45% equity) and PwC (45% equity) to deliver the Aus $30 (US $21.10 million) million Australian Government–funded Project Synergy (2017-2020), a 3-year program for the transformation of mental health services and to lead transformation of mental health services internationally through the use of innovative technologies. The other authors have no conflicts of interest to disclose. The source of funding does not entail any potential conflict of interest for the other members of the Project Synergy Research and Development Team.

Multimedia Appendix 1
Older adult participatory design agenda.
[DOCX File , 48 KB - aging_v4i1e21461_app1.docx]

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Abbreviations

BMC: Brain and Mind Centre
HIT: health information technology

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Original Paper

Using Consumer-Grade Physical Activity Trackers to Measure Frailty Transitions in Older Critical Care Survivors: Exploratory Observational Study

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Abstract

Background: Critical illness has been suggested as a sentinel event for frailty development in at-risk older adults. Frail critical illness survivors are affected by increased adverse health outcomes, but monitoring the recovery after intensive care unit (ICU) discharge is challenging. Clinicians and funders of health care systems envision an increased role of wearable devices in monitoring clinically relevant measures, as sensor technology is advancing rapidly. The use of wearable devices has also generated great interest among older patients, and they are the fastest growing group of consumer-grade wearable device users. Recent research studies indicate that consumer-grade wearable devices offer the possibility of measuring frailty.

Objective: This study aims to examine the data collected from wearable devices for the progression of frailty among critical illness survivors.

Methods: An observational study was conducted with 12 older survivors of critical illness from Kingston General Hospital in Canada. Frailty was measured using the Clinical Frailty Scale (CFS) at ICU admission, hospital discharge, and 4-week follow-up. A wearable device was worn between hospital discharge and 4-week follow-up. The wearable device collected data on step count, physical activity, sleep, and heart rate (HR). Patient assessments were reviewed, including the severity of illness, cognition level, delirium, activities of daily living, and comorbidity.

Results: The CFS scores increased significantly following critical illness compared with the pre-ICU frailty level (P=.02; d=−0.53). Survivors who were frail over the 4-week follow-up period had significantly lower daily step counts than survivors who were not frail (P=.02; d=1.81). There was no difference in sleep and HR measures. Daily step count was strongly correlated with the CFS at 4-week follow-up (r=−0.72; P=.04). The average HR was strongly correlated with the CFS at hospital discharge (r=−0.72; P=.046). The HR SD was strongly correlated (r=0.78; P=.02) with the change in CFS from ICU admission to 4-week follow-up. No association was found between the CFS and sleep measures. The pattern of increasing step count over the 4-week follow-up period was correlated with worsening of frailty (r=.62; P=.03).

Conclusions: This study demonstrated an association between frailty and data generated from a consumer-grade wearable device. Daily step count and HR showed a strong association with the frailty progression of the survivors of critical illness over time. Understanding this association could unlock a new avenue for clinicians to monitor and identify a vulnerable subset of the older adult population that might benefit from an early intervention.

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KEYWORDS

frailty; frail elderly; wearable electronic devices; fitness trackers; activity trackers; heart rate; sleep monitoring; critical care outcomes

Introduction

Frailty Among Critical Illness Survivors

Frailty is a state of increased vulnerability to adverse health outcomes due to the loss of physiological and cognitive reserves [1]. Although frailty often overlaps with terms such as disability and comorbidity, it has been well described that frailty is an independent concept that can be quantitatively separated [2]. Frailty is recognized as a dynamic state, and recent studies have highlighted the need to quantify changes between the stages of frailty to better inform clinicians with the development of tailored treatments [3].

Critical illness has been suggested as a sentinel event for the development of frailty, especially for at-risk older adults [4]. Frailty is frequently evaluated as a prognostic tool in critical care settings to better guide decision making by clinicians and to manage the expectations of patients and families on health outcomes [5]. Critical illness survivors who were frail before the illness, in comparison with those who were not frail, have a significantly higher mortality rate [5-7], are more likely to acquire functional dependence [5,8], have lower quality of life [5], and are more frequently rehospitalized within 12 months [7]. However, no studies have examined the progression of frailty throughout and beyond critical illnesses and how physical and functional recovery is related to changes in frailty.

Wearable Device Uses in Research

Older adults are the fastest growing group of consumer-grade wearable device users [9]. The potential uses of these devices for general wellness and clinical purposes have gathered the interest of many stakeholders, including patients, care providers, funders, governments and policy makers, and technology developers [10-14]. The opportunity to leverage data generated from such devices for clinical and medical purposes is expected to increase as these devices are becoming smaller, cheaper, and ever more accessible in the recent years [15]. Coupled with the logistic and financial challenges of monitoring critical illness survivors' functional recovery outside the hospital setting, many recent research studies investigated several possible uses, including wearable devices as a tool to objectively measure the physical activity level [16,17], sedentary behaviors [18], and mobility [19] and to screen for frailty [20].

Objectives

We examined the data generated from wearable devices for their association with the progression of frailty after hospital discharge and hypothesized significant associations between frailty and physical activity, sleep quality, and heart rate (HR), as reported by the wearable devices. In particular, we hypothesized that survivors who are frail would have lower physical activity, diminished sleep quality, and impaired HR control compared with those who are not frail. We also hypothesized that survivors whose frailty returns to the precritical illness level would have a higher physical activity level, better sleep quality, and tighter HR control than those who have a persistent increase in frailty after hospital discharge.

Methods

Study Design and Settings

This observational study was conducted at Kingston General Hospital in Kingston, Ontario, Canada. Patients were recruited from the FORECAST (Frailty, Outcomes, Recovery and Care Steps of Critically Ill Patients) study, which assessed an array of clinical measurements and frailty. For this study, patients were recruited during their admission to the intensive care unit (ICU) from July 2017 to August 2018. Participants were followed up at 4 weeks after hospital discharge.

A convenience sampling method was used to recruit patients aged 55 years and older. They were included in this study if they lived within the city or close by to ensure feasibility of attending the 4-week follow-up session. Patients were excluded if shared decision makers were not available to collect collateral history. We also excluded patients who had medical conditions that might have interfered with the proper use of the wearable devices, including those admitted to the ICU with catastrophic neurological illness that was not likely to be altered by ICU care (eg, massive stroke requiring ICU care, spinal cord injury with neurological deficit), those diagnosed with primary neuromuscular pathology or atrial fibrillation, or those dependent on a wheelchair for mobility. Patients with nonsinus rhythms were excluded. Patients were further excluded if they had an expected survival of less than 1 month.

Data Collection and Instrumentation

Determination of Frailty

Frailty was assessed using the Clinical Frailty Scale (CFS), a tool that has been widely used in critical care settings [1]. The CFS has been shown to outperform other frailty assessment tools in the geriatric population in correctly differentiating major health outcomes such as hospital admission and fall incidents [21]. It is especially suitable for older adults and critically ill populations who may lack cognitive or physical capabilities to answer and perform necessary tasks to be assessed for frailty with other tools [1]. The CFS ranges from 1 to 9, where 1 denotes very fit and 9 represents terminally ill. CFS scores of 1 to 3 are considered not frail, a score of 4 is considered prefrail, and 5 or higher is considered frail. However, a CFS score of 4 or higher was considered frail in this study. Frailty was assessed by one of the 3 experienced research coordinators available at a given time.

Wearable Device

Fitbit Charge HR (Fitbit; hereafter referred to as Fitbit) is a commercially available wearable device worn on the wrist. It uses a triaxial accelerometer to measure motion. These data are used to estimate physical activity, sedentariness, and sleep quality. Fitbit also measures the changes in elevation using an

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altimeter. Fitbit uses an optical HR sensor (ie, photoplethysmography) to measure the HR between 30 and 220 beats per minute.

In this study, we collected physical activity levels including daily step count, active time, and sedentary time. Fitbit automatically deems the active time when a physical activity of at least three metabolic equivalents is performed. Sleep-related information is generated, including total time in bed, total sleep time (TST), awake time, and awake count. Sleep efficiency was calculated as the percentage of sleep time over the TST. Sleep time was determined by subtracting the awake time from the TST. HR was measured every minute. HR data were used to assess the average daily HR, SD of average daily HR, and average nocturnal HR. The average nocturnal HR was calculated using only the HR recorded during sleep as classified by the TST.

Other Variables

The research coordinators reviewed the patients' medical charts and collected demographic information, including age, sex, height, and weight. The degree of comorbidity and the ability to perform activities of daily living were calculated using the Charlson Comorbidity Index [22] and the Katz index [23], respectively. The severity of illness and delirium were collected and calculated using the Acute Physiology and Chronic Health Evaluation II (APACHE II) [24] and the Confusion Assessment Method-ICU [25], respectively. The major critical care treatments received during the ICU stay, including invasive mechanical ventilation, noninvasive ventilation, vasopressor use, corticosteroid use, continuous renal replacement therapy, and intermittent hemodialysis, were collected. The ICU length of stay (ICU LOS) and hospital LOS were calculated from chart reviews.

Procedure

A total of 3 trained research coordinators interviewed the patients at 3 different time points: ICU admission (T1), hospital discharge (T2), and 4-week follow-up (T3). The assessment conducted at T1 was used to establish the baseline information (ie, pre-ICU admission). Figure 1 outlines the study procedure and time points for the assessments and measurement tools. All participants received a wearable device at ICU discharge and were trained on its use during the hospital ward stay before hospital discharge. Participants were encouraged to wear the device during the ward stay, but only the posthospital discharge data were used for analyses. The time between T1 and T2 is referred to as D1, between T2 and T3 as D2, and between T1 and T3 as D3, hereafter.

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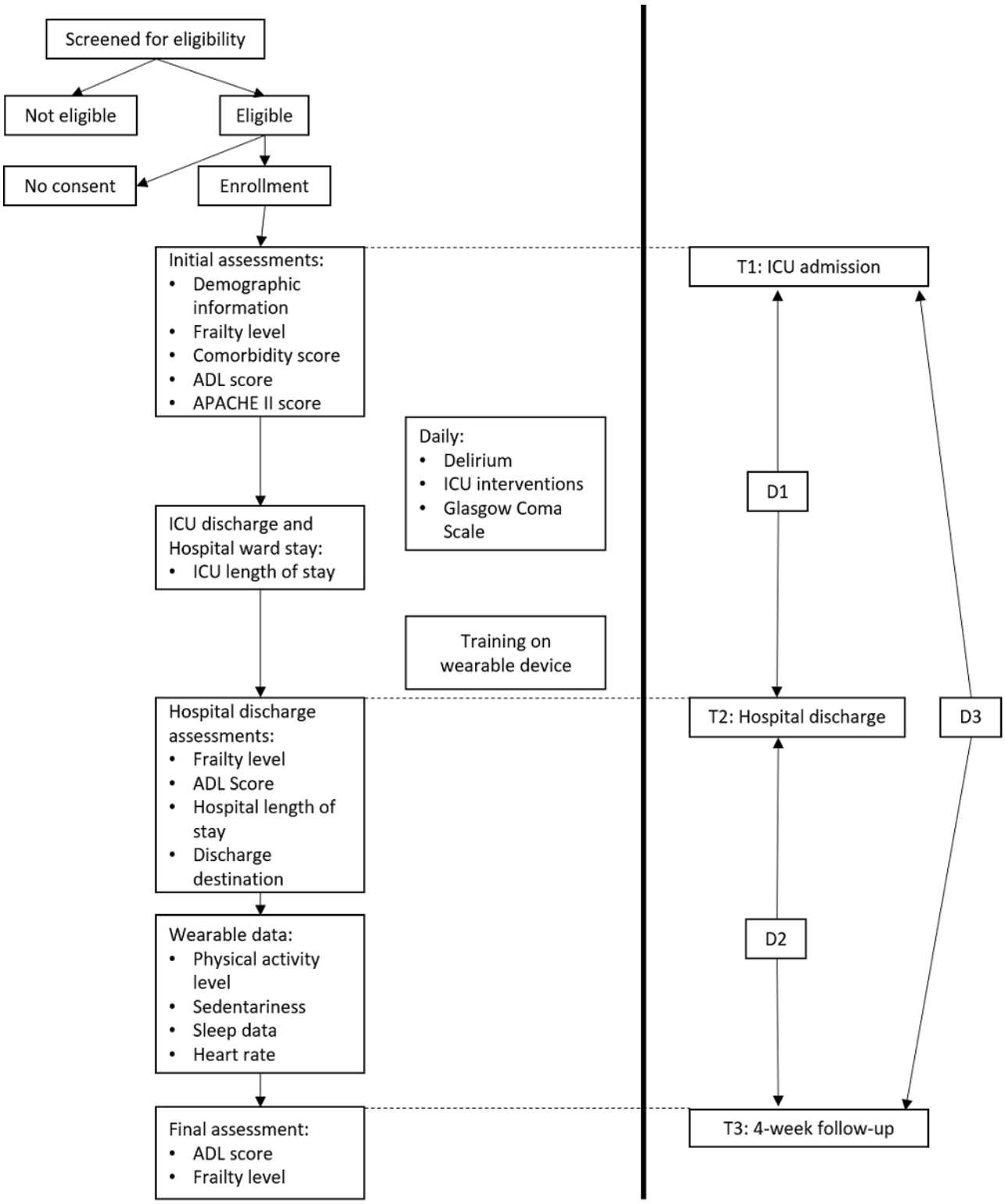
Figure 1. Study procedure and time points of assessment and measurement tools. ADL: Activities of Daily Living; APACHE: Acute Physiologic Assessment and Chronic Health Evaluation; ICU: intensive care unit.



Data Analyses and Interpretation

Descriptive statistics and univariable comparisons of means, medians, and proportions were performed to describe the demographic information and patient characteristics according to frailty status. The Shapiro-Wilk normality test was performed to check for normality. Student *t* test, Mann-Whitney *U* test, or chi-square test was performed to check for independence between frail and nonfrail survivors at T3. Cohen *d* was used to evaluate the effect size when a statistically significant difference was found.

The Pearson correlation coefficient and Spearman rank correlation coefficient were calculated to analyze the correlation between the data collected from the wearables and the changes in the CFS score over D1, D2, and D3. Their relationships with patient demographics and medical data were further examined.

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A linear regression was performed for individual patients' daily step count, daily TST, daily awake duration, and HR over D2. The slope of the regression line (hereafter referred to as the slope) was examined for its relationship with the changes in the CFS score over D1, D2, and D3 by performing Spearman rank correlation analysis. Patients with fewer than 5 days of wearable data were excluded from this analysis.

Statistical significance was set at α=.05 for all statistical results. Statistical analysis was performed using R Studio (R version 3.6.0, R Studio version 1.2.1335, R Studio Inc).

Ethics, Consent, and Permissions

This study was approved by the office of research ethics at the University of Waterloo (ORE22219) and the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics (ROMEO/TRAQ 6020644).

Results

Recruitment

A total of 16 patients admitted to the ICU were recruited after they provided informed consent between July 2017 and August 2018. Overall, 2 patients withdrew from the study, and 2 patients' data were lost because of technical issues. In total, we had 12 patients with wearable device data collected successfully (Table 1).

Table 1. Baseline characteristics, frailty, disability, and comorbidity scores.

Patient characteristics	Frail at T3[a]	Nonfrail at T3[b]	*P* value
Demographics			
Patients, n	7 (58.33)	5 (41.67)	N/A[c]
Age (years), mean (SD)	66 (8.12)	67.8 (5.07)	.81
Sex (female), n (%)	6 (85.71)	1 (20.00)	.02[d]
BMI, kg m^{-2}	30.22 (8.36)	26.34 (16.01)	.21
Type of admission			
Medical, n (%)	1 (8.33)	10 (83.33)	N/A[c]
Surgical, n (%)	0 (0.00)	1 (8.33)	N/A
Intensive care unit length of stay (days), mean (SD)	15.29 (5.19)	13.40 (9.63)	.67
Hospital length of stay (days), mean (SD)	24.57 (10.49)	20.60 (16.32)	.62
Acute Physiology and Chronic Health Evaluation II score	26.71 (6.63)	29.00 (2.45)	.81
Glasgow Coma Scale score	7.43 (4.54)	5.20 (2.28)	.56
Charlson Comorbidity Index score	1.57 (2.07)	1.00 (1.22)	.21
Katz at T1[a] score	5.00 (1.29)	5.60 (0.55)	.59
Katz at T3[b] score	5.71 (0.76)	6.00 (0.00)	.50

[a]ICU admission.
[b]4-week follow-up.
[c]N/A: not applicable, as *P* value cannot be computed.
[d]*P*<.05.

The patients were aged between 55 and 77 years, with a mean age of 66.75 (SD 6.80) years, and 7 patients were female. There were significantly more frail female participants than male participants (*P*=.02). The mean ICU LOS was 14.50 (SD 7.03) days and hospital LOS was 22.92 (SD 12.69) days. The mean APACHE II score at T1 was 27.67 (SD 5.25). Overall, 7 of the 12 patients were classified as frail at T3. There were no other major differences in baseline characteristics between frail and nonfrail patients at T3.

Clinical Frailty

Critical illness had a profound effect on the patient's frailty level (Figure 2). Compared with the baseline CFS score at T1, the CFS score at T2 increased significantly (*P*=.007; *d*=−1.13). A general trend of improvement in frailty level was observed over D2; however, the difference was not statistically significant (*P*=.10; *d*=0.59). At T3, the frailty level returned to that at the baseline for 6 patients, whereas it worsened for 6 patients. Overall, the CFS score increased significantly over D3 (*P*=.02; *d*=−0.53). The changes in frailty level at different time points are summarized in Table 2.

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Figure 2. A boxplot of the Clinical Frailty Scale score at T1: ICU admission, T2: hospital discharge, and T3: 4-week follow-up (n=12). ICU: intensive care unit.

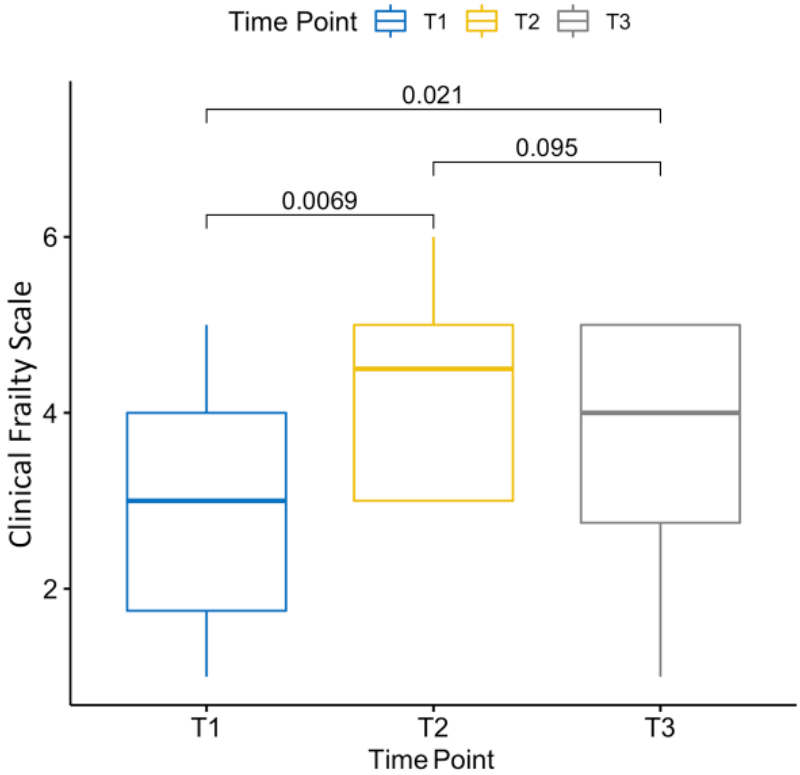

Table 2. Changes in Clinical Frailty Scale score between ICU admission and 4-week follow-up.

Frailty changes	ICU[a] admission to hospital discharge, n	Hospital discharge to 4-week follow-up, n	ICU admission to 4-week follow-up, n
Improved	0	2	0
No change	5	4	6
Worsened	7	6	6

[a]ICU: intensive care unit.

Frailty and Wearables Data

Of the 12 patients, 3 wore the wearable devices for fewer than 5 days over D3 (Table 3). On average, patients wore the wearables for 26.33 days. Frail patients at T3 had significantly lower daily step counts than nonfrail patients (1336.40 vs 3781.04 steps; P=.02; d=1.81). They engaged in lesser daily physical activity than their counterparts (2.02 vs 16.34 minutes per day; P=.04; d=0.94). There was no difference in sleep and HR measures between the frail and nonfrail groups.

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Table 3. Data collected from the wearable devices (n=9).

Wearable device measures	Frail at T3[a]	Nonfrail at T3[b]	*P* value
Patients, n (%)	5 (56)	4 (44)	N/A[c]
Days worn, mean (SD)	30.20 (8.73)	21.50 (8.27)	.17
Physical activity variables			
Daily step count, mean (SD)	1336.40 (1091.07)	3781.04 (1389.37)	.02[d]
Sedentary time (min per day), mean (SD)	84.11 (55.75)	104.95 (49.78)	.58
Active duration (min per day), mean (SD)	2.02 (3.83)	16.34 (10.66)	.04[d]
Sleep measures			
Total sleep time (min per night), mean (SD)	419.71 (166.62)	336.25 (134.07)	.81
Total time in bed (min per night), mean (SD)	456.31 (182.49)	362.16 (144.88)	.84
Awake time (min per night), mean (SD)	24.427 (11.20)	21.30 (11.33)	.69
Awake count (times per night), mean (SD)	1.65 (0.62)	1.54 (1.10)	.85
Sleep efficiency (%), mean (SD)	91.72 (2.35)	92.70 (2.00)	.53
HR[e] measures			
Average HR (bpm[f]), mean (SD)	86.93 (7.10)	80.38 (13.18)	.38
Heart rate standard deviation, bpm (SD)	8.81 (1.97)	10.66 (3.16)	.32
Average nocturnal HR, bpm (SD)	86.42 (5.87)	74.10 (20.27)	.27

[a]T1: Intensive care unit admission.

[b]T3: 4-week follow-up.

[c]N/A: not applicable.

[d]$P<.05$.

[e]HR: heart rate.

[f]bpm: beats per minute.

The correlations between the wearable device data and frailty are summarized in Table 4. Daily step count strongly correlated with the baseline CFS at T1 ($r=-0.76$; $P=.03$) and the CFS score at T3 ($r=-0.72$; $P=.006$). Sedentary time strongly correlated with the CFS score at T1 but did not reach statistical significance ($r=-0.66$; $P=.07$). The average HR strongly correlated ($r=-0.72$; $P=.046$) with the CFS score at T2, and HR SD also strongly correlated ($r=0.78$; $P=.02$) with the CFS change over D3. No relationship was found between sleep measures and CFS scores. No patient characteristics had a significant relationship with the CFS score (see Multimedia Appendix 1 for the exact *P* values for each correlation coefficient).

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Table 4. Correlations between the data collected from the wearables and the frailty level and its change overtime (n=9).

Wearable device measures and patient characteristics	Correlation (*r*)					
	Frailty at T1[a]	Frailty at T2[b]	Frailty at T3[c]	Frailty change over D1[d]	Frailty change over D2[e]	Frailty change over D3[f]
Physical activity data						
Daily step count	−0.76[g]	−0.35	−0.72[g]	0.55	−0.46	0.14
Active time	−0.62	0.03	−0.53	0.63	−0.56	0.18
Sedentary time	−0.66	−0.39	−0.53	0.41	−0.24	0.25
Sleep data						
In bed	0.10	0.13	0.42	−0.01	0.32	0.45
Total sleep time	0.08	0.13	0.40	0.01	0.31	0.46
Awake time	−0.26	−0.07	0.07	0.22	0.13	0.50
Awake count	−0.31	0.06	−0.10	0.37	−0.15	0.33
Sleep efficiency	0.23	−0.10	0.12	−0.32	0.20	−0.19
HR[h] data						
Average HR	−0.24	−0.72[g]	−0.16	−0.28	0.37	0.13
Heart rate standard deviation	−0.55	−0.05	−0.05	0.54	−0.01	0.78[g]
Average nocturnal HR	0.06	−0.21	−0.19	−0.22	−0.04	−0.37
Patient characteristics						
Age	0.18	0.56	<0.01	0.24	−0.45	−0.27
BMI	0.42	0.38	0.47	−0.11	0.15	0.04
Intensive care unit length of stay	−0.01	0.21	<0.01	0.17	−0.17	0.02
Hospital length of stay	0.15	0.15	0.05	−0.03	−0.07	−0.14
Charlson Comorbidity Index	0.56	0.12	0.29	−0.44	0.19	−0.44
Glasgow Coma Scale	0.24	−0.06	0.15	−0.27	0.19	−0.16
Changes in activities of daily living	0.06	0.34	0.05	0.20	−0.23	−0.02
Acute Physiology and Chronic Health Evaluation II	0.19	0.47	−0.12	0.17	−0.50	−0.47

[a]T1: Intensive care unit admission.
[b]T2: Hospital discharge.
[c]T3: 4-week follow-up.
[d]D1: Intensive care unit admission to hospital discharge.
[e]D2: Hospital discharge to 4-week follow-up.
[f]D3: Intensive care unit admission to 4-week follow-up.
[g]$P<.05$.
[h]HR: heart rate.

Frailty and Wearable Data Trends Over Time

The slope of the linear regression line for daily step count, TST, and HR was calculated to investigate the relationship between frailty and wearable device data trends over time (Figure 3). The slope of the daily step count demonstrated strong correlations with the CFS change over D1 (r=0.71; P=.01) and D3 (r=0.65; P=.03) (Table 5). The slope of HR strongly correlated with frailty change over D3 (r=0.62; P=.03).

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Figure 3. Example of the slope of linear regression line for daily step count, total sleep time, and heart rate. The slope of linear regression line represents the changes over over hospital discharge to 4-week follow-up.

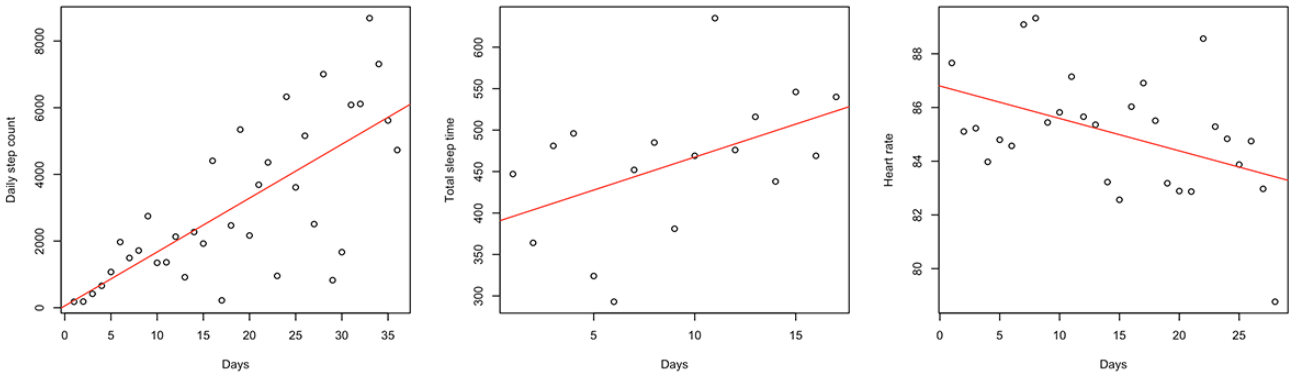

Table 5. Correlation between the slope of daily step count, total sleep time, heart rate and the Clinical Frailty Scale (CFS) scores at intensive care unit admission, hospital discharge, and 4-week follow-up and changes in CFS over intensive care unit admission to hospital discharge, hospital discharge to 4-week follow-up, and intensive care unit admission to 4-week follow-up.

Time points and frame	Slope					
	Step count (*r*)	*P* value	Total sleep time (*r*)	*P* value	Heart rate (*r*)	*P* value
CFS[a] score at T1[b]	−0.55[c]	.08	0.59[c]	.07	−0.31	.32
CFS score at T2[d]	0.27	.43	0.12	.74	−0.12	.72
CFS score at T3[e]	−0.18	.60	0.32	.36	0.10	.75
CFS change over D1[f]	0.71[g]	.01	−0.49	.15	0.21	.52
CFS change over D2[h]	−0.38	.25	0.21	.56	0.20	.54
CFS change over D3[i]	0.65[g]	.03	−0.52	.13	0.62[d]	.03

[a]CFS: Clinical Frailty Scale.
[b]T1: intensive care unit admission.
[c]*P*<.10.
[d]T2: Hospital discharge.
[e]T3: 4-week follow-up.
[f]D1: Intensive care unit admission to hospital discharge.
[g]*P*<.05.
[h]D2: Hospital discharge to 4-week follow-up.
[i]D3: Intensive care unit admission to 4-week follow-up.

Discussion

Frailty Transitions Following Critical Illness

In this exploratory observational study, we observed 12 older adult survivors of critical illness from the time of their admission to the ICU until 4-weeks after their hospital discharge. Physical recovery was monitored using a wearable device. Frailty was assessed at multiple time points throughout their ICU and hospital stay and at 4 weeks after discharge. A total of 6 patients became frailer after their critical illness, whereas the frailty of the other 6 returned to their precritical illness levels. No participant's frailty improved above their pre-ICU baseline state. The incidence rate of worsening frailty over 3 years is reported to be approximately 0.6% and 1.3% for healthy men and women, respectively [26]. A noticeably higher incidence rate in the study sample confirms the notion that critical illness is a triggering event in the transition to a frail state [4].

Patterns of Wearable Measures and Frailty Transitions

We demonstrated the association between a lower physical activity level and increased frailty level. This was evident from a significantly lower daily step count and active time by the frail survivors compared with their nonfrail counterparts. This finding is consistent with a previous study that used a wearable device worn on the upper arm and reported a significantly reduced step count by frail survivors compared with a healthy control group [16]. Our results suggest that the rate at which an individual increases daily step count following critical illness may be an important indicator for the recovery of frailty back to the precritical illness level. Those whose frailty worsened showed a significantly higher rate of increase in their daily step counts (*P*=.03). We initially suspected that the magnitude of the positive slope was amplified because of lower step counts among those whose frailty worsened. However, the average step count was not significantly different between those whose frailty worsened and those whose frailty did not change (*P*=.63).

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We further speculated that the difference in baseline frailty level may contribute to this finding; however, there was no significant difference in baseline frailty between the 2 groups (P=.49). Another possible explanation may be an increase in frailty because of nonphysical characteristics such as impaired cognitive function. Future research should confirm this relationship and investigate possible explanations. Understanding this relationship may help clinicians to accurately identify patients who will benefit from strengthened transitional care.

The pattern of increasing HR and the SD of HR were shown to be related to the worsening of frailty following critical illness. These findings are in line with the theoretical understanding of frailty as a concept of impaired homeostasis [27]. These patterns may be caused by the inability to evoke dynamic physiological processes to restore equilibrium. Studies that examined HR variability have concluded that frailty is associated with impaired cardiac autonomic control [28,29]. However, empirical evidence for the relationship between HR and frailty is lacking. Increased resting HR was found to be associated with functional decline among older adults [30], increased inflammatory markers [31], and an increased mortality rate among trauma patients [32].

To the best of our knowledge, this is the first study to investigate frailty by collecting and analyzing longitudinal HR data from a consumer-grade wearable device. The use of consumer-grade wearable devices to monitor HR has garnered the interest of many researchers in recent years. Its feasibility and accuracy have been researched in different populations, including patients who are critically ill [33]. Many studies have demonstrated its feasibility and acceptable compliance level, but its capacity to measure HR accurately has been questioned, especially for the detection of nonsinus rhythms such as tachycardia and bradycardia [33,34]. Despite this, our study used longitudinal HR data to successfully uncover the association among frailty, HR, and its SD. Future studies should expand on this relationship and its potential use as a screening and monitoring tool for frailty and the detection of early signs of clinical deterioration among critical illness survivors.

Poor sleep quality, particularly nighttime disturbances, was reported to be associated with an increased risk of frailty among community-dwelling older adults [35,36]. Frequently perturbed sleep in hospitals adversely affects patient's recovery [37]. However, we found no significant association between sleep measures and changes in frailty. This may be explained by the inaccurate measures of sleep quality using wearable devices. The exact model of the device used in this study has been validated against polysomnography (PSG) for healthy adolescents and the same device brand among young adults [38,39]. However, it was noted that the performance of these devices may be poor in populations with low sleep quality or a high number of motionless wake episodes. Continued efforts to use consumer-grade wearable devices for routine sleep monitoring should be encouraged because the current methods such as PSG and sleep journals are not feasible because of their high cost and inaccuracy among patients who are critically ill [33].

Implications for Consumer-Grade Wearable and Frailty Research in Critical Care Setting

Survivors of critical illness are uniquely situated as their physiological and cognitive reserves (ie, frailty) have been pushed to their limit and beyond. The successful recovery of frailty back to the precritical illness level is crucial for protection from subsequent critical illness. Unsuccessful recovery of frailty places an individual in a vulnerable state in which a lesser illness may lead to amplified adverse health outcomes, thereby requiring greater health care resources [40,41]. Our study demonstrated the possibility of early detection of unsuccessful frailty recovery in the first 4 weeks of post-ICU discharge using a wearable device. Identifying such a vulnerable subset of critical illness survivors warrants the timely delivery of frailty interventional programs that have been shown to improve frailty as well as various functional capabilities for community-dwelling older adults [42]. Furthermore, wearable devices have the potential to enhance the monitoring of physical activities in ecological settings, which can guide clinicians and researchers further by complementing the supervised data acquired in traditional settings [43].

Limitations

Our study has several limitations. The exploratory nature of the study resulted in a restrictive sample size from a single ICU that is not representative of the entire critical ill population. It limited the generalizability of the findings to other populations. Other research studies reported significant differences in the age between frail and nonfrail patients, but our study sample did not. The small sample size prevented us from stratifying patients into nonfrail, at-risk, and frail groups. The addition of another level of frailty may have helped us interpret the slope of linear regression in more detail for daily step count, sleep time, and HR. Furthermore, patients who were critically ill were discharged from the ICU to a hospital ward before being discharged, which led to varied hospital ward LOS. This may have affected the assessment of frailty at the 4-week follow-up session. However, the hospital ward LOS was not significantly different between patients who are frail and not frail (13.4 vs 7.0 days; P=.20). We chose a 4-week follow-up to investigate the early recovery process immediately following the critical illness. A longer observation period of critical illness survivors will benefit future studies as full functional and physical recovery is achieved over 6- to 12-month periods for 25% to 50% of older critical illness survivors [44,45].

Conclusions

In this study, we observed the physical recovery of critical illness survivors using a wearable device. Unsuccessful recovery of frailty to precritical illness level at 4 weeks after hospital discharge was related to a significantly lower step count followed by a high rate of increase in step count. This unsuccessful recovery was also related to an increase in HR over the same period. Sleep measures did not correlate with frailty. Our study demonstrated the possibility of using consumer-grade wearables as a tool to understand frailty progression for survivors of critical illness. We also demonstrated the added value of longitudinal wearable data. Consumer-grade wearables evolve rapidly, and future research

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should focus on leveraging new features such as electrocardiogram and more accurate measures of physical activity, sleep, and HR.

Acknowledgments

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Authors' Contributions

BK, DM, and JL formulated and designed the research. MH conducted data collection under the supervision of DM and JM. BK and JL conducted the analyses, and BK prepared the manuscript under the supervision of JL. DM contributed to the development and refinement of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Correlations between the data collected from the wearables and the frailty level and its change overtime with exact P values.
[DOCX File , 25 KB - aging_v4i1e19859_app1.docx]

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Abbreviations

APACHE II: Acute Physiology and Chronic Health Evaluation II
CFS: Clinical Frailty Scale
HR: heart rate
ICU: intensive care unit
ICU LOS: intensive care unit length of stay
PSG: polysomnography
TST: total sleep time

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