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Editorial

Technological Innovations and Data-Driven Support for Older Adults

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Abstract

Entering a new digital era where novel devices and emerging technologies, including artificial intelligence, are playing an incredible role with significant impact on health and health care delivery, *JMIR Aging* commits to supporting the community of patients and families, clinicians, and scientists to improve the efficiency, equity, and effectiveness of older adult care through the dissemination of cutting-edge evidence.

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KEYWORDS

technological innovation; JMIR Aging; older adults; innovation; technology; digital ageism; digital health; older adult care

One in every six people in the world will be aged 60 years or over in 2030, totaling 2.1 billion by 2050 [1]. As people age, they are more likely to experience complex health conditions that will need support from families, health systems, and society. To “add life to years” of older adults, one promising solution may lie in the appropriate use of technology. To date, technological innovations in health care, such as smart wearable devices [2], remoting patient monitoring [3], socially assistive robots [4], augmented reality and virtual reality [5], automatic medication dispensers [6], and synchronized electronic health record systems that enable patients to virtually communicate with the care team [7], have been shown to help older adults stay physically active, live independently, monitor changes in medical conditions, and build social connections. More recently, advanced data science approaches have also been used to provide clinicians with point-of-care support for informed patient care decisions [8], speed up vaccine development [9], and support patients with shared decision-making [10].

Though the rise of technological and data science innovations brings promises, it also poses challenges. For example, many older adults, due to the lack of familiarity with technology, digital literacy, access to technological tools, or access to internet services, are negatively affected by the digital divide [11,12]. Digital ageism—the neglect of older adults’ needs, experience, and preferences in the user interaction design of some of the technologies—makes it even more difficult for them to engage in and enjoy the use of digital health technologies.

As an open-access journal, *JMIR Aging* strives to serve as a platform to support information-sharing and communications about older adults’ health and health care among clinicians, patients, caregivers, researchers, and policy makers. Our mission is to promote the use of technological innovations and data science to inform and improve health care services and health outcomes for older adults. Our focus includes digital health; emerging technologies; health informatics applications; patient education; and preventative care, clinical care, home care, and self-management support for older adults. *JMIR Aging* also covers aging-focused big data analytics using data from electronic health record systems, health insurance databases, federal reimbursement databases (eg, US Medicare and Medicaid), and other large data sets.

Founded in 2018, *JMIR Aging* has published 254 articles on various topics, such as the use of remote monitoring and artificial intelligence or robotic-driven systems [13], telehealth

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visits among underserved older adult populations [14], and fall risk prevention mobile health solutions [15]. *JMIR Aging* has been indexed in PubMed, PubMed Central, DOAJ, Scopus, and the Emerging Sources Citation Index (Clarivate), and it is expected to receive an influential impact factor in 2023.

Entering a new digital era where novel devices and emerging technologies, including artificial intelligence, are playing an incredible role with significant impact on health and health care delivery, *JMIR Aging* commits to supporting the community of patients and families, clinicians, and scientists to improve the efficiency, equity, and effectiveness of older adult care through the dissemination of cutting-edge evidence.

Conflicts of Interest

None declared.

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Guest Editorial

Shaping the Future of Older Adult Care: ChatGPT, Advanced AI, and the Transformation of Clinical Practice

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Abstract

As the older adult population in the United States grows, new approaches to managing and streamlining clinical work are needed to accommodate their increased demand for health care. Deep learning and generative artificial intelligence (AI) have the potential to transform how care is delivered and how clinicians practice in geriatrics. In this editorial, we explore the opportunities and limitations of these technologies.

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KEYWORDS

generative AI; artificial intelligence; large language models; ChatGPT; Generative Pre-trained Transformer

Introduction

The older adult population in the United State is ballooning: by 2030, one in 5 Americans will be aged 65 years or older, and by 2060, that number will climb to nearly 1 in 4 [1]. As this demographic grows, their need for health care will increase as well. At the same time, 1 in 5 doctors and 2 in 5 nurses say they are likely to leave clinical practice in the next 5 years, whereas 1 in 3 physicians, advance practice providers, and nurses intend to reduce their current working hours [2]. The World Health Organization projects a shortfall of up to 10 million health care workers globally by 2030 [3]. To close this impending gap between health care needs, especially in older adult care, and available clinical resources, it is imperative that health care be fundamentally reimagined.

Opportunities in Generative AI

Deep learning, and large language models (LLMs) in particular, offer promise in their potential to transform how clinicians work to meet the health care needs of the older adult population. LLM applications such as ChatGPT (OpenAI) [4] have a unique ability to create humanlike responses from a conversational prompt, opening new possibilities for interacting with and generating insights from data, streamlining everyday tasks, and automating routine work for clinicians. Early work has explored the effectiveness of LLMs in facilitating activities that are burdensome and time-consuming but require relatively little actual clinical decision-making, such as managing messages and work tasks in the communication hub of the electronic health record (EHR) system [5]. Researchers at the University of California, San Diego demonstrated that ChatGPT could effectively respond to patient messages: a group of health care professionals was asked to review ChatGPT's responses to questions along with physicians' responses to the same questions, and they consistently rated ChatGPT's responses as higher quality and more empathetic than those composed by the physicians [6]. Several other institutions are trialing the same approach, independently or in partnership with EHR providers [7].

Some of the most exciting applications of generative AI might be those that use these tools to boost clinical reasoning and decision-making. LLMs can take in and synthesize immense amounts of unstructured data. This means that nearly everything in EHRs could be used by LLMs in an analysis, including clinical notes, lab results, imaging scans, genetic information, and patient-generated health data. For example, it can be challenging for a busy hospitalist to distill a patient's entire chart

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during admission. Yet through experience, clinicians learn to prioritize which part of a patient's story has the highest yield. Combining this clinical expertise with LLM-based tools can help identify patterns, correlations, and subtle relationships in the clinical data that may not be immediately apparent. As a result, this approach can help clinicians to work more efficiently and effectively and make more accurate and data-driven diagnoses. LLMs can also help identify patterns associated with high-risk patients with chronic conditions to facilitate the development of personalized preventive care strategies [8].

Another the top innovation priority in health care is the patient experience. ChatGPT can provide valuable information and support to older adults who often face health challenges and need assistance in personal and health care [9]. Generative AI–powered chatbots and virtual assistants can help remotely monitor high-risk older adults with multiple chronic conditions and provide personalized health, nutrition, and fitness advice to help them manage their conditions [10]. Through a sense of virtual companionship, connections, and nonjudgmental emotional support, ChatGPT can also help address social isolation and loneliness in older adults [11,12]. Creative applications of generative AI to advance health care for older adults, including remote health monitoring, mental health support, and personalized prevention of cognitive decline, have been increasingly explored in the literature and are expected to demonstrate effects and impacts in the future [13-16].

Potential Risks and Limitations

To err is human. Likewise, despite the incredible abilities of these technologies, no predictive or generative model will perform perfectly. It is critical to understand the sources of bias and errors in AI tools and develop realistic benchmarks for safe performance. For instance, the training data for the largest current LLMs are mostly "general knowledge": these models are trained using a huge and broad data set sourced from the internet. As a result, these models excel at a wide variety of tasks, but they can fall short when specialized medical knowledge is required [17,18]. Disconcertingly, these models can fail in ways that are misleading or nonobvious, which raises concerns regarding the ability of these models to support clinical decision-making [19]. Further, using these models can come with a substantial cost, including either the direct cost to access them via a vendor or third-party platform or the development, implementation, or maintenance costs for internally building open-source products [20]. Finally, many LLMs are energy and resource intensive to run, raising substantial concerns about the environmental impact of a large-scale adoption of these tools [21].

Conclusion

Deep learning and generative AI have the potential to transform health care; if used well, as they are incorporated into clinical workflows, they could fundamentally change how clinicians practice. As the population ages and demand for care increases, the sustainability of health care depends on developing new, smarter, and more effective ways of managing the routine and complex tasks that make up clinicians' day-to-day work while facilitating high-quality care and support for the older adult population.

Conflicts of Interest

None declared.

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Abbreviations

AI: artificial intelligence
EHR: electronic health record
LLM: large language model

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Original Paper

Feasibility, Safety, Enjoyment, and System Usability of Web-Based Aerobic Dance Exercise Program in Older Adults: Single-Arm Pilot Study

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Abstract

Background: During the COVID-19 epidemic, opportunities for social interaction and physical activity among older people are decreasing, which may have a negative impact on their health. As a solution, a web-based group exercise program provided through a videoconferencing platform would be useful. As a web-based exercise program that older adults can easily, safely, and enjoyably perform at home, we developed a short-duration, light-intensity aerobic dance exercise program. Before studying the effectiveness of this exercise program, its characteristics, such as feasibility, safety, enjoyment, and system usability, should be examined among older adults.

Objective: This pilot study aimed to examine the feasibility, safety, and enjoyment of a web-based aerobic dance exercise program and the usability of a web-based exercise delivery system using a videoconferencing platform for older adults.

Methods: This study was designed as a prospective single-arm pilot study. A total of 16 older adults participated in an 8-week web-based aerobic dance program held every morning (8:30 AM to 8:50 AM) on weekdays at home. Retention and adherence rates were measured for the program's feasibility. Safety was assessed by the heart rate reserve, an index of exercise intensity calculated from heart rate, and the number of adverse events during exercise sessions. Enjoyment of this exercise program was assessed by an 11-point Likert scale ranging from 0 (not enjoyable at all) to 10 (extremely enjoyable) obtained through telephone interviews after the first-, third-, sixth-, and eighth-week intervention. For usability, the ease of the videoconferencing platform system was assessed through telephone interviews after the intervention.

Results: A female participant with hypertension dropped out in the second week because of the continuously reported high blood pressure (≥180 mmHg) before attending the exercise session in the first week. Therefore, the retention rate was 93.8% (15/16). Among the remaining participants, the median (IQR) overall adherence rate was 97.4% (94.7-100). Regarding safety, the mean (SD) heart rate reserve during the aerobic dance exercise was 29.8% (6.8%), showing that the exercise was relatively safe with very light to light intensity. There were no adverse events during the exercise session. The enjoyment score (0-10 points) significantly increased from the first (6.7 [1.7]) to sixth (8.2 [1.3]) and eighth week (8.5 [1.3]). Regarding usability, 11 participants reported difficulties at the beginning, such as basic touch panel operations and the use of unfamiliar applications; however, all got accustomed to it and subsequently reported no difficulty.

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Conclusions: This study showed high feasibility, enjoyment, and safety of the web-based aerobic dance exercise program in older adults, and the web-based exercise delivery system may have areas for improvement, albeit without serious problems. Our web-based aerobic dance exercise program may contribute to an increase in physical and social activities among older adults.

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KEYWORDS

low-intensity exercise; home exercise; online exercise; supervised exercise; elderly; COVID-19; smartphone; tablet; videoconferencing platform

Introduction

Previous studies have reported that physical activity and social interaction positively influence the physical, cognitive, and mental health of older adults [1-4]. However, for some, access to places for exercise and social participation is difficult due to environmental limitations (such as limited transportation, low walkability, and remote location) as well as physical limitations and social factors [5,6]. During the initial period of COVID-19, the existing barriers were exacerbated because of political countermeasures to stay home and the closure of public sports and recreational facilities [7,8]. Although several restrictions have been eased, COVID-19 is ongoing, and some older people have not restarted physical activity [8]. Therefore, opportunities to participate in physical and social activities at home are crucial.

To address these issues, a solution could be a web-based exercise program at home [9,10]. With the development of communication technology, people can participate in group exercises at home with guidance from an instructor through videoconferencing platforms such as the Zoom application (Zoom Video Communications) [11,12]. Although a web-based exercise through videoconferencing platform is beneficial, the feasibility, safety, and enjoyment of the web-based exercise program and ease of use of a web-based exercise delivery system should be carefully considered especially in older adults [13]. Feasibility can be assessed using the individuals' retention and adherence rates. As a program for older adults, safety is important because participants exercise at home without receiving on-site support from an instructor or supervisor. To mitigate the risk of adverse events during the web-based exercise program, light intensity and short duration of exercises are preferred. Additionally, to ensure its wide acceptance and long-term use, it should be easy to implement and enjoyable [14]. Regarding the system's usability, its operations should be simple and easy for older adults because technical issues are the main barriers to using information and communication technology (ICT) devices [9,15].

Then, we have focused on a short-duration (20 minutes) and light-intensity aerobic dance exercise program considering these conditions. Dance is widely accepted as a group exercise for older adults [16] and does not need equipment. To safely perform dance exercises in a confined space at home, we developed a light-intensity aerobic dance program mainly comprising upper limb and trunk movements and confirmed that it was enjoyable for the older adults to perform, and it transiently enhanced cognitive function and mood in a laboratory setting [17,18]. Moreover, to deliver the web-based exercise program, we focused on the Zoom videoconferencing application on a tablet device because it is free and widely used in society, and recent studies reported no major problems with its usability among older adults [13,19,20]. Although several studies have examined the feasibility and effectiveness of web-based exercise programs using strength training, aerobic exercise, and yoga [13,19,20], to the best of our knowledge, no prior study has investigated this kind of short-duration and light-intensity web-based aerobic dance exercise program among older adults.

Therefore, before assessing its effectiveness, as a pilot study, we conducted a single-arm intervention to examine the feasibility, safety, and enjoyment of the web-based aerobic dance exercise program, alongside the usability of the exercise delivery system among older adults.

Methods

Participants

The participants were recruited from community-dwelling older adults who belonged to the Hachioji medical consumer cooperative. This organization provides medical and nursing support during illness or frailty, and members range from those in good health to those with some form of illness. The staff of the cooperative distributed flyers about the study to community members, and 24 interested older adults (n=6, 25% male and n=18, 75% female) voluntarily participated in an information session where they were fully informed about its purpose and experimental procedures. After the session, 8 participants declined to participate (7 did not match the schedule and 1 was unable to exercise due to sciatica). Finally, 16 older adults (n=4, 25% male and n=12, 75% female) provided their written informed consent. The inclusion criteria were as follows: aged 65 years or older; living in Hachioji City, Tokyo; no restriction regarding exercise by a medical doctor because of a cardiovascular or orthopedic disease; and no diagnosis of mental illness, including dementia. Given this study's exploratory nature, no power analysis was performed to determine the sample size. Table 1 shows the participants' demographic data.

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Table 1. Characteristics of the participants (N=16).

Variable	Value
Age (years), mean (SD)	77.6 (4.5)
Sex, n (%)	
Male	4 (25)
Female	12 (75)
Living alone, n (%)	7 (43.8)
Current working, n (%)	2 (12.5)
Social participation[a], n (%)	
No	4 (25)
Yes	12 (75)
Physical activity or exercise[a], n (%)	
No	1 (6.3)
Yes	15 (93.8)
Clinical treatment[b], n (%)	
No	6 (37.5)
Yes	10 (62.5)
Pain status[c], n (%)	
No	5 (31.3)
Yes	11 (68.8)
Devices ownership, n (%)	
PC	6 (37.5)
Cell phone	4 (25)
Smartphone	13 (81.3)
Tablet	3 (18.8)
Purpose of internet use, n (%)	
Email	7 (43.8)
Messaging app	10 (62.5)
Information collection	12 (75)
Videoconference	1 (6.3)
Shopping	2 (12.5)
Online game	1 (6.3)
Audios or videos	8 (50)

[a]Classified as “yes” if participating at least once a month.

[b]Classified as “yes” if receiving any treatment.

[c]Classified as “yes” if feeling any physical pain.

Ethics Approval

The ethics committee of the Physical Fitness Research Institute of Meiji Yasuda Life Foundation of Health and Welfare approved the study protocol (approval number: 2020-0001).

Procedures

The participants took part in an 8-week web-based aerobic dance exercise program through the videoconferencing platform using a tablet device at home. Before starting the intervention, we lent 4 electronic devices to every participant free of charge for accessing the exercise program and monitoring their heart rate (HR) during exercise, as follows: (1) tablet (iPad [Apple Inc]) for web-based exercise, (2) HR monitoring device (OH1 [Polar Electro Oy]), (3) smartphone (iPhone SE2 [Apple Inc]) for HR measurement, and (4) Wi-Fi router (Pocket WiFi 801ZT [Softbank]) with a maximum downstream speed of 112.5 Mbps and a maximum upstream speed of 37.5 Mbps for data transmission. As the recommended bandwidth for group video calling on Zoom is 3.8 Mbps/3.0 Mbps (up/down), we prepared

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the Wi-Fi router that met these requirements. We paid for the data communication fees used in this study. Before lending these devices, we installed LINE WORKS (WORKS MOBILE Corp) and Zoom on the iPad and the HR monitoring app on the iPhone for each participant. LINE WORKS is a messaging app that includes group chat, calling, and survey functions. We used it to send the participants the Zoom URL and check their health condition through a simple checklist on the app.

During the exercise session, the HR of each participant was measured with the monitoring device and tracked on the screen at the laboratory in real time by the research staff. Moreover, participants' subjective feelings regarding enjoyment of the exercise program were obtained through telephone interviews at the end of the first, third, sixth, and eighth weeks of the intervention. Figure 1 shows the participants exercising at home using the devices.

Figure 1. Participant exercising at home. Participants exercised following the guidance of the instructor via tablet. All the devices were set up by the research staff.



Exercise Program

The total duration of the web-based exercise program was 20 minutes, comprising a 5-minute warm-up (stretching), a 10-minute light-intensity aerobic dance exercise called Slow Aerobic Dance Exercise (SADE), and a 5-minute cooldown (stretching). The details of the SADE have been reported in a previous study [11]. Briefly, it included 3 upper-body dynamic movements (twisting the upper body, pulling back the elbows, and clapping hands while shaking the waist from side to side, and waving arms like wiping the windows while shaking the waist from side to side). All movements were performed to music with a tempo of 90-120 beats per minute (bpm) because we confirmed that older adults can comfortably practice the aerobic dance program at 90-120 bpm [17,18]. Additionally, the movements were slightly changed every 2 weeks to avoid boredom. Moreover, 1 of the 3 female professional aerobic exercise instructors led the exercise program using Zoom. The exercise started at 8:30 AM, from Monday to Friday, for 8 weeks without national holidays (February 1 to March 27, 2021). In total, 37 sessions were conducted during the intervention period.

Web-Based Exercise Delivery System

We used Zoom as the videoconferencing platform to deliver the web-based exercise program to the participants. On the morning of the exercise day, the Zoom URL was sent to the participants through LINE WORKS. The participants only needed to access the LINE WORKS application and click on the Zoom URL to participate in the web-based exercise session.

Safety Management

To monitor and manage participants' safety during the exercise, we obtained information on their health conditions using a simple checklist on LINE WORKS every morning before the session. Moreover, we monitored their movements and HR during the exercise. The simple health checklist included the following three questions: (1) "How is your overall health condition today?" (Excellent/Good/Poor), (2) "What is your systolic (SBP) and diastolic (DBP) blood pressure before the session?" (SBP: less than 140 mmHg/140-179 mmHg/180 mmHg or higher; DBP: less than 90 mmHg/90-109 mmHg/110 mmHg or higher), and (3) "Did you attend the session today?"

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(yes or no). Every participant had to measure their resting blood pressure before starting the session at home using an automatic sphygmomanometer provided by the research team. Before the session, the research staff members checked their answers. Regarding the overall health condition, if any participant answered "Poor" on the day of the session, a research staff called them to check how they were feeling and whether they could safely participate. Regarding blood pressure, based on the report of the Ministry of Health, Labor, and Welfare [21], an individual with an SBP of 180 mmHg or higher or DBP of 110 mmHg or higher was suggested not to participate in the exercise on the day for safety reasons. Additionally, in case of adverse events (eg, falls, injuries, or cardiovascular events) during the intervention, we were prepared to call the participant, a relative living with the participant, or someone who lived nearby to check on their situation and to call an ambulance in case of an emergency.

An overview of the web-based HR monitoring system is shown in Multimedia Appendix 1. Every participant was asked to wear the HR monitor on their upper arm before the exercise began. Each participant's HR was displayed on the iPhone app through Bluetooth, and the HR information was transmitted to a web application on a PC at the laboratory using the internet in real time. Using this system, we monitored the HR and heart rate reserve (HRR) of each participant during the exercise. Before starting the session, we checked if the HR was displayed correctly on the web application. If someone's HR was not displayed due to Bluetooth, Wi-Fi, or other issues, the participant called the research staff, or we called them to solve the problem. The HRR of each participant was calculated using the following equation:

$$\text{HRR (\%)} = (\text{HR during exercise} - \text{resting HR}) / (\text{predicted maximum HR} - \text{resting HR}) \times 100$$

The predicted maximum HR was calculated using the following equation [22]: $208 - 0.7 \times \text{age}$. The resting HR was measured during a visit to the participants' homes to install apps and set up the devices. Each participant managed to exercise at an intensity of less than 60% of their HRR throughout the exercise because exercise above 60% HRR is defined as high intensity according to the American College of Sports Medicine [23], and the risk of cardiovascular events may be higher [24]. If the HRR of the participant remained over 60% for a few minutes, the research staff called them to confirm whether the exercise intensity was appropriate, advising them to slow down the exercise movement according to the situation. Along with monitoring the HR, we checked whether the participants were exercising safely and correctly. Figure 2 shows the monitoring screens of each participant's movement during the session.

Figure 2. All participants shown on a monitor screen in the laboratory. The research staff checked the movements of the participants on the screen for safety during the exercise session.



Measures

Feasibility

The retention rate was calculated as the proportion (expressed as a percentage) of the number of participants who completed the 8-week assessment to the total number. The adherence rate was calculated individually as the percentage of the sessions attended to the total number (37 sessions) throughout the intervention period, and the average adherence rate was obtained.

Safety

Safety was examined in terms of the intensity of the exercise program and the number of adverse events. The exercise intensity was measured using the average HR and HRR during SADE across all sessions for each participant. An adverse event was defined as any unfavorable health-related events such as falls, injuries, or cardiovascular events that occurred during the exercise intervention.

Enjoyment

Regarding enjoyment, the participants were asked to rate their subjective enjoyment on a scale at the end of weeks 1, 3, 6, and 8 of the intervention during telephone interviews. Enjoyment was assessed by a single question, "How do you feel about the exercises?". Participants were asked to rate them on an 11-point Likert scale ranging from 0 (not enjoyable at all) to 10 (extremely enjoyable).

Usability of the Web-Based Delivery System

The usability of the system was evaluated from the participants' perceived experiences with using the devices providing a web-based exercise program and monitoring HR (tablet, OH1, smartphone, and Wi-Fi router). They were asked to provide their perceived experiences using the devices over the phone

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by research staff. Telephone interviews were conducted after the last session of the intervention using a single question, "What do you think about your experiences with using the system for delivering web-based exercises?". For the usability assessment, the interviewer recorded the participants' comments and extracted the main ones. The participants were classified into the following 3 categories owing to their comments based on the discussions among all the coauthors: (1) category A: those who reported no problems with using the system throughout the intervention period; (2) category B: those who reported some challenges at the beginning but gradually got used to it or could use it without support by the end of the intervention; and (3) category C: those who reported difficulty or unfamiliarity throughout the intervention period.

Statistical Analysis

The participants' adherence rates to the session, as well as HR and HRR during the exercise, were reported as mean (SD) or median (IQR) whenever they comprised either a normal or nonnormal distribution, respectively. To obtain the enjoyment score, a repeated measure ANOVA was conducted to examine the change in the enjoyment of the exercise program during the intervention period (weeks 1, 3, 6, and 8). If a significant difference was observed in the ANOVA, the post hoc multiple comparisons with Bonferroni correction were performed. For the assessment of the system's usability, 3 categories were tested using the chi-square test for goodness of fit. Furthermore, Cohen *d* effect size was calculated to assess the change in outcome measure in response to the intervention, while ηp^2 was computed as a measurement of the effect size for ANOVA. A significant level was set at 0.05 for all analyses. We employed R version 4.1 (R Foundation for Statistical Computing) [25] for the data analysis.

Results

Feasibility: Retention and Adherence

One female participant with hypertension continuously reported high SBP (≥180 mmHg) before attending the exercise since the first session. Based on the safety concerns, in the second week, we suggested that she consult a family doctor and withdraw from this study. Therefore, 15 participants completed the 8-week intervention, resulting in a retention rate of 93.8%. For the analysis of adherence, data from the remaining participants (n=4, 27% male and n=11, 73% female) were used. The median (IQR) adherence rate was 97.4% (94.7-100).

Safety

Based on 15 participants, the mean (SD) overall HR and HRR during the SADE were 93.4 (5.7) bpm and 29.8% (6.8%), respectively, indicating the SADE was light intensity for the participants [26]. No adverse event was reported during the exercise session throughout the entire intervention period.

Enjoyment

The mean (SD) enjoyment scores of the exercise program at weeks 1, 3, 6, and 8 were 6.7 (1.7), 7.5 (1.4), 8.2 (1.3), and 8.5 (1.3), respectively. The repeated measures ANOVA revealed a significant difference among the weeks—$F_{1.98,\ 27.73}$=7.67, P=.002, ηp^2=0.35. Post hoc analysis with Bonferroni correction showed that enjoyment scores at weeks 6 and 8 were significantly higher than at week 1—t_{14}=–3.14, P=.04, d=–0.81; t_{14}=–3.81, P=.01, d=–0.98, respectively).

System Usability

The results from the telephone interview to assess the system usability of the web-based exercise showed that 4 (27%) participants had no problems (category A), 11 (73%) had some challenges at the beginning but got used to it or were able to use it without support at the end of the intervention (category B), and none reported any difficulties or unfamiliarity in use throughout the entire intervention period (category C). The chi-square test for goodness of fit showed significant differences between category B and category A or C.

Discussion

Principal Findings

A single-arm pilot study was conducted to evaluate the feasibility, enjoyment, and safety of the web-based aerobic dance exercise program and the usability of the web-based system for providing the exercise program for older adults. In this study, the following findings were obtained: (1) regarding feasibility, the retention rate and average adherence rate were high; (2) regarding safety, the average HRR during the SADE was within the range of light-intensity exercise, and there were no adverse events during the sessions; (3) regarding enjoyment, the score for the exercise program increased gradually until the end of the intervention period; and (4) regarding system usability, about a third of the participants faced some challenges in using this system at the beginning, but all got to use it at the end. These results suggest that our web-based aerobic dance program is highly feasible, enjoyable, and safe for older adults, with some areas that could be improved in the web-based exercise delivery system.

Comparison With Previous Research

A recent systematic review based on 22 selected papers reported the process characteristics of technology-based exercise intervention programs [27]. It highlighted that there were marked differences in the attrition (0%-36%) and adherence rates (67.78%-100%) for a technology-based group training exercise program for older adults. The authors suggested that the differences in these variables were because of the varying intervention characteristics, such as implementation time; frequency; duration; intensity; mode of exercise program, including interactive or noninteractive communication, individual or group, with or without a supervisor; technology-based delivery system component, such as commercially available or customized technology systems; and participants' characteristics, such as living independently or institutionalized. In this study, the participants showed high retention rates (15/16, 93.8% participants) and adherence rates (36/37, 97.4% sessions) to the web-based exercise program, which is consistent with the results of a previous study that used the similar intervention characteristics, such as intervention period, sample age, living status, home setting, and session duration. Schoene et al [28] reported a retention rate of 83.3%

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(15/18) and an adherence rate of 100% for an unsupervised, home-based, 15- to 20-minute dance step exercise program using a video game. Daly et al [29] suggested that an exercise program was feasible if the retention rate was higher than 90% and the average overall adherence rate was higher than 75%. Considering this, our exercise program was highly feasible for older adults. This seems to be related to the characteristics of the exercise, including an aerobic dance with light intensity and short session time. Dance exercise is widely accepted as a group exercise for older adults in Western countries [16]. This exercise type also seems to be acceptable for Japanese older adults. Moreover, even though the frequency (5 days/week) of our exercise program was higher than that (3 days/week) in the study by Schoene et al [28], the retention rate was a little higher. This might be because the participants were supervised using a videoconferencing platform during the session by the instructor, and they conducted the session at the same time every morning on weekdays. Kim et al [30] reported high feasibility (100% in retention and adherence rates) of their exercise intervention using Tai Chi and yoga programs, with 60 minutes per session, 3 days per week, for 8 weeks. However, they conducted the intervention using a motion capture sensor and virtual reality avatar to provide real-time visual feedback of the movement at the university research laboratory, which would not be practical as a home-based intervention program.

In a previous systematic review, Valenzuela et al [27] showed that the reasons for dropouts from their technology-based exercise intervention included low motivation, loss of interest, arthritic discomfort, lack of time, inability to travel to the session, limited space at home to set up the system, inability to use the technology, and being ashamed of playing computer games. Considering these reasons, the high feasibility of our exercise program might be because of the high level of enjoyment and safety. The participants showed a relatively high enjoyment score at the end of the first intervention week, and thereafter, there was a gradual increase during the intervention period. These results showed that the exercise program was enjoyable for the participants throughout the period. This seems to be partly because of the adaptation of the exercise program to each participant's skill and ability. This might have reduced their state of boredom and increased their motivation. Additionally, our exercise program was constructed with light intensity and simple movements, which are favorable for older adults [31]. These conditions might have motivated the participants to engage in the exercise session every morning throughout the intervention period. This was also supported by the participants' feedback through telephone interview after the intervention. Many participants commented that the instructors were very professional and friendly, making it easy to follow the aerobic dance program. Furthermore, they reported that the movements of the aerobic dance were not too difficult, and they could catch up even if they skipped or missed the sessions. They also experienced feeling refreshed after the exercise, which made them want to continue the program.

Regarding safety, we examined exercise intensity during the SADE using the HRR and the number of adverse events. The average HR and HRR during the exercise had a mean of 93.4 (SD 5.7) bpm and a mean of 29.8% (SD 6.8%), respectively. The average HRR ranged from very light to light intensity according to the American College of Sports Medicine guideline [26], showing that the exercise intensity was relatively safe. Regarding adverse events, any adverse events during the exercise session, such as cardiovascular events, falls, or injuries, did not occur. Among the previous technology-based exercise intervention studies, there were a few cases of knee and calf pain during strength training [29] and a fall during an exergame intervention using a balance board [32]. Since the aerobic dance exercise in this study mainly comprised upper body movements and was not physically demanding, it is considered that the risk of falls was low and joint and muscle pain did not occur.

From a safety management perspective, it should be mentioned that 1 participant with hypertension repeatedly reported high SBP (≥180 mmHg) before attending the exercise session since the first session. Although the causal relationship between the intervention and reported high SBP is unclear, it is possible that the anxiety to participate in the web-based exercise session elicits psychological stress, and this consequently causes high SBP. This case suggests the importance of management of blood pressure before attending the web-based exercise session to reduce the risk of exercise-related adverse events.

Another important condition of a web-based exercise program for older adults is the system's usability. We examined this condition through telephone interviews at the end of the intervention. Since nobody reported any difficulties or unfamiliarity in using the system at the end of the intervention, there could be no serious problems with its usability. This is partly consistent with the previous study reporting that the operation of Zoom for participating in web-based exercise classes was easy for older adults [13]. However, about a third of the participants had some challenges using it at the beginning, suggesting that there could be usability improvements. According to the participants' comments, a difficult point was the touch panel operations of smartphones or tablets, such as tapping, scrolling, and swiping. Some participants also commented that when operating unfamiliar apps, such as Zoom and LINE WORKS, it was difficult to know what to do next when unfamiliar screens appeared due to unusual operations. Although many had smartphones or tablet devices, most of them had never used the lent devices or apps, and it could take them some time to get used to them. For further improvement in usability, it may be necessary to make the operation of devices easier and older-adults–friendly, such as by reducing the number of taps to participate in the web-based exercise and providing detailed instructions on how to use devices and apps [33].

Moreover, it should be considered that the high rate of smartphone or tablet ownership among participants (87%) may have contributed to ensuring no significant usability issues. According to a recent national survey on the use of communication devices, the rate of internet users was 73.4% among 60-year-old people and 40.8% among those aged ≥70 years in Japan [34]. Therefore, older adults unfamiliar with ICT may have some problems using this web-based exercise delivery system. Although the number of internet users in the older population has been rapidly increasing in Japan [35], further examination of usability among older adults with low ICT literacy is needed.

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Limitations and Future Directions

In this study, there are several limitations and, hence, further research is required. First, participants' characteristics could influence the results. The participants were volunteers, and many belonged to the community organizations as leaders. Therefore, they could have been highly motivated to participate in the intervention program, which may have influenced their adherence rate and enjoyment. Moreover, many participants owned smartphones or tablets, which may have contributed to the results of the system's usability. Further studies with a larger sample size are needed to examine whether similar results can be obtained with older adults who are physically and socially inactive or are unfamiliar with using ICT devices. Second, to strictly examine the safety of the exercise program, we used a smartphone and HR monitor to check the exercise intensity, and asked research staff to monitor participants' health condition and movements during the exercise session. However, from a cost-effectiveness standpoint, the system needs to be simplified for implementation in the real world. Finally, since this is a single-arm pilot study, the effectiveness of the exercise program is unknown. A future study on the effect of this web-based exercise program on physical, mental, and cognitive function in older adults should be conducted using a randomized controlled design.

Conclusions

This pilot study indicates that an 8-week intervention using a web-based aerobic dance program with short duration (20 minutes), high frequency (5 days per week), and light intensity (HRR 29.8%) is feasible, safe, and enjoyable for older adults. Moreover, although there were no serious issues with the web-based exercise delivery system using a videoconferencing platform, some areas for improvement were found. These results suggest that our web-based exercise program could be valuable in enabling healthy behaviors for older adults. Future studies on the generalizability of the results and effectiveness of this web-based aerobic dance exercise program and usability improvements for real-world implementation are needed.

Acknowledgments

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Data Availability

The data that support the findings of this study are available from the corresponding author (KH) upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Overview of the heart rate (HR) online monitoring system. Participants' HR was measured by an OH1 HR monitor on their arm, and the data were sent to the smartphone app via Bluetooth. The participants could see their HR on the smartphone app. Moreover, the HR data were sent to the web application via the internet, and the research staff could check the HR of all participants in one screen. Once the name of a participant was clicked, the time series data on their individual HR would be displayed.
[PNG File , 282 KB - aging_v6i1e39898_app1.png]

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Abbreviations

bpm: beats per minute
DBP: diastolic blood pressure
HR: heart rate
HRR: heart rate reserve
ICT: information and communication technology
SADE: Slow Aerobic Dance Exercise
SBP: systolic blood pressure

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Original Paper

Exploring the Potential of Technology to Promote Exercise Snacking for Older Adults Who Are Prefrail in the Home Setting: User-Centered Design Study

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Abstract

Background: Older adults are at increased risk of falls, injury, and hospitalization. Maintaining or increasing participation in physical activity during older age can prevent some of the age-related declines in physical functioning that contribute to loss of independence and low reported quality of life. *Exercise snacking* may overcome some commonly cited barriers to exercise and encourage older adults to engage in muscle strength and balance activity, but the best way to deliver and support this novel format remains unknown.

Objective: Our aim was to explore how the novel *exercise snacking* approach, that is, incorporating short bouts of strength and balance activities into everyday routines, could be supported by technology within a home setting and what types of technologies would be acceptable for older adults who are prefrail.

Methods: Following a user-centered design process, 2 design workshops (study 1) were conducted first to understand older adults' (n=11; aged 69-89 years) attitudes toward technology aimed at supporting exercise snacking at home and to inform the design of 2 prototypes. Next, based on the findings of study 1, an exploratory pilot study (study 2) was conducted over 1 day with 2 prototypes (n=5; aged 69-80 years) at the participants' homes. Participants were interviewed over the telephone afterward about their experience. Transcripts were analyzed using framework analysis.

Results: The results showed that the participants were positive toward using technology at home to support exercise snacking, but both exercises and technology would need to be simple and match the participants' everyday routines. Workshop discussions (study 1) led to the design of 2 prototypes using a pressure mat to support resistance and balance exercises. The exploratory pilot study (study 2) participants reported the potential in using smart devices to support exercise snacking, but the design of the initial prototypes influenced the participants' attitudes toward them. It also hampered the acceptability of these initial versions and highlighted the challenges in fitting exercise snacking into everyday life.

Conclusions: Older adults were positive about using technology in their homes to support strength and balance exercise snacking. However, although promising, the initial prototypes require further refinement and optimization before feasibility, acceptability, and efficacy testing. Technologies to support exercise snacking need to be adaptable and personalized to individuals, to ensure that users are *snacking* on balance and strengthening exercises that are appropriate for them.

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KEYWORDS

physical activity; older adults; Internet of Things; user-centered design; qualitative research; mobile phone

Introduction

Background

The benefits of physical activity (PA) across the life span are well documented [1]. Within the United Kingdom, older adults (aged ≥65 years) should accumulate 150 minutes per week of moderate-intensity aerobic activity [2]. Furthermore, the guidelines highlight that any level of PA should be encouraged, and activities to improve or maintain muscle strength and flexibility should be incorporated at least 2 days per week [2]. However, many older adults are failing to meet these guidelines and report low levels of muscle and bone strengthening activities [3]. Older adults are at increased risk of falls and injury owing to age-related declines in physiological functioning [4], which can impede their quality of life and independence and place an enormous strain on health and social care costs at the societal level [5].

Recent studies have also indicated that older adults spend a high proportion of their day engaged in sedentary behaviors [6], that is, any waking activity in a sitting, lying, or reclining posture where energy expenditure is <1.5 metabolic equivalents [7]. As the proportion of older adults in our society increases [8], strategies to promote PA and reduce sedentary behavior in this age group are important to maintain physical functioning [9] and improve health-related quality of life [10].

To promote and sustain participation in strength and balance exercise as individuals age, there is a need to develop interventions for this population that are effective, inclusive, acceptable, and safe [11]. Furthermore, interventions should enable older adults to overcome some of the commonly cited barriers to current participation in PA. Such barriers include dislike for activities that are structured or sport based, time commitments, and limited access to facilities [12-14]. Integration of functional exercise into daily routines may provide another alternative to PA promotion in this population and overcome the recognized barriers in relation to structured exercise programs [15].

Incorporating short bouts of exercise across the day or *exercise snacking* [16] represents an innovative approach to PA promotion among older adults. It is similar to Snacktivity [17,18], which is mostly used in the context of aerobic PA. Both promote opportunities to engage in exercises that are safe and compatible with individuals' surroundings and lifestyle [16]. So far, exercise snacking has been shown to be an accessible, acceptable, and effective alternative to traditional exercise in older adults [16,19].

Technology has the potential to support PA at home. Recent studies have focused on wearables and activity trackers such as Fitbit [20], which can be effective in encouraging PA and reducing sedentary behaviors [21]. However, these devices tend to focus on supervising or monitoring older adults and tend to support a limited number of activities, especially cardiovascular activities such as walking [20]. Given their reliance on measuring steps and location, they are unsuitable for supporting strength and balance exercises. Similarly, previous studies on supporting older adults' exercise at home have focused on more complex solutions such as Kinect [22] or social robots to support (predominantly aerobic) PA [23]. These solutions are expensive and require planning to fit the exercise sessions into one's day. Owing to the situated nature of exercise snacking and its links with everyday routines, Internet of Things (IoT) devices are well suited to provide technological support. IoT devices can be easily embedded at home and provide both monitoring and guidance, such as reducing office workers' sedentary behavior [24], supporting good posture while sitting [25], or exercising [26]. As such, they could be used to support exercise snacking at home as part of routine everyday activities.

Objectives

This project explored how ubiquitous technology could be embedded in the home setting to support community-dwelling older adults who are prefrail with exercise snacking activities to improve strength and balance. It builds on previous studies that have demonstrated exercise snacking to be as effective as resistance training in improving muscle functioning [16] but has the added benefit of overcoming barriers to engagement in PA for older adults.

The main objective was to develop and test a set of interactive prototypes that could be embedded in the home environment to support strength and balance exercises. To do so, we engaged older adults who are prefrail in the design of the prototypes and conducted an exploratory home evaluation. Health technologies tend to be designed without consideration of older adults' perspectives about PA [27], which can reduce their usability or adoption within this user group. Therefore, our goal was to work directly with older adults and use their input and ideas as a starting point to ensure that the prototypes addressed their needs.

Methods

Approach

This project followed an iterative, user-centered design (UCD) process [28] to identify the requirements for initial prototypes and explore their potential; however, we did keep in mind the principles of person-based approach [29], as this work will be used as a starting point for the development of a future behavior change intervention. Study 1 (design workshops) aimed to identify appropriate exercises that older adults are willing to do at home and attitudes and preferences toward technologies that might support PA. Study 2 (home evaluation) then developed and piloted new prototype technology informed by the results of study 1.

Participants and Recruitment

We recruited 16 community-dwelling older adults who are prefrail from participants of a randomized controlled trial

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(focused on encouraging PA among older adults [30]) who consented to be approached for future research projects. Of the 16 individuals, 11 (69%) participated in study 1 (mean age 74, SD 5.5; range 69-89 years). Of the 11 participants, 7 (64%) were women and all (n=11, 100%) were White British. A further 5 participants participated in study 2 (mean age 74, SD 4.87; range 69-80 years), and 3 (60%) of them were women. Participants who responded to the study email advertisements were sent a participant information sheet describing the study.

Study 1—Design Workshops

Materials

Study 1 involved two 2-hour design workshops in Bristol, the United Kingdom. To facilitate discussions, participants were provided with handouts showing examples of specific muscle strengthening and balance exercises and simple Tai Chi movements they could do at home, which were also demonstrated to participants by a trained exercise instructor (IJL). A set of electronic components (eg, proximity sensors, pressure mats, vibrating components, and lights), examples of wearable devices (eg, a smartwatch and an activity tracker), and an Amazon Alexa were used to facilitate the discussions about technology supporting exercise snacking at home.

Procedures

Workshops were conducted on the same day in February 2020 within a Sensor Platform for Healthcare in a Residential Environment (SPHERE) smart home [31]. The smart home belongs to the University of Bristol and is a terraced house with several rooms equipped with various sensors such as movement sensors and near-field communication (NFC) tags. The sensors were visible throughout the home; however, they were not used as part of this study. Nevertheless, participants were able to see how smart technologies could be implemented in a home environment, which facilitated discussions about how new devices could fit into their existing homes.

Each session started by discussing the participants' current PA levels, including home-based and group activities and any barriers to exercise that they had encountered. Exercise snacking and exercise handouts (preferred format and content) were then discussed. A researcher and trained exercise instructor demonstrated 5 exercise snacking and 5 Tai Chi snacking movements [19], with participants trying each. This session was conducted in a living room, and participants were able to use chairs and a sofa as part of the exercises. Participants then discussed their thoughts about the exercises and how they could be fit into their daily routines and home environments.

Participants then moved through the house (kitchen, bathroom, bedroom, and dining room), discussing suitable exercises for each room, how rooms differed from their own environment, and how that difference could affect the exercise. In addition, any technology that could support and prompt exercise was discussed. This was facilitated by a member of the research team. Subsequently, 1 researcher presented examples of various technologies and sensors, explaining how each item worked and how it could be used in practice. Participants then discussed which components and devices could be useful to support exercise snacking in their home environment.

After the study, participants received a shopping voucher worth £10 (US $12.91) for participating in the workshop.

Study 2—Feasibility Evaluation With Semistructured Interviews

Materials

On the basis of the key findings from study 1, a total of 2 types of interactive prototypes were built: 1 to support 1-legged balance exercises and 1 to support sit-to-stand exercises (Figure 1). These 2 activities were chosen because participants agreed that they were useful and were the easiest to be integrated into their everyday routines, that is, were easy to master and could be done anywhere at home. Each prototype consisted of a pressure mat and a companion screen. As their design was influenced by study-1 results, more details are provided in the *Prototype Development* section after study-1 results.

The prototypes were accompanied by a booklet explaining exercise snacking and the 2 selected exercises, with advice about how to do them correctly and suggestions of times and places at home where they could be done. The booklet also included a setup and troubleshooting guide.

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Figure 1. Exercise snacking prototypes for supporting (A) 1-leg balance and (B) sit-to-stand exercises. Images were captured by the researchers to demonstrate potential locations for the prototypes.



Procedures

The evaluation study consisted of 2 parts (an exploratory home evaluation and an interview) and was conducted in Bath, the United Kingdom, between May 2021 and June 2021. Written informed consent was obtained from all participants. No personally identifying information was collected and the data were anonymized. Prototypes were delivered to participants' homes by a researcher; participants also received written setup instructions, and the researcher was available via telephone to provide any further technical and exercise support. Owing to COVID-19 restrictions, the researcher followed a COVID-19–secure process, which involved contactless delivery and collection, with no entry into the participant's home. Each participant received both prototypes (balance mat and sit-to-stand mat) and was requested to use them for a single day. They were asked to think about their everyday routines and place the prototypes and the feedback screen in spaces where they would be the most likely to see and use them without having to go to a dedicated room. After delivering the prototypes, the researcher explained each exercise to the participant over the telephone.

At the end of the day, a researcher collected the prototypes and, later, conducted the telephone interview. Interviews lasted approximately 30 to 45 minutes and covered participants' general experience of setting up and using the prototypes, views about the utility of the technology going forward, and their general views about how to improve the prototypes or better integrate technology into their daily lives. After that, participants received a shopping voucher worth £30 (US $41.67) for testing the prototypes at home and participating in the phone interviews.

Ethics Approval

Both studies received favorable ethical opinion from the University of Bristol (project ID 99482) and Cardiff University (COMSC/Ethics/2020/071).

Data Analysis

Study-1 workshop discussions were audio recorded and transcribed verbatim for subsequent analysis. Any mention of participants' names in the transcripts was replaced by participant numbers before the analysis. Transcripts were analyzed thematically [32] using both deductive and inductive approaches to explore insights related to the specific topics we focused on and any unexpected findings. Before analysis, transcripts were read to identify specific features for the prototypes, so that they could be incorporated by the developer while data analysis continued. One of the authors (IJL) coded all the transcripts. Codes were then reviewed and discussed by 2 other authors (KS and MW), who identified the provisional themes and drafted the results. The themes and draft findings were then reviewed and discussed with all authors until the final themes were fully defined.

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Study 2 ended with semistructured telephone interviews, which were audio recorded and transcribed verbatim. Transcripts were anonymized. Framework analysis [33] was applied to the data, as the authors were interested in specific topics. Following familiarization and coding of the transcripts, one of the authors (AW) created a framework table using interview questions as categories (columns), and each participant was allocated a row, with codes in corresponding cells. Then, 2 authors (AW and KS) summarized the findings in each cell to identify potential themes. Provisional themes were drafted by 2 authors (KS and MW) and then discussed with all authors, leading to the strengthening of some themes and removal of others.

Results

Study 1—Workshops

Overview

We were interested in understanding participants' views about and attitudes toward exercise, PA at home, and technology—these discussion topics formed the initial structure for resulting themes. Within each topic, themes and subthemes identified through the analysis are reported. They are summarized with representative quotes in Multimedia Appendix 1 and described in more detail in the following sections.

Topic 1—Attitudes Toward Exercise

Several themes were identified in relation to common *barriers to participation*. A common point of discussion centered around leisure settings being viewed as a nonwelcoming space for older adults. Several participants pointed to leisure centers and gyms as being young and male dominant, whereas others recognized that much of the provision for older adults was group based, with participants noting that they felt a lack of confidence in exercising with others. There were also barriers relating to individuals' motivation to do regular exercise. This was linked to the fear of falling and injury or lack of baseline strength, which made exercise a perceived risky prospect. However, despite these participation barriers, there was a strong sense that *exercise was important to the participants*, with many highlighting the health and well-being benefits it brings. Participants also recognized exercise to be a way of building confidence to stay engaged in other forms of social and leisure activity. Similarly, the social aspect of exercise itself was regarded as a key driver for participation, particularly for walking and aerobic activities.

Participants generally agreed that exercise should match the profile and ability of the target user and saw *potential inexercise snacking* to overcome this issue. For example, there were exercises that were much more suited to people in their later life, particularly owing to their physical capabilities, such as balance or sit-to-stand exercise. In this regard, the exercise snacking concept was viewed favorably, as it was seen to enable people to build up from different baselines and progress on their own terms and appeared to be easy to master as a set of exercises. In addition, it could help to overcome other barriers that participants had mentioned—including the ability to do PA in a low-risk environment that was not a leisure setting. Tai Chi movements, as a proposed format of exercise snacking, had more of a mixed reception, with preconceptions both acknowledging it as a useful, relaxing exercise but potentially tricky to learn.

Topic 2—Exercising in the Home Environment

The second topic explored how the home environment might support or hinder regular engagement in exercise snacking. While walking around the smart home environment, some participants commented about the *impact of location* and how different spaces lend themselves to exercise more than others. For example, it was apparent that the amount of floor space in a room was important for it to be seen as a space to exercise in. Another consideration was the need to work around other people at home, including partners, spouses, grandchildren, or pets. There was also a sense that certain rooms had a particular function that would preclude them from being a place for exercise, such as the dining room.

Much of the conversation about the suitability of spaces to exercise centered on *safety in the home environment*. Having solid objects to hold on and to support balance and stability where necessary was seen as an important consideration, with key examples in the more spacious rooms being kitchen worktops and chairs. In addition, for some formats of exercise, such as balancing, having soft furnishings and carpeted floors would make the environment feel safer than hard spaces.

A final theme related to the home environment was how certain spaces or everyday tasks could be used as opportunistic *contextual cues to prompt exercise snacking*. For example, the lounge was suggested as a good place to be prompted and do exercise, as it is typically the space where older adults would otherwise sit for long periods—as such, it would be suitable for exercises that can be done while sitting. Some people identified everyday actions that could prompt their exercise snacking, such as brushing teeth, boiling the kettle, or washing dishes. As they were part of the routine and usually occurred in the same spot, they could be linked with exercises suitable for that space, for example, balance exercises.

Topic 3—Opportunities and Challenges of Using Technology at Home

Finally, when discussing the use of technology, it was apparent that participants were already familiar with a range of technologies (eg, apps, Amazon Alexa, Fitbit for tracking steps, and YouTube videos to support exercise) and referred to existing solutions to highlight their strengths and weaknesses. On the basis of this previous experience, they had clear *expectations* of what technologies would work and would not work for them. For example, they all agreed that any system that aims to support PA at home should be discreet or even hidden, as not everyone felt comfortable "advertising" with technology that they were trying to be more active. In addition, such systems should also work for people with low technology literacy and be as simple and easy to use and set up as possible. As such, some participants also thought that limiting functionality would help to make the technology easy to use.

This need for simplicity was also linked with a *need to consider the context of use*. This included accounting for the realities of everyday life and characteristics of the users. A participant

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mentioned that ideal technology would be something they could use without having to wear glasses. Another participant pointed out that the technology would be a part of a wide ecosystem and, therefore, would need to easily connect to the local wireless network and work with other devices at home. Furthermore, it should be inexpensive, as even smartphones or smartwatches were seen as being beyond the reach of a regular person.

Participants also identified several *opportunities for exercise snacking technologies*. They agreed that technology should provide instructions, feedback, and reminders. Instructions were seen as an important feature that could help to introduce the correct movements; help users understand how to exercise (eg, frequency and when to stop); and later, help check whether they were exercising correctly, especially if no additional support was provided. Regarding the latter point, participants expressed a desire to have access to either support groups or someone they could discuss their progress with. Furthermore, visual prompts could also be used to provide ongoing feedback and situated instructions, for example, by showing the movements one is supposed to execute or simply providing encouragement to motivate the user. In addition, some participants thought that this type of interaction could be more playful and "witty." Overall, participants were open to trying new technologies. Having identified the best locations and types of exercises, they also suggested building devices that could be incorporated into everyday objects to encourage exercise snacking in a specific location.

Prototype Development

Study-1 results informed the design of the prototypes. Given that participants expressed interest in exercise snacking and engaging with simple exercises at home, we decided to develop prototypes based around a pressure mat that could be placed anywhere at home, where it would fit best into participants' daily routine. This form factor would also allow participants to just use it (stand or sit on it) without having to set things up in preparation, which was another aspect identified by participants. Finally, as participants expressed interest in systems that are discreet or hidden, a light-emitting diode (LED) companion screen was included to provide additional visual feedback that did not explicitly mention exercise.

We developed 2 prototypes. Each consisted of a pressure mat and a battery pack. We used SensingTex Switch mat that enabled a single pressure point recognition (Figure 2). We selected a pressure mat as the basis of each prototype, as it would not require any complex interactions, and participants would only need to stand on it if they were ready to exercise. Each mat was connected via Bluetooth to a Raspberry Pi 4 and a Unicorn HAT LED Matrix. The LED screen provided feedback to the user because without it, owing to the mat's minimal interface, it was not clear whether the prototype was active or whether participants were reaching their goals. The screen also provided encouragement and motivation.

Although both prototypes appeared similar, they had different underlying algorithms to account for differences in the exercises. The balance mat was set up for 2 daily repetitions, 60 seconds each, as a default, and the sit-to-stand mat was set up to measure movement repetitions for 60 seconds during each exercise session, with the target of 30 repetitions per day. When stepped on, the prototype would trigger a timer, which was shown on the LED screen. The devices recorded the number of repetitions and time spent on each exercise. Figure 3 shows examples of the visual feedback—a smiling face if the daily target has been reached, a frowning face if it has not been reached yet, and a progress bar to help count down time during an exercise session.

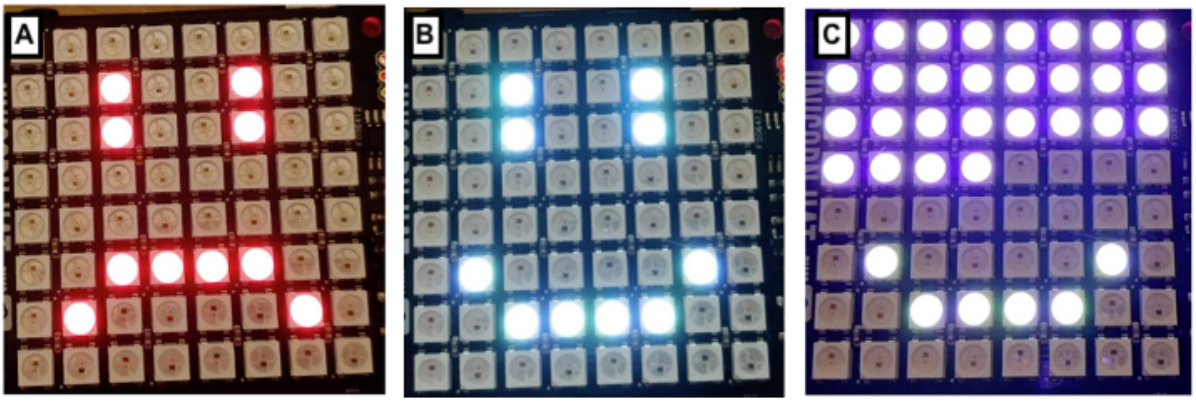
A flow diagram showing how the prototypes worked is available in Multimedia Appendix 2.

Figure 2. A pressure mat and a battery pack that were used as a basis of the prototypes.



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Figure 3. Companion light-emitting diode displays available to the user, showing (A) that the total number of activities for the day has not been reached yet, (B) that the activities for the day have been completed, and (C) a progress bar that fills the screen showing the user how long they should engage with the exercise.



Study 2—Home Evaluation

The second study focused on evaluating the prototypes at home. Unlike study 1, it was more exploratory in nature—we did not have predefined topics in mind beyond understanding how the participants used the prototypes and what they thought about them.

Participants' Use of Technology

All participants (5/5, 100%) reported using the internet and having previous experience in using mobile phones, laptops, PCs, and tablets. Consumer electronics they used were often Apple products, the sleek design of which was referenced by participants when discussing the study prototypes. Most participants (4/5, 80%) reported that they used some type of activity tracker (often step counters on their phone) and were generally positive toward these types of technologies. Of the 5 participants, 1 (20%) participant mentioned using a heart rate monitor and 2 (40%) reported watching exercise videos on YouTube (fitness and yoga) during the COVID-19 lockdowns to help them stay active.

These technologies and participants' experiences influenced how they interacted with our prototypes and their expectations toward the devices. In the following sections, we describe 4 themes identified in the interviews conducted after the home evaluation.

Importance of Design Esthetics and Reliability

The study findings highlighted the importance of selecting the right level of complexity and polishing the design of initial prototypes used for testing. As the study's goal was to explore how the technology fits into people's homes and could support exercise snacking, we focused primarily on the functionality and did not prioritize the design at this stage. Therefore, our participants thought the prototypes were crude ("The graphics I thought were very crude. I think they could have been more pixels in the display to make the pictures easier to understand." [Participant 5]) and unfinished ("That equipment was quite awkward, you know, the cables and the fittings and the plugs didn't seem to fit very securely. It was all kind of it all looked a bit fragile." [Participant 3]), which affected how they used them. Some participants were not sure whether they could fold the mats for storage or whether that would damage them.

Participants also found it cumbersome to assemble the prototypes and to remember to switch them on and off to preserve the battery. This led to technical issues when they connected things incorrectly or the prototypes were not working properly, which discouraged participants from using the devices. Therefore, although participants agreed that the devices had potential and "tools like this" could be useful, they did not see a clear benefit of using the prototypes in their current form:

> *The technology is too crude and intrusive at this early stage, compared with either a) doing without or b) doing something clever with it.* [Participant 1]

Challenges With Fitting the Device Into Everyday Life

The prototypes were designed such that they could be used in different places at home to enable participants to fit exercise snacking into their routines. Although it mostly worked, participants highlighted a few practical considerations. A participant reported that they had to rearrange their house and move a chair to the kitchen so that they could do the sit-to-stand exercise:

> *I've got lots of things all over the place. For this trial, I put them in the kitchen. But it would be in the way if I left there every day. I'd have to find somewhere else.* [Participant 1]

In addition, the balance mat was perceived as a potential trip hazard and participants were not keen to leave it on the floor when not in use:

> *If I kept it there during the day, I could easily trip on it. Anybody could trip or slip as well because I have a wooden floor so it could slip quite easily.* [Participant 2]

In addition, some did not want the prototypes to always be visible owing to their looks and found packing and unpacking the devices to be cumbersome. Similarly, the limited battery life required the device to be switched off when not in use, which added an extra burden.

Overall, although exercise snacking was supposed to be easy and effortless, having to set things up defeated the purpose of the prototypes. Participants acknowledged that although having a dedicated tool could, in principle, make exercising easy, using preexisting methods or devices was perceived as easy and more

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useful. Improved reliability, more polished look, and easy set up would make exercise snacking systems more motivating and appealing:

> *I think [the prototypes] just feel, um, they don't feel user friendly and they don't feel...they feel like old technology. I think it would need to have a screen; it would need to look like a phone; it would need to have a digital reader, you know, all of that, like the apps we have on our phone.* [Participant 3]

Need for Personalization

The initial design of the prototypes allowed changes to the difficulty levels and the number of repetitions. However, in scaling down the project owing to the COVID-19 pandemic, the researcher gave all participants (5/5, 100%) the same device with default settings. This proved to be problematic, and participants consistently commented that the exercises were either very easy or very difficult:

> *The balance exercise is quite easy, and the sit-to-stand is more strenuous. It's hard work. It takes more energy and makes me tired.* [Participant 5]

A positive side effect observed was increased motivation of a participant who started using weights to make the exercises more challenging ("I put a rucksack on my back and weights in it and I did it like that to get myself...to make [sit-to-stand exercises] harder." [Participant 3]), which suggested that the device could be useful for initiating exercise behavior or as a gateway to people forming a new routine:

> *If it's there, you'll use it. And that's just getting into the regime, it's like, in the morning, you'll sort of do 10 minutes of different exercises...And it just becomes a habit.* [Participant 4]

Issues with difficulty levels and progression led to discussions about exercise personalization and suggestions for future improvements. Participants believed that exercises needed to be adapted to the user and therefore suggested including some progression to keep users engaged, for example, by increasing the complexity or difficulty of movements:

> *Trick is to make it sufficiently interesting and challenging to those who find it fairly easy, but also not to put off people who find it harder and struggle to get out of the chair, so maybe if you had a series of levels so you could come in at level one or you could jump to level three.* [Participant 3]

They also highlighted the need for feedback about the movements and progress, which would help with motivation and could support the increasing difficulty levels (a participant suggested a potential app similar to the Couch to 5K running program but for strength and balance).

Future Opportunities

When asked for views about the potential of technology to support home-based exercise after using the prototypes, participants identified several desirable features to improve utility. Features included linking of the devices to a more sophisticated app or sensors to provide more detailed feedback ("If the mat sensed the growing extent of my imbalance and reduced the time, or increased it if my balance was perfect, that would be a bit more useful, and if it sensed where my toes or heel or whatever was going wrong, and issued warnings about posture then that would make it more useful." [Participant 1]), adding voice or sound as a way of providing feedback about performance of exercises and encouragement, and prompts and reminders to do the exercise.

Participants also discussed how the prototypes could be improved. Some suggestions focused more on how the mat could support a more diverse array of exercises:

> *It would be nice to have a wider range of exercises. I mean, as you get old your backs get stiff. You get stiffness in lots of joints. I think that it could be done to use more joints as a body, try and create more flexibility.* [Participant 5]

Participants also provided positive perspectives about the role of technology in supporting home-based exercise, for example, providing visual prompts:

> *The little pad would be sitting on the floor, would be a reminder.* [Participant 5]

Others discussed how functioning technology could provide structure to support current activity and could be useful for engaging people in new activities in the short term, even if not used continuously:

> *At the moment I do it when I can see I've got two or three minutes to do sit to stand. So I do.* [Participant 1]

Discussion

Principal Findings

Overview

The aim of this project was to develop and test interactive prototypes to be used at home to support strength and balance exercise snacking in older adults who are prefrail. Our workshops identified that participants were open to using technology in the home setting, but personalization of the exercise snacking regime and simplicity in technology use are important. Participants who subsequently tested 2 prototypes (balance mat and sit-to-stand mat) in a home evaluation demonstrated that this technology had the potential to support exercise snacking in the home setting with further development and testing. In the following sections, we discuss the main results and implications for designing systems that support exercise snacking at home for older adults who are prefrail.

Home Environment as a Space to Exercise

Exercise was identified as an important activity for participants, and using the home setting as a location for exercise snacking elicited both positive and constructive views, which will inform the next iterative step in the design process. The home setting has been frequently used for rehabilitative exercise for multiple conditions such as musculoskeletal joint replacement, neurological conditions, and cardiorespiratory conditions and has been shown to be as effective as supervised or group exercise at 12 weeks on health outcomes for women with type

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2 diabetes [34]. A recent pilot randomized controlled trial has demonstrated that resistance exercise snacking is safe and acceptable for community-dwelling older adults over a 4-week period. Although this project focused on only 1 strength exercise and 1 balance exercise, the results align with those of Fyfe et al [35] and Liang et al [19], who found the exercises to be feasible and safe.

Role of Technology for Overcoming Barriers

A key challenge for any exercise program, especially those targeting individuals in the home setting, is prolonged adherence [36]. Participants in this study were largely positive about the potential for technology to support the implementation of home-based exercise snacking as long as the technology was simple, reliable, and unobtrusive to use. The need for simplicity and reliability as key guiding principles for the adoption and sustained use of technology has been found in other studies of older adults' perceptions about technology [37]. Technology, if designed appropriately, also enables the integration of some key behavioral science principles that can help with exercise motivation, such as self-regulatory behavior change techniques (eg, feedback and goal setting) and gamification to make exercise fun and engaging [37-39], and nudges or cues to help turn exercise into a more automatic behavior [40]. Our preliminary evaluation suggested that more work could be done to improve the reliability of the technology, better integrate feedback, and make the device more personalized to the user's needs and preferences for exercise.

Recommendations for Future Practice and Studies

Accordingly, we provide design recommendations for developing home-based systems that support exercise snacking and other types of PA aimed at older adults. Researchers and developers working in this area should do the following:

1. *Support personalization*—As older adults can have varying levels of activity, any home-based system that facilitates and supports exercise needs to be able to accommodate different baseline circumstances, from fully sedentary routines to physically active users who may want to move more at home. As such, systems should allow users to change difficulty levels, which should then progressively adapt based on the user's progress.
2. *Provide clear and meaningful feedback*—As exercise snacking is a situated activity, any system that supports it needs to recognize and clearly communicate that it has started and notify the user when they can finish, regardless of whether they are doing timed exercises or a specific number of repetitions. It should also notify the users when they reach their goals and show their progress. Furthermore, different feedback modalities need to be considered to improve accessibility and usability through combinations of visual and auditory feedback to support older adults with hearing and visual impairments.
3. *Take the environment into account*—Any system that supports exercise at home needs to be sufficiently flexible, so that people can use it in the most suitable location. Different people have different routines, and the living situation of older adults varies, which makes it impractical to design a one-size-fits-all solution. For example, some people may prefer to *exercise snack* in the living room, whereas others would prefer to do so in the kitchen; ideally, the system should work in both.
4. *Remember the esthetics*—The design of technologies aimed at older adults is often based on a wrong assumption that esthetics do not matter for this user group. However, increasing access to consumer electronics influences the perceptions about technology and people's expectations and values; older adults are not different [41]. Furthermore, any device that is meant to become part of an environment should fit into that environment and ideally provide subtle and discreet feedback, as not all users may want to advertise to visitors that they are trying to be more active.
5. *Ensure the system is accessible and easy to use*—As older adults' experiences with technology or digital literacy may be limited, any system aimed at them should have an intuitive design and require minimal setup. Switching technology on and off and selecting user goals and preferences should be implemented in a user-friendly manner that is suitable for the target population. Furthermore, systems should be compatible with the technologies that people already have at home, for example, wireless networks. As most IoT systems rely on the internet connection, the ease of setup and seamless connectivity are key.
6. *Provide guidance to reduce risks*—Finally, any system that supports PA needs to be able to guide the users, as the movements may not be familiar to them or they may require a reminder. This can be directly embedded in the physical system or be provided through a companion app. Regardless of the format, guidance could help to reduce risks of falls, support older users, and educate users about PA.

Limitations and Future Studies

This was an exploratory project focusing on the early stages of the iterative UCD process and as such had some limitations. Study-1 participant numbers were limited by space and maximum capacity for people in the smart home at the time; however, the numbers were consistent with those in previous design research using workshops to design digital interventions [42]. Study 2 involved 5 participants who used the prototypes for 1 day. As our goal was to assess the usability of the prototypes and gather early feedback, this was sufficient, because usually 4 to 6 participants are required to identify key usability issues [43]. Participants were vocal about issues and constructive suggestions for improvement. Overall, our participant numbers are consistent with UCD studies, and evidence has shown that these methods can provide generalizable design guidelines [44-47].

Participants were recruited from a cohort that had previously participated in a PA trial [48], albeit a mixture of intervention and control participants. Selection bias may have influenced the results obtained, as the participants may have had more positive attitudes toward PA. However, as this was the initial phase in the design process, both benefits of and challenges to developing technology were identified, and future stages in this process (acceptability, feasibility, and efficacy testing) will ensure a wide, representative, and large recruitment of older adults who are prefrail to avoid potential bias [49]. In addition,

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recruitment from this population enabled participants to reflect about their previous experiences with exercise snacking and provide feedback and suggestions for improvement, which was crucial for this study.

Study 2 was a home study conducted during the COVID-19 pandemic and, consequently, was subject to several deviations from the initial protocol. These limitations influenced the participants' experiences, which is reflected in the themes. Nevertheless, key lessons were learned about the design and delivery of technology home testing during COVID-19, which can be embedded in the future stages of this project to ensure successful delivery and completion, regardless of whether there is face-to-face or remote delivery. Furthermore, as home testing occurred over a single day, we were unable to evaluate the adherence to exercise snacking. As adherence is crucial to the acceptability and feasibility of the exercise snacking technology design, factors predicting adherence to home-based rehabilitation (intention to engage, self-motivation, self-efficacy, previous adherence, and social support [50]) will be incorporated into subsequent iterations of the design process.

Finally, the design of our prototypes may have influenced the results. Our primary focus was the functionality of the prototypes; we did not fully consider esthetics or visual design at this stage. This resulted in negative comments and, to some degree, affected participants' interactions with the prototypes. Although we were still able to gather relevant feedback, more polished prototypes and user interfaces would have helped to concentrate the feedback on functionality. As we are following the UCD process, this will be incorporated into the next iterative phase of development of the prototypes.

Conclusions

Exercise snacking offers a promising approach for incorporating balance and strength PA into older adults' routines. Our results demonstrated that technology has the potential to support exercise snacking in the home environment for older adults who are prefrail. However, the design of devices not only needs to be easy to use and set up but must also fit into users' routines and physical spaces. Exercise snacking technology devices also need to be adaptable and personalized to individuals, to ensure that users are *snacking* on balance and strengthening exercises that are appropriate for them.

Acknowledgments

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Data Availability

The data sets generated and analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
A table with quotes to illustrate the subthemes identified in the workshops for each discussion topic.
[PDF File (Adobe PDF File), 203 KB - aging_v6i1e41810_app1.pdf]

Multimedia Appendix 2
A flow diagram showing how the prototypes work.
[PNG File , 127 KB - aging_v6i1e41810_app2.png]

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Abbreviations

IoT: Internet of Things
LED: light-emitting diode
NFC: near-field communication
PA: physical activity
SPHERE: Sensor Platform for Healthcare in a Residential Environment
UCD: user-centered design

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Original Paper

Video Calls as a Replacement for Family Visits During Lockdowns in Aged Care: Interview Study With Family Members

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Abstract

Background: Lockdowns have been used to prevent the spread of transmissible illnesses such as influenza, norovirus, and COVID-19 in care homes. However, lockdowns deny care home residents supplemental care and the socioemotional enrichment that comes from seeing family members. Video calling has the potential to enable ongoing contact between residents and family members during lockdowns. However, video calls can be considered by some as a poor substitute for in-person visits. It is important to understand family members' experiences with video calling during lockdowns to ensure the effective use of this technology in the future.

Objective: This study aimed to understand how family members use video calls to communicate with relatives living in aged care during lockdowns. We focused on experiences during the COVID-19 pandemic, which involved extensive lockdowns in aged care homes.

Methods: We conducted semistructured interviews with 18 adults who had been using video calls with relatives living in aged care during pandemic lockdowns. The interviews focused on how participants had been using video calls, what benefits they gained from video-based interactions, and what challenges they encountered when using the technology. We analyzed the data using the 6-phase reflexive approach to thematic analysis by Braun and Clarke.

Results: We developed 4 themes through our analysis. Theme 1 interprets video calling as a medium for the continuation of care during lockdowns. Using video calls, family members were able to provide social enrichment for residents and engaged in health monitoring to uphold residents' welfare. Theme 2 highlights how video calling extended care by supporting frequent contact, transmitting nonverbal cues that were essential for communication, and negating the need for face masks. Theme 3 interprets organizational issues such as the lack of technology and staff time as impediments to the continuation of familial care through video. Finally, theme 4 highlights the need for 2-way communication, interpreting residents' unfamiliarity with video calling and their health conditions as further barriers to the continuation of care.

Conclusions: This study suggests that, during restrictions arising from the COVID-19 pandemic, video calls became a medium for enabling family members to continue participating in the care of their relatives. The use of video calls to continue care illustrates their value for families during times of mandatory lockdown and supports the use of video to complement face-to-face visits at other times. However, better support is needed for video calling in aged care homes. This study also revealed a need for video calling systems that are designed for the aged care context.

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KEYWORDS

aged care; COVID-19 pandemic; lockdowns; older adults; video calls; videoconferencing; mobile phone; COVID-19

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Introduction

Background

Lockdowns are a common measure for preventing the spread of viral diseases in aged care homes [1,2]. In recent years, lockdowns have been used to slow the spread of COVID-19 in care homes worldwide [3,4]. These lockdowns were essential because of considerable outbreaks of COVID-19 within care facilities [5,6] and because care home residents were highly susceptible to mortality from the disease [7]. Examples of measures implemented during lockdowns include the confinement of residents to their rooms and the suspension of all face-to-face visits from family and friends [8-10].

Although lockdowns can be an effective way to prevent disease transmission, prolonged periods of isolation are highly detrimental to the cognitive and emotional well-being of care home residents [11]. Loneliness and isolation have long been salient problems in aged care [12,13], and there is evidence suggesting that these problems worsened during the pandemic lockdowns [10,14]. This can be partly attributed to the loss of physical visits from residents' family members, who were not able to visit in person while restrictions were in place [15]. Beyond the positive health and well-being effects of visits from family [16,17], family members have been described as "central to the care of residents" [14]. Families are a primary source of cognitive and emotional enrichment [18] and contribute to advocacy, emotional support, and assistance with the personal care of residents [14,19-21]. The loss of such support during the pandemic restrictions has placed renewed focus on enabling meaningful communication between residents and families during lockdowns [9,22,23].

After the onset of the pandemic, many aged care homes adopted video calling systems as a replacement for face-to-face visits [13,24]. These systems—which include Skype (Skype Technologies), FaceTime (Apple), and Zoom (Zoom Video Communications)—allow 2 or more people to see each other and participate in real-time conversations using high-fidelity video and audio feeds transmitted over the internet [25]. Several studies have used survey methods to understand the availability of video calling hardware during the pandemic [26,27] and whether care homes had to adjust the provision of technology for social connection [13]. These studies provide important data to illustrate care providers' adoption of video calling but do not offer insights into the experiences of people who had to rely on video calling in lieu of face-to-face visits during the lockdowns.

The need to understand the utility of video calling as a replacement for face-to-face visits, especially during lockdowns, is important for multiple reasons. First, the pandemic was perhaps the first time that video calling was deployed en masse in care homes. There have been studies illustrating the benefits of video calls for aged care residents, including positive impacts on social connection [28], emotional enrichment [29], and feelings of depression and loneliness among residents [30]. However, many such studies have involved short-term trials coordinated by research teams in which residents used video calls with relatives who could not visit the care home [28,31,32]. This setup partially replicates the circumstances of a lockdown, but it may not capture issues and experiences that arise in real-world use when support from researchers is unavailable. The recent lockdowns because of COVID-19 afford an important learning opportunity in this regard given that care homes had to pivot quickly to using the technology without external support from research teams.

Second, studies conducted before and during the pandemic have identified that video calling is affected by challenges in long-term care. A study conducted in Canada by Chu et al [33] found that essential family caregivers were highly dissatisfied with the provision of video calls during the lockdowns. The reasons given included poor internet availability, unsuitable devices, and technical problems, all of which have been identified as barriers in previous work [27,31,34]. Moreover, many aged care residents are frail, have complex health conditions such as dementia, and have little experience with information and communications technologies. These issues may make it hard for them to use commercial video calling systems [35,36], and care staff usually need to provide extensive assistance [37]. However, care staff typically have limited time for activities that fall outside their core duties [27,32], meaning that video calls risk placing additional burdens on an already overstretched workforce [37]. In addition, staff shortages were prevalent during the COVID-19 pandemic owing to high rates of infection within care homes [38]. These issues may have affected the quality of experience for residents and their families, but there remains scant understanding of people's experiences of video calling as a substitute for in-person visits during the restrictions.

Objectives

This study aimed to understand how family members used video calls to communicate with relatives living in aged care homes during COVID-19 lockdowns. We focused on experiences of video calling in Australia, where there were extensive and protracted lockdowns that prevented families from visiting relatives during the first 2 years of the pandemic.

This study explored the following questions:

1. How did family members use video calling with relatives in aged care during lockdowns?
2. In what ways was video calling beneficial for family members?
3. What challenges or barriers need to be overcome to support high-quality video calling experiences during lockdowns in aged care?

Methods

Ethics Approval

This study was approved by the University of Melbourne Human Research Ethics Committee (ID 1851239.5).

Study Design

This study used semistructured interviews to investigate family members' experiences with video calling. We used a semistructured approach to guide each interview using a broad set of questions while enabling participants to bring their own topics and experiences into the conversations [39].

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The reflexive thematic analysis (RTA) approach by Braun and Clarke [40,41] was used to analyze and interpret the data. RTA champions the researcher's interpretation as central to making sense of and generating meaning from qualitative data [41]. This means that RTA does not attempt to define a codebook or demonstrate validity based on metrics such as interrater reliability [42,43]. Rather, the emphasis is on the researcher's reflexive engagement with data and on interpretation developed through iterative rounds of coding and analysis. The goal of RTA is to develop themes that capture patterns of shared meaning relevant to the research questions [44,45].

Consistent with the assumptions of RTA, we adopted a constructionist and experiential orientation for our data collection and analysis. This means that we prioritized participants' own accounts of their experiences while using our interpretations to interrogate the meaning within those experiences [43]. We adopted RTA as we did not enter the study with a specific theory or deductive lens through which to interpret the data. RTA provided the flexibility to incorporate relevant theory and use existing knowledge on video calling to inform and develop the evolving analysis [41].

Research Context

We collected data for this study from July 2021 to October 2021 in the state of Victoria, Australia. Victoria was the site of several major COVID-19 outbreaks in 2020 and 2021. The state government imposed a total of 6 lockdowns that lasted a cumulative 8 months [46]. These lockdowns involved measures such as mandatory social distancing, stay-at-home orders, and the use of face masks both indoors and outdoors [47]. Aged care facilities in Victoria had to adhere to these restrictions, with many imposing bans on visitors because of COVID-19 outbreaks among residents and staff [48]. These restrictions meant that the participants in this study were reliant on video calls as their primary method of seeing relatives during the lockdowns.

Participant Recruitment

We recruited participants through the University of Melbourne internal staff mailing list and web-based noticeboards, advertisements on Twitter and LinkedIn, and word of mouth. Participants enrolled in the study by contacting the first author via email. There were no preexisting relationships before study commencement.

Our sample size was evaluated throughout the research process [49], and we stopped recruiting after 18 participants had completed the study. In line with RTA, we do not claim this as evidence of data saturation [50]. Rather, we ceased recruitment as the lead researcher (RMK) made the assessment that the data contained sufficient information power to address our aims and research questions [41,49]. Specifically, we felt that no further participants were required as our study had a narrow aim (to understand video calling in aged care); our sample specificity was dense (family members); and participants had conveyed rich experiences, indicating a strong quality of dialogue [49].

Procedure

Interviews were one-to-one and were conducted by the first author. Before study commencement, we emailed participants a Plain Language Statement containing information about the study's aims and procedures. Participants also signed a consent form, which they returned to the first author via email.

The researcher met with participants individually using Zoom videoconferencing software. We used Zoom to comply with social distancing requirements, which were in place when our data were collected. We used a semistructured interview guide, with an initial set of open-ended questions that enabled participants to share their personal experiences (see Multimedia Appendix 1 for the questions). The interview questions were developed as a team, drawing on our collective experience of research on digital communication technologies [51,52], older adults [53,54], and aged care [29,55]. The researcher took notes during the interviews and asked follow-up questions to probe responses in detail. The interviews lasted 19 to 47 (mean 32, SD 9) minutes. All interviews were audio recorded with participants' consent. Each participant received an Aus $30 (US $20.02) digital gift voucher for their time.

Analysis Approach

Recordings of the interviews were transcribed and combined with the researcher's notes from each interview. A pseudonym was assigned to each participant to ensure anonymity. We analyzed the data using the 6-phase approach to RTA by Braun and Clarke [40]. The lead researcher (RMK) conducted the analysis as follows.

Phase 1 involved familiarization with the data. RMK read through each transcript twice using Microsoft Word (Microsoft Corp). RMK highlighted passages that were relevant to the research questions and used the comment functionality to capture potential codes and thoughts about the data [43]. In phase 2, RMK imported the data into NVivo (QSR International) and coded each interview using an inductive, data-driven approach. RMK coded the interviews at the sentence level and created codes to capture key ideas. Some codes were semantic (ie, those that captured overt ideas), whereas others were latent codes (ie, those reflecting the researcher's interpretations) [41]. An example semantic code was *peace of mind*, which was a phrase used by participants, whereas a latent code was *using video calls to monitor health*. Consistent with other examples of RTA [43], we made no attempt to prioritize either form of code. RMK revised and refined the names of the codes as he progressed through the data and used annotations within NVivo to capture additional reflections. Textbox 1 provides an example of a coded data extract [56].

In phase 3, RMK assembled the codes into initial candidate themes by manually grouping codes using NVivo and sketching thematic maps using pencil and paper. RMK discussed the evolving analysis with author YX, who also read through the coded data, sense-checked interpretations, and reviewed the candidate themes.

In phase 4, RMK refined the themes and discussed them with author JW. The authors felt that an initial "benefits and challenges" framing could be helpful to capture the essence of

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participants' experiences. This discussion resulted in 6 initial subthemes related to benefits and 5 subthemes related to challenges. In phase 5, RMK defined and named each theme, selecting participant quotes and data extracts to illustrate key ideas. Phase 6 involved writing an initial draft of the report, which involved further theme refinement [41].

After receiving feedback and peer reviewers' comments on the report, RMK went back through phases 3 to 6 and revised the themes to develop primary interpretations and address the research questions. We also changed our framing to focus on the continuation of care, removing the initial ideas regarding benefits and challenges. Returning to earlier phases in this way is consistent with the tenets of RTA, which champions iteration and argues that analysis "becomes increasingly recursive" [45] as the interpretation progresses. RMK and JW also reviewed the themes to consider whether each one was sufficiently anchored to a central organizing concept [42]. Finally, RMK created a table to describe how the analysis activities align with guidance on establishing trustworthiness in the 6 phases of thematic analysis (Multimedia Appendix 2 [57]). This was done to provide evidence of a trustworthy and credible analysis [58].

From this iterative process, our analysis converged on the central interpretation of video calling as enabling the continuation of care during lockdowns. That is, video calls were not simply a medium for social connection but were being used to continue care practices that would ordinarily take place during face-to-face visits. We created one theme to capture uses that spoke to continuation of care and a second theme to highlight how video calling extended care. We developed 2 further themes: one that interprets organizational issues as impediments to continuing care through video calling and another that highlights the need for 2-way communication for continuation of care. The *Results* section details these themes after presenting demographic data on the participants.

Textbox 1. Example data extract from the interview with participant 7 (Gloria) and codes associated with the extract.

Data extract

- RMK: How do you think going on the video calls helps with that?
- Gloria: I don't really know that it does help him, but it certainly helps me because I'm reassured seeing that he's all right or not too bad. And I have noticed particularly, if I don't see him, if the video call doesn't come about, then I go in [to see him] and I go, "Oh, he's gone downhill." So, it's more noticeable that way. It's very, very lonely for him being in there, he's really not communicating with other residents because of the PSP. So, he's just either stuck in his room or sitting, looking out of the window in the lounge areas.

Codes

- Feeling reassured by video calls
- Importance of visual information and seeing the resident
- Concern about resident decline
- Resident loneliness
- Communication impairment
- Family members are concerned for residents' emotional well-being

Results

Participant Characteristics

We recruited a total of 18 participants (n=15, 83% women and n=3, 17% men) between the ages of 20 and 76 (mean 48, SD 17.3) years. Table 1 lists the participants using pseudonyms along with the relatives they discussed and the technologies they used for the video calls.

Of the 18 participants, 17 (94%) participants lived in Australia, in the state of Victoria, and 1 (6%) participant (Margaret in Table 1) lived in New Zealand but was an expatriate who used video calling to contact her parents in an Australian care home. All had experience living under lockdown conditions in their respective places of residence.

Participants discussed using video calls with a total of 22 relatives, all of whom lived in residential aged care. Of the 22 relatives, 17 (77%) were living in Australia, and 5 (23%) were living in care homes abroad (n=2, 40% in the United States; n=2, 40% in Japan; and n=1, 20% in Italy). The relatives' ages ranged from 69 to 98 (mean 84, SD 7.3) years. Of the 22 relatives, 18 (82%) were described as having at least one health condition or impairment that affected their use of video calls (Table 1). All the relatives had endured periods of lockdown or isolation at the care homes in which they lived.

All participants had been using video calling with their relatives living in aged care during the pandemic. However, video calling was a new activity for 44% (8/18) of the participants. These individuals had previously visited their relatives in person but turned to video calls during the lockdowns. The remaining 56% (10/18) of the participants had some previous experience using video calling with their relatives in care before the emergence of COVID-19 but became solely reliant on the technology during lockdown periods.

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Table 1. Participant characteristics and details of the relatives they discussed. All names are pseudonyms.

Pseudonym	Gender	Relative or relatives discussed	Relative's age (years)	Relative's impairments affecting use of video calls	Video calling software used	Video calling hardware used
Alison[a]	Woman	Mother	80	Advanced dementia	Zoom	iPad
Ben[b]	Man	Father	83	N/A[c]	Facebook Messenger	Kindle Fire
Charmaine	Woman	Father	75	PSP[d], nonverbal, and slightly deaf	FaceTime and Zoom	Laptop and smartphone
Deborah[b]	Woman	Mother	86	Advanced dementia	Zoom	iPad
Elaine	Woman	Father	69	Left-side paralysis because of stroke	Facebook Messenger	Laptop
Fiona[b]	Woman	Mother	78	Moderate dementia	Facebook Messenger	Smartphone
Gloria[a]	Woman	Husband	82	PSP	Zoom	iPad
Hannah	Woman	Grandmother and grandfather (married)	75 and 84	Vision impairment and noticeable cognitive decline (grandmother)	WhatsApp	Smartphone
Irene[a]	Woman	Mother	90	Dementia	Zoom	iPad
Jackie[a]	Woman	Mother	88	Advanced dementia, nonverbal, and cannot use her hands	Zoom	iPad
Katherine[a]	Woman	Mother	98	Deafness and vision impairment	Zoom	Laptop, iPad, and smartphone
Luca[a]	Man	Father	90	Moderate dementia and frail with limited mobility	FaceTime	iPad and smartphone
Margaret	Woman	Mother and father	86 and 87	Dementia (mother) and cognitive impairment and memory problems (father)	Zoom	Laptop
Nicole[a]	Woman	Mother	92	Dementia, nonverbal, and limited mobility	Zoom and FaceTime	Laptop and smartphone
Olive	Woman	2 great-aunts	91 and 94	N/A	FaceTime and Facebook Messenger	Smartphone
Paul	Man	Grandmother	84	Deafness and rheumatoid arthritis	Zoom	iPad and smartphone
Quinn[b]	Woman	Grandmother and grandfather (married)	74 and 77	Deafness (grandmother)	Skype	Laptop
Robin[a]	Woman	Grandmother	87	Advanced dementia	FaceTime	iPad and smartphone

[a]Denotes that video calling was a new activity adopted only after the onset of the COVID-19 pandemic.

[b]Denotes that the participant's relative or relatives lived in an aged care facility outside Australia.

[c]N/A: not applicable.

[d]PSP: progressive supranuclear palsy.

Theme 1: Video Calls as Enabling the Continuation of Care

Summary

This theme responds to our initial question of how video calling was used by family members. The central idea developed through our analysis was that video calling enabled family members to continue participating in the care of their relatives during lockdowns. In other words, video calls provided a way to maintain some of the activities that typically occur during a face-to-face visit. Specifically, participants discussed using video calls for social enrichment and for monitoring residents' health—both of which would ordinarily take place in person. These uses can be interpreted as relevant to the provision of care—one is about providing social and emotional care, whereas the other is about monitoring physical and mental well-being. Both are about ensuring that the resident is being "cared for" in an appropriate way.

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"It's So Good to See Them": Using Video Calls to Continue Social Enrichment

The first aspect of continuing care was demonstrated through participants' descriptions of providing social enrichment when physical visits were not possible. These accounts were often couched in the need to prevent "decline." Gloria, for example, discussed the welfare of her husband, who had moved into care because of progressive supranuclear palsy. She said that her husband had become "very lonely" during the lockdowns. Therefore, video calling was her husband's primary source of social enrichment, and Gloria felt that there was a clear and noticeable impact on his well-being if video calls did not occur. Upon visiting him in person between lockdowns, she observed the following:

> *I have noticed particularly, if I don't see him, if the video call doesn't come about, then I go in [to see him] and I go, "Oh, he's gone downhill." So, it's more noticeable that way. It's very, very lonely for him being in there, he's really not communicating with other residents because of the PSP. So, he's just either stuck in his room or sitting, looking out of the window in the lounge areas.*

Participants described diverse uses of video calls for the continuation of social enrichment. In some cases, video calls were used for short "catch ups" and "chit-chat," which provided opportunities to share updates about happenings outside the care home, keeping the resident involved in family life. Other cases involved the use of video calls for in-depth relationship maintenance. Quinn described how Skype calls with her grandparents would typically last over an hour and would involve different activities:

> *I always use my laptop when we Skype and I share my screen when I want to show them something. It's always good to show them photos of everything while we are Skyping so that we can talk about them together. And we also watch videos together sometimes.*

Quinn's quote shows how video calls were used to mediate intergenerational activities that constitute an enriching social life and that would otherwise be impossible during lockdowns without using technology. Video calls were also used to continue with other events and social situations. Katherine described how, when it was her mother's birthday, she was able to visit the facility between lockdowns and use a video call to host a celebration with extended family members:

> *When it was her 98th birthday in June (2021), I took my laptop in...Then my brother and I had the laptop and we Zoomed my other brother. We had him sort of in the background, chatting away while we had a birthday cake and some of the staff came in with more cake.*

Although these findings reinforce the notion that video calls can support social connections between family members and care home residents [28,31,59-61], we interpret them as the continuation of care. That is, family members wanted residents to feel cared for and know that someone cares about them. This was reinforced by descriptions of the positive emotional outcomes that arose from video calls and how they benefited residents:

> *I have a four-year-old son, so I try to get him to say hello too, which always puts a smile on dad's face...then if I'm at home with my son, I can put him on and my husband and we can all say hello.* [Charmaine]

> *[Dad] would be happy and smile and be positive about having received our calls. It's good for him to see us and remember us, and to see my mother and talk to my mother and me and my brother.* [Luca]

"It's Important to Have My Own Sense of His Health": Using Video Calls to Continue Health Monitoring

The second aspect of continuing care involved family members using video to monitor the health of their relatives. Outside of a lockdown, such monitoring might naturally occur as part of a physical visit. The fact that this took place through video calls further evidences their use for continuation of care.

For participants such as Jackie, monitoring her mother's health was a key motivator for adopting video calls during lockdown. She felt that information from care staff was useful but not entirely sufficient, and she expressed a need to do "checking up" on her mother:

> *When we went into lockdown, we couldn't see how she was. She can't talk to us. Even though the nursing staff will give us some information, you still want a little bit of checking up, if you know what I mean? So we started to have Zoom meetings with her.*

Participants described making inferences about their relatives' health during video calls based on visual appearance and the tidiness of their living environment. These actions can be understood as constitutive of care given that they represent attempts to determine whether something is wrong and, hence, whether intervention is required. Olive described how she used video calls to check for what she called "signs of deterioration":

> *I'm attuned to looking for particular things. Have they done their hair? Have they done their nails? What's their environment like? Are they taking care of themselves? Are their clothes clean? Those kinds of things are very important to me. That's part of me knowing that they're in good health, because that's how they normally present themselves.*

A participant, Ben, provided a compelling example in which he used a video call to infer that his father had contracted COVID-19. His father had previously tested negative for the disease following an outbreak within his facility, but interactions during a video call convinced Ben that further action was required. The following extract reveals how Ben's intervention led to his father receiving treatment and emphasizes the role of the video call in making his assessment:

> *I noticed things were off in his voice. And I just kept asking him, "Are you okay?" And it finally led to me saying [to the staff], "I think you need to test him again." I just got the sense that he wasn't well. Based*

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> *on how he looked, how he was physically presenting on the video, as well as how he sounded. And don't take the audio too far on that one, because I think a lot of it came from his visual appearance. He just doesn't look well. They wound up finally having a closer look and he was eventually taken to the hospital and treated* [for COVID-19]

In addition to monitoring health and well-being, Ben's quote alludes to the role of video in enabling participants to advocate for care to be provided. In this case, Ben contacted the staff via telephone and requested additional care. Another participant, Fiona, described how video calls enabled discussions with other family members when monitoring the health of her mother, who was living with dementia:

> *Having the video is good, especially for her sake. I can see her health and how she's behaving. Because my brother will say, "Her memory's not good. She's kind of spacey," and it's one thing to say it, but then for me to actually see her and how she behaves, it's a lot easier.*

Here, Fiona used video to verify information obtained from other people—in this case, her brother—when maintaining an understanding of her mother's health. Video calls also provided the opportunity to speak with nursing staff at the care homes. Gloria described how she would often be able to speak to staff during the video calls. This helped relieve anxiety about her husband's well-being:

> *I can ask them questions about how he's been, "Is he depressed today? Because he has been quite depressed." And they can reassure me or say, "Look, talk to him for a few minutes."*

Using video calls in this manner helped participants alleviate feelings of anxiety and provided "peace of mind." For example, Olive told us that using video enabled her to feel reassured about her aunt's welfare when she could not visit:

> *I was able to physically see in the room, and I was able to make sure that she had the things that she needed. Now, she was fine, but the peace of mind it gave me that the room was clean, that her personal effects weren't being interfered with, that she had the basics...Those sorts of things are really important to me.*

These examples illustrate how video calls provided opportunities to continue care practices that would ordinarily be conducted face to face and that might have been difficult or impossible when in-person visits were restricted.

Theme 2: The Role of Video in Extending Care

This theme responds to our initial question of how video calling was beneficial to family members, that is, how specific qualities associated with using video calls contributed to the continuation of care. This means emphasizing the value that video calls add to care—not just how video calls contributed to the continuation of care but how they enhanced care as well.

"I Get to Speak to Her More Than Before": Video Calls Enabled Increased Frequency of Contact

The availability of video calling enabled some participants to contact their relatives more frequently after the pandemic began. Several participants (8/18, 44%) lived far from their relatives' care homes and, hence, incurred substantial costs when visiting. These participants described visiting once per week or several times per month before the lockdowns. The transition to video calling allowed these participants to "visit" more frequently than before. Olive, for example, commented on how the frequency of contact with her great-aunts had increased after the lockdowns and how it involved extended family members:

> *In terms of frequency, I would visit once a month on a Sunday [before the pandemic]. During COVID we would FaceTime once a week...That was done as a family, as well. We would have two- or three-way conference calls.*

Although face-to-face visits were still preferred, the ability to be in more frequent contact was important to those who were concerned about their relative's health. Ben, for example, valued the ability to pay more attention to his father when there was an outbreak of COVID-19 at his facility. However, some participants (2/18, 11%) mentioned that facilities had discontinued support for video calling when the lockdowns were lifted as they viewed it as nonessential. These individuals wished that video calling had continued so that they could maintain the increased frequency of contact. Gloria, for example, commented on the inconsistent availability of video calling at her husband's facility:

> *Once lockdown is over, that's the end of the video calls and it would be so much better if they could keep it going. And then, I could just touch base with him every day to see how he's going and he knows that I'm there and caring for him.*

This extract speaks to frequent contact as a means for families to convey the sense that the resident is being cared for. Although increasing the frequency of contact does not guarantee higher-quality interactions [62], our participants' experiences speak to the value of having a communication channel available and highlight the importance of being able to contact a family member during times of distress.

"It's Crucial for Us to See Him": Video Provided Access to Nonverbal Cues

Many participants' experiences stressed the importance of the visual layer associated with a video call. Being able to see the resident is a key differentiator between video and other communication technologies such as the telephone.

We interpreted participants' experiences as signaling the importance of nonverbal cues for the continuation of care. Such cues include gestures and body movements, facial cues such as lip and eye movements, and the tone of voice. Previous work has argued that nonverbal cues contribute to the "richness" of video calls and enhance feelings of social presence [30,57,63], which refers to the salience of the other person in the interaction [64]. Higher social presence is thought to promote a sense of togetherness when using video calls [18,59].

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Our analysis of participants' experiences suggested that transmitting nonverbal cues played other roles in providing care. First, nonverbal cues were crucial for participants whose relatives had severe communication impairments. These people emphasized that it was essential to *see* their relatives when communicating with them, which made video calling more helpful than modalities such as the telephone. As an example, Charmaine discussed how nonverbal cues were crucial for interacting with her father, who had become largely mute because of progressive supranuclear palsy. She said the following:

> *...he will mouth words, but he doesn't generally speak out loud and he has trouble finding his words. So we've really found that video conferencing works best so you can get the non-verbal cues.*

When asked to elaborate on what kinds of cues are important and how they help, Charmaine said that nonverbal cues were useful for the following:

> *...being able to see that he's thinking, because you can see where he's looking often...And I guess we're getting better at reading his body language too. He tends to nod, or shake his head, or mouth the words "no" or "yes," or he'll just shrug. We also prompt him to speak out loud which used to work more effectively than it does now. But sometimes he can come up with a sentence, and I'll put my hand up. So I'll use nonverbal cues as well, like putting my hand up [to show] that I can't hear.*

Charmaine's quote points to the role of eye gaze direction, speed of response, and body language when conversing with her father. It also reveals that the utility of nonverbal cues is bidirectional, with Charmaine using her own gestures to convey information back to her father. These interactions illustrate the complexities of communicating with people living in aged care and highlight the additional value that video-mediated exchanges brought during the lockdowns.

A second role of nonverbal cues was to support the conveyance of warmth and affection during emotive communication. Deborah recalled the importance of gestures when interacting with her mother, who has dementia:

> *Gesture communication is very important, especially being Italian. When on the video call, we send kisses to each other, not only at the end, but during the communication itself. I always try to smile to her, she recognizes it. Sometimes I sing songs to her. So it's not only verbal communication but many other things. I showed her a soft toy and she started laughing. It was funny, she reminded me of a little girl smiling to a doll. It works, somehow, I feel that she is there. She is in a connection with me, a member of the family again.*

The importance of nonverbal cues also came to the fore when discussing the widespread use of face masks during the pandemic. Several participants (6/18, 33%) were able to visit their relatives in between periods of lockdown, when bans on visitors were lifted temporarily. These visits required the use of face masks to comply with government regulations. Participants reported that masks made conversations difficult as they occlude facial cues that can underpin nonverbal communication. Masks also made it difficult for residents to understand what was being said, especially among those who were hard of hearing. The fact that video calls did not require masks was said to make conversations "closer to normal." For example, Elaine told us the following:

> *One difference between face to face and video is that we are not wearing our masks on video calls. When we go there we have to wear a mask in person. So we have these face shields, and that means it is more natural on video calls. It doesn't seem like there is so much of a barrier, even though we're not physically there, it just feels like a barrier, a perceived barrier, when we are wearing masks.*

Taken together, the availability of nonverbal cues can be seen as making a video call feel more like a physical visit compared with wearing a mask or using a modality such as the telephone.

Theme 3: Organizational Constraints Threatened the Continuation of Care Through Video Calling

This theme brings together organizational issues that negatively affected participants' use of video calling. Our interpretation is that these issues were problematic as they hampered participants' ability to enact continuation of care.

"There's Problems With the Connection There": Video Calling Was Hampered by Limited Technology Infrastructure

Consistent with prior work [33,34], the lack of high-quality technology infrastructure in care homes was a problem with video calls. Participants reported that their relative's aged care facility did not have reliable internet. This led to mixed experiences and unpredictable call quality. Margaret shared the following:

> *Some weeks, we'll have a beautiful conversation and it doesn't drop out at all. Then, more often, we'll have parts of the conversation where we freeze or they freeze. Sometimes they drop-off completely.*

These connectivity problems led to anxiety and stress for residents and sometimes caused them to think that they had "broken" the technology. Participants described having to spend time reassuring relatives in this situation and had to fix technical problems over the telephone. This was not always easy without the ability to visit in person.

In addition to the lack of stable connections, it became apparent that many homes had a limited pool of technologies available to support video calls. Katherine, for example, said that her mother's aged care home had "only one iPad for 63 families." This meant that video calls were sometimes cut short as the device was needed for other residents. In some cases, staff members tried to overcome this problem by loaning their personal devices to residents. However, it seemed that the loaning of devices further increased the likelihood of calls being cut short. Robin, who had been using video to see her

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grandmother, felt that this made some video calls "rushed and inauthentic." She said the following:

> *...the worst part is when they cut you off...if they use their personal phones, it's like, "Oh, sorry, I have to take this, there's something urgent I need the phone for."*

We interpret these experiences as limiting participants' ability to carry out actions relevant to continuing care. That is, poor connections and rushed calls impeded the ability to continue care by providing insufficient information about the residents' well-being.

"It Was Like Calling a Prison": Video Calls Had to Be Booked in Advance

A putative benefit of video calling is that family members can potentially make and receive calls at any time and at their own convenience. However, the interviews revealed that this benefit was not realized for all participants. Instead, the lack of technology in some homes meant that video calls had to be scheduled in advance. This was done using booking systems created from an assemblage of web-based calendars, email, and telephone. There were also cases where video calls were available only during restricted "visitation hours"—such as at fixed times in the morning, afternoon, and evening. This meant that participants had to schedule their days around these windows, and if they could not be available at the specific time, they were not able to see their relatives.

The need to schedule calls was a repeated source of frustration and became a barrier to continuing care. Nicole, for example, described it as "a pain" and wished video calls could be used similarly to telephone calls as "they [the home] allow you to ring anytime." The restrictions around call times, together with the lockdown conditions in care homes, were described as creating a "prison-like setup." Irene said that the following occurred during one of the lockdowns:

> *You could not ring anybody in the facility, nor the front desk. It was like a prison, they had one number you could ring and then you could organize something and so you would send an email and say, "Can I have the appointment to Zoom at this time?" And if that one worked, then we could say, "Same time tomorrow, please." And they'd pencil it in.*

Despite participants' attempts to work around the schedules imposed by the care homes, there were cases in which prearranged calls were late or failed to materialize, causing frustration. Gloria told us the following:

> *[the home] might set up a time, but they're never on time. So, you have to be available for, let's say, a frame of two hours. I keep telling myself, just be patient.*

Finally, there was considerable variation in the duration and frequency of calls. Gloria stated that one lockdown involved "two calls a week set up by the staff, but five-minute duration," whereas Alison said that calls lasted "half hour or a 15-minute session." These calls were the only source of outside social contact for the residents. Although these short calls may be better than no contact at all, they should raise questions about the adequacy of solutions provided during the pandemic and how these might be improved in the future.

"The Staff Are Flat Out Now": Staff Involvement Was Needed but Was Often Scarce

Consistent with prior work [36,37], participants raised the need for staff to sometimes assist residents with video calling. Staff were involved in making calls, manipulating the hardware and software, and fixing technical issues. Staff were seen as essential for supporting video calls with residents who had complex care needs, especially those living with dementia. In this case, staff were needed for actions such as directing the resident's attention to the call, explaining who the resident was talking to, and repeating phrases and words if residents could not hear the video call properly. However, staff were reported to be time-pressured and not always available to assist with these activities.

The need for staff involvement was especially challenging during the COVID-19 lockdowns because of staff shortages and outbreaks within the aged care sector [65]. Some participants (5/18, 28%) felt that staff turnover was a problem that affected video calling. These individuals had developed co-operative relationships with specific staff members. Video calls were reported to be difficult or impossible when these staff members were absent. For example, Ben said the following:

> *Like most aged care facilities, they're at their capacity to provide health assistance. And so it took a while to identify a couple of the nursing staff who both are willing and can find the time to actually help him do calls. And so far, the only ones we've been able to do is when I'm calling him and they answer for him.*

Theme 4: Successful Continuation of Care Required 2-Way Communication

This final theme highlights 2 issues that further impeded continuation of care but that focus on the need for the people in aged care to be able to use and respond to video calls.

"She Was Never What You Would Call Tech-Savvy": Some Residents Were Unfamiliar With Video Calls

Some participants (6/18, 33%) stated that their relatives in care were unfamiliar with video calls and had received no training on how to use them. This was a challenge as their relatives did not know how to operate the software and hardware independently, meaning that calls failed to happen or went unanswered.

Participants also mentioned that their relatives did not always understand the concept of positioning oneself in the camera feed. This led to situations in which the participants saw their relatives from awkward angles or without their faces in the frame. Gloria said that her husband did not understand how to manipulate the iPad provided to him at the care home. She recounted the following:

> *[He] just never had anything to do with computers or really technology at all. He didn't get the concept that you can see yourself on the screen if you've got it aimed correctly. That made it rather difficult.*

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To overcome this problem, Gloria and other participants noted that staff involvement was needed. However, as noted previously, this was not always possible. She said the following:

> *[The staff often] go away and leave him, and I would end up looking at the ceiling because the iPad would fall over or something like that, and all I could see was the ceiling.*

This challenge can be interpreted as further affecting participants' ability to continue care, especially in monitoring health. This is because the underlying concern relates to acquiring visual cues; when the camera is not angled correctly, it becomes impossible to make inferences about the residents' welfare.

"For Her, This Could Be a Broken Mirror": Residents' Health Conditions Make Video Calls Challenging

Many people in aged care are living with profound health challenges, some of which precipitate their move into care [66,67]. Participants reported that residents' health problems affected their ability to participate in video calls, often because commercial systems are ill-suited to the aged care setting [35] and require adaptation to be successful [61].

For example, Paul discussed how his grandmother had arthritis in her hands, making it difficult for her to use computers for video calls. To overcome this issue, Paul and his family purchased a large-screen smartphone and "jacked up the size of the keyboard" to make the device more usable for her.

More challenging cases were reported by participants whose relatives had moderate or advanced dementia. Some (4/18, 22%) stated that, although video calls were valuable for checking on their relative's well-being, the conversation was limited as the relative did not fully understand the nature of video calling technology. Our first participant, Alison, had been using video calls to see her mother but decided to abandon them as her mother could no longer comprehend what was happening. She said the following:

> *Sadly, because my mum had dementia, she couldn't actually use the technology. It didn't work for her, so we essentially got cut off from her for 18 months. In that way, they made it an option, but it wasn't an option for someone with [advanced] dementia.*

When asked to elaborate on why the technology "didn't work," Alison discussed how her mother became confused when seeing an image of herself on screen, which is a common feature of video calling applications such as Skype and Zoom. Alison said the following:

> *My mother couldn't understand what was going on. She wouldn't interact with it. She wouldn't look at the screen. If she saw herself on it, she'd just be staring and trying to figure out who that person was. She was better at engaging in person.*

This example highlights that, although family members may still obtain some benefits from seeing relatives through a video feed, different approaches may be required to enable families to continue seeing residents who have advanced care needs during times of social distancing.

Discussion

Principal Findings

This study aimed to understand family members' uses of video calling during lockdown restrictions in aged care. The main finding of our analysis was that video calling became a medium for family members to enact the continuation of care during lockdown restrictions. Although participants' experiences of video calling were complex and multifaceted, there was an underlying goal of using the technology to continue care and ensure that care was provided. However, the use of video calls was affected by organizational constraints and the need for 2-way communication with relatives, which was often difficult. These findings contribute to an improved understanding of why video calls were valued during the pandemic lockdowns and extend the knowledge of the challenges that families encountered [33].

Previous research on the use of video calls in aged care has focused primarily on the potential to support social interaction and the technological barriers that can affect their use. Our study is the first to suggest that video calling systems are used for the continuation of care when families cannot visit the facility. This interpretation moves beyond existing characterizations of video as a tool for social connectedness [27] to one in which video calls are used to continue care practices when physical visits are restricted. Many of the activities conducted by participants in this study, including relational maintenance and health monitoring, align with the findings of ethnographic studies on the coordinated work of families in care homes [67]. Our analysis suggests that, when video calls were used to replace in-person visits, they became a modality for families to continue these contributions to care. However, they can also enable new kinds of interactions, such as sharing digital content over distance and supporting meetings with extended family. This speaks to the potential for video to enrich caregiving in ways that go beyond what is possible in a face-to-face visit.

This study also suggests that video calling supports family members' own peace of mind. The COVID-19 pandemic was an extremely stressful time for families, and it has been suggested that the inability to visit during lockdowns produced feelings of helplessness and anxiety [9]. Concerns about residents' health may have been especially salient given the high rates of mortality in aged care [65], leading family members to request more frequent updates about residents' welfare [11,68]. However, video calling can convey information that provides peace of mind without placing additional burden on staff members to provide such information. This raises the importance of video calling from a platform of conversation to one that can enhance care in multiple ways, emphasizing the need to improve provision of video calls and develop solutions that are better suited to the aged care context. Our findings highlight the urgent need for video calls to be seen within the aged care sector not just as a secondary means of providing social support but also as a vital tool that allows families to contribute to the ongoing care of their loved ones.

In addition to continuing care, our analysis indicates that video calling can enhance family members' caring practices when

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forced to see their relatives from a distance. When video calling worked well, participants were able to have more frequent contact than before and were able to access nonverbal cues that were essential for communicating with residents who had impairments. This finding is important as, in some countries, care homes are mandated to provide telephone communication with relatives [13], but video calling is an optional extra. Providing better support for video calling can help families whose relatives have hearing and speech impairments and who depend on gestures and lip movements to understand what is being said. This also speaks to the value of supporting video calling outside of lockdown periods for family members who cannot easily visit the care home [28,58].

Finally, our analysis identified that the continuation of care through video calling was impeded by multiple challenges. One problem relates to the constraints of the aged care context, where homes are often underresourced and understaffed [67]. This was especially challenging during the pandemic [65] and influenced the quality, reliability, and length of video calls. Residents' unfamiliarity with video calling and their health problems were additional barriers that affected the success of video calls [35,37]. Given the important role that video calls can play in the continuation of care, addressing these challenges can no longer be seen as a secondary concern that is relegated to the periphery of lifestyle programs but must be seen as central to supporting the ongoing welfare of aged care residents.

Comparison With Prior Work

The notion of video calling as a medium for the continuation of care aligns with ideas from early studies that used videophones, which were a primitive form of video calling technology. Demiris et al [60] suggested that videophones could support "distant caregiving." Our work substantiates and adds weight to this claim by showing how the high-fidelity feeds of modern systems can be used in the practice of continuing care. We also emphasize the ability of video to support caregiving during periods of lockdown, which may become more common in the future if COVID-19 becomes endemic [22] and because of seasonal variation in other viral diseases [69].

The challenges identified in this study align with findings of previous trials of video calling in aged care. Examples include limited technology literacy among some residents, low device accessibility, poor Wi-Fi, the lack of devices in care homes, and the need for staff to help with video calls [30,34,35]. In addition, our findings resonate with a study conducted in Canada during the COVID-19 pandemic [33]. Similar to our work, the Canadian study found that care homes had very few devices to facilitate video calls, that video calls were often missed and late, and that staff lacked time to help with facilitation [33]. Taken together, these findings suggest that there are systemic issues in aged care that need to be addressed to better support video calls and the crucial role they play when in-person visits are not possible.

A novel finding of this study was that resource constraints required care homes and families to coordinate call times using booking systems, which may have also helped ensure fair and equitable access to limited devices. However, this coordination was effortful for family members and led to unsatisfying interactions when calls were late or missed. It is likely that this issue was not documented in previous studies as they did not examine the use of video calling during periods of lockdown. This addition to the literature is important as it reveals a negative experience for families and residents that should be avoided during future lockdowns in care homes.

Implications for Video Calling in Aged Care

This study highlights that ongoing support for video calling in aged care is essential. We argue that video calling should, therefore, be elevated to the status of critical infrastructure given its potential to enable the continuation of care and mitigate the negative consequences of enforced isolation.

However, video calling needs more infrastructural support in care homes. It must be recognized that social connection is an essential human right and must be supported as a basic activity. Policy makers should recognize that staff may need additional time to assist with video calling. Better resourcing is needed for technologies that can be shared among residents at times when face-to-face visits are not possible, and aged care workers should not have to use their own devices to support the social well-being of residents.

The problem of coordinating video calls between families and residents should also receive attention in terms of improving residents' freedom to make and receive calls during lockdown. If video calls are used at times when in-person visits are prohibited, there is a need for care providers to consider ways of ensuring that calls can happen on a regular basis and to support interactions that go beyond mere glimpses of the resident. Although short video calls may be better than no contact at all, they are unlikely to constitute sufficient social contact and can create anxiety among families. This can also be seen as an equity issue in that being able to see a loved one should be a right, not a privilege.

Improving the design of video calling systems for aged care can also help lower the burden placed on staff when it comes to administering and running video calls. Our findings reiterate that commercial video calling systems can be hard to use for care home residents [35,59]. To provide a suitable user experience, future designs should aim for the ease of use, learnability, and accessibility of software, especially for those with dexterity impairments [70,71]. Video calling hardware could also be made more suitable for aged care, such as by using physical stands or supports that enable residents to maneuver the video calling device into a comfortable position without needing substantial involvement from caregivers [61]. An ideal video calling system for aged care would be accessible and support independent use, incorporating software that is easy to understand and hardware that can be positioned according to the resident's needs. This, in turn, would reduce the need for staff involvement.

Strengths and Limitations of This Study

This study has 2 main strengths. First, our analysis is grounded in real-world experiences of video calling deployment during lockdowns. This is different from most previous studies, which typically involved participants who were given a technology to trial by a research team [28,31,32,66]. Our findings reflect the

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experiences of families and care homes who had to manage the technology by themselves during unexpected and indeterminate periods of lockdown, evidencing the issues that arise in this situation.

The second strength of this study lies in our focus on close family members, many of whom played an important role in caring for their relatives. Previous studies have often been designed to test the feasibility of using video calls to initiate connections with family members who do not typically visit the home (eg, distant grandchildren who play no substantial caring role [28]). Our work expands the scope of the literature to provide an understanding of why video calls are valuable to family members who play considerable caring roles.

The main limitations of this study are 2-fold. First, the focus on family members does mean that we excluded the views of aged care residents and staff on video calling during periods of lockdown. We were not able to interview these groups as care facilities were inaccessible during data collection. Future research should address this gap. Second, this study focused solely on the experiences of people living in Australia and New Zealand. Aged care systems in other countries may have procedures in place to better support video calling during lockdowns, although as we have noted, a Canadian study highlighted similar concerns [33]. Future studies that compare video call experiences in diverse aged care contexts and in other countries are warranted.

Finally, trustworthiness is an important consideration when evaluating the credibility of qualitative research [58], but there is an open question as to what makes RTA trustworthy. We consider our analysis trustworthy as it matches well with guidance for producing trustworthy thematic analysis [57] and for high-quality reflexive analysis [45]. Examples of practices that evidence trustworthiness in our approach include a clear rationale for using RTA [45], prolonged engagement with the data [72], and full disclosure of our analytic process [57] (Multimedia Appendix 2). To improve our practice in the future, we recommend using a reflexive journal to document the analytic process [73] and create an audit trail [57].

Conclusions

This study investigated how family members used video calls with older adults in residential aged care during lockdowns arising from the COVID-19 pandemic. Overall, our findings suggest that video calls were used by family members to continue care practices at times when face-to-face visits were not possible. Families were able to provide social enrichment and monitor the residents' health and well-being, which they could then use to ensure continuity of care. Video calls extended care by enabling frequent contact and were crucial for those who were reliant on nonverbal cues for communication, sometimes making them preferable to physical visits in which masks were required.

However, this study shows that family members' ability to engage in the continuation of care was hampered by organizational issues, particularly the lack of digital technology in aged care. Although this can be partly attributed to the speed at which care homes needed to adapt and to the loss of staff during the pandemic, the situation revealed the paucity of support for video calling in many care homes. If video calls are to be used to mitigate social isolation arising from infection control measures, there is an urgent need for better provision of technology and improvement of infrastructure to enable calling. There may also be a need to allow for staff to support video calling, especially for residents who cannot operate the technology independently.

To conclude, our findings emphasize that governments and aged care providers should fully support the implementation of video calls between residents and their family members during times when social distancing is required. This study also reiterates the need for video calling solutions that are better suited to aged care such that families can remain connected with residents even when they are forced to be physically apart.

Acknowledgments

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Data Availability

The data sets generated and analyzed during this study are not publicly available as ethics approval was not given for the data to be made public. Requests to access the data sets should be directed to RMK. The data may be made available upon reasonable request.

Authors' Contributions

RMK and JW conceived and designed the study. RMK collected the data and conducted data analysis. RMK drafted the manuscript. YX, SB, and JW provided comments, edits, and suggestions. RMK revised the manuscript in response to reviewers' comments. SB, YX, and JW provided feedback and made additional revisions. All authors provided input for the final version of the manuscript.

Conflicts of Interest

None declared.

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Multimedia Appendix 1
Interview questions used in the study.
[DOC File , 31 KB - aging_v6i1e40953_app1.doc]

Multimedia Appendix 2
List of techniques used to establish trustworthiness in our analysis based on the Means of Establishing Trustworthiness by Nowell et al [57].
[DOCX File , 17 KB - aging_v6i1e40953_app2.docx]

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Abbreviations

RTA: reflexive thematic analysis

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Original Paper

Within-Person Associations of Accelerometer-Assessed Physical Activity With Time-Varying Determinants in Older Adults: Time-Based Ecological Momentary Assessment Study

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Abstract

Background: Despite the availability of physical activity (PA) interventions, many older adults are still not active enough. This might be partially explained by the often-limited effects of PA interventions. In general, health behavior change interventions often do not focus on contextual and time-varying determinants, which may limit their effectiveness. However, before the dynamic tailoring of interventions can be developed, one should know which time-dependent determinants are associated with PA and how strong these associations are.

Objective: The aim of this study was to examine within-person associations between multiple determinants of the capability, opportunity, motivation, and behavior framework assessed using Ecological Momentary Assessment (EMA) and accelerometer-assessed light PA, moderate to vigorous PA, and total PA performed at 15, 30, 60, and 120 minutes after the EMA trigger.

Methods: Observational data were collected from 64 healthy older adults (36/64, 56% men; mean age 72.1, SD 5.6 y). Participants were asked to answer a time-based EMA questionnaire 6 times per day that assessed emotions (ie, relaxation, satisfaction, irritation, and feeling down), the physical complaint fatigue, intention, intention, and self-efficacy. An Axivity AX3 was wrist worn to capture the participants' PA. Multilevel regression analyses in R were performed to examine these within-person associations.

Results: Irritation, feeling down, intention, and self-efficacy were positively associated with subsequent light PA or moderate to vigorous PA at 15, 30, 60, or 120 minutes after the trigger, whereas relaxation, satisfaction, and fatigue were negatively associated.

Conclusions: Multiple associations were observed in this study. This knowledge in combination with the time dependency of the determinants is valuable information for future interventions so that suggestions to be active can be provided when the older adult is most receptive.

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KEYWORDS

ecological momentary assessment; EMA; associations; emotions; physical concerns; intention; self-efficacy; older adult; mobile phone

Introduction

Over the years, the World Health Organization has established and updated physical activity (PA) guidelines. Currently, the recommendation for older adults is to perform at least 150 to 300 minutes of moderate PA, at least 75 to 150 minutes of vigorous PA, or an equivalent combination of both throughout the week [1]. The level of PA typically decreases with age, and this decrease is associated with a decline in functional fitness [2,3], which in turn has negative consequences for healthy aging. Despite the awareness of the PA guidelines and the availability of PA interventions, meeting these guidelines is a challenge for many older adults: they are the least active age group compared with the other age groups [3,4].

Many PA interventions often have limited or only short-term health effects [5,6], which might be partly explained by the fact that the behavioral determinants of PA have been considered relatively stable over time and contexts. In real life, determinants are not stable but vary over time and depend on contextual factors [7]. For example, an individual might have the intention to go for a walk, but during the day, their back starts to hurt, and as a result, their intention to be active changes and they might choose to stay at home and read a book instead. Such contextual and time-varying variables are not usually the focus of PA interventions. Recently, more attention has been drawn to the dynamic aspects of behavioral determinants [8-10]. Current technology (eg, smartphones) provides easy opportunities to monitor individuals more frequently and continuously and consequently could help tailor interventions to the constantly changing determinants of individuals. However, before dynamic tailoring of interventions can be developed, one should know which time- and context-dependent determinants are associated with PA and how strong these associations are. Thus, the most influential determinants can be targeted or incorporated into eHealth and mobile health (mHealth) [11] interventions to promote PA more effectively and achieve long-term health benefits.

Ecological Momentary Assessment (EMA), also known as the Experience Sampling Method or Ambulatory Assessment, is a method with high potential to assess the time- and context-dependent fluctuations in determinants. EMA captures real-time data at multiple points in time in an individual's natural environment and facilitates the examination of short-term changes in, for example, emotions, temporal dynamics, and the effects of specific contexts [7]. Guidance from theoretical frameworks is needed to decide which determinants to examine [12]. Although many theoretical frameworks can be used as dynamic frameworks to interpret behavioral determinants as time and context dependent, studies are often not designed in this manner. In this study, the capability, opportunity, motivation, and behavior (COM-B) framework was used to identify the behavioral determinants of PA and develop an EMA questionnaire. The COM-B framework consists of 3 constructs: capability, opportunity, and motivation. Capability is the psychological or physical ability of a person to enact the health behavior, which can include physical complaints such as fatigue. Opportunity comprises the physical and social environment that enables behavior, but this component was not assessed in this study. Finally, motivation contains the reflective and automatic mechanisms that activate or inhibit behavior including, for example, emotions, intention, and self-efficacy. Capability and opportunity can both influence motivation. Furthermore, capability, opportunity, and motivation can influence health behavior, but performing a certain behavior (eg, PA) can also alter these 3 constructs [13]. By identifying the time- and context-dependent variations of determinants and by examining their influence on subsequent PA, future eHealth and mHealth interventions such as just-in-time adaptive interventions (JITAIs) can take the individuals' emotional, cognitive, and physical momentary states into account to determine the "right" time to stimulate individuals to be active [14]. For example, the intervention can be programmed to provide suggestions to be active (eg, take a short walk) through a smartphone app when the intention to be active is high, and there are no physical complaints (eg, absence of pain).

The knowledge of which determinants are influential and how strong their influence is essential to target these dynamic determinants in eHealth and mHealth interventions. In the research field of PA, some research has been conducted to examine the associations of determinants with subsequent PA using EMA, but most studies have been conducted in children [15], adolescents [16,17], and adults [18-21]. To our knowledge, only a few studies have been conducted in older adults [22-24]. These were mainly focused on interrupting subsequent sedentary behavior or studies in which PA was self-reported. For example, intention to stand and move as well as self-efficacy beliefs about one's ability to stand or move predicted increases in the subsequent time spent upright in the 2 hours following the EMA trigger. Furthermore, intentions to limit time spent sitting as well as self-efficacy beliefs about one's ability to limit time spent sitting resulted in more time spent upright in the subsequent 2 hours in older adults [22]. Another study found that greater levels of self-reported energy led to more time standing and stepping in the subsequent 15 and 30 minutes after the EMA trigger [23]. However, no associations between positive and negative affect with subsequent standing or stepping were found [23]. Dunton et al [24] found that greater self-efficacy and positive affect predicted higher levels of subsequent self-reported PA, whereas greater negative affect predicted lower levels of subsequent self-reported PA. In the same study, fatigue was unrelated to subsequent PA [24]. Therefore, although a few studies have examined the association of determinants with subsequent standing and stepping or subsequent self-reported PA, research examining the associations of time-dependent determinants with accelerometer-assessed subsequent PA in older adults is lacking.

The aim of this study was to examine predictive within-person associations between multiple determinants of the capability

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and motivation components of the COM-B framework (ie, emotions, physical complaints, intention, and self-efficacy) that were assessed using time-based EMA and subsequent accelerometer-assessed PA. Specifically, the study examined within-person associations with light PA (LPA), moderate to vigorous PA (MVPA), and total PA (TPA) performed in the 15, 30, 60, and 120 minutes after the EMA trigger. Various time frames were selected to capture the acute temporal nature of the associations and to examine whether the associations differed or changed depending on the time frame. On the basis of the results of previous research in adults [19-21] and previous research on motivators and barriers to PA [25], we hypothesized that the positive emotions, intention, and self-efficacy are positively related to subsequent PA, whereas negative emotions and physical complaints are negatively associated with subsequent PA. By exploring these predictive within-person associations, we aimed to identify important time-dependent determinants that should be targeted in future JITAIs to more effectively promote PA in older adults. The target population of this study was older adults. As the importance of psychosocial factors (eg, motivation) differs depending on age [26-28], it might be possible that different psychosocial determinants concerning PA are important for different age groups. Consequently, the associations between these individual-level determinants may differ between age groups. In addition, the activity radius of older adults is limited compared with other age groups; therefore, they presumably have a limited number of contexts in which they interact. Furthermore, older adults often have a more flexible day schedule (because most of them are retired) and they are a crucial age group to target in health interventions during this time of increased life expectancy and "healthy aging." All these aspects make them a very appropriate target group to receive "in-the-moment" interventions.

Methods

Participants

This study was conducted in Belgium. Healthy older adults (aged ≥65 y) were recruited between November 2019 and March 2020 using convenience sampling (ie, flyers on social media and contacting associations for older adults). Self-reported exclusion criteria were (1) impaired cognition (ie, diagnosed with dementia and Alzheimer or other cognitive diseases), (2) severe impairment of vision and hearing, (3) inability to walk 100 m and stand or sit independently, (4) impairment of fine motor skills, and (5) insufficient knowledge of the Dutch language.

Procedures

The Checklist for Reporting EMA Studies reporting guidelines proposed by Liao et al [29] were used to describe this EMA study. Participants were visited twice at home. During the first visit, informed consent was signed; sociodemographics (ie, sex; age; BMI; educational level, ie, nontertiary education—none, primary education, or secondary education—and tertiary education—higher education or university education), main occupation before retirement, marital status, having children and grandchildren were collected through a paper-based questionnaire; and instructions for the measurement period were given. In addition, the EMA app was installed on the participants' smartphones, followed by a brief training on how to use it (ie, opening the app and answering the EMA questionnaires) by providing printed screenshots of the app. The visit was followed by one monitoring period of 7 consecutive days, consisting of 5 weekdays and 2 weekend days, although not all participants started the measurement period on the same day of the week. During this measurement period, participants were asked to answer 6 EMA questionnaires per day using a smartphone app and to wear an Axivity AX3 accelerometer to monitor their PA. After these 7 days, a second home visit was performed, during which the measurement materials were reassembled.

Ethics Approval

Ethics approval was obtained from the Ghent University Hospital Ethics Committee before the start of the study (2019/0192).

EMA Protocol

The Smartphone EMA^3 (SEMA^3) app is a suite of software for intensive longitudinal survey research that can be used on iOS and Android smartphones [30]. The SEMA^3 app triggered 6 time-based EMA questionnaires per day, between 9 AM and 10 PM, for 7 consecutive days (ie, the participants were required to answer 42 questionnaires in total). Each EMA questionnaire was randomly triggered within a predefined time frame of 1 hour (eg, the time frame from 9 AM to 10 AM, in which the EMA trigger randomly appeared at 9:38 AM). In total, 6 time frames were predefined per day. If the participants did not respond to the initial trigger, 2 reminders were given after approximately 5 minutes and 10 minutes; 20 minutes after the initial trigger, the questionnaire was unavailable until the next scheduled trigger. Participants were asked to use their own smartphone during the measurement period (the lowest acceptable operating systems were Android 5.0 and iOS 12.4), but participants who did not own a smartphone were provided with a Wiko Lenny 3 smartphone (Android 6.0).

EMA Questionnaire

The COM-B framework was used as a guiding framework to compile the first version of the questionnaire from items previously used in research [31-33]. Experts in psychology, health sciences, and EMA were involved at multiple stages in the development of the EMA questionnaire. Subsequently, cognitive interviews were conducted with 10 older adults, which led to further adjustments of the questionnaire, mainly concerning the comprehensibility of the items. The final version of the EMA questionnaire assessed the following components in this fixed order: emotions, physical complaints, and the constructs' intention and self-efficacy. However, the order of the questions within the components' emotions and physical complaints was randomized and therefore could change over the EMA triggers. In total, the EMA questionnaire consisted of 18 items [34]. However, based on the results of a previous analysis of the same EMA data [34], only those determinants with more within-subject variation (>50%) than between-subject variation were selected for this study. Consequently, only 7 items of the EMA questionnaire were analyzed in this study:

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relaxation, satisfaction, irritation, feeling down, fatigue, intention, and self-efficacy. The items for the emotions relaxation, satisfaction, irritation, and feeling down were originally developed by the research group of Philippe Delespaul at the University of Maastricht [31]. The item for physical complaint fatigue was selected from the validated Patient Health Questionnaire-15 [32]. Finally, the items assessing intention and self-efficacy toward PA were based on items that are frequently used in our research group [33] but were specifically adapted by the authors for this EMA study. All items were assessed on a 7-point Likert scale and were presented in Dutch (their English translation is available in Multimedia Appendix 1).

Axivity AX3 Accelerometer

To capture participants' PA, all participants wore an Axivity AX3 accelerometer on their nondominant wrist during the same 7 consecutive days as the time-based EMA. The Axivity AX3 accelerometer is a reliable and valid device for measuring PA [35]. Participants were instructed to wear the accelerometer during the whole day and night and to remove the accelerometer only during water-based activities. Data were extracted using the OMGUI software (Open Movement) [36] and then processed in R (version 4.0.1; R Foundation for Statistical Computing) [37]. The raw data downloaded from Axivity AX3 were first reduced by averaging the Euclidean norm minus one values (in milligravitational units, ie, mg) over 1-second epochs and then 1-minute epochs, after which cut points for older adults by Sanders et al [38] were applied to categorize individual minutes as sedentary (≤57 mg), LPA (57-104 mg), or MVPA (≥104 mg). The total number of LPA and MVPA minutes was calculated for the time frames of 15, 30, 60, and 120 minutes after the trigger. In addition, the total number of TPA minutes was obtained for these time frames by summing LPA and MVPA minutes.

Analyses

Multilevel regression analyses were performed using the lme4 package [39] in R [37]. Residuals were plotted and visually inspected to check for linearity and normality assumptions. Because the PA data in the 4 time frames after the EMA trigger (ie, 15, 30, 60, and 120 min) included an excessive number of "true" null values (ie, not all participants were physically active during all time frames), Hurdle models [40,41] were fitted. The Hurdle models consist of 2 parts: a logistic regression model, estimating the odds of engaging in PA after the EMA trigger, and a linear model, estimating associations with the amount of PA among those who performed at least some PA at 15, 30, 60, and 120 minutes after the EMA trigger. First, the logistic regression model was applied, for which all PA variables were recoded into dichotomous variables (ie, 0 vs at least 1 min of LPA, MVPA, and TPA, respectively). For each determinant, a separate model was created with each PA variable (ie, LPA, MVPA, and TPA in the 4 different time frames) as an outcome variable, which led to 84 models in total (ie, 7 determinants × 3 PA outcome variables × 4 time frames). Further model assumptions were visually checked (ie, outliers and influential observations). Second, to construct the linear model, 3 different models were applied to the original PA values for each determinant separately to check which model best fitted the data (ie, Gaussian, Poisson, and negative binomial). The models were fitted separately for each determinant and each PA outcome. Of these 3 models, the model with the lowest Akaike information criterion value indicating a better model fit was chosen. The Akaike information criterion was, in all cases, the lowest for the negative binomial model; therefore, the negative binomial was applied in all cases. The models were fitted for each determinant as between-subject (ie, mean of the variable at the subject level) as well as within-subject (ie, individuals' score minus their mean score), but only the within-subject associations were considered in this study. In addition, for the linear models, further model assumptions were visually checked (ie, homoscedasticity, outliers, and influential observations). The level of significance was set at $\alpha<.05$. To limit the number of results for this study, all results for TPA can be found in Multimedia Appendices 2-4.

Results

Descriptive Statistics

In total, 67 older adults participated in this study. All participants completed the measurement period of 7 days. To be included in the analysis, participants had to respond to at least one-third of all triggers (ie, 14 out of 42). As a result, data from 3 participants were excluded, and 64 participants were included in the analysis. Their descriptive statistics are presented in Table 1. In total, 11 participants used a Wiko Lenny 3 smartphone because they did not have a smartphone of their own.

A total of 2690 triggers were sent during the study, of which 30 were not delivered as intended because of technical issues (ie, more than 6 triggers a day were sent or triggers were sent outside the predefined time frames, eg, during the night) and were excluded from the analysis. Of the remaining 2660 triggers, 2057 EMA questionnaires were completed (response rate of 2057/2660, 77.33% and a mean of 32.1 completed questionnaires per participant). The median response latency was 0.00 (quarter 1=0.00, quarter 3=4.00) minutes. The median time needed to complete the EMA questionnaire was 1.79 (quarter 1=1.43, quarter 3=2.31) minutes. Descriptive statistics for LPA and MVPA are presented in Table 2, and those for the EMA items are presented in Table 3.

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Table 1. Descriptive statistics of the study sample (N=64).

Demographics	Values
Sex (male), n (%)	36 (56)
Age (y), mean (SD; range)	72.1 (5.9; 65-86)
BMI (kg/m^2), mean (SD; range)	25.6 (4.1; 15.2-36.0)
Nontertiary education, n (%)	37 (58)
Main occupation before retirement, n (%)	
Household	3 (5)
Blue collar worker[a]	23 (36)
White collar worker[b]	34 (53)
Other	4 (6)
Marital status, n (%)	
Single	2 (3)
Married or living together	54 (84)
Divorced	2 (3)
Widow or widower	6 (9)

[a]Self-employed and worker.

[b]Employee, education, executives, free professions, and officer.

Table 2. Descriptive statistics of the physical activity (PA) data for light PA (LPA) and moderate to vigorous PA (MVPA) in the 15, 30, 60, and 120 minutes after the trigger.

	Active min, mean (SD)	Active min, median (range)	Quarter 1-quarter 3	Percentage of people who did not perform any PA
LPA (min after trigger)				
15	1.8 (2.6)	0.0 (0.0-15.0)	0.0-3.0	51.6
30	3.4 (4.5)	2.0 (0.0-27.0)	0.0-5.0	37.5
60	6.8 (7.9)	4.0 (0.0-55.0)	1.0-10.0	21.9
120	13.0 (13.3)	9.0 (0.0-88.0)	3.0-19.0	9.8
MVPA (min after trigger)				
15	0.6 (1.8)	0.0 (0.0-15.0)	0.0-0.0	80.8
30	1.3 (3.3)	0.0 (0.0-27.0)	0.0-1.0	70.8
60	2.4 (5.6)	0.0 (0.0-53.0)	0.0-2.0	58.3
120	4.5 (9.3)	1.0 (0.0-95.0)	0.0-4.0	43.5

Table 3. Descriptive statistics of the Ecological Momentary Assessment items[a].

Item	Score, mean (SD)	Score, median	Quarter 1-quarter 3
Relaxation	4.7 (1.5)	5.0	4.0-5.0
Satisfaction	4.8 (1.4)	5.0	4.0-6.0
Irritation	1.5 (1.0)	1.0	1.0-1.0
Feeling down	1.3 (0.8)	1.0	1.0-1.0
Fatigue	1.9 (1.1)	1.0	1.0-3.0
Intention	3.7 (2.1)	3.0	2.0-5.0
Self-efficacy	4.2 (2.1)	4.0	3.0-6.0

[a]All items had a minimum of 1 and a maximum of 7 (range 1-7), that is, for example, 1=not at all and 7=very relaxed.

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Within-Person Associations With Subsequent PA

Overview

In Table 4, detailed results for the logistic models and negative binomial models are presented. A visual summary of the direction of the associations of all determinants with LPA and MVPA in the 15, 30, 60, and 120 minutes after the EMA trigger is provided in Multimedia Appendix 5. A summary of the significant associations found in the logistic and negative binomial models is provided in subsequent sections.

Relaxation

A 1-unit increase in "relaxation" was associated with 9%, 10%, 11%, and 24% lower odds of performing any LPA in the 15 minutes (*P*=.03), 30 minutes (*P*=.02), 60 minutes (*P*=.04), and 120 minutes (*P*=.002) after the trigger, respectively. In participants who performed any LPA, a 1-unit increase in "relaxation" was associated with 5% and 6% fewer minutes of LPA, both in the 60 minutes (*P*=.006) and 120 minutes (*P*<.001) after the trigger, respectively.

A 1-unit increase in "relaxation" was associated with 9% lower odds of performing any MVPA, both in the 60 minutes (*P*=.03) and 120 minutes (*P*=.03) after the trigger. In participants who performed any MVPA, a 1-unit increase in "relaxation" was associated with 6% fewer minutes of MVPA in the 60 minutes (*P*=.05) after the trigger.

Satisfaction

A 1-unit increase in "satisfaction" was associated with 9% lower odds of performing any LPA in the 15 minutes (*P*=.04) after the trigger. In participants who performed any LPA, a 1-unit increase in "satisfaction" was associated with 4% and 5% fewer minutes of LPA in the 60 minutes (*P*=.02) and 120 minutes (*P*=.002) after the trigger, respectively.

No significant associations were found between satisfaction and MVPA in the negative binomial model.

Irritation

A 1-unit increase in "irritation" was associated with 13% and 28% higher odds of performing any LPA in the 30 minutes (*P*=.04) and 120 minutes (*P*=.03) after the trigger, respectively. In participants who performed any LPA, a 1-unit increase in "irritation" was associated with 6% more minutes of LPA in the 120 minutes (*P*=.01) after the trigger.

A 1-unit increase in "irritation" was associated with 16% higher odds of performing any MVPA within the 120 minutes (*P*=.01) after the trigger. No significant associations were found between irritation and MVPA in the negative binomial model.

Feeling Down

A 1-unit increase in "feeling down" was associated with 23%, 19%, 22%, and 45% higher odds of performing any LPA in the 15 minutes (*P*=.003), 30 minutes (*P*=.03), 60 minutes (*P*=.03), and 120 minutes (*P*=.02) after the trigger, respectively. In participants who performed any LPA, a 1-unit increase in "feeling down" was associated with 7% more minutes of LPA in the 120 minutes (*P*=.02) after the trigger.

No significant associations were found between feeling down and MVPA in the logistic model nor in the negative binomial model.

Fatigue

A 1-unit increase in "fatigue" was associated with 18% and 26% lower odds of performing any LPA in the 60 minutes (*P*=.002) and 120 minutes (*P*=.001) after the trigger, respectively. In participants who performed any LPA, a 1-unit increase in "fatigue" was associated with 5%, 7%, 8%, and 12% fewer minutes of LPA in the 15 minutes (*P*=.06), 30 minutes (*P*=.006), 60 minutes (*P*<.001), and 120 minutes (*P*<.001) after the trigger, respectively.

A 1-unit increase in "fatigue" was associated with 18% and 21% lower odds of performing any MVPA in the 60 minutes (*P*<.001) and 120 minutes (*P*<.001) after the trigger, respectively. In participants who performed any MVPA, a 1-unit increase in "fatigue" was associated with 8% and 12% fewer minutes of MVPA in the 60 minutes (*P*=.05) and 120 minutes (*P*<.001) after the trigger, respectively.

Intention

A 1-unit increase in "intention" was associated with 33%, 40%, 45%, and 46% higher odds of performing any LPA in the 15 minutes (*P*<.001), 30 minutes (*P*<.001), 60 minutes (*P*<.001), and 120 minutes (*P*<.001) after the trigger, respectively. In participants who performed any LPA, a 1-unit increase in "intention" was associated with 8%, 12%, 19%, and 24% more minutes of LPA in the 15 minutes (*P*<.001), 30 minutes (*P*<.001), 60 minutes (*P*<.001), and 120 minutes (*P*<.001) after the trigger, respectively.

A 1-unit increase in "intention" was associated with 38%, 42%, 45%, and 48% higher odds of performing any MVPA in the 15 minutes (*P*<.001), 30 minutes (*P*<.001), 60 minutes (*P*<.001), and 120 minutes (*P*<.001) after the trigger, respectively. In participants who performed any MVPA, a 1-unit increase in "intention" was associated with 12%, 14%, 22%, and 28% more minutes of MVPA in the 15 minutes (*P*<.001), 30 minutes (*P*<.001), 60 minutes (*P*<.001), and 120 minutes (*P*<.001) after the trigger, respectively.

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Table 4. Outcomes of the logistic models and negative binomial models for light physical activity (LPA) and moderate to vigorous physical activity (MVPA) in the 15, 30, 60, and 120 minutes after the trigger.

	Logistic model		Negative binomial	
	OR[a] (95% CI)	*P* value	expB[b] (95% CI)	*P* value
Relaxation				
LPA (min after trigger)				
15	0.91 (0.84-0.99)	.03	0.99 (0.95-1.03)	.49
30	0.90 (0.82-0.98)	.02	0.98 (0.95-1.02)	.32
60	0.89 (0.80-0.99)	.04	0.95 (0.92-0.99)	.006
120	0.76 (0.64-0.90)	.002	0.94 (0.90-0.97)	<.001
MVPA (min after trigger)				
15	0.91 (0.83-1.01)	.09	1.01 (0.94-1.08)	.85
30	0.93 (0.85-1.02)	.11	0.95 (0.89-1.01)	.11
60	0.91 (0.84-0.99)	.03	0.94 (0.89-1.00)	.05
120	0.91 (0.83-0.99)	.03	0.95 (0.91-1.00)	.06
Satisfaction				
LPA (min after trigger)				
15	0.91 (0.83-1.00)	.04	0.99 (0.95-1.03)	.64
30	0.91 (0.83-1.00)	.06	0.97 (0.93-1.01)	.16
60	0.94 (0.84-1.05)	.25	0.96 (0.92-0.99)	.02
120	0.88 (0.75-1.04)	.14	0.95 (0.91-0.98)	.002
MVPA (min after trigger)				
15	1.00 (0.90-1.12)	.97	0.99 (0.91-1.07)	.79
30	1.00 (0.91-1.10)	.99	0.99 (0.93-1.06)	.85
60	0.96 (0.88-1.06)	.42	1.03 (0.96-1.09)	.42
120	0.94 (0.86-1.03)	.21	1.02 (0.97-1.08)	.49
Irritation				
LPA (min after trigger)				
15	1.01 (0.91-1.12)	.87	0.99 (0.94-1.04)	.67
30	1.13 (1.01-1.28)	.04	0.99 (0.94-1.04)	.66
60	1.14 (0.99-1.31)	.06	1.03 (0.98-1.08)	.27
120	1.28 (1.03-1.58)	.03	1.06 (1.01-1.11)	.01
MVPA (min after trigger)				
15	1.01 (0.88-1.16)	.88	1.01 (0.88-1.16)	.52
30	1.01 (0.90-1.14)	.83	0.95 (0.87-1.04)	.28
60	1.06 (0.95-1.19)	.30	0.97 (0.90-1.06)	.53
120	1.16 (1.03-1.31)	.01	0.98 (0.91-1.05)	.55
Feeling down				
LPA (min after trigger)				
15	1.23 (1.07-1.42)	.003	0.99 (0.93-1.05)	.66
30	1.19 (1.02-1.38)	.03	1.05 (0.99-1.11)	.12
60	1.22 (1.02-1.47)	.03	1.05 (0.99-1.11)	.11
120	1.45 (1.06-1.99)	.02	1.07 (1.01-1.12)	.02
MVPA (min after trigger)				

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	Logistic model		Negative binomial	
	OR[a] (95% CI)	*P* value	expB[b] (95% CI)	*P* value
15	0.96 (0.80-1.15)	.66	0.94 (0.82-1.08)	.36
30	0.94 (0.81-1.10)	.46	0.98 (0.88-1.10)	.79
60	1.00 (0.87-1.16)	.96	1.02 (0.91-1.13)	.77
120	1.07 (0.92-1.24)	.36	1.01 (0.92-1.09)	.89
Fatigue				
LPA (min after trigger)				
15	0.94 (0.85-1.05)	.29	0.95 (0.90-1.00)	.06
30	0.92 (0.83-1.03)	.15	0.93 (0.89-0.98)	.006
60	0.82 (0.72-0.93)	.002	0.92 (0.87-0.96)	<.001
120	0.74 (0.61-0.89)	.001	0.88 (0.85-0.92)	<.001
MVPA (min after trigger)				
15	0.88 (0.76-1.01)	.07	1.03 (0.93-1.14)	.58
30	0.93 (0.82-1.04)	.21	0.97 (0.89-1.06)	.51
60	0.82 (0.73-0.92)	<.001	0.92 (0.85-1.00)	.05
120	0.79 (0.71-0.89)	<.001	0.88 (0.82-0.94)	<.001
Intention				
LPA (min after trigger)				
15	1.33 (1.26-1.41)	<.001	1.08 (1.05-1.10)	<.001
30	1.40 (1.32-1.50)	<.001	1.12 (1.10-1.15)	<.001
60	1.45 (1.34-1.57)	<.001	1.19 (1.16-1.22)	<.001
120	1.46 (1.29-1.66)	<.001	1.24 (1.22-1.27)	<.001
MVPA (min after trigger)				
15	1.38 (1.28-1.48)	<.001	1.12 (1.07-1.17)	<.001
30	1.42 (1.31-1.54)	<.001	1.14 (1.09-1.19)	<.001
60	1.45 (1.36-1.55)	<.001	1.22 (1.17-1.27)	<.001
120	1.48 (1.39-1.58)	<.001	1.28 (1.23-1.32)	<.001
Self-efficacy				
LPA (min after trigger)				
15	1.26 (1.19-1.35)	<.001	1.05 (1.02-1.08)	<.001
30	1.32 (1.23-1.41)	<.001	1.09 (1.06-1.12)	<.001
60	1.37 (1.26-1.49)	<.001	1.15 (1.12-1.18)	<.001
120	1.37 (1.21-1.56)	<.001	1.18 (1.15-1.21)	<.001
MVPA (min after trigger)				
15	1.30 (1.21-1.41)	<.001	1.10 (1.05-1.15)	<.001
30	1.36 (1.27-1.46)	<.001	1.15 (1.10-1.21)	<.001
60	1.39 (1.30-1.49)	<.001	1.24 (1.19-1.29)	<.001
120	1.39 (1.30-1.49)	<.001	1.21 (1.16-1.26)	<.001

[a]OR: odds ratio.

[b]expB: beta exponent.

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Self-Efficacy

A 1-unit increase in "self-efficacy" was associated with 26%, 32%, 37%, and 37% higher odds of performing any LPA in the 15 minutes (P<.001), 30 minutes (P<.001), 60 minutes (P<.001), and 120 minutes (P<.001) after the trigger, respectively. In participants who performed any LPA, a 1-unit increase in "self-efficacy" was associated with 5%, 9%, 15%, and 18% more minutes of LPA in the 15 minutes (P<.001), 30 minutes (P<.001), 60 minutes (P<.001), and 120 minutes (P<.001) after the trigger, respectively.

A 1-unit increase in "self-efficacy" was associated with 30%, 36%, 39%, and 39% higher odds of performing any MVPA in the 15 minutes (P<.001), 30 minutes (P<.001), 60 minutes (P<.001), and 120 minutes (P<.001) after the trigger, respectively. In participants who performed any MVPA, a 1-unit increase in "self-efficacy" was associated with 10%, 15%, 24%, and 21% more minutes of MVPA in the 15 minutes (P<.001), 30 minutes (P<.001), 60 minutes (P<.001), and 120 minutes (P<.001) after the trigger, respectively.

Discussion

Principal Findings

This study examined the within-person associations of multiple determinants of the capability and motivation component of the COM-B framework with subsequent LPA, MVPA, and TPA. Multiple associations with LPA and MVPA in the 15, 30, 60, and 120 minutes after the trigger were found: irritation, feeling down, intention, and self-efficacy were positively associated with subsequent PA, whereas relaxation, satisfaction, and fatigue were negatively associated with subsequent PA. All results for TPA can be found in Multimedia Appendices 2-4.

In line with our hypothesis, intention and self-efficacy were positively associated with subsequent PA, and fatigue was negatively associated with subsequent PA.

Higher levels of intention or self-efficacy were associated with higher odds of performing subsequent PA or with more minutes of subsequent PA. This finding is in line with previous EMA research in adults and older adults [20,22,24]. In adults, it was found that intentions and self-efficacy positively predicted subsequent accelerometer-assessed MVPA in the 2 hours after the EMA trigger [20]. In older adults, greater levels of self-efficacy predicted higher levels of subjectively measured subsequent MVPA in the 4 hours after the EMA trigger [24]. Intention and self-efficacy were also found to predict increases in the subsequent time spent upright in older adults [22]. Multiple theoretical frameworks [42-44] stress the importance of intention and self-efficacy as a gateway to or as a condition for behavior change, and therefore, positive associations between these constructs and subsequent PA seem natural. However, these theories often do not assess these concepts as dynamic, whereas in a previous study using the same data [34], we found that these are time dependent. Thus, the novelty observed in this study is that these generic associations among intention, self-efficacy, and PA also occur in shorter time frames.

Furthermore, in this study, a negative association was found between the physical complaint fatigue and subsequent LPA in the 15, 30, 60, and 120 minutes after the trigger and subsequent MVPA in the 60 and 120 minutes after the trigger. This means that a higher level of fatigue resulted in lower odds of being physically active and in fewer minutes of subsequent PA. In previous research, fatigue was often mentioned as a barrier to performing PA [25], which consequently might lead to less subsequent PA. However, Dunton et al [24] and Liao et al [19] observed that fatigue was unrelated to subsequent accelerometer-assessed LPA in the 15 and 30 minutes after the EMA trigger in adults [19] and unrelated to subjectively measured subsequent MVPA in the 4 hours after the EMA trigger in older adults [24]. In contrast to the study by Liao et al [19], in this study, significant negative associations of fatigue with LPA were found in all time frames. Although Liao et al [19] did not examine longer time frames, differences in the associations detected 15 and 30 minutes after the trigger might be explained by differences in participants (ie, low-active adults in the study by Liao et al [19]). Differences in results with the study by Dunton et al [24] might be explained by the large time frame and subjective assessment of subsequent PA.

Some of the associations found in this study were unexpected and in contrast with our hypothesis. Irritation and feeling down were seen as negative emotions and were expected to be negatively associated with subsequent PA. However, in this study, the opposite was observed, that is, higher levels of irritation and feeling down resulted in higher odds of being physically active or in more minutes of subsequent PA. Previous research found that higher negative affect (ie, measured as emotionally upset, annoyed, angry, sad, or depressed [45] and as anxious, stressed, depressed, and angry [19]) was associated with lower levels of MVPA in subsequent time frames in older adults [24] and in adults [19]. However, in some other studies, negative affect was positively associated with LPA in the 4 hours after the trigger in older adults [24] and with bodily movement in 15- and 30-minute time frames in adults aged 18 to 73 years [46]. Engaging in PA can improve mental health [1,47-50]; therefore, PA might be used as a coping strategy to counter or reduce the negative emotions of irritation and feeling down to improve affect [51]. In a previous study using the same data [34], we found that for both irritation and feeling down, participants reported in more than 90% of their answers that they were not feeling irritated or feeling down at all, which might have caused a floor effect and influenced the associations identified here. Finally, in this study, higher levels of relaxation and satisfaction resulted in lower subsequent PA. Although relaxation and satisfaction are positive emotions and therefore positive associations with PA were expected, the association with PA might be different than in the case of other positive emotions (eg, cheerfulness). It is possible that older adults who felt relaxed or satisfied did not wish to be active but rather further enjoyed their state of relaxation or satisfaction. However, this is merely an assumption and should be examined further.

In this study, associations were found in different or multiple time frames depending on the determinant that was examined. In light of JITAIs, insight into the importance of determinants in specific time frames is crucial to achieving the greatest behavioral change. For example, when associations are found in the 30 and 60 minutes after the trigger, it might be interesting

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to examine whether suggestions that encourage the older adult to be active in the next hour instead of "right now" might lead to an increase in their subsequent PA or to examine whether suggestions to be active can be sent after 30 to 60 minutes (after the assessment of the determinant) and in this way increase the older adults' PA. Both can be examined by using multiple mini interventions. Intention and self-efficacy were positively associated with subsequent PA over all time frames, which shows the importance of these constructs in relation to PA in both short and long time frames. When intention and self-efficacy are already high, it might be sufficient for JITAIs to provide an activity suggestion to increase PA levels. In contrast, when intention and self-efficacy are low, it might be an opportunity for JITAIs to offer behavior change techniques aiming to increase intention and self-efficacy and consequently increase PA. For example, previous research showed that the behavior change technique "provide information on the consequences of behavior in general" is associated with positive changes in intention [52] and that "action planning" was associated with higher self-efficacy [53].

Another observation that could be drawn from the results of this study is that, for some determinants, stronger associations were found with LPA, whereas other determinants were associated with MVPA. For example, emotional satisfaction and feeling down are mainly important for LPA, whereas fatigue is also associated with MVPA. However, these findings are not surprising because they concern different behaviors (ie, examples of LPA are walking and climbing the stairs, while running and cycling are classified as MVPA); therefore, different determinants might be important. Nevertheless, these are important findings for the development of tailored interventions, as different individual determinants may be important for different types of PA that older adults wish to increase. Specifically, suggestions can be tailored according to the behavior of interest, for example, in the case of LPA, providing suggestions to be active when the older adult feels down, and in the case of MVPA, avoiding giving suggestions to be active when the older adult feels fatigued. Intention and self-efficacy showed positive associations with both LPA and MVPA, which provides interesting information for future PA interventions, because both LPA and MVPA can be enhanced in older adults by targeting both determinants.

A previous study using the same data [34] found that multiple individual-level determinants (eg, satisfaction, intention, self-efficacy, and fatigue) are time dependent and therefore can vary within subjects within days. These time-dependent fluctuations are important to keep in mind for the personalization of JITAIs, so that the moment to provide suggestions to be active can be adjusted to the emotional, cognitive, and physical state of the individual. By regularly assessing the time-dependent determinants (eg, multiple times per day) in JITAIs, individually tailored suggestions to improve PA can be provided. Furthermore, it was found that the variation between days was limited in older adults [34]. Therefore, it might be possible to monitor older adults for just a few days before introducing a JITAI to capture the most receptive moments without overburdening them with an extensive monitoring period (eg, 2 weeks). This information, combined with the identified within-person associations found in this study, provides useful information for the development of future JITAIs.

Strengths and Limitations

A first strength of the study was the repeated assessment throughout the day using EMA. The use of EMA reduces recall biases by capturing present experiences rather than beliefs or ratings based on memory. Furthermore, the assessment occurs in the individuals' natural environments and social contexts, which increases ecological validity. Finally, fine-grained information was provided using multiple repeated assessments over time. A second strength is that this study fills an important gap in the literature, as previous research on the associations of determinants with subsequent PA is limited, especially in older adults. Third, participants' PA was accelerometer-assessed using Axivity AX3 accelerometers rather than using self-reported measures.

This study had some limitations. The first limitation is the limited generalizability of the study results, as nonprobability sampling was used to recruit older adults. Therefore, the findings of this study might be specific to the study sample used in this study. It is recommended that future studies use a more random sampling approach to obtain a more heterogeneous study sample and generalize the study results to a wider population of older adults. Second, in this study, PA was considered an outcome variable, with determinants as predictors. However, examining accelerometer-assessed PA as a predictor and the determinants as outcome variables in an EMA study might contribute to a better understanding of the influence of PA on subsequent emotions, physical complaints, and intention and self-efficacy. Third, it is possible that in some cases there was less than 2 hours between 2 triggers, which might have caused some overlap and influenced the associations found in the 120 minutes time frames. This aspect should be considered in future studies. Fourth, although most items of the EMA questionnaire (ie, 4 out of 7) were specifically developed for EMA research, psychometric information was unavailable. It is recommended that future EMA studies use items that are validated for EMA or conduct a validation study before the start of the study. Fifth, we did not consider possible confounders, such as preceding PA, emotions, or other unmeasured variables (eg, sleep). Possible confounders, especially preceding PA, should be considered in future EMA studies. To do so, we first need to explore which time frame of the preceding PA is best to use, since many different time frames can be considered (eg, 15 min, 30 min, and 60 min). However, this exploration was beyond the scope of this study. Sixth, although wrist-worn devices are a common wearing position for the assessment of PA, it might still be possible that there is an overestimation of PA. However, the possibility of an overestimation of PA is limited because the validated cutoff points [38] were used in this study. Although a different accelerometer and different sampling rates were used in the study of Sanders et al [38], the equivalence of the key PA outcomes for GENEActiv and Axivity accelerometers has been proven in previous research [54].

Conclusions

Overall, this study showed that the emotions irritation and feeling down and the constructs intention and self-efficacy were

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positively associated with subsequent PA in older adults, whereas the emotions relaxation and satisfaction and physical complaint fatigue were negatively associated with subsequent PA. Using EMA, this study yielded new knowledge about these associations and the time dependency of the determinants, which is valuable for future interventions. By monitoring older adults for a few days, the most receptive moments for triggering them to be more active can be captured, and this information can be used in JITAIs to provide individual tailoring and promote PA more effectively.

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Authors' Contributions

IM, LM, and DVD developed the study protocol and research questions and prepared the data. IM collected and processed the data. RB helped in processing the physical activity data. IM, LM, LP, and DVD analyzed the data and conducted multilevel regression analyses. IM, LM, and DVD drafted the manuscript. All authors revised the manuscript for important intellectual content and have read and approved the final version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Ecological Momentary Assessment questionnaire translated in English.
[DOCX File , 30 KB - aging_v6i1e44425_app1.docx]

Multimedia Appendix 2
Descriptive statistics of the total physical activity data.
[DOCX File , 26 KB - aging_v6i1e44425_app2.docx]

Multimedia Appendix 3
Outcomes of the logistic models and negative binomial models for total physical activity.
[DOCX File , 32 KB - aging_v6i1e44425_app3.docx]

Multimedia Appendix 4
Overview of the associations of the determinants with total physical activity in the 15, 30, 60, and 120 minutes after the trigger.
[DOCX File , 27 KB - aging_v6i1e44425_app4.docx]

Multimedia Appendix 5
Overview of the associations of the determinants with light physical activity moderate to vigorous physical activity in the 15, 30, 60 and 120 minutes after.
[DOCX File , 16 KB - aging_v6i1e44425_app5.docx]

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Abbreviations

COM-B: capability, opportunity, motivation, and behavior
EMA: Ecological Momentary Assessment
JITAI: just-in-time adaptive intervention
LPA: light physical activity
mHealth: mobile health
MVPA: moderate to vigorous physical activity
PA: physical activity
SEMA3: Smartphone Ecological Momentary Assessment3
TPA: total physical activity

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Original Paper

Older Persons' and Health Care Professionals' Design Choices When Co-Designing a Medication Plan Aiming to Promote Patient Safety: Case Study

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Abstract

Background: Harm from medications is a major patient safety challenge among older persons. Adverse drug events tend to arise when prescribing or evaluating medications; therefore, interventions targeting these may promote patient safety. Guidelines highlight the value of a joint plan for continued treatment. If such a plan includes medications, a medication plan promoting patient safety is advised. There is growing evidence for the benefits of including patients and health care professionals in initiatives for improving health care products and services through co-design.

Objective: This study aimed to identify participants' needs and requirements for a medication plan and explore their reasoning for different design choices.

Methods: Using a case study design, we collected and analyzed qualitative and quantitative data and compared them side by side. We explored the needs and requirements for a medication plan expressed by 14 participants (older persons, nurses, and physicians) during a co-design initiative in a regional health system in Sweden. We performed a directed content analysis of qualitative data gathered from co-design sessions and interviews. Descriptive statistics were used to analyze the quantitative data from survey answers.

Results: A medication plan must provide an added everyday value related to safety, effort, and engagement. The physicians addressed challenges in setting aside time to apply a medication plan, whereas the older persons raised the potential for increased patient involvement. According to the participants, a medication plan needs to support communication, continuity, and interaction. The nurses specifically addressed the need for a plan that was easy to gain an overview of. Important function requirements included providing instant access, automation, and attention. Content requirements included providing detailed information about the medication treatment. Having the plan linked to the medication list and instantly obtainable information was also requested.

Conclusions: After discussing the needs and requirements for a medication plan, the participants agreed on an iteratively developed medication plan prototype linked to the medication list within the existing electronic health record. According to the participants, the medication plan prototype may promote patient safety and enable patient engagement, but concerns were raised about its use in daily clinical practice. The last step in the co-design framework is testing the intervention to explore how it works and connects with users. Therefore, testing the medication plan prototype in clinical practice would be a future step.

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KEYWORDS

co-design; engagement; medications; medication plan; older people; older adults; participatory; patient experience; patient safety; remote

Introduction

Supporting Patient Safety

Patient safety, referred to as the prevention of harm to patients [1], is essential in health care. Older people are at an increased risk for adverse drug events (ADEs), harm caused by the use of medications [2,3], as they have a higher prevalence of frailty, multiple medical conditions, and polypharmacy [4,5]. Polypharmacy is commonly referred to as the use of multiple medications, but there is no universally accepted definition. An alternative definition is the use of more medications than medically necessary [6,7]. ADEs tend to occur during the entirety of medication use, but for older people in ambulatory care, most ADEs tend to arise when their medications are prescribed or evaluated [8]. Therefore, interventions targeting these steps may promote patient safety.

In an interview study with older people about how they experienced the evaluation of their medications, we found that they wanted to be involved in their care, and they called for specific written information regarding plans for the evaluation of their medications [9]. Patients participating in their own care may help prevent adverse events and can be seen as a source of insight, enhancing the safety of health care [10]. Patients and their next of kin can detect changes in patients' condition, and if health care professionals enable them to interact, these signals may help optimize medication treatment [11]. Nurses and physicians identify good communication among persons involved in an older person's medication treatment as a facilitator of proper evaluation [12]. To support safe treatment, pharmaceutical information, such as medication lists and care plans, can be shared among health care professionals [13,14].

International guidelines targeting multimorbidity and polypharmacy in older people highlight the value of a joint plan for continued treatment, that is, a "medication plan" for both older people and health care professionals to facilitate safer medication treatment [15]. Moreover, an agreement between older persons who use medications and health care professionals on health-related goals for treatment may benefit all those involved and prevent harm [16-18]. In a similar spirit, Sweden has a national program for the implementation of "Patient Contracts" [19,20], an agreement regarding the patient's planned health care, created collaboratively, documented in the electronic health record (EHR), and intended to strengthen the relationship between a patient and health care professionals. To work effectively in clinical practice, a joint plan must meet the needs of potential users. So far, the needs and requirements for a medication plan, as expressed by patients and health care professionals, have not informed such plans.

Co-Designing a Medication Plan

There is growing evidence for the benefits of including patients and health care professionals in initiatives for improving health care products and services [21]. Specifically, co-design is a way to improve health care that offers health care organizations new ways of creating services or products by harnessing the experiences of patients and health professionals [22]. Co-design has been integrated into improvement projects to develop interventions that enhance medication safety and has been recognized as a useful approach that puts the users' input at the center [23]. There are several models for co-design, all focusing on the lived experiences of the participants and encouraging collaborative work to identify problems and solutions [24,25]. Therefore, we first explored older persons' and health care professionals' experiences of the evaluation of medications [9,12]. On the basis of these findings, a remote co-design initiative involving older persons, physicians, and nurses was applied to define and develop a medication plan with the aim of supporting medication evaluation. In a previous study, we found that the participants experienced the remotely completed co-design initiative to be inclusive, to facilitate learning, and to increase opportunities to collaboratively design a medication plan [26]. This study aimed to identify the participants' needs and requirements for a medication plan and explore their reasoning for different design choices.

Methods

Study Design

A case study design was used, as it is useful when studying improvement efforts in complex systems such as health care [27,28]. According to the case study approach, qualitative and quantitative data were first analyzed separately and then compared side by side in the *Discussion* section [27].

Setting and Participants

The co-design initiative was established in 1 of the 21 regional public health care systems in Sweden. Most health care organizations in Sweden use EHRs. Access to medical data is regulated by the Patient Data Law [29]. Each health care organization has its own EHR but can share data, for example, medical notes or lists of prescribed medications, with the National Patient Overview (NPO) [30], which gives authorized health care professionals access to medical information about a patient previously cared for elsewhere. In addition, patients can access their own EHR digitally through the secure web interface 1177 [30]. In Sweden, electronic prescriptions are standard and visible to patients and authorized health care professionals through the Swedish National Medication List [31]. For patients with multiple dose drug dispensing support, prescriptions are managed in a web-based service available to authorized health care professionals [30].

Participants were recruited through existing contacts within the regional public health care system's office for the Patient Contracts program. To reach a variety of perspectives and experiences [32], we sought a group including older persons (aged >75 years) with lived experience of taking long-term medications, next of kin, general practitioners, and nurses

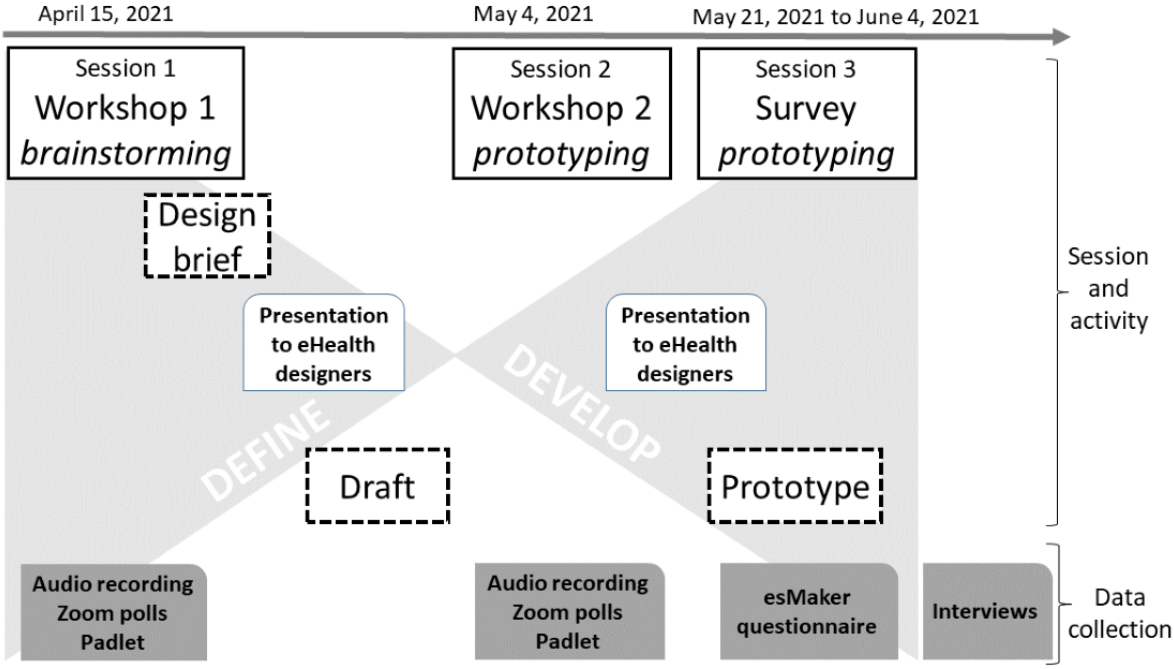
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working in municipality-based home health care. Inclusion required adequate communication capability in Swedish, access to and proficiency in using the internet, and the possibility to participate in all 3 parts of the co-design initiative. No exclusion criteria were applied. For the older persons, we noted gender, age, and the number of current medications; for the health care professionals, we noted gender and years in the profession. The initiative involved 14 participants, namely 5 (36%) older persons aged 72 to 82 years using 3 to 8 medications daily, 6 (43%) nurses who had worked for 4 to 35 years, and 3 (21%) physicians who had worked for 5 to 39 years. We did not succeed in including next of kin through the existing contacts, but one of the older persons reported also having the experience of being next of kin.

The Co-Design Initiative

The "Double Diamond" framework, which consists of 4 phases, namely *Discover*, *Define*, *Develop*, and *Deliver* [33], was used to co-design a medication plan prototype, that is, a model of a proposed solution, incorporated within the existing EHR structure. The co-design initiative, involving the define and develop phases in the double diamond framework, is described in detail elsewhere [26]. As the COVID-19 pandemic brought restrictions on physical meetings, the initiative was performed remotely digitally over a 2-month period (Figure 1). It included 3 sessions: 2 time-scheduled workshops lasting 2 hours each conducted via web-supported Zoom videoconferencing software (Zoom Video Communications, Inc) and 1 web-based survey. A quality improvement adviser and the first author facilitated the workshops. eHealth designers in the regional public health care system prepared drafts and the prototype between the sessions based on outputs.

Figure 1. The structure of the co-design initiative and data collection.



In the *Define* phase including the first session, workshop 1, insights from older persons, nurses, and physicians identified in the *Discover* phase [9,12] were presented to the participants along with information from research and regulations related to the initiative topic. The participants were asked to describe their needs for the medication plan, that is, what the medication plan must satisfy for them to get the right outcome [34] or, in practice, what the medication plan should contribute and add to existing practice. Then, they were asked to identify function and content requirements for the medication plan. Function requirements were the specific functionalities wanted for the medication plan to support its usability, and content requirements were the various pieces of information wanted in the medication plan [34]. Brainstorming was used to gather ideas and build a shared understanding of the orientation of the group. After workshop 1, the first author prepared a written design brief, which was a core reference point, based on the data gathered during workshop 1. The design brief was presented to the eHealth designers, who used it to prepare medication plan drafts, which were preliminary prototypes presented as a Microsoft Word (Microsoft Corp) document with 3 different images for each draft: 1 image from the EHR in the regional health care system, 1 image from NPO and 1177, and 1 image as a paper-printed copy.

The *Develop* phase included sessions 2 and 3, workshop 2 and a survey. In workshop 2, the drafts were presented to the participants, who were invited to develop the drafts further into 1 prototype by designing the components in detail and iteratively refining the drafts. Experience prototyping [35], a way to test and refine a solution in interactive feedback loops, using fictitious patient cases, was used to enable the participants to gain first-hand understanding and receive feedback. After workshop 2, the first author gathered the data and presented them to the eHealth designers, further informing their design of the medication plan prototype. In the third session, the resulting prototype was sent to all the participants in a Word

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document together with the survey to collect final feedback on the prototype in a final feedback loop.

Data Collection

This case study of the co-design initiative draws on both quantitative and qualitative data (Figure 1). The 2 workshops were audio recorded and then transcribed verbatim. During the workshops, the participants captured the discussions and their own reflections using notes on a digital notice board (Padlet web platform, Padlet). The notes were downloaded after each workshop. Zoom polls, that is, questions asked on Zoom, were used to narrow down the discussions and prioritize the needs, requirements, and final specifications. Overall, 9 Zoom polls were single-choice questions, and 7 were multiple-choice questions. To reflect the ongoing discussions, the prewritten Zoom polls were refined during each workshop by the first author. The design briefs, drafts, and prototype also constituted the case study data.

A survey, developed specifically for this study in the web-based survey tool esMaker NX3 (Entergate), was sent to all participants in the third session to collect feedback and reflections on the prototype. It consisted of 2 yes or no questions with space to add free-text comments, 6 questions with response options on a 10-grade Likert scale and a "do not know" option, and 7 additional free-text questions (Multimedia Appendix 1). The participants were asked to respond within 2 weeks; they received reminders after 1 week and on the last day for completion.

After the initiative, all the participants were invited to participate in an individual semistructured interview on Zoom. The interview guide (Multimedia Appendix 2), developed by the research team based on the results of the survey, included questions about the prototype and the co-design process. A total of 7 participants, specifically 1 (14%) physician, 4 (57%) older persons, and 2 (29%) nurses, volunteered. The interviews were audio recorded, lasted between 21 and 46 (median 28.5) minutes, and were transcribed verbatim.

Data Analysis

The qualitative data, that is, transcriptions from workshops and interviews, answers from free-text questions, and notes from Padlet, were gathered in NVivo software (QSR International) and analyzed through directed content analysis [36]. This method was chosen to broaden the understanding of the concepts used in relation to a medication plan. Following the method, the analysis started with the 3 predetermined and defined key concepts addressed in the co-design initiative, namely "needs," "function requirements," and "content requirements." These 3 key concepts formed 1 main category each. The first author read the transcripts, notes, and free-text answers to the survey questions. Quotes representing the preformed main categories were highlighted and placed into the relevant main category. Similar quotes in each main category were put together in codes. Then, each code was reviewed and read through for a first impression. Quotes not relevant to that code were either uncoded or moved to another code. Codes with similar content were compared and grouped together by abstraction to generate subcategories. In addition, quotes relevant to the study aim but not to the 3 predetermined main categories were also highlighted. These quotes were analyzed by putting them together in codes and by abstraction, forming 3 subcategories in 1 additional main category. The results of the preliminary analysis were first presented to and discussed and refined with the last author. Then, the results were presented to and discussed and refined with the entire research group. Matrix coding queries [37] within NVivo were applied to the data, which assessed how the quotes from the older persons, nurses, and physicians underpinned the different design choices (the identified codes and categories) and how different design choices were expressed over time.

Quantitative data from Zoom polls and the survey were analyzed and summarized using descriptive statistics such as number, median, and range.

Ethical Considerations

This study was approved by the Swedish Ethical Review Authority (dnr 2020-04781) and adheres to the Declaration of Helsinki [38]. All the participants received written information regarding the study and provided written consent before the first session. Data were deidentified to maintain confidentiality and were presented such that no single individual could be identified. Data from the study were kept secure in accordance with national and local routines.

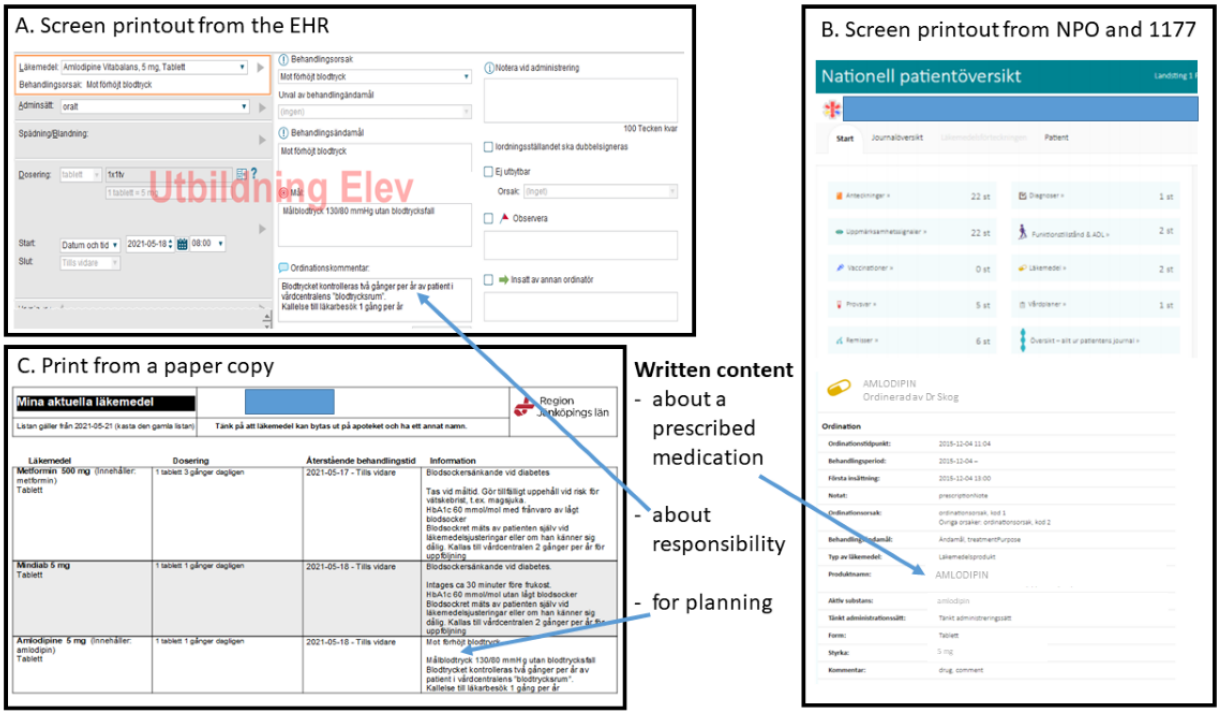
Results

The Co-Designed Medication Plan Prototype

On the basis of the design brief with compiled information from Padlet notes and Zoom poll answers in the first session, the eHealth designers created 2 different drafts of a medication plan. One draft was based on the medication list, and the other draft took the form of a medical note. After refinements of the drafts, as suggested in workshop 2, the eHealth designers finalized a medication plan prototype derived from the medication list. The prototype was presented to the participants in the third session and remained intact after the survey (Figure 2).

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Figure 2. Illustration (in Swedish) of the content displayed in the final medication plan prototype: (A) electronic health record (EHR) screen printout; (B) National Patient Overview (NPO) and 1177 screen printout; and (C) print from a paper copy.



Qualitative Data Regarding the Participants' Design Choices for the Medication Plan

Overview

The three predetermined key concepts formed the following three main categories: (1) *needs supporting communication, continuity, and interaction;* (2) *functions providing instant access, automation, and attention;* and (3) *content providing detailed information about the medication treatment*. Together with one additionally formed main category, (4) *the medication plan must provide added everyday value*, they described the participants' reasoning for design choices for the medication plan. These main categories are presented in the subsequent sections with associated subcategories and codes as well as illustrative quotes.

Needs Supporting Communication, Continuity, and Interaction

During the initiative, the participants discussed the needs that the medication plan must meet to promote patient safety and work as intended. This means that the plan must support interaction and communication about the plan and be transparent and continuously updated. The needs are elaborated on in 3 subcategories: *adequate and adapted information*, *an updated and transparent source*, and *clarified responsibility and interaction* (Table 1).

A comparison of the data showed that the participants reasoned about the need for a medication plan mostly in the workshops, focusing more on the need for a balance of sufficient information and a plan that is easy to overview in workshop 2. Generally, the nurses had less input about needs, except for the need for a medication plan that is easy to gain an overview of. The physicians highlighted the need for a plan with a balanced amount of information. The older persons raised the need for understandable and clear information.

Adequate and adapted information that supports communication concerned striking a balance of sufficient information. It described the need to concentrate information into a reasonable amount and provide appropriately detailed information, as EHRs today tend to risk generating information overload. Exclusively, oral information is easy to forget; therefore, written information about the plan, printed on paper or digitally, is needed to allow reading afterward. This also allows other involved persons, who did not attend the visit, to take part in updates. In addition, the presentation of information must be adapted not only to the patient, but also to colleagues within health care to make it an understandable and clear plan.

An updated and transparent source reflected the need for the medication plan to be a living document, that is, to be continuously updated, for example, by updating it at the annual visit or when changing a patient's medication. A medication plan can support the continuity of care if it is adapted to present conditions, which is important for older persons, in whom medical conditions can change quickly. There is also a need for the medication plan to be easy to gain an overview of, meaning that it should be clear and easy to find in a collected medical note. On the one hand, having the plan included in the medication list would make it easy to overview, but on the other hand, if many medications are prescribed, it may make the plan difficult to grasp.

Clarified responsibility and interaction addressed the need to make responsibilities visible, as who is doing what tends to be vague. The physician is primarily responsible for the prescribed medications, and patients trust the physician to take that responsibility. Even so, patients may have the responsibility to ensure that the treatment works as intended, provided that they

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know what to expect. In addition, home health care staff must know when they should support the older person. There is also a need for the medication plan to facilitate communication about treatment among the involved persons. Knowing whom to contact if there are questions or concerns promotes a sense of security. Mutual communication about medications may also help all those involved understand the next step in treatment.

Table 1. Overview of the main category *needs supporting communication, continuity, and interaction* with subcategories, codes, and illustrative quotes.

Subcategories and codes	Illustrative quotes
Adequate and adapted information	
A balance of sufficient information	"There is already a lot of information in the medical record. It can be difficult to find the plan" (Group Padlet, workshop 2).
An understandable and clear plan	"Sometimes it is written in a language that they do not understand, so it is also important that a non-medical language is used in the plan. If it says when they are going to evaluate the medicine, what it [the medication] is for in Swedish, when they are supposed to discontinue [the medication], then I think it will be easier" (Nurse, survey).
Available written information	"I would like to have it in writing so I can remember it when I get home too" (Older person, workshop 1).
An updated and transparent source	
Continuously updated	"It may be that when I start this plan, I may be quite alert. Then something happens and all of a sudden, I'm not that alert and then you might need to revise what applies again" (Nurse, workshop 1).
Easy to gain an overview of	"We would like to have this collective contract...well, we have the same view as group one that it can be difficult to find in the medical record. There's a lot in there from different...it's...Some people have a lot of contacts and then it can be extremely difficult to find the medication list, if it's only in the medical record" (Older person, workshop 2).
Clarified responsibility and interaction	
Facilitate communication	"Enables better communication on why medicines are used and how they should be followed-up and by whom" (Group Padlet, workshop 2).
Make responsibilities visible	"When prescribing, it is the doctor who is responsible for writing a plan and how to carry out the follow-up." (Older persons, workshop 1).

Functions Providing Instant Access, Automation, and Attention

The participants specified the following function requirements for the medication plan to be usable: accessibility, embedded attention, and automation. The participants reasoned about these requirements, which are presented subsequently in 3 subcategories, namely *accessible for all involved, embedded alerts and communication*, and *automatically and instantly displayed* (Table 2).

A comparison of data showed that having the medication plan linked to the medication list was addressed mainly in workshop 2. Generally, the physicians addressed more function requirements. The older persons had fewer function requirements related to embedded alerts and automatically displayed information, something that the physicians addressed more. Instantly obtainable information was the major function requirement expressed by the nurses.

Accessible for all involved addressed a function of a connected EHR, meaning that EHRs from different health care providers have to be connected or at least should communicate with each other so that information is not lost in transition. Laws and regulations regarding confidentiality between caregivers may limit connections, and not all involved persons are digital today but probably will be in the future. According to the participants, this called for a printing option in the EHR to not exclude persons who do not have digital access at home or at work. However, there are challenges with printouts, as they may disappear, and it may be difficult to know which is the current one. The medication plan must also be readily accessible for eligible persons, such as authorized persons, including the older persons, next of kin, physicians, home health care staff, or even pharmacists. A function that makes the medication plan linked to the medication list could also make it more accessible, as this may facilitate management and the addition of complementary information to content that already exists there, thereby supporting an already existing structure.

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Table 2. Overview of the main category *functions providing instant access, automation, and attention* with subcategories, codes, and illustrative quotes.

Subcategories and codes	Illustrative quotes
Accessible for all involved	
A connected electronic health record.	"In the same medical record that everyone can access. And patients can also look on the web. Healthcare professionals must have the right information" (Older person, workshop 1).
A printing option	"Digitally for healthcare professionals and in paper form for patients who need it" (Group Padlet, workshop 1).
Readily accessible for eligible persons	"The patient in the first place, as we said, but also that relatives could access it if they are involved in the patient's care. And, of course, healthcare professionals" (Nurse, workshop 1).
Linked to the medication list	"It would be good if medication-related questions could be added to the medication list physically. If you hand it to the patient, that's what you think. And also if it is sent or emailed to the municipality's employees, it would be very good if you could comment directly on it" (Physician, workshop 1).
Automatically and instantly displayed	
Automatic display of updated information	"It should be the same information throughout. No possibility of misunderstanding, and as you say here, four medical records! It is as if there is a risk of error" (Older person, workshop 1).
Instantly obtainable information	"Risk if it is not easily obtainable to all healthcare professionals or if the information cannot be linked to Pascal [a web-based service for multiple dose drug dispensing]" (Group Padlet, workshop 2).
Embedded alerts and communication	
A digital communication platform	"That you...as a user of medicines, can go in, and contact your doctor digitally, and say that it's working well and...So you get this extra contact" (Older person, workshop 2).
An embedded alert system	"This is somehow not all medications, but applies to some of them...Well, we need to be able to 'flag' which medications we should observe and which we do not need to be so observant about" (Physician, workshop 1).

Automatically and instantly displayed meant an automatic display of updated information, that is, not having to document the medication plan in several places in the medical record but having a function that copies text into places where it is needed. Ready-made suggestions for text phrases could simplify this, and it should be easy to see when the plan is updated. Having instantly obtainable information was requested, whereby the older persons, as well as health care professionals, can immediately read the medication plan. According to the participants, this is not always possible today, and easily obtaining information without having to go through unnecessary data creates a sense of security.

Embedded alerts and communication concerned having a digital communication platform where involved persons can communicate about the medication plan. Digital communication within the EHR already exists among health care professionals but should also enable older persons to communicate digitally in a secure manner. An embedded alert system that can draw attention to important issues in the plan and signal when a medication is altered or when it is time for follow-up was also raised as a desired function.

Content Providing Detailed Information About the Medication Treatment

The participants identified content requirements that could provide involved persons with detailed information about how to act and about the next step in treatment. These requirements were elaborated on in 3 subcategories: *written content about a prescribed medication*, *written content about responsibility*, and *written content for planning* (Table 3).

A comparison of the data showed that content requirements were mainly discussed during workshop 1, with a focus on planning. In workshop 2 and the survey, the content focused mainly on information about the prescribed medications. The older persons focused on content about the prescribed medications, the nurses focused on what to alert about, and the physicians focused on when to evaluate.

Written content about a prescribed medication described what the medication is used for and when to take the medication, that is, during the day or together with food and other medications. It also addressed the intended treatment duration and information about the refill of a prescription, that is, the quantity and number of withdrawals from the pharmacy.

Written content about responsibility described whom to contact for questions about the medication and who is responsible for follow-up and evaluation.

Written content for planning described how to monitor and evaluate, that is, the plan for evaluation, and treatment goals such as blood pressure targets. In addition, the participants called for information regarding what to alert about, such as potential side effects, and when to evaluate a medication, such as frequency or a date in a month.

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Table 3. Overview of the main category *content providing detailed information about the medication plan* with subcategories, codes, and illustrative quotes.

Subcategories and codes	Illustrative quotes
Written content about a prescribed medication	
Treatment duration	"And how long is the duration of the treatment" (Nurse, workshop 1).
Refill of a prescription	"It would have been great if, in addition to the date, the quantity and number of withdrawals had been included in the list, as then the patient would have direct control over the prescriptions at the same time and could see that medicines are prescribed for a year" (Physician, survey).
What the medication is used for	"And a short description of why to take the tablet" (Group Padlet, workshop 2).
When to take the medication	"What many patients want to know is 'How should they take their medicine?' Should it be with a meal, with water, or when" (Older person, workshop 2).
Written content about responsibility	
Who is responsible	"It is important that it is clear who. That is different responsibilities...What responsibility does the patient have and what responsibility we have as health care providers?" (Nurse, workshop 1)
Whom to contact	"And it is not always necessary to have contact with a doctor, it can be a nurse" (Older person, workshop 2).
Written content for planning	
How to monitor and evaluate	"And then you can discuss, either you have your own blood pressure monitor, or you go to our blood pressure room" (Physician, workshop 1).
Treatment goal	"That it is important that the goal is clear, for example it is important that the minimum and maximum are stated for certain medicines, such as blood sugar levels" (Nurse, survey).
What to alert about	"Potential side effects that may occur" (Nurse, workshop 1).
When to evaluate	"And for my part, I think that it should be clearly written, when follow-up should take place" (Older person, workshop 1).

The Medication Plan Must Provide Added Everyday Value

According to the participants, a medication plan must provide added everyday value related to safety, effort, and engagement for older persons and health care professionals involved in daily clinical practice. The challenges and opportunities that the participants emphasized are elaborated upon in 3 subcategories: *challenges for clinical practice*, *enable patient engagement*, and *make medication treatment safer* (Table 4).

A comparison of the data showed that the physicians especially addressed challenges in prioritizing time wisely, if required to create medication plans, and challenges in individualizing the medication plan to each older person. Challenges in individualization were not addressed much by the older persons, who instead raised the possibility that a medication plan may empower patients to become more involved. During the initiative, enabling patient engagement was discussed more in workshop 1, whereas the challenges in applying the medication plan in clinical practice and safer medication treatment were discussed more in workshop 2.

Challenges for clinical practice reflected difficulties in applying a medication plan in a usable way in everyday clinical practice, where time can be scarce and the implementation of new ways of working can be difficult. Today, during a regular patient visit, physicians have limited time to prepare a medication plan. Introducing an additional task to the visit may generate stress and make it necessary to prioritize time wisely. Furthermore, using a medication plan may result in the older person having questions about their treatment, which may require additional time to handle. Therefore, introducing a medication plan may call for stepwise implementation, that is, for an implementation that is not rushed and tests the plan on a small scale, as innovations are not always welcomed in health care. To avoid shortcuts, such as not applying the medication plan properly, benefits such as enhanced safety must be highlighted.

Enable patient engagement addressed the opportunity that a medication plan provides to make older persons more involved in their medications; even so, there might be challenges, as older persons are a heterogeneous group, which calls for adaptions to their preferences and abilities. A medication plan can empower patient involvement if health care professionals invite the older person to engage in a dialog about their treatment. The older person can also take greater responsibility for their health and care, which might be desirable for both the older person and health care services. To enable patient engagement, it is necessary to individualize to suit the older person by making adjustments to every situation and every person involved, including the older person's own capabilities and wishes as well as the physician's preferences.

Making medication treatment safer dealt with the promotion of patient safety. The resources used for regular medication re-evaluation could be beneficial for safety. A shared understanding of the plan between the older persons and involved health care professionals can create security in collaboration and provide support for better medication re-evaluation. Although the medication plan may require resources, such as time to prepare and discuss the plan, it may

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reduce unnecessary care, such as unwanted admissions to hospitals or extra phone calls, if all involved persons know what to monitor and how to act in time before a complication related to medications evolves.

Table 4. Overview of the main category *the medication plan must provide added everyday value* with subcategories, codes, and illustrative quotes.

Subcategories and codes	Illustrative quotes
Challenges for clinical practice	
Call for stepwise implementation	"Risk of not filling in everything [information] every time" (Group Padlet, workshop 2).
Prioritize time wisely	"There must be time to create the plan so the doctor does not rush it" (Nurse, survey).
Enable patient engagement	
Empower patient involvement	"I think it will activate us older people, so that we become more interested in our medicines" (Older person, workshop 2).
Individualize to suit the older person	"The older you are, the less you can take that responsibility. It may also be somewhat individual, how you put responsibility on the patient. At least I think so...But they have to know that [about their medications]" (Physician, workshop 1).
Make medication treatment safer	
Create security in collaboration	"I would feel more secure with information on how to take the medicine and when check-ups will take place and what measurements apply to each diagnosis" (Older person, survey).
Reduce unnecessary care	"I think you should still be able to spend some time on it because you probably gain a lot from it in the end. You avoid contact with us as well many times...To doctors when we ask things that could already have been answered" (Nurse, interview).

Quantitative Data Regarding the Participants' Design Choices for the Medication Plan

Zoom polls conducted during workshop 1 were used to narrow down the participants' views about what needs the medication plan must meet (Zoom polls 1-4) and their views about function and content requirements for the medication plan (Zoom polls 5-10). In workshop 1, 2 (14%) of the 14 participants participated together via the same computer, resulting in 13 respondents on the Zoom polls (Table 5). In workshop 2, Zoom polls were used to address the final specifications for the medication plan (Zoom polls 11-16). Moreover, in workshop 2, of 14 participants, the same 2 (14%) participants participated via the same computer, and 1 (7%) participant did not respond to the Zoom polls, resulting in 12 respondents (Table 5).

The survey was answered by 13 (93%) of the 14 participants. All (13/13, 100%) participants agreed that treatment goals and when and how treatment should be evaluated constituted the most important content in a medication plan and that this content was included in the prototype. In addition, everyone (13/13, 100%) agreed that the medication plan should be integrated into the medication list. In the questions with response options (Table 6), the older persons' responses had higher median scores, and the nurses and physicians had lower median scores than those of the entire group. How well the prototype corresponded to a perfect medication plan had a slightly lower median score than the other questions.

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Table 5. Presentation of the Zoom polls and the participants' responses during the workshops.

Zoom polls	Responses, n (%)
Needs for the medication plan (n=13)	
1. What needs are most important for a medication plan to be safe and usable? (choice of 3)	
Easily available in the medical record	3 (23)
Information easy to understand	4 (31)
Same information to everyone involved	10 (77)
One way to communicate	2 (15)
Can be printed in paper	4 (31)
Clear agreement about responsibilities	11 (85)
"Contact person" for continuity	5 (38)
2. How will a medication plan be accessible for those needing it? (multiple choices)	
Displayed in the EHR[a] within the regional health care system	5 (38)
Be visible digitally at 1177[b]	10 (77)
Be visible digitally in the NPO[b,c]	8 (62)
Be printed on paper	4 (31)
Within the medication list	12 (92)
Do not know	0 (0)
3. A clear division of responsibilities between persons included is (single choice)	
Very important	11 (85)
Important	2 (15)
Not that important	0 (0)
Unimportant	0 (0)
Do not know	0 (0)
4. The medication plan must be completed during the visit to a physician (single choice)	
Yes, it should be ready to hand over at the visit.	6 (46)
No, it can be sent home or be available in 1177[b] and NPO[b] after the visit.	6 (46)
Unimportant	0 (0)
Do not know	1 (8)
Function and content requirements for the medication plan (n=13)	
5. What information should be included in a medication plan? (multiple choices)	
Why the treatment is initiated	10 (77)
Treatment aim	13 (100)
When a medication will be reevaluated	11 (85)
How a medication will be followed up	9 (69)
Who will do the tests, measures, and take blood sample	8 (62)
Clear agreement	7 (54)
Who will follow up the treatment	10 (77)
6. Who will use the medication plan? (multiple choices)	
The patient	13 (100)
Next of kin	12 (92)
Physicians	12 (92)
Nurses in home health care	12 (92)

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Zoom polls	Responses, n (%)
Home care service staff	7 (54)
Care coordinators	13 (100)
Nurse in telephone counseling	8 (62)
Other	1 (8; pharmacist)
7. When will the medication plan be used? (multiple choices)	
At the annual check-up at the primary care center	12 (92)
At all visits to the primary care center concerning medications	11 (85)
At home when you want to know the next step	7 (54)
In-home health care when planning care and treatment	12 (92)
Do not know	0 (0)
8. How often should a medication plan be updated? (multiple choices)	
At each change of medication	12 (92)
At an annual check-up	9 (69)
At each physician's visit	2 (15)
Unimportant	0 (0)
Do not know	0 (0)
9. Where should the information be available? (single choice)	
Included in the medication list, visible in the health care provider's EHR, at 1177[b] and NPO[b]	5 (38)
As text in a medical note visible in the health care provider's EHR, at 1177[b] and NPO[b]	3 (23)
In a shared care plan, visible in the health care provider's EHR, 1177[b] and NPO[b]	2 (15)
Do not know	2 (15)
10. Could a medication plan promote safer medication treatment? (single choice)	
Yes	8 (62)
Partly	5 (38)
No	0 (0)
Do not know	0 (0)
Specifications for the medication plan (n=12)	
11. Do you agree with the summary presentation from the last session? (single choice)	
Fully agree	10 (83)
Agree	2 (17)
Partly agree	0 (0)
Do not agree	0 (0)
12. Where should the medication plan be positioned in the EHR? (single choice)	
As a separate care plan within the medical notes	1 (8)
Within the medication list	11 (92)
Do not know	0 (0)
13. What 3 keywords are the most important in a medication plan, to make it usable and safe? (multiple choices)	
Indication (why treatment is given)	6 (50)
Medication (and dosage)	12 (100)
Treatment aim	8 (67)
Effect and side effects	5 (42)
Duration of treatment	5 (42)

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Zoom polls	Responses, n (%)
Planning and follow-up (in what way)	10 (83)
Responsibility	4 (33)
14. If it takes 15 min to complete a medication plan, within a 45-min visit, which option do you prioritize? (single choice)	
The medication plan is documented during the visit and handed over directly	8 (67)
The medication plan is documented after the visit, available afterwards	2 (17)
Do not know	2 (17)
15. How safe for patients does the medication plan feel? (single choice)	
0=not safe at all	0 (0)
1	1 (8)
2	10 (83)
3=very safe	0 (0)
Do not know	1 (8)
16. How usable does the medication plan feel? (single choice)	
0=not usable at all	0 (0)
1	0 (0)
2	7 (58)
3=very usable	5 (42)
Do not know	0 (0)

[a]EHR: electronic health record.

[b]Secure web interface where patients (1177) and health care professionals (National Patient Overview) can access EHR.

[c]NPO: National Patient Overview.

Table 6. Median scores from the survey with responses on a 10-grade Likert scale[a].

Question	Total (n=13), median (IQR)	Older persons (n=5), median (IQR)	Nurses (n=5), median (IQR)	Physicians (n=3), median (IQR)
1. To what extent do you feel that the prototype meets your objectives for a medication plan?	9 (7-10)	10 (8-10)	8 (7-10)	9 (7-10)
2. Do you think that the time it would take to create or maintain a medication plan at a health care visit corresponds to its contribution to patient safety?[b]	9[b] (7-10)	9.5[b] (9-10)	9[b] (8-10)	8 (7-9)
3. To what extent do you think that the medication plan may contribute to increased patient safety in medication treatment?	9 (7-10)	9 (7-10)	8 (7-10)	8 (7-9)
4. To what extent do you think the prototype is usable for you?	9 (6-10)	10 (9-10)	8 (6-10)	8 (2-9)
5. Would you consider using the prototype as a medication plan?	9 (7-10)	10 (9-10)	9 (7-10)	9 (7-10)
6. Imagine a perfect medication plan; how well does the prototype match your image?[c]	8[c] (7-10)	9[c] (8-10)	7 (7-9)	7 (7-8)

[a]Response on the Likert scale for questions 1 to 5: 1=do not agree and 10=totally agree; response on the Likert scale for question 6: 1=worst possible match and 10=best possible match.

[b]Three participants (n=2, 67% nurses and n=1, 33% older person chose “do not know”).

[c]One participant (1 older person did not answer).

Discussion

Principal Findings

In studying a co-design initiative, we explored how older persons, physicians, and nurses in home health care reasoned about different design choices that would make a medication plan work out in clinical practice and promote patient safety. The participants had partly diverging views about the needs and requirements for a medication plan; for instance, the older persons raised the need for understandable and clear information, and the physicians highlighted the need for a balanced amount of information. The nurses emphasized a function that could

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make information instantly obtainable. After reasoning about 2 generated drafts, they agreed on 1 medication plan prototype linked to the existing medication list (Figure 2). According to the participants, a medication plan needs to support communication, continuity, and interaction. To do so, they noted that information in the plan has to be adequate and adapted to all involved persons, which was further highlighted as important as the initiative progressed, as well as that the plan must be updated and transparent. An important function requirement that the participants agreed on and emphasized repeatedly was accessibility for all involved. The group defined accessibility as the possibility to share the plan easily within the EHR or as a printout. Embedded alerts and digital communication within the system, as well as automatically and instantly displayed information, were other key functions. Together with relevant medications, the participants found treatment aims and a plan for re-evaluation to be important content to include in the medication plan. Having a heterogeneous group of potential users reason together about the needs and requirements for the medication plan generated discussions on the potential everyday value of using the medication plan. The participants said that the medication plan had the potential to promote safer medication treatment and patient engagement, but they raised challenges related to its application and use in daily clinical practice.

Comparison of Data and With Prior Work

Constantly updating the medication plan at annual visits at the primary care center or when medications were changed was prioritized by the participants according to the Zoom polls. Including the medication plan in the existing medication list was a requirement that was increasingly asked for over time according to both qualitative and quantitative data. Functions that made information instantly obtainable, automatically displayed, and updated were specified in general. The older persons asked for functions that would make the medication plan readily accessible to them and persons who support them. Sharing of and access to information similarly emerged as key issues in a qualitative study about patients' perceptions of safety in primary care [39]. Likewise, an Australian co-design study addressing what older people want from integrated care showed that important aspects included the transfer of information among persons involved in a patient's care [40]. Providing patients with access to their medical notes in the EHR improves their confidence in managing their own care [41], and digital health is increasingly embraced by older persons as well [42], indicating the importance of digital access to a medication plan for all those involved. In addition, the participating nurses raised the need for a medication plan that was easy to gain an overview of and with functions that made information instantly obtainable. The function requirement of having a plan obtainable via instant access to EHRs corresponded well with other studies performed with nurses in home health care in Sweden, as limited access to medication lists and medical record systems causes problems [43,44]. Variable access to medical records may also explain why the nurses in this study were not as satisfied as the other participants with how the final prototype met their expectations of a usable medication plan. In Sweden, comprehensive medical record keeping is regulated by a law on comprehensive health and care documentation [45], which allows organizations connected to the NPO to share medical information about a patient. The interoperability among EHRs seems to positively influence medication safety [46].

On the basis of all the participants' responses to the Zoom polls, treatment aims, plans for follow-up, and clarity about responsibilities were prioritized content throughout the initiative. In addition, a need for the provision of consistent information in the medication plan to all those involved was emphasized. According to the qualitative data, the older persons prioritized content related to medications, whereas the health care professionals asked more specifically for content related to what situations to alert about and when to evaluate. Moreover, the older persons particularly highlighted the need for information that was understandable to them. The importance of receiving understandable information has also been reported in other studies addressing older persons' experiences with information on medications [47] and their perceptions of safety [48,49]. Throughout the sessions, the physicians highlighted the need for a plan with a balance of sufficient information and with functions that could optimize documentation, for instance, by automatically copying information written in one note to other places in the EHR where the same information is needed. Since the implementation of EHRs in health care, there has been an ongoing debate addressing the physicians' increasing workload related to excessive data entry requirements, long medical notes, and inaccessibility of information from other health care providers [50]. Moreover, questions about the amount of important therapeutic data in medical records have been addressed in an observational study in the Netherlands [51], exploring the ways in which therapeutic information in medical records is structured. Addressing the need for an optimal amount of data with a good structure is, therefore, important for a medication plan.

The participants highlighted the challenges and opportunities associated with a medication plan during the initiative. In the Zoom polls, the participants reflected on the notion that a medication plan would initially require extended time to create. In the discussions, the physicians especially addressed the challenges of not only prioritizing time but also individualizing the plan for each older person. The limited time during visits with older persons to discuss issues beyond acute problems and challenges in including their own goals and preferences into decisions around medications have been reported on previously [52] and will be important to address to make the medication plan work out well.

According to the survey, the older persons agreed more than the nurses and physicians that the medication plan might contribute to increased patient safety. The older persons also emphasized the potential for increased patient involvement. Empowering patient involvement and increased safety may be interrelated, as emerging evidence suggests that patients can, as cocreators of resilience, positively impact outcomes within health care [10]. To involve patients in both the health care they receive and the design of health care processes is in general both moral and logical according to O'Hara et al [53], as such involvement may support the resilience of the system. Having patients and others involved in the patient's medication use

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process, knowing what to observe, when to act, who should act, and what actions they should take in case of deviation from the plan, can promote resilient performance [54,55], that is, the capacity to adapt to challenges and changes to maintain safety.

Even if the participants had partly diverging views during the initiative, their responses to the final survey showed that the medication plan prototype met their objectives to a large extent. In addition, they perceived that the prototype was jointly developed and accepted by consensus [26]. Undertaking a co-design process in which needs and requirements are specified can involve challenges [56,57] in achieving a shared understanding, managing the complexity of the different participants' perspectives based on their different knowledge of the system, and transforming ideas into concrete functions. Even so, by involving users in the design of a medication plan, the chance that they will start using it in clinical practice increases [58].

Strengths and Limitations

To ensure trustworthiness and that the findings in this case study mirrored the participants' views of a medication plan prototype, we considered credibility, confirmability, dependability, and transferability throughout the analysis [59].

The co-design initiative involved 14 persons, namely older persons, physicians, and nurses in municipality-based home health care. The older persons we recruited, within the initiative Patient Contracts, may be considered as extra knowledgeable about and interested in strengthening patients' role in health care. Persons who could not speak Swedish or who were unable to use a computer were excluded. Before starting, we hoped to involve next of kin as well, as they often play an important role in medication management for older persons [60]. The recruitment strategies and lack of the next-of-kin perspective can affect the *transferability* of the identified needs and requirements to other persons' views. Testing the prototype will, therefore, be important to see whether it is consistent with other people's views.

To support *dependability*, we conducted a pilot test of the setup for the initiative to determine whether the sessions allowed the participants to share their views about the needs and requirements for a medication plan. This resulted in some minor adjustments to the setup.

When considering the *confirmability* of data, objectivity is important. Therefore, peer debriefing was used in the directed content analysis, where the first and last authors refined the data and then presented the findings to and discussed the findings with the entire author group.

Finally, to ensure *credibility* and link the findings to reality, the drafts and findings from each session were shared continuously with the participants during the initiative. This allowed the participants to clarify their intentions, correct errors, and provide additional information in iterative loops. To ensure that the voices of all the participants were heard, the facilitators arranged moderated discussions. According to the participants, they were able to express their views during the co-design initiative and were listened to [26].

Future Directions

The last step in the Double Diamond co-design framework [33], the *Delivery* phase, involves testing the co-designed intervention to explore how it works and connects with users in the setting it is intended for. Therefore, user testing of the medication plan prototype in clinical practice is a natural future step. This could be seen as a complex intervention, containing several interacting components and possibly producing varied outcomes, making it important to first test it on a small scale to find ways to collect data and evaluate outcomes [61].

Conclusions

After reasoning about the needs and requirements for a medication plan, the participants agreed on an iteratively developed medication plan prototype linked to the medication list within the existing EHR. They stated that the needs for a medication plan are to support communication, continuity, and interaction; provide information that is adequate and adapted to everyone; and be easy to access and gain an overview of. According to the participants, the medication plan prototype may promote patient safety and enable patient engagement, but concerns were raised related to its use in daily clinical practice.

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Data Availability

The data generated during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

All the authors contributed to the design of the study and the discussion of the findings and approved the final manuscript. MH and BL arranged the setup for the co-design initiative together with a quality improvement adviser at Region Jönköping County. MH participated in the workshops, performed the interviews, analyzed the data, and drafted and revised the manuscript. AR and

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LJ participated in the analysis and interpretation of data and in reviewing and editing the manuscript. JT and BL participated in the interpretation of data and editing of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey.
[DOCX File , 29 KB - aging_v6i1e49154_app1.docx]

Multimedia Appendix 2
Interview guide.
[DOCX File , 24 KB - aging_v6i1e49154_app2.docx]

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Abbreviations

ADE: adverse drug event
EHR: electronic health record

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NPO: National Patient Overview

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Review

Digital Intergenerational Program to Reduce Loneliness and Social Isolation Among Older Adults: Realist Review

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Abstract

Background: There is a compelling need for an innovative and creative approach to promote social connectedness among older adults to optimize their well-being and quality of life. One possible solution may be through a digital intergenerational program.

Objective: This realist review aimed to identify existing digital intergenerational programs that were used to reduce loneliness or social isolation among older adults and analyze them in terms of strategy, context, mechanisms, and outcomes.

Methods: We performed a realist review with an extensive search of published and gray literature. For scholarly literature, we searched PubMed, Embase, CINAHL, PsycINFO (Ovid), and Social Sciences Citation Index databases for articles published between January 2000 to August 2020. A grey literature search was performed using the Google search engine, and the search was completed in May 2021. We included programs that evaluated digital intergenerational programs for older adults, which described outcomes of loneliness or social isolation. We included quantitative, mixed methods, and qualitative studies, as well as relevant theoretical papers, policy documents, and implementation documents. The studies were appraised based on their relevance and rigor. We synthesized the available evidence from the literature into Strategy-Context-Mechanism-Outcome (S-C-M-O) configurations to better understand what, when, and how programs work.

Results: A total of 31 documents reporting 27 digital intergenerational programs were reviewed. Our final results identified 4 S-C-M-O configurations. For S-C-M-O configuration 1, we found that for community-dwelling older adults, provision of access to and training in digital technology may increase older adults' self-efficacy in digital devices and therefore increase the use of digital communication with family. In S-C-M-O configuration 2, digital psychosocial support and educational interventions from nurses were found to be useful in reducing loneliness among community-dwelling older adults. In S-C-M-O configuration 3, a video call with a student or family was found to reduce loneliness among older adults residing in long-term residential care facilities. Finally, for S-C-M-O configuration 4, we found that behavioral activation provided through videoconferencing by a lay coach may be useful in reducing loneliness among older adults who are lonely. However, as almost half (11/27, 41%) of the included programs only reported quantitative results, this review focused on screening the discussion section of publications to identify author opinions or any qualitative information to elucidate the mechanisms of how programs work.

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Conclusions: This review identified the key strategy, context, and mechanism influencing the success of programs that promote intergenerational interaction through digital means. This review revealed that different strategies should be adopted for different groups of older adults (eg, older adults who are lonely, older adults who reside in long-term residential care facilities, and community-dwelling older adults). The S-C-M-O configurations should be considered when designing and implementing digital intergenerational programs for older adults.

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KEYWORDS

aged; loneliness; older people; review; social isolation

Introduction

Background

Driven by decreased fertility rates and increased life expectancy, worldwide population aging is expected to continue [1]. The number of people aged 65 years or older is projected to grow from an estimated 524 million in 2010 to nearly 1.5 billion in 2050, representing around 16% of the total world population in 2050 [2]. Loneliness and social isolation in older adults affect a significant proportion of older adults worldwide, with current estimates of the extent of loneliness among older adults living in the community to be around 50% [3], and around half of people aged >60 years are at risk of social isolation [4]. Loneliness and social isolation pose serious public health risks as they are associated with adverse health outcomes [5,6]. Loneliness may be associated with higher blood pressure, worse sleep, immune stress responses, and worse cognition over time in older adults [7]. A meta-analysis demonstrated that social isolation among older adults significantly increases the likelihood of mortality, and its influence on mortality risk is comparable with well-established risk factors such as smoking, obesity, and physical inactivity [8].

One possible solution to mitigate loneliness and social isolation among older adults may be through an intergenerational program that leverages digital technology [9]. An intergenerational program can be defined as “vehicles for the purposeful and ongoing exchange of resources and learning among older and younger generations for individual and social benefits” [10]. Intergenerational programs can strengthen connections among different age groups and promote organized shared experiences, which may enhance the health of older adults by decreasing the risk of loneliness and social isolation [11-13]. An added advantage of intergenerational interaction over peer interaction is that it provides younger generations with an opportunity to break down agist stereotypes [14], which will help in strengthening community cohesion [15]. Previous reviews have demonstrated the advantage of intergenerational interaction over peer interaction, including allowing younger counterparts to develop new communication skills and improved perceptions toward older adults [9,13,16]. In fact, the Decade of Health Ageing by the World Health Organization has emphasized the need for intergenerational solidarity [17]. Intergenerational programs are usually conducted face to face, and some examples include conducting home visits or organizing large-scale events involving people from different age groups [13,18]. Although there are systematic reviews available that summarize the interventions for reducing social isolation and loneliness in older persons [19-22], these reviews did not focus on intergenerational programs.

During the COVID-19 pandemic, social isolation among older adults intensified with the implementation of social distancing measures [23-26]. Therefore, using digital technology such as video calls to achieve intergenerational bonding becomes more compelling considering the social distancing measures implemented worldwide [27]. The other advantages of digital intergenerational programs in combating loneliness and social isolation among older adults are their ability to connect and reconnect people across large geographic distances, and their support for both synchronous and asynchronous forms of communication [28]. Current reviews of intergenerational programs are primarily based on face-to-face interventions [29-31], with a lack of emphasis on digital interventions. Although there is a scoping review by Reis et al [32] on technologies that foster intergenerational connectivity and relationships, it did not provide an analysis of program outcomes.

In addition, previous traditional reviews tend to predominantly focus on whether the intervention “worked,” often without an understanding of the complexity of the intervention in terms of for whom they may or may not work, under what context and mechanism [33]. The realist review methodology used in this study seeks to provide an explanatory analysis aimed at discerning what works for whom, in what circumstances, in what respect, and how [34]. The emphasis on strategies, contexts, and mechanisms in our realist review can provide an in-depth understanding of how and why interventions are successful or unsuccessful [22,35], which is lacking in existing reviews on intergenerational programs [29,31]. In addition, as studies on intergenerational programs are unlikely to be randomized controlled trials, a realistic review looking at strategy, context, mechanisms, and outcomes will be more appropriate.

Objective

This review aimed to identify existing digital intergenerational programs used to reduce loneliness or social isolation among older adults and analyze them in terms of strategy, context, mechanisms, and outcomes. The findings of this study will inform the design and implementation of digital intergenerational programs to reduce loneliness or social isolation among older adults.

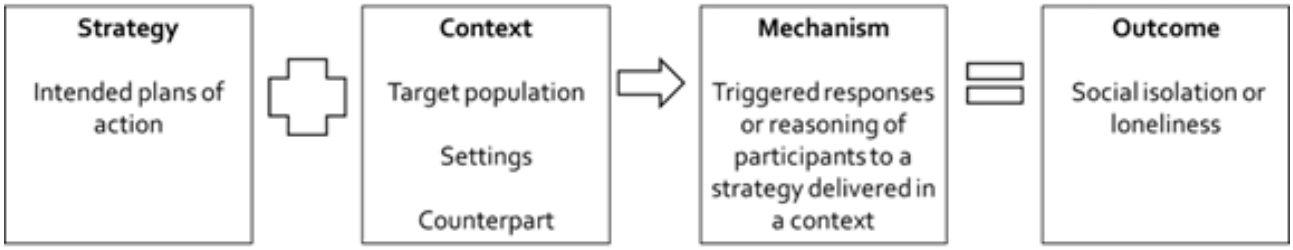
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Methods

Overview

Our review followed the realist synthesis principles recommended by Pawson and Tilley [36] and was anchored based on the Realist And Meta-narrative Evidence Synthesis: Evolving Standards criteria [37]. In this review, we used the Strategy-Context-Mechanism-Outcome (S-C-M-O) configuration (Figure 1) as this review aimed to understand which digital intergenerational program strategies have been implemented and why some of these strategies were successful [38]. Therefore, the strategies were explicitly identified, along with the context in which they were implemented, the mechanism that was triggered, and which outcome was consequently generated [39]. In this review, we focus on the target population, settings, and counterparts under the context. This S-C-M-O configuration has also been adopted in other realist reviews [40,41].

Figure 1. Strategy-Context-Mechanism-Outcome (S-C-M-O) formula.



Evidence Search

We performed a systematic review of the scholarly and gray literature. We searched the PubMed, Embase, CINAHL, PsycINFO (Ovid), and Social Sciences Citation Index databases for articles published between January 2000 to August 2020. Although intergenerational programs have existed for many decades, most empirical studies assessing the influence of intergenerational interactions on health-related outcomes in older adults have been conducted since 2000 [30,42]. The search in the electronic databases was performed on September 17, 2020. A search strategy with 3 components (ie, "elderly," "digital communication," and "intergenerational relationships"), which was devised in collaboration with an information specialist librarian, was utilized (Multimedia Appendix 1). The search filter of the English language was applied when available to minimize potential information loss during the translation process. We downloaded the search records into Endnote and duplicates were removed. A gray literature search was performed using the Google search engine with "intergenerational and elderly and digital" search strings. All 197 results from the Google search engine were screened, and the search was completed on May 2, 2021. Snowball searching was used to identify additional articles based on the reference lists of the included studies and relevant systematic reviews.

Two members of the study team (JKP and HG) independently screened all identified articles. For the scholarly literature, a 2-stage screening process was used where title and abstract were reviewed in the first stage, followed by a review of full-text articles in the second stage. The disagreement rates between the 2 reviewers were 0.14% (6/4382) and 0.9% (2/226) at the title or abstract and full-text screening stages, respectively. For gray literature, the entire document was reviewed because of a lack of executive summary or equivalent in some documents. Any discrepancies in article eligibility were discussed with a third reviewer (YHK) until consensus was reached.

Quantitative, qualitative, and mixed method studies were included. Studies met the inclusion criteria if they described 2-way digital interaction involving older adults with nonfamilial younger generations or with family, were written in English, were evaluative, and described outcomes of interests including loneliness, social isolation, or other related concepts such as social participation and social connectedness. These outcomes are selected given the lack of consistent definition of social isolation in the literature [43] as well as the interchangeable use of "loneliness" and "social isolation" in literature [43]. As there are various definitions of the age range of "older" populations [32,44], a cutoff for the lower age limit was also not specified. As such, we included programs that identified themselves as focusing on older adults or grandparents [32]. The nonfamilial younger generation was defined as either being 30 years old or younger for nonfamily members based on criteria from a previous review [31]. In cases where the characteristics of the intergenerational counterparts were unclear (eg, age of the nurses or coaches involved in communicating with older adults were not clearly described), we contacted the corresponding author to clarify, and only included programs where the counterparts (eg, nurses and coaches) were aged 30 years old or younger. We excluded programs (n=3) [45-47] where the corresponding author did not respond. However, because of the small number of programs focusing solely on digital intergenerational communication (n=1) after an initial review of the literature, we included programs that allow both intergenerational and nonintergenerational digital communication (eg, peer communication). For the familial intergenerational program, we included programs that described digital interaction with family in general, as most of the quantitative studies did not specify the types of digital familial interaction, and this allows a more comprehensive view of the programs available for digital intergenerational communication. More importantly, studies have demonstrated that similar programs are likely to increase contact with younger generations such as children and grandchildren who are well versed with digital technology [48,49]. Descriptive, nonevaluative articles were also included if they were related to a program that had been formally evaluated and included in the review. Articles that were not

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program specific (eg, commentaries or discussion papers) were excluded.

Data Extraction and Appraisal of Studies

Relevant information from the documents was extracted using a data extraction template. The studies were appraised based on their relevance and rigor. Relevance was defined as the level of contribution to the review, and rigor was defined by the methodological quality of a study conducted on a digital intergenerational program. Relevance was assessed by reviewing the details provided for (1) context (eg, user, program features, or design components), (2) mechanism: hypotheses as to how specific strategy worked or did not work, and (3) outcome: reasons for effect or lack of effect on outcomes related to loneliness or social isolation. These details were obtained by reviewing the documentation of usability evaluation, program or study protocols, and publications related to evaluations (eg, clinical intervention studies evaluating efficacy or effectiveness). In programs where authors did not describe how they thought their program worked or did not work, this was inferred by the study team after careful reading of the description of the program. The relevance was rated as low (little or no information), medium (some information), and high (well-described information). The criteria for assessment of relevance were adopted from a previous realist review [33], in which "strategy" was considered in the mechanism section. The methodological quality of evidence (rigor) around each therapy was assessed using the Mixed Methods Appraisal Tool (MMAT) [50]. The MMAT assesses the quality of qualitative, quantitative, and mixed methods studies. It focuses on methodological criteria and includes five core quality criteria for each of the following five categories of study design: (1) qualitative, (2) randomized controlled, (3) nonrandomized, (4) quantitative descriptive, and (5) mixed methods.

Evidence Synthesis

We examined the strategy, context, mechanism, and outcome in each program and looked for recurrent patterns of outcomes and their associated strategies, contexts, and mechanisms. We concentrated on what appeared to be recurrent patterns of contexts and outcomes in the data and then sought to explain them through the strategies and mechanisms by which they occurred. The proposed S-C-M-O configurations were analyzed at different levels of abstraction (within and across programs) to determine the most robust and plausible explanations of how, in a context, with the strategy and mechanism, the outcomes observed could be generated. The evaluation of relevance and rigor was considered when generating and revising S-C-M-O configurations. The initial list of S-C-M-O configurations was revised based on the consensus between study team members, based on the synthesis process recommended by Pawson [51], including synthesis to adjudicate between rival program theories and synthesis to consider the same theory in comparative settings.

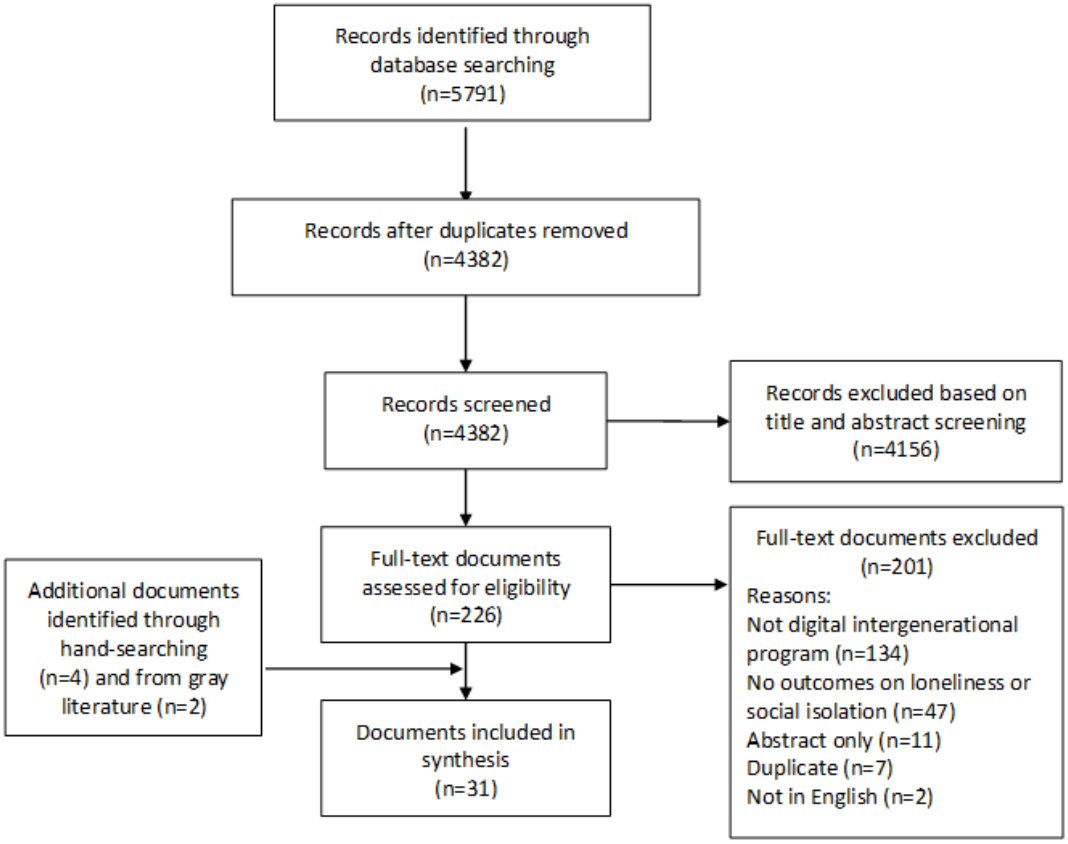
Results

Overview

Figure 2 presents a flow diagram outlining the evidence-based search process. We retrieved 5791 records from the scholarly literature search of 5 databases (PubMed, CINAHL, PsycINFO, and Social Sciences Citation Index databases). After removing duplicates, a total of 4382 unique and potentially eligible documents were reviewed for inclusion. We excluded 4156 records and 201 documents at the title or abstract and full-text screening, respectively. The reasons for exclusion at the full-text screening stage can be found in Multimedia Appendix 2. We added 4 documents from the snowball searching method based on the reference lists of already included studies and relevant systematic reviews. In addition, we also retrieved 2 relevant documents from the grey literature search using the Google search engine. In total, 31 documents from the scholarly and grey literature search detailing 27 unique digital intergenerational programs were included for synthesis in this realist review.

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Figure 2. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram.



Structure and Delivery Features

Table 1 presents an overview of the structure and delivery features of the 27 programs. A total of 10 programs were for older adults residing in long-term residential care [52] (including nursing home [53-55], retirement homes [56], aged care facilities [57], assisted living retirement facilities [58], social housing [59], care homes [60], and veterans' care facility [61]), 16 programs for community-dwelling older adults [62-75], and 2 programs included both community-dwelling older adults and older adults residing in long-term residential care facilities [48,76]. Only 1 program (StoryBox) was designed for exclusive digital intergenerational interactions [70]. Most (8/27, 30%) programs were conducted in the United States [53,58,60,66,72,74,76,77].

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Table 1. Structure and delivery characteristics of digital intergenerational program.

Program, country	Participants			Program detail					
	Age (years)	Older adults, n	Lonely or socially isolated	Settings	Duration	Strategy	Intergenerational component	Device	Training for older adult
ACTION [62], Norway	57-85	19	Not specified	Community-dwelling	12 months	Participants received a modern broadband-linked PC, and an ICT[a] course consisting of three 3-hour classes dispersed over a 3-week period.	Email with grandchildren	Computer	Yes
ACTION (redesigned) [63], Sweden	66-85	8	Not specified	Community-dwelling	Not specified	The app integrated a web-based multimedia system and the video communication system into a single user interface. Users could access a variety of multimedia information programs in the ACTION database and use the videoconferencing device for consultation and social purposes.	Video call with family	Computer	Yes
ACTIVE [52], Norway	Mean 78.3 (SD 12.5)	15	Not specified	Long-term residential care	1 year	Participants were provided with an internet connected tablet, free of charge, to use as they liked for an unlimited period. The iPad was set up with an individual user account, including email, Apple-ID, Skype-ID, passwords, and codes.	Messaging, video call, and email with younger generations of family, for example, grandchildren	Apple iPad	Yes
AGES 2.0 [48], United Kingdom	60-95	53	Not specified	Community-dwelling and long-term residential care (care homes)	12 months	Participants received a customized computer platform with a simplified touchscreen interface (“EasyPC”) and any necessary broadband infrastructure. “Care technologists” administered the training.	Digital interaction (email, Skype, or Facebook) with younger generations of family, for example, children and grandchildren	Customized computer platform with a simplified touchscreen interface	Yes

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Program, country	Participants			Program detail					
	Age (years)	Older adults, n	Lonely or socially isolated	Settings	Duration	Strategy	Intergenerational component	Device	Training for older adult
AO [73], Australia	58-81	7	Yes	Community-dwelling	8 months	Participants were provided Apple iPad with cellular access, along with vouchers for data access throughout the project, and App Store card for buying apps.	Messaging with younger generations of family, for example, children	Apple iPad	Yes
Collage and storytelling [71], Australia	Not specified	3	Not specified	Community-dwelling	3 weeks	The system used combines the "Collage" component and the "Storytelling" component.	Digital intergenerational play and storytelling with grandchildren	Touch screen monitor	No
Demiris et al [58], United States	>65	4	Not specified	Long-term residential care (assisted living retirement facility)	3 months	The videophone can display 3 kinds of real-time images during a video call: self, other party, and a combination of both, depending on user preference. It plugs into a regular telephone and does not interfere with its use. A video call is possible only when both parties have videophone units and consent to a video call.	Video call and email with younger generations of family, for example, grandchildren	Video-telephone	No
Digital age [59], Northern Ireland	Not specified	82	Not specified	Long-term residential care (social housing)	10 weeks	Digital Age consisted of a free, in-house, 10-week IT course for residents. The program also provided free IT hardware for each participating housing scheme, free web-based digital toolkits for older learners and their supporters, and a series of intergenerational digital projects to encourage links between older and younger people, further develop residents' digital capabilities and help to sustain the program beyond the program lifetime.	Video call with family	Not specified	Yes

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Program, country	Participants			Program detail					
	Age (years)	Older adults, n	Lonely or socially isolated	Settings	Duration	Strategy	Intergenerational component	Device	Training for older adult
Esc@pe [75], Netherlands	Mean 66	12	Yes	Community-dwelling	3 years	At the start of the project, participants were given five 2-hour lessons at home by experienced teachers. During these lessons, the participants learned how to email and how to use the internet. During the rest of the project, the participants were supported and coached by visiting volunteers who had also paid home visits to the participants once every 2 or 3 weeks before the start of the pilot project.	Using internet and email to communicate with family	Computer	Yes
InTouch [61], Canada	Mean 92.2 (SD 3.0)	11	Not specified	Long-term residential care	12 weeks	Veteran and volunteer participants were each given an iPad with the InTouch app on it, as well as a detailed instructions manual.	Using InTouch app to communicate with family	Apple iPad	Yes
LINE [54], Taiwan	Mean 81.1 (SD 8.5)	32	Not specified	Long-term residential care (nursing home)	6 months	Participants interacted with their family members once a week for 6 months using a smartphone and the "LINE" app. Discussion topics were provided to nurses and the participants, such as their meals, organized activities, and "news" on nursing home life.	Video call with family	Smartphone	No
Loi et al [57], Australia	Mean 69.9	5	Not specified	Long-term residential care (aged care facility)	6 weeks	Structured 6-week, twice weekly program of 45-minute duration based on a local program was used for older adults (internet for Seniors). Apple iPads were used.	Digital interaction with family	Apple iPad	Yes

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Program, country	Participants				Program detail				
	Age (years)	Older adults, n	Lonely or socially isolated	Settings	Duration	Strategy	Intergenerational component	Device	Training for older adult
Media Parcels [64], United Kingdom	82	1	Not specified	Community-dwelling	Not specified	A facilitator, upon specific requests to participants, collects media and wraps them in text commentary, bringing out their memories and meaning. Next, the facilitator passes the wrapped media parcel to a target person, who in turn unwraps them.	Digital interaction with children	Not specified	Not specified
MSN[b] or Skype [55],Taiwan	Mean 74.4 (SD 10.2)	24	Not specified	Long-term residential care (nursing home)	3 months	The videoconference program was designed for once a week (the in-person visiting frequency for most families) and to last for 3 months to provide time for adjustment to a new program. The residents were helped to use the videoconference technology by a trained research assistant, who spent at least 5 minutes per week with the residents at the appointment time.	Video call with family	Computer	No
Neves et al [56], Canada	74-95	12	Not specified	Long-term residential care (retirement home)	3 months	The app allowed residents to send and receive photos, audio, video, and text messages with sent messages being predefined to increase simplicity. The residents' contacts could respond using their own emails and devices.	Using app to communicate with younger generations of family, for example, children	Apple iPad	Yes
Plymouth SeniorNet [65], United Kingdom	One-to-one help: mean 79.0 (SD 7.5); group help: mean 74.3 (SD 8.2)	144	Not specified	Community-dwelling	Depends	Sessions by volunteers covered basic computer use, how to get on the web and search the internet, shopping, email, Skype or FaceTime, and web-based news and entertainment.	Digital interaction with family	Computer	Yes

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Program, country	Participants			Program detail					
	Age (years)	Older adults, n	Lonely or socially isolated	Settings	Duration	Strategy	Intergenerational component	Device	Training for older adult
PRISM [66], United States	Mean 76.9 (SD 7.3)	300	Not specified	Community-dwelling	12 months	PRISM software app included internet access, an annotated resource guide, a dynamic classroom feature, a calendar, a photo feature, email, games, and web-based help.	Digital interaction with family	Computer	Yes
Skype [53], United States	71-97	40	Not specified	Long-term residential care (nursing home)	14 weeks	The Skype videoconferencing intervention took place on a weekly for a total of 10 sessions over a 14-week period in a private room at the nursing home.	Video call with family	Computer	No
Skype on Wheel [60], United States	Not specified	20	Not specified	Long-term residential care (care home)	6 weeks	Students from local school and older adults across 3 care homes in engaged in Skype video calls over a 6-week study. Residents were supported by care staff; students accessed Skype from school laptops. A conversational aid was trialed with students to assist their conversation with an older generation.	Video call with students	Wheeled device that could hold an iPad and handset	No
StoryBox [70], country not specified	63-76	8	Not specified	Community-dwelling	2-4 weeks	StoryBox alleviates the barriers of communication between different generations. For young grandchildren, this often means the sharing of crafts, drawings, stickers, and short exclamations. For grandparents, the device provides a way to digitize analog memories and use handwriting for communication.	Digital sharing of photos and audio recordings with grandchildren	Smartphone and tablet	No

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Program, country	Participants			Program detail					
	Age (years)	Older adults, n	Lonely or socially isolated	Settings	Duration	Strategy	Intergenerational component	Device	Training for older adult
Tech Allies [77], United States	Mean 75 (SD 7.9)	83	Yes	Community-dwelling	2 months	Participants took part in 8 weekly, 1:1 digital training sessions. Participants each received a tablet, a tablet case, a stylus, broadband access or a hot spot device, and a certificate of completion at the end of the program.	Digital interaction with family	Tablet	Yes
Tele-BA [74], United States	Mean 74.4 (SD 8.2)	43	Yes	Community-dwelling	12 weeks	Lay counselors delivered videoconference behavioral activation	Videoconference behavioral activation by lay counselors	Computer	No
Telesenior [67], Belgium	Mean 72 (SD 9.3)	71	Not specified	Community-dwelling	Not specified	The telenurses delivered psychosocial support and educational interventions based on 3 principles: contact and communication, safety and protection, and care mediation.	Video call with nurse	Video-telephone	No
Tlatoque [68], Mexico	Not specified	2	Not specified	Community-dwelling	21 weeks	Tlatoque communicates to Facebook site to expose photographs in the participant's home and provides means of reciprocating information into Facebook.	Digital interaction with younger generations of family, for example, children and grandchildren	Digital picture frame with wireless capabilities or PC with multitouch screen	Yes
White et al [76], United States	Mean 71 (SD 12)	48	Not specified	Community-dwelling and long-term residential care (nursing facility)	5 months	Participants received 9 hours of small group training in 6 sessions over 2 weeks. Computers were available for continued use over 5 months and the trainer was available 2 hours per week for questions.	Digital interaction with family	Computer	Yes

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Program, country	Participants				Program detail				
	Age (years)	Older adults, n	Lonely or socially isolated	Settings	Duration	Strategy	Intergenerational component	Device	Training for older adult
Williams et al [72], United States	Phase 1: 59-86; phase 2 54-82	Phase 1: 16; phase 2: 29	Yes	Community-dwelling	2 weeks	The course on computer-mediated communication lasted for six 2-hour classes. Each course followed the same module: introduction to computer-mediated communication, email and instant messaging, microblogging: Twitter, social networking sites: Facebook, video chat, and web-based safety.	Digital interaction with family	Computer	Yes
You, me and television [69], Portugal	65-73	3	Not specified	Community-dwelling	3-6 weeks	The system has three main features: (1) user feed; (2) managing groups of friends; and (3) photo viewing and sharing.	Digital interaction with family	Television	Yes

[a]ICT: information and communications technology.

[b]MSN: Microsoft Network.

Level of Contribution and Methodological Quality

An overview of the level of contribution and methodological quality of the documents elaborating the 27 programs is presented in Table 2. On the basis of the level of contribution assessment, 20 programs were rated as having a high level of contribution to the context, mechanism, and outcome. Across the programs, descriptions of mechanisms and outcomes were less developed than descriptions of contexts. All studies met at least 2 of the 5 MMAT criteria. The detailed MMAT appraisal of documents evaluating the digital intergenerational program is shown in Multimedia Appendix 3.

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Table 2. Level of contribution and methodological quality.

Program	Quality appraisal			Associated MMAT[a] scores
	Context	Mechanism[b]	Outcome	
ACTION	High	Low	Low	5 [62]
ACTION (redesigned)	High	Low	Low	2 [63]
ACTIVE	High	Medium	Low	5 [52]
AGES 2.0	High	High	High	3 [48]
AO	High	High	Medium	5 [73]
Collage and storytelling	High	High	High	4 [71]
Demiris et al	High	Medium	Low	4 [58]
Digital age	High	High	Low	5 [59], 5 [78]
Esc@pe	High	High	High	5 [75]
InTouch	High	High	High	5 [61]
LINE	High	High	High	5 [54]
Loi et al	High	High	Low	4 [57]
Media parcels	High	High	High	5 [64]
MSN[c] or Skype	High	High	High	5 [55], 5 [79]
Neves et al	High	High	High	5 [56]
Skype	High	High	High	5 [53]
Skype on Wheel	High	High	High	5 [60], 5 [49]
StoryBox	High	High	High	2 [70]
Tech Allies	High	High	High	3 [77]
Tele-BA	High	High	High	3 [74], 3 [80]
Telesenior	High	High	High	4 [67]
Tlatoque	High	High	High	5 [68]
PRISM	High	High	High	4 [66]
White et al	High	High	High	3 [76]
Williams et al	High	High	High	5 [72]
Plymouth SeniorNet	High	High	High	5 [65]
You, me and television	High	High	High	2 [69]

[a]MMAT: Mixed Methods Appraisal Tool.

[b]Consists of strategy and mechanism.

[c]MSN: Microsoft Network.

S-C-M-O Configurations

Of the candidate S-C-M-O configurations based on the authors' description (Multimedia Appendix 4), 4 S-C-M-O configurations were substantively supported by the available evidence (Figures 3-6). We present the configurations with key examples of strategies, contexts, mechanisms, and outcomes from the reviewed documents. S-C-M-O configurations 1 and 2 focused on community-dwelling older adults, S-C-M-O configuration 3 focused on older adults residing in long-term residential care facilities, and S-C-M-O configuration 4 focused on older adults who are lonely.

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Figure 3. Strategy-Context-Mechanism-Outcome configuration 1 involving provision of access and training to digital technology for community-dwelling older adults.

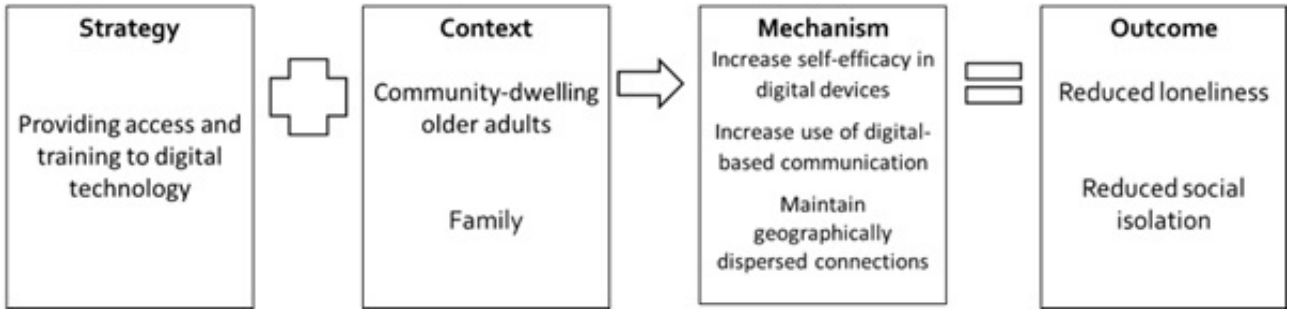


Figure 4. Strategy-Context-Mechanism-Outcome configuration 2 involving provision of digital psychosocial support and education by nurses for community-dwelling older adults.

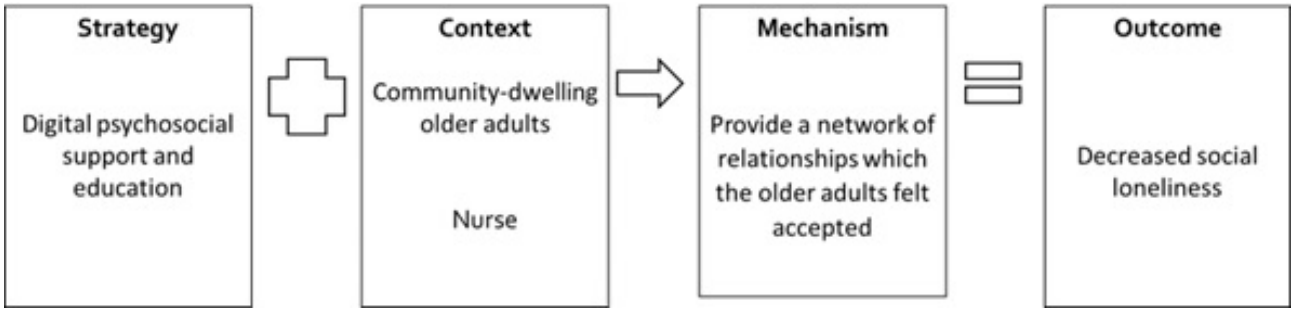


Figure 5. Strategy-Context-Mechanism-Outcome configuration 3 involving video call with older adults in long-term residential care facilities.

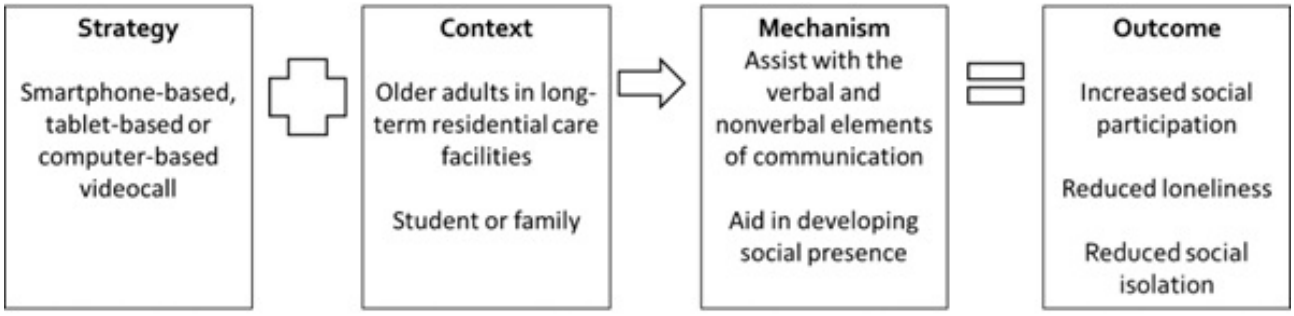
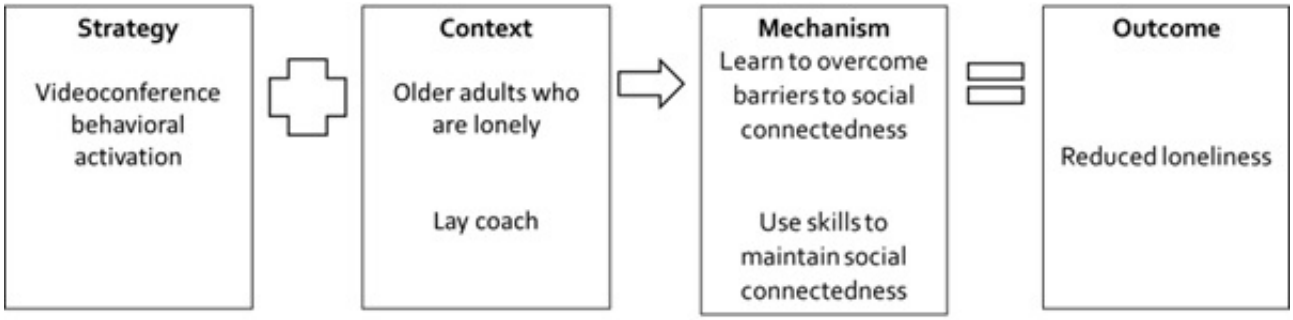


Figure 6. Strategy-Context-Mechanism-Outcome configuration 4 involving videoconference behavioral activation for older adults who are lonely.



S-C-M-O Configuration 1

A total of 4 programs contributed to this S-C-M-O configuration: ACTION [62], Plymouth SeniorNet [65], PRISM [66], and Tlatoque [68]. For community-dwelling older adults, provision of access to and training in digital technology may increase their self-efficacy in digital devices, thereby increasing the use of digital-based communication with family (Figure 3). The outcomes observed for the 4 programs included reduced loneliness [65,66], reduced social isolation [66], and increased frequency of contact [62,68].

In all 4 programs, the devices were provided free of charge for older adults. Of the 4 programs, 2 (PRISM [66] and Tlatoque [68]) used apps or systems specially designed for older adults, which may have "eased the adoption of the technology" [68]. The other programs used commercially available digital communication modes, for example, email (n=2) [62,65] and Skype (n=1) [65].

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The mode of training included one-to-one, group, and a combination of one-to-one and group training. In the Plymouth SeniorNet program, older adults attending group sessions appeared to have a greater reduction in loneliness as compared with those in one-to-one sessions, although the results from the two modes of training may not be comparable, as the allocation was not random [65]. Participants in the Plymouth SeniorNet program also mentioned that training conducted by someone closer to their age was important [65].

S-C-M-O Configuration 2

One program (Telesenior [67]) contributed to the S-C-M-O configuration. For community-dwelling older adults, digital psychosocial support and educational interventions from nurses were useful in reducing loneliness (Figure 4). In the Telesenior program, digital psychosocial support and educational interventions were delivered through video-telephone to homebound older adults based on 3 principles: contact and communication, safety and protection, and care mediation [67]. The digital psychosocial support and educational interventions from nurses can provide "a network of relationships which the older adults felt accepted, had common interests and concerns, and found help, advice, and support" [67]. In the Telesenior program, older adults who were older (>66 years old), were widowed, lived alone, had financial problems, and used several health and social services showed improvement in feelings of social loneliness after participating in the program [67].

S-C-M-O Configuration 3

A total of 7 programs—ACTIVE [52], Demiris et al [58], Digital Age [59], LINE [54], Microsoft Network (MSN) or Skype [55], Skype [53], and Skype on Wheel [60]—contributed to this S-C-M-O configuration. In this review, we found that video calls with students or families may be useful in reducing loneliness among older adults residing in long-term residential care facilities (Figure 5). Only 1 program (Skype on Wheel [60]) evaluated intergenerational communication with students from a local school, whereas the other 6 programs (LINE [54], MSN or Skype [55], Skype [53], ACTIVE [52], Demiris et al [58], and Digital Age [59]) were designed to facilitate communication with family members or friends of older adults in long-term residential care facilities. It has been hypothesized that a video call helps in language interaction as well as verbal and nonverbal elements of communication. Video calls may also aid in promoting a social presence for older adults and family members [58]. The outcomes observed for the 7 programs included reduced loneliness [53,54,58,79], reduced social isolation [58], and improved social participation [52,59,60].

A total of 4 programs used existing software programs, including LINE [54], MSN [55], and Skype [52,53,55] for video calls, whereas 1 program used videophones [58]. For programs using commercially available software, smartphone [54], tablet [52,60] and laptop [55] have been used. The frequency of contact between older adults and their families was designed to be once per week in 4 programs—LINE [54], MSN or Skype [55], Skype [53], and Demiris et al [58].

As highlighted in the Skype on Wheel [60] program, "younger generations (grandchildren) may not be sure of how to communicate with their elderly relatives"; therefore, it may be helpful to provide conversational aid to facilitate intergenerational communication, such as a list of possible conversational topics as seen in 2 programs (Skype on Wheel [60] and LINE [54]). Although not developed for older adults residing in long-term residential care facilities, other programs have investigated digital storytelling [70] and exposure to photographs in the older adults' environment [68] as ways to facilitate intergenerational conversation.

A total of 2 programs (ACTIVE [52] and Digital Age [59]) explicitly included training on using digital technology for older adults residing in long-term residential care facilities. In the ACTIVE program, the authors highlighted that "a carefully selected, smaller set of basic apps was installed when the intervention started" to avoid overwhelming the older adults [52]. The content of the training is well described in the Digital Age program [59], which includes the following core subjects: learning how to use a tablet, browsing the internet, staying safe on the internet, emailing, using an App Store, and video calling. The content of the training sessions was flexible and tailored to the needs of older adults in the Digital Age program [59].

S-C-M-O Configuration 4

One program, Tele-Behavioral Activation (BA) [74], contributed to this S-C-M-O configuration. We found that behavioral activation provided through videoconferencing by a lay coach may be useful in reducing loneliness among older adults who are lonely (Figure 6). Several studies have evaluated the effectiveness of digital training courses [72,73,75,77] in reducing loneliness or social isolation for older adults who were lonely or socially isolated. However, as highlighted in the Assertive Outreach (AO) program, establishing "even a small web-based social network proved very difficult in many cases" for older adults who were socially isolated, which may have resulted in the lack of improvement in the outcomes in most of these studies [73]. BA is a brief, structured behavioral approach that aims to increase and reinforce wellness-promoting behaviors that can be conducted by lay coaches [74]. In the Tele-BA program, lay coach "worked with participants to identify and schedule value-based activities, rewarding social engagement and activities, and using strategies to reduce and solve barriers to social connectedness [74]. Participants first reviewed their daily activity patterns, then chose activity goals, worked on specific implementation plans, and reviewed their successes and areas for improvement" [74]. This may have enabled older adults to learn to overcome barriers to social connectedness and to use skills for maintaining social connectedness over time, leading to reduced levels of loneliness that were sustained beyond the 5 sessions of tele-BA.

Discussion

Principal Findings

In this review, we sought to answer the following question: "How do different digital intergenerational programs interact with different contexts to produce certain outcomes?" This review revealed that different strategies should be adopted for different groups of older adults (eg, older adults who are lonely, older adults who reside in long-term residential care facilities,

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and community-dwelling older adults). For example, providing training and access to digital technology may be useful in reducing loneliness among community-dwelling older adults but not for older adults who are already lonely or socially isolated. This may be because establishing "even a small web-based social network proved very difficult in many cases" for older adults who are socially isolated as discussed in the AO program [73]. Similar to AO, Tech Allies program also pointed out the older adults "were already facing many contextual factors in their daily lives, such as physical disability and a lack of close friends and living relatives" would make "their loneliness more systemic and harder to change" [77]. Although tele-BA by lay coaches may be helpful for lonely older adults, future studies should explore different program strategies for this subgroup of older adults with more complex needs. A possibility is to entail young volunteers to befriend older adults who lack existing social support [81]. Williams [72] investigated the effect of a 2-week computer-mediated communication course for lonely older adults and found "no significant difference in loneliness between pre-test and post-test" [72]. However, as explained by the author, the lack of observed differences after the intervention was not unexpected with the short duration of the intervention (2 weeks) [72]. Therefore, the duration of intergenerational programs should be considered before implementation.

Among the digital intergenerational programs included in this realist review, 2 programs (AGES 2.0 [48] and White et al [76]) targeted both community-dwelling older adults and older adults residing in long-term care facilities by providing training in digital technology. However, both the programs demonstrated unsuccessful outcomes [48,76]. A possible reason for the unsuccessful outcome from these 2 programs may be that although providing training in digital technology may be useful to reduce loneliness among community-dwelling older adults based on S-C-M-O configuration 1 (all 4 programs in S-C-M-O configuration 1 achieved successful outcomes), this program strategy may not be useful for older adults in long-term residential care facilities. This further supports the importance of designing targeted digital intergenerational programs for different groups of older people (eg, older adults residing in long-term residential care facilities and community-dwelling older adults). The AGES 2.0 study also found that "feelings of self-competence, social engagement, and maintenance of identity were critical to the intervention's success" [48]. Future research should explore whether interventions that enhance these aspects are useful in promoting social connectedness among older adults.

Comparison With Prior Work

In a previous realistic review exploring the use of technology to engage hospitalized patients, the authors found that a user-centered design may increase the engagement level [82]. However, in our realistic review of digital intergenerational programs based on digital technology, only 3 programs designed for community-dwelling older adults incorporated a user-centered design [63,66,69], and 2 programs were evaluated in a small sample (n<10) [63,69]. Studies in long-term residential care facilities using existing digital communication tools such as LINE and Skype demonstrated beneficial effects on reducing loneliness [54,55], which implies that user-centered design may not be critical for the success of digital intergenerational design. However, this could be because staff are available at long-term residential care facilities to assist with the set-up of the video call tools in these programs, which facilitates intergenerational communication with family members or students [54,55,60] and mitigates the potential problem of digital illiteracy among older adults [83,84]. Future research should be conducted to examine whether a user-centered design may have contributed to a reduction in loneliness or social isolation among specific groups of older adults.

Strengths and Limitations

This review is the first to use a realist framework to study digital intergenerational programs for older adults. The realist framework allowed us to consider empirical findings and theories together to understand how these programs worked. Previous reviews on the effectiveness of intergenerational programs have focused primarily on scholarly literature [29-31] and, therefore, have provided limited insight into the complex causal pathways that may underpin the efficacy or effectiveness of intergenerational programs. The inclusion of diverse research designs, such as quantitative, qualitative, and mixed methods studies, enabled this review to leverage the strengths of each approach. From a realistic perspective, this diversity has huge explanatory value and can help uncover contexts and mechanisms not typically captured in traditional systematic reviews and meta-analyses [33].

However, a limitation of this realist review is that nearly half (11/27, 41%) of the programs reported only quantitative results. A problem with conducting a realist review of quantitative studies is that their primary emphasis is on quantitative results; thus, there may be fewer descriptions and explanations of the mechanisms [85]. Thus, our realist review generally focuses on screening the discussion section of publications to identify author opinions or any qualitative information that may provide information on the mechanisms of how certain programs work. As we inferred most of the information regarding the mechanism from the authors' comments and discussions in the quantitative studies, we acknowledge the subjectivity of these inferences. Nevertheless, the S-C-M-O configurations derived from this study may serve as a basis for further studies to corroborate the proposed theory and mechanisms that drive program outcomes in different contexts.

Second, we acknowledge that for some programs, the outcome observed may not be solely attributable to intergenerational interaction, as the participants may interact with their peers or spouses using digital technology. We decided to include these studies, as there was only 1 study [70] focusing solely on intergenerational interaction using digital technology. However, the inclusion of programs that accommodate both nonintergenerational and intergenerational communication provides a more comprehensive list of programs available for intergenerational communication. As such, some programs in this review may need to be adapted for intergenerational interactions only, and their effectiveness in addressing isolation and loneliness may require investigation in future studies.

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Third, as the search in the scholarly literature was restricted to articles published before August 2020, our review may have excluded studies published after the cutoff date. Nevertheless, the findings of this review can serve as a foundation for future research on digital intergenerational programs.

Finally, another limitation of this study was the inclusion of only English-language documents, which may have potentially led to the omission of relevant programs from English-speaking countries. Among the 27 programs included in this review, only 2 (7%) programs were conducted in Asian countries [54,79]. However, the inclusion of only English-language documents minimizes potential information loss during translation.

Conclusions

This review identifies the key strategy, context, and mechanism that influence the success of programs in reducing loneliness or isolation among older adults by potentially promoting intergenerational interaction through digital means. Digital interventions are becoming increasingly popular to tackle social problems, such as loneliness and social isolation. We identified 4 S-C-M-O configurations to consider when developing intergenerational programs for older adults. Future studies, especially quantitative studies, should consider clearly describing the components of the program and their corresponding contexts and mechanisms driving the improvement of outcomes in digital intergenerational programs. With a better understanding of the components and mechanisms of digital intergenerational programs, well-informed decisions can be made when planning or developing digital intergenerational programs.

Acknowledgments

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Data Availability

The data sets generated during and/or analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategies in databases.
[DOCX File , 15 KB - aging_v6i1e39848_app1.docx]

Multimedia Appendix 2
List of studies excluded during full text screening.
[DOCX File , 29 KB - aging_v6i1e39848_app2.docx]

Multimedia Appendix 3
Mixed Methods Appraisal Tool appraisal for documents evaluating digital intergenerational program.
[DOCX File , 19 KB - aging_v6i1e39848_app3.docx]

Multimedia Appendix 4
Candidate Strategy-Context-Mechanism-Outcome configurations for digital intergenerational programs based on the authors' description.
[DOCX File , 27 KB - aging_v6i1e39848_app4.docx]

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Abbreviations

AO: Assertive Outreach
BA: Behavioral Activation
MMAT: Mixed Methods Appraisal Tool
MSN: Microsoft Network
S-C-M-O: Strategy-Context-Mechanism-Outcome

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Review

Use of Digital Technologies to Maintain Older Adults' Social Ties During Visitation Restrictions in Long-Term Care Facilities: Scoping Review

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Abstract

Background: Digital technologies were implemented to address the disruption of long-term care facility residents' socialization needs during the COVID-19 pandemic. A literature review regarding this topic is needed to inform public policy, facility managers, family caregivers, and nurses and allied health professionals involved in mediating the use of digital devices for residents' social ties.

Objective: Our study outlines key concepts, methodologies, results, issues, and gaps in articles published during pandemic-related visitation restrictions.

Methods: Following the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) protocol, a scoping review was conducted by searching 3 database aggregator platforms (EBSCO, ProQuest, and PubMed) for studies published in peer-reviewed journals from early 2020 to the end of June 2021, when the most stringent restrictions were in place. We included qualitative and quantitative studies, reviews, commentaries, viewpoints, and letters to the editors in French or English focusing on digital technologies aiming to support the social contact of residents in long-term care facilities during pandemic-related visitation restrictions.

Results: Among 763 screened articles, 29 met our selection criteria. For each study, we characterized the (1) authors, title, and date of the publication; (2) country of the first author; (3) research fields; (4) article type; and (5) type of technology mentioned. The analysis distinguished 3 main themes emerging from the literature: (1) impact and expectations of remote social contact on the physical and mental health and well-being of the residents (n=12), (2) with whom or what the social contact took place (n=17), and (3) limitations and barriers to significant social contact related to digital technologies (n=14). The results first underlined the highly positive impact expected by the authors of the digital technologies on health and quality of life of residents of long-term care facilities. Second, they highlighted the plurality of ties to consider, since social contact takes place not only with family

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caregivers to maintain contact but also for other purposes (end-of-life videoconferences) and with other types of contact (eg, with staff and robots). Third, they exposed the limitations and barriers to significant contact using digital technologies and outlined the required conditions to enable them.

Conclusions: The review demonstrated the opportunities and risks outlined by the literature about the implementation of digital technologies to support remote social contact. It showed the plurality of ties to consider and revealed the need to evaluate the positive impact of remote contact from the residents' perspectives. Therefore, to go beyond the risk of digital solutionism, there is a need for studies considering the holistic impact on health regarding the implementation of digital technologies, including the meaning residents give to interpersonal exchanges and the organizational constraints.

Trial Registration: OSF Registries osf.io/yhpx3; https://osf.io/yhpx3

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KEYWORDS

social isolation; COVID-19 pandemic; remote care; nursing homes; social ties; digital devices; older adults

Introduction

Background

One of the most significant issues of the COVID-19 pandemic has been the effects on long-term care facility residents, who represent 50% of deaths in Europe [1]. Beyond the increase in mortality directly caused by COVID-19, the social distancing measures themselves accelerated declines in mental and physical health among some long-term care facility residents [2], as strict social isolation can cause psychological distress [3]; worsen depression, anxiety, and dementia; and contribute to failure to thrive [4]. In addition, there is some collateral damage caused by delayed surgery and dental care, which has been associated with depression issues [5].

Information and communication technology use has been considered a means to maintain older adults' quality of life and provide them with solutions to fight the onset of depression, while also limiting face-to-face contact to protect them from the risks of viral transmission [6]. Beyond the impact on health and quality of life, this study considered the socialization needs of residents as important, considering socialization as a basic human need [7]. People in vulnerable situations require particular attention, especially when their ability to communicate their needs is altered, making such expression often difficult to comprehend. Therefore, we were particularly interested in the way digital devices have been implemented or envisaged meeting these socialization needs during visitation restrictions due to the pandemic.

Previous research has addressed the topic of long-term care facility residents' remote social contact—social contact being defined as an exchange between 2 (or more) people [8]. Televisits with residents' families were analyzed from the perspective of enhancing social presence or degree of salience and thus refer to the quality or state of being there when using a communication medium [9]. Televisits were compared with traditional telephone exchanges [10]. Videoconferencing with relatives has been reported to have a positive impact on social support, loneliness, and depressive status [11,12]. Social support is a "multi-dimensional construct, including emotional, appraisal, instrumental (or tangible), and informational support [...]. One important aspect of social support for older nursing home residents is the continued involvement of family members" [11]. Researchers have identified limitations such as inhibited videoconferencing use due to age-related cognitive decline and physical frailty [13] and the acceptability of videoconferencing by residents' families, which is inversely proportional to the length of a resident's stay [14].

A major contribution from work on this topic, which has primarily focused on cognitively intact residents, is that those most likely to use videoconferencing, considered the "second best option for visitation" [12], are those whose relatives live far away. During the COVID-19 pandemic, the problem of distance arose in another form, as even family members who lived nearby were not allowed to visit their relatives for a relatively long period. Each country and region implemented different restrictions, ranging from strict isolation in rooms to supervised visits during certain circumstances or with mitigating procedures. These restrictions have evolved over time, moving in some institutions from an initial absolute ban to adjusted visitation procedures as knowledge about the virus has evolved [15].

Objective

Thus, this scoping review aimed to report on research articles that emerged during the period when the most stringent restrictions were in place, from March 2020 to June 2021. We focused on how technological devices have been or should be mobilized, according to the authors, to meet long-term care facility residents' socialization needs. Although other recent scoping or rapid reviews addressing the pandemic context focused on social isolation among older adults [16], strategies and actions to enable residents to maintain meaningful family connections [17], or the impact of the pandemic on older adults [18], to our knowledge, our scoping review is the first to specifically address the socialization needs through digital means during visitation restrictions of long-term care facility residents. We therefore conducted a scoping review to provide an overview of existing research on the links between digital technologies and social isolation in long-term care facilities during the COVID-19 pandemic, guided by the following research question: How are the links between digital technologies and social isolation described in the current scientific literature for older adults living in nursing homes during the COVID-19 pandemic?

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Methods

Protocol and Registration

This review was conducted according to the scoping review stages described by Arksey and O'Malley [19] and in the extension by Peters et al [20]. 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 the results; and (6) consultation. We used PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) [21]. The study was preregistered (see Multimedia Appendix 1 for details).

Eligibility Criteria

Our eligibility criteria were developed within the PICo (Population or Problem, Interest, Context) framework (see Multimedia Appendix 2 for details). We included qualitative and quantitative studies, reviews, commentaries, viewpoints, and letters to the editors in French or English focusing on digital technologies aiming to supporting the social contact of residents in long-term care facilities during visitation restrictions due to the COVID-19 pandemic. A central criterion was that specific concepts are used to account for the social contact of residents (eg, social networks, social support) or lack thereof (eg, social isolation, loneliness). Even if the use of digital technologies in long-term care facilities was not the main topic, at least part of the article should be dedicated to it. We included articles published in peer-reviewed journals when the most stringent restrictions were in place, from March 2020 to June 2021.

We excluded articles in a language other than French and English and those in which we were unable to clearly identify the target population and context (eg, quantitative studies on older adults without specific focus on long-term care facility residents). We also excluded articles that did not focus on the older adult population and those with no clear correlation between technology use and visitation restrictions during the COVID-19 pandemic.

Information Sources (Database Selection) and Search Strategy

Database selection was conducted in collaboration with librarians from the University of Strasbourg, who were specialists in this type of research. Our aim was to cover a broad disciplinary spectrum, combining research in the social sciences, humanities, management studies, economics, and health sciences. Thus, on June 29, 2021, we conducted research on 3 major platforms: EBSCO, ProQuest, and PubMed. Comprehensive searches were performed, combining keywords correlated with the following: (1) older adults, (2) their need for socialization, covered by (3) technological devices in (4) long-term care facilities during (5) the COVID-19 pandemic. First, we brainstormed to select terms related to these 5 themes, for example: (1) "Older people" OR "elderly" OR "aged." Then, we searched each database to find related terms out of the Thesaurus (EBSCO and ProQuest) or MeSH Terms (PubMed). For an extensive overview of the search terms selected, please refer to Multimedia Appendix 3, and for a full overview of the searches conducted in each database, please refer to Multimedia Appendix 4. We limited the publication years at the beginning of 2020, that is, shortly before the time when stay-at-home orders emerged in most countries worldwide due to the pandemic, and included all articles meeting our criteria up to the day we conducted the search.

Data Charting Process and Analysis

Several precautions were taken to limit selection bias. We separated the selected articles into 2 equal parts. All the titles were screened by CS and CH in the first subsection and by CL and CH in the second subsection. CL was responsible for arbitrating selection conflicts between CS and CH, and CS was responsible for arbitration between CL and CH. In the second stage, we followed a similar approach, this time focusing on the abstracts. All the titles were screened by CL and CH in the first subsection and by CS and CH in the second subsection. We adopted a 4-point scoring system, with a score of 1 being used to denote articles that were off-topic and a score of 4 for those that were fully aligned. To this, we added comments for the other authors. Papers scoring 4 twice, or at least 3 and 4, were immediately selected. Those below this score were excluded from the first round. We excluded works that did not specifically address the older adult population or clearly excluded long-term care facility residents (eg, "community-dwelling older adults" in the title or abstract). We also excluded articles written in a language other than French or English. CS was responsible for arbitrating selection conflicts between CL and CH, and CL was responsible for arbitration between CS and CH.

In the third step, we screened the full text of the retained articles, each of us responsible for one-quarter of the articles. Together, the study authors formalized a standardized data extraction sheet, in which each author recorded the following for the articles relevant to them: authors, scientific discipline, title, year and month of publication, country of origin, keywords, type of article (eg, view, review, qualitative research), purpose, methods, technology type, key findings (text quote), key concepts, variables used, practical implications, and research perspectives. A simplified version of this table is available in Multimedia Appendix 5.

Results

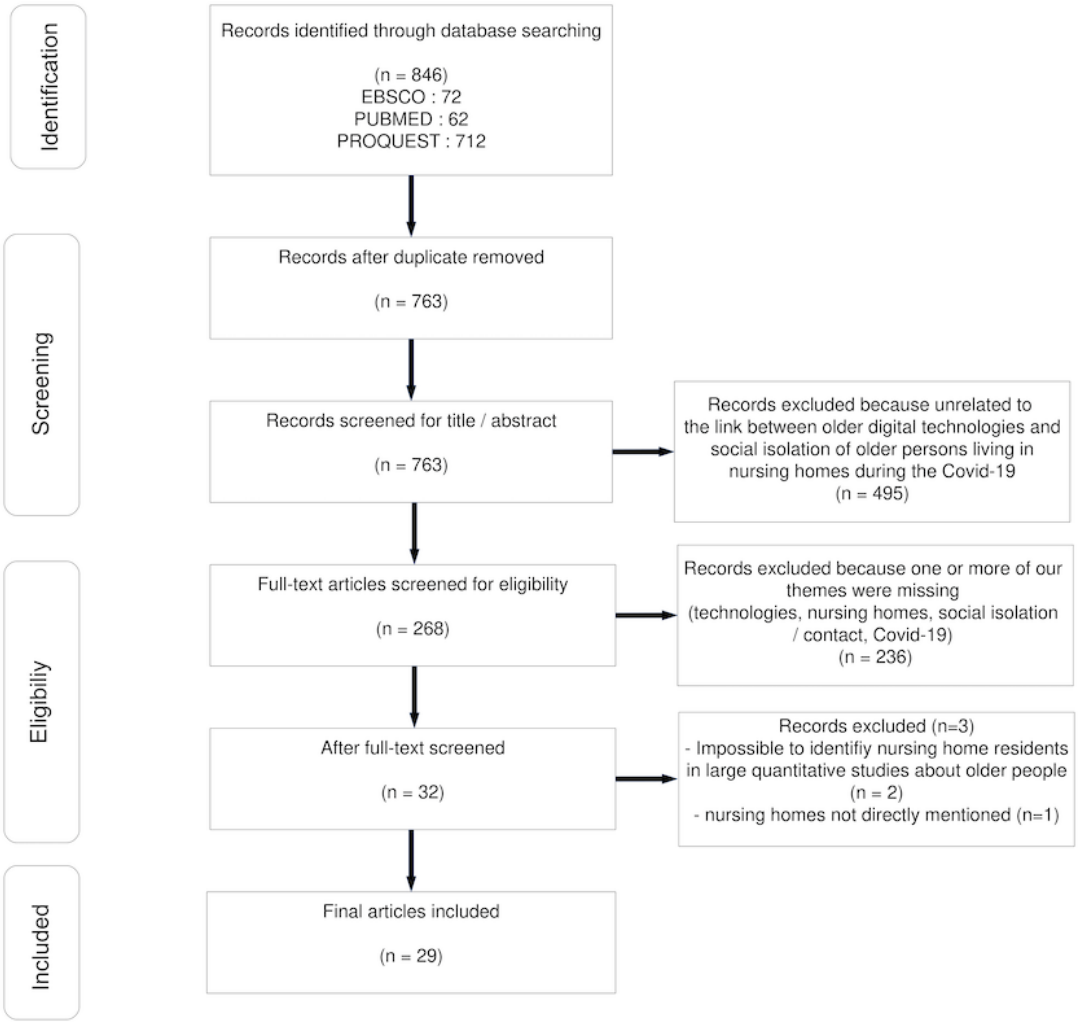
Selection of Sources of Evidence

Once duplicates were removed, we had retrieved 763 articles. These were mainly published by researchers or hospital practitioners with the aim of shedding light on the situation. Only articles from peer-reviewed journals were selected. Excluded articles were those in which resident socialization and use of digital devices were not directly correlated as a primary or secondary theme (in a subsection). However, we chose to include articles on past research if the authors discussed it in relation to the current pandemic context. This led us to select 268 articles that were screened for eligibility. We rejected 232 articles because one or more of our selected themes was missing. Finally, of the 32 articles selected at this stage, 3 more were removed: 2 were quantitative studies in which long-term care facility residents were included in a larger panel of older adults,

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without this population being analyzed specifically. Another viewpoint article was removed because long-term care facilities were not directly specified. We thus selected 29 articles for analysis (Figure 1).

Figure 1. Flow diagram for the search and selection process.



Characteristics of Articles Included in the Review

Multimedia Appendix 5 details the characteristics of the 29 articles: (1) authors, title, and date of publication; (2) country of the first author; (3) research fields; (4) article type; (5) type of technology mentioned.

Among the 29 included articles, 12 were published between March 2020 and July 2020, during the early months of the pandemic; 22 were published in 2020, and 7 were published between January 2021 and June 2021.

Regarding the first authors of the articles, 13 were from North America, 11 were from Europe, 2 were from Australia, 2 were from Asia, and 1 was from the Middle East. Of the articles, 4 were from an international perspective, 6 were multidisciplinary (crossing disciplines from health sciences, human and social sciences, and engineering), 18 were primarily from a health sciences perspective (nursing science, psychiatry, public health, psychogeriatric, geriatrics, medicine), 4 were written mainly by social science researchers (anthropology, social work, psychology), and 1 was written by a "think-and-do tank" director.

Regarding article type, 14 articles were commentaries (n=9), viewpoints (n=4), or a letter to the editor (n=1). There were 7 review articles, including systematic (n=1), narrative (n=2), scoping (n=2), protocol for a scoping (n=1), and rapid (n=1) reviews, and 8 articles were based on either qualitative (n=5) or quantitative (n=3) empirical studies.

We then conducted a qualitative analysis of the papers included to answer our research questions. It appeared heuristic to distinguish the articles according to the following: (1) impact and expectations of remote social contact on the physical and mental health and well-being of the residents (n=12), (2) with whom or what the social contact took place (n=17), and (3) limitations and barriers to significant social contact related to digital technologies (n=14).

Expectations of Remote Social Contact on Residents' Health and Well-being

The first expectation regarding digital technologies used in long-term care facilities during the visitation restrictions related to the COVID-19 pandemic was enablement of residents' social contact because of its positive effects. To address the positive effects of social contact, the authors used several terms. Many

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articles referred to the residents' socialization needs through the lack of social contact [7,16,22-24]. Authors used the concept of "social isolation" to describe the absence of face-to-face contact, which can be measured objectively [16]; it usually correlated with the concept of "loneliness," which is the "subjective experience of feeling alone or disconnected from others" [25]. Other authors referred to the residents' socialization needs through social connection [7,17,23,26-28]. Bethell et al [7] defined "social connection" through the combination of the following interrelated concepts: social networks (webs of social relationships), social support (emotional, social, physical, and financial help), social engagement (taking part in activities), and social connectedness (feelings of being cared for and belonging). Social integration was related to the belonging to a social network [29].

Most authors cited in this subsection assumed that technology use would necessarily have a positive effect. The use of technologies to communicate (eg, video calls via phones and tablets) was reported to promote social connection [7] and allow residents with dementia to engage well with others [24]. The impact of technology use on quality of life by facilitating communication with family members or for video consultations was also noted [22]. Social isolation could be alleviated by connecting with the outside world, gaining social support, boosting self-confidence, and engaging in activities of interest [30]. Social connections through technology were linked to enhanced well-being, protecting and improving mental health, and maintaining physical health and independence among older adults [18]. Office et al [31] noted the positive impact of a telephone befriending program on older adults' perceived health and well-being. Providing technology-dependent amenities to long-term care facility residents could also increase their self-perceived health [32]. In their narrative review, Gorenko et al [25] cited a study demonstrating that video calls set up by staff could have positive effects on depression and loneliness.

However, some work did not address so much the positive effects of social contact at a distance but rather the prevention of the negative effects of social distance. Thus, the integration of digital connectivity could help overcome social isolation and loneliness [26] or at least reduce their prevalence [33]. Social isolation can lead to fear, depression, anxiety [34], cognitive decline, fatigue, and sleep disturbances [23]. This implies less infection resistance, more emergency admissions to the hospital, and extended lengths of stay [31]. Technologies were presented as a "key tool" for reducing social isolation [23] for long-term care facility residents who essentially became prisoners in their 1-bedroom living spaces, with this extreme loneliness potentially inducing anxiety, depression, malnourishment, and worsening dementia [32]. Technological devices have been presented as "a boon for residents feeling isolated" [34] regardless of the type: Videoconferencing has shown the same positive effects on depressive symptoms or loneliness regardless of whether a smartphone or a laptop is used [30]. For example, programs were developed for medical student volunteers to have weekly telephone calls with long-term care facility residents [16,31].

Telephone befriending programs can have bidirectional benefits, as students feel empowered by being able to make a difference in the lives of socially isolated seniors [31]. Thus, the authors of the selected articles not only addressed the effects of remote social contact on residents but also focused on their interlocutors, both human and nonhuman, as in the case of interactions with social robots.

With Whom (or What) the Social Contact Takes Place

The selected articles paid particular attention to families, with whom it would be essential to maintain a connection. Information and communication technologies should mainly improve meaningful connections between older people and their families in long-term care facilities during the pandemic [17].

Initiatives have emerged worldwide to provide older adults with a connection to the "real world" and means for communicating with friends and family [26]. Public authorities have also addressed this issue. For example, the Italian Ministry of Health published a circular requiring residential facilities to provide residents with access to their families and friends through technological communication to facilitate social occasions and affective interactions [33].

Many interventions to maintain connections between residents and their families were addressed [27], such as the "Friend in Deed" program [28] or the Rhode Island assisted living facility program, which distributed tablets to residents to video call their families, thus facilitating social engagement [23]. Other "useful social contacts" included other care home residents, increasing their social networks by connecting two or more care homes through video calls over a long period, within the framework of a study [35].

There was a specific issue of concern in 3 articles included in this scoping review: the use of technology to avoid dying alone despite the impossibility of visits [27]. Videoconferencing was useful for family visits or consultations for patients dying from COVID-19 complications [16], providing a last chance for older adults and their relatives to "say goodbye" [17]. Two articles addressed the perspectives of residents' relatives, showing that online communication provided them with support through their social networks [36] to cope with their loved one's end of life and death. It is indeed possible to share online resources for bereavement support [28].

In addition to family relationships, care modalities (and, consequently, social contact with professionals) also evolved with technology during the pandemic, although not much discussion was provided on this issue. The topic was addressed by 2 articles, showing, for example, that telehealth solutions for geriatric mental health care [26], such as telephone or video conferences [34], allowed for the delivery of convenient, accessible, and affordable care [26]. Although rarely mentioned in the literature, staff members have also asked to use technological solutions to connect with residents (virtual therapy sessions, telehealth visits, video calls with friends and family, virtual activities in their rooms [16]). Special attention was also paid to families, as some social workers developed telesupport interventions for family caregivers [37].

From another perspective, 4 articles addressed the relationships between humans and technology, showing that direct contact with technological devices can help long-term care facility residents cope with social distancing related to COVID-19.

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Social robots can have a positive impact on loneliness by enhancing autonomy, increasing levels of engagement [38], and encouraging attachment and social integration among older adults [29]. For example, Sunshine's robot's (a Korean-manufactured, English-speaking doll-chatbot system) conversations (playing songs, cueing reminiscences, quoting inspirational passages, telling stories, playing "Simon Says") could encourage exercise and social engagement and calm agitation; may have positive effects on geriatric depression, sleep quality, and cognition; and can encourage previously unresponsive residents to express themselves [39]. Further, direct social robots are considered a means to empower older adults with few social resources: Playing a mediating role in the care of older adults, they contribute to creating social connectivity [29]. Augmented reality was also noted as a way to reduce the burden of frailty and increase well-being and social participation [32].

However, the impact of direct social robots (eg, animal robots with various sensors that can react to stimuli or software humanoid agents that assess older adults' affective states and engage in daily conversations with the aim of reducing social isolation) is nuanced [40]. They mainly provide emotional support, whereas online social platforms, for example, provide easy access to information sources and opportunities to communicate. Online social platforms are multifaceted systems that are expected to promote social participation, cognition, physical activity, nutrition, and sleep.

Authors do not always take for granted that technological solutions are easy to implement and correspond to residents' needs. Some articles selected for this systematic scoping review also pointed out obstacles and limitations, which we address in the following subsection.

Limitations and Barriers to Significant Social Contact Related to Digital Technologies

This review showed that neither the use of technology nor the establishment of real social ties is automatic. Implementing video communications requires an adequate organizational structure and consideration of the ability of the residents' family members to use the technology [41]. Some authors have considered the digital exclusion of residents' families [28,33] as well as infrastructural and staffing constraints in long-term care facilities [7,25,42-44]. Moyle et al [13] outlined the time needed to mediate videoconferencing and the difficulty of adding it to the team's workload, which requires the long-term care facility teams to reorganize their functioning.

Among the 29 articles, 14 highlighted the barriers of using technology to meet long-term care facility residents' social needs. This subsection discusses the limits of technology used to reduce isolation in general; however, the authors of the reviewed articles mainly focused on the digital divide and (the limits of) technological devices. Only Vernooij-Dassen et al [45] stated that "older adults need more than virtual contacts."

The digital divide was approached in the reviewed studies from several angles. First, older adults often need assistance using digital technologies, and the most vulnerable have no access to web resources or the required digital skills [18]. Older age, combined with lower income and less education, can lead to reduced access to technology [26], inducing a notably negative impact on access to mental health care [46]. According to Eghtesadi [32], exclusion from technological advances may be due to negative representations of older adults (eg, passivity and lack of capacity to learn), combined with the fact that this population often cannot self-advocate. The digital divide concerns not only older adults but also their families [28], insofar as social disparities restrict technology access [33].

Some authors posited correlations between digital socialization and quality of life but noted that this will not systematically be efficient for residents with low digital literacy [22], especially those with cognitive impairments [22,26]. Fears regarding the security of personal data, difficulties in accessing dedicated tools, and visual or hearing impairments were also identified as barriers [16], which add to the fact that long-term care facility residents do not necessarily understand the interest of digital tools, as in the case of telehealth visits [47]. Several infrastructural issues and limitations have been highlighted, such as staff members' availability to set up video calls, their access to these types of devices, their capacity to schedule and facilitate these interactions [42], and staff commitment and turnover [25]. Access to technology in long-term care facilities does not necessarily dictate its optimal use [43]. To have a real impact on social isolation and loneliness, professionals need to assist older adults use digital tools [44].

Several considerations should be taken into account: the purchase of dedicated equipment and infrastructure (eg, wireless networks), the allocation of dedicated professional time to accompany each resident, and the issue of human resource capacities (eg, staff training, volunteer recruitment [7].

Discussion

Principal Findings

Overall, this scoping review gives a comprehensive overview of the current literature and shows how the scientific papers published during the period of restricted visits due to the COVID-19 pandemic considered the contribution of digital technologies to residents' social contact. We can summarize our main findings in 3 points. First, we outlined the main expectations for digital technologies to prevent social isolation and loneliness and defined the terms used. The positive impacts expected of remote connections are detailed as well as the negative effects prevented by the use of digital technologies. Second, while prepandemic work on the topic, as described in the Introduction section, mainly focused on the tie between residents and their families, our study shows that articles published during the COVID-19–related confinement and visitors' restrictions focused on a plurality of ties. Indeed, social contact took place not only with family caregivers to maintain contact with the residents but also for other purposes (end-of-life videoconferences) and with other types of contact: Several articles addressed remote ties with professional caregivers, student volunteers, and residents of other institutions and even direct contact with social robots. Digital socialization thus concerns intrafamily ties and a broader network of ties. Third, we reported on the limitations and barriers to significant contact

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using digital technologies (digital divide and access difficulties, notably due to cognitive impairment and the low digital literacy of residents and their relatives) and outlined the required conditions to enable them, in particular organizational settings (technological infrastructure, dedicated professional time, human resource capacities).

Comparison With Prior and Recent Work

In the literature, the expectations for digital technologies to ensure significant remote connections are high. Digital solutions are generally seen as a natural alternative to face-to-face contact (one exception is Vernooij-Dassen et al [45]). They are considered as suitable methods to care for chronically ill, frail, or dependent older adults while also reducing health care costs [48]. These devices could allow residents to have a new, interesting device to show to visitors, making them an object of social mediation [49] and contributing to the creation of social connectivity [28]. To avoid a tendency for technological solutionism [50], considering that the implementation and appropriation of technologies are synonyms, it seems essential to finely define the implications and entanglements and identify the contributions and limitations of digital solutions used to maintain or develop social ties. This aim can be achieved through an increased number of studies based on empirical methods [51]. Indeed, previous studies on long-term care facility residents' remote social ties have used standardized scales, such as the Geriatric Depression Scale [10], combined with loneliness and social support behavior scales [11] or with loneliness and quality of life scales [30]. In the corpus studied in our review, some empirical articles evaluating the impact of remote social contact through the lens of health and quality of life issues were conducted before the COVID-19 crisis [29,30,38]. However, the pandemic context itself can be anxiety-provoking [52] and thus influence evaluations related to residents' health, solitude, and quality of life. Studies conducted during the crises and questioning the significance of the connections are thus required. Moreover, expectations cannot be addressed in a uniform manner, as if residents all have the same identity and history. Multiple dimensions of social identity, such as gender, age, or migration status [53], need to be considered in the studies because they impact the use of digital technologies and meaning of social contact. Conversely, it is necessary to consider the barriers to remote social contact and virtual care, which increased following the pandemic, due to old age [54,55] combined with other characteristics like ethnicity [56].

Regarding the plurality of ties through remote social contact stated in our review, we found that most of the previous studies focused on the relationships between residents and their families [41]. Above all, our results show that extrafamilial ties need to be considered, not only because family involvement after long-term care facility admission can quantitatively decrease [14] but also because other ties are important. Indeed, some residents have remote contact with residents from other long-term care facilities [35], some professionals request digital contact with long-term care facility residents [16], and some meaningful exchanges occur via telehealth solutions [26,34]. Since the related practices are based on affects and moral feelings [57,58] for both caregivers and care receivers [59], we could consider all their social ties: the "family structure, the state and nature of their social relationships both inside and outside the nursing home, and their social practices" [60].

Concerning the barriers and enabling settings for significant remote social contact in long-term care facilities, consideration of organizational issues is novel in the COVID-19–related studies. Although past work did not focus on this subject [41], the organizational perspective of remote social contact mediation is addressed in various articles, particularly in terms of staffing constraints. The literature shows that, since an increase in social service and activity staff has a positive impact on residents' quality of life [61], long-term care facilities could train their staff to mediate and implement remote social contact. This could be a way to better respond to crises, prepare for the future needs of the residents, and limit the turnover of professionals, as stated in previous work [62].

This review enables us to consider the opportunities for residents' literacy (highlighted as a barrier to significant remote social contact) by collecting and taking into account their requests for remote connection. The articles reviewed for this scoping review report on neither the residents' needs for digital contact nor their lived experiences, even in the articles that referred to direct interventions [27,28,31]. Indeed, qualitative studies developed during the pandemic assessed the impact of volunteer phone calls on social isolation [31] or the effect of remote Quizz sessions between residents of several long-term care facilities [35] or stated the usefulness of the technologies used in the research [42]. Quantitative studies measured the number of long-term care facilities reporting the use of digital devices [23] or residents' preferences between phone and video calls [63]. None of the studies considered the perspective of the residents, as previous research has stated. The need for well-developed and tested interventions was indeed highlighted by Palmdorf et al [51], who showed that there is a lack of information about the actual needs of the users of digital technologies.

Limitations

Several limitations concerning our review need to be highlighted. First, the systematic search approach may have been biased, particularly because we were limited by the subscriptions to which our affiliated university provided us access. We cannot exclude the possibility that we overlooked some work published during the examined time period that was related to our research questions. In the future, this bias could be avoided by soliciting co-authors from other universities. Second, our inclusion criterion that only articles from peer-reviewed journals should be included potentially led us to not identify certain work, such as from the grey literature. A less restrictive scoping review, including this grey literature, could be conducted on the same basis. The third limitation is specifically related to our research topic and the period covered. It is very difficult to conduct research during large-scale crises, especially in long-term care facilities that have been particularly affected. Therefore, the empirical material collected by the authors of the reviewed articles is hardly representative or may even be nonexistent in most of the selected articles. A new scoping review using our approach could be conducted covering

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a longer period, assuming that some work may have appeared later.

Future Directions

To capture the demand and need of the residents, more in-depth evaluations should be methodologically conducted. Social support, social network, social engagement, and social connectedness should be distinguished in the measurements. These approaches should be complemented by qualitative methodologies to outline residents' subjective experiences regarding digital device use and elucidate the individual, interpersonal, and organizational specifics that impact the experience. Further, we should investigate the social support provided by the staff [42].

Future studies should situate their analyses in a temporal context (before, during, and after social distancing and visitor restrictions), as has been done by researchers with older adults living at home [64], and consider the organizational, geographical, and material dimensions in which the interactions take place. Taking into consideration the expectations of the individuals would also state the gap between the imagined future (generally idealized) and the actual appropriation of the devices [65]. Regarding direct contact with social robots, the *nature* of this type of tie needs could also be further questioned.

Research programs could be implemented on an international scale in the digital health field, considering the pandemic context, to provide solutions for maintaining and improving the living conditions of older adults in a broad sense, including those living in long-term care facilities [66].

Future studies should analyze if and how remote social contact allows families to stay effective care partners and not solely remote "visitors" during and after COVID-19 epidemic peaks [67]. In other words, it is a matter of evaluating whether these digital devices allow relatives to carry out the family's care work "at a distance."

Conclusions

This review demonstrated the opportunities and risks outlined by the literature about the implementation of digital technologies to support remote social contact. If the expectations for digital technologies to support significant remote connections are high, the review showed that studies conducted during the crises and questioning the significance of the connections are thus required. This review also showed the plurality of ties to consider and revealed the need to evaluate the positive impact of remote contact from the resident's perspective. Therefore, to go beyond the risk of digital solutionism, there is a need for studies considering the holistic impact of digital technology implementation on health, including the meaning residents give to interpersonal exchanges and the organizational constraints.

This scoping review opens up perspectives for policy makers in terms of political planning and for long-term care facility managers who have to implement these policies with their staff. Beyond the sole epidemic context, this review's findings make it possible to identify points of vigilance for implementing digital devices dedicated to socialization among long-term care facility residents, in anticipation of the "digital revolution in health" [68] and care, in the context of demographic aging [69] and increased geographical mobility among new generations [70].

Acknowledgments

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Data Availability

The data sets generated during or analyzed during the current study are available from the corresponding author on reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA ScR checklist.
[DOC File , 66 KB - aging_v6i1e38593_app1.doc]

Multimedia Appendix 2
Application of the Population or Problem, Interest, Context (PICo) framework.
[DOC File , 30 KB - aging_v6i1e38593_app2.doc]

Multimedia Appendix 3

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Search terms.
[DOC File , 34 KB - aging_v6i1e38593_app3.doc]

Multimedia Appendix 4
Search equations.
[DOC File , 38 KB - aging_v6i1e38593_app4.doc]

Multimedia Appendix 5
Main characteristics of the selected articles.
[DOC File , 71 KB - aging_v6i1e38593_app5.doc]

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Abbreviations

PICo: Population or Problem, Interest, Context

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Original Paper

Implementing Active Assisted Living Technology in the Long-term Care of People Living With Dementia to Address Loneliness: European Survey

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Abstract

Background: In the lives of people with dementia, loneliness is an important issue with psychological and physical consequences. Active assisted living (AAL) technology has been gaining visibility in the care of persons living with dementia, including addressing loneliness. However, to the best of our knowledge, there is a lack of evidence concerning the factors influencing the implementation of AAL technology within the context of dementia, loneliness, and long-term care (LTC).

Objective: We aimed to identify the familiarity with AAL technology that is promising for addressing loneliness in persons living with dementia in LTC in Europe and the factors influencing AAL technology implementation.

Methods: A web-based survey was developed based on findings from our previous literature review. The Consolidated Framework for Implementation Research guided the development and analysis of the survey. Participants included 24 representatives of Alzheimer Europe member associations from 15 European countries. The data were analyzed using basic statistical methods (descriptive statistics).

Results: The baby seal robot Paro was reported to be the most familiar AAL technology by 19 of 24 participants addressing loneliness in people with dementia living in LTC. Participants from Norway (n=2) reported familiarity with 14 AAL technologies, and participants from Serbia (n=1) reported zero familiarity. It seems that countries that invest less in LTC facilities are familiar with fewer AAL technologies. At the same time, these countries report a more positive attitude toward AAL technology, express a higher need for it, and see more advantages than disadvantages than those countries that invest more in LTC. However, a country's investment in LTC facilities does not seem to be linked to other implementation aspects such as costs, planning, and the impact of infrastructure.

Conclusions: Implementation of AAL technology to address loneliness in dementia seems to be linked to familiarity with the technology in a country as well as national investment in LTC facilities. This survey confirms the literature on higher investment countries' critical stance in regard to AAL technology implementation to address loneliness in persons living with dementia living in LTC. Further research is needed to clarify the potential reasons why familiarity with more AAL technology does not seem to be directly linked with acceptance, positive attitude, or satisfaction with AAL technology addressing loneliness in persons living with dementia.

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KEYWORDS

loneliness; social isolation; active assisted living technology; long-term care; dementia; Alzheimer; implementation; CFIR

Introduction

Dementia is a growing concern worldwide. The World Health Organization estimates that 10 million people are diagnosed with dementia each year [1]. This growing group of people has specific needs and issues, and one of them is loneliness. Loneliness is defined "as a subjective feeling state of being alone, separated or apart from others and is an imbalance between desired social contacts and actual social contacts" [2,3]. Loneliness among older adults is found to be a factor that may add to the progression of symptoms of dementia and mild cognitive impairment [4]. The predictive power of loneliness on the progression of dementia and MCI is comparable to that of some biological measures, such as higher cortical amyloid burden [5], genetics, diabetes, and vascular diseases [6].

For persons living with dementia, needing to transfer from home to a long-term care (LTC) facility due to disease progression [7] or no longer being able to live safely at home without additional support beyond the care provided by informal caregivers [8] exacerbates the likelihood of loneliness, social isolation, and depression [9]. Loneliness among LTC residents is often addressed by a number of psychosocial interventions, for example, telephone befriending or horticultural therapy [10]. However, the experience of loneliness is largely subjective. As there is no one-size-fits-all approach to addressing loneliness, the need to tailor interventions to suit the needs of individuals is growing [10]. Therefore, adopting technology into the delivery of psychosocial interventions could be seen as an opportunity to address loneliness in the growing group of persons living with dementia. However, it can be a challenge to implement these technologies in LTC settings [11].

Implementation involves a set of planned, intentional activities that aim to put into practice evidence-informed policies and practices in real-world services. The goal of effective implementation is to benefit end users of services—children, youth, adults, families, and communities [12]. Researchers have explored ways to implement technology to aid in the care of persons living with dementia [11]. However, the process of using technology to deliver psychosocial interventions has not often been investigated [13].

In the past 2 decades, there has been an increase in research concerning technology in dementia care [14]. These technological advancements targeted to support persons living with dementia are typically called assistive technology [14]. Assistive technology contains a wide range of technological applications with a potential application to dementia care. These include self-contained devices (eg, tablets, wearables, and personal care robots) and software applications (eg, mobile or web-based apps) [15].

Assistive technology specifically for persons with dementia has been defined as "any item, piece of equipment, product or system driven by electronics, whether acquired commercially, off-the-shelf, modified or customized, that is used to help persons with dementia in dealing with the consequences of dementia" [16]. Assistive technology based on this definition is called active assisted living (AAL) technology [15]. Examples of AAL technology include specialized tablets, wearables, social robots, and integrated smart home systems [15]. AAL technology implementation in real-life practice can still be seen as a challenge [11,16-18], with only a few examples noting some promising insights into the positive impact on loneliness in persons living with dementia [16,18].

A recent review on the implementation factors of social robots in LTC reported a range of barriers, such as complexity, physical accessibility, and cost [17]. The high acquisition and maintenance costs of social robots are one of the primary barriers reported by multiple stakeholders [17]. For example, the average price of a popular robot called Paro is approximately €7000 (a currency exchange rate of 1€=US $1.08) [19], and with funding for LTC facilities ranging from one country to another, those costs can be a barrier [20]. The authors of the review also reported that the beliefs and attitudes of stakeholders present an important barrier to the implementation of AAL technology [17]. The authors noted that there is a scarcity of studies that have explored the perceptions of key stakeholders in LTC, such as care professionals, family, and persons living with dementia, even though it is known that these stakeholders play important roles in the implementation process of technology in LTC [17]. Therefore, an understanding of these stakeholders' perspectives and experiences is needed to bridge the knowledge gap between research and clinical practice.

To the best of our knowledge, there is a lack of evidence on the range of factors affecting AAL technology implementation in the context of loneliness and dementia. Therefore, this study aimed to identify the influencing factors that hinder or facilitate the implementation of AAL technology for residents with dementia in LTC across Europe and the potential impact of such technology on feelings of loneliness. We focus on countries in Europe for the need to bridge the gaps between dementia care across Europe where different sectors have resulted in a patchwork of approaches to technology without a coherent model while competing with rapid advances in the world [21,22]. Specifically, we were interested in answering the following research questions: (1) How do the European Alzheimer association's view factors that affect the implementation of AAL technology in LTC facilities to address loneliness in persons living with dementia in their respective regions? (2) What is the perspective of dementia associations on the AAL devices that have been implemented in LTC facilities in their region to address loneliness in persons living with dementia? (3) Are there any other factors regarding AAL technology implementation in LTC that might have potential influence?

Methods

Overview

The paper reports on a web-based survey consisting of a quantitative questionnaire combined with open-ended questions.

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Participants were asked fifteen 5-point Likert-scale questions and open-ended questions based on Damschroder "Consolidated Framework for Implementation Research" (CFIR) [21]. The web-based survey tool (LimeSurvey) was used.

Participants

The participants included stakeholders who were experts from European national and regional Alzheimer associations and thus were knowledgeable about the use of AAL technology in their respective country or region. We reached out to Alzheimer associations in 47 European countries, but we were able to contact only 34 Alzheimer associations. All were members of Alzheimer Europe, which is the most comprehensive collaboration of Alzheimer associations in Europe.

We aimed to determine which implementation barriers are experienced in each region and which are perceived to be more relevant to loneliness. Thus, we addressed national and regional Alzheimer associations and inquired whether they were familiar with the general trend of the overall beliefs and attitudes of stakeholders toward the use of AAL technology in LTC facilities. We believe that surveying European Alzheimer associations provided a more comprehensive outlook of the region, whereas asking individual LTC facilities may have resulted in points that could not be generalized.

For this web-based survey, representatives from 34 National Alzheimer associations of Alzheimer Europe were informed about the study and invited to participate in the survey via a personalized email. With this initial email contact, Alzheimer association representatives were also asked to forward the survey information to their regional Alzheimer association contacts. The researcher (KBB) identified 34 Alzheimer associations' contacts through publicly available information on their respective websites.

The inclusion criterion for participants was that they spoke sufficient English to understand the study information and complete the web-based survey. Alzheimer associations were given the opportunity to register and provide written informed consent via email. The participants were asked to respond to the survey within 21 days, with email reminders sent every 5 days, and the survey was closed after 28 days. Another reminder was sent out within the extended deadline to solicit additional completed surveys.

Following the first descriptive analyses, we decided to include national LTC expenditure, that is, national funds invested in LTC facilities, as a factor for implementation. We used the data from the Organisation for Economic Co-operation and Development (OECD) to see the national expenditure on LTC facilities measured with current prices in Euro (€) [20]. Consequently, 2 groups of participating countries formed according to their national expenditure on LTC facilities, namely, higher and lower expenditure groups.

The respondents' countries are as follows: Portugal, Germany, Belgium, France, Netherlands, Norway, Bulgaria, Czech Republic, Finland, Greece, Luxembourg, Malta, Serbia, Slovenia, and Switzerland. Next, we grouped the countries by annual national expenditure on LTC facilities, yielding lower- and higher expenditure groups. National expenditure is the amount of capital invested in LTC facilities by government/compulsory and private/out-of-pocket budgets [23]. Lower and higher expenditure groups (per capita) are defined by the latest OECD values available for all participating countries, which were from 2019 (Multimedia Appendix 1) [24].

Methodological Framework

We used the CFIR [25] to identify barriers to and facilitators of AAL technology implementation. We chose the CFIR because it provides a useful structure for identifying potential factors influencing implementation at multiple levels [25]. The CFIR includes 39 constructs (ie, determinants) organized into 5 domains: innovation characteristics (eg, complexity and strength of the evidence), outer setting (eg, external policy and incentives), inner setting (eg, organizational culture and the extent to which leaders are engaged), characteristics of individuals involved (eg, self-efficacy using AAL technology in a sustainable way), and process (eg, planning and engaging key stakeholders) [25,26]. All constructs interact to affect the process and effectiveness of implementation [25,27]. Therefore, using this framework enables the identified barriers and facilitators to be presented in a structured and systematic manner. It also allows findings to be easily compared to those of other implementation studies to identify research gaps.

Design of the Web-Based Survey

Damschroder et al [25] recommended that researchers try to identify CFIR constructs early on, assess them based on their relevance to the study, and then determine at what level each construct should be measured. In our scoping review [3], we identified 10 of the 39 CFIR constructs as relevant in implementing AAL technology to address loneliness in persons living with dementia in LTC and therefore relevant for our web-based survey:

1. Intervention characteristics
   - Relative advantage: Q1 and Q3
   - Cost: Q5
2. Outer setting
   - Patient needs and resources: Q4 and Q6
   - External policies and incentives: Q13
3. Inner setting
   - Structural characteristics: Q7 and Q8
   - Culture: Q9
   - Implementation climate
     - Tension for change: Q2
     - Compatibility: Q10 and Q11
     - Relative priority: Q12
4. Process
   - Planning: Q14
   - Engaging
     - Key stakeholders: Q15

Our team reviewed and revised the survey, and the final version had 15 questions. Questions were adapted from the CFIR interview guide from the relevant 10 domains identified by the

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scoping review. Then, we reviewed the survey and answer choices with an English language expert to ensure suitability for nonacademic staff in Alzheimer associations. Furthermore, we asked 3 Alzheimer associations to pretest and validate the survey for suitability. Two of them responded and gave detailed feedback. We revised the survey accordingly. The survey was then designed in a web-based survey tool (LimeSurvey) [28] and tested for any technical issues.

The web-based survey questionnaire, the recruitment plan, and the deployment plan were extensively discussed with Alzheimer Europe, with whom the researcher (KBB) worked closely using a participatory approach within the project DISTINCT (Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology), where this study was funded [21]. Alzheimer Europe was involved because they are the most comprehensive union of Alzheimer associations in Europe, and they are one of the collaborative partners of the DISTINCT consortium, which is an EU-funded Marie Skłodowska-Curie research and training project.

Ethics Approval

This study received ethical approval from the University of Witten/Herdecke with approval number SR-205/2021. This survey was conducted with ethical principles in mind. In accordance with recommendations for good internet-based research by Gupta [29], the participants were shown an information form and were asked to provide consent before they were able to see the questionnaire. The information form provided complete details of the study, including contact information, study aims, data collection procedure, potential benefits and harms, and steps taken to maintain the anonymity and confidentiality of the participants. These steps enabled the participants to reach out to the investigators and clarify whether they had any questions or concerns. Cookies were used to prevent accessing the survey twice. No personal information about the participants was collected. Survey data were saved in a secure server upon completion and were accessible only to the first author. The participants were informed that they could request to opt-out at any time and could request to delete their records. More detailed information about this process can be obtained from the CHERRIES (Checklist for Reporting Results of Internet E-Surveys) checklist in Multimedia Appendix 2.

Analysis

Descriptive statistics were generated using SPSS (IBM Corp) and Excel (Microsoft) [30,31]. The visualization of the data by the balloon plots was performed with the statistical software R (R Foundation) [32], and graphical representations of the data were created with the package ggplot2 [33]. Due to the low response rate (50%), the available data were analyzed using basic statistical methods, and descriptive statistics were calculated. CFIR was used to guide the analysis process [25].

Results

Participants

This survey yielded 24 full responses across 15 European countries from the 34 national and regional Alzheimer associations across 30 European countries (see Table 1) that were contacted, for a response rate of 50%. Thirty national and regional associations were contacted and 15 responded (15/30×100). Organizations in Austria, Croatia, Cyprus, United Kingdom, Denmark, Estonia, Hungary, Ireland, Iceland, Italy, Jersey, Poland, Romania, Slovakia, Spain, Sweden, and Scotland were contacted but did not respond to the survey. For this purpose, we considered both national and regional Alzheimer associations. Therefore, 4 regional responses were added to the national responses.

Two of the participants reported their age group as 18-30 years, 12 participants were between the ages of 31 and 50 years, and 10 were older than 50 years. Seventeen participants were female, 6 were male, and 1 participant was nonbinary. Eleven participants were from national Alzheimer associations, whereas 13 participants were from regional Alzheimer associations. The highest number of responses from 1 country came from Portugal (n=4), followed by Germany (n=3) and then Belgium, France, the Netherlands, and Norway (n=2). The remaining responses came individually (n=1) from the following countries: Bulgaria, Czech Republic, Finland, Greece, Luxembourg, Malta, Serbia, Slovenia, and Switzerland.

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Table 1. Participating Alzheimer associations.

	How many answered	National expenditure in LTC[a] per capita (€)[b]
Answered from a national Alzheimer association		
Bulgaria	1	1.3
Czech Republic	1	188
France	1	417.7
Germany	1	424.6
Luxemburg	1	340
Malta	1	523.3
Netherlands	1	1047
Norway	2	705.1
Portugal	1	28.7
Slovenia	1	147.2
Answered from a regional Alzheimer association		
Belgium	2	474.4
Finland	1	363.5
France	2	417.7
Germany	2	424.6
Greece	1	20.6
Netherlands	1	1047
Portugal	3	28.7
Serbia	1	N/A[c]
Switzerland	1	816.6

[a]LTC: long-term care.

[b]A currency exchange rate of 1€=US $1.08.

[c]N/A: not applicable.

Perceived Familiarity With AAL Technology Across Europe

Overview

Perceived familiarity is considered a factor affecting the implementation of AAL technology to address loneliness in persons living with dementia. The following sections on perceived familiarity are structured based on types of AAL technology (see Multimedia Appendix 3 for an overview).

Familiarity of AAL Technology and Social Robots

The participants were asked whether they were familiar with the following type of AAL technology with regard to addressing loneliness in persons living with dementia: pet robots, for example, “Paro”; humanoid robots, for example, “Pepper”; multimedia computer systems, for example, “Xbox”; and telepresence robots, for example, “Giraff.” The most familiar pet robot was the baby seal robot “Paro” (n=19), followed only by the “Joy for All” cat (n=6), while 6 participants were not familiar with any pet robots (n=6). Ten of the 15 countries reported having Paro. Humanoid robots were less popular, and the respondents were most familiar with Pepper, as reported by 7 countries. Papero was reported only in Czech Republic, and Cuddler was reported only in Finland. More countries were unfamiliar with humanoid robots than pet robots; 9 of the 15 countries were not familiar with them.

Open-Ended Questions

The participants were asked to manually report any other AAL technology in case the devices that they were familiar with were not on the list. These data are presented as a list of technologies the participants were familiar with (Table 2). One technology that was identified was “Tovertafel.” A gesture-controlled multimedia table was reported by 3 participants, and “KOMP,” a simple tablet computer for video-calling, was reported by 2 participants. The remaining answers were “smart assistants” such as “Siri or Alexa”; “BeleefTV,” a touchscreen on wheels with sensory games and reminiscence; the “Cogweb,” computer system that provides cognitive exercises; “Smartmacadam,” an app for daily planning; “Music doll,” a therapy doll with a built-in music player; “Easy music player”; and the “Motitech” stationary bike with video. We also asked the participants how they became familiar with these technologies, for example, having direct knowledge of their implementation or having heard about them from other regions or countries. Six participants reported that the technology was actively implemented in their regions, and 5 reported demonstrations

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by the manufacturers, while 1 participant did not report their source of knowledge.

Table 2. Pet and humanoid robots in Europe.

Country	Paro	Aibo	JustoCat	JoyforAll Cat	JoyforAll Dog	Papero[a]	Pepper[a]	Cuddler
Belgium	✓		✓	✓	✓		✓	
Bulgaria								
Czech Republic						✓		
Finland							✓	✓
France	✓			✓				
Germany	✓		✓	✓	✓		✓	
Luxemburg	✓			✓				
Malta	✓							
Netherlands	✓						✓	
Norway	✓	✓	✓	✓			✓	
Portugal	✓							
Slovenia	✓						✓	
Switzerland	✓	✓					✓	
Serbia								
Greece								

[a]Humanoid robots.

Familiarity With Multimedia Computer Systems

Fourteen participants were not familiar with any of the multimedia computer systems, whereas 9 participants were familiar with the Digital Lifestorybook. None of the countries were familiar with CIRCA, VENSTER, or ChitChatters. Digital Lifestorybook, on the other hand, was familiar to the respondents in 9 out of 15 countries. Nevertheless, 11 countries reported being unfamiliar with multimedia computer systems. On the other hand, more countries (n=12) were familiar with Nintendo Wii and Xbox than any other options. Although 10 countries were familiar with PlayStation, only 6 countries were unfamiliar with any of the systems (Table 3).

Table 3. Multimedia computer systems by country.

Country	Digital Lifestorybook	Nintendo Wii	Xbox	PlayStation
Belgium	✓	✓	✓	✓
Bulgaria				
Czech Republic	✓	✓	✓	✓
Finland	✓		✓	
France	✓	✓		
Germany	✓	✓	✓	✓
Luxemburg	✓	✓	✓	✓
Malta		✓	✓	✓
Netherlands		✓	✓	✓
Norway	✓	✓	✓	✓
Portugal	✓	✓	✓	✓
Slovenia		✓	✓	
Switzerland			✓	✓
Serbia	✓			
Greece		✓	✓	✓

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Familiarity With Telepresence Robots and Other Technology

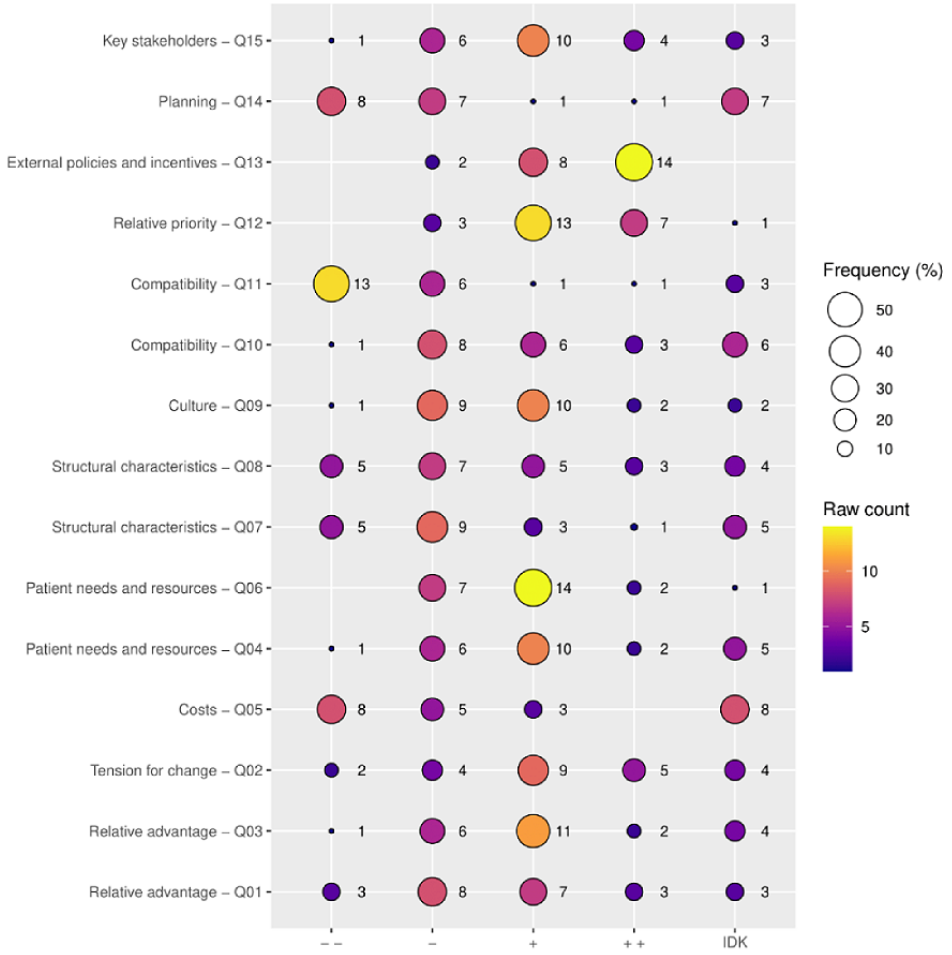
Most participants (n=20) reported no familiarity with telepresence robots, with some (n=3) participants familiar with Giraff. The respondents from 13 of 15 countries reported being unfamiliar with telepresence robots. CompanionAble was unknown by all respondents, and the Guide was reported by only 1 participant. Other technologies were reported to be actively implemented only in certain countries. “Cogweb” was reported to be actively implemented in Portugal, “Tovertafel” was reportedly implemented in some care homes in Germany, and “Motitech,” “KOMP,” “The music doll,” and “Easy music player” were reported to be popular in LTC facilities in Norway. Smartmacadam was reported only in France.

Factors Influencing the Implementation of AAL Technology and Social Robots Across Europe

Overview

The participants were asked 15 multiple-choice questions on the factors affecting the implementation of AAL technology in LTC facilities regarding loneliness in persons living with dementia. All questions were fully answered by all participants (n=24). In the following section, the results are presented according to the CFIR implementation domains (see Figure 1).

Figure 1. Survey results by Consolidated Framework for Implementation Research (CFIR) domains. Statistical frequencies displayed by survey questions and CFIR domains. (− −): highly negative; (−): slightly negative; (+): slightly positive; (++): highly positive; IDK: I don’t know.

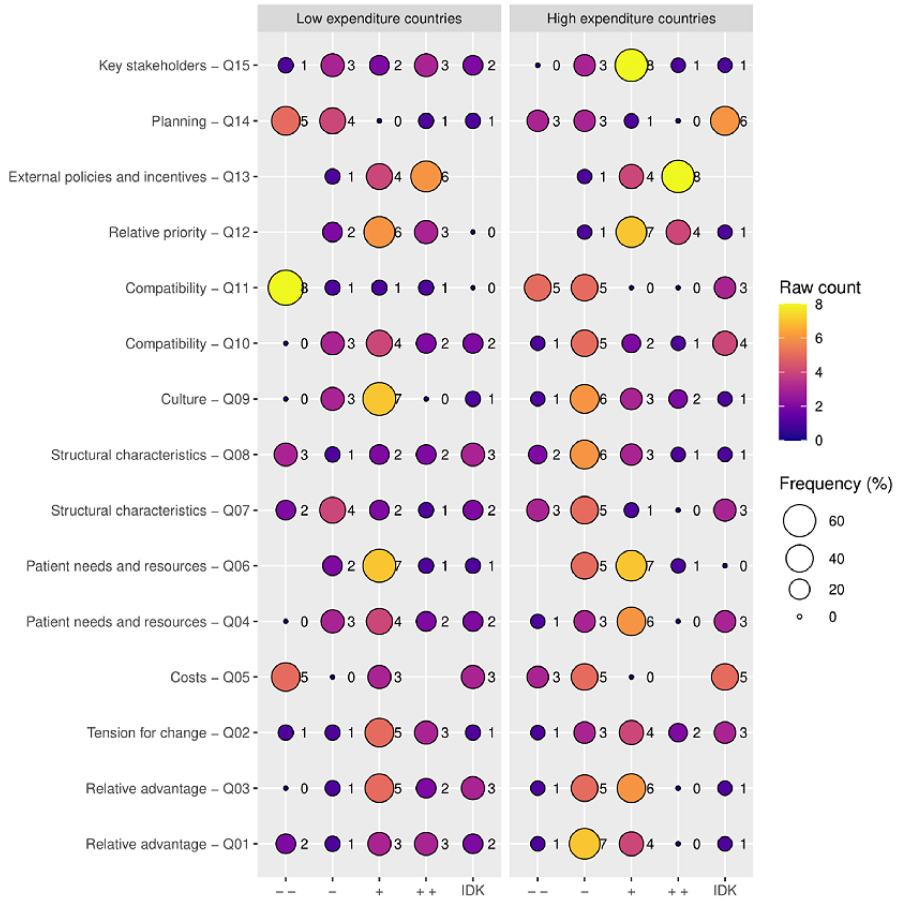


Innovation Characteristics—Relative Advantage

The participants pointed out that the team atmosphere in an LTC facility influences how care professionals perceive AAL technology and its impact on loneliness (slightly positive=7, slightly negative=8). The team atmosphere concerning the use of AAL technology was reported to be *slightly more positive* in countries in the lower expenditure group (see Figure 2). Countries in the lower expenditure group reported more advantages of AAL technology in LTC facilities than countries in the higher expenditure group.

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Figure 2. Low- and high-expenditure countries' differences by Consolidated Framework for Implementation Research domains. Frequencies displayed by 2 groups divided by national expenditure on long-term care. Notable differences between low- and high-expenditure countries in Q1: relative advantage; Q2: tension for change; Q3: relative advantage; Q5: costs; Q8: structural characteristics; Q9: culture; Q15: key stakeholders. (− −): highly negative; (−): slightly negative; (+): slightly positive; (++): highly positive; IDK: I don't know; Q: survey question.



Innovation Characteristics—Cost

Eight participants reported that AAL technology aimed at loneliness comes with *high additional costs*, and another 8 reported that *they are not aware of the costs*. No participants reported that they had *no additional costs*. The higher expenditure group reported slightly more *noticeable additional costs*, while the lower expenditure group noted slightly more *high additional costs*.

Outer Setting—Patient Needs and Resources

Ten participants revealed a *somewhat positive attitude* among persons living with dementia about AAL technology addressing loneliness, whereas 6 noted a *somewhat negative* attitude among persons living with dementia. Fourteen participants reported that AAL technology meets *some needs and preferences of* persons living with dementia, and this response was shared by most participants, making it one of the most agreed-upon subdomains. No participants reported that AAL technology *meets no needs at all*. The respondents in the lower expenditure group reported a slightly more *positive attitude* toward persons living with dementia than those in the higher expenditure group. Again, those in the lower expenditure group reported a slightly more *positive* response regarding the ability of AAL technology to meet more needs than those in the higher expenditure group.

Outer Setting—External Policies and Incentives

Fourteen participants responded that external financial support would *definitely increase* AAL technology use to address loneliness in persons living with dementia. This response was given by most participants, making it one of the most agreed-upon subdomains. No participants reported that financial support would not increase AAL technology use or that they did not know. Countries in the higher expenditure group reported *slightly higher* chances of an increase in AAL technology use than those in the lower expenditure group.

Inner Setting—Structural Characteristics

Nine participants revealed that the infrastructure of the LTC facilities corresponds *slightly negatively* to AAL technology implementation aimed at addressing loneliness, and 5 noted that it corresponds *highly negatively*. Seven participants answered that there were *some building plan changes* necessary to implement AAL technology, and 5 noted that *many building plans* were necessary. The participants from countries in the lower expenditure group reported that the infrastructure of their regions had a slightly more *positive* impact on implementation than the participants from countries in the higher expenditure group. Additionally, the participants indicated whether they needed any infrastructure changes to implement AAL technology, and the lower expenditure group reported that *fewer changes were necessary* than the higher expenditure group.

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Inner Setting—Culture

Ten participants noted that LTC culture corresponds *slightly positively* with the implementation of AAL technology addressing loneliness, and 9 reported a *slightly negative* correspondence. Two added that they were not aware, 1 reported that it corresponds *highly negatively*, and 2 reported *highly positively*. The lower expenditure group reported that culture corresponds slightly more positively with implementation than the higher expenditure group.

Inner Setting Implementation Climate—Tension for Change

The participants reported how stakeholders, for example, care professionals, persons living with dementia, and informal caregivers, consider the need for AAL technology for persons living with dementia in their region to help decrease loneliness. Nine reported a *considerable need*, 4 reported *only a little need*, and another 5 reported that there was a *strong need*. Countries in the lower expenditure group reported that more AAL technology is needed than those in the higher expenditure group. Countries in the lower expenditure group reported that AAL technology was *needed slightly more* than countries in the higher expenditure group.

Inner Setting Compatibility

The participants reported how well AAL technology fits with the values and norms of stakeholders, for example, care professionals and persons living with dementia in LTC, to address loneliness in persons living with dementia. Eight participants noted that AAL technology *does not truly fit* the stakeholders' values and norms, 6 revealed that they were not aware, and another 6 noted that AAL technology *somewhat fits their values and norms*. Thirteen participants reported that AAL technology *did not replace* any nontechnological interventions for loneliness, and 6 noted that it *did not really replace* any interventions. Countries in the lower expenditure group reported *higher fit* than countries in the higher expenditure group. When asked whether AAL technology replaced any existing programs for loneliness, both groups reported *no replacement*.

Inner Setting—Relative Priority

When asked about the importance of AAL technology aimed at addressing loneliness compared to other priorities, such as fall prevention, 13 of the participants responded that it was *somewhat important* in comparison to other priorities in the LTC facility. Seven reported that it was *very important*, 3 declared that it was *not really important*, and 1 did not know. No participants reported that AAL technology is *not at all important*. There were no differences between the lower and higher expenditure groups.

Process—Planning

Eight of the participants noted that LTC facilities in their area had *no plan in place at all* to implement AAL technology to address loneliness in their region; 7 had *hardly any plan in place*, 1 had a *partial plan*, and another had *considerable plans* in place. Seven participants were not aware. Lower expenditure countries reflected that they had fewer plans than higher expenditure countries.

Process—Engaging Key Stakeholders

Ten participants reported that Alzheimer associations provided *some encouragement* to the LTC facilities in their regions to implement AAL technology to address loneliness in persons living with dementia, 6 reported that the associations *didnot really encourage* LTCs in their area, 4 reported that they *encouraged them highly*, 1 reported that they *did not encourage LTCs at all*, and 3 reported no knowledge. The participants were asked whether Alzheimer associations encouraged LTCs in their regions to implement AAL technology, and the higher expenditure group reported *slightly higher* encouragement than the lower expenditure group.

Additional Factors

According to OECD data [23], national expenditure on LTC facilities appears to be a factor that might mitigate the familiarity of AAL technology in a given country or region. It also appears that Northwestern European countries are familiar with more AAL technology than Southeastern European countries. This can be observed in the expenditure on LTC facilities (see Multimedia Appendix 1).

Discussion

Principal Findings

In this survey, we investigated familiarity with AAL technology in Europe and the factors influencing the implementation of AAL technology in LTC. We have found that the seal pet robot Paro was the most familiar AAL technology being used to address loneliness in persons living with dementia across Europe. Pet robots were more familiar than other types of AAL technologies. The least familiar AAL technology was telepresence robots. Survey respondents were on average familiar with 7 AAL technologies, ranging between 14 and zero.

Comparison to Prior Work

The literature suggests an array of implementation barriers when implementing AAL technology in LTC to address loneliness in persons living with dementia, such as user capabilities, user willingness, and family support [34]. In this paper, we investigated the perceptions of European Alzheimer associations regarding implementation barriers. Those countries in the lower expenditure group appeared more accepting toward AAL technology implementation in LTCs, in accordance with previous research [35]. At the same time, the respondents from these countries reported being familiar with fewer technologies. The participants from countries in the higher expenditure group generally reported less acceptance, more disadvantages, less fit with norms and values, and less interest from persons living with dementia. This group also reported being familiar with a higher number of technologies. It seems that the fewer technologies a country has, the higher the interest in more technology. This may be due to the active experience of the implementation phase, where care professionals experience the implementation barriers first hand. For example, in Spain, a lower expenditure country, it was found that the effective use of AAL technology could allow care professionals to spend more time on social intervention and less on administrative tasks [35]. Despite hardships, care professionals displayed an

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optimistic point-of-view toward AAL technology [35]. However, in Norway, implementation of a social communication tool (KOMP) changed work routines and created additional responsibilities for care professionals [36]. Even though care professionals tried to come up with creative ways to motivate persons living with dementia, using KOMP was limited by the physical and cognitive abilities of its users [36]. This is a novel finding considering the lack of studies in the literature focusing on lower expenditure countries [35] and a number of studies focusing on higher expenditure countries [34,36,37].

In Germany, a higher expenditure country, lower acceptance of Giraff in persons living with dementia was found to be linked to the lower psychological well-being and lower cognitive abilities of residents, unlike the case of Paro [38,39]. This could be explained by the lower cognitive requirements of using Paro as opposed to using more complicated technologies such as Giraff. Additionally, in Germany, using digital technology for social engagement increased 72.8% (n=349) during the COVID-19 pandemic [34]. However, relatively slow uptake of the technology by residents with dementia due to the absence of adequate support from staff and the lack of staff training were indicated as barriers to implementation alongside costs [34]. This confirms our finding on the critical stance of higher expenditure countries toward AAL technology not meeting many needs of residents and not fitting with existing workflows. In the United Kingdom, a high-expenditure country, technological illiteracy, the low technological confidence of staff, and persons living with dementia being distressed by the robotic voice of the device were reported as barriers to implementing smart speakers in LTC facilities [40]. In Ireland, another high-expenditure country, interviews with care professionals revealed that costs, lack of personnel, and concerns about meeting the needs of persons living with dementia were perceived barriers to the implementation of social robots in LTC facilities [41].

The findings of a review that included studies from the United Kingdom, the Netherlands, Finland, and Sweden suggest that persons living with dementia can potentially benefit from using digital technologies such as videoconferencing to help them maintain and create social networks [37]. However, the usability of the technology, supporting individuals in using the technologies, and training the family caregivers are issues that need further research [37]. Higher expenditure countries seem somewhat more experienced but also more critical toward the implementation of AAL technology. Therefore, this survey confirms the literature findings on the higher expenditure countries' critical stance on AAL technology implementation due to, but not limited to, concerns about costs, staff resources, the technological illiteracy of staff, and the cognitive abilities of residents.

Based on our findings, we argue that there is no direct link between the funds spent on AAL technology in LTC and the satisfaction gained from it for both residents and staff. The technological literacy of both staff and residents seems to play an important role in implementation. Care practitioners need to match the needs of the residents and staff with the functionality of the AAL technology. Policy makers are likely to benefit from facilitating a dialog with stakeholders involved in co-design [42] and co-research [43] efforts in dementia and in AAL technology, approaches that are becoming increasingly relevant both in practice and in research.

Study Limitations

First, the staff involved in implementing AAL technology in nursing homes were not included in the sample. This may have affected the results in such a way that we might not be informed about the first-hand experiences of AAL technology implementation. The survey inquired about only participants' perspectives on factors potentially influencing AAL technology implementation and the status quo of AAL technology implementation in relation to addressing loneliness in persons living with dementia based on their expertise as regional or national dementia organizations. Including LTC facilities in different European countries in the web-based survey could have provided first-hand perspectives on the implementation of AAL technologies, in addition to the broader picture provided by Alzheimer associations. However, the expected effort needed to obtain contact data, translate the survey into different national languages, and obtain a representative sample of LTCs outweighed the expected added value given the available time and human resources.

In addition, the original names of the AAL technologies were used as in the scoping review prior to the survey. However, the authors point out that some of the technology might have been known by other names in the field of LTC. For example, a multimedia technology, ChitChatters, is also known by the Dutch name "de Klessebessers." This might have impacted the familiarity of the respondents with this particular AAL technology.

Additionally, familiarity with AAL technology was explored in the context of addressing loneliness in persons living with dementia in LTC, whereas the survey respondents might have considered a certain AAL technology as familiar for other reasons, such as personal usage.

Furthermore, the respondents from 5 of the 7 countries in the lower expenditure group reported familiarity with the multimedia computer systems Xbox, PlayStation, and Nintendo Wii. This result must be taken with caution due to the worldwide availability of these devices for various contexts. These devices are known throughout the world for video gaming, and there are no data showing that they are known in LTC settings specifically and not from personal entertainment experience.

Finally, the sample size was small (N=24), which can be seen as a factor that limits the generalizability of the results. It was also somewhat unbalanced, with some countries being more represented than others. The same applies to the representation of national and regional associations within the countries.

Conclusions

Paro was found to be the most familiar AAL technology, and telepresence robots were the least familiar. Northwestern European countries were familiar with more devices than Eastern and Southern European countries. This finding corresponds with the national LTC expenditures of participating countries [20].

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It seems that the expenditure of European countries on LTC facilities might be linked with the number of AAL technologies their citizens are familiar with. The respondents from higher expenditure countries reported that they encourage their associations to implement AAL technology in their areas more than those in the lower expenditure group, despite their critical stance toward AAL technology. Future research is needed to clarify the potential reasons why LTC expenditure is not linked with acceptance, attitudes, or satisfaction with AAL technology in LTC.

European Alzheimer associations generally seem to agree that AAL technology meets only some needs and preferences of persons living with dementia; that AAL technology is somewhat more important than other priorities in LTC facilities, such as fall prevention; and that external financial support would increase AAL technology use to address loneliness in persons living with dementia.

Finally, the attitude of stakeholders seems to have a more positive impact in lower expenditure countries. Therefore, further research is needed to extend and diversify the role of AAL technology in addressing loneliness in persons living with dementia.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Participant countries' long-term care (LTC) expenditure per capita.
[PNG File , 34 KB - aging_v6i1e45231_app1.png]

Multimedia Appendix 2
CHERRIES (Checklist for Reporting Results of Internet E-Surveys).
[PDF File (Adobe PDF File), 174 KB - aging_v6i1e45231_app2.pdf]

Multimedia Appendix 3
Active assisted living technology per country.
[DOCX File , 14 KB - aging_v6i1e45231_app3.docx]

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Abbreviations

AAL: active assisted living
CFIR: Consolidated Framework for Implementation Research
CHERRIES: Checklist for Reporting Results of Internet E-Surveys
DISTINCT: Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology
LTC: long-term care
OECD: Organization for Economic Cooperation and Development

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Review

Strengthening Social Capital to Address Isolation and Loneliness in Long-Term Care Facilities During the COVID-19 Pandemic: Systematic Review of Research on Information and Communication Technologies

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Abstract

Background: The COVID-19 pandemic has disproportionately and severely affected older adults, namely those living in long-term care facilities (LTCFs). Aside from experiencing high mortality rates, survivors were critically concerned by social isolation and loneliness (SIL). To address this serious public health concern and stay connected with LTCF residents, information and communication technology (ICT) platforms (eg, video calls) were used as an alternative to maintaining social interactions amid the visiting restriction policy.

Objective: This paper aimed to synthesize the effects of ICT-related communication interventions using SMS text messaging or chat, video, voice mail, or photo to address SIL in LTCF residents during the COVID-19 pandemic.

Methods: In total, 2793 references published in English and French in 2019 and onward were obtained from 10 relevant databases: PsycINFO-Ovid, Ovid-MEDLINE, CINAHL-EBSCO, Cochrane Library, Web of Science, Scopus, DirectScience, Communication & Mass Media Complete, IEEE Xplore, and ACM Digital Library. A 2-person screening approach was used, and the studies were screened independently and blindly. A narrative synthesis was performed to interpret the results of the included studies, and their quality was appraised.

Results: In total, 4 studies were included in the review. ICT-related applications were used to ensure connectedness to address SIL. ICT interventions consisted mainly of videoconferencing, intergroup video call sessions between residents, and chatting (SMS text messages and phone calls). Roughly 3 classes of mediating ICT tools were used: video calls using software applications (eg, Skype); robot systems embedding video telephones; and ordinary telecommunication such as telephone, internet, social media platforms, and videoconferencing. This review has included the role of humanoid robots in LTCFs as an innovation avenue because of their multipurpose use (eg, communication tools and remotely operable).

Conclusions: Remote social capitalization through ICT applications has become an avenue to reduce SIL among LTCF residents. This review examined a social connection approach that will remain relevant and even be fostered after the COVID-19 pandemic. As families remain the main stakeholders of LTCFs, this study's findings could inform policy makers and frontline managers to better shape programs and initiatives to prevent or reduce SIL in LTCFs.

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KEYWORDS

information and communication technology; ICT; long-term care facilities; COVID-19; social isolation; loneliness; pandemic; implementation sciences; protocol; nursing home; mobile phone

Introduction

Background

The COVID-19 pandemic has caused extreme loss of life, especially in long-term care facilities (LTCFs). We can acknowledge that this global crisis disrupted the entire health care system sector [1]. In Canada, LCTFs house 6.8% of people aged ≥65 years [2]. Health care systems experienced an unprecedented crisis. Approximately 80% of deaths occur in the long-term care (LTC) sector, with Canada being among the worst performers, with a rate double the average death rate of the Organization for Economic Co-operation and Development countries' mortality (42%) [3]. In response to the spread of the COVID-19 pandemic, tight visitation restrictions were levied, isolating the LTCFs from the rest of the community, subsequently isolating older adults, already fraught with the morbidity of social isolation and loneliness (SIL) [4,5]. These measures removed the main sources of support (care, social, etc) provided in the pre–COVID-19 era by informal family caregivers (FCs). Consequently, to address the SIL induced by the lockdown on older adults, almost all previous in-person interactions with older adults were replaced by web-based chatting using information and communication technology (ICT) applications, such as FaceTime, Zoom, and Microsoft Teams video chatting.

A wealth of literature has demonstrated that SIL is negatively associated with several adverse outcomes, such as teeth loss acceleration as reported in a longitudinal study [6], risk of premature mortality [7], and mental health disorders (eg, depression and anxiety) [8], to cite a few. Before the pandemic, the importance of families' partnership with the health care sector was well-documented. Strong family or community support is essential to maintain social ties with families, friends, and the community at large [9,10]. Approximately one-fifth of families directly care for their older adults [11]. The pandemic has been associated with worsening SIL, which preexisted at a rate of ≥40% [4,5]. It also appears that most older adults are unenthusiastic about leaving their community home to move to an LTCF [12,13]. Many residents who experience marginalization associated with sexual orientation—4% of the general population [14]—or race (Black, Asian, etc) or religion (eg, Muslim) possibly faced more SIL during the pandemic.

ICT applications have been overwhelmingly used as an innovative alternative avenue to stay in touch with loved ones and bolster resilience to increasing SIL worsened by the pandemic's restrictions. Therefore, families substituted their traditional face-to-face visits with virtual visits (video calls, phone calls, chat, or photo posting) [15,16]. This initiative was welcomed, although the Canadian system's LTCFs are poorly equipped with IT infrastructure. Indeed, LTCFs operate outside of the Canada Health Act, which provides universal access, public funding, and transferable physician care in hospitals [17]. In contrast, LTCFs operate to meet social needs as opposed to medically necessary needs. Social activities (bingo, painting, outings, walks, etc) that were traditionally conducted in person [18] were consequently suspended during most of the pandemic. In addition, some authors have stated that video interactions showed effectiveness in terms of learning, and stimulation of cognitive activity [19] as well as knowledge transfer [20]. ICT has emerged as a promising, new, and innovative avenue for maintaining social connections. Unfortunately, some studies highlight the lack of technological literacy among older people and their families [21]. The use of ICT to reduce SIL has been extensively studied, even in the pre–COVID-19 pandemic era [22,23]. These studies included the effects of internet-based interventions [24-26] and humanoid robot approaches [27]. However, systematic reviews on remote interventions are still undecided regarding the positive outcomes of social loneliness. Nevertheless, we have witnessed an increased use of ICT applications—from the conventional telephone to web-based platforms, such as Skype, FaceTime, Zoom, or Google Meet. Banskota et al [28] have identified 15 types of applications—social networking (FaceTime and Skype), medical telemedicine (Teladoc, K health, and Doctor on Demand), medical prescription management (GoodRX and Medisafe Medication Management), health and fitness (Calm, Headspace Medication and Sleep, Yoga Down Dog, and MyFitnessPal), food and drink (DoorDash and Instacart), and visual and hearing impairment (Be My Eyes Helping the Blind and Glide)—that older adults have used during the COVID-19 pandemic. Chen and Schulz [29] underscored the ones used by families to interact with their loved ones in LTCFs as well as with the LTCF staff members because of the rising incidence of COVID-19 cases and associated visitation restrictions.

As the population ages worldwide and the family size decreases, SIL is becoming an increasingly pertinent public health issue. In Canada, according to the International Federation on Aging, keeping older people socially connected and active is a challenge [30]. In the past decade, many high-income countries have implemented large-scale programs to address the growing concern that SIL poses in societies [31-35]. The estimated cost of voluntary work by FCs a decade ago was valued at approximately CAD $25-$26 billion in Canada (a currency exchange rate of CAD $1=US $0.76 is applicable) [36]. In a 2012 study, 22% of caregivers provided 10 hours a week of personal care for older adults in collective dwellings [11]. This shows how FCs remain an essential labor force in the health care system. For example, for older Canadian adults living with complex conditions, frailty, and impairments, FCs provide up to 70% to 90% of the care [37].

Before the COVID-19 pandemic, reviews were conducted to demonstrate the impact of ICT on addressing SIL in LTCFs. Although the most recent Cochrane rapid review [22] did not prove a conclusive advantage, an earlier systematic review

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[29,38] on the use of ICT to combat SIL concluded that ICT was effective at reducing SIL in older adults. In the context of COVID-19, the use of commercial ICT has peaked in the general population as well as in LTCFs to sustain social connections and address SIL [39]. This was observed in various ways. On the one hand, older adults want to learn and strengthen their ability to use social media platforms to keep themselves connected to the outside world, meanwhile, some LTCFs have created ICT-mediated internet-based platforms (eg, Facebook to keep connected with their residents) to maintain vital interactions. Finally, some governments have provided programs and utility hardware (iPad). In Quebec, for instance, public LTCFs have implemented a budget to allow health network managers to purchase iPad devices for telemedicine, remote social interaction, and other psychoeducational activities.

Research Questions and Objectives

This review intends to assess the effects of ICT interventions implemented in LTCFs to address SIL among residents during the COVID-19 pandemic. The following objectives will be considered to address the research question:

1. To synthesize the effects of ICT-related communication interventions to address SIL in LTCF residents during the COVID-19 period.
2. To identify studies that use ICT, namely through various means of communication, such as texting or chat, video, voice mail, or photo, as a strategy for interaction and connection with older family members living in LTCFs.

Methods

Overview

We used a comprehensive and current database to catalog the literature on the use of ICT interventions to address SIL during the COVID-19 pandemic crisis. This systematic review considered world literature, and the selected criteria were based on a scrutiny framework (Population, Interventions, Comparators and designs, Outcomes [PICO]) and a robust search strategy. The review protocol was registered at Open Science Framework [40]. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist was implemented to provide all relevant information related to the systematic review [41]. We adhered to the Cochrane Collaboration guidelines [42]. The Synthesis Without Meta-analysis guideline [43] was consulted to guide the use of alternative synthesis methods.

Types of Participants

This systematic review included studies dealing with older adults living in any form of congregate institutional arrangement settings, such as nursing homes, municipal homes for older adults, and charitable homes for older adults. As per the inclusion criteria, the study should include people aged ≥65 years without severe mental illness.

Inclusion and Exclusion Criteria

Inclusion and exclusion criteria were based on the PICO framework.

Population

The inclusion criterion was studies including participants aged ≥65 years and those residing in an LTCF that is a congregate institutional arrangement setting (eg, nursing homes or assisted living arrangements). Exclusion criteria included studies of people (1) with a terminal illness, (2) who were hospitalized, (3) who had severe neurocognitive disorders, (4) with severely impaired cognition (measured by specific tools, such as the Mini-Mental State Examination) [44], or (5) who were community dwellers.

Intervention

As this systematic review targets the use of information technology applications, we included video, voice mail, photo, or any form of chat using any commercial applications (eg, TikTok, FaceTime, Facebook, and Zoom) for conversation through a digital tool (eg, computers, smartphones, or tablets). These accommodations help maintain or improve the connection between families and their older loved ones residing in an LTCF with the ultimate goal of combating SIL. The main ICT intervention component had to involve the use of the internet to fulfill social networking needs. We also considered the standard telephone use. The interventions had to be delivered individually or in a collective format. We excluded any form of digital accommodation requiring an important face-to-face discussion component or telecommunication for medical assessment and treatment.

Comparator and Designs

This study included quantitative design studies, namely quasi-experimental studies, cohort studies, cross-sectional studies, randomized controlled trials, quasi–randomized controlled trials, and pre-post intervention studies. Qualitative and mixed methods studies were also targeted. Studies that compared ICT interventions with alternative interventions, such as visits through windows or contactless control groups during the pandemic, were included. As planned in the protocol [45], all ICT-based therapeutic interventions such as telehealth or telemedicine, as defined by the World Health Organization [46], were also excluded. Further comparisons among virtual technology–enabled groups such as telephone versus video calls were included.

Outcome

Primary Outcomes

The primary outcomes were as follows:

1. Measures of SIL (ie, scores on any qualitative appropriation)
2. Measures of SIL through proxy outcomes (ie, the lack of companionship, the lack of friendship, a feeling of being forgotten and not belonging, and the lack of connection with family)

Secondary Outcomes

The secondary outcomes were as follows:

1. Self-reported measures of symptoms of depression (ie, scores on any self-report questionnaire designed to quantify the severity of depression symptoms)

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2. Self-reported measures of quality of life (QOL; ie, scores on any self-report questionnaire designed to allow people to rate the QOL either overall or within specific domains)

Timeline

This study covered publications completed since the onset of the COVID-19 pandemic from December 2019 onward.

Data Source and Search Strategy

An exploratory search of the MEDLINE database was first performed to scan for titles, abstracts, keywords, and descriptors. Subsequently, the complete search strategy was developed to shape each database's specificities accordingly. We used an iterative process to enhance the search strategy and adjusted the search results for each database to help capture all potential studies.

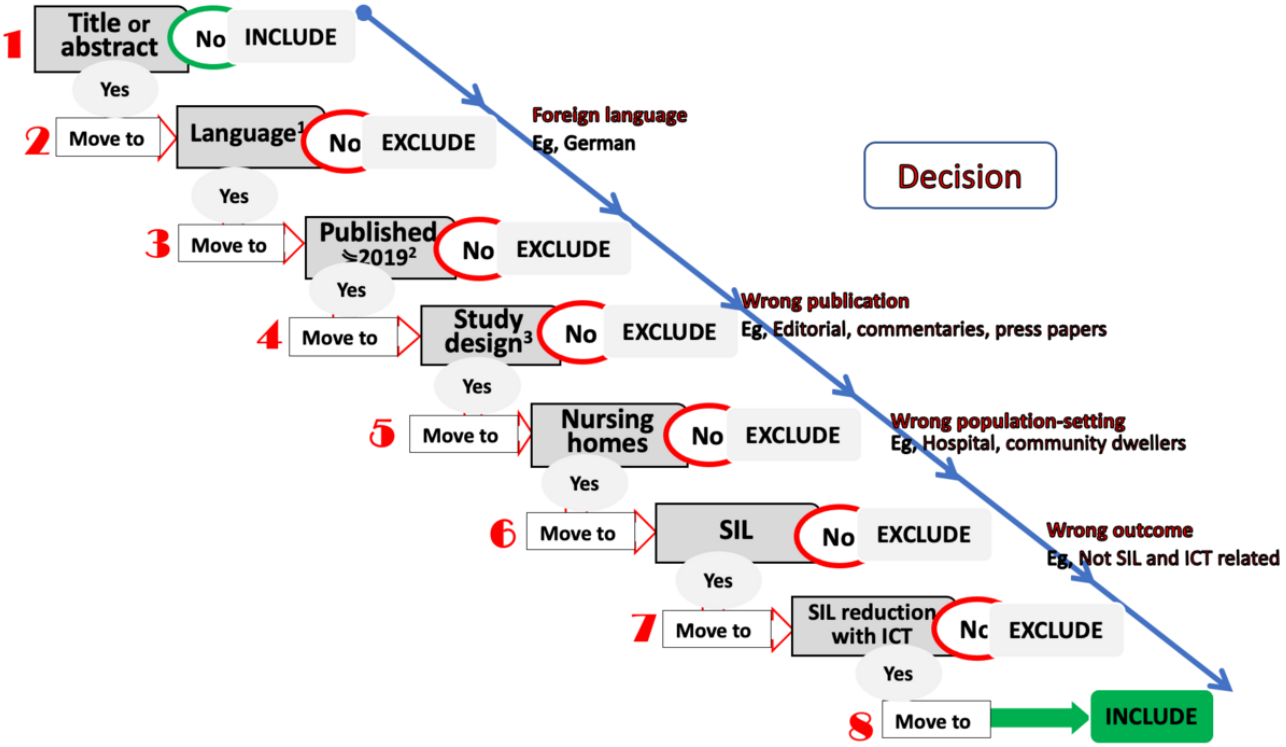
Multimedia Appendix 1 presents the final search strategy that consists of the following databases: PsycINFO-Ovid, Ovid-MEDLINE, ACM Digital Library, CINAHL-EBSCO, Cochrane Library, Web of Science, Scopus, DirectScience, Communication & Mass Media Complete, and IEEE Xplore.

The final search of the Chinese databases planned in the protocol was inconclusive (CNKI, WanFang, Weipu [VIP], and SinoMed). Finally, we only considered studies published in French and English from these databases.

Study Selection and Data Extraction

All records from the queried databases were first transferred to the EndNote package, where duplicates were removed electronically and manually and then transferred to the Rayyan web platform [47]. We implemented a 2-person screening approach, in which 2 research assistants and coauthors (APG and MCL) independently screened the titles and abstracts of potentially eligible studies. A structured algorithm (Figure 1) developed and implemented by IB, DS, and ETN in previous studies was used to support the process. Finally, conflicts were solved by the principal investigator (PI) IB.

Figure 1. Screening Algorithm.



Data Extraction

APG proceeded with data extraction under the supervision of the PI. This was preceded by a pilot test with the PI. A Microsoft Excel spreadsheet was used to analyze the data extracted. For each publication included, systematic data extraction was performed to summarize (1) the objectives, (2) the intervention objectives, (3) the participants' characteristics, (4) the experimentations (technology used and duration), (5) the method of the study (study design, inclusion of a control group, and the assessment tools used), (6) the barriers and enablers to the implementation of the technology, (7) the benefits of the intervention on social interactions, and (8) the solutions to overcome barriers to the implementation of the technology (Multimedia Appendix 2).

Data Analysis and Synthesis

The analysis consisted of identifying relevant data or segments of data linked to the objective of the review in each article. For qualitative-like study used, findings were organized according to the purpose of the use of ICT-related applications, the feelings of older adults regarding the applications, and their impact on their relatives. A thematic approach was used to identify themes from the presented data. Because the study explored a better understanding of users' experiences, we used a descriptive phenomenological approach [48] and thematically dealt with data analysis because of the high flexibility of this approach

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[49]. We considered inductive coding to determine the final themes [50]. A recurring emergent pool of subthemes derived from data was consensually retained as main themes, either naturally or aggregated based on the objectives and prevalent literature [51]. No theme categories were preset. Finally, 6 main themes were considered: (1) the focus area of the technology, (2) the use of the temi robot (Medisana GmbH), (3) the use of ordinary telephone versus the use of video call, (4) virtual remote communication, (5) effects of technology on SIL, and (6) effects of technology on other outcomes. Analyses were performed manually. Subsequently, a thematic analysis was performed.

Ethics Approval

As this systematic review is part of the Social Isolation and Loneliness project, we received ethics approval from the Ethics Committees for Research of the University of Ottawa (H-08-21-7314), the University of Moncton (dossier 2021-073), and the Research Ethics Board of the Primary Care and Population Health Research Sector of the Centre intégré universitaire de santé et de services sociaux of the Capitale-Nationale (2021-2303_SPPL).

Results

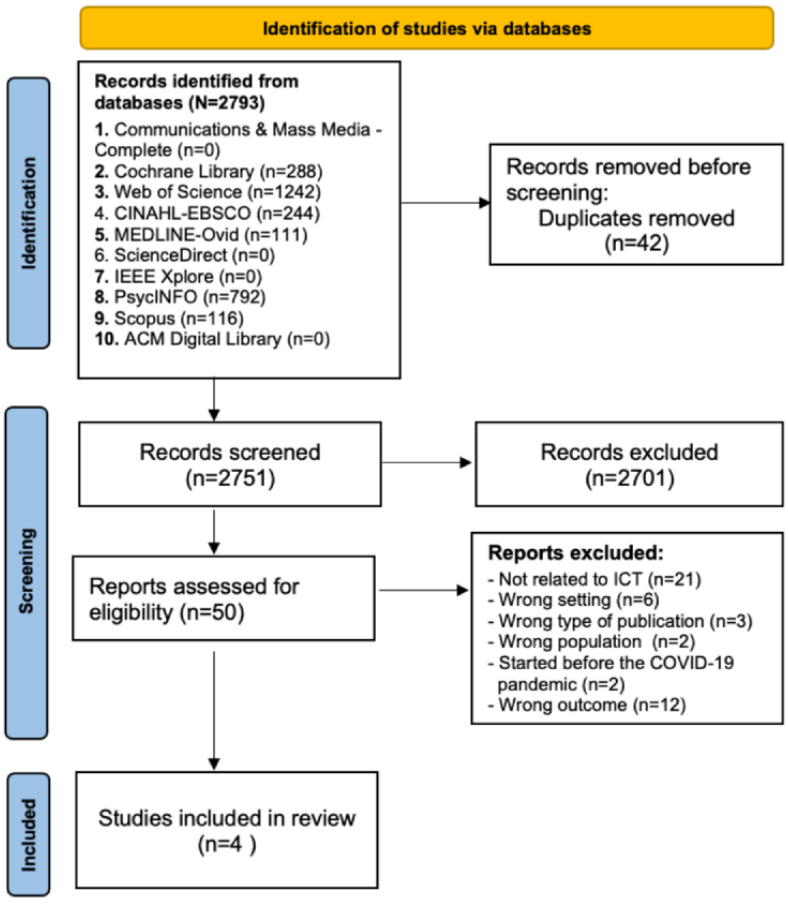
Overview

The flow diagram illustrated in Figure 2 illustrates the selection flow of the initial yield of 2793 articles. The screening of titles in the abstracts led to 49 studies. Their plain texts were read for further eligibility assessment. Finally, 4 studies [39,52-54] were retained for the review. The list of excluded publications (n=45) and the reasons for exclusion are provided in Multimedia Appendix 3. We excluded records that are not focused on settings other than LTCFs. We also excluded records that discussed interventions other than ICT-related applications to address SIL.

Studies were conducted in Germany [52], the United States [53], France [39], and the United Kingdom [54]. The following different types of LTCFs were included: nursing homes, LTC homes, and assisted living facilities.

The following designs were used in this study: implementation study [52], observational trial, collaborative action research [54], and cross-sectional study [39,53]. The included studies reached 349 participants ranging from 22 [54] to 132 [39] studies. Several study designs were included in this review and are detailed in Multimedia Appendix 2. We organized the findings of the included studies into themes and further grouped them into natural clusters around certain topics, that is, we identified the following three key promising best practices themes: (1) strategic approach (example), (2) COVID-19 prevention–related interventions (primary and secondary), and (3) COVID-19 free interactive.

Figure 2. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram illustrating the search strategy. ICT: information and communication technology.



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Intervention Type

Numerous types of social-oriented applications were implemented in this review. This includes roughly the use of the ordinary telephone and a variety of platforms for social conversation, that is, in the included studies, the authors dealt with the following platforms: video calls using software, such as Skype, Zoom, and FaceTime [54]; robot temi embedding videotelephony [52]; telephone or video [39]; and desktop computers, laptops, tablets, smartphones, the internet, social media platforms, and videoconferencing [55].

Focus Area of the Technology

Several types of tools mediating conversations between families and older adults were used in the included studies. The first category of implementation studies in which the intervention object was implemented for 2 to 8 months included Skype [52] and several other types of commercial applications such as FaceTime, Skype, and Zoom [54]. The second batch of studies used a cross-sectional approach to portray the use of ICT-based applications in the context of COVID-19 by older adults to maintain the connection between families and LTCF residents [39,53]. Finally, a third group included the use of robot technology incorporating remote communication systems through video telephony.

Use of the temi Robot

Follmann et al [52] implemented the use of robots to establish connections between families and residents. These robots have some features that allow the residents to establish connections with relatives through embedded Skype applications. temi served as a companion to the residents. A comparison was made between the 2 study sites. The use of temi resulted in a significant decrease in loneliness compared with the control group, in which residents had no contact (P=.01). Several benefits have been demonstrated with the use of temi. For residents, temi's implementation advantage extends beyond social networking mediation. Because of its autonomy, it rules out the risk of infection with controllable and comfortable operating features (comfort and quality of voice), to cite a few. For relatives, it allows for the continuity of contact with both residents and nursing staff. The absence of financial burden and the risk of infection were also reduced with the implementation of this robot. For the nursing staff, temi offered direct contact with relatives. The possibility of having temi autonomously in a quarantine room, the absence of a need for its supervision, and its ease of disinfection were all factors that facilitated its adoption by the staff.

The Use of Ordinary Telephone Versus Video Call

The study by Sacco et al [39] compared the use of telephones by older adults in LTCFs versus acute geriatric care. Older adults in an acute geriatric care unit, LTCF, and nursing home found it easier to use a telephone independently compared with video-enabled technology (video calls). Participants reported ease of use of the telephone (73/132, 55.3%) compared with video calls (59/132, 44.7%). Moreover, patients hospitalized in the acute geriatric care unit were more often satisfied with video communication (73/79, 92%) than residents of the LTC and nursing homes (20/27, 74%; P=.02), although the latter's satisfaction experience with video calls was still high.

Virtual Remote Communication

The study by Schuster and Cotten [53] reported high rates of benefits of socializing virtually with family members (26/34, 77%) and friends (16/34, 47%). However, barriers were identified, such as time to assist residents with the technology, issues related to device maintenance and repair, and residents' fear of sharing communication devices because of possible contamination (9/34, 26%).

Effects of Technology on SIL

The study by Zamir et al [54] focused on intergroup video call sessions between residents of 3 care homes and demonstrated that video calls for socialization helped residents to "pass the time," and gave them "something to do." The themes generated included feelings of happiness, having a space for expression, and other social activities that allowed older adults to fill their spare time. The following excerpts demonstrate the use of ICT and the expressive feelings of older adults during the COVID-19 pandemic on the topic of their social life. First, the LTCF managers aimed to switch the social activity from in-person (before the COVID-19 pandemic) to a virtual format with an interesting consequence. The following excerpt is an illustration of residents expressing their feelings of happiness: "...With this (quiz), we spoke about our lives and even when I used to live in the country because [resident] also did. I got to share with them... someone new who is happy to hear!" In addition, the following resident from the same study [54] laid out the fact that remote communication in such a situation gave them an opportunity to chat and beyond to share their memories, as portrayed in the following quotation:

> *When I first came across ... it was amazing ... felt like such an expert! This box was able to communicate from up there ... but now yes it is similar but the technology has changed. Had we been able to see faces then ... well I doubt we could have it was too old.*

Another resident added:

> *Good to see them face-to-face, something to do ... I know it's not good to speak to people you don't know ... but ... she's a talker. Maybe it's good to use on certain occasions when with friends something to see. I don't have a house or wife and the years go by now.*

Effects of Technology on Other Collateral Outcomes

The use of the temi humanoid robots in the Follamn et al [52] study showed the importance of this technology for every group, including families, staff members, and older adults. temi's main purpose is to reduce SIL through chatting. It can be remotely driven; therefore, this technology can reduce some communicable diseases by reducing infectious contact between the staff members and LTCF residents. temi also offers the possibility of being autonomous in a quarantine room, does not require supervision, and is easily disinfected. Finally, temi was seen to be a useful tool for employees in the study by Follmann et al [52].

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Quality Appraisal

To address the variation in study designs, we appraised the quality by using the Specialist Unit for Review Evidence (SURE) critical appraisal checklists [56], as reported by other authors [57]. All 12 items were critically considered to offer an in-depth appraisal of quality. We found it useful to portray the quality of all the components of each study (Multimedia Appendix 4 [39,52-54]). Of these studies, one lasted 78 days [52] and another lasted 8 months [54]. The 4 included studies [39,52-54] used a quantitative and participatory design. All studies implemented nonprobabilistic sampling. Studies unclearly reported participant sampling, and their size was insufficiently described. None of the 4 studies reported any attempt to blind participants from the intervention outcomes being examined or disclose information about whether assessors were aware of the intervention. Only 1 study [52] included a control group; Zamir et al [54] presented a control-like group, and 2 studies used a cross-sectional design [39,53]. The authors did not explain how a certain location, nursing home, or community was selected and why. Finally, although the studies mentioned the number of participants, none of them described how the study size was determined.

Discussion

Principal Findings

We found that ICT-related applications were used to ensure connectedness in addressing SIL in LTCFs during the COVID-19 pandemic. There were 3 main categories of ICT: (1) video calls; (2) robot systems; and (3) ordinary telephone, internet, and social media platforms.

To date, SIL is known to be one of the most prevalent issues associated with the aging population trend [58]. This systematic review aimed to portray the available evidence of ICT use in addressing SIL in LTCFs during the COVID-19 pandemic compared with SIL in the long term before the pandemic [59]. Overall, 4 studies were included [39,52-54].

On the basis of the results of this review, we can acknowledge that few studies have been published so far on the topic of ICT use in LTCFs in the context of COVID-19. There is wide heterogeneity in the quality of the studies assessed by the SURE checklist, possibly because of the complex nature of the proposed tool, the design, the duration of the implementation, or the weak sample size.

As stated by Seifert et al [60], the COVID-19 pandemic has incurred a double burden for the residents of LTCFs. First, a large proportion of them were naturally excluded from digital services because of technological illiteracy or their lack of necessary devices and network connectivity [60]. When considering the included studies, there was a clear positive outcome in the few proposed tools in terms of addressing SIL [52,54].

The use of digital tools is a new paradigm for older adults, notably those located in LTCFs, as most of those being relocated to these congregate settings are either older in age or living with disabling comorbidities [61]. Therefore, they tend to have more comorbidities and frailty, affecting their ability to engage with digital tools or learn new associated competencies. Notably, dementia, which affects praxis, language, knowledge acquisition, and mood, is highly prevalent among LTCF residents [62]. Apart from these challenges, our results have shown that some older adults remain averse to digital technology, preferring to use an ordinary telephone [63]. The use of available telephones to reach out to families of older adults, according to the US federal government policy, is mandatory. In several studies [64-66], preference was given to the ordinary telephone to take news of residents. This reluctance might be associated not only with the perception of the complexity of digital tools [67] but also with the resistance to change [68] and difficulties adjusting to change with advancing age and prevalence of cognitive decline. Another reason highlighted in the literature is that, in the context of some group activities with coresidents, some older adults have expressed discomfort and reluctance to open their camera [54].

All these aspects must be considered in the future. First, current older adults face e-technology issues that are overwhelming whereas other older adults are enthusiastic about adopting technology even with limited skills. Growing older tends to be associated with limited digital literacy, but baby boomers are now approaching old age. Worldwide, baby boomers reach retirement age and work longer [69,70] with innovative labor market policies that prolong the working period [71]. Second, as shown in the review, the use of digital technologies is rapidly emerging as an important avenue in LTCFs. Humanoid robot technology is a new innovative avenue for geriatric institutions [72] with multiple purposes, offering live interactions, games, and other friendly companionship features. More research is currently being conducted in Japanese laboratories in the field of robotics to improve human well-being, particularly in old age. They are fraught with a simultaneous risk of 2 major issues: social isolation and nursing care personnel shortage. The avenue of robot technology offers recreational programs to promote communication among older adults in LTCFs [73]. Recreational activities, almost the core activity in an LTCF, subsequently improve the QOL of older adults. Nevertheless, the consequences of robot implementation require upfront capital investment in human resources, equipment, and infrastructure. Overall, the current results on the humanoid robot avenue are beneficial for older adults [73].

In the LTCFs, the added value of the humanoid robot goes beyond serving as a communication tool between older adults and their families. It could also mitigate the risk of communicable disease transmission, as discussed earlier, and can be remotely incorporated. Nevertheless, digital technology is accompanied by limitations. For example, those with dementia tend to have problems with digitally implying tools [15].

This review did not strictly adhere to standard Cochrane methodology. We did not consider gray literature, preprints, conference abstracts, and proceedings. Although the literature published in English and French was included, we recognize the limitations associated with the fact that we ignored publications in other languages (eg, Chinese, Portuguese, and Arab and North Germanic languages). We also planned to exclude hospitalized older adults from the study. However, the study by Sacco et al [39] was retained by the research team

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because the participants belonged to the same institution (geriatric acute care unit and in the LTC unit and nursing home, University Hospital of Angers, France). Finally, the review included very few studies, despite the tremendous scientific productivity of the COVID-19 pandemic. We hypothesized that many projects are ongoing.

Recommendations for Policy, Practice, and Future Research

Although heightened during the pandemic, SIL was a pervasive issue in LTCFs in the pre–COVID-19 pandemic era. The findings of this study have important implications for older adults' QOL agenda for first-line managers in LTCFs and policy makers. Indeed, ICT-related application use offers a convincing perspective for strengthening social connections between families and their loved ones to reduce SIL. The latter is a serious public health concern, such that maintaining LTCF residents' social capital, namely social sustained connection, is paramount to their QOL. Moreover, ICT platforms (eg, video calls) offer practical means in the post–COVID-19 pandemic era to mitigate the consequences of SIL. Information technology infrastructures (eg, the internet) are acutely lacking—in Canada, for instance [74]—and are therefore needed in 24-hour residential LTC (herein nursing homes in Canada) as defined by Health Canada [75]. Besides crises such as the COVID-19 pandemic, seasonal influenza and gastrointestinal virus outbreaks in nursing homes are very common [76] and often lead to visit bans, although socialization must continue remotely because the goal of LTCFs' care is to prioritize QOL. This includes QOL at the end of life, avoidance of distress, transfers to the hospital, invasive investigation and interventions, and peaceful death. Because of the lack of available studies, more research is needed to update these review findings and validate the effectiveness of ICT-related applications in combating SIL in LTCFs.

Conclusions

To the best of our knowledge, this study is certainly one of the first systematic reviews examining the effect of the use of ICT social applications for the purpose of reducing SIL in LTCFs during the COVID-19 pandemic. Undoubtedly, virtual communication has become a new avenue for connecting people, particularly those more at risk of SIL. This is the case for older adults who relocated to congregate settings. It has been the forefront tool used by families to keep in touch with older adults in LTCFs throughout the multiple lengthy and deadly waves of the COVID-19 pandemic. Not reiterating the potential issues of e-technology, some powerful improvements, such as humanoid robots, are coming to the ground. The review has shown positive effects in terms of social connectivity, as well as acceptance by staff members who value its potential to mitigate infectious contact because of its ease of disinfection.

The findings of this systematic review draw attention to the relevant stakeholders of health systems, notably those involved with LTCFs, to address SIL as an urgent and emerging public health issue. This review, the first of the COVID-19 pandemic era, is an initial step to inform policy makers of the need for higher-quality programs for interventions addressing SIL with a special place given to virtually and technologically enabled social interactions. SIL is a socially complex concern in the modern and aging world; therefore, it necessitates a multisectoral approach that includes families, health care workers, managers, and policy makers.

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Data Availability

The data sets generated and analyzed during this study will be made publicly available, as requested by the funding institution. All requests should be addressed to the corresponding author, as data will be stored on a secured server of the University of Ottawa.

Authors' Contributions

IB conceived the initial idea of the study and is the guarantor of the review. IB, DS, ETN, MPG, SC, JR, APG, and MCL were involved in writing and reviewing the draft of this manuscript. All authors have read and approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategy.
[DOCX File , 39 KB - aging_v6i1e46753_app1.docx]

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Multimedia Appendix 2
Characteristics of included studies.
[DOCX File , 36 KB - aging_v6i1e46753_app2.docx]

Multimedia Appendix 3
List of excluded studies and reasons.
[DOCX File , 23 KB - aging_v6i1e46753_app3.docx]

Multimedia Appendix 4
Critical appraisal of quality—Specialist Unit for Review Evidence (SURE) checklist.
[DOCX File , 17 KB - aging_v6i1e46753_app4.docx]

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Abbreviations

FC: family caregiver
ICT: information and communication technology
LTC: long-term care
LTCF: long-term care facility
PI: principal investigator
PICO: Population, Interventions, Comparators and designs, Outcomes
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QOL: quality of life
SIL: social isolation and loneliness
SURE: Specialist Unit for Review Evidence

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Original Paper

The Nursing Home Severity Index and Application to Pressure Injury Risk: Measure Development and Validation Study

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Abstract

Background: An assessment tool is needed to measure the clinical severity of nursing home residents to improve the prediction of outcomes and provide guidance in treatment planning.

Objective: This study aims to describe the development of the Nursing Home Severity Index, a clinical severity measure targeted for nursing home residents with the potential to be individually tailored to different outcomes, such as pressure injury.

Methods: A retrospective nonexperimental design was used to develop and validate the Nursing Home Severity Index using secondary data from 9 nursing homes participating in the 12-month preintervention period of the Turn Everyone and Move for Ulcer Prevention (TEAM-UP) pragmatic clinical trial. Expert opinion and clinical literature were used to identify indicators, which were grouped into severity dimensions. Index performance and validation to predict risk of pressure injury were accomplished using secondary data from nursing home electronic health records, Minimum Data Sets, and Risk Management Systems. Logistic regression models including a resident's Worst-Braden score with/without severity dimensions generated propensity scores. Goodness of fit for overall models was assessed using C statistic; the significance of improvement of fit after adding severity components to the model was determined using the likelihood ratio chi-square test. The significance of each component was assessed with odds ratios. Validation based on randomly selected 65% training and 35% validation data sets was used to confirm the reliability of the severity measure. Finally, the discriminating ability of models was evaluated using propensity stratification to evaluate which model best discriminated between residents with/without pressure injury.

Results: Data from 1015 residents without pressure injuries on admission were used for the Nursing Home Severity Index–Pressure Injury and included laboratory, weights/vitals/pain, underweight, and locomotion severity dimensions. Logistic regression C statistic measuring predictive accuracy increased by 19.3% (from 0.627 to 0.748; $P<.001$) when adding four severity dimensions to Worst-Braden scores. Significantly higher odds of developing pressure injuries were associated with increasing dimension scores. The use of the three highest propensity deciles predicting the greatest risk of pressure injury improved predictive accuracy by detecting 21 more residents who developed pressure injury (n=58, 65.2% vs n=37, 42.0%) when both severity dimensions and Worst-Braden score were included in prediction modeling.

Conclusions: The clinical Nursing Home Severity Index–Pressure Injury was successfully developed and tested using the outcome of pressure injury. Overall predictive capacity was enhanced when using severity dimensions in combination with Worst-Braden scores. This index has the potential to significantly impact the quality of care decisions aimed at improving individual pressure injury prevention plans.

Trial Registration: ClinicalTrials.gov NCT02996331; http://clinicaltrials.gov/ct2/show/NCT02996331

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(JMIR Aging 2023;6:e43130) doi:10.2196/43130

KEYWORDS

geriatrics; nursing homes; pressure ulcer; propensity scores; severity of illness index; development; validation; clinical; treatment; pressure injury; injury; risk; prevention

Introduction

The aging of the population has resulted in over 1.3 million residents living in nursing home facilities in the United States [1]. Improving the quality of care and containing overall costs will require substantial research efforts to find solutions for how to provide optimal levels of care to these residents. More specifically, an area requiring quality of care improvement for this nursing home population is understanding how to prevent pressure injuries (PrIs), given our inability to control the associated pain, infection, and the potential for death once the injury develops. Current prevention approaches have not been as effective as needed; in fact, just being a nursing home resident increases one's risk of developing a PrI [2]. Nursing home prevention care is guided by the international PrI prevention guidelines [3] that advocate for risk assessment. The Braden Scale for Predicting Pressure Sore Risk (hereafter Braden score) [4] is a commonly used assessment tool to quantify PrI risk represented by a total score and risk categories (low, mild, moderate, high). Many practitioners focus their prevention efforts on residents considered at moderate or high risk. However, PrI incidence remains high among all residents regardless of the Braden score–assessed risk category [5]. The high prevalence of residents who are severely ill makes determining overall PrI risk challenging. Resident attributes beyond the Braden score may add insights to help discriminate those who are at risk of a PrI developing.

Clinical severity, the extent of physiologic decompensation, reflects the overall complexity of a resident's health status. The severity of illness measures initially were developed in the 1980s using supervised techniques that predict a specific target value, applying statistical methods with historical data. These measures helped to explain why patient mortality, cost, or length of stay differed among hospitals. Their ability to accurately predict a variety of outcomes, however, was limited given that patient attributes were in part defined by specified treatments and created using regression analyses to predict one outcome [6-9].

The Comprehensive Severity Index (CSI) [10,11], which was also developed in the mid-1980s for the evaluation of overall clinical severity levels, applied a substantively different unsupervised method based on judgments of disease-specific medical experts, literature, and clinical textbooks rather than statistical methods, specific outcomes, and use of historical data. This objective measure of clinical severity used physiological, functional, and psychosocial data, including demographics and over 2200 diagnosis-specific signs, symptoms, and physical findings (no treatments). The methodology and CSI are well established and have been validated extensively for over 30 years in patients with many different clinical conditions [10-18].

The development of a clinical severity measure targeted for nursing home residents requires the construction of a new measure with the potential to be individually tailored to different outcomes, such as a PrI. The CSI and other existing clinical severity measures are not appropriate for use with nursing home residents who have large variations in their length of stay, the time windows for data collection, and documentation frequency. This paper reports on the creation of a new clinical severity measure, Nursing Home Severity Index (NHSI), tailored for PrI risk prediction for nursing home residents, and validation using propensity modeling to predict PrI development and explore the measure's predictive accuracy beyond the Braden score.

Methods

Overview

Development of the NHSI and the selected attributes associated with PrI risk (NHSI-PrI) required initial variable selection, scoring, validation, and propensity modeling to account for independent and confounding variables that affect PrI development and exploration of the measure's predictive accuracy and validity. A retrospective nonexperimental design was used to examine a broad range of resident attributes to develop the NHSI-PrI. Current study data were based on a 12-month longitudinal data set from each study nursing home to account for seasonal differences.

Study Setting and Population Sample

Residents from 9 skilled nursing homes participating in a 12-month preintervention period (hereafter study period) of the Turn Everyone And Move for Ulcer Prevention (TEAM-UP) embedded pragmatic cluster randomized trial (R01NR016001; ClinicalTrials.gov NCT02996331) [5,19] were involved in this aspect of the study. All 9 participating Medicare and Medicaid–certified skilled nursing homes with ≥100 operating beds were in the same long-term care company and used the same electronic health record (EHR) systems with comprehensive resident clinical information. The population sample included all nursing home residents aged ≥18 years without an existing PrI on study period entry and without regard to diagnoses or demographic attributes.

Ethics Approval

Duke University Institutional Review Board (Duke IRB-Pro00069413) approved the parent project with a waiver of informed consent for nursing home residents.

Development of the Nursing Home Severity Index–Pressure Injury

The NHSI-PrI is a measure of clinical severity for nursing home residents focused on the outcome of PrI risk and development. The first step in creating the NHSI-PrI was selecting the resident attributes to include those that are relevant to a nursing home population. The NHSI-PrI differs from prior clinical severity

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measures for acute, ambulatory, or rehabilitation care as it needs to account for greater variability in the length of time residents live in nursing homes and lower frequency of assessments, laboratory, and radiological tests. Skilled care in nursing homes often involves extended stays and uses different frequencies of diagnostics and treatments (including palliative care) from those of other care environments. Acute illness is less common, so laboratory tests are drawn infrequently and often only when there is an acute event. Assessments are made periodically such as at initial admission, quarterly, annually, and on condition change. Residents may need short- or long-term skilled care while recovering from an illness or surgery. Skilled care is characterized by wound and postsurgical care; injected medications; intravenous therapy; physical, occupational, and speech therapy; and regular monitoring of vital signs or disease-specific parameters such as blood glucose levels. Thus, a refined approach to severity measurement was needed to develop a meaningful profile of nursing home residents' clinical severity.

International Classification of Diseases, Ninth Revision (ICD-9) and International Statistical Classification of Diseases, Tenth Revision (ICD-10) diagnosis codes used for residents within the study period were extracted and similar diagnoses combined (eg, codes for various types of pneumonia were aggregated into one severity criteria set including ICD-9 codes 055.1, 112.4, 136.3, 306.1, 480-486, 506.3, 507-507.1, 516.8, 517-517.1, 518.3, 668-668.04, 997.3, and 998.81, and ICD-10 codes J09.0-J18.9). For each diagnosis aggregate, a comprehensive set of relevant clinical severity indicators of resident attributes was derived from a combination of CSI criteria sets and other sources including Minimum Data Set (MDS) elements, nursing point of care documentation, and Risk Management System data elements: demographics (age, gender, race, and ethnicity) and clinical attributes (eg, laboratory test values; BMI categories, calculated as weight in kgs divided by height in m2: <18.5, 18.5-25.0, 25.1-30.0, 30.1-40.0, >40.0; weights/vital signs/pain data; and additional severity indicators of continence, dementia, locomotion, and dehydration). The inclusion of several of the NHSI severity indicators derived from the federally mandated assessment documentation for Medicare and Medicaid–certified long-term care facilities (MDS) used standardized clinical measures of functional capabilities and health needs specific to nursing home residents.

The second step in the NHSI-PrI development examined the associations and correlations of the severity indicators. Multiple indicators considered as alternative ways to describe the same resident attribute were combined into a single equivalence set (eg, highest or lowest pulse rate, electrocardiogram rhythm, and highest or lowest systolic and diastolic blood pressure to describe cardiovascular abnormality).

The third step developed algorithms to score the NHSI-PrI. A matrix was created to establish up to 4 severity levels for each indicator, their metrics, and the range of metric values applicable for nursing home residents: level 1 (normal to mildly abnormal), level 2 (moderate, nonsustained derangements that are not worrisome), level 3 (severe and worrisome derangements), and level 4 (most severe, catastrophic, life-threatening, or likely to result in organ failure). Equivalence sets were scored only once using the most abnormal indicator level during a specified time window to eliminate double scoring. Also, the most severe score of one or more indicator observations during a specified time window was used only once (eg, most abnormal body temperature recorded on different dates). The choice of severity levels was based on unsupervised methods using expert clinical judgment, literature, and clinical textbooks [10]. An expert panel of nurses and physicians on our research team reviewed the selected indicators and the associated 4 levels of severity thresholds necessary to create a measure of severity appropriate for nursing home residents. Based on previous literature and expert panel opinion, indicators were grouped into dimensions, laboratory, weights/vitals/pain, locomotion, and underweight. Next, expert panel reviewers interpreted the four indicator severity level scores as nonlinear and applied an exponential weighting function using a complex heuristic to create continuous NHSI-PrI dimension scores.

The final step in NHSI-PrI development involved validity testing. Secondary data from nursing home EHR, MDS, and Risk Management System data were used to validate the NHSI-PrI. The most commonly used measure in the United States to predict PrI risk, the Braden score [20], was examined in predictive models with and without severity dimensions. The Braden score is comprised of six subscales (sensory perception, mobility, activity, moisture, nutrition, and friction and shear) that are summed in a rating scale to help clinicians identify those at-risk for PrI development and to guide preventive measures based on risk factors. The subscales are rated from 1 to 4 (except friction and shear rated from 1 to 3), with 6-23 total points possible. Predictive validity varies by setting [21,22]. Risk categories for PrIs are based on total Braden scores: low (19-23), mild (15-18), moderate (13-14), and high (10-12) PrI risk.

A unique feature of the NHSI-PrI development used automatic severity scoring based on EHR, MDS, and Risk Management System data avoiding manual time-consuming abstraction. A computer algorithm was designed to generate the 4 severity levels according to extent of abnormality: the more abnormal the resident attributes, the higher the severity indicator levels and the NHSI-PrI's severity dimension scores.

Data and Data Management

Categories of EHR data used were vital signs, MDS elements, laboratory test values, and nursing point-of-care activities of daily living documentation. Data were extracted directly from EHRs with computer algorithms (code) created with SAS version 9.4 (SAS Institute Inc) [23]. All electronic data downloads were performed by the nursing home company in a Health Insurance Portability and Accountability Act–compliant format with the creation of a study identification number for each resident prior to data downloading and being transferred to Duke University's secure drive space designated for the TEAM-UP study.

Issues Defining Time Window of Exposure and Clinical Severity Measurements

Nursing homes conduct laboratory tests and other assessments infrequently, and enough time is needed to have sufficient data

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when resident clinical severity is most likely related to the outcome of interest. Also, residents' severity measure comparisons depend on the standardization of an exposure window for the amount of time a person is observed and at risk for the outcome of interest. An exposure time window should reflect the period during which its effects are relevant to the specified outcome. Important factors to consider when defining exposure are the length of time, changes in exposure status, and consistency and accuracy of exposure measurements. Frequency, format, and intensity of residents' observations are other important considerations. Clinical judgment was used to establish a 92-day window prior to the first PrI, which was a similar period to the typical quarterly Braden score and other resident assessments. For residents who did not develop PrIs, severity scores were based on indicator values during the final 92 days before discharge (death, transfer) from the nursing home or the end of the study period since residents are often sickest when they are older.

Statistical Analysis

Descriptive statistics (means, SDs, frequencies, percentages) were used to describe demographic and clinical resident attributes with/without PrIs and were compared using 2-tailed *t* tests or chi-square tests as appropriate. A resident's most severe Braden score (Worst-Braden) occurring during the 92 days prior to PrI development, discharge/death, or end of the study period was used to define risk categories of low (19-23), mild (15-18), moderate (13-14), and high (10-12). Validation methods included correlations overall and by Worst-Braden risk category followed by logistic regression models with/without severity dimensions to generate propensity scores or probabilistic estimates that a resident develops a PrI. Predictors (independent variables) included NHSI-PrI dimension scores and Worst-Braden score. The goal of these analyses was to assess the predictive capacity of three models: model 1 based on Worst-Braden scores alone, model 2 based on four NHSI-PrI dimensions, and model 3 based on Worst-Braden scores plus four severity dimensions.

Goodness of fit for logistic regression models was assessed in several ways. First, the overall models (relationship between the independent variables and the dependent variable) were assessed using a C statistic with a minimum value of 0.50 corresponding to chance and a maximum value of 1.0 (perfect prediction). To test the significance of improvement in fit after adding severity dimensions to the model, differences in C statistics between models with/without severity were examined using a likelihood ratio chi-square test. Second, the significance of each severity dimension was assessed by examining odds ratios (ORs) to determine the relative amount by which the odds of the dependent variable increased (OR≥1.0) or decreased (OR<1.0) when the value of the corresponding dimension variable increased by 1 unit. Third, the predictive accuracy or discriminating ability of the models was evaluated using propensity stratification. Observations were divided into equally sized strata defined by deciles of their sorted propensity scores to examine which model best discriminated between residents with/without PrIs. As a final validation of the NHSI-PrI, the study sample was randomly divided into a 65% training data set and a 35% validation data set, and the same validation statistics specified above were computed for each data set.

Results

There were 1015 residents in 9 nursing homes during the study period who met the study inclusion criteria and had comprehensive EHR data in the relevant 92-day window for risk of PrI development. Across all 9 nursing homes, between 2.3% (n=3) to 18.3% (n=31) of residents developed PrIs for a total of 8.8% (n=89) having PrIs during the study period.

Table 1 compares attributes of residents with/without PrIs. There were no significant differences in age, gender, or race/ethnicity. However, the length of stay during the study period was significantly longer, although only 16 days, or 4.9%, for residents who developed PrIs versus those who did not. Significantly fewer residents with BMI ≥30 (n=21, 6.6%) and significantly more residents with BMI <18.5 (n=15, 18.5%) developed PrIs. Residents who developed a PrI had significantly lower (more severe) Worst-Braden scores and a greater percentage of residents in higher risk categories. All 4 of the NHSI-PrI severity dimensions (laboratory, weights/vitals/pain, locomotion, and underweight) indicated significantly greater clinical severity during the 92-day period before residents developed a PrI compared to the 92-day period prior to discharge for residents who did not develop PrIs.

Textbox 1 describes examples of clinical severity indicators contained in each of the 4 NHSI-PrI dimensions. The most abnormal values for these indicators during the 92-day window were used to quantify the severity of each indicator.

Different severity dimensions were associated with PrI development in residents classified by each of the Worst-Braden risk categories (Table 2). The higher the severity dimension score the more likely a PrI was to develop. The locomotion and underweight dimensions were significantly associated with PrI development for residents in low- and mild-risk categories, while the laboratory and weights/vitals/pain dimensions were significantly associated with PrI development for residents in moderate- and high-risk categories.

The C statistics from three logistic regression models captured the magnitude of improvement associated with adding severity dimensions to predictive models starting with the Worst-Braden score alone (Table 3). Age, gender, and race/ethnicity were not significant in predicting PrIs. The Worst-Braden score alone (model 1) provided limited predictive accuracy (C=0.627); the C statistic was 0.725 or 15.6% better using all four NHSI-PrI severity dimensions (model 2); C increased a little further to 0.748 or 19.3% better when the Worst-Braden score was added to the four NHSI-PrI dimensions (model 3), which improved the goodness of fit (model 1 vs model 3) significantly (P<.001).

The magnitude of this improvement is best gauged by examining the ORs of the individual severity dimensions. For model 3, an increase of 5 points in the locomotion dimension score increases the likelihood of PrI by 75%. A 5-point increase in the underweight dimension score increases the likelihood of PrI by 50%.

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Table 1. Comparison of characteristics for residents without and with pressure injuries (PrIs) during the preintervention time period (N=1015).

Demographic and clinical characteristics	Total population (N=1015)	Residents without PrI (n=926)	Residents with PrI (n=89)	*T* test, *F* test, or chi-square (*df*)	*P* value
Resident age (years), mean (SD)	77.94 (12.9)	77.85 (12.9)	78.87 (12.5)	–0.71 (1013)	.48
Male, n (%)	357 (35.17)	329 (35.5)	28 (31.5)	0.77 (1013)	.44
BMI (kg/m^2), n (%)				18.33 (3)	<.001
<18.5	81 (8.0)	66 (7.1)	15 (16.9)		
18.5 to <25	383 (37.7)	341 (36.8)	42 (47.2)		
25.0 to <30	233 (23.0)	222 (24.0)	11 (12.4)		
>30	318 (31.3)	297 (32.1)	21 (23.6)		
Race/ethnicity, n (%)				1.36 (2)	.51
Asian	32 (3.2)	29 (3.1)	3 (3.4)		
Black	333 (32.8)	299 (32.3)	34 (38.2)		
White	650 (64.0)	598 (64.6)	52 (58.4)		
Braden-First score[a], mean (SD)	18.00 (2.9)	18.13 (2.9)	16.66 (2.7)	4.57 (108.80)	<.001
Braden-MEAN score[b], mean (SD)	17.61 (2.7)	17.78 (2.7)	15.84 (2.2)	7.75 (115.41)	<.001
Braden-Worst score[c], mean (SD)	16.43 (3.3)	16.55 (3.3)	15.19 (2.7)	4.42 (115.11)	<.001
Braden-MEAN risk categories based on Braden-MEAN scores[b], n (%)				20.95 (3)	<.001
Low risk (score 19-23)	469 (46.2)	448 (48.4)	21 (23.6)		
Mild risk (score 15-18)	434 (42.8)	382 (41.3)	52 (58.4)		
Moderate risk (score 13-14)	82 (8.1)	71 (7.7)	11 (12.4)		
High risk (score 10-12)	30 (3.0)	25 (2.7)	5 (5.6)		
Braden-Worst risk categories based on Braden-Worst scores[c], n (%)				12.17 (3)	.007
Low risk (score 19-23)	282 (27.8)	270 (29.2)	12 (13.5)		
Mild risk (score 15-18)	442 (43.6)	401 (43.3)	41 (46.1)		
Moderate risk (score 13-14)	171 (16.9)	149 (16.1)	22 (24.7)		
High risk (score 10-12)	120 (11.8)	106 (11.5)	14 (15.7)		
Weights/vitals/pain severity dimension score, mean (SD)	14.70 (12.2)	14.37 (12.2)	18.16 (11.8)	–2.81 (1013)	.005
Locomotion (On_Off) severity dimension score, mean (SD)	2.34 (3.1)	2.20 (3.0)	3.83 (3.7)	–4.08 (99.37)	<.001
Laboratory severity dimension score, mean (SD)	6.22 (11.1)	5.71 (10.5)	11.54 (15.1)	–3.56 (96.44)	<.001
Length of stay-total[d] (days), mean (SD)	1349 (1287)	1326 (1287)	1591 (1270)	–1.86 (106.15)	.06
Length of stay during preintervention study period[e] (days), mean (SD)	327 (821)	326 (83)	342 (66)	–2.11 (116.37)	.04

[a]Braden-First score: first Braden score occurring during the preintervention period.

[b]Braden-MEAN score: mean of all Braden scores occurring during the preintervention period.

[c]Braden-Worst score: worst Braden score occurring during the 92 days prior to pressure injury development, discharge/death, or end of the preintervention period.

[d]Length of stay total: number of days from nursing home admission to end of preintervention period, mean (SD).

[e]Length of stay preintervention study period: number of days during preintervention time period, mean (SD).

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Textbox 1. Description of the Nursing Home Severity Index-Pressure Injury (NHSI-PrI) clinical severity dimensions and their indicators. Weights for each indicator comprising a dimension are summed to produce a dimension score.

Laboratory dimension

- Lowest platelets (10^3/uL), lowest female hemoglobin (HGB; g/dl), lowest female hematocrit (HCT; %), lowest male HGB (g/dl), lowest male HCT (%)
- Highest glucose (mg/dl), highest hemoglobin A_{1c} (n x norm)
- Highest/lowest potassium (K; mEq/L)
- Highest blood urea nitrogen (mg/dl), highest creatinine (mg/dl), lowest albumin (mg/dl)
- Highest aspartate transaminase (serum glutamic-oxaloacetic transaminase; n x norm), highest alanine transaminase (serum glutamic-pyruvic transaminase; n x norm)
- Highest sodium (NA; mEq/L), lowest sodium (mEq/L)
- Highest 24 hr urine protein (mg/dl), highest urine protein via dipstick
- O_2 saturation on pulse oximetry (%), arterial blood gases, lowest pH (no units), lowest pO_2 (mm/Hg), highest pH (no units), lowest total venous CO_2 (mEq/L)
- Highest white blood cell count (WBC; k/cu mm), highest bands (%), lowest WBC (k/cu mm)
- Lowest lymphocytes (%)
- Highest total bilirubin (mg/dl)
- Highest total calcium (mg/dl)
- Highest alkaline phosphatase (u/l)

Underweight dimension

- BMI <18.5 kg/m^2

Weights, vitals, pain dimension

- Infiltrates/consolidation in lungs, rales/rhonchi/wheezes, dyspnea, breath sounds, kussmaul breathing, sputum/secretions
- Highest temperature, rigors/chills, lowest temperature
- Highest pulse rate, electrocardiogram rhythm, highest blood pressure systolic, highest blood pressure diastolic, lowest pulse rate, lowest systolic blood pressure, orthostatic blood pressure
- Weight loss, cachexia, weight gain, general pain
- Pulse characteristics
- Chest pain

Locomotion dimension (locomotion dimension indicators are calculated as average/day frequency)

- Locomotion OFF unit with wheelchair
- Locomotion OFF unit with wheeled recliner
- Locomotion OFF unit one person assist
- Locomotion OFF unit total dependence
- Locomotion ON unit one person assist
- Locomotion ON unit total dependence

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Table 2. Correlations among predictor variables and outcome of pressure injury used in logistic regression models.

Predictor variable	Total residents (N=1015; PrI[a] n=89)	Pressure injury low risk (n=282; PrI n=12)	Pressure injury mild risk (n=442; PrI n=41)	Pressure injury moderate risk (n=171; PrI n=22)	Pressure injury high risk (n=120; PrI n=14)
Worst-Braden					
r	–0.12	–0.09	–0.12	0.02	0.13
P value	<.001	.12	.01	.79	.17
Laboratory dimension					
r	0.15	0.07	0.12	0.22	0.29
P value	<.001	.22	.01	.003	.001
Weights/vitals/pain dimension					
r	0.09	0.28	0.09	0.09	0.19
P value	.004	.64	.05	.23	.04
Locomotion dimension					
r	0.15	0.21	0.15	0.09	0.10
P value	<.001	<.001	.002	.23	.26
Underweight dimension					
r	0.10	0.17	0.11	0.08	0.02
P value	.001	.005	.02	.32	.83

[a]PrI: pressure injury.

Table 3. Logistic regression models predicting pressure injury development.

Logistic regression model	Estimates	Standard error	*P* value	Odds ratio (95% CI)	C statistic (*df*)	Likelihood ratio chi-square test	
						Chi-square (*df*)	*P* value
Model 1 (Braden)					0.627 (1)	N/A[a]	N/A
Worst-Braden score	–0.126	0.035	<.001	0.88 (0.82-0.94)			
Model 2 (NHSI-PrI[b])					0.725 (4)	50.33 (4)[c]	<.001
Underweight dimension	0.098	0.036	.006	1.10 (1.03-1.18)			
Laboratory dimension	0.030	0.008	<.001	1.03 (1.01-1.05)			
Weights/vitals/pain dimension	0.024	0.009	.009	1.02 (1.01-1.04)			
Locomotion dimension	0.149	0.034	<.001	1.16 (1.09-1.24)			
Model 3 (Braden + NHSI-PrI)					0.748 (5)	61.72 (5)[d]	<.001
Worst-Braden score	-0.121	0.037	.001	0.89 (0.82-0.95)			
Underweight dimension	0.097	0.360	.007	1.10 (1.03-1.18)			
Laboratory dimension	0.031	0.008	<.001	1.03 (1.02-1.05)			
Weights/vitals/pain dimension	0.025	0.009	.007	1.03 (1.01-1.04)			
Locomotion dimension	0.140	0.034	<.001	1.15 (1.08-1.23)			

[a]N/A: not applicable.

[b]NHSI-PRI: Nursing Home Severity Index–Pressure Injury.

[c]Comparing goodness of fit of two models: model 2 versus model 1.

[d]Comparing goodness of fit of two models: model 3 versus model 1.

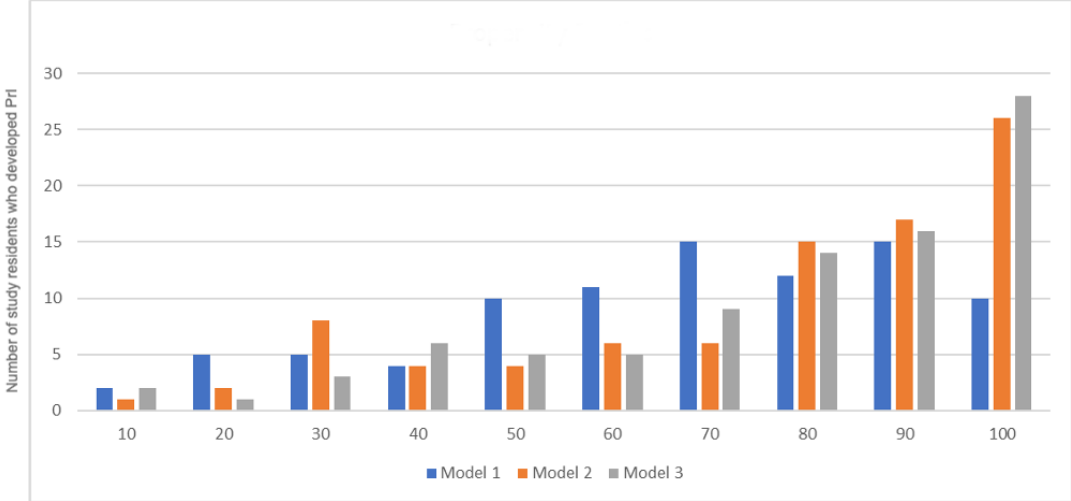
The histogram in Figure 1 summarizes the propensity score results generated from prediction models using model 1 (only Worst-Braden score) versus model 2 (only 4 NHSI-PrI dimensions) or model 3 (Worst-Braden score plus 4 NHSI-PrI dimensions). The top decile for each model contains 10% of the population most likely to develop a PrI and the bottom decile contains 10% of the population with the lowest likelihood of PrI. The deciles and number of study residents who actually

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developed PrIs in that decile are graphed on the x and y axes, respectively. Models 2 and 3 exhibit patterns of mostly "staircase" increases for each decile demonstrating that the models "binned" the residents correctly from those least likely to develop a PrI to most likely. In contrast, model 1 exhibits an irregular pattern for each decile, both up and down, indicating that the model is not doing as good a job of predicting a resident's likelihood for PrI. More than 65% (n=58) of residents with PrIs are identified in the three highest propensity deciles using models 2 and 3 compared to only about 42% (n=37) of residents with PrIs in the three highest deciles using model 1. Thus, using propensity score analysis, the inclusion of severity dimensions in models 2 and 3 resulted in the identification of 21 more residents at greater risk (in the three highest propensity deciles) of developing a PrI than in model 1.

The outcome of PrI development was also used to validate the NHSI-PrI results for training and validation data sets. The randomly selected training data set contained 56 PrIs in 658 residents, and the validation data set contained 33 PrIs in 357 residents. For training data, the corresponding predicted C statistics were 0.618 (model 1), 0.717 (model 2), and 0.735 (model 3), resulting in an 18.9% improvement from model 1 to 3. For validation data, the C statistics were 0.648 (model 1), 0.810 (model 2), and 0.816 (model 3), resulting in a 25.9% improvement from model 1 to 3.

Figure 1. Propensity deciles for all models. PrI: pressure injuries.



Discussion

Principal Findings

Multiple different approaches were used to validate the NHSI-PrI to predict residents at risk for PrI development. Model statistics improved from using the Worst-Braden score alone (C=0.627) to using NHSI-PrI alone (C=0.725) to combining the Worst-Braden score and NHSI-PrI (C=0.748). Looking at propensity score deciles versus actual results also validated the improvement indicated by NHSI-PrI. Finally, randomly dividing the data into training and validation data sets showed that the training values had similar corresponding C statistics for Worst-Braden scores alone versus NHSI-PrI alone versus the combination of the two.

Measuring resident clinical severity and predicting a specific outcome such as PrI involves an examination of numerous resident attributes (eg, physiologic, functional, and psychosocial variables during a specified window of time) and potentially hundreds of data points. Using existing and relevant data, nursing home outcomes can only be evaluated accurately when pertinent resident attributes that impact the resulting outcomes are included. There is no way to demonstrate whether differences in outcomes are associated with either health interventions, differences in clinical severity, or both if critical aspects of a resident's clinical severity are not included.

Clinical severity in nursing home residents is challenging to define given the multitude of factors affecting the overall health status of older adults who are potentially further compromised by residing in a nursing home [2]. Significant differences are evident in clinical severity definitions for adults in differing care settings. For example, a severity indicator label may be the same for an adult cared for in acute care or a nursing home setting, but nursing home resident outcome prediction required modification in that indicator's thresholds due to substantial differences in age-related attributes. Identification of new severity indicators and new thresholds for some of those indicators were needed when applied to older adult residents.

Multiple different data sources with varied recording formats and coding patterns for the same indicator were encountered in developing and programming the new NHSI-PrI measure, making synchronization of data elements challenging. Yet, it was required to avoid subsequent issues interpreting analysis results.

Strengths

The new NHSI-PrI measure has two unique features: (1) capacity for automatic scoring and (2) daily calculation. First, the NHSI-PrI was designed by clinical experts to be scored automatically from downloaded structured EHR data including vital signs, MDS data elements, laboratory test values, weights, etc. Second, the NHSI-PrI measure can be calculated daily based on findings during the most recent prior 92-day time window,

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allowing for evolving clinical severity changes to be monitored over time.

There is a substantial benefit to identifying and monitoring known PrI predictors and improving prediction using electronic data in addition to the existing Braden score. Little is known about differences in who does and does not develop a PrI, especially among nursing home residents. PrI prevention efforts are well established according to international guidelines, yet PrI incidence has remained high in nursing homes. Historically, clinically assessed PrI risk among residents has resulted in most preventive resources being allocated to residents evaluated at moderate or high risk. However, significant numbers of PrIs also occur in residents in low and mild Worst-Braden risk categories [5]. This research supports the value of a well-discriminating model that differentiates residents with a higher likelihood of developing a PrI from those with a lower likelihood. These findings suggest that relying on the Worst-Braden score alone is a weak predictor. The use of the Worst-Braden score in combination with four severity dimensions of the NHSI-PrI significantly enhances the accuracy of PrI prediction. This new knowledge can be used to design and modify resident-specific PrI prevention plans. Thus, the addition of specific NHSI-PrI dimensions to current risk assessment resources has the potential to substantively impact quality care decisions aimed at improving PrI prevention outcomes, especially among different Worst-Braden risk categories.

Limitations

This study had several limitations that may affect the reproducibility and generalizability of results. First, nursing home populations have several unique characteristics that provide challenges for identifying comparable discrete times of exposure or defined time frames. For example, it was assumed that residents' exposure time had a clearly defined start and end date when in fact this varied across residents. An up to 92-day window was determined to be most clinically relevant and applied to define exposure duration to measure and compare clinical severity for residents with and without PrIs. Results may differ if shorter or longer time windows are applied. The approach used in computing the NHSI-PrI directly from downloaded structured electronically available data may have limited the variety of indicators that could be included in the NHSI-PrI and may need updating as more relevant structured electronic data become available.

Second, our models are not directly linked in real time to measures for risk mitigation. This is due to the fact that clinical severity data in nursing homes are captured less frequently than ongoing clinical appraisals in other settings. Some observations that may be useful predictors are recorded only every quarter. This limits the precision of risk indicators that can be used. More frequent measurement of relevant severity clinical indicators would likely improve the predictive ability of NHSI-PrI.

Future Directions

Substantive strides are needed to standardize health care data to facilitate process improvements in data interpretation for future studies. Determination of severity levels required complex data interpretation from various sources for which there is currently no data field standardization. The substantial amount of coding across electronic data formats was a fundamental challenge. Data values needed to be converted to equivalents and interpreted for descriptive data fields to assign severity levels. Data standardization and interpretive processes were carefully performed, checked, and further evaluated taking clinical judgment into account. This process required significant effort to minimize inconsistencies.

Finally, the effectiveness of the NHSI-PrI using a larger sample of nursing home facilities and residents is unclear. Our sample was divided into training and validation data sets, each of which well represented the whole data set to test generalizability. Larger confirmatory studies with a different cohort of nursing home residents and facilities should establish the reliability and validity of the new NHSI-PrI and its results.

Conclusions

The newly created NHSI-PrI was successful in developing a meaningful profile of clinical severity among nursing home residents and accurately predicting the risk of PrI development. Findings support that clinical severity dimension scores can be used in combination with Worst-Braden scores to augment PrI prediction and potentially impact the quality of care decisions aimed at improving individual PrI prevention plans.

Data Availability

The data used in this publication include protected health information and therefore cannot be freely shared. Data sharing will be possible with case-by-case approval from the authors' institutional review board; requests may be directed to the principal investigator.

Conflicts of Interest

TLY is a *JMIR Aging* editorial board member at the time of this publication and is on the Smith and Nephew speaker bureau. The other authors have no conflicts of interest to declare.

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Abbreviations

CSI: Comprehensive Severity Index
EHR: electronic health record
ICD-9: International Classification of Diseases, Ninth Revision
ICD-10: International Statistical Classification of Diseases, Tenth Revision
MDS: Minimum Data Set

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NHSI: Nursing Home Severity Index
NHSI-PRI: Nursing Home Severity Index–Pressure Injury
OR: odds ratio
PrI: pressure injury
TEAM-UP: Turn Everyone and Move for Ulcer Prevention

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Original Paper

Exploring the Role of Active Assisted Living in the Continuum of Care for Older Adults: Thematic Analysis

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Abstract

Background: Active assisted living (AAL) refers to systems designed to improve the quality of life, aid in independence, and create healthier lifestyles for those who need assistance at any stage of their lives. As the population of older adults in Canada grows, there is a pressing need for nonintrusive, continuous, adaptable, and reliable health monitoring tools to support aging in place and reduce health care costs. AAL has great potential to support these efforts with the wide variety of solutions currently available; however, additional work is required to address the concerns of care recipients and their care providers with regard to the integration of AAL into care.

Objective: This study aims to work closely with stakeholders to ensure that the recommendations for system-service integrations for AAL aligned with the needs and capacity of health care and allied health systems. To this end, an exploratory study was conducted to understand the perceptions of, and concerns with, AAL technology use.

Methods: A total of 18 semistructured group interviews were conducted with stakeholders, with each group comprising several participants from the same organization. These participant groups were categorized into care organizations, technology development organizations, technology integration organizations, and potential care recipient or patient advocacy groups. The results of the interviews were coded using a thematic analysis to identify future steps and opportunities regarding AAL.

Results: The participants discussed how the use of AAL systems may lead to improved support for care recipients through more comprehensive monitoring and alerting, greater confidence in aging in place, and increased care recipient empowerment and access to care. However, they also raised concerns regarding the management and monetization of data emerging from AAL systems as well as general accountability and liability. Finally, the participants discussed potential barriers to the use and implementation of AAL systems, especially addressing the question of whether AAL systems are even worth it considering the investment required and encroachment on privacy. Other barriers raised included issues with the institutional decision-making process and equity.

Conclusions: Better definition of roles is needed in terms of who can access the data and who is responsible for acting on the gathered data. It is important for stakeholders to understand the trade-off between using AAL technologies in care settings and the costs of AAL technologies, including the loss of patient privacy and control. Finally, further work is needed to address the gaps, explore the equity in AAL access, and develop a data governance framework for AAL in the continuum of care.

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(JMIR Aging 2023;6:e40606) doi:10.2196/40606

KEYWORDS

ambient assisted living; active assisted living; AAL; internet of things; aging well; aging in place; older adults; geriatrics; standards; policies; health care

Introduction

Background

Canada has a growing aging population, which has led to a pressing need for nonintrusive, continuous, and reliable health monitoring tools that can support aging in place [1-4] and reduce health care costs [4,5]. One of the biggest challenges in helping older adults continue to age in their own homes and communities is the increasing prevalence of chronic diseases as individuals continue to live longer [6]. Moreover, the COVID-19 pandemic has accelerated the need for remote monitoring tools that enable clinicians to support their patients from a distance with fewer clinic visits and hospital admissions [7,8].

Active assisted living (AAL) technologies can improve the quality of life, aid in independence, and create healthier lifestyles for those who need assistance at any stage of their lives. Three years ago, the demand for services and technologies that support telehealth, AAL, and internet of things (IoT) for health was not met, as many technologies were still in their infancy when the pandemic began [9]. Consequently, the pandemic incentivized the accelerated commercialization of products, and the market was flooded with products of lower quality [9]. This, in turn, increased the need for technology guidelines and an ecosystem capable of accommodating new technologies as they become available [10].

Other concerns arising from the rapid integration of AAL and IoT into care, such as the loss of care recipients' privacy and control over their own information, have not been adequately addressed [11]. In addition, care recipients may fear the loss of independence owing to actions taken by caregivers and care providers based solely on AAL data or a growing dependence on the technology without making other considerations [2,9].

Goal of This Study

The study was conducted in close collaboration with care providers and other stakeholders to ensure that the recommendations for system-service integrations aligned with the needs and capacity of the health care and allied health systems. This study also recognized that the individual needs of users extend beyond the home environment to include services and data collected at the community and city levels. Therefore, this was an exploratory study with the aim of understanding the opportunities for and challenges of integrating AAL technologies into the health system at the community level (eg, into the practice of paramedicine and other emergency services, pharmacies, allied health professional services, and medical clinics).

Study Rationale

As a core goal of the AAL technology ecosystem is to promote independent living and improve the quality of life for vulnerable individuals, the authors not only considered the user's home but also addressed the individual AAL requirements beyond the home environment, including services and data collected at the community and city levels. Unfortunately, AAL technologies are rarely integrated with external services, especially community health services [11-13]. The primary use of AAL in the continuum of care is to support integrated care [14], and successful integrated care depends on seamless transitions between care services and settings. Integrated care should also include coordinated care that offers access to services within a reasonable time frame, as well as effective treatment, self-care support, respect for care recipients' preferences, and appropriate involvement of family members and other informal caregivers [14,15]. Some simple solutions identified in the literature for improving the continuity of AAL include accurate contact information for care providers and discharge information that is clear and tailored to the care recipient [16,17].

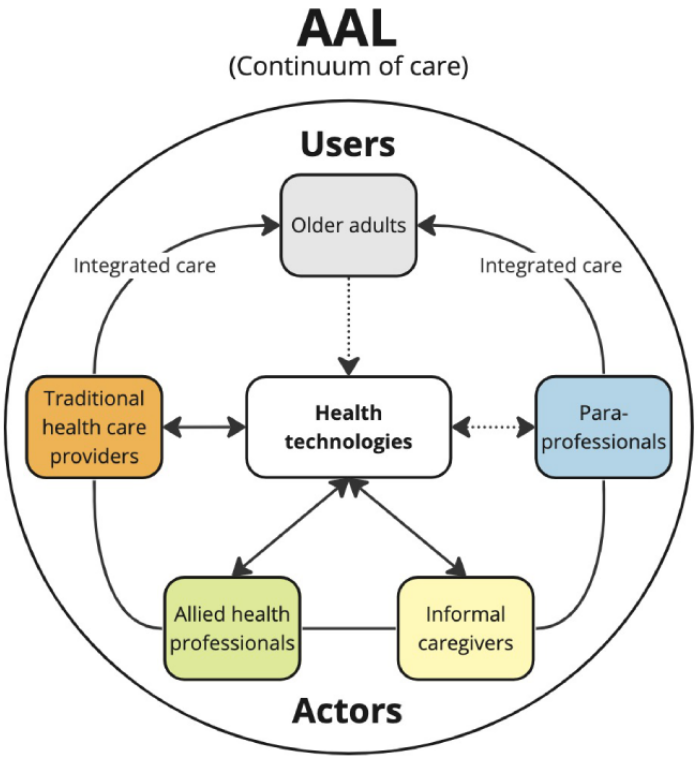
Over the years, attempts have been made to integrate IoT and AAL technologies into the homes of older adults; however, there are practical and financial considerations for developing and implementing these integrations [8,13,18]. Besides these considerations, there is a trade-off between health technology use and the right to privacy, but the incentive must be at least greater than the effort of learning how to use the technology and loss of one's privacy because of sharing data with service providers [19-22]. Specifically, the advantages offered to older adults from adopting a health technology (ie, better support for independent living, reduced dependence on others, or the ability to navigate the physical environment of their home or care setting) must be perceived to be greater than the loss of privacy and perceived loss of control [11,22].

Conceptual Framework

In this conceptual framework for an AAL system, a *user* is a care recipient who becomes a *data participant* when their personal data are collected by different technologies. An *actor* refers to an entity that communicates and interacts in the system, including persons, technical components, software applications, systems, databases, and other bodies that play a role in the system. In an AAL system, an *agent* refers to any person interacting with the system, excluding the care recipient, or any person interacting with the care recipient along the continuum of care, including traditional health care provider users, allied health professionals, informal caregivers, and paraprofessionals. A visualization of the conceptual framework is presented in Figure 1.

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Figure 1. Existing landscape of active assisted living (AAL) technologies and their applications in the continuum of care.



Traditional health care providers are traditional in the sense that, in addition to being naturally associated with the term health care providers, past pilot projects that have sought to integrate data from AAL technologies into care typically first seek to include them. This group includes physicians, nurses, pharmacists, and social workers. Agents playing additional roles associated with the care of older adults, such as transition care coordinators or geriatric care managers, are included here if they perform these roles in the context of their work as a nurse or social worker. Allied health professionals refers to agents who work in the health care context and are paid through public funding but have not commonly been included in past pilot projects of integrated AAL systems. Agents in this group can still benefit from the data obtained from AAL systems (eg, data related to movement, room temperature, and use of tracked or radio-frequency identification–tagged items) if they are properly interpreted and targeted to their work. Examples of agents in this group include physical therapists, occupational therapists, patient navigators, community health workers, and personal support workers. Informal caregivers refers to agents who are not compensated for the care they provide and are involved in the continuum of care owing to their personal relationship with the care recipient. These agents are usually family members and close friends, and in some cases, they may act as the legal guardian or substitute decision maker if the care recipient has a high degree of impairment. Informal caregivers who live with the care recipient, such as a spouse or other cohabitants, are in a unique situation with regard to the AAL system because they also live in the smart living environment, so devices collecting data on the care recipient may also collect data on them. This raises the need to consider how the AAL system manages different needs, consents, and data sources.

Paraprofessionals are agents who directly impact the quality of life but are unlikely to directly interact with AAL technologies. Examples include agents hired for home maintenance, meal delivery, transportation, or housekeeping or volunteers who provide similar services. Finally, *health technologies* refers to any technology developed to prevent, diagnose, or treat medical conditions; promote health; provide rehabilitation; or organize health care delivery [23]. In the context of AAL, the goal of health technologies is to facilitate the wellness of and help maintain the independence of older adults.

Methods

Study Design

One round of 18 semistructured, small-group interviews was held with stakeholders involved in the care of older adults or development, manufacturing, or integration of care-related technologies between March and May 2022. This interview method was chosen because of its flexibility in obtaining targeted and unique perspectives of different stakeholders and understanding the interactions between different staff members in the same organization (where applicable) [24]. A semistructured interview guide with 16 questions was developed (Multimedia Appendix 1). An expert in the field of user-centered design and human factors methods provided guidance on the formulations of the questions for the interview.

In the interviews, the agents were asked for details about their experiences with the use of technology in the care of older adults; the interviews were guided by a data governance framework that was intentionally broad (ie, not AAL specific). Participants were recruited from the following four groups:

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1. Care organizations: stakeholders working for organizations directly involved in care delivery (eg, retirement communities, long-term care homes, and community care organizations)
2. Technology developers: stakeholders working for companies or groups involved in the development or manufacturing of AAL technologies
3. Technology integrators: stakeholders working for companies or groups involved in the integration of AAL technologies into care
4. Reception: potential care recipients and patient advocates representing the interests of older adults

In total, >40 stakeholders from Canada and the United States were invited to participate in the interviews. Some of the stakeholders contacted also forwarded the study's information to other groups that they felt would be interested in participating. An informational letter with a description of the project objectives was included in the invitation. After potential participants read the informational letter and confirmed their interest in participating, they received an informed consent letter to be signed before the interview appointment. In cases where the participant was not able to submit a signed consent letter before the interview, they were asked to verbally provide consent to participate in the study on the day of the interview, which was recorded and stored separately from the recording of the interview itself.

A total of 18 interviews were held comprising 1 to 3 participants per organization, depending on participant availability. The interviews with reception participants were held individually, as they were not representing an organization. Of the 18 interviews, 6 (33%) were held with care organizations, 4 (22%) with technology developers, 3 (17%) with technology integrators, and 5 (28%) with reception. The participants were assigned letters and numbers to deidentify them, ranging from P1 to P25.

The interviews were conducted over Zoom (Zoom Video Communications, Inc) and began with a brief presentation to contextualize the project. Following the presentation, questions were posed using a semistructured interview guide, which allowed for the questions to be adapted to each participant's context. A basic version of the interview guide was shared with the participants before the interview to give them time to consider the questions. Whenever possible, the interviews were conducted with groups of participants who worked in different positions within the same organization to gather diverse perspectives. Following their interview, the participants received a feedback letter thanking them for their participation, reminding them of the purpose of the study, and providing them with details on confidentiality and ethics.

A thematic analysis of the interview transcripts was then conducted by summarizing the benefits, concerns, and barriers regarding the use of AAL data in the care of older adults and describing the current state of data flow in the context of AAL technologies. This method was chosen for its applicability when identifying topics within semistructured interviews [25,26]. After the first 4 interviews, open coding began, and a set of inductive codes was developed collaboratively with the members of the research team. These codes were revisited and revised iteratively as needed as new concepts emerged in the subsequent interviews. Coding was done using the NVivo software (QSR International) by GBN and HD. Six interviews were chosen at random to be coded by both GBN and HD to ensure consistency. Any discrepancies in coding were discussed between the 2 researchers, and conclusions were then applied to the remaining analysis. After this process, codes were grouped into themes and shared and discussed with the rest of the research team and an advisory panel of experts in older adult care for approval.

Ethics Approval and Informed Consent

The procedure of this study and the semistructured interview guide, informed consent letter, and informational letter used in this study were reviewed and provided ethics approval by a University of Waterloo Research Ethics Committee (ORE# 43958). No risks were anticipated in the study, although the participants were warned that, given that they were being interviewed in a group setting, confidentiality could not be guaranteed from the other participants in the interview. No remuneration for participation was offered.

Results

During the interviews, the participants described the benefits, concerns, and barriers that they perceived regarding the use of AAL data in the care of older adults. This section is divided among these 3 topics, with further subheadings to distinguish key insights provided by the participants.

Benefits of AAL Systems

Monitoring and Alerting

The participants outlined several benefits that AAL can provide to the care of older adults at varying points in the continuum of care. The most consistently cited benefit was the potential of sensors and other monitoring technologies to predict and alert care providers and caregivers to incidents in which the care recipient is at risk, such as injury or illness. The system would detect deviations and abnormalities compared with the typical parameter metrics. For example, P11, who came from a technology development organization, described the value of their technology as follows:

> *Most senior people have some chronic condition or multiple chronic conditions, and with good electronic devices, we can collect data on a daily basis so that we can monitor their general health condition and identify problems early, right, before they become a big issue.*

As described here, continuous monitoring can potentially detect when a care recipient is experiencing a decline by detecting deviations and abnormalities compared with their typical parameter metrics. In general, the participants described monitoring as taking 1 of 2 forms. The first was the tracking of regularly measured parameters to examine whether they have exhibited a recent change, with participants describing solutions such as smart thermometers and glucose monitoring (cited by participant P6) or blood pressure monitoring (cited by participant P8); the second was a more sophisticated option in which

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machine learning was used to identify the usual behaviors and patterns of the care recipient to establish a baseline for daily functioning, such as "monitoring activities of daily living" (cited by participant P6), "collecting data on (...) how they're sleeping, when they're getting up to go to the bathroom" (cited by participant P2), and "time spent (...) sitting, standing, lying" (cited by participant P11). The latter was described as preferable, as it allows care providers to be more proactive, with participant P4 explaining that "if someone has typically got normal morning routines (...) and you're not seeing those routines and there's alerts, we can go check on her" and several participants (participants P2, P8, P15, P21, P22, and P25) noting its potential to promote independence.

Health care providers can receive alerts of incidents, but more importantly, the continuous monitoring of data can accurately capture changes in the health of care recipients. These data can be used to adjust their care plan as needed. Such systems are particularly desirable, as they mitigate the burden of identifying and reporting relevant information about care recipients, especially about care recipients who cannot report on their own well-being because of cognitive or language difficulties. Participant P24 provided the example of a care recipient with a comorbidity of Parkinson disease and dementia who was experiencing issues with their movement (ie, freezing or hyperactivity) stemming from the dose and timing of medication delivery:

> *The problem with Parkinson's is by the time you get to that degree of Parkinsonism, you have cognitive issues, and so trying to get people to remember how they were at some time during the day, it's hard.*

The use of AAL would allow for the circumvention of this issue, providing a record of when symptoms occurred that a care provider can then cross-reference against a medication schedule.

Confidence in Aging in Place

Another potential benefit described by the interview participants is a greater confidence in aging in place for both care recipients and their various caregivers. Two participants (P7, who came from a care organization, and P15, a technology integrator) remarked on the potential of technological supports to prevent "premature" moves into assisted care settings, allowing the older adult to be in their preferred space. Beyond the safety and convenience that AAL technologies provide, they can also offer caregivers peace of mind.

P16 (technology integrator) described how caregivers can benefit from AAL technologies:

> *For a family member or caregiver, being able to actually see the information around daily activities or movement (...) I see that playing important role in elder care so that they can better understand (...) what's happening with their family member, because oftentimes what we've been finding (...) the individual older adult living in their home doesn't want to share everything that's happening, they don't want to tell them about if they had a fall or if they've been feeling ill and staying in bed much longer than usual.*

This was presented as an opportunity to reduce the burden of reporting among care recipients, as they may not want to share information that will worry their loved ones or make them appear unwell. By contrast, if all is well, the caregiver may feel more comfortable with not intervening and instead allowing the care recipient to continue aging in place.

Empowerment and Access

Some participants described how the use of AAL could contribute to greater access and empowerment with regard to care. Rather than going to a different care setting for assessment and adjustments, care recipients can get themselves assessed and their treatment adjusted without traveling and on their own schedule. P10 (technology developer) described these advantages:

> *Technology allows people who are more vulnerable in many ways to be able to access really quality services within the comforts of their home or wherever they are and get more help in a more real time and sustainable manner. Over time, these interactions add up to better care, more empowered care, more informed care in the long run.*

Care recipients could access information about their own well-being in a timely manner and, ideally, in a manner that would be compatible with their health literacy level.

Another benefit highlighted during the interviews was the potential of AAL to not only aid in the management of care but also enrich care recipients' lives. The participants (P1 and P2, who came from a care organization, and P14 and P16, technology integrators) discussed technologies' potential to provide entertainment or connection or otherwise help the care recipient work toward something they would be motivated for, in other words, "meeting their motivation" (cited by participant P14).

Concerns Regarding the Use of AAL Systems in Care

Data Governance

In Ontario, Canada, compliance with the Personal Health Information Act is crucial for health data gathered by devices [27]. When asked about their concerns regarding the current use of data from AAL technologies in care, many participants raised two key questions: (1) who owns and stores the data? and (2) what are they doing with them? The participants from care organizations and technology developers described this question as often being the first question asked when a new technology was proposed for care recipient use. Participant P1 (care organization) expressed further concerns:

> *Do I really know how things are being regulated, how it's being stored? Not until I ask about it, right? It's still very much up to me, and I think that's by design. I would love to see the conversation shift (to) how information is being stored, or even to servers, like, are the servers in Canada, are they somewhere else? Those types of things are important.*

For devices that gather nonhealth data, regulations or guidelines for the use and protection of data are less clearly defined. Participant P18 (a technology integrator) suggested that these

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questions reflect care recipients' and health care providers' discomfort with using the cloud infrastructure:

> *I guess the analogy I can give is that people are used to knowing that their data is sitting on a hard drive in the hospital, for example. It is not being sent to some cloud server which is holding data from that hospital, potentially next to someone's Amazon shopping experience preferences or whatever else, right? And so, I think they there may be concern—I don't have evidence for this exactly—but there may be some concern about mixed use of the information.*

The same participant (P18) noted that users would sign away the rights to their data for their data to be used by algorithm developers and suggested that this might not be something a user would naturally agree to if they were aware of the terms:

> *We could frame it to them as like they're accelerating the development of these algorithms by allowing us to use the data, but I'm wondering if there will be some that are hesitant in sort of signing off that data and realizing it's not only a benefit to them specifically, for example.*

However, this concern was not universally shared. Potential care recipients who were also interviewed (participants P21 and P22) did not express opposition to the idea when directly prompted, and a patient advocate (P23) offered a potential explanation:

> *One of the things that continually comes up (in conversations with policy groups is) people's dissatisfaction with commercial uses of their health data. Generally speaking, people are totally happy for their deidentified health data to be used to improve health care services, improve public health, and to help other people (...) but when the data are used for commercial ends to make a company money then they just disapprove.*

Accountability and Liability

As AAL systems continue to grow, more agents with different foci and concerns will be required. The participants raised concerns about this expansion, noting that when more agents are engaged with the care recipient, it would become more difficult to determine the true source of and, therefore, the solution for an incident. Participant P4, who came from a care organization, provided an example:

> *If in the unit, as an example, there's a [proprietary emergency alert device], alerts for water leaks, alerts for smoke detectors. The smoke alarm went off, the toilet flooded, the door was opened. Which health authority does the smoke alarm fall under, the fire department or the infection control?*

Furthermore, with alerting systems, there is the question of whether they could be held legally responsible for an incident resulting from a false positive or false negative they flagged. Participant P24 provided examples of how these systems might fail:

> *If [a technology used to identify aggressive behaviour] were to prompt a response inaccurately, if somebody was not engaging in an aggressive behavior, but a response was prompted against an aggressive behavior by long term care staff, that could cause a confrontation where previously there wouldn't have been one (...) or having heart rate, blood pressure and weights displayed on the mirror in the bathroom for somebody with congestive heart failure, if there's an inaccuracy in how that's conveyed or if those are being built into an interpretive algorithm to indicate when to call a doctor, somebody places their trust in that, and it's just displayed inaccurately for some reason, then that could cause a major medical event.*

Barriers to the Use and Implementation of AAL Systems

Value Trade-off

The participants raised many barriers to the use and implementation of AAL systems. The most heavily discussed of these was the perceived trade-off between the value of the technology and its cost and encroachment on care recipients' privacy, as this calculation is key to agents' willingness to invest and engage. Costs here can mean several things, with the most obvious meaning being financial expenses. AAL technologies are often expensive, and as participant P15 (a technology integrator) pointed out, there is little support available for interested users:

> *Technology is not provided in the form of a prescription. Therefore, there's no pay model described, so who pays for it is always a big question. Although there could be a long list of benefits and validation as to why this is useful, whether for the health of the home or the health of the person, but the reimbursement model is not existent for it even with valid proof.*

Similar concerns were expressed by the members of care organizations, with participant P3 noting that the situation may become further complicated for institutions procuring AAL rather than individual caregivers:

> *We talked about the cost factor, if it's a cost that has to be absorbed by the client or its costs absorbed by the organization. Do you recoup the money from that? How does that work?*

In addition, the participants expressed that an AAL system needed to be worth the time and effort involved in implementing and maintaining it. Participant P11 (a technology developer) referred to this as an "investment of time," and participant P24 (a patient advocate) offered insight into what that time might be needed for:

> *Are providers given resources to adopt new technologies? Are they given extra slack time? Are they given education? Is there extra resource built into their day-to-day work so that they can take on*

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> *issues that arise as they're going through this adoption process?*

Finally, regarding the privacy encroachment component of the trade-off, the participants noted that this affects the openness to the technology but emphasized the importance of understanding that the meaning of "privacy" may differ between a care recipient and others. Although the protection of users' data is important, the focus that emerged in these interviews was more on a reluctance to be "spied on" or "nannied" by caregivers. Participant P17 (a technology integrator) explained this as follows:

> *[Privacy is] not where your data is going, that doesn't come up that often to be honest. It's about what people want. It's almost like if I want to get up and watch TV at 3am I don't need an alert going to my son. I can do whatever I want (...) I have earned the right to do whatever I want.*

Decision-making Process

Within an organizational context, the participants discussed issues related to the oversight and management of devices in an AAL system, as well as the expectations of management. Technology developers mentioned roadblocks such as the "long, slow decision chain" (participant P13) and "innovation-averse" nature of the Canadian health care system (participant P10). Furthermore, participant P11 discussed the difficult balancing act that technology developers must perform within the confines of health regulations:

> *In a long-term care facility, based on their current protocols, the nurse has to visit each room every two hours. If they couldn't change that policy, that means even if they have new technology (...) they still have to visit this room every two hours. Then this will not save them any labor. (...) But then on the other hand, if the technology is really useful, it can reduce their workload, then the union will object because then some of them might fear they will lose their jobs.*

Another aspect of management was the issue of care transitions with AAL systems. Participant P4 (care organization) described it as follows:

> *Some (devices) take a lot of time and pre-planning to set up into a room (...) but sometimes we get the calls that (a resident) can be released from the hospital, but they need these mechanisms in place, so we need to be able to pivot and set up a unit within hours and sometimes less to be able to accommodate that.*

Agents working in care organizations must move swiftly to accommodate care recipients' changing needs; however, the contexts in which they operate do not always allow for this. The participants expressed confusion regarding processes and procedures, which adds to their perception of effort.

Equity

Although equity was mentioned less frequently than other barriers, issues of equity cannot be ignored. The issue of cost potentially being prohibitive was already discussed; however, it must also be acknowledged that the affordability of devices is impacted by other factors. When defining "barriers," a patient advocate (participant P23) posited the following:

> *[Barriers] implies that anything that interferes with use exists on the same plane, whereas (...) we live in a very high-level context that is a particular kind of capitalism, and that system incentivizes particular kinds of people to build particular kinds of technologies.*

In some cases, the issues raised by the participants are not simply barriers to overcome but are in fact exclusionary roadblocks. Consideration of how to meet the needs of excluded groups is an important pursuit but may be outside the scope of this study.

Discussion

Overview

This study aimed to obtain recommendations from stakeholders regarding the best practices for system-service integrations for AAL. The recommendations were to align with the needs and capacity of health care and allied health systems. To this end, an exploratory study was conducted to understand stakeholders' perceptions of and concerns with AAL technology use.

Principal Findings

The participants discussed several potential benefits of the use of AAL systems, paying particular attention to the potential for more continuous monitoring. This may be especially valuable for the care of older adults with chronic conditions, and continuous monitoring could be used to detect when a care recipient is experiencing a decline and allow for more proactive care [28,29]. This relieves some of the burden of reporting from the care recipients themselves, meaning that they are not obligated to remember minute details or admit frailty [29,30]. That being said, any technologies brought into the home, for monitoring or other purposes, must be appropriate for the care recipient's needs and consider the level of personal privacy and independence they wish to maintain.

Similar to the findings in the literature [13,20-22], one of the barriers discussed by some participants was whether the benefits of AAL systems justified the encroachment, real or perceived, on care recipients' privacy, as well as the cost of the systems. The participants suggested that this may have been due to a lack of understanding of how these technologies work. Therefore, it would be beneficial to take the time to better inform care recipients of (1) the benefits of collecting data and (2) their own rights to choose and refuse the technology as desired, as well as to know which agents have access to their data. That being said, there was some disagreement regarding who that "privacy" is from, whether it be from external agents wanting access to the data, which is more common in the literature, or from informal care recipients with an interest in the care recipient's daily activities.

Another part of this challenge is the perceived value of AAL systems when weighed against the financing, time, and resources necessary for their implementation because funding programs for home modifications vary between jurisdictions with no

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specific funding allocated to AAL. Therefore, care recipients and caregivers may struggle or be unable to afford these systems [31,32]. Even when the technologies are procured, it is still necessary to take time to learn how to use them and allow care providers to integrate them into their workflow and deal with any issues. The participants noted that the extra time required to incorporate these new practices often does not exist or is not accounted for during implementation of the AAL system.

Care facilities must contend with the fact that they do not necessarily have control or oversight over all devices in their facilities, as some devices might be brought in by care recipients and their families. There are advantages to this model, as it is often not feasible to bulk purchase devices at the facility level, and care recipients are more likely to agree with the use of a technology that they or their caregiver chose [33,34]. However, because the facility does not manage these devices, if there is an issue or a device failure of some sort (eg, a depleted battery), the facility would not be aware or be able to help, and there would be no way of integrating the data from these devices into the facility's own alerting systems or record keeping unless a staff member were to maintain records of this data independently. In addition, AAL systems come with certain prerequisites that many homes and facilities lack. For example, Wi-Fi access is not guaranteed in facilities, and many facilities do not have a strong information technology team [35].

Another barrier described by the participants from care organizations was the difficulty in providing continuous care with AAL systems, such as when care recipients have moved from one care context to another. A dimension of this is the lack of interoperability between AAL systems and health information systems or among AAL systems abiding by the standards set by different manufacturers. If an entirely new system is required, the data from older devices may not be transferable. This lack of interoperability can add complexity, as care recipients' data cannot follow them as technology evolves or as they move to different care settings [13,14,29]. Furthermore, the more comprehensive or detailed a solution is, the more time is required to set it up. However, when transitions need to happen very rapidly, this is not always feasible [35-38].

During procurement and implementation, managing the expectations and regulations of governing bodies, including unions, is particularly important. A recurring theme in interviews and literature was that health care providers were already overregulated to the point where regulations can get in the way of care [6,8,39,40]. The participants emphasized that if something is being introduced to the workflow, then governing bodies would need to consider what can be taken away to simplify procedures. Conversely, if the integration of the technology creates so much efficiency that the jobs of staff members could potentially become redundant, their union might object.

Governing bodies may raise valid concerns when integrating a new system that need to be addressed, such as compliance with regulations, budget concerns, and privacy concerns [13,39,41]. Two such concerns are technological capability and digital health literacy among both care recipients and their care partners [41]. Some participants expressed a concern that the eagerness to implement more technologically advanced and smart solutions has led to a skipping of "basic tech," arguing that developers assume a level of competency that is not realistic. However, others argued that assuming that older adults cannot use technologies is agist and that they are highly capable of using technologies if the technologies are designed with their use in mind. Nevertheless, technologies are rarely designed for older adults' use or able to accommodate the technological limitations of older adults with cognitive or dexterity issues [23,42].

There is also the question of how exactly care providers are expected to use the data from AAL systems. AAL systems generate a very high volume of data, leading to concerns among the interview participants about how these data can be used to improve care and coordination. Specific concerns included how alert fatigue can be prevented and how the data can be interpreted in a manner that is personal to the care of the recipient. Creating strategies for the interpretation of the data with the intended use in mind could then produce alerts for care providers that they could understand, trust, and act on to improve the health or well-being of a care recipient.

Limitations

First, although this study used the term *barriers* for simplicity, the authors acknowledge the point made by participant P23 that this term does not account for the fact that the issues preventing AAL systems' widespread use are multidimensional and sometimes exclusionary of marginalized groups. The equity aspects of access to AAL technologies in their current form include not being affordable for all, not being feasible for all, and often not being trusted by all [20,22,31]. Second, although the positions of a wide range of stakeholders were sought, it is not possible to conclude that all perspectives were represented. The study attempted to mitigate this by encouraging a debate between colleagues in the group interviews.

Future Directions

This research points to a need for better clarity and role definition regarding the use of AAL systems in older adult care. Some pertinent issues include the lack of clarity regarding who can gain access to AAL data, how the data should be interpreted, which agent is responsible for action based on the collected data, and the trade-off of using AAL technologies in care settings. This may be addressed through further interdisciplinary research, including the development of a comprehensive data governance framework for AAL in the continuum of care.

In addition, future work should explore the external influences that guide the development of technologies at large. One such external influence is the fact that AAL development is often funded through a venture capitalist system that incentivizes technology companies to develop particular types of health technologies depending on what is most likely to be funded, rather than depending on evidence-informed needs [43-45]. Researchers should be cautious of assuming that the resources available to caregivers in a high-income, majority White, and socially connected semiurban community are also available to those elsewhere. If only the challenges of adoption and use faced by care recipients in this group are considered, then

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benefits will accrue only for them and enhance the health disparities faced by those who cannot afford AAL systems [31].

Summary of the Findings and Conclusions

This exploratory study used a conceptual framework and interviews with participants to explore the needs and requirements for AAL systems and identify opportunities for standards in this area. The goal was to identify and understand the opportunities for and challenges of integrating these technologies into the health system at the community level (ie, into the practice of paramedicine and other emergency services, pharmacies, allied health professional services, and medical clinics). The study was conducted in close collaboration with care providers and other stakeholders to ensure that the recommendations for system-service integrations aligned with the needs and capacity of the health care and allied health systems.

The findings from our research have shown that although several potential benefits exist for the use of AAL systems within the continuum of care for older adults, additional work is needed to address concerns and barriers before these benefits can be fully realized. Much of the potential of AAL lies in its ability to support integrated care, meaning continuous and coordinated care that is quick, effective, and includes self-care support, respect for care recipients' preferences, and appropriate involvement of family members and other informal caregivers [18,19]. AAL can improve care by facilitating better monitoring of care recipients' health and empowering care recipients to pursue their health goals. However, to accomplish this, further work is necessary to define how data should be managed as AAL systems grow larger and more complex and more agents become involved, with an awareness of the perceptions of care recipients and their care partners as well as the equity issues inherent to AAL technology.

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Data Availability

The data sets generated or analyzed during this study are not publicly available because of confidentiality promised to the participants as part of the informed consent process but are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Semistructured interview guide.
[DOCX File , 14 KB - aging_v6i1e40606_app1.docx]

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Abbreviations

AAL: active assisted living
IoT: internet of things

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Original Paper

A Tablet-Based App to Support Nursing Home Staff in Delivering an Individualized Cognitive and Physical Exercise Program for Individuals With Dementia: Mixed Methods Usability Study

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Abstract

Background: The promotion of physical activity in individuals with dementia living in nursing homes is crucial for preserving physical and cognitive functions and the associated quality of life. Nevertheless, the implementation of physical activity programs in this setting is challenging, as the time and expertise of nursing home staff are limited. This situation was further exacerbated by the COVID-19 pandemic. Mobile health apps may be a sustainable approach to overcome these challenges in the long term. Therefore, the Individualized Cognitive and Physical Exercise-App (the InCoPE-App) was developed to support nursing home staff in delivering and implementing tailored cognitive and physical exercise training for individuals with dementia.

Objective: This study aims to assess the usability of the InCoPE-App in terms of user performance and user perception in a laboratory setting using a mixed methods approach.

Methods: Nursing home staff were encouraged to perform 5 basic tasks within the InCoPE-App. Their thoughts while using the app were captured by implementing a think aloud protocol. Then, participants completed the System Usability Scale questionnaire. The think aloud transcripts were qualitatively evaluated to unveil usability issues. All identified issues were rated in terms of their necessity to be fixed. Task completion (ie, success rate and time) and perceived usability were evaluated descriptively.

Results: A total of 14 nursing home employees (mean age 53.7, SD 10.6 years; n=13, 93% women) participated in the study. The perceived usability of the InCoPE-App, as assessed by the System Usability Scale questionnaire, can be rated as “good.” The main usability issues concerned navigation logic and comprehensibility of app content.

Conclusions: The InCoPE-App is a user-friendly app that enables nursing home staff to deliver and implement cognitive and physical exercise training for individuals with dementia in nursing homes. The InCoPE-App can be used with little training, even by people aged ≥50 years, who may have low digital literacy. To achieve sustainable use and high user satisfaction of the InCoPE-App in the long term, it should be implemented and evaluated in a field study.

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KEYWORDS

dementia; individualized physical exercise; tailored exercise; physical activity; older adults; app; mobile health; mHealth; usability; mobile phone

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Introduction

Background

More than 55 million people worldwide have dementia, with approximately 10 million new cases every year [1]. By 2050, the number of individuals with dementia is expected to increase to up to 150 million individuals worldwide [2,3]. As dementia is a noncurable disease, treatment possibilities to stop or slow the progression of disease-specific symptoms (eg, declining cognitive function and physical performance) are critical. In addition to pharmacological therapies, nonpharmacological approaches such as physical activity (PA) have gained increasing attention. A growing body of research has shown that PA may have a beneficial impact on cognitive and physical performance in individuals with dementia [4]. However, only small and mainly nonsignificant effects of PA on quality of life (QoL) among individuals with dementia have been reported [5,6]. Overall, results from studies are conflicting, mainly owing to heterogeneous sample sizes and characteristics and differing intervention contents, periods, frequency, and duration of PA training [4]. Some studies also pointed out the heterogeneous prerequisites of individuals with dementia such as varying interindividual degrees of cognitive and motor impairments. Thus, a *one-size-fits-all* PA approach may fall short [7]. In addition, individual vulnerabilities and needs of individuals with dementia may need to be considered when designing, planning, and conducting PA interventions [8-10].

According to several studies [11-14] and a systematic review [15], up to 80% of individuals living in nursing homes in European countries experience dementia. Individuals with dementia residing in nursing homes often have decreased life expectancy [16], more advanced dementia stages, and more impaired physical performance compared with community-dwelling individuals with dementia [17]. Moreover, living in a nursing home is associated with negative changes in QoL [18]. Overall, promoting PA in nursing home settings is therefore crucial. In many nursing homes, PA promotion is not regarded as a task or responsibility of nursing home staff and is usually delegated to external providers (eg, physiotherapists) [19]. During the COVID-19 pandemic, this practice was no longer feasible, as many nursing homes in Germany and other European countries were closed to visitors or external service providers, and PA programs had been discontinued in many nursing homes owing to increased safety measures [19]. The resulting social isolation and restricted movement possibilities led to worsening of cognitive function and physical performance among individuals with dementia, as perceived by nursing home staff [20]. Moreover, some studies reported significant impact on the mental well-being of nursing home residents (eg, QoL) [21]. A conclusion that can be drawn from the COVID-19 pandemic with its far-reaching health consequences is that PA promotion in nursing homes should be designed and implemented in a way that allows continuation even as new challenges arise (eg, changing circumstances owing to the pandemic or similar events) and without access to external PA instructors. Therefore, mobile health (mHealth) apps may be a viable solution in this context. Various definitions of the term *mHealth* exist and most include key aspects such as mobile computing, medical sensor, and communications technologies [22], health information and services [23], patient monitoring devices, and personal digital assistants [24] to improve health outcomes. mHealth can be considered as a subsection of eHealth [23]. mHealth solutions are considered to be feasible, can be implemented at little or no cost [25], and have wide reach among various patient groups or populations.

So far, a large number of mHealth apps for use in care settings are available, with most of them providing support for medication management or health information, and they can be accessed free of charge from app stores [26]. However, to the best of our knowledge, no mHealth app for individualized PA promotion in nursing homes is available so far [27]. mHealth apps are promising tools in this setting and may help alleviate nursing home staff shortages; for example, a standardized, mHealth-based training manual may facilitate the instructions of PA sessions. Moreover, such an app may contain pictures and detailed exercise descriptions and information about the possible risk factors of certain exercises. These advantages may reduce the potential barriers for nursing home employees to deliver PA programs to individuals with dementia and enable the implementation of PA even in times of a pandemic. Nevertheless, a recent Cochrane review showed that health care workers with limited experience in using mobile apps and low digital literacy had concerns about making mistakes when using a mobile device [28], which might, in turn, affect the usability and acceptability of such apps.

However, to guarantee the long-term use and acceptability of mHealth apps in nursing homes, the feasibility and usability of an app must be considered, ideally in the design and development phase of the app [29]. Usability indicates how a product is perceived by an intended user to achieve a specific goal in a specific context of use [30]. Nevertheless, most of the currently existing mHealth apps have not been scientifically designed and empirically evaluated [31,32], and publications addressing their feasibility and usability are lacking [33]. This is a main research gap, particularly because theory-based design and development of apps with subsequent scientific evaluation of usability and acceptability may be among the most important criteria to ensure the long-term implementation of mHealth apps, particularly in special settings such as nursing homes [34]. Moreover, studies have shown that involving nursing home staff in the development process of a mobile app makes them feel valuable and appreciated, which, in turn, could have a positive impact on acceptance [35]. Therefore, an iterative development process of an app including qualitative and quantitative methods to integrate possible end users in the development process is recommended [36], where designing, testing, and redesigning of a mobile app are embedded in a regular circle [29]. Examples for qualitatively collected data could be the identification of specific problems. In contrast, quantitative data may provide insight into use times or success rates [33]. A multistep development approach is intended to increase end users' acceptability of an mHealth app and to ensure long-term use.

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Objective

To address the current need for a scientifically derived mHealth-based PA promotion for individuals with dementia in nursing homes, we developed the Individualized Cognitive and Physical Exercise-App (the InCoPE-App). The InCoPE-App is a tablet-based app aimed at assisting nursing home staff in delivering tailored cognitive and physical exercise training for individuals with dementia in a nursing home setting. The content of the InCoPE-App is based on previous studies of our research group on PA for individuals with dementia [8-10]. The goal of this study was to evaluate the usability of the InCoPE-App with possible end users, that is, nursing home staff, using a mixed methods approach in a laboratory setting. Specifically, we examined user performance and perception, existing problems, and possible solutions regarding the InCoPE-App by integrating qualitative and quantitative methods. The results of this study will be used for further improvement and adaption of the InCoPE-App with the ultimate goal of implementation and long-term use of the app in nursing homes. Furthermore, this procedure can be used as an example for future studies of app development in nursing home settings.

If and when the InCoPE-App has high usability, we anticipate that its use by nursing home staff will likely increase PA among individuals with dementia residing in nursing homes, as the app is designed such that it empowers nursing home staff to administer tailored physical exercise training to individuals with dementia in an easy and low-threshold way. Importantly, the InCoPE-App can be used by staff without previous PA-specific training or expertise.

Methods

Study Design and Participants

To evaluate the usability of the InCoPE-App, we used a mixed methods approach. We used a combination of qualitative and quantitative methods and considered a sample of 14 individuals, as previous studies have shown that 8 participants are sufficient to identify the main usability problems of a system [37]. Participants were recruited in April 2021 from 5 nursing homes in South-Western Germany. To be included in the study, participants (ie, nursing home staff) were required to have had previous experience with PA programs for individuals with dementia in the nursing home setting. Before the study, eligible participants received a project description regarding the objectives, participation, and benefits of the study and provided written consent for participation. The study was registered in the German National Register of Clinical Trials (DRKS00024069).

Ethics Approval

The study was approved by the Ethics Committee of the Karlsruhe Institute of Technology (Karlsruhe, Germany).

The InCoPE-App: Content and Development

The InCoPE-App was designed to be used by nursing home staff and not by individuals with dementia themselves, as individuals with dementia in nursing homes would not be able to perform structured physical exercise alone, and they need supervision for safety reasons. Specifically, the InCoPE-App supports nursing home staff in assessing current levels of cognitive and physical performance of individuals with dementia and, based on this assessment, guiding and delivering physical exercise sessions to individuals with dementia, without the need of having completed specific training or certification in sports or exercise science or kinesiology. A unique feature of the InCoPE-App is its integrated algorithm that uses data from 1 cognitive (ie, Mini Mental Status Examination [38]) and 3 physical performance tests (ie, Frailty and Injuries: Cooperative Studies of Intervention Techniques [39], 6-meter walk test [40], and modified 30-second chair stand test [41,42]) to tailor the recommended exercise program to the participant's individual needs (Figure 1). The cognitive and physical tests integrated into the InCoPE-App are oriented to recommendations for individuals with dementia [43,44]. On the basis of the individual performance results, each individual with dementia is assigned to one of four exercise clusters, which are integrated in the app [45]: (1) individuals with below-average cognitive and physical performance, (2) individuals with average cognitive performance and above average physical performance, (3) individuals with above average cognitive performance and below average physical performance, and (4) individuals with above average cognitive and physical performance. The clustering into these 4 groups is based on previous studies by our group that have demonstrated the need for individualization of PA programs for individuals with dementia [8-10,46]. Depending on the cluster assignment, the InCoPE-App generates an exercise plan that fits the current performance level and needs of the individual with dementia. To adjust the exercise plan to individual changes in cognitive and physical performance, the InCoPE-App reminds the nursing home staff to repeat and record cognitive and physical performance tests every 3 weeks. In general, the exercise plan integrated into the InCoPE-App consists of ritualized warm-up and cooldown and 2 individualized workout phases that integrate exercises for balance, mobility, and upper and lower body strength [45].

The generated exercise plan is presented in the app through brief descriptions along with pictures of the exercises to provide guidance about how to perform the exercises correctly and avoid common mistakes (Figure 2). Each training session lasts 60 minutes and is intended to be performed in one-on-one sessions or small groups of up to 2 individuals with dementia. For more information about the main functions of the InCoPE-App, refer to Multimedia Appendix 1.

The iterative development process of the InCoPE-App included several steps (Figure 3), of which 3 are already completed. First, we defined a general *product vision* of the InCoPE-App. We then conducted a web-based survey to collect information about sex, age, profession, and daily tasks from nursing home staff. Furthermore, we gathered information about potential previous implementations of PA programs or interventions in participants' nursing homes. On the basis of the results of this study, we were able to sketch *personas* as possible end users of the InCoPE-App [26]. In the second step, based on our product vision and the design of personas, we developed the first prototype of *theInCoPE-App 1.0* in collaboration with a software expert team. The InCoPE-App was developed on Android 9.0. For

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study purposes, an offline-capable version of the InCoPE-App was locally installed on tablets (Lenovo Tab M10; 10 inch). Currently, the app is available only in German. The usability of the InCoPE-App 1.0 was tested by 7 experts in the areas of psychology, IT, sports science, and software development using a think aloud protocol and the System Usability Scale (SUS) [47]. The *expert review* unveiled relevant information about the usability of the InCoPE-App. The experts rated the InCoPE-App as acceptable but also noted some usability problems.

Figure 1. Chair stand test. (A) Written and illustrated description of the test procedure; (B) description of the measurement recording; (C) input field for the measured value; (D) integrated stop watch; and (E) required tools or equipment and possible risks.

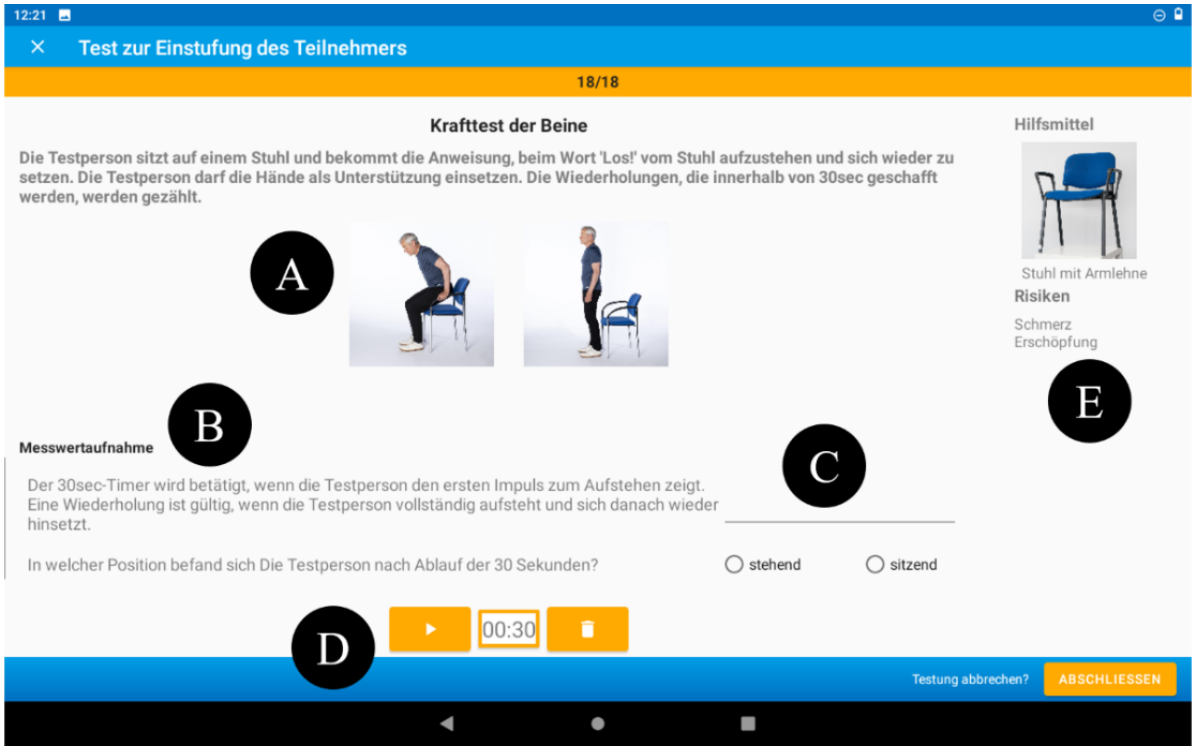
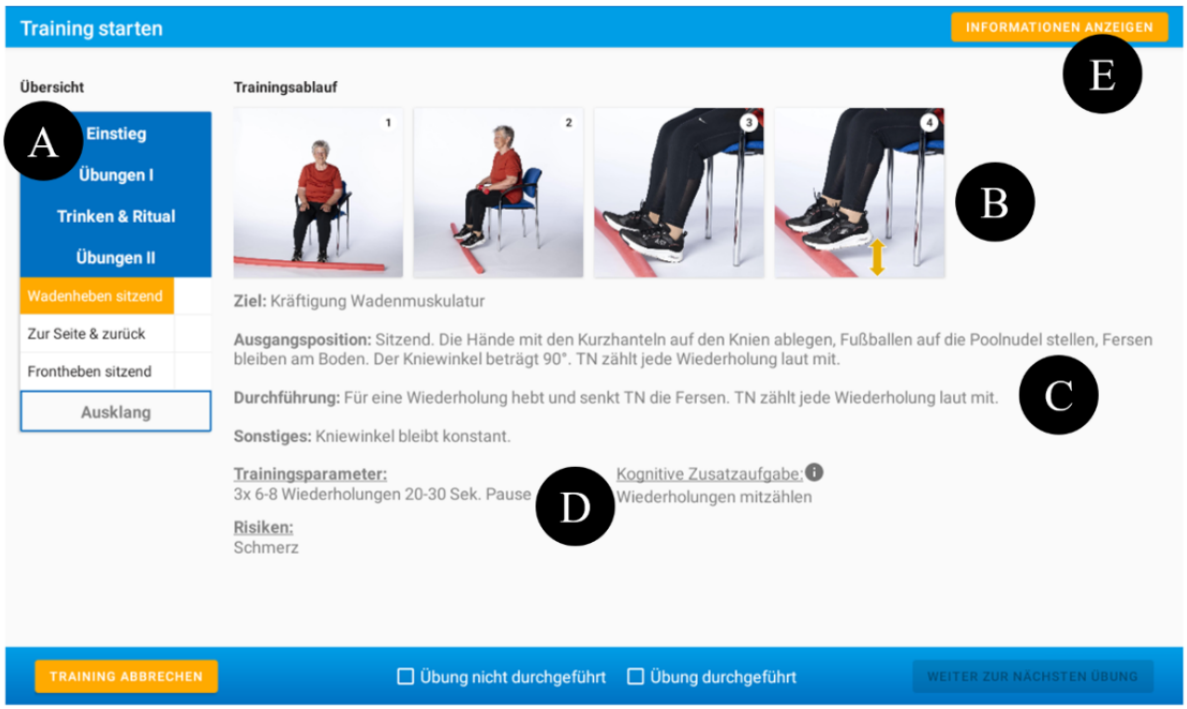
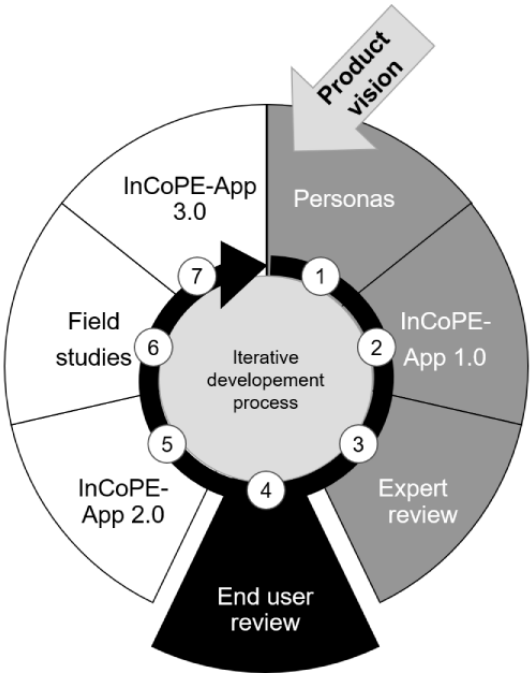


Figure 2. Exercise for lower limb strength. (A) Overview of the training schedule; (B) exercise sequence in pictures; (C) description of aims and correct conduct of the exercise; (D) training parameters (eg, repetitions), possible risks (eg, pain), and cognitive input (eg, counting the repetitions); and (E) further information (eg, required equipment).



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Figure 3. The iterative development process of the Individualized Cognitive and Physical Exercise-App (InCoPE-App) (step 1 results are published in a paper by Barisch-Fritz et al [26]; step 3 results are published in another paper by Barisch-Fritz et al [47]).



Outcomes and Procedure

After the participants signed the consent form, demographic information and data about general smartphone, tablet, and app use were collected from each participant using a short survey. Usability was assessed qualitatively and quantitatively in individual sessions during the first use of the InCoPE-App. To collect qualitative usability data, the think aloud technique was applied as it was found to be the most frequently used qualitative approach in usability testing of eHealth applications [31]. At the beginning, we explained to the participants that they would be required to speak their running thoughts aloud while interacting with the InCoPE-App. To become familiarized with this method, participants received a sample task within the InCoPE-App (ie, “Go to ‘exercise pool,’ choose exercise ‘Rope Pulling’ and tell me possible risks of this exercise”). Then, they were asked to perform 5 tasks (Table 1) with the InCoPE-App along a standardized protocol. These tasks were representative of a real-world situation when using the InCoPE-App in the nursing home setting [37]. During the think aloud session, a researcher was present and only interrupted participants if they stopped talking for >10 seconds while performing the tasks. Running thoughts of the participants were recorded via a voice recorder. Following the think aloud session, participants were asked three final questions: (1) “Which parts of the InCoPE-App are well designed?” (2) “Which parts of the InCoPE-App need to be revised?” and (3) “Do you have any other further comments on the InCoPE-App?”

For quantitative usability assessment, the time spent on each individual task and all tasks overall was assessed by using the screen recorder function of the tablet. Furthermore, the success rate of each task was coded as “success,” “problem,” or “failure,” as described by Ehrler et al [48]. After the think aloud protocol, participants completed the German version of SUS [49,50], which is one of the most frequently used questionnaires in usability research [31]. The German version of SUS has reasonable reliability (0.84), concurrent validity (0.74), and sensitivity (0.83) [50]. SUS comprises 10 statements about the usability of a system (eg, “I think that I would like to use this system frequently”), each rated on a scale ranging from “I don’t agree” to “I totally agree.” Negatively worded statements (even numbers) are coded from 4 to 0, whereas positively worded (odd numbers) statements are coded from 0 to 4 [51]. The items are added to a sum score (minimum 0; maximum 40 points), which is multiplied by 2.5 (sum score—minimum 0; maximum 100 points). Published literature suggests a mean SUS score of 68 as a useful “benchmark” [52]. Furthermore, the total SUS score can be interpreted as follows: scores <60 indicate substantial usability problems, scores between 60 and 80 indicate marginal to good usability, and scores >80 indicate good to excellent usability of a system [49]. According to the Subjective Rating Scale of Bangor et al [53], a mean SUS score of 71.4 indicates good usability.

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Table 1. Standardized "think aloud" protocol.

Task	Description of the task
1	"Create a new test person."
2	"Start and complete cognitive and physical testing with the test person."
3	"Create an exercise plan and replace two exercises."
4	"Start and finish a training session with the test person."
5	"Start and finish a training session with two participants simultaneously."

Data Collection and Analysis

Each think aloud session and the 3 interview questions were recorded with a voice recorder (Philips DVT2050) and transcribed verbatim using a transcription software (software F4transkript, from audiotranskription, dr.dresing&pehl GmbH). The transcribed protocols contained time stamps to estimate the time for task completion. To identify usability problems, bottom-down developed categories (ie, navigation, screen layout, graphics, comprehensibility, and overall usability) were used to analyze the protocols divided according to the think aloud tasks. This categorization was adjusted and based on a proposal by Kushniruk and Patel [54]. Two researchers (JK and ST) coded the transcripts independently. In case of ambiguities and discrepancies, a third researcher (BBF) was consulted. The identified usability problems were further rated by 1 researcher (JK) using the Nielsen severity scale (0=I do not agree that this is a usability problem at all, 1=cosmetic problem only, 2=minor usability problem, 3=major usability problem, and 4=usability catastrophe) [55]. This allows ranking of the usability problems and helps to prioritize them for a further revision cycle of the InCoPE-App. For presentation in this paper, the quotations from the final interviews were translated from German to English.

The total SUS score, time spent on each task and in total (derived from the screen records), and frequencies of identified usability problems were evaluated descriptively (mean, SD, and range) using SPSS (version 27.0; IBM Statistics). The success rate for each task was evaluated in percentages.

Results

Participants

We included 14 employees (n=13, 93% women and n=1, 7% men) from 5 nursing homes. The mean age was 53.7 (SD 10.6) years. Data about general smartphone and tablet use showed that all participants (14/14, 100%) owned a smartphone, with 93% (13/14) of the participants reporting daily use. Only 21% (3/14) of the participants reported using a tablet. Of the 14 participants, 12 (86%) had several apps installed on their personal smartphones or tablets and 7 (50%) reported daily app use. For study purposes, all participants (14/14, 100%) used the InCoPE-App installed on a tablet. Participants' demographics and information about technical experience are presented in Table 2.

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Table 2. Sample characteristics (N=14).

Characteristics	Values
Age (years), mean (SD)	53.7 (10.6)
Sex, n (%)	
Female	13 (93)
Male	1 (7)
Age group (years), n (%)	
20-29	1 (7)
30-39	1 (7)
40-49	1 (7)
50-59	6 (43)
>60	5 (36)
Certificate of secondary education, n (%)	
Hauptschule (diploma after 5 y)	5 (36)
Realschule (diploma after 6 y)	2 (14)
High school diploma (diploma after 8-9 y; university entrance qualification)	5 (36)
University degree	2 (14)
Use of mobile devices, n (%)	
Smartphone	14 (100)
Tablet	3 (21)
Frequency of smartphone use, n (%)	
Daily	13 (93)
Several times/wk	1 (7)
Several times/mo	—[a]
Rarely	—
Never	—
Frequency of tablet use, n (%)	
Daily	1 (7)
Several times/wk	2 (14)
Several times/mo	1 (7)
Rarely	—
Never	10 (71)
Use of apps, n (%)	12 (86)
Frequency of mobile app use, n (%)	
Daily	7 (50)
Several times/wk	3 (21)
Several times/mo	—
Rarely	2 (14)
Never	—

[a]Not applicable.

SUS Scores

The mean SUS score was 72.3 (SD 18.9; range 45-95), indicating good to marginal usability. According to the Adjective Rating Scale by Bangor et al [53], usability can be rated as *good*. When dividing the sample into 3 age groups (ie, nursing home staff aged <50 years: 4/14, 29%; aged between 50 and 60 years: 5/14, 36%; and aged >60 years: 5/14, 36%), the mean SUS

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scores were 77.5 (SD 16.2), 78 (SD 17.1), and 60 (SD 22.1), respectively, indicating better usability in participants aged <60 years. The results for single items of the SUS are presented in Table 3.

Table 3. Scores for the single items of the System Usability Scale.

Item	Statement	Score of the total group (N=14), mean (SD)[a]	Score of participants aged ≤50 years (n=4), mean (SD)[b]	Score of participants aged 51-59 years (n=5), mean (SD)[c]	Score of participants aged ≥60 years (n=5), mean (SD)[d]
1	"I think that I would like to use this system frequently."	3.2 (1)	3.5 (0.6)	3.6 (0.9)	2.6 (1.1)
2	"I found the system unnecessarily complex."	2.9 (1.2)	3.3 (1)	2.6 (1.7)	2.8 (1.1)
3	"I thought the system was easy to use."	2.8 (0.7)	3 (0.8)	3 (0.7)	2.4 (0.5)
4	"I think that I would need the support of a technical person to be able to use this system."	2.7 (1.4)	3.8 (0.5)	2.6 (1.3)	2 (1.6)
5	"I found the various functions in this system were well integrated."	3.1 (0.8)	3 (0.8)	3.4 (0.5)	2.8 (1.1)
6	"I thought there was too much inconsistency in this system."	3.2 (0.7)	3.3 (0.5)	3.4 (0.9)	3 (0.8)
7	"I would imagine that most people would learn to use this system very quickly."	3.2 (0.8)	3.3 (1)	3.6 (0.5)	2.8 (0.8)
8	"I found the system very cumbersome to use."	2.9 (1.1)	2.5 (1.3)	3.0 (1.2)	3.0 (1)
9	"I felt very confident using the system."	2.4 (1)	2.8 (0.5)	2.8 (0.8)	1.6 (1.1)
10	"I needed to learn a lot of things before I could get going with this system."	2.9 (1)	2.8 (1.3)	3.2 (0.8)	2.6 (1.1)

[a]Total mean 72.3 (SD 18.9).

[b]Total mean 77.5 (SD 16.2).

[c]Total mean 78 (SD 17.1).

[d]Total mean 60 (SD 22.1).

Think Aloud Session and Final Interviews

The mean duration of the think aloud sessions in total was 45 minutes and 56 seconds (SD 5 min and 42 s; range 33 min and 34 s to 53 min and 7 s), including the instructions and the familiarization task at the beginning. The most time-consuming part was cognitive and physical testing (mean 16 min and 26 s, SD 3 min and 44 s; Table 4). Creating a test person profile was completed by all participants without any problems. Most usability problems (n=71) arose with cognitive and physical testing. The last task ("Start and finish a training with two participants simultaneously") could not be performed by any participant (Table 4).

On the basis of the think aloud protocols, 71 different usability problems could be identified that were mentioned 134 times in total. The categorization of the usability problems according to Kushniruk and Patel [54] revealed most problems in the category, "navigation" (64/134, 47.8%), within the InCoPE-App. In particular, problems with finding the button to start a training for 2 participants simultaneously were mentioned by 79% (11/14) of the participants. The frequency of the mentioned problems and the most common examples are displayed in Table 5.

Table 4. Task duration and task completion.

Task	Duration, mean (SD)	Completion (N=14), n (%)		
		Success	Problem	Failure
"Create a new test person."	3 min, 53 s (2 min, 4 s)	14 (100)	0 (0)	0 (0)
"Start and complete cognitive and physical testing with the test person."	16 min, 26 s (3 min, 44 s)	3 (21)	10 (71)	1 (7)
"Create an exercise plan and replace two exercises."	3 min, 54 s (1 min, 36 s)	3 (21)	4 (29)	7 (50)
"Start and finish a training session with the test person."	5 min, 14 s (2 min, 19 s)	2 (14)	8 (57)	4 (29)
"Start and finish a training session with two participants simultaneously."	—[a]	0 (0)	0 (0)	14 (100)

[a]Not applicable.

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Table 5. Frequency and rating of the mentioned usability problems identified via the think aloud protocol.

Category	Mentioned frequency (N=134), n (%)	Most common problems and rating
Navigation	64 (47.8)	• Finding the start button to initiate a training for 2 people—"Usability catastrophe" • Changing or replacing exercises in an exercise plan—"Major usability problem" • Noticing the stopwatch during assessment—"Usability catastrophe"
Screen layout	20 (14.9)	• Small font type—"Major Usability Problem" • Overloaded screens during exercising—"Major Usability Problem"
Graphics	6 (4.5)	• No "zoom in" function—"Cosmetic problem only"
Comprehensibility	28 (20.9)	• Uncertainty in cognitive test procedures—"Usability catastrophe" • Unclear scientific terminology—"Major Usability Problem"
Overall usability	16 (11.9)	• Drag-and-drop function is not intuitive—"Minor usability problem" • Lot of information on most of the screens, owing to which app use was perceived as time consuming—"Minor usability problem"

Of the 71 identified usability concerns, 4 (6%) were rated as *usability catastrophe* according to Nielsen 48 and must be corrected before the InCoPE-App can be used in the field. Of the 71 problems, 29 (41%) were rated as a *major usability problem* with high priority to fix; 23 (32%) as *minor usability* with low priority to fix; and 8 (11%) as *cosmetic problems only*, which should only be fixed if there will be extra time for app development. Of the 71 problems, 7 (10%) mentioned usability concerns were rated as *not a usability problem at all*. Examples are displayed in Table 5.

During the final interviews, participants were able to explain which parts of the InCoPE-App were well designed. They explicitly mentioned that creating a test person within the InCoPE-App was very simple and easy to conduct:

> *I think, the beginning, when creating a participant profile – this was very good and clear.*

Moreover, the participants highlighted the good interface and the clear user paths within the InCoPE-App:

> *I liked that it [the app] is well pictured.*
>
> *What I totally like is that something is highlighted in orange, when I have to do [enter] something...and it is suggested to me.*

The participants also liked the instructions on the training screens within the InCoPE-App:

> *So you're just being carried through the exercise plan, exercise by exercise. That is well designed.*
>
> *[The exercise plan] is already divided into what counts as warm-up, the workout part itself, and the cool-down. I found that to be very clear.*

Overall, the participants appreciated that using the app only needs little practice and is beginner-friendly:

> *I generally have very little idea about a tablet or a smartphone... For me it was plausible. It [the app] has also actually indicated to me what I have to do next.*
>
> *You also tried to keep it as simple as possible.*

In addition to the question about the parts of the InCoPE-App they liked the most, the participants were asked to name the parts that need to be revised in their opinion. Regarding this aspect, it was mentioned that exercise videos instead of pictures would be more user-friendly:

> *It [the training] would take too long with the participant. I would be lost in details. Videos and especially a voice explaining it [the exercises] to me briefly, that would be very helpful for me.*

This statement was accompanied by comments about information overload on the screens within the InCoPE-App:

> *That is a lot of text. You lose a lot of time. By the time I read this, the participants no longer have any desire* [to exercise]
>
> *I would have liked it better if the text had been shortened and presented in sections.*

In contrast to the comments about the beginner-friendliness of the InCoPE-App, a person also mentioned barriers to the first use:

> *Well, if you don't use a tablet every day, you don't know where to push [a button]. For me as a person with limited media experience, it was hard.*

Finally, when participants were asked for further comments about the InCoPE-App, they underlined that even though they had some problems with the app at first or with technologies in general, they liked the app:

> *At the beginning, I was really concerned. I thought that I have no idea about computer and tablets and so on. ...And I think, this is a great application, even I can handle that.*

Discussion

Principal Findings

Promoting physical and cognitive exercise for individuals with dementia in nursing homes is critically important, particularly in terms of the reduction of PA in this setting during the COVID-19 pandemic. Nevertheless, most interventions available

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today have limitations regarding long-term use and implementation. With the InCoPE-App, we aimed to develop an effective and easy-to-use app that requires a multistage development process considering feedback from future end users. In this study, we analyzed the usability of the InCoPE-App, which assists nursing home staff in delivering a tailored cognitive and physical exercise program for individuals with dementia in nursing homes.

Here, we applied a mixed methods approach to get an in-depth impression of how the InCoPE-App is perceived by potential end users. Our results show that the usability of the InCoPE-App can be rated as "good" [53]. Considering the results of the single items of SUS, the least agreement was given to the statement, "I felt very confident using the system." In contrast, the highest agreement was given to the statements, "I would imagine that most people would learn to use this system very quickly" and "I think I would like to use this system frequently." These results indicate that on the one hand, participants felt that they needed additional information or training with the InCoPE-App. However, in contrast, they assumed that app use can be learned quickly. Overall, participants would like to use the InCoPE-App frequently and did not find the app to be unnecessarily complex.

On the basis of think aloud task completion, cognitive and physical testing required the most time. It can be assumed that this corresponds well with real-life situations, as conducting tests among individuals with dementia requires a rather large amount of time and personnel resources. We observed that, particularly, reading test instructions was time consuming. However, it is likely that time to read instructions within the InCoPE-App may decrease with more regular app use. The most difficult task (100% failure) was to start a simultaneous training of 2 individuals. This app feature needs to be revised with high priority and has to be placed more prominently within the app menu. Overall, we can assume that the InCoPE-App is a user-friendly tool and that most of the problems mentioned by participants could be solved by frequent app use.

Comparison With Previous Studies

Although mobile devices have become increasingly popular over the past decade [28], so far, there is no scientifically evaluated mHealth app available in the context of PA promotion in nursing homes [27]. To the best of our knowledge, our study is the first to evaluate the usability of an mHealth-based app, developed to assist nursing home staff in implementing tailored cognitive and physical exercise for individuals with dementia in nursing homes. A unique feature of the InCoPE-App is that it is not used by the group considered vulnerable (ie, individuals with dementia) directly but by nursing home staff who serve as a mediator. To the best of our knowledge, there are no studies that have used this approach.

The methods used in our study are consistent with the current literature and recommendations for usability testing [37]. Both applied methods exhibit important advantages in gathering a comprehensive impression of the usability of the InCoPE-App. So far, SUS is the most frequently applied questionnaire in the usability testing of digital health solutions [31]. Although there are usability scales specially tailored for mHealth solutions (eg, mHealth Usability Questionnaire [56]), these newly developed scales have not been widely used, and only a few comparative studies exist [57]. As the sole administration of SUS as a stand-alone usability method is not recommended [58], using a think aloud protocol is a complementary approach that provides direct insight into a person's cognitive and problem-solving processes while using an app and is therefore essential and effective for uncovering usability issues in addition to a quantitative questionnaire [37,58]. A recent systematic review showed that, even for the evaluation of usability among older participants, questionnaires and qualitative assessments such as think aloud protocols are commonly used and feasible methods [59]. Furthermore, other studies in the context of health care rehabilitation also used a mixed methods approach to assess usability [48,60,61].

In our study, we obtained a mean SUS score that is slightly above the benchmark of 68 points according to Sauro and Lewis [52] and the mean SUS for "good" usability according to Bangor et al [53]. A recent meta-analysis by Hyzy et al [62] explicitly focused on the SUS sum scores of 114 digital health apps and reported a mean score of 76.16 (SD 15.12) for all the included apps. By further categorizing the included apps, they observed a mean SUS score of 83.28 (SD 12.39) for "physical activity" apps (n=66) and a mean SUS score of 71.3 (SD 12.72) for "health care" apps [62]. Owing to the unique content of the InCoPE-App, the content-related results of the think aloud protocols and task completion are not comparable with other studies. Nevertheless, a study by Ehrler et al [48], which examined a mobile app for nurses in a hospital setting, identified "navigation within an app" to be one of the major problems. This is consistent with our results, as 47.8% (64/134) of the problems mentioned by study participants were related to the navigation structure within the InCoPE-App. These results imply that mobile apps to be used by staff in health care settings should be intuitive to navigate because complex navigation is perceived as time consuming and may thus be a barrier for long-term use by the end users [63]. Nevertheless, as the usability results of our study can be interpreted as "good," we assume that the InCoPE-App is well designed and suitable for its primary target group, that is, nursing home staff.

The perceived usability of the InCoPE-App could also be related to the mean age and the experience with mobile apps in our sample, that is, participants aged <60 years had fewer problems with using the InCoPE-App when compared with those aged >60 years. This was also observed in another study, where older participants reported more usability problems than younger ones, who were also more likely to have used apps before study participation [48]. Furthermore, existing literature has already demonstrated generational differences and a high likelihood of problems when implementing digital (health) solutions among older adults [33,64]. Thus, an age-based digital divide in mHealth adoption has been proposed in the literature [65]. Moreover, individuals often experience a loss in digital literacy if and when they do not use digital devices on a regular basis [28]. To overcome possible age-related and experience-related barriers to app use, current literature recommends education and familiarization training [48,66]. Moreover, as the fear of making mistakes could also be perceived as a barrier [28], "undo" functions should be included in an app [48].

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Strengths and Limitations

The main strength of our study is the novelty of the presented the InCoPE-App and its user-centered development and testing process. This helps to gain new insights into a, thus far, little-explored research field. Although our participants were predominantly women and aged >50 years, they can be considered to be representative of the population of end users (ie, nursing home staff) who will use the system in the future. It is very crucial to include a representative target group to generate valid usability data and to avoid biases [37]. In addition, our sample was heterogeneous in terms of age, education, and technical experience. This allowed us to detect usability problems from different perspectives and gave us a nuanced impression of the potential end users. Moreover, engaging individuals with less access to or knowledge about technology is very important to ensure high usability of a system for individuals with low digital literacy [67]. Another strength of the study is the mixed methods approach. Particularly in usability research, 1 method alone is not suitable to cover all the important aspects of a system's usability. Combining SUS with the think aloud task and the interview questions therefore allowed us to gain deep insight into the usability problems, as opposed to only evaluating usability on the basis of a sum score.

A limitation of our study is the relatively late inclusion of the end users in the direct development process of the InCoPE-App. Although we created fictitious end users on the basis of a questionnaire in early development stages [26], the main content and the basic structure of the data model has been developed and finalized without the input of nursing home staff. In other studies, end users were included from the very beginning of the app development process [60]. It is likely that some of the frequently mentioned usability problems (eg, navigation within the app) could have been avoided by the early inclusion of end users in the development process. Another limitation is that members of our research team ranked the usability problems according to the method of Nielsen [55], and it is possible that the end users would have rated the severity of the problems differently. Thus, the revision of the app based on the prioritization done by the researchers may not fully correspond to the expectations and wishes of the end users as they may have chosen another prioritization. Therefore, in future studies, end users should also be included in this step. Furthermore, it should be differentiated which usability problems should be further addressed from different perspectives (eg, experts, developers, researchers, and end users).

Conclusions

The InCoPE-App is a novel and innovative app that assists nursing home staff in delivering tailored cognitive and physical exercise to individuals with dementia residing in nursing homes. We showed that the usability of the current version of the InCoPE-App can be rated as good according to 14 potential end users. Furthermore, even older participants found the InCoPE-App as easy to use after some familiarization. Nevertheless, certain aspects such as navigation features within the app must be further improved to increase the usability of the app in the future. To overcome potential barriers to using the app, further development should follow a "less is more" approach, for example, by minimizing navigation screens or reducing the complexity and length of text on the screens. Overall, the inclusion of end users in the app's development process continues to be critically relevant and highly important. Therefore, the InCoPE-App was further tested in an 18-week intervention study [68].

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Authors' Contributions

All authors (JK, BB-F, JK-R, AS, ST, and AW) contributed to the conception, design, and implementation of the study. JK, BB-F, and AS collected the data. JK, ST, and BB-F analyzed and interpreted the data. JK wrote the manuscript, and all authors provided critical feedback. All authors approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Main functions of the Individualized Cognitive and Physical Exercise-App.
[DOCX File , 29 KB - aging_v6i1e46480_app1.docx]

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Abbreviations

the InCoPE-App: the Individualized Cognitive and Physical Exercise-App
mHealth: mobile health
PA: physical activity
QoL: quality of life
SUS: System Usability Scale

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Original Paper

Examining the Impact of Selected Sociodemographic Factors and Cancer-Related Fatalistic Beliefs on Patient Engagement via Health Information Technology Among Older Adults: Cross-Sectional Analysis

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Abstract

Background: Despite the role of health information technology (HIT) in patient engagement processes and government incentives for HIT development, research regarding HIT is lacking among older adults with a high burden of chronic diseases such as cancer. This study examines the role of selected sociodemographic factors and cancer-related fatalistic beliefs on patient engagement expressed through HIT use for patient engagement in adults aged ≥65 years. We controlled for cancer diagnosis to account for its potential influence on patient engagement.

Objective: This study has 2 aims: to investigate the role of sociodemographic factors such as race, education, poverty index, and psychosocial factors of cancer fatalistic beliefs in accessing and using HIT in older adults and to examine the association between access and use of HIT in the self-management domain of patient activation that serves as a precursor to patient engagement.

Methods: This is a secondary data analysis of a subset of the Health Information National Trend Survey (Health Information National Trend Survey 4, cycle 3). The subset included individuals aged ≥65 years with and without a cancer diagnosis. The relationships between access to and use of HIT to several sociodemographic variables and psychosocial factors of fatalistic beliefs were analyzed. Logistic and linear regression models were fit to study these associations.

Results: This study included 180 individuals aged ≥65 years with a cancer diagnosis and 398 without a diagnosis. This analysis indicated that having less than a college education level (*P*=<.001), being an individual from an ethnic and minority group (*P*=<.001), and living in poverty (*P*=.001) were significantly associated with decreased access to HIT. Reduced HIT use was associated with less than a college education (*P*=.001) and poverty(*P*=.02). This analysis also indicated that fatalistic beliefs about cancer were significantly associated with lower HIT use (*P*=.03). Specifically, a 1-point increase in the cancer fatalistic belief score was associated with a 36% decrease in HIT use. We found that controlling for cancer diagnosis did not affect the outcomes for sociodemographic variables or fatalistic beliefs about cancer. However, patients with access to HIT had a self-management domain of patient activation (SMD) score of 0.21 points higher (*P*=.003) compared with patients who did not have access. SMD score was higher by 0.28 points (*P*=.002) for individuals who used HIT and 0.14 points higher (*P*=.04) who had a prior diagnosis of cancer.

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Conclusions: Sociodemographic factors (education, race, poverty, and cancer fatalistic beliefs) impact HIT access and use in older adults, regardless of prior cancer diagnosis. Among older adults, HIT users report higher self-management, which is essential for patient activation and engagement**.**

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KEYWORDS

health information technology; patient portals; older adults; digital health; self-management; mobile phone

Introduction

Background

Patient engagement (PE) has gained prominence as a major component of achieving key performance indicators in health care [1-3]. PE in health care decision-making has become an expectation worldwide but lacks planning, design, and precision in specific medical settings and populations, specifically older adults [4,5]. Engagement is described as a cognitive and emotional state expressed through observable behaviors [6]. As a process, PE can go through significant stages: engaging, staying engaged, disengaging, and reengaging [7]. Health information technology (HIT) is a powerful yet underutilized tool for PE across many medical specialties [8-12]. HIT is a broad term encompassing an array of technologies referring to electronic health records, personal health records, patient portals, secure access to email providers, or requesting electronic prescribing [13-15] to collect, store, share, and analyze health information [16]. HIT has shown promising results in improving the quality of life and self-management of people with multiple chronic illnesses [17]. The prevalence of chronic diseases among older adults is considerably higher, with almost 95% having at least 1 and approximately 80% experiencing 2 or more such conditions [18].

Despite the emphasis and government spending on HIT and its role in PE, critical discussions regarding its access and use among older adults are insufficient. Evidence suggests that using HIT to communicate with providers is not always discussed during medical consultations [19]. Furthermore, in most cases, HIT access has been discussed in previously engaged patients [20]. Therefore, digital inclusion emerges as a social determinant of health when specific populations, including older adults, face barriers owing to limited access, non-English language availability, or insufficient knowledge to use digital technology [21]. Older adults are part of a growing and racially diverse group in the United States [22]. Despite being late adopters of technology, their use of the internet has been on the rise. From a reported 14% in 2000, it skyrocketed to 64% in 2016, and more recently reached 75% [23,24]. Nevertheless, there is a lack of comprehensive understanding of the impact of HIT access and use on self-management and engagement processes in older adults [25-27].

Cancer is a chronic disease that requires patients to engage with a health care team over time to discuss different treatment options [28]. PE in cancer care delivery results in higher quality of care, greater patient satisfaction, and improved cost containment [29-31]. Although further research is needed on the use of HIT among older adults diagnosed with cancer, it has been observed that these patients tend to demonstrate higher levels of activation and engagement in their health care. This can be attributed to the existing body of literature that underscores the advantages of HIT and the supportive role played by oncology health care providers [32-36]. Therefore, to investigate the influence of HIT use in older adults, we examined specific sociodemographic and psychosocial factors of fatalistic beliefs while accounting for the potential impact of a cancer diagnosis, which might affect their level of engagement.

In this analysis, we used selected demographic variables such as age, sex, race, education level, household income, and poverty level on the access and use of patient portals in older adults. All these variables are associated with HIT access and use in adults [37-39]; however, these variables have been limited to older adults, where the burden of chronic disease is high [40]. Furthermore, the association between HIT use and PE in older adults has not been previously assessed. Consequently, we introduced an additional objective to examine the relationship between HIT use and the self-management domain (SMD) of patient activation, which is a precursor to PE [41,42].

Accessing HIT entails using tools to access health information. It describes passive, one-way information access and can replace or enhance in-person interaction with the health care system or provider [43]. Use refers to actions taken after access to HIT to generate knowledge to engage in health care [44]. In addition, PE is a phenomenon that is deeply psychological and results from the cognitive, emotional, and behavioral endorsement of individuals toward their health care [6]. Therefore, in addition to focusing on sociodemographic factors, we examined fatalistic beliefs about cancer regarding access and use of HIT. Cancer fatalism refers to a belief or attitude that cancer is an unavoidable and inevitable disease and that there is little or nothing individuals can do to prevent it or improve their chances of survival if diagnosed. This fatalistic perspective may lead the general public to dismiss the importance of adopting healthy behaviors and participating in preventive screenings [45-48]. The impact of these beliefs on the use of HIT tools for PE is unknown; hence, we included cancer fatalism in our analysis.

Finally, we included an SMD for patient activation. Patient activation, as developed by Hibbard et al [49], refers to an individual's knowledge, skills, and confidence in managing their own health and health care especially in older adults [49,50]. The concept of patient activation was found to have 5 domains: self-management, collaboration with the provider, maintenance of health functions, prevention of decline, and access to appropriate and high-quality care. We used the SMD, which refers to behaviors associated with taking action to manage and engage in one's care and is negatively associated with fatalism about one's health [49]. Recent evidence indicates that self-management and patient activation can be supported

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by the use of HIT [51]; however, this relationship has not yet been examined in older adults. Patients with a diagnosis of cancer are reported to have 70% higher odds of being activated [32,35], hence we controlled for the effect of cancer diagnosis.

Specific Aims

Below are our specific aims and hypotheses.

Aim 1

We aim to examine the relationship between selected patient-specific sociodemographic (education, income, and race) and psychosocial factors (fatalistic beliefs) on access to and use of HIT in individuals when controlled for cancer diagnosis:

- Hypothesis 1-a: we hypothesize that a stronger association exists between older adults' education and access to and use of HIT in individuals when controlled for cancer diagnosis.
- Hypothesis 1-b: we hypothesize that there is a stronger association between access and use of HIT among White individuals and people of color when controlled for cancer diagnosis.
- Hypothesis 1-c: we hypothesize that there is a stronger association between older adults' income and access to and use of HIT in individuals when controlled for cancer diagnosis.
- Hypothesis 1-d: we hypothesized that having more fatalistic beliefs about cancer will negatively affect access to and use of HIT in individuals when controlled for cancer diagnosis.

Aim 2

We aim to examine the relationship between access to and use of HIT and the SMD score of patient activation measures in older adults, when controlled for cancer diagnosis:

- Hypothesis 2-a: low access to and use of the HIT will result in lower scores of the SMD of patient activation measure in individuals controlling for cancer diagnosis.

Methods

Data Source

This study is based on the Health Information National Trends Survey (HINTS), a dynamic resource for studying consumer engagement in health communication research [52]. Since its first cycle in 2003, a total of 14 cycles have addressed different health communication topics. HINTS 4 cycle 3 is the only cycle that has a measure for the SMD of patient activation, one of the main outcome variables for this proposed study, and is a precursor to the PE process. Therefore, we used HINTS 4 cycles 3 for this analysis.

In the original data set, the target population was adults aged 18 years or older in the civilian noninstitutionalized population of the United States. The third of 4 cycles, cycle 3, was conducted from September 2013 to December 2013. One respondent per household was selected for this cycle. The adults were selected by asking those with the next birthday to complete the survey. The Spanish questionnaire was also included in the package. The sampling frame consisted of a database of all nonvacant addresses used by the Marketing System Group to provide random samples of addresses. The sampling frames of the addresses were grouped into 3 explicit sampling strata. These groups consisted of addresses in areas with a high concentration of racial minority populations, areas with low concentrations of racial minority populations, and addresses located in counties comprising Central Appalachia regardless of the racial minority population.

Study Design

The cross-sectional analysis for this study was limited to a subset of the original data set and included participants aged ≥65 years. The total number of individuals over 65 years of age with a diagnosis of cancer was 261 (180 after accounting for the missingness of variables used in the analyses) and without diagnosis was 604 (398 after accounting for the missingness of variables used in the analyses). HINTS 4 cycle 3 data were weighted using jackknife variance estimation to produce a representative sample of the US population [53].

Measurements

Overview

First, access to HIT and use of HIT were dependent variables, and the independent variables were education, race, poverty level, income level, and fatalistic beliefs about cancer. For the second aim, we used access to and use of HIT as independent variables and the SMD of patient activation as a dependent variable to predict the effect of access to and use of HIT on SMD.

Access to HIT

In this study, access to the HIT variable was determined if an individual had access to the internet and knowledge about their provider maintaining electronic medical records. Access to the HIT was measured by combining 2 items, B1 and E1. The first variable, B1, asked individuals if they had access to the internet, and the second variable, E1, asked if they knew if their physician maintained their medical information in a computerized system. Access was given a score of 1 if both variables were affirmative and a score of 0 if one or both variables were reported to be absent. These 2 variables were combined to form a dichotomous variable that describes an individual's access to HIT as a yes or no response.

Use of HIT

In this study, the use of the HIT was quantified by creating a score variable by combining answers to 6 questions in the survey. One point was given for affirmative responses to item B5 (g), "In the last 12 months, have you used the internet to keep track of personal health information such as care received, test results, or upcoming appointments?"; item B5 (h), "In the last 12 months, have you used email or the Internet to communicate with a doctor or a doctor's office?"; and 4 items in B6, "In the past 12 months, have you used any of the following to exchange medical information with a health care professional: a. email, b. text message, c. an app on a smartphone or mobile device, d. video conference." Owing to the minimal number of patients indicating text and app use, we dichotomized the use variable. If any individual used any of the communication channels with a provider in the last 12 months,

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they had a value of 1 for utility, and if they did not use these channels, they had a value of 0. These items were selected based on the use of the term HIT in the literature [54,55].

The Self-Activation Domain of Patient Activation

The domain of self-management for patient activation was operationalized using 6 questions from HINTS, adapted from the work by Hibbard et al [49]. In this study, these 6 items indicate that the patient has the confidence and ability to obtain the desired information about treatment or therapy. These questions were item D3 of the survey. One point each was given to the affirmative responses to questions, "In general, how often do you take with you a list of questions or concerns; take a list of all their prescribed medicines to the doctor; ask the doctor to explain a test, treatment, or procedure to them in detail; read information about new prescriptions, such as side effects and precautions; do research on a health and medical topic after seeing their doctor, and take with them any kind of health information they have found during doctor visits." This resulted in scores ranging from 0 to 6, with 0 indicating the lowest level of self-management and 6 the highest level. Our use of these items was consistent with their previous use [55].

Sociodemographic Variables

Sociodemographic variables included race, education level, and income. Race was coded as a binary variable (White vs person of color), whereas education level and income were coded as categorical variables. Education level was used as a proxy for health literacy because a significant number of participants were missing observations related to health literacy items in the survey, and education had a high correlation with the items used to quantify health literacy. Education was divided into 3 categories, and income was divided into 4 categories. See Table 1 for the details of each category. In addition to conducting our analysis with income categories, we created a poverty variable by combining household income and the US poverty index from 2013 to (ASPE 2013 Poverty Guidelines, office of the assistance secretary for planning and evaluation [56]) run our analysis with both income and poverty index.

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Table 1. Descriptive statistics of sample (N=578)[a].

	With a diagnosis of cancer (n=180)	Without a diagnosis of cancer (n=398)
Outcomes (engagement process)		
Utility of HIT[b], n (%)		
Yes	45 (25)	75 (18.8)
No	135 (75)	323 (81.2)
Access to HIT, n (%)		
Yes	96 (53.3)	192 (48.2)
No	84 (46.7)	206 (51.8)
Self-management domain score, mean (SD)	2.737 (0.6)	2.608 (0.7)
Sociodemographics, n (%)		
Race and ethnicity		
White	157 (87.2)	306 (76.9)
People of color	23 (12.8)	92 (23.1)
Socioeconomic, n (%)		
Education		
<12 y	22 (12.2)	48 (12.1)
12 y or completed high school	65 (36.1)	160 (40.2)
Post high school training and college	93 (51.7)	190 (47.7)
Income (US $)		
0-14,999	32 (17.8)	84 (21.1)
15,000-49,999	73 (40.6)	185 (46.5)
50,000-99,999	58 (32.2)	91 (22.9)
>99,000	17 (9.4)	38 (9.5)
Poverty		
Yes	78 (43.3)	216 (54.3)
No	102 (56.7)	182 (45.7)
Psychosocial , mean (SD)		
Fatalistic beliefs	2.36 (0.60)	2.53 (0.62)

[a]Values are n (%) for binary and categorical variables and mean (SD) for continuous variables.

[b]HIT: health information technology.

Cancer Fatalistic Belief

Cancer fatalistic beliefs were operationalized with questions in items M5 (a, b, c, and e): "It seems like everything causes cancer," "There is not much you can do to lower your chances of getting cancer," "There are so many different recommendations about preventing cancer, it's hard to know which ones to follow," and "When I think about cancer, I automatically think about death." These questions have been used in several previous studies to determine fatalism [47,57,58]. The last item, "When I think about cancer, I automatically think of death," was new to this survey. All items were pretested with cognitive interviews and included in a national pilot test of 172 adults to ensure content validity before being included in the HINTS survey [59]. The answers to these questions ranged from 1 to 4 (from strongly agree to strongly disagree). For this analysis, the items were combined to yield a score for fatalistic beliefs.

Statistical Analyses

We fit logistic regression and linear regression models in 2 independent samples of older adults: those with and those without a diagnosis of cancer using Stata (version 15; StataCorp). This analysis was run on weighted data to generalize the results to the entire US population. We included interaction terms to test each hypothesis and examine whether there is a difference among individuals who have had a diagnosis of cancer compared with those who have not.

Ethical Consideration

This study was granted exempt status by the Institutional Review Board at the University of Massachusetts Boston, as the data used in this research is publicly accessible and has been

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de-identified per guideline(s): 45 CFR 46.104(d)(4) for secondary research for which consent is not required.

Results

Aim 1

To examine the relationship between selected patient-specific sociodemographic (education, income, and race) and psychosocial factors (fatalistic beliefs) on access to and use of HIT in individuals when controlled for cancer diagnosis.

Hypothesis 1-a

We hypothesized that a stronger association exists between older adults' education and access to and use of HIT in individuals when controlled for cancer diagnosis.

Education level was used as a proxy for health literacy because a significant number of participants had missing observations related to health literacy items in the survey, and education had a high correlation with the items used to quantify health literacy. Two separate logistic regression models were used to analyze the association between education level and access to and use of HIT for cancer diagnosis. For access, individuals with an education level higher than college level or above were 7.52 (95% CI 3.66-15.48; *P*<.001) times more likely to have access to HIT, whereas those with a high school diploma or post high school training were 1.93 times (95% CI 1.005-3.70; *P*=.048) more likely to use HIT, compared with those with less than 12 years of schooling (Table 2). For the use of HIT, this analysis showed that higher education levels were associated with higher odds of using HIT. Those who had a college education or above were 3.43 (95% CI 1.32-8.9; *P*=.001) times more likely to use HIT, whereas those with a high school diploma or post–high school training were 1.33 (95% CI 0.54-3.3; *P*=.53) times more likely to use HIT, compared with those with less than 12 years of schooling. The result was statistically significant at the α =.05 level for individuals with at least a high school education for access to HIT and for those with a college education or higher for use of HIT. Hence, this hypothesis was supported in this analysis. There was no significant difference in access to (*P*=.28) or use of HIT (*P*=.20) in individuals when controlled for cancer diagnosis.

Table 2. Results of univariate models controlling for education.

Predictor	Access to HIT[a]		Use of HIT	
	OR[b] (95% CI)	*P* value	OR (95% CI)	*P* value
Cancer	2.13 (0.53-8.4)	.28	1.03 (0.802-2.73)	.20
Education				
Reference (<12 years of schooling)	1	N/A[c]	1	N/A
High school or after high school	1.93 (1.005-3.70)	.048	1.33 (0.54-3.3)	.53
Some college and graduate	7.5 (3.66-15.48)	<.001	3.43 (1.32-8.9)	.001

[a]HIT: health information technology.

[b]OR: odds ratio.

[c]N/A: not applicable.

Hypothesis 1-b

We hypothesize that there is a stronger association between access and use of HIT among White individuals and people of color when controlled for cancer diagnosis.

Similar to the models mentioned above, we fit 2 logistic regression models to analyze the association between race and access and use of HIT, controlling for cancer diagnosis. Our sample size of people of color was small. Only 12.8% (23/180) of the individuals with a cancer diagnosis and 23.1% (92/398) of those without a cancer diagnosis were people of color. Due to the limited number of people of color in the sample, we did not stratify the individuals by race.

For access, compared with people of color, individuals who identified as White were 2.47 (95% CI 1.51-4.05; *P*<.001) times more likely to have access to HIT, whereas there was no significant difference about their use of HIT (*P*=.68). Hence, this hypothesis was supported for access to HIT but not for the use of HIT in this analysis. There was no significant difference in access to (*P*=.68) or use of HIT (*P*=.16) in individuals when controlled for cancer diagnosis in this hypothesis as well (Table 3).

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Table 3. Results of univariate models controlling for race.

Predictor	Access to HIT[a]		Use of HIT	
	OR[b] (95% CI)	*P* value	OR (95% CI)	*P* value
Cancer	0.95 (3.52-1.87)	.68	1.52 (0.84-2.7)	.16
Race				
Reference (ethnic and minority groups)	1	N/A[c]	1	N/A
White	2.47 (1.51-4.05)	>.001	1.13 (0.616-2.08)	.68

[a]HIT: health information technology.

[b]OR: odds ratio.

[c]N/A: not applicable.

Hypothesis 1-c

We hypothesized that there is a stronger association between older adults' income and access to and use of HIT in individuals when controlled for cancer diagnosis.

We fit 2 logistic regression models for this hypothesis to analyze the association between income and access to and use of HIT to control for cancer diagnoses. In addition to household income, we incorporate the number of individuals living in a household to create a dichotomous poverty index. Income alone, as well as poverty, were significantly associated with access to and use of HIT. Individuals living in poverty were 79% less likely to have access to HIT (odds ratio 0.21, 95% CI 0.14-0.32; *P*<.001) and used 44% less HIT (odds ratio 0.56, 95% CI 0.33-0.93; *P*=.02) compared with individuals not living in poverty. Using income alone, compared with those with a household income of CAD $13,499 (US $14,999) or less, those with household incomes of CAD $13,500 (US $15,000) to CAD $4410 (US $49,000) were 4.4 (95% CI 2.5-7.8; *P*<.001) times more likely to access and 1.9 (95% CI 0.98-3.90; *P*=.06) times more likely to use HIT. Those with household incomes of CAD $45,000 (US $50,000) to CAD $89,100 (US $99,000) were 13.42 (95% CI 6.7-26.50; *P*<.001) times more likely to have access and 2.83 (95% CI 1.3-6.17; *P*=.008) times more likely to use HIT. Those with household incomes of above CAD $89,100 (US $99,000) were 18.7 (95% CI 7.4-46.86; *P*<.001) times more likely to have access and 4.05 (95% CI 1.57-10.47; *P*=.004) times more likely to use HIT. Hence, this hypothesis was supported in this analysis for access and use of HIT. Similar to the above 2 hypotheses, there was no significant difference in access to (*P*=.79) or use of HIT (*P*=.21) in individuals when controlled for cancer diagnosis (Table 4).

Table 4. Results of univariate models controlling for poverty and income.

Predictor	Access to HIT[a]		Use of HIT	
	OR[b] (95% CI)	*P* value	OR (95% CI)	*P* value
Cancer	1.07 (0.63-1.8)	.79	1.54 (0.9-2.64)	.21
Poverty				
Reference (not living in poverty)	1	N/A[c]	1	N/A
Living in poverty	0.21 (0.14-0.32)	<.001	0.56 (0.33-0.93)	.02
Cancer	1.74 (0.55-5.55)	.80	1.01 (0.26-3.8)	.98
Income (US $)				
Reference (0-14,999)	1	N/A	1	N/A
15,000-49,999	4.44 (2.5-7.8)	<.001	1.95 (0.98-3.90)	.06
50,000-99,000	13.42 (6.7-26.50)	<.001	2.83 (1.3-6.17)	.008
>99,000	18.7 (7.4-46.84)	<.001	4.05 (1.57-10.47)	.004

[a]HIT: health information technology.

[b]OR: odds ratio.

[c]N/A: not applicable.

Hypothesis 1-d

We hypothesized that having more fatalistic beliefs about cancer will negatively affect access to and use of HIT in individuals when controlled for cancer diagnosis.

We used 2 logistic regression models were used to test this hypothesis. The model showed that the cancer fatalistic belief score was not associated with access to HIT (odds ratio 0.64, 95% CI 0.46-0.88; *P*=.07). However, the cancer fatalistic belief score was significantly associated with the use of HIT (odds ratio 0.64, 95% CI 0.42-0.96; *P*=.03); specifically, a 1-point

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increase in the fatalistic belief score was associated with a 36% decrease in the use of HIT. Hence, this hypothesis was not supported for access to HIT but was supported for the use of HIT. In line with all the aforementioned hypotheses, no significant differences were observed in access to (*P*=.75) or use of HIT (*P*=.87) among individuals after controlling for cancer diagnosis (Table 5).

Table 5. Results of univariate models controlling for cancer fatalistic beliefs score.

Predictor	Access to HIT[a]		Use of HIT	
	OR[b] (95% CI)	*P* value	OR (95% CI)	*P* value
Cancer	0.78 (0.18-3.42)	.75	1.14 (0.211-22)	.87
Fatalistic beliefs score	0.64 (0.46-0.88)	.07	0.64 (0.42-0.96)	.03

[a]HIT: health information technology.

[b]OR: odds ratio.

Aim 2: Hypothesis 2-a

To examine the relationship between access to and use of HIT and the SMD score of patient activation measures in older adults, when controlled for cancer diagnosis.

Low access to and use of the HIT will result in lower scores of the SMD of patient activation measure in individuals controlling for cancer diagnosis.

To test this hypothesis, we conducted a linear regression analysis to investigate the association between the SMD and access to and use of HIT diagnoses. Patients with access to HIT had an SMD score of 0.21 (95% CI 0.07-0.34; *P*=.003) points higher than patients who do not have access to HIT when controlling for cancer diagnosis. This finding was significant at α=.05 significance level. There was no difference in this association when controlling for cancer (*P*=.11; Table 6).

Table 6. Model coefficients and *P* values for the association between self-management domain (outcome) and access to health information technology (HIT) and cancer diagnosis (predictors).

Predictor	Coefficient (95% CI)	*P* value
Cancer	0.137 (−0.03 to 0.31)	.11
Access to HIT	0.21 (0.07 to 0.34)	.003

The second model indicated that the SMD score was higher by 0.28 (95% CI 0.11-0.45; *P*=.02) points for individuals who used HIT when controlling for cancer. Moreover, on average, those with cancer diagnosis reported an SMD score 0.14 (95% CI 0.006-0.278; *P*=.04) points higher than those who did not have the diagnosis when controlling for HIT use (Table 7).

Table 7. Model coefficients and *P* values for the association between self-management domain (outcome) and use of health information technology and cancer diagnosis (predictors).

Predictor	Coefficient (95% CI)	*P* value
Cancer	0.142 (0.006-0.278)	.04
Use	0.28 (0.11-0.45)	.002

Discussion

Principal Findings

The results of this analysis indicated that lower than a college education level, being a person of color, and living in poverty were significantly associated with access to HIT. Lower use of HIT was associated with lower than college education level and living in poverty. An additional finding of this analysis is the role of fatalistic beliefs in the use of HIT. Higher cancer fatalistic belief scores were significantly associated with lower use of HIT: a 1-point increase in the cancer fatalistic belief score was associated with a 36% decrease in the use of HIT. Furthermore, higher SMD scores for patient activation measures were significantly associated with higher access to and use of the HIT. Controlling for the diagnosis of cancer did not result in significant differences in the above findings, except for the SMD score and use of HIT.

Our first aim related to sociodemographic characteristics of education, race, and income and their effect on HIT use in older adults was similar to the general population use of HIT [20,37]. Being a person of color was significantly associated with lower access but not with lower use of HIT. One novel finding of our study was the role of psychological factors of fatalistic beliefs in the use of HIT. This association was not true for access to HIT. This provides evidence that fear related to the trigger factor of a cancer diagnosis may also drive engagement behaviors in treatment decision-making by having a negative effect on the HIT, which is a tool for PE [2,12]. We controlled for cancer diagnosis in this analysis as cancer patients are reported to be more actively engaged in their care [35,60]; hence, we originally hypothesized that having that diagnosis may affect the association between access to and use of HIT and education, race, household income, poverty level, and cancer fatalistic

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beliefs. However, we did not find no significant difference was observed.

Our second aim was to observe higher SMD scores in the SMD of patient activation in cancer patients, consistent with prior research suggesting that dealing with the health care system for an extended period may increase patient activation in patients with or before the diagnosis of cancer [32]. After adjusting for the presence of a cancer diagnosis to consider its impact on preexisting health care engagement, we observed that patients who reported access to and use of HIT had significantly higher SMD scores. This suggests that HIT may enhance self-management in older adults irrespective of whether they have a prior cancer diagnosis. Consequently, our findings may have broader implications for other chronic diseases, as HIT can play a crucial role in encouraging older adults' active engagement in their health care.

It is also important to consider that using HIT tools is not a replacement for actual patient-provider interaction and does not diminish the human factor of health care. HIT is not able to incorporate emotional experiences, even though it may change with wider adoption of artificial intelligence in the health care universe [61]. Instead, it is a facilitator of engagement behaviors that could potentially bridge socioeconomic and communication gaps [36,62,63]. Even when patients mostly rely on medical professionals for medical knowledge regarding their diagnosis and treatment [64], those with better access to medical information technology support have a more positive attitude toward engaging in medical decision-making, as it helps in relative information seeking to relieve anxiety [65,66]. Nevertheless, face-to-face encounters or other communication methods are essential to clarify information, as test results can occasionally be misinterpreted by patients or caregivers, leading to anxiety [37].

In older adults, the use of HIT tools may not always be desired because of functional impairments, lack of self-efficacy related to lower internet-related literacy, or preference to speak to the provider [67-70]. Various other factors, such as age over 75 years [71], gender, socioeconomic status, ease of use, facilitating conditions, and individuals' attitudes and behaviors are also reported to be associated with the preference for use of HIT in older adults [71]. However, such a preference should not be automatically assumed, given the advantages that HIT use can offer. Providers and health systems should provide equal opportunities for older adults to use various HIT tools as additional channels to engage in medical care if they are interested in using such tools [72]. In addition, different age cohorts of adults above 65 years may have different use of HIT channels, such as patient portals [36,73]. Current literature on digital health interventions often treats older adults as a uniform group, overlooking the diversity in age definitions among seniors [74]. In addition, using social media to acquire health knowledge is significantly linked to the use of HIT. The use of social media to deal with social isolation is increasing among older adults [75,76], making the incorporation of HIT highly desirable for them. This is particularly true regarding facilitating communication with health care providers and alleviating caregiving responsibilities placed on their family members [71]. Notably, psychosocial factors were equally important. Miller [77] broadly characterizes people as either "monitors" or "blunters" in the face of perceived medical threats. "Monitors" are individuals who are highly attentive and sensitized, and tend to amplify threats, whereas "blunters" avoid and minimize the same threats. Information needs may differ among individuals based on their personality styles [78,79]. HIT can act as a supplementary resource of information for individuals when older adults or their caregivers need more comprehensive details to alleviate their anxiety, especially when time constraints prevent health care providers from addressing all their questions and concerns. Hence, the preference for the use of HIT should be tailored according to the needs and preferences of a particular patient, regardless of age. Our analysis adds fatalistic beliefs about cancer as an additional psychosocial factor that may impact an individual's preference for HIT use regardless of having a past cancer diagnosis. Cancer fatalism refers to a belief or attitude held by some individuals that cancer is an inevitable and uncontrollable disease and that there is little or nothing that can be done to prevent or treat it effectively [80]. Previous research has demonstrated that enhancing perceived confidence in overcoming health information-seeking challenges can potentially alleviate cancer fatalism [81]. HIT functions as an additional information-seeking tool, making it worthwhile for health care providers to promote its use. Importantly, provider encouragement stands out as a significant factor that can positively influence an individual's adoption of HIT [82-84].

Limited access and use are social determinants of health [21], and older adults are one of the main groups where HIT is underutilized [85,86]. There are still opportunities to explore new directions and future applications of HIT implementation to engage older adults [27]. On the basis of our analysis, it is evident that a digital divide still exists among older adults regarding access to and use of HIT. Factors such as race, education, income, poverty, and fatalistic beliefs contribute to disparities in benefiting from HIT use at the individual level. With race, it is interesting to note that access is associated with being a person of color; however, use is not, which may suggest that if access is available, use of HIT may not be associated with being a person of color. In addition, higher SMD scores were associated with increased use of HIT, indicating HIT's potential in promoting patient activation, leading to engagement in health care in older adults.

Given the widespread adoption of HIT, it is crucial to carefully assess interventions to ensure that they do not inadvertently exacerbate social health inequalities [87]. Future research should include diverse cohorts of older adults when designing HIT channels, such as patient portals, to ensure user-friendly interfaces tailored to their needs. Such an approach is embedded in user-centered design, which is in line with precision medicine that considers an individual's specific sociodemographic and psychosocial factors [88]. User-centric design identifies genuine user requirements, reactions, and behaviors during design iterations, and optimizes usability and functionality [89,90]. Exploring different user-centric designs for specific diseases, such as cancer care, can be helpful for older adults who are at a higher risk of being diagnosed, and the information needs of patients are higher [91]. In the context of cancer or other chronic

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diseases, older adults may use web-based HIT tools in collaboration with family members or friends to make complex medical decisions [92,93]. Consequently, even if older adults have limited electronic literacy, the support of a caregiver in seeking information through HIT can still enhance their engagement in health care.

The unique needs and preferences of older adults will enable health care systems to effectively engage this population in their care and ultimately improve overall health outcomes. During chronic disease management visits for older adults, it is vital to regularly evaluate their preferences and issues related to HIT use and access. By addressing access barriers and enhancing the use of HIT among older adults, health care systems can advance health equity and diminish health disparities within this demographic.

Limitations

The small sample size was a limitation of this study. Although HINTS has multiple cycles, questions about SMD, a precursor to PE processes, were only included in HINTS 4 cycle 3 and were not included in any other cycle. Therefore, no other cycles were combined with the data used to increase the sample size. As survey weights were included in this analysis, these results are applicable to the entire US population. However, as we were unable to implement multiple imputations for missing values, our sample size remained small. Furthermore, we dichotomized the use of HIT because we did not have sufficient observations for each of the HIT categories, such as email, text, electronic medical records, video chat, or use of an app to communicate with the provider. Therefore, we could not examine the association of the combined effect of multiple channels of HIT use on the SMD of patient activation.

Finally, only 12% of individuals with a cancer diagnosis and 23% of those without a cancer diagnosis were people of color. Along with the dramatic aging of the US population over the next several decades, there will be significant increases in racial and ethnic diversity. Thus, it is insufficient to distinguish between White individuals and people of color. Although a dichotomous race variable was significantly associated with less access to HIT, the numbers were too low, and further stratification of race could not be performed. Hence, this analysis does not portray a true picture of access to HIT across various races in the United States.

Conclusions

Sociodemographic factors, including education, race, poverty, and fatalistic beliefs about cancer, can impact the access and use of HIT in older adults, regardless of whether they have a history of a chronic disease such as cancer. These factors can either hinder or promote technology adoption within this population. Furthermore, older adults who use HIT frequently report elevated levels of self-management, a crucial element of patient activation that drives active engagement in managing their health.

Conflicts of Interest

None declared.

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Abbreviations

HINTS: Health Information National Trends Survey
HIT: health information technology
PE: patient engagement
SMD: self-management domain

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Original Paper

Remote Monitoring of Physiology in People Living With Dementia: An Observational Cohort Study

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Abstract

Background: Internet of Things (IoT) technology enables physiological measurements to be recorded at home from people living with dementia and monitored remotely. However, measurements from people with dementia in this context have not been previously studied. We report on the distribution of physiological measurements from 82 people with dementia over approximately 2 years.

Objective: Our objective was to characterize the physiology of people with dementia when measured in the context of their own homes. We also wanted to explore the possible use of an alerts-based system for detecting health deterioration and discuss the potential applications and limitations of this kind of system.

Methods: We performed a longitudinal community-based cohort study of people with dementia using "Minder," our IoT remote monitoring platform. All people with dementia received a blood pressure machine for systolic and diastolic blood pressure, a pulse oximeter measuring oxygen saturation and heart rate, body weight scales, and a thermometer, and were asked to use each device once a day at any time. Timings, distributions, and abnormalities in measurements were examined, including the rate of significant abnormalities ("alerts") defined by various standardized criteria. We used our own study criteria for alerts and compared them with the National Early Warning Score 2 criteria.

Results: A total of 82 people with dementia, with a mean age of 80.4 (SD 7.8) years, recorded 147,203 measurements over 958,000 participant-hours. The median percentage of days when any participant took any measurements (ie, any device) was 56.2% (IQR 33.2%-83.7%, range 2.3%-100%). Reassuringly, engagement of people with dementia with the system did not wane with time, reflected in there being no change in the weekly number of measurements with respect to time (1-sample *t*-test on slopes of linear fit, P=.45). A total of 45% of people with dementia met criteria for hypertension. People with dementia with α-synuclein–related dementia had lower systolic blood pressure; 30% had clinically significant weight loss. Depending on the criteria used, 3.03%-9.46% of measurements generated alerts, at 0.066-0.233 per day per person with dementia. We also report 4 case studies, highlighting the potential benefits and challenges of remote physiological monitoring in people with dementia. These include case studies of people with dementia developing acute infections and one of a person with dementia developing symptomatic bradycardia while taking donepezil.

Conclusions: We present findings from a study of the physiology of people with dementia recorded remotely on a large scale. People with dementia and their carers showed acceptable compliance throughout, supporting the feasibility of the system. Our findings inform the development of technologies, care pathways, and policies for IoT-based remote monitoring. We show how

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IoT-based monitoring could improve the management of acute and chronic comorbidities in this clinically vulnerable group. Future randomized trials are required to establish if a system like this has measurable long-term benefits on health and quality of life outcomes.

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KEYWORDS

dementia; remote monitoring; physiology; Internet of Things; alerts; monitoring; technology; detection; blood pressure; support; feasibility; system; quality of life

Introduction

Dementia engenders a significant burden to patients, carers, and health care services. In the United Kingdom (UK), there are an estimated 850,000 people with dementia, a number expected to rise to over 2 million by 2051 [1]. Dementia care costs the National Health Service approximately £23 (US $27.88) billion per year. There is a pressing need for interventions that reduce the burden on health care services and carers.

In addition to cognitive and behavioral symptoms, dementia is commonly associated with long-term comorbidities, including hypertension, diabetes, malnutrition or unintentional weight loss, and heart disease [2-5]. Many such comorbidities are adverse factors in its progression [2,3,6-10] but are underrecognized and undertreated [11,12]. People with dementia are also at increased risk of hospital admission especially for infections and falls [3,13-15]. People with dementia are more likely to die during admissions, and over a third who go into hospital from home are discharged to a care home [16,17]. Abnormal physiological measurements are more common in people with dementia because of autonomic dysfunction, comorbidities, medication side effects, and acute illnesses [18-21]. People with dementia are also at increased risk of frailty [22]. The interaction between frailty and acute illnesses confers a multiplicative risk for significant morbidity and mortality [23]. A combination of poor premorbid function with atypical presentations and a reduced ability to describe and communicate symptoms drives the increased risk [24]. Recognizing and treating illnesses early leads to better outcomes, especially in the elderly [25].

Using “Internet of Things” (IoT) technology, physiological measurements can be recorded at home and transmitted automatically to caregivers [26]. Such technology can improve the monitoring and treatment of comorbidities and detect developing acute illness [26]. Higher temporal frequency of measurements in a more “naturalistic” setting can potentially provide more accurate, granular data on patients’ health. It also reduces the need for patients with reduced mobility to travel to access care. Therefore, IoT could improve the health and quality of life of people with dementia and reduce the burden on services [26]. Furthermore, by involving people with dementia in their own care, we can maximize empowerment regarding their own health [27]. This is vital for effective ethical care and can be in part enabled through technology [28]. There are also likely benefits to carers who can be involved directly in the ongoing assessments while having increased confidence to leave the people with dementia alone.

There is considerable interest from health and social care policy makers in systems that enable remote monitoring of physiological parameters in community-dwelling people with dementia [29,30], especially given the COVID-19 pandemic [31]. However, in-home monitoring creates new challenges for clinical practice. Guidelines for the frequency of remote measurements (eg, daily, weekly), definitions of clinically significant abnormalities (eg, the threshold heart rate [HR] of clinically relevant tachycardia), and algorithms for best-practice care are not established, unlike in the inpatient setting. The UK-wide National Early Warning Score 2 (NEWS, Table S1 in Multimedia Appendix 1) defines illness severity for hospitalized patients using a score aggregated from 6 physiological domains, where a higher subscore means the parameter is further from normal [32]. However, it is unclear whether NEWS, validated for inpatients, is suitable in the home setting. Also, little is known about the distribution of physiological measurements in people with dementia recorded in the community, which is crucial to establish when designing a system to detect abnormalities.

We are unaware of any published data from long-term studies employing IoT devices for physiological monitoring in the homes of people with dementia.

We have developed an IoT platform, “Minder,” that enables physiological measurements to be recorded at home and monitored remotely [33]. Here, we carried out an analysis of the physiology (HR, systolic blood pressure [SBP] and diastolic blood pressure [DBP], oxygen saturation, and body weight) recorded by a group of people with dementia at home. We report on the effectiveness of our Minder system, designed to detect abnormal measurements (“alerts”) and direct a clinical monitoring team. We also retrospectively applied the NEWS criteria to the data as a comparator. Finally, we present case studies highlighting the potential benefits of remotely monitoring people with dementia.

Our aims are to (1) characterize the physiology of people with dementia in their home setting, (2) test whether our system is sensitive to comorbidities and dementia subtypes, and (3) test how well NEWS-style alerts systems translate to community measurements.

Methods

Study Design, Participants, and Recruitment

We are conducting an ongoing longitudinal community-based cohort study of people with dementia living at home using Minder, passive infrared sensing, and data analytics to enable remote health care monitoring [33]. Patients with an existing

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clinical diagnosis of dementia of any cause were recruited from primary care, adult social care services, and memory clinics across Surrey and Borders Partnership NHS Foundation Trust and Hammersmith and Fulham Partnership. People with dementia were enrolled with an associated "study partner," defined as "a relative or friend who has known the people with dementia for at least 6 months." A distinction was not made between "study partner" and "carer"; however, the average number of hours the study partners spent caring for their respective people with dementia was 5.4 (range 1-8) for the 40 study partners for whom we have this data. Full inclusion and exclusion criteria are listed in "Methods" in Multimedia Appendix 2. Owing to the developmental and exploratory nature of the ongoing study, the number of participants was not predetermined by a power calculation. The study is reported according to the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) statement (Multimedia Appendix 3), guidelines for reporting observational studies [34].

Ethics Approval

The study was approved by the Health Research Authority's London-Surrey Borders Research Ethics Committee (19/LO/0102). All people with dementia and study partners provided written informed consent for participation and for their data to be included in publications.

Study Procedures and Physiological Measurements

The study protocol and devices used were based on a previous trial [26]. That trial was co-designed with 20 people with dementia, carers, health care and social workers, and academics, who designed the system to be appropriate for use in people with dementia, in addition to data from an Alzheimer's Society survey on technology-enhanced care. The system was first tested in a laboratory setting and home mock-up scenario before being deployed in participants' homes.

At baseline, people with dementia and their study partners completed demographics questionnaires and people with dementia completed the Standardized Mini-Mental State Examination (SMMSE). All people with dementia received up to 4 IoT medical devices to record 6 physiological measurements: a blood pressure machine for SBP and DBP, a pulse oximeter measuring oxygen saturation and HR, and body weight scales (provided by iHealth), and a thermometer (provided by Withings), and were asked to use each device once a day at any time. Measurements recorded by each device, annotated with a datetime stamp, were automatically transmitted immediately to a centralized secure server.

Study Oversight and Minder Alert Criteria

All people with dementia and study partners provided written informed consent. To oversee the study, a monitoring team was established, operating from 9 AM to 5 PM daily, to respond to clinical or technical alerts. The monitoring team was supervised by a consultant psychiatrist, 2 consultant neurologists, a general practitioner, and an occupational therapist. The team had near real-time access to the physiological measurements via a clinical dashboard, which additionally alerted staff when observations met standardized criteria devised by the study team (Table S2 in Multimedia Appendix 4). For any alert, the monitoring team would follow a predefined flowchart to investigate the abnormality, beginning by attempting to contact the people with dementia or study partner (Figures S1-S4 in Multimedia Appendices 5-8, respectively).

Statistical Analyses

All analyses were performed in MATLAB [35]. Data distributions were assessed for normality. Mean and SD are reported for Gaussian data (as per the Shapiro-Wilk test), whereas median and IQR are used for non-Gaussian data. We calculated descriptive statistics for baseline demographics and SMMSE, and grouped these data by dementia subtype, defined as Alzheimer disease (AD), vascular dementia (VD), and α-synuclein–associated dementias (ASyn), that is, combining participants with Parkinson disease dementia and Lewy body dementia.

We summarized the 24-hour timing of measurements by grouping timestamps into hourly bins. We calculated the overall frequency of recordings by dividing the number of days where a participant took at least 1 complete set (ie, all devices available) of measurements by the number of days of observation; we also counted the days when any measurement was taken. To examine whether the frequency of measurements changed over time, for each participant, we counted the number of measurements per week; fit a linear model to this time series; and, at the group level, tested whether the slopes of these fits were significantly different to zero (1-sample *t* test).

For subsequent analyses, measurement values were excluded as outliers if values were greater than 4 SD from the mean for that participant. For blood pressure, we calculated the proportion of people with dementia whose mean values met clinical criteria for hypertension (SBP/DBP ≥135/85 mg) [36] or hypotension (SBP/DBP ≤90/60 mm Hg) [37].

We charted the body weight of people with dementia over time, using a sliding window average of 5 values. To identify clinically significant weight loss (or gain) [38] in participants with at least 6 months of data, we identified averaged weights that were >5% different, in either direction, from the most recent value recorded at least 6 months previously.

We refer here to 2 different sets of alert thresholds: our own Minder thresholds and the established NEWS thresholds (Table S1 in Multimedia Appendix 1 and Table S2 in Multimedia Appendix 4). The Minder thresholds were used in real time during the study, to alert the monitoring team, whereas the NEWS thresholds were applied retrospectively to the data for comparison. When applying the subscore thresholds of the NEWS [32] to the data, we first removed any repeat measurements recorded within 60 seconds. For each domain within the NEWS criteria, a normal value is scored 0, but 1-3 when values meet predetermined criteria for abnormality (Table S1 in Multimedia Appendix 1), and these subscores are aggregated into a single NEWS score [32]. For each participant, we calculated the number of individual measurements that triggered Minder alerts and NEWS thresholds of 1+ (less abnormal) and 2+ (more abnormal). We then summarized the overall "burden" of alerts per day per participant.

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We used the Spearman rank to test for correlations between physiological summary measures and baseline SMMSE scores and 1-way ANOVA to test for differences between the dementia subtypes (AD, VD, ASyn), with post hoc Tukey tests. Owing to the exploratory nature of the analysis, we did not correct for multiple comparisons.

Case Studies

Four case studies, each based on a snapshot from an individual person with dementia, have been identified. These are included for the purpose of demonstrating the use of this monitoring system for detecting acute clinical events as well as chronic changes in physiological measures over time.

Results

Participant Characteristics, Dementia Subtypes, and Analysis Period

Data from 82 people with dementia were analyzed, with a mean age of 80.4 (SD 7.8, range 60.5-96.4) years at study entry; 36 (44%) were women. Table 1 shows baseline participant characteristics including SMMSE scores (mean 23.0, SD 4.2), grouped by dementia subtypes—AD, VD, and ASyn. The medical history of people with dementia was accessed via their general practitioner (GP) records on enrollment: 1 had type 1 diabetes mellitus and 2 had type 2 diabetes mellitus. Although 18 records stated that they had a diagnosis of essential hypertension, 29 were on at least 1 medication with antihypertensive action (calcium channel blockers, angiotensin-converting enzyme inhibitors, β-blockers, α-blocker, angiotensin receptor blockers, and diuretics). There was a significant difference in age between dementia subtypes (1-way ANOVA $F_{2,79}$=5.346, P=.007), with participants with AD older than those with ASyn (post hoc Tukey test, P=.004). There was no difference in baseline SMMSE scores between dementia subtypes ($F_{2,78}$=2.324, P=.11). Recruitment to the study was ongoing throughout, and thus those included commenced the study at different points in the analysis period: April 1, 2019, to March 14, 2022 (1078 days; Figure 1A). The median number of days of observations per patient, defined as the days between the first and last recorded measurement, was 432.5 (IQR 164.9-764.0, range 15.8-1077.1) days, a total of 957,861 participant-hours. A total of 37 participants withdrew from the study during the analysis period, including 5 (6%) who died. The most frequent reason for withdrawal was people with dementia moving to a care home. Full details of the withdrawals are reported in Table S3 in Multimedia Appendix 9. Given the nature of the population in this observational study, it was expected that a significant proportion would withdraw or pass away, as their condition progressed.

Table 1. Baseline participant characteristics, grouped by dementia subtype (N=82).[a]

Variable	Overall	Dementia type		
		AD[b] (n=68)	VD[c] (n=5)	ASyn[d] (n=9)
Age (years), mean (SD)	80.4 (7.8)	81.5 (7.5)	80.1 (10.2)	72.8 (4.8)
Sex, n (%)				
Female	36 (44)	33 (49)	1 (20)	2 (22)
Male	42 (56)	35 (52)	4 (80)	7 (78)
Other	0 (0)	0 (0)	0 (0)	0 (0)
White ethnicity, n (%)	77 (94)	61 (90)	4 (80)	8 (89)
SMMSE[e] (out of 30), mean (SD)	23.0 (4.2)	22.8 (4.1)	26.8 (2.9)	22.3 (4.7)
Education, n (%)				
Up to 16	35 (45)	28 (44)	2 (40)	5 (56)
Up to 18	14 (18)	14 (22)	0 (0)	0 (0)
Vocational[f]	8 (10)	5 (8)	1 (20)	2 (22)
University degree	21 (27)	17 (27)	2 (40)	2 (22)

[a]Data from questionnaires completed by participants on enrolment.

[b]AD: Alzheimer disease.

[c]VD: vascular dementia.

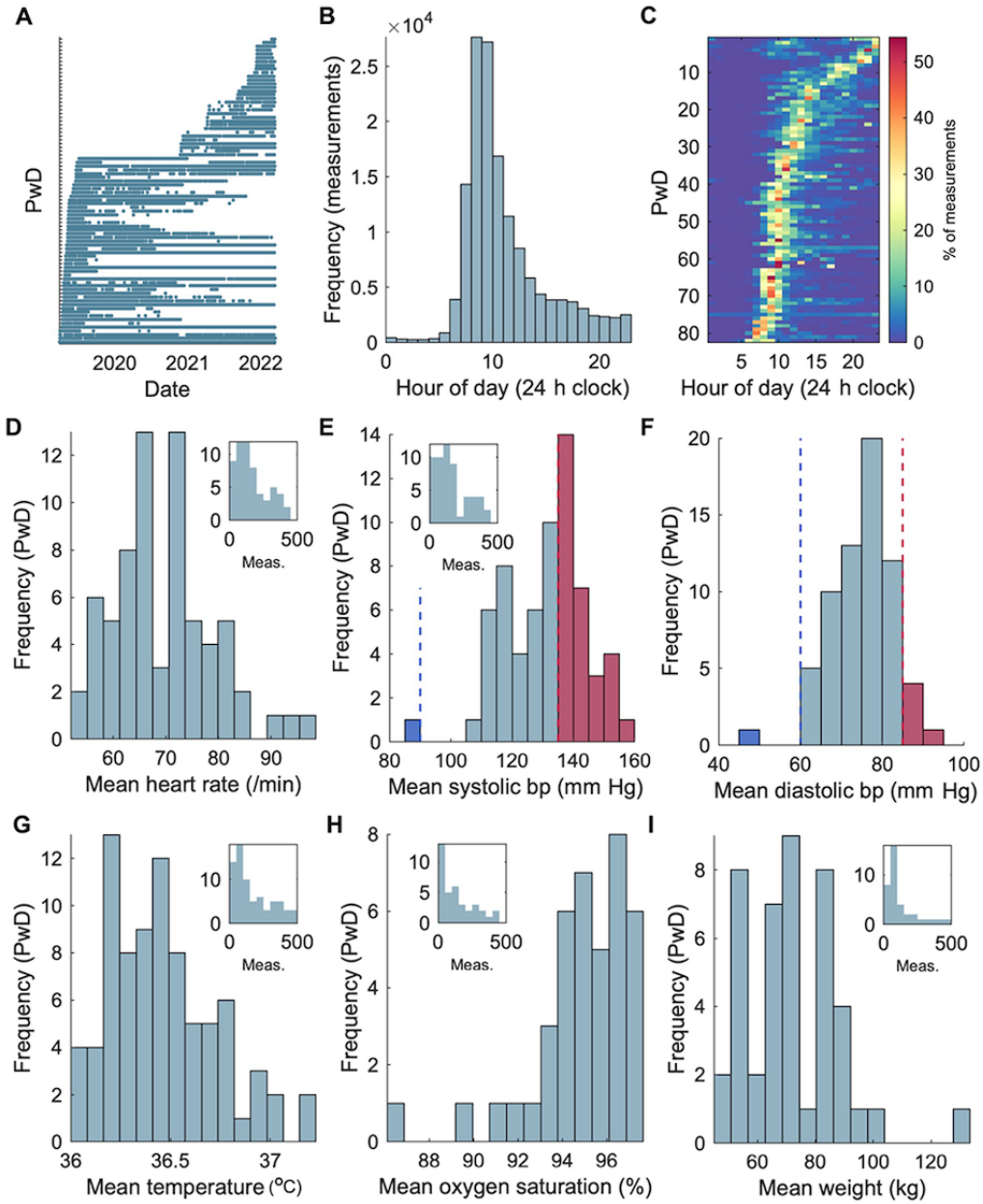
[d]ASyn: α-synuclein–associated disorders (Parkinson disease dementia and Lewy body dementia combine).

[e]SMMSE: Standardized Mini-Mental State Examination.

[f]Where data are incomplete, percentage calculated from available data only. Vocational education refers to higher education course (above the age of 16 years) toward a specific vocation, rather than 16- to 18-year-old schooling or university degree.

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Figure 1. Timings and mean values of in-home measurements taken by PwD. (A) Each horizontal line represents a participant, and each dot represents a recording. Rows have been ordered by date of first observation. (B) Count of measurements by each hour of the day, across the cohort. (C) Timing of each participant's measurements group per hour of the day, expressed as a percentage of that participant's total measurements. Rows have been ordered by the hour of maximum percentage of most observations (earliest to latest; a different ordering to panel A). (D) Within-participant mean heart rate (beats per minute, n=66 participants); only participants with more than 7 days' data are included for D-G. The inset histograms show the number of measurements (x-axis) recorded by each participant (y-axis) for the domain. (E) Systolic blood pressure (bp, mm Hg, n=66). Coloring of bars indicate cutoffs for clinical diagnoses of hypertension (≥135 mm Hg, red) and hypotension (≤90 mm Hg, blue). (F) Diastolic blood pressure (bp, mm Hg, n=66). Coloring of bars indicate cutoffs for hypertension (≥85 mm Hg, red) and hypotension (blue, ≤60 mm Hg). (G-I) Mean calculated from all measurements for each individual of body temperature (°C, n=82), oxygen saturation (%, n=40), body weight (kg, n=44). bp: blood pressure; PwD: people with dementia.



Number, Timing, and Frequency of Physiological Measurements

There were 147,203 individual measurements recorded among the 82 participants. Measurements were most often recorded in the morning, with 8-9 AM the most frequent hour (Figure 1B), but there was wide between- and within-participant variability (Figure 1C). We defined participants' frequency of physiological measurement recording in 2 ways. The median proportion of days of observation during which any participant took at least 1 full set of measurements was 13.9% (IQR 1.2%-33.1%, range 0%-61.0%). The median percentage of days when people with dementia took at least 1 measurement using any device was 56.2% (IQR 33.2%-83.7%, range 2.3%-100%) and did not differ between dementia subtypes ($F_{2,79}$=0.944, P=.91). By either definition, there was no correlation between frequency and SMMSE (Spearman ρ P=.17 and P=.095, respectively). We also examined whether measurement frequency changed over the study, that is, that might reflect study fatigue or difficulties with devices. There was no change in the weekly number of measurements in people with dementia with respect to time

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(1-sample *t* test on slopes of linear fit, *P*=.45). There was also no correlation between any change in frequency (fitted slopes) and SMMSE (*P*=.34).

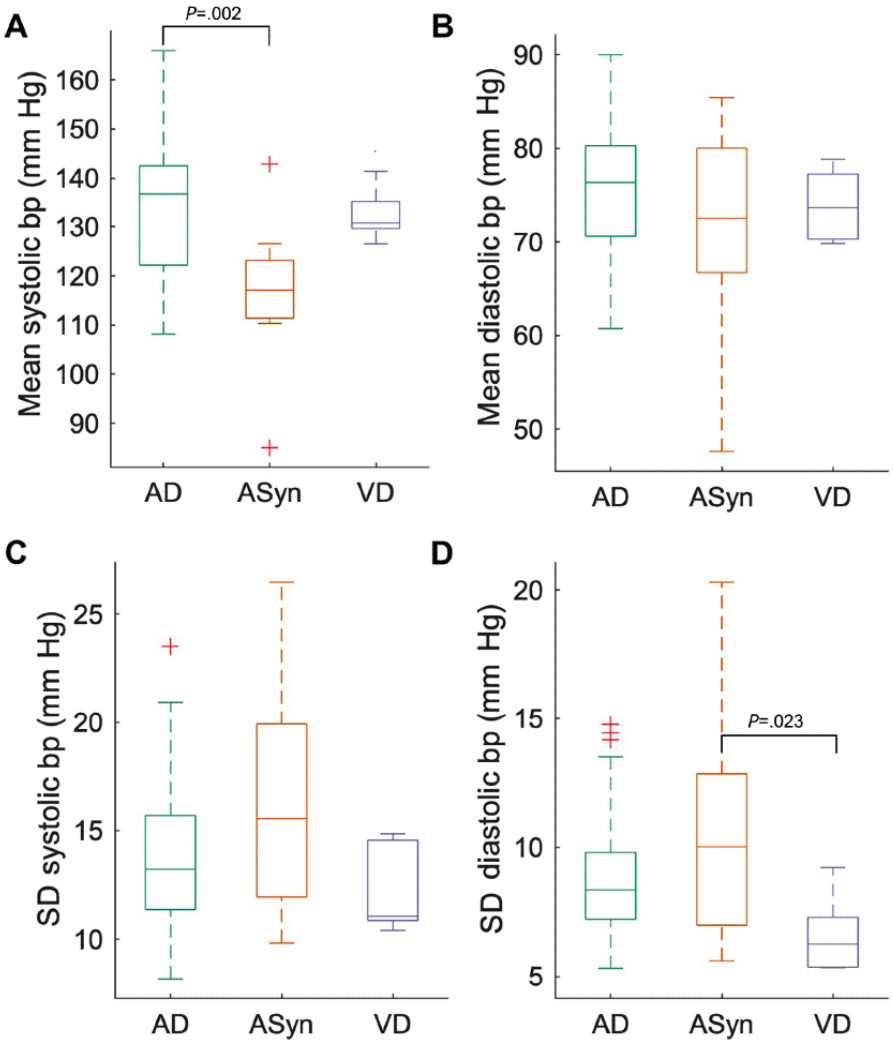
Values of Physiological Measurements and Prevalence of Hypertension

Figure 1D-I shows for each measurement domain the distributions of participants' mean values recorded during the study for people with dementia with more than 7 days of measurements. Grand means, calculated as the mean of all the within-subject means, were as follows: group mean HR 69.6 (SD 9.4, range 53.5-97.4) bpm, mean SBP 131.7 (SD 14.1, range 85.0-165.9) mm Hg, mean DBP 74.9 (SD 7.5, range 47.7-90.0) mm Hg, median temperature 36.4 (IQR 36.2-36.6, range 36.0-37.2) °C, median oxygen saturation 95.2% (IQR 94.4%-96.5%, range 86.7%-97.5%), median body weight 71.4 (IQR 61.8-83.1, range 48.7-132.0) kg. Using typical clinical criteria [36,37], 45.4% of people with dementia with available data had hypertension (within-subject mean either SBP/DBP ≥135/85 mg), and 1 had hypotension (within-subject mean either SBP/DBP ≤90/60 mm Hg; Figure 1D and E**)**. Figure S5A-F in Multimedia Appendix 10 shows the distributions of within-participant SDs of values.

Physiological Measurements Between Dementia Subtypes

We grouped the within-participant means and SDs by dementia subtypes (Figure 2A-D for SBP/DBP; see Figure S6 in Multimedia Appendix 11 for other domains). There was a significant difference across subtypes in mean SBP ($F_{2,63}$=6.203, *P*=.003), SD of DBP ($F_{2,63}$=3.790, *P*=.03, post hoc Tukey test results shown in Figure 2), and SD of oxygen saturation ($F_{2,37}$=6.317, *P*=.004), with ASyn higher than AD participants (post hoc Tukey test, *P*=.005) and VD participants (post hoc Tukey test, *P*=.01).

Figure 2. Within-participant means and SDs of physiological measurements in people with dementia, grouped by dementia subtypes. Only participants with more than 7 days of data are included. Results of post hoc Tukey test are shown where significant (*P*<.05). (A) Mean systolic blood pressure (SBP, mm Hg). (B) Mean diastolic blood pressure (DBP, mm Hg). (C) SD of SBP (mm Hg). (D) SD of DBP (mm Hg). AD: Alzheimer disease; ASyn: α-synuclein–associated disorders; bp: blood pressure; VD: vascular dementia.

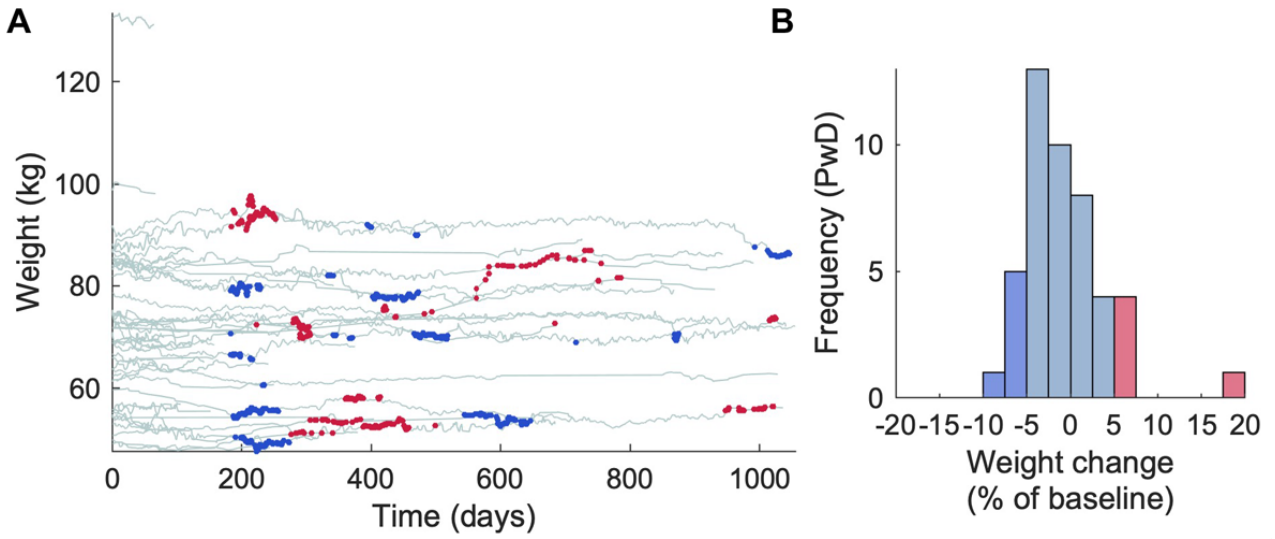


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Body Weight and Prevalence of Clinically Significant Weight Loss

Using the criteria of >5% change over 6 months [38] (Figure 3A), 13 (28%) participants who recorded weight measurements for at least 6 months had at least 1 period of weight loss during the study; 15 (33%) had weight gain. The median percentage change in body weight over the whole study was –1.6% (IQR –3.4% to 1.7%, range –8.4% to 17.6%; Figure 3B). There was no relationship between change in body weight and SMMSE (*P*=.54).

Figure 3. Body weight over time in PwD. (A) Participants' body weight over time. Each line represents a different PwD, and each point on the line represents the sliding window average value of 5 body weights. The blue segments indicate values that were >5% less than values 6 months previously, suggesting clinically significant weight loss [38]; the red segments indicate >5% weight gain. (B) Participants' final body weight (average of 5 measurements) is expressed as a percentage of their baseline weight; bins for >5% weight change are colored blue (loss) and red (gain). PwD: people with dementia.



Physiological Measurements Generating Alerts

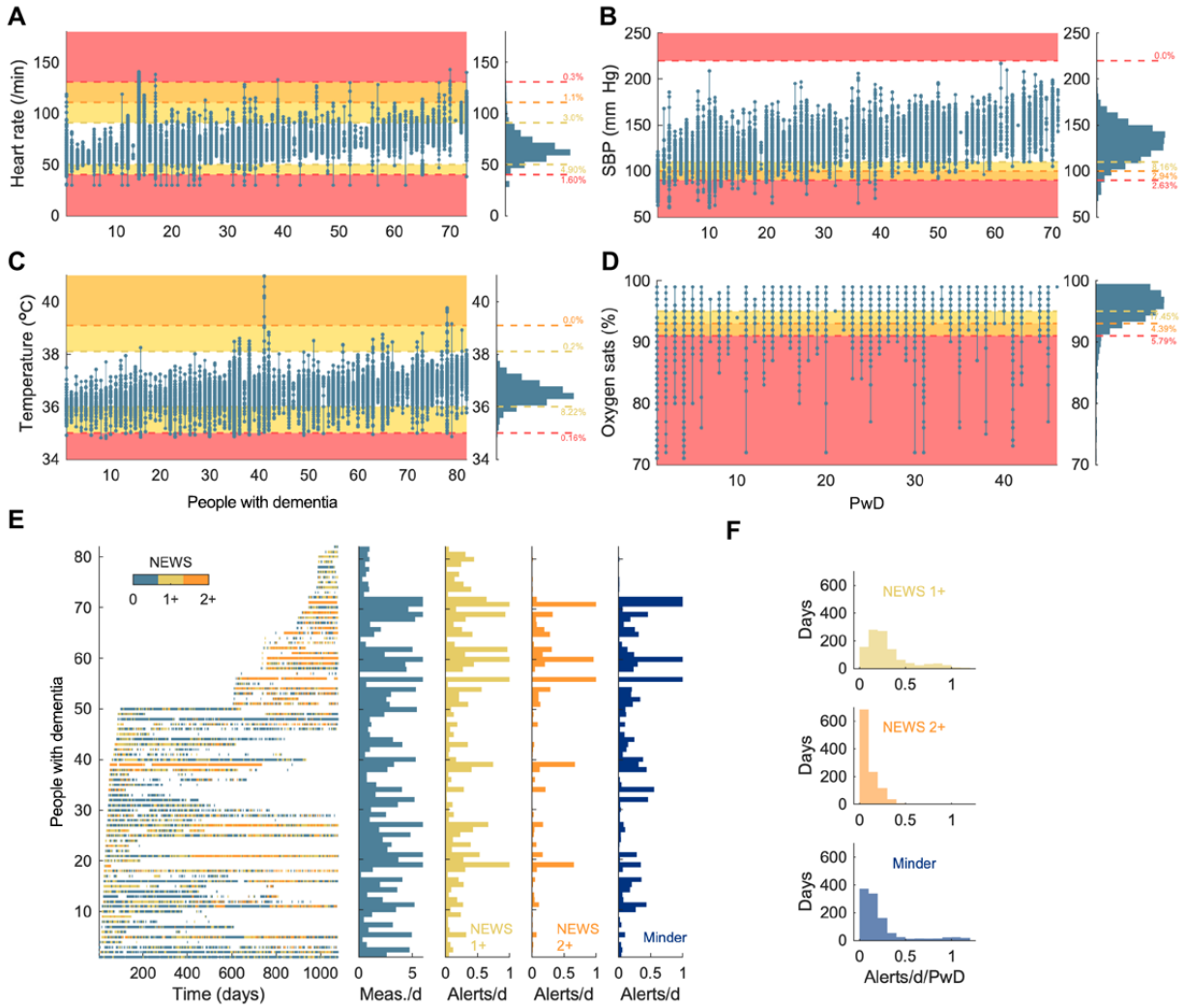
To inform the development of remote monitoring services, we calculated the prevalence of abnormalities generating "alerts" according to several criteria.

The prevalence of abnormalities recorded by people with dementia according to NEWS subscore criteria is shown in Figure 4A-D. In-home measurement domains were here treated independently, that is, not combined into a single NEWS score, because people with dementia did not necessarily record measures contemporaneously and because the full NEWS data, that is, respiratory rate and conscious level, were not captured. Instead, alerts could be generated for measurements in a single domain if they crossed either the 1+ or 2+ thresholds.

We retrospectively calculated the burden of alerts that would have been generated using NEWS subscore criteria, that is, the proportion and rate of measurements that exceeded different subscore thresholds (Figure 4). A total of 9.46% of all measurements would generate an alert for meeting the criteria of a NEWS subscore of 1 or more (1+), and 3.03% of measurements using a NEWS subscore of 2+. By comparison, the proportion using our Minder study criteria (Table S2 in Multimedia Appendix 4) was 7.88%. We summarized the alerts per participant per day to indicate the potential overall alert burden (Figure 4). The median frequency of alerts per day per participant was 0.233 (IQR 0.14-0.37; range 0-1.33) using NEWS 1+ and 0.066 (IQR 0.02-0.15; range 0-0.67) using NEWS 2+. Using our Minder criteria, the median frequency was 0.140 (IQR 0.07-0.25; range 0-1.17). There was no relationship between alerts per day, using either NEWS (1+ or 2+) or Minder criteria and SMMSE (*P*=.56, *P*=.54, *P*=.79, respectively) or dementia subtype (*P*=.92, *P*=.26, and *P*=.95).

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Figure 4. Frequency of physiological measurement alerts in people with dementia, by NEWS and Minder criteria. For each domain, each line with superimposed circles shows the minimum, maximum, and individual observations for each PwD, after first removing any measure recorded within 60 seconds of another in the same domain. The shaded areas correspond to a NEWS subscore of 1 (yellow), 2 (orange), or 3 (red). The histograms show the distribution of measurements across the group, in relation to the ranges for NEWS subscores, annotated with the percentage of measurements in each range. (A) Heart rate (beats per minute); (B) SBP (mm Hg); (C) temperature (°C); (D) oxygen saturation (%). Data were first filtered by removing any measure recorded within 60 seconds of another in the same domain. Alert for meeting the criteria of a NEWS subscore of 1 or more = NEWS 1+; alert for meeting the criteria of a NEWS subscore of 2 or more = NEWS 2+. (E) Data were labeled by a NEWS subscore of 0 (turquoise), 1+ (yellow), or 2+ (orange). Each horizontal row of circles (left) shows measurements for each participant, colored accordingly. Each subsequent column (left-right) shows the daily number of measurements (turquoise), and then the frequency of alerts using the criteria of NEWS 1+, NEWS 2+, and the Minder platform. (F) Histograms of the alerts per day per participant across the duration of the study, for criteria of NEWS 1+ (top), NEWS 2+ (middle), and the Minder platform (bottom). NEWS: National Early Warning Score 2; PwD: people with dementia; SBP: systolic blood pressure.



Case Studies

Here we report four case studies demonstrating the ability of the monitoring system to detect clinically relevant changes in physiological measurements. This provides evidence for the use of the system in picking up acute illness in a timely manner while also allowing clinicians to monitor chronic changes in individual patients.

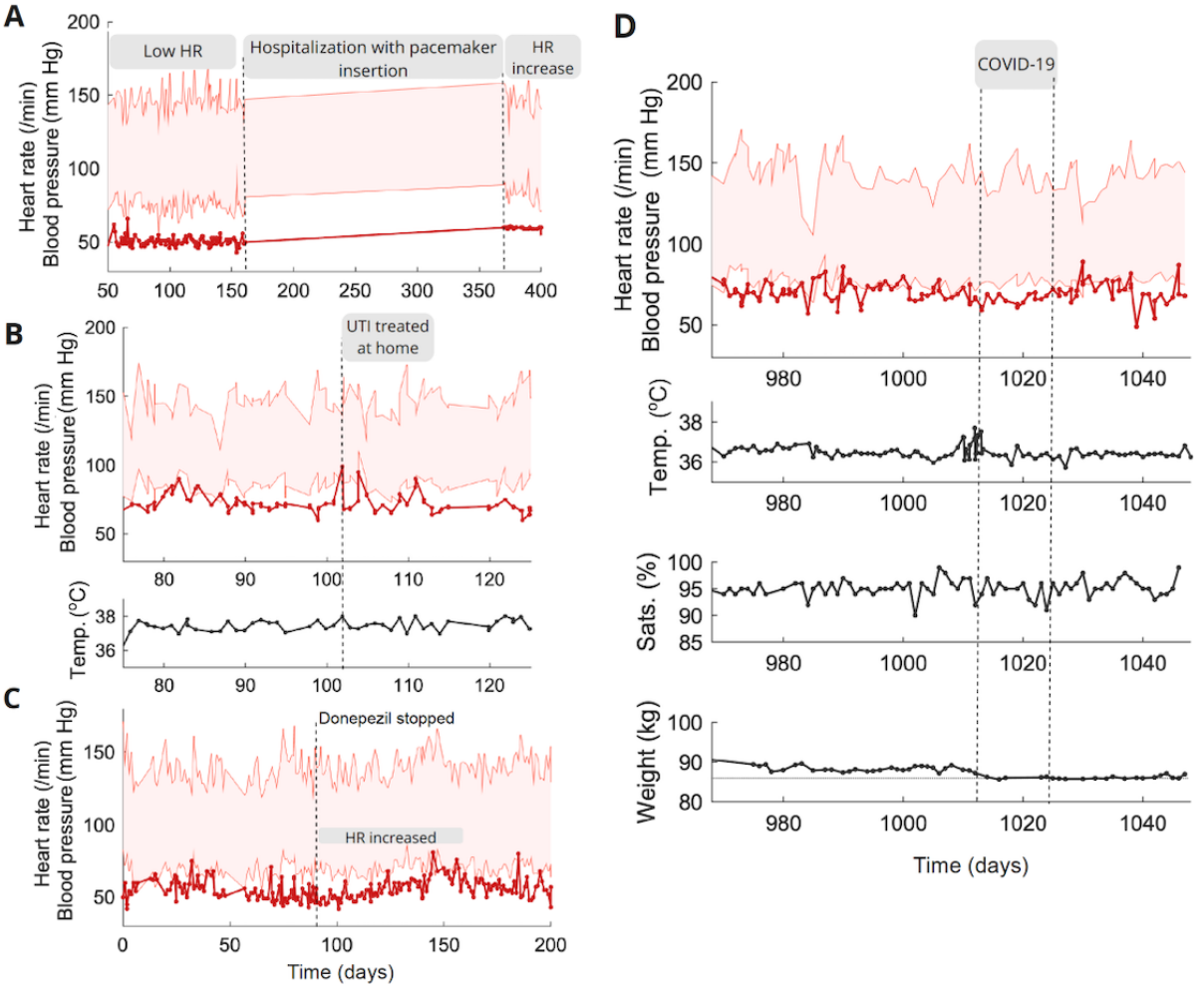
1. Change in HR observations after pacemaker insertion: An 83-year-old man with AD was admitted to the hospital after a posterior myocardial infarction, resulting in a long gap in measurements (Figure 5A). After the infarction, he was persistently bradycardic (40-50 bpm) and had a permanent pacemaker fitted. Frequent HR readings of approximately 60 bpm followed the recommencement of home monitoring.
2. Physiological measurement abnormalities leading to urinary tract infection (UTI) diagnosis: An 81-year-old woman with AD had a temperature of 37.9 °C and HR of 102 bpm (Figure 5C). The monitoring team called the carer who relayed symptoms of a UTI. The carer was advised to call 111 (a public service for immediate health advice) and was seen at the hospital. A UTI was subsequently diagnosed, and treatment commenced at home.
3. Symptomatic bradycardia in a person with dementia on donepezil: A 78-year-old man with AD on donepezil recorded a series of low HR measurements over 3 weeks (lowest=44 bpm; Figure 5C), generating alerts for the

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monitoring team. The carer told the team that the person with dementia was more fatigued. He was advised to see the GP who switched donepezil, known to cause bradycardia and fatigue, for memantine. Our system showed a resultant increase in HR.

4. Remote physiological monitoring in a person with dementia with COVID-19 infection: An 81-year-old man with AD developed coryzal symptoms, a nonproductive cough, and a temperature of 38.37 °C (Figure 5E). Oxygen saturation remained >95%. Two days later, he was pyrexial again (38.57 °C) and tested positive for COVID-19 at home. The person with dementia was closely monitored with daily check-ins by the monitoring team. Ten days later, he tested negative. The person with dementia lost weight (89 to 85.7 kg after the infection). This was subsequently followed up by the GP.

Figure 5. Case studies highlighting the potential benefits and challenges of remote physiological monitoring in people with dementia. Case studies are labeled according to descriptions in text. HR: heart rate; UTI: urinary tract infection.



Discussion

Study Scale

We have deployed IoT medical devices in the homes of a cohort of people with dementia, providing a rich data set of naturalistic physiological measurements. We believe that this is the first time the physiology of people with dementia has been recorded in this setting at such a scale and sustained period (approximately 150,000 measurements, approximately 1,000,000 participant-hours). We found a system of this nature to be realizable and effective in detecting acute and chronic physiological abnormalities.

Principal Findings

We found that people with dementia recorded a full set of observations on 13.9% of days; however, at least 1 measurement was taken on more than half the study days, on average. Although the data were often incomplete, with measurement in some domains more likely to be recorded than others, there was no decline in compliance over time. Overall, concerns that people with dementia are unlikely to remember or be unwilling to have measurements taken in the community appear misplaced. However, these findings show that serial naturalistic data in people with dementia obtained remotely are likely to be patchy compared with what is possible in a nurse-led inpatient setting. Although there was no correlation between compliance and SMMSE in our data, it is possible that in more advanced dementia, there may be a reduction in compliance. However,

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although people with dementia with a lower SMMSE may be less likely to remember to take measurements, they are more likely to have a carer to support measurements.

Our system has provided an opportunity to describe the hitherto poorly understood behavior of physiological measures over extended periods in an older adult, cognitively impaired population, and to consider how physiology relates to comorbidity. On the basis of the data collected in this study, we detected a high prevalence of hypertension, an important factor in dementia development [8,9]. We also detected physiological differences between dementia subtypes, with lower and more variable blood pressure seen in people with dementia with ASyn, in keeping with the known associated autonomic dysfunction [39]. Our case studies provide further evidence that, at the individual level, remote monitoring can detect symptomatic bradycardia, acute infections, and medication side effects.

The relationship between cognitive decline and physical health is complex. For example, regarding blood pressure, both hypo- and hypertension have been implicated in the progression of cognitive decline [40]. Furthermore, because they have been largely excluded from previous randomized trials [41], the value of treating hypertension in older adult, cognitively impaired patients is not established. Body weight, as a marker of nutritional status, also has an important but complex interaction with dementia. We did not find an association with SMMSE, but it is likely that a longer time course would be required to detect one.

IoT-based platforms like Minder represent a new paradigm for clinical measurement, that is, large-scale, long-term, sporadic, patient-initiated, and remotely recorded. Definitions and care pathways for significant abnormalities in this context are not well established. These are important differences versus the established settings of primary care (infrequent, supervised, in-person measurements), secondary care (high-frequency in-person multimodal monitoring of acutely unwell patients), and ambulatory monitoring (devices worn continuously for several days). When we applied the NEWS criteria, validated for hospital use, we found that the median rate of alerts generated was 0.066 or 0.233 per day per participant, depending on the threshold used, which spanned the rate (0.114) from our own criteria. These findings provide an indication of the potential workload that would be placed on remote monitoring service (approximately 100 alerts per day per 1000 patients). There is, however, potential to improve the clinical use of such alerts, for example, by using personalization, whereby thresholds are set according to patients' own historical data and constantly updated in response to their measurements.

Future Directions

Our study highlights the benefits and risks of remote monitoring systems. With such systems, there is the potential to detect developing acute illness, facilitating early intervention, improving outcomes, and avoiding hospital admission [42,43]. Remote physiological monitoring of this kind could identify trends over weeks to months, relating to, for example, comorbidities like hypertension, malnutrition, and drug side effects. Both timescales are pertinent in people with dementia who, less able to recognize and communicate when they become acutely unwell, are more likely to develop comorbidities.

We are currently scaling up the size of the cohort in the study to 200 people with dementia in the form described here. There are further plans to provide a cut-down version of the system to a cohort of 1000. A key part of the ongoing work is ascertaining, which features are most informative, in order to design a system that is scalable.

It remains to be established the measurable benefit a system like this can have on long-term health outcomes and quality of life. A previous randomized trial did not point toward benefit, but this may well be due to a piecemeal approach [44]. In fact, successful implementation will depend on systematic work understanding how best to use technology in the home.

Limitations

We have identified the following limitations to our IoT system and to the analysis presented. First, we were limited in our ability to reliably characterize and record every change in patients' medical status and medication over the course of the study. This has implications for interpretation of the physiological findings. The association between changes in physiological observations and medication may be addressed using data linkage with the patient electronic clinical record—something we are exploring as the study develops. Second, we did not have a control group of age-matched healthy participants to provide comparisons for measurement compliance and physiological values. The normative values are for vital signs are well established, but not necessarily in the context of elderly people, in their own homes. Third, our analysis of compliance was limited as we could not discern which recordings were initiated by people with dementia versus in response to contact by the monitoring team. We therefore have likely overestimated the frequency with which people with dementia recorded measurements. However, the value in allowing people with dementia to record their vital signs remotely withstands, even if they have had to be prompted. Fourth, our alert rates are instead likely to be underestimates, because we excluded extreme outliers and duplicate values and did not evaluate abnormalities relating to DBP or body weight.

Conclusions

There is growing interest in establishing remote monitoring within care services, amplified by the COVID-19 pandemic and calls for "hospital and home" initiatives [29,30]. We believe that remote monitoring technology can be transformative for the health and social care of people with dementia. Future research must demonstrate the clinical use of remote monitoring and address how such technologies are best integrated with existing care. Together, our findings inform the development of technologies, pathways, and policies for remote monitoring of people with dementia.

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Acknowledgments

We thank the patients and study partners who took part in the study. We also thank all members of the UK Dementia Research Institute Care Research & Technology Centre who contributed in some way to this work. A full list of members can be found in Multimedia Appendix 12. This work was funded by UK Dementia Research Institute award. Surrey and Borders partnership is the sponsor of this study.

Data Availability

The data collected during the current study are available from the corresponding author on reasonable request. The institute intends to store data in a public repository on dementiasplatform.uk in due course.

Authors' Contributions

JT, RN, PB, HR, D Wilson, DJS, and GS designed the study. HL, JT, EB, RN, PB, D Wingfield, and SD collected the data. MCBD, MK, MDG, HL, and GS analyzed the data. MCBD, MDG, LML, RN, D Wingfield, PAM, DJS, and GS prepared the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Threshold values for abnormal measurements in the National Early Warning System 2.
[DOCX File , 17 KB - aging_v6i1e43777_app1.docx]

Multimedia Appendix 2
Methods: inclusion and exclusion criteria of study partners.
[DOCX File , 15 KB - aging_v6i1e43777_app2.docx]

Multimedia Appendix 3
STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) checklist.
[DOCX File , 33 KB - aging_v6i1e43777_app3.docx]

Multimedia Appendix 4
Threshold values for abnormal measurements defined in the Minder platform.
[DOCX File , 13 KB - aging_v6i1e43777_app4.docx]

Multimedia Appendix 5
Within-participant standard deviation for all six measurement domains; only participants with more than 7 days data are included. PwD: people with dementia.
[PNG File , 312 KB - aging_v6i1e43777_app5.png]

Multimedia Appendix 6 [PNG File , 287 KB - aging_v6i1e43777_app6.png]

Multimedia Appendix 7
Flowchart followed by monitoring team in response to alerts for abnormal oxygen saturation. GP: General physician.
[PNG File , 154 KB - aging_v6i1e43777_app7.png]

Multimedia Appendix 8
Flowchart followed by monitoring team in response to alerts for body temperature. GP: general physician; UTI: urinary tract infection.
[PNG File , 166 KB - aging_v6i1e43777_app8.png]

Multimedia Appendix 9
Participant withdrawals.
[DOCX File , 13 KB - aging_v6i1e43777_app9.docx]

Multimedia Appendix 10

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Flowchart followed by monitoring team in response to alerts for abnormal heart rate. CMT: clinical monitoring team.
[PNG File , 191 KB - aging_v6i1e43777_app10.png]

Multimedia Appendix 11
Flowchart followed by monitoring team in response to alerts for abnormal blood pressure readings. BP: blood pressure; GP: general physician.
[PNG File , 224 KB - aging_v6i1e43777_app11.png]

Multimedia Appendix 12 [DOCX File , 19 KB - aging_v6i1e43777_app12.docx]

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Abbreviations

AD: Alzheimer disease
ASyn: α-synuclein–associated dementias
DBP: diastolic blood pressure
HR: heart rate
IoT: Internet of Things
NEWS: National Early Warning Score
SBP: systolic blood pressure
SMMSE: Standardized Mini-Mental State Examination
UTI: urinary tract infection
VD: vascular dementia

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Identifying Preferred Appearance and Functional Requirements of Aged Care Robots Among Older Chinese Immigrants: Cross-Sectional Study

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Abstract

Background: Older Chinese immigrants constitute the largest older Asian ethnic population in New Zealand. Aging in a foreign land can be complex, presenting increasing challenges for gerontology scholars, practitioners, and policy makers. Older Chinese immigrants are more susceptible to experiencing loneliness and social isolation compared to native older people, primarily due to language, transportation, and cultural barriers. These factors subsequently impact their physical and mental health. With advancements in robotic technology, aged care robots are being applied to support older people with their daily living needs. However, studies on using robots with older immigrants living in the community are sparse. Their preferences for the appearance and function of aged care robots are unclear, which impacts the acceptance and usability of robots, highlighting the need for a user-centered design approach.

Objective: This study aims to explore older Chinese immigrants' needs and preferences toward the appearance and function of aged care robots and to examine their relationships with the demographic characteristics of participants.

Methods: A cross-sectional design was used in this study, which was undertaken between March and May 2020. A total of 103 participants completed a web-based survey.

Results: The average age of participants was 68.7 (SD 5.5) years. The results suggest that 41.7% (n=43) of the 103 participants preferred a humanlike adult appearance, while 32% (n=33) suggested an animallike appearance. These participants reported higher scores in both rigorousness and friendliness compared to others who preferred different robot appearances. Participants expressed a greater preference for the functions of housework assistance (n=86, 83.5%), language translation (n=79, 76.7%), health monitoring (n=78, 75.7%), facial expressions (n=77, 74.8%), news reading (n=66, 64.1%), and security monitoring (n=65, 63.1%). These preferences were found to be significantly associated with marital status, financial status, and duration of immigration.

Conclusions: To support immigrant populations to age well in a foreign country and address the growing shortage of health and social professionals, it is important to develop reliable robotic technology services that are tailored based on the needs and preferences of individuals. We collected and compared the perspectives of immigrant and nonimmigrant participants on using robots to support aging in place. The results on users' needs and preferences inform robotic technology services, indicating a need to prioritize older Chinese immigrants' preference toward aged care robots that perform housework assistance, language translation, and health and safety monitoring, and robots with humanlike features.

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KEYWORDS

robotic technology services; appearance; function; aged care; immigrant; Chinese; robot; robots; robotic; robotics; older adults; elderly; preference; cross sectional; cross-sectional; survey; healthy aging; aging in place; social; isolation; companion; companionship; Asian; Asian population; population; population studies; aging

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Introduction

Older Chinese immigrants are more prone to experiencing loneliness and social isolation than native older people due to language, transportation, and cultural barriers, which subsequently impact their physical and mental health [1]. In 2017, 11 million people emigrated from China to their destination countries [2]. New Zealand is one of the most popular host countries for Chinese immigrants, and as a result, it faces the growing needs of an increasingly diverse aging population. According to the New Zealand Census results in 2018, there were 247,770 Chinese immigrants 45 years or older, with 23,625 (9.5%) of them 65 years or older [3]. Compared to the statistics from the 2013 census, there was an increase of 76,359 (44.5%) Chinese immigrants [4]. Older Chinese immigrants are the largest older Asian ethnic population in New Zealand [3].

Aging in a foreign land can be complex, posing increasing challenges for gerontology scholars, practitioners, and policy makers. Self-supported aging in place has been reported as a benefit for enhancing older people's health and quality of life, as it supports the continuity of the environment and promotes independent living within the community [5]. However, a large and rapidly growing social and health workforce shortage in New Zealand has been unable to meet the increasing needs of older Chinese immigrants to access social and care services in the community [6]. With innovations and advancements in computer systems, robotic technology and information and communication technologies have been applied to support older people with their daily living needs.

In a New Zealand study, a daily care robot was used at home to assist older community-dwelling adults who had different aging-related health needs. The robot's purpose was to remind them of daily activities, and it showed promising potential in old age care, especially in providing reminders for taking medication [5]. Most existing studies on using robots to support older people have focused on dementia care and cognitive training, and have been undertaken in dementia care units. For example, a recent study in Italy reported that a humanoid robot called NAO effectively supported memory training among 24 patients with mild cognitive impairment, enhancing their therapeutic compliance and reducing symptoms of depression [7]. The study reported significant changes in prose memory and verbal fluency measures [7]. Additionally, the social robot Paro (an animal seal robot) was tested in Taiwan with 20 older adults in a long-term care facility for 8 weeks using a single-group pre-post quasi-experimental design and showed a statistical decrease in depression and loneliness and an increase in quality of life among the participants [8]. Our pilot study in Hong Kong has reported good feasibility and acceptance of using a humanoid social robot called KaKa among older Chinese adults and their family caregivers in their homes [9]. However, studies of using robots among older immigrants living in the community are sparse. Their preferences for the appearance and function of aged care robots are unclear, which impact the acceptance and usability of robots, and therefore, a user-centered design is required. It is imperative to understand users' needs and preferences before designing and developing a robot to meet their specific care needs [10].

Aged care robots, including health care assistive robots and socially assistive robots, should be tailored for older people to be easy to use, flexible, and able to support natural older people–robot interaction [10]. In particular, the design should consider those people with less experience in using technological devices [10]. Gaseiger and colleagues [5] reported that older people living alone at home accepted a robot as a companion, and the functions of an aged care robot should be more personalized to meet older people's health and social needs. A cross-sectional survey among middle-aged and older Taiwanese living in the community revealed that female participants preferred an animallike robot, while male participants favored a humanlike robot [11]. The most popular functions of a robot recommended by those participants included dancing, singing, storytelling, and news reading [11]. Moreover, the New Zealand study indicated that older Chinese immigrants were more likely to accept the companionship of robots when they were feeling lonely, yet more evidence is needed regarding their preferences for robot features [12]. Therefore, this study aimed to explore older Chinese immigrants' needs and preferences toward the appearance and function of aged care robots. Additionally, it sought to examine the relationships between these needs and preferences and the demographic characteristics of participants.

Methods

Participants

Adults 60 years or older, as defined by the World Health Organization [13], who self-identified their ethnicity as Chinese; held a permanent resident visa in New Zealand or were New Zealand citizens; were able to read, write, and understand traditional or simplified Chinese; were able to access the internet; and had completed the web-based survey were eligible to participate. There were no specific exclusion criteria. We screened each participant's eligibility through their individual demographic information.

Instrument

We used a web-based survey design tool, SurveyCake, to create a structured anonymous survey written in the traditional Chinese language. A simplified Chinese version was also made available as an alternative option. At the beginning of the survey, there was a 5-minute video using images from various online sources that was made for research purposes only. The video introduced different types of aged care robots, including health care assistive robots and socially assistive robots, each with a variety of appearances and features. The content of the video was presented in Mandarin with traditional Chinese subtitles, providing participants with a general idea about the types of robots and their capabilities. Following the video, participants were asked to complete the survey, which included four sections: (1) demographic information, (2) five personality traits, (3) eHealth literacy, and (4) preference for robot appearance and functions. Screenshots of the video are shown in 1-3.

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Figure 1. Screenshot of a video depicting an older adult chatting with a robot.



Figure 2. Screenshot of a video depicting a robot's companionship role for an older lonely adult.



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Figure 3. Screenshot of a video depicting a humanlike infant robot.



Participants were asked 18 questions regarding demographic information, including age, gender, education level, etc. The 15-item International Personality Item Pool, Five Personality Scale (extroversion, friendliness, rigorousness, emotional stability, and intelligence/imagination) was used [14]. The eHealth literacy of participants (ie, the internet use and search skills, ability to find reliable web-based content, and confidence in their abilities to search the internet) was assessed by the eHealth Literacy Scale [15]. Participants' preferred or favorite appearance (ie, animallike, humanlike infant, humanlike adult, or another form) and functions of the robots (eg, assisting with housework, health monitoring, and instant language translation) were collected. The survey was developed based on our previous study in Taiwan on middle-aged and older Chinese adults [11].

Ethical Considerations

The study protocol was approved by the institutional review board of the affiliated university (No. A-ER-105-509). Before participating in the web-based survey, each participant had to provide informed consent. They were introduced to the aims and content of the study, potential risks and benefits, and the right to withdraw from the study at any time. Each participant was asked to click a box to confirm their willingness to proceed. All respondents in this study have ticked this box, and their responses were anonymous.

Procedure

The study was undertaken between March and May 2020 using a cross-sectional design. The recruitment was supported by a local social service organization for older people in Auckland and several Chinese community groups from different regions of Auckland. Following the ethics approval, an electronic version of the flyer (in both traditional and simplified Chinese), advertising the study and linking to the web-based survey, was circulated by social workers and community group leaders via word of mouth, WeChat groups, and WhatsApp groups. No incentives were offered for participation in this web-based survey study. The completeness check was done by two team members after the questionnaire had been submitted.

Data Analysis

Descriptive analyses and inferential statistics were performed on R (version 4.1.1; R Foundation for Statistical Computing). Descriptive statistics were used for analyzing the demographic information, five personalities, eHealth literacy, and preference for robot appearance and functions. For each item, we calculated descriptive statistics as appropriate (eg, mean and SD or frequency and percentage). ANOVA and χ^2 test were adopted to analyze the correlations between demographic factors and preferences for robot functions.

Results

Demographic Information

A total of 103 older Chinese immigrants completed the survey, resulting in a response rate of 89.6% (103/115). Among the participants, the minimum age was 60 years, and the maximum age was 87 years, with an average age of 68.7 (SD 5.5) years. Of the participants, 74 were female and 29 were male. Most of the 103 participants attained a bachelor's degree or above (n=72, 70%), and had a good self-reported financial status (mean 22.7, SD 4.7). Most of the participants were married or had a partner (n=88, 85.4%) and lived with family or others (n=90, 87.4%). Most of them immigrated to New Zealand to reunite with family (n=83, 80.6%), and about half of them had lived in this country for more than 10 years. Participants reported higher scores in

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rigorousness and friendliness than other personalities. Details on the data distribution are shown in Table 1.

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Table . Demographic information of participants (N=103).

Demographic variables		Values
Age (years), mean (SD)		68.7 (5.5)
Gender, n (%)		
	Female	74 (71.8)
	Male	29 (28.2)
Level of education, n (%)		
	Under bachelor's degree	31 (30.1)
	Bachelor's degree or above	72 (69.9)
Marital status, n (%)		
	Married or have a partner	88 (85.4)
	Unmarried, widowed, or no partner	15 (14.6)
Live alone, n (%)		
	Yes	13 (12.6)
	No	90 (87.4)
Type of occupation, n (%)		
	Nontechnical	15 (14.6)
	Semitechnical/technical	29 (28.2)
	Professional/management	52 (50.5)
	Others	7 (6.8)
Whether or not retired, n (%)		
	Retired	95 (92.2)
	Employed	8 (7.8)
Reasons for immigration[a], n (%)		
	Job opportunity	7 (6.8)
	Family reunion	83 (80.6)
	Retirement	18 (17.5)
Duration of immigration (years), n (%)		
	<10	51 (49.5)
	≥10	52 (50.5)
Original living place, n (%)		
	Mainland of China	74 (71.8)
	Taiwan	16 (15.5)
	Hong Kong and Macau	9 (8.7)
	Other Asian countries or regions	4 (3.9)
Self-rated financial status (range 1-5), mean (SD)		3.6 (0.9)
Five personality scale (range 0-15), mean (SD)		
	Extroversion	10.3 (2.1)
	Friendliness	11 (2.1)
	Rigorousness	11.1 (2.1)
	Emotional stability	10.5 (2.4)
	Intelligence/imagination	9.7 (1.8)
eHealth literacy (range 8-40), mean (SD)		22.7 (4.7)

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[a]Participants could provide multiple answers to this question.

Participants' Preferences for Appearance of Aged Care Robots

Table 2 shows that most of the 103 participants, both female and male, preferred a humanlike adult appearance (n=43, 41.7%), and their second preference was an animallike appearance (n=33, 32%). The remaining participants reported their preferences for a humanlike infant appearance (n=20, 19.4%) and other forms (n=6, 5.8%). Participants who preferred humanlike adult or infant and animallike appearances reported higher scores in rigorousness and friendliness than other personalities. Participants who desired other appearances, rather than animal and humanlike appearances, were more likely to report high scores in extroversion, friendliness, rigorousness, and emotional stability as well as in eHealth literacy. Participants who were married or had a partner were more likely to choose humanlike adult and animallike appearances.

Table . Participants' preference for the appearance of a robot (N=103).

		Preference for robot's appearance[a]			
		Animallike	Humanlike infant	Humanlike adult	Other forms
Participants, n (%)		33 (32.0)	20 (19.4)	43 (41.7)	6 (5.8)
Gender, n (%)					
	Female (n=74)	25 (33.8)	17 (23.0)	28 (37.8)	4 (5.4)
	Male (n=29)	8 (27.6)	3 (10.3)	15 (51.7)	2 (6.9)
Personality (range 0-15), mean (SD)					
	Extroversion	10.5 (2.2)	10.8 (2.0)	9.9 (2.2)	12.3 (2.0)
	Friendliness	11.2 (2.4)	11.3 (1.7)	11.0 (2.0)	12.3 (2.0)
	Rigorousness	11.4 (2.1)	11.1 (1.9)	11.2 (2.1)	12.5 (1.9)
	Emotional stability	10.7 (2.6)	10.9 (2.5)	10.4 (2.2)	12.3 (2.4)
	Intelligence/imagination	10.1 (2.0)	9.6 (1.5)	9.9 (1.7)	9.8 (1.5)
eHealth literacy (range 8-40), mean (SD)		23.6 (3.1)	21.7 (4.1)	23.6 (4.3)	25.3 (3.3)
Marital status, n (%)					
	Married or have a partner (n=88)	32 (36.4)	17 (19.3)	40 (45.5)	6 (6.8)
	Unmarried, widowed, or no partner (n=15)	1 (6.7)	3 (20.0)	3 (20.0)	0 (0.0)

[a]Participants could provide multiple answers to this question.

Participants' Most Preferred Functions of Aged Care Robots

Participants' most preferred functions of aged care robots were housework assistance, language translation, health monitoring, facial expressions, news reading, and security monitoring. By analyzing the correlations between the demographic factors and the preferred functions of a robot, participants who were married or had a partner were more likely to choose functions of facial expressions (71/88, 81%; *P*=.002), news reading (61/88, 69%; *P*=.02), and security monitoring (60/88, 68%; *P*=.02) than their counterparts. High financial status showed a significant correlation with the function of facial expressions (mean 3.7, SD 0.7; *P*=.001). Participants who had immigrated for fewer than 10 years were more likely to use the function of facial expressions (43/51, 84%; *P*=.05) than people who had immigrated for 10 years or more. Detailed information is shown in Table 3.

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Table . Participants' most preferred six functions of robots (N=103).[a]

		Preference for robot functions[b]					
		Housework assistance	Language translation	Health monitor	Facial expressions	News reading	Security monitor
Participants, n (%)		86 (83.5)	79 (76.7)	78 (75.7)	77 (74.8)	66 (64.1)	65 (63.1)
Marital status, n (%)							
	Married or have partner (n=88)	72 (81.8)	70 (79.5)	69 (78.4)	71 (80.7)	61 (69.3)	60 (68.2)
	Unmarried, widowed, or no partner (n=15)	14 (93.3)	9 (60.0)	9 (60.0)	6 (40.0)	5 (33.3)	5 (33.3)
	P value	.46	.19	.23	*.002*	*.02*	*.02*
Financial status							
	Mean (SD)	3.6 (0.9)	3.6 (0.8)	3.6 (0.8)	3.7 (0.7)	3.6 (0.8)	3.6 (0.8)
	P value	.86	.49	.41	*.001*	.50	.42
Duration of immigration (years), n (%)							
	<10 (n=51)	41 (80.4)	41 (80.4)	41 (80.4)	43 (84.3)	34 (66.7)	32 (62.7)
	≥10 (n=52)	45 (86.5)	38 (73.1)	37 (71.2)	34 (65.4)	32 (61.5)	33 (63.5)
	P value	.57	.52	.39	.05	.74	>.99

[a]Statistically significant results ($P<.05$) are in italics.

[b]Participants could provide multiple answers to this question.

Discussion

Principal Findings

With the advancement of robotic technology, care robots are being used to assist older adults with their daily living needs. However, there is a lack of research on the use of robots with older immigrants residing in the community and their preferences regarding the appearance and functionality of aged care robots. Therefore, this study aimed to investigate the needs and preferences of older Chinese immigrants toward the appearance and function of aged care robots, and examine the relationship between these preferences and the demographic characteristics of the participants. The findings revealed that older Chinese immigrants favored a humanlike adult appearance for the robots. Additionally, participants with different marital status, financial status, and duration of immigration had varying needs for the robot's functionalities.

Robot Appearance

In this study, the most popular appearance of a robot rated by older Chinese immigrants were those with a humanlike adult appearance, where no difference was identified between female and male participants. Our findings are consistent with Chiu et al's [11] study that the favorite appearance of robots among middle-aged and older Taiwanese people was a humanlike adult appearance, but the correlation to marital status was less significant. Prakash and Rogers [16] reported distinctive differences in preferences for a robot appearance between young and older adults, whereas older adults had a higher preference for humanlike robots. The authors suggested that the differences might be attributed to their experiences with robots [16], and older adults felt comfortable talking with robots with human traits such as eyes and a mouth [17]. Moreover, a rural study in China reported that older adults perceived small-sized robots as more friendly, and steel machinelike robots were less preferred [18].

According to the research on human-robot interaction, the appearance and morphology of a robot are known to be important in increasing the acceptance and use of and interaction with a robot among older adults [19]. However, there is less evidence showing that robots were developed based on the characteristics of older adults. This study uniquely found that older Chinese immigrants who preferred humanlike adult or infant appearances reported higher scores in rigorousness and friendliness. This knowledge may help inform future robot designs for older adults from a morphological perspective [19].

User Needs and Preferences

Results of the study showed that participants with different marital status, financial status, and duration of immigration had different needs for robot functions. Designing robot services to support older people must be based on individually collected information [20]. In this study, older Chinese immigrants mostly desired family service functions (ie, housework assistance), language translation, health monitoring, facial expressions, news reading, and security monitoring. The findings were different from the reported results among middle-aged and older Taiwanese, where the most preferred functions were the skill and recreation functions, followed by family services (ie, housework) and then health status monitoring [11]. The difference might be explained by the immigrant context of individual circumstances and the purpose of immigration. In

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this study, over 80% of the participants immigrated to reunite with their adult children, which is aligned with Zhao et al's [21] study that found that most Chinese late-life immigrants relocated to New Zealand to share house chores with their adult children or look after their grandchildren. The burden of housework adversely impacted their health and became a risk factor for their experiences of loneliness and social isolation [1,12,21]. The same issue was also observed among other Asian immigrant groups due to the value of filial piety [22]. Assistive functions of robots were required by participants to relieve their workload and address the language barrier in a host country.

The evidence of this study found that the safety- and health-monitoring functions of the robot were regarded as essential for participants to meet their health and well-being needs, and our data supports Chiu et al's [11] findings that different ages were significantly related to the preference for the safety-monitoring function of the robot. Most of our participants lived independently and expected to maintain their independence, which is consistent with Park et al's [20] study that early detection of emergencies by using robot technology to assist with community-dwelling older adults' daily living is necessary. Moreover, living with others was significantly correlated to participants' preference for the health-monitoring robot function, which might be justified by several studies in New Zealand on Asian immigrant groups that have barriers to access health services due to their language, culture, and transportation barriers, and they intended to stay healthy and avoid becoming a burden to their family [1,21,23].

Moreover, participants who were married or had a partner, had good financial status, and had immigrated fewer than 10 years ago were more likely to choose the function of facial expressions. The finding is consistent with the previous study that older adults with lower technology acceptance preferred friendly and familiar robot designs with humanlike facial features [19]. However, the needs of those who were single with lower education levels might be underreported in this study, as the majority of our participants had higher education levels and were married or had a partner.

Limitations and Future Work

This study recognizes several limitations. First, due to the web-based survey, we might have excluded potential participants without access to the internet, computer, cellphone, etc, or who were not able to answer the survey on the web. Second, it is possible that the responses of participants were biased due to the self-reported data. Third, the data collection was undertaken in Auckland. The generalizability of the study results for the whole of New Zealand and other destination countries is limited. In the future, larger representative samples are needed to further investigate the needs and preferences of using robots in the later phase of life and to generalize the relationships between demographic factors, characteristics of older adults, and preferences for robots among immigrant populations. Mixed methods and co-design research methods are recommended to gain in-depth insights into end users' needs and preferences for robots to support their functions and independence in old age.

Conclusion

To support immigrant populations to age well in a foreign country and to fill the gaps of increasing shortages in the health and social workforce, it is important to develop reliable robotic technology services that are tailored based on the needs and preferences of individuals. We collected and compared the opinions on using robots to support aging in place among immigrant and nonimmigrant groups. The results of users' needs and preferences would inform robotic technology services to prioritize older Chinese immigrants' preference toward housework assistance, language translation, health and safety monitoring, and robots with humanlike features.

Data Availability

The data sets generated or analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

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Original Paper

Factors Influencing Continued Wearable Device Use in Older Adult Populations: Quantitative Study

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Abstract

Background: The increased use of wearable sensor technology has highlighted the potential for remote telehealth services such as rehabilitation. Telehealth services incorporating wearable sensors are most likely to appeal to the older adult population in remote and rural areas, who may struggle with long commutes to clinics. However, the usability of such systems often discourages patients from adopting these services.

Objective: This study aimed to understand the usability factors that most influence whether an older adult will decide to continue using a wearable device.

Methods: Older adults across 4 different regions (Northern Ireland, Ireland, Sweden, and Finland) wore an activity tracker for 7 days under a free-living environment protocol. In total, 4 surveys were administered, and biometrics were measured by the researchers before the trial began. At the end of the trial period, the researchers administered 2 further surveys to gain insights into the perceived usability of the wearable device. These were the standardized System Usability Scale (SUS) and a custom usability questionnaire designed by the research team. Statistical analyses were performed to identify the key factors that affect participants' intention to continue using the wearable device in the future. Machine learning classifiers were used to provide an early prediction of the intention to continue using the wearable device.

Results: The study was conducted with older adult volunteers (N=65; mean age 70.52, SD 5.65 years) wearing a Xiaomi Mi Band 3 activity tracker for 7 days in a free-living environment. The results from the SUS survey showed no notable difference in perceived system usability regardless of region, sex, or age, eliminating the notion that usability perception differs based on geographical location, sex, or deviation in participants' age. There was also no statistically significant difference in SUS score between participants who had previously owned a wearable device and those who wore 1 or 2 devices during the trial. The bespoke usability questionnaire determined that the 2 most important factors that influenced an intention to continue device use in an older adult cohort were device comfort (τ=0.34) and whether the device was fit for purpose (τ=0.34). A computational model providing an early identifier of intention to continue device use was developed using these 2 features. Random forest classifiers were shown to provide the highest predictive performance (80% accuracy). After including the top 8 ranked questions from the bespoke questionnaire as features of our model, the accuracy increased to 88%.

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Conclusions: This study concludes that comfort and accuracy are the 2 main influencing factors in sustaining wearable device use. This study suggests that the reported factors influencing usability are transferable to other wearable sensor systems. Future work will aim to test this hypothesis using the same methodology on a cohort using other wearable technologies.

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KEYWORDS

usability; older adults; remote sensing; sensor systems; wearable device; mobile phone

Introduction

Background

Advancements in health care have resulted in increases in life expectancy. As a consequence, a growing proportion of the population are older adults [1]. This aging population, accompanied by an increasing number of older adults becoming physically inactive [2], is placing an additional burden on health care systems and directing research toward early detection or prevention of future medical issues. Remote rehabilitation and monitoring provide an opportunity to reduce demands on health care systems and the inevitable costs associated with providing care for an aging population [3]. Remote rehabilitation can allow for access to health-based resources such as nurses, health practitioners, and specialists through technology while avoiding associated costs such as travel [4]—from both a monetary and environmental perspective. Some technology solutions have been adapted for remote rehabilitation over the last decade. Synchronous videoconferencing, for example, is one of the most commonly used technologies to deliver rehabilitation therapy to clients who are in a different location from their therapist [5]. Wearable sensor systems have recently been used to provide insights into physical activity, physical function, and general health, and as a result, therapists and clinicians can provide more detailed insights into a patient's health and progress on a remote basis. At present, most research on wearable sensor technology is developed with accuracy at the center of the study design. This often comes at the expense of usability [6] even though research studies have indicated that perceived ease of use is just as important as perceived usefulness when it comes to technology acceptance [7]. Indeed, Mancini and Horak [8] note that, to achieve successful adoption of remote rehabilitation technologies, the solution must be both practical and usable, which is of particular importance when considering wearable sensor systems.

The Smart Sensor Devices for Rehabilitation and Connected Health project focuses on monitoring the physical capacity of older adults. The project evaluated wireless sensor systems and their capabilities for remote rehabilitation with a particular focus on end-user acceptance. The ultimate goals of technology-assisted personal health management are both continued long-term use of the device and improved well-being [9]. This study specifically focused on understanding the factors influencing continued long-term use.

Understanding the factors that influence continued device use is important as this will inform future wearable device design, ensuring that adoption and the impact of that adoption has the highest possible chance of success. This will, in turn, allow for the successful rollout of telehealth services in the future, such as remote rehabilitation, and overall increase the likelihood of improved well-being.

Related Work

Previous work has already shown that, for monitoring technology to be accepted by older adults, it must be easy to use and not impair mobility and independence [10]. Research has also shown that human factors such as portability and resilience are the main factors that influence continued device use [11].

Older adults are interested in smart wearable devices that offer functionality for daily living and are more likely to consider using one if compatible [12]; thus, device selection is important [13]. The user's attributes and device features are the main characteristics to observe when evaluating wearable devices [14]. Environmental and individual features need to be considered when deciding on a sensor technology device; in particular, a device that is user focused would be valuable [15]. A wearable device offering user-friendly features for everyday tasks is more appealing to individuals as they trust the information provided. If an individual trusts the device, there is an increased chance of continued use [14]. A positive finding from previous research related to older adults using activity monitoring technology showed that older adults did not struggle to use new technology [16].

The literature shows that usability challenges must be addressed to increase the likelihood of continued device use. Therefore, technology must be designed and implemented such that it is practical, unobtrusive, and well-received by older adults and, ultimately, promotes health benefits.

Balance is one of the critical characteristics used to assess the functional capacity of older adults in the literature. However, despite the growing number of articles supporting the use of balance assessment technology, there are still substantial gaps in the full understanding of the technology. In particular, existing literature in the area does not consider factors that may affect the continued long-term use of wearable technology in real-world conditions. A previous study examined the real-world use of multiple wearable sensors, noting that participants found wrist-worn sensors to be the most favorable as they were adaptable and user-friendly [15]. Core areas to focus on are preferred features of the wearable device and possible issues arising from older adults operating the device [17]. Longitudinal studies have also been suggested as an approach when assessing the usability of wearable sensors to ascertain whether ratings change with extended device use and user experience [14].

There are limited quantitative studies on long-term device usability to observe the associated influencing factors [18]. User

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feedback is key to understanding participants' experience in a study and is necessary for determining whether older adults will continue to use wearable technology [19]. A previous study focused on individual preferences and asked participants to share their experiences using a fitness device; the main issues were remembering to wear the device, lack of comfort when wearing it, limited sharing support to determine a baseline with others, and inaccurate data recorded during activities [20].

We conducted a study aimed to better understand the usability factors that most influence whether an older adult will decide to continue to use a wearable device. We hypothesized that initial perceptions related to human factors of a wearable sensor system can be used as a predictor of continued device use in the future. To test this hypothesis, a study was designed to analyze data related to older adults' perceptions of wearable activity trackers after 7 days of use. Data were collected related to participant perceptions of wearable device human factors as well as measurements of participant functional status, health status, and wearable device activity tracker measurements from a cohort of 65 older adults aged ≥65 years. One of the objectives of the research was to assess what specific factors may affect participants' intention to continue using the wearable device beyond the 7-day study period. There are three key methodologies that could be used for usability assessment: (1) inspection involving expert observation (eg, heuristic evaluation), (2) inquiry involving qualitative data collection (eg, surveys), and (3) testing involving quantitative data collection in a real environment (eg, remote usability testing) [13]. The methodology used in this study applies both inquiry and testing methods based on a bespoke usability questionnaire completed by participants after the 7-day study period during which they used a Xiaomi Mi Band 3.

Methods

Overview

This section will cover the protocol used during the data collection process and describe each of the questions asked and how they relate to measuring usability. Detailed information will also be provided for the participant cohort and the hardware used to capture their activity data. This section establishes the methods used to process and analyze the data and, finally, predict continued device use.

Protocol

This was a retrospective case series–based study. A series of older adults aged ≥65 years were given a wearable device and observed over a 1-week period. The usability data of the wearable device were then characterized among the participant series.

The study was based on a free-living data collection protocol conducted over a 7-day period. A free-living data collection protocol is a common method of collecting data from participants, particularly in sensor-based studies. The *free-living* aspect indicates that data are collected from a participant's normal everyday living environment, typically over a period of ≥24 hours. This approach aims to eliminate any social, behavioral, and environmental biases that would otherwise be present in other testing or simulated environments.

Participants for this study were recruited from 4 different countries within the Northern Periphery and Arctic regions of Europe. These were namely Northern Ireland, Ireland, Finland, and Sweden. Inclusion criteria required participants to be aged ≥65 years, have the physical capacity to walk 20 m without the assistance of another person, and be cognitively able to answer questionnaires.

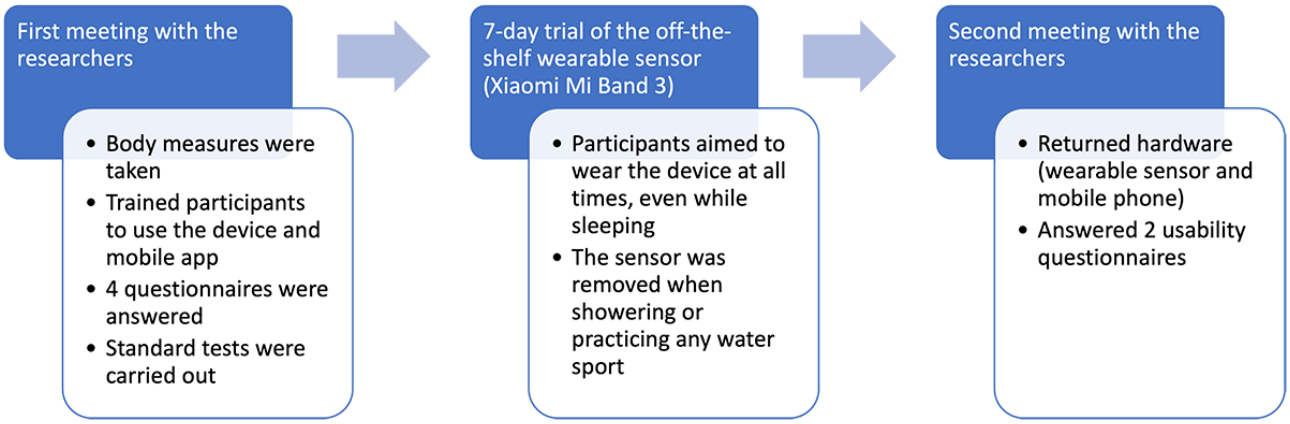
Participants met the researchers performing the trial in person twice—once at the start of the trial and again 7 days later at the end of the trial. In the first meeting, the researchers took body measurements (height, weight, and grip strength for both hands), trained the participants in device use using a standardized training manual, and asked them to complete 4 health-related questionnaires. Participants were then asked to complete two physical function tests: (1) the Five-Time Sit-to-Stand test (STS5) and (2) two 10-m walk tests. For the STS5 test, the total time to complete 5 repetitions of going from a seated position to a standing position was recorded. For the 10-m walk test, the time to complete each of the two 10-m walks was recorded (WT10M1 and WT10M2) as well as the number of steps taken in each walk (WS10M1 and WS10M2).

A date for the second meeting was agreed upon, and participants were given the wearable device to wear and bring home with them. At the second meeting, the participants met with the researcher and returned the wearable device. The participants were then asked to complete 2 posttrial questionnaires focusing on usability and human factors. Figure 1 provides an overview of the study process. Ethics approval for the research study was granted at each of the 4 test sites (Ulster University, United Kingdom; Tyndall National Institute, University College Cork, Ireland; Umeå University, Sweden; and Karelia University of Applied Sciences, Finland).

The standard tests (eg, sit-to-stand and timed walk) and measures that were carried out as part of this study were used to assess the physical health of the participants. Although this study focused on usability and intention to continue using the device, data from the standard tests are part of a larger study, and further data analyses will be performed for potential future publication.

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Figure 1. Flowchart of the study protocol.



Questionnaires

The trial used 6 questionnaires to collect various data from the participants. A total of 4 questionnaires were administered before the trial began, and 2 were administered after trial completion. The four *Pretrial Questionnaires* were as follows: (1) the 36-item Short Form Health Survey (SF-36) [21], a set of generic, coherent, and easily administered quality-of-life measures; (2) the Mini-Mental State Examination (MMSE) [22], a set of questions used to assess a patient's cognitive impairment; (3) the Geriatric Depression Scale (GDS) [23], used to assess depressive symptomatology in older adults; and (4) the Mobile Device Proficiency Questionnaire (MDPQ) [24], used to accurately assess the mobile device proficiency of older adults. Each questionnaire was administered using an interview-based approach where the researcher asked the participants each question and indicated the possible answers they could give. The participants provided a verbal answer to each question, and the researcher recorded the results on paper and, subsequently, electronically. The questionnaires at the first meeting were administered in the following order: (1) SF-36, (2) MMSE, (3) GDS, and (4) MDPQ.

The SF-36 questionnaire was used to understand the participants' general health status. The MMSE and GDS questionnaires were used to understand the mental health status of the participants. A score of <25 on the MMSE indicates some degree of dementia, whereas a score of >4 on the GDS indicates some degree of depression. The data were used to characterize the overall health of the participant group and understand the relative health of the participants compared with the general population. The MDPQ was used to estimate their level of familiarity and experience using technology and whether this was linked to continued device use afterward. Questionnaire scores and statistics are discussed in the *Results* section.

The two *Posttrial Questionnaires* were as follows: (1) the System Usability Scale (SUS) [25], used as a standardized method to evaluate the usability of wearable devices and facilitate benchmarking with other studies, and (2) the usability questionnaire, a bespoke questionnaire designed by the research team to specifically understand older adults' opinions on wearable sensor technology (Multimedia Appendix 1). This usability questionnaire gathered user opinions on perceived usefulness, comfort, and ease of use as previous research studies have indicated that these are the crucial factors that influence the usability of a wearable device and can ultimately affect the likelihood of continued long-term use [26-28]. Each of these questionnaires was administered using an interview-based approach following the same methodology as the pretrial meeting. The participants were first administered the SUS questionnaire, followed by the bespoke usability questionnaire.

The SUS is a standardized and validated short 10-question survey to help validate the usability of a piece of hardware, software, or wearable device. However, to better understand the participants' specific opinions of the wearable device usability, a bespoke usability questionnaire was designed, entitled "Accuracy, feasibility and acceptability of wireless monitoring in older people." The questionnaire first collected dichotomous data on the participants' familiarity with wearable devices and whether they liked the appearance. Then, a series of questions related to usability, accuracy, and acceptability were asked using an ordinal 5-category scale ranging from *strongly agree* to *strongly disagree*. The questionnaire ended with 4 general questions that gathered data on length of time worn and use at night. The final and most important question regarding this study asked the participants if they would continue to use the device after the trial had finished. Responses to this final question were analyzed to gain further insights into what factors influence the intention to continue using the device.

The bespoke usability questionnaire was designed as part of the European Union Interreg Northern Periphery and Arctic Smart Sensor Devices for Rehabilitation and Connected Health project. Experts on this project—who were from clinical, physiotherapy, and technological backgrounds in Sweden, Finland, Ireland, and Northern Ireland—worked together in a workshop meeting that was held in May 2019 in Derry/Londonderry to propose, agree, and finalize a set of questions appropriate to assess the different human factors associated with the wearable sensor system. The bespoke questionnaire was applied for the first time in this study.

Hardware and Software

Each participant in the study was provided with a Xiaomi Mi Band 3 activity tracker, which was secured on the wrist of their nondominant hand. In addition, the participant was provided with a Huawei Y6 smartphone to facilitate interaction with the activity tracker software. Anonymous Google accounts were

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created to capture the activity data from each participant. Approximately half (37/65, 57%) of the participants were also requested to wear an Axivity AX3 wrist-worn accelerometer on their dominant hand. The initial plan was to have all participants wear 2 trackers as the raw data collection capabilities of the Axivity AX3 would have facilitated benchmarking between potentially new algorithms and the Xiaomi Mi Band 3. However, an initial feasibility study conducted in Finland on a small number of participants used the bespoke usability questionnaire to conclude that, generally, participants reported usability issues because of wearing 2 trackers. To help keep this from becoming an issue, it was decided to only allow half of the participants to wear 2 trackers. The distribution of those wearing 2 trackers versus 1 was approximately 50% across all the sites (Sweden: 9/20, 45%; Finland: 13/23, 57%; Northern Ireland: 7/14, 50%; Ireland: 8/8, 100%) except for the 100% (8/8) of participants at the site in Ireland who wore 2 trackers. Unfortunately, because of the unexpected impact of COVID-19 in March 2020, the trial in Ireland was interrupted midway, which resulted in 40% (8/20) of the participants receiving 2 trackers and the remaining 60% (12/20) of the participants being unable to take part.

Cohort Description

In total, 65 participants from the 4 locations took part in the study. The mean age of the participants was 70.52 (SD 5.65) years. The mean height of the population was 169.43 (SD 9.05) cm, and the mean weight was 73.45 (SD 13.09) kg. The cohort comprised 57% (37/65) women and 43% (28/65) men. A total of 91% (59/65) of the participants were right-handed, and 9% (6/65) were left-handed. The participants were recruited using leaflets and posters. Recruitment sought older adult volunteers wanting to experience the use of wearable technology such as activity trackers in their daily lives. They should be physically able to walk 20 m unaided and cognitively able to answer questionnaires. The participants were to have no underlying health conditions other than frailty. Targeted recruitment focused on recruiting participants in community centers focusing on older adults (Eglinton Community Centre, Old Library Trust Healthy Living Centre, and U3AFoyle, all in Northern Ireland) and clinics (in Ireland, Sweden, and Finland).

Data Processing, Analysis, and Classification

Overview

An analysis was performed on the collected data to understand the usability factors that most influence whether an older adult will decide to continue using a wearable device. The analysis was divided into four main areas: (1) cohort characteristic analysis, (2) SUS analysis, (3) bespoke usability questionnaire analysis, and (4) predictive modeling. The following sections describe the methods used for each of these areas.

Cohort Characteristic Analysis

Statistical analysis of participants' demographics, health status, and selected usability results was performed to provide information on the characteristics of the cohort being analyzed in further sections. The cohort of 65 people comprised volunteers from Northern Ireland (n=14, 22%), the Republic of Ireland (n=8, 12%), Finland (n=23, 35%), and Sweden (n=20, 31%). For each participant, a set of 69 features were recorded. The features comprised body metrics, functional test measures, wearable device data, and questionnaire results.

Analysis of the data was performed using SPSS (version 26; IBM Corp) and the Spyder Python integrated development environment (version 5.1.5). Statistical analyses were performed using the Kendall τb, Pearson, or Spearman correlations where appropriate. The analysis also involved computing features such as the mean, variance, and SDs as well as exploring frequencies, histograms, distributions, and statistical tests.

SUS Analysis

Participants were asked to answer the SUS questionnaire to evaluate the Xiaomi Mi Band 3 activity tracker after an average device use of 7.12 (SD 1.53) days. Only the usability of the wearable device was to be considered by the participants.

SUS scores were analyzed to investigate whether geographical location, sex, number of wearables used, or age affected the usability rating. For our analysis, the participants who took part in the trial from Northern Ireland and the Republic of Ireland were grouped into 1 cohort comprising 22 participants because of the relatively small sample size (8/65, 12%) available for the Republic of Ireland and because of their geographical proximity, encompassing the island of Ireland. For the age analysis, we created 3 bins (<70 years, between 70 and 74 years, and >74 years) and categorized the participants accordingly.

The analysis of the SUS data aimed to understand whether geographic location, age, sex, or number of devices worn had an influence on the perceived usability of the device.

Bespoke Usability Questionnaire Analysis

Analysis of data from the bespoke questionnaire focused on understanding responses to question 21: "Would you continue to use the device and app again after the trial is finished?" Various analyses were performed on this question to gain insights into what factors influence continued device use. Analysis of the statistical distributions of participants from the 2 groups (participants who indicated that they would continue using the device and participants who indicated that they would not continue using the device) was carried out. Independent 2-tailed *t* tests were carried out on SUS scores for the 2 groups. In addition, correlations between question 21 and all other questions from the bespoke questionnaire were carried out using the Kendall τb rank to identify specific factors that are linked to the intention to continue using the device.

Predictive Modeling

A predictive model is frequently used in statistics and machine learning techniques to model the current data and predict future outcomes. For this part of the analysis, we evaluated models that may predict the intention to continue using a device after the monitoring period. These predictions were based on the usability questionnaire, where the answer to question 21 was predicted based on the answers to the other questions.

An important criterion for wearable technologies is user acceptance. This increases the likelihood that individuals will continue to use the device long-term and beyond periods when

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they are being actively monitored. Factors potentially influencing a user's acceptance of a wearable device include comfort, simplicity, and device intrusiveness. For example, if a device requires frequent interaction, then it could become too much of a burden.

Ethics Approval

Approval for the research study was obtained from each of the participating institutions where required. The Ulster University Research Governance Ethics Committee granted approval under reference REC/19/0026; the University College Cork Clinical Research Ethics Committee of the Cork Teaching Hospitals granted approval under reference ECM 4(a) 16/10/19; and the Regional Research Ethical Review Board of Umeå University, Sweden, granted approval under reference 07-031M with extensions. At the Karelia University of Applied Sciences, Finland, no ethics approval from an institutional review board was required as the research adhered to the ethical principles of research with human participants as per the Finnish National Board on Research Integrity TENK guidelines [29]. The research was conducted in accordance with the principles of the Declaration of Helsinki and in accordance with local statutory requirements. All participants provided written informed consent to take part in this study. Consent was provided for publication by all participants under the condition that the data were anonymized.

Results

Pretrial Questionnaire Results

Summary statistics for each of the 4 health questionnaires (SF-36, MMSE, GDS, and MDPQ) are presented in Table 1, with the general health variable selected to represent the SF-36 questionnaire and the overall MDPQ variable selected to represent the MDPQ questionnaire.

Table 1. Pretrial questionnaire results.

	Values, mean (SD)	Variance
SF-36[a] general health	72.54 (18.96)	359.471
MMSE[b]	28.49 (1.55)	2.410
GDS[c]	1.43 (2.11)	4.468
MDPQ[d] overall	3.53 (1.26)	1.577

[a]SF-36: 36-item Short Form Health Survey.

[b]MMSE: Mini-Mental State Examination.

[c]GDS: Geriatric Depression Scale.

[d]MDPQ: Mobile Device Proficiency Questionnaire.

Results show that the cohort comprised participants who were, on average, in good health as defined by SF-36 results (mean 72.54 out of 100, SD 18.96). Results showed that only 9% (6/65) of the participants scored <50 on the SF-36 general health component, implying that a small number of participants in the study perceived that they were struggling with health issues. The average MMSE value among all participants was 28.49 (SD 1.55). As previously stated, a score of <25 on the MMSE indicates some degree of dementia, whereas a score of >4 in the GDS indicates some degree of depression. Only 2% (1/65) of the participants scored <25 on the MMSE, with a score of 24. The average GDS score among all participants was 1.43 (SD 2.11), with only 9% (6/65) of the participants reporting scores of >4 in the GDS. The average MDPQ value was 3.53 (SD 1.26), which is between 3 ("not very easily") and 4 ("somewhat easily"), indicating that our participants were between states when it comes to overall mobile phone device proficiency.

Table 2 shows the relevant background characteristics of all cohorts by region. The table includes summary statistics for age, sex, height, weight, SUS score, and bespoke usability questionnaire—questions 10 (The activity tracker was comfortable to wear at night), 17 (Using the activity tracker helped me be more active), and 21 (Would you continue to use the device and app again after the trial is finished?) and the 3 functional test scores (WT10M1, WT10M2, and STS5). The 3 usability questions are presented as device comfort and becoming more active were identified as the top 2 influencing factors for continuing to use the device. In total, 3 physical function measures were chosen: the two 10-m walking tests and the STS5 as these are deemed important measures when wearing an activity tracker.

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Table 2. Summary of background characteristics of the participants (N=65).

Background characteristic and cohort or subcategory	Participants, n (%)	Values, mean (SD)
Age (years)		
Whole group	65 (100)	70.5 (5.65)
Finland	23 (35)	71.1 (5.98)
Northern Ireland and Ireland	22 (34)	70.4 (7.69)
Sweden	20 (31)	70 (0)
Sex (female)		
Whole group	37 (57)	N/A[a]
Finland	13 (20)	N/A
Northern Ireland and Ireland	14 (22)	N/A
Sweden	10 (15)	N/A
Sex (male)		
Whole group	28 (43)	N/A
Finland	10 (15)	N/A
Northern Ireland and Ireland	8 (12)	N/A
Sweden	10 (15)	N/A
Height (cm)		
Whole group	65 (100)	166.9 (22.88)
Finland	23 (35)	168.9 (8.18)
Northern Ireland and Ireland	22 (34)	158.7 (36.42)
Sweden	20 (31)	173.5 (9.53)
Weight (kg)		
Whole group	65 (100)	72.3 (15.95)
Finland	23 (35)	69.7 (12.55)
Northern Ireland and Ireland	22 (34)	72.2 (20.51)
Sweden	20 (31)	75.5 (13.81)
SUS[b] score		
Total	65 (100)	67.2 (18.27)
Not acceptable (0≤SUS<50)	12 (18)	40 (6.99)
Marginal (50≤SUS<70)	20 (31)	59.5 (6.57)
Acceptable (70≤SUS≤100)	33 (51)	81.7 (9.74)
Question 10		
Whole group	65 (100)	4.1 (0.92)
Finland	23 (35)	3.8 (0.98)
Northern Ireland and Ireland	22 (34)	4.4 (0.73)
Sweden	20 (31)	4.2 (0.99)
Question 17		
Whole group	65 (100)	3.4 (1.17)
Finland	23 (35)	3.4 (1.08)
Northern Ireland and Ireland	22 (34)	3.8 (1.01)
Sweden	20 (31)	3 (1.34)
Question 21 (no)		

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Background characteristic and cohort or subcategory	Participants, n (%)	Values, mean (SD)
Whole group	23 (35)	N/A
Finland	11 (17)	N/A
Northern Ireland and Ireland	4 (6)	N/A
Sweden	8 (12)	N/A
Question 21 (yes)		
Whole group	42 (65)	N/A
Finland	12 (18)	N/A
Northern Ireland and Ireland	18 (28)	N/A
Sweden	12 (18)	N/A
WT10M1[c] (seconds)		
Whole group	65 (100)	8.0 (1.70)
Finland	23 (35)	8.3 (1.07)
Northern Ireland and Ireland	22 (34)	8.3 (2.52)
Sweden	20 (31)	7.3 (0.81)
WT10M2[d] (seconds)		
Whole group	65 (100)	7.7 (1.40)
Finland	23 (35)	7.8 (1.01)
Northern Ireland and Ireland	22 (34)	8.3 (1.94)
Sweden	20 (31)	7.1 (0.73)
STS5[e] (seconds)		
Whole group	65 (100)	11.6 (6.55)
Finland	23 (35)	11.0 (1.92)
Northern Ireland and Ireland	22 (34)	12.8 (10.90)
Sweden	20 (31)	10.8 (2.41)

[a]N/A: not applicable.

[b]SUS: System Usability Scale.

[c]WT10M1: 10-m walk test time 1.

[d]WT10M2: 10-m walk test time 2.

[e]STS5: Five-Time Sit-to-Stand test.

SUS Results

Overview

The results of the SUS questionnaire showed that the average SUS score (N=65) was 67.15 (SD 18.27). Table 3 shows the mean SUS scores for the region, sex, age, and number of wearables used.

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Table 3. Summary of statistics of the participants (N=65).

Statistic description	Participants, n (%)	SUS[a] score, mean (SD)	*t* test (*df*)	*P* value
Region			0.091 (2)	.91
Finland	23 (35)	68.3 (11.95)		
Northern Ireland and Ireland	22 (34)	65.9 (19.34)		
Sweden	20 (31)	67.3 (23.28)		
Sex			0.447 (63)	.66
Male	28 (43)	65.98 (18.25)		
Female	37 (57)	68.04 (18.50)		
Wearables used			0.851 (63)	.40
Xiaomi Mi Band	28 (43)	69.4 (19.30)		
Xiaomi Mi Band+Axivity AX3	37 (57)	65.5 (17.50)		
Age (years)			0.411 (2)	.81
<70	23 (35)	71.3 (14.60)		
70-74	32 (49)	67.6 (19.30)		
>74	20 (31)	67.3 (23.30)		

[a]SUS: System Usability Scale.

Analyzing the SUS Score by Cohort Region

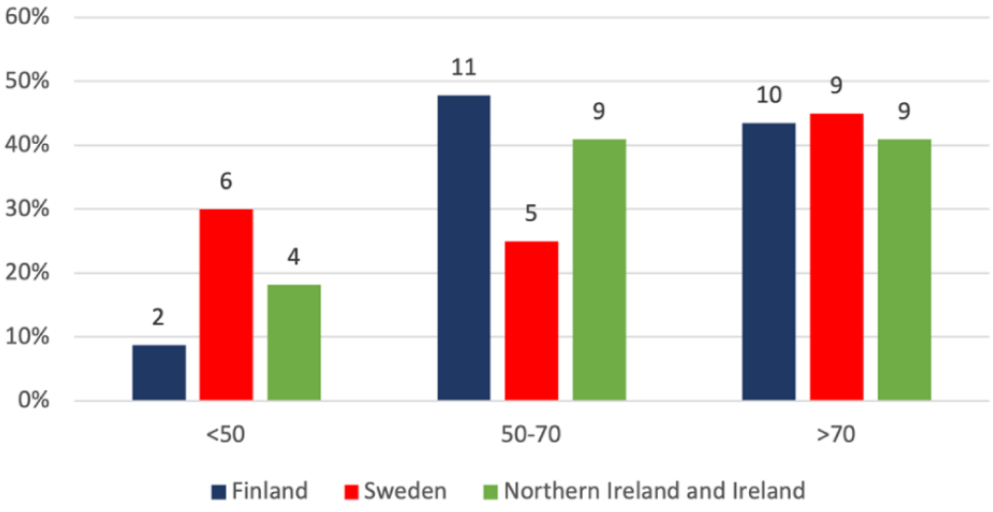
SUS scores can be represented using either grades or acceptability ranges. Acceptability ranges use 3 categories: not acceptable (0≤SUS<50), marginal (50≤SUS<70), and acceptable (70≤SUS≤100) [30]. Analysis of SUS scores by region showed that Finland had both the largest (11/23, 48%) percentage in the marginal category and the lowest (2/23, 9%) percentage in the unacceptable category, making it the best-performing region given that scores in the acceptable category were similar across regions. Northern Ireland and Ireland performed equally well in both the marginal and acceptable categories, with 41% (9/22) of people. Sweden had the largest (9/20, 45%) percentage in the acceptable category, but conversely, scored the worst in the unacceptable category (6/20, 30%). Across all regions, a total of 43% (28/65) of people thought that the device had an acceptable SUS score of >70.

As shown in Figure 2, the distributions were not identical; therefore, a 1-way ANOVA was applied to compare the mean ranks. The results presented in Table 3 show that the differences between the mean ranks of the SUS scores for each region were not statistically significant.

The group means were compared using a 1-way ANOVA. A Levene test was performed, resulting in a *P* value of .85; therefore, the variances can be assumed to be homogeneous, and equal variances are assumed. Observing the normal quantile-quantile plots for each region in Figure 3, the quantiles mainly lie on or close to the red line, suggesting a normal distribution.

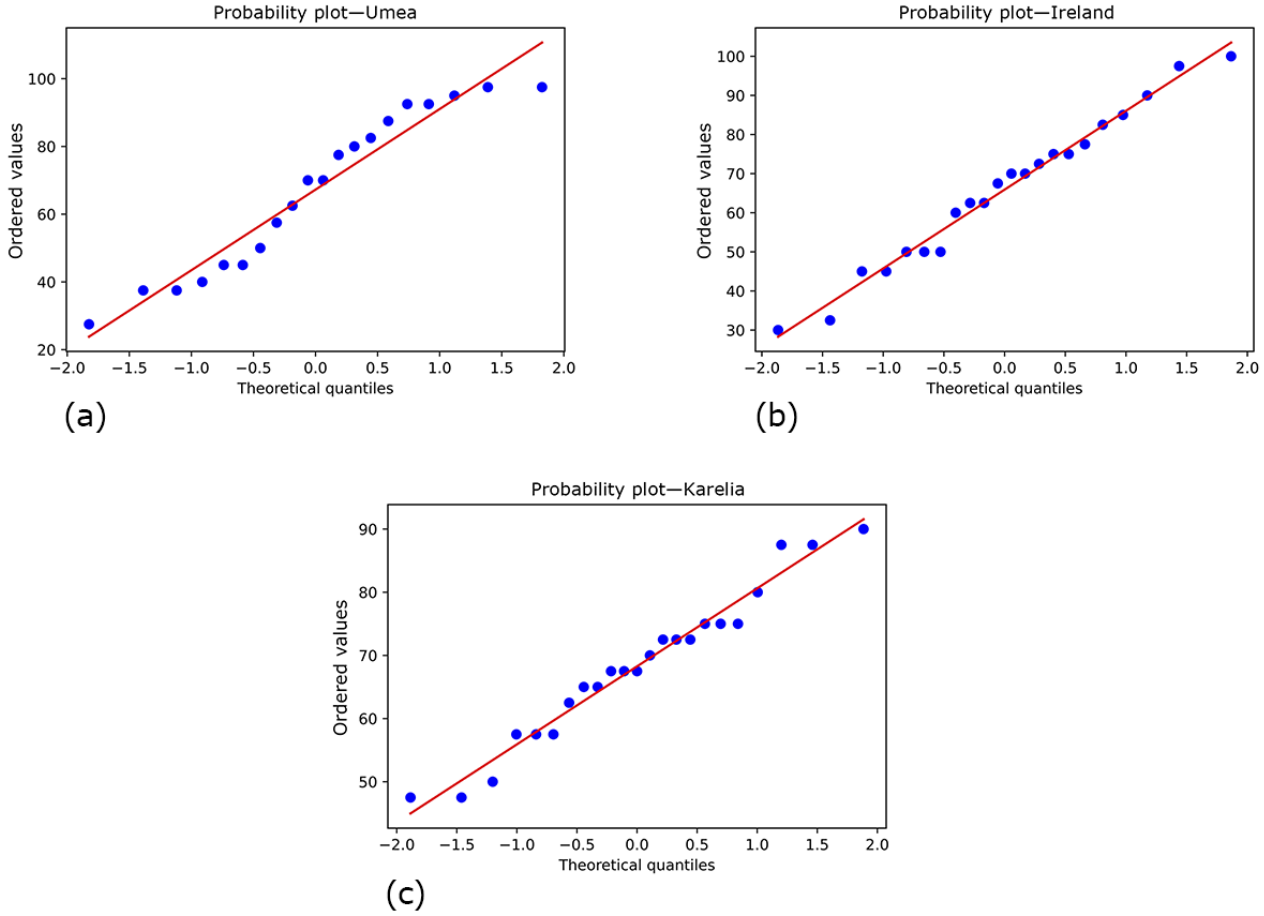
On the basis of the results in Table 3, the means of the SUS scores for each region were not statistically significant.

Figure 2. Histogram of System Usability Scale (SUS) categories from each region.



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Figure 3. Quartile-quartile plots of the System Usability Scale (SUS) scores from each region. Plot (a) shows the scores from Umea, (b) the scores from Ireland, and (c) the scores from Karelia.



Analyzing the SUS Score by Sex, Number of Wearables Used, and Age

An independent-sample *t* test was conducted to compare the SUS score between (1) the sexes and (2) the number of wearables used. The results suggest that there was no statistically significant difference in perceived system usability either given the participants' sex (*P*=.66) or whether the participants wore 1 or both activity trackers (*P*=.40).

To analyze the SUS score by age, a Kruskal-Wallis *H* test was conducted, allowing for a comparison between the 3 age categories. The Levene test *P* value was <.001; therefore, the variances can be assumed to be not homogeneous. The results from the statistical test suggest that the means of the SUS scores for each age category were not statistically significant (*P*=.81).

Each of the SUS analyses showed that, regardless of comparing region, sex, wearables used, or age, there was no difference in perceived system usability.

Bespoke Usability Questionnaire

Overview

The final question in the bespoke usability questionnaire asked the participants if they intended to continue using the device after the trial had finished. In total, 65% (42/65) of the participants said that they would like to continue using the wearable device and phone app, whereas 35% (23/65) of the participants said that they would not like to continue using the wearable device and phone app. Figure 4 shows the distribution of SUS scores for participants who intended to continue using the device compared with participants who indicated that they would not continue using the device.

To evaluate whether there was a significant difference in SUS scores between participants who indicated that they would continue using the device and participants who indicated that they would not, an independent *t* test was performed on the SUS questionnaire scores. The results are presented in Table 4. The participants who indicated that they would continue using the device averaged an SUS score of 71.8; thus, the "continue using" group on average considered the usability of the device to be within the "acceptable" category (range >70). In comparison, those who indicated that they would not be interested in continuing to use the device averaged an SUS score of 51.7 and, thus, the "not continue using" group on average ranked the usability of the device within the "marginally low acceptability" category (range >50 and <65). Results from an independent *t* test showed that the SUS scores of the 2 "continued use" groups were statistically significant.

In addition to comparing usability with the intention to continue using the device, we evaluated what effect previous activity tracker experience (usability question 2) had on usability. In total, 20% (13/65) of the participants said that they had previously used a wrist-worn activity tracker, whereas 80% (52/65) of the participants said that they had never used a

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wrist-worn activity tracker before the trial. Statistical significance was evaluated for the SUS score of participants who had previous experience versus those who did not have previous experience. The results from an independent *t* test (Table 5) showed that there was no significant difference between a user's SUS score and whether they had previous experience with a wrist-worn activity tracker (*P*=.28).

Further analysis was performed on the intention to continue using the device (question 21) to evaluate how continued use was linked to other human factor and usability elements. Therefore, correlations between question 21 and the other bespoke questions were analyzed. The description of the correlation values and associated rank are presented in Table 6, where the direction of the relationship is indicated by the sign of the coefficient. The results of the Kendall τb rank correlations are presented in Table 7. The results revealed 5 usability questions that had a strong correlation with the continued device use question. Questions 10 and 17 were the top-ranking features, each with a *P* value of .003, highlighting that both comfort at night and becoming more active are key early indicators of whether a user will continue using and wearing a device.

Further analysis was performed to evaluate the possible links between participants' physical function and continued use in the future. Two 10-m walk test measurements and a sit-to-stand test (WT10M1, WT10M2, and STS5) were compared with continued device use using the Kendall rank correlation coefficient. On the basis of question 17 (*Using the activity tracker helped me be more active*) being highly correlated with continued device use, the aim was to assess whether physical function, measured before the study period, influenced continued device use. The results of this analysis are presented in Table 8. The results showed that none of the 3 physical function measures—WT10M1, WT10M2, and STS5—correlated with continued device use. This indicates that physical function before using the device is not likely to influence whether the participant will continue using the device in the future.

Figure 4. Histogram of the System Usability Scale (SUS) scores of the 2 different continued use groups.

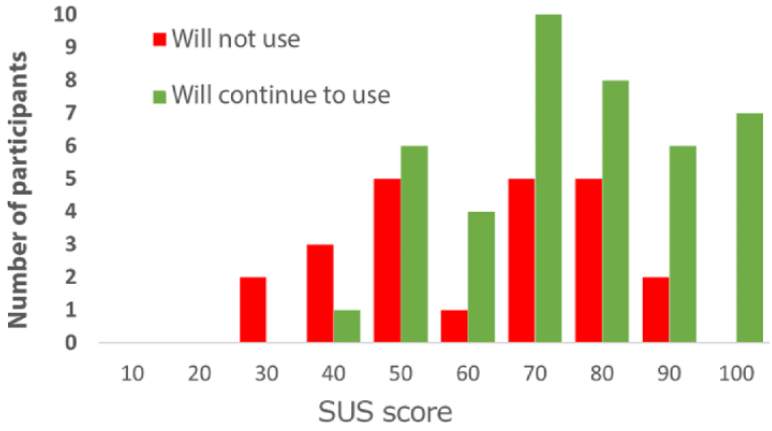


Table 4. Summary statistics of the System Usability Scale scores for question 21 (N=65).

Continue to use the wearable device?	Participants, n (%)	Values, mean (SD)	*t* test (*df*)	*P* value
Yes, I would like to	42 (65)	71.8 (17.08)	−2.92 (63)	.005
No, I am not interested	23 (35)	58.7 (17.64)	−2.92 (63)	.005

Table 5. Summary statistics of the System Usability Scale scores for question 2 (N=65).

Previously worn an activity tracker?	Participants, n (%)	Mean (SD)	*t* test (*df*)	*P* value
Yes	13 (20)	72.12 (15.61)	−1.10 (63)	.28
No	52 (80)	65.91 (18.81)	−1.10 (63)	.28

Table 6. Kendall τb correlation ranks.

Correlation	Rank
±0.10[a]	Very weak
±0.10 to 0.19	Weak
±0.20 to 0.29	Moderate
±0.30	Strong

[a]A positive sign indicates a positive relationship, and a negative sign indicates a negative relationship. A ± value means that the correlation value can either be positive or negative for each rank (eg, a 0.15 correlation would be weak, as would a –0.15 correlation).

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Table 7. Continued device use Kendall τb correlation for each usability question.

Question number	Question	Rank	*P* value
10	The activity tracker was comfortable to wear at night.	0.348	.003
17	Using the activity tracker helped me be more active.	0.340	.003
15	The activity tracker accurately tracked my physical activity.	0.317	.005
6	I was able to wear the device easily without help from another person.	0.308	.009
9	The activity tracker was comfortable to wear during the day.	0.306	.01
4	I think that monitoring my health 24 hours a day, 7 days a week is a good thing.	0.264	.02
5	I am comfortable with my health data being stored on the internet.	0.264	.02
13	I had no concerns about my privacy while wearing the device.	0.253	.04
2	Have you previously used a wrist-worn activity tracker before the project?	0.209	.09
14	I was happy to wear the sensor in public.	0.206	.08
8	I was able to perform my daily tasks as usual while wearing the device.	0.202	.09
18	Over the last week, how many days did you wear the device?	0.187	.12
19	Did you wear it at nighttime?	0.169	.18
16	I was happy to wear the sensor around the house.	0.164	.18
12	I was able to put on the device in a reasonable amount of time.	0.119	.31
1	Have you heard of wearable smart devices before the project?	0.115	.36
7	I was able to remove the device easily without help from another person.	0.083	.50
20	Did you remove the device during the day for reasons other than getting the device wet?	−0.078	.53
3	Did you like the appearance of the wrist-worn activity tracker?	0.054	.66
11	I was concerned that the device was not securely attached to me.	−0.019	.87

Table 8. Continued device use (question 21) Kendall τb correlation for each walking activity feature.

Question	Rank	*P* value
WT10M1[a]	−0.194	.06
WT10M2[b]	−0.083	.42
STS5[c]	0.057	.58

[a]WT10M1: 10-m walk test time 1.

[b]WT10M2: 10-m walk test time 2.

[c]STS5: Five-Time Sit-to-Stand test.

Some qualitative data were also recorded using the bespoke usability questionnaire. Namely, participants were asked to provide any comments on the activity tracker that were not covered by the previous 21 questions. Some participants commented that the fastening buckle used by the Xiaomi Mi Band 3 was difficult to secure at times, which is likely to have affected scoring on questions related to comfort and donning and doffing (questions 6, 7, 9, 10, 11, and 12). In addition, some participants reported that they believed that the wearable sensor had to be fastened extremely tightly to obtain an accurate reading. This factor may have also influenced their comfort perception.

A Predictive Model for Continued Device Use

To train the predictive model, features were chosen from the results of the Kendall τb correlation from Table 7. A total of 3 feature subsets were chosen. The first subset was based on the 2 highest-correlated features (questions 10 and 17) such that the selected features had a *P* value of ≤.005. A second subset was selected to include features with a *P* value of ≤.01 (questions 6, 9, 10, 15, and 17). Finally, a third subset was selected to include features with a *P* value of ≤.10 (questions 4, 5, 6, 9, 10, 13, 15, and 17). For the remainder of the paper, the models developed using each of the 3 feature subsets will be known as the 2-feature model, 5-feature model, and 8-feature model.

Initial experimentation was performed using multiple classifiers to obtain a performance baseline. This preliminary experimentation tested the following classifiers: decision tree, support vector machine, random forest, and k-nearest neighbor. From this experimentation, we found that random forest provided the highest predictive performance in classifying whether users would have an intention to continue using the device after the trial ended. For comparison with the random

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forest models, regression multinomial models were also performed. These multinomial models are helpful for the simplicity and interpretability of the predictive model.

For the multinomial models, all data were included to observe and assess the statistical or discrimination power of the model at once. For the random forest models, validation of the final classification was achieved using a train-test split validation of 70 to 30 to check model accuracy.

The results from each of the 2-, 5-, and 8-feature models for both the multinomial and random forest models are shown in Table 9.

Table 9. Classification confusion matrix for the 2-, 5-, and 8-feature models.

Number of features and class type	Multinomial model—predicted class		Random forest model—predicted class	
	No	Yes	No	Yes
2 features				
Actual class				
No	15	8	5	1
Yes	5	37	3	11
5 features				
Actual class				
No	16	7	5	1
Yes	4	38	3	11
8 features				
Actual class				
No	17	6	5	0
Yes	4	38	3	12

The findings from the multinomial 2-feature model display an overall accuracy of 80%, and the findings from the random forest 2-feature model correlate with an average accuracy of 80%, an average precision of 0.80, and an average recall value of 0.80. Both sets of results show that a reasonably accurate prediction can be made for usability question 21.

After increasing the model's features to 5, the multinomial model displays an overall percentage of 83.1%, and the random forest model correlates with an average accuracy of 80%, an average precision of 0.80, and an average recall value of 0.80. The multinomial results improved slightly compared with the findings from the 2-feature model, whereas the random forest results remained the same.

The final model used 8 parameters. The findings from this multinomial model displayed an overall percentage of 84.6%, whereas the random forest model's average accuracy increased to 85%, displaying an average precision of 0.88 and an average recall value of 0.85. Both sets of results improved from the 2-feature and 5-feature model findings. Nonetheless, the improvement from the 2-feature model to the 8-feature model was 5%.

Discussion

Principal Findings

Analysis of the usability of the wearable system by older adults indicated a significant correlation between usability and intention to continue using the system. Comparing SUS scores of participants who intended to continue using the device with SUS scores of those who did not resulted in a statistically significant difference (P=.005). On average, users who indicated that they would continue using the wearable device also indicated that the device had good usability, whereas users who indicated that they would not continue using the wearable device indicated that the device had poor usability. Therefore, participants who found the system easier to use were also more likely to want to continue using it. These results are in line with previous research findings that suggest that ease of use and device usability are important measures for technology acceptance yet are often overlooked in favor of device accuracy [7].

Additional evaluations conducted using the standardized SUS scores showed that neither sex, age, geographical location, previous experience, nor the number of wearable devices used influenced the results of system usability. Although a subset of participants wore 2 activity trackers, the results showed no statistical difference in SUS score depending on whether the participant was asked to use 1 or 2 wearables. This is likely because 2 wrist-worn sensors are still deemed unobtrusive in everyday life. Further research is required to observe whether these results can be scaled based on anatomical location or additional wearable sensors.

Furthermore, there was no statistically significant difference in the usability scores for a wearable sensor system regardless of whether the participant had previous experience using a wearable device. This finding implies that technology literacy is not necessarily an influencing factor when it comes to the perceived usability of a wearable device. A possible explanation for this finding is that each participant in the study received a standardized training session lasting 10 to 15 minutes at the

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beginning of the trial and a user manual for reference. These results indicate that a lack of experience using wearable devices does not need to be a barrier to adoption if appropriate training can be provided.

Usability is clearly an influencing factor for continued device use. However, there are other human factors that could influence continued use. A 21-question bespoke questionnaire was used to further evaluate these human factors. The results showed that the human factors that had the strongest correlations with continued device use were (1) device comfort at night and (2) perception that the device helped increase activity. Inspecting the 5 questions that correlated the most with continued device use, 3 of the questions related to human factors, whereas 2 related to perceived accuracy.

On the basis of feature subsets from 8 questions that correlated the most with continued device use, machine learning models were implemented to predict whether a participant would indicate that they would continue using a wearable device. These 8 questions related to opinions on comfort, data privacy concerns, and the participants' perception (beliefs or attitudes) of device accuracy or monitoring their health. These models have the potential to act as an early indicator of participants not continuing to use the device. Factors such as discomfort at night can be identified early before users decide to stop using it. This may allow for interventions to be made to address user concerns early in research studies, for example. As an additional benefit, the accuracy of these models provides insights into what design features are important to encourage wearable technology uptake in older adult populations.

The results indicated that the models could predict the likelihood of a participant having an intention to continue using the device with 80%-85% accuracy. Interestingly, the accuracy of the model only dropped by 5%-80% when we greatly simplified the questionnaire and only selected the top 2 correlated questions for prediction. As mentioned, these questions were related to evening comfort and whether the device helped increase activity levels. These results indicate that, by using a simple 2-question survey approach, it is possible to make accurate predictions about the likelihood of an older adult wanting to continue using a wearable device. This is useful as focus groups could leverage these questions to gain meaningful insights into their product development, or these questions could be included in a mobile app or web-based application to frequently report the usability of wearable products to ensure client satisfaction and better standards of quality assurance.

Future design of devices should keep in mind that wearable sensors are likely to be used by older adult patients with health complaints who often have reduced fine motor skills [31]. Therefore, to ensure maximum customer buy-in, manufacturers need to ensure that such devices are easy to don and doff.

Comparison With Previous Work

Most research on wearable sensor technologies currently places accuracy at the center of the design. This often comes at the expense of usability, which can ultimately have negative effects on continued device use [6]. Previous research suggests that, to achieve successful adoption of remote rehabilitation technologies, the solution must be both practical and usable [8]. This is particularly relevant when considering wearable sensor systems.

Previous research has been conducted on usability evaluations by older adults using activity trackers [32]. This study asked 20 older adults to evaluate 5 different activity trackers over a 2-hour period. On average, the trackers tested in that study had an SUS of 56.38 (SD 11.86). Although a different cohort, review time, and number of devices were used, it is interesting to note that the Xiaomi Mi Band 3 used in our study, evaluated across 4 independent locations, obtained a similar average SUS score of 67.15 (SD 18.27) compared with the top-performing trackers in the previous study: the Fitbit Flex (SUS=66.25) and Nike FuelBand (SUS=65). SUS scores for the Xiaomi Mi Band 3 in this study were significantly higher than those of the other 3 sensors assessed by Steinert et al [30]. There is some evidence collected using posttrial interviews with some participants suggesting that the high score obtained by the Xiaomi Mi Band 3 may be related to a specific element of comfort. Participants indicated that the rubber material of the activity tracker made the device very comfortable to wear.

To achieve the potential health benefits presented by wearable sensors and remote digital health technologies for older adult populations, it is vital that users continue to use the wearable sensors over long periods. However, there is limited work in the literature exploring the factors that influence long-term wearable device use among older adults.

Strengths and Limitations

One of the key strengths of this study is that it assessed a broad spectrum of factors that could potentially influence continued device users among a diverse set of participants. This study provides clear evidence that usability, comfort, and motivation are key elements that must be considered for any wearable sensor-based application requiring long-term use.

There are some limitations to this study that could be addressed in future research. First, the sample size was limited to 65 participants, and as such, may not be large enough to provide accurate insights into the behaviors of older adults. This limitation was imposed as data collection had to cease at the onset of the COVID-19 pandemic. Second, there may be bias in the results owing to the ethics approval granted for the study. Given that participants were to have no underlying health conditions other than frailty, the vast majority of the volunteers were considered healthy, reflected by the mean score of 72.54 achieved for general health in our cohort, calculated using the SF-36 questionnaire. To contextualize this, in a normative study on older adults (N=8117; aged ≥65 years) where no screening was imposed, the mean general health score was 53.06 [33]. The factors that influence continued device use may be different for older adults considered unhealthy. To verify this, further research with a larger cohort of both healthy and unhealthy participants would be required. Third, although the findings of this study are based on the Xiaomi Mi Band 3, it is unknown whether they would be transferable to other devices. Therefore, further research would be required administering the same bespoke usability questionnaire to older adults testing a range of wearable sensor devices.

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Conclusions

This study used a combination of validated questionnaires to gather 65 participants' opinions on the usability of an off-the-shelf wearable sensor system, the Xiaomi Mi Band 3. To gain further insights into the factors that may influence an older adult intending to continue using a wearable device, we also designed a bespoke usability questionnaire for this study. Various analyses were performed examining the statistics from the pretrial questionnaires; summary statistics of the SUS score with respect to region, sex, wearables used, and age; and findings that focused specifically on the final question from the bespoke usability questionnaire to determine what factors influence continued device use.

The results from the SUS show that there was no notable difference in perceived system usability depending on region, sex, age, or previous experience, eliminating the notion that usability perception differs based on geographical location, sex, or deviation in participant age. Previous studies have suggested that usability and ease of use are as important as device accuracy when it comes to technology acceptance and device uptake. One of the main lessons learned from the results of this study was that the most important factor that influenced continued device use in an older adult cohort was device comfort. Feeling that the device was fit for purpose (ie, it helped them achieve the task it claimed it would) was the second most important factor. In addition, it was observed that comfort matters the most when a wearable device is used while sleeping. These lessons could better inform the design of future wearable sensor systems for applications specifically targeting older adults.

We presented a random forest model with 80% accuracy using these 2 features, which could be used as an early identifier of continued device use—for example, if the user is asked these 2 questions after the first day of the study, their response would be a clear sign of whether they are interested in using a wearable sensor system long-term. After including the top 8 ranked questions from the bespoke questionnaire as features of our model, the accuracy increased to 88%.

Acknowledgments

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Data Availability

The data sets generated and analyzed in this study are not publicly available as the data contain information that could compromise the privacy of the research participants. The data are available from the corresponding author upon reasonable request.

Authors' Contributions

KME, JG, DK, and ST contributed to conceptualization. KME, JG, DK, and ST contributed to methodology. KME, JG, DK, WD, and CM contributed to analysis. KME, JG, DK, WD, and CM contributed to writing (original draft preparation). KME, JG, DK, JC, RD, WD, CM, EN, AA, JJ, ST, and JB contributed to writing (review and editing). JC contributed to funding acquisition. All authors read and agreed to the published version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Accuracy, feasibility and acceptability of wireless monitoring in older people: posttrial usability questionnaire.
[DOCX File , 27 KB - aging_v6i1e36807_app1.docx]

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Abbreviations

GDS: Geriatric Depression Scale
MDPQ: Mobile Device Proficiency Questionnaire
MMSE: Mini-Mental State Examination
SF-36: 36-item Short Form Health Survey
STS5: Five-Time Sit-to-Stand test
SUS: System Usability Scale

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Original Paper

Development of a Smart Home Interface With Older Adults: Multi-Method Co-Design Study

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Abstract

Background: Smart home technologies have the potential to support aging in place; however, older people's perceptions of the value of smart homes may be influenced by their access to the information gathered by the technology. This information is needed to support their informed decision-making. Limited research has been conducted on how best to design visualizations of smart home data in keeping with the needs and wishes of older people.

Objective: We aimed to investigate the design options that impact the usefulness of smart home systems, older people's information needs, their perceptions of data visualization, and the ways they would like information displayed to them.

Methods: We used a qualitative approach to empower the participants as co-designers. Data collection comprised a sequence of methods such as interviews, observation, focus groups, scenario design, probes, and design workshops. Each phase informed the next. Overall, 13 older adults (n=8, 62% female and n=5, 38% male; aged 65-89 years) consented to participate. A thematic approach was used to analyze the data set, and participants were actively involved in designing the in-home interface, which enabled them to better conceptualize their needs.

Results: The information collected was clustered into 5 themes: enabling home, health, and self-monitoring; enabling opportunities for social inclusion and engagement; enhancing cognitive abilities; customizability of the display; and promoting inclusion in recreation and leisure activities. These themes informed 5 design sessions in which participants co-designed visual metaphors for the themes based on their own experiences in an age-inclusive manner. Together, the participants produced a user-friendly prototype, which they chose to call *My Buddy*. They found it useful to receive social and cognitive triggers, as well as recommendations for special diets or activities based on their mood, health, and social status.

Conclusions: Smart home data visualization is much more than a nice-to-have option. Visualization is a must-have feature because it deepens the understanding of the information collected and means that technology provides information of value and relevance to older people. This may improve the acceptability and perceived utility of in-home technology. By understanding what older people want to know from smart home technology and considering how to visualize data in ways that work for them, we can provide an appropriate in-home interface. Such an interface would suggest ways or opportunities to connect and socialize; stimulate contact with close friends or family members; maintain awareness of health and well-being; provide support in decision-making, cognitive tasks, and daily life activities; and monitor health status. Older adults are the best co-designers for the development of visual metaphors that resonate with their own experiences. Our findings promote the development of technologies that foreground and reflect the information needs of older people and engage them as designers of the display.

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KEYWORDS

data visualization; digital health; smart homes; older people; technology acceptance; qualitative research; mobile phone

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Introduction

Background

Smart home technologies for older adults are becoming increasingly popular. This growth is complemented by interest in older people's information needs as well as those of professional and family caregivers and other stakeholders. Although research into information needs often includes stakeholders, few studies have involved older people in the design process to visualize sensor data [1-6]. By working with older people to identify the information that they need and how best to view, access, and share this information, research can address the possible barriers to the adoption of smart home technology [7-9]. Appropriately designed data visualizations can help older people make the best use of smart home technologies and promote their engagement in health care and social activities [7,10].

Most studies related to data visualization from monitoring technologies have only included researchers or clinicians [2,11-15]. Many older people recognize the value of data visualizations for personal use to track changes in health and wellness and to support their decision-making and cognition [7,16-18]. However, many older people do not have a priori knowledge of the types of data collected or what it might mean for their health and well-being [18].

Table 1 presents a selection of studies that address data visualization for older people as primary users. Most studies include visualizations that were designed by researchers or technical staff and were then evaluated to determine the usability and usefulness of the interface [19], sometimes based on findings from interviews or focus groups [1,3,18]. Data visualizations have been assessed through questionnaires [19], interviews [2,3,18-21], and focus groups [14,21,22] with older people. Although visualizations have shown potential to support older people in their daily activities, the usability of the display has been questioned. Concerns about usability relate to the ease of use and effectiveness of the interface in terms of the provision of information to users and facilitation of user interaction with the system. This suggests that such interfaces may have been challenging to use or failed to meet user requirements.

Table 1. A summary of a selection of references.

Study author, year	Designed by researchers	Evaluated by older people	Information presented to older people	Participants	Evaluation methods
Le et al [2], 2018	2 visualizations	Limited understanding of data	Health visualization	21 older people	Semistructured interviews
Reeder et al [3], 2014	3 visual displays	Useful for caregivers, no information about how data are useful for older people	Activity level, fall scenarios	7 older people	Semistructured interviews
Ayoade et al [23], 2013	2 visualization tools	N/A[a]	Home rehabilitations	5 people who have fallen and 6 patients with knee replacements	2 user studies: falls prevention and knee replacement rehabilitation
Mynatt et al [24], 2001	In-home interface	Complex design	Communication	1 grandmother and 2 grandchildren	Field trial
Doyle et al [20], 2015	Visualizations Informed by interviews	Complex design, need for more information	Sleep activity, heart rate, weight, blood pressure, and activity level	7 older people	Semistructured interviews, focus groups
Le et al [1], 2014	1 sensor visualization, Informed by interviews	Very difficult to understand	Activity data	8 older people	Semistructured interviews
Castelli et al [25], 2017	2 visualizations and 1 visualization creation tool	First version: hard to understand and complex design	Energy, temperature, security, diary, and weather forecast	12 households (29 inhabitants, various ages)	3 interview studies, a design workshop, and system log data
Jo et al [10], 2021	Sensors available in the market	Complicated to understand and hard to read	Smart band and indoor air quality sensor's display	9 older people	Focus groups
Caldeira et al [18], 2021	Informed by interviews	N/A	Activity status and heart rate Records	9 older people	Final product not evaluated

[a]N/A: not applicable.

Nonetheless, older adults find value in data visualization through self-tracking [2,3]. In a 6-month pilot study, Reeder et al [3] found that visualizations of sensor data were useful for older people with cognitive impairment and their caregivers. This resonates with findings from a study by Le et al [2], in which they investigated the utility of health visualizations and potential barriers by introducing 2 visualizations to 21 older adults, followed by a semistructured interview. Similar studies developed visualizations to engage older people in home exercises [23] and showed that visualizations improved the ability and confidence of the participants compared with a booklet. Other studies have used graphs and icons to support older people's understanding of blood pressure measurements [13]. As part of a pilot study to evaluate the feasibility of using

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smart home devices to support aging in place, Choi et al [26] reported that participants were interested in accessing their activity level and environmental data to help them monitor and manage their health status. Visualization can also facilitate communication between older people, caregivers, and relatives [1,3,21,24] and offer a better understanding of health status [5].

Older people often face challenges in accessing and interpreting information, including data visualization. They may experience physical and cognitive changes that impact their information needs and ability to access such information. For instance, aging may be associated with changes in eyesight, cognition, and physical abilities, all of which should be considered in future visualization design [27,28]. In addition, in light of changes related to aging, some studies indicate that older people might find it difficult to locate specific information in complex interfaces, understand infographics, and control moving components [3,28,29]. Several studies have investigated the features of interfaces that can affect older people's interactions with smart home technologies, such as the sliding method [30], bar graph [1], numerical representations, and button size [31,32]. Participants in such studies also expressed concerns about data visualization formats that have limited utility and can lead to data misinterpretation, and it is better to produce data visualizations that match older people's own lives [32]. For instance, Mynatt et al [24] developed a digital portrait that comprised a visualization of the data collected from a motion sensor in a smart home with "butterfly" icons bordering the digital picture frame representing activity level of the participant. Mynatt et al [24] found that the design of the interface was too complex, as it conveyed 10 levels of information; however, the design did change activity levels of older people and triggered communication between them and their family members. Le et al [2] noticed that participants expressed interest in using visualizations as an intervention tool. In another study, Reeder et al [3] developed 3 interactive interfaces based on participants' views of smart home technologies, and the evaluation phase revealed the need to reduce complexity and facilitate ease of use. Users found the bar charts difficult to understand, and the use of color created visual confusion for some. These findings were similar to those reported by Jo et al [10], who studied the usability of an indoor air quality sensor display, and by Castelli et al [25], who studied the usability of a set of sensor display by 29 participants.

A better understanding of older people and their home living environments is crucial to design appropriate technology for them [4]. Although certain studies concern data abstraction, to the best of our knowledge, there are no published studies focusing on the information needs of older people, such as how they would like to access the information and how to display it [4,5,18,33]. As Table 1 illustrates, when older people evaluate data interfaces, the data are often not presented in a way that is meaningful or appropriate for them. A substantial challenge in identifying and presenting these data lies in establishing tangible insights gathered from the real-life experiences of older people. For instance, older people are not usually familiar with the collected data sets that may require technical knowledge to understand. Furthermore, similar to people of any age, they might not be interested in all the information collected and need to select or customize what they want to visualize and access. Engaging older people as co-designers for creating visual metaphors derived from their culture or experience helps avoid ageism, with older adults having the option to select and customize the data to visualize, and helps to make the display appropriate to older people rather than creating a "big brother" style of approach [7]. Our research, which involved older people as coresearchers, highlights key points for consideration when designing visualizations for older people.

Objectives

Our aim was to identify and describe information that older people think is essential for supporting them in decision-making, daily life activities, and cognitive tasks. We aimed to identify the types of data that older people want to access so that together we could design an interface to visually represent such data and thereby enhance the usability and utility of smart home technology.

Methods

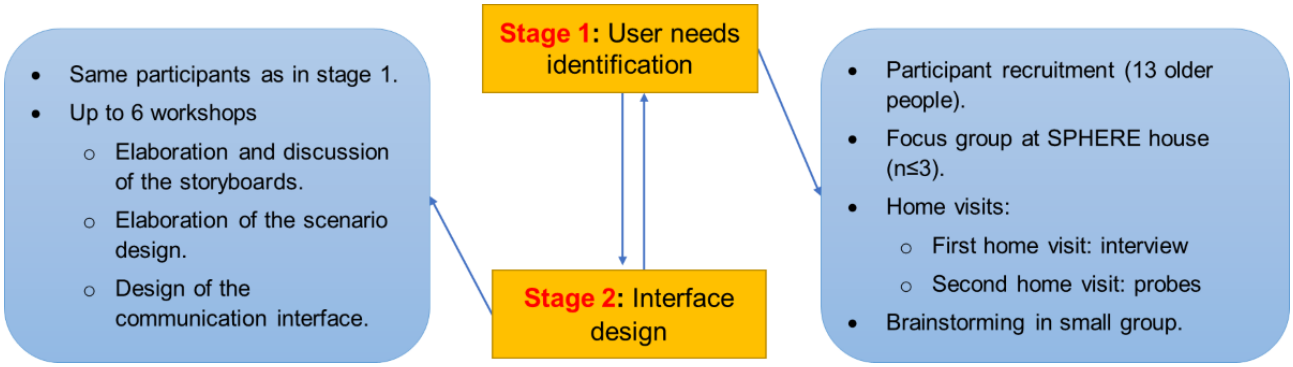
Overview

We followed a qualitative approach in this study. We used different methods to empower the participants as co-designers and partners, as shown in Figure 1. "Co-design is meaningful end-user engagement in research design and includes instances of engagement that occur across all stages of the research process and range in intensity from relatively passive to highly active and involved" [34]. The ethics of co-design derive from an approach to community engagement that aims to go beyond passive consultation with stakeholders so that communities or groups are actively engaged. This acknowledges the importance of real-world experience in the design process. It also recognizes that as stakeholders, communities will ultimately be the most affected by design outcomes and should therefore have great influence.

We used and customized a combination of well-known participatory co-design methods to achieve our objectives. The methods comprised interviews, observation, focus groups, scenario design [35], and probes [36] (Figure 1).

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Figure 1. Development structure. SPHERE: sensor platform for healthcare in a residential environment.



Participant Recruitment

Older people familiar with the SPHERE (sensor platform for healthcare in a residential environment) smart home technology [37] were identified and invited to participate in the study. In partnership with a local community engagement center, participants with no background in smart home technology were invited to participate. Through this partnership, we attended gatherings for older people, including an older people's forum and dancing, knitting, and film clubs. We also placed participant information booklets in 2 public libraries, and we reached out to local organizations that support older people for assistance with the recruitment processes.

We contacted everyone who might be interested by sending out recruitment packs (invitation letters, participant information booklets, reply slips, and freepost envelopes). The aim was to include older people with a wide range of ages, education levels, health, and interests.

Ethics Approval and Informed Consent

The study was approved by the University of Bristol Faculty of Health Sciences Research Ethics Committee (approval 57781) on November 21, 2017.

All participants provided written informed consent to participate in the study, to be audio recorded, and to have anonymous quotations and photos to be published. The participants were given the opportunity to ask and clarify any concerns before signing the consent form. A copy of the signed consent form was provided to each participant, and a second copy was kept with the researcher and held securely in university premises. Participants were made aware that they could withdraw from the study at any time without explanation or repercussions. Participants in the focus groups and workshops were provided with refreshments, and travel expenses were reimbursed. Transcripts and notes were anonymized by removing details that could lead to participant identification. The names of the participants used in this study are pseudonyms.

Preliminary Work: Focus Groups

This work was informed by earlier findings cited in our previous work [7], in which 4 focus group sessions were conducted to investigate older people's views and expectations of smart home technology. All participants had a positive view of smart home technology, although most participants did not recognize that they needed the technology at this point in their lives. However, the participants said that they would be willing to use such technology as they grew older or frail. In addition, participants said that they would be more receptive to the use of smart home technology if it provided access to their own health data or made it easier to participate in social events. They also wanted technology to offer new ways to have fun, shop, play web-based games, enroll in educational courses, communicate securely with others, assist family members, and fulfill other social roles. The findings of the focus groups informed our home visits and interviews.

Home Visits and Interviews

In total, 2 home visits were made to each participant to learn about their behaviors and attitudes toward the existing technology. The first visit comprised a semistructured interview. Discussions and observations were kept informal to reassure participants. Handwritten notes were taken, and the interviews were audio recorded. During this visit, participants were observed in their proper environment while they pointed out any item they considered particularly "smart" [38] (Figure 2). They discussed their technology use and attitudes in the context of their homes. This discussion was guided by the same topic areas. Explored topics included the use of everyday communications, privacy issues, and the identification of information needs. The first section included information about the person such as occupation, age, sex, activities, leisure, family status, the number of children and close friends, and technology use. We also attempted to learn more about the participants' state of health, physical abilities, and particular incidents (eg, falls). In the second section, participants were asked their opinions about aging at home, smart home technology, and the reasons why older people move home. Finally, we discussed any concerns or worries that smart home technology raised and their attitudes toward being monitored and communicating remotely. The participants described activities they could no longer perform but which technology made possible and the communication issues they encountered. During the visits, the activities were flexible, depending on each participant's abilities, interests, and capabilities.

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Figure 2. Smart gadgets at participant's home: smart window closing when it is raining, smart alarm clock, smartphone, and tablet holder.



Probes

Cultural probe techniques [35] were used to empower the participants to share their preferences and knowledge. Cultural probes allow participants to report information about themselves and their values, thoughts, and activities. Information gathered during the first visit informed the design of our cultural probe kit, which included a camera, a diary, and questionnaires given to participants to record specific events. We began by sketching the layout of the probe on paper, ordering the questions, and leaving space for responses. Subsequently, we created and tested a prototype within the team. Our goal was to optimize the design for accessibility, attractiveness, and ease of use to ensure better results. We then conducted a trial period of 3 days with 3 participants, collecting their feedback and integrating it into the probe's design. This included making a few questions clearer, avoiding repetition, and incorporating a scale to reflect the participants' daily moods. After incorporating the initial feedback received, the final design revisions were made. The participants were asked to record their daily activities for 2 weeks, including their reading, listening, watching, concerns, phone use, and the types and purposes of the technology they used. We made follow-up phone calls or visits as necessary to ensure that participants understood the process and to answer any questions they may have had.

Cultural probes allowed the participants to record their lives in their own contexts and in their free time, with minimal intrusion. We gathered insights into participants' environments that helped to identify specific issues, uncover new opportunities, and inspire the development of new design concepts. Kits were delivered to the participants in person so that each item and the overall purpose of the research could be explained. These activities were entirely voluntary, and of the 13 participants, 9 (69%) participants agreed to complete the probe kit process. They had 1 month to complete and return the documents after completing as much as they desired. Of the 9 participants, 6 (67%) completed all the elements of the probe kits.

Design Workshops (My Buddy)

The focus group, home visits, interviews, and probe findings informed the design phase, in which we used iterative group design sessions. Of the 13 participants, 5 (38%) participants agreed to participate in the design activities. In the first session, we presented and discussed the findings of the previous phases together on a whiteboard (Figure 3) and asked the participants to identify the functionalities they would like to include in the visualization of the "in-home interface." They were asked to write down each functionality using their own words on sticky notes (Figure 4).

In the second session, we presented all the sticky notes on a wall and took pictures of the participants organizing and discussing the different information, as pictures were the best way to capture the details. Participants were asked to group these items by topic and to give each topic an appropriate title.

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The sticky note for the title differed in color and shape (Figure 5).

In the third session, we divided the participants into 2 groups and asked them to draw the main interface, resulting in 2 different prototypes by the end of the session. After a thorough discussion between the 2 groups, they selected 1 interface for development. The participants called this *My Buddy* (Figure 6).

In the last session, the participants evaluated the interface built using the Adobe XD software (Adobe Inc). We presented early prototypes to older people through focus groups. On the basis of these findings, we refined the interactive interface design. They suggested some improvements and proposed adding more features such as bus timetables and levels of pollen. We then developed the final version of *My Buddy* (Figure 7).

Figure 3. Summary of findings.

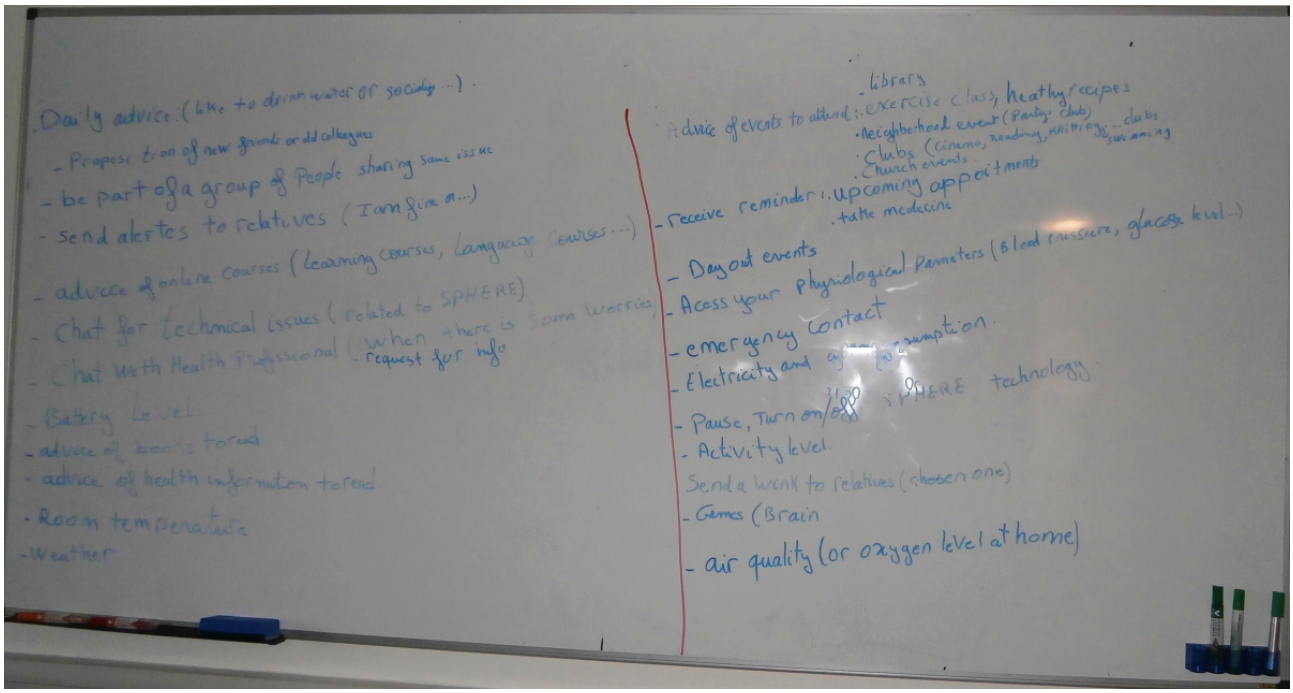


Figure 4. Participants using their own words to describe each functionality they wanted.



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Figure 5. Participants organizing data.

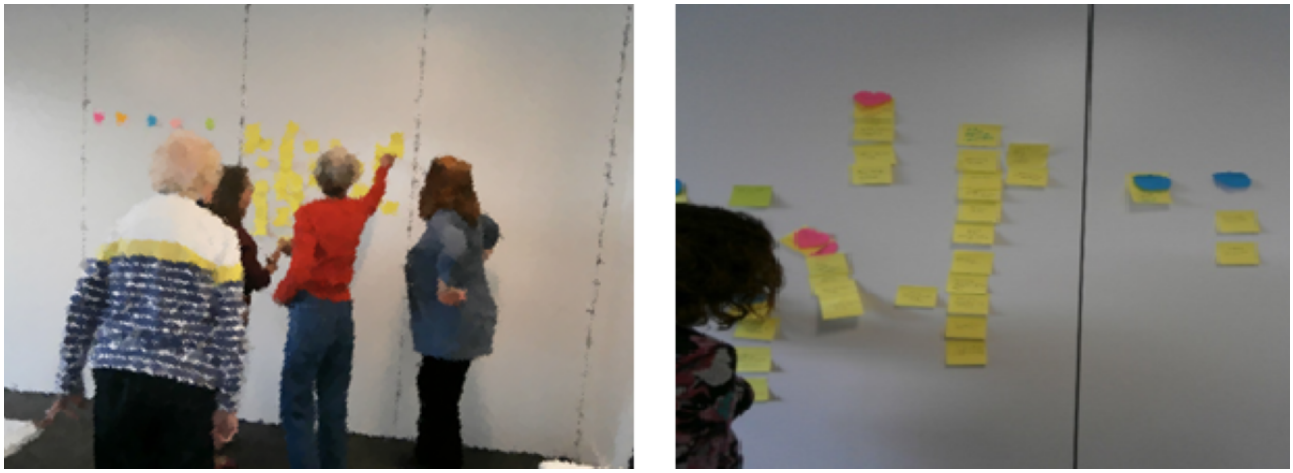
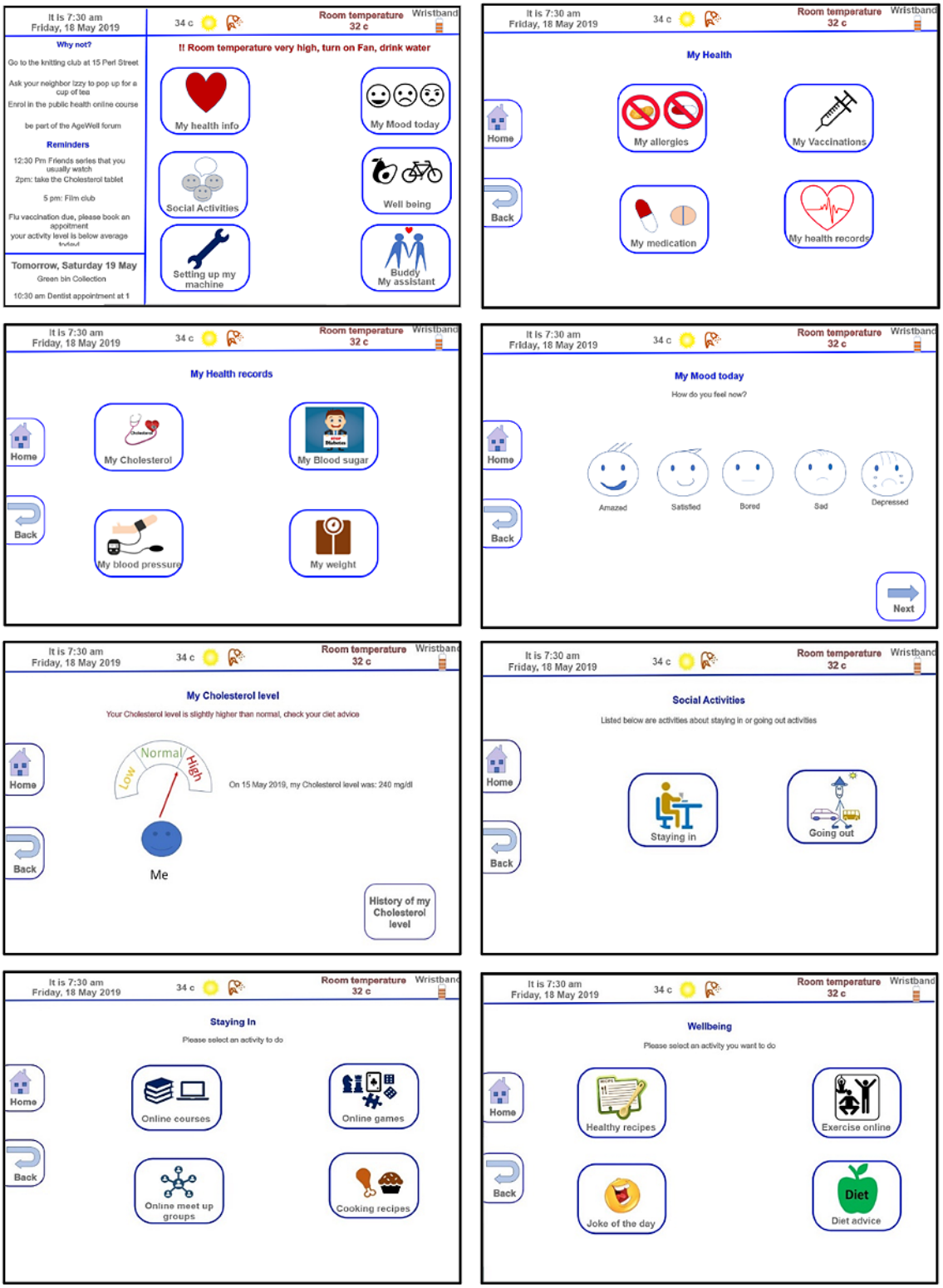


Figure 6. Participants drawing the main interface.



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Figure 7. My Buddy: main and some interfaces.



Results

Participants

In total, 13 older adults, aged between 65 and 89 years, with varying levels of education, health, and interests, were recruited through various channels. Of the 13 participants, 7 (54%) had prior experience using smart home technology in their homes for 8 to 12 months as part of the SPHERE project [6]. The remaining 6 (46%) of the 13 participants were members of the public who had never used smart home technology.

Table 2 summarizes the participant characteristics. Of the 13 participants, 2 (15%) participants self-identified as belonging to a minority ethnic group, and 5 (38%) participants were male. Of the 13 participants, 8 (62%) participants lived alone in their homes or apartments, whereas the rest (n=5, 38%) lived with their partners. Of the 13 participants, regarding educational background, 3 (23%) participants held school qualifications, 3

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(23%) participants completed university degrees, and 7 (54%) participants had postgraduate degrees. Of the 13 participants, 2 (15%) participants had never worked before, and 1 (8%) participant was employed part time as a researcher. Most of the participants were retired but remained active and volunteered at various locations.

Table 2. Participant characteristics.

Participants' pseudonym	Sex	Age (years)	Qualification
Edward	Male	73	Postgraduate qualification
Alice	Female	67	Postgraduate qualification
Bethan	Female	67	Degree qualification
Christine	Female	89	School qualification
Daniel	Male	81	Degree qualification
George	Male	81	Postgraduate qualification
Florence	Female	79	School qualification
Molly	Female	66	Postgraduate qualification
Lyam	Male	70	Postgraduate qualification
Kelly	Female	72	Postgraduate qualification
Henry	Male	68	Degree qualification
Izzy	Female	66	Postgraduate qualification
Jemma	Female	74	School qualification

Interviews and Probes Analysis

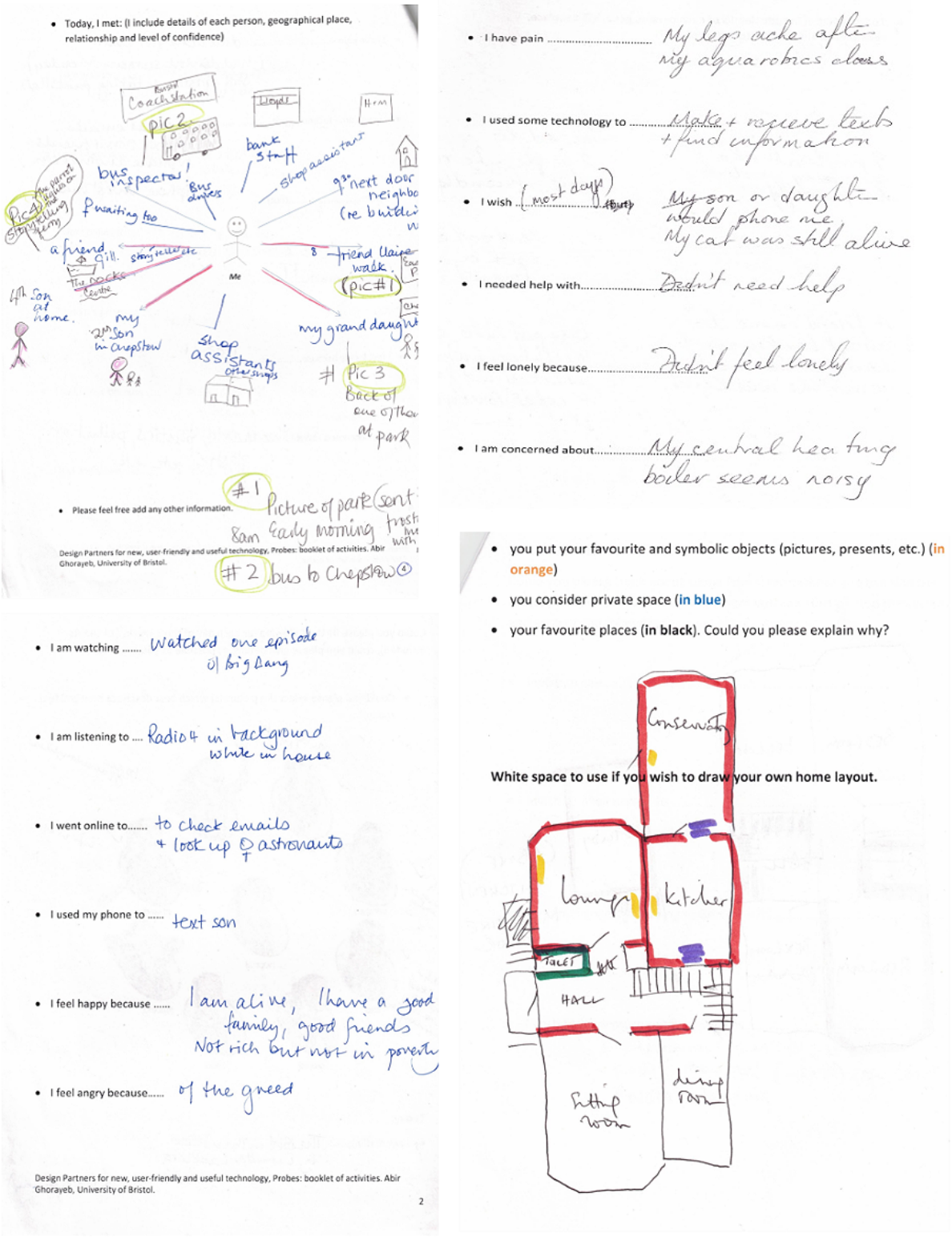
Data Analysis

The probe kits produced diverse results, as illustrated in Figure 8. Initially, we read through and cleaned the probe documents and notes to remove unrelated data. Some participants provided detailed accounts of their daily routines, including their trips to stores, items they purchased, and people they met. These activities helped us gain valuable insights into their daily lives and inspired the design ideas that we explored with the participants. We then conducted an inductive thematic analysis of the interviews, probe documents, and notes, with the first and last authors collaborating on the coding and theme development. Regular data meetings were held to discuss and modify the content and analysis, including the coding and thematic development. We read and reread the transcripts, assigned codes to the data, and classified them into themes and categories [39]. As the interview feedback informed the probe questions and activities, the data analysis of one supplemented the study of the other with a number of overlapping themes.

As a result of the previous phase, most participants requested more functionalities and information from the smart home systems [7]. On the basis of the codes, we grouped the data and themes into different categories linked to enabling home and health monitoring and self-monitoring; enhancing opportunities for social inclusion and engagement; enhancing cognitive abilities; customizing the display; and promoting inclusion in recreation and leisure activities.

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Figure 8. Illustrations of participants' diary.



Enable Home, Health, and Self-monitoring

Participants were eager to track their health, behavior, and homes. They looked for particular details.

Health Parameters, Diet, and Auto-order Medication

The participants were keen to understand and manage their blood pressure, cholesterol and blood sugar levels, pulse, and activity levels. They requested results over time to help them track any changes and better manage their lifestyles. We noticed that each participant suggested what they thought was better for their health status. Some participants used the health portal to order their prescriptions:

> *…blood, cholesterol level and blood sugar level,...I could actually read about results for things and work out what a good blood sugar level is or not and I can perhaps do something about my lifestyle...the results of my pulse's activity through the course of a day or through the course of a week or through the course*

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> *of a month and I think for something to be perhaps meaningful, it needs to be seen in the context of time...* [Henry]
>
> *...[She uses the health portal] To order my prescriptions...* [Kelly]
>
> *...When I run out of the drugs I'm using the health portal, that goes straight to the surgery.* [Daniel]

Participants believed that a smart home could help them by providing a diet plan tailored to their specific health concerns. The new interface would offer an easy-to-follow recipe considering the health conditions of each person:

> *I'm sure there would be things around cooking.* [Bethan]
>
> *If I can do something about having a healthy lifestyle or improving my health, then, if it's about diet, if it's about exercise, it's about things, that I guess that might improve my health or longevity or chances of remaining healthy, then I'm interested.* [George]

Enable Remote and Self-monitoring

Participants explained that they used to do some activities that they could not do anymore, such as running for the bus or going to the gym. Most participants were affected by age-related diseases and cognitive impairment. Smart home data might be used to drive behavior change, as participants wanted the system to recommend a walk, TV program, or other activities that the system indicated that they would enjoy or find helpful:

> *...like tell me how much I've moved all day and like how far I've walked or something...It is like if something had come on the telly every day and said, "Now Bethan, we're going to do our exercises. Sit in the chair," and I would have felt like I'd seen somebody and talked to somebody...You don't think you've slept very much. Actually, it would be quite good to know, you've got five hours sleep or six hours sleep a day...I think things like that [monitoring steps around the home] so that you could think, "Oh, I must up it a bit," or "Oh gosh! I've done well." Could get some feedback for myself.* [Bethan]
>
> *Because I think from the data you could monitor your life because you don't monitor yourself, right, and I could be sitting here watching TV for about four hours and then if you keep on looking at the data, this is what you are doing every day, you will think my God is this what I'm doing, maybe I should do something different, I should go out for a walk or something, so it's quite important.* [Molly]
>
> *I would expect it to monitor my behaviour and my presence in the house or the environment...if it could choose a TV programme that it knows that I like or a radio programme which I really enjoy. So I could use something which would select things and draw my attention to them so that I could not miss a good radio programme on a Thursday morning, for instance...* [Edward]

If an emergency arose, all participants said that they would agree to share their data with health professionals. In total, 10 (77%) of the 13 participants agreed to share their data with trusted people only:

> *I mean if I was lying on the floor, and I hadn't got my mobile phone or the landline nearby, I would want to be able to shout and know that some speaker is going to pick it up. And if there was something that you could trigger off an alarm response, then I think that would be a very good idea. I wouldn't want to be found a week later.* [Kelly]
>
> *If I was being monitored for certain things by a healthcare professional of some kind, I wouldn't necessarily want to be engaged with that. I would be happy to, abdicate responsibility and allow that information to be used on the understanding that it was for my benefit in the end anyway.* [Edward]
>
> *...I suppose things like Google and Alexa that would be helpful because, you might fall but you can't move, so you could say, Alexa get help and that should be helpful. I think I would want it as part of a care package.* [Izzy]

Most participants wanted to keep control of the system in all cases as described in the study by Ghorayeb et al [7].

Enable Home Monitoring

Participants required home monitoring, as they believed that smart home technologies should accommodate common aging frailties such as lower vision, decreased mobility, increased risk of falls, and cognitive decline. They wanted to feel safer and have assistance with their daily duties. They required smart lights for dark passageways, smart plugs, and the ability to monitor who is at the entrance. They wanted the technology-enabled reminders to close an open tap or switch off the oven when necessary. They wanted to control the room temperature, air quality, and electricity consumption:

> *Monitor the environment itself maybe, temperature, er, yeah high temperature or low temperatures, Maybe monitor some of the appliances to see whether they were on too long or something like that...I could see whether, got a leaking tap for instance, whether someone's left the tap on...* [Edward]
>
> *I think that it would be very useful if you could look at that information and say "I'm leaving too many lights on, I'm using too much electricity"...* [Jemma]
>
> *...The front door opening and closing is one of things that they would monitor as well as say the kettle and say the microwave or perhaps a toilet or...* [Christine]
>
> *I think I would expect a smart home to monitor air conditioning and turn on filters if it thought it was necessary. I would expect it if a room is not occupied and the sun is shining brightly through it and it's in the middle of summer, I would expect it to close blinds so that the room would not get unnecessarily hot...monitor air quality and levels of background noise...air quality.* [Daniel]

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Enhancing Opportunities for Social Inclusion and Engagement

Overview

Although social engagement has always been associated with better health and quality of life [40], it is still a real concern for older people because of the life-changing events that can be associated with aging. Although all the participants considered in-person visits as the best means of communication and interaction, they highlighted the importance of the new interface being able to suggest new ways or opportunities to connect and socialize and stimulate contact with close friends or family members. Through the probe activities, we identified the social networks of the participants, that is, the number of contacts with relatives and friends, memberships in charitable or social groups or organizations (church services), and so forth (Figure 8).

Communication Opportunities and Social Activities Engagement

The way that older people socialize and interact is changing, especially given their increasing use of communication technology and the role this can play in supporting social engagement. Most of the participants had already used social engagement technologies such as email, Facebook, and WhatsApp (few participants used Twitter):

> *I spend a bit of time doing emails and business and friends emails.* [Liam]
>
> *We have a little family WhatsApp. So we do often share something that will come up or they'll send a picture...* [Alicia]
>
> *I either read on my Kindle or I faff about on Facebook or I might do my emails, or my bank...* [Bethan]
>
> *By WhatsApp, by Messenger, by email, occasionally and by telephone. I prefer it when he rings on my landline so I can sit in comfort on my sofa and I can hear better.* [Kelly]

Smart home technologies should promote and facilitate social inclusion by recommending social groups with similar interests. The participants suggested that smart home technologies might be useful to meet like-minded people. Older people need to feel confident, and "they have something of interest to say instead of talking about their illness all the time," as 1 participant suggested:

> *...So, you could have maybe set up a group online of people in their 70s who live in this neighbourhood who have similar interests and you could maybe have a conference call or a virtual meeting for people who can't get out, that would be very good...they've all got different likes, dislikes, so I think the smart home, it got to have some personal tweaks, it's got to have a pick and mix maybe. One size doesn't fit all, maybe.* [Kelly]
>
> *Maybe you've had the experience of having elderly relations that can only talk about their illness...but so I think is really important that we're still able to maintain a relationship with the world. So, in that way and by the fact that you are at least in regular contact with some people online, that helps to maintain your self-confidence, which is such an important part of actually reaching out to new people...it gives you things to talk about.* [Alice]

However, 1 participant was resistant to the idea of contacting new people or joining new groups on the web.

Enhancing Family Links

Most participants were concerned that smart technologies might disturb social ties and emphasized that any new technology should enhance communication with relatives, friends, and neighbors:

> *The biggest concern for me is the human factor which might get stopped because of this technology. I mean so you know the children, the grandchildren they might not keep in touch with the parents.* [Molly]

Communication topics varied largely because the participants wanted to share their life experiences with their family members. They mainly discussed childcare, family, work and health issues, and common passions such as gardening, birds, and hobbies:

> *We have a little family WhatsApp. So, we do often share something that will come up or they'll send a picture. The other day, one of the children won a little football medal so, you know, it circulated and then we all chatted a bit about how proud we were and one thing and another.* [Alicia]
>
> *Oh Jonny in America, oh how he is, one of my passions is square foot gardening and he does square foot gardening and I like to hear about that...* [Christine]

Of the 13 participants, 12 (92%) participants described their neighborhood as safe and friendly. Few of them cited a good neighborhood as the reason for their lack of need for such a system, as discussed in the study by Ghorayeb et al [7].

Enhancing Cognitive Abilities

Overview

Most participants expressed worries about their cognitive faculties. They tried to use technology to improve their abilities by enrolling in educational courses, games, reading, and web-based activities. Smart home technologies can predict users' activity quality and promote their cognitive health by reminding them or suggesting new ways based on their usual comportment.

Cognitive Reminders or Enhancement

The participants suggested that the smart home interface should remind them of the day and date, time, weather, temperature, bus timetable, bin collection schedule, appointments, the location of the wearable device (if not worn at the time), and the renewing time of nearly expired cards:

> *With older people, it might be useful, at some point, to know what the weather is like outside because I think that does affect what people do or wear...It would be really useful if it had something on it telling me where the wearable...* [Bethan]

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> *I'd quite like to know temperature change, that would be quite useful, times of the day, you know what sort of activity, intensity of activity, things like that would be quite useful...Power use, water use is quite interesting.* [Edward]
>
> *...Remind him that he's now six weeks before he's 65, so he should apply for his bus pass...it would be better if like the news in the morning said...or something came up saying, "Good morning. It's Tuesday," because then you'll think "Oh Tuesday, I..."* [Bethan]

Smart home technologies should play a crucial role in enabling older people to monitor their daily activity levels, as this helps maintain health and achieve personal objectives. Maintaining an active lifestyle can help older people to prevent disease, lower the risk of falls, improve mental health and well-being, strengthen social ties, and improve cognitive function:

> *...It would be useful, at the beginning of dementia when you think you've got things but somebody says, "Well, actually, you didn't turn the tap on all day today, so what have you been drinking?...chivvy them up and make sure they have a drink and whatever?" Walking...* [Bethan]
>
> *If you have the average levels of activity of all 70 other people that are involved or all the hundreds of people that are involved as a comparison. [Comparing between participants to challenge.]* [George]

Visualizing a meaningful series of data would enable older people to see the utility of this technology as one participant explained:

> *I would adopt this technology if I could get a meaningful series of data, then I'd consider it probably being worthwhile.* [Liam]

Enable Web-Based Learning, Cognitive Games, and Shopping

If older people have the opportunity to engage in activities and learn relevant skills, this may improve their efficacity and ability to live independently and reduce their risk of developing Alzheimer disease [41]. e-Learning and educational programs helped participants feel more confident, and brain exercises helped delay memory loss. Therefore, board games, crosswords, puzzles, reading and other types of web-based adult education classes, web-based shopping, memory games, or video games may help slow memory loss, improve daily tasks, and increase the ability to perform housework. This will also satisfy the learning and self-esteem needs of older people:

> *I'm very worried that I might get dementia. FutureLearn [web-based education classes], they're usually three week, four weeks, six-week, eight week courses. So, for instance, I've done one about dementia, and I've done about 30 or 40 courses now, and they're from all the different universities around the world and they're free!* [Bethan]
>
> *Also, I'm interested in languages. I have the iPad, I watch German television...* [Daniel]
>
> *Watch TV, read a book, or sometimes even bake, looking for recipes...* [Molly]
>
> *Newspapers and books, I've got loads, I haven't read all of them,...They're all different sorts of books.* [Christine]
>
> *There are several apps that I quite often look at chess problems. They're quite good actually...* [Daniel]
>
> *I get a newspaper and I walk back and drink my drink and do my Sudoku and things like that.* [George]

Web-based shopping is gaining popularity among older people at an accelerating rate. To some extent, interest in web-based shopping for groceries or clothes is defined by older people's knowledge and experience. Being confined to the home, some older people show interest in shopping for food and clothes on the web [42]:

> *Living in isolated communities, showing how to use the internet and particularly for older women, the first thing they want to do is to buy clothes online as it helps give them back their self-respect...* [Alice]

Customizability of the Display

Overview

Older people should be given the option to select the features that they think they need or they like [7]. They should be able to select which data to visualize and who can access their data and when. The technology must be tailored to the person's individual needs:

> *I think they need to be tailored to the individual person's needs so you shouldn't just have a one plan for everybody, although it's smart technology it has to be tailored to the person's individual needs...I think everybody now is gradually used to smart things in their homes, whether it's their electricity meter or whatever, within the next five to ten years it will be normal to have certain...and I guess you could just extend that as you get older and more frail.* [Izzy]
>
> *...I mean obviously we get our water bill so because we're on a meter so we know what we're consuming...* [Florence; as she had a smart meter, she was not interested to visualize information about water or electricity consumption, and she wants to omit this feature]
>
> *I don't want more technology than I need, you know, I don't like excess technology.* [Liam]
>
> *Well, only if they were useful.* [Bethan; when asked about data to visualize]

Layout Consistency

Few participants stated that the display should conserve the same layout to keep them engaged, as changes to some social media displays caused them to disengage:

> *I have not used it much lately [about a social media tool]. I think they've changed the layout and I thought, oh, I can't be bothered...I'd want to have a say in maybe designing and choosing what I'd have.* [Kelly]

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Some participants required the ability to add information, such as to inform friends or families that they would be away for a while:

> *...There should be a way to say, "Well, I'm, I'm not here for a week.*" [Bethan]

Smart Home Friendly Behavior

Future systems should communicate information to older people in a friendly and easy-to-understand manner:

> *So, you know, I don't want it to be too Big Brotherish but somehow...* [Bethan]
>
> *...make it user friendly, make it a bit larger so they can get hold of it, because they've got problems or issues with their fingers and thumbs...make sure that it's functioning...* [Molly]

Promoting Inclusion in Recreation and Leisure Activities

Overview

Social inclusion is a complex concept for many older people, as it reflects their sense of belonging in a community where they can participate in activities based on their individual preferences. Smart home technologies should provide services and information that promote social inclusion and keep people active and occupied.

Old but Active: Exercises and Going Out

Coping with physical and emotional changes is particularly challenging for older people. From children moving away to the death of relatives or friends, declining health, and changes in lifestyle, participants tried to revive themselves by enjoying new things and learning to adapt to change. They tried to be involved in their community by attending local events or volunteering at different places and in different roles. They liked passing on their skills and helping other people. The participants felt young in their minds and kept themselves busy most of the week:

> *I don't want to grow old being, you know, frightened of everything...Monday, Tuesday, Wednesday, Thursday, I go for a walk early with a friend who's got a dog and Mondays and Fridays, I go to Zumba Gold and Tuesdays and Thursday, try and go to badminton and I try and make that, like, sacrosanct. I'm on several committees, so I go out on a regular basis; like once a month to this or twice a month to that; that sort of thing...I also do FutureLearn [web-based social learning platform].* [Bethan]
>
> *I walk a lot...I used to play tennis but I've got a bad shoulder, so I gave up...at the moment and all depending on the time of the year, I go quite often down to my allotment, so it's either planting or picking...* [Florence]
>
> *During the day, well I usually go out somewhere, yesterday I went to a meeting at the church, today I'm going to a lunch club. Tomorrow I'm probably going to do some shopping. Thursday I'm having my hair done and do a big shop and Friday I shall wait and see what I'm going to do.* [Christine]

Through this study, we learned about the participants' daily behaviors and activities. The interface should reflect their desire to lead active and engaged lives and be aligned with their self-views. Ageist attitudes are common in the community, and as age is a relative concept, we noticed that most of the participants would accept the technology much more if it did not treat them as "old":

> *[When talking about his neighbor refusing to use monitoring technology] I think she thinks that it conflicts with her pride to be independent. She's 97, you know!* [Liam]

Volunteering Activities

Among other benefits, volunteering and being active can make older people feel better. It reduces stress, prevents loneliness, and improves mood. Volunteering allows older people to maintain their physical and mental health by keeping them physically and mentally active. Meaningful and productive activities can help older people feel happier and have a positive outlook on their lives:

> *I'm the Treasurer to two different organisations. I'm part of the Older People's Forum.* [Bethan]
>
> *I volunteer for about four different things. So, I volunteer at an international charity bookshop, half day a week. I befriend a refugee and her child, so I take them out and I visit them and so on. I volunteer at St. Georges which is a music venue...and I volunteer at a retirement home, I do a coffee morning and the poetry group. So that's quite a regular thing.* [Kelly]
>
> *I help out as a volunteer, trying to help people learn either rudimentary computer skills or how to use software that they have with phones and tablets and laptops and the other commitment I have in the course of a week is I have been spending a day or at least part of a day at a community farm, where we attempt to grow organic produce...* [Henry]
>
> *I work with an organisation for retired people who like to provide something for the community, so I went down and volunteered at my doctor's surgery and I started off a tea and talk club or something for people who live on their own...So we started off with about half a dozen people who, the volunteer drivers would pick up and bring them to the pub and we'd provide tea, coffee, cakes and talk once a month only about some of the things which they might be interested in, and then we started inviting more and more people...But now we've got 30 people and the people who identify the people who live on their own are the doctors and nurses in the surgery, so they are the ones who get in touch with them and after they've agreed that we can get in touch with them, then we'll start ringing them up and provide this service. In the last four years we've realised that the visits they make to the doctor's surgery have dropped!* [Molly]

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My Buddy

My Buddy, the in-home interface, was designed and developed by older people for older people. The design sessions were extremely beneficial for exploring the needs of users. During the brainstorming session, the idea of designing a new interface for older people became clearer and more concise. Consequently, they began to propose new functions and more intriguing features. They carefully chose the system functionalities they required (Figure 7).

On the primary smart home interface, the participants found it useful to have information about the wearable's battery level, room temperature, weather and pollen level, date, and time. On the left side of the screen, participants recommended social and cognitive triggers. These triggers would be customized based on the user's mood, health, and social status. The system may recommend a special diet, walk, web-based courses, or TV programs. They divided the reminders into 2 sections: one for "today events," such as going to a movie or an appointment or taking medication and another for "tomorrow events," such as "bin collection day" or an approaching appointment, allowing older people to get ready earlier. Given the weather and the advance reminders, older people can plan their trips. On the right side of the main display, older people can access their health information; specify their mood for the day; select a social activity; take care of their well-being; configure the system; or contact the assistant, dubbed *My Buddy* during the design sessions.

On the "health records" screen, participants desired access to their allergies, vaccinations, medications, and health records, including their cholesterol and blood sugar levels, weight, and blood pressure. They wanted the system to recommend activities and suggestions based on their "mood today." Participants designed and drew 5 emojis to express their moods (Figures 6 and 7); therefore, this was not a standard scale of measurement. In their health records, participants wanted to view their current and historical blood pressure, cholesterol, blood sugar, and weight readings. They preferred customized recipes, diet advice, exercise, and consultations.

Social activities were categorized as either "local" or "going out" activities. The system may recommend web-based courses, games, meet-up groups, and recipes based on the users' preferences, health status, and mood for the day. The "going out" option would provide the user with the ability to search for social events; nature walks or activities; sports; or "the suggestion of the day," where the system will recommend daily events, such as knitting, dancing, and book clubs. The well-being feature would provide the user with healthy recipes, jokes, web-based exercises, and diet advice. If necessary, "Buddy my assistant" would enable the user to communicate with a health professional or technical support. The "setting up my machine" option will allow the user to customize the technology by adding or removing features, configuring data access permissions, turning the system on or off, and so forth.

Discussion

Principal Findings

There is a lack of research on what information older people would like to visualize and how to display it on a smart home interface [1,4,43]. Data visualization helps older people to make an informed decision about their self-care [18] and adopt smart home technology [1]. Visualized data can enable older people to self-monitor and understand and reflect on their own activities, allowing them to become more active and change their behavior. In addition, older people may become more active in monitoring their health or environment. In this study, we attempted to address this gap by understanding older people's views of information and considering individuals' experiences and cultures. The participants played an active role in developing and designing the in-home interface. As we started this project, we had no presumptions; rather, we sought to identify the information that older people would consider useful or vital to support their daily life activities and how they would like this information to be presented.

Main Contributions and Links With Prior Work

Although studies have investigated how collected data would be translated into data visualization, no research has focused on the information needs of older people [4]. This work supplements the existing literature by identifying the information that would enable older people to feel able to adopt smart home technologies and to visualize and access this information. The work described in this paper was informed by an earlier study [7] and individual interviews in which older people stated that smart home technology could be stigmatizing, could signify frailty, and should provide what they consider attractive and useful. Participants expressed an interest in technologies that provide customized group lessons, learning tools or classes, cognitive triggers and activities, social events, health and diet advice, and suggestions for connecting with like-minded people. A well-designed visualization that translates collected data into a usable interface should promote active engagement of older people in health care and well-being and further social communication and activities. Participants found that the collected data and visualizations could be used mainly as prompts or triggers to enhance and provoke cognition.

Some participants were willing to share some visualizations with family members or health care professionals when needed while maintaining control over the transmitted data. Monitoring an individual's health parameters can aid in early intervention and clinical decision-making [44]. The visualization should allow users to customize the system and gradually add features that respect their preferences and abilities as their needs evolve over time [7]. This was one of the findings of Castelli et al [25], who studied data visualization for people using smart homes, not just older people.

To improve the acceptability of smart home technology among older people, it is essential to raise awareness of its usefulness and emphasize its potential to promote independence, social interaction, and safety. It is vital to "enable the user to present the image that they want to convey to others" [45]. As discussed in our previous work [7], the in-home interface should provide

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older people with control over transmitted data, such as the ability to turn off or temporarily pause the technology. Most participants wanted to select which data to visualize and when and who can view their data. It should provide access to their current and historical health-related data, as well as bus timetables, healthy recipes, and dietary advice. Participants wanted *My Buddy* to remind them to take their medications, as well as to provide advice related to the weather, their health status, and mood. In addition, they wanted to be able to play web-based games, access information about physical activities, and participate in gatherings and discussions with other older people. In our study, we did not suggest which data to visualize, as we prioritized the needs of the participants. Real-life metaphorical representations were suggested by users themselves. As seen in the study by Mynatt et al [24] and others [1,10,13], visualizations that are not co-designed with potential end users may be susceptible to information overload or a lack of understanding of data abstractions. For instance, 3 interactive interfaces provided by Reeder et al [3] were found to be difficult to use; the bar chart was challenging to interpret; and the use of color led some participants to experience visual discomfort. In the study by Jo et al [10], the display of an already designed interface of an air quality sensor was difficult to read and understand. In contrast, involving participants as designers helps to identify the right information to display, as shown in the work by Doyle et al [20], who developed a display based on the analysis of semistructured interviews with 7 older people. In their study, participants complained about the ambiguity of the displayed information and expressed the need for more information. This affects people's ability to interpret data accurately [33]. Previous studies have demonstrated the potential of visualizations to affect health and well-being [2,24]. However, these studies typically did not provide participants with actionable recommendations to follow, which limited their ability to translate visualizations into meaningful behavior changes. Moreover, older people in these studies had difficulty interpreting the visualizations and translating them into actionable steps themselves [2]. In contrast, this study involved participants who not only proposed actions based on the observed data and trends but also designed the way in which these actions should be presented to the user. These recommendations on health, social, and physical activities are likely to have a positive impact on behavior and health outcomes. This "data-to-information-to-action" approach has been suggested to be particularly effective for older individuals [2].

In this analysis, we did not observe that experiences living in smart homes, educational level, and varying age affected the choices of interface design. However, the 2 participants who had no experience with mobile phones or social media technologies were among the participants who did not want to participate in the design workshop, which may highlight a need for future research to consider how best to include individuals with less experience of technologies.

Design Insights

In this study, participants designed the in-home interface, which they called *My Buddy*, by sketching the visual metaphors that they believed would make the tool meaningful and user-friendly. It is essential to use various research methods to uncover the requirements of older people. When asked in the interview, some older people described themselves as "healthy," despite the activity using probes indicating that they had various chronic diseases. They did not consider themselves ill if they could perform their daily tasks independently. Thus, it was important for the design of *My Buddy* to reflect the multiple ways in which older people constructed their own health—as physical, social, and cognitive. Technology that isolated aspects of this would not be welcomed. In contrast, for instance, most of the participants used their smartphones for similar purposes, such as playing web-based games, sending or checking emails, reading the news, and searching for recipes or health-related information. They anticipated that the same functionality would be provided on the smart home display, but in a "smarter" manner, where the system recommended activities, diets, social events, or cognitive triggers based on user behavior and needs. Smart home technology should promote older people's confidence, self-esteem, personal and social acceptance, and recognition of the contributions they made in their youth. Moving our starting point from "diagnosis" to empowerment reflects the participants' own desires about the way to live their lives in the healthiest way possible.

Our study has shown that older people must be included in the analysis and design of their own in-home interface to incorporate their contextual knowledge, preferences, and needs. Co-design methods have been incorporated in many studies to investigate older people's perceptions of smart home technologies. However, it may be time to consider older people as designers rather than simply informers. We suggest that it is always preferable to involve end users in the design of the new in-home interface, for instance, because graphics that a designer might use, such as pie and bar charts, may not be the most accessible to the population who will use the technology [2,28,29].

Older people are ideal co-designers for the creation of visual metaphors based on their own culture or experience, and their input enhances the production of user-friendly displays that enable older people to engage in social activities, communicate with family and friends, monitor health, seek assistance when necessary, and have the option to select and customize the data visualization.

Limitations

This study was limited by its duration and the number of users who were involved as participants. However, previous studies indicate that usability issues can be identified using a sample of 5 to 8 participants [46]. The iterative nature of our study and the details and depth achieved indicate that the findings are relevant and transferable. Future work could involve health care professionals and relatives of end users in the design process; investigate accessibility features, such as voice control and sound alerts; and explore the next steps in the design of the interface and evaluate such a system in situ. We would also encourage future research to consider how to maximize inclusion and diversity in the research design and potential participants, in terms of sociodemographic characteristics, ethnicity, sex, and gender, as well as the cognition and experience of

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technology. All these factors may influence design needs and engagement with displays and technology.

Conclusions

Smart home data visualization is essential for improving the acceptability and perceived utility of smart home technologies. To the best of our knowledge, this study is the first to address older people's need for information and perspectives on smart home data visualization. To explore the information essential to supporting older people in their daily life activities and decision-making, we used a qualitative research approach with 13 participants as partners to design a user-friendly in-home interface. We conducted focus groups, semistructured interviews, home visits, and probe activities. From the thematic analysis of the collected data, we extracted key themes related to older people's behaviors and interests, and these informed the design sessions. Presenting data to older people may offer them the opportunity to engage in social activities, make timely adjustments to their actions, contact relatives or friends, monitor their health status, and ask for help when needed.

Our work highlights key points for consideration when designing visualizations for older people, who were involved as co-designers in this study. The in-home interface was created by older people to present the data in an easy and meaningful way. Participants provided detailed feedback to guide improvements in the graphical user interface, content, and design changes to increase the usefulness of smart home technologies. They were interested in visualizing data about their health records and activity levels to control their blood pressure, cholesterol and blood sugar levels, pulse, and activity levels. They asked for results over time, which would help them to track any changes and to manage their lifestyle better. An in-home interface that offers people the chance to select the features needed; add further features in the future; visualize cognitive triggers and customized health, social, and diet advice; and offer communication and social engagement opportunities would be essential for future smart home technology adoption. Data visualizations should support their well-being by promoting social engagement, enhancing cognitive abilities, and enabling inclusion in recreation and leisure activities. Finally, our findings may be used to inform smart home technology developers and may apply well to other age groups. The results may increase the utility and the potential for acceptance and adoption of smart home technologies by older people.

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Data Availability

Anonymous data related to this study are available to bone fide researchers on request to the corresponding author. In keeping with the research ethics approval received, the data will be available until May 2028.

Authors' Contributions

AG was responsible for the study design, data collection, evaluation, analysis, interpretation and conceptualization, funding acquisition, and writing of the original draft. RG-H contributed to the study design, funding acquisition, analysis, interpretation, and conceptualization, and review and editing of the draft. RC contributed to the study design, funding acquisition, review, and editing. All authors agreed to the submission of the final version.

Conflicts of Interest

None declared.

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Abbreviations

SPHERE: sensor platform for healthcare in a residential environment

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Original Paper

Acceptability and Feasibility of a Socially Enhanced, Self-Guided, Positive Emotion Regulation Intervention for Caregivers of Individuals With Dementia: Pilot Intervention Study

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Abstract

Background: The responsibilities of being a primary caregiver for a loved one with dementia can produce significant stress for the caregiver, leading to deleterious outcomes for the caregiver's physical and psychological health. Hence, researchers are developing eHealth interventions to provide support for caregivers. Members of our research team previously developed and tested a positive emotion regulation intervention that we delivered through videoconferencing, in which caregiver participants would meet one-on-one with a trained facilitator. Although proven effective, such delivery methods have limited scalability because they require significant resources in terms of cost and direct contact hours.

Objective: This study aimed to conduct a pilot test of a socially enhanced, self-guided version of the positive emotion regulation intervention, Social Augmentation of Self-Guided Electronic Delivery of the Life Enhancing Activities for Family Caregivers (SAGE LEAF). Studies have shown that *social presence* or the perception of others in a virtual space is associated with enhanced learning and user satisfaction. Hence, the intervention leverages various social features (eg, discussion boards, podcasts, videos, user profiles, and social notifications) to foster a sense of *social presence* among participants and study team members.

Methods: Usability, usefulness, feasibility, and acceptability data were collected from a pilot test in which participants (N=15) were given full access to the SAGE LEAF intervention over 6 weeks and completed preintervention and postintervention assessments (10/15, 67%). Preliminary outcome measures were also collected, with an understanding that no conclusions about efficacy could be made, because our pilot study did not have a control group and was not sufficiently powered.

Results: The results suggest that SAGE LEAF is feasible, with participants viewing an average of 72% (SD 42%) of the total available intervention web pages. In addition, acceptability was found to be good, as demonstrated by participants' willingness to recommend the SAGE LEAF program to a friend or other caregiver. Applying Pearson correlational analyses, we found moderate, positive correlation between social presence scores and participants' willingness to recommend the program to others (r_9=0.672; P=.03). We also found positive correlation between social presence scores and participants' perceptions about the overall usefulness of the intervention (r_9=0.773; P=.009). This suggests that participants' sense of social presence may be important for the feasibility and acceptability of the program.

Conclusions: In this pilot study, the SAGE LEAF intervention demonstrates potential for broad dissemination for dementia caregivers. We aim to incorporate participant feedback about how the social features may be improved in future iterations to enhance usability and to further bolster a sense of social connection among participants and study staff members. Next steps include partnering with dementia clinics and other caregiver-serving organizations across the United States to conduct a randomized controlled trial to evaluate the effectiveness of the intervention.

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KEYWORDS

dementia; caregiving; eHealth; digital interventions; positive emotion; stress; coping

Introduction

Background

The persistent and progressive nature of dementia has deleterious effects not only for the care recipient but also for the caregiver, adversely affecting key aspects of psychosocial functioning [1,2]. The protracted burdens of caregiving may lead to elevated depression or anxiety [3], with increased duration and severity of symptoms heightening this risk among caregivers [4]. This has a tandem effect on outcomes for care recipients, where increased caregiving burden and stress results in diminished quality of care and quality of life for the patient [5].

To address the issue of caregiver burden, researchers are using new technologies to deliver resources to caregivers. One such intervention, Life Enhancing Activities for Family Caregivers, is a web-based positive emotion regulation intervention delivered through videoconferencing [6-8]. A randomized controlled trial of Life Enhancing Activities for Family Caregivers found that participation led to significant increases in positive emotion (Cohen d=0.58; P<.01) and positive aspects of caregiving (Cohen d=0.36; P<.01) and decreased symptoms of depression (Cohen d=−0.25; P=.02) and anxiety (Cohen d=−0.33; P<.01) compared with an emotion-reporting waitlist control group [6]. During this study, participants met one-on-one with a trained facilitator to learn the skills via videoconference. However, such delivery formats can be costly in terms of the time, effort, and logistics required to meet participants individually. To maximize the scalability of the intervention, there is a need for other delivery options that are more time efficient and cost efficient.

One such delivery format that has been widely adopted is the *self-guided* eHealth intervention, in which participants have access to the content on their own with minimal guidance from facilitators. However, although such interventions reduce barriers to participation, they are beset by high rates of attrition and poor adherence [9,10]. Parallel studies of other self-guided resources, namely Massive Open Online Courses, have found that the construct of *social presence*—or the perception of others being present in a web-based environment—can improve retention and engagement [11]. Features that enhance social presence include welcome messages, sharing participant profiles, and discussion boards [12]. Therefore, the application of such social features may improve engagement with eHealth and mobile health interventions.

Objectives

Social features may be particularly beneficial for caregivers, who experience high levels of social isolation and loneliness compared with noncaregivers [13,14]. This study builds on data collected from focus groups and interviews conducted with providers and caregivers about the social features that might be most helpful for participants (Kwok, I, unpublished data, 2022). For example, focus group participants made suggestions to create podcast content, framing our reminder messages in an encouraging tone, and noted the potential challenges of creating a "buddy system" in which participants would be paired up. On the basis of these suggestions, we adapted the existing caregiver intervention and created Social Augmentation of Self-Guided Electronic Delivery of the Life Enhancing Activities for Family Caregivers (SAGE LEAF)—a socially enhanced, self-guided, web-based intervention for dementia caregivers that incorporated features that would enhance participants' sense of social presence. In this study, our goal was to conduct a pilot study to determine the feasibility and acceptability of SAGE LEAF.

Methods

Participants and Study Procedures

A total of 15 dementia caregivers were recruited from social media advertisements and caregiver support groups and organizations, which often serve as the first point of contact for caregivers who are seeking resources and support. Although the age of onset and disease progression varies across different forms of dementia, caregivers experience a high level of emotional stress and burden, with similar support needs that include respite care, psychotherapy, and support groups.

Interested individuals were sent a screener survey to determine their eligibility based on the following inclusion criteria: (1) identify as the primary family caregiver of a person with dementia, (2) speak and read English, and (3) have access to high-speed internet. In our screener survey, we explained that a primary family caregiver is the caregiver who spends most time with the care recipient. However, we did not define what constitutes a family member to ensure that we were being inclusive of diverse familial arrangements. Caregivers were ineligible if they had participated in a previous version of the intervention. Study staff contacted eligible participants to explain the requirements of the study and seek informed consent. Once consented, participants were sent a link for the SAGE LEAF platform with instructions for creating their password. They were then able to access the intervention content, which included 8 positive emotion skills unlocked over the course of 6 weeks (description of the skills is given in the following section). During this period, they had access to all the social features of the platform.

Previous studies have found that 5 users may be sufficient to identify 80% of usability issues, with diminishing returns from additional testing [15]. Hence, the first 33% (5/15) of the participants were invited for a feedback interview at week 3 to identify any critical usability issues at the halfway point of the intervention that might significantly affect participation. This allowed them to provide feedback about the various features while they were still accessing the website. The subsequent 67% (10/15) of the participants were invited for a feedback interview at the end of the entire course. This would allow us

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to collect feedback from participants who had completed the whole intervention. However, the structure of the interview remained the same for all the participants (15/15, 100%).

Intervention Content and Features

The SAGE LEAF intervention consists of 8 empirically validated positive emotion regulation skills that were delivered over 6 weeks. Each week, new content was unlocked for participants, with daily home practice exercises to reinforce the skills delivered that week. Similar to the previous versions of the intervention [6,16-19], the skills include noticing positive events, savoring, gratitude, mindful awareness, personal strengths, positive reappraisal, self-compassion, and attainable goals. SAGE LEAF is distinct from previous versions in that it has an emphasis on *social features* that are specifically designed based on the feedback we received from focus groups and interviews conducted with caregivers and clinicians who work with patients with dementia (Kwok, I, unpublished data, 2022). Such features include the design or functional elements of the platform that may enhance participants' perceptions of social presence—the extent to which they sense the presence of others during their participation in the intervention. This includes sensing the presence of other caregiver participants and members of the study team. Textbox 1 shows a list of social features that were added to SAGE LEAF.

An example of how we incorporated the feedback from the focus groups and interviews (Kwok, I, unpublished data, 2022) was adopting a more encouraging tone in our automated support features. For instance, if a participant did not log in for a week, an encouraging message was sent to them through their preferred communication method (email or SMS text message). Other social features that we created based on feedback include the multimedia elements of the intervention. For example, in addition to an introduction video shown at the beginning of the study, the study team members recorded a skill-building video at the beginning of each lesson, briefly describing the skill and how it may be potentially helpful for caregivers. Furthermore, we recorded podcasts at the end of each lesson, which provides caregivers with optional content that they can review at their own schedule. The podcasts comprised interviews with study team members explaining how caregivers could overcome some of the challenges with applying the skills in everyday life and how to enhance their practice of the skills. On the basis of the feedback received, we also added more fields for the user profiles, so that participants could choose to share various aspects of their caregiving experience, for example, the relationship between the caregiver and recipient and some of the challenges and positive experiences that they may have had as a caregiver.

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Textbox 1. A list of social features in the Social Augmentation of Self-Guided Electronic Delivery of the Life Enhancing Activities for Family Caregivers intervention.

Videos

- When participants log into the website for the first time, they are shown a short welcome video in which a study team member provides an overview of the study. At the beginning of each skill-building lesson, participants can view a short video in which study team members introduce the skill and provide key takeaways about the topic. This also allows participants to see the team members behind the study, which lends a personal touch to their learning.

Podcasts

- At the end of the skill-building lessons for each week, participants have the option to listen to a short audio recording of staff members discussing how to apply the skills for the week in an informal, conversational format. This enhances the sense that team members have unique, personal perspectives about the skills.

Library

- This is a repository for all unlocked videos, podcasts, and mindfulness meditation recordings that participants can access.

Discussion board

- Participants have access to the moderated discussion board, which is organized according to the different positive emotion skills and is moderated by a study team member. This encourages social interaction around the content being delivered. Participants also have the option to post their home practice activities for each skill on the discussion board. Participants can respond to others' posts or send a "like" or "thank you."

Community tab

- Participants are able to view the profiles of other participants who are on the web at the same time and the profiles of all enrolled participants. This enhances the perception that there are other caregivers going through the study at the same time.

Emotions chart

- Participants' daily emotion survey data are displayed in a graph representing their positive and negative emotions over the past week. Although this feature does not allow for social interaction, it enhances the perception that participants' inputs are being reflected in the feedback provided by the system or study team.

Social notifications

- Participants receive notifications on their dashboard, via email, or via SMS text message if others responded to their posts or sent "like" or "thank you." These prompts call attention to social interactions that are occurring around caregivers' posts and encourage continued dialogue or interaction.

Automated reminders

- On the basis of their preferences, participants receive encouraging email or SMS text message reminders to complete their daily home practice and emotion surveys or if they do not register their password or log into the website for several days during the intervention. This may enhance caregivers' perceptions that the study team is responsive to them and that their continued participation is important.

User profiles

- Participants have their own user profile page where they can select their own avatar or provide answers to questions around their caregiving experience or circumstance; for example, "What are some challenges that you've experienced as a caregiver?" Participants are able to view each other's profiles through the discussion board or community tab, which reduces the anonymity of participating in the intervention and allows participants to learn more about other caregivers participating in the study.

Control panel

- Within their user profiles, participants have access to settings that allow them to select whether they would like to receive notifications and reminders through email or SMS text message. This feature is not inherently social but provides participants with control over features that may have a social component.

Study Evaluation and Measures

All participants completed a 45- to 60-minute phone interview to provide feedback about their experience of using the platform, with a focus on the social features being implemented. Participants dialed into an audio-only Zoom (Zoom Video Communications) session that was recorded. The interview followed a semistructured guide and was conducted with a trained facilitator who has experience with conducting focus groups and interviews (Kwok, I, unpublished data, 2022). The questions evaluated participants' (1) use of the social features, (2) facilitators of or barriers to using the social features, and (3) recommendations for future improvements for each of the social features: for example, "One of the features of the website was the discussion board. Were you able to use the discussion boards? How often did you use them? If not, what kept you from using them? What are some aspects of the discussion boards that you found helpful? What are some aspects of the

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discussion boards that you didn't find helpful? What do you think we could do to encourage people to participate in the discussion boards? How might the discussion boards be improved?" These questions were repeated for each social feature.

Qualitative Analyses

All interviews were recorded and automatically transcribed using Zoom's cloud recording feature. Content analysis was conducted by categorizing user feedback as positive, negative, or implementation suggestions corresponding to each social feature. In addition, we noted any issues that participants might be having with the other aspects of using the SAGE LEAF website.

Measures

Participants completed the surveys at baseline and after the intervention at week 8. We added a 1-week buffer before and after the 6-week intervention, so that we could ensure that participants had fully completed the study before sending out the postintervention surveys. The postintervention survey included our primary measures that assessed the (1) usability, (2) usefulness, (3) feasibility, and (4) acceptability of the SAGE LEAF platform. Furthermore, we measured the participants' perceptions of others on the SAGE LEAF platform by using an adapted version of the original Social Presence Scale [20]. Although the study was not designed to determine the efficacy of the intervention, we included measures to examine pre-post changes in measures of caregiving burden and psychological well-being. A list of measures is shown in Table 1.

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Table 1. List of measures and constructs with descriptions.

Measures and constructs	Description and examples
Primary measures and constructs	
System Usability Scale	This is a 10-item measure widely adopted in user experience studies to determine system usability across diverse technologies.
Feature-specific usefulness	We adapted the Perceived System Usefulness scale to rate the perceived usefulness of the individual social features of the website (eg, "Using the discussion board would be helpful for my learning," with a 5-point Likert scale ranging from 1 [strongly disagree] to 5 [strongly agree]).
System-wide usefulness	This is a measure that was tailored to rate the perceived usefulness of the SAGE LEAF[a] website as a whole (eg, "The system was useful in helping me learn the positive emotion skills," with a 5-point Likert ranging scale from 1 [strongly disagree] to 5 [strongly agree]). This system-level evaluation of usefulness is often adopted in health care technology studies [21].
Feasibility	Adherence was assessed as the proportion of pages viewed out of the total possible pages in the intervention, and retention was assessed as the percentage of participants who completed the postintervention assessment.
Acceptability	We asked participants' willingness to recommend the SAGE LEAF program to a friend or dementia caregiver using an 11-point Likert scale ranging from 0 (definitely no) to 10 (definitely yes).
Social Presence Scale	An adapted version of the original Social Presence Scale [20], which includes 14 items relating to social presence on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Items include "The SAGE LEAF website is an excellent place for social interaction" and "I felt comfortable participating in discussions on the SAGE LEAF discussion boards." We added an additional item to account for perceptions of social presence of other participants and study staff separately. The Social Presence Scale has been shown to have a high level of reliability (Cronbach α=.88) and has been adapted to evaluate a broad range of web-based communities [11].
Social connection	This comprises 4 items to capture a general sense of social connection to others, where participants reported the extent to which they felt isolated or connected to others, had a lot in common with others, or had people they can relate to. These items were rated on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree).
Preliminary outcomes	
Zarit Burden Interview	This is a 22-item measure that evaluates caregiving burden [22]: for example, "Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?"
OCBS[b]	This is a 15-item measure that assesses the (1) perceived amount of time spent (OCBS-Time) or (2) difficulty of tasks (OCBS-Difficulty) relating to various caregiving activities [23]: for example, "Emotional support, 'being there' for the patient; Please select how much time you spend on this task and Please select how difficult it is to do this task."
Positive Aspects of Caregiving Scale	This is an 11-item measure that evaluates caregivers' outlook about life and self-affirmations [24]: for example, "Providing help to (Care Recipient) has made me feel needed, appreciated, important, etc."
Caregiver Reaction Scale	This is a measure that evaluates the socioemotional effects of caregiving, for which the 2 domains of role captivity and overload relate to caregiving burden [25]: for example, "How much does each statement describe your thoughts about caregiving? Wish you could just run away. Feel stressed by your relative's illness and needs."
Differential Emotions Scale	Positive and negative affect was assessed as the extent to which participants may or may not have experienced various emotions (eg, peaceful, interested, and guilty) over the past week [7].
Perceived Stress Scale	This is a 10-item measure that assesses the extent to which participants evaluate their circumstances to be uncontrollable, unpredictable, or overloaded [26]: for example, "In the last month, how often have you felt that you were on top of things?"
Satisfaction With Life Scale	This is a widely administered 5-item measure of global evaluations of life satisfaction [27]: for example, "In most ways my life is close to ideal."
Patient-Reported Outcomes Measurement Information System	This is a toolbox of instruments developed by the National Institute of Health [28], which measures broad aspects of psychosocial functioning. We included the instruments for positive affect, social isolation, anxiety, depression, meaning and purpose, and sleep disturbance, which represent salient aspects of a caregiver's psychosocial functioning.

[a]SAGE LEAF: Social Augmentation of Self-Guided Electronic Delivery of the Life Enhancing Activities for Family Caregivers.

[b]OCBS: Oberst Caregiving Burden Scale.

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Statistical Analyses

We calculated the medians and IQR for primary measures that assessed the (1) usability, (2) usefulness, (3) feasibility, and (4) acceptability of the SAGE LEAF platform. In addition, we calculated supplementary user metrics based on data collected by the platform (eg, percentage of home practice activities completed and percentage of videos watched) that reflect various aspects of engagement. We calculated the means and SDs for the Social Presence Scale and applied them as a correlate with measures of usability, usefulness, feasibility, and acceptability. For measures related to preliminary outcomes, we performed paired, 1-tailed *t* tests on the data collected during the baseline and postintervention assessments to examine changes in means. Analyses were conducted using Excel (Microsoft Corporation) and R Studio (Posit).

Ethics Approval

The Northwestern University Institutional Review Board reviewed and approved the protocol for this study (Reference number: STU00215548).

Results

Study Recruitment, Enrollment, and Retention

Participants were recruited from a group of individuals who responded to social media advertisements for another caregiver study but were not eligible (3/15, 20%) and from dementia caregiver support groups (12/15, 80%). A total of 25 participants were screened, of which 10 (40%) were excluded owing to the following reasons: the care recipient did not have a diagnosis of dementia (4/25, 16%), they were no longer interested in participating in the study (2/25, 8%), and they dropped out before enrollment (4/25, 16%). Eligible participants provided web-based informed consent; completed a baseline assessment; and were subsequently sent an email with instructions about how to set up their account on the SAGE LEAF website, which would give them access to the 6-week program. Upon the completion of the SAGE LEAF course, they completed a follow-up assessment. In addition, all participants (15/15, 100%) completed a feedback interview, with (1) the first 33% (5/15) of the participants scheduled to complete the interview at week 3 to determine if there were significant usability issues early in the progression through the program, and (2) the next 67% (10/15) of the participants scheduled to complete the same feedback interview after they had completed the intervention. Initially, the qualitative feedback from the first 33% (5/15) of the participants was examined separately. However, given that there were no significant usability issues identified among them and that the subsequent 67% (10/15) of the participants completed exactly the same version of the intervention, the qualitative feedback and quantitative data were combined for analysis. The baseline characteristics of participants are shown in Table 2.

Table 2. Baseline characteristics (N=15).

Participant characteristics	Values
Gender, n (%)	
Female	11 (73)
Male	4 (27)
Age (years), mean (SD)	62.80 (11.31)
Race and ethnicity, n (%)	
Hispanic or Latinx and White	2 (13)
Non-Hispanic and White	13 (87)
Relationship with patient, n (%)	
Spouse	13 (87)
Other family member	2 (13)
Duration of caregiving (years), mean (SD)	4.27 (2.94)
Diagnosis, n (%)	
Frontotemporal dementia	11 (73)
Uncategorized dementia	4 (27)

Feasibility, Acceptability, Usability, and Usefulness

User metrics and measures for feasibility, acceptability, usability, and usefulness were collected upon completion of the intervention. Feasibility of the SAGE LEAF intervention was determined as the average percentage of number of web pages viewed out of the total 139 pages available in the intervention. These data were collected by the SAGE LEAF website. Participants demonstrated good adherence, completing an average of 72% (SD 42%; 100/139 pages) of the pages of the intervention.

Other measures for acceptability, usability, and usefulness were collected using the postintervention survey. As these data were not normally distributed owing to a relatively small number of participants, we calculated the medians and IQRs for these variables. Acceptability was evaluated to be good, with participants rating their willingness to recommend the SAGE

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LEAF program to a friend (median 8; IQR 6-8) or dementia caregiver (median 8; IQR 6.25-9.5), with 1 indicating *definitely not* and 10 indicating *definitely yes*. Usability was assessed using the System Usability Scale, with a median score of 73.75 (IQR 57.5-85.63) out of a total of 100, which can be interpreted as "good" from a usability perspective [29]. In terms of *feature-specific* usefulness, on a scale of 1 to 5, participants rated the discussion board with a median score of 3 (IQR 2-3), email reminders with a median score of 3 (IQR 2-4), user profiles with a median score of 2 (IQR 2-3), videos with a median score of 3 (IQR 3-3.75), podcasts and audio recordings with a median score of 3.50 (IQR 3-4), and social notifications (ie, alerts about likes and comments) with a median score of 3 (IQR 2-3). The ratings suggest that the podcast and audio recordings were determined to be the most useful feature. In terms of *system-wide* usefulness, participants rated SAGE LEAF with a median score of 3.70 (IQR 3-4.75) on a scale of 1 to 5.

Regarding social presence, participants rated the SAGE LEAF program with a median score of 3 (IQR 2.66-3.33) on a range of 1 to 5. Studies of the Social Presence Scale have not yet established benchmarks for what constitutes optimal levels for web-based platforms. However, past studies demonstrate strong associations between social presence scores and student's satisfaction and learning, in the context of e-learning platforms [11]. Hence, we performed exploratory Pearson correlational analyses with social presence scores as a correlate with feasibility, acceptability, usability, and usefulness ratings. Our analyses found moderate, positive correlation between social presence scores and participants' willingness to recommend the program to others (ie, friends and other caregivers; r_9=0.672; P=.03). We also found positive correlation between social presence scores and participants' perceptions about the overall usefulness of the intervention (r_9=0.773; P=.009). We found no statistically significant associations with other feasibility, usability, and usefulness measures. Table 3 shows the results of these measures.

Table 3. Usability, usefulness, feasibility, and acceptability measures.

Metrics and measures	Values
SAGE LEAF[a] website metrics (N=15), mean (SD)	
Total number of skills content pages reviewed	106.73 (62.50)
Total skills content completed (%)	72 (42)
User measures (n=10; scale ranging from 1 to 5 or as indicated), median (IQR)	
System Usability Scale (total=100)	73.75 (57.5-85.63)
Feature-specific usefulness	
Discussion board	3 (2-3)
Email reminders	3 (2-4)
User profiles	2 (2-3)
Videos	3 (3-3.75)
Podcasts and audio recordings	3.50 (3-4)
Social notifications	3 (2-3)
System-wide usefulness	3.33 (3-4.75)
Social Presence Scale	3 (2.66-3.33)
Acceptability (n=10; scale ranging from 1 to 10), median (IQR)	
Would recommend to a friend	8 (6-8)
Would recommend to a caregiver	8 (6.25-9.5)

[a]SAGE LEAF: Social Augmentation of Self-Guided Electronic Delivery of the Life Enhancing Activities for Family Caregivers.

Preliminary Outcomes

Of the 15 participants, 5 (33%) were lost to follow-up. The remaining 67% (10/15) of the participants completed both the baseline and postintervention surveys, which included measures relating to preliminary outcomes (Table 4). One-tailed paired t tests demonstrated a statistically significant (1) decrease in negative affect from baseline (M=1.71, SD 0.78) to after the intervention (M=1.34, SD 0.72; t_9=−2.49, P=.03); (2) decrease in perceived stress from baseline (M=9.00, SD 1.63) to after the intervention (M=7.50, SD 1.78; t_9=−2.29, P=.05); and (3) decrease in anxiety from baseline (M=61.42, SD 5.00) to after the intervention (M=57.45, SD 7.96; t_9=−2.52, P=.03); we also found a statistically significant (4) increase in meaning and purpose from baseline (M=43.56, SD 7.33) to after the intervention (M=47.19, SD 5.63; t_9=2.60, P=.03). No other statistically significant changes were found between the baseline and postintervention findings. However, no definitive conclusions about efficacy can be made, because our pilot study did not have a control group and was not sufficiently powered.

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Table 4. Preliminary outcome measures (n=10).

Measures	Baseline score, mean (SD)	Postintervention score, mean (SD)	Difference, mean (SD)	*t* test (*df*)[a]	*P* value	Cohen *d*
Primary measures						
Zarit Burden Interview	16.40 (4.17)	15.67 (3.54)	−0.89 (3.10)	−0.86 (9)	.41	−0.29
OCBS[b]—time	3.07 (0.75)	3.07 (0.75)	−0.01 (0.27)	−0.06 (9)	.95	−0.02
OCBS—difficulty	2.71 (0.78)	2.77 (0.82)	0.05 (0.41)	0.40 (9)	.70	0.13
Positive Aspects of Caregiving Scale	22.23 (8.91)	22.23 (9.27)	0.09 (6.75)	0.03 (9)	.98	0.01
CRS[c]—role captivity	2.58 (0.64)	2.55 (0.70)	−0.03 (0.55)	−0.14 (9)	.89	−0.05
CRS—overload	2.92 (0.69)	2.65 (0.83)	−0.27 (0.74)	−1.14 (9)	.28	−0.36
Caregiving Mastery Subscale	2.55 (0.71)	2.66 (0.45)	0.11 (0.59)	0.57 (9)	.58	0.18
Other measures						
Positive affect (Daily Emotion Survey)	1.65 (0.68)	1.82 (0.68)	0.18 (0.46)	1.20 (9)	.26	0.38
Negative affect (Daily Emotion Survey)	1.71 (0.78)	1.34 (0.72)	−0.38 (0.48)	−2.49 (9)	.03[d]	−0.79
Cohen Perceived Stress Scale	9 (1.63)	7.50 (1.78)	−1.50 (2.07)	−2.29 (9)	.05[d]	−0.73
Satisfaction with Life Scale	16.60 (5.19)	17.80 (5.69)	1.20 (3.74)	1.02 (9)	.34	0.32
PROMIS[e]—social isolation	53.30 (6.93)	51.27 (5.73)	−2.03 (4.75)	−1.35 (9)	.21	−0.43
PROMIS—anxiety	61.42 (5)	57.45 (7.96)	−3.97 (4.98)	−2.52 (9)	.03[d]	−0.80
PROMIS—depression	59.59 (4.44)	57.96 (5.05)	−1.63 (4.30)	−1.20 (9)	.26	−0.38
PROMIS—meaning and purpose	43.56 (7.33)	47.19 (5.63)	3.63 (4.41)	2.60 (9)	.03[d]	0.82
PROMIS—sleep disturbance	51.65 (5.22)	52.73 (7.27)	1.08 (4.45)	0.77 (9)	.46	0.24
NIH[f]—positive affect	39.20 (11.45)	42.20 (10.71)	3 (6.18)	1.53 (9)	.16	0.49

[a]One-tailed *t* test.

[b]OCBS: Oberst Caregiving Burden Scale.

[c]CRS: Caregiver Reaction Scale.

[d]Statistically significant *P* values; $P \leq .05$.

[e]PROMIS: Patient-Reported Outcomes Measurement Information System.

[f]NIH: National Institute of Health.

Feedback Interviews

Initial Feedback About Social Features

The first 33% (5/15) of the feedback interviews (conducted midway through the 6-week program) revealed that participants' use and understanding of how the social features worked varied greatly. For example, some participants noticed the social notifications and the number of "post views" on the discussion board, visited other members' profiles, and commented or liked other users' posts. Other participants did not realize that they could customize their own user profile or view other users using the community tab. One of the initial user test participants suggested that we should provide more guidance about the various features of the website. Hence, we recorded a brief tutorial video about how to use the SAGE LEAF website, which was then included as a link in an email to all participants, highlighting the different social features of the website:

> *Yes, I did see them [social notifications]...and then I realized that you know someone was actually reading...because i've done that to other people's posts...it's like being on Facebook, but it's good because it makes it makes you feel you know someone is actually realizing what you're going through and thanking you for sharing that.* [Participant 02]

No other usability issues were identified from the feedback. Hence, we did not make any other additional modifications to

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the website or intervention following the first 33% (5/15) of the user tests. As all participants (15/15, 100%) received the same version of the intervention, the subsequent feedback was aggregated and organized according to the various social features.

Podcast and Video Content

Generally, there was positive feedback about the video and podcast content. Participants liked being able to learn more about the skills from the perspective of team members while being able to see or hear the people behind the study:

> *It was nice to get that personal touch I did like that...You know the fact that it was you know people that are working as part of the study...it shows that there's a...sense of ownership...* [Participant 01]

Participants described how the videos were able to enhance their awareness about the study staff involved in running the intervention. In addition, they praised the format of the videos in terms of being able to communicate key takeaways in a short amount of time:

> *...Hearing other people's voices or we're seeing their faces, I think that made it feel more like being part of like a class or something a little more social aspect to it than just the reading and answering the questions.* [Participant 08]

However, there were suggestions about how this content could be improved. For example, a participant mentioned that the combined time required to complete the video, didactic content, and podcasts in one sitting might be a lot for caregivers with busy schedules. Although the videos and podcasts were optional and participants could choose to return to this content at any point, this participant suggested that we send out optional content such as the podcasts sometime later in the week to reinforce their learning.

In addition, 13% (2/15) of the participants mentioned that they felt that some of the information provided in the videos overlapped with that in the lessons. They offered suggestions to include case studies and testimonials featuring other caregivers in the videos or podcasts, which would complement the lessons. They also suggested including examples of how the skills could be used in more stressful caregiving situations:

> *Case studies would be good, you know where you could see maybe how they've [positive emotion skills] helped other people...maybe have some people who would be willing to give things from an actual caregiver perspective...Like if you're talking about you know positive reinforcement or whatever, if someone could say, well, I had this experience, and this is how it helped me.* [Participant 11]

Discussion Board

Several participants expressed positive feedback about the discussion boards, which provided them with a medium to share their feelings or experiences with using the positive emotion skills:

> *I thought, "Okay we'll give it [discussion board] a try."...and it was nice getting the feedback, "Oh, you know I understand where you are."...I guess it was kind of nice to read through some of them and realize that I'm not the only one dealing with with all of this, which I knew before, but it's nice to be reminded of that...* [Participant 06]

Furthermore, most participants noticed the social notification feature, which provided them with a prompt when other users liked or replied to their posts on the discussion board. However, other participants did not find the discussion board as helpful because they noticed that participants were primarily posting answers to their home practice activities instead of responding to each other's posts:

> *I look to see what other people were putting down and out of all the people who were on there, I think, maybe, only three of us actually put information down about ourselves. And the rest of the people I think chose not to reveal anything about themselves. So there really wasn't any bonding, so to speak.* [Participant 13]

A participant suggested promoting "popular" or recent posts on the home page as a way of encouraging engagement among caregivers by highlighting content that may be interesting to them. Additional feedback indicated that there was interest in broadening the scope of the discussion board to include more general topics. This would allow participants to foster a sense of community and social connection:

> *I wish to keep the skill-focused discussion, which is great...people trying to understand the skills and that's important...and then have the open-ended conversation where people are talking about day to day life in their situation...hopefully they're bringing their own understanding of the skills to that situation.* [Participant 03]

Automated Reminders

The pilot test revealed that most participants were completing their daily emotion surveys and home practice activities regularly. This may be attributed to the automated reminders that we programmed for when new lessons were unlocked or when participants did not register their accounts or log into the platform for several days. When asked about whether it might be helpful to increase the frequency of reminders, a participant suggested that the frequency might become very high. Another participant suggested that the reminders sounded "generic" and could be personalized by study staff members:

> *And it just occurred to me another thing that the emails were generic...there was no personality there. Since we're meeting people in the course of the video program, it might be something where you can take advantage of these people and use them as the voice and face of some of these emails. This is so, and so, and you know I spoke to you this week about that and just want to...just know that we're all here to support you...So its not just another email.* [Participant 05]

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A participant suggested that having the reminders worded differently each day with a thoughtful message may encourage future participants to read these emails and to log into the platform:

> *I think, for me it would be just a simple reminder, but it wouldn't say the same thing, every day, I would get an email saying, "Oh it's Earth Day...and don't forget to do your daily check in."...So it's not the same thing every day, because I'm sure that most people are like me, and I get so many emails every day.* [Participant 06]

User Profiles and Control Panel

Although 33% (5/15) of the participants completed their user profiles, others were not aware that they could customize their user profile by selecting an avatar, providing answers to questions about their caregiving circumstance, or customizing their preferences to receive notifications via email or SMS text message. On the basis of preliminary feedback, we had created a tutorial video explaining how the various social features worked and sent it to pilot test participants via an email link. However, participants' lack of awareness about the user profile feature suggests that they may not have watched this video. In addition, some participants were not aware about the community tab, which showed the profiles of all participants in the study. Hence, a participant suggested that the study should encourage users to complete their profiles and select their control panel preferences before the beginning of the lessons:

> *I think when we initially sign in that's usually like the best time where you can kind of be like, "Oh, do you want to receive text message notifications?" And you can kind of like set it all up at the very start.* [Participant 08]

Emotions Feedback Chart

Most participants had accessed the emotions chart tab on the landing page, and several found this feature to be helpful because this feedback enhanced their awareness about the emotions that they were experiencing. However, similar to the community tab that was located on the landing page, some users were not aware that the website included this feature. This feedback reiterates the need to explain how the social features work or how they may be beneficial for participants. For example, when participants are completing their daily emotion surveys, we could remind them that their data will be reflected in the emotions chart as a way of encouraging them to complete the surveys:

> *It was interesting...and kind of reflect back on, "Oh well, you know I wasn't having a good day that day," or, "That day went pretty well," so it was just kind of interesting to see about how many days are bad or how many days are good.* [Participant 11]

Other Feedback

We also asked participants for suggestions about other social features that might encourage social connection. A participant suggested the use of chat rooms, which would allow future users to connect in real time. Another participant discussed how it might be helpful to have caregivers join the study in small groups and have their profiles shared among each other before joining the study:

> *If there was five or six people or whatever...and that we would have the opportunity to kind of get to know each other and our backgrounds and to make our sharing about our situations and our challenges more meaningful...I'd be more inclined to do that, rather than just all these people up there...I don't know is there 2000 of them, or eight of them, or what you know...* [Participant 06]

The importance of the onboarding process was reiterated by another participant who suggested that future participants may be motivated to use the various social features if they were informed about how they could use them as tools for fostering social connection.

Other participants suggested that future users would benefit from having additional context about how and why the features might be beneficial for them in various ways. This could be included in reminders or brief instructions on the SAGE LEAF website, which would encourage the use of the social features:

> *Give them like a reminder, like you can even put a little note in the "Community" thing like, "Hey don't forget to fill out your profile and you can look at other people's profile," or you know what I mean just a little reminder like that.* [Participant 05]

Taken together, this feedback suggests that providing timely reminders about how the social features work and how they might be helpful may encourage future participants to use them. A summary of the feedback collected about each social feature and potential implementation ideas is presented in Table 5.

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Table 5. Summary of feedback and potential implementation ideas.

Feature	Summary of feedback	Future implementation ideas
Videos and podcasts	Participants enjoyed the multimedia content, and these features allowed them to hear from the study team members involved in the study. However, some participants found the content as repetitive and wanted to hear from other caregivers.	• Including testimonials and case studies from other caregivers in the video and podcast content
Discussion board	Participants generally liked the discussion boards but found that other participants were mostly posting their home practice activities instead of engaging with each other.	• Promoting recent or popular posts • Including additional discussion boards that are more open ended and unrelated to the skills
Automated reminders	Participants suggested that the automated reminders seemed "generic." They also indicated that sending daily reminders might be very overwhelming for caregivers.	• Including thoughtful or customized messages in the reminders • Maintaining the existing frequency of reminders instead of daily reminders
User profiles and control panel	In total, 33% (5/15) of the participants completed their profile information, with several other participants indicating that they did not know about the user profile and control panel features.	• Incorporating the completion of user profiles during the onboarding process
Emotions feedback chart	Some participants were not aware about this feature.	• Reminding participants that their daily emotion survey data will be displayed in the emotions feedback chart when they are completing the survey
Other feedback	Participants' understanding of how the features worked varied greatly.	• Creating tutorial slides or videos that participants access during the onboarding process, which would explain how the features work and why they might be helpful for caregivers • Adding brief instructions for the features, explaining how they work and why they might be helpful for caregivers
Other feedback	Participants suggested implementing features that could further enhance a sense of connection among caregivers.	• Including chatrooms • Recruiting small cohorts of caregivers

Discussion

Principal Findings

In this study, we adapted an existing intervention that has been previously tested with caregivers by incorporating social features into the design of the platform, which include podcasts and videos from the study team, multimedia library, discussion board, community tab, emotion feedback chart, social notifications, automated reminders, and user profiles. We then conducted a pilot test to determine its feasibility and acceptability. Participants' ratings showed that the SAGE LEAF intervention demonstrated a high level of feasibility and acceptability.

Participants provided feedback about how to improve the social features in a way that would foster great social presence. Participants liked the format and content of the videos and podcasts, which enhanced their perception of the presence of study team members involved in the intervention. However, these could be improved by featuring caregivers through case studies or testimonials or discussing how the skills could be used in acutely stressful situations. The interviews revealed that most participants used the discussion board to post their home practice answers. However, there was less interaction among participants in response to each other's posts. A suggestion was to highlight new or relevant posts that might entice users to interact with each other. The feedback indicates that the participants' experience with using the discussion board may be enhanced if they had had more understanding about how other related social features work, including the user profiles, social notifications, automated reminders, and community tab—which may have synergies in enhancing the perception that there are other caregivers using the platform. Several participants also liked the emotions feedback chart because it provided feedback about their emotion data, but some participants were not aware about this feature.

In general, participants suggested that it would be important to explain why the features might be beneficial for caregivers early in the intervention. Hence, future versions of SAGE LEAF may incorporate this information in a tutorial video or slides during the registration process or encourage participants to select an avatar and complete their profile when they first log into the website, so that it can help them connect with other caregivers. Hence, we hope to enhance the onboarding process in future versions of SAGE LEAF, so that it sets up participants for successful social interactions during their time in the program. Given the web-based, self-guided format of the intervention, this initial setup process may be particularly crucial owing to the lack of direct contact between participants and study staff members. Other implementation suggestions from participants include enrolling small cohorts of participants and sharing relevant aspects of their profiles with the group. This may help

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establish a more personal context for interacting over the web and foster a strong sense of social connection.

Further Studies and Implications

Building on these early findings, future studies may include a randomized controlled trial of the SAGE LEAF intervention, in which a large pool of participants may be assigned to different combinations of the social features through a factorial design. A previous iteration of the intervention for individuals with depression showed that the combination of internet-based rewards and brief facilitator contact resulted in participants completing more of the intervention compared with those who only had access to only 1 feature [30]. A factorial design may be helpful in understanding which SAGE LEAF social features may have unique synergies for dementia caregivers. For example, for SAGE LEAF, the combination of user profiles with the discussion board may allow participants to learn more about the other participants who they are communicating with, thereby enhancing a sense of social presence. It is also plausible that other social feature combinations may work against each other such that a lot of social features may be burdensome for participants because our feedback interviews revealed that receiving daily reminders or completing the videos, skill lessons, and podcasts in one sitting is difficult for many caregivers. In addition, participants might feel pressured to share information or compete in internet-based challenges if all the activities have a social component. Hence, this future study will be helpful in teasing apart how such social feature combinations may influence outcomes.

Moving forward, once shown to be efficacious, the program may be broadly disseminated through dementia clinics across the country. For example, a local clinic may implement the SAGE LEAF intervention by enrolling a cohort of caregivers living in the same geographic area, which may complement their ongoing support group programming. Furthermore, dementia clinics may use the SAGE LEAF platform to connect participants who provide care for recipients with more uncommon forms of dementia. The web-based format of SAGE LEAF could facilitate participation across clinics in different geographic locations, allowing caregivers to connect with others who might share their unique circumstances.

Strengths and Limitations

One of the strengths of this study is that the social features that we incorporated were based on a previous study in which we collected qualitative feedback from clinical providers and caregivers about which features would be most helpful for caregivers (Kwok, I, unpublished data, 2022). We also performed a pilot test in which participants were given access to a fully functional version of the SAGE LEAF website, which would allow them to engage in these social features as if they were actual users with other participants enrolled at the same time. Typically, user experience evaluation studies are conducted through brief *momentary evaluations* or *episode tests*, with a trained facilitator having participants go through various tasks, collecting participants' comments in real time, and recording the time that it takes to complete these tasks and their completion rates [31]. Instead, the pilot test allowed participants to evaluate the usefulness of our social features in a more naturalistic way and help us identify any significant usability issues.

A limitation of our study is our small sample size (N=15), which limits the generalizability of the findings. The small sample size allowed for a detailed and in-depth examination of usability and feasibility concerns through a mix of quantitative and qualitative methods. However, a large cohort of participants may have revealed more insights about the usability of the social features.

Another limitation of the study is that our sample lacked diversity in the type of diagnosis of dementia, with most participants being caregivers of a family member with frontotemporal dementia. There are >100 known forms of dementia, with Alzheimer disease being the most common diagnosis [32], and there is significant variation in the presentation of these diagnoses. In terms of differences in the presentation of dementia, Alzheimer disease affects individuals at an older age compared with frontotemporal dementia. In addition, Alzheimer disease results primarily in memory impairments as compared with the significant changes in language skills and personality exhibited by individuals with frontotemporal dementia. However, although care needs may differ, caregiving burden remains high across diagnoses, and the positive emotion skills may be helpful in managing the stress of caregiving. Therefore, the insights collected about feasibility and acceptability from this pilot study are likely to be generalized across diagnoses. Future studies may involve comparing cohorts of participants with care recipients with similar diagnoses and confirming that the intervention is effective across diagnoses. These cohorts may also be recruited based on the relationship between the caregiver and care recipient (eg, children caring for their parent or parent-in-law vs caregivers who are partners or spouses), which may enhance a sense of social connection among participants who share similar caregiving circumstances.

Furthermore, our sample lacked ethnic diversity, with non-Hispanic, White participants comprising 87% (13/15) of all participants. This warrants recognition because racial and ethnic minority communities are disproportionately affected by dementia. For example, dementia is approximately 50% more prevalent among Mexican American older adults [33] and Alzheimer disease is twice as prevalent among Black older adults than among their White counterparts [34]. In addition, as internet access varies across ethnic groups, our sample may have been more familiar with using the internet and email to participate in the study. Future collaboration with community groups relating to older adult services, family services, faith-based groups, and so on may help with outreach for underserved caregivers [35]. For large-scale evaluations of SAGE LEAF, relevant recruitment strategies may include tailoring our efforts according to geographic location, providing monetary incentives for engaging in more specific components of the study (eg, completion of each lesson and home practice activity), affording great flexibility in how we contact participants, and providing more extensive recruitment training [36-38].

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Conclusions

Through our pilot test, we found the SAGE LEAF intervention to have a high level of feasibility and acceptability. In general, participants liked the social features that were implemented and expressed feedback about how they could be improved to enhance their usability and foster a sense of social connection. Future iterations of the SAGE LEAF intervention may include a more extensive onboarding process describing how the social features work and how they may benefit caregivers. We hope that future refinements to the intervention will enhance the perception that there are other caregiver participants and study staff involved, thereby fostering great engagement among participants.

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Conflicts of Interest

Authors EGL is currently employed by Lyra Health.

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Abbreviations

SAGE LEAF: Social Augmentation of Self-Guided Electronic Delivery of the Life Enhancing Activities for Family Caregivers

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Original Paper

Differences in Life Space Activity Patterns Between Older Adults With Mild Cognitive Impairment Living Alone or as a Couple: Cohort Study Using Passive Activity Sensing

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Abstract

Background: Measuring function with passive in-home sensors has the advantages of real-world, objective, continuous, and unobtrusive measurement. However, previous studies have focused on 1-person homes only, which limits their generalizability.

Objective: This study aimed to compare the life space activity patterns of participants living alone with those of participants living as a couple and to compare people with mild cognitive impairment (MCI) with cognitively normal participants in both 1- and 2-person homes.

Methods: Passive infrared motion sensors and door contact sensors were installed in 1- and 2-person homes with cognitively normal residents or residents with MCI. A home was classified as an MCI home if at least 1 person in the home had MCI. Time out of home (TOOH), independent life space activity (ILSA), and use of the living room, kitchen, bathroom, and bedroom were calculated. Data were analyzed using the following methods: (1) daily averages over 4 weeks, (2) hourly averages (time of day) over 4 weeks, or (3) longitudinal day-to-day changes.

Results: In total, 129 homes with people living alone (n=27, 20.9%, MCI and n=102, 79.1%, no-MCI homes) and 52 homes with people living as a couple (n=24, 46.2%, MCI and n=28, 53.8%, no-MCI homes) were included with a mean follow-up of 719 (SD 308) days. Using all 3 analysis methods, we found that 2-person homes showed a shorter TOOH, a longer ILSA, and shorter living room and kitchen use. In MCI homes, ILSA was higher in 2-person homes but lower in 1-person homes. The effects of MCI status on other outcomes were only found when using the hourly averages or longitudinal day-to-day changes over time, and they depended on the household type (alone vs residing as a couple).

Conclusions: This study shows that in-home behavior is different when a participant is living alone compared to when they are living as a couple, meaning that the household type should be considered when studying in-home behavior. The effects of MCI status can be detected with in-home sensors, even in 2-person homes, but data should be analyzed on an hour-to-hour basis or longitudinally.

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KEYWORDS

passive monitoring; in-home sensor; mild cognitive impairment; 2-person home; life space activity; sensor; older adult; aging; elder; gerontology; geriatric; cognition; cognitive impairment; activity pattern; at home; daily activities; activities of daily living; digital health; old age; technology

Introduction

Mild cognitive impairment (MCI) is a syndrome characterized by impairment of 1 or multiple cognitive domains that is perceived to not cause major functional impairment in daily life [1]. By definition, people with MCI can function independently [2], that is, they do not have dementia. Half of those with MCI progress to the syndromic stage of dementia within 3 years [3], which means that functional decline worsens over time to the point where impairment clearly interferes with activities of daily living. To prevent loss of independence, which also leads to a high caregiver burden and high health care costs, improving function is thus an important target in clinical trials.

Functional decline is usually reported by people themselves or their informants, using questionnaires such as the Amsterdam Instrumental Activities of Daily Living Questionnaire (Amsterdam iADL-Q [4]), the Functional Activities Questionnaire (FAQ [5]), or the Clinical Dementia Rating (CDR [6]). These methods rely on recall or subjective interpretation of decline during a brief period (eg, “in the past week”), can only be administered periodically, and need active involvement of the participant and a partner, which can be burdensome. Further, the assessment does not consider whether the person lives alone or with a partner, nor does it consider the individual routine of the person with MCI or their coresident. As an alternative to address these limitations, remote monitoring technologies (RMTs), such as in-home sensors, can measure function objectively, continuously, and passively and in the home environment, meaning that no active involvement of the participant or their partner is needed while being observed in the real world.

Previous studies indicate that participants with MCI show altered activity levels and sleep patterns, as measured with wearables [7], and changing patterns of daily life activities, as measured with in-home sensors [8-10], compared to cognitively normal participants. However, many of these studies have a short measurement period or inclusion criteria that limit participation to those living alone. Additionally, studies that include participants living with a coresident may not fully consider the influence of one resident’s activity on the other. These factors can limit the interpretability and generalizability of the findings. With this context in mind, the aim of this study was to compare the everyday behavior activity patterns of older adults living alone with those of older adults living as a couple and to compare older adults with MCI with older adults who are cognitively normal using in-home passive sensors in both 1- and 2-person resident homes. Outcome measures included measures that can be calculated for both 1- and 2-person homes, such as room use, independent life space activity (ILSA), and time out of home (TOOH).

Methods

Recruitment

Participants from 3 cohorts in the Collaborative Aging Research Using Technology (CART) initiative were included: (1) a cohort (n=69 homes) from the Oregon Health & Science University (OHSU) of participants living in low-income, subsidized housing in Portland, Oregon (OHSU group); (2) a cohort (n=61 homes) of military veterans residing in the catchment area of the Veterans Integrated Service Network 20 (US Pacific Northwest), which included largely rural residing veterans (VA group); and (3) a cohort (n=51 homes) from the Rush University Medical Center (RUSH) of older African Americans (RUSH group) participating in the Minority Aging Research Study (MARS) [11]. Inclusion criteria for CART participants were as follows: (1) age≥62 years, (2) living alone (1-person home) or with a partner (2-person home), (3) absence of dementia, (4) not being wheelchair bound, (5) having current or willing to acquire internet access in the home, and (6) having basic technology knowledge (sending/receiving email) [11,12]. CART was a feasibility demonstration project where at least 60 participants per cohort site were planned for enrollment. The age of 62 years and above was chosen to be inclusive of younger older adults, including spouses. The low-income housing cohort was recruited via invitations to potential participants following presentations to several low-income (US Section 202 subsidized housing) facilities in the Portland metropolitan area. Veterans were recruited through community presentations to veterans’ groups and word of mouth among these veterans. The African American cohort was derived from the existing ongoing MARS study cohort in Chicago [13].

Unique to this study is that homes were treated as a unit, rather than looking at individual people living in those homes. A home was classified as an MCI home when at least 1 of the people living in that home was diagnosed with MCI at baseline. The “MCI home” label in this study did not change when the diagnosis changed during the study. The average age and education of a home were the average age and education of the persons living in that home.

Study Protocol

Passive infrared (PIR) sensors (NYCE Sensors) were fixed to the wall of each room in every home. Door contact sensors (NYCE Sensors) were fixed to each door in each home, leading to outside the home to detect whether a door was open or closed. Initially, the sensors were installed for 1 year, but participants were asked to stay longer in the study once the sensors were installed. Weekly questionnaires were sent out to the participants asking whether in the past week any visitors stayed in the home for a night or more or whether the participants were away from home overnight.

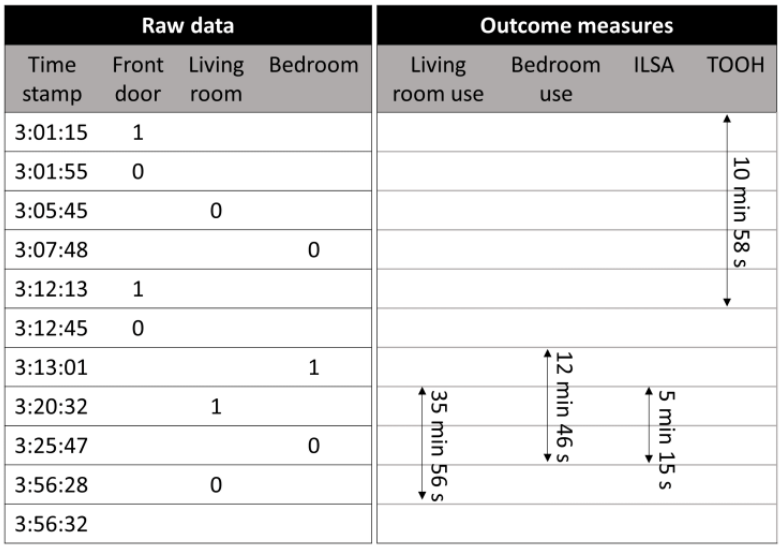
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A baseline visit and yearly follow-up visits included a neuropsychological assessment, physical and neurological examinations, assessment of cognitive status, activities of daily living, depression, anxiety, medical history and medication use, and life habits, as well as questionnaires assessing physical and mental health, loneliness, social activity, technology use, and function [11]. Participants were classified as having MCI based on a CDR global score of 0.5 [6] for the OHSU and VA groups. For the RUSH group, cognitive status was based on a clinical diagnosis by a neuropsychologist evaluating a cognitive assessment battery and a diagnostic classification by a clinician [14,15]. Basic demographic characteristics were collected for all residents in each home.

Outcome Measures

For this study, outcome measures were chosen that could be applied to both 1- and 2-person homes. Although, generally, PIR motion sensors detect only motion and cannot unambiguously differentiate between 2 persons, there are 3 conditions that can be extracted from the data with certainty: (1) when no one is in the home (no motion detected in any room between 2 door openings), (2) when there is at least 1 person in the home (motion detected in 1 room), and (3) when at least 2 persons are using 2 different rooms (motion detected in 2 different rooms at the same time). This resulted in the following outcome measures (Figure 1):

Figure 1. Outcome measures of in-home sensors. Here, 1 indicates door open (for door contact sensors) or motion detected (for room PIR motion sensors), while 0 means door closed (for door contact sensors) or no motion detected/motion no longer detected (for room PIR motion sensors). Room use was defined as the point from the moment motion was detected (1) to the moment motion was no longer detected (0), resulting in the living room being used between time stamps 3:20:32 and 3:56:28 (35 minutes and 56 seconds) and the bedroom being used between time stamps 3:13:01 and 3:25:47 (12 minutes and 46 seconds). The living room and bedroom were being used simultaneously between time stamps 3:20:32 and 3:25:47 (ie, motion detected in both rooms at the same time), resulting in ILSA being 5 minutes and 15 seconds. If there was only 1 person in the home who transitioned from the bedroom to the living room at 3:20:32, the bedroom motion sensor would have shown a 0 at time stamp 3:20:32. We therefore know for sure that there were at least 2 persons moving in the home. TOOH is the moment from time stamp 3:01:15 (door opens) to time stamp 3:12:13 (door opens after being closed), while no motion was detected in the rooms. ILSA: independent life space activity; PIR: passive infrared; TOOH: time out of home.



- Room use: Room use was calculated using PIR motion sensors. It was defined as the time of first motion detection by a sensor up to the time that motion was no longer detected by that sensor. Since PIR sensors detect motion as a change in the environment, sensors cannot detect motion when someone in a room is stationary (eg, when asleep). In 1-person rooms, it can be assumed that someone stays stationary in a room when no motion is detected in any other room in the home. However, when no motion is detected in a specific room in 2-person homes, there is no way to unambiguously verify whether a person has left the room or whether that person has stayed in the room without moving, since motion detection in another room can be caused by another person. Hence, room use duration is the length of time for which it is known with certainty that a room is being used and can therefore be shorter than the actual dwell time. In this study, room use duration for both 1- and 2-person homes was calculated using the same method (without looking at motion in other rooms in the homes), and results were therefore comparable between 1- and 2-person homes. If there was more than 1 room of the same type present in a home (eg, bedroom 1 and bedroom 2), only bedroom 1 (the main bedroom) was analyzed.
- TOOH: TOOH was calculated using the door contact sensor on egress doors and PIR motion sensors. It was defined as the time between 2 door status changes (open–close–open) when no motion was detected by the motion sensors during

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that time. For 2-person homes, this means that both residents had to leave the home before it was counted as TOOH.
- ILSA: ILSA was calculated using PIR motion sensors. It was defined as the time that 2 rooms in the home were used simultaneously, which means at least 2 people in the home using 2 different rooms. For 1-person homes, these people could be the participant and a visitor (overnight visitors were excluded as noted later) or a large pet.
- Percentage of rooms used: The percentage of rooms used was calculated using PIR motion sensors. It was defined as the number of rooms where motion was detected per day divided by the total number of rooms in the home. The total number of rooms in the home was defined as the total number of PIR motion sensors in the home based on the deployment protocol specifying that there was 1 PIR motion sensor installed in each room in the home.

Data Processing

Days were excluded from analyses when the participant indicated on the weekly questionnaire that there were overnight visitors or the residents were away from home overnight and when 1 or more sensors were inactive (eg, due to a low battery). Furthermore, to avoid the influence of COVID-19–pandemic related restrictions, declared on March 20, 2020, in Illinois and on March 23, 2020, in Oregon, data collected after these dates for the respective cohorts were excluded. Moreover, if participants moved to a new home during the study or when they indicated that a person moved in or out of the home for longer than a month (eg, when relatives moved in or 1 of the partners passed away), data collected after the move or after the household resident change were excluded. To avoid the potential effect of participants behaving differently because they knew they were being monitored, the first 2 weeks' data of each home were excluded from the analyses. Of the 232 homes included in CART [11], 209 (90.1%) had both complete clinical data and home sensor data. Of these 209 homes, 28 (13.4%) did not have sufficient data (>4 weeks of data) after excluding the days on which someone moved in or out of the home or the residents moved to a new home and after excluding the first 2 weeks of data.

We used 3 methods to compare 1-person homes with 2-person homes and MCI homes with no-MCI homes:

- Daily summaries: All outcome measures were calculated for each day per home and averaged over all the days afterward, leading to 1 outcome per outcome measure per home. Based on a trade-off between the number of homes with sufficient days of data collection and smaller variances (Figure S1 in Multimedia Appendix 1), we chose to take the mean of the first 4 weeks of eligible data from each home (after the exclusion of the first 2 weeks of data collection). Only weekdays were used for the analyses to avoid the effect of changing patterns during the weekend [16]. Data collection interruptions were ignored.
- Hour-to-hour summaries: All outcome measures were calculated for each hour for each day per home and averaged per hour across days afterward, leading to 24 outcomes for each outcome measure per home. Again, the first 4 weeks of eligible data and only weekdays were used for the analyses. This means that each hour for each participant was a representation of their average activity for that hour of the day over the 4-week study period.
- Daily change over time: All outcome measures were calculated for each day per home. The slope and variability were calculated for those daily measures. To capture meaningful changes, only homes that had a minimum measuring period of 6 months were included.

Statistical Analysis

The 4 study groups (1-person MCI and no-MCI homes and 2-person MCI and no-MCI homes) were compared based on age, sex, and years of education using ANOVA, the Kruskal-Wallis test, or the chi-square test, as appropriate. Outliers deviating more than 5 SDs from the mean for each outcome variable were removed.

For daily summaries, linear models were used, with the daily summaries as the dependent variable and MCI status (MCI/no-MCI) and household-type (1-person/2-person) as independent variables, including the interaction effect between those variables, corrected for the mean age of the home, the number of females in the home, the number of males in the home, the number of White people in the home, the number of people of an ethnicity other than White in the home, the total number of rooms in the home, and the mean years of education of the home, according to the following model formula: PIR motion outcome ~ β_0 + β_1(2-person) + β_2(MCI) + β_3(2-person × MCI) + β_4(age) + β_5(females) + β_6(males) + β_7(White) + β_8(other ethnicity) + β_9(rooms) + β_{10}(education).

Sex and ethnicity were treated as nominal variables, while age, rooms, and education were treated as continuous variables. The household type and MCI status were dummy variables (2-person vs 1-person and MCI vs no-MCI, respectively). To reduce the number of levels, only White and other ethnicities were used, as White was the most prevalent ethnicity in this sample. If the interaction effect of MCI status × household type was significant, analyses were stratified for household type, other the interaction effect was removed. For the percentage of rooms used, the covariate number of rooms was not included in the formula, as this was already included in the percentage of rooms used.

Hour-to-hour summaries were compared between groups using latent class trajectory analysis. The framework proposed by Lennon et al [17] was used to find the optimal model and the number of classes for each outcome measure separately using the *LCTMtools* and *lcmm* packages in R (R Core Team and the R Foundation for Statistical Computing). Models A (fixed effect: homoscedastic), B (fixed effect: heteroscedastic), C (random intercept), D (random slope), E (random quadratic: common variance structure across classes), F (random quadratic: proportionality constraint to allow variance structures to vary across classes), and G (random quadratic: unrestricted, class-specific variance structure) from Lennon et al [17] were tested, together with models H (model G but cubic instead of quadratic) and I (model G but quartic instead of quadratic). More detailed information about the models can be found in Table S1 from Lennon et al [17]. The chosen number of classes

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and model was based on the lowest Bayesian information criterion (BIC) among those models that converged. If there was a class with less than 2 homes (<1% according to Lennon et al [17]), a lower number of classes was chosen. Whether the household type and MCI status influenced in which class a home was classified was tested using multinomial logistic regression, again corrected for the mean age of the home, the number of females in the home, the number of males in the home, the number of White people in the home, the number of people of an ethnicity other than White in the home, the total number of rooms in the home, and the mean years of education of the home, with 1 model per outcome measure. The class with the largest group of homes assigned was chosen as the reference group: Class ~ β_0 + β_1(2-person) + β_2(MCI) + β_3(2-person × MCI) + β_4(age) + β_5(females) + β_6(males) + β_7(White) + β_8(other ethnicity) + β_9(rooms) + β_{10}(education).

For the daily change over time, slopes and variances were compared using a linear model, with the slopes or variances as dependent variables and the MCI status and household type as independent variables and corrected for age. Only homes with more than 180 days (6 months) of data were included in the longitudinal analyses.

P<.05 was considered statistically significant. Statistical analyses were performed in R (V4.1.3).

Ethical Considerations

All participants provided written informed consent before the start of the study. The study protocol was approved by the Oregon Health & Science Institutional Review Board (eIRB 17123), the Portland Veterans Affairs Institutional Review Board (IRB 4089), and the Rush University Institutional Review Board (16011407-IRB01).

Results

Participant Characteristics

We included 181 homes with more than 4 weeks of data after applying all the previously mentioned exclusion criteria, of which 129 (71.3%) were 1-person homes and 52 (28.7%) were 2-person homes (Table 1), leading to a total of 233 individual participants. The mean age and education were similar for all groups, but there were more females than males in 1-person no-MCI homes and more males than females in 1-person MCI homes. In 2-person homes, there was 1 home with a female+female couple, while all other homes included female+male couples. The mean age difference between 2 residents in 2-person homes was 2.9 (SD 5.7) years, with a maximum of 14.5 years. The majority of participants were White. The 2-person MCI homes had 2 residents, of which at least 1 resident had MCI, whereas in the 2-person no-MCI homes, neither resident had MCI. There were 5 (20.8%) 2-person MCI homes in which both residents were classified as having MCI, while the remaining 2-person MCI homes only had 1 resident classified as having MCI.

Table 1. Characteristics of the 4 study groups.

Characteristics	1-person homes		2-person homes	
	No MCI[a] (n=102)	MCI (n=27)	No MCI (n=28)	MCI (n=24)
Age (years), mean (SD)	74 (6)	72 (6)	70 (4)	74 (7)
Sex, n (%)				
Female	76 (74)	12 (44)	—[b]	—
Male	26 (26)	15 (56)	—	—
Female+male	—	—	27 (96)	24 (100)
Female+female	—	—	1 (4)	0 (0)
Education, mean (SD)	15 (3)	15 (2)	15 (2)	14 (2)
Race, n (%)				
White	59 (58)	22 (82)	—	—
Other	43 (42)	5 (18)	—	—
White+White	—	—	21 (75)	20 (84)
White+other	—	—	1 (4)	2 (8)
Other+other	—	—	6 (21)	2 (8)
Number of rooms, mean (SD)	6 (3)	5 (3)	10 (3)	10 (3)
Follow-up (days), mean (SD)	640 (271)	631 (338)	898 (278)	943 (267)

[a]MCI: mild cognitive impairment.

[b]—: not applicable.

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An overview and summary of all analyses results is presented in Table 2. Detailed results will be discussed in subsequent sections.

Table 2. Summary of all results.

Outcome measures and methods	2-person (vs 1-person homes)	MCI[a] (vs no-MCI homes)	Was there a 2-person × MCI interaction effect?[b]
TOOH[c]			
Daily summaries	Lower	—[d]	No
Hour-to-hour summaries	Lower all day	Lower at midday (in 2-person homes)	Yes
Daily change over time	—	—	No
ILSA[e]			
Daily summaries	Higher	Lower in 1-person homes, higher in 2-person homes	Yes
Hour-to-hour summaries	Higher all day	Lower in the afternoon (in 1-person homes), lower at night/in the morning (in 2-person homes)	Yes
Daily change over time	—	Higher change	No
Kitchen use			
Daily summaries	Higher	—	No
Hour-to-hour summaries	Higher at night, lower in the early morning	Higher at night (in 2-person homes)	Yes
Daily change over time	—	—	No
Bathroom use			
Daily summaries	—	—	Yes[f]
Hour-to-hour summaries	Lower in the evening/at night	Higher at night (in 2-person homes)	Yes
Daily change over time	—	Higher change (1-person only)	Yes
Living room use			
Daily summaries	—	—	No
Hour-to-hour summaries	Higher at night	—	No
Daily change over time	—	—	Yes[f]
Bedroom use			
Daily summaries	—	—	No
Hour-to-hour summaries	Higher at night	Lower value in the morning (in 2-person homes)	Yes
Daily change over time	—	Higher change	No

[a]MCI: mild cognitive impairment.

[b]If an interaction effect was found, the analyses were stratified for household type.

[c]TOOH: time out of home.

[d]—: not applicable.

[e]ILSA: independent life space activity.

[f]Effects of the household type or MCI status disappeared after stratification for household type.

Daily Summary Measures

Data for 2 example homes are shown in Figures 2A and 2B (data for all homes can be found in Figure S2 in Multimedia Appendix 1). Overall, TOOH was shorter in 2-person homes than in 1-person homes (β=–2.8, SE 1.39, *P*=.047); see Figure 3. ILSA was longer in 2-person homes, with a significant interaction effect with MCI (β=0.59, SE 0.25, *P*=.02). After stratification for household type, in 1-person homes, MCI homes showed a shorter ILSA than no-MCI homes (β=–0.33, SE 0.16, *P*=.046) but a longer ILSA in 2-person homes (β=0.31, SE 0.18, *P*=.09). Highlighting that room use does not necessarily display the actual dwell time, because it only shows the duration for which someone is moving, excluding the time that someone is stationary in the room, kitchen use was longer in 2-person homes (β=1.60, SE 0.73, *P*=.03), independent of MCI status. A

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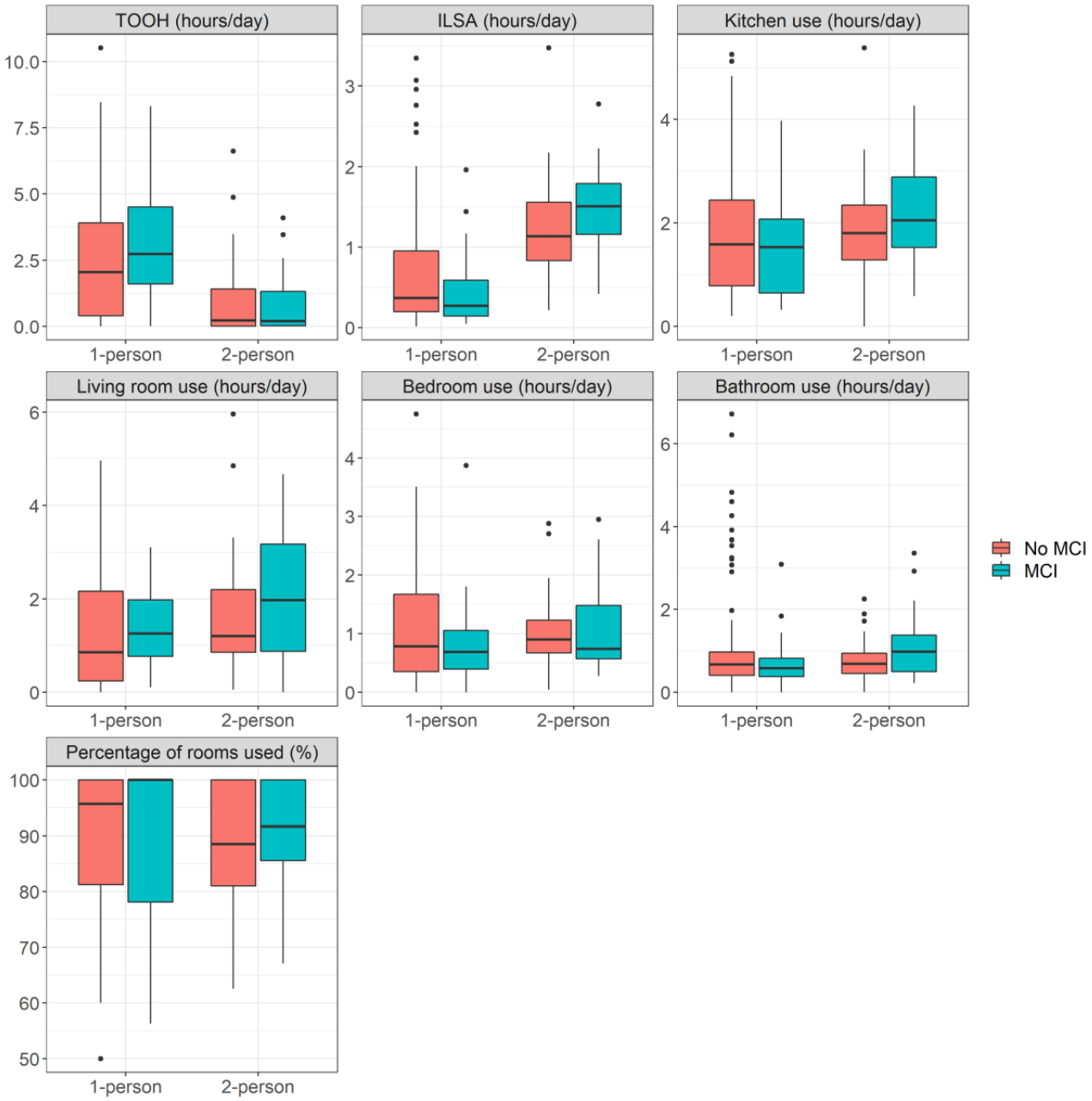
significant interaction effect for bathroom use was found (β=0.82, SE 0.40, *P*=.04), with a shorter time in the bathroom in 1-person MCI homes (β=–0.47, SE 0.28, *P*=.098) but a longer time in 2-person MCI homes (β=0.39, SE 0.22, *P*=.08), although the difference was not significant. No effects were found for bedroom use, living room use, and percentage of rooms used.

Figure 2. Data from 2 example homes. Home 1 (A and C) is a 1-person no-MCI home and home 2 (B and D) is a 2-person MCI home. (A and B) Change over time; each point represents 1 week. Home 2 was enrolled later in the study than home 1. Home 1 shows overall more TOOH, while home 2 shows more living room use. (C and D) Averaged hour-to-hour summaries, with variation over the day. The participant in home 1 leaves the house regularly during daylight hours, while the participants in home 2 leave the house usually during the evening. ILSA: independent life space activity; MCI: mild cognitive impairment; TOOH: time out of home.



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Figure 3. Boxplots from the life space activity metrics averaged over the first 4 weeks with data for 1- and 2-person homes and for MCI and no-MCI homes. ILSA: independent life space activity; MCI: mild cognitive impairment; TOOH: time out of home.

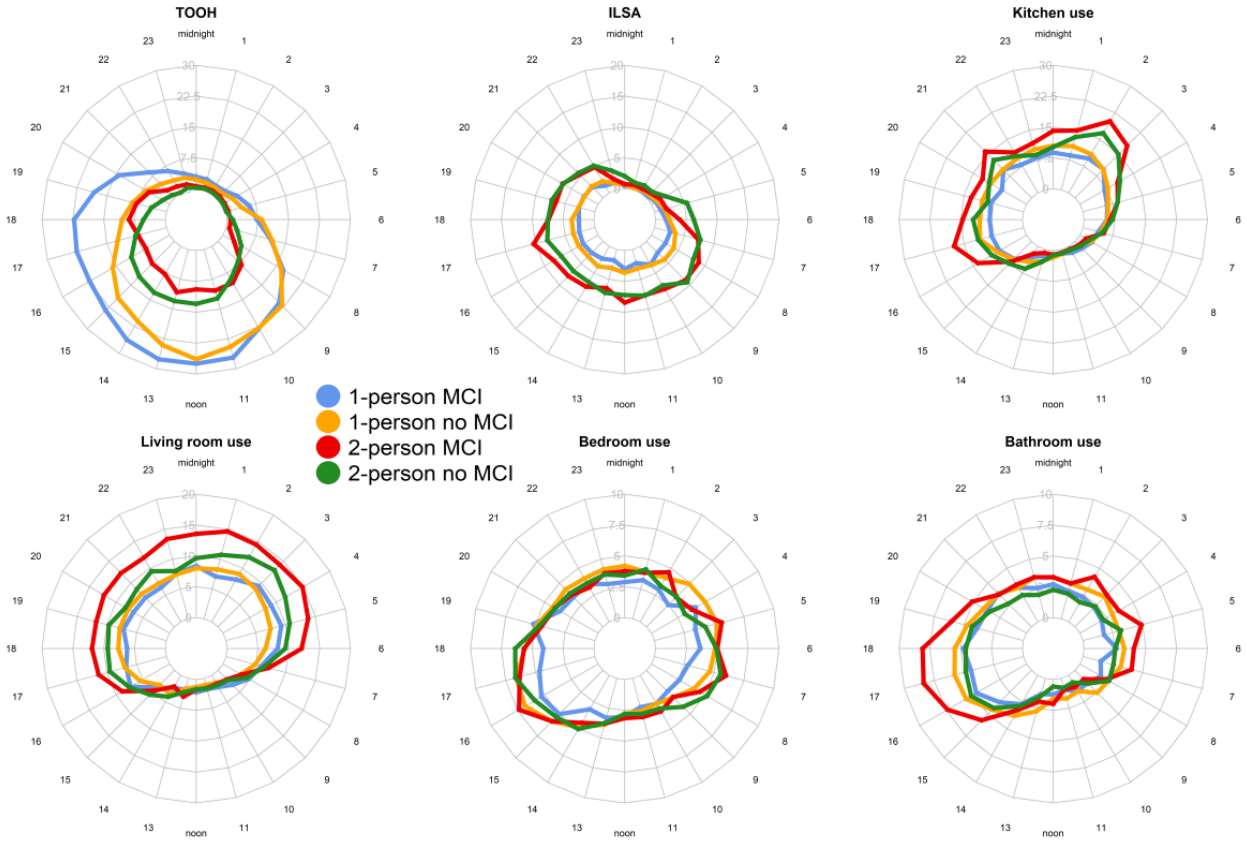


Hour-to-Hour, Time-of-Day Summaries

Data for 2 example homes are shown in Figures 2C and 2D (data for all homes can be found in Figure S3 in Multimedia Appendix 1). Figure 4 shows the hour-to-hour group means. From this figure, it can be seen that TOOH was the highest in 1-person homes, with MCI homes showing the highest TOOH, even during the night. ILSA was higher in 2-person homes. Kitchen use was the highest in the early morning and late afternoon for 2-person homes, with the highest use in 2-person MCI homes. Living room use remained on the same level for the entire day for all homes. Bedroom use was the lowest for 1-person MCI homes for the entire day. Bedroom use was low at night because PIR motion sensors detect only motion and cannot detect stationary people (eg, when asleep). Bathroom use was similar for all groups, except for a large peak in the early morning and evening for 2-person MCI homes.

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Figure 4. Spider plots with the group means for each study group for each life space activity metric. The hour-to-hour data were averaged over the first 4 weeks of data, including only weekdays. The axis represents percentage/hour for TOOH, ILSA, and room use in the kitchen, living room, bedroom, and bathroom. ILSA: independent life space activity; MCI: mild cognitive impairment; TOOH: time out of home.



The chosen number of classes and best-fitted model per outcome measure are presented in Multimedia Appendix 2, together with the number of homes per class. The classes were determined for each outcome measure separately, meaning that the classes extracted for each outcome do not contain the same set of homes. Overall, 5 classes with model H (random cubic: unrestricted covariance structure) were found to be optimal, except for bathroom use, which identified 3 classes with model E (random quadratic: equal covariance structure). For TOOH and living room use, model I (random quartic: unrestricted covariance structure) showed the lowest BIC but did not converge, and therefore, model H with the second-lowest BIC was chosen. For all outcome measures, the class with the majority of homes was the "overall low" class, meaning that the majority of homes showed low values for each outcome measure during the entire day. Later, the results of the multinomial logistic regression models are discussed per outcome measure. A positive 2-person effect means that compared to 1-person homes, 2-person homes were more likely to follow the corresponding trajectory than the overall low trajectory. A positive MCI effect means that compared to no-MCI homes, MCI homes were more likely to follow the corresponding trajectory than the overall low trajectory. A positive interaction effect means that MCI homes were more likely to follow the corresponding trajectory in 2-person homes but less likely in 1-person homes. Classes with ≤5 homes assigned are not discussed to avoid potential accidental findings because of too few homes for informative analysis.

For TOOH, night high, midday high 1 and 2, and evening high trajectories were found, apart from the overall low trajectory. Overall, participants in 2-person homes were less likely to leave the home for the complete day (Table 3). Participants in 2-person MCI homes left the home less at midday, while participants in 1-person MCI homes left the home more at midday (interaction effect).

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Table 3. Outcomes of the multinomial logistic regression models for TOOH[a].

Class comparison	Trajectory	2-person homes		MCI[b] homes		2-person × MCI interaction	
		OR[c] (SE)	*P* value	OR (SE)	*P* value	OR (SE)	*P* value
1 vs 2 (n≤5)[d]	Night high	–19.62 (1.11)	<.001	–14.33 (1.11)	<.001	40.29 (1.11)	<.001
3 vs 2	Midday high 1	–15.40 (0.87)	<.001[e]	0.42 (0.64)	.51	–0.04 (1.10)	.97
4 vs 2	Evening high	–16.34 (0.93)	<.001[e]	–0.01 (0.63)	.98	–0.29 (1.47)	.84
5 vs 2	Midday high 2	–7.62 (0.00)	<.001[e]	0.47 (0.87)	.59	–3.70 (0.00)	<.001[e]

[a]TOOH: time out of home.

[b]MCI: mild cognitive impairment.

[c]OR: odds ratio.

[d]Classes with ≤5 people assigned are not discussed in the results.

[e]Significant results.

For ILSA, morning/night high and afternoon high 1, 2, and 3 trajectories were found, apart from the overall low trajectory. Participants living together were more likely to follow the afternoon high trajectory compared to participants living alone (Table 4). MCI homes were more likely to follow the afternoon high 3 trajectory in 2-person homes but less likely in 1-person homes. In addition, MCI homes were less likely to follow the morning/night high trajectory in 2-person homes but more likely in 1-person homes.

Table 4. Outcomes of the multinomial logistic regression models for ILSA[a].

Class comparison	Trajectory	2-person homes		MCI[b] homes		2-person × MCI interaction	
		OR[c] (SE)	*P* value	OR (SE)	*P* value	OR (SE)	*P* value
2 vs 1	Afternoon high 1	–6.72 (0.83)	<.001[d]	–0.02 (0.58)	.97	–1.19 (1.62)	.46
3 vs 1	Morning/night high	0.92 (1.69)	.58	–0.89 (1.43)	.53	–23.80 (0.00)	<.001[d]
4 vs 1	Afternoon high 2	–5.47 (0.99)	<.001[d]	–0.50 (0.68)	.47	–0.17 (1.47)	.91
5 vs 1	Afternoon high 3	28.70 (0.64)	<.001[d]	–15.80 (0.72)	<.001[d]	14.61 (0.72)	<.001[d]

[a]ILSA: independent life space activity.

[b]MCI: mild cognitive impairment.

[c]OR: odds ratio.

[d]Significant results.

For kitchen use, night high 1 and 2, night/morning high, and evening high trajectories were found, apart from the overall low trajectory. Compared to 1-person homes, 2-person homes were less likely to follow the night high 1 trajectory and less likely to follow the night/morning high trajectory (Table 5). MCI homes were more likely to follow the night high 2 trajectory in 2-person homes but less likely in 1-person homes.

Table 5. Outcomes of the multinomial logistic regression models for kitchen use.

Class comparison	Trajectory	2-person homes		MCI[a] homes		2-person × MCI interaction	
		OR[b] (SE)	*P* value	OR (SE)	*P* value	OR (SE)	*P* value
1 vs 2	Night high 2	325.17 (1.61)	<.001[c]	–476.82 (0.76)	<.001[c]	478.95 (0.76)	<.001[c]
3 vs 2	Night high 1	–18.04 (0.73)	<.001[c]	0.03 (0.54)	.95	0.58 (0.94)	.54
4 vs 2	Night/morning high	–132.45 (0.99)	<.001[c]	0.56 (0.77)	.46	–0.39 (1.36)	.78
5 vs 2 (n≤5)[d]	Evening high	9.86 (0.00)	<.001	–116.94 (0.00)	<.001	–23.58 (0.00)	<.001

[a]MCI: mild cognitive impairment.

[b]OR: odds ratio.

[c]Significant results.

[d]Classes with ≤5 people assigned are not discussed in the results.

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For bathroom use, night high and evening high trajectories were identified, apart from the overall low trajectory. MCI homes were more likely to follow the night high trajectory in 2-person homes but less likely in 1-person homes (Table 6). People living together were less likely to follow the evening high trajectory compared to people living alone.

Table 6. Outcomes of the multinomial logistic regression models for bathroom use.

Class comparison	Trajectory	2-person homes		MCI[a] homes		2-person × MCI interaction	
		OR[b] (SE)	*P* value	OR (SE)	*P* value	OR (SE)	*P* value
1 vs 2	Night high	–27.75 (0.65)	<.001[c]	–0.41 (0.72)	.56	16.42 (0.65)	<.001[c]
3 vs 2	Evening high	–3.99 (1.08)	<.001[c]	0.51 (0.97)	.60	0.62 (1.33)	.64

[a]MCI: mild cognitive impairment.

[b]OR: odds ratio.

[c]Significant results.

For living room use, afternoon/evening high and night high 1, 2, and 3 trajectories were found, apart from the overall low trajectory. The 2-person homes were more likely to follow the night high trajectory than the overall low trajectory compared to 1-person homes (Table 7).

Table 7. Outcomes of the multinomial logistic regression models for living room use.

Class comparison	Trajectory	2-person homes		MCI[a] homes		2-person × MCI interaction	
		OR[b] (SE)	*P* value	OR (SE)	*P* value	OR (SE)	*P* value
1 vs 4 (n≤5)[c]	Night high 3	197.04 (1.05)	<.001	–491.80 (0.90)	<.001	492.73 (0.90)	<.001
2 vs 4 (n≤5)[c]	Afternoon/evening high	112.95 (0.12)	<.001	–318.37 (0.12)	<.001	152.04 (0.12)	<.001
3 vs 4	Night high 1	89.21 (0.88)	<.001[d]	0.80 (0.61)	.19	–0.68 (1.05)	.52
5 vs 4	Night high 2	202.78 (0.45)	<.001[d]	–1.06 (1.25)	.40	1.52 (1.65)	.36

[a]MCI: mild cognitive impairment.

[b]OR: odds ratio.

[c]Classes with ≤5 people assigned are not discussed in the results.

[d]Significant results.

For bedroom use, the optimal number of classes was 5. However, when both 5 and 4 classes were chosen, this resulted in 1 class with n=1. Therefore, only 3 classes were chosen as the optimal number of classes. This resulted in evening high and night high trajectories, apart from the overall low trajectory. Only the night high trajectory had more than 5 homes and showed that 2-person homes were less likely to follow the night high trajectory compared to 1-person homes (Table 8).

Table 8. Outcomes of the multinomial logistic regression models for bedroom use.

Class comparison	Trajectory	2-person homes		MCI[a] homes		2-person × MCI interaction	
		OR[b] (SE)	*P* value	OR (SE)	*P* value	OR (SE)	*P* value
2 vs 1 (n≤5)[c]	Evening high	–11.51 (2.39)	<.001	–21.84 (0.00)	<.001	–0.63 (0.00)	<.001
3 vs 1	Night high	–4.65 (1.28)	<.001[d]	–0.76 (1.15)	.51	2.18 (1.79)	.22

[a]MCI: mild cognitive impairment.

[b]OR: odds ratio.

[c]Classes with ≤5 people assigned are not discussed in the results.

[d]Significant results.

Daily Change Over Time

After excluding homes with less than 180 days of data, we included 75 (n=16, 21.3%, MCI, n=59, 78.7%, no-MCI) 1-person homes and 28 (n=16, 57.1%, MCI, n=12, 42.9%, no-MCI) 2-person homes. The mean number of eligible days was 291 (SD 76) days. Differences in slopes were small (Figure 5): a greater change was found for MCI homes compared to no-MCI homes for ILSA (β=0.0006, SE 0.0002, *P*=.02) and bedroom use (β=0.002, SE 0.0006, *P*=.02), corresponding to 2.2 and 7.3 seconds per day and thus 13.4 and 44.4 minutes per year change, respectively. For bathroom use, an MCI status × household type interaction effect was found (β=0.0014, SE 0.0006, *P*=.03). After stratification for household type, only in

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the 1-person homes, MCI homes showed a greater change than no-MCI homes (β=0.002, SE 0.0005, *P*=.001). No other differences were found. For variability (Figure 6), an interaction effect was found for living room use (β=–0.45, SE 0.21, *P*=.04), but this effect disappeared when stratifying for household type. No other associations were found.

Figure 5. Boxplots of the slopes of the daily change over time for each outcome measure. ILSA: independent life space activity; MCI: mild cognitive impairment; TOOH: time out of home.

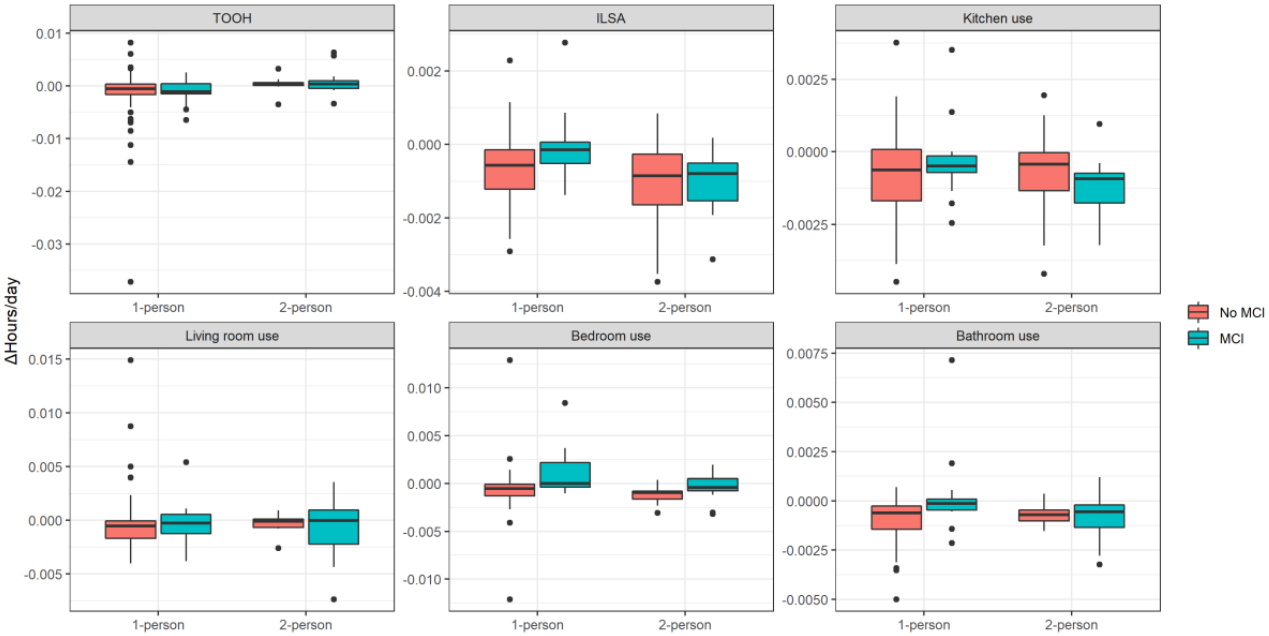
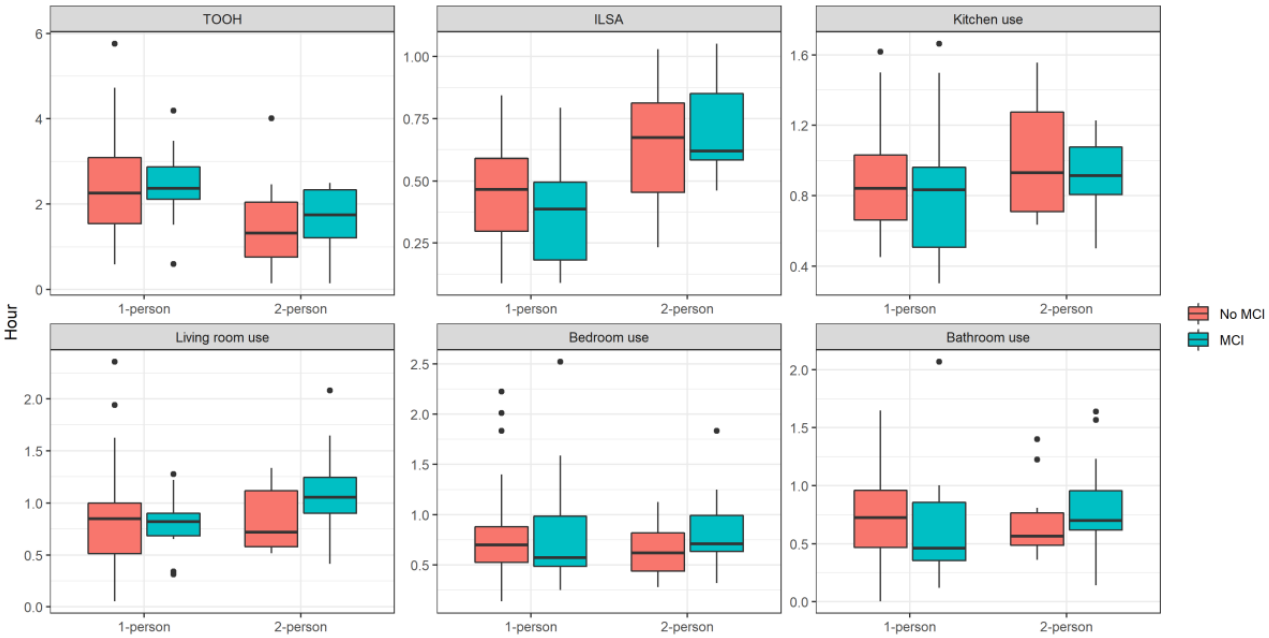


Figure 6. Boxplots of the variability (SD) of the daily change over time for each outcome measure. ILSA: independent life space activity; MCI: mild cognitive impairment; TOOH: time out of home.



Discussion

Principal Findings

The aim of this study was to compare the everyday behavior patterns of people with MCI with those of cognitively normal participants using in-home passive sensors in both 1- and 2-person resident homes to determine whether there are differences in life activity patterns around the home that differ according to whether one lives alone and has MCI. TOOH, ILSA, bedroom use, bathroom use, living room use, kitchen use, and percentage of rooms used were analyzed in 3 ways: daily measures averaged over 4 weeks, hour-to-hour measures averaged over 4 weeks, and change over time. The most important outcome of this study is that the living situation of the participants was highly important when using objective measures, since we found that people living together have a shorter TOOH, a longer ILSA, and longer room use independent of analysis type. The effects of MCI status depended on whether

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someone was living alone or as a couple: In MCI homes, ILSA was, for example, lower in 1-person homes but higher in 2-person homes.

Difference Between No-MCI and MCI Homes

When looking at daily measures, only ILSA was affected by MCI status: ILSA was higher in MCI homes compared to no-MCI homes in 2-person homes but lower in 1-person homes. This suggests that in 1-person homes, people without MCI have more visitors compared to people with MCI. This is according to expectations, as people with MCI tend to withdraw more from social activities [18]. In 2-person homes, a possible explanation for these findings is that a person without MCI living in a home with someone with MCI takes over more household duties, leading to more rooms being used at the same time. These results were confirmed by the hour-to-hour analyses.

To find the effects of MCI status on other outcome measures, hour-to-hour or longitudinal measures were needed: a greater change in ILSA, bedroom use, and living room use was seen in MCI homes. In the hour-to-hour analyses, the effects of MCI status were found on TOOH, ILSA, kitchen use, and bathroom use, but these effects depended on the household-type. These findings confirm what was already found by Wu et al [10,19]: hour-to-hour analyses and longitudinal changes over time need to be considered when one wants to find the effects of cognitive decline. A review by Yamasaki and Kumagai [20] of 10 studies that used in-home sensors to detect MCI also shows that especially day-to-day variability or a change in the time of day of activity patterns indicates cognitive decline. Our study adds to this evidence since this was also the case for 2-person homes, implying that the household type should be considered when analyzing activity data.

Difference Between 1- and 2-Person Homes

Around 28% of the older population living in the United States in 2019 lived alone [21], meaning that 72% lived in a 2-or-more-person home. However, until now, almost all previous research using in-home unobtrusive objective measures has included people living alone [8-10], which is an important but different class within the general population. Our study showed that 1- and 2-person homes differ in terms of in-home everyday behavior patterns. All 3 analysis methods (daily summaries, hour-to-hour summaries, and change over time) showed effects of 1- and 2-person homes, which confirms that the household type is highly relevant when determining someone's in-home behavior. To the best of our knowledge, this is the first study that shows the difference in life space activity patterns between people living alone and living as a couple.

The mean daily TOOH was higher in 1-person homes, which was expected, because in 2-person homes, 2 persons need to leave the home instead of 1 before it counts as TOOH. When looking at the hour-to-hour analyses, again, 1-person homes were more likely to follow trajectories with a high TOOH, especially at midday. Day-to-day variation was also higher in 1-person homes, meaning that TOOH varies more from day to day when someone is living alone instead of living with someone. ILSA was higher in 2-person homes, which was expected as well, since 1-person homes need a person to visit the home to have ILSA. This result was confirmed with the hour-to-hour analyses, where 2-person homes were also more likely to follow the high-ILSA trajectories independent of the time of day. We also found a greater change over time in 2-person homes compared to 1-person homes, but this change was small (13 minutes/year). The mean daily bedroom use did not differ between 1- and 2-person homes. The time-of-day analyses confirm the results of the daily measures as the majority of homes (88%) were in the class that followed the overall low trajectory. Bedroom use during the night was low, both in 1- and 2-person homes, which highlights the nature of PIR motion sensors: stationary people (eg, when sleeping) are not detected by the sensors. Bedroom use should therefore be interpreted as the time to prepare for bed or the day rather than the actual bedroom dwell time. The mean bathroom use did not differ between 1- and 2-person homes, which was unexpected, because it is unlikely that a person living in a 2-person home always uses the bathroom at the same time as their coresident. When looking at the hour-to-hour analyses, 1-person homes were more likely to use the bathroom at night compared to 2-person homes. The mean daily kitchen use was lower in 1-person homes than in 2-person homes, suggesting that people in 2-person homes spend more time preparing food.

Unexpected findings were that the kitchen was also used during the night by a large group (56% of the homes followed trajectories with kitchen use at night). These homes were more likely 2-person homes, suggesting that people in 2-person homes show more night-eating behavior. The kitchen is not always used only for eating purposes and can therefore also be used when someone is unable to sleep, implying that people in 2-person homes have more sleeping problems. These explanations are, however, speculations and should therefore be confirmed by follow-up research using various techniques, including selected direct visualization (eg, cameras), sleep sensors indicating poor sleep, and questionnaires (eg, the Ecological Momentary Assessment of sleep). Similar to kitchen activity, the mean living room use was lower in 1-person homes than in 2-person homes, and this was mainly seen in nighttime behavior: people in 2-person homes were more likely to use the living room around midnight, which again may suggest sleeping difficulties. A possible reason for this is that a person wakes up due to noises or movements from their partner. Further research with a bed mat, also incorporated in the CART data set [11], should confirm these findings.

Strengths and Limitations

The strengths of this study are the passive, ecologically authentic data capture, a long follow-up time, a large sample size (>180 homes), and participants with different backgrounds and socioeconomic statuses. The fact that the 3 measuring methods converged in their results provides good evidence for the strength of the findings.

However, this study also has some limitations. First, for analysis of the daily change over time, we assumed that the change over time was linear, while change might be more complex, such as exponential or first marked by a slow change and then, after a change point, by a more precipitous increase or decrease. Second, the decision to omit the first 2 weeks of data to avoid

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the potential effect of being self-conscious of the activity about the home, which is being "observed" by the sensors, was made arbitrarily: further research should confirm that the potential observation effect receded after 2 weeks. Third, the effect of pets was not considered. When pets are large (eg, a large dog), they could activate the PIR motion sensors when no one is using the room or is even out of the house. However, the expected findings that TOOH was lower and ILSA was higher in 2-person homes suggest that this is not a major issue in these data. Fourth, the designation of MCI or dementia is a static state label given until a subsequent clinical assessment is performed that suggests a new diagnostic milestone has been reached. However, these designations may be unstable during 2-3 years of follow-up, with 4%-55% people reverting from MCI to normal cognition [22]. In this context, we note that there were 19 homes where a resident transitioned from normal cognition to MCI or from MCI to dementia during the study. We did not consider these changes, as there were too few cases in the different groups to be included in the analysis. It will be interesting to investigate in future research the change in life space activity patterns in different resident settings where a person transitions to MCI and dementia. Lastly, the measures we chose for this study are just illustrations to show that the household type can have an effect and are not meant to be an exhaustive list of examples.

Future Research and Clinical Applicability

Future research should combine the outcome measures into 1 composite score to quantify overall in-home behavior. Adding continuous information, such as individual mobility (eg, steps on an actigraph) or sleeping information (eg, time in bed or out of bed from a bed mat), could improve the results. Furthermore, a longer follow-up duration would help model which behavior could possibly predict a conversion to dementia. Finally, examining specific activities more closely would enlarge our knowledge of which particular in-home activities are performed at a particular time, for example, if the kitchen used for cooking, the bedroom for sleeping, and the bathroom for showering. After these clarifications, the results of this study can be used to monitor people more sensitively, continuously, at home, and without the need for active interaction from the participants. This can, for example, be used in a clinical trial or as a screener for needed assistance.

Conclusion

This study demonstrated that life space activity patterns, as measured with passive in-home sensors, are influenced by both the household type and the MCI status. This confirms that changed in-home behavior can be seen if 1 person in the home has MCI, even if the sensors cannot distinguish between residents. To show the influence of MCI status, data should be analyzed as time-of-day changes or longitudinal changes. Future research needs to consider the household type, as 2-person homes show different behavior than 1-person homes and this can affect the clinical assessment of functional activity patterns unique to those experiencing cognitive decline over time.

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W-TMA-Y developed the algorithms to calculate TOOH and ILSA. This work was supported by the National Institutes of Health (P30-AG008017, P30AG066518, and U2C AG054397 to JAK and RF1AG22018, P3010161, and R01AG17917 to LLB.) and the Department of Veterans Affairs Health Services Research and Development (IIR 17-144 to LCS). Research by Alzheimer Center Amsterdam is part of the neurodegeneration research program of Amsterdam Neuroscience. Alzheimer Center Amsterdam is supported by Stichting Alzheimer Nederland and Stichting VUmc fonds. MM would like to thank Alzheimer Nederland for its grant, which made it possible to visit Oregon Center for Aging & Technology (ORCATECH) and write this paper.

Conflicts of Interest

The Oregon Health & Science University (OHSU) and JAK and ZB have a financial interest in Life Analytics, Inc, a company that may have a commercial interest in the results of this research and technology. This potential conflict of interest has been reviewed and managed by OHSU.

Multimedia Appendix 1
Supplementary figures.
[DOCX File , 1047 KB - aging_v6i1e45876_app1.docx]

Multimedia Appendix 2
Chosen number of classes and best-fitted model per outcome measure.
[DOCX File , 431 KB - aging_v6i1e45876_app2.docx]

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Abbreviations

BIC: Bayesian information criterion
CART: Collaborative Aging Research Using Technology
CDR: Clinical Dementia Rating
ILSA: independent life space activity
MARS: Minority Aging Research Study
MCI: mild cognitive impairment
OHSU: Oregon Health & Science University
PIR: passive infrared
RUSH: Rush University Medical Center
TOOH: time out of home

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Original Paper

Gluu Essentials Digital Skills Training for Middle-Aged and Older Adults That Makes Skills Stick: Results of a Pre-Post Intervention Study

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Abstract

Background: A number of real-world digital literacy training programs exist to support engagement with mobile devices, but these have been understudied.

Objective: The purpose of this study was to examine the effectiveness and program acceptability of a digital skills training program among middle-aged and older adults (aged ≥50 years) and to gather participants' recommendations for lifelong digital skills promotion.

Methods: The Gluu Essentials digital skills training program includes learning resources to support tablet use. Through pre-post surveys, this study assessed mobile device proficiency, confidence in going online and in avoiding frauds and scams, the frequency of engaging in online activities, program engagement, acceptability, and suggestions for continued support.

Results: A total of 270 middle-aged and older adults completed baseline surveys. Of these 270 participants, 145 (53.7%) completed follow-up surveys. Our findings indicate that mobile device proficiency increased (P<.001), whereas confidence was unchanged. Participants also reported going online more frequently to shop (P=.01) and access government services (P=.02) at follow-up. Program engagement varied considerably, but program acceptability was high. Participants' recommendations included the need for providing ongoing programs for support and training because technology constantly changes, reducing costs for technology and internet access, and keeping learning resources simple and easy to access.

Conclusions: The Gluu Essentials digital skills training program increased mobile device proficiency and frequency of web-based activities (shopping and accessing government services) among middle-aged and older adults.

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KEYWORDS

digital literacy; digital skills; older adults; mobile device proficiency; online; mobile phone

Introduction

Background

In Canada and in many nations, there has been an increase in technology reliance, with many aspects of life now optionally or necessarily being navigated in digital terms; for example, online banking has become the norm in managing financial matters, and virtual health care options are becoming increasingly more available. We use the term *online* to refer to connecting to the internet for activities such as accessing

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websites, online services, and email. Although the internet can provide access to important financial, health, and social resources and information [1], the aging population has created a universal challenge to the ongoing digitalization of key services because older adults use the internet at lower rates than younger adults—a phenomenon known as the "grey digital divide" [2]. In 2022, the World Health Organization projected that 17% of the world's population will be aged ≥60 years in 2030, increasing to 22% by 2050 (compared with 12% in 2015) [3]. According to the Pew Research Center, nearly 100% of young adults reported using the internet in 2022 in nearly every country surveyed, whereas use ranged from 57% to 93% among older adults; still, this use was much higher than in 2002, indicating that the number of older adults engaging with technology has been steadily increasing [4]. To meaningfully participate in society, older adults increasingly need digital literacy [5], or the skills to locate, understand, generate, organize, and evaluate information using digital technology [6].

Mobile and smartphone devices afford greater access to connectivity even in rural areas [7], yet one area where a greater gray digital divide has been reported is in mobile device uptake. Although nearly all young adults in the 18 countries surveyed reported smartphone ownership in 2022, the rates of ownership among adults aged ≥50 years in some countries were as low as 55% in 2022 [4]. Previous research showed that mobile devices offer advantages in terms of supporting independence over a PC (a computer in a fixed location) for communication, transportation, navigation, entertainment, and health [8]. Indeed, advanced personalization and user-centric apps have been developed for mobile devices over the recent past; for example, mobile health apps designed to remind users of upcoming appointments or medicine intake are much more useful if implemented on a mobile device that is carried with the user throughout the day [9].

However, extant literature reported that older adults face numerous barriers to digital technology adoption, such as a lack of confidence [10]; negative or ambivalent attitudes toward technology, including privacy concerns [11,12]; and the need for ongoing support from others [13,14]. To address these challenges, several programs have been introduced to promote digital literacy among middle-aged and older adults [15].

To date, the majority of digital literacy programs have been focused on increasing technology acceptance, adoption, use, or interest, with some success [16-21]. As technology has the potential to help older adults stay connected to friends and family, many technology-based interventions have been focused on reducing loneliness, but these have had mixed results, often attributed to failure to target socially isolated older adults [22-25]. Studies have reported that social support to set up new devices plays an important role in initiating and motivating tablet use among older adults [18] and that consideration of older adults' needs, preferences, and lived experience is essential to success [17,19]. Indeed, a recent systematic review of instructional strategies to promote the learning of digital technology among older adults reported that collaborative, personalized, relevant, and experience-based learning strategies accompanied by repetition and effective teaching aids (such as print resources) were themes present throughout many of the 17 studies reviewed [26]. However, previous studies have reported primarily qualitative results [21] or were conducted in specific settings (eg, Castilla et al [20] examined training on Butler 2.0, a system application designed to increase social support) or in highly controlled settings (eg, the randomized controlled trial conducted by Arthanat [16]), with few real-world assessments of training implementation.

Indeed, in Canada, a number of digital literacy training programs exist, yet often these have been understudied. More research is needed on the impact of digital skills training on middle-aged and older adults' digital engagement. Gluu Society is a Canadian nonprofit organization that provides free digital skills training to middle-aged and older Canadians [27]. Gluu is not an acronym; rather, it is a name selected to convey ensuring that digital skills *stick* and are not forgotten. A report on a national digital literacy program that incorporated the Gluu Essentials courses (ie, foundational training on tablet use) outlined a number of best practices for program delivery, including community-based and flexible program delivery [28]; however, as in the case of many existing digital literacy training programs, there has been no systematic evaluation of the impact of the Gluu Essentials program, particularly on middle-aged and older adults' digital skills acquisition related to mobile device use. Measuring mobile device proficiency is 1 way to gauge the effectiveness of training [9]; however, few previous studies have focused on mobile device proficiency in particular [29].

Objectives

The primary objective of this study was to examine the effectiveness of the Gluu Essentials training program for improving participants' mobile device proficiency. The secondary objective was to explore the impact of the training on the frequency of participants' engagement in online activities (eg, shopping, banking, and accessing government services); their confidence; and their satisfaction with, and acceptability of, the program.

Methods

Study Design

This study used a pre-post cross-sectional survey design in which data were collected from middle-aged and older adults in rural and urban communities in Canada before and after participation in the digital skills training program.

Digital Skills Training Program

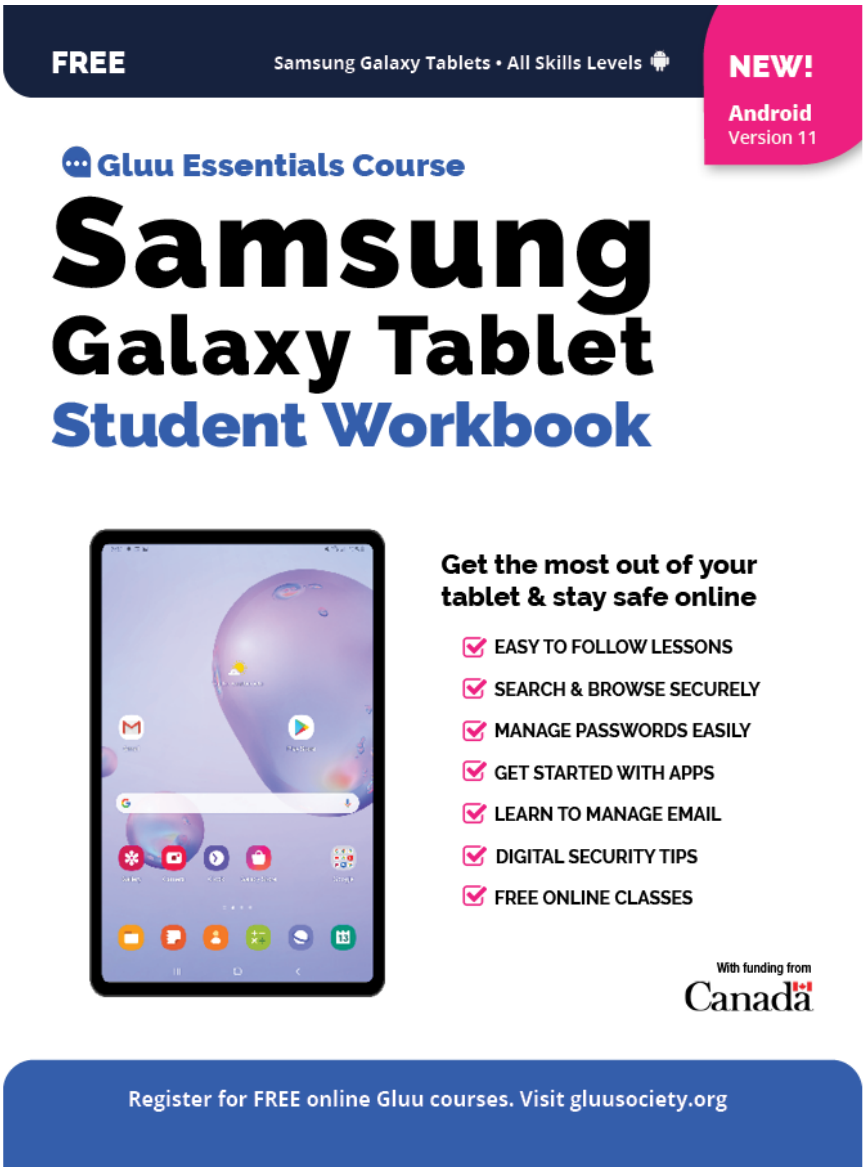
The digital skills training program was developed by Gluu Society and delivered in partnership with local community organizations and volunteer coaches. Gluu's target audience consisted of adults aged ≥50 years. The Gluu Essentials resources included (1) printed student workbooks; (2) support for coach volunteers: training, lesson plans, and teaching resources; and (3) online support for participants and volunteers.

The Gluu Essentials courses included learning resources to help middle-aged and older adults use Apple iPads or Samsung Galaxy tablets. Courses were centered around these devices because they are top sellers; have user-friendly interfaces; and their manufacturers emphasize security, ensuring that users have

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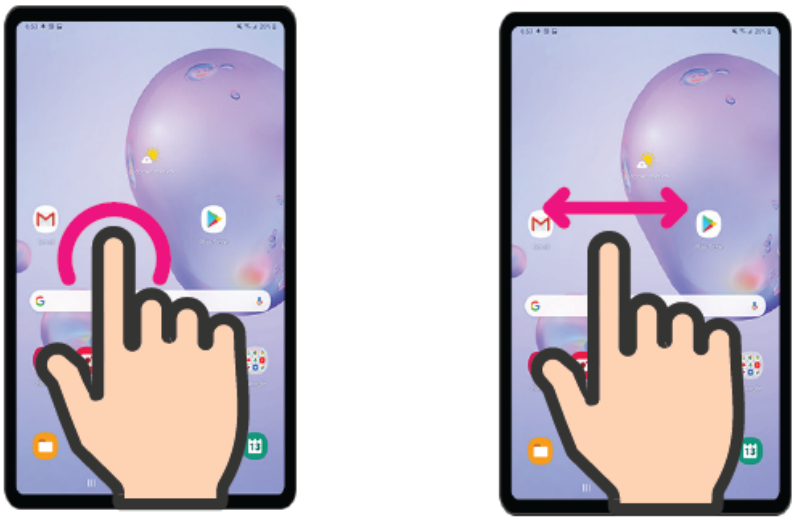
a safe digital experience. The printed workbooks included a 96-page Gluu Essentials iPad Student workbook and a 96-page Gluu Essentials Samsung Galaxy Tablet Student workbook (Figure 1). Within the workbooks, user-friendly images were used throughout to display touch screen actions (refer to the example gestures presented in Figure 2). Twelve lessons were included in the Gluu Essentials training program, beginning with (1) the basic features of the tablet (eg, overview of where everything is and powering the tablet on and off) followed by (2) an introduction to the touch screen and gestures, (3) settings and tablet care, (4) the camera app, (5) email as well as Gmail or email app, (6) managing contacts, (7) find what is needed online, (8) how to download apps, (9) using the calendar app, (10) digital security basics, (11) Facebook basics, and (12) Zoom basics. Although Gluu recommended 3 months of weekly classes of no more than an hour to cover each topic (ideally with at least 70% attendance), community organizations and volunteer coaches were free to deliver the programming in the way that worked best for their learners and staff availability. Thus, program duration varied across participants according to the self-paced nature of the delivery, and we were unable to track programming delivered by local community organizations in this real-world assessment. The Gluu Essentials training was provided free of charge; however, the devices were not provided by Gluu.

Figure 1. Cover of the Gluu Essentials Samsung Galaxy Tablet Student Workbook.



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Figure 2. Examples of images depicting basic touch screen gestures.



Sample Recruitment and Procedures

Organizations in 23 communities across Canada (n=14, 61% in British Columbia) were interested in partnering with Gluu to deliver digital skills training. A total of 820 paper surveys (in batches of 10-60) were sent to the community organizations along with the printed Gluu Essentials workbooks. The paper surveys included postage-paid return envelopes addressed to the University of British Columbia (Okanagan Campus) research team. Approximately half of the organizations (10/23, 43%) fully engaged with the Gluu Essentials program (ie, recruited a combined total of 36 volunteers to complete Gluu's volunteer training program and join a Slack workspace—a digital platform for coach-to-coach communication managed by the Gluu Support Crew Leader); of the 10 organizations that stayed connected to Gluu one-third (3/10, 30%) provided lessons in person (eg, small groups), and two-thirds (7/10, 70%) had volunteers who provided support to learners from a distance (eg, telephone support). At least 1 other organization that we were aware of delivered the workbooks and training in-person and without Gluu support, but we were unable to track how programming was delivered by the remaining organizations that did not stay connected to Gluu. The online survey was also advertised on Gluu's Facebook page in fall 2022, emailed to Gluu's mailing list, and sent through a provincial community response network with >85 rural community affiliates. Online survey participants were individually mailed their preference of Gluu Essentials iPad or Samsung Galaxy Tablet Student workbooks. In terms of inclusion and exclusion criteria, although the recruitment advertisements were targeted at middle-aged and older adults, they only specified that participants must be Canadian residents; however, only participants aged ≥50 years were recruited for follow-up and included in the study analysis.

On the baseline survey, participants were asked to check whether they were willing to be contacted for a follow-up survey. Those who selected *yes* were sent up to 5 follow-up invitations by email, and those who provided mailing addresses were mailed paper follow-up surveys with postage-paid return envelopes. To promote participation, three CAD $100 (US $75) draw prize incentives were advertised after the completion of baseline data collection and again after the completion of the follow-up survey.

Ethical Considerations

All participants provided informed consent before completing the survey. This study was reviewed by, and received ethics approval from, the University of British Columbia's behavioral research ethics board (H21-02116).

Measures

Sociodemographics, participant characteristics, and postal codes were gathered at baseline. Self-report measures of mobile device proficiency, confidence, and the frequency of engaging in online activities were collected at both baseline and follow-up. Finally, several questions exploring program engagement, acceptability, and suggestions were completed at follow-up only. Tables 1 and 2 present a detailed description of all survey measures.

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Table 1. Summary of study measures collected at baseline only and those collected at both baseline and follow-up.

Time point and name	Description	Response options and score range	Score calculation	Psychometric and interpretation information
Measures collected at baseline only				
Sociodemographic characteristics	Age, sex, ethnicity, education, and devices used (ie, desktop computer, smartphone, or tablet)	N/A[a]	N/A	N/A
Community and remoteness	Participants provided their postal code, and by using the Canadian *Find a postal code* tool [30], community or city name and province were determined; based on the census subdivision of the community, a score was assigned from Statistics Canada's Index of Remoteness (RI[b] scores are based on population size and cost to travel to nearest population center [31])	Possible scores range from 0 to 1; the method developed by Subedi et al [32] was used to classify each community's RI score into 1 of 5 categories: easily accessible (<0.1500), accessible (0.1500-0.2888), less accessible (0.2889-0.3898), remote (0.3899-0.5532), or very remote (>0.5532)	*Easily accessible* and *accessible* were further collapsed as *urban*, and *less accessible*, *remote*, and *very remote* were categorized as *rural*	Scores closer to 1 indicate greater remoteness
Measures collected at both baseline and follow-up				
Mobile device proficiency	Participants responded to 18 items (eg, "Using a mobile device I can use the on-screen keyboard to type") from the MDPQ[c] [9]; we included items to measure 7 MDPQ subscales: mobile device basics (2 items), communication (3 items), internet (3 items), calendar (2 items), entertainment (2 items), privacy (2 items), and troubleshooting or software management (4 items)	Response options range from 1 (*never tried*) to 5 (*very easily*)	The mean of all 18 items was computed as an overall measure of digital literacy, and the mean of responses to the items making up each subscale were also computed	Higher scores represent greater literacy; the MDPQ has demonstrated internal reliability as well as convergent and divergent validity in previous research [9,33]; in this study, the Cronbach α value for the overall MDPQ scores was high (.96)
Confidence in going online and confidence in online security	On the basis of the 1977 study by Bandura [34], single investigator-developed items asked participants about their confidence in going online ("Over the next 6 months, how confident are you about going online [eg, to use websites, online services, etc.]?") and about online security ("Over the next 6 months, how confident are you about identifying online frauds and scams?")	Both items were rated on a Likert scale ranging from 1 (*not at all confident*) to 5 (*extremely confident*)	N/A	Single-item measures of self-efficacy have demonstrated moderate correlations with multi-item scales as well as correspondence with measured outcomes [35]
Frequency of online activities	Questions were adapted from the MTUAS[d] emailing and internet subscales (Rosen et al [36]) to assess participants' frequency in going online for 7 different activities (sending and receiving emails, online shopping, online banking, accessing government services, searching for information, accessing COVID-19–related information, and accessing emergency preparedness information or alerts)	Ordinal response choices included 1 (*never*), 2 (*once a year*), 3 (*several times a year*), 4 (*once a month*), 5 (*several times a month*), 6 (*once a week*), 7 (*several times a week*), 8 (*once a day*), and 9 (*several times a day*)	Binary variables were also created by grouping participants who responded with *never* versus those who responded with any frequency above *never*	N/A

[a]N/A: not applicable.

[b]RI: remoteness index.

[c]MDPQ: Mobile Device Proficiency Questionnaire.

[d]MTUAS: Media and Technology Usage and Attitudes Scale.

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Table 2. Summary of study measures collected at follow-up only.

Name	Description	Response options and score range	Score calculation	Psychometric and interpretation information
Program engagement	Participants were asked to indicate the portion they had completed of each of the 12 lessons included in the Essentials training; they were also asked the following questions: "To what extent did you use the printed Gluu Workbook?" "How did you access a Digital Coach?" "Did you view materials/posts on Gluu social media via Facebook or Instagram?" "Are you still using the Gluu digital skills resources?"	Response options for each of the 12 lessons ranged from 0 (*did not start*) to 4 (*completed*), or participants could indicate *unsure*; workbook use response options included 0 (*did not use*), 1 (*used once a month or less*), 2 (*used several times a month*), 3 (*used weekly*), and 4 (*used daily*); digital coach response options included 0 (*I did not*) and 1 (*by telephone or in-person classes*); those who accessed a coach by telephone or in person were asked to specify how many times they did so; social media and continued use of Gluu resources response options were 0 (*no*) or 1 (*yes*)	Participants were given a score of 1 (*yes*) if they indicated starting at least 1 of the Gluu Essentials lessons and a score of 0 (*no*) if they selected *did not start* in response to all 12 lessons; participants were given dichotomous scores based on engagement (*yes*) or not (*no*) with each of the program components	N/A[a]
Program acceptability	Participants were asked 4 questions ("Overall I was satisfied with the Gluu digital skills training," "I learned new ways to use my device through the Gluu digital skills training," "I learned new information about online security through the Gluu digital skills training," and "After this training, I am more likely to use technology to support my aging plan [eg, aging in place]"); finally, the 10-item SUS[b] [37] was adapted to refer to the Gluu resources (eg, "The Gluu resources were easy to use")	Response options for acceptability questions ranged from 1 (*strongly disagree*) to 5 (*strongly agree*); for the SUS, response options ranged from 0 (*disagree*) to 4 (*agree*)	Ratings of *agree* and *strongly agree* were combined to denote acceptability; for the SUS, 5 negatively worded questions were reverse scored, and responses to items were summed and normed on a scale ranging from 1 to 100, with higher scores reflecting greater perceptions of usability	Scores of >68 are considered above average in terms of usability [38]
Open-ended suggestions	Participants were asked, "What would support you to be on a lifelong learning digital skills journey?"	N/A	Open-ended responses were reviewed; informative quotes were extracted using inductive thematic analysis	N/A

[a]N/A: not applicable.

[b]SUS: System Usability Scale.

Data Processing and Statistical Analysis

Data were analyzed using SPSS for Windows (version 28.0; IBM Corp) [39]. The baseline characteristics of participants who completed the follow-up survey and those who did not were compared to determine whether the 2 subsets of participants differed on any variables at baseline. Fisher exact tests were used for categorical variables, independent 2-tailed *t* tests were used for continuous variables, and Mann-Whitney *U* tests were used for ordinal frequency of going online for different activities variables.

Separate paired samples 2-tailed *t* tests were used to compare baseline and follow-up Mobile Device Proficiency Questionnaire (MDPQ) and confidence variables. Wilcoxon signed rank comparisons were conducted to compare the baseline and follow-up frequency of online activities variables. In addition, separate linear mixed models for repeated designs were conducted following the intent-to-treat principle to compare baseline and follow-up MDPQ scores, as well as frequency and confidence variables to provide confirmation of the findings from the *t* tests and Wilcoxon signed rank comparisons. The models included a fixed effect for time and an unstructured covariance structure (which provided improved model fit over more basic compound symmetry models for all variables).

Furthermore, change in MDPQ scores was calculated by subtracting baseline scores from follow-up scores, with higher numbers representing greater increases in proficiency. Independent samples 2-tailed *t* tests were used to compare changes in MDPQ scores according to program engagement variables. All variables were inspected for normality and outliers. A P value of <.05 was considered statistically significant. Open-ended responses were analyzed by 2 research team members (CS and KR), and inductive thematic analysis was used to code and determine central themes.

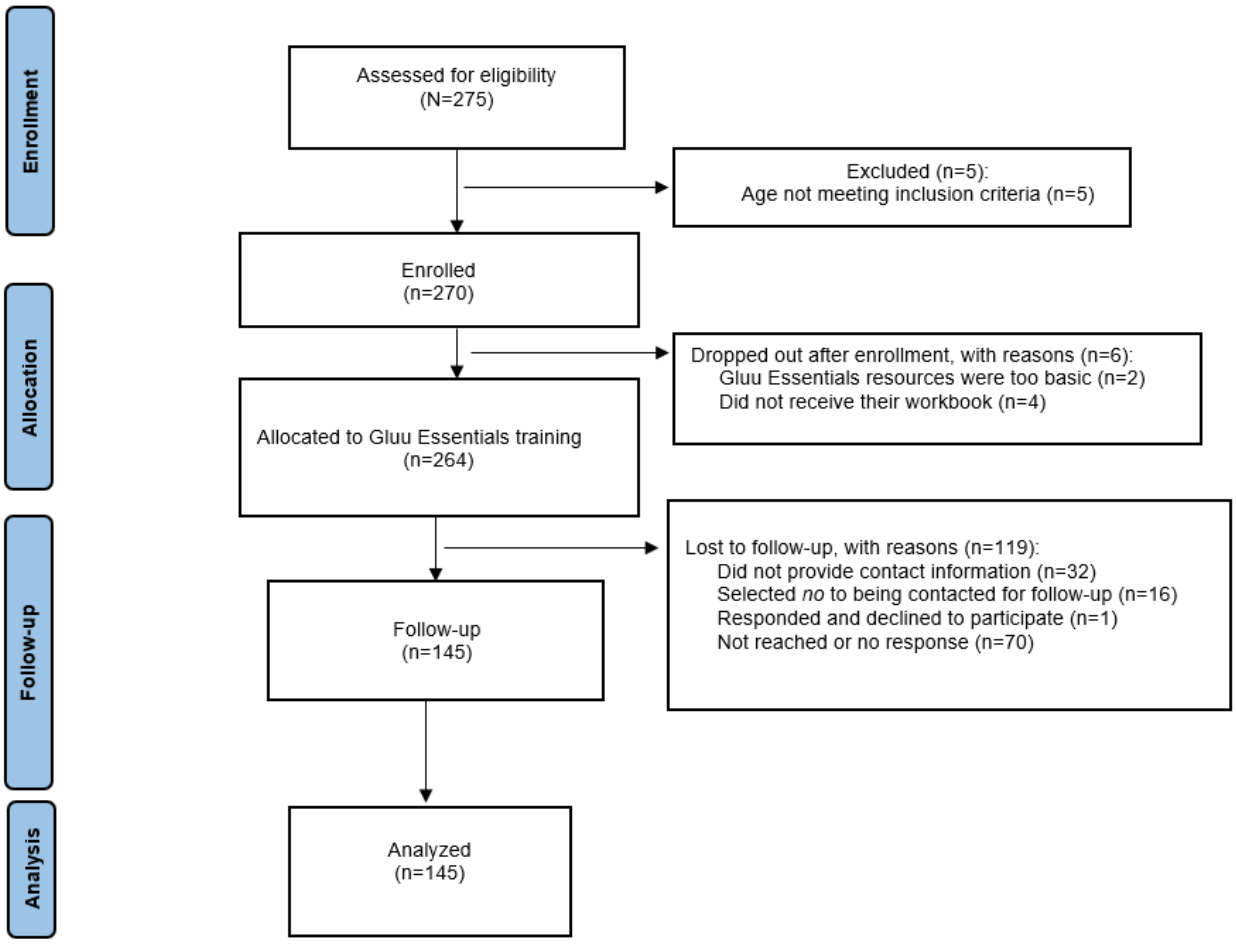
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Results

Survey Completion

A total of 275 participants completed baseline surveys (n=8, 2.9% paper surveys in fall 2021; n=55, 20% paper surveys in spring or summer 2022; and n=61, 22.2% paper surveys and n=151, 54.9% online surveys in fall 2022). Of these 275 participants, 5 (1.8%) aged <50 years (aged 37, 39, 42, 45, and 47 years) were removed, and 6 (2.2%) subsequently dropped out, resulting in 264 (96%) enrolled in training at baseline. Of these 264 participants, 145 (54.9%) completed follow-up surveys (Figure 3). Participants completed follow-up surveys an average of 19.5 (SD 5.8) weeks after completing their baseline surveys.

Figure 3. CONSORT (Consolidated Standards of Reporting Trials) flow diagram modified for nonrandomized trial design.



Sample Characteristics

The mean age of the participants was 72.93 (SD 6.73; range 51-93) years, and they were primarily female, White, and residing in the province of British Columbia (refer to Table 3 for participant characteristics at baseline, separated by whether or not follow-up surveys were completed). There were no differences between participants who completed the follow-up survey and those who did not in terms of age, ethnicity, education, or province; however, more of the female participants completed the follow-up survey than male participants, more of the urban participants completed the follow-up survey than rural participants, and more of the participants who completed online surveys at baseline completed the follow-up survey than those who completed paper surveys at baseline. More participants who used computers and tablets and used more apps completed the follow-up survey.

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Table 3. Participant characteristics and mean scores on all variables at baseline (n=270).

Characteristics	All participants at baseline, n (%)	Follow-up survey completers (n=145), n (%)	Missing follow-up survey (n=125), n (%)	*P* value[a]
Age (years)				.91
50-64	27 (10)	12 (8.3)	15 (12.3)	
Just answered “65+”	10 (3.7)	4 (2.8)	6 (4.9)	
65-69	44 (16.3)	25 (17.2)	19 (15.6)	
70-74	80 (29.6)	46 (31.7)	34 (27.9)	
75-79	69 (25.6)	36 (24.8)	33 (27)	
80-84	24 (8.9)	14 (9.7)	10 (8.2)	
85-89	8 (3)	4 (2.8)	4 (3.2)	
≥90	2 (0.7)	1 (0.7)	1 (0.8)	
Sex				.002
Female	227 (84.1)	132 (91.7)	95 (77.2)	
Male	40 (14.8)	12 (8.3)	28 (22.4)	
Other	1 (0.4)	0 (0)	1 (0.8)	
Prefer not to answer	1 (0.4)	1 (0.7)	0 (0.0)	
Missing	1 (0.4)	0 (0)	2 (1.6)	
Ethnicity				.51
Asian	7 (2.6)	5 (3.4)	2 (1.6)	
Indigenous (First Nations or Métis)	19 (7)	7 (4.8)	12 (9.6)	
Latin and South American	1 (0.4)	1 (0.7)	0 (0)	
White	230 (85.2)	127 (87.6)	103 (82.4)	
Other (eg, Canadian)	6 (2.2)	4 (2.8)	2 (1.6)	
Prefer not to answer	3 (1.1)	1 (0.7)	2 (1.6)	
Missing	4 (1.5)	0 (0)	4 (3.2)	
Highest education level				.31
No high school diploma	14 (5.2)	4 (2.8)	10 (8)	
High school diploma	44 (16.3)	24 (16.6)	20 16)	
Trade or college diploma	44 (16.3)	22 (15.2)	22 (17.6)	
Some college or university	45 (16.7)	27 (18.6)	18 (14.4)	
University degree	113 (41.9)	64 (44.1)	49 (39.2)	
Other	6 (2.2)	2 (1.4)	4 (3.2)	
Prefer not to answer	2 (0.7)	2 (1.4)	0 (0)	
Missing	2 (0.7)	0 (0)	2 (1.6)	
Province				.32
British Columbia	233 (86.3)	126 (86.9)	107 (85.6)	
Alberta	3 (1.1)	3 (2.1)	0 (0)	
Manitoba	26 (9.6)	12 (8.3)	14 (11.2)	
Saskatchewan	2 (0.7)	2 (1.4)	0 (0)	
Ontario	3 (1.1)	1 (0.7)	2 (1.6)	
New Brunswick	1 (0.4)	1 (0.7)	0 (0)	
Missing	2 (0.7)	0 (0)	2 (1.6)	
Remoteness index (rural or urban)				.001

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Characteristics	All participants at baseline, n (%)	Follow-up survey completers (n=145), n (%)	Missing follow-up survey (n=125), n (%)	*P* value[a]
Easily accessible	107 (39.6)	69 (47.6)	38 (30.4)	
Accessible	32 (11.9)	20 (13.8)	12 (9.6)	
Less accessible	56 (21.5)	24 (16.6)	32 (25.6)	
Remote	58 (21.5)	28 (19.3)	30 (24)	
Very remote	15 (5.6)	4 (2.8)	11 (8.8)	
Missing	2 (0.7)	0 (0)	2 (1.6)	
Survey format				<.001
Online	147 (54.4)	97 (66.9)	50 (40)	
Paper	123 (45.6)	48 (33.1)	75 (60)	
"Which device(s) do you use?"				
Computer	195 (72.2)	113 (77.9)	82 (65.6)	.02
Smartphone	213 (78.9)	118 (81.4)	95 (76)	.23
Tablet	208 (77)	121 (83.4)	87 (69.6)	.005
"I don't use any device yet"	3 (1.1)	0 (0)	3 (2.4)	N/A[b]
Missing	2 (0.7)	2 (1.4)	0 (0)	N/A

[a]*P* value based on Fisher exact tests (with missing data excluded). Comparisons for sex were dichotomized to male or female and for remoteness to rural or urban.

[b]N/A: not applicable.

Multimedia Appendix 1 presents a full breakdown of participant responses to all study variables at baseline separated by whether or not follow-up surveys were completed. Briefly, participants who completed the follow-up survey had higher values at baseline in overall mobile device proficiency, as well as higher values on the mobile device basics, internet, entertainment, privacy, and troubleshooting subscales, than those who did not complete the follow-up survey. Participants who completed the follow-up surveys also had higher confidence in going online as well as higher confidence in avoiding frauds and scams and were going online more frequently at baseline for email, accessing government services, information, and accessing COVID-19–related information than noncompleters.

Pre-Post Differences in Mobile Device Proficiency, Confidence, and Frequency of Online Activities

Table 4 presents descriptive data for mobile device proficiency and confidence at baseline and follow-up along with results of the pre-post comparisons. Overall MDPQ scores improved from baseline to follow-up. Specifically, the largest improvements were seen in the mobile device basics, communication, internet, and troubleshooting subscales. On the basis of Cohen *d* values, the effects were small to approaching medium. Confidence in going online and in avoiding frauds and scams did not change significantly from baseline to follow-up.

The comparison of the groups (ie, Wilcoxon signed rank tests) shows that the frequency of going online for shopping (*P*=.01) and accessing government services (*P*=.02) increased, whereas the frequency of going online for email (*P*=.47), banking (*P*=.10), information (*P*=.96), and emergency services (*P*=.42) did not change significantly. The frequency of going online for COVID-19–related information significantly decreased (*P*=.01). Inspecting the distributions of responses to these ordinal scales showed that many of the participants who had selected *never* at baseline seemed to have instead selected some frequency above *never* at follow-up (except in the case of going online for COVID-19–related information). To aid the interpretation of these ordinal scales, Multimedia Appendix 2 displays the proportion of participants (n=145) who reported engaging in each of the online activities at any frequency above *never* at baseline and follow-up.

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Table 4. Mobile device proficiency and confidence at baseline and at follow-up (n=145).

Variables	Baseline survey, mean (SD)	Follow-up survey, mean (SD)	*t* test[a] (*df*)	*P* value	Cohen *d*
MDPQ[b] total score	3.93 (0.91)	4.13 (0.79)	4.46 (143)	<.001	0.37
MDPQ subscales					
Mobile device basics	4.32 (0.87)	4.50 (0.68)	3.36 (143)	<.001	0.28
Communication	4.32 (0.94)	4.45 (0.88)	2.17 (137)	.03	0.18
Internet	4.13 (0.99)	4.41 (0.79)	4.66 (137)	<.001	0.40
Calendar	3.58 (1.48)	3.64 (1.48)	0.73 (137)	.47	0.06
Entertainment	3.49 (1.33)	3.55 (1.26)	0.79 (136)	.43	0.07
Privacy	3.55 (1.10)	3.65 (1.03)	1.44 (137)	.15	0.12
Troubleshooting	3.91 (1.08)	4.16 (0.95)	4.14 (143)	<.001	0.35
Confidence in going online	3.74 (0.91)	3.71 (0.88)	−0.45 (135)	.66	−0.04
Confidence in identifying frauds and scams	3.04 (0.73)	3.08 (0.77)	0.62 (137)	.54	0.05

[a]Separate paired samples 2-tailed *t* tests were used to compare baseline and follow-up scores among participants who completed surveys at both time points. Linear mixed models were also conducted following the intent-to-treat principle. The pattern of results was the same, although this was more pronounced in the linear mixed model analyses; therefore, the more conservative paired samples 2-tailed *t* test results are reported.

[b]MDPQ: Mobile Device Proficiency Questionnaire.

Program Engagement and Change in Mobile Device Proficiency

Change in mobile device proficiency (ie, baseline MDPQ scores subtracted from follow-up scores), ranged from −0.94 to 2.78 (mean 0.20, SD 0.53). The negative numbers denote that, for some of the participants (43/144, 29.9%), the MDPQ scores actually decreased slightly from baseline to follow-up. Nevertheless, the MDPQ scores increased for the majority of the participants (101/144, 70.1%), with the greatest increase being 2.78 points on the 5-point scale. Change in mobile device proficiency also varied with some program engagement metrics. Table 5 presents changes in mobile device proficiency according to program engagement. At follow-up, the majority of the participants (105/134, 78.4%) who responded reported starting at least 1 of the Gluu Essentials lessons, and those who started or completed some lessons had a greater change in mobile device proficiency than those who did not start any lessons. Of the 138 participants who responded, 29 (21%) reported having a digital coach and reported taking between 0 and 15 (mean 6.41, SD 3.62) in-person, typically weekly, classes. Of the 143 participants who responded, 26 (18.2%) reported that they did not use the Gluu Essentials workbook, 53 (37.1%) used it once a month or less, 42 (29.4%) used it several times a month, 20 (14%) used it weekly, and 2 (1.4%) used it daily. Of the 141 participants who responded, 103 (73%) received the iPad workbook, 24 (17%) received the Samsung Galaxy Tablet workbook, 2 (1.4%) received both, 5 (3.5%) reported using the workbook for other devices (eg, *smartphone* or *laptop*), and 7 (5%) did not receive or use a workbook. Having a digital coach, using a printed workbook, and following Gluu on social media were all unrelated to change in mobile device proficiency; however, participants who reported still accessing Gluu resources had a greater change in mobile device proficiency than those no longer accessing these resources.

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Table 5. Change in mobile device proficiency by program engagement (n=144).

Program engagement	Change in mobile device proficiency, mean (SD)	*t* test (*df*)	*P* value
Started or completed some lessons		2.78 (132)	.007
Yes (n=105)	0.24 (0.58)		
No (n=29)	0.03 (0.28)		
Had a digital coach		1.23 (136)	.22
Yes (n=29)	0.31 (0.61)		
No (n=109)	0.17 (0.50)		
Followed Gluu on social media		0.07 (129)	.94
Yes (n=54)	0.16 (0.50)		
No (n=77)	0.15 (0.41)		
Used printed workbook		0.93 (140)	.36
Yes (n=116)	0.22 (0.55)		
No (n=26)	0.11 (0.36)		
Still accessing Gluu Essentials resources		2.17 (136)	.03
Yes (n=94)	0.27 (0.55)		
No (n=44)	0.07 (0.41)		

Program Acceptability

Participant feedback on the Gluu Essentials training program was positive: 88% (82/93) reported being satisfied with Gluu Essentials digital skills training, 82% (75/92) reported learning new things about their device, 78% (73/93) reported learning new things about digital security, 78% (74/95) agreed or strongly agreed that the printed workbook was important, and 69% (60/87) stated that they were more likely to use technology to support their aging plan (eg, aging in place). System usability scores ranged from 25 to 90 (mean 72.76, SD 9.39), with 76 (79%) of the 96 participants who completed this scale assigning a score of >68 (ie, *above average*) to the Gluu Essentials program.

Open-Ended Suggestions to Enable Lifelong Digital Skills Learning

Participants' open-ended responses reflected 3 main themes: attitudes, program preferences, and support needs.

Theme 1: Attitudes

Many of the participants expressed positive attitudes toward digital skills training in general and the Gluu Essentials training specifically to keep up with changing technology and as part of their lifelong learning journey. A handful of participants were negative about such a digital skills journey—in some cases, even admitting agism—conveying that it was not for them and that "the technology changes all the time" and was "all too much" for them.

Theme 2: Program Preferences

Participants shared several sentiments about their program preferences and ways to enhance or supplement the program. Many enjoyed the availability of printed material, with some requesting the next level or step; some indicating ongoing programming preferences, such as "weekly newsletters" or "tips"; and some referring to the need for learning supports to be "simple," "easy to access," and "easy to follow," as well as paced to learning needs, with 1 skill being practiced at a time.

Theme 3: Support Needs

Participants highlighted 2 principal support needs: human support and affordability support. Their predominant *human* support need was for one-on-one people support through coaching, accessing information, or calling a help desk if needed. Several participants mentioned that "reduced costs" for internet and new technology would support them. Textbox 1 displays several participant quotes corresponding to the emergent themes from the analysis of the open-ended suggestions.

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Textbox 1. Responses to the open-ended question ("What would support you to be on a lifelong learning digital skills journey?") gathering participant suggestions for supporting their lifelong digital skills learning journey (n=107).

Attitudes

- "A continued program such as Gluu that I am able to access as I age, to keep pace with the constant changing technology that we elderly are facing."
- "I feel very fortunate to have access to digital help through several sources in the community as well as through friends whose skills are more extensive than mine."
- "I would only learn something if I can see a value in learning the task. I feel I am a lifelong learner. Always looking things up or reading about something new."
- "I am convinced I need to keep on learning."
- "The need to keep up with the technology."
- "If that is even remotely possible. My days are numbered."
- "I have no interest on being on such a digital journey."
- "At my age I don't have enough time. Would eventually surpass my learning skills."

Program preferences

- "I need print material to refer to."
- "I like having clear instructions like the workbook has."
- "Your workbook was helpful. If there was another with more advanced learning that would be great."
- "I would love another GLUU workbook at the next level up from basic."
- "Weekly or bi-weekly newsletters, workshops, etc.... will there be any other online lessons?"
- "Perhaps a scheduled regular monthly or bimonthly webinar with updates and tips."
- "Regular newsletter or emails with the tip of the week is one possibility."
- "Easily accessible link that would take an individual through one aspect of technology each week with an opportunity to practice that one skill through the week. Too much information at once gets complicated."

Supports

- "A person to help with my iPad. It's difficult to look at the book without some help."
- "An actual one-on-one REAL live coach at my side when needed. I really appreciate the support at my local library with one-on-one help."
- "Talking with other people in the classes helps be prepared for different problems."
- "More in-person workshops with Gluu. Also, access to a helpdesk would be most helpful."
- "Access to a chat/support system."
- "Ongoing person available for 1 to 1 learning, having money and access to keep up with new technology."
- "To have enough money to afford newer devices."
- "Cheaper costs for everything."
- "A less exorbitant cost to internet service and cell service."

Discussion

Principal Findings

The purpose of this study was to examine the effectiveness of the Gluu Essentials digital skills training program for improving participants' mobile device proficiency and to explore the impact of the training on the frequency of participants' engagement in online activities (eg, shopping, banking, and accessing government services) and on their confidence, as well as to assess their satisfaction with, and acceptability of, the program. Overall, participants' mobile device proficiency was higher after the program than at baseline, and they were going online more frequently for some activities; however, confidence was unchanged. Program acceptability was high, and participants who started or completed some lessons as well as those who were still accessing the Gluu Essentials resources had the greatest changes in proficiency.

Participants in the Gluu Essentials digital skills training program were middle-aged and older adults interested in learning about tablets; indeed, the Gluu Essentials program is targeted at basic tablet skills specifically, although there are a few broader digital skills touched on, such as digital security as well as Facebook and Zoom basics. As such, we found positive changes in mobile device proficiency after the program. Overall mobile device proficiency reflected increases primarily in the subscale competencies of mobile device basics, communication, internet,

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and troubleshooting. The increase in troubleshooting scores is noteworthy because it reflects participants' growing capacity to problem solve issues that arise without dependence on others, such as family and friends. In a recent scoping review, the lack of technical support that included troubleshooting was highlighted as a barrier to using technology for older adults [14]. Gluu Essentials program participants evidently received the support they needed from the program to demonstrate an improvement in their ability to troubleshoot.

In addition to increased mobile device proficiency, we found that there were increases in the frequency of going online for shopping and accessing government services among the participants. It is possible that having achieved greater mastery of their devices combined with the fact that mobile devices are *handy*, participants increased the frequency with which they went online for these activities. By contrast, going online for COVID-19–related information was reduced after the training, which was likely a reflection of the timing of most of the follow-up surveys because COVID-19–related measures lessened in Canada in the summer of 2022, although the COVID-19 pandemic was not officially downgraded until May 4, 2023 [40]. Similar to other research [41,42], we found that going online for email was so ubiquitous that there was little room for improvement. Our study also reported that going online for information was already fairly common at baseline. Going online for banking increased, although not significantly, and going online for emergency services did not change. Interventions targeted more directly at how to engage with emergency preparedness services may be needed to increase this specific activity.

Likewise, confidence in going online and avoiding fraud and scams was not significantly higher at follow-up than at baseline. It could be that training targeted more to these specific skills (especially for confidence in avoiding frauds and scams) is needed to improve confidence in these areas because digital security was only a small component of the Gluu Essentials program. Indeed, the Gluu Essentials digital skills training program and manual were intended to build proficiency—the essentials of actually using a tablet. Nevertheless, it is perplexing that confidence in going online did not increase, especially because the participants were going online more frequently for some activities. Other similar digital skills training programs for older adults improved self-efficacy [43]. Research indicates that repetition and opportunities to practice along with ongoing support are needed to build confidence [18,20,44]. In a recent cross-sectional study, social influence (ie, opinions of others about using the internet) was a bigger predictor of self-efficacy than social support (ie, having someone to help) [45], and social influence may play a role in motivating older adults to seek training. Indeed, reflected in our participants' open-ended responses was a desire for greater support. In a qualitative study of 10 older adults, confidence was bolstered by positive experiences (eg, successfully figuring out how to use an app) and opportunities to integrate personal interests (eg, photos, art, and games) in weekly technology training sessions, whereas frustrating experiences (eg, being unable to solve a problem) eroded confidence [46]. In future, adding opportunities in the Gluu Essentials digital skills training program for participants to engage with personal interests and support to build positive experiences might build greater confidence. Despite several studies conducted to improve mobile device proficiency among older adults, several others describe the lack of technology engagement among this population. Indeed, among older adults in Canada, age is the primary determinant of internet use, with only 40% of seniors aged >80 years using the internet in 2016 [47]. Tailored rather than one-size-fits-all programming may be needed for different age cohorts of older adults. In the study by Roque and Boot [9], younger adults scored nearly twice as high as older adults on all MDPQ subscales; our sample was more advanced in terms of mobile device proficiency than the older adult sample in the study by Roque and Boot [9] (mean scores ranged from 2.3 to 3.4) but not as proficient as their young adult sample (mean scores ranged from 4.7 to 4.9).

Of the 143 participants who responded, 117 (81.8%) made use of the printed workbooks (monthly, weekly, and daily) that accompanied the training, and 78% (74/95) believed that the workbook was an important component of their learning; in addition, qualitative feedback from the workbook users indicated their need for it and its helpfulness. This aligns with qualitative evidence that older adults prefer using self-training text materials, such as a manual [48]. However, many of the participants (53/143, 37.1%) used the workbook once a month or less, which may have reflected the less structured lesson delivery for online participants who were mailed printed workbooks. Finally, only a few participants (29/138, 21%) accessed digital coaches as part of the program, and the participants' open-ended responses identified their need for more real-life support. Indeed, 48 (33.1%) of the 145 follow-up survey participants had completed paper surveys at baseline, meaning they were engaged in person through a community organization, yet only 21 (44%) of these 48 participants reported having a digital coach or digital classes. It is possible that some of the participants may have misunderstood the digital coach question and not interpreted their local organization's support as being the equivalent of the role of a digital coach. It is also possible that some organizations simply handed out the workbooks and surveys but did not recruit volunteers to complete the Gluu Essentials training and act as digital coaches. In the future, a mechanism to ensure that community organizations are prepared to support learners may improve program fidelity.

Although the majority of participants (101/144, 70.1%) reported increased mobile device proficiency at follow-up compared with baseline, notably, several participants (43/144, 29.9%) reported a slight decrease in proficiency. It is possible that some participants did not have the one-to-one support that they were asking for or felt overwhelmed with the unpaced volume of information and how they could practice as was noted in some open-text responses. Furthermore, engagement with many of the program components was not related to mobile device proficiency, and this may reflect the smaller number of participants who reported engagement (eg, with a digital coach), or it could reflect the variability among learners (eg, those struggling the most needing to refer to the workbook more frequently than the others); however, encouragingly, those who engaged with the 12 Gluu Essentials lessons did report a greater

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increase in mobile device proficiency than those who did not start any lessons, reflecting the impact of the workbook. Indeed, engaging with the content or lessons might be considered foundational to all other program resources; other program supports (such as coaches) cannot provide optimal support if learners have not engaged with the lessons. Furthermore, continuing to access the Gluu Essentials resources was related to increased mobile device proficiency; therefore, ongoing engagement and practice are likely important for success.

Despite variation in self-reported program engagement, the majority of the participants did find the program acceptable, with more than two-thirds reporting being satisfied (82/93, 88%), having learned new things (75/92, 82%), and being more willing to use technology for their aging plan (60/87, 69%). Likewise, 79% (76/96) rated the usability of the Gluu Essentials programming as *above average*. Continued research is needed on middle-aged and older adults' attitudes toward, and satisfaction with, digital skills training, specifically with individual training components, to inform the development of relevant and acceptable programming [16,48].

This study focused primarily on what has been referred to as the *second-level* digital divide, namely having the skills and literacy to access information and communication technology [49]; however, the open-ended feedback from participants also highlighted cost—of devices as well as the internet—as significant barriers to access, suggesting that, at least for some, the first-level divide in access is still a challenge. Future work is needed that offers digital literacy training alongside access to devices and connectivity at low or no cost to begin to reduce these inequities.

Strengths and Limitations

This study has several strengths. The Gluu Essentials digital skills training program was implemented in the *real world*, that is, community organizations and participants adopted the training, and the program was delivered voluntarily. This allowed for an assessment of the potential and effectiveness of digital skills training in a natural environment, which may be influenced by external variables (eg, available support and resources, motivation, location or transportation, and cost) that are not necessarily apparent in highly controlled or specific settings. Furthermore, the assessment of program engagement allowed us to examine the impacts of different program components on change in mobile device proficiency, illuminating the importance of engagement with the core programming (ie, lessons).

Despite these strengths, this study has several limitations. Participants were motivated to learn digital skills, and although training was free, participants had to have their own device or have a means of obtaining a device (eg, through senior service organizations or family or friends); therefore, the results may not generalize to other populations. In addition, as this was an ongoing and freely offered community organization–delivered program, we were not able to use a randomized controlled study design. Relatedly, owing to challenges with the organizations tracking the distribution of the paper surveys, we were unable to report the baseline survey response rate as well as the total number of participants engaged by the community organizations during the study period. Likewise, our inability to document how and in what structure the organizations offered the training was another limitation. Despite efforts to mail follow-up paper surveys to participants who had completed paper surveys at baseline, more participants who had completed paper surveys at baseline were lost to follow-up overall. However, those lost to (survey) follow-up did not necessarily drop out of training; all paper baseline survey completers received a printed workbook and had some level of support from their community organizations. Engaging community organizations to distribute paper follow-up surveys may have improved response rates. Follow-up survey completers also had higher mobile device proficiency scores at baseline; despite this, our follow-up participants represented the full range of mobile device proficiency scores (ranging from 1 to 5). Likewise, we retained some participants who *never* went online for each activity at baseline (just proportionately fewer of them). We also observed increases in mobile device proficiency and the frequency of going online for 2 activities, and linear mixed model analyses suggested that the observed differences could have been even greater if more participants with lower scores at baseline had been retained at follow-up.

Conclusions

This study is unique in that we examined the impact of an existing digital literacy training program on middle-aged and older adults' digital engagement. Middle-aged and older adults participating in a real-life implementation of the program had higher follow-up scores on mobile device proficiency and greater frequency of going online for shopping and accessing government services compared with the baseline. The Gluu Essentials program was an acceptable and effective approach to digital skills acquisition, and future efforts should focus on strengthening program delivery to ensure that all components are available to all participants. Altogether, these findings advance the understanding of middle-aged and older adults' digital skills acquisition, particularly with respect to learning to use mobile devices, and have implications for other programs designed to engage and support middle-aged and older adults.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Characteristics at baseline of all participants, completers, and participants missing from follow-up.
[DOCX File , 161 KB - aging_v6i1e50345_app1.docx]

Multimedia Appendix 2
Proportion of participants (n=145) who completed both baseline and follow-up surveys and reported engaging in online activities at any frequency above never.
[PNG File , 26 KB - aging_v6i1e50345_app2.png]

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Abbreviations

MDPQ: Mobile Device Proficiency Questionnaire

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Original Paper

Acceptance of the Apple Watch Series 6 for Telemonitoring of Older Adults With Chronic Obstructive Pulmonary Disease: Qualitative Descriptive Study Part 1

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Abstract

Background: The Apple Watch is not a medical device per se; it is a smart wearable device that is increasingly being used for health monitoring. Evidence exists that the Apple Watch Series 6 can reliably measure blood oxygen saturation (SpO_2) in patients with chronic obstructive pulmonary disease under controlled circumstances.

Objective: This study aimed to better understand older adults' acceptance of the Watch as a part of telemonitoring, even with these advancements.

Methods: This study conducted content analysis on data collected from 10 older adults with chronic obstructive pulmonary disease who consented to wear the Watch.

Results: Using the Extended Unified Theory of Acceptance and Use of Technology model, results showed that participants experienced potential health benefits; however, the inability of the Watch to reliably measure SpO_2 when in respiratory distress was concerning. Participants' level of tech savviness varied, which caused some fear and frustration at the start, yet all felt supported by family and would have explored more features if they owned the Watch. All agreed that the Watch is mainly a medical tool and not a gadget.

Conclusions: To conclude, although the Watch may enhance their physical health and well-being, results indicated that participants are more likely to accept the Watch if it ultimately proves to be useful when experiencing respiratory distress.

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KEYWORDS

Apple Watch; chronic obstructive pulmonary disease; digital health; older adults; qualitative descriptive; technology acceptance; telemonitoring

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Introduction

Overview

Although the market for smartwatches has existed for many years, they have only recently been incorporated into the domain of health care delivery [1]. The advances in artificial intelligence and the use of sophisticated sensors capable of measuring vital signs such as heart rate (HR), respiratory rate, peripheral blood oxygen saturation (SpO_2), and electrocardiograms are changing the self-monitoring landscape for patients while facilitating communication of their clinical data in real time with a health care provider. The Apple Watch Series 6 (Apple Inc) introduced an optical sensor that has been shown to reliably measure HR and SpO_2 in patients with respiratory conditions such as chronic obstructive pulmonary disease (COPD) under controlled circumstances when compared with traditional commercial pulse oximeters [2].

In addition to the measurement accuracy, recent studies examining the feasibility of using an Android Wear smartwatch for continuous monitoring of patients with COPD have supported their potential for self-management, demonstrating the viability of the smartwatch-smartphone platform for early detection of acute exacerbations when worn consistently [3,4]. Although participants appreciated the inclusion of some biometric data, such as HR and activity level, they did not want a "passive monitoring device." They wanted more feedback on their coughing and SpO_2 values and expressed an interest in having access to COPD educational material, breathing exercises, and physical activity exercises to better manage their chronic condition [3]. Wearing the device may reduce feelings of anxiety associated with exacerbations and provide reassurance, yet in terms of usability, some older adults expressed concern about being a "prisoner of the numbers," which they described as the "need to keep checking the device to know how they were doing, leading to the device dominating their lives" [4]. Other acceptability factors toward the smartwatch were related to the design of the device and its level of accuracy without significant technical issues. Specifically, patients with COPD desired a stylish device that does not label them as being sick and would enhance their sense of normalcy. In terms of affordability, these patients with COPD indicated that the cost of a smartwatch was a major concern, as many are living on a fixed income [4]. Similar concerns regarding the appeal of the smartwatch size, the interface design, and personalization were found to be important for older adults who tested an alternative smartwatch system for reporting pain, mood, fatigue, and sleep quality [5].

Specifically, regarding the Apple Watch, limited evidence exists on its acceptability and usability factors in older populations. To our knowledge, only Chen et al [6] explored the usability of the Apple Watch among 8 older patients in an emergency department with a recent fall using the Unified Theory of Acceptance and Use of Technology (UTAUT) conceptual model [7]. Results indicated that patients, after brief training, were able to wear and charge the Watch; however, their ability to engage with various features was influenced by their previous experience and comfort with technology, as well as the support and encouragement from family members and health care providers [6]. This significant gap in knowledge exploring the cognitive and behavioral aspects of acceptance of the Apple Watch as a device for facilitating health care delivery [5], is further compounded by a lack of understanding within the older adult population with health conditions such as COPD, where limitations and barriers to adoption associated with previous devices may be mitigated by the Apple Watch Series 6. In order to address this research gap, this qualitative descriptive study aimed to explore the acceptance and adoption of the Apple Watch among community-dwelling older adults with COPD for telemonitoring purposes using the Extended Unified Theory of Acceptance and Use of Technology (UTAUT2) model [8].

The UTAUT2 Model

One of the most influential models to describe the factors influencing the acceptance of technology is the Technology Acceptance Model (TAM) [9], the subsequent UTAUT model [7], and its extended revision (UTAUT2) [8]. From the TAM, the beliefs of "perceived ease of use" (effort expectancy) and "perceived usefulness" (performance expectancy) are of primary relevance in explaining the attitudes that lead to "behavioral intention to use" (acceptance) and ultimately "actual use" [9]. The UTAUT added "social influence" and "facilitating conditions" as influencing "behavioral intention" and "use behavior" (actual use) [7], and the UTAUT2 added "hedonic motivation," "price value," and "habit" as intrinsic contributing factors, both including moderators such as age, sex, and experience that affect multiple pathways [8]. One of the driving factors in the revision of these models has been their limited applicability in fields such as health care, where additional determinants or moderators have been necessary to confer predictive value [10,11]. Therefore, the UTAUT2 model balanced extrinsic motivators such as "social influence" and "facilitating conditions" with intrinsic motivators to generate a more comprehensive predictive model, especially important when considering the adoption of personal devices such as smartwatches that are intended to be worn continuously.

Methods

Design, Sample, and Recruitment

This qualitative study was part of a larger mixed methods project that evaluated the use of an integrated telehealth nursing system to enhance patients' health-related outcomes and reduce emergency room visits and hospitalizations, which took place from June 2020 to November 2021. Due to vendor-related issues, the project needed to switch to a different telemonitoring platform in June 2021, which presented the opportunity to offer an Apple Watch Series 6 to 10 participants. All 25 participants enrolled in the larger study were called and recruited for this qualitative study if they were interested in using the Watch for a period of 5 months. In order to be eligible for participation in the larger study, participants must (1) be diagnosed with COPD Global Initiative for Chronic Obstructive Lung Disease (GOLD) grade 2 or above, (2) have at least 1 emergency room visit or hospital admission in the previous year of enrollment, (3) be speaking English or French, (4) provide consent, (5) agree to

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be audio-taped, and (6) be followed at the COPD clinic of a regional acute hospital.

As shown in Table 1, participants had an average age of 71.6 (range 64-82) years. All participants were female except 2 (P1 and P4), 4 (P1, P5, P8, and P9) were legally married, 2 (P2 and P6) were divorced, and 1 (P7) was single. Of the 10 participants, all were retired except P6, who was unable to work. Participants' levels of education varied: 1 (P6) had a middle school diploma, 7 (P2-P4 and P7-P10) had a secondary diploma of professional studies, and 2 (P1 and P5) had a bachelor's degree. On average, participants were diagnosed with COPD for 6.4 (range 3-10) years, and 9 participants had an average of 2.2 hospitalizations since being diagnosed, except for P3, who had more than 20 hospitalizations since being diagnosed in 2012. Using the staging system of the GOLD, which considers a variety of factors, such as exacerbations, symptom severity, and forced expiratory volume, 3 people (P4, P6, and P10) were classified as GOLD grade 4 with "very severe COPD," 3 (P1, P8, and P9) as GOLD grade 3 with "severe COPD," and 3 (P3, P5, and P7) as GOLD grade 2 with "mild to moderate COPD" [12]. In terms of the ABCD assessment [13], all participants were labeled in the GOLD level D, meaning that they experienced more severe symptoms, such as greater dyspnea or exercise tolerance. All participants were provided with a Health Canada–approved digital fingertip pulse oximeter and an Apple Watch, and 7 (P1, P4, and P6-P10) received a project iPhone (Apple Inc).

Table 1. Sociodemographic data.

Participant	Age (years)	Sex	Marital status	Education	Native language	Year of diagnosis	GOLD[a] level	Hospital admission, n
P1	82	Male	Married	Bachelor's	French	2018	3D	2
P2	70	Female	Divorced	Secondary	English	2016	4D	1
P3	82	Female	Widowed	Secondary	French	2012	2D	>20
P4	68	Male	Widowed	Secondary	French	2016	4D	1
P5	68	Female	Married	Bachelor's	English	2016	2D	1
P6	64	Female	Divorced	Middle school	French	2019	4D	4
P7	77	Female	Single	Secondary	French	2014	2D	1
P8	71	Female	Married	Secondary	English	2013	3D	4
P9	67	Female	Married	Secondary	English	2017	3D	3
P10	67	Female	Common law partner	Secondary	English	2016	4D	4

[a]GOLD: Global Initiative for Chronic Obstructive Lung Disease.

Home Telemonitoring Nursing Intervention

Once patients agreed to use the Watch, the fourth author scheduled a 1-hour home visit to install and educate them on how to use the Watch and the commercial telemonitoring platform on their personal smartphone or a project iPhone. Participants were allowed to use all features on the Watch, download any apps, and were instructed to wear the Watch during awake hours. For a period of nearly 5 months, participants' SpO_2 and HR data were collected using the Watch, and they were asked to answer 5 specific COPD-related questions once every day using the platform. "How would you describe your level of shortness of breath today?" "How many times did you spit today?" "What color was your spit today?" "Was your spit thicker than usual?" "How often did you cough today?" Participants submitted their SpO_2 and HR values using the fingertip pulse oximeters daily. Tailored patient education material was made available on the telemonitoring platform to complement their knowledge regarding lifestyle changes. When a measurement of clinical data was outside of expected patient-specific parameters, the telenurse would contact the patient, provide the necessary interventions, and, if needed, communicate with the interdisciplinary team at the COPD clinic of a local community hospital.

Data Collection

After using the Watch for approximately 5 months, an individual semistructured interview was conducted with each participant during the months of September-October 2021. At the start of each interview, the purpose was re-explained, and a sociodemographic questionnaire was completed at the start of the larger study. The interviews were conducted in English or French through Zoom (Zoom Video Communications) by the first and fourth authors at a convenient time for the participant and lasted approximately 60-90 minutes. Both authors were present for all interviews. The interview with P3 was conducted in the presence of her daughter, as the participant had hearing problems. The interview guide included questions such as, "What did you know about the Apple Watch prior to the project?" "Please describe your initial thoughts when the Apple Watch was presented to you for telemonitoring purposes." "How did you decide to participate in this Apple Watch project?" "What were the major difficulties you have encountered as of now regarding the Apple Watch?" "Can you explain how you have used the Watch over the span of one day?" "Which features have you used so far?" "How do you feel about the continuous monitoring of your SpO_2 and HR?" To ensure alignment between the study aim and the interview questions, the guide was pilot-tested and validated with 2 key informants, and further refinements were made after the first few interviews [14].

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Data Analysis

All interviews were transcribed in the language of the interview and directly coded without translation, as all authors were fluently bilingual. Each transcript was manually analyzed using the inductive content analysis approach described by Elo and Kyngäs [15] and supplemented with field notes. A process of open coding was used to assign captions to segments of the transcripts. Codes were organized into categories and themes according to the UTAUT2 model, which captured similar concepts, from which descriptive statements were formed and supported with quotes. Several strategies were used to enhance the trustworthiness of the findings [16]. Peer debriefing and member checking were used to avoid possible biases and preconceptions and to ensure that the participants' experiences were adequately represented. To address confirmability, dependability, and transferability, the interviewers wrote reflexive notes immediately after each interview, documented personal feelings and insights, and committed to a detailed description of the research methods, participants, and settings. Investigator triangulation through concurrent coding was also used throughout the analysis process to ensure credibility and confirmability.

Ethical Considerations

Research ethics approval was obtained from the research ethics committee of an integrated health and social services center (Centre intégré universitaire de santé et de services sociaux de l'Ouest-de-L'Ile-de-Montréal) on August 16, 2019 (SMH #19-11). All participants signed the consent form before the start of the larger study, and written information was provided explaining the study purpose, participant involvement, the right to withdraw at any stage, and data confidentiality.

Results

Overview

Except for the component "price value," all exogenous UTAUT2 constructs were used to explore the behavioral attitudes of older adults with COPD toward the adoption of the Apple Watch. Although the majority of participants had an overall positive judgment of the Watch, discrepancies in opinions are presented for each of the constructs. In terms of "performance expectancy," some experienced health benefits and found the Watch more reliable, while others trusted the manual oximeter, especially in times of respiratory distress. The novelty of the Watch generated among many a mixture of emotions, from curiosity to fear and frustration, because of the practical issues with the Watch, which made it difficult to navigate the device and are covered by the construct "effort expectancy." As discussed in the sections Social Influence and Facilitating Conditions below, participants' families were supportive, and while some older adults were tech-savvy, others relied entirely on a family member to operate the device. Not owning the Watch was a hindrance to exploring new features. All participants perceived the Watch primarily as a medical tool, which is reflected in the construct "hedonic motivation." Finally, as described in the section Moderators: Age and Sex below, male participants found it vital for older adults to learn and stay up to date with new technologies.

Performance Expectancy

Specifically for the Watch, "performance expectancy" described the degree to which participants believed the device worked for the intended purpose of health monitoring and helped them to gain specific health benefits.

Gratitude for Health Benefits of the Watch

Although some participants (P5 and P9) felt fortunate to have the Watch and found it "absolutely genius," their appreciation in terms of health benefits varied. Participants P3, P4, and P6-P8 used the "stand-up" feature and found that the Watch improved their overall health, as stated by P8: "I feel so much better physically. I haven't thought of COPD since I got this Watch." P4 continued: "My overall health and well-being has improved by 25%-30%. I won't disobey the laws of the Watch; I will stand up if it tells me. That is a tool that someone like me needs." In contrast, P2 had a different view: "I have a degenerative disease. The Watch gives me an idea of my SpO_2 and HR, but it doesn't improve my health." Others (P5 and P6) were happy to better understand their sleep patterns. P10, however, ignored a message from the Watch suggesting that she had atrial fibrillation; "At the start, I was just using the Watch for the oxygen only [...] it kept telling me 'You are having fibrillation problems, your heart is not beating properly,' and I kept swiping [the message] aside thinking 'oh it's being sensitive for those kinds of things,' but the reason for my hospitalization was due to my heart problems, and not my COPD."

Reliability of Watch Versus Traditional Pulse Oximeter

Participants' opinions were split regarding the use of the Watch or the traditional pulse oximeter for SpO_2 measurements. In the occurrence of respiratory distress, the finger pulse oximeter was for some participants (P4, P7, P9, and P10) a more reliable option to capture their SpO_2. P4, who had not yet mastered the use of the Watch, said: "The first thing I will get is the [traditional] oximeter because it is easier to put on my finger [than the Watch]. I do not understand the Watch well enough yet." Due to the specific requirements of the positioning of the wristband, P9 was disappointed in the continuous monitoring of SpO_2 and stated: "I had to manipulate the Watch 6 to 7 times, because it kept saying 'unable to read, make sure your Watch is secure, comfortable,' and I would move it and I would still get those messages, and I was annoyed by it." On the contrary, others (P1, P2, P5, and P8) would vote in favor of the Watch. P1 stated: "I have the impression that the oximeter is less precise compared to the Watch because the manual oximeter we put it from finger to finger, hand to hand." For P5 and P8, the Watch was more reliable because the manual one needed batteries. P8 said: "If you change the battery, you know that the light is brighter, and it is giving you a more accurate read. Whereas the technology of the Watch relies on your [wrist] positioning to get accurate measurements." In terms of safety, P9 shared that the continuous monitoring of the Watch made her "feel even safer" but ended that she "felt safe with the [traditional] oximeter also."

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Effort Expectancy

In terms of "effort expectancy" or "perceived ease of use" of technology, participants shared their experiences and challenges associated with the efforts needed to operate and navigate the Apple Watch.

Mix of Reactive Emotions Toward Watch Novelty

Except for 1 male tech-savvy person (P1) who expressed being "pretty up to date" with new technologies, the novelty of the smartwatch and its usage brought about a blend of reactive emotions for the majority of participants (P2, P5, and P6-P10), including curiosity, hesitancy, fear, frustration, anger, and stress. Although curious about the functionalities of new technologies, P9 felt anger when she did not know the workings: "I am curious [about new technologies] but there are things on my phone I don't know how to do, and then I get angry." However, being persistent, she described this process as fighting with the new piece of technology to "finally gain control over it." In terms of being curious and not knowing what to do, P2 followed her daughter's advice, saying, "I push a button till I get the right one. I am just using [the Watch], and I guess I become more confident." Before being more confident, P2, P8, and P10 expressed initial hesitancy and fear, as P10 stated: "I am afraid I will do something that I won't be able to correct [...]. I don't like screwing up. I am sensitive about pushing buttons that I don't know what is going to happen." A total of 3 participants (P4-P6) did not find it difficult to use the Watch after receiving the instructions; they considered themselves quick learners. P5 said, "I am not a dummy. Once I learned how to [take the readings correctly], it was cool." Although being able to learn fast, both female participants (P5 and 6) experienced stress and frustration when the Watch did not take the SpO_2 measurement correctly at rest and when experiencing shortness of breath (SOB).

One's Health and Manual Dexterity Affect Watch Usability

In terms of usability challenges, 5 participants (P2-P4, P6, and P10) stated that their personal health status and level of manual dexterity affected their ability to use the Watch. Although the Watch is a tool for monitoring health conditions, P6, who had severe COPD, mentioned that the Watch was unable to capture her SpO_2 during frequent episodes of SOB. She shared: "Most of the time, when I am out of breath, the Watch cannot take my oxygen level. [...] I move a lot [when I am out of breath]. This tells me that the app doesn't work." Given that the Watch did not take her SpO_2 when she needed it the most, she stated, "Is it worth it, I don't know." Participant P2, who did not feel well, indicated that her low energy level influenced her ability and interest in using and exploring various features of the Watch. The other 3 participants (P3, P4, and P10) expressed that there is a level of manual dexterity required to manipulate the Watch, as stated by P10: "I am pretty dexterous with my hands, but getting the Watch on and off, is a bit of a challenge with one hand." This was validated by P3, who stated that the arthritis of her fingers affected her manual dexterity, which influenced the ease with which she could touch the Watch given its small size. Similarly, P4 stated that the size of his fingers affected his ability to use the device's touch screen, saying, "It is so small compared to my fingers."

Proper Wristband and Watch Placement Necessary

Participants shared usability challenges related to the Watch placement and the size and fit of the wristband. Improper placement of the Watch, which is a potential limitation of smartwatches, was a barrier for 3 participants (P5, P6, and P10) when attempting to measure their SpO_2. In addition to the trouble of getting the Watch on and off, P10 found it challenging to find the correct placement of the Watch to ensure that the sensors were making skin contact. She stated, "It took months to know exactly where [the Watch] has to be on my arm. I have to do it a number of times [...] it is a little sensitive." Participants P5, P6, and P9 experienced similar measurement reading issues until the telenurse suggested using a smaller wristband. P5 said: "With the other [larger size] wristband, it wasn't reading. I was just trying to find the right position and thinking what I was doing wrong. But when switching to the smaller band, everything was Ok." In terms of the wristband, P10 shared the following complaint: "The band has to be tight to take any readings, but the band is thick and rubber, and it makes you sweat. I would not wear this in bed."

Social Influence

"Social influence" was defined as the extent to which others in the participants' social environment have impacted their decision to use the Apple Watch.

Positive Sentiments From Social Circle

Feedback from participants' social circle to use the Watch varied; it fluctuated from a neutral response from loved ones to positive encouragement, curiosity, and 1 family member who decided to purchase a Watch for personal use. Except for the family of P9, who exhibited a neutral reaction, the social circle of the majority of participants (P3, P5, P6-P8, and P10) shared sentiments of being impressed and content that their loved one had access to the device. Friends of P5 stated: "They think it's great. They want to know how they can get it, especially my friends think it's phenomenal." Along with the support of her daughter and friends, participant P3's family physician also indicated that "it is a very a good idea" that the participant is part of this Apple Watch project. P6 said: "When I told them [3 daughters] about this new program, they said, 'Take [the Watch], it's good for you [...] they thought it was important that I was followed like this.'" For P8, the Watch health monitoring was "a family affair" and was seen as a source of comfort for her husband, stating, "If something happens to me, he could find out right away because I wear the Watch. It's a comfort for him [...] he feels secure." Furthermore, P8's daughter was also happy to hear that her mother started using an Apple Watch. Specifically, "My daughter is happy that I get a Watch because it's just a little security for the family [...] it is a positive thing for us, not just for me, for us." For 1 participant (P2), her brother was influenced by her Apple Watch use and ended up purchasing one. She stated, "He bought it because he saw mine, he was interested when I told him." Ultimately, despite being encouraged by family, P6 emphasized that "It's not [my

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daughters] who decide, it's me." Similar reactions were voiced by the 2 male participants (P1 and P4).

Intergenerational Inspiration

Although participants tech savviness varied in using these devices, 3 participants (P6, P9, and P10) in particular spoke about the effect of intergenerational relationships in using novel technology. Participant P6 mentioned that her daughter influenced her curiosity about using different features on the Watch, while P10, who relied on her daughter to guide her with new technology, believed that she was "a little behind in technology." When asked whether she felt a certain pressure to keep up with new technology, P10 stated, "No, only when my grandkids laughed at me," and that the only reason she keeps up with technology is to "keep up with [the grandchildren] and to know what to buy for Christmas and birthdays." Although P9 did not want to display any feelings of pride when using the Watch, she indicated, "I should [keep up with new technology] to stay in touch [with family and friends]. I love FaceTime and like to scroll Facebook." Nonetheless, P9 stated, "I think a lot of older people are not comfortable enough with technology." Furthermore, "the younger people want so much more information than my generation. I think if I had been able to have a Watch when I was 35-40, I would have jumped on it."

Facilitating Conditions

Various "facilitating conditions," such as participants' level of tech savviness, having the Watch on loan, and confidentiality issues, were influencing factors for acceptance of the Watch.

Personal Level of Tech Savviness

Participants' comfort level and readiness with new technology either facilitated or impeded Apple Watch usage. Of the 10 participants, 2 (P8 and P10) identified themselves as not being tech-savvy and needing varying levels of support from family to manage their Watch; 5 (P2-P4, P6, and P9) were comfortable using the Watch after initial instructions; however, they may need help for technical problems; and 3 (P1, P5, and P7), who self-identified as being curious individuals and not fearful about the Watch, had the ability to use the device and find the necessary resources when encountering technical issues. Participants P8 and P10 completely relied on their respective daughters and husbands because of their fear of pressing buttons, deleting things, or breaking the Watch. P8 stated: "My husband sets me up and all I do is press that little button. I don't have any patience with that [...] he usually sits beside me, and we do this together." Although not very tech-savvy, participant P9 felt comfortable using the device by herself, saying, "I am comfortable with it now [after using it for 2 months]. I don't use it for anything else [except for HR and SpO_2]. I find it easy." During the joint interview, the daughter of P3 shared that she teaches her mother how to use any new device, saying, "She learns superfast. I show her 1 or 2 times, and then she knows how to do it." Participant P6, however, stated that her first instinct is to call her daughter when encountering a technical issue with the Watch. Although P4 described himself as "being resourceful," which allowed him to use the Watch without any difficulties, he noted that his son lives at home and is available to him if needed. He said, "The Watch is more complicated than the telephone. I am techno, I am not an expert, but I can handle it [...]. At the start, my son showed me sometimes, but he is not patient." The 3 tech-savvy participants (P1, P5, and P7) did not need support when they encountered any issues related to the Watch; they relied on themselves to research and resolve the issues on their own. Participant P7 stated: "I pulled out the little manual when I have a problem. I learn from my mistakes." Participant P5 expressed her excitement about getting the Watch, and stated, "I always like to learn new things. This Watch was a new thing that I was going to learn as it was going to benefit me." Her excitement and curiosity toward using the Watch were facilitated by her perception that she "can't do damage to the Watch" because the "Watch can't crash" like a computer can. Lastly, P1 is fearless about the technology: "I explored all applications [on the Watch]. I am absolutely not afraid, electronics and stuff like that, it's part of our lives now."

Apple Watch on Loan

Although participants were informed that they could use the Watch to its full capacity, 6 participants (P1, P3, and P5-P9) were reluctant and careful given that they did not own the device. Only P4 had no concerns about the Watch being loaned to him, stating, "No, I won't eat it. Its waterproof [...] I have taken my bath sometimes and it never did anything. When I do the dishes, I don't remove it either." Contrarily, P6 felt that she needed to ask permission from the researchers before using the device in the shower. Participant P1 knew that the watch was waterproof "but did not dare" to test this feature. Furthermore, P8 stated, "I do not want to break your Watch," and "When I have my own, I'll play with it more than now. This belongs to you; I'm just doing the 2 things on it: the heart monitor and the oximeter." Participants P6 and P7 expressed the same sentiment, stating that they use the Apple Watch just for the apps that are needed for the project and would not download more apps given that the Watch does not belong to them. During the project, participants P1, P2, P5, and P9 explored other features, such as the calendar, calculator, and photo apps, and were using the Watch to send and receive SMS text messages and emails and to answer phone calls. P9 shared: "The other day I answered the phone on it. I have never done that before, because I was in a store, and I just couldn't get my phone, so I answered the call on the Watch."

Watch Safety and Security

Only 3 participants (P1, P5, and P9) expressed their views on scams, security, and confidentiality issues. Participant P9 expressed her fear of being scammed through technology: "I'm afraid at some point I will push [a button] because I was scammed once with makeup on my iPad and it cost me like $800 because I pushed accept." For P1, "hackers" accessing medical data was a concern. He said, "You have to have some fear of these things. There is still a level of confidentiality that is not yet 100%, I like my Watch but not banking things." In contrast, P5 stated that she had no concern about sharing her COPD medical data with medical professionals, as it is "important for clinicians to see how much I am walking, how active I am [...] I know that the measures that are being monitored are all confidential anyways."

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Hedonic Motivation

"Hedonic motivation" in the UTAUT2 refers to the fun and pleasure derived from using a new technology, for example, the Apple Watch.

The Watch, Fun but Primarily a Medical Tool

When asked if participants perceived the Apple Watch as a tool or gadget, all participants described this novel device primarily as being a medical tool. Participant P4 emphasized that "it is a tool, not a gadget. It has to be used intelligently. I used it 99% for the COPD; it is dedicated for that, and if I want to fool around, I go on Google and the TV." Although both female participants (P5 and P8) stressed that the Watch is a physical health tool, they agreed that this smart device is fun. P5 stated, "I am using it for my benefit, but it is fun to look at. It is most definitely a physical health tool; it tells me every once in a while, stand-up, you have been sitting too long. [...] And the funniest thing is when I answered the telephone with my Watch." She continued: "You should watch Dick Tracy; he could communicate with his police officers with his telephone watch." In a similar fashion, P4 joked, "I feel like James Bond when I answer the phone using his Watch." Participant P8 further shared: "It is our fun thing every day, we are enjoying the Watch. You lent me one of your toys and I am playing with it." To conclude, P1 described the Watch as "a tool we cannot go without anymore." He continued: "I have known the time that there was nothing like this. Now we are talking on the phone and seeing the person at the same time, it's kind of science-fiction, but what do you want, we are there [today]."

The Watch, a Fashion Item

A total of 3 female participants (P3, P5, and P9) expressed how they perceived the Watch aesthetically. For participant P9, the Watch was seen as "big, perhaps because I have a small wrist, but I am not a good advertisement for the Watch, I would never buy one." In contrast, participants P5 and P9 mentioned that it was not a physical change, as they are both accustomed to wearing watches. Participant P3 said, "I am a Watch lover. I see [the Apple Watch] as an ordinary watch. But if I go out to a big party like before, I think I would take it off and put on a nice watch." Participant P5 furthered this sentiment when describing the Watch as being "cute and fashionable" and described herself as "trending," given that "larger watches are trending right now." In terms of the color of the Watch band, she joked, "I wish it was a little fancier black. Black is safe because white would get dirty."

Habit

Although participants only used the Watch for about 2 months, the new theoretical construct "habit" added to the UTAUT2 describes the extent to which they incorporated the device into their daily routines and their awareness of its capabilities.

Awareness of Watch and its Features

Except for P4, who did not have a computer or smartphone before participating in the project, all participants had various experiences with computers or mobile devices. Participant P1, who called himself a "neophyte in electronics," said: "I use the phone for a million things. I talk to our daughters, I text, send, and receive emails. I go on Skype, twitter, and all of that." Others, like participants P2 and P6, have used computers at work; as stated by P2: "I have been somewhat self-taught, I learned to use Excel. I have worked as an accounting technician and managed to work with the computer software there." Overall, 3 of the 10 participants (P5, P8, and P10) had a FitBit, and P5 joked: "My children bought a FitBit and I said, 'I don't need it anymore, I have my Apple.'" Participant P8 added: "My husband bought me a FitBit, a pain in the butt. I don't like it at all. It just beats 5000 more steps and 5 stars and whistles. I don't like bells and whistles. It is simple [with the Watch], I push a button and get my HR, I push a button and get my oxygen." Participants' knowledge, awareness, and experience with the Watch greatly differed. Participant P4 mentioned: "I have heard talking about the smartwatches on television, but I had never one in my hands." Others (P1, P3, P6, P7, and P9) have seen their children, family members, or friends using their Watch for health and entertainment purposes; however, only P9 mentioned knowing that the Watch could monitor one's HR and SpO_2.

The Watch, Part of the Daily Routine

Although there was some variability, all 10 participants incorporated the Watch into their daily routines. They were wearing the Watch throughout the day, unless it needed to be charged or they took a shower, and 3 of them (P2, P5, and P6) used the Watch at night. P4 admitted that incorporating the Watch into his daily routine was an effort and commitment, and for P6 and P9, who did not wear a Watch for a long time, it was often annoying at the beginning. Participant P2 shared: "It sure changes the routine a little bit, but it fit in what I was doing before." Participant P10 described herself as a "creature of habit" and stated that the device became "part of her daily routine regime." The rigidity of her daily routine was evident as, even when hospitalized, P10 continued using the Apple Watch to measure her SpO_2 daily.

Moderators: Age and Sex

Despite their differences as to the awareness of the Watch and its related features before their project enrollment, both male participants (P1 and P4) were comfortable using the device compared to many female participants. Although P4 did not own a computer or a smartphone, the Watch gave him an opportunity to learn, saying, "It gave me a chance to wake up and educate myself." The idea that the Watch was an opportunity to learn was shared by P5, who believed that "anyone should learn about new technologies as long as they know the benefits." This sentiment was supported by P1, who found it important for older adults to stay up to date with technology but simultaneously acknowledged that technology has its limitations. He concluded: "I can survive without technology, it is not a necessity, but it can facilitate things, such as communication."

Discussion

Overview

Although COPD is a degenerative disease, findings showed that the use of various Apple Watch monitoring apps, such as "Sleep Cycle," "Stand Up," etc, may improve an individual's physical

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health and overall well-being. People were encouraged by family to use the Watch; it was a fun experience, and some were eager to learn to use the wearable and felt that older adults should remain up to date with new technologies. Despite the benefits, the findings brought out concerns related to Apple Watch use in older adults with COPD. Hence, the following two points warrant discussion about the Watch: (1) feasibility of measuring SpO_2 values of patients with COPD in their natural environment; and (2) perceived value of the Apple Watch.

Feasibility of Measuring SpO_2 Values in Patients With COPD in Their Natural Environment

As indicated above, the Apple Watch Series 6 is a reliable device for obtaining HR and SpO_2 in patients with lung diseases under controlled conditions [2]. More specifically, the study observed strong positive correlations between the Apple Watch device and commercial finger pulse oximeters [2]. However, our study participants with severe COPD who used the Watch in real life shared their stress and frustration as the SpO_2 app did not work when experiencing SOB. This finding was supported by Spaccarotella et al [17], as they were unable to measure SpO_2 with the Watch for 8 of their participants with lung or cardiovascular diseases. The authors believed that skin perfusion and anatomical variability of the wrists could be a plausible reason for this defect [17]. Interestingly, the device's makers, Apple Inc [18], supported these claims and stated, "Even under ideal conditions, your Apple Watch may not be able to get a reliable blood oxygen measurement every time. For a small percentage of users, various factors may make it impossible to get any blood oxygen measurement, including motion, watch placement on the wrist, skin temperature, skin perfusion, permanent or temporary changes to the skin such as tattoos, and HR above 150 bpm while at rest" [18]. Essentially, Apple Inc designed the oxygen monitor for general fitness and wellness purposes and is not considered a Class II medical device by the Federal Drug and Administration (FDA), which does not require clearance. This information-only offering approach of all health-focused apps on the Apple Watch is in contrast with Apple's electrocardiogram feature, which was designed and marketed as a medical-grade feature and obtained FDA clearance in 2020.

Despite the instructions and suggestions provided by the company on how to use and measure SpO_2 values and the fact that the blood oxygen monitor is a "wellness feature" and not intended for medical diagnostic use, the following questions remain: "Is it appropriate for patients with lung diseases, such as COPD, to use the Watch oxygen monitor in daily situations? Does it cause more harm than good for these patients?" Despite the fine-print warnings, people will primarily use the Watch SpO_2 feature as a medical tool, as indicated by our study participants. The Watch was not a gadget but a tool to monitor their respiratory status and communicate with the telenurse. In cases of inconclusive results, some participants would repeatedly retake their measurements, which may cause them unnecessary anxiety. Dr Rosman, a cardiologist who is currently studying the effects of devices on anxiety, indicated that the use of the Watch "opens the door to a lot of questions and concerns from patients that are currently being unaddressed" [19]. In addition, Dr Friedman, a cardiologist, strongly emphasized that a distinction must be made between measurements for wellness and medical purposes [19].

While Apple Inc is marketing the Watch as a device with medical functions while insisting it is not a medical device, patients who are not well versed in the limits and particularities of the pulse oximeter feature can develop overreliance and, as a result, experience negative health effects. A common consequence may be that people will call their health care practitioner more often due to falsely low SpO_2 readings; however, a more concerning and dangerous scenario would manifest when the Watch provides false reassurance and people do not seek health care advice [20,21]. Although more research will be needed on continuous SpO_2 measurements using wrist-worn wearable devices for patients with COPD, 1 observational study, which tested the $WristOx_2$ pulse oximeter among patients with clinical stability, concluded that significant SpO_2 fluctuations occurred between and within multiple days and nights for their study patients [22]. They suggested that knowing these continuous SpO_2 values is key to setting tailored SpO_2 alerts for patients using telemonitoring, as no protocols are available [23]. Despite using a traditional or smart wearable pulse oximeter, physicians are often debating the need for a pulse oximeter at home for people with COPD. It may be useful if supplemental oxygen therapy is used, yet a home pulse oximeter is not a substitute for COPD management, nor does it replace the patient's own personal assessment of their situation [24].

Perceived Value of the Apple Watch

Despite the SpO_2 measurement challenges and those related to the wristband and placement of the Watch, some study participants were inclined to use the Apple Watch. According to Hsiao [25], this technology adoption behavior may be attributed to the perceived value of the wearable [26]. First, the health benefits gained by using the Watch were critical for some study participants' acceptance of the technology. Second, the remark made by participant P5, who did not want her FitBit anymore as she had "an Apple" now, demonstrated that the Apple brand name and its quality and performance may influence one's adoption intention toward the Watch. Third, in terms of social value, some study participants were influenced and needed support from family to use the Watch, and, in turn, they influenced other loved ones to purchase a personal device. Chen et al [6] confirmed those findings, as their participants also needed support from family to navigate some of the advanced features of the Watch. Lastly, smartwatches are known to be fashion accessories, which may also enhance adoption intentions [27]. Participant P5, in particular, admitted that wearing a big Apple Watch is trendy, cute, and fashionable nowadays. When the Apple Watch, which is an extension of one's iPhone, made its debut in 2015, it was seen as a fashion accessory [28]. However, as mentioned by our study participants P1 and P5, it makes things more convenient now, for example, answering phone calls. In addition to the health and fitness tracking functions of the Watch, the value of convenience may perhaps not be underestimated for older adults or people with disabilities [29], and, as such, increase its perceived value.

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Study Limitations and Recommendations

The fact that the Apple Watches were lent to participants can be seen as a limitation, as some did not explore their full capabilities out of fear of damaging the device. Second, participants only had 5 months to use their Watch, and in addition, the majority were female users. These factors may also have influenced the acceptance of the technology in terms of "perceived usefulness" and "ease of use." Lastly, study participants could be considered to have a baseline level of curiosity given their interest in and acceptance of using the Watch in this project. The actions of our participants demonstrated their comfort or interest in technology, even though many did not self-identify as being "tech-savvy." Although different strategies were used to enhance trustworthiness, the researchers are aware that subjectivity is always present in qualitative research; however, it may become an inspiration for further research. Knowing that a widespread uptake of wearables among older adults with various chronic conditions may be expected, more research is needed regarding the acceptability of the Watch and foremost on the "black box of wearable algorithms" for health monitoring [30].

Conclusions

The findings of this study have shown that the UTAUT2 is a suitable model to obtain valuable insights into how older adults with COPD experienced the use of the Apple Watch for telemonitoring purposes. Despite their different views, participants were inclined to use the Watch for health monitoring and communication purposes, and some enjoyed interacting with the novel device. Nonetheless, results have shown that the Watch must be used with caution given that the SpO_2 feature is not intended for medical use and does not function reliably when patients experience SOB. With the uptake of these smartwatches, it is imperative that health care providers are aware of these limitations and remind their patients of the current limits of the Apple Watch.

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Data Availability

The data sets generated and analyzed during this study are not publicly available due to their confidential nature but are available from the corresponding author on reasonable request.

Authors' Contributions

AA and ZD contributed to the conceptualization of the study. AA was involved in the methodology. AA, PS, DDD, and YL were responsible for the formal analysis, data curation, writing, reviewing, and editing. AA, ZD, and SC were responsible for resources, project administration, and funding acquisition. All authors have read and agreed to the published version of the manuscript, and all authors contributed equally.

Conflicts of Interest

None declared.

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Abbreviations

COPD: chronic obstructive pulmonary disease
FDA: Federal Drug and Administration
GOLD: Global Initiative for Chronic Obstructive Lung Disease
HR: heart rate

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SOB: shortness of breath
SpO_2: blood oxygen saturation
TAM: Technology Acceptance Model
UTAUT: Unified Theory of Acceptance and Use of Technology
UTAUT2: Extended Unified Theory of Acceptance and Use of Technology

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Original Paper

Exploring the Needs and Requirements of Informal Caregivers of Older Adults With Cognitive Impairment From Sensor-Based Care Solutions: Multimethod Study

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Abstract

Background: With the increase in the older adult population, sensor-based care solutions that can monitor the deviations in physical, emotional, and physiological activities in real-time from a distance are demanded for prolonging the stay of community-dwelling older adults with cognitive impairment. To effectively develop and implement these care solutions, it is important to understand the current experiences, future expectations, perceived usefulness (PU), and communication needs of the informal caregivers of older adults with cognitive impairment regarding such solutions.

Objective: This comprehensive study with informal caregivers of older adults with cognitive impairment aims to (1) highlight current experiences with (if any) and future expectations from general sensor-based care solutions, (2) explore PU specifically toward unobtrusive sensing solutions (USSs), (3) determine the information communication (IC) needs and requirements for communicating the information obtained through USSs in different care scenarios (fall, nocturnal unrest, agitation, and normal daily life), and (4) elicit the design features for designing the interaction platform in accordance with the persuasive system design (PSD) model.

Methods: A multimethod research approach encompassing a survey (N=464) and in-depth interviews (10/464, 2.2%) with informal caregivers of older adults with cognitive impairment was used. The insights into past experiences with and future expectations from the sensor-based care solutions were obtained through inductive thematic analysis of the interviews. A convergent mixed methods approach was used to explore PU and gather the IC needs from USSs by using scenario-specific questions in both survey and interviews. Finally, the design features were elicited by using the PSD model on the obtained IC needs and requirements.

Results: Informal caregivers expect care infrastructure to consider centralized and empathetic care approaches. Specifically, sensor-based care solutions should be adaptable to care needs, demonstrate trust and reliability, and ensure privacy and safety. Most informal caregivers found USSs to be useful for emergencies (mean 4.09, SD 0.04) rather than for monitoring normal daily life activities (mean 3.50, SD 0.04). Moreover, they display variations in information needs including mode, content, time, and stakeholders involved based on the care scenario at hand. Finally, PSD features, namely, reduction, tailoring, personalization, reminders, suggestions, trustworthiness, and social learning, were identified for various care scenarios.

Conclusions: From the obtained results, it can be concluded that the care scenario at hand drives PU and IC design needs and requirements toward USSs. Therefore, future technology developers are recommended to develop technology that can be easily adapted to diverse care scenarios, whereas designers of such sensor-driven platforms are encouraged to go beyond tailoring and strive for *strong personalization* while maintaining the privacy of the users.

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KEYWORDS

informal caregiving; cognitive impairment; unobtrusive sensing solutions; in-home care; aging in place; assistive technologies

Introduction

Background

The global population of older adults with cognitive impairment who live alone is increasing tremendously. This demographic shift necessitates the implementation of advanced sensor-based care solutions to support both individuals with cognitive impairment and their caregivers [1,2]. The advanced solutions having the ability to monitor 24/7 can not only provide peace of mind to caregivers but are also advantageous in optimizing care by using long-term monitored information. Thus, they appear more promising in prolonging the stay of community-dwelling older adults with cognitive impairment who are living alone and receiving home care [3].

Broadly, any sensor-based monitoring solution has 3 parts: a physical sensing unit, a computing unit, and an interaction unit. The physical sensing unit deployed in the homes of older adults with cognitive impairment is responsible for collecting data related to the person being monitored or the surrounding environment. These collected sensing data are then processed by the computing unit, which typically uses machine learning algorithms to extract meaningful insights regarding the activities, behaviors, and well-being of the person being monitored. Finally, the communicating unit, often in the form of an eHealth app, serves as a channel of communication between the sensing system and the caregivers or other stakeholders involved in the care of older adults with cognitive impairment. It facilitates real-time communication and collaboration among caregivers, ensuring timely information exchange and coordinated care efforts for the benefit of the care recipient (CR). For example, the My Guardian watch can support older adult care by providing alerts or notifications for day-to-day tasks to the older adult, whereas caregivers can monitor them from a distance (such as tracking their location, etc) via an app [4]. The watch can be seen as a sensing unit coupled with a computing unit collecting data from the older adult and performing the necessary computations to generate insights. The app, developed on top of this system, acts as an interaction platform, responsible for communicating the information obtained by the watch from the older adults to the informal caregivers to enable care from a distance.

A variety of in-home, sensor-based monitoring solutions for older adult care are available [5] such as wearable systems (eg, fall alarm pendants and medical guardians) [6], vision-based systems (eg, nest cam and ring indoor cam) [7], and device-free sensing systems (eg, Sensara) [1]. Literature has delineated the disadvantages of camera-based and wearable solutions in the care of older adults with cognitive impairment; the former enables monitoring only in the line of sight and is prone to privacy issues, whereas the latter mandates the continuous wearing of the device for continued monitoring. Nevertheless, device-free sensing systems overcome the abovementioned disadvantages, as they are unobtrusive in nature and do not impose an active region of operation, making them more suitable for the care of older adults with cognitive impairment [1].

In this study, first, we aimed to cross-examine the experiences (both positive and negative), if any, of informal caregivers of the older adults with cognitive impairment who use sensor-based monitoring solutions (such as cameras, wearables, or device-free systems) in their caregiving practices. The insights into current experiences can facilitate the informed development of novel sensing solutions. Along with experiences, the expectations of informal caregivers from future care solutions were highlighted [8]. The expectations can inspire technology developers and designers by anticipating the attitudes, demands, and challenges that informal caregivers face on a daily basis [3]. For example, informal caregivers expect to attain peace of mind by ensuring the safety of the CR via care solution, but their experiences regarding privacy, reliability, and usability might vary with respect to the sensing solution at hand.

Currently, considerable efforts are made in the direction of exploring novel sensing technologies for unobtrusive or device-free sensing (such as Wi-Fi, mmWave, etc) [9-11]. These unobtrusive sensing solutions (USSs) can be defined as solutions that do not draw the user's (in this case, older adults) attention or demand their direct involvement while blending well with the surroundings [1]. For example, Wi-Fi signals (which can be imagined as invisible waves traveling through the air that get affected by the surrounding movements) carry sensing information about the surrounding environment (even beyond the wall) [12], which can be analyzed using machine learning algorithms to detect human activities such as fall, continuous sitting and standing, gestures or behaviors such as emotional states, sleeping patterns, and so on. [13,14]. Therefore, they are found to be more compatible with older adult care [15]. In this study, we use the term "unobtrusive" specifically to define the proposed technology and do not extend it to information communication (IC) with other stakeholders.

In the past decade, rapid growth in developing USSs has been noticed [16,17], making it necessary to obtain a broad view of their implementation prospect. Therefore, the second objective of this study was to understand the perceived usefulness (PU) of USSs among informal caregivers when deployed in the care of older adults with cognitive impairment. Along with the development of USSs for robust performance (such as the use of deep neural networks to minimize false alarms), studies to understand the IC needs of informal caregivers toward USSs to provide them with optimal and on-time care information is required. USSs are intended to monitor older adults with cognitive impairment continuously, leading to a substantial amount of monitoring data that could be overwhelming or can cause information overload, if directly communicated to informal caregivers [18-20]. Therefore, it is crucial to optimize IC by considering the needs and requirements of informal caregivers of older adults with cognitive impairment in diverse care scenarios. For example, informal caregivers expect to be notified immediately during an emergency such as a fall,

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whereas they might not want to receive notification for nocturnal unrest immediately. Therefore, the third objective of this study was to determine the IC needs and requirements of informal caregivers for 4 care scenarios including emergencies (falls), short-term monitoring (nocturnal unrest), long-term monitoring (agitation), and normal daily life. Finally, to facilitate the design process of such an interaction platform, the design features were elicited based on the obtained IC needs and requirements in accordance with the persuasive system design (PSD) model [21].

Research Objectives

In summary, this study had four research objectives:

1. To cross-examine the current experiences, if any, and highlight the future expectations from sensor-based care solutions; the knowledge about current experiences can inform the development of new sensing solutions, and knowledge about future expectations can help in anticipating the potential benefits and challenges that may arise during the deployment of USSs
2. To explore the PU of USSs among informal caregivers; exploring the PU during the development stage can inform the technology developers and designers about the possible acceptance of the developed technology
3. To determine the IC needs and requirements to design an interaction platform for communicating the information obtained through unobtrusive sensing systems in different care scenarios including fall, nocturnal rest, agitation, and normal daily life among informal caregivers of older adults with cognitive impairment and living alone
4. To elicit the *design features* based on the obtained needs and requirements for designing the interaction platform in accordance with the PSD model

Methods

Ethical Considerations

The Ethics Committee of the Behavioral, Management, and Social Sciences at the University of Twente granted formal ethical approval for the execution of this study (request 220250). Prior to participation in surveys and interviews, all participants were presented with a comprehensive oral or written description outlining the study's objectives, methodologies, data collection procedures, storage protocols, and the intended use of the collected data. Subsequently, a signed consent form was obtained from each participant. Participants were assured of their right to withdraw from the survey or interview at any stage if they felt uncomfortable.

In the survey, no personal details of the participants were collected to maintain their anonymity. However, it is essential to note that the surveyed individuals were users of the Caren platform. Consequently, obtaining additional permission from NEDAP N.V. will be imperative for any secondary analysis of the data collected. For interview data, which included intricate personal information about the care recipients and their corresponding informal caregivers, de-identification was done before analysis, ensuring confidentiality and privacy. If required, a summary of the qualitative data can be made available upon request. Lastly, as a token of appreciation for their valuable time and contributions, a small honorarium was provided to the participants.

Study Design

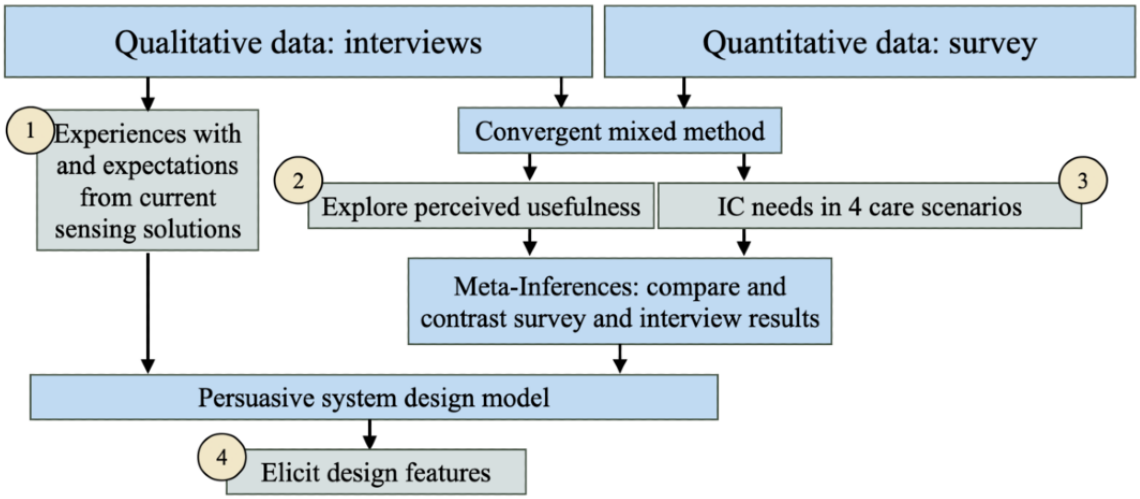
Overall, a multimethod design encompassing survey (quantitative) and in-depth interview (qualitative) was used. Particularly, the survey was conducted on the Caren platform (NEDAP Healthcare) [22], a digital caregiving platform widely used by informal caregivers, CRs, and occasionally formal caregivers in the Netherlands to gain insights into their own health or the health of their CR. The Caren platform has no restrictions based on age group or type of illness.

The survey itself had two objectives: (1) to gather feedback about the use of the Caren platform from all users (CRs, informal caregivers, and formal caregivers) and (2) to specifically investigate the IC needs and requirements of informal caregivers. To achieve these objectives, the survey included questions about the use of the Caren platform (constructed by the Caren development team) and was presented to all users active during the survey duration (7 days). However, users who identified themselves as informal caregivers were shown questions related to PU and IC needs. Furthermore, informal caregivers who participated in the survey and expressed interest in further caregiving-related studies were invited for interviews. The methodologies used to address each research objective are as follows:

1. For *objective 1*, insights into past experiences and future expectations regarding sensor-based care solutions were obtained through interviews (Figure 1).
2. To address *objectives 2 and 3*, a convergent mixed methods approach was used. Scenario-specific questions, based on previous study [2], were used to gather IC needs from informal caregivers. This approach allowed for the combination of different methods, overcoming individual weaknesses and facilitating comparison, validation, and identification of any contradictions in the results. Meta-inferences were derived as a result [23] (Figure 1).
3. *Objective 4* aimed to elicit design features, which were derived using the PSD model based on the meta-inferences drawn from the IC needs and requirements of informal caregivers (Figure 1).

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Figure 1. Study design depicting the 4 research objectives undertaken in this comprehensive study. IC: information communication.

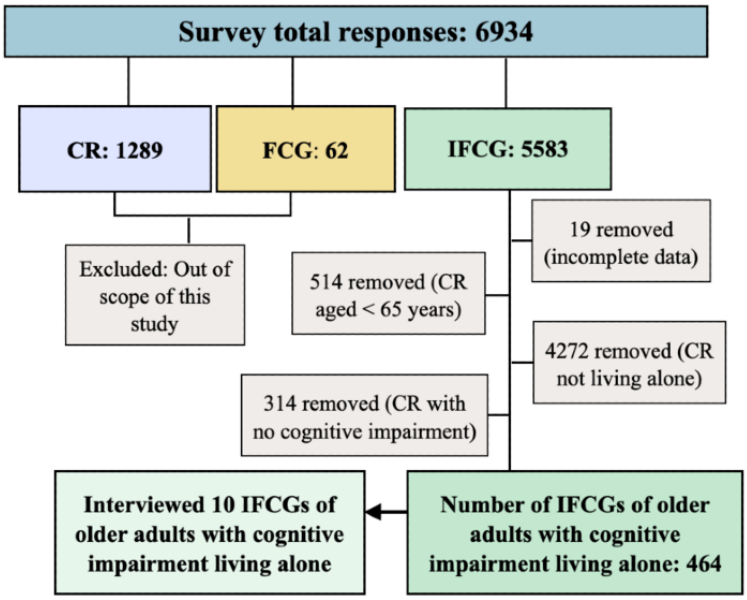


Participants

A total of 6934 responses, including 1289 (18.59%) from self-managing CRs, 5583 (80.52%) from informal caregivers, and 62 (0.89%) from formal caregivers using the Caren platform were recorded. As the focus of the study was specifically on identifying the IC needs and requirements of informal caregivers, responses regarding the feedback about the Caren platform from all users were excluded from the analysis.

The inclusion criteria for this study were as follows: (1) should be informal caregivers (friends or family) providing unpaid care, (2) should provide care for older adults (aged ≥65 y) who have cognitive impairment (can be mild or high), and (3) older adults with cognitive impairment should be living alone in their own homes. Purposive sampling was performed on the 80.52% (5583/6934) of responses of informal caregivers to select those who met these criteria. Initially, we excluded 0.34% (19/5583) of incomplete responses from informal caregivers who dropped out of the survey before completion or did not respond to mandatory questions. Thereafter, responses from informal caregivers who care for individuals aged <65 years (514/5583, 9.2% of responses) and do not live alone (4272/5583, 76.51% of responses) and whose CRs show no signs of cognitive impairment (314/5583, 5.62% of responses) were also excluded from the analysis. This resulted in a final sample size of 8.31% (464/5583) of responses. In addition, 10 informal caregivers were recruited for interviews from the same sample. Figure 2 illustrates the sample selection process from the survey data and for the interviews.

Figure 2. Participant sampling procedure for survey and interviews. CR: care recipient; FCG: formal caregiver; IFCG: informal caregiver.



Finally, it is important to highlight that the indication of cognitive impairment in this study was solely based on the observations and indications provided by informal caregivers. Formal diagnoses of cognitive impairment are not always available unless the condition has reached an advanced stage. In such cases, informal caregivers serve as the primary identifiers of initial symptoms and changes indicative of cognitive decline [24,25]. Therefore, in this study, we also gave significant value to the personal experiences and insights of informal caregivers.

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Materials

Survey

The survey was used for gaining quantitative insights into the possible needs and requirements of informal caregivers of older adults with cognitive impairment toward a sensor-dependent interaction platform. In the survey, participants' demographics (age and sex) and care elements information (age of informal caregiver and CR, sex, relationship with the CR, and the number of CRs they provide care to) were recorded. PU was measured with the help of 3 questions from the PU (Cronbach α=.898) construct of Technology Acceptance Model 2 [26] using a 7-point Likert scale (1=strongly disagree to 7=strongly agree). Given the exploratory stage of technology (Technology Readiness Level 2/4) [27], only a subset of 3 questions from the PU construct was used to obtain a broad view about its usefulness. However, additional customized questions were used to gain a more comprehensive understanding of changes in PU, if any, owing to different care scenarios (monitoring daily life activities and emergencies) and the stakeholders involved (themselves and their CRs) by using a 5-point Likert scale (1=strongly disagree to 5=strongly agree).

Furthermore, to identify the needs and requirements of informal caregivers, different care scenarios, namely, fall, nocturnal unrest, agitation, and normal daily life, were defined. These care scenarios were selected based on previous studies that highlighted important monitoring goals for USSs in 4 categories: safety (fall), health related (hygiene), psychological (nocturnal unrest), and psychosocial (agitation) [2]. Each of these scenarios contained custom-designed questions that were developed by the involved researchers' team comprising various stakeholders in older adult care such as care platform designers or managers, design or eHealth researchers, and experts in the field. This approach was adopted owing to the absence of a standardized questionnaire in the existing literature addressing the IC needs of informal caregivers. The developed questionnaire underwent refinement and face validation through feedback from informal caregivers before its launch to ensure its appropriateness and relevance.

All scenarios had 5 similar questions: type of situation (what: emergency, acute, or normal), mode of IC (how: voice call, notification, SMS text message, email, or self-check), timing of IC (when: immediately, after a few minutes, or self-check), content of the information (what: raw data, interpreted, or interpreted with suggestion), and intended stakeholder or recipient of the information (whom: formal caregivers, wait for primary informal caregiver's response, secondary informal caregivers, ambulance, self-check, or no information). Here, "raw data" refers to data directly obtained from sensors (such as numbers), for example, "Mr. X fall, and his heart rate is 120bpm." "Interpreted data" means raw data that are further processed to make them more intuitive and insightful for informal caregivers to understand, for example, "Mr. X fall in the bathroom and his heart rate is higher than normal, which could indicate a heart attack." The "interpretation with suggestion" option provides suggestions along with the interpretation, so that informal caregivers can make informed decisions, for example, "Mr. X fall in the bathroom and his heart rate is high. You might consider visiting him as soon as possible and informing the doctors." Here, the preferred choice or choices for the respective questions were recorded.

In addition, for the scenarios of nocturnal unrest and agitation, a question was included to obtain the preference for the need for a detailed report (every day to informal caregivers, observe for a few days or weeks and then send to informal caregivers or formal caregivers, or no reports required). Participants were also asked for the possibility to provide feedback (yes, no, or maybe) about improving the system, considering the possibility of false alarms. Furthermore, a question was included to assess the need for providing compliments for the care tasks they perform (yes, no, or maybe).

It should be noted that all participants were asked to answer about normal daily life scenario, and they can choose 1 relevant care scenario among falls, nocturnal unrest, and agitation. Table 1 provides an overview of these questions. The English version of the survey questions can be found in Multimedia Appendix 1.

Table 1. Overview of the questions used in the survey for identifying the information communication (IC) needs.

Questions	Options
Type of situation	Emergency, acute, and normal
Time (when) of IC	Immediately, few minutes after, and self-check
Mode (how) of IC	Voice call, notification, SMS, email, and self-check
Care information recipient (whom) along with primary caregiver	Formal caregivers, wait for primary informal caregiver's response, secondary informal caregivers, emergency services (ambulance), self-check, and no information
Content (what) of the information	Raw, interpreted, interpreted with suggestion, and others
Need of detailed report for nocturnal unrest and agitation scenarios	Every day to informal caregivers, observe for a few days and then send to informal caregivers, observe for a few weeks and then send to informal caregivers, send reports to formal caregiver, and no reports required
Feedback to improve USS[a]	Yes, maybe, and no
Compliment for the care tasks undertaken	Yes, maybe, and no

[a]USS: unobtrusive sensing solution.

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Interviews

Semistructured interviews were conducted with 3 objectives: first, to highlight the current experiences and future expectations from sensor-based solutions; second, to gain an overview of PU (codefined with the survey); and third, to determine the IC needs and requirements of informal caregivers toward the interaction platform for different care scenarios (codefined with the survey).

Open-ended questions were asked about their experience with current technology use in facilitating care, with a focus on possible bottlenecks they face on a daily basis with these systems or in general care tasks. Then, questions were asked to understand their expectations from in-general care infrastructure and care solutions. To explore PU, their opinions about the use of USSs in different care scenarios by different stakeholders and in-general value of the system in organizing care (positive or negative) were discussed.

In-depth questions were asked about the 4 care scenarios including mode (how), time (when), content (what), information-receiving stakeholder (whom), feedback to the system, and need for compliments (consistent with survey questions and as shown in Table 1). In addition, they were asked about the influence of reporting the prediction of the system in the form of confidence percentage, such that, when the system is not very confident in the output but is suspicious of certain activity, it can indicate its confidence in the prediction as a percentage, for example, “System is 20% sure that your care recipient has fallen.” Finally, the participants’ opinions about adding social support to the interaction platform to facilitate communication between similar user groups were discussed. Multimedia Appendix 2 lists the questions asked in the interviews.

Procedure

Survey

At the beginning of the survey, the idea of a USS or device-free sensing, specifically Wi-Fi Channel State Information (CSI), was introduced with the help of pictures depicting the placement of the sensor in the corner of the house, facilitating the detection of normal and fall situations (Multimedia Appendix 1). These pictures were inspired by previous studies of using CSI for detecting human activities [28]. Thereafter, web-based consent was obtained from the participants. Then, participants’ demographics and care elements information were recorded. Finally, questions about PU and design needs regarding the interaction platform were posed. All the survey questions were adapted in the Dutch language as it was conducted in the Netherlands. The overall completion time for the survey was approximately 15 to 20 minutes.

Interviews

At the beginning of the interviews, informal caregivers were provided with an oral and written explanation about the aims of the interview and USSs. Upon obtaining their consent, demographics and care elements (consistent with the survey) were asked. Thereafter, open-ended questions about current experience and future expectations were asked. Semistructured questions regarding PU specific to USSs (Wi-Fi CSI based) were posed. Then, a simple prototype showing a few screens of the interaction platform was presented to participants to provide them with a basic idea of the interaction platform (Multimedia Appendix 2). Participants were then asked to choose and answer for 1 scenario from a list of care scenarios including falls, nocturnal unrest, and agitation. Comparative questions were posed about normal daily life when no anomalies are detected, to understand the IC needs during a normal day in care. The interviews were conducted in Dutch by a native Dutch speaker and were audio recorded to facilitate analysis. The duration of the interviews was approximately 60 to 75 minutes. Overall, the information obtained from 10 interviews was found to be optimal, and no further interviews were conducted.

Data Analysis

Survey

SPSS (version 28.0.1.0; IBM Corp) was used for analyzing the survey data. First, data corresponding to the included sample, that is, informal caregivers of older adults with cognitive impairment and living alone, were extracted. Descriptive statistics were used to analyze participants’ demographics (age and sex), care elements (age of CR, relationship with the CR, and number of CRs), response to questions corresponding to PU, and IC needs for different monitoring scenarios (fall, agitation, nocturnal unrest, and normal daily life).

Interviews

The interviews were translated into English and transcribed verbatim, and the thematic analysis approach described by Braun and Clarke [29] was used. Overall, transcripts were coded in 3 steps: open coding, axial (thematic) coding, and selective inductive coding for understanding the experiences and expectation of informal caregivers. A mix of inductive and deductive approaches was used to determine the themes related to PU and IC needs. First, all the transcripts were read by 1 researcher (NS), and useful relevant fragments were selected and initially coded. Then, open codes were examined and arranged into themes. A second researcher (LMAB-J) coded 25% of the transcripts independently to validate the codes. The joint probability of agreement was 80%. The final categories were discussed by the 2 researchers until consensus was reached. This was done to deal with the researchers’ bias (if any). ATLAS.ti (ATLAS.ti Scientific Software) was used for these analyses [30].

Meta-Inferences and Design Features

The understanding obtained from the survey and interview results was gleaned together in the form of meta-inferences by comparing, validating, and contrasting them, that is, more pragmatic interpretations. These meta-inferences were further used to elicit the design features for the interaction platform in accordance with the PSD model [21]. In general, the aim of the PSD model is to help designers or developers in developing solutions that facilitate behavior or attitude change. The intended interaction platform does not aim for behavior change in informal caregivers, but it requires persuasion to form or alter the behavior of informal caregivers for complying with the

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information communicated [31]. In this direction, the persuasion context and available categories of features in the PSD model appear to be advantageous and a step close to the design process [21]. Overall, 4 feature categories of the PSD model—primary task support, dialogue support, system credibility, and social support—were used here. Primary task support features can help caregivers in performing their primary task, that is, to organize and provide optimal care to the CR. Dialogue support features can help maintain a feedback loop and provide motivation for accomplishing the primary task of informal caregivers. System credibility features help designers in developing more credible and trustable systems. Finally, social support features help in intertwining the users with social communities in the same domain, thus supporting users through social influence. In the following sections, the obtained themes across this study were explored to observe their association with respective feature categories, if any.

Results

Participant Demographics and Care Elements

Survey

A total of 464 (6.69%) informal caregivers (mean age 58.3, SD 8.14 y) of older adults (mean age 86.7, SD 6.20 y) living alone were identified from the obtained 6934 responses. From the descriptions, it was observed that 76.9% (357/464) of the informal caregivers were women, and most informal caregivers (385/464, 82.9%) provide care to 1 older adult. A large group of informal caregivers were sons or daughters (360/464, 77.6%) of the CRs. While considering the high number of women as informal caregivers, it can be deduced that most of them were daughters of CRs. Finally, out of 464 informal caregivers, 119 (25.6%) responded for fall, 59 (12.7%) for nocturnal unrest, 81 (17.5%) for agitation, and all of them (n=464, 100%) responded for normal daily life. Table 2 provides an overview of the characteristics of the survey participants.

Table 2. Survey and interview participant demographics.

Demographics and care elements	Survey (N=464)	Interview (n=10)
Age of informal caregivers (y), mean (SD)	58.3 (8.14)	57.1 (6.45)
Age of CRs[a] (y), mean (SD)	86.7 (6.20)	88.8 (6.01)
Sex, n (%)		
Male	107 (23.1)	3 (30)
Female	357 (76.9)	7 (70)
Number of CR, n (%)		
1	385 (82.9)	10 (100)
≥2	79 (17)	0 (0)
Relationship with CR, n (%)		
Son or daughter	360 (77.6)	10 (100)
Son or daughter-in-law	46 (9.9)	0 (0)
Other family and friends	58 (12.5)	0 (0)
Participants or care scenarios, n (%)		
Fall	119 (25.6)	10 (100)
Nocturnal unrest	59 (12.7)	4 (40)
Agitation	81 (17.5)	3 (30)
Normal daily life	464 (100)	10 (100)

[a]CR: care recipient.

Interviews

A total of 10 informal caregivers (mean age 57.1, SD 6.45 y) of older adults with cognitive impairment (mean age 88.8, SD 6.01 y) and living alone participated in the interviews. Among the 10 participants, 7 (70%) informal caregivers were women and 3 (30%) were men, and all of them (n=10, 100%) were either sons or daughters of the CR. All informal caregivers (10/10, 100%) had 1 CR. Of the 10 participants, all (n=10, 100%) answered for fall and normal daily life, whereas 4 (40%) answered for nocturnal unrest and 3 (30%) for agitation. Table 2 provides an overview of the characteristics of the interview participants.

Experiences With Current Care Solutions

Theme 1: Experiences With Sensing Systems

From the interviews, it can be concluded that most informal caregivers (9/10, 90%) use multiple technological interventions in their current caregiving situations to assist them in delivering timely care to their loved ones. These sensing modalities include cameras (P6 and P10), voice-activated systems having microphones (P6), door alarms (P2 and P4), wearable fall alarms

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(P1, P4, P5, P3, P7, and P8), and device-free systems (P5 and P6).

Camera-Based Sensing System

The informal caregivers reported both positive and negative experiences with camera-based monitoring solutions. Although such solutions provide a precise picture of the situation in the house of the CR, they require constant attention from the informal caregivers:

> *Cameras really helps a lot, because she sometimes forgets [that her mother is not alive] and wants to go to see her mother. But when she is packing a bag and if we see that on camera, we can stop her.* [P6]

The informal caregivers must either monitor continuously or make a conscious effort to periodically check on the CR. This process is fatiguing and causes informal caregivers to worry about times when they are unable to observe the CR:

> *Usually, I am watching her more now-a-days [because of her illness] with the camera. But for example, I am not watching now, she could be doing anything right now and I have no idea. With such a system, she can actually monitored 24 hours a day.* [P6]

In addition, using cameras for monitoring requires line of sight, necessitating multiple cameras to cover different areas of the house:

> *The camera in the living room does not give notification. I can just watch continuously as long as she is line of sight.* [P6]

Informal caregivers also mentioned ethical and privacy concerns, especially when it comes to personal spaces such as bedrooms or bathrooms, and oppose their use in such areas.

Voice-Activated System

To get an insight into the real-time situation in the house of older adults with cognitive impairment, an informal caregiver deployed a voice-activated (microphone-embedded) system. The informal caregiver reported that microphones in Google Nest are very sensitive and can catch sounds from neighbors:

> *Google Nest is advantageous, because if she's in the bedroom with the doors closed, I can still hear her if she makes some noise.* [P6]

> *Google nest is so sensitive that at times when she is turning the pages of a book near to the system, it seems as if an earthquake is going on or when you are in the kitchen, picking up a pan, then you think: the building is collapsing. That's how much noise is there. At first it really frightened me.* [P6]

Alarm-Based Sensing System

Most informal caregivers (7/10, 70%) used an alarm system, which included either a door or wearable fall alarm. Informal caregivers found the door alarm to be highly practical, as it enables (known) visitors to enter the house without disturbing the CR and can also be activated in case of an emergency. In contrast, the wearable fall alarm, which can be activated in the event of a fall, was not frequently used. The reason for this is that CRs often dislike consistently wearing the alarm. Even if informal caregivers convince them to wear it during the day, CRs often remove it at night, increasing the risk of falls when they wake up in the night (eg, for toilet visits). Furthermore, cognitive impairment often causes CRs to forget to charge or replace the batteries or even forget to press the button during an incident. However, despite these disadvantages, informal caregivers take a leap of faith that the personal alarms will function in case of emergencies, providing them with a sense of security and reassurance:

> *Well, the personal alarm has one big disadvantage: my mother fell once, and she has one of those nice alarms around her neck, but she just forgets to press it.* [P5]

Device-Free Sensing System

Some of the informal caregivers (P5 and P6) were using device-free sensing systems to monitor the real-time situations in the house of the CR. An informal caregiver deployed a sensor in the corridor near the main entrance of the house to track the movements of the CR:

> *The sensor in the corridor gives a signal when there is any movement. The door to the toilet and the bathroom is also in the corridor, so for example, if I get a notification I see [with the help of camera] that she is going to the bathroom. I can also see if she walks to the front door then she usually goes outside but she doesn't do that very much anymore.* [P6]

Another informal caregiver, who used a more advanced device-free sensing solution called Sensara highlighted its value in providing insights into the daily life activities of the CR. However, they also identified a major drawback, which was the lack of communication of logical and situation-aware information:

> *Yes, I think it's a nice system but one shortcoming. I think that it should be actually linked to the agenda of care recipient. At the moment, when she's not at home, for example, she has to walk outside for physiotherapy, she's out for an hour. The system doesn't take that into account. It only registers visitors coming in and visitors going out. And since my mother has no physical sensor on her body, the system registers and sends notifications that she has no movement during that time which is not true.* [P5]

Theme 2: Experience With IC

In the current health care infrastructure, the sharing of information between informal caregivers and formal caregivers is still a bit conventional, Such that, when informal caregivers want any specific information, they can try to contact formal caregivers or care organizations, where, if they are persistent with their request, they can get the answers. An informal caregiver said the following:

> *I am proactive. I intervene with organization if I see that things are really not going well. Every now and then I have a conversation with the management because they get stuck in their own rules or they fail*

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> *because they just have too few resources/people. In these situations, I go to the management, until I have sorted things out for my mother.* [P5]

In contrast, advanced interaction platforms such as Caren exist to facilitate direct connections among CRs, formal caregivers, and informal caregivers. In general, various types of formal caregivers, such as district nurses and personal care assistants, are involved in providing care for older adults with cognitive impairment. According to informal caregivers, formal caregivers tend to primarily communicate and share information among themselves, with limited active communication directed toward informal caregivers. However, to keep informal caregivers informed, formal caregivers often provide brief written reports or updates. If more detailed information needs to be conveyed, informal caregivers are typically responsible for arranging it themselves, such as by making phone calls. Thus, informal caregivers feel a lack of active involvement from responsible care organizations and a lack of a comprehensive overview of the information flow in care platforms:

> *I must say that there is not a lot of communication. They communicate mainly with themselves [different formal caregivers], but they do note everything in the folder, so I can see that.* [P2]

> *If I write something in a message [one of the functionality in Caren platform], I don't know if the home care can see those messages or they are only for other informal carers. But, it would be nice if I could communicate with home care company via platform. Because last week it was her birthday, we picked her up for the evening meal. Then we must call the organization responsible for food. And they don't really have an emergency number or direct contact.* [P6]

Taking a step further, when modern sensing systems are leveraged in care, care platforms (web or mobile app) are developed specifically to communicate the gathered sensing information such as Sensara alarm. Through such systems, notification or reports can be sent to informal caregivers, enabling them to gain a comprehensive understanding of various daily life activities and emergencies:

> *I can estimate that [daily-life activities] quite well I can also see how often she goes to the toilet, how often she walks during the day, how often she walks around the room, how often she goes to the kitchen. I also see when she goes to bed and when she goes out at night and when she goes back, that's all information that comes through fairly well.* [P5]

Expectations From Future Care Solutions

Theme 1: Centralized Care Approach

Informal caregivers perceive the current care infrastructure as fragmented, characterized by the use of diverse communication channels among different care organizations. For instance, the Caren platform facilitates communication with daily care assistants, but contacting the care organization responsible for food planning can only be done by calling their customer support. Among all communication challenges, informal caregivers find it particularly challenging to establish connections with geriatricians or general practitioners owing to their limited time availability. Therefore, informal caregivers expect care solutions that integrate multiple formal caregivers or organizations into a unified platform to optimize their care planning. According to informal caregivers, a centralized approach to care can also enhance care insights for formal caregivers. A history of actions taken by different formal caregivers can help other caregivers (such as emergency services) to understand the situation and address problems simultaneously:

> *In my experience when I need the doctor in Boekelo, it is often difficult. If it is Friday, I can only go or call the doctor until three o'clock. Otherwise, I have to call the weekend service who might not have idea on my father's health. So, if I could still get in touch with the GP or something via that platform to discuss something, it would be nice.* [P3]

Furthermore, informal caregivers also acknowledge that not all formal caregivers or informal caregivers require the same level of information. Therefore, they should be able to customize which information will be shared with which stakeholder in centralized care:

> *In care, you always have to make sure that you are sending the right message. There should also be a possibility that you only communicate with informal caregiver or formal, but we don]t have that. You still send the message, but now you should always be conscious that you are going to share the correct message [as it goes to everyone].* [P8]

Theme 2: Empathy in Care

In general, empathy is considered as a crucial aspect of our society as it enables individuals to understand and connect with others on a deep level. In the context of care of older adults with cognitive impairment, empathy becomes even more important. It involves recognizing and experiencing the emotions, experiences, and perspectives of older adults with cognitive impairment and responding with appropriate care and concern. Informal caregivers expect the entire care system, including modern care solutions and formal caregivers, to demonstrate more empathy toward older adults with cognitive impairment. According to them, it can foster better relationships between daily care providers and older adults with cognitive impairment:

> *That's actually the empathy, that the staff have towards my mother. My mother has only one interest that is animals/pets and they all show pictures of their pets to her. But also, when they walk their dog, they come in for a second with the dog and to make her happy. They should definitely not reduce that.* [P5]

However, most informal caregivers felt the lack of emotional connection from formal caregivers toward older adults with cognitive impairment. This lack of connection may be attributed to the fact that, in many cases, a new care staff attends to the older adults with cognitive impairment, which in combination with cognitive impairment can lead to increased irritability or aggression toward the caregivers. Overall, informal caregivers

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suggest that formal caregivers should adopt empathic care approaches when interacting with older adults with cognitive impairment. They feel that offering a personal touch, such as discussing emotional matters, is necessary as it gives confidence to older adults with cognitive impairment and can provide them comfort—for example, engaging in conversation before starting their work and sitting next to them during meals as opposed to a more transactional or corporate care approach, where caregivers simply complete their tasks and leave:

> *It sounds a bit corporate, but home care organizations come, finish their tasks, and as soon as they're done with that, they're gone too. A better way to do it, for example on Sunday, when they come to provide her a meal. They don't sit next to my mother and say: I have heated the food. It's nice now. When are you going to start eating? They don't do all this. There is some discontent there.* [P9]

Theme 3: Adaptable Sensing Solution

Across the interviews, a wide variation in care situations was observed. This divergence could be attributed to the progression of illness, comorbidities among CRs, and personal changes in the lives of older adults with cognitive impairment or their informal caregivers. For example, for most informal caregivers, fall emerged as a priority monitoring concern, whereas another informal caregiver (P7) reported that it was not a priority for them as their CR was bedridden and unable to move around in the house. Such evolving changes affect the overall care needs, necessitating adaptive sensing solutions that can adjust to evolving care needs.

Moreover, it was interesting to note that informal caregivers became more willing to accept diverse sensing solutions, including cameras, depending on the specific care situation. This willingness stemmed from their desire to ensure the safety of their loved ones, despite the ethical concerns associated with cameras or voice-activated devices. For example, an informal caregiver (P6) installed a camera in the living room to track the movements of the CR and a voice-activated device (having a microphone) for situations when the CR is out of sight from the cameras.

However, the use of voice-based coaching solutions in the care of older adults with cognitive impairment was found to be somewhat debatable based on the opinions expressed during the interviews. An informal caregiver emphasized that voice-based coaching could facilitate the eating and drinking habits of older adults with cognitive impairment, especially in cases where sensing systems are limited in their capabilities such as motivating the older adults with cognitive impairment to have warm meals or inquiring about their well-being if no movement was detected for an extended period among other functions:

> *What I do notice is that she eats less and less hot meals and more and more bread. So, she does eat, but not always well or healthy, but those are things you can't force, and that's what I find so difficult. The system can't do that either, if system can pass a voice message, then someone would think: oh yes, I can make a warm meal or eat something warm instead of bread. So, you can guide someone in that. It would apply to certain people and not all.* [P2]

However, another informal caregiver expressed concerns about the potential confusion that voice-based instructions may cause for older adults with cognitive impairment who are not very alert:

> *Yes, we don't really want to use the voice. Because she is demented and then suddenly she hears a voice that she doesn't actually see, I have the idea that she will not comprehend it.* [P6]

Overall, it is evident that integrating multiple sensing modalities can be crucial in developing a comprehensive and adaptable care solution that addresses the emerging needs of both CRs and informal caregivers.

Theme 4: Trust and Reliability

Most informal caregivers showed trust in the care solutions. They widely use different types of technology to assist them in the care for older adults with cognitive impairment, which helps them to attain some level of peace of mind*:*

> *I trust technology, so I trust the system, if set up properly, the sensors will do their job and the data will be recorded and filtered into something that is useful to me. This useful information can give me peace of mind.* [P5]

However, to trust the system, they expect it to be reliable, such that it should not have several false alarms:

> *So, it must be reliable. There shouldn't be false alarms every time that make you think: it's not really that much use to me.* [P9]

Theme 5: Privacy and Security

An ethical dilemma regarding the choice between privacy and security was observed among informal caregivers of older adults with cognitive impairment. As the condition of cognitive impairment advances or comorbidities emerge, the demands for care increase, leading to the prioritization of safety or well-being of the CR over privacy. In such scenarios, they may advocate for the installation of obtrusive sensing devices such as cameras in the homes of their CRs. However, this does not imply that privacy is disregarded entirely but they place their trust in technology developers:

> *Yes, look, with camera privacy is gone. And yes, she just needs to be watched, and whether that is done with a USS or with a camera, or with someone being present, the privacy is just a lot less. And then you don't put a camera in the bedroom because of privacy, yes, but you still want to keep an eye on her, because she can also fall in the bedroom.* [P6]

> *Privacy should be granted but it is secondary to security. But no one should be able to influence the system with false information [like hacking the system].* [P5]

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PU of USSs

Table 3 presents the results of both the survey and interviews. PU of USS measured through the Technology Acceptance Model PU construct was found to be positive across the informal caregivers (mean score 4.61, SD 1.32; 7-point scale). They believe that it provides reassurance and peace of mind owing to the 24/7 monitoring of CRs, thus reducing the time and effort invested in monitoring. With proper IC, informal caregivers can also prioritize and optimize their care plans, which can improve the quality of life and ensure timely care of older adults with cognitive impairment. Moreover, the long-term monitoring capabilities of USSs can provide insights into the onset of new illnesses, thereby helping formal caregivers to tailor care plans accordingly:

> *It would give me peace of mind. The quality of care can also be improved by using this system, because I would be able to provide more targeted care. I think that the same data is also important for the professional as they can also adjust their professional care much more specifically.* [P5]

> *With such a system, she can be actually monitored 24 hours a day.* [P6]

Furthermore, regarding usefulness for stakeholders, informal caregivers found USSs more supporting for themselves in facilitating their care task (mean score 3.72, SD 0.05; 5-point scale) compared with enabling independent living of their CR (mean score 3.27, SD 0.06; 5-point scale). In interviews, informal caregivers expressed that although USSs appear as a logical choice for them, older adults with cognitive impairment themselves may not perceive their value, as they may not acknowledge the necessity for care:

> *My mother herself would not be in favor because she does not see the problem. But yes, it [USSs] seems logical to me. Yes, I would be willing to use.* [P2]

They further added that these solutions are more appropriate for CRs whose motor functions are intact, rather than patients who are terminally ill, unless USS also provides insights into physiological activities:

> *I am one hundred percent convinced that the system has added value for people who have not yet reached the stage [terminally ill] and can still stand on their own feet in a safe and responsible manner. For example, it can keep a track of medication or food intake.* [P7]

Finally, regarding monitoring scenarios, informal caregivers found USS to be comparatively more useful for monitoring emergency scenarios (mean score 4.09, SD 0.04; 5-point scale) than monitoring daily life activities (mean score 3.50, SD 0.04; 5-point scale). This is because in case of emergencies, failing to take appropriate, timely actions could potentially worsen the CR's condition:

> *Suppose he falls, and I am unable to visit him that day, and Livio [the care organization] also doesn't come to shower him. In that case, there might be no one to attend to him. If I were to go there the next day, it is quite possible that he would be lying there all night or throughout the day. Such a situation is completely unacceptable.* [P3]

Table 3. Perceived acceptance of USS obtained using the mixed methods approach[a].

	Survey score, mean (SD)
Perceived usefulness (TAM[b])[c]	4.61 (1.32)
For stakeholders	
Support for informal caregivers[d]	3.72 (0.05)
Independent living of older adults with cognitive impairment[d]	3.27 (0.06)
Care scenarios	
Daily life activities[d]	3.50 (0.04)
Emergency[d]	4.09 (0.04)

[a]Findings from interviews—reassurance and peace of mind, 24/7 monitoring, prioritization and optimization of care plans, and more useful during emergencies.

[b]TAM: Technology Acceptance Model.

[c]Question from TAM scale, measured using a 7-point scale.

[d]Customized question, measured using a 5-point scale.

IC Needs and Requirements

Overview

The IC needs of the informal caregivers of the older adults with cognitive impairment living alone were gathered by using both survey and interviews for 4 care scenarios including fall, nocturnal unrest, agitation, and normal daily life. These needs are presented in the 6 themes: mode of IC, content of the communicated information, timing of IC, intended users for IC, feedback to the system for self-learning, and dialogue support needed to users. Finally, meta-inferences based on the survey and interview results were deduced.

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Theme 1: Mode of IC

The mode of IC varies with respect to type of situation. The multiple response set indicated that most informal caregivers (61/152, 40.1%) wanted to receive emergency (such as fall) information immediately via call. In contrast, for the situations that are urgent but not emergency such as nocturnal unrest and agitation, they preferred either self-check on the platform (26/68, 38% and 42/112, 37.5%, respectively) or a notification on time indicated by them (25/68, 37% and 40/112, 35.7%, respectively). However, for normal daily life updates, they prefer to self-check when they have time (267/464, 57.6%).

The interviews were found to be consistent with the survey results. In emergency situations, informal caregivers preferred to receive immediate calls or notifications to ensure timely response, whereas for urgent scenarios, they preferred self-check options as it allows them to check whenever they have time. When considering agitation scenario, an informal caregiver said the following:

> *If system indicates agitation, would I go to my mother for that? No, because that can wait, and I'll go tonight and then check it.* [P7]

Regarding normal daily life, another informal caregiver said the following:

> *If I don't get a message, then I assume that it's going well. Otherwise, you get lots of messages.* [P3]

Theme 2: Content of the Communicated Information

Notification

Interestingly, most informal caregivers prefer to receive the information about emergency in either raw (48/115, 41.7%) or interpreted (48/115, 41.7%) manner, whereas they preferred raw data (24/59, 41%) as content of IC in nocturnal unrest situation. Their preference changes for agitation and normal daily life notification—they wanted interpreted data with suggestion (27/81, 33% and 147/464, 31.7%, respectively). On the basis of interviews, it can be observed that, along with care scenario, each informal caregiver has their own preference for the content of the notification. In the context of fall situation, an informal caregiver said the following:

> *A quick notification that something is wrong, something short. If I need to know more about this, I can click further.* [P6]

It was also observed that some informal caregivers were unaware of the significance of interpreted data; after explaining, they were inclined toward getting notification in interpreted way*:*

> *I hadn't really looked at it this way yet. Interpreted data can be important, especially with a heart attack, then I know, I must call in other help, I must act quickly.* [P2]

Reports

For situations requiring long-term monitoring such as nocturnal unrest (21/59, 36%) and agitation (28/81, 35%), informal caregivers prefer the system to observe for a few days and then share a report to them and formal caregivers. This is because scenarios such as nocturnal unrest can be experienced owing to some personal circumstances and thus should be measured for a bit longer period before sending. Regarding nocturnal unrest, an informal caregiver said the following:

> *Suppose the system signals that she has been sleeping more restlessly for two weeks than the entire period before. And if I know her friend died recently, then I think it can be explained, but is then the system can be made aware by caregivers that there is no need to monitor more carefully.* [P4]

Regarding agitation scenario, another informal caregiver added the following:

> *It is good to know if something occurs structurally. If it happens every night for a week, then of course you want to make sure that there are indeed precautions. And if you notice she, does it once every three nights and after three weeks it's over. Then you don't want any extra solutions. So, if you get this report, you can make decisions based on that information than your own intuition.* [P9]

Confidence Prediction

It was observed that sharing the confidence percentage of system's predictions might be more informative rather than just providing binary outputs:

> *With 20 percent [prediction confidence percent] you worry a little less. But that doesn't say everything. Then, yes, the system hasn't seen it well enough, but at least you can take action. You can call and say: "Oh, is it true that you have fallen?"* [P2]

> *That does increase confidence. Then I understand that it is very difficult for system to notice her eating behavior. So, then I can always call her and ask: what did you eat? It is nice indication and then I can still determine what happened that way.* [P4]

Some informal caregivers also indicated that knowing the confidence in prediction will not change their level of concern and they will still call and ask if their CR is doing well.

Theme 3: Timing of IC

According to the survey, most informal caregivers wanted to receive emergency (such as fall) information immediately (58/115, 50.4%) or within 5 minutes of the incident (51/115, 44.3%). The immediate notifications were found to be valuable as it can help informal caregivers in providing on-time care:

> *I would like to be notified immediately [about fall] because then I can react and ask how it's going, even if she gets up straight away.* [P2]

Regarding the nocturnal unrest scenario, most informal caregivers (33/59, 56%) wanted to personalize when and if they want to receive the alert about whether the CR is in and out of the bed. According to them, nocturnal unrest is not an emergency scenario, but having detailed information about it is also important to gain better insights into the CR's health:

> *Next morning, I would like to know, if she is slept, when she wakes up, when and how much she sleeps, and what does she do if she is awake?* [P1]

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Moreover, most informal caregivers indicated that they can receive alert about agitation and normal daily life at any point of time (52/81, 64% and 295/464, 63.6%, respectively). However, contrasting opinions were found in interviews. Informal caregivers express a preference for not receiving agitation information during nighttime, but rather desire it to be personalized (similar to nocturnal unrest):

> *Well, when it comes to sending notification in night, it will be at the expense of my own night's sleep unless there is actually no life-threatening situation so I would like to personalize that [the time of receiving alert].* [P9]

Regarding the timing of information sharing in normal daily life scenarios, mixed opinions were identified among informal caregivers. Although some caregivers value receiving positive information at the end of the day, others believe that such information is unnecessary and could contribute to information overload. Consequently, they prefer to look at information at a more convenient time by themselves:

> *It is always good to receive something when things are going well, and not only when things are not going well, so that is a bit of reassurance and I appreciate that. The notification can be sent at the end of the day.* [P1]

> *I will look that up myself when it suits me.* [P5]

Theme 4: Intended User for IC

A preference about the stakeholder to whom information can be communicated was observed. Survey suggested that most informal caregivers (44/115, 38.3%) want the system to alert them along with formal caregivers. This is because formal caregivers can ensure medical care if needed. An informal caregiver stated the following:

> *You must ask yourself: what is the contribution that someone can make to the problem, and who has priority? Is it important that I know that my mother is lying there with a broken leg or first a doctor who can offer real help knows. I do think you should inform me, but not first.* [P7]

Moreover, in nocturnal unrest and agitation scenario, they expect the system to directly contact formal caregivers (21/59, 36% and 39/81, 48%, respectively). Informal caregivers believe that formal caregivers are usually available at night and can act promptly, and thus, they should be alerted first:

> *The first, formal caregivers should be informed because they are on call and if necessary, home care will decide to call [inform] family.* [P10]

Finally, in normal daily life scenario, informal caregivers did not expect the system to communicate with any stakeholder. They strongly insisted to personalize who can see this information:

> *Well, you should be able to set that up with your own group of family caregivers so that they see that, but the GP doesn't need to see that, I think.* [P6]

Theme 5: Feedback to the System for Self-Learning

Most informal caregivers (in both survey and interviews) indicated their willingness to provide feedback to the system based on its predictions. Specifically, 59.1% (68/115) of the informal caregivers who responded for fall, 64% (38/59) of the informal caregivers who responded for nocturnal unrest, 25% (20/81) of the informal caregivers who responded for agitation, and 42.2.% (196/464) of the informal caregivers who responded for normal daily life were willing to give feedback to the system with an aim to improve the system's predictions in the future.

In the interviews, all the informal caregivers (10/10, 100%) were positive about giving feedback to the system to improve it for future users. Informal caregivers said the following:

> *Well, it would be short and sweet, but I would do it.* [P2]

> *Yes, I would also like to help improve the system.* [P6]

> *Yes, it's good to improve the system again for future users.* [P10]

Furthermore, an informal caregiver further explained and understood the need of such feedback for the improvement of such novel technology. The informal caregiver added the following:

> *That's the most important thing, you really need feedback, and certainly in the initial phase. I always say like this: hey, it starts with chaos and then you go to structure. And when you put structure into practice, you need feedback on it. Today there are enough digital possibilities for getting the feedback to make the system reliable and that is very important.* [P7]

Theme 6: Dialogue Support (Compliments and Suggestions)

A mixed response from informal caregivers in survey about receiving compliment from the system was observed based on care scenario at hand. Most of those who responded for fall (48/115, 41.7%), agitation (31/81, 38%), and normal daily life (147/464, 31.7%) were not sure if they want to receive a compliment. In contrast, most of those who responded for nocturnal unrest (21/59, 36%) were willing to receive compliments for their care tasks. The interviews partially supported the survey results. It was observed that if the compliment is followed by some suggestion to coach informal caregivers based on their actions, it appears more logical to informal caregivers:

> *I am always open to advice. Compliments are always nice too.* [P2]

> *Well, I think a compliment without explanation can be debatable. I think and completely agree that we should get compliments also in a normal daily situation. Like we want to underline the things that are not going well in feedback, but things that are going well, you should certainly also be acknowledged. So, in that respect I am in favor of it.* [P7]

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Design Requirements

Meta-inferences were drawn by pragmatically comparing and contrasting the IC needs obtained from the survey and interviews (Table 4). Furthermore, these meta-inferences were used to elicit design features in accordance with the PSD model. Table 4 illustrates the identified PSD features among 4 feature categories (primary task support, dialogue support, system credibility, and social support) by the authors to facilitate the designing of the interaction platform.

In the primary task support category, 3 features, namely, *reduction*, *tailoring*, and *personalization* were identified as useful in supporting informal caregivers in caregiving via the interaction platform. The *reduction* feature facilitates the breakdown of complex tasks into small ones, such as calling or notifying informal caregivers in the event of an emergency or urgent scenario, without requiring them to access the platform. The *tailoring* feature enables the platform to cater to different stakeholder groups, such as formal and informal caregivers, by tailoring the content as per their needs. Finally, the *personalization* feature appeared to be very crucial in developing such an interaction platform, as every care situation is different and results in diverse care needs. Personalization is required to account for differences in informal caregiver preferences, followed by the updating of care needs owing to disease progression or emerging comorbidities. These features can be found useful irrespective of care scenarios.

In the dialogue support category, 2 features, *reminder* and *suggestion*, were used to enhance the interaction between informal caregivers and the interaction platform specifically for emergency scenarios. *Reminders* can be sent to informal caregivers in case they fail to respond to emergency calls or notifications. In addition to notifications, *suggestions* can be sent to aid informal caregivers in dealing with emergency or urgent scenarios. When faced with emergency situations, informal caregivers may become overwhelmed and unable to think or act quickly. Suggestions with actionable steps can assist in providing the appropriate care to the CR.

Finally, regarding system credibility support and social support, 2 features, *trustworthiness* and *social learning*, were recognized to make the platform persuasive in general. To establish *trustworthiness*, the interaction platform is expected to send reliable, unbiased, and fair information to informal caregivers. For example, the system's confidence percentage in prediction can be shared through notifications to maintain transparency. *Social learning* can benefit informal caregivers of older adults with cognitive impairment in multiple ways. It can facilitate connections with other caregivers for sharing knowledge, skills, and strategies to provide care in an efficient way. Furthermore, caring for older adults with cognitive impairment can be emotionally challenging, and social communities, if they exist, can provide empathetic support and help develop effective coping strategies for managing stress, anxiety, and other negative emotions that may arise during caregiving.

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Table 4. Requirements (meta-inferences) drawn from the obtained information communication (IC) needs and persuasive system design (PSD) features.

Theme	Requirements (meta-inference)	Category-wise PSD features

Mode of IC	Preferences for the mode of IC were found to vary based on the severity of scenarios. Emergencies, such as falls, require a *call or alarm notification* to immediately alert informal caregivers. *Reminders* may be sent if needed, if the informal caregiver is not responding to the sent notification. Scenarios that require awareness of informal caregiver but not immediate attention, such as nocturnal unrest or agitation, were preferred to be *communicated via direct notification*. However, no communication is necessary for scenarios where everything is going well, and informal caregivers may self-check the updates at their convenience.	• Primary task support
		  • Reduction
		• Dialogue support
		  • Reminders

Content of the communicated information	The content of notifications was discovered to be more influenced *by individual preferences* than by the care scenario. Certain informal caregivers favored receiving raw information, whereas others preferred interpreted information with suggestions. However, for immediate situational comprehension, informal caregivers generally preferred short and concise information, such as raw data. After being informed about the significance of interpreted data, they recognized its potential. For long-term monitoring scenarios such as nocturnal unrest or agitation, detailed reports were deemed useful for analyzing, revisiting, and concluding the care needs, for both informal caregiver and formal caregivers. Thus, *these reports can be adapted depending on the stakeholder (formal caregiverorinformal caregiver).*	• Primary task support
		  • Personalization
		  • Tailoring

Timing of IC	Time of sending the notification varies across scenarios. During emergencies, where the life of the older adult with cognitive impairment is at risk, information should be *communicated immediately (without requiring effort of log-in from the involved stakeholders)*. For other significant scenarios, which do not constitute an emergency, informal caregivers can *personalize the notification's timing*. Monitoring CR's[a] daily well-being is reassuring, but informal caregivers may self-monitor on the platform. Informal caregivers intended to seek updates on daily activities such as eating, drinking, walking, and medication intake, but receiving notifications for each activity may be overwhelming unless requested otherwise based on their individual circumstances.	• Primary task support
		  • Reduction
		  • Personalization

Intended users for IC	*Informal caregiversdesired to keepformal caregiversinformed, albeit on varying levels*. During emergencies, they preferred immediate system contact with formal caregivers as they can provide the necessary medical care. If the primary informal caregiver is unresponsive during an emergency, other informal caregivers can be contacted. Long-term monitoring reports about nocturnal unrest and agitation can be shared with formal caregivers to offer insight into disease emergence or progression, allowing for timely diagnosis. Similarly, informal caregivers wished to store normal daily life well-being information to draw insights together with formal caregivers if needed.	• Primary task support • Tailoring
Feedback to the system for self-learning	Informal caregivers were willing to provide feedback to the system based on its predictions to improve the trust of future users in the system. It was interesting to note that although *informal caregiverdesires a trustable system*, they understand the need for feedback to make the technology more robust.	• System credibility • Trustworthiness

Dialogue support needed for users	A mixed response about providing compliments to informal caregivers for their care task was observed. However, if the compliments can be combined with *suggestions from experts* or *other (in)formal caregivers*, they are seen as more meaningful.	• Dialogue support
		  • Suggestion
		• Social support
		  • Social learning

[a]CR: care recipient.

Discussion

This study offers insights into the development and use of sensor-based care solutions for the care of older adults with cognitive impairment from the perspective of informal caregivers. The findings from the study are discussed in 5 main aspects: experiences with diverse sensing solutions, expectations toward care infrastructure and sensing solutions; PU of USSs; varying IC needs; and use of PSD features.

Experiences With Diverse Sensing Solutions

This study provided an overview of the different sensing technologies (such as cameras, wearables, and device-free sensors) currently being used by informal caregivers in care. Previous studies also indicated the need for technological interventions in in-home care [5,32]; however, they also highlight the disadvantages of obtrusive solutions such as wearables and cameras [17], despite that informal caregivers were found leveraging these solutions. In this study also, the participants reported some limitations of these sensing modalities, such as the need to be in the line of sight, privacy concerns, requirement to wear them 24/7, and lack of logical communication, but they also highlighted several benefits such as accurate and instantaneous monitoring, outdoor tracking, unobtrusive monitoring, and comprehensive understanding of the daily activities of the CR from them. Although these outcomes indicate the lack of solutions adhering to all the needs of informal caregivers, they also highlight the possibility that various sensing modalities can be advantageous in different applications. For instance, device-free solutions may be a

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suitable choice for in-home care [1], whereas wearables are more useful for outdoor tracking of older adults with cognitive impairment [33]. Nonetheless, to achieve a complete care solution, multiple sensing modalities might need to be integrated.

Expectations Toward Care Infrastructure and Sensing Solution

To facilitate the future development of sensor-based care solutions, the study highlighted the expectation of the informal caregivers from in-general care infrastructure and sensing solutions. The existing care infrastructure in the care of older adults with cognitive impairment was also found to be fragmented. Specifically, the care information about older adults with cognitive impairment was found to be scattered at different avenues, a lack of coordination between the different stakeholders was evident, and informal caregivers experienced limited access to care services. In general, the fragmentation of care is a global problem that has been persistent in the care infrastructure for a long time [34], and so far, no concrete solution has been devised. Certainly, centralizing care infrastructures offers potential benefits in terms of reducing overall care costs, particularly in administration; improving the coordination of care services; and facilitating knowledge transfer among different organizations [35,36]. However, it is important to acknowledge the associated challenges, such as the initial setup efforts, potential perceived loss of control at the local level, potential increases in government expenses, and different policies at the national or organizational level [35-37].

Furthermore, a lack of empathy in care, specifically from formal caregivers, was observed in this study. Informal caregivers believe that taking an empathetic care approach will not only foster a relationship between the CR and formal caregiver but will also have positive and calming effects on older adults with cognitive impairment and hence should be integrated into care. According to the review by Moudatsou et al [38], several factors influence the development of empathy among care workers. These factors include a high number of care receivers, insufficient time, fear of violating professional boundaries, and a lack of education regarding empathy. To foster the integration of more empathetic practices, it is important to address these inhibiting factors during the training of formal caregivers and in their workplace environments [39].

Moreover, care situations are found to be dynamic; they are largely influenced by the progression of illness in the CR, emergence of comorbidities of the CR, and personal situations or preferences of both the CR and informal caregiver's. Traditionally, informal caregivers are expected to become a part of the care team and are viewed as a conduit for information between care professionals and extended family members [40,41]. These caregivers are also responsible for managing their own physical, mental, social, and financial well-being. Therefore, any changes in their personal lives directly affect their ability to be present and provide care to their CRs. Furthermore, owing to the advanced age of CRs, they are more susceptible to chronic diseases, necessitating timely and meticulous supervision of care plans [42]. Overall, given these unpredictable situations, adaptable care solutions that take the specific needs of the CR and involved informal caregiver into account are required.

Most informal caregivers expressed trust in sensor-based care solutions, citing their reliance on technology to assist them in the care of older adults with cognitive impairment. A similar observation was made in a study with older adults, that is, older adults also emphasize the importance of reliability, as false alarms can undermine their trust in the system [43]. Informal caregivers recognize the trade-off between privacy and safety and express the need to strike a balance. They understand that installing cameras or other sensing devices may compromise privacy, but they see it as a necessary measure to ensure the well-being of their CRs, particularly as cognitive impairment advances or comorbidities emerge [44,45]. In addition, from the perspective of older adults, the use of ambient technological solutions was perceived as beneficial, as it can increase the sense of security among older adults who prefer to live alone in their houses [5,43]. Overall, the concerns regarding trust, reliability, privacy, and security are far more complex for informal caregivers than they appear; therefore, other responsible stakeholders such as designers, developers, and researchers should take these factors into account while designing or developing technology for the care of older adults with cognitive impairment.

PU of USSs

The positive attitude of informal caregivers toward PU of USS appears to be encouraging for the development of such solutions. Interestingly, informal caregivers perceived USSs as more useful in assisting them in comparison with facilitating the independent living of older adults with cognitive impairment in their own homes, specifically in emergency scenarios. Upon successful implementation, USSs might reduce the care time needed from caregivers by monitoring older adults with cognitive impairment 24/7 [46]. Nevertheless, their response was still on a positive spectrum, indicating that if the system appeared to be useful after implementation for emergencies, the chances are high that they would accept it for monitoring daily life scenarios also. Existing literature also indicates the usefulness of USSs among other stakeholders including formal caregivers and older adults with cognitive impairment depending on care situations [3]. Interestingly, USSs can be used not only to cope up with the shortage of experienced formal caregivers but also to support formal caregivers with low education levels or caregiving experiences [47].

Varying IC Needs

The findings suggest that IC needs vary depending on care scenarios and individual preferences. Specifically, IC needs were found to be consistent across emergency scenarios (falls) and normal daily life scenarios, with most informal caregivers having similar preferences. However, for short-term or long-term monitoring scenarios, such as nocturnal unrest and agitation, preferences varied and contradicted among informal caregivers, thus highlighting the importance of providing flexible communication options that cater to different levels of urgency and individual preferences. In general, the IC needs of informal caregivers of older adults is an understudied topic, but these findings resonate with the situation-dependent varying

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information needs of other care-requiring avenues such as caring for patients with cancer [48,49]. Therefore, the development of solutions that intend to communicate the information to caregivers might benefit from using user-centered design approaches, such as Centre for eHealth Research Roadmap, where at first, user needs are studied and prototypes are cocreated with end users [50].

Use of the PSD Model

The use of the PSD model to elicit design features can help future design works in making informed choices [21]. Although the aim of this interaction platform is not to change a caregiver's behavior or attitude, it focuses on establishing a trusted link between informal caregivers and the system itself, so that informal caregivers comply with the system when needed [30]. On the basis of the findings, it can be implied that a "one size fits all" approach for designing an interaction platform is not suitable [51,52]. Design features that facilitate personalized communication such as tailoring and personalization are strongly recommended. For example, the tailoring feature appears to be useful in catering to different stakeholders, whereas the personalization feature accommodates the individual needs of users within the same or different stakeholder group [53,54]. However, the level of personalization remains as a topic of ongoing debate, given the delicate balance between personalized experiences and potential intrusions on privacy [55,56]. Features such as reminders and suggestions were found to be particularly useful in emergency situations, whereas features such as reduction, trustworthiness, and social learning were identified as in-general design considerations for an interaction platform. Overall, the intended use (advantages and disadvantages) of PSD features should be considered carefully before their implementation [53].

Strengths and Limitations

This study is a first of its kind, which provides a comprehensive understanding of the various perspectives (such as experiences, expectations, and usefulness) of the informal caregivers toward the development and implementation of USS. The early knowledge about factors that are critical for development can strengthen the future implementation of these advanced technologies. The study also adds to the limited literature about IC needs of informal caregivers. Another major strength of this study lies in the methodology used. The complementary use of survey and interviews helped in deriving informative results.

Furthermore, some limitations to this study can also be identified. First, most of the informal caregivers indicated the presence of cognitive impairment through their experience with the CR, but they might not have been formally diagnosed. This is a prevalent challenge in the realm of older adult care, as timely formal diagnosis of dementia is often elusive. In such cases, informal caregiver's opinions are usually considered in the literature [24,25], and they hold substantial value in this study. Although this can be seen as a limitation in the context of older adults with cognitive impairment, the findings possess a high potential for generalizability in the broad realm of older adult care. Second, this study was conducted in the Dutch context, limiting the generalizability of results to other nations' health care infrastructures, as different countries have different models and approaches to health care delivery and financing, influenced by factors such as cultural norms, political systems, and economic considerations.

Third, it is important to note that our study focused solely on the perspective of informal caregivers and did not include the perspectives of other directly associated stakeholders, such as formal caregivers (eg, case managers and general practitioners) or CRs. Considering the diverse roles of various stakeholders in the care of older adults with cognitive impairment, it is crucial to identify and involve them from the early stages of system development to ensure successful implementation [50,54].

Fourth, a lack of knowledge about advanced solutions such as USSs among survey respondents can be imagined. Although during interviews, comprehensive explanation was provided (both written and oral) to ensure participant satisfaction, the potential lack of understanding about the survey may have led to optimistic responses, particularly regarding PU. Therefore, future studies examining such solutions should consider educating participants beforehand to ensure a more informed and unbiased assessment of their opinions. Finally, it is worth noting that the number of informal caregivers interviewed in our study was relatively small compared with the survey participants. Although saturation was reached for responses related to normal daily life and the fall scenario, contradictory responses were obtained for the scenarios involving nocturnal unrest and agitation. However, these contradictory responses can be attributed to the need for personalization.

Conclusions

In conclusion, the study empowers the future development and implementation of such advanced solutions by highlighting the experiences, expectations, needs, and requirements from the perspective of informal caregivers. The findings highlight the possibility of merging diverse sensing modalities, including wearables, cameras, and device-free sensors, to develop a more inclusive care solution for the care of older adults with cognitive impairment based on the care needs of the informal caregivers. Furthermore, informal caregivers expect the care infrastructure to adopt a centralized and empathetic care approach, with care solutions that are more adaptable, trustable, and privacy aware. They showed trust in sensor-based care solutions but also emphasized the importance of reliability and striking a balance between privacy and safety.

PU of USSs was on a positive spectrum, particularly for emergencies, indicating its potential in optimizing care plans for caregivers. The preferences for IC needs varied depending on the care scenarios at hand and individual preferences, thus mandating the involvement of concerned stakeholders in the development (ie, iterative user testing) and implementation stages (ie, selecting the right settings together with other stakeholders). The use of the PSD model resulted in various useful PSD features, which can be used in future studies aiming to design such platforms.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
The survey questionnaire used for quantitative data collection.
[DOCX File , 513 KB - aging_v6i1e49319_app1.docx]

Multimedia Appendix 2
The interview script used for qualitative data collection.
[DOCX File , 1187 KB - aging_v6i1e49319_app2.docx]

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Abbreviations

CR: care recipient
CSI: Channel State Information
IC: information communication
PSD: persuasive system design
PU: perceived usefulness
USS: unobtrusive sensing solution

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Patient Portal Use Among Family Caregivers of Individuals With Dementia and Cancer: Regression Analysis From the National Study of Caregiving

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Abstract

Background: Family caregivers are often inexperienced and require information from clinic visits to effectively provide care for patients. Despite reported deficiencies, 68% of health systems facilitate sharing information with family caregivers through the patient portal. The patient portal is especially critical in the context of serious illnesses, like advanced cancer and dementia, where caregiving is intense and informational needs change over the trajectory of disease progression.

Objective: The objective of our study was to analyze a large, nationally representative sample of family caregivers from the National Study of Caregiving (NSOC) to determine individual characteristics and demographic factors associated with patient portal use among family caregivers of persons living with dementia and those living with cancer.

Methods: We conducted a secondary data analysis using data from the 2020 NSOC sample of family caregivers linked to National Health and Aging Trends Study. Weighted regression analysis by condition (ie, dementia or cancer) was used to examine associations between family caregiver use of the patient portal and demographic variables, including age, race or ethnicity, gender, employment status, caregiver health, education, and religiosity.

Results: A total of 462 participants (representing 4,589,844 weighted responses) were included in our analysis. In the fully adjusted regression model for caregivers of persons living with dementia, Hispanic ethnicity was associated with higher odds of patient portal use (OR: 2.81, 95% CI 1.05-7.57; *P*=.04), whereas qualification lower than a college degree was associated with lower odds of patient portal use by family caregiver (OR 0.36, 95% CI 0.18-0.71; *P*<.001. In the fully adjusted regression model for caregivers of persons living with cancer, no variables were found to be statistically significantly associated with patient portal use at the .05 level.

Conclusions: In our analysis of NSOC survey data, we found differences between how dementia and cancer caregivers access the patient portal. As the patient portal is a common method of connecting caregivers with information from clinic visits, future research should focus on understanding how the portal is used by the groups we have identified, and why.

(JMIR Aging 2023;6:e44166) doi:10.2196/44166

KEYWORDS

patient portal; palliative care; family caregiver; caregiver; dementia; cancer; clinic; age; race; gender; employment; education; model; ethnicity; health system; intervention; regression analysis

Introduction

Family caregivers include spouses, partners, other family members, and close friends, who provide uncompensated assistance to individuals with illness or disability in managing their health care [1]. Family caregivers are predominantly female and spend approximately 3 hours per day on caregiving tasks, though more advanced conditions such as cancer and dementia require more caregiving hours daily [1]. Family caregivers often lack formal training and rely on credible external information sources to perform their tasks competently and deliver effective care to their care recipients [2]. The need for information has increased in recent years primarily due to patients' preference for receiving care within their homes, rather than within nursing homes or other staffed care facilities. This shift has led to family caregivers requiring more, and increasingly specific, information from health care systems [3,4].

The informational needs of family caregivers are particularly elevated in the context of patients receiving palliative care. Caregivers have reported the need for understanding medication

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side effects, disease progression, and pain management strategies [5]. As conditions progress, caregivers are often asked to provide increasingly complex care, which may involve managing multiple medications, administering complex injections, and coordinating care among multiple health care providers [6-8]. Caregivers of individuals with complex needs express concerns regarding the timing, dosage, and proper administration of medications [5].

Currently, patients with cancer and dementia constitute approximately 35% of those receiving palliative care [9]. By 2040, the number of patients with cancer using palliative care services is projected to increase by 45%, whereas the number of patients with advanced dementia using palliative care services is projected to increase 370% [10]. Caregivers of patients with cancer and dementia report experiencing higher levels of burden, emotional stress, and psychological distress than other caregivers; they also tend to provide assistance with a similarly high number of caregiving tasks when compared to other caregivers [11]. Although there are important differences in the nature of their caregiving tasks, such as acute care associated with cancer treatments provided by caregivers of individuals with cancer, and the prolonged cognitive challenges faced by caregivers of individuals with dementia, both caregiver groups deliver complex care, resulting in increased informational needs [12]. The informational needs of caregivers are particularly heightened when the individuals they care for are approaching the end of life, since conditions may change frequently, and caregivers may find themselves less confident in their caregiving responsibilities [13].

Electronic patient portals, which are online health record systems that facilitate messaging and information exchange among patients, caregivers, and health care providers, can be helpful for caregivers, especially those with high-intensity caregiving situations such as cancer and dementia [14].

A systematic review of studies focusing on family caregivers with information from clinic visits identified the patient portal as a primary pathway for engaging family caregivers [15]. However, little is known about the demographic factors associated with family caregiver use of the patient portal to augment their caregiving responsibilities. A study comprising 3026 family caregivers found that 49% of the caregivers thought that the patient portal could be helpful for their caregiving duties; however, the authors did not inquire about their use of the patient portal [16].

Health systems have recognized patient portals as a primary means of engaging with clinic visit information. These portals represent a vital source of information for family caregivers, especially for caregivers of individuals living with dementia [17]. Although individuals with dementia are just as likely to be registered for patient portals as those without dementia, those with dementia are three times more likely to have a family caregiver who accesses their portal and actively engages with the portal's information [18]. Qualitative work in regional health systems have found that caregivers with lower health literacy are more likely to face navigational barriers when accessing patient portals [19,20]. However, it remains uncertain how other demographic characteristics of caregivers assisting high-need patients may be associated with patient portal use. A recent cohort study of 49,382 patients from Johns Hopkins Health System concluded that there is a critical need to better support patients and caregivers through patient portals [18]. It is important to discern which groups may benefit the most from targeted interventions and support.

The objective of our study was to analyze a large, nationally representative sample of family caregivers from NSOC to determine the characteristics of family caregivers of individuals with dementia and cancer and the demographic factors associated with their use of patient portals. Understanding these factors will allow researchers and health systems to better comprehend disparities in usage and develop strategies and interventions to help improve access and use of patient portals by family caregivers. We hypothesized that caregivers of different demographic characteristics would access the patient portal at different rates.

Methods

Data Source

This secondary data analysis used data from NSOC Round IV, conducted in 2021. NSOC surveyed 1938 family caregivers identified by Medicare beneficiaries who were aged 65 years or older and had participated in Round XI of the 2020 National Health and Aging Trends Study (NHATS), an annual health-related nationally representative study designed for individuals aged 65 years and older in the United States. NHATS collects detailed information on participants' physical and cognitive capacity, demographic features, and living situations [21]. NSOC does not specifically identify caregivers of individuals with dementia or cancer. However, we derived this information by linking the restricted NSOC files with NHATS by using the anonymous patient identification number and using patient-level information of the presence or absence of dementia and cancer to determine whether their linked caregiver provided care for a patient with cancer or dementia. The reporting of this study complies with the Reporting of Studies Conducted Using Observational Routinely-collected Data (RECORD) Statement (Checklist 1).

Inclusion Criteria

For inclusion in our analysis, participants in NSOC must have provided care for an individual person in NHATS, as defined by matching the NSOC and NHATS sampling person ID variable in the survey year, regardless of whether the NHATS participant was alive at the end of the survey year. NSOC participants must provide care to an individual with either cancer or dementia, as defined in the NHATS "CONDITION" variable.

Relevant Measures

Covariates were selected a priori by the study team based on their clinical expertise and knowledge, including race or ethnicity, age, employment status, education, caregiver health, and religiosity. We used precoded NSOC demographic variables for race, ethnicity, and age. For employment status, we considered a caregiver employed if they currently worked for payment. We categorized the level of education based on whether a caregiver had completed college or whether they had

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a college degree or higher. Caregiver health and religiosity were dichotomized as good or poor and religious or nonreligious, respectively, based on the Press-Ganey Top Box Scoring system [22].

For our outcome measure, we considered a caregiver as a user of the patient portal in a caregiving capacity when they responded "yes" to using online patient portals to access information about the patient. Dementia and cancer were dichotomized as "yes" or "no" based on the presence and absence of either condition in NHATS. The severity or stage of condition was not collected in NHATS and, therefore, it was not accounted for in our analysis. Although participants could select both cancer and dementia, we excluded those with both cancer and dementia due to small cell sizes per the NHATS/NSOC analytic guidelines [23].

Analytic Strategy

We conducted weighted logistic regression analysis on our outcome measure and variables of interest. We established a predefined alpha level of .05 to determine statistical significance.

We used the NSOC-provided analytical survey weights and included domain variables for the presence of cancer or dementia in the relevant analyses to preserve the effects of the sampling weights in our analysis. Of note, this analysis only included family caregivers who provided care to individuals residing in community or non-nursing home settings.

We tested for collinearity between independent variables using the variance inflation factor (VIF), with defined problematic collinearity as a VIF greater than 10. No problematic collinearity was detected. We did not impute or otherwise include caregivers who provided data with missing responses for the measures included in our models. All analyses were conducted in R (version 3.4.1).

Ethical Considerations

NHATS and NSOC were approved by the Johns Hopkins Institutional Review Board [24]. Our analyses were approved by the University of Alabama at Birmingham institutional review board (IRB) as Not Human Subjects Research (IRB #300011796).

Results

Participant Characteristics

We analyzed 463 responses representing 4,589,844 weighted family caregivers. Participants' characteristics are summarized in Table 1.

Table . Participants' characteristics.

Caregivers' characteristics		Total sample, unweighted (N=463)	Caregivers of individuals with dementia (n=369)		Caregivers of individuals with cancer (n=104)	
		Value	Value	*P* value	Value	*P* value
Age in years, mean (SD)		63.4 (12.8)	63.4 (12.9)	.70	62.8 (13.1)	.13
Race, n (%)				.04		.27
	White	286 (64.6)	216 (60.8)		79 (78.2)	
	Black	126 (28.4)	109 (30.7)		18 (17.8)	
	Hispanic	31 (7)	30 (8.5)		4 (4)	
Gender, n (%)				.01		.51
	Male	157 (34.0)	128 (34.1)		34 (32.4)	
	Female	305 (66.0)	247 (65.9)		71 (67.6)	
Employment status, n (%)				.21		.23
	Employed	166 (37.4)	134 (37.3)		38 (38.4)	
	Unemployed	278 (62.6)	225 (62.7)		61 (61.6)	
Health, n (%)				.49		.83
	Good	230 (50.1)	181 (48.9)		60 (58.3)	
	Poor	229 (49.9)	189 (51.1)		43 (41.7)	
Education level, n (%)				<.001		.26
	College degree or higher	167 (40.7)	130 (39.6)		39 (42.9)	
	Lower than college degree	243 (59.3)	198 (60.4)		52 (57.1)	
Religiosity, n (%)				.39		.27
	Not religious	193 (43.6)	159 (44.5)		40 (40.8)	
	Religious	250 (56.4)	198 (55.5)		58 (59.2)	

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Statistical Results

Univariate statistical modeling results showed that, for caregivers of individuals with dementia, race (*P*=.04), gender (*P*=.006), and education level (*P*<.001) were associated with patient portal use. For caregivers of individuals with cancer, no covariates were associated with patient portal use (Table 1).

In the fully adjusted regression model for caregivers of individuals with dementia, identification with Hispanic ethnicity (OR: 2.81, 95% CI 1.05-7.57; *P*=.04) was associated with higher odds of patient portal use, whereas education lower than a college degree (OR 0.36, 95% CI 0.18-0.71; *P*<.001) was associated with lower odds of patient portal use. In the fully adjusted regression model for caregivers of individuals with cancer, no variables were statistically significantly associated with patient portal use at the .05 level. See Table 2 for more information on the fully adjusted regression modeling.

Table . Patient portal use by caregivers of individuals with dementia and cancer per fully adjusted regression modeling.

Predictors	Dementia			Cancer		
	Odds ratio	95% CI	*P* value	Odds ratio	95% CI	*P* value
Intercept	0.684	0.14-3.38	.64	0.16	0.01-3.5	.25
Caregiver age (years)	0.99	0.97-1.02	.54	1.01	0.96-1.05	.98
Female gender	1.49	0.71-3.14	.29	1.11	0.26-4.71	.89
Caregiver race or ethnicity						
White (reference)	-	-	-	-	-	-
Black or African American	0.64	0.30-1.34	.24	.34	0.06-1.94	.23
Hispanic	2.81	1.05-7.57	*.04*[a]	0.98	0.12-8.15	.98
Unemployment	0.79	0.38-1.66	.54	1.64	0.41-6.59	.49
Poor caregiver health	1.16	0.59-2.27	.67	0.98	0.29-3.25	.97
Education level						
College degree or higher (reference)	-	-	-	-	-	-
Lower than a college degree	0.36	0.18-0.71	*<.01*[a]	1.44	0.41-5.06	.58
Religiosity	1.01	0.52-1.97	.98	1.88	0.57-6.12	.31

[a]Italicized values are statistically significant.

Discussion

Principal Results

Caregivers of individuals with cancer used the patient portal more than did caregivers of individuals with dementia. According to the regression modeling data, no caregiver demographics were associated with patient portal use among caregivers of individuals with cancer; however, among caregivers of individuals with dementia, Hispanic ethnicity was associated with higher odds of patient portal use, whereas education lower than a college degree was associated with lower odds of patient portal use.

Comparison With Prior Literature

Our study expands on prior findings by Wolff et al [17] and Gleason et al [18], who identified the patient portal as an important method for engaging caregivers of patients living with dementia. Their studies conclude that family caregivers, especially those with high-need conditions, require additional informational support through the patient portal. Through a weighted analysis of a large national data set, our study examined the characteristics associated with portal use of two important groups of family caregivers who may benefit from future targeted intervention and support.

Our results underscore the need for tailoring approaches toward caregivers of individuals with cancer or dementia differently rather than using a one-size-fits all approach for interventions targeted at family caregivers. Differences between these caregiver groups have previously been identified as relevant to the caregiving experience, with caregivers for patients with cancer tending to provide care for a shorter duration, while caregivers of those living with dementia tending to provide care for comparatively longer periods [11,12]. A study comparing psychological distress in palliative care settings found caregivers of patients with dementia to have greater distress but similar burden, concluding that more work is needed to identify methods to further support family caregivers of patients with dementia [25]. Our findings highlight the need for tailored interventions that consider different patient conditions.

We found that caregivers of individuals with dementia who identify as Hispanic ethnicity had higher odds of using the

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patient portal, whereas caregivers of those with dementia with lower educational levels had relatively lower odds of using the patient portal.

In a study of 252 family caregivers who were provided access to physicians' notes as part of a pre-post study, it was found that 87.5% of caregivers viewed these notes but that 46.7% did not know they were able to access the patient's individual portal [14]. Caregivers' reasons for viewing the physicians' notes included seeking knowledge regarding the patient's health (59.9%) and ensuring they understood what the doctor said (49.3%) [14]. Using the physicians' notes was associated with improved communication with the patient's health care provider [14]. While this study included patients aged 18 years and above and their caregivers with access to the patient portal account, the authors did not report on portal use categorized by condition or caregiver demographics. Our analysis expands on these findings by suggesting potential differences in informational needs based on caregivers' demographic characteristics within different conditions, and these varied needs may influence the patient portal use by family caregivers. Indeed, there have been calls for a demographically diverse group of family caregivers to be engaged in the design of expanded electronic medical record systems [26]. Our findings highlight the importance of including Hispanic caregivers and those with lower educational attainment in the development of health record systems.

Studies involving Hispanic patients have found cultural and linguistic barriers to patient portal use. In one study, Hispanic patients were more likely to indicate that they did not require the patient portal for their own care [27]. The finding in our study that Hispanic family caregivers of individuals living with dementia had higher odds of using the patient portal could be attributed to cultural and linguistic factors. Hispanic cultures place high emphasis on familism [28-30]. Hispanic caregivers may have found the patient portal to be a valuable tool to assist them with their caregiving responsibilities.

When considering potential linguistic differences between caregivers and providers, especially when visits lack a certified medical interpreter, the patient portal could allow the caregiver to revisit information discussed during visits, facilitating a better understanding in the presence of linguistic differences. Nonetheless, information should ideally be communicated in the preferred language of the patient and caregiver [31]. This could be of particular importance for conditions like dementia and cancer, where visits are information-intensive, and recall can be negatively affected [32].

A study of 1996 caregivers through the 2011 NSOC found that Hispanic caregivers reported a higher percentage of unmet needs (49%) than did non-Hispanic caregivers (46.5%). Moreover, Hispanic caregivers had a much higher percentage reporting two or more unmet needs (42.6%) than did non-Hispanic caregivers (21.4%) [33]. Although this study does not examine the specifics of these informational needs, our findings suggest that these needs could be addressed by elements in the patient portal, such as direct messaging or validated informational documents. Future work examining what Hispanic caregivers find valuable in the patient portal, and what informational gaps the patient portal may or may not be addressing, is warranted and may have implications for other ethnic groups.

Other studies have also noted the differences in portal use among patients with lower educational attainment [34]. One barrier that has been identified is the ability to access the portal or comfortably use a computer [34]. As patient portals are often accessed online, internet access is a prerequisite, and comfort using technology is of high importance. About 25.9% of patients reported lack of comfort using a computer, although more work is needed to understand caregivers' comfort using computers, especially as aging patients and caregivers may be becoming more familiar with computers [27]. A systematic review that sought to improve patient portal use by patients found that educational training sessions facilitated patient portal access by patients with lower educational attainment and lower levels of comfort using technology [35]. However, these interventions were also patient-focused and provided no data for family caregivers. Future work should include educational interventions for family caregivers.

Our analysis did not focus on palliative care specifically; however, we included conditions of individuals that commonly need palliative care as their conditions progress; specifically, about 35% of patients seeking palliative care do so for cancer or dementia [9].

Limitations

Although our study is a weighted analysis of a methodologically strong, nationally representative data set, it is not without limitations. Comparatively few caregivers of cancer were included in the data set: only 22% (n=104) of caregivers in NSOC reported caring for individuals with cancer. As new, more complex treatments are developed and individuals with cancer are living longer with more advanced disease [33], it is important to target additional research to better understand and meet caregivers' informational needs. Weighted analyses can make the sample representative by certain characteristics (in this case, age and race), but the weighting can artificially inflate the responses of the respondents being weighted, which can increase the sampling variance, standard error, and standard deviation. Although we adjusted for these characteristics in our regression model, the potential for sampling bias still exists. Additionally, we could not account for location in our sample, as those variables are part of a restricted file due to concerns of patient and caregiver privacy. Future research could consider the impact of rurality on patient portal use.

We also considered the limitations associated with multiple testing, but our study was exploratory in nature. While common adjustment methods such as the Bonferroni Correction or the Benjamini-Hochberg procedure can limit type 1 error rates, these methods can inflate type 2 error rates, which makes them less ideal for exploratory studies [36,37]. Previous studies have identified patient preference for in-person communication as an important factor when engaging with patient portals and health systems [38,39]. However, we did not have access to this information, and we were unable to include this as a factor in our analysis. Hence, future research should consider this important component that may influence caregiver behavior.

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Conclusion and Implications

Family caregivers often use the patient portal; however, we found differences in the patient portal use by different caregiver groups. We identified that caregivers of individuals with dementia use the patient portal at different rates, particularly those identifying as Hispanic and those with lower educational attainment. As the patient portal is a tool used by family caregivers to engage with health systems, health systems should consider cultural and educational interventions to support family caregivers with this critical aspect of their caregiving.

Conflicts of Interest

RJ is the Owner of DementiaCentric Solutions, LLC and receives book royalties from Amazon.

Checklist 1
RECORD (Reporting of Studies Conducted Using Observational Routinely-Collected Data) checklist.
[PDF File, 357 KB - aging_v6i1e44166_app1.pdf]

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Abbreviations

IRB: institutional review board
NHATS: National Health and Aging Trends Study

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NSOC: National Study of Caregiving
RECORD: Reporting of Studies Conducted Using Observational Routinely-Collected Data
VIF: variance inflation factor

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Enhancing Caregiver Empowerment Through the Story Mosaic System: Human-Centered Design Approach for Visualizing Older Adult Life Stories

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Abstract

Background: Various older adult care settings have embraced the use of the life story approach to enhance the development of comprehensive care plans. However, organizing life stories and extracting useful information is labor-intensive, primarily due to the repetitive, fragmented, and redundant nature of life stories gathered from everyday communication scenarios. Existing life story systems, while available, do not adequately fulfill the requirements of users, especially in the application of care services.

Objective: The objective of this study is to design, develop, and evaluate a digital system that provides caregivers with the necessary tools to view and manage the life stories of older adults, enabling expedited access to pertinent information effectively and visually.

Methods: This study used a multidisciplinary, user-centered design approach across 4 phases: initial design requirements, prototyping, prototype refinement workshops, and usability testing. During the initial phase, we conducted field research in the Hefei Tianyu Senior Living Service Nursing Home, China, to discover how caregivers currently store and use life stories and their needs, challenges, and obstacles in organizing and retrieving information. Subsequently, we designed a low-fidelity prototype according to the users' requirements. A prototyping workshop involving 6 participants was held to collaboratively design and discuss the prototype's function and interaction. User feedback from the workshops was used to optimize the prototype, leading to the development of the system. We then designed 2 rounds of usability testing with 7 caregivers to evaluate the system's usability and effectiveness.

Results: We identified 3 categories of functionalities that are necessary to include in the design of our initial low-fidelity prototype of life story visualizations: life story input, life story organization, and timeline generation. Subsequently, through the workshops, we identified 3 categories for functional optimization: feedback on user interface and usability, optimization suggestions for existing features, and the request for additional functionalities. Next, we designed a medium-fidelity prototype based on human-centered design. The Story Mosaic system underwent usability testing in the Hefei Tianyu Senior Living Service Nursing Home. Overall, 7 users recorded and organized 1123 life stories of 16 older adults. The usability testing results indicated that the system was accessible and easy to use for caregivers. Based on the feedback from the usability testing, we finalized the high-fidelity prototype.

Conclusions: We designed, developed, and evaluated the Story Mosaic system to support the visual management of older adults' life stories. This system empowers caregivers through digital technology and innovative design, pioneering personal narrative integration in caregiving. This system can expand to include informal caregivers and family members for continued adaptability and empathy.

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KEYWORDS

life story visualization; Story Mosaic system; human-centered design; prototype refinement workshops; eldercare; caregiver; elder; older adult

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Introduction

Background

The growing aging population is projected to reach 1.5 billion by 2050, with around 50% of older adults experiencing loneliness and social isolation, which poses serious public health risks and is associated with adverse health outcomes [1]. The use of life stories as a medium for communication with older adults has evolved into a potent intervention that is capable of mitigating their social obstacles and enhancing their quality of life [2]. Professional caregivers can benefit from this approach by engaging older adults to talk about their life experiences, extracting meaningful messages from these stories, and applying these insights to personalized care for these older adults [3].

Some nursing homes have started incorporating older individuals' life stories into their health information archives [4]. During the admission process, through communication with older adults or their family members, information is gathered about their life experiences, interests, hobbies, social relationships, and more [5]. These data serve as the foundation for personalized care plans, aligning with the person-centered care approach [6]. However, life stories in daily settings are rarely narrated in their entirety but are often fragmented and disorganized [7], making interpretation and application by caregivers challenging.

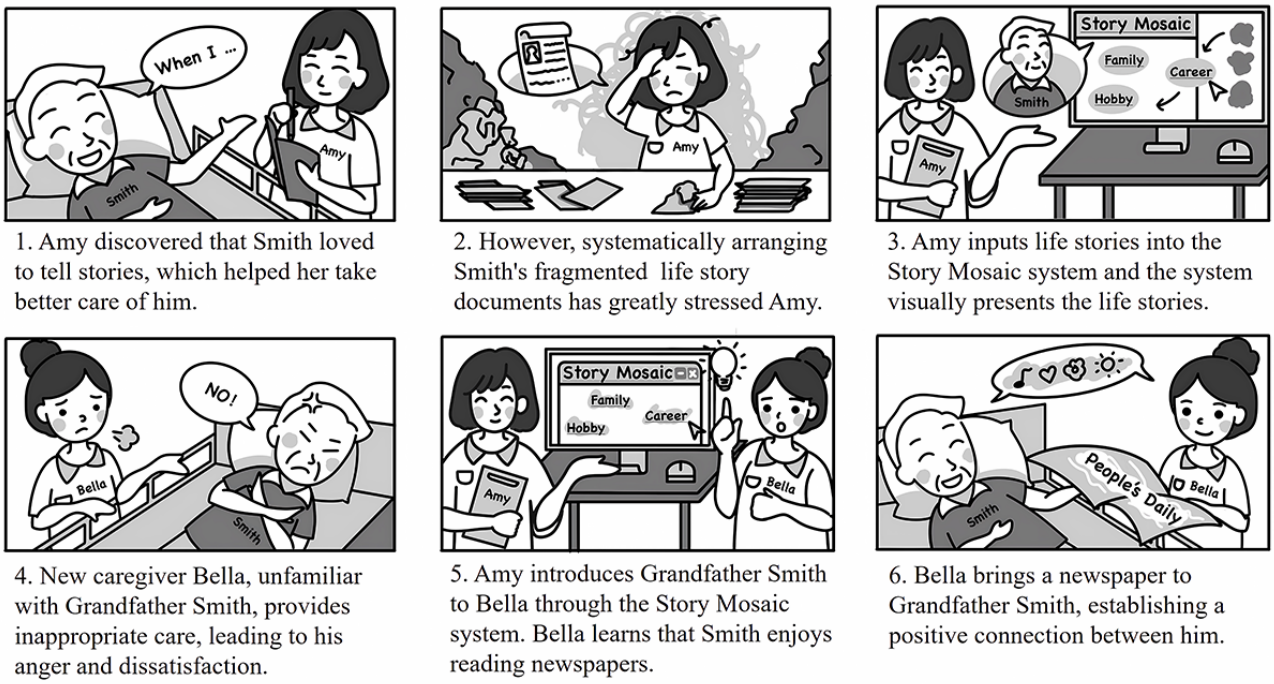
Although most of the existing research has relied on the manual organization of the life stories of older adults [8], there is an effort to automate this process [9]. Even when automated, the lack of effective visualization hinders the full realization of life stories' potential, marking a gap in using life stories in caregiving practice.

Objective

This study sought to design, develop, and evaluate the Story Mosaic system, a tool specifically crafted to visually represent the life stories of older adults for professional caregivers. The Story Mosaic system intends to facilitate efficient information extraction, enable automated organization, and promote enhanced management of these narratives. By rationally organizing life stories, the presentation becomes more straightforward and intuitive, aiding caregivers in better understanding older adults, having an insight into the needs of older adults, and providing personalized care. The system enables life stories to continue to enrich and grow dynamically as caregivers interact more deeply with older adults, fostering a virtuous service cycle.

We drew a use case, as shown in Figure 1, to describe the Story Mosaic system's users and features and the real-world problem it solves. The system is designed for professional caregivers involved in the daily care of older adults. The life stories that older adults share with their caregivers are often fragmented and marked by redundancy and disarray, creating considerable challenges in their organization and interpretation. Caregivers can input older adults' life stories into the Story Mosaic system in batches. The system performs tasks such as categorizing stories by themes, arranging them chronologically, and generating a timeline. It visualizes crucial information within these life stories, providing caregivers with data to offer personalized services to older adults.

Figure 1. A big-picture storyboard for the Story Mosaic system.



1. Amy discovered that Smith loved to tell stories, which helped her take better care of him.

2. However, systematically arranging Smith's fragmented life story documents has greatly stressed Amy.

3. Amy inputs life stories into the Story Mosaic system and the system visually presents the life stories.

4. New caregiver Bella, unfamiliar with Grandfather Smith, provides inappropriate care, leading to his anger and dissatisfaction.

5. Amy introduces Grandfather Smith to Bella through the Story Mosaic system. Bella learns that Smith enjoys reading newspapers.

6. Bella brings a newspaper to Grandfather Smith, establishing a positive connection between him.

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Methods

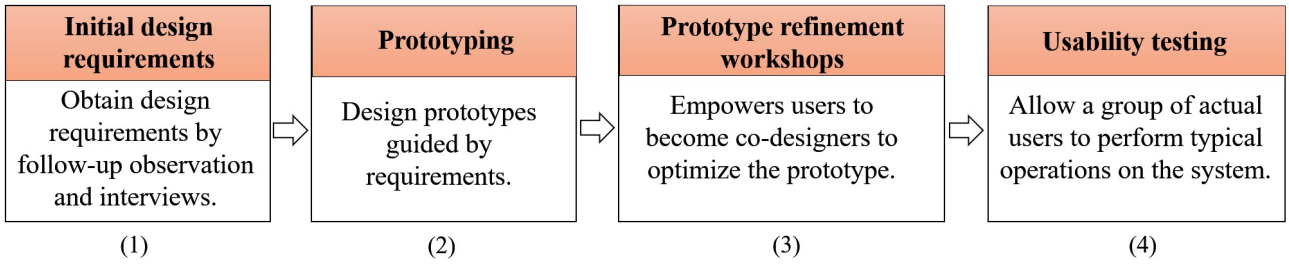
Ethical Considerations

Approval was obtained from the research ethics board of the Hefei University of Technology (HFUT20220921001). All participants provided informed consent and participated voluntarily; no compensation was involved. The information and pictures of older adults included in this study adhere to privacy policies.

Study Overview

This study used human-centered design (HCD) methodology to ensure the efficacy and efficiency of the final product for the intended user population [10]. In this study, we implemented the Story Mosaic system using a 4-phase strategy consisting of initial design requirements, prototyping, prototype refinement workshops, and usability testing, as shown in Figure 2.

Figure 2. The implementation of the Story Mosaic system: (1) initial design requirements, (2) prototyping, (3) prototype refinement workshops, and (4) usability testing.



Software Language

When analyzing interview and observational data, we used the speech-to-text tool provided by iFlytek (China Mobile) [11] and Quirkos (Quirkos Software) [12] to expedite data coding and analysis. For the prototype design, we used the collaborative web-based prototyping tool, MoDao (Wondershare) [13], to facilitate the design process among multiple team members. In developing the system, we used Node.js (OpenJS Foundation) [14] and TypeScript (Microsoft) [15] to construct the web server, providing a robust platform for handling incoming requests.

Phase 1: Initial Design Requirements

We conducted field research between February and April 2023 in the Hefei Tianyu Senior Living Service Nursing Home, China. The aim was to comprehensively understand the initial design requirements that should be included in the Story Mosaic system.

Recruitment

We recruited 2 administrators and 3 caregivers. The inclusion criteria for the participants were (1) more than 2 years of nursing experience and (2) current participation in life story intervention in older adult care. Table 1 displays the characteristics of the participants in acquiring the initial design requirements.

Table . Participants' characteristics in initial design requirements acquisition.

ID	Identity	Sex	Age (years)	Years of older adult care
A1	Administrator	Male	34	10
A2	Administrator	Female	26	3
C1	Caregiver	Female	53	7
C2	Caregiver	Female	42	6
C3	Caregiver	Male	33	2

Procedure

We conducted a follow-up observation, supplemented by 5 semistructured one-on-one interviews during the observation [16,17]. The follow-up observation was to observe the 3 caregivers interacting with older adults in clinical care and the way they organized and looked up their life stories. The 5 semistructured one-on-one interviews were conducted with administrators and caregivers to gain insight into their difficulties in organizing the life stories of older adults and their design needs for a life story visualization system. Based on the data analysis results of the follow-up observation, we mainly discussed the following questions with the participants in the semistructured interview:

1. What types of life stories do older adults usually tell in daily interactions?
2. How do you generally organize the life stories of older adults? What are the difficulties?
3. When you look it up again, can you quickly find the target life story?
4. What do you hope the Story Mosaic system can provide you?
5. What do you think is the most essential function of the Story Mosaic system?

Data Analysis

The above tasks were audio recorded with participant consent and transcribed into words by team members to familiarize

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themselves. The team members then annotated and categorized the data based on the observations, initially identifying distinct user requirement themes [18]. Subsequently, data from 3 semistructured interviews were chosen for in-depth analysis to validate whether the identified themes aligned with the findings from the follow-up observation. Necessary adjustments and enrichments were made to the themes during this process. Subsequently, the theme framework was further validated using data from 2 additional semistructured interviews.

Phase 2: Prototyping

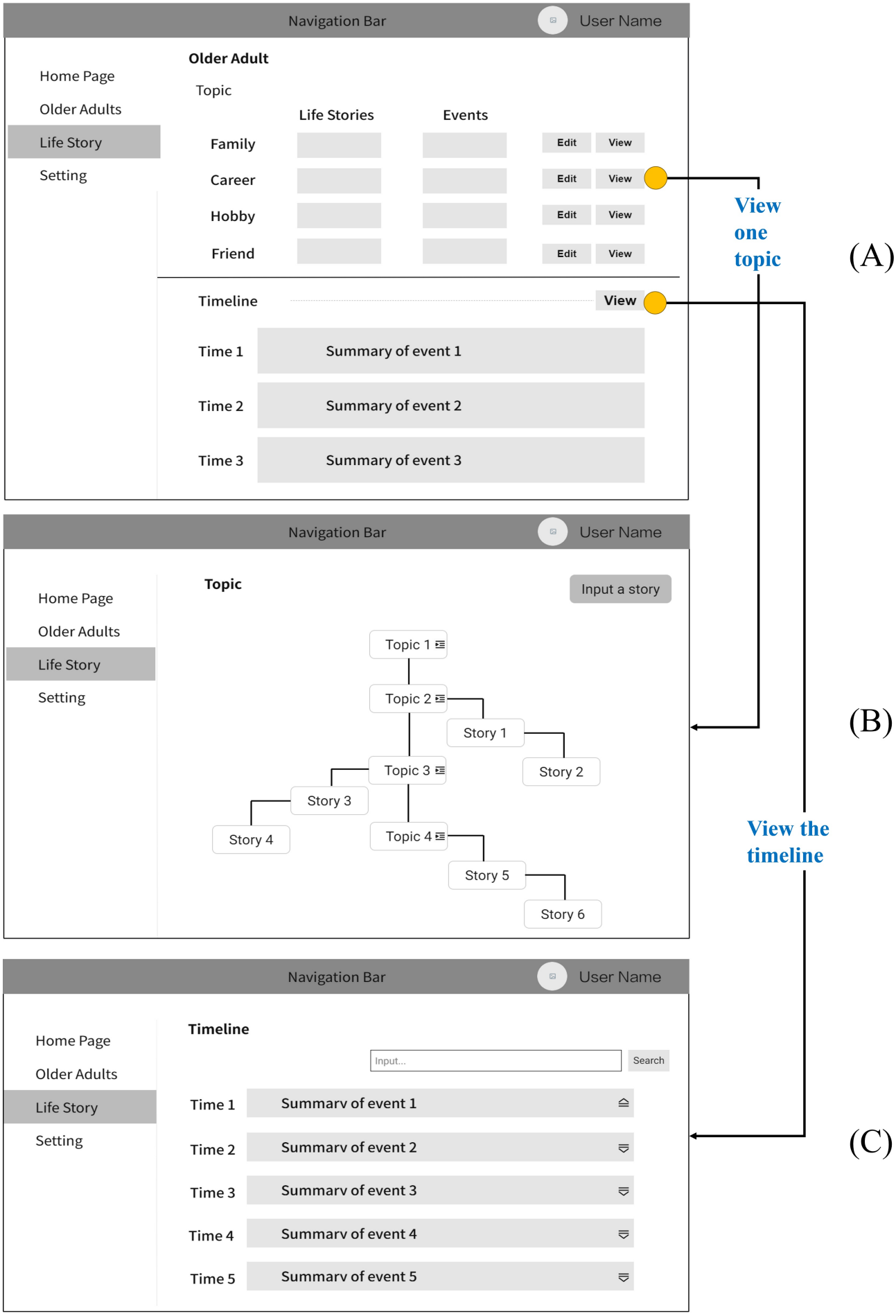
Low-Fidelity Prototype

We designed a low-fidelity prototype (Figure 3) of the Story Mosaic system with the initial design requirements. The mapping relationship between initial design requirements and prototype functions is shown in Multimedia Appendix 1. The system completes tasks including organizing stories chronologically, categorizing them according to topics, and creating a timeline. It depicts crucial information from these life stories, giving caregivers information they can use to provide individualized care for older adults.

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Figure 3. Low-fidelity prototype mock-ups of the Story Mosaic system. (A) The visual interface for older adults' life stories is bifurcated into 2 distinct modules: topic and timeline. (B) Detailed diagram of the topic module in (A), where life stories are organized hierarchically by topics. The topics form the trunk, and the life stories are the branches beneath each topic. (C) Detailed diagram of the timeline module in (A), displaying the older adult's important life experiences as a timeline, with each node representing a key event from their life story.

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Procedure

We discussed and iterated sketches of the system within our multidisciplinary team, which included 2 user experience designers, 2 computer science researchers, and 2 caregivers (C1 and C2, who participated in the initial design requirements study). Once we finalized the initial design of our system, we converted the sketches to a digital low-fidelity prototype using MoDao (a prototyping tool that facilitates collaborative web-based interaction among multiple users).

Given the relatively older age of caregivers [19], we adopted an age-friendly interaction design based on HCD during prototyping [20-22].

Regarding font size and colors, our design used large font sizes and warm colors to foster a friendly interface [23].

We considered features to make the system easy to click. As individuals age, they may experience a decline in hand-eye coordination and motor functions, making it challenging for them to interact with a user interface (UI) [24]. Tasks such as clicking on interface targets, moving between interface elements, and responding to on-screen targets become difficult. We addressed this difficulty by ensuring that the interactive UI components were sufficiently large with a minimum diagonal length of 11 mm and adequately distanced from other elements with at least a 2-mm gap. Additionally, scroll bars could pose usability issues. The system was designed to simplify scroll bars and provide users with alternative options such as clicking on scroll bar arrows, using the keyboard's up and down keys, and having action buttons that return them directly to the top of the page [25].

Lastly, we aimed to have consistent layouts. We established a well-defined grid system during the prototype design phase to maintain consistent spacing and alignment. We adhered to a unified typography and color scheme while consistently implementing a standardized set of UI elements and components across the entirety of the design [26].

Phase 3: Prototype Refinement Workshops

In this phase, we organized participatory design workshops to refine system prototypes. Participatory design is a method that empowers users to become co-designers, actively involving them throughout the design process [27].

Recruitment

We recruited 6 participants for the workshops on the Story Mosaic system prototype, comprising 1 UI designer, 1 aging-product designer, and 4 caregivers. In total, 2 of the 4 caregivers were participants in the phase-1 study, and the other 2 were new participants. Table 2 displays the characteristics of the participants in the prototype refinement workshops.

Table . Participants' characteristics in the prototype refinement workshops.

ID	Identity	Sex	Age (years)	Years of older adult care
D1	UI[a] designer	Male	33	N/A[b]
D2	Aging-product designer	Female	42	6
C1	Caregiver	Female	53	7
C2	Caregiver	Female	42	6
C4	Caregiver	Male	32	3
C5	Caregiver	Female	28	3

[a]UI: user interface.

[b]N/A: not applicable.

Procedure

The primary objective of these design workshops was twofold: to acquire feedback on the prototype and to identify unanticipated requirements. Before commencing the participatory design workshops, we obtained informed consent and demographic information from the participants. We conducted 4 workshops with the same group of participants, each consisting of 6 participants, to acquire feedback on the content, presentation, and interaction of our proposed prototype. We conducted participatory workshops with the same group of participants every 2 weeks at the nursing home, recording the audio of each session. The initial 3 workshops focused on seeking feedback and suggestions on different parts of the prototype [28]. After analyzing the data gathered in the first 3 design workshops, we designed an interactive medium-fidelity prototype, ensuring that all issues raised during the initial 3 workshops were addressed. Finally, we presented the medium-fidelity prototype in the fourth workshop, followed by a final round of feedback.

Data Analysis

We conducted a thematic analysis of the prototype refinement workshops. The primary objective of this analytical process was to synthesize the feedback received concerning our prototype and to unveil latent user requisites that may have been overlooked during the initial phase of the study. We transcribed the proceedings of the initial 3 design workshops, leading to the inception of preliminary themes. Subsequently, we used the records from the fourth design workshop for validation and refinement. Finally, we curated illustrative quotations corresponding to each thematic category and succinctly encapsulated our discoveries. We refrained from presenting quantitative details, such as enumerating the frequency of information occurrences. The objective of this phase was to unveil unexpected insights through an inductive approach to data collection and analysis [29].

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Phase 4: Usability Testing

It is imperative to consider whether usability testing would produce anything meaningful in the system design stage [30].

Recruitment

We recruited 7 participants to participate in usability testing. Table 3 displays the characteristics of the participants in the usability tests.

Table . Participants' characteristics in the usability tests.

ID	Identity	Sex	Age (years)	Years of older adult care
A1	Administrator	Male	34	10
A2	Administrator	Female	26	3
C3	Caregiver	Male	33	2
C6	Caregiver	Female	45	3
C7	Caregiver	Male	23	1
C8	Caregiver	Female	54	5
C9	Caregiver	Female	45	3

Procedure

We conducted observational studies to better understand users' natural interactions with the product, monitoring users as they engaged with the Story Mosaic system. Following literature guidelines [31], we adopted an iterative approach for our usability tests, dividing them into batches. The initial test involved 3 participants, and we addressed their predominant usability issues. We then tested the system again with 4 participants. The moderator asked the participants to use different functionalities within the system while reflecting on the experience of using life stories. During the usability tests, the moderator noted any difficulties the participants encountered. The participants filled out the System Usability Scale (SUS) at the end of the usability tests. We deployed the Story Mosaic system in the Hefei Tianyu Senior Living Service Nursing Home for practical use verification. The usability task and interview questions are presented in Multimedia Appendix 2.

Data Analysis

We systematically analyzed and categorized user interactions with our system during each task. The *Results* section details the usability test results and provides the associated optimization recommendations.

Results

Phase 1: Initial Design Requirements

We preliminarily identified 3 categories of functionalities within the life story visualization module of the system: (1) life story input, (2) life story organization, and (3) timeline generation. Caregivers can input multimodal life stories (text, picture, video, etc) into the system, and during the input process, they can annotate elements such as time. Subsequently, the system categorizes and organizes life stories by themes, producing a thematic visual timeline for older adults. We established the initial design requirements list, as shown in Multimedia Appendix 3.

Phase 2: Prototyping

Overview

The prototype of the Story Mosaic system primarily encompasses functionalities within 3 modules: older adults management, life story management, and system settings. The life story management module is the core of the Story Mosaic system, and we describe it in detail in the following section. The life story management module contains 3 important functions: life story input, automated life story organization, and timeline generation. The mapping relationship between initial design requirements and prototype functions is shown in Multimedia Appendix 1. The low-fidelity prototype of the life story management module is shown in Figure 3.

Life Story Input

The life story input module empowers users to manually input pivotal components, including time, location, individuals, and event summaries, with the flexibility of these particulars being nonmandatory. Moreover, the platform provides an algorithmic mechanism for automated padding in instances where the above information is absent. Users can enrich life stories with various formats, encompassing textual content, images, and videos. Furthermore, the system supports theme personalization, enabling users to establish, modify, eliminate, and retrieve the topics for older adults' life stories within the framework.

Automated Life Story Organization

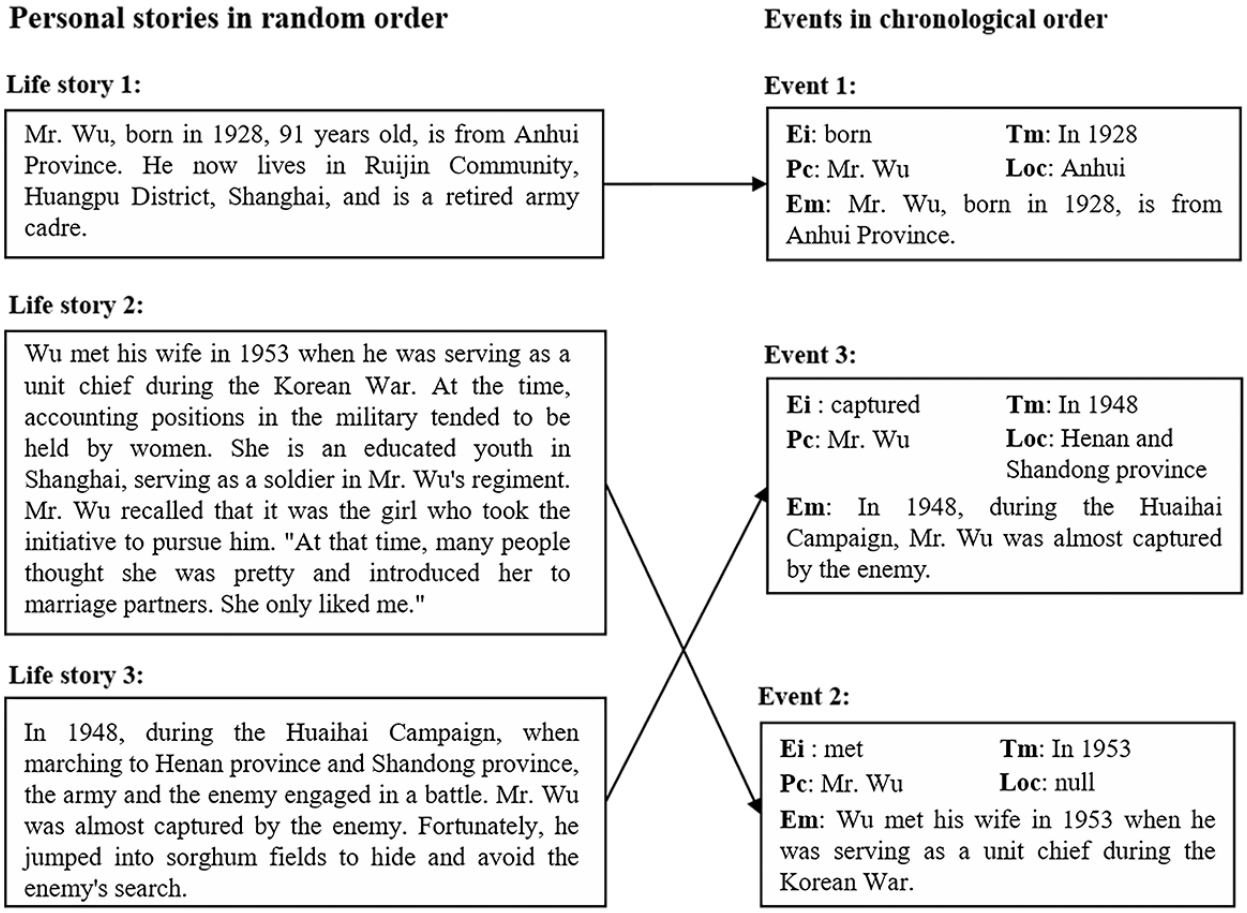
In the low-fidelity prototype, we established 5 primary themes: "Friends and Family," "Career," "Achievement," "Marriage," and "Interests." It is within the prerogative of users to exercise adaptability, enabling the customization and introduction of novel themes, all contingent on the idiosyncratic life experiences of older adults. The automated life story organization module allows users to classify life stories through manual themes specification. In the absence of specified themes, the system defaults to an algorithm for automated organization. Narratives are methodically sequenced based on temporal attributes, from earlier experiences to the most recent events. Additionally, the life story presentation interface incorporates a search box, facilitating the execution of fuzzy searches across these narratives.

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Timeline Generation

The primary objective of the timeline generation module is to construct a chronological framework of older adults' life journey, furnishing caregivers with a swift avenue to comprehend the older adult. The core functionality of this module revolves around streamlining details within the older adult's life narratives, highlighting pivotal events within each life story. Subsequently, the crucial events are organized based on chronological order, generating a cohesive timeline. Each node on the timeline is represented as "Time: Story Summary." Figure 4 shows an example of the timeline generation process [32].

Figure 4. The timeline generation process extracts the crucial event from each life story and sorts them chronologically. Ei: event induction; Em: event mention; Loc: location; Pc: participant; Tm: time.

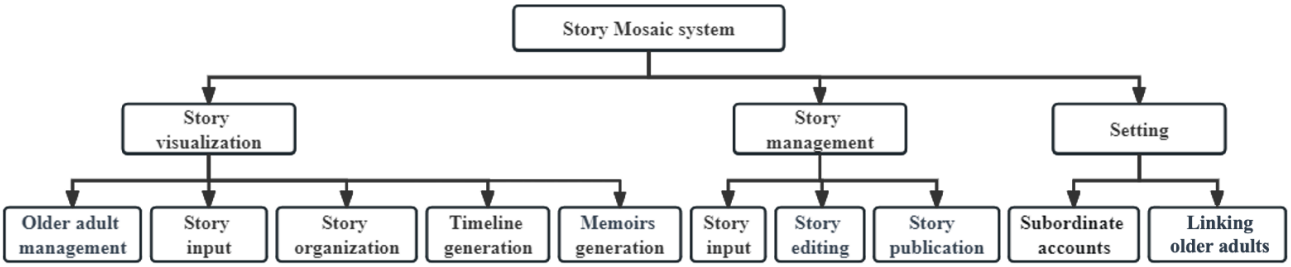


Phase 3: Prototype Refinement Workshops

Overview

The participants had valuable insights and feedback on the prototype, which helped us to identify several areas for functional design and improvement during the prototype refinement workshops. We also discovered some unanticipated requirements. We analyzed the results of the prototype refinement workshops to establish the functional architecture of the Story Mosaic system and design the medium-fidelity prototype. The functional architecture diagram is shown in Figure 5. The medium-fidelity prototype of the story visualization, which is the most important module of the Story Mosaic system, is shown in Figure 6. Multimedia Appendix 4 provides the feedback analysis of the workshops.

Figure 5. The functional architecture diagram of the Story Mosaic system.



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Figure 6. Medium-fidelity prototype mock-ups of the Story Mosaic system. (A) The interface visually depicts the older adult's life story. Using workshop feedback, the top section displays vital information, easing caregiver memory strain. The lower part emphasizes life story themes and quantities while integrating content from the timeline module into the topic module. (B) By clicking on a specific theme, users can access the viewing interface for life stories associated with that theme. The visual representation of life stories from the low-fidelity prototype is harmoniously integrated with the timeline display, resulting in a reduction of user interactions. (C) Caregivers can click on a specific event node within the timeline to view all fragmented life stories associated with that event node.

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Visualization of Story Mosaic

Visualizing older adults' life stories is a central aspect of the Story Mosaic system. In the prototype refinement workshops, we extensively discussed the visualization methods with the participants. Considering their work requirements and suggestions, we iteratively optimized the forms of visualizing life stories. Table 4 presents the participants' perspectives on the strengths, weaknesses, and improvement suggestions for each visualization approach in the prototype refinement workshops.

Table . Participants' comments and suggestions of the story mosaic.

Approach	Advantages	Disadvantages	Improvement suggestions
A	• The hierarchical structure, consisting of a main trunk and branches, can effectively assist caregivers in organizing the life trajectory of older adults [C1 and D2]	• It hinders the expansion of life stories and results in crowded content when displaying story details within the nodes [D2]	• Maintain the hierarchical structure while adopting a zigzag-shaped multilevel visualization approach [D1 and D2]
B	• Organize life stories according to chronological or logical rules, maintaining a clear hierarchical structure that facilitates the web-based expansion of life stories [D1, C3, and C4]	• The presence of potential information overload • The absence of prominent highlighting of essential information, resulting in significant reading barriers [D1 and C3]	• Implement filters and sorting options to manage and retrieve data effectively • Differentiate important information by using various colors based on the frequency of story occurrences [D2 and C4]
C	• Retain approach B's advantages while highlighting important information with colors • Comprehensive and detailed [C2 and C5]	• Lack of interactivity • Complex content may confuse users [D1 and C4]	• Incorporate interactive elements to enhance user engagement and exploratory behavior • Simplify the interface without sacrificing important information [C3 and D2]
D	• Efficient and well organized • Visually appealing • User-friendly with simple and intuitive interactions [C1, C4, and C5]	• The customization options are limited in scope [C2 and C5]	• The participants expressed satisfaction with this approach and did not suggest improvements

Feedback on UI and Usability

Participants offered insights regarding the system's usability and visual design. They indicated a desire for clear instructional cues, such as an evident "click here to return" prompt during page navigation. They also noted difficulties in interacting with the system's button, primarily when solely represented by icons or text. A preference emerged for buttons combining icons and text, accompanied by an adequately sized font. Moreover, the frequency of retelling life stories carries varying implications for an individual. Stories mentioned often indicate events that had a profound impact or left a strong impression on the older adult, thus forming suitable topics to initiate engagement in care. On the other hand, seldom recounted experiences could signify events the individual prefers not to discuss, suggesting possible areas necessitating tactful handling in their care plan. Responding to feedback from nursing home caregivers who participated in the survey, we adopted the progressive color representation method.

Request for Additional Functionalities

The following additional functionalities were requested. (1) The life story management function was deemed valuable, designed to preserve life stories that have yet to be included in the life story structure. Users can add, delete, and review life stories in the story bank. (2) The memoir function was desired to enable users to choose some life stories from the life story structure and create an electronic memoir for older adults or their family members. (3) An interface for older adults' children was also deemed beneficial. The system management module of older adults' care homes could incorporate individual accounts for older adults' children. This could let them see caregiver efforts for their parents and help strengthen parent-child bonds through exploring life stories.

Phase 4: Usability Testing

Overview

The Story Mosaic system underwent usability testing in the Hefei Tianyu Senior Living Service Nursing Home. In all, 5 caregivers and 2 administrators collaborated on inputting 1123 life stories from 16 older adults into the system. The usability task and interview questions are presented in Multimedia Appendix 2. In the usability testing feedback, we summarized the following issues: interaction, bootstrap operation, input errors, and complex operation. Multimedia Appendix 5 details the problems encountered by participants during usability testing and our proposed fixes. We analyzed the results of usability testing to design the high-fidelity prototype. Figure 7 is the high-fidelity prototype of the life story organization and visualization, and the home page of the Story Mosaic system is shown in Multimedia Appendix 6.

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Figure 7. High-fidelity prototype mock-ups of the Story Mosaic system. (A) The interface visually presents the life story of the older adult. Different themes are represented by different colored circles, and the size of the circle is proportional to the number of life stories it contains. (B) By clicking on a specific theme, users can access the viewing interface for life stories associated with that theme. Different event nodes have different color backgrounds. As the life stories contained under an event become more fragmented, the background color of the event node becomes darker. (C) Caregiver can click on a specific event node within the timeline to view all fragmented life stories associated with that event node.

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Interaction Operation

Some participants raised concerns about whether the interactive functions were identifiable. For example, the search button represented by a magnifying glass icon was not recognized, or instead of clicking the "view" button, they clicked directly on the story to view its details. It was also difficult for some to view the target life stories. To address these issues with interactive operation, we made the following optimizations:

1. For icons representing "search," "add," and other operations, we used a combination of icons and text.
2. We increased the interaction area for viewing life stories so that users could click anywhere on the life story to view its details.
3. The system supported a search function for life stories, allowing users to search for target events based on keywords.

Bootstrap Operation

By observing the participants' actions, we identified opportunities for improvement in the guided processes. For example, participants exhibited prolonged hesitation when returning to the previous page from the current interface, and they overlooked the "one-click return to top" button on the page when scrolling to the bottom while viewing life stories. In response to the usability issues encountered in the guided operations, we implemented the following optimizations:

1. Besides the system menu navigation, we added breadcrumb navigation to each interface in the navigation settings.
2. When users scroll to the middle or bottom of the story-viewing interface, the "one-click return to top" button would be highlighted, prompting users to quickly return to the top of the page from this location.

Input Errors

Some participants made input errors when adding their life stories, such as ignoring the theme selection. Therefore, in all input operations of the system, input prompts, input warnings, and input error prompts were added. We marked the operation prompt as "required*" for all required fields, to indicate that they must be filled in.

Complex Operation

To prevent batch upload failures, the system offered format guidelines, sample files, and preupload format verification with informative error messages for any related issues. Furthermore, we improved password handling by eliminating the need for both uppercase letters and symbols, and we provided accessible guidance for password recovery and resetting.

In the study follow-up, participants completed the SUS, an industry-standard tool offering a holistic measure of usability [33]. As shown in Table 5, the first set of SUS scores was 70.00, 75.00, and 75.00 (mean 73.33), achieving a B– on the SUS grade and indicating higher usability than 65% of other websites. The second set of SUS scores was 82.50, 77.50, 80.00, and 82.50 (mean 80.63), achieving an A– on the SUS grade and indicating higher usability than 85% of other websites. These responses indicate that participants felt the tool was intuitive and valuable enough to use frequently.

Table . System Usability Scale (SUS) scores from 2 usability evaluations

Item	First usability evaluation, SUS score	Second usability evaluation, SUS score
1. I think that I would like to use this system frequently.	3.33	3.75
2. I found the system unnecessarily complex.	1.67	1.50
3. I thought the system was easy to use.	3.67	4.00
4. I think that I would need the support of a technical person to be able to use this system.	1.67	1.50
5. I found the various functions in this system were well integrated.	3.67	3.75
6. I thought there was too much inconsistency in this system.	1.67	1.50
7. I would imagine that most people would learn to use this system very quickly.	3.67	4.25
8. I found the system very cumbersome to use.	1.67	1.50
9. I felt very confident using the system.	4.00	4.00
10. I needed to learn a lot of things before I could get going with this system.	2.33	1.50

Discussion

Principal Findings

This study presents the design, development, and evaluation of the Story Mosaic system's prototypes, aiming to empower caregivers to harness valuable insights from older adults' life stories through a structured 4-phase HCD approach.

In phase 1 (initial design requirements), evidence revealed a substantial gap in digital tools that can organize and visually depict life narratives, despite the growing use of life stories in older adult care. This deficit could inadvertently intensify

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caregiver workloads, underscoring the urgent need for practical digital solutions.

In phase 2 (prototyping) and phase 3 (prototype refinement workshops), we progressed from low-fidelity and medium-fidelity to high-fidelity prototypes. The Story Mosaic system has evolved to include modules for life story management, life story visualization, memoir generation, and system settings. Our team's diversity, consisting of professional caregivers and user experience designers, was instrumental in refining a practical, user-centric system. Feedback in phase 3 accentuated caregivers' design preferences, highlighting larger fonts, clear color contrasts, ample-sized buttons, and uniform layouts. Participants were keenly engaged in discussing the visual organization of life stories. They offered essential suggestions for optimizing the visual organization of life stories, emphasizing hierarchy, simplification, and minimized complexity.

In phase 4 (usability testing), the results validated the system's efficacy in addressing challenges in manually organizing and retrieving life stories, marking it as a pertinent instrument for personalized care.

Although the feedback trended positively, we recognized specific design shortcomings, including interaction operation, bootstrap operation, input errors, and complex operation. Moving forward, it is imperative to address these challenges, particularly when crafting digital tools for the older caregiver demographic.

Limitations

Our study has noteworthy limitations. Primarily, although the Story Mosaic system is designed to organize and extract pertinent details from life stories in a text format, we discovered that audio recordings tend to be the preferred mode for capturing these narratives. Thus, a focal point of our subsequent work will involve efficient collection methods for life stories. We envision the future integration of the Story Mosaic system with digital mobile storytelling tools, mitigating the challenges caregivers currently encounter when manually inputting life narratives.

Furthermore, the application of emerging natural language processing techniques for organizing and extracting information from life story text remains in its infancy. Such techniques may occasionally generate unintended outcomes [34], which can inadvertently influence caregivers' perceptions of older adults. However, our confidence in the system's potential is bolstered by its application in the Tianyu Senior Living Service Nursing Home. We remain committed to refining the system based on real-world user feedback.

Lastly, the Story Mosaic system was trialed with a limited number of caregivers from a single nursing home. Its efficiency and effectiveness might differ with a broader set of caregivers who possesses varied experiences. Future endeavors will engage a wider and more diverse group of caregivers across multiple nursing facilities. Gleaning insights from this expanded user group will be instrumental in fortifying the system's algorithms and features, ensuring its reliability and versatility across varied contexts.

Conclusion

As the global aging population continues to grow, the importance of tools such as the Story Mosaic system becomes increasingly evident. This system, designed to empower caregivers, capitalizes on advanced digital technology, participatory design, and iterative feedback. Consequently, the Story Mosaic system emerges as a trailblazer in weaving personal narratives into contemporary caregiving. The Story Mosaic system streamlines information extraction, automates organization, and improves narrative management for caregivers to better understand and provide personalized care to older adults by organizing life stories intuitively, fostering ongoing enrichment through dynamic interactions. Given the wealth of memories and experiences that older adults contribute, it is crucial to keep their stories at the heart of caregiving innovations. Looking forward, expanding the scope of the Story Mosaic system to encompass informal caregivers and family members holds promise. This expansion ensures that the continued evolution of the Story Mosaic system remains as adaptable and empathetic as the caregivers who will come to depend on it.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
The mapping relationship between user requirements and prototype functions.
[DOCX File, 18 KB - aging_v6i1e50037_app1.docx]

Multimedia Appendix 2
Usability test plan.
[DOCX File, 19 KB - aging_v6i1e50037_app2.docx]

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Multimedia Appendix 3
Initial design requirements.
[DOCX File, 19 KB - aging_v6i1e50037_app3.docx]

Multimedia Appendix 4
Feedback analysis of the workshops.
[DOCX File, 23 KB - aging_v6i1e50037_app4.docx]

Multimedia Appendix 5
Problems encountered by participants during usability testing and our proposed fixes.
[DOCX File, 19 KB - aging_v6i1e50037_app5.docx]

Multimedia Appendix 6
The home page of the Story Mosaic system.
[PNG File, 692 KB - aging_v6i1e50037_app6.png]

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Abbreviations

HCD: human-centered design
SUS: System Usability Scale
UI: user interface

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Original Paper

A WeChat-based Intervention, Wellness Enhancement for Caregivers (WECARE), for Chinese American Dementia Caregivers: Pilot Assessment of Feasibility, Acceptability, and Preliminary Efficacy

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Abstract

Background: Chinese American family caregivers of persons with dementia experience high rates of psychosocial distress and adverse health outcomes. Due to their immigrant and minority status, they face substantial obstacles to care and support, including stigma and misperception of dementia, limited knowledge and use of welfare and services, and poor social support. Few interventions have been developed or tested for this vulnerable population.

Objective: This study aims to pilot-test the Wellness Enhancement for Caregivers (WECARE) intervention, a culturally tailored program delivered via WeChat, a social media app highly popular in the Chinese population. The 7-week WECARE was designed specifically for Chinese American dementia caregivers to improve their caregiving skills, reduce stress, and enhance psychosocial well-being. Feasibility, acceptability, and preliminary efficacy of the WECARE were assessed in this pilot.

Methods: A total of 24 Chinese American family caregivers of persons with dementia were recruited for a pre-post 1-arm trial of the WECARE. By subscribing to the WECARE official account, participants received interactive multimedia programs on their WeChat account multiple times a week for 7 weeks. A backend database automatically delivered program components and tracked user activities. Three online group meetings were organized to facilitate social networking. Participants completed a baseline and a follow-up survey. Feasibility was assessed by the follow-up rate and curriculum completion rate; acceptability was assessed by user satisfaction and perceived usefulness of the program; and efficacy was assessed with pre-post differences in 2 primary outcomes of depressive symptoms and caregiving burden.

Results: The intervention was completed by 23 participants with a retention rate of 96%. Most of them (n=20, 83%) were older than 50 years and the majority (n=17, 71%) were female. The backend database revealed that the mean curriculum completion rate was 67%. Participants also reported high rates of user satisfaction and perceived usefulness of the intervention and high ratings of weekly programs. The intervention led to significant improvement in participants' psychosocial health outcomes; their depressive symptoms reduced from 5.74 to 3.35 with an effect size of −0.89 and caregiving burden decreased from 25.78 to 21.96 with an effect size of −0.48.

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Conclusions: This pilot study suggests that WeChat-based WECARE intervention was feasible and acceptable; it also demonstrated initial efficacy in improving psychosocial well-being in Chinese American dementia caregivers. Further research with a control group is needed to assess its efficacy and effectiveness. The study highlights the need for more culturally appropriate mobile health interventions for Chinese American family caregivers of persons with dementia.

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KEYWORDS

Alzheimer disease; dementia; caregiver; Chinese American; mHealth intervention; social media; WeChat; mHealth; mobile health; informal care; caregiving; family care; spousal care; minority; ethnic; cultural; Chinese

Introduction

The American population is rapidly aging and becoming more diverse. The number of adults aged 65 years and older is projected to increase from 16.9% in 2020 to 22% in 2050, and the proportion of racial and ethnic minorities is expected to grow from 38.4% in 2020 to 50.3% in 2045 [1]. Currently, there are 6 million persons with dementia and 19 million family caregivers of persons with dementia in the United States. These numbers are expected to double by 2050 due to aging of the population [2].

Family caregivers of persons with dementia face a myriad of challenges related to the length, complexity, and intensity of caregiving. As a result, they have reported high levels of physical and emotional stress [3,4], depression and anxiety [5-7], poorer quality of sleep [8,9], and poorer quality of life [10-12]. Some develop chronic conditions including impaired immune functions, hypertension, and coronary health diseases [13]. Despite high rates of psychosocial distress in dementia caregivers, the existing interventions for racial or ethnic minority dementia caregivers are rather limited compared to those available to the White population [14].

Asian Americans are the fastest-growing racial group with a growth rate of 88% from 2000 to 2020 [15]. Chinese Americans make up 23% of the Asian American population with nearly 70% of them being foreign-born [16]. To date, the literature on Chinese American dementia caregivers is limited and mostly descriptive. Available literature suggests that Chinese American dementia caregivers face triple challenges. First, their perceptions of dementia, appraisals of stress, coping, and help-seeking behaviors are shaped by Chinese cultural norms of “filial piety” and “family harmony” [17]. Caring for older family members is not only a sign of love and pride but also a moral obligation [18,19]. Adherence to such cultural values helps caregivers find positive aspects of caregiving and also leads to psychosocial stress when perceived performance or outcomes could not match their filial expectations [20,21]. Under the “family harmony” cultural values, caregivers are more likely to internalize stress and less likely to seek external help. Second, as most Chinese American family caregivers are foreign-born, their immigration status and unfamiliarity with the health care and welfare systems render limited knowledge and use of formal services [18,22,23]. Third, compared to long-time residents, first-generation immigrants have smaller social networks, less buffer zones, and limited social support. Chinese American family caregivers with limited English proficiency face additional linguistic and cultural barriers and are more socially isolated [24,25].

Despite these unique challenges and barriers, few caregiving interventions are tailored to the needs of Chinese American dementia caregivers [26]. In a recent review of global literature on existing interventions for Chinese dementia caregivers, only 2 were designed specifically for Chinese Americans [27]. One was a home-based behavioral management program and the other was a DVD-based psychoeducation program [28,29]. Both pilot interventions, developed by Gallagher-Thompson and colleagues [28,29] in early 2000s, cannot meet the current needs of Chinese American dementia caregivers. A strong need exists for easy-to-access and easy-to-scale mobile health (mHealth) intervention for this vulnerable population. This need has become more salient since the COVID-19 pandemic when in-person contact was restricted and the need for remote services was increasing.

Racial or ethnic minority populations are more likely to be smartphone-dependent for internet access (without computer or other mobile devices) and rely on social media as a primary source of health information [30]. With a 90% penetration rate in Chinese-speaking Chinese Americans, WeChat is the most popular social media app in this population [31]. The key functions of WeChat include “moments” for sharing photos and stories with friends and receiving “likes” and feedback, texting, voice call, video call, private chat, group chat, location sharing, file transfer, and payment. These built-in functions allow intervention developers to focus on program content rather than technical aspects of development maintenance, thus saving time and cost. It also enables easy adoption and long-term use, especially in populations with lower levels of health literacy [32]. Literature has shown the feasibility, acceptability, efficacy, and even long-term effectiveness of WeChat-based interventions in Chinese populations [33-36]. Thus, a popular and versatile social media app like WeChat could serve as a viable delivery channel for mHealth interventions to reach Chinese American dementia caregivers.

To address the literature gaps and public health needs of culturally tailored intervention for Chinese American dementia caregivers, we developed a WeChat-based intervention called Wellness Enhancement for Caregivers (WECARE) to address their psychosocial distress [37]. This paper reports the results from piloting WECARE, including its feasibility, acceptability, and initial efficacy.

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Methods

Overview

This is a 1-arm, pre-post pilot trial. A total of 24 Chinese American dementia caregivers completed a baseline survey and received the 7-week WECARE intervention; their activities on WECARE were tracked by the backend database. Participants completed a follow-up survey 2 to 3 weeks after the intervention. Feasibility was assessed by the retention rate and curriculum completion rate. Acceptability was assessed by user satisfaction and perceived usefulness scale in the follow-up survey. Preliminary efficacy was evaluated by effect sizes of psychosocial health outcomes assessed at baseline and follow-up surveys.

Participation Eligibility

Participation eligibility included (1) self-identifying as Chinese or Chinese Americans and can read Chinese, (2) at least 21 years old, (3) currently living in the United States, (4) using WeChat, and (5) providing care at least 12 hours a week for a family member or loved one with Alzheimer disease, dementia, or other neurodegenerative conditions. Exclusion criteria included (1) being cognitively impaired or has serious mental health problems and (2) care partner has less than 6 months of life expectancy or in hospice care. When a potential participant contacted, our research staff conducted the screening. Those who met the participation criteria were invited to participate. A separate Zoom meeting was scheduled to obtain informed consent.

Recruitment

Participants were recruited from 2 sources. One was through our community partner, a community-based organization that serves Chinese Americans in the greater Washington, DC metropolitan. A recruitment flyer was distributed through social media and email newsletters. The other source was the University of California San Francisco Collaborative Approach for Asian Americans, Native Hawaiians, and Pacific Islanders Research Education registry [38]. Potentially interested participants contacted a designated phone number for more information and screening. Those who met the participation eligibility would learn more about the study and be invited to participate. A separate Zoom meeting would be scheduled for informed consent. Participants who completed the 7-week intervention plus the baseline and follow-up surveys would receive a gift card of US $100.

Ethics Approval

The study protocol was approved by the Institutional Review Board of George Mason University (IRB#1849712). All eligible participants had a one-on-one online meeting with a research staff who explained the study procedure and answered all questions. All participants provided verbal informed consent before they started the study.

WECARE Intervention

The 7-week WECARE intervention was developed to reduce caregiving burden, decrease distress, and enhance psychosocial well-being of Chinese American family caregivers of persons with dementia. Its protocol development and key features were detailed elsewhere [37]. By subscribing to the WECARE official account, participants would receive 6 multimedia articles on their WeChat accounts each week for the first 6 weeks and 4 in the final week for a total of 40 articles. Each week was focused on a theme. The seven major themes included (1) facts and knowledge of dementia and caregiving; (2) enhancement of caregiving skills; (3) effective communication with health care providers, care partners, and family members; (4) problem-solving skills for caregiving stress management; (5) stress reduction and depression prevention; (6) practice of self-care and health behaviors; and (7) social support and local resources. All multimedia articles required 3 to 6 minutes read time. Embedded in the articles were pictures, short video clips, and downloadable forms; all articles were culturally tailored for the target population and accompanied by audio recordings in case some older caregivers would prefer listening to audio recordings over reading texts. Three moderated group meetings were organized at weeks 3, 5, and 7 to facilitate social networking. Participants could also use the built-in functions in WeChat to initiate group chats, private chats, or video calls for additional networking and peer support. The official account of WECARE had a backend database that managed intervention delivery and tracked user activities [37].

Intervention Delivery and Data Collection Procedure

A total of 24 participants were enrolled in the study. After the informed consent, participants completed a web-based baseline survey and then subscribed to the WECARE official account via their WeChat app. WECARE automatically sent multimedia program components 4-6 times a week, at a prescheduled time Monday to Saturday, for 7 weeks. During the 7 weeks, participants' activities on WECARE, including whether a program component was opened, how many times it was opened, and for how long, were tracked by the backend database. Participants who had not opened WECARE for a week would receive a friendly reminder via WeChat. Those who were not responsive to our reminders for 3 consecutive weeks were considered dropped out. A follow-up survey was administered 2 to 3 weeks after the intervention completion. Surveys were in Chinese, the links to the online surveys were sent to participants in their WeChat accounts or emails, and they could open the link in any browser.

Measurement

Overview

Two sets of data were collected in the pilot study: (1) baseline and follow-up surveys administered online before and after the intervention (see Multimedia Appendix 1 for complete baseline and follow-up surveys) and (2) user activities tracked by the backend databases (see Multimedia Appendix 2 for screenshots of WECARE frontend and backend). These data were used to assess the feasibility, acceptability, and initial efficacy of the WECARE intervention. Table 1 illustrates the domains of measures and data sources.

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Table 1. Data sets and domains of measures.

	Baseline survey	Backend database	Follow-up survey
Demographics	✓		
Feasibility			
Retention rate	✓		✓
Curriculum completion rate		✓	
User activities: total and weekly read counts; total and weekly reading minutes		✓	
Acceptability			
User satisfaction			✓
Perceived usefulness of WECARE[a]			✓
Perceived usefulness of weekly program			✓
Efficacy			
Depressive symptoms	✓		✓
Caregiver's burden	✓		✓
Life satisfaction	✓		✓
Perceived social support	✓		✓

[a]WECARE: Wellness Enhancement for Caregivers.

Feasibility

Feasibility was measured by three indicators about how participants have completed the intervention trial: (1) retention rate was assessed by the percentage of participants who completed the follow-up survey. (2) Curriculum completion rate was assessed by the percentage of a participant's completion of all 40 articles of the WECARE curriculum. For example, if a participant completed 20 articles, his or her curriculum completion rate was 50%. If an article was opened, it was considered read or completed, which was tracked by the backend database. We calculated the mean value of all curriculum completion rates of all participants. (3) User activity was assessed by read counts and reading minutes tracked by the backend database. A "read count" was the number of times a participant had opened an article; "weekly read count" was the sum of read counts on a week's program; and "total read count" was the sum of all read counts. "Reading minutes" was the minutes a participant spent on an article; "weekly reading minutes" was the sum of reading minutes for a week's program; and "total reading minutes" was the sum of all reading minutes. These indicators of user activity reflected user engagement.

Acceptability

Acceptability was measured by three indicators, all were drawn from our previous digital health intervention evaluation [39]. The first two were about their experience of the overall WECARE program; the last one was about each of the weekly program. (1) User satisfaction was assessed with a 7-item user-satisfaction in the follow-up survey on how participants liked the WECARE program, for example, "it was easy to use," "it was fun to use," and "I would recommend it to my friends or family." Each question has response options from strongly disagree to strongly agree. The total score had a range of 5-35 with a higher score indicating a higher level of user satisfaction. The Cronbach α for the scale was .737. (2) Perceived usefulness of WECARE was assessed with a 5-item scale in the follow-up survey on how participants perceived the WECARE intervention had helped them, for example, "become a better caregiver" and "learn more about stress management and mental health." Each item has 5 response options from strongly disagree to strongly agree. The total score had a range of 5-25 with a higher score indicating a higher level of perceived usefulness The Cronbach α for the scale was .834. (3) Perceived usefulness of weekly program: The follow-up survey included questions asking participants how useful the weekly programs and moderated group meetings were. The response options ranged from not useful at all (1) to very useful (5). The mean score was calculated for each weekly program and the group meetings.

Intervention Efficacy

Intervention efficacy was measured by whether the 4 psychosocial health outcomes have meaningful effect sizes as a result of the intervention. The primary outcomes were depressive symptoms and caregiver's perceived burden, and the secondary outcomes were life satisfaction and perceived social support. (1) Depressive symptoms were assessed by the Center for Epidemiologic Depression Scale (CES-D) 10-item [40]. Participants were asked to rate whether they experienced symptoms associated with depression the past week (0=no and 1=yes) with a total score ranging from 0 to 10 with a clinical cutoff point of 4 as an indicator of elevated depressive symptoms [41]. The CES-D has been used to monitor and identify trajectories of depressive symptoms and has been validated with Chinese populations [42,43]. In this study, the Cronbach α for depressive symptoms at baseline was .809. (2) Caregiving burden was assessed by the Zarit Burden Interview (ZBI). The 12-item ZBI is one of the most reliable measures of caregiver burden in the literature. Each item has 5 response categories from "never" to "nearly always" with individual scores from 0 to 4 for each item [44]. Across the 12 items, the total ZBI score has a range of 0-48 with a cutoff point of 13 for

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community-dwelling caregivers [45]. ZBI has been validated in Chinese populations [46,47]. The Cronbach α for ZBI at baseline was .824. (3) Life satisfaction was assessed by the Satisfaction With Life Scale (SWLS) [48]. The SWLS contained 5 items and used a 7-point Likert-type scale from 1 (strongly disagree) to 7 (strongly agree). The SWLS assessed the individual's evaluation of his or her life by using the person's own criteria (eg, "In most ways, my life is close to my ideal"). It has been validated in Chinese older adults and Chinese dementia caregivers [49]. The Cronbach α for SWLS at baseline was .915. (4) Perceived social support was assessed by a 10-item scale adapted from Social Support Scale (SSC). Validated in the REACH II study, this scale used a 4-point Likert scale from 0=never, 1=occasionally, 2=sometime, and 3=always to assess how often caregivers receive social support from family or friends [50]. The total score of social support ranged from 0 to 30 with a higher score indicating a higher level of social support. The Cronbach α for SSC was .756.

Demographic Characteristics

Demographic characteristics of participants were assessed in the baseline survey. Caregivers' characteristics assessed included age, sex, marital status, education, employment status, years of living in the United States, English proficiency, health status, and having difficulty paying for the basics. Care-partner characteristics assessed included age, sex, relationship to caregiver, living arrangement, and functional status measured by activity of daily living (ADL) [51] and instrumental activities of daily living (IADL) [52].

Statistical Analysis

First, descriptive statistics were used to describe the sample characteristics, feasibility and user engagement, acceptability, and user satisfaction. Cronbach α was used to calculate internal consistency of the scales. Then, paired *t* test was used to compare pre-post differences in efficacy measures of psychosocial health outcome; the statistical significance was set as *P* value ≤.10. Finally, given the small sample size, we calculated effect sizes for the health outcomes [53]. The small sample size also limited the power for stratified analysis, so we did not conduct multivariate analysis to examine the independent relationship between the outcome variables and independent variables such as demographics and user engagement. All analyses were conducted using Stata (version 14; StataCorp).

Results

Participant Characteristics

As shown in Table 2, a total of 24 participants were enrolled in the study, 71% (n=17) were female, and 88% (n=21) were married or living with a partner. Their ages ranged from 38 to 85 years, with 83% (n=20) were older than 50 years of age, and the mean age was 60 (SD 11.99) years. All participants were born in China and had lived in the United States for 23 years on average (ranged 3 to 44 years). About 54% (n=13) had limited English proficiency, and 46% (n=11) had difficulty paying for the basics. Many caregivers (n=16, 67%) were taking care of their parents or parents in-law, 29% (n=7) were taking care of a spouse, and 1 was taking care of a friend. Care partners' ages ranged from 60 to 91 years with a mean of 81 years. Care partners' mean ADL score was 12 (ranged 0 to 27) and mean IADL score was 20 (ranged 7 to 24).

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Table 2. Demographics of caregivers and care partners.

Characteristics	Values
Caregiver (CG) (N=24)	
Age (years), mean (SD)	59.58 (11.99)
Female sex, n (%)	17 (71)
Married or living with a partner, n (%)	21 (88)
Years of living in the United States, mean (SD)	23.4 (10.5)
Limited English proficiency, n (%)	13 (54)
Speaks Chinese or Mandarin at home, n (%)	22 (92)
Has difficulty paying for basics, n (%)	11 (46)
Care partner (CP) (N=24)	
Age (years), mean (SD)	81.38 (8.65)
Female sex, n (%)	13 (54)
CP and CG live together, n (%)	16 (67)
Relationship to CG	
Spouse, n (%)	7 (29)
Child, n (%)	16 (67)
Other relative or friend, n (%)	1 (4)
ADL[a] score, mean (SD)	11.54 (9.47)
IADL[b] score, mean (SD)	20.08 (5.64)

[a]ADL: activity of daily living.

[b]IADL: instrumental activities of daily living.

Feasibility

Three indicators were used to assess feasibility: (1) follow-up rate, (2) curriculum completion rate, and (3) user activities. Out of 24 participants who were enrolled at baseline, a total of 23 completed the intervention and follow-up survey, with a retention rate of 96%. The backend database revealed that out of the 23 participants in the follow-up, the curriculum completion rate ranged from 8% to 100% with a mean value of 67%. Participants' total read counts of program components ranged from 5 to 154 with a mean of 54. Participants' total reading minutes ranged from 1 to 7196 minutes with a mean of 465 minutes (see Multimedia Appendix 3 for a table on each participant's read count, reading minutes, and completion rates). Out of 23 participants, 6 (27%) completed less than one-third of the WECARE program, 4 (17%) completed one-third to two-thirds of the program, and 13 (56%) completed more than two-third of the program, suggesting most participants had a high level of user engagement (see Multimedia Appendix 3).

Acceptability

Acceptability was assessed with four indicators, including (1) user satisfaction and (2) perceived usefulness of overall WECARE program, and (3) perceived usefulness and (4) user activity on the weekly program. Table 3 depicts user satisfaction of the WECARE program, and the mean total score was 32.52 out of the possible range of 5 to 35. Table 4 illustrates the perceived usefulness of the WECARE program, and the mean total score was 23.17 out of the possible range of 5 to 25. Table 5 details users' perceived usefulness of each week's program, and the score ranged from 4.35 to 4.65 out of a range of 1 to 5. Table 5 also lists the mean read counts and reading minutes by weekly program. The read counts for weekly program ranged from 6.5 to 10.6 times; the average total reading minutes of 23 participants for weekly program ranged from 40 to 132 minutes, with a big variation between weeks, see Multimedia Appendix 3 for mean weekly read counts and mean weekly reading minutes.

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Table 3. User satisfaction (N=23).

Item	Mean (SD)
1. It was easy to use	4.87 (0.34)
2. It was useful for me	4.70 (0.47)
3. The time needed for the program was appropriate	4.65 (0.49)
4. It was boring to use (reversed score)	4.48 (0.95)
5. It was fun to use	4.48 (0.67)
6. I would recommend it to others	4.70 (0.47)
7. Overall, I'm satisfied with the program	4.65 (0.49)
Total score	32.52 (2.54)

Table 4. Perceived usefulness (N=23).

Item	Mean (SD)
1. WECARE[a] has helped me understand Alzheimer disease better	4.74 (0.45)
2. WECARE has motivated me to become a better caregiver	4.78 (0.42)
3. WECARE has helped me become a better caregiver	4.65 (0.49)
4. WECARE has helped me better manage stress and improve my psychosocial well-being	4.48 (0.67)
5. WECARE has helped me to better prepare the upcoming journey of caregiving	4.52 (0.51)
Total score	23.17 (1.99)

[a]WECARE: Wellness Enhancement for Caregivers.

Table 5. Perceived usefulness and engagement by weekly program (N=23).

	Usefulness (range 1-5), mean (SD)	Read counts by week, mean (SD)	Reading minutes by week, mean (SD)
1. Week 1: Dementia facts and knowledge	4.52 (0.59)	10.6 (8.03)	132.1 (465.15)
2. Week 2: Caring for patients with dementia	4.65 (0.49)	8.3 (5.89)	113.5 (400.76)
3. Week 3: Effective communication	4.43 (0.66)	7.3 (6.46)	22.5 (31.38)
4. Week 4: Problem-solving in caregiving	4.35 (0.65)	7.1 (5.53)	40.4 (118.16)
5. Week 5: Stress reduction and depression prevention	4.35 (0.65)	8.7 (7.15)	49.3 (135.38)
6. Week 6: Becoming a healthy caregiver	4.39 (0.72)	6.5 (5.88)	40.3 (126.20)
7. Week 7: Course summary and local resources	4.57 (0.59)	8.2 (5.48)	66.5 (210.90)
8. Three group meetings online	4.39 (0.78)	—[a]	—

[a]Not available.

Preliminary Efficacy

The intervention efficacy was assessed with pre-post differences of 4 psychosocial outcomes: depressive symptoms, caregivers' burden, life satisfaction, and social support. Table 6 lists the results of the pre-post differences and effect sizes of these measures. Despite a small sample size, 3 out of 4 outcomes had statistically significant differences. Specifically, depressive symptoms decreased from 5.74 at baseline to 3.35 at follow-up; the effect size was −0.89. Caregiving burden decreased from 25.78 to 21.91, and the effect size was −0.48. Life satisfaction increased from 11.35 to 14.83, and the effect size was 0.55. However, there was no significant change in social support.

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Table 6. Caregivers' psychosocial well-being pre- and postintervention comparison (N=23).

Outcome	Baseline, mean (SD)	Follow-up, mean (SD)	Change, mean (95% CI)	Effect size	*P* value
Depressive symptoms (range 0-10)	5.74 (2.56)	3.35 (2.72)	−2.39 (−3.56 to −1.23)	−0.89 (−1.37 to −0.40)	<.001[a]
Caregiving burden (range 0-48)	25.78 (7.19)	21.91 (6.69)	−3.87 (−7.38 to −0.36)	−0.48 (−0.90 to −0.04)	.03[b]
Life satisfaction (range 0-30)	11.35 (6.66)	14.83 (7.11)	3.48 (0.73 to 6.23)	0.55 (0.10 to 0.98)	.02[c]
Social support (range 0-30)	14.78 (5.15)	13.96 (6.39)	−0.83 (−3.39 to 1.74)	−0.14 (−0.55 to 0.27)	.51

[a]*P*<.005.

[b]*P*<.05.

[c]*P*<.01.

Discussion

Principal Findings

Our data strongly suggest that WECARE was a feasible and acceptable intervention in Chinese American dementia caregivers; it also demonstrated preliminary efficacy in improving participants' psychosocial well-being. First, the intervention was feasible. A total of 24 participants enrolled in the study and 23 completed the intervention with a retention rate of 96%. The backend database that tracked user activities showed that the mean curriculum completion rate was 67%; in other words, on average participants had completed 67% of all 40 multimedia papers in the 7-week program. The mean read counts was 57, and the mean total reading minutes was 465 minutes, suggesting a good level of user engagement. Second, the intervention had good acceptability. The follow-up survey indicated that participants reported high levels of user satisfaction (32 out of 35), high levels of perceived usefulness of the intervention (23 out of 25), and high levels of perceived usefulness of weekly programs (4.3-4.5 out of 5). Third, the intervention demonstrated preliminary efficacy. The pre-post analysis of psychosocial outcomes revealed that, despite a small sample size, 3 out of 4 health outcomes, that is, depressive symptoms, caregivers' burden, and life satisfaction, had statistically significant changes after the intervention, and the effect sizes ranged from 0.55 to 0.89. However, perceived social support for caregiving remained unchanged.

Data Interpretation

To the best of our knowledge, the WECARE represents the first mHealth intervention for Chinese American dementia caregivers and one of the first for immigrant and racial minority dementia caregivers. The results from the trial were comparable to earlier in-person interventions for Chinese American dementia caregivers [28,29] and other in-person interventions for other racial or ethnic minority dementia caregivers [54,55]. It is worth noting that the demographic characteristics of the participants in this study were comparable to earlier community-based studies on Chinese American dementia caregivers [21,29]. As underserved Chinese American dementia caregivers have high rates of psychosocial distress due to high intensity, duration, and complexity of caregiving, the success of the WECARE suggests a promising solution to deliver effective mHealth interventions to address the needs of this vulnerable group.

The feasibility, acceptability, and initial efficacy demonstrated in this study could be attributed to the following strengths of the WECARE. First, the curriculum of the WECARE was developed based on evidence-based interventions [50,56]. Second, the culturally tailored program components were developed using community-engaged user-centered design principles [57]. We worked closely with our community partners through an iterative process of design, test, and revise. The resulting WECARE program consists of 40 interactive multimedia articles that reflect Chinese American family values and social norms of caregiving; it also includes relevant information and resources urgently needed by these linguistically isolated caregivers. Third, the WECARE was delivered via WeChat, a popular social media app used frequently by participants; it was easy to adopt for continuous use [37].

We noted that despite significant improvement in 3 out of the 4 health outcomes (depressive symptoms, caregiving burden, and life satisfaction), participants still reported high levels of depressive symptoms (mean 3.35) and caregiving burden (mean 21.91) at the follow-up, suggesting elevated psychosocial distress despite the intervention. More resources and continuous support are needed to meet the needs of this vulnerable population.

One of the 2 secondary outcomes for efficacy evaluation, perceived social support for caregiving, did not change significantly after the intervention. There were 2 possible explanations. One, it might be that the sample size was too small to detect the change. Two, the WECARE had minimal effect on improving perceived social support in caregiving, even though 3 moderated online meetings were organized and participants could use the built-in functions in WeChat like group chat and private chat to initiate additional contacts. Social support requires long-term trust building and tangible support to address daily needs. A 7-week online program with limited interactions might not be the most effective approach to improve social support.

An important feature of the WECARE was its backend database that automatically sent program components and tracked user activities, including whether and when an article was opened, how many times it was read, and for how long. User activity data such as curriculum completion rate, total read counts, and total reading minutes could be used as objective measure of user engagement. These data also complemented the self-report survey data on user satisfaction and perceived usefulness to provide a more comprehensive understanding of the program's

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feasibility and acceptability and inform further revision of the intervention. For example, high levels of user engagement tracked by the backend database and high levels of perceived usefulness reported in the follow-up survey for a particular week's program might indicate its good acceptability; otherwise, it might suggest the need for further revision.

Limitations

This pilot study has several limitations. First, there was no control group, so we could not affirm whether the changes in health outcomes observed in this pre-post trial were a result of the intervention only instead of testing effects or other factors. The main purpose of the pilot study was to assess the feasibility, acceptability, and preliminary efficacy of the WECARE; thus, future research would need to test its efficacy through a rigorous randomized controlled trial. Second, all acceptability measures and health outcome measures were based on self-report, there were potential self-report biases. Third, the follow-up survey was administered 2-3 weeks after the intervention, so we were not able to observe the long-term effect of WECARE. A future study with long-term follow-ups is needed. Fourth, though the intervention retention rate was 96% with only 1 participant dropped out, the curriculum completion rate was suboptimal with 67%, suggesting some participants stayed in the intervention but did not complete the entire curriculum. However, these numbers were higher or comparable to other mHealth interventions for caregivers or other WeChat-based interventions [35,36]. Fifth, our sample size was rather small, so we were not able to perform any stratified analysis or examine the independent relationships between the intervention effects and key covariates such as demographics and user engagement, for example, if the intervention was more effective in some demographic groups. A future study with a larger sample size would be able to address this limitation.

Conclusions

The WECARE pilot study demonstrated that this WeChat-based intervention demonstrated a high level of feasibility and acceptability; it also showed promising efficacy in improving psychosocial well-being in Chinese American family caregivers of persons with dementia. It reduced participants' depressive symptoms, decreased caregiving burden, and increased life satisfaction but had no effect on perceived social support for caregiving. Our next step is to conduct a randomized controlled trial with a larger sample and long-term follow-up to further test WECARE's efficacy and effectiveness. Based on the promising results from this study, we call for more research on culturally tailored and digitally delivered interventions for immigrant and racial or ethnic minority family caregivers of persons with dementia.

Acknowledgments

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Data Availability

This pilot study has a sample size of 24 only, and all participants were underserved Chinese American dementia caregivers. Even deidentified day poses potential risks of tracing back to some participants. Per our institutional review board requirement, we do not submit the data to a repository. Any fellow researcher interested in this data set may contact the corresponding author directly.

Conflicts of Interest

None declared.

Multimedia Appendix 1
WECARE project baseline and follow-up survey.
[PDF File (Adobe PDF File), 203 KB - aging_v6i1e42972_app1.pdf]

Multimedia Appendix 2
WECARE intervention frontend and backend screenshots.
[PDF File (Adobe PDF File), 439 KB - aging_v6i1e42972_app2.pdf]

Multimedia Appendix 3
User activities tracked by the backend database.
[DOCX File , 17 KB - aging_v6i1e42972_app3.docx]

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Abbreviations

ADL: activity of daily living
CES-D: Center for Epidemiologic Depression Scale
IADL: instrumental activities of daily living
mHealth: mobile health
SSC: Social Support Scale
SWLS: Satisfaction With Life Scale
WECARE: Wellness Enhancement for Caregivers
ZBI: Zarit Burden Interview

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Original Paper

Usability of a Community-Based Dementia Resource Website: Mixed Methods Study

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Abstract

Background: Many individuals living with dementia want to live in their own homes for as long as possible. To do so, they frequently require assistance with activities of daily living, which is often provided by friends and relatives acting as informal care partners. In Canada, many informal care partners are currently overworked and overwhelmed. Although community-based dementia-inclusive resources are available to support them, care partners often struggle to find them. Dementia613.ca was created to make the process of finding community dementia-inclusive resources simpler and more straightforward by bringing them together in one eHealth website.

Objective: The objective of our study was to determine if dementia613.ca is meeting the goal of connecting care partners and persons living with dementia to dementia-inclusive resources in their community.

Methods: A review and assessment of the website was conducted using 3 evaluation methods: web analytics, questionnaires, and task analysis. Google Analytics was used to collect data related to website use over a 9-month period. Data on site content and user characteristics were collected. Furthermore, 2 web-based self-administered questionnaires were developed: one intended for care partners and persons living with dementia, and the other intended for businesses and organizations interested in serving persons living with dementia. Both gathered data on user characteristics and included standard questions used in website evaluations. Responses were collected over a 6-month period. Scenarios, tasks, and questions were developed for the moderated, remote, and task-analysis sessions. These tasks and questions determined how effectively persons living with dementia and their care partners can use dementia613.ca. Overall, 5 sessions were held with persons experiencing moderate cognitive decline and with care partners of persons living with dementia.

Results: This evaluation showed that the idea behind dementia613.ca is strong and appeals to persons living with dementia, their care partners, and the businesses and organizations serving this market. Participants indicated that it is a useful community resource that meets a previously unfulfilled need in the area, and highlighted the benefits of bringing community resources together on 1 website. In our questionnaire, >60% (19/29, 66%) of people living with dementia and their care partners and 70% (7/10) of businesses and organizations agreed that the website made it easier to find relevant dementia-inclusive resources. There is room for improvement; participants indicated that the navigation and search features could be further developed.

Conclusions: We believe that the dementia613.ca model could be used to inspire and guide the creation of dementia resource websites in other regions in Ontario and beyond. The framework behind it is generalizable and could be replicated to help care partners and persons living with dementia find local resources more easily.

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KEYWORDS

dementia; caregivers; eHealth; community resources

Introduction

Background

In 2020, it was estimated that 597,300 Canadians were living with dementia [1]. As of 2021, there are an estimated 36,991,981 Canadians, meaning that approximately 1.6% of the population is living with dementia [1,2]. The number of Canadians with dementia will continue to rise, with 78,600 new cases being diagnosed every year in Canada [3]. By 2030, the number of people living with dementia in Canada is projected to be close to 1 million [1].

Most persons living with dementia want to live in their own homes for as long as possible, and approximately 61% of persons living with dementia in Canada are able to live at home [4,5]. Those living with dementia at home frequently require assistance with activities of daily living, which is often provided by their friends and relatives acting as informal care partners [1,6]. In Canada, informal care partners spend an average of 26 hours a week supporting their loved one with dementia [7]. Many care partners are currently either overworked or overwhelmed. The Change Foundation's 2019 Spotlight on Caregiving Report [8] presents current data on the well-being of care partners, and many are struggling with this role. The report noted that 75% of care partners wished that there was somewhere they could go for advice. In addition, >45% of care partners of older adults with dementia exhibit symptoms of emotional distress, which is almost double the number of care partners of older adults without dementia [7].

To maintain a good quality of life, persons living with dementia must engage in physically [9] and mentally stimulating activities [9] and avoid social isolation [10]. A lack of these enriching experiences can lead to boredom, which is linked to anxiety, apathy, wandering, and agitation [11], and contributes to many of the "challenging" or "difficult" behaviors associated with dementia [12]. It can also be challenging for already overwhelmed care partners to determine the best way to provide these activities. With the many community-based dementia-inclusive resources that are available, finding the appropriate ones can be difficult or even overwhelming for care partners who are already managing multiple tasks.

Currently, there are few community-based platforms with organized and reliable information regarding dementia-inclusive resources in an easy-to-search place [13]. Web-based resource directories could provide this service and transform how persons living with dementia and care partners access information regarding community resources. Although some studies have evaluated projects that aim to connect persons with dementia and care partners with information regarding community resources [14,15], there is a lack of web-based Canadian dementia-friendly resource directories.

The website, dementia613.ca, was created to make the process of finding community dementia–inclusive resources simpler and more straightforward by bringing them together in one website. The "613" in the name of the site refers to the area code for the greater Ottawa area. Before its launch, there was no similar directory in the Ottawa and Renfrew County areas. This website was created through a partnership between The Dementia Society of Ottawa and Renfrew County (DSORC) and the Bruyère Research Institute, supported by funding from the Centre for Aging and Brain Health Innovation Spark program. There were 3 distinct phases involved in the development of dementia613.ca: phase 1, obtaining end user feedback to guide website development; phase 2, low-fidelity prototyping and participatory evaluation and design development; and phase 3, launch and evaluation. This study focuses on the third phase.

The Creation of Dementia613.ca

Input from care partners and other stakeholder groups (eg, individuals with cognitive impairment, clinicians, and DSORC staff member) was sought during the entire design and development process. During the first phase of this project, held before the development process began, stakeholders were invited to participate in a web-based questionnaire to help inform website content and development. It was promoted to memory clinic physicians, as well as DSORC staff members, volunteers, and clients. The questionnaire included 17 questions, and responses were collected using a mixture of open-ended prompts and Likert-type scales. It gathered data on the participants' characteristics, the types of information they wanted the website to contain, and suggestions for ease of use. Responses informed and guided website development and were referred to throughout the development process. The complete questionnaire and all the collected responses are shown in Multimedia Appendix 1. The questionnaire was available in English and all 46 respondents who started the questionnaire completed it. Most respondents identified as woman (37/46, 80%) and were aged between 45 and 64 years (25/46, 54%). Half of the respondents (23/46, 50%) identified their role as being a care partner for individual living with memory difficulties or dementia.

On the basis of the feedback gathered from these stakeholders, a website format was selected; searching on the internet was the second most common method for finding dementia-related resources. In addition, the questionnaire results indicated that the website should be mobile friendly so that it could be easily accessed on multiple types of devices. Several stakeholders indicated that they preferred to directly call the DSORC to receive information regarding resources. However, this service is only available during business hours. Stakeholder feedback provided evidence that creating a searchable web-based directory to bring existing resources together would provide a valuable service.

The second phase of this project, the development and design of the website, involved 2 rounds of participatory design testing, using 2 distinct methods. In both rounds, wireframe mock-ups of the website were created, and the participants were asked to complete simple tasks and provide feedback. Between rounds,

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the website design was refined, and after the second round, the final design was reached.

The first round involved unmoderated, remote tree testing. It focused on testing the overall ease of use of the website's navigation structure and how easily the information could be found. The participants completed a series of simple tasks and questions to evaluate their ability to follow the proposed navigation logic of the website. A total of 83% (25/30) of individuals completed the study (of the participants who started the study). This round of testing was conducted for 2 weeks in May 2020. The results indicated that the overall navigation structure was efficient, and only minor adjustments were needed where participants struggled. The second round of testing involved live one-on-one task-analysis sessions. This study focused on testing the ease and efficiency of its use. During the sessions, participants were asked a series of questions and navigated the wireframe to find answers. In total, 5 individuals participated in this round of testing for over 1 week in June 2020. The results indicated that users had trouble finding and using the filter-and-sort functions of the website.

On the basis of the results of the second phase, the main features incorporated into dementia613.ca included web-based filtering tools for finding relevant resources from the database with a category search and map view, organizational listings that included specific environmental features to help users better plan a visit, information for businesses about training to become dementia-inclusive, and the ability for organizations and businesses to submit a request for their resources to be considered for inclusion on the website.

The dementia613.ca website is also fully bilingual, available in French and English, because approximately 16% of Ottawa's population and approximately 5% of Renfrew County's population is primarily French speaking [16].

Goal of This Study

With the launch of demetia613.ca, this project entered its third phase, which is the focus of this study. We wanted to determine if dementia613.ca meets its goal of connecting care partners and persons living with dementia to dementia-inclusive resources in their community. The specific objective of our analysis was to evaluate feedback obtained from website users on the utility of dementia613.ca. Thus, a review and assessment of the website is required. In this paper, we present the findings from the multiple evaluation methods used during this phase, including data from web analytics, a questionnaire, and task analysis.

This study focused on evaluating website user demographics, reasons for website use, website use characteristics, and suggestions for ongoing improvement of the website.

Methods

In phase 3 of this project, several methods were used to evaluate the launch of dementia613.ca. This included web analytics, self-administered questionnaires, and task analysis.

Web Analytics

Google Analytics was used to collect data related to website use [17]. We collected information regarding the number of individuals who used dementia613.ca; the number of sessions (ie, the period in which a user is actively engaged with the website) that have occurred since the launch of the website; as well as demographic information regarding the visitors, geographic locations of the visitors, the frequency of the sessions, when the sessions occurred, and the top site contents viewed. Google Analytics was used to collect information from January 2021 to October 2021.

With regards to web analytics, a "session" refers to the time period users are actively engaged with the website from when they click on the link to enter the site, to when they exit the site; it includes all and any form of interaction (eg, viewing the screen or scrolling through pages on the website) per session by a single user. A page view is the number of pages viewed by a user, and the repeated views of a single page are counted.

Self-administered Questionnaires

A total of 2 web-based, self-administered questionnaires were developed, one was intended for care partners and persons living with dementia and the other was intended for businesses and organizations interested in serving persons living with dementia. Both gathered data on users' characteristics and included standard questions used in website evaluations. The questionnaires were reviewed and piloted internally by hospital colleagues who did not have background information on the website evaluation project.

The version for individuals collected general demographic information regarding the individual, such as gender, age, and role (role options included individual living with memory difficulties or dementia, care partner to an individual living with memory difficulties or dementia, individual who works with persons living with dementia, health care professional or other). The version for organizations collected information such as organization type and number of employees. Both versions of the questionnaire assessed satisfaction with the design, content, and navigation of the website; frequency of use; users' perceived trust of the information; and future intentions. Responses to the questions were acquired using a Likert-type scale. In addition, there were open-ended questions for additional comments regarding the website, including reasons for use and features that users would like to see added. The complete questionnaires are shown in Multimedia Appendices 2 and 3. Both questionnaires were developed to align with others in the literature, including evaluation of eMentalHealth.ca by Jeong et al [18]. The questionnaire used in that study was based on the Commission of the European Communities' quality criteria for health-related websites [19]. In addition, questions were added to both versions of the questionnaire to ensure that they addressed the 7 categories in the User Experience Honeycomb developed by Peter Morville [20,21], that is, useful, valuable, usable, credible, accessible, desirable, and findable. The questionnaires were customized for this study, including questions regarding the specific and unique features of the design, such as map and search functionality. Finally, the questionnaire was developed to align with previous work done

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in phases 1 and 2, including questions that followed up on the topics of ease of use and relevancy of information.

Questionnaire responses were collected over a 6-month period, from January 2021 to July 2021. The questionnaire was made available through a link on dementia613.ca from March 2021 to July 2021 in both French and English languages. The questionnaire was promoted on posters displayed in a Geriatric Day Hospital and Memory Clinic and in the Dementia Society Monthly Newsletter. It was also sent to the Champlain Dementia Network, a collection of organizations that support persons living with dementia, to share among their networks. To encourage participation, a draw for gift cards was done over an 8-week period.

Task Analysis

The testing team developed a scenario, tasks, and questions for a moderated, remote, task analysis session to be held with persons experiencing moderate cognitive decline and the care partners of persons living with dementia. These tasks and questions aimed to determine how effectively persons living with dementia and their care partners could use dementia613.ca. The methods and sample sizes used to evaluate dementia613.ca aligned with the best practices in usability testing. To reach close to the user testing's maximum benefit:cost ratio, it is standard to perform the test with 5 users per round [22-24]. This allows for multiple rounds of testing on iterations of the application, allowing designers and developers to identify and fix problems and then test the redesigned versions [25].

Tasks were created to test the 2 main features of the website (ie, web-based filtering tools and organizational listings with detailed information). The tasks centered on participants finding resources using the categories in the directory and using the map view to find resources near them. Participants who were not located in the Ottawa or Renfrew County areas were asked to complete the tasks assuming that they lived in downtown Ottawa. The tasks were based on 7 categories in User Experience Honeycomb by Morville [20,21]. To drill deeper into issues of accessibility, questions were also developed to determine whether the site content aligned with Web Content Accessibility Guidelines 2.1 [26]. Questions were designed to reach at principle 1: perceivable and principle 3: understandability [26].

The tasks and questions were reviewed and piloted internally by DSORC colleagues who did not have background information on the website evaluation project. The participants were recruited from the DSORC mailing list. The list included persons experiencing cognitive decline, current and former care partners, and DSORC dementia care coaches.

Between March 3, 2021 and March 15, 2021, five task analysis sessions, with one participant per session, were conducted. They were conducted remotely over Zoom (Zoom Video Communications, Inc) and video recorded. The participants had varying levels of experience with dementia613.ca; 3 of them had never used the site and the remaining 2 had. Sessions took between 30 and 40 minutes to complete and started with the participant accessing dementia613.ca from their own laptop or tablet and screen sharing their view with the moderator. The moderator started the task analysis by describing the scenario to the participant and then asked them to complete a series of tasks and respond to the questions. Although there were multiple ways to complete the tasks, they did have the correct end state. As such, they were marked "complete" or "incomplete" in the analysis. The time taken by each participant to complete each task was recorded. The questions were open-ended, asking about participants' opinions and beliefs regarding the tasks and the experience of using dementia613.ca. The responses were analyzed thematically using categories from the User Experience Honeycomb of Morville [20,21].

In this scenario, participants were asked to imagine that their relatives had recently been diagnosed with dementia. The participant knew that over time, their relatives' care needs will increase, and so the participant wanted to learn more regarding local organizations and businesses that were dementia inclusive. They planned to do this using the website dementia613.ca. For the first task, participants started on the dementia613.ca home page and were asked to find information regarding courses or programs related to the arts and crafts. The correct end-state for this task was navigating to the categories *Fitness, Exercise & Learning*. During the second task, the participants were asked to determine which listings were close to their location. To do this, they had to select *See Map View* and navigate the provided map. In the third task, the participants were asked to obtain more detailed information on an individual resource. To do this, they had to click on an individual resource, which took them to the resource's full listing page. For the final task, participants were asked to find information regarding the organizations that run dementia613.ca. The correct end-state for this task was to find and select the *About* link. After completing the tasks, the participants were asked 4 follow-up questions to examine their overall impressions.

Ethics Approval

The ethics application was submitted to and approved by The Bruyère Research Institute Ethics Board (# M16-19-042).

Results

Web Analytics

Between January and October 2021, Google Analytics reported 3924 sessions and 11,127 page views of dementia613.ca. The average length of each session was 1:40 minutes, and during that time, each user viewed an average of 2.84 pages. The list of *Resource Categories* and the French version of the site were among the top 5 viewed site features. Tables 1 and 2 and Textbox 1 summarize the web analytics collected via Google Analytics.

The vast majority of users (3143/3453, 91.02%) were new to dementia613.ca. More than two-thirds (2326/3453, 67.36%) were Canadian, and more than one-third (1212/3453, 35.1%) were located in Ottawa, Ontario. Approximately 10% (258/3453, 7.47%) were located near Ottawa, such as Gatineau, Quebec, and Ashburn, Ontario. This means that <45% (1470/3453, 42.57%) of users were in relevant locations.

Most users (62/74, 84%) accessed the website using desktop computers. In most sessions, users (2402/3924, 61.21%) reached the website directly. In other sessions, users (736/3924, 18.76%)

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reached the website with a referral, of which dementiahelp.ca, facebook.com, and bruyere.org were the 3 most common websites.

Table 1. General Google Analytics data collected from dementia613.ca from January to October 2021.

Analytic	Data collected from dementia613.ca
Timeframe	January 21, 2021 to October 28, 2021
Sessions	3924
Page views	11,127
Pages/session	2.84
Average session duration	1:51 minutes
New visitors, n (%)	3143 (91.02)
Returning visitors, n (%)	310 (9.86)

Table 2. Google Analytics data on device type used to access website and website traffic collected from dementia613.ca from January to October 2021.

	Values, n (%)
Device of access to website (n=74)	
Desktop	62 (84)
Mobile	11 (15)
Tablet	1 (1)
Website traffic (n=3924)	
Direct	2402 (61.21)
Referral	736 (18.76)
Organic search	556 (14.17)
Social	228 (5.18)

Textbox 1. Google Analytics data on top website content viewed collected from dementia613.ca from January to October 2021.

Top website content viewed

- /resources/
- /category/fitness-exercise-learning/
- /category/health-well–being-caregiver-services/
- /fr/acceuil/
- /category/food-beverage/
- /add-resource/
- /category/safety-monitoring/
- /category/housing-transportation/

Self-administered Questionnaires

Overview

For the English and French versions of the website, 64% (39/61) of the respondents completed the questionnaire (out of the respondents who started it). Of these completed responses, 96% (28/29) of the responses were to the *Care Partner and Persons Living with Dementia Questionnaire* in English, 3% (1/29) to the *Care Partner and Persons Living With Dementia Questionnaire* in French, and 10 responses to the *Business and Organization Questionnaire* in English.

Most *Care Partner and Persons Living with Dementia* respondents (26/29, 90%) identified as woman and were aged >65 years (15/29, 52%). The majority of respondents (19/29, 66%) identified their role as being a care partner to an individual living with memory difficulties or dementia. Most *Business and Organization* respondents (6/10, 60%) worked for a health care organization.

Most *Care Partners and Persons Living With Dementia* respondents had been to dementia613.ca >5 times. The largest segment of *Business and Organization* respondents had used dementia613.ca between 2 and 4 times. Table 3 presents the results of the dementia613.ca questionnaires.

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Table 3. Descriptive characteristics and frequency distribution for users of dementia613.ca, care partners and person living with dementia, and businesses and organizations.

Characteristics	Care partner and person living with dementia questionnaire (N=29), n (%)	Business and organization questionnaire (N-10, n (%)
Gender		
Man	3 (10)	N/A[a]
Woman	26 (90)	N/A
Age (years)		
18-35	3 (10)	N/A
36-45	3 (10)	N/A
46-55	0 (0)	N/A
56-64	8 (28)	N/A
>65	15 (52)	N/A
Role		
Individual living with memory difficulties or dementia	0 (0)	N/A
Care partner to an individual with memory difficulties or dementia	19 (66)	N/A
Individual who works with people living with dementia	5 (17)	N/A
Health care professional	3 (10.3)	N/A
DSORC[b] volunteer	2 (7)	N/A
Organization type		
Government	N/A	1 (10)
Health care	N/A	6 (60)
Other	N/A	3 (30)
Approximate number of employees		
<20	N/A	4 (40)
Between 20 and 99	N/A	3 (30)
Between 100 and 499	N/A	1 (10)
>500	N/A	2 (20)
Frequency of use		
Once	2 (7)	1 (10)
<5 times	8 (28)	4 (40)
Between 5 and 9 times	10 (34)	3 (30)
>10 times	9 (31)	2 (20)

[a]N/A: not applicable

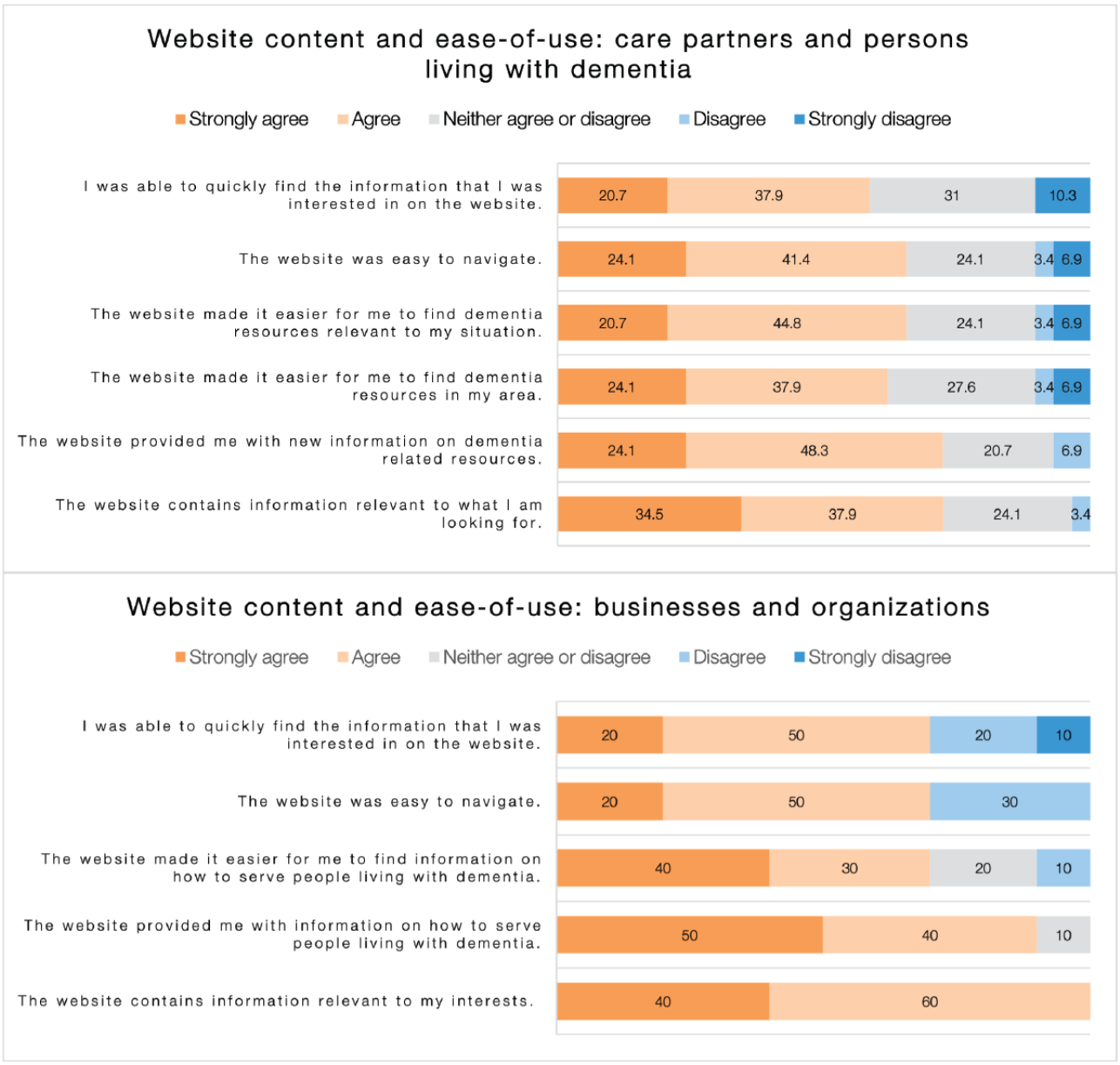
[b]DSORC: Dementia Society of Ottawa and Renfrew County

Content and Ease of Use

More than 70% (21/29, 72%) of the *care partners and Persons Living* respondents and 100% (10/10) of *Businesses and Organization* respondents strongly agreed or agreed that the website contained relevant information. Figure 1 presents the respondents' ratings of the design, content, and ease of use of dementia613.ca.

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Figure 1. Users' ratings of website content and ease of use of the website dementia613.ca, care partners and persons living with dementia (N=29), and businesses and organizations (N=10).



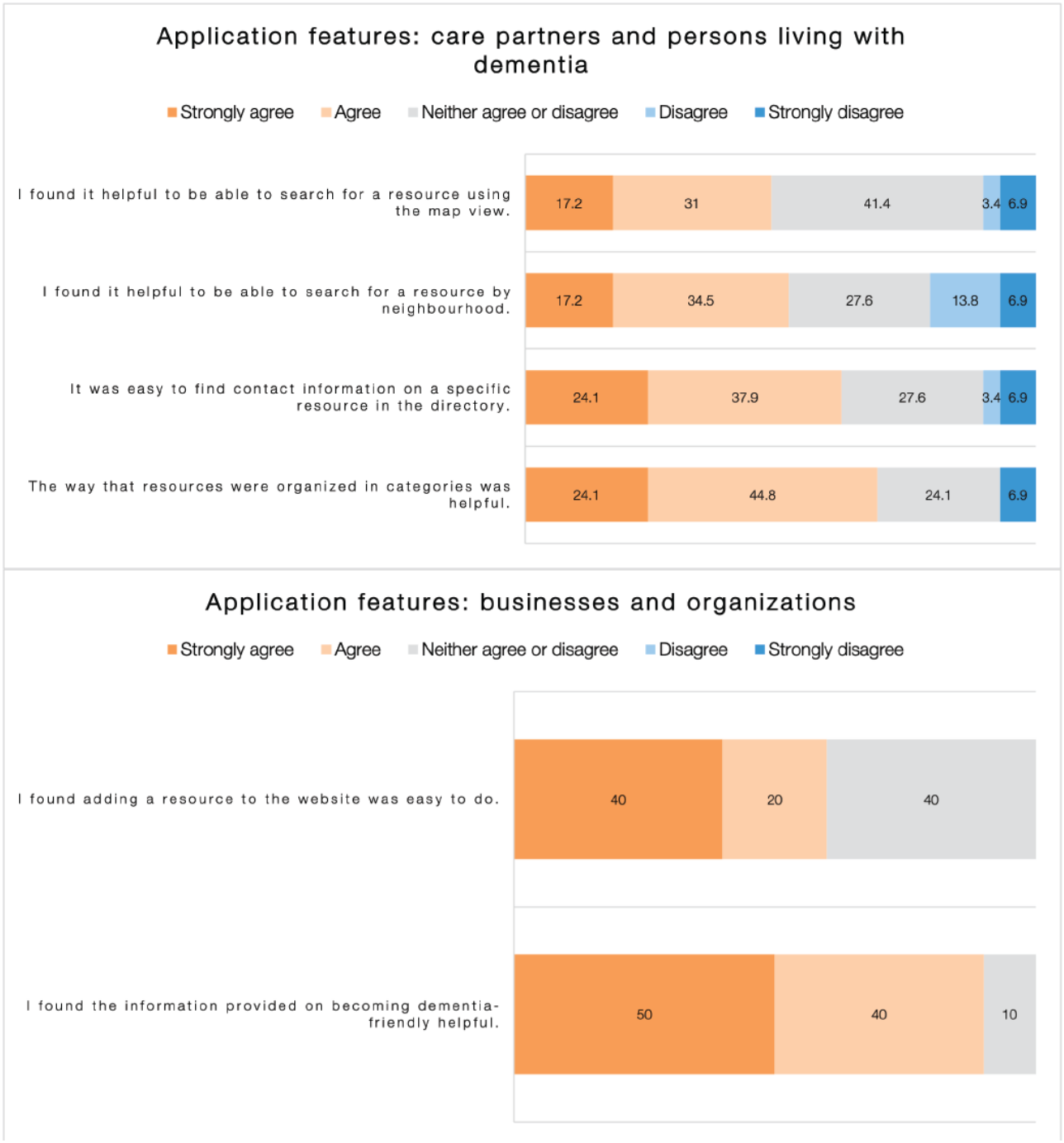
Usefulness of Features

Most of the questionnaire respondents found features of dementia613.ca helpful (Figure 2). Approximately 70% (20/29, 69%) of *Care Partners and Persons Living With Dementia* respondents strongly agreed or agreed that the way the resources were organized in categories was helpful, and 90% (9/10) of *Businesses and Organizations* respondents strongly agreed or agreed that the information provided on becoming dementia friendly was helpful.

However, some features of dementia613.ca were not viewed favorably. Only 48% (14/29) of *Care Partners and Person Living with Dementia* respondents strongly agreed or agreed that it was helpful to search for resources using the map view.

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Figure 2. Users' ratings of specific features of the website dementia613.ca, care partners and persons living with dementia (N=29), and businesses and organizations (N=10).



User Satisfaction With Website

As shown in Figure 3, the overall user satisfaction with dementia613.ca was very high. More than 90% (27/29, 93%) of *Care Partners and Persons Living With Dementia* respondents and 100% (10/10) of *Businesses and Organizations* respondents were very satisfied or somewhat satisfied with the website. In addition, users came away with an overall positive impression of dementia613.ca. More than 80% (24/29, 83%) of *Care Partners and Persons Living With Dementia* respondents and 100% (10/10) of *Businesses and Organizations* respondents plan to visit dementia613.ca again (Figure 4).

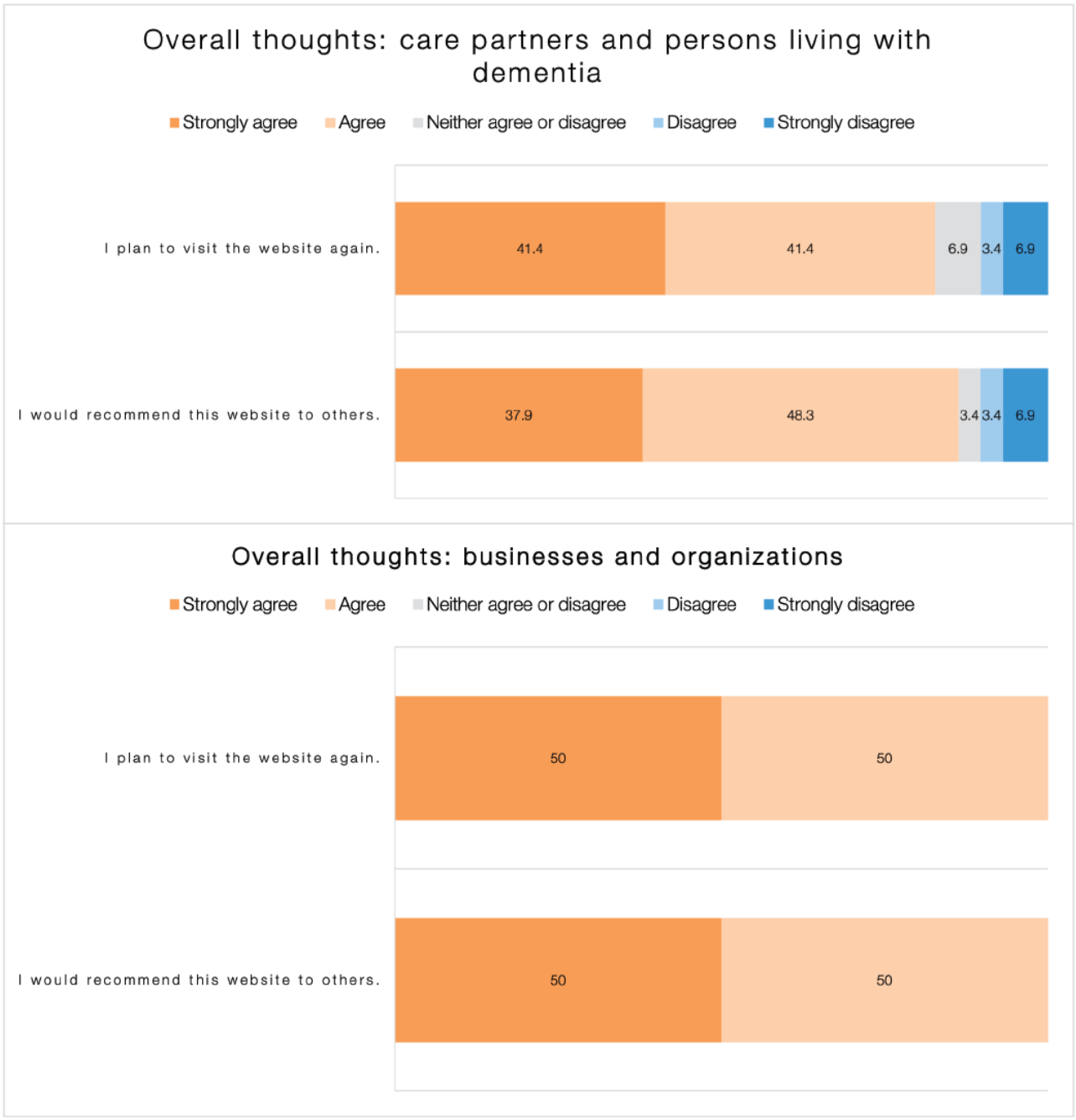
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Figure 3. Overall satisfaction with the website dementia613.ca, care partners and person living with dementia (N=29), and businesses and organizations (N=10).



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Figure 4. Users' overall thoughts for the website dementia613.ca, care partners and persons living with dementia (N=29), and businesses and organizations (N=10).



Open-ended Responses

The respondents were asked to answer specific questions at the end of the questionnaire. Descriptive coding, a type of first-cycle qualitative coding, was used to analyze the comments. In "descriptive coding," codes are used to summarize the main topic of a passage of qualitative data [27]. This method allows responses to be grouped by theme. All the comments can be found in Multimedia Appendix 4.

Most comments were positive, stating that the website was a good resource for finding local resources, and that there was no equivalent local resource. Examples of the positive comments for each identified theme are listed in Table 4.

Negative comments were helpful because they often either critiqued specific features or offered advice on how to improve websites. Several comments noted that the lack of a search function made it challenging to find specific resources. Other comments noted that although the categories used to organize resources were helpful, the resources in each category appeared disorganized. Representative negative comments for each theme are presented in Table 5.

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Table 4. Open-ended responses from respondents—positive and neutral comments.

Question and theme	Questionnaire type	Comment
If you only used the website once, why did you NOT return?		
Newly launched resource	• Business and organization • Care partner and person living with dementia	• "Will use more in future. Just brought to my attention." • "I did not know it existed until I saw this post."
What is the reason or reason(s) you are using the website?		
Supporting friends and family	• Care partner and person living with dementia • Care partner and person living with dementia	• "As a resource for education and activities for my husband." • "Looking for educational resources so I can better help my friend with dementia"
Supporting clients	• Care partner and person living with dementia • Business and organization	• "To learn more about dementia friendly resources in our community that I can recommend to caregivers and people dealing with dementia." • "To send information/upcoming relevant events to members."
Supporting care partners	• Care partner and person living with dementia • Care partner and person living with dementia	• "Find resources, support groups, activities!" • "Help!"
Supporting business development	• Business and organization	• "For learning purposes and to find resources on becoming more Dementia friendly."
Education on dementia	• Care partner and person living with dementia • Care partner and person living with dementia	• "Good information helps to understand illness." • "Educate myself"
Convince	• Care partner and person living with dementia	• "All available resources are together."
Do you have any other thoughts you would like to share about the website?		
Website is helpful	• Care partner and person living with dementia • Care partner and person living with dementia	• "This website has great potential." • "It has been very helpful for me. I have learned how to cope better. THANK YOU!"

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Table 5. Open-ended comments from respondents—negatives and suggestions for improvement.

Question and theme	Questionnaire type	Comment
If you only used the website once, why did you NOT return?		
Hard to navigate	• Care partner and person living with dementia	• "No alphabetical index. No search engine. Topic categories too broad."
Location	• Care partner and person living with dementia • Care partner and person living with dementia	• "Because I found it was more suited if you lived in Ottawa." • "I need a list of Memory Care facilities in [my neighborhood] but your website has none listed."
Are there any other features you would like us to add?		
Navigation features	• Care partner and person living with dementia • Care partner and person living with dementia	• "Search engine and index." • "Search engine...and a comprehensive clickable index"
Listing order	• Care partner and person living with dementia • Business and organization	• "List things alphabetically in categories. It's very scattered." • "Alphabetical order would be helpful—or maybe list the agencies that are dementia friendly first, then the others? There seems to be absolutely no logical order."
Categories	• Care partner and person living with dementia • Care partner and person living with dementia	• "Make the categories less broad—under Food & Beverage, I found 211 Ontario." • "Separate out listings by region."
Cost information	• Care partner and person living with dementia	• "If there is a cost involved for example; fitness the cost should be stipulated."
Do you have any other thoughts you would like to share about the website?		
Hard to navigate	• Care partner and person living with dementia • Business and organization	• "Search filter feature per category seems unreliable...hard to navigate to find what you're looking for." • "The search features are not working properly."

Task Analysis

We conducted 5 task analysis sessions. Three participants had been care partners for a family member with dementia. Two participants had mild cognitive impairments. Furthermore, 2 of the participants were in Ottawa and the other 3 were in rural communities. Two participants self-identified as older adults (aged ≥65 years). Further details can be found in Table 6.

During the task analysis sessions, the participants were given a scenario and asked to complete 4 related tasks. The amount of time it took for users to finish the tasks was recorded, and the average successful completion time for each task is presented in Table 7. The reasons for unsuccessful task completion were as follows: in task 1 a participant did not know what category to select and gave up on the task; in task 2, a participant selected individual listings one-by-one and looked at their addresses on the full resource listing page; in task 4, a total of 2 users selected *Contact Us* instead of the correct choice *About*.

The data collected during the task analysis sessions were synthesized into takeaways based on 7 categories from User Experience Honeycomb of Morville [20,21]. Overall, most of the feedback participants provided during these sessions was positive.

Fundamentally, participants found the idea behind dementia613.ca to be good and they found the information provided to be helpful. Participants thought that the information was reliable, in large part, because of the positive reputation of the DSORC. The participants also found dementia613.ca to be accessible. The positive takeaways are listed in Table 8. However, participants also identified several areas in which dementia613.ca could be improved. The area that needs the most improvement is the overall website navigation. Users found that the organization of the website content could be improved and that specific listings were difficult to find. In addition, some users would have liked to see that business and organization listings contained more specific information. Negative and neutral takeaways are presented in Table 9.

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Table 6. Demographic information on task analysis participants.

Code	Previously used dementia613.ca	Device	Location	Age (years)	Relation to research
P1	Yes	Desktop	Ottawa, Ontario	<65	Care partner
P2	Yes	Tablet	Renfrew, Ontario	≥65	Care partner
P3	No	Tablet	Ottawa, Ontario	≥65	Mild cognitive impairment
P4	No	Desktop	South Hampton, Ontario	<65	Mild cognitive impairment
P5	No	Desktop	South Hampton, Ontario	<65	Care partner

Table 7. Success rate and average completion time for tasks given to participants during task analysis sessions (n=5).

Task	Question asked	Success rate, n (%)	Average time for successful completion (min:sec)
Task 1: finding information about courses or programs related to arts and crafts	Where would you expect to find information about courses or programs related to arts and crafts?	4 (80)	1:31
Task 2: finding which listings are close to your location	How would you go about finding which listings are close to your location?	4 (80)	1:27
Task 3: finding detailed information about a resource	Once you have found a resource that interests you, how might you find out more detailed information about it?	5 (100)	0:24
Task 4: finding information about the organizations(s) that run dementia613.ca	Where would you expect to find information about the organizations(s) that run this website?	3 (60)	1:11

Table 8. Takeaways from task analysis session data synthesized using categories from Peter Morville's User Experience Honeycomb—positive.

Category and key takeaways	Comments
Useful	
The resources provided are relevant to user needs.	"These listings look like places I would go."
The full listing pages of resources provide important and relevant information.	"This page provides a good overview of information (contact, blurb, etc.)."
Valuable	
Provides enough information for a user to know if a resource is relevant.	"Gives the information you need to make a decision."
Provides users with multiple ways to connect organizations to find more information.	"Gives enough information to know if organization is of interest and to contact them to learn more."
Credible	
Strong positive reputation of DSORC[a].	"I assume that I can trust it because it was put there by The Dementia Society."
Can directly contact organizations from listings.	"I see this information as reliable. I like that there are multiple methods to contact the organization."
Accessible	
Content is legible.	"Content is easy to see; bold items, font size, it's easy to read, and gives the right information."
Content is easy to understand.	"Wording was good, and language was understandable."
Desirable	
Concept behind dementia613.ca initiative is good.	"Overall, this could be a good resource."
Findable	
Information on resource listings is well organized.	"The listing is good and makes finding things easier."

[a]DSORC: Dementia Society of Ottawa and Renfrew County.

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Table 9. Takeaways from task analysis session data synthesized using categories from Peter Morville's User Experience Honeycomb—negative or neutral.

Category	Key takeaways	Comment
Useful	The full listing pages of resources does not provide enough information.	"I would want more detailed and specific information about this resource."
Valuable	Some resource descriptions are not specific enough.	"Some of the descriptions for the resources are not helpful. They should say exactly what the resources are."
Usable	Overall navigation needs improvement.	"Navigation should be made easier, without so much clicking."
Accessible	Content legibility could be improved.	"Font size needs work in places."
Findable	Content is poorly organized.	"Content is useful, but could be organized better."

Discussion

Principal Findings

Our evaluation showed that the idea behind dementia613.ca is strong and appeals to persons living with dementia and the stakeholders who serve them. Our evaluation found that although most users were new to the site, they were interested in using it again. Users saw the information on dementia613.ca as credible and felt that it provided them with relevant resources and information. Overall, the website reflects the basic ingredients needed to support a good user experience, aligning with Morville's principles of "valuable" and "useful" [20,21].

The evaluation also identified some areas where dementia613.ca could be improved, namely navigation and search, and clarity around the website's purpose. The needed changes will align the website with the principles of "findable" and "usable" by Morville [20,21]. We are hopeful that with these refinements, and as dementia613.ca becomes a more established and well-known resource, the site will better serve new and existing users.

Relevance to Community

Participants shared that dementia613.ca is a useful community resource. The development process we went through to create the website involved consulting relevant members of the community (persons living with dementia, care partners, businesses, and organizations). The website was shaped by an image of their needs and desires. Our success can be seen by users citing reasons that aligned with the motivation behind its creation, such as supporting the community and providing convenient resources when asked why they were using the website. Furthermore, in task analysis sessions, several participants indicated that they saw the website as desirable, as exemplified by the comment "Overall, this could be a good resource." This shows dementia613.ca's alignment with the principle of "valuable" by Morville [20,21] by demonstrating that the website provides users with important information. Dementia613.ca is a useful resource that meets previously unmet local needs.

More specifically, dementia613.ca provided relevant resources and information to persons living with dementia and their care partners and to businesses and organizations that want to be dementia-inclusive. When asked, >60% (19/29, 66%) of persons living with dementia and their care partners and 70% (7/10) of businesses and organizations agreed that the website made it easier to find relevant dementia-inclusive resources. In open-ended responses, one participant said, "It has been very helpful for me. I have learned how to cope better. THANK YOU*!*" This shows dementia613.ca's alignment with Morville's principle of "useful" [20,21], demonstrating that the website serves a purpose for our stakeholders. All of this illustrates that dementia613.ca is meeting local needs by providing relevant resources and information.

Dementia613.ca is aimed at care partners, who can be of a wide variety of ages, and persons with mild cognitive impairment. It was designed to meet the needs of these users; however, we recognize that it may also be used by people outside of those demographics. To ensure that the site would be as wide as possible, we were guided by Peter Morville's User Experience Honeycomb framework [20,21] and usability design best practices promoted by the Nielsen-Norman Group [22,23]. We also referred to Web Content Accessibility Guidelines 2.1 [26] to develop the site. Because of the principles we followed during its creation, we feel that dementia613.ca supports accessibility and the inclusion of a variety of stakeholders, recognizing that there is always room for improvement as we learn about the site in use over time.

Areas for Improvement and Future Research

Participants provided constructive feedback that was used to produce further iterations of the design. Areas for improvement include the following:

- Refining how a website is organized as many users found it challenging to navigate. The most suggested improvement was organizing the service listings in an alphabetical order. Another suggestion is to narrow or further specify the categories provided or allow users to filter results within a category. The literature in this area aligns with these recommendations, finding that users appreciate well-designed tools to narrow search results [28]. In the next round of design and development for dementia613.ca, we will work with stakeholders to develop a more usable navigation structure. This will increase the website's alignment with Morville's principles of "findable" and "usable" [20,21] by improving website navigation and making it easier for users to find information they seek.
- Adding a search feature, as many users noted that the map view was not sufficient for finding specific resources. Research in this area has found that website users are goal-driven and look only for the one thing they have in

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mind and often rely on searching in pursuit of their goal [29]. This supports the findings of our task analysis and strengthens the case of adding a search feature. There are established best practices for developing strong on-site search engines that enable good user experience [30]. However, best practices also caution against prioritizing searches at the expense of navigation [31]. Thus, in the next round of design and development for dementia613.ca, we will work to develop both search and navigation and ensure alignment between these tools. This will further increase the website's alignment with the principles of "findable" and "usable" [20,21].

- It is more explicit about who the website is for and what information it provides. Some users seemed unclear about the purpose of the website. In addition, a surprisingly high number of users from outside Ottawa have accessed this website. We are not sure why this occurred but it could be due to the site appearing in people's search queries, word of mouth from people receiving the recruitment notice and passing the information onto community members outside the region, or other potential factors. This may mean that we need to clarify the purpose of the website and make it more obvious that the resources are for Ottawa and the surrounding areas.

The Google Analytics data we collected indicate that users, on average, did not spend a long time on individual pages of dementia613.ca. This could mean that individuals were looking for a specific resource or answering a specific question and were able to find the page they needed quickly. This interpretation aligns with the results from our questionnaire; approximately 60% (17/29, 59%) of the *care partners and Persons Living With Dementia* respondents strongly agreed or agreed that they were quickly able to find the information they were interested in on the website. However, short site visits could also indicate that individuals visiting the site only quickly browsed the resources before leaving, perhaps not finding useful information. Further studies are needed to understand this phenomenon. In addition, only 9% (310/3453, 8.98%) of the website visitors returned. This may be due to the timing of Google Analytics data collection, which was shortly after the launch of the website. This did not give the site much time to build a user base. Taken together, Google Analytics data brings up good points for future work to evaluate the website, which should aim to include a sample of previous website users. It should ask questions about their perceptions of the site's utility, their primary uses for the site (using the website to find one specific resource vs using it to search for multiple different types of resources available in the area), and their reasons for returning to the site.

Relevance to the Development of eHealth Resources

Not all web-based health resources are created equally, and the best attempts at providing useful information can fall short. To address this, there is a growing body of research on the specific information needs of internet users and their requirements for web-based health information [32]. There is also more specialized research on the barriers faced by users from marginalized populations [33,34]. A common thread among these studies is the importance of incorporating user feedback, priorities, and concerns into the design of web-based health resources. This information can be gathered by conducting evaluations with users, making it a critical step in creating useful web-based health resources.

Currently, there is a limited amount of literature evaluating public-facing health resource websites. Much of the existing research focuses on e-mental health resources [18,35-38]. These studies have found that the general public is interested in accessing quality-health resources on the web [35,39]. This aligns with our results and demonstrates the need for an increased number of reliable, public-facing health resource websites.

Other studies have found that there is a specific interest in accessing quality health resources on the web among traditionally underserved populations, including people in rural communities [40], persons with mild-intellectual disability [38,41], and adolescents and their parents [33,42]. Currently, there are scant quality web-based health resources for care partners of persons living with dementia; however, they are an overworked and overwhelmed group [7,8] that would greatly benefit from the support that this type of resource can provide. Persons living with dementia are a similarly underserved population. Dementia613.ca aims to serve both types of demographics.

Within the context of design, there is growing literature on best practices for evaluating websites in the health sector. Currently, work in this area often focuses on the websites of health institutions, such as hospitals and health departments [43-46]. This literature emphasizes the importance of working with communities and using a mixed methods approach to ensure that feedback is well-rounded and relevant [43,45]. Although dementia613.ca is a website for community resources, not for a health institution, we feel that the broader principles advanced in this body of research are aligned with these principles and approaches.

Limitations

This study has several limitations. First, web analytics were only collected for 9 months, which is a shorter time frame than has been used in comparable research projects where the analytics have captured 12 months of data [18]. Furthermore, during the initial weeks in which web analytics were collected, final changes were made to the website design. In addition, during the data collection period, dementia613.ca was a newly launched website without an established user base. Thus, there is limited traffic to capture in the web analytics data. In future research, analytics should be conducted over a longer period. In addition, in any future evaluation, dementia613.ca will be more established, presumably with a larger flow of traffic.

The number of responses to the web-based questionnaires was small, leading to a limited sample size, especially for the *Businesses and Organizations* group. There were only 10 responses from this group, representing the health care and government sectors. This limited sample size could be viewed as homogenous. Future studies could benefit from purposive sampling to engage broader sector representation (ie, government organizations, community organizations, and private

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industry) to determine how well the site serves different needs and expectations among service providers.

The *Care Partners and Persons Living With Dementia* respondents skewed toward older adults and woman. Dementia613.ca was not specifically created for this demographic, suggesting that its responses may not be representative of all website users. Further research should gather feedback from a broader range of users; however, the testing done during phases 1 and 2 had responses from participants with a wide range of ages. Approximately 70% (34/46, 74%) of the responses to the phase 1 questionnaire were from individuals aged <65 years. Similarly, in phase 2, all 5 participants in the task analysis sessions were between the ages of 40 and 65 years. Thus, the site was developed using feedback from different age groups.

Furthermore, no one who self-identifies as an "individual living with memory difficulties or dementia" completed the web-based questionnaire. We promoted the study to this population through posters displayed at a Geriatric Day Hospital and Memory Clinic and in the Dementia Society Monthly Newsletter, but unfortunately did not receive any responses from this population. This limits the usability of the questionnaire results for understanding the population. However, 2 of the 5 participants in the task analysis sessions had mild cognitive impairment. Thus, the data from the task analysis sessions indicate that the initial design of dementia613.ca is appropriate for this stakeholder group. This information will be helpful to DSORC staff member when planning the future promotion of the website to both care partners and persons living with dementia.

Although Neilsen [22,23] suggested that 5 users are a reasonable number to conduct an evaluation of a website, a limited number of task analysis sessions were conducted. It has also been suggested that for qualitative studies using nonprobability sampling techniques with a homogeneous population, saturation (where potentially similar patterns emerge and no new information or insight emerges) can occur with 4-12 participants [47,48]. The small number of participants could mean that the results of the task analysis were not representative of all website users. This could be addressed in future research by reaching out to more potential participants (eg, from each stakeholder group of persons living with dementia, care partners, and businesses or organizations) and having a longer testing period. Despite this, we believe that there were enough participants to achieve saturation for the initial design of dementia613.ca.

Taken together, the amount of data collected through web analytics, questionnaires, and task analysis sessions provided enough information for an initial evaluation of the utility and ease of use of the website. The data will be used as the basis for future work aimed at improving dementia613.ca.

Conclusions

Dementia613.ca was well received by most of the visitors. It will be a useful resource for the Ottawa area; according to the feedback we were able to collect from business owners and care partners. The participants indicated that they met a previously unfiled need in the area. Participants highlighted the utility of bringing local resources together in a web-based format in dementia613.ca. Both persons living with dementia and their care partners and businesses and organizations said that dementia613.ca provided reliable and relevant information. There is still room for improvement; participants pointed out that navigation and search features could be developed further. With further updates to the website, methods similar to those outlined in this paper will be used to obtain additional user feedback for further evaluation.

This website model can be used to inspire and guide the creation of dementia resource websites in other regions in Ontario and Canada. We believe that the framework behind dementia613.ca is generalizable and could be replicated in other regions to help care partners and persons living with dementia find local resources more easily.

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Conflicts of Interest

DH is an employee of the Dementia Society of Ottawa and Renfrew County. Authors MT, CT, and NT have no conflicts of interest to declare.

Multimedia Appendix 1
Phase 1 survey: questions and responses.
[XLSX File (Microsoft Excel File), 19 KB - aging_v6i1e40762_app1.xlsx]

Multimedia Appendix 2
Complete the questionnaire in English. Care partners and persons living with dementia filled out questions 1-14, and businesses and organizations filled out questions 1 and 15-26.
[DOCX File , 80 KB - aging_v6i1e40762_app2.docx]

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Multimedia Appendix 3
Complete questionnaire in French. Care partners and persons living with dementia filled out questions 1-14, and businesses and organizations filled out questions 1 and 15-26.
[DOCX File , 83 KB - aging_v6i1e40762_app3.docx]

Multimedia Appendix 4
Questionnaire responses in English and French.
[XLSX File (Microsoft Excel File), 19 KB - aging_v6i1e40762_app4.xlsx]

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Abbreviations

DSORC: Dementia Society of Ottawa and Renfrew County

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Original Paper

Development and Initial Evaluation of Web-Based Cognitive Behavioral Therapy for Insomnia in Rural Family Caregivers of People With Dementia (NiteCAPP): Mixed Methods Study

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Abstract

Background: Informal caregivers of people with dementia frequently experience chronic insomnia, contributing to stress and poor health outcomes. Rural caregivers are particularly vulnerable but have limited access to cognitive behavioral therapy for insomnia (CBT-I), a recommended frontline treatment for chronic insomnia. Web-based delivery promises to improve insomnia, particularly for rural caregivers who have limited access to traditional in-person treatments. Our team translated an efficacious 4-session standard CBT-I content protocol into digital format to create NiteCAPP.

Objective: This study aimed to (1) adapt NiteCAPP for dementia caregivers to create NiteCAPP CARES, a tailored digital format with standard CBT-I content plus caregiver-focused modifications; (2) conduct usability testing and evaluate acceptability of NiteCAPP CARES' content and features; and (3) pilot-test the adapted intervention to evaluate feasibility and preliminary effects on sleep and related health outcomes.

Methods: We followed Medical Research Council recommendations for evaluating complex medical interventions to explore user needs and adapt and validate content using a stepwise approach: (1) a rural dementia caregiver (n=5) and primary care provider (n=5) advisory panel gave feedback that was used to adapt NiteCAPP; (2) caregiver (n=5) and primary care provider (n=7) focus groups reviewed the newly adapted NiteCAPP CARES and provided feedback that guided further adaptations; and (3) NiteCAPP CARES was pilot-tested in caregivers (n=5) for feasibility and to establish preliminary effects. Self-report usability measures were collected following intervention. Before and after treatment, 14 daily electronic sleep diaries and questionnaires were collected to evaluate arousal, health, mood, burden, subjective cognition, and interpersonal processes.

Results: The stepped approach provided user and expert feedback on satisfaction, usefulness, and content, resulting in a new digital CBT-I tailored for rural dementia caregivers: NiteCAPP CARES. The advisory panel recommended streamlining content, eliminating jargon, and including caregiver-focused content. Focus groups gave NiteCAPP CARES high usefulness ratings (mean score 4.4, SD 0.79, scored from 1=least to 5=most favorable; score range 4.2-4.8). Multiple features were evaluated positively, including the intervention's comprehensive and engaging information, caregiver focus, good layout, easy-to-access intervention material, and easy-to-understand sleep graphs. Suggestions for improvement included the provision of day and night viewing options, collapsible text, font size options, tabbed access to videos, and a glossary of terms. Pilot-test users rated usefulness (mean score 4.3, SD 0.83; range 4.1-4.5) and satisfaction (mean score 8.4, SD 1.41, scored from 1=least to 10=most satisfied; range

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7.4-9.0) highly. Preliminary effects on caregiver sleep, arousal, health, mood, burden, cognition, and interpersonal processes (all $P<.05$) were promising.

Conclusions: Adaptations made to standard digital CBT-I created a feasible, tailored digital intervention for rural dementia caregivers. Important next steps include further examination of feasibility and efficacy in a randomized controlled trial with an active control condition, a multisite effectiveness trial, and eventual broad dissemination.

Trial Registration: ClinicalTrials.gov NCT04632628; https://clinicaltrials.gov/ct2/show/NCT04632628

(JMIR Aging 2023;6:e45859) doi:10.2196/45859

KEYWORDS

arousal; caregivers; cognitive behavioral therapy; CBT: cognitive behavioral therapy for insomnia; CBT-I; dementia; insomnia; internet

Introduction

Overview

Approximately 16 million Americans serve as informal caregivers, providing 18.5 billion hours of care, which translates into US $234 billion in health care savings [1]. Dementia caregiving in particular is more demanding than other types of caregiving, due in part to time-consuming and unpredictable caregiving demands and associated emotional and physical exhaustion [1,2]. Informal caregivers of people with dementia frequently experience insomnia [3,4]. The number of people with dementia in the United States is projected to rise from 5.7 million to more than 14 million in the next 30 years [5]. Most people with dementia (70%) are cared for at home by a family member [1]. Thus, there is a critical need to evaluate the health of dementia caregivers and provide treatment for prevalent medical conditions such as insomnia.

In addition, because rural areas are aging faster than urban areas, the proportion of people at risk for dementia is growing faster, which translates to faster growth in the proportion of rural caregivers [6]. Compared to their urban counterparts, rural caregivers face additional challenges, including more difficulty accessing health care, a greater likelihood of social isolation, and increased vulnerability to sleep problems, stress, and depression. Rural caregivers have less access to care due to significant shortages of both primary and specialty care providers in rural areas [7,8] and are also at disproportionate risk for poverty and unemployment [2], which further limits their access. On average, they travel 144 km roundtrip to see their nearest health care provider [9]. Lengthy travel combined with the lack of public transportation in rural areas represent an additional major barrier to access. Thus, developing and evaluating treatments for medical conditions that are prevalent in caregivers (eg, insomnia) that can be accessed remotely (eg, on the internet) is a critical and currently unmet need in the health care community.

Research from our group and others verifies that caregivers have poorer sleep quality [10,11], take longer to fall asleep [10], spend more time awake during the night [3], and sleep less [10,12] than same-aged noncaregivers. Chronic insomnia (more than 3 months of difficulty initiating or maintaining sleep, early morning awakening, or nonrestorative sleep) affects up to 63% of caregivers [3,13] and tends to endure (18 years on average in our previous caregiver trial) [14,15]. Factors associated with caregiver insomnia include age-related sleep architecture changes, increased sympathetic nervous system arousal [3,15], increased vigilance [3], stress, depression, cognitive dysfunction, increased dementia risk, and person-related dementia behaviors (including nighttime wandering).

Cognitive behavioral therapy for insomnia (CBT-I) improves sleep (moderate or large effects) and mood (large effects) in adults of all ages [16] and is recommended by the American College of Physicians as a first-line treatment for chronic insomnia [17]. While research [18-20] shows that CBT-I is an efficacious treatment for the chronic insomnia experienced by caregivers, rural caregivers face particular difficulties accessing behavioral treatments, which require specially trained providers and administration over multiple sessions in a provider's office. In a recent randomized controlled trial, our group found that brief CBT-I delivered through telehealth (videoconferencing) reduced caregiver sleep onset latency compared to sleep hygiene education in caregivers. Our CBT-I protocol was adapted with permission from McCurry and colleagues' [3] earlier version [21] and included standard CBT-I techniques (sleep hygiene, stimulus control, and cognitive therapy), modified CBT-I techniques (sleep compression replaces sleep restriction, which is potentially burdensome for caregivers due to temporary sleep deprivation; brief hybrid relaxation is included given caregiver time constraints [22]; and muscle tensing is excluded given potential pain or musculoskeletal issues in older caregivers), additional techniques for caregivers (problem-solving, as skill deficiency can contribute to caregiver insomnia [23,24]), and stress management (respite, staying healthy, and communication). Our findings indicate CBT-I tailored for caregivers translates well to telehealth delivery and that technology holds great potential to increase rural caregiver access to behavioral interventions. However, telehealth delivery still requires considerable time commitment from trained therapists (who are already in short supply).

A small but growing body of evidence shows that web interventions have been successfully implemented in rural areas using the internet and other mobile platforms and improved noninsomnia health outcomes in stroke and caregivers [25-32]. Moreover, web-based CBT-I has been implemented and found to be efficacious in noncaregiver patient populations. For example, Taylor et al [33] translated 6-week CBT-I to a web format and conducted a randomized controlled trial in military personnel (N=100; n=33 received web CBT-I, n=34 received in-person CBT-I, and n=33 received minimal contact control).

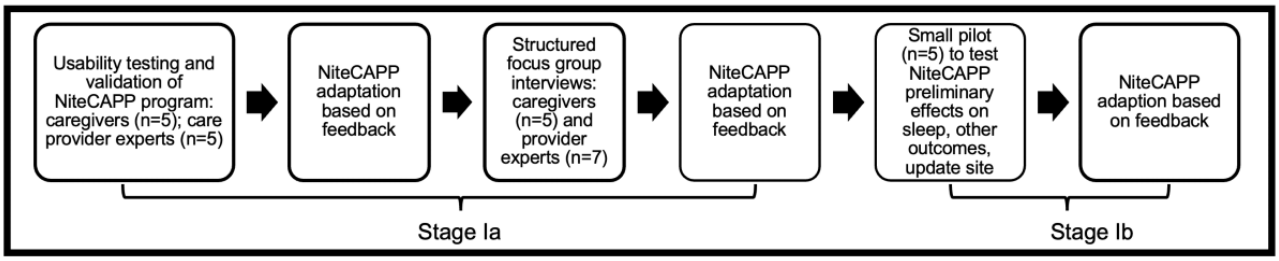
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Compared to control, web-based and in-person CBT-I improved sleep efficiency, sleep onset latency, and wake time after sleep onset (effects moderate for web-based, large for in-person). Internet CBT-I also improved insomnia severity and decreased sleep-related cognitive arousal [33]. Another 6-week web-based CBT-I program (SHUTi) [34] was shown to improve insomnia severity (as measured through the insomnia severity index) relative to a no-contact control (large effect size) in adults with insomnia. Noted limitations of internet-based treatments include a lack of personal contact to address treatment questions or concerns without a face-to-face or telephone component. Additionally, personal support or guided delivery has been associated with larger treatment effects for both in-person and web-based CBT-I [26]. Taken together, these findings provide support for the development of web-based CBT-I for caregivers and suggest personal support or guided delivery is important to maximize treatment adherence and efficacy. Thus, our team developed a web-based CBT-I for caregivers through an iterative process.

Iterative Development Process

Following the Medical Research Council recommendations [35] for the evaluation of complex medical interventions, we conducted several steps in the initial development, pilot-testing, and evaluation of NiteCAPP CARES [36] (see Figure 1).

Figure 1. NiteCAPP usability testing, content evaluation, adaptation, and efficacy.



This paper describes stages 1a and 1b, which were conducted from 2019 to 2020. The goal of stage 1a was to translate (through feedback from caregivers and primary care providers; PCPs) an efficacious 4-session CBT-I into a web-based "NiteCAPP CARES," a web-based behavioral treatment for insomnia for dementia caregivers that incorporates guided delivery through weekly therapist moderator feedback. A second goal of stage 1a was to conduct NiteCAPP CARES usability testing to evaluate the acceptability of its content and features. The goal of stage 1b was to pilot-test NiteCAPP CARES on several key outcomes (feasibility, favorability, satisfaction, sleep, arousal, mood, burden, and cognition) in a small sample of dementia caregivers. We hypothesized that NiteCAPP CARES would produce high ratings regarding favorability of program content. Further, we hypothesized that in the pilot study, participants would complete all 4 sessions on average and that satisfaction ratings would be at least more than 7 of 10 (highest) and usefulness ratings would be at least more than 4 of 5 (highest). Although the single-arm design of this pilot study precludes examination of efficacy, within-group effects of the treatment on sleep and related behaviors were also examined. We hypothesized that subjective sleep would improve immediately following treatment using NiteCAPP CARES. We further hypothesized that daytime functioning (ie, mood, caregiving burden, perceived stress, and cognition) would improve.

Methods

Stage 1a: Explore Stakeholder Views and Focus Groups

Participants

Purposeful criterion-i sampling, a nonrandom sampling method where individuals are selected because they have expertise or experience related to the study purpose, was used for both the advisory panel and focus group [37-39].

Advisory Panel

Stage 1a usability testing and validation of NiteCAPP content was first conducted by our web-based advisory panel of dementia caregivers (n=5; 3 of which were part of our community advisory board) and dementia experts, or PCPs (n=5; 2 of which are also part of our community advisory board). Participants were recruited through University of Missouri clinics, other providers, and the participant recruiter (AC). These individuals tested the NiteCAPP website on their own computers, tablets, or phones in their homes and then completed a modified structured internet intervention usefulness questionnaire (modified from existing surveys [34,40] as well as other studies evaluating web-based behavioral interventions [27,41,42]) to provide ratings of program content (1=least favorable to 5=most favorable) regarding ease of use, amount of information, website maintaining interest, adequate font size, videos maintaining interest, easy to understand, and helpful. Participants in the advisory panel also provided open-ended verbal and written feedback.

Focus Group

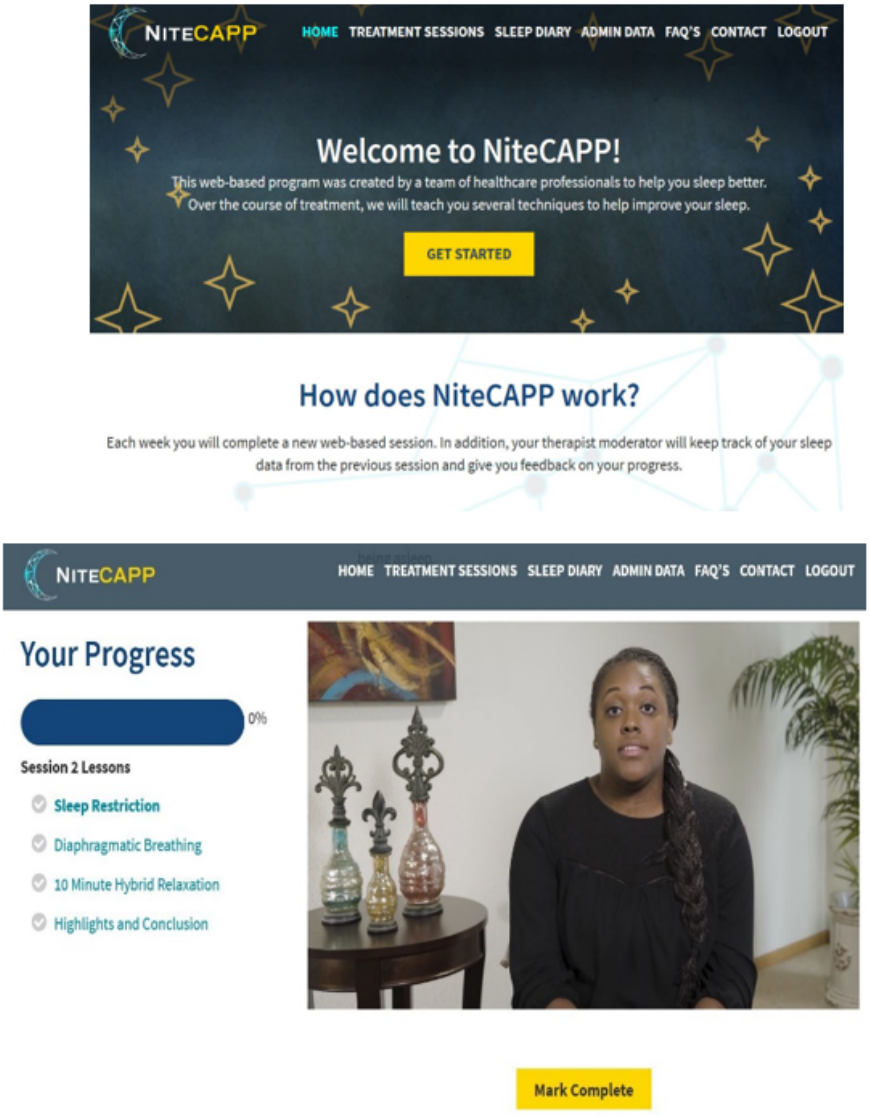
Next, CSM (primary investigator) and AC (community caregiver consultant) led in-person focus groups consisting of caregivers (n=5; mean age 51.4, SD 15.9 years, age range 23-59 years; 3 female, 1 male, and 1 nonbinary; 4 White and 1 multiracial) and PCPs (n=7; mean age 45.29, SD 15.01 years; age range 26-66 years; 5 female and 2 male; 6 White and 1 multiracial). Users were provided logins and could review the NiteCAPP website (see Figure 2) on their own devices before and during the focus group.

Participants were encouraged to explore the site freely, read content, and watch and listen to audiovisual materials before

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and during the focus group. CSM and AC had a list of specific questions to ask, such as the usability of the website for caregivers and how they felt about the amount of text or number of pictures and asked the questions from the internet intervention usefulness questionnaire and satisfaction questionnaire in an open-ended format. They also encouraged participants to provide open-ended verbal comments or feedback on NiteCAPP. The focus group lasted approximately 90 minutes. At the end of the focus group, participants were asked to fill out a quantitative version of the internet intervention usefulness questionnaire.

Figure 2. NiteCAPP CARES website home page.



Participants' open-ended verbal comments were transcribed, and content analyses were performed to identify recurrent themes by CSM and AFC. Frequent topics were categorized and merged into common themes during a consensus meeting of CSM and AFC. Participants also indicated whether they had at-home internet access, indicated their method of internet access, and provided open-ended feedback on NiteCAPP.

Stage 1b: Testing Feasibility and Preliminary Effectiveness

Participants

Stage 1b development involved testing NiteCAPP CARES in a single-arm pre-post-intervention pilot study to determine feasibility. The sample included dementia caregivers who had insomnia (n=5; see Table 1). Participants were recruited through physician or investigator referral (AFC or DQB) from Columbia, Missouri, and the surrounding regions and compensated with US $40 in gift cards (US $15 at the beginning of the study and US $25 at the end of the study).

Inclusion criteria for caregivers were (1) age older than 18 years; (2) primary caregiver living with person with dementia; (3) able to read and understand English; (4) no prescribed or over-the-counter sleep medicines or stabilized for more than 6 weeks; and (5) insomnia diagnosis based on sleep complaints for more than 6 months; adequate opportunity and circumstances for sleep; and more than 1 of the following: difficulty falling asleep, staying asleep, or waking too early; daytime dysfunction (mood, cognitive, social, or occupational) due to insomnia; and Insomnia Severity Index score ≥10. Exclusion criteria for caregivers were (1) unable to consent; (2) sleep disorder other

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than insomnia (ie, sleep apnea); (3) bipolar or seizure disorder; (4) other major psychopathology except depression or anxiety (eg, suicidal ideation or intent or psychosis); (5) severe untreated psychiatric comorbidity; (6) psychotropic or other medications (eg, β-blockers) that alter sleep; and (7) nonpharmacological treatment for sleep or mood outside of the current trial.

Table 1. Pilot study caregiver participant demographics (n=5).

Characteristics	Values
Age (years), mean (SD)	62.4 (18.2)
Age range (years)	33-78
Female, n (%)	3 (60)
Relation to person with dementia, n (%)	
Spouse	4 (80)
Daughter	1 (20)
Comorbid medical conditions, mean (SD)	3.2 (1.8)

Procedures

Participants were contacted through referral (AFC and DQB) and provided web-based documentation of informed consent. They were then asked to fill out a web-based screening form, including demographic information and medical history. If they qualified for the study, they filled out baseline questionnaires and electronic sleep diaries (see Measures section) and were then given access to NiteCAPP and completed the web-based 50 to 60–minute treatment sessions once per week for 4 weeks. They continued to fill out electronic daily sleep diaries throughout treatment to guide sleep prescription recommendations during treatment. Posttreatment assessment occurred immediately after treatment sessions ended and included questionnaires and daily diaries (for 2 weeks).

Intervention

A user-centered design approach was used and took into consideration age-related cognitive or perceptual concerns in our target population [43-47]. Interface features included (1) support for older adult readability [43,45] (eg, sans-serif typeface; font larger than 14 points; clear content headings; noncluttered backgrounds; brief videos; bright colors; visual contrast or ample white space; representative icons, such as a sleep diary icon with written diary on a bed; content enhancing, no distracting audio; clear navigation; and limited pull-down menus) and (2) ease of use (eg, simplified language, videos, pictographs, and guidance). Consistent with computer digital reminiscence and conversation aid recommendations [45], community member feedback was solicited on all aspects. Moderator feedback was provided to caregivers regarding their sleep and treatment progress. See Table 2 for session content.

Table 2. Session-by-session overview of NiteCAPP CARES.

Session number	
1	Sleep education, sleep hygiene, and stimulus control
2	Sleep compression, relaxation, and problem-solving
3	Coping, stress management, and cognitive therapy
4	Review, education, and planning for maintenance of behavior change

Measures

Measures were administered at baseline and immediately after treatment, unless otherwise specified.

Usability and Satisfaction

The modified internet intervention usefulness questionnaire (see Methods for stage 1a) was administered at the completion of NiteCAPP CARES. A proprietary 9-item satisfaction measure was also developed and administered at the completion of NiteCAPP CARES to obtain feedback on aspects of the study, including its structure, assessments within the NiteCAPP CARES site, scheduling, working with study staff, and whether they would recommend the study to others using a 10-point Likert scale (1=strongly disagree to 10=strongly agree).

Feasibility

Feasibility was assessed as the number of treatment modules completed (1-4, expressed as percentage) as well as the percentage of instructions followed (assessed through treatment adherence logs completed by participants within the session modules and confirmed by therapist moderators).

Sleep

Daily electronic diaries were completed for 14 days at baseline and immediately after treatment on the NiteCAPP CARES website and measured sleep onset latency (lights-out until sleep onset), wake after sleep onset, and sleep efficiency (total sleep time/time in bed×100%).

The Insomnia Severity Index [48] is a 7-item measure designed to assess the nature, severity, and impact of insomnia using a 5-point Likert scale, ranging from 0 (no problem) to 4 (very

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severe problem). Previous studies have shown excellent internal consistency (α=.91), convergent validity when compared to other measures (eg, fatigue), and that a cutoff score of 10 had 86.1% sensitivity and 87.7% specificity when determining insomnia [48].

Arousal

The Perceived Stress Scale [49] is a 10-item measure designed to assess past-month stress levels in response to everyday situations using a 4-point Likert scale, ranging from 0 (never) to 4 (very often). It has high reliability (α>.70) [50].

The Kingston Stress Scale [51] is 10-item measure designed to assess 3 categories: caregiving, family, and financial issues using a 5-point Likert scale, ranging from 1 (feeling fine or no stress) to 5 (extreme stress). It has high validity (α=.82) and reliability (α=.85) [51].

The Dysfunctional Beliefs and Attitudes about Sleep [52] is a 30-item measure designed to assess dysfunctional beliefs and attitudes about sleep using a 10-point Likert scale, ranging from 0 (strongly disagree) to 10 (strongly agree). Previous research has shown strong reliability (α=.77 for clinical and .79 for research samples) and temporal stability (*r*=0.83) [52].

Health and Mood

The Beck Depression Inventory-II [53] is a 21-item measure designed to assess depressive symptomatology using a 4-point Likert scale, ranging from 0 (absence of symptoms) to 3 (severe). Internal consistency is 0.90, and retest reliability ranges from 0.73 to 0.96 [53].

The State-Trait Anxiety Inventory [54] is a 20-item measure designed to assess anxiety using a 4-point Likert scale, ranging from 1 (not at all) to 4 (very much so). Reliability is high, with α=.93 for clinical and α=.92 for nonclinical samples [55].

Burden

The Zarit Burden Scale [56] is a 22-item measure designed to assess burden using a 5-point Likert scale, ranging from 0 (never) to 4 (nearly always). This measure has high reliability (α=.93) and convergent validity (*r*=0.53-0.73) [57].

The Dementia Patient's Caregiver-Quality of Life [58] is a 20-item measure designed to assess how caregiver quality of life changes after beginning caregiving using yes-or-no questions and a 10-point sliding scale ranging from 0 (easy) to 10 (hard).

Cognition

Subjective cognition was measured using the Cognitive Failures Questionnaire [59], a 25-item measure designed to assess an individual's perception of their own daily cognitive failures (eg, memory failures and distractibility) using a 5-point Likert scale, ranging from 0 (never) to 4 (very often). Higher scores indicate worse overall subjective cognition. Reliability is excellent, with α=.90 [60].

Qualitative Data

Participants were asked to provide qualitative feedback regarding how they felt about the written materials, audiovisual materials, and any comments or suggestions they felt would help to improve NiteCAPP CARES. Therapist moderator feedback was also solicited regarding suggestions to refine and improve the guided web-based support.

Ethics Approval

This study was approved by the University of Missouri Institutional Review Board (2017125) and registered on ClinicalTrials.gov (NCT04632628).

Results

Stage 1a: Explore Stakeholder Views and Focus Groups

Advisory Panel

The advisory panel advised streamlining NiteCAPP content, eliminating jargon, and including caregiver-focused content.

Focus Group

For the focus group, average ratings for NiteCAPP features were high (see Table 3), with ratings ranging from 4.21 of 5 to 4.82 of 5 across all measured items.

Common themes included written material, audiovisual material, moderator feedback, and aesthetics of the website. Examples of comments on written materials included: "Easy to read and understand, but should have font size options," "Great content but written at a pretty high literacy level," and "Some sentences had too many clauses or more than one idea." Focus group members stated that the audiovisual materials had "great information," "were good...[and] engaging," but should be "captioned or have a header." NiteCAPP was then updated to incorporate suggestions for improvement based on common themes and titled NiteCAPP CARES (see Table 4). After that update, NiteCAPP CARES was pilot-tested in stage 1b.

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Table 3. Stage 1a focus group usefulness ratings (n=5 dementia caregivers; n=5 dementia primary care providers). Scores based on a scale from 0 to 5, with higher scores indicating more favorable ratings.

Features	Mean score, (SD)	Minimum-Maximum score
Website		
Ease of use	4.23 (1.40)	3-5
Amount of info	4.40 (1.16)	2-5
Maintains interest	4.24 (0.53)	4-5
Font size	4.82 (0.79)	3-5
Videos		
Maintain interest	4.21 (0.89)	3-5
Easy to understand	4.40 (1.00)	3-5
Helpful	4.44 (0.98)	3-5

Table 4. Stage 1a focus group feedback.

Feature	Themes		CG[a] and PCP[b] quotes
	Positive	Negative	
Written material	• Thorough for target group • Promotes independent completion of intervention • Therapist moderator visual feedback helpful.	• No font size options • Excessive medical jargon • Some instructions may elicit stress	• "Easy to read and understand, but should have font size options." [CG-001] • "Information broken down into easy to digest chunks and not overwhelming to read through." [CG-005] • "I like the sense that one could complete these modules independently." [PCP-001] • "Minimize clinical/diagnostic terms." [PCP-001] • "I think incorporation of graphs and charts for sleep feedback is awesome." [PCP-002] • "Change the word 'homework' to something less stressful." [CG-003]
Audiovisual material	• Rich, engaging information • Important communication tool for target population • Good pacing	• Difficult to find on mobile	• "Great information!" [CG-003] • "The videos were good, and I found them to be engaging." [PCP-004] • "The videos feel a bit hidden, hard to find. Having a tab with all videos might be an option." [CG-005] • "I think videos are integral to the program. I think her pace is probably good for this patient population, since they will not have heard most of this before." [PCP-002]
Aesthetics	• Good use of visual contrast	• Lack of viewing options for daytime/nighttime	• "Have a dark mode or night mode option, will help user's eyes, especially if using at night." [CG-005] • "Bolding specific words and phrases helps make information accessible." [CG-005]
Navigation	• Good layout and use of links/tabs to intervention material	• Page content requires too much scrolling • Too much text, should be hidden/collapsible	• "Good links to other sessions and lessons." [CG-001] • "It's a lot to navigate on mobile." [CG-005] • "Caregivers are exhausted and need things in small allotments...devices this will be viewed on are smaller in terms of landscape and how one moves beyond the initial screen." [PCP-001] • "Have collapsible tabs that can be expanded/collapsed when necessary to help people scrolling on their phone." [CG-005] • "I think the pages could also benefit from drop down menus to hide information and have text appear when the user clicks on it. It might make the pages less cluttered and feel more interactive." [PCP-003]
Resources		• Lack of glossary	• "Build in a glossary or a 'terms to know'" [CG-003]

[a]CG: caregiver.

[b]PCP: primary care provider.

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Stage 1b: Testing Feasibility and Preliminary Effectiveness

Feasibility and acceptability were excellent, with high average completion (>100% of sessions), adherence (76% for sleep hygiene, 80% for stimulus control, and 81% for relaxation based on daily logs), satisfaction (>8.4/10 on the Satisfaction Survey; see Table 5), and usefulness ratings (>4.3/5 on the Internet Intervention Utility Questionnaire; see Table 6). As shown in Table 7, NiteCAPP CARES led to improvements in subjective sleep (sleep onset latency, wake after sleep onset, sleep efficiency, and the Insomnia Severity Scale), arousal, mood (depression), burden, quality of life, perceived stress, and subjective cognition.

Table 5. Stage 1b pilot test satisfaction ratings (n=5 caregivers with insomnia). Scores based on a scale from 0 to 10, with higher scores indicating more favorable ratings.

	Mean score (SD)	Minimum-Maximum score
Expected experience	7.44 (3.98)	1-10
Scheduling convenience	9.03 (1.73)	7-10
Surveys and forms tolerable	8.49 (1.73)	7-10
Daily diaries tolerable	8.54 (1.41)	7-10
Therapist moderator	8.04 (1.41)	7-10
Recommend to a friend	9.05 (1.41)	7-10

Table 6. Stage 1b pilot test usefulness ratings (n=5 caregivers with insomnia). Scores were based on a scale from 0 to 5, with higher scores indicating more favorable ratings.

	Mean score (SD)	Minimum-Maximum score
Website		
Ease of use	4.50 (0.83)	3-5
Amount of info	4.33 (0.55)	4-5
Maintains interest	4.29 (0.84)	3-5
Font size	4.32 (0.50)	4-5
Videos		
Maintain interest	4.13 (0.84)	3-5
Easy to understand	4.40 (0.89)	3-5
Helpful	4.18 (0.89)	3-5

Following this pilot test, additional participant qualitative feedback (see Table 8) was used to update NiteCAPP CARES a third time. Participants stated that the written and audiovisual materials were clear, though audiovisual materials were repetitive. Comments and suggestions included moving relaxation techniques to the morning and the importance of a schedule. Therapist moderator feedback was used to refine the guided web-based support and develop a moderator manual with clear, step-by-step instructions, schedule for administration of support, and case examples (see Textbox 1).

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Table 7. Stage 1b pilot results. Caregiver subjective sleep, arousal, mood, burden, and cognition (n=5). Measures collected electronically.

Measure	Base		Post		Base to post			
	Mean (SD)	SE	Mean (SD)	SE	Δ	*t* test (*df*)	*P* value	Effect size[a]
Subjective sleep								
Sleep onset latency (min)	23.2 (8.67)	3.88	10.69 (4.34)	1.94	12.53	4.01 (4)	.01	1.46 (very large)
Wake after sleep onset (min)	54.95 (23.03)	10.30	22.30 (8.70)	3.89	32.65	4.05 (4)	.01	1.50 (very large)
Sleep efficiency[b] (%)	79.64 (9.92)	4.44	92.67 (1.96)	0.88	13.03	3.53 (4)	.02	1.46 (very large)
Insomnia Severity Index[c]	15.20 (4.09)	1.82	8.00 (6.00)	2.68	7.20	2.25 (4)	.04	0.81 (large)
Subjective arousal								
Perceived Stress Index	25.40 (5.50)	2.46	20.00 (8.97)	4.01	5.40	2.09 (4)	.05	0.58 (moderate)
Kingston Stress Scale	20.60 (3.65)	1.63	6.20 (2.95)	1.30	2.60	1.73 (4)	.08	0.63 (moderate)
DBAS[d]	130.80 (30.47)	13.63	77.40 (36.10)	16.14	53.40	3.87 (4)	.01	1.28 (large)
Health or mood								
BDI-II[e]	11.80 (4.32)	1.93	6.20 (2.95)	1.32	5.60	2.89 (4)	.02	1.21 (large)
STAI[f]	61.40 (11.08)	4.96	57.20 (8.67)	3.88	4.20	1.36 (4)	.12	0.34 (small)
Burden								
Zarit Burden Scale	23.40 (9.74)	4.35	17.20 (10.76)	4.81	6.20	2.16 (4)	.05	0.48 (small-moderate)
CG-QOL[g]	51.00 (19.81)	8.86	63.00 (14.40)	6.44	12.00	2.33 (4)	.04	0.55 (moderate)
Subjective cognition								
CFQ[h]	43.80 (14.38)	6.43	39.20 (10.52)	4.71	4.60	2.44 (4)	.04	0.29 (small)
Interpersonal processes								
PCFUS[i]	39.20 (13.52)	6.04	37.40 (16.88)	7.55	1.80	0.64 (4)	.28	0.09

[a]Within-group effect sizes based on Hedges g_{av}. Values of .20=small, .50=moderate, and .80=large.

[b]Sleep efficiency: ratio of time spent sleeping/time in bed×100%.

[c]Insomnia Severity Index: 0=none, 28=severe.

[d]DBAS: Dysfunctional Attitudes and Beliefs about Sleep.

[e]BDI-II: Beck Depression Inventory-II.

[f]STAI: State Trait Anxiety Inventory.

[g]CG-QOL: Dementia Patient's Caregiver Quality of Life.

[h]CFQ: Cognitive Failures Questionnaire.

[i]PCFUS: Patient-Caregiver Functional Unit Scale.

Table 8. Stage 1b caregiver evaluation comments.

Feature	PCG[a] quotes
Written material	• "It was clear and easy to understand." [PCG-01] • "I think it is straight forward and easy to understand." [PCG-04]
Audiovisual material	• "They were clear but somewhat repetitive." [PCG-02] • "I think they are well done and easy to understand." [PCG-04]
Comments or suggestions	• "The questions about using the relaxation techniques that particular night should be moved to the a.m. questionnaire sleep diary in the morning." [PCG-05] • "As a caregiver for someone with dementia and a livestock owner. It's difficult to maintain a set schedule." [PCG-01] • "This is a useful tool for a caregiver in conjunction with methods to get the care partner to sleep on a schedule." [PCG-03]

[a]PCG: pilot-test caregiver.

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Textbox 1. NiteCAPP CARES stage 1b pilot-test moderator feedback.

Moderator feedback to incorporate

- A clear schedule for therapist moderator notes (eg, a set schedule of when to complete notes and send them to participants)
- A manual with templates for moderator notes for each stage of the study.
- Automated emails informing the moderator when a participant finishes a particular assignment
- Automated reminders for participants to complete diaries

Discussion

Overview

This study used mixed methods of qualitative and quantitative expert (PCPs) and participant-focused (rural dementia caregivers) feedback to iteratively adapt a 4-session web-based CBT-I (NiteCAPP) into a tailored digital format with standard CBT-I content plus caregiver-focused modifications (NiteCAPP CARES). The usability and acceptability of NiteCAPP CARES were then evaluated. The website was evaluated as easily accessible and useful, and the feasibility of the web-based intervention was high, suggesting that NiteCAPP CARES is highly functional for rural caregivers and PCPs. Preliminary efficacy testing also indicated that NiteCAPP CARES improved subjective sleep as well as several key aspects of daily functioning (eg, arousal, mood, burden, and subjective cognition).

Consistent with our hypotheses, the acceptability and usability of NiteCAPP CARES were high. In comparison to other in-person or telehealth versions of CBT-I [61-64], NiteCAPP CARES may offer unique advantages for treating insomnia, particularly in dementia caregivers. For example, NiteCAPP CARES provides greater caregiver accessibility given their demanding schedules since caregivers can access the materials on their schedule without having to make any appointments. NiteCAPP CARES is also less burdensome for both the patient and the therapist moderator, as trained behavioral sleep therapists who can conduct in-person or telehealth CBT-I are in short supply [8]. Further, compared to other web-based insomnia treatments [65-69], NiteCAPP CARES provides important enhancements for older caregivers. For example, although other 5 to 6–session, web-based CBT-I platforms [65,66] provide audiovisual content, NiteCAPP CARES provides tailored audio and visual recommendations for dementia caregivers. In addition, unlike other web-based CBT-I platforms, NiteCAPP CARES also provides a help forum to provide 24-7 assistance from therapist moderators. Other web-based CBT-I platforms [67] use sleep diaries and have a clinician and patient portal but function as adjuncts to in-person treatment, whereas NiteCAPP CARES is a standalone moderated treatment that allows the caregiver to access all the materials on their schedule. Other web-based CBT-I platforms [68,69] offer 6 sessions with tailored sleep recommendations based on either sleep diaries or screening questionnaires. One web-based CBT-I [69] even provides a web-based therapist who advises the patient on restructuring their cognitions, but this feedback does not extend to the patient's sleep. However, none of these web-based insomnia treatments provide a simpler interface tailored for older caregivers or provide tailored and moderated therapy throughout treatment. In addition, the NiteCAPP CARES website itself was rated very highly in terms of its ease of use and readability (eg, font size), which were part of its initial user-centered design that took age-related cognitive or perceptual concerns in our target population into consideration (see Methods section) [70-74]. Second, caregiver use was likely promoted through the use of nonstructured session times (caregivers were encouraged to complete the sessions on their own schedule), simplified language, videos, and pictographs.

As expected, preliminary results also reveal that NiteCAPP CARES shows promise for improving the majority of our key outcomes. The moderate to large improvements across sleep outcomes (sleep onset latency, wake after sleep onset, sleep efficiency, and insomnia severity) found for NiteCAPP CARES are similar or greater than those found for other web-based CBT-I platforms [65,66,69]. Extending findings from previous web-based CBT-I interventions, our preliminary results also provide novel findings regarding NiteCAPP CARES' potential impact on stress or arousal and subjective cognition (a treatment outcome that has not previously been assessed). NiteCAPP CARES showed improvements in subjective arousal (moderate to large effects) and cognition (small effects), as well as burden (small to moderate effects). Unlike other web- and app-based CBT-I platforms [65-69], the use of a therapist moderator was noted as a positive feature of the intervention during pilot-testing and likely contributed to its acceptance and high completion rate. Previous completion percentages of therapist-led CBT-I treatment range from 63% to 88% [61,62] for telehealth treatment and 80% to 98% [63,64] for in-person treatment, both below NiteCAPP CARES' 100%. Similarly, average treatment adherence for therapist-led CBT-I is 38% and digital CBT-I is 35%, both lower than NiteCAPP CARES' 76%-81% [75]. NiteCAPP CARES suggests that moderated web-based interventions may be comparable to or surpass the completion rates for in-person and telehealth delivery of CBT-I in this population. This will provide increased accessibility for caregivers living in rural areas that are not close to health care providers.

Clinical Implications

Although further testing of NiteCAPP CARES is currently underway [76], these preliminary findings potentially suggest several clinical implications. Improving caregiver sleep is critical given that caregiver insomnia is associated with negative changes in central stress processing, resulting in poor physical health (altered heart rate and heart-rate variability) [77] and mood (anxiety and depression) [18,78]. Insomnia is also associated with poor caregiver cognition (processing speed

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[79,80], attention [79,81,82], executive functioning [82], and memory [82,83]) and neurodegenerative biomarkers associated with Alzheimer disease [83]. Poor mental and physical health makes it harder for caregivers to serve as caregivers and poor caregiver sleep contributes to early institutionalization [84]. Thus, treating caregivers' insomnia may allow them to continue to provide care longer. Further, NiteCAPP CARES is a moderated, web-based intervention, as opposed to more traditional in-person or telehealth interventions that involve therapist-led sessions [85,86]. Thus, this intervention can be disseminated broadly, and the therapist moderator manual will enable other health care providers (eg, nurses and PCPs) to learn the treatment quickly and use NiteCAPP CARES in various treatment settings.

Limitations and Future Directions

This study provides a foundation for future sleep research in rural dementia caregiver populations, which have largely been ignored. Our study has several limitations. First, the small number of individuals in our focus group and pilot test may not generalize to a broader population of caregivers and PCPs. Similarly, our small sample may have inflated our effect sizes; however, our previous studies in similar populations have shown these effect sizes to be robust [18,20,36]. Future studies should include a larger sample size that includes individuals from many different facets of life. For instance, it would be beneficial to gain insight from people with dementia, as NiteCAPP CARES treatment modules can be expanded to include resources specific to the care recipient. Furthermore, it would also be important to seek more evaluation from health care administration teams, who are likely to be the ones to give patients step-by-step instructions on how to log in and navigate NiteCAPP CARES. Future studies should focus on gaining feedback from dementia patient advocates, who have a considerable amount of insight on how to effectively care for and work with people with dementia and caregivers. The promising results from this preliminary development and initial evaluation study suggest a future randomized controlled trial that examines the efficacy of NiteCAPP CARES compared to an active web-based control in a larger sample of rural dementia caregivers is an important and warranted next step. Such future work may also benefit from a tailored, dyadic approach that involves the person with dementia in the treatment to the extent they are capable. Following further development and the establishment of efficacy, additional future steps include an effectiveness trial and broader implementation and dissemination efforts, as well as the development of a web-based, stand-alone sleep treatment for dementia caregivers. Specifically, as noted above, NiteCAPP CARES's moderated web-based intervention provided excellent adherence and engagement compared to completion rates for other web-based treatments [58-61]. While this preliminary study's results support our use of a moderated approach, a web-based, stand-alone option may be preferred by some caregivers and would provide them with an additional access option for obtaining CBT-I.

Conclusions

A brief, web-based CBT-I platform called NiteCAPP CARES was created for caregivers to address caregiver sleep issues. Initial website feedback was accessed by asking rural caregivers and PCPs their opinions on NiteCAPP CARES. They thought the site was easy to understand, engaging, and well designed. Preliminary pilot-test data indicated that caregivers used the site (high treatment adherence and session completion), found it useful, and reported high satisfaction. NiteCAPP CARES also improved subjective sleep and daily functioning. These promising outcomes suggest that NiteCAPP CARES can be a beneficial sleep tool for both rural dementia caregivers and health care providers. Underserved populations who have difficulty obtaining evidence-based health care may particularly benefit from NiteCAPP CARES given its web-based delivery, which can be accessed anywhere the internet is available. A future randomized controlled trial to evaluate NiteCAPP CARES compared to an active web control in a larger sample is needed.

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Authors' Contributions

All authors made substantial contributions to the concept and design of the study. CSM and AFC drafted the initial study design with input from all authors. MG, NN, and AFC conducted statistical analysis. CSM and DQB drafted screening procedures. DQB, JIS, AC, and MAR drafted recruitment and referral procedures. CSM, AFC, and MAS drafted the manuscript. All authors reviewed and approved the revised manuscript.

Conflicts of Interest

None declared.

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Abbreviations

CBT-I: cognitive behavioral therapy for insomnia
PCP: primary care physician

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Original Paper

Financial, Legal, and Functional Challenges of Providing Care for People Living With Dementia and Needs for a Digital Platform: Interview Study Among Family Caregivers

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Abstract

Background: Alzheimer disease and Alzheimer disease–related dementia represent complex neuropathologies directly challenging individuals, their families, and communities in the United States. To support persons living with dementia, family or informal caregivers often encounter complex financial, psychological, and physical challenges. A widely used solution such as a consolidated web-based assistance or guidance platform is missing, compounding care challenges.

Objective: In preparation for designing an internet-based artificial intelligence–driven digital resource platform, a qualitative interview study was conducted to characterize the challenges and needs of family caregivers in the United States.

Methods: A semistructured interview topic guide in English was developed by engaging community partners and research partnerships. Family caregiver participants were purposefully recruited via various means, such as word of mouth, local dementia community service providers, digital recruitment emails, flyers, and social media. Interested individuals were first invited to complete an eligibility screening survey, and eligible individuals were then contacted to arrange a web-based in-depth interview via Zoom (Zoom Video Communications) from January 1, 2022, to May 31, 2022. A follow-up survey was administered in May 2022 to provide an overview of the participants' demographics, socioeconomic characteristics, and caregiving information. Thematic analysis in a framework approach was used to identify and organize themes and the study findings.

Results: Following the prescreening of 150 eligible respondents, 20% (30/150) individuals completed both the interviews and follow-up survey, allowing for an in-depth look into the challenges, experiences, and expectations of primary caregivers of people living with dementia. Most participants (20/30, 67%) were primary caregivers of persons with dementia, and 93% (28/30) had provided care for at least a year. Most participants were aged >50 years (25/30, 83%), female (23/30, 77%), White (25/30, 83%), and non-Hispanic (27/30, 90%) and held a bachelor's or graduate degree (22/30, 73%). Collectively, all participants acknowledged challenges in caring for people living with dementia. Thematic analyses elicited the challenges of caregiving related to functional care needs and financial and legal challenges. In addition, participants identified the need for an integrative digital platform where

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information could be supplied to foster education, share resources, and provide community support, enabling family caregivers to improve the quality of care and reducing caregiver burden.

Conclusions: This study emphasized the difficulties associated with the family caregiver role and the expectations and potential for a supportive web-based platform to mitigate current challenges within the caregiving role.

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KEYWORDS

family caregiver; Alzheimer disease; dementia; caregiving challenges; digital health; community-based participatory research; mobile phone

Introduction

Background

Approximately 6.5 million Americans aged ≥65 years live with Alzheimer disease (AD) and AD-related dementia (ADRD)—a debilitating and progressive neurocognitive disease leading to the loss of memory and motor function and other negative psychosocial symptoms [1,2]. The number of persons living with AD or ADRD is expected to grow to 13.8 million by 2060, calling for innovative solutions to address this increasing public health crisis [1]. Persons living with dementia often require many aspects of care, including dressing and support with daily activities as well as arranging for specialized health professionals such as nurses for personal care, advisors for legal issues, or accountants for financial assistance [3]. Most people living with dementia are cared for by family or informal caregivers, and the largest proportion of these caregivers comprises spouses, followed by children and children-in-law, with most being female [3]. The caregivers of people living with dementia face a significant burden considering that these caregivers themselves are often older or juggling their own professional and other family responsibilities [3]. To combat the increasing public health burden, the National Plan to Address Alzheimer's Disease called for enhancing support for people living with dementia and their families as well as further funding for AD research and the development of effective interventions [4,5].

The family caregivers of people living with dementia provide the vast majority of direct care and care management, and they face a high degree of psychological, physical, and financial stress [1]. These caregivers are most often family members or friends (eg, unpaid, family, or informal caregivers) [6]. There are >11 million family caregivers of people living with dementia in the United States providing an aggregate of >16 billion hours annually, with an estimated economic cost of US $271.6 billion for their care needs in 2021 alone [1]. These family caregivers are at greater risk of developing depression, anxiety, social isolation, and physical health problems because of the chronic stress associated with caregiving [6,7]. Moreover, caregivers encounter various additional challenges in their role, including difficulties in accessing relevant caregiving services and information, dissatisfaction with the quality or lack of trust in available services, and the inflexibility of existing service options [8]. Although previous research has highlighted general caregiving challenges, there is a lack of studies that specifically explore the financial (eg, where to find assistance if there are difficulties in paying for caregiving services), legal (eg, issues of guardianship), and functional (eg, assistance in meeting activities of daily living) difficulties experienced by family caregivers of people living with dementia. Therefore, it is imperative to highlight the importance of enhancing family caregiving support and gaining a comprehensive understanding of caregivers' challenges. Gaining a comprehensive understanding of caregivers' challenges and needed supports is essential for deriving real-world, practical solutions to improve caregivers' quality of life and, in turn, that of their care recipients living with dementia [9].

Several studies have suggested the importance of innovative technological solutions for empowering and supporting people living with dementia and their family caregivers [10,11]. Digital tools have presented promising means to assist family caregivers in seeking information to improve the care they provide to people living with dementia [12]. However, the information provided by currently available digital search engines and web-based educational resources is not always easily accessible or useful and is rarely individualized or tailored to the diverse needs of family caregivers. There is a need for more theory-driven digital tools to assist caregivers [13] and involve them in developing and designing digital health solutions [14]. A conceptual model derived from a web-based caregiver forum suggested that understanding individuals with ADRD, their caregivers, the caregiver–individual with ADRD dynamic, and the context of care is essential to improve care for individuals with AD or ADRD and their caregivers [15]. Future programs, tools, and services developed must involve caregivers early and be both accessible and tailored to caregivers' specific needs, which can, in turn, reduce the caregiving burden [7,16].

Objectives

Considering the need for caregiver-centered assistance tools, and in preparation for designing an interactive web-based artificial intelligence (AI)–driven digital resource platform, this study aimed to investigate (1) the legal, financial, and functional challenges that caregivers face in providing care for people living with dementia and (2) their expectations for the features of a digital health platform that assists in identifying and accessing the legal, financial, and functional care support and services needed to provide quality care and reduce caregiver burden.

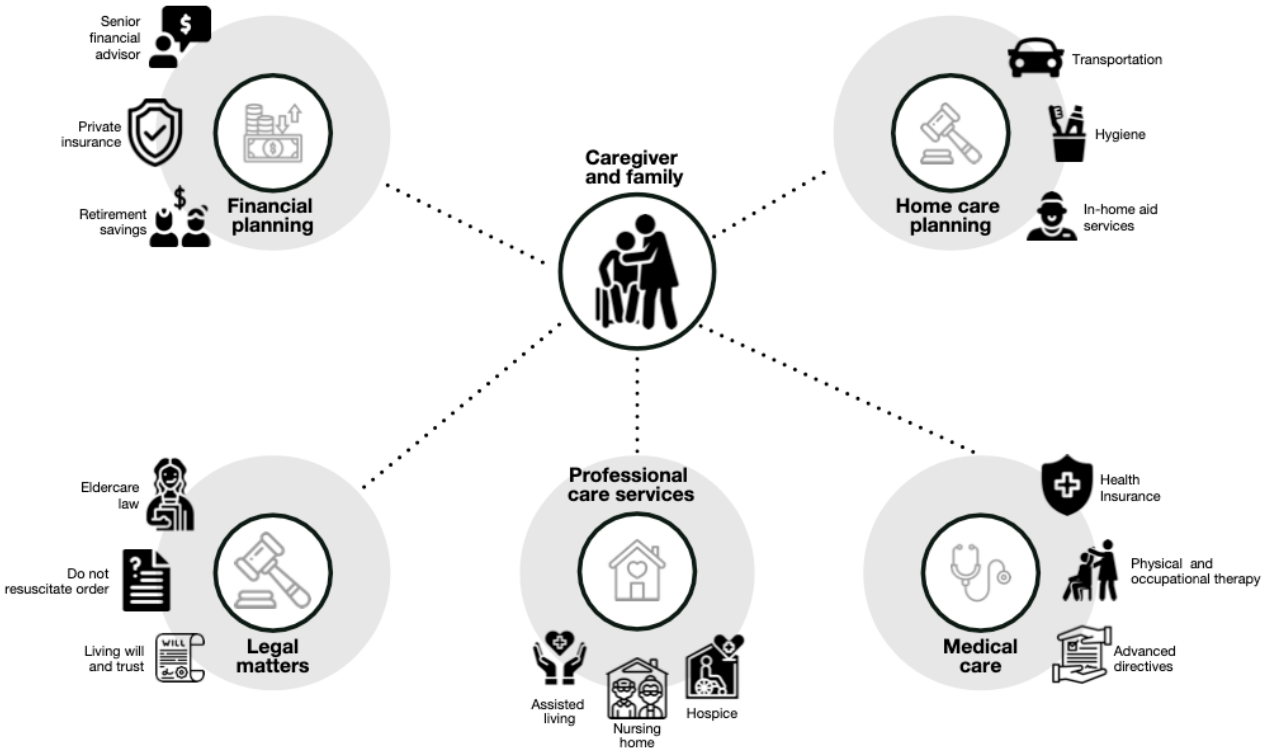
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Methods

Overview

In this study, a community-engaged research framework [17] was used to engage both researchers and communities of people living with dementia to identify and define health problems, determine the research questions asked, interpret results, develop interventions to address public health problems, and disseminate the results of the study. By engaging community members and researchers in understanding the key aspects of caregiving for individuals with AD and ADRD (Figure 1), a semistructured interview topic guide was developed.

Figure 1. Aspects of caregiving for individuals with Alzheimer disease or Alzheimer disease–related dementia.



The interview topic guide was formulated by leading researchers after considering the priorities expressed by relevant stakeholders who were part of our preliminary formative work. Pretesting of the interview topic guide was conducted with multiple caregivers. The final version (Multimedia Appendix 1) was achieved through collaborative discussions involving caregivers, community partners, and researchers. The following are some illustrative interview questions aimed at exploring the challenges and experiences related to caregiving as well as the expectations for a web-based tool designed to assist caregivers: (1) What was the most challenging aspect of finding and securing living arrangements or financial services or legal services for your care recipient? (2) Did you consult with any professionals to help you with caregiving responsibilities? If not, why not? If so, what kind of professionals and how did you select them? and (3) If you could have a "magic wand" to create a web-based tool or platform that would assist you with your caregiving, what kind of features would it have?

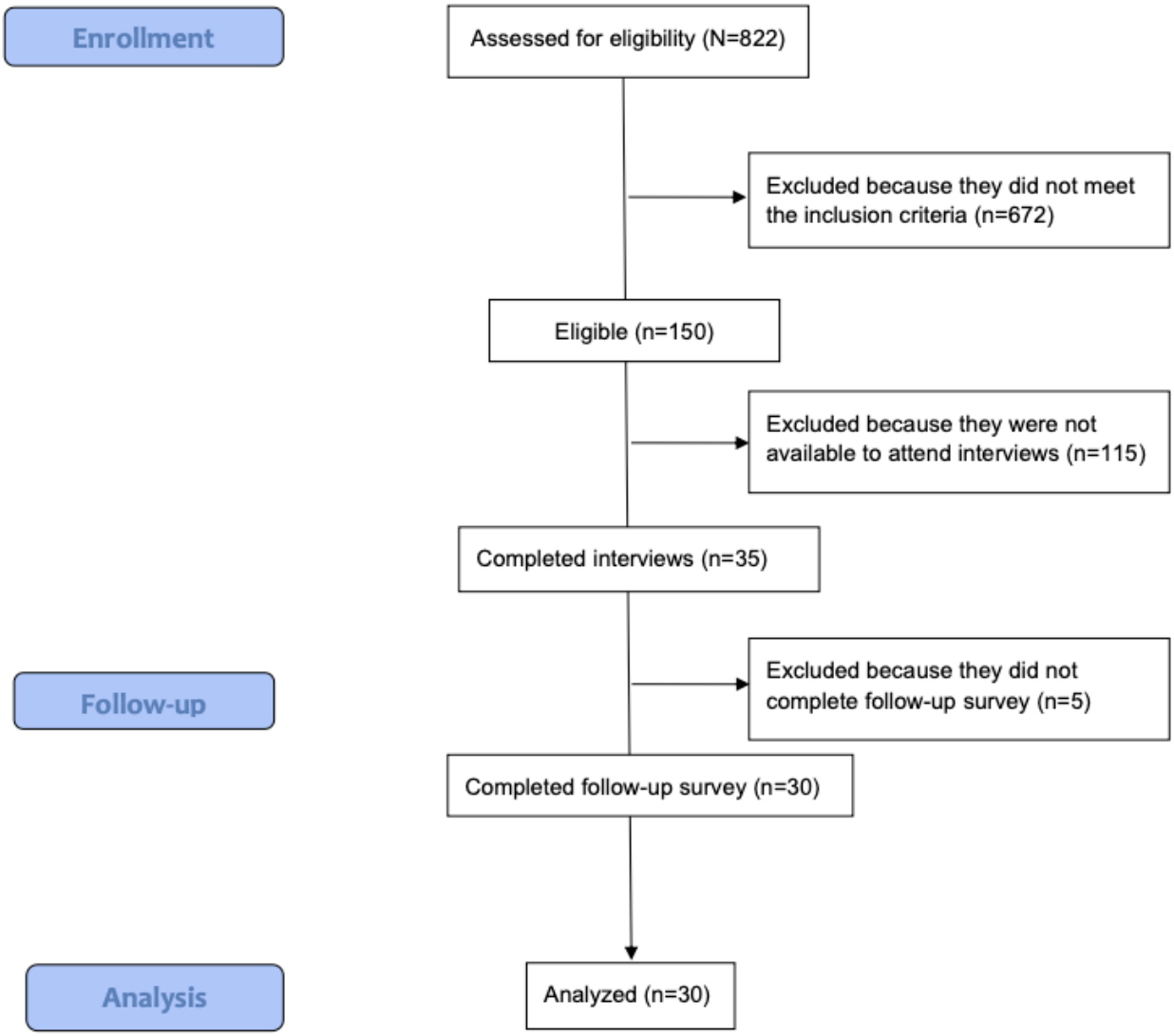
The findings of this study will contribute to the design of a digital health platform funded by the National Institute on Aging through the Small Business Innovation Research program aimed at enhancing caregiving support.

Study Setting

This qualitative study was conducted between January 1, 2022, and May 31, 2022. This study adopted a purposeful sampling method to recruit caregivers of people living with dementia through local dementia community service providers; word of mouth; and web-based approaches such as recruitment emails, flyers, and social media (eg, Facebook and LinkedIn). The sample size of the study was determined based on data saturation, referring to the stage at which further data collection is unlikely to provide novel information or alter the existing analysis and interpretations in qualitative studies [18]. All in-depth interviews were conducted in English using the Zoom (Zoom Video Communications) web-based platform. The research team consisted of members from diverse cultural, ethnic, and gender backgrounds, bringing together expertise in biomedical engineering, business, medicine, computer science, and public health. The process of enrollment, follow-up, and analysis is presented in the study flow diagram (Figure 2).

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Figure 2. Study flow diagram.



Participants

Individuals who conveyed an interest in the study were invited to complete a web-based screening questionnaire to assess their eligibility and willingness to participate. The questionnaire included an electronic informed consent agreement in English, which provided essential details about the study, including a description of the study objectives and activities, contact information of the study leaders and the institutional review board (IRB) agency that approved the study, confidentiality and privacy, compensation, and instructions on how to indicate voluntary participation.

The inclusion criteria for participants were as follows: individuals aged ≥18 years who were nonpaid caregivers of people living with dementia. These potential participants included adult children, spouses, partners, other family members, or legal guardians of people living with dementia who were actively involved in making legal and financial decisions. Moreover, participants had to be seeking eldercare services within the United States and had to have expressed concerns or a perceived need for more information on financial management and legal planning related to caregiving. In addition, access to a smartphone or computer with internet connectivity was necessary. Conversely, the exclusion criteria ensured that care recipients were living in the community, excluding nursing homes, locked memory care units, or other institutional settings. Furthermore, this study intentionally excluded formal caregivers, such as paid or professional caregivers, to focus solely on the experiences and challenges faced by nonpaid caregivers.

Procedures

Interested individuals were first invited to complete a web-based eligibility screening survey to assess their eligibility and willingness to participate. Eligible individuals were contacted via email and phone to arrange web-based in-depth interviews conducted in English. The interviews were conducted by study personnel via Zoom video calls that took place between January 2022 and May 2022. The study personnel who conducted the interviews were graduate students who had received training on human participant research and digital health information to familiarize themselves with the study context and participants. The study personnel began each interview with an information session and obtained verbal informed consent from the

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participants to take part and be recorded. Each interview was guided by the pretested semistructured interview topic guide, lasted approximately 40 to 60 minutes, and concluded by asking participants if they had additional questions. After the participants exited the session, there was often a short debriefing session among the study personnel. The recorded audio of the Zoom meeting in English was first transcribed using either Zoom or Otter.AI, an AI-powered automatic and real-time transcription tool. The transcripts were then cleaned by the study personnel and uploaded to a shared encrypted Dropbox drive (Dropbox, Inc). In May 2022, participants who had completed the interviews were contacted to complete a follow-up survey, which aimed to collect information regarding their demographic characteristics.

Analysis

Using the qualitative research framework approach [19], thematic analysis was conducted to identify and organize themes and the study findings. The framework approach was developed in the 1980s [20] and is widely used in analyzing qualitative data in health research [19]. This approach involves several key steps, including transcribing interviews, becoming familiar with the interview material, coding, developing an analytical framework, applying the analytical framework, charting data into the framework matrix, and interpreting the data [19]. The researchers read the transcripts to familiarize themselves with the data and developed the codebook in 3 steps. First, the researchers (QF, LD, MNH, and JV) developed a preliminary codebook using the interview topic guide and several randomly selected transcripts. Randomization was conducted by selecting transcripts represented by study ID numbers using analytical software. The researchers then determined a transcript with abundant findings to code together and revised the codebook in a group meeting. Finally, 2 independent coders (QF and MNH) coded 5 transcripts to refine and finalize the codebook with the guidance of experienced eldercare and qualitative research advisors (MGO, SL, and CLK). No new themes or codes came up while coding the remaining transcripts. The 2 coders (QF and MNH) independently coded all the transcripts using the Windows version of the NVivo (version 12.0; QSR International) software. The intercoder reliability was evaluated, with an average agreement rate of 98.52%, indicating almost perfect agreement. The study personnel (QF, LD, MNH, and JV) discussed any disagreements and reached a consensus after a thorough review. After completing the coding process, the researchers (QF and MNH) developed a framework and charted the findings into a framework matrix in a Microsoft Excel sheet (Microsoft Corp). This involved documenting the identified major themes, with subthemes nested under each major theme. For each subtheme, explanations and key quotes from participants reflecting the subtheme were provided.

Ethics Approval

The research team obtained ethics approval from the IRB at Texas A&M University (IRB approval IRB2021-0943D).

Informed Consent

The study personnel asked all participants for electronic informed consent in the screening survey and obtained verbal informed consent from participants before they were interviewed.

Results

Description of the Sample

Prescreening surveys were completed by 822 respondents, of whom 150 (18.2%) were eligible. Of those 150 eligible respondents, 30 (20%) participated in the in-depth interviews and completed the study survey. The background characteristics of the 30 interview participants are presented in Table 1. More than two-thirds (20/30, 67%) of the participants were primary caregivers for people living with dementia, and 93% (28/30) had provided care for at least 1 year. In total, 40% (12/30) of the participants had provided care for >40 hours a week for the past 3 months.

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Table 1. Background characteristics of the study participants (n=30).

Background characteristics	Values, n (%)
Role in providing care for ≥1 adults aged >50 years	
Participant is the primary caregiver	20 (67)
Someone else is the primary caregiver	4 (14)
The participant shared caregiving responsibilities approximately equally with someone else	5 (17)
Unknown	1 (3)
How long has the participant been providing care or assistance for the care recipients?	
At least 6 months but <1 year	2 (7)
At least 1 year but <5 years	14 (47)
At least 5 years but <10 years	8 (27)
≥10 years	6 (20)
Over the past 3 months, approximately how many hours per week has the participant provided some form of care for ≥1 adults aged >50 years?	
<20	9 (30)
20-40	9 (30)
>40	12 (40)
Participant's age (years)	
35-49	5 (17)
50-64	12 (40)
≥65	13 (43)
Sex	
Male	7 (23)
Female	23 (77)
Race	
American Indian or Alaska Native	1 (3)
Asian, Native Hawaiian, or Pacific Islander	1 (3)
Black or African American	2 (7)
White	25 (83)
Multiracial	1 (3)
Ethnicity	
Spanish, Hispanic, or Latino origin or descent	3 (10)
Other	27 (90)
Highest level of education completed	
Some college but no degree	5 (17)
Associate degree	3 (10)
Bachelor's degree	8 (27)
Graduate degree	14 (47)
Employment status	
Employed for wages	12 (40)
Homemaker or self-employed	4 (13)
Unemployed or unable to work	2 (7)
Retired	12 (40)
General financial status at the end of the month	

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Background characteristics	Values, n (%)
End up with some money left over	20 (67)
Have just enough to make ends meet	7 (23)
Does not have enough money to make ends meet	2 (7)
Does not know	1 (3)
Recruitment channel	
Web-based advertisement (eg, Facebook and LinkedIn)	11 (37)
Email invitation	13 (43)
In-person presentation	2 (7)
Personal connection	3 (10)
Other	1 (3)

A total of 83% (25/30) of the participants were aged >50 years. This study had 77% (23/30) female participants and 23% (7/30) male participants. In total, 83% (25/30) of the participants were White; the remainder were American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Pacific Islander, or multiracial individuals (5/30, 17%). The participants were 90% (27/30) non-Hispanic and 10% (3/30) Hispanic individuals. Regarding the highest level of education, 47% (14/30) of the participants had a graduate degree, 27% (8/30) had a bachelor's degree, 10% (3/30) had an associate degree, and 17% (5/30) had attended some college but did not have a degree. Of the 30 participants, 12 (40%) were employed for wages, 4 (13%) were homemakers or self-employed, 2 (7%) were unemployed or unable to work, and 12 (40%) were retired. A total of 67% (20/30) of the participants had some excess money at the end of each month, whereas other participants (9/30, 30%) had just enough to make ends meet or did not have enough to make ends meet. Most participants were recruited through email invitation (13/30, 43%) and web-based advertisements (11/30, 37%), but some were recruited through in-person presentations and personal connections (5/30, 17%).

Themes and Main Findings

Overview

The final codebook (Table 2) consisted of 7 topical codes and 30 secondary codes with specific definitions for each secondary code. On the basis of the codebook and coding results, Table 3 summarizes the findings of the interviews by presenting the major themes, subthemes, and subtheme descriptions.

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Table 2. Analytic codebook of this study after a 3-step testing procedure

Topical code and secondary code	Definition
Other caregiving challenges	
Caregiving challenges	Any other challenges that caregivers face and do not specifically belong in challenges related to older adult living, financial, and legal services for the care recipient
Living arrangements	
Had living arrangement challenges	Challenges regarding living arrangements (eg, nursing homes, assisted living, home care, hospice, and postacute care placement) for the care recipient
No challenges regarding living arrangements	Statement that living arrangements were simple in their case or description of the ease of living arrangement for the care recipient
Services used for living arrangements	Services, professionals, businesses, and facilities that a caregiver used to secure living arrangements for the care recipient
Factors for identification and selection	Factors (eg, cost, location, quality, and referral) that influenced identifying and selecting living facilities or at-home care agencies for the care recipient
Other	Any other information that was related to older adult living for the care recipient but did not fall into other existing codes
Financial	
Had financial challenges	Any stated challenges regarding the financial aspects of arranging care for a care recipient (eg, paying for care, accessing finances, and working with financial consultants)
No financial challenges	The participant stated that financial considerations for their caregiving experience were simple or not challenging for them. Description of the ease of arrangement of the financial situation of the care recipient.
Financial services used	Services, professionals, businesses, and consultants that a caregiver used to navigate any financial responsibilities associated with caring for a care recipient
Consulted financial professionals	The participant consulted financial professionals to help them navigate financial aspects of older adult care for the care recipient.
Did not consult financial professionals	The participant did not consult financial professionals to help them navigate financial aspects of older adult care for the care recipient.
Awareness of benefits and other support	Whether the participant was aware of any additional support or any available social benefits to help pay for care or navigate the financial aspects of caregiving
Other	Any other information that was related to the financial aspects of older adult care for the care recipient but did not fall into other existing codes
Legal	
Had legal challenges	Any stated challenges regarding the legal aspects of arranging care for the care recipient
No legal challenges	Description of the ease of arrangement of the legal situation of the care recipient
Consulted legal professionals	Confirmation of having consulted legal professionals to help them navigate the legal aspect of older adult care for the care recipient
Did not consult legal professionals	Confirmation of having not consulted any legal professionals to help them navigate the legal aspect of older adult care for the care recipient.
Advanced directives	The participant's comments or experiences with setting up advanced directives for the care recipient (advanced directives include 3 categories: living will, power of attorney, and health care proxy)
Other	Any other information that was related to the legal aspect of older adult care for the care recipient but did not fall into other existing codes
Caregiver support group	
Used caregiver support groups	Confirmation that the participant used or participated in any caregiver support groups
Did not use caregiver support groups	Confirmation that the participant did not use or participate in any caregiver support groups
Educational resources	
Educational resources that caregivers used in the past	Any educational topics or resources that participants had used in the past
Expected features of a platform	

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Topical code and secondary code	Definition
Education	The need for education materials, classes, programs, and peer-reviewed research evidence about caregiving for people living with dementia
Caregiver support group	The need for support groups or forums to connect with other caregivers of people living with dementia
Communication with health providers about care recipient's condition	Timely communication with health care providers to ask questions about the care recipient's condition
Information or database to find facilities, providers, or services	Obtaining information to find trustworthy facilities, providers, and services for care recipients
Mental health support for caregivers	The need for mental health support features of the digital platform, such as stress or anxiety management, affirmation techniques, or communication with mental health care providers about their own mental health
Task-based notifications or reminders	The need for task-based notifications or reminders, such as taking medication, submitting paperwork, and scheduling appointments
Quality of the platform	Any other qualities or ideal aspects of a web-based platform that should be included
Other	Other features that participants need that should be included in a web-based platform that did not fall into other existing codes

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Table 3. Themes, subthemes, and descriptions of subthemes

Theme and subtheme	Subtheme description
Emotional challenges and stressors	
Lack of support for mental health	Difficulty in obtaining mental health support or resources for caregivers themselves or a lack of mental health resources for the caregivers themselves
Physical health problems of family caregivers	The actual well-being and health of the caregiver as disabilities and other physical problems could hinder providing care for care recipients
Balancing multiple responsibilities	Various and multiple responsibilities in personal and professional lives that do not directly encompass caregiving
Evolving relationship with care recipients	Changes in dynamics between caregiver and care recipient because of dementia that can lead to conflicts or difficulties
Functional challenges of daily living	
Lack of information	Difficulty in obtaining educational information related to caregiving for people living with dementia or specific to the care recipient's stage of dementia to make decisions about older adult living arrangements
Availability of resources	Difficulty in obtaining older adult living resources (eg, professional caregivers, facilities, and housekeeping) because of the scarcity of resources was mentioned
Accessibility to resources	Difficulty in obtaining access to or receiving qualification for older adult living services or resources for the care recipient
Affordability of resources	Situations where cost of older adult living resources or services for the care recipient was prohibitive or the costs were too high to be affordable
Multiple caregiver dynamics	Situations or relationships that have influenced decisions made regarding caregiving for the care recipient because of caregiving responsibilities shared by multiple caregivers
Challenges with paying for dementia care	
Hard to understand the financial procedures	Challenges associated with understanding the necessary financial aspects or procedures associated with caring for a person living with dementia
Hard to navigate financial benefits programs	Challenges associated with navigating or using the materials or pecuniary support, programs, insurance, or other benefits that cover some costs of caregiving for people living with dementia
High cost of caregiving	Challenges associated with financially supporting or paying for necessary caregiving resources or services for people living with dementia
Difficulty in finding reliable financial professionals	Challenges associated with finding reliable financial professionals to seek advice or guidance from experts in financial aspects of caregiving for people living with dementia
Legal challenges	
Setting up advanced directives	Written statement of care recipient's wishes, such as will and powers of attorney
Lack of information for legal procedures	Challenges associated with understanding the legal aspects or necessary procedures associated with caring for a person living with dementia, including preparing documents
Difficulties in finding eldercare law attorneys	Difficulties encountered while attempting to find lawyers who specialize in eldercare law
Expectations for a web-based platform	
Mental health support groups	Groups of caregivers of people living with dementia in similar circumstances who can provide emotional support and practical advice to each other
Educational resources	Educational resources to educate caregivers on topics and useful practices related to dementia and caregiving for people living with dementia
Information database to obtain services	A comprehensive database tailored to the needs of caregivers and care recipients for specific caregiving services, including older adult living services, financial services, legal services, and mental health
Other qualities of a web-based platform	Any other qualities (eg, easy to use, esthetic, reliable, and interactive) or features (eg, communication tools and task-based reminders) of a web-based platform that should be included

Theme 1: Emotional Challenges and Stressors

All participants reported having some challenges when it came to caring for people living with dementia. These challenges included a lack of reliable guides and information on caregiving, a lack of support for caregivers' emotional health, caregivers' physical health issues, balancing multiple responsibilities, and evolving relationships and conflicts between caregivers and care recipients (Textbox 1).

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Textbox 1. Emotional challenges and stressors.

- Lack of support for caregivers' mental health
- Physical health issues with family caregivers
- Balancing multiple responsibilities
- Evolving relationships and conflicts between caregivers and care recipients

Many participants described caring for their loved ones as "stressful" and "overwhelming." One participant noted a sense of guilt and emotional conflict:

> *You feel like a failure for having to put him somewhere...It is not easy to navigate all that. And you do have those yucky feelings in the back of your mind that you do not want to do this, but yet, you know you should...* [PID030]

Another caregiver reported the mental toll of caregiving:

> *Because she was no longer handling things the way she had previously been able to, I found it very challenging, trying to maintain a kind of calmness and peace and stability in our home.* [PID0129]

Caregivers needed to balance many other professional and personal responsibilities, such as working and caring for other family members, and this often led to significant stress. One participant said the following:

> *I do not have the mental capacity right now. I am trying to get tenure, and I have a kid, and I am trying...to sell my mom's house...* [PID003]

Another participant mirrored the difficulties of balancing many responsibilities:

> *You know, trying to take care of my mom and then try to work a full-time job and then the other myriad other responsibilities. Things are pretty busy.* [PID006]

Another participant said the following:

> *Even though I work from home, to be able to take time off to attend a Zoom meeting or to go in person has not been feasible.* [PID0129]

Furthermore, caregivers were emotionally taxed by the evolution of their relationship with the people living with dementia as their loved one's cognition and memory declined. These evolving relationships sometimes led to conflicts that were excessively stressful to resolve. With spouses, several participants expressed emotional distress, with one saying the following:

> *One day, he was going to bed. I said, "I will be up soon." He turned around to me all seriously [and] said, "What does your husband think about this?" I was devastated. I thought, "Oh my goodness, he does not realize [he is my husband]."* [PID058]

Another familiar caregiver relationship that was often strained as the care recipient became increasingly dependent on the caregiver was the parent-child relationship. One participant said the following:

> *It is just hard seeing a parent on the slow decline...It is hard, as you can see, the cognition...It is sometimes sad. You know the person that you once knew is not the same person, but that does not make you love any less, but it tugs at your heart a little bit.* [PID092]

Another participant shared the strain on the parent-child relationship:

> *I see my mom and her behaviors that are all related to dementia. Sometimes, I have to have these walls that tell me it is not [that] she is not doing this to me, it is just the illness, so I do not take it personally.* [PID018]

Theme 2: Functional Challenges of Daily Living

Family caregivers often arranged living and functional assistance for care recipients. Some options usually included in-home professional caregivers; independent living arrangements; and senior communities such as assisted living facilities, nursing homes, or memory care. Furthermore, higher-acuity circumstances called for escalated care, such as that delivered in skilled nursing facilities and by palliative and hospice services. In a postacute illness situation (acute hospitalization, surgery, or significant illness), families may have needed to consider acute and subacute rehabilitation facilities, home health care services, and physical and occupational therapy agencies. Challenges that participants reported in finding suitable acute, subacute, and long-term living conditions included a lack of information on the types of assistance, difficulty comparing communities or support services, inability to pay or afford care, and difficulty assessing the quality of services (Textbox 2). For many participants, it was difficult to obtain educational information about the services offered by each type of entity and which types of services were recommended in different situations. This ambiguity affected the caregivers' decision-making and led to stress.

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Textbox 2. Functional challenges of daily living.

- Lack of information on types of assistance
- Difficulty comparing communities or support services
- Difficulty assessing the quality of services
- Difficult obtaining information about types of services appropriate for different situations
- Inability to pay or afford care

One participant directly expressed these difficulties:

> *[It's] been our experience when you look up assisted living facilities near me or whatever...If you check on one, there's no real way to contact that one. I don't even know where to begin. Do I even want to look at this facility if we can't afford it?...You can't get that information.* [PID030]

Another caregiver shared the difficulties of obtaining adequate information on older adult living services:

> *I was starting from nowhere and having to research...As for dementia, there's not a lot of information because everybody's different. Everybody, everyone, and every person with dementia have different meanings. So, it's a little learning as you go.* [PID113]

When another participant was asked about the challenges of finding older adult living services, the caregiver responded as follows:

> *[I] feel lost. We feel like we don't know what to do sometimes.* [PID022]

Another participant shared the difficulty of hiring reliable professional caregivers for the home:

> *Finding good caregivers was very difficult and a lot of time [was] having to manage the caregivers. [The caregiver] was as much work as having to help my mom and be there for my mom. There are many issues with the quality of care and people not showing up on time or things like that.* [PID003]

Theme 3: Challenges With Paying for Dementia Care

Family caregivers were also responsible for managing their older loved ones' financial arrangements, often being the sole managers of the care recipient's finances. In many cases, participants mentioned that the overall expenses for care, especially professional assistance, were too high, preventing them from initiating or maintaining such services (Textbox 3).

Textbox 3. Challenges with paying for dementia care.

- High expenses for care and professional assistance
- Challenges in finding affordable care
- Difficulty obtaining financial assistance
- Difficulty utilizing benefits
- Confusion of management of property, estate, and funds

One participant shared that finding affordable care was the primary challenge regarding eldercare:

> *She needs someone with her pretty much most of the time. It's something that we're not sure we can afford yet. That's the biggest thing is not being able to afford it.* [PID022]

Another participant shared the high cost of constant care for an older parent:

> *We have 24/7, 365 care for him. It's costly, but he can't be left alone for any real period of time.* [PID021]

Some caregivers immediately recognized their inability to pay for professional caregiving services, with one participant stating as follows:

> *I know that I financially could not pay for the cost of nursing home care.* [PID058]

Another financial challenge was caregivers' or care recipients' inability to qualify for certain financial health care benefits. One participant shared their difficulty using benefits:

> *He is a veteran. I've contacted the veteran association (VA), but you have to have a 70% or higher disability to gain access to their homes...He could eventually go on a waiting list, but the waiting list is long.* [PID058]

Another participant shared the difficulties of obtaining financial assistance because of specific qualifying parameters:

> *Medicare doesn't step in and won't help even with the in-home health unless she has a broken hip. And then they'll help with that. But for dementia alone, they don't want you to put them in a nursing home, but they also won't let you keep them [at] home or [give] help.* [PID064]

Some family caregivers found the management of property, estate, and funds stressful and confusing. For many,

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understanding the process of setting up financial documents was a daunting task, as one participant said:

> *For me, the most challenging has been finding out what I needed to do, getting the right paperwork done.* [PID109]

One participant expressed the difficulties of navigating the financial aspects of caregiving:

> *That was hard. There's just a lot of paperwork with being a power of attorney, the financial power of attorney, because every bank, every medical office, everything wants a copy of all this stuff...It's just very daunting and time-consuming for a person that doesn't know that going into it.* [PID003]

For many family caregivers, navigating insurance or other benefits that cover some caregiving costs was also challenging. One participant mentioned insurance policies:

> *Understanding the insurance and health things is overwhelming for me. I don't like sitting down trying to read insurance policies...Trying to navigate through that is overwhelming.* [PID093]

Many participants expressed difficulties completing the necessary steps to qualify for financial assistance programs. One participant shared their experience with such difficulties:

> *I guess the biggest thing is I'm having some issues with her [Social] security. My father passed away in March. And when he passed away, she was supposed to get his social security automatically and they haven't done that yet. And I'm still in the process of working on that...But with all the COVID and nobody having offices open, it's been tough.* [PID034]

Family caregivers were usually responsible for providing additional financial support, including supplementing the care recipients' resources (eg, savings, benefits, and insurance) when they were inadequate to cover the costs of needed services. One participant expressed the financial burden of caregiving:

> *[We pay] all out of pocket. There's no help that I know, and I have to pay for this kind of stuff...You know, you're always trying to calculate...What are we going to do if he lives beyond his money? It's not a great position to be here.* [PID021]

Another participant discussed the high out-of-pocket costs:

> *We don't have any long-term care insurance, and the costs are pretty high. It's going to go into our savings.* [PID027]

Theme 4: Legal Challenges

Families and caregivers often must prepare legal documents such as advanced directives so that their loved one's wishes can be communicated legally. Most participants admitted that setting up these advanced directives was a difficult decision and process that had to be made with family members and legal professionals (Textbox 4). One participant expressed the difficulties in setting up advanced directives:

> *I had spoken to my mother about, "Mom, you need to get these things in place." And we need to take care of these things. And she would just put it off, so it would have been much easier for me if all of this had already been put in place.* [PID129]

Textbox 4. Legal challenges.

- Challenges setting up legal documents including:
  - Advanced directives & living wills
  - Medical power of attorney
  - Financial power of attorney
  - Will / Probate
  - Guardianship
- Difficulty finding lawyers specializing in eldercare law

Another participant shared an aspect of setting up advanced directives that was particularly challenging:

> *The most challenging [aspect] was all the forms need[ed] a notary, so you [got to] get everything and get everybody together to go someplace and have it notarized.* [PID050]

Owing to the process of obtaining the necessary documents, many participants found it time-consuming, with one participant stating as follows:

> *[It is] time-consuming...It just takes forever to get it done.* [PID006]

In addition, participants reported a lack of available educational information about estate and asset management, making it hard for family caregivers to understand the legal aspects or necessary procedures for securing a loved one's belongings. Some participants shared the need for understanding such procedures:

> *Having the whole process more transparent would be phenomenal...It is convoluted and hard to understand, hard to figure out...* [PID102]

When addressing the challenges associated with asset management, one participant said the following:

> *It would be great to have that [professional legal advice], but I do not know how to find the help that I need in that area.* [PID106]

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Other participants also reported difficulty finding lawyers specializing in eldercare law when they realized that they lacked an understanding of the nuances of eldercare law, thus needing specialized legal assistance. One participant found deciding between different recommended lawyers difficult:

> *Just trying to decide among the different ones that were recommended was probably the most challenging part.* [PID027]

Another caregiver noted the following:

> *...the choices for a lawyer are very slim. There are very few lawyers that do senior law. And you want one that does senior law. We found one who eventually helped us with getting the durable power of attorney, which is the financial aspect and the medical power of attorney.* [PID064]

In addition, those who hired eldercare lawyers found working with them stressful and shared their experiences:

> *Knowing when to call them, wondering, "Is this phone call going to cost? Are there add-ons that my current attorney has told me about?" And she put everything in the hands of her paralegal, which I am only [able] to communicate with through email, so I try synthesizing my questions and thoughts and only write one email at a time.* [PID110]

Theme 5: Expectations for a Web-Based Platform

As the participants discussed the challenges mentioned in previous sections, they expressed their expectations of a future digital solution and how it would ideally assist caregivers of people living with dementia (Textbox 5). There was evidence of a need for a comprehensive digital platform that integrates mental health support, educational resources, an information database on older adult care services, and other quality features. One participant expressed the need for such a comprehensive digital platform:

> *To have one place that would say, "Have you thought about this? Have you thought about this?" would be helpful.* [PID030]

Textbox 5. Expectations for a web-based platform.

- A comprehensive database of commonly needed professional services
- Mental health support and caregiver support groups
- Educational resources on dementia and caregiving
- A platform that is easy to use, aesthetic, reliable, and interactive

Many participants reported that mental health– and caregiver-specific support groups on the digital platform would help them and reduce the dearth of mental health care available for caregivers of people living with dementia. They mentioned that caregiver groups could provide emotional support and practical advice to each other when experiencing similar situations. One participant expressed the need for online support groups:

> *I feel like a support group where you can communicate as much as you want...Then have a place to ask question[s]. That would be beneficial.* [PID003]

Another participant shared the need for self-care support:

> *Finding support groups is critical. We have to take care of ourselves before we take care of others.* [PID106]

Another participant shared the need for localization of these web-based support groups saying there should be "a chat function so you can connect with others from your area...the ability to connect with local people" (PID064).

Participants also would like a digital platform to provide caregivers with educational resources on dementia and caregiving for people living with dementia. Caregivers requested an increased number of web-based educational topics related to dementia that would be helpful in providing information on and good practices related to dementia and caregiving for people living with dementia. Some participants believed that these educational resources would be helpful in guiding them on the decision-making process, especially because there was a lack of information and understanding regarding dementia progression, older adult care, securing older adult living arrangements, and understanding the financial and legal processes involved. One participant expressed the importance of educational resources:

> *I think educating people on what is coming next is something that would at least help me. So, I know she is going to lose her memory, and she is not going to be able to remember anything or 90% of things. It is like mentally, physically, and around the house, I can now prepare for that. I have got to be able to think [about], this is what I am doing for them right now, [and] this is what it is going to be [in the future].* [PID106]

Other participants also shared that an educational resource on the progression of dementia would be helpful, such as one participant who stated as follows:

> *A timeline of progression in terms of someone's dementia...so I can have a view of the future.* [PID050]

One participant summarized their ideal digital platform for caregiving by saying the following:

> *We need a handbook on this saying, "Okay, you have got someone you love who has been diagnosed with dementia." Or even start before that, where "I think*

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> *my loved one might have dementia" and have a checklist of things to do next...I want a manual [on] how to do this [caregiving]*. [PID102]

There was widespread consensus among participants that a comprehensive database of commonly needed professional services would help caregivers and care recipients find older adult living communities, home care agencies, financial services, legal assistance, and mental health services. One participant said that a valuable aspect of a web-based platform would be "a database of available services. I think it would be great if there were some ways just to say, you know how I can get help with this, like getting [transportation for] my mom to the doctor" (PID007). Other participants expressed the desire for a system to review and compare caregiving services and said that there should be a functionality that allows caregivers to leave "...feedback or comments or reviews [from] people who work in the industry and their families who used the service" (PID003).

Participants also expressed their expectations regarding other qualities of a web-based platform. Many participants hoped that the web-based platform would be easy to use, esthetic, reliable, and interactive. One participant said that the platform should be "easily navigated by those of us who are not that tech savvy" (PID030). As they had limited time, several participants said that the web-based platform should be easy to use and understand. One participant said the following:

> *Just some of that stuff [in] more in plain language, where people do not have to research so much because it takes so much time [to research]*. [PID113]

Discussion

Principal Findings

This study focused on the legal, financial, and functional challenges of caregiving for a person living with dementia. Our thematic analysis of interviews with caregivers of people living with dementia showed that they are an underresourced group with widespread struggles as they balance a multitude of responsibilities, including familial obligations, work, financial burdens related to care, finding reliable services and assistance, navigating legal necessities, and seeking emotional support. To address these challenges, caregivers shared their expectations for a future digital tool that could help relieve some of their caregiving burden. Family caregivers reported their expectations for a comprehensive and easy-to-use digital health platform where they could search for educational and caregiving information; seek support from peer caregivers; and find reliable medical, financial, and legal professionals. Our results suggest that a comprehensive database is needed to locate reliable living facilities, find financial and legal professionals to set up documents, obtain timely advice from health care professionals and dementia experts, manage caregiving-related stress through support groups, and prepare for specific caregiving tasks by providing organized reminders and relevant caregiving education.

Following previous findings [21-23], our study confirmed that family caregivers face a variety of challenges, including a lack of mental health support, difficulties balancing multiple responsibilities, and a lack of information about various services. In addition, consistent with previous studies [8,24-26], caregivers reported limited availability, accessibility, and affordability of resources and difficulty finding reliable legal and financial professionals. Furthermore, we found that caregivers expressed concern about the insufficiency of current social benefits programs to cover the costs of caring for a loved one, underscoring a significant public policy landscape and indicating the need to develop, implement, maintain, and evaluate additional caregiver support programs [27].

In addition to supporting previous literature, there are several ways in which this study contributes to a current research gap. First, we found that the relationship between caregivers and their care recipients and the dynamics among multiple caregivers are significant factors in the care decisions of people living with dementia. Therefore, eldercare services must consider engaging families in a holistic decision-making process that accounts for multiple family caregivers and diverse stakeholders [28,29]. Furthermore, it is difficult for family caregivers to locate readily available and reliable information on the web about older adult living options and functional care, legal procedures, and navigating financial benefits and professionals. This indicates the unmet needs of family caregivers and the significant demand for comprehensive interventions and programs that provide information and assistance in navigating these processes and services. Therefore, solutions must be developed to support caregiving for people living with dementia and resolve conflicts between caregiving and work.

Owing to the various demands on their time, many caregivers face conflicts between family and work obligations that, in turn, may lead to possible work-related strain and a decrease in caregiving performance and quality [30]. Providing care for people living with dementia has also been reported to negatively affect caregivers' physical, mental, and social self-care [31], indicating the need to provide educational resources about self-care practices and a platform to connect caregivers faced with similar challenges. Therefore, providing care support such as task-based reminders, mental health support, and aid in locating professional services would be particularly beneficial to relieve the stress associated with balancing work and caregiving. This study also revealed that many family caregivers hoped that the digital tool would be easy to use, esthetic, reliable, and interactive. These findings may provide insights into the future development of digital platforms seeking to engage family caregivers of people living with dementia as target users.

It is critical to develop a digital platform that provides helpful and usable information to caregivers of people living with dementia. To provide more sophisticated care recommendations and support to caregivers of people living with dementia, AI and large language models can be used to offer a tailored yet comprehensive experience to these users. Large language models are highly efficient at processing large amounts of data, which can be used to sort through thousands of care options informed by the needs, location, and financial situation of the care recipient to find the right care solutions. To ensure that the AI-powered personalized care-matching model offers accurate

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and safe recommendations, quality control and standardization of the data used to train the model are critical. In addition, expert supervision should be used to validate and improve the accuracy and quality of the results. Finally, such a model must be regularly trained and updated using new data to ensure that it is current and accurate.

Limitations and Strengths

This study has several limitations. It was conducted via Zoom with relatively few participants, who tended to be well educated and had access to technology. As a result, this study may not reflect the full range of caregiving experiences. Relatedly, the participants' characteristics may not be representative of all family caregivers of people living with dementia. In addition, there may be biases in the analysis and interpretation of the study findings as 2 primary coders had varying degrees of direct experience providing care to people living with dementia. Finally, because of the focus of the analytical framework and predetermined research questions, as well as the potential limitation of using saturation as end point for recruitment [32], other personal caregiving experiences and participants' perspectives may be yet to be shared in full detail.

However, there are unique strengths to this study. First, this study reached data saturation based on group discussion and analysis [18], suggesting that the study findings summarized the perspectives of the study sample comprehensively. Second, participants were diverse regarding their socioeconomic characteristics, such as age and occupation, so their perspectives were valuable and applicable to many people. Most participants in this study were female (23/30, 77%), non-Hispanic White (27/30, 90%), and aged >50 years (25/30, 83%). This demographic composition aligns with the findings of the 2020 Caregiving in the U.S. report [33], which also highlighted that >50% of family caregivers share such demographics. Furthermore, the study team was composed of interdisciplinary researchers, multigroup coding was conducted, discussions regarding the analysis and results were thorough, and participants were fully engaged in the design and reporting of the study. Therefore, this study is one of the few studies carried out using a participatory-based approach [17] and has incorporated the theory of community-based research [34].

Conclusions

This study re-emphasizes the legal, financial, and functional challenges that caregivers face in providing care to persons living with dementia. All participants acknowledged challenges in their caregiving roles. Realities such as caregivers' physical and financial limitations were shown to exist within the context of many other challenges, demonstrating a complex, intersectional environment for family caregivers. Specifically, the most common challenges included balancing other family obligations and work, managing financial burdens, finding reliable services, navigating the legal or financial process, and seeking emotional health support. This offered a comprehensive view of this population's current challenges and a clear vision of potential resources and interventions that may support caregivers. Notably, participants expressed a need for a comprehensive digital platform. It was identified that such a platform should integrate mental health support, educational resources, an information database on older adult care services, and other quality features. Such a platform, coupled with a further comprehensive analysis of the struggles and limitations of current caregiver support, has the potential to assist this population of caregivers of people living with dementia significantly in their role.

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Authors' Contributions

LD, TF, SL and MGO contributed to study design; LD, TF, MNH, and QF contributed to study implementation and data collection; QF, MNH, LD, and JV contributed to data analysis; QF and MNH contributed to data interpretation; SL, MGO, and CLK contributed to supervision; QF, MNH, JV, DD contributed to the original draft writing; All authors contributed to critical revision of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Adapted caregiver interview script guide.
[PDF File (Adobe PDF File), 61 KB - aging_v6i1e47577_app1.pdf]

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Abbreviations

AD: Alzheimer disease
ADRD: Alzheimer disease–related dementia
AI: artificial intelligence
IRB: institutional review board

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Original Paper

Uptake and Use of Care Companion, a Web-Based Information Resource for Supporting Informal Carers of Older People: Mixed Methods Study

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Abstract

Background: Informal carers play a major role in supporting relatives and friends who are sick, disabled, or frail. Access to information, guidance, and support that are relevant to the lives and circumstances of carers is critical to carers feeling supported in their role. When unmet, this need is known to adversely affect carer resilience and well-being. To address this problem, Care Companion was co-designed with current and former carers and stakeholders as a free-to-use, web-based resource to provide access to a broad range of tailored information, including links to local and national resources.

Objective: This study aimed to investigate the real-world uptake and use of Care Companion in 1 region of England (with known carer population of approximately 100,000), with local health, community, and social care teams being asked to actively promote its use.

Methods: The study had a convergent parallel, mixed methods design and drew on the RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance) framework. Data included metrics from carers' use of Care Companion, surveys completed by users recruited through general practice, and interviews with carers and health and social care providers regarding their views about Care Companion and their response to it. Quantitative data were analyzed using descriptive statistics. Interview data were analyzed thematically and synthesized to create overarching themes. The qualitative findings were used for in-depth exploration and interpretation of quantitative results.

Results: Despite awareness-raising activities by relevant health, social care, and community organizations, there was limited uptake with only 556 carers (0.87% of the known carer population of 100,000) registering to use Care Companion in total, with median of 2 (mean 7.2; mode 2) visits per registered user. Interviews with carers (n=29) and stakeholders (n=12) identified 7 key themes that influenced registration, use, and perceived value: stakeholders' signposting of carers to Care Companion, expectations about Care Companion, activity levels and conflicting priorities, experience of using Care Companion, relevance to personal circumstances, social isolation and networks, and experience with digital technology. Although many interviewed carers felt that

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it was potentially useful, few considered it as being of direct relevance to their own circumstances. For some, concerns about social isolation and lack of hands-on support were more pressing issues than the need for information.

Conclusions: The gap between the enthusiastic views expressed by carers during Care Companion's co-design and the subsequent low level of uptake and user experience observed in this evaluation suggests that the co-design process may have lacked a sufficiently diverse set of viewpoints. Numerous factors were identified as contributing to Care Companion's level of use, some of which might have been anticipated during its co-design. More emphasis on the development and implementation, including continuing co-design support after deployment, may have supported increased use.

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KEYWORDS

informal carers; information technology; internet; information needs; mixed methods evaluation; Reach, Effectiveness, Adoption, Implementation, and Maintenance; RE-AIM; mobile phone

Introduction

Background

Informal carers (in this paper, referred to as carers but also known as family caregivers or unpaid carers) provide a substantial amount of support and care to adult family and friends who live with disability and declining health. In the United Kingdom, it has been estimated that there are approximately 10.6 million carers, and during 2020, the first year of the COVID-19 pandemic, they provided an estimated £193 billion (US $243 billion) of care [1,2]. Carers experience significant personal costs in terms of their own health and overall well-being, with many failing to receive the support that they require. This reflects the time-consuming, emotionally and physically exhausting, and often multifaceted caring activities associated with the complex needs of the care recipient [2]. The lack of support for carers is a contributory factor that may limit the capacity to continue caring [3]. With the increasing pressures on both health services and residential and community-based social care [4], there is a need for better ways of providing carer support [5].

In the United Kingdom, the Care Act (2014) recognizes the importance of information and guidance for developing and maintaining carers' skills and resilience [6]. However, many carers describe a lack of awareness about and access to information resources that are relevant to their changing needs and circumstances [2,7]. They often describe struggling to access and gain help from health and care systems that are difficult to navigate [7]. Reviews of in-person interventions that provide information and advice for carers of people with dementia have found varied results, but there is some evidence of benefit in alleviating caregiver symptoms of depression [8]. However, only a small minority of carers access in-person carer support services, in part owing to the difficulty of leaving the care recipient [9,10].

The internet provides ubiquitous access to information and advice, but it can feel impersonal, difficult to navigate, and unresponsive to individual circumstances [11]. It may be difficult to identify reliable, relevant sources of information [2]. Well-recognized barriers to carers' use of the internet for information include health and IT literacy, emotional strain, intensity of caring, and financial hardship [12]. Overall, 20% of carers aged >64 years (compared with 10% of young carers) feel that a lack of digital skills hinders their ability to use digital technology [2].

Although information about support services has traditionally been provided in paper format, there is evidence that many carers now prefer to receive information via web-based sources and that this can lead to improved well-being [5]. Compared with face-to-face services, internet-based support interventions are likely to be relatively low cost and potentially more readily tailored to individual needs and hence experienced as useful [13,14]. Their availability 24/7 can also help address the social isolation associated with caring [15]; several systematic reviews of internet-based supportive interventions for carers have reported their potential usefulness and impact on psychological outcomes [5,14-18]. However, many of these studies are small-scale, pilot studies, and the overall evidence base for internet-based interventions for carers remains limited [12].

In this paper, we have reported an evaluation of the real-world uptake and use of Care Companion, when made freely available in 1 region of England, including how registered users and local stakeholder organizations perceived its usefulness. As described in the following section, Care Companion is a web-based information resource that was co-designed to address the need for personalized information for carers, as described in previous *JMIR Aging* publications [19,20].

Care Companion

Care Companion was co-designed using a *person-based* approach that incorporated the perspectives of carers by synthesizing evidence from the research and policy literature, with active input from carers and stakeholders throughout the developmental process [21]. It was aimed at addressing 4 key challenges: burden of care, lack of knowledge, enhancing self-efficacy, and lack of time [19]. A panel of 5 carers recruited from local support groups provided detailed input regarding the design of its features and content, reflecting their first-hand experience of carers' needs, and input from a stakeholder group (representatives from local health service commissioning organizations, public health, social care, health providers, third sector, and voluntary organizations) allowed the incorporation of provider and policy perspectives [19].

Care Companion is underpinned by a biopsychosocial model that covers 5 independent domains (extending social assets, strengthening psychological resources, ensuring timely availability of key external resources, maintaining physical

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health, and safeguarding quality of life), targeted to strengthen carer resilience and coping [22]. A key feature is a rigorously curated library of trusted sources of web-based information and guidance on the broad range of issues that are relevant to the challenges that carers face in their caring roles [19]. Users are encouraged to regularly update their profile with information about their own and their care recipient's needs and circumstances. Care Companion draws on these data to filter information that is most likely to be of relevance to the carer and care recipient's circumstances.

Care Companion was launched in June 2018 as a free-to-use resource for people with adult caring responsibilities, tailored to the Coventry and Warwickshire subregion of the West Midlands, England. Its launch was included as part of the local government's Carers' Strategy and had the support of local Members of Parliament; local government policy makers and politicians; and key health, social care, and third-sector stakeholder organizations. Over the following 3 years, a broad range of local promotional activities were undertaken with health, social care, and community groups to encourage carer uptake. Alongside this, Care Companion was regularly updated with new content, and its functionality was improved in light of user feedback. From 2020, this included the addition of up-to-date COVID-19–related guidance and locally available support, including information about vaccines and local testing services.

Methods

Overview

The study design initially drew on the RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance) framework [23], an approach that assesses how public health interventions translate to real-world settings, using a convergent parallel, mixed methods approach [24]. The RE-AIM framework requires both qualitative and quantitative methods to understand its dimensions. We planned to explore how the characteristics of registered users compared with those of the wide population of carers within the study setting and how patterns of use were associated with mental health, well-being, and carer resilience to investigate effectiveness. Using qualitative methods, we also intended to explore factors affecting the reach, adoption, implementation, and maintenance of use of Care Companion from carer and stakeholder perspectives. However, the quantitative study was scaled back once it became evident that the level of use of Care Companion was insufficient to support meaningful data analysis. Instead, we focused data collection and analysis on data from Care Companion's user profiles and use histories; carer surveys; and interviews with carers and stakeholders relevant to consideration of the uptake, adoption, and ongoing use of Care Companion.

Setting

The study was conducted in Coventry and Warwickshire (a mixed urban and rural area with a total population of 963,173). According to the 2011 census, 66% of Coventry's population and 93% of Warwickshire's population are of White ethnic background, and approximately 100,000 people identified themselves as carers [25].

Carers' Panel

A panel of carers (chaired by GGS) was recruited from carers' groups in the study area to support the ongoing development, refinement, and implementation of Care Companion and the design and conduct of the study. The panel commented on all carer-facing research materials and contributed to data analysis and interpretation of findings.

Participants

The following three groups were included:

1. The study included carers who had registered as users of Care Companion before October 2020 (hereafter, referred to as group 1), following local public-facing and stakeholder organization promotional activity, described previously. They were informed about the study via email and notifications from Care Companion and invited to download participant information and complete a web-based consent form. The consent form included confirming that they had read and understood the participant information. Contact details were also provided, so that participants could ask any questions they had about the study.
2. The study included carers who registered to use Care Companion following signposting from their general practitioner (GP; hereafter, referred to as group 2). Between January 2021 and March 2021, a total of 14 general practices in geographically diverse (rural, urban, and semiurban) areas identified eligible individuals through their registers of patients' carers. Carers were excluded according to the following criteria:
   a. Carer or care recipient aged <18 years
   b. Not residing in Coventry or Warwickshire
   c. Unable to understand written English or provide informed consent
   d. Care recipient known to be acutely ill (eg, currently in hospital) or in the last few weeks of life

   Eligible carers were contacted either via SMS text message or mail, depending on the preference of each practice, and informed about Care Companion and the opportunity to participate in the study. SMS text messages contained links to web-based participant information and consent forms. Mailed letters included the participant information leaflet and a Freepost expression of interest reply slip; on its receipt, a member of the study team made contact to provide access to the consent form. Consented participants were asked to register with Care Companion and, if needed, were offered guidance on the registration process from a member of the research team.
3. The study also included local stakeholders. A wide range of individuals and organizations that provide services for carers, including representatives of charities, local authorities, health and social care commissioning organizations, and people working in the community such as librarians were encouraged to promote the use of Care Companion to their clients, patients, or members. They were contacted directly and via existing networks, newsletters, and phone calls. The same organizations were invited to consider participating in the evaluation, and those that expressed interest were provided with more detailed

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information about the study and followed up by the research team.

Data Collection

Data for the study were collected in the following ways.

Routine Data About the Use of Care Companion and Associated Materials

Data from the web hosting service were downloaded to provide anonymous information about individual user's visits to Care Companion, including visit duration and webpages accessed. In addition, data about the opening and use of web-based user guides, videos, email notifications aimed at new users, and monthly Care Companion newsletters were downloaded.

Carer Experiences of Care Companion

Carers (both group-1 and group-2 participants) were invited to participate in a semistructured phone interview. Topics included previous digital experience, views about and experiences of caring, motivation to use Care Companion, factors influencing their level of use, and intentions for future use.

In addition, participants recruited via general practice (group 2) were also asked to complete a web-based baseline survey to collect sociodemographic information and a follow-up survey (4-6 months after registration) covering the use of Care Companion, perceived barriers and facilitators, and a free-text space for further comments. Although a similar set of surveys was planned for carers who had registered with Care Companion directly (group 1), owing to the very low response rate to invitations to participate, we decided not to proceed with the second round.

Stakeholder Views About Care Companion

Stakeholders were invited to participate in a semistructured phone interview.

The recruitment of stakeholders occurred over a 12-month period, with approximately 350 organizations targeted initially. These covered a range of geographical areas and organization types identified through existing contacts, internet searches, recommendations from other groups, social media searches, and suggestions from the carer's panel. They included health-related organizations such as general practices; hospital-based teams; hospices; charities; and community-based groups including faith groups, support groups, community networks, and library services. Stakeholders were approached via email, phone calls, Facebook (Meta Platforms, Inc), or Teams (Microsoft Corp) or Zoom (Zoom Video Communications, Inc) meetings.

Of the those contacted, 52 (approximately 15% of the 350 organization) expressed interest and received further information via email, information leaflets, or meetings and were invited to participate in an interview.

The topic guide explored awareness and views about Care Companion; how they had promoted Care Companion to potential users; and perceptions about factors affecting its adoption, use, and relevance.

Data Analysis

Web Analytics

User logs were analyzed to identify the number of visits per user, number of actions performed by each user, and total time spent on Care Companion.

Survey Data

Descriptive statistics were produced using SPSS (IBM Corp) [26].

Interview Data

All interviews were digitally recorded and transcribed verbatim. Transcripts were entered into NVivo (QSR International) [27]. The interview data for the 3 groups of participants were coded separately by team members, overseen by VN, according to the steps proposed by Braun and Clarke [28]: familiarization with the data, generating initial codes, searching for themes, reviewing themes, and defining and naming themes. Themes were reviewed and discussed with all members of the project team and presented to the study's carers' panel. Further codes were generated to reflect the feedback from these sessions and applied to the data informing further thematic development.

Convergent Analysis

To identify and explore similarities and differences between the findings emerging from the quantitative and qualitative data analyses, we triangulated the themes identified in the analysis of the patient and stakeholder qualitative data sets and mapped these against the quantitative findings [29]. We then developed thematic categories that provide a representation of the whole data set to support the understanding of the factors that appear to influence the uptake and use of Care Companion.

Data Interpretation

Regular meetings were conducted with the carers' panel and a stakeholder panel to support the interpretation of findings and their implications. A workshop to gain further input was conducted with local health care, social care, and third-sector organizations, together with members of the study's carers' panel at the end of the study.

Ethical Considerations

The study received ethics approval from National Health Service (ID 271605; West Midlands–Edgbaston research ethics committee). All eligible individuals were provided with an information leaflet and consent form to be completed before their participation in the study. Consent was confirmed at the time of interview. Participants had the opportunity to withdraw from the study at any stage of data collection. The information leaflet explained that all study data would be deidentified to ensure the anonymity of participants. Participants did not receive any incentive or payment.

Results

Care Companion Users and Study Participants

By October 2020, there were 476 registered users of Care Companion (0.74% of the registered carer population of 100,000 in the catchment area). Between January 2021 and March 2021,

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a further 80 (3.8% of the 2105 invited to participate in the study) by general practices registered with Care Companion, giving a total of 556 users (0.87% of the registered carer population of 100,000).

Overall, 62 different care recipient conditions were recorded in the user profiles; the most frequent were Alzheimer disease and other dementias (188/556, 33.8% of the profiles), anxiety (146/556, 26.3%), depression (120/556, 21.6%), osteoarthritis (104/556, 18.7%), type 2 diabetes (76/556, 13.6%), and urinary incontinence (68/556, 12.2%).

Carer Interviews and Surveys

In total, 60 carers expressed interest in being interviewed, and 29 (48%) consented and were interviewed; this comprised 67% (10/15) from group 1 and 42% (19/45) from group 2, with a range of characteristics (Table 1). They had experience of caring that ranged from 2.5 to 30 years in duration.

Table 1. Characteristics of interview participants.

Characteristics	Group-1 carers, n (%)	Group-2 carers, n (%)
Age group (years)		
<50 (n=7)	3 (43)	4 (57)
50-64 (n=7)	1 (14)	6 (86)
≥65 (n=13)	4 (31)	9 (69)
Missing (n=2)	2 (100)	0 (0)
Sex		
Female (n=19)	5 (26)	14 (74)
Male (n=10)	5 (50)	5 (50)

In addition, 80% (64/80) of the carers who consented to participate following general practice recruitment (group 2) completed the baseline survey (Table 2). Most (50/64, 78%) were female, 42% (27/64) were aged ≥65 years, 95% (61/64) were of White ethnicity, and 50% (32/64) had a higher education qualification. They reported a wide range of different caring responsibilities, with more than half (39/64, 61%) caring for someone who did not receive professional care; the mean time they reported as spent in caring was 6 days per week and 10 hours per day. In total, 33 (52%) of the 64 group-2 participants completed the follow-up survey.

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Table 2. Characteristics of group-2 carers who completed the baseline survey (n=64).

Characteristics	Group-2 participants, n (%)
Age group (years)	
<50	13 (20)
50-64	24 (38)
≥65	27 (42)
Sex	
Male	14 (22)
Female	50 (78)
Qualification	
General Certificate of Secondary Education or equivalent	18 (28)
Level A or equivalent	7 (11)
Higher education	32 (50)
Other	7 (11)
Employment status	
Full-time paid work	18 (28)
Part-time paid work	5 (8)
Retired	24 (38)
Looking after family or home	10 (16)
Other	6 (9)
Presence of any long-term health condition	
Yes	22 (34)
Ethnic group or background	
Ethnic minority group	3 (5)
White	61 (95)

Stakeholder Interviews

From 349 invitations to participate sent to relevant stakeholders (individuals and organizations), 52 (14.9%) expressed interest in being interviewed and 12 (3.4%) interviews were completed (Table 3). This included frontline workers and managers of related organizations from charities, local authorities, and health services. Recruitment occurred during the first year of the pandemic; it proved difficult to engage stakeholders' interest in the study at a time when the health and social care systems were under considerable pressure.

Table 3. Organization types and role of stakeholders who were interviewed.

ID	Stakeholder role	Organization type
S-01	Manager	Dementia charity
S-02	Frontline worker	Community outreach
S-03	Manager	Health services
S-04	Frontline worker	Health services
S-05	Frontline worker	Community group
S-06	Manager	Cancer charity
S-07	Manager	Carers charity
S-08	Frontline worker	Secondary care
S-09	Manager	Social enterprise
S-10	Manager	Secondary care and community nursing provider
S-11	Frontline worker	Carers charity
S-12	Manager	Local authority

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Key Findings

Overview

From the integrated findings, seven overarching themes were identified that were associated with the reach, adoption, implementation, and maintenance of Care Companion:

1. Stakeholders' signposting of carers to Care Companion
2. Expectations about Care Companion
3. Care Companion activity levels and conflicting priorities
4. Experience of using Care Companion
5. Relevance to personal circumstances
6. Social isolation and networks
7. Experience with digital technology

These are presented in the following sections with illustrative quotes for each theme: S indicates a stakeholder participant, C1 indicates a group-1 carer participant who registered with Care Companion directly, and C2 indicates a group-2 carer participant who registered following an invitation sent by their GP.

Stakeholders' Signposting of Carers to Care Companion

Although several stakeholder participants described ways in which they had publicized the availability of Care Companion to carers in the area, such as through notices in their newsletters or by adding links to Care Companion through their website, only 1 of the interviewees had actively promoted its use as part of the service they provide to patients or clients. Others felt that it was inappropriate to "promote" Care Companion in preference to other available resources and apps:

> *We signpost to it for the benefit of the carers on our courses...So we don't send out the link. The link is on the form...for them to read if they want to.* [S-09]

> *I send out newsletters to carers in Coventry and Warwickshire and I often feature some of the apps that are on there and Care Companion is one of the ones that I do promote...And that goes out to 4,600 carers in Coventry and nearly 2,000 carers in Warwickshire.* [S-11]

> *We do promote it at our health and wellbeing events which we have monthly...they should be getting a leaflet in their pre-assessment packs.* [S-06]

These promotional activities had led some carers to register with Care Companion:

> *I think [signpost to Care Companion] must have been from a Carers Trust thing.* [C1-15]

Expectations About Care Companion

Carers gave wide-ranging reasons for registering with Care Companion. There was a general expectation that Care Companion might help with the challenges associated with their current circumstances but often without a view about how this would happen:

> *It was suggested to me by a friend actually. They'd heard of it, they hadn't actually used it, but...they said to me, "Do you know what, this might actually be really useful for you...Probably worth having a look at."* [C1-10]

> *I thought it would probably be a good idea as a way to find out about it and to see if it would be useful to me and help my life be a bit more easier.* [C1-12]

Some were clear about how they expected Care Companion to help them address information needs that were condition specific or service related:

> *I was very conscious of the fact that when we come out of lockdown I need to know about local services and things and what's...going on...and what's on offer.* [C1-13]

Although Care Companion does not provide functionality to enable contact with other carers for peer support, some carers mistakenly expected that it would offer this benefit and help address feelings of being alone:

> *I really just wanted someone to talk to someone, you know, someone who understood.* [C2-03]

A stakeholder interviewee also misunderstood what Care Companion offers and thought that it allowed interaction with "care companions" through direct communication or on the web:

> *Oh, I think if the Care Companions have the training and the knowledge, and I'm sure they do, of the signs to look out for when a carer's not so mentally well, and how they can support them...* [S-10]

Care Companion Activity Levels and Conflicting Priorities

As shown in Table 4, analysis of the web logs indicated that most carers who registered with Care Companion made little use of the resource. The mode and the median number of visits to the resource was 2, the median total number of actions (web pages clicked on, diary entries, etc) was 37, and the median total time spent on Care Companion was 26.7 minutes.

Table 4. Number of visits and actions and total time spent on Care Companion per registered user.

	Values, mean	Values, median (range)	Values, mode
Total number of visits/user	7.2	2 (1-125)	2
Total number of actions/user	85	37 (2-1479)	40
Total time spent on Care Companion (min)/user	75.5	26.7 (1.5-1210)	N/A[a]

[a]N/A: not applicable.

There were relatively high levels of engagement with the 6-week Care Companion email campaign that was automatically sent to users following their initial registration. These each focused on a specific topic related to *Getting the most out of Care*

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Companion, However, the opening rate for these emails dropped from 73% in week 1 to 54% by week 6, with the click rate (measuring interaction with an email) dropping from approximately 20% to <5%.

There was similar attenuation in the viewing of the YouTube tutorial videos that were associated with each of the engagement emails, from approximately 60 views each for the first videos that introduced how to use Care Companion to <10 views per video for latter ones that covered specific functions, suggesting diminishing interest over time.

From the interviews with carers, lack of time was a frequently described barrier to the use of Care Companion. Many carers attributed this to competing demands, whether at work or at home, in the context of already feeling that they were "at full stretch" and viewing Care Companion as something that involved a time investment:

> *If I'm honest I dipped in...I think the, the problem is because I'm working and I've got loads on...I really need to sort of sit down and set up, if that makes sense. And I haven't really had time to do so.* [C2-69]

> *It takes time for me to invest in [Care Companion] by recording things or entering information, or putting details in the address book and things like that, that's the biggest limitation to me.* [C1-12]

This view was echoed by a stakeholder who had heard it expressed by carers:

> *They might not have time to prioritise it and it's not something which they feel is worth prioritising because it's a, a, "Nice to have as a carer," rather than a, "It's going to provide me with immediate results now in this minute.*" [S-03]

Experience of Using Care Companion

The follow-up carer survey found that, of the 33 participants, only 7 (21%) described having used Care Companion within the previous 3 months, 4 (12%) felt that it had useful information, and 3 (9%) agreed that it had helped them cope with their role as a carer. The most frequently used functions within Care Companion were its diary, the resources section, and the help videos. Other parts (eg, mood monitor, directory of useful contacts, and frequently answered questions and glossary section) were rarely or never used. Of the 33 participants, 4 (12%) participants anticipated their use of Care Companion to increase in future, 11 (33%) anticipated that it would stay the same, and the remainder (18/33, 55%) anticipated a decline. Although 70% (19/27) of the participants agreed or were neutral about viewing Care Companion as relevant to their personal situation, most tended to agree or were neutral regarding with statements that they could find the information more easily elsewhere (22/28, 79%) and that Care Companion being time consuming to use (20/29, 69%).

Several stakeholders felt that Care Companion was relevant to supporting the needs of carers in terms of offering a supportive resource, accessible at any time and from anywhere:

> *I think it's important to utilise, you know the online world that we have internet and all that...And, you know, you don't necessarily have to go to, drive to, a class or, or you know, see a counsellor, or something like that.* [S-13]

> *I think there's so much information and resources that carers are able to tap into, and I think because [Care Companion] helps with sort of looking at what's available in their local community...that's really important to the carers. As is having sort of diary functions on there, with the address book where they can sort of put in the information. I think that's all really, really useful.* [S-11]

Some carers felt that there was a lack of breadth in the resources included, whereas others felt that it needed a more narrowly defined focus on the needs of a specific subgroup of carers:

> *My only complaint would be that everything is now coming from the same place...But there's no other, you know, no other point of view and, and no other opinion.* [C1-10]

> *I think you need to narrow the focus down significantly...I mean, by trying to do everything, you're doing everything badly, if I could be brutally honest...* [C2-72]

Some felt that Care Companion was most likely to be of value to those who were taking on new caring roles; however, some felt that it needed to offer a more directive, instructional approach:

> *If somebody is just starting to look after someone, you're floundering about knowing which organisations – should it be social services, should it be health services, should it be a particular support group? So having a central website that you can log onto, would be very useful, and yes I would recommend it.* [C2-73]

> *I was hoping that there would be a bit more on, "I'm a new carer. What do I do?"...From my past experience, it helps if you've got like this first thing, roadmap or whatever you want to call it...* [C1-15]

Relevance to Personal Circumstances

Some carers described ways in which Care Companion had helped them access local services or find information that was relevant to their needs and their care recipients at times when this was needed:

> *There is loads and loads of information. And it's all in one place which is good. And there's links, isn't there, so it goes off to other pages if you need them.* [C1-09]

> *I was having a really bad week, I thought, "Oh, I'm gonna have a look at Care Companion] and see what I can find." And I came across, I think it was the Carers Team. Anyway, I contacted them, somebody rang me back...* [C2-10]

> *I did spend quite a lot of time [on Care Companion] researching things, sometimes for my own health, not just my mother's health.* [C1-15]

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However, other carers described difficulty in finding information that was directly relevant to the complex situation and challenges that they were facing:

> *There is a lot of information on there, and it is quite easy to navigate around, it's just obviously knowing what bit you're looking for. For me, that's where I find it difficult...such a complex situation.* [C2-101]

> *I don't think Care Companion can help me on that, because it's really a very tricky thing, dementia.* [C1-05]

Several carers described how they already had established ways of managing their carer responsibilities (eg, using paper diaries, spreadsheets, and web-based search engines) and saw little added value from Care Companion. This view was also recognized by some stakeholders:

> *I keep like a proper address book anyway...And my diary tends to be written on the calendar or even, you know, occasionally I'll, I'll put stuff on the computer if it's something that, that I need a definite reminder about.* [C1-10]

> *They already use their smartphone for example which allows them to collate some of that information already or they've already got an app...or they already use a hard copy journal or various different things and they don't feel that [Care Companion] gives them anything extra.* [S-03]

Some features, although viewed as being valuable by stakeholders, were not felt by carers to be important. Potentially, they could be burdensome, and their usefulness, in terms of how this would help the carer and the person they cared for, was unclear:

> *The mood monitor [in Care Companion], I think that's really beneficial for people. For the cared for and the carer. Particularly that it can help them to kind of highlight any patterns.* [S-12]

> *I'm not that interested in putting smiley faces [Care Companion's mood monitor].* [C2-19]

Social Isolation and Networks

Both carer and stakeholder participants expressed disappointment that Care Companion does not tackle social isolation more directly as one of the most important issues for carers:

> *There's a high percentage [of carers] that are socially isolated 'cause they can't leave the home. So they would physically benefit from having somebody come in and physically seeing them...I do know that they enjoy, speaking face-to-face is their preferred option.* [S-11]

> *I'm sure it's good, I'm not criticising it...But I'm the sort of person who'd rather talk to someone, you know.* [C2-29]

However, participants recognized that Care Companion might enable access to social networks, by providing information about their availability and how to access them, and to services. This provided reassurance:

> *I can see they've got lists of contacts and things like that would be really good...things that I haven't used yet, but I might use in the future...Kind of reassuring knowing it was there for the future. It'll be on the day when I, I'm tearing my hair out that you...reach for it.* [C2-105]

Being unable to share appointments or have multiple carers on 1 care recipient profile was seen by some as limiting the usefulness of Care Companion:

> *I wouldn't use it for appointments and things. Because I need to see my appointments and my husband's appointments and my mum's appointments, and my husband needs to see them as well.* [C2-73]

Experience With Digital Technology

From the baseline carers' survey, when asked about their use of the internet in general, of the 33 participants, 28 (85%) reported using a smartphone daily, 26 (79%) checked emails daily, and 22 (67%) used the internet daily to check the news and weather, whereas 21 (64%) used internet searches daily. Approximately two-thirds (20/33, 61%) did weekly web-based shopping and one-third (10/33, 30%) were using apps and websites (not including Care Companion) to assist in their caring role.

Carer interviews identified differing levels of confidence in using digital technology, which in turn affected their view about Care Companion. For some, IT experience had developed considerably during the COVID-19 pandemic, for example, by obtaining a smartphone and becoming skilled at meeting family and friends via videoconference. Many already used search engines for information regarding services or particular health conditions related to their caring roles:

> *My daughter lives 300 miles in xxx, so I've bought a smartphone so I can WhatsApp her and message her. I use a computer for ordering food, you know. I wouldn't say I'm, I'm very good, but I've got a smartphone and I can order stuff and, and WhatsApp my daughter.* [C2-03]

> *And also Zoom which a couple of months ago I'd never heard about or, well, I've heard about but never done anything with it, but I have Zoom meetings now nearly almost twice a week...[C1-05]*

The benefit of using Care Companion instead of search engines to avoid the risk of being overwhelmed by links to websites of spurious quality was generally recognized; however, there were some carers who expressed being comfortable with using search engines:

> *...To have information] in one place is very good. 'Cause as soon as you start, you put some of this stuff in Google, it just brings, brings a huge list out and...massive list. And also, you don't know the quality of the sites that you're looking at...* [C2-99]

> *And the resources are good. I like the resources. But...it's trying to decide how are the resources*

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> *different on Care Companion to what I can just Google.* [C1-12]

Some stakeholders expressed concerns that carers who lacked IT access or literacy would be unable to use Care Companion:

> *None of our clients or the people that we work with have been significantly interested in, in pursing it...common reasons include that they aren't very technological savvy...[S-03]*
>
> *There is that downside that there are those carers who can't access [Care Companion] because...they don't have the technology or up-to-date smartphones and things like this to be able to.* [S-07]

Discussion

Principal Findings

This study of the real-world use of Care Companion, a freely available web-based information resource codeveloped to address the needs of informal carers, found that in the first 3 years following its launch, uptake remained low. Only 476 carers (0.74% of the area's known carer population of 100,000) registered to use it following general promotion via health care, social care, third-sector, and voluntary organizations and a further 80 (3.8% of the known population of 2105 carers in the participating practices) registered following invitations from GPs. Most registered users only logged into Care Companion once or twice. Although most stakeholder and carer participants identified potential value in Care Companion's content, many felt that it was likely to be more relevant when first becoming a carer or when the care recipient's needs were undergoing significant change.

Overall, 7 themes were identified, which affected carers' uptake and use of Care Companion. Key issues included mixed understanding of Care Companion's purpose and content (both by carers and stakeholders); the lack of time to explore what Care Companion's offers, reflecting conflicting carer priorities and concerns; perceived lack of relevance to current personal needs, such as social isolation and the need for hands-on support; and the perceived effort required to use Care Companion outweighing any expected benefit. Many carers felt that their existing coping strategies limited their immediate need for a resource of this type, and some believed that their current situation was very complex for Care Companion to be of benefit.

Although Care Companion was launched before the COVID-19 pandemic, data collection was undertaken at the time when social distancing, lockdown, and shielding restrictions were still in place. Although carers had to cope with extra demands, great isolation, and significantly great strain on their mental health [2,30,31], there was no evidence that this increased the interest in using Care Companion; instead, these extra demands may have limited the time and the privacy that carers had available to explore Care Companion.

Few stakeholder organizations appeared to have actively encouraged their frontline staff to promote the use of Care Companion to their carers. This may have reflected skepticism about the importance or value of providing an information resource and agnosticism over the endorsement of apps or web-based services in general. In addition, stakeholders had mixed understanding of Care Companion's content and functions and concerns that the use of Care Companion might exacerbate inequalities, given the limited digital literacy and access to IT for some older carers [2].

The multidimensional focus of Care Companion reflected the priorities that emerged during its co-design [19], but there were widely divergent views expressed in this study about whether this was a strength or a limitation. Some carers viewed Care Companion as lacking focus and direction, especially for individuals who are new to caring roles, whereas for others, it was felt to lack relevance to the complexity of their caring needs and situation. This highlights the need for widely diverse views to be included in the co-design process, as this was an issue that had not emerged previously.

Although Care Companion could be used by the carer and care recipient together to support mutual dependency [32], its design did not facilitate such interaction. Furthermore, its profile could not accommodate the carer having >1 care recipient to care for or conditions where a couple were cocaring for each other. This may have limited perceptions about its usefulness. An element that was intended for shared use was the mood monitor that provided a means of recording carer and care recipient moods. However, this emerged as being one of the least used components of Care Companion, with few carers feeling that it was meaningful in the context of managing their carer and care recipient relationship.

At the time of this study, Care Companion was internet-based and not available as an app. Apps are generally experienced as being more convenient, faster, and easier to browse than websites [33]. Although Care Companion provided multiple functions, which emerged as a recommendation in a recent review of mobile apps for carers [34], not being available in an app format may have contributed to the time and difficulties involved in its use.

Comparison With Previous Studies

Older adults' willingness to adopt new technologies is most influenced by its perceived value, the perceived improvement in quality of life that might follow, and their confidence in being able to use it [35]. Although the co-design of Care Companion was intended to optimize its relevance and ease of use, the findings from this study indicate that carers had mixed views about the relevance of Care Companion, effort involved in its use, and likelihood of it having a significant impact on their caring role and quality of life, which contributed to the low level of use.

However, Care Companion is not unusual in its low levels of uptake among carers; multiple studies have reported low uptake rates for digital interventions and decreasing use over time [36,37]. As has been observed for other digital and telehealth interventions for carers, time and effort are key barriers to uptake and use, in addition to how they fit into carers' current routines [38,39]. Care Companion was described by some carers as lacking sufficient relevance to their personal needs to merit the time and effort required to fully engage with it. Many carers felt that the task of setting up an alternative approach, such as

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that needed to use Care Companion's diary function, would add to their problems rather than relieve them.

Care Companion was based on a transactional approach to the support of carers: it provided information and methods for organizing the day and keeping track of events and contacts. This was intended to help carers feel more in control, be better informed, and build resilience. However, recent evaluations of interventions, both digital and face to face, have emphasized the relational or emotional aspects of caring and the need for information provision and other supportive measures to acknowledge and take account of these in their methods of delivery [40,41]. Exploratory investigation adopting a *capabilities approach* has also highlighted the relational nature of caring, focusing on the value of the capability for caring in relation to other valued capabilities and their potential conflict [42].

A number of multiple-component interventions have found that facilitating interaction with professionals is more beneficial than information alone [43,44], with carers expressing frustration when required to review information that was not directly relevant to their specific needs [45,46]. The Europe-wide InformCare web platform, for example, also found that its information resources area was infrequently used but that its interactive services, social network, and private messaging, which addressed caregivers' needs to communicate with others and share experiences, were more widely accessed [47].

A limitation of Care Companion perceived by several stakeholders and carers was that it did not directly provide a means of interaction with peers or professional support. During the co-design of Care Companion, consideration had been given to the inclusion of peer interaction through some kind of forum, but it was decided that rather than replicating the availability of several established web-based forums, Care Companion should promote awareness of such forums and support groups through its resources section. The benefits of web-based peer networks, either alone or as an element within a broad intervention, have been demonstrated [36,48]. However, studies delivering multicomponent programs that included unstructured support by professionals and peers did not show significant changes in psychological outcomes [49,50],

Strengths and Limitations

A key methodological strength of this study is that it involved a mixed methods exploration of real-world patterns of use and the reasons underlying this. The study drew on a wide range of quantitative and qualitative data sources to describe what happens when a resource such as Care Companion is made available to the carer population without any requirement for carers to commit to using it in a particular way or within a specific time frame. However, the comparatively low levels of registration in and use of Care Companion severely limited the extent to which meaningful quantitative and qualitative analyses could be undertaken. However, the overarching themes that emerged from the convergent data synthesis enabled a broad representation of the reach, adoption, and use of Care Companion.

The interviews with carers and stakeholders allowed a range of perspectives to be identified and provided insights into the possible facilitators of and barriers to the uptake and use of Care Companion. In addition, there was regular patient and public involvement throughout the study, which aimed to ensure that the design, data collection, and interpretation of findings reflected the priorities of carers. However, the study was limited to carers who had registered with Care Companion, and hence, it was beyond its scope to evaluate why carers did not register. The experiences and views described by the study participants who registered and then made little use of Care Companion are likely to overlap with those of carers who chose not to register at all; there may have been other reasons that contributed to carers not registering with Care Companion that we failed to identify.

The COVID-19 pandemic added to the difficulties of promoting interest in Care Companion among stakeholders and carer groups. Carer groups completely stopped meeting or attempted to meet on the web during the pandemic. This may have adversely affected registration with the resource and participation in the study. For example, the recruitment of stakeholders occurred during the last few months of 2020, a time during the COVID-19 pandemic when many stakeholders were working from home and difficult to reach or had been furloughed and when involvement in research may not have been viewed as a priority.

Conclusions

This evaluation of Care Companion found a very low level of uptake and use following an area-wide launch and signposting to carers by stakeholder organizations. The gap between the views of carers and stakeholders expressed during the co-design and user acceptance testing [19,20], with the subsequent real-world experience following its launch, raises 2 issues. The first is about the inclusivity and diversity of the carers and stakeholders participating in the co-design and the extent to which their views were heard and reflected in the development and implementation of Care Companion. Inevitably, carers and stakeholders who volunteer to participate in a co-design process are likely to be more interested and committed to its intended outcome than their peers. This highlights the importance of actively seeking as diverse a range of viewpoints as possible during intervention co-design: more rigorous testing of the design with the target population before proceeding with its development may then have seen more of the 476 people who registered with Care Companion make significant use of it. However, when introducing an innovation, there is only so much that can be learned about users' requirements before they have the opportunity to use it in practice [51]. The second issue is about the provision of support after deployment that will enable an innovation to evolve alongside users' emerging requirements [52,53]. The importance of designing effective, interactive, and dynamic ways of addressing carers' complex and varied information needs as a key part of their support remains as an issue.

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Data Availability

The data sets generated and analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

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Abbreviations

GP: general practitioner
RE-AIM: Reach, Effectiveness, Adoption, Implementation, and Maintenance

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Viewpoint

A Perspective on Using Virtual Reality to Incorporate the Affective Context of Everyday Falls Into Fall Prevention

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Abstract

Virtual reality (VR) is a promising and cost-effective tool that has the potential to reduce the prevalence of falls and locomotor impairments in older adults. However, we believe that existing VR-based approaches to prevent falls do not mimic the full breadth of perceptual, cognitive, and motor demands that older adults encounter in daily life. Researchers have not yet fully leveraged VR to address affective factors related to fall risk, and how stressors such as anxiety influence older adult balance and real-world falls. In this perspective paper, we propose developing VR-based tools that replicate the affective demands of real-world falls (eg, crossing the street) to enhance fall prevention diagnostics and interventions by capturing the underlying processes that influence everyday mobility. An effort to replicate realistic scenarios that precipitate falls in VR environments will inform evidence-based diagnostics and individualize interventions in a way that could reduce falls in older adults in daily life.

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KEYWORDS

aging; balance; perturbation; locomotion; cognition; exergame; anxiety

Introduction

Annually, 1 in 4 older adults are injured from falling [1], and the incidence rates [2] and resulting morbidities continue to rise [3]. Alongside rapidly advancing virtual reality (VR) technology, scientists and clinicians are working to predict and prevent falls using a range of nonimmersive and immersive techniques [4-6]. Yet, researchers are only beginning to understand the potential benefits of VR technologies and their capabilities to target the perceptual, cognitive, and motor processes related to fall risk [7]. We believe there is a disconnect between how VR is currently used to understand and prevent falls in experimental settings and its capacity to identify and target the processes that are involved when older adults fall in daily life.

We argue that scientists currently using VR technology to evaluate and modify fall risk often overlook stressors such as anxiety or the “fear of falling” that are associated with higher prevalence of falls [8,9]. As we age, we use more attentional capacity while walking and stepping becomes less “automatic” [10]; thus, the added cognitive demand of fear of falling could be detrimental to balance and gait for older people [11-14]. Our underlying argument is that the context of balance control is important, and scientists should aim to create paradigms that better replicate the challenges that older adults experience during everyday walking to understand and prevent falls. By not representing the affective context that exists in the real world in VR-based tasks and interventions, we fail to address the interactions between perceptual, cognitive, and motor processes that underlie effective or maladaptive balance in daily life [15-18]. Scientists now have a unique opportunity to develop VR-based tools that facilitate interactions with realistic mobility contexts that induce anxiety as in the real world (eg, crossing a busy street at night and walking in a crowded mall). By using

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VR to engage with realistic contexts, we could better identify older adults who are most at risk of falling and develop refined interventions to prevent falls.

Our overarching interests are to establish early diagnostics that identify who is at greatest risk of falling and develop specific interventions that reduce the risk of falls in everyday life. In this perspective paper, we discuss leveraging the rising popularity of VR to develop meaningful protocols for diagnosing and treating the risk of falling in older adults. Specifically, we discuss how VR simulations can recreate the typical perceptual, cognitive, motor, and affective demands of daily life to facilitate diagnostics and interventions that reduce the risk of falling. The key points discussed in this paper are shown in Textbox 1.

Textbox 1. Key points discussed in this perspective.

- Scientists should aim to better replicate the challenges that older adults experience during everyday walking to understand and prevent falls.
- We do not yet know if the experimental outcomes emerging from laboratory-based studies are representative of behavior in everyday life. However, virtual reality (VR) technology allows us to probe mobility-related affective responses with threats to stability and balance control.
- VR can simulate everyday situational demands and quantify responses with high resolution, thereby helping to bridge the gap between laboratory-based research outcomes and everyday fall risk.
- We propose a focus on scenarios where older individuals experience a fear of falling to identify associated deficits in perceptual, cognitive, and motor processes.
- To better detect everyday fall risk, scientists should incrementally challenge sensory, motor, and cognitive systems using a contextually appropriate VR-based stress test for fall risk.
- Using VR to address individual differences by measuring learning trajectories allows for tailored challenge points and appropriate difficulty levels that optimize learning.
- VR therapies successfully reduce anxiety in younger people; it is not hard to imagine a future where VR could help older adults overcome a fear of falling and cope with mobility-related anxiety.

The Problem: Research on Fear of Falling and Fall Risk in Older Adults

As a result of poor "balance confidence" or low "falls efficacy," many older adults report a "fear of falling" and experience mobility-related anxiety during locomotion [16]. We provide a brief overview of how fear and anxiety influence fall risk (ie, the physiological and cognitive response to a perceived threat in a balance or walking task). We refer the reader elsewhere for detailed reviews that distinguish these processes from concepts such as concern about falling [13,16,18]. Older adults who experience a fall are more likely to exhibit gait impairments and suffer higher incidents of falling [19,20]. We define "mobility-related anxiety" as a phobia specific to walking that is associated with increased physiological arousal and cognitive stress, which interferes with perceptual, cognitive, and motor processes during walking in young and older adults [12,21-24]. Both self-reported fear of falling and mobility-related anxiety are believed to impair cognitive-motor control, predisposing older adults to a greater risk of slips, trips, and falls [13,14,18]. However, there may be some protective element to mobility-related anxiety, encouraging older adults to compensate for poor balance by "consciously monitoring" their actions in efforts to remain safe [17]. The degree that mobility-related anxiety impedes or protects older adult balance is still unclear because current evidence is only supported by cross-sectional associations between fear of falling and motor outcomes [25], fall incidences [26], or anxiety-related responses from experimental manipulations (eg, raising participants on a platform) [11,23,27]. The experimental tasks used by scientists and clinicians are strictly controlled, and consequently, these tasks may not induce anxiety in a way that represents the anxiety-inducing experiences of older adults in real-world mobility scenarios (eg, crossing a busy street at night). We argue that scientists should leverage advances in technology to develop representative mobility tasks within VR simulations while simultaneously retaining experimental control. VR presents an ideal tool to create realistic contexts that would enhance and individualize fall-risk detection and prevention.

Current Ways to Use VR to Study Mobility-Related Anxiety

Scientists interested in the effects of anxiety on mobility have predominantly used VR to create controlled experiments that answer fundamental science questions. Unfortunately, often the experimental conditions induced have limited relation to situations encountered in daily life. For example, our previous work has shown that immersive VR can be used to increase mobility-related anxiety in healthy people by simulating standing on a wooden plank and raising the walkway approximately 15 meters above ground level [24,28]. Although our approach allowed us to answer important questions about anxiety and motor control, we are hesitant to equate our results to behaviors in daily life. Historically, obtaining results that are representative of everyday tasks, or "representative task design," has been a persistent limitation across many fields [29,30]. We do not yet know if the experimental outcomes emerging from controlled, laboratory-based studies are representative of behavior in everyday life. However, existing VR technology lends itself to probing affective responses by systematically imposing mobility-related threats to stability and testing balance control across external task constraints.

Scientists have typically used VR to induce mobility-related anxiety by replicating laboratory-based studies that physically raise participants to elevated heights [23,27,31]. The aim is to stimulate affective systems by increasing the perceived consequences of falling, also known as "postural threat" [23,31].

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Simulating elevated heights in VR elicits similar changes to state anxiety (ie, subjective ratings) and motor behavior (ie, smaller postural sway area) as in the real world [32-34]. Various types of threatening contexts can elicit anxiety-related responses, ranging from simulated heights in a replicated laboratory environment [33,35,36] to riding an open elevator [37] and walking across a deep pit [38,39].

Another approach to study mobility-specific anxiety is to increase the difficulty of the locomotor task by walking on a narrow path. By increasing attentional demand and the energy cost of gait patterns [40,41], a narrower path imposes a demanding locomotor constraint that requires participants to continuously adapt and monitor their steps. A narrower step width also involves intrinsic risk appraisal by challenging stability; participants must evaluate their balance and devote added attentional resources to compensate for their anticipated missteps [42]. We interpret the added cognitive load of taking narrower steps as analogous to the "conscious monitoring" experienced by older adults who are anxious while walking [13,43].

VR-based tools can combine environmental and task-specific influences on mobility-related anxiety, emphasizing their potential to systematically examine the interactions between key perceptual, cognitive, and motor behaviors. Walking in VR on broad and narrow roads, and at low and high elevations, can reveal complex interactions between anxiety, cognition, and motor behavior in young and older adults [44]. For instance, combining path width and height manipulations in VR increases motor difficulty in addition to multiplying to consequences of a fall, forcing participants to prioritize performing the task safely versus quickly, revealing the interactions between mobility-related anxiety and motor performance [44]. Challenging balance in threatening VR environments (an increasingly narrowing path) reveals that balance confidence mediates the efficacy of older adults' stepping responses [45,46]. Cumulatively, these results highlight the salience of mobility-related anxiety in locomotor behavior and its potential importance in improving balance and reducing fall risk.

However, while VR has led to advances in understanding mobility-related anxiety and balance, there remains a disconnect between experimental manipulations of anxiety responses and the lived experience of older adults suffering from mobility-related anxiety in daily life. We propose that researchers use VR to simultaneously test the influence of task- and environmentally driven affective responses on locomotion, while working to develop generalizable applications. We envision VR could be used as a tool to generate outcomes that are experimentally controlled, while simultaneously being representative of everyday contexts that precipitate real-world falls.

Current Ways to Use VR-Based Technology for Fall Prevention

Overview

While our perspective details ways to enhance the application of VR for fall prevention, existing empirical evidence already supports the use of VR-based tools for preventing falls in older adults. We overview the current use of VR technology in fall-prevention research with reference to the following three general categories of current technology: (1) nonimmersive VR; (2) augmented reality (AR); and (3) immersive VR. We consider the advantages and disadvantages of each approach with regard to older adult fall prevention.

Nonimmersive VR

The majority of published reports focusing on the benefits of VR-based tools in older adult fall prevention use nonimmersive devices that range in design and application [47-54]. Nonimmersive technology typically delivers a gamified rehabilitation goal and provides 2D visual feedback of body position or motor performance on a television display. Position detection capabilities vary and include simpler platform or controller-based devices, such as a Wii balance board or Wii Fit (Nintendo), as well as optical tracking systems ranging from the X-box Kinect (Microsoft) to high-speed infrared cameras using expensive motion capture techniques such as the CAREN (Motek). Visual stimuli range from a low-cost flat-screen television presented at eye level [55] to digital projections onto a treadmill belt [56], to a 180 curved floor-to-ceiling projection screen [45,57,58]. Interactions within VR afford many options for providing biofeedback [59], where the majority of nonimmersive video games present both feedback of body position and knowledge of performance outcomes [6,55]. However, a lack of consistency in delivery and application of visual biofeedback in immersive VR [24,38,60] makes it difficult to determine if nonimmersive therapeutic protocols and positive effects are replicable or might be enhanced with advanced technology [61,62]. One significant issue relating to standardization of protocols relates to limited accessibility, as many nonimmersive VR tools are no longer commercially available. Nonimmersive VR applications therefore require custom programming, rendering the product commercially unscalable and only suitable for research purposes.

Augmented Reality

AR, or mixed reality, is a unique technology with great potential to train balance and reduce falls using ecologically valid locomotor tasks. AR overlays 3D virtual illusions through interactive games within the individual's real-world setting, typically using face-worn eyeglasses or goggles. Integrating the game into the real-world setting and feedback of oneself likely enhances the "task specificity" of AR-based tools for transferring performance to real-world balance and gait tasks [63]. AR has also shown promise in providing social interaction and psychological support for older people; its primary advantage for health-related applications may be its capacity to increase motivation to engage in physical training [63,64]. Perhaps a result of shifting gaze to look at or look through a peripheral display, lateral stability is compromised by AR glasses [65], which may be particularly detrimental for older adult fallers who are worse at controlling mediolateral balance [66]. AR technology shows great promise for everyday fall prevention, but development is lagging with respect to user-friendly programming and commercial accessibility, especially for older adults [63].

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Immersive VR

Typically delivered via a head-worn virtual display, or head-mounted display (HMD), immersive VR replaces one's current setting with an interactive 2D (eg, video-based) or 3D (eg, digitally rendered) environment. By blocking out sensory feedback from the outside world, immersive VR presents an opportunity to stimulate sensory, and motor systems for fall prevention. Advances in graphic design and rendering capabilities have drastically improved the realism of immersive VR simulations and multiplied the potential experiences representative of daily life. Impaired older adults (ie, immobile or cognitively impaired) can experience 2D images using an HMD (usually video-based stimuli), without negative side effects such as motion sickness [67]. An HMD obstructs visual feedback of body position without added accessories or specific game development, which influences the control of basic perception and action [68] and locomotor control in VR simulations [62]. We speculate that ongoing bodily feedback may be a key difference between immersive and projection-based treadmill VR environments, facilitating a greater sense of immersion (measured as self-reported "presence") during an elevated height simulation [69,70], and higher levels of reported anxiety in projection-based approaches when compared to an immersive HMD [71,72]. Table 1 presents the advantages and disadvantages of different VR types to prevent falls.

Table 1. Advantages and disadvantages of different types of virtual reality (VR) to prevent falls.

VR types	Advantages	Disadvantages
Nonimmersive VR	• Feasible for use with older adults in community settings [51] and people with Parkinson disease [73] • Benefits impaired populations such as stroke survivors [74,75] and people with Parkinson disease [76,77] • Interventions improve performance on physical function tests related to fall risk [52,53,78], reduce fear of falling and depression [79,80], and reduce the incidence of falls in frail older adults [78] • Can replicate balance perturbation training techniques with visual perturbations [35,58] that improve balance recovery and reduce real-world falls [81,82].	• A lack of consistency in delivery or application of visual biofeedback (ie, displaying motor performance versus results, or both) make it difficult to determine if therapeutic results are replicable • Most nonimmersive VR equipment is no longer commercially available and requires custom programming that is only suitable for research purposes
AR[a]	• AR interactions take place in everyday settings and can serve as realistic substitutes for environmental manipulations or cues. Placing AR obstacles in one's path simulates the task of avoiding them as if they existed in reality, but without the trip hazard [83] • AR-based visual and audio cues often improve gait characteristics in people with neurological conditions, particularly people with Parkinson disease [84]	• Lateral stability is compromised by AR glasses [65], which may be particularly detrimental for older adults prone to falling or those with deficits in controlling mediolateral balance [66] • Older adults report current AR goggles as heavy and uncomfortable during balance training [85], an issue that could be addressed by forthcoming technology mimicking traditional spectacles • Development is lagging with respect to user-friendly programming and commercial accessibility, especially for older adults [63]
Immersive VR	• Can systematically implement visual perturbations (ie, shifting the room suddenly) that induce a sensation of falling [86], leading to a decline in stability and forcing older adults to practice and train reactive balance recovery in a safer way [87,88] • Using immersive VR to manipulate visual input during clinical physical function tests better detects fall risk [89]	• Immersive HMD[b] technology can be difficult to operate [90] • Bulky and uncomfortable to wear [91] • Limiting the visual field of view [92] • Sometimes causing motion sickness [93] that could be interpreted as a sign of a potential fall by at-risk older adults • HMDs obstruct visual feedback of body position without added hardware or customized programming to track body position. The absence of visual feedback influences basic perception and action [68], locomotor control [62], and interactions between anxiety and motor control in anxiety-inducing VR simulations [94]

[a]AR: augmented reality.

[b]HMD: head-mounted display.

Incorporating the Context of Everyday Falls Into Fall Prevention

Rehabilitation scientists are limited in their ability to replicate complex everyday scenarios and elicit representative anxiety, hindering the ecological validity and translation of existing approaches. Simultaneously, we have yet to find a way to measure perceptual, cognitive, and motor processes in the real world without using disruptive and resource-heavy equipment. To address both limitations, VR can simulate everyday situational demands and quantify responses with high resolution,

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thereby helping to bridge the gap between laboratory-based research outcomes and everyday fall risk. As opposed to evaluating physical function in sterile clinical settings with clear hallways, using VR to challenge older adult mobility within an ecologically valid setting would better reveal real-world mobility deficits, thereby potentially leading to enhanced therapies to reduce fall risk.

Crossing the street at night is an example of a locomotor context that elicits a specific mobility-related anxiety and requires effective perceptual (eg, judging the distance to oncoming hazards with low-quality visual feedback), cognitive (eg, gathering and retaining limited visual and spatial information in working memory to monitor position), and motor adaptations (ie, neuromuscular coordination and step targeting) to achieve safely. It may therefore be no surprise that older adults experience a higher prevalence of traffic-related injuries compared to younger pedestrians; a consequence attributed to a host of individual, task, and environmental factors [95], including self-reported fear of falling [96]. The capability of VR-based tools to replicate a street-crossing simulation for older adults was demonstrated in a series of studies using a projection-based room with a 360° simulation of a busy street and crosswalk [97], allowing people to move through a realistic 3D visual surround. The results show when older pedestrians avoid moving traffic, their cognitive-motor “workload” is higher than when crossing an empty street, leading older adults to walk faster and ignore traffic-avoidance–related tasks [98]. These latter behaviors are reminiscent of older adults in artificial anxiety-inducing settings (ie, a narrow or elevated walkway) [44]. A similar study recently used a street-crossing paradigm in an immersive commercial HMD apparatus measuring eye tracking, locomotor behavior, and cognitive performance to draw inferences about pedestrian behaviors in young adults [99]. Such studies highlight the potential to use VR to simulate realistic everyday contexts that challenge affective responses while being feasible for older adult users. We believe further efforts are needed to develop similar immersive, yet effective, VR-based approaches using simulations of real-world contexts where falls are common.

The greater challenge is to capture behavior from fearful older adults during threatening walking scenarios and best use VR to quantify behaviors that perpetuate falls. We propose a focus on scenarios where older individuals experience a fear of falling, especially in settings leading to real-world falls such as stairwells, escalators, crowded sidewalks, shopping malls, or nighttime streets. Borrowing from the concepts developed from successful trauma-focused VR-based treatment of posttraumatic stress disorder (PTSD) in soldiers [99,100], combat scenarios are predictable sources of phobic anxiety. Therefore, presenting a realistic combat scenario in VR is likely to elicit a phobic response. Yet, we cannot be certain which scenarios cause anxiety responses for older adults in real life and how those vary individually. We propose qualitative interview-based inquiry [101], a type of “needs assessment” or “task analysis,” as a step toward determining the scenarios that are anxiety inducing for older adults with motor impairments related to a concern about falling. Our previous qualitative work interviewed fearful older adults to examine their thoughts during hypothetical scenarios leading to falls, and our findings debunked popular theories about attentional focus (ie, attentional control theory) under anxiety or stress developed using data from athletes [102]. Whereas athletes are distracted by a "threat bias" in attentional control that is maladaptive in competitive settings [103], we showed that some degree of "conscious monitoring" dring walking is protective for older adults who realistically appraise their sense of control in the situation [17]. Only individuals who expressed lacking a sense of control demonstrated a maladaptive fear of falling [17], highlighting the value of qualitative inquiry in translating theory into population-specific interventions.

VR environments that represent everyday situations associated with a fear of falling would allow clinicians to examine locomotor performance on a range of functional tasks in a fall risk "stress test". Such a virtual “stress test” was recently demonstrated in a functional VR game using an urban scenario designed for rehabilitating activities of daily living [104]. The “UrbanRehab” VR tool was created to optimize ecological validity and challenge outdoor mobility in urban settings to train and enhance movement. The creators of the UrbanRehab program began with a focus group of rehabilitation specialists and aimed to create an environment where patients could be challenged with a variety of different tasks in a realistic cityscape. The challenges and achievements of the UrbanRehab program are reported from a developer’s perspective in further detail [104], highlighting the development-related challenges of designing and implementing realistic VR games for rehabilitation. For example, designing realistic games that enable functional movement is limited by in-home space constraints, presenting a common and difficult challenge that developers must overcome. However, the UrbanRehab initiative represents an exciting first step in realizing the potential for VR to reduce real-world falls.

A major advantage of VR is the capability to address individual differences due to its capacity to change the level of task difficulty and create appropriate “challenge points” or “desirable difficulties” [105]. To better detect everyday fall risk, a range of typical sensory, motor, and cognitive challenge points can be incorporated into a contextually appropriate VR-based stress test for fall risk. For instance, incorporating increasingly physiologically demanding locomotor tasks as challenge points, such as changes in walking speed along a crosswalk, could better reveal fall risk related to poor lower limb strength or power [106] and may be a better predictor of fall risk than measuring walking at comfortable speeds [107]. VR-based challenge points can present increasingly difficult but realistic obstacles for avoidance such as potholes, puddles, or oncoming pedestrians [108], which would better identify people who struggle to maintain balance during complex stepping tasks [109]. Challenging balance control in VR with dynamic locomotor tasks such as turning would reveal deficits in motor control mechanisms that are relevant to everyday falls [110,111]. Using challenge points to progressively manipulate visual flow during walking [46,57] or walking in increasingly low-light settings [112] would flag sensory integration deficits for intervention (ie, proper corrective eye wear, visuo-motor training) before they become a problem [113]. Finally, presenting increasingly complicated but realistic concurrent

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cognitive tasks as challenge points, such as concurrently monitoring a clock or oncoming pedestrians [99], would better identify older people at risk of real-world falls due to cognitive-motoric deficits [114,115]. In sum, VR allows scientists to measure performance across different challenge points, whereby participants are pushed to perform at, or near, the limits of their capability in everyday cognitive-motor performance, highlighting locomotor deficits before they lead to a fall in daily life.

The individual differences in learning outcomes detected across challenge points in diagnostics can optimize VR-based interventions for each learner and lead to enhanced transfer of skills to the real world. VR lends itself to quantifying and adjusting training loads for individual responses to an intervention and augmenting training loads for learners [105]. Commercially available VR systems boast multiple ways to measure performance (eg, eye tracking and kinematics) to achieve goal-related outcomes (eg, a gamified performance goal), and either aspect of a simulation can be tailored to target individual needs and training goals. Advances in data modeling and machine learning allow us to measure individual differences in learning by analyzing changes in performance versus goal-related outcomes (ie, speed versus accuracy analyses) across repeated practice sessions or challenge points. Using VR to quantify individual learning trajectories allows for tailored challenge points and maintaining appropriate difficulty levels [105], and VR-based approaches could adjust training loads to optimize learning for each participant throughout an intervention.

Practitioners are already using VR with younger populations to rehabilitate those with anxiety-related disorders, pioneering a wider application of VR for “exposure therapy” to reduce anxiety [100]. For example, the Bravemind program builds on evidence highlighting that VR-based exposure therapy can reduce depression and anxiety in veteran soldiers with PTSD [116]. Bravemind uses VR to simulate combat-related scenarios in combination with cognitive behavioral therapy, which reframes anxiety-based reactions with “cognitive restructuring,” providing a low-threat context where a patient can therapeutically decondition the cycle of anxiety via habituation [100]. The immersive VR program trains soldiers to compensate and adapt to their PTSD symptoms over time with prolonged exposure to threatening stimuli in VR, guided by evidence from successful VR treatments leveraging exposure therapy for specific phobias [69,117]. Similar exposure effects are reported in VR-based anxiety-inducing settings; the effects of mobility-related anxiety on motor performance (ie, gait speed) decay as participants acclimate to the simulated scenario [23,24], suggesting a similar approach may work to train older adults at risk for maladaptive mobility-related anxiety.

The use of VR-based approaches in conjunction with cognitive behavioral therapy could be effective in reducing fear of falling in older adults [118]. VR-based therapies for treating anxiety disorders are rising in popularity, and meta-analyses support using VR for treating anxiety when compared with traditional therapies [119], especially in preventing patient attrition [119,120]. While no substantive advantages are associated with current VR-based programs compared to traditional therapy, participants are more likely to adhere to VR-based therapies, thus improving their efficacy. We speculate that higher levels of adherence could be a result of greater engagement, which improves motor learning outcomes in gamified rehabilitation programs as compared to the sterility of traditional rehabilitation settings [64]. If VR technology can be refined and harnessed, we believe that the effectiveness (and relative affordability) of such therapies can outperform traditional treatment methods. Because of the success of programs such as Bravemind and the increasingly immersive VR experiences, it is not difficult to imagine a future where older adults are trained to optimize their performance on everyday mobility tasks using controlled exposure to stressful virtual environments.

Conclusions

VR is an appealing and practical tool to enhance and maintain older adult mobility. We envision a future where realistic contexts for individualized VR-based fall-prevention diagnostics and interventions will reduce the risk of real-world falls in older adults. By incorporating the context of daily tasks into VR-based approaches, we can quantify movement within complex and realistic environments that better represent the demands that older adults navigate every day. Focusing on using VR to mimic the influence of affect on cognitive, perceptual, and motor behaviors should guide industry, researchers, and clinicians toward therapies that prevent everyday falls.

Conflicts of Interest

None declared.

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Abbreviations

AR: augmented reality
HMD: head-mounted display
PTSD: posttraumatic stress disorder
VR: virtual reality

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Association of Prospective Falls in Older People With Ubiquitous Step-Based Fall Risk Parameters Calculated From Ambulatory Inertial Signals: Secondary Data Analysis

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Abstract

Background: In recent years, researchers have been advocating for the integration of ambulatory gait monitoring as a complementary approach to traditional fall risk assessments. However, current research relies on dedicated inertial sensors that are fixed on a specific body part. This limitation impacts the acceptance and adoption of such devices.

Objective: Our study objective is twofold: (1) to propose a set of step-based fall risk parameters that can be obtained independently of the sensor placement by using a ubiquitous step detection method and (2) to evaluate their association with prospective falls.

Methods: A reanalysis was conducted on the 1-week ambulatory inertial data from the *StandingTall* study, which was originally described by Delbaere et al. The data were from 301 community-dwelling older people and contained fall occurrences over a 12-month follow-up period. Using the ubiquitous and robust step detection method *Smartstep*, which is agnostic to sensor placement, a range of step-based fall risk parameters can be calculated based on walking bouts of 200 steps. These parameters are known to describe different dimensions of gait (ie, variability, complexity, intensity, and quantity). First, the correlation between parameters was studied. Then, the number of parameters was reduced through stepwise backward elimination. Finally, the association of parameters with prospective falls was assessed through a negative binomial regression model using the area under the curve metric.

Results: The built model had an area under the curve of 0.69, which is comparable to models exclusively built on fixed sensor placement. A higher fall risk was noted with higher gait variability (coefficient of variance of stride time), intensity (cadence), and quantity (number of steps) and lower gait complexity (sample entropy and fractal exponent).

Conclusions: These findings highlight the potential of our method for comprehensive and accurate fall risk assessments, independent of sensor placement. This approach has promising implications for ambulatory gait monitoring and fall risk monitoring using consumer-grade devices.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12615000138583; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=367746

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KEYWORDS

fall risk biomarkers; prospective falls; sensor placement; inertial measurement units; fall prediction; older adults; older adult; geriatric; geriatrics; elderly; fall; sensor; sensors; inertial measurement; model; predict; prediction; predictive

Introduction

Falls in older people are a major cause of mobility loss, morbidity, and mortality. With over one-third of people aged 65 years and older falling at least once a year [1], identifying individuals at risk and providing them with appropriate interventions is crucial [2]. However, traditional approaches typically rely on a single clinical evaluation session (eg, St Thomas's Risk Assessment Tool in Falling Elderly Inpatients [3] or the Balance Evaluation Systems Test and its variants [4]) and have demonstrated inconsistent and limited predictive power. Therefore, recent studies have moved toward continuous

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monitoring approaches. For example, positive results were obtained using electronic health records from long-term care facility residents [5]. However, this approach is restricted to a specific population in a specific setting and, therefore, might not apply to the general population.

Fall risk biomarkers based on ambulatory gait monitoring are increasingly used to complement the initial clinical evaluations [6-10]. Such daily-life gait monitoring offers improved performance of fall prediction by incorporating daily-life gait, which enables the assessment of participants' actual gait performance in real-life situations rather than solely in laboratory settings [9,11,12]. For example, van Schooten et al [8] showed that adding 7-day ambulatory measures to clinical measures increases the ability of the model to discriminate people who sustained a fall during the 12-month follow-up period from those who did not: the area under the curve (AUC) increased from 0.68 to 0.82.

Numerous models have been proposed for predicting falls based on sensor-based data. However, the vast majority of these models lack essential properties required for generalizability [13]. Only a few study remained [8,10,14,15] when focusing exclusively on studies that meet three criteria: (1) reliance on ambulatory or real-life inertial data collected from a single unit, (2) the use of prospective falls collected during a follow-up period as a criteria to identify fallers, and (3) the inclusion of a sufficient population of community-dwelling older people (>100). These studies draw from a similar data set to the one used in this study, but they differ slightly in terms of the types of fall predictors (different gait domains), modeling approaches (binomial regressions with extreme or median value of predictors [8,10], survivor analysis [14], and the use of deep learning techniques [15]), and subsets of the database used. The resulting AUC ranged from 0.71, when using only accelerometric data [8], to as high as 0.74, when selecting gait data samples [15]; the AUC was even higher when incorporating clinical variables (0.81-0.82) [8,10]. These results showed that fall risk can be predicted with a reasonable accuracy when using ambulatory gait data obtained with a single inertial measurement unit placed on the lower torso.

Consumer-grade devices, such as smartphones and smartwatches, almost systematically embed inertial measurement unit sensors whose quality is largely sufficient for gait monitoring applications (eg, the study by Manor et al [16]). More importantly, they are well accepted and already widely available. The integration of gait monitoring into consumer-grade devices would enable the monitoring of fall risk on a large scale, which could lead to a substantial improvement in fall risk identification and subsequent prevention. However, up until now, ambulatory gait monitoring of fall risk parameters has been limited to a dedicated inertial sensor and a fixed body placement, usually on the trunk or feet. Switching to consumer-grade device monitoring presents several challenges. Some issues relate to the devices themselves, such as memory and battery use. However, one of the most critical challenges is to develop a gait-monitoring approach that can withstand the flexibility of consumer-grade device placement (eg, wrist or pocket) and carrying modes for handheld devices (eg, swinging, hand in pocket, or texting). Indeed, imposing a fixed body position or type of motion strongly limits the utility of the approach [17]. A ubiquitous solution should be (1) predictive of prospective falls, (2) independent of sensor placement, and (3) modest in terms of data processing (ie, computational cost, size of data set, and complexity of method).

One of the key issues to making the solution ubiquitous is the type of parameters from which fall risk is estimated. Most fall prediction models rely on parameters estimated from the inertial sensor time series, such as the Lyapunov exponents [8,10]. These *signal-based* parameters are indeed relatively straightforward to calculate. However, a major drawback is that they are affected by sensor placement both in terms of value and the strength of their association with the risk of falls [18,19].

In this context, fall risk estimated using parameters calculated based on step instants offers potential, with promising results in laboratory settings and pathological gait [20-23]. Importantly, there exists a robust step detection method that allows the estimation of these step instants independently of sensor placement. An example is the recent *Smartstep* algorithm [24], relying on 2 machine learning models (1 for the gyroscope and 1 for the accelerometer data) plus a decision process that determines which machine learning model is to be used as the main step detector. Its robustness against sensor body placements (waist, pants or jacket pockets, or handheld), different walking conditions, and real-life challenges (eg, blind people walking outside with or without aids, older adults in a hospital hallway open to the public, etc) has been demonstrated [24,25]. Using Smartstep, it is thus possible to estimate some *step-based* parameters independently of the sensor placement. They can be gait variability indicators such as the SD and coefficient of variance of stride time, gait complexity indicators such as fractal exponent and sample entropy of stride time, gait intensity indicators such as cadence, and gait quantity indicators such as the total number of steps. Demonstrating that fall risk can be assessed using such *step-based* parameters calculated from ambulatory data could be a decisive step toward a ubiquitous fall risk prediction solution that is insensitive to device location.

Therefore, this study aims to evaluate the association of *step-based* parameters, calculated using the ubiquitous step detection method Smartstep, and prospective falls [24]. The study is a secondary analysis using a data set collected by Delbaere et al [26]. It involves ambulatory gait inertial signals from the lower back.

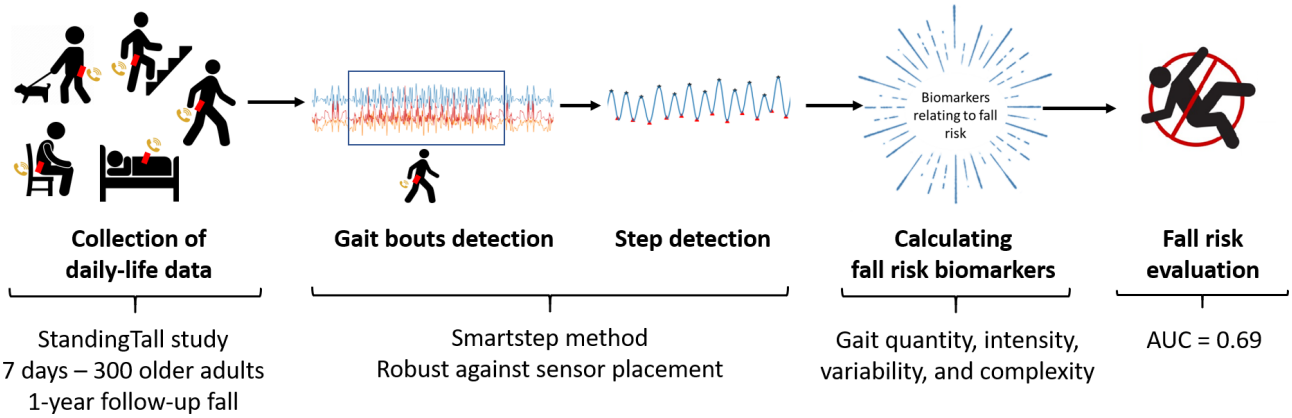
Methods

Overview

An overview of the whole approach is depicted in Figure 1 [24,26].

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Figure 1. Overview of the approach used to build a fall risk prediction model based on ambulatory inertial measurement unit data. AUC: area under the curve.



Data Set

This study analyzed ambulatory inertial data from the *StandingTall* study, which is described by Delbaere et al [26]. The data set includes valid inertial sensor data of 301 older people aged >70 years, who are independent in activities of daily living and without cognitive impairment, progressive neurological disease, or any other unstable or acute medical condition precluding exercise. Half of the participants were assigned to an intervention group and followed a balance-exercise program (StandingTall), whereas the other half were assigned to a health education control group. Participants wore a triaxial accelerometer (DynaPort MoveMonitor, McRoberts) for 1 week. This accelerometer had a sample rate of 100 Hz and was worn tightly on the lower back using an elastic belt. Participants were instructed to wear the accelerometer at all times, except during aquatic activities such as swimming or showering. Prospective fall incidences were obtained over a 12-month follow-up period using weekly fall diaries through a tablet computer. A fall was defined as "an unexpected event in which the participant comes to rest on the ground, floor or lower level" [27]. Table 1 summarizes the demographic characteristics of the participants.

Table . Demographic characteristic of the participants.

Characteristics	Fallers (n=116)	Nonfallers (n=185)
Age (y), mean (SD)	78 (5)	77 (5)
Female, n (%)	81 (69.8)	122 (65.9)
BMI (kg/m²), mean (SD)	28 (6)	28 (5)

Walking Bout and Step Detection

Nonwear periods were removed using the algorithm of van Hees et al [28], and sedentary or inactive periods were removed using the accelerometer cutoff points based on the study by Migueles et al [29]. Walking bouts were then detected in 2 steps. First, Smartstep [24] was used to detect steps. Then, the detected steps were grouped into a walking bout if they were separated by less than 2 seconds. Only walking bouts longer than 200 steps, or 120 seconds of walking on average, were considered in this study. This criterion was chosen for different reasons: (1) shorter walking bouts might lead to inconclusive results [30,31], and (2) the application of some algorithms to calculate certain fall risk parameters requires a minimum number of data points [32,33].

Fall Risk Parameters

A total of 12 *step-based* fall risk parameters were calculated. They describe four main gait domains:

1. Gait quantity: the total number of walking bouts, total number of steps, and average number of steps per walking bout
2. Gait intensity: cadence, step time, and stride time
3. Gait variability: coefficient of variance of stride time and step time
4. Gait complexity: fractal exponent and sample entropy calculated on stride and step time series

The initiation and termination phases of gait in each walking bout were discarded by removing the first 5 and last 5 steps of all walking bouts. Gait variability, intensity, and quantity parameters were calculated considering all remaining steps of the walking bouts. Gait complexity parameters were calculated on the middle 200 steps (ie, longer walking bouts were cut into a constant length of 200 steps), because the gait complexity parameters used (fractal exponent and sample entropy) are known to be dependent on the number of data points considered. Using different numbers of data points between walking bouts and participants would lead to inconsistent results.

Statistical Analysis

Correlation Between Fall Risk Parameters

For each participant, we estimated the median of all fall risk parameters over all walking bouts. Spearman correlations were performed to assess the relationship between the fall risk parameters. Correlation coefficients between 0.7 and 1.0 were

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considered strong, between 0.4 and 0.7 were considered moderate, and between 0 and 0.4 were considered weak.

Statistical Model

We used a negative binomial regression model to assess the relationship between fall risk parameters and the occurrence of falls (being a faller vs nonfaller) during the follow-up period. We corrected for inclusion in the intervention group as a covariate to cancel out its potential effect. Different combinations of uncorrelated gait parameters were chosen as candidates for the model.

The interaction between gait quantity and other exploratory parameters was also considered because earlier research showed that such interactions may exist [8]. Parameters that gave the best performance were retained. Then, a backward elimination of these parameters was done in the following way. Using cross-validation, the data were split into 10 different subsets, each containing 70% of the population. A model was built on each subset. A parameter was retained if it was stable across all 10 models (ie, the mean and SD of *P* values through the models' coefficients were less than .20). This means that the parameter maintained its stability for every chosen subset. In addition, the interaction of group allocation with the selected gait parameters were added to control for the potential effect of the intervention on the predictive ability of gait for falls.

Evaluation of Model

The model was evaluated using 2 methods. First, a training-testing split evaluation involved training and testing the model on the same data set. This approach was chosen for the ease of comparison with existing literature. Second, a repeated learning-testing cross-validation [34] was used for a more robust assessment. In this process, the data set was randomly divided into an 80% training set and a 20% testing set. This division was repeated 10 times and the results from each cross-validation were averaged. Concerning cross-validation, the *ShuffleSplit* method from the Python *scikit-learn* package (Python Software Foundation) was used. At each fold, the method shuffled the data set and split it into a 80% training group and a 20% testing group. The model was created or tuned in the training group and evaluated in the testing group. The AUC was calculated at each stage. The model's performance and stability were evaluated through the mean and SD of the AUC.

Ethical Considerations

No ethical approval was required since data for this study were obtained from a previous study (StandingTall study [26]), whose reanalysis is covered by its ethics approval.

Results

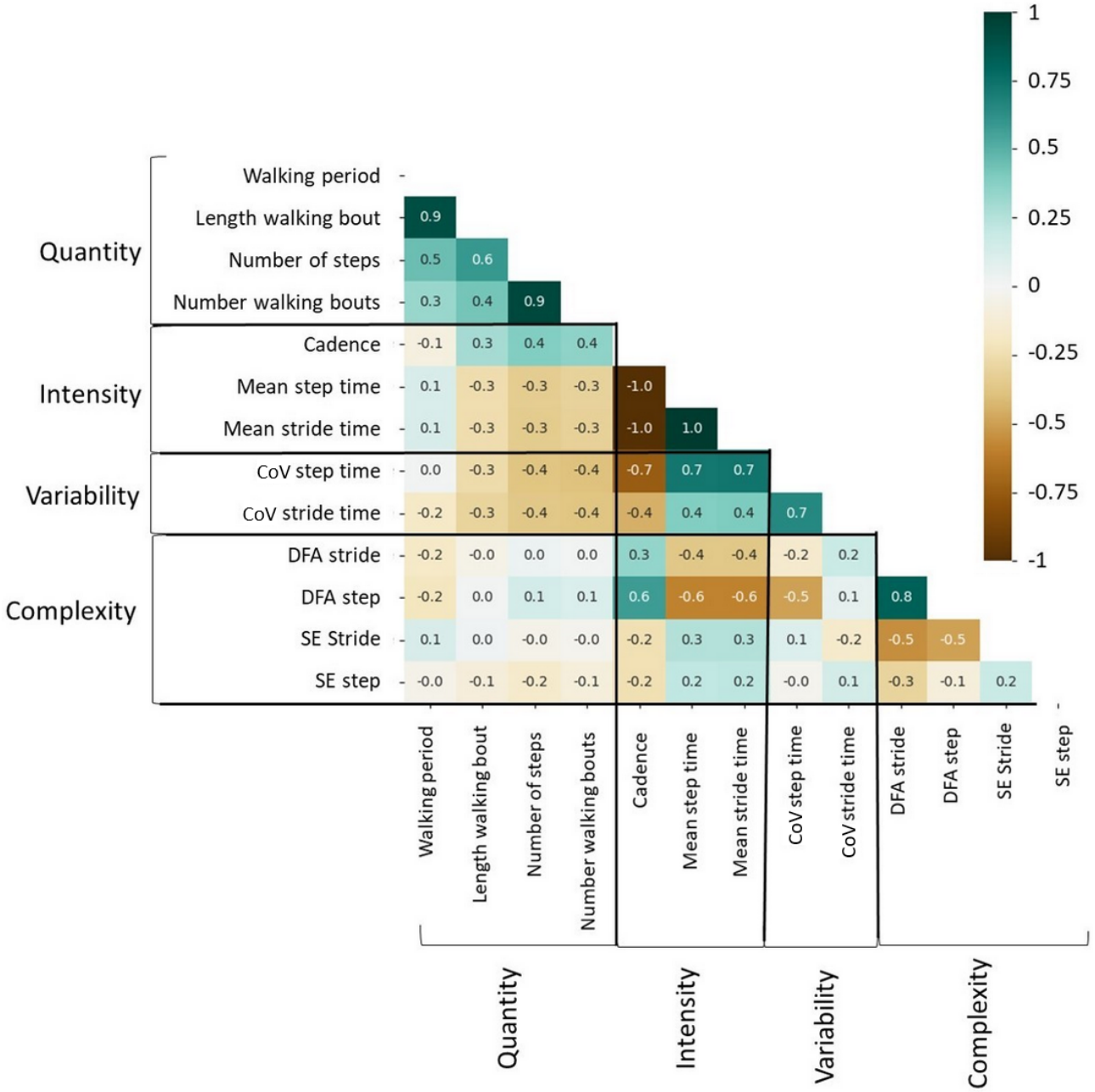
The selection of long walking bouts (>200 steps) caused the exclusion of 6% (18/301) of the population. The correlation heat map between fall risk parameters is shown in Figure 2. Gait quantity had moderate correlations with gait intensity and variability. Gait intensity had moderate correlations with gait complexity and strong correlations with gait variability. Finally, gait complexity and variability were not correlated.

The final fall prediction model included the total number of steps, cadence, coefficient of variance of stride time, fractal exponent on step time, sample entropy on stride time, and sample entropy on step time. The AUC of this model, which was trained and tested on the whole data set, was 0.69. The cross-validated AUC was 0.67 (SD 0.05). The model can be accessed via a public data set [35].

Table 2 displays the coefficients and *P* values of the fall risk parameters based on *z*-transformed data. All parameter coefficients were statistically significant at $P<.05$. The likelihood of being a faller increased with lower gait complexity, higher gait variability, higher gait quantity, and higher gait intensity.

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Figure 2. Correlation heat map between the different fall risk parameters. CoV: coefficient of variance; DFA: detrended fractal analysis; SE: sample entropy.



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Table . Multivariable negative binomial regression of selected falling risk parameters built with the whole population at a minimum of 200 steps. *B* coefficient and *P* values were based on *z*-transformed data. The area under the curve was 0.69.

Gait domain and parameter		*B* coefficient	*P* value
Quantity			
	Number of steps	0.20	.03
Intensity			
	Cadence (steps/min)	1.50	.02
Variability			
	CoV[a] of stride time	0.43	<.001
Complexity			
	DFA[b] on step time	−1.79	.02
	SE[c] on step time	−1.08	.04
	SE on stride time	−1.30	.04

[a]CoV: coefficient of variance.

[b]DFA: detrended fractal analysis.

[c]SE: sample entropy.

Discussion

Principal Findings

To our knowledge, this is the first study that used *step-based* parameters, obtained with a ubiquitous step detection method, to predict fall risk based on a large-scale, real-life gait monitoring data set.

First, the developed model demonstrated an AUC of 0.69 when tested and trained on the same data set and an AUC of 0.67 (SD 0.05) with cross-validation. These results are comparable to prediction models built solely on ambulatory data collected with a single inertial sensor (AUC=0.68-0.74) [8,10,15].

Unlike these models that rely on *signal-based* parameters—that is, requiring a fixed sensor placement, usually on the lower back—our proposed model relies on *step-based* parameters. These parameters can reliably be estimated independently of the sensor placement using Smartstep, a step detection algorithm whose robustness against sensor placement, population, and walking conditions has been demonstrated in previous validation studies [24,25]. This represents a great improvement in terms of acceptability and potential dissemination of such monitoring approaches. Furthermore, the integration of simple initial clinical assessments into these models can enhance their performance [8].

The coefficients obtained from our model (see Table 2) are in line with previous findings, suggesting that older people at high risk of falls have lower gait complexity (as indicate by negative regression coefficients for detrended fractal analysis on step time, sample entropy on step time, and sample entropy on stride time) and higher gait variability and gait quantity (as indicated by positive regression coefficients for coefficient of variance of stride time and the number of steps, respectively). These findings are consistent with previous studies on fall risk and pathological gait [8,22,36,37]. However, the positive regression coefficient for gait intensity (cadence) seems to show that higher gait intensity would be associated with a higher risk of falling, which was not reported in the literature. It is important to further investigate whether this result is a modeling artifact due to the simplicity of our model [38] (eg, potential nonlinearity or interactions with another parameter were not included) or whether this is a meaningful finding.

The correlation matrix suggested that gait variability in real life is associated with cadence or gait intensity, similar to previous findings in laboratory settings [39]. Gait complexity was also correlated with gait intensity, which aligns with the effect of gait speed on complexity in other studies [40]. The correlation between such parameters has not been studied before in ambulatory gait settings. This study provides a foundation for future studies using such variables in ambulatory settings.

Limitations

This study has several limitations. First, the inertial data were collected from a fixed body placement on the lower back. We expect the Smartstep step detection method to be robust against sensor placement, as previously demonstrated [24,25]. However, future research should confirm this by carrying out a similar study with a different or uncontrolled sensor placement. Second, the study excluded short walking bouts (<200 steps), which in turn excluded individuals who do not walk long enough (18/301, 6% of the population). This walking period (approximately 2 min) cannot be achieved within the home. Thus, it obliges the person to go for walks outdoors, likely selecting more fit and active older people. Future studies should focus on including and analyzing short walking bouts and identifying fall risk parameters relevant to those with short walking bouts. Another limitation comes from the use of a relatively simple model (negative binomial regression) to link the occurrence of falls with the fall risk parameters. This traditional approach might have limitations in capturing more complex relationships between risk factors and occurrence of falls (such as nonlinear relations or critical thresholds) and, thus, could impede the understanding of individual effects of multiple related

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parameters [38]. Although the primary objective of this study was to demonstrate the feasibility of fall prediction from accelerometric data independent of the sensor placement, the logical next step would be to further investigate the modeling approach. This could include investigating data aggregation [41] or using more advanced meta-modeling approaches [38]. Furthermore, as the generalization of fall prediction models has been identified as a known challenge [13,42], it would be interesting to test the resulting fall prediction model on a new cohort.

Implications and Future Work

The results of this study suggest that fall risk parameters can be monitored if a robust step detection algorithm is applied. This study provides the groundwork for using consumer-grade devices for fall risk monitoring. Future work can include two main topics: (1) improving the fall prediction model and (2) implementing and testing the approach on consumer-grade devices.

Several tracks could be considered to improve the fall prediction. Adding health data (eg, history of falls, results of clinical tests, and questionnaires) should further increase the model's performance. Other propositions include adding parameters related to turning quality, GPS position, and gait spatial parameters to enhance fall prediction. More advanced modeling approaches could also be investigated.

Technical aspects and user acceptability are important considerations for implementing the approach on consumer-grade devices. The initial challenges to be tackled relate to the computation capacity, memory requirements, and battery consumption of consumer-grade devices. An option that we are currently considering is running the step detection algorithm in real time, detecting step instants, and saving them to the device for further analysis.

Finally, in this study, we focused primarily on predicting the risk of falls from a 1-week record period. An auspicious perspective offered by the proposed ubiquitous approach would be to monitor the evolution of the risk of falls or of chosen fall risk parameters through long periods and bring more insights into how they build up toward a fall event.

Conclusion

Our study addresses the limitations of traditional fall risk assessments by proposing a set of step-based fall risk parameters that can be obtained independently of sensor placement. Our results demonstrated that the proposed parameters were comparable to models using fixed sensor placement. Specifically, higher gait variability, intensity, and quantity were associated with an increased fall risk, whereas lower gait complexity was also identified as a significant factor. These findings highlight the potential of our method for comprehensive and accurate fall risk assessments, independent of sensor placement, thus offering promising implications for ambulatory gait monitoring and fall prevention strategies.

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Data Availability

The data (fall risks parameters and the outcome of the fall follow-up for the 301 participants), the code to build the model, and its full results have been made available in a public repository [35].

Authors' Contributions

NAA and TR contributed to conceptualization. KSvS and KD contributed to data collection. NAA and TR contributed to data analysis. KSvS, KD, NAA, and TR contributed to methodology. NAA contributed to writing (original draft). NAA, TR, KSvS, KD, and VR contributed to writing (review and editing). TR and VR contributed to supervision.

Conflicts of Interest

None declared.

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Abbreviations

AUC: area under the curve

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Original Paper

Canadian Older Adults' Intention to Use an Electronic Decision Aid for Housing Decisions: Cross-sectional Web-Based Survey

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Abstract

Background: Older adults with disabilities such as loss of autonomy face the decision of whether to stay at home or move to a health care facility such as a nursing home. Therefore, they may need support for this difficult decision.

Objective: We assessed the intention of Canadian older adults to use an electronic decision aid (eDA) to make housing decisions and identified the factors that influenced their intention.

Methods: We conducted a cross-sectional study using a web-based survey targeting older adults across 10 Canadian provinces and 3 territories. We included respondents from a web-based panel who were aged ≥65 years, understood English or French, had access to an electronic device with an internet connection, and had made a housing decision over the past few months or were planning to make a decision in the coming year. We based the web-based survey on the Unified Theory of Acceptance and Use of Technology (UTAUT). We adapted 17 UTAUT items to measure respondents' intention to use the eDA for housing decisions, as well as items measuring 4 intention constructs (performance expectancy, effort expectancy, social influence, and facilitating conditions). We also assessed eHealth literacy using both subjective and objective scales. We used descriptive statistics and multivariable linear regression analyses to identify the factors influencing the intention to use the eDA.

Results: Of the 11,972 invited panelists, 1176 (9.82%) met the eligibility criteria, and 1000 (85.03%) respondents completed the survey. The mean age was 72.5 (SD 5.59) years. Most respondents were male (548/1000, 54.8%), White (906/1000, 90.6%), English speakers (629/1000, 62.9%), and lived in Ontario or Quebec (628/1000, 62.8%) and in urban areas (850/1000, 85%). The mean scores were 27.8 (SD 5.88) out of 40 for subjective eHealth literacy and 3.00 (SD 0.97) out of 5 for objective eHealth literacy. In our sample, the intention score was 4.74 (SD 1.7) out of 7. The mean scores of intention constructs out of 7 were 5.63 (SD 1.28) for facilitating conditions, 4.94 (SD 1.48) for performance expectancy, 5.61 (SD 1.35) for effort expectancy, and 4.76 (SD 1.59) for social influence. In the final model, the factors associated with intention included mother tongue (β=.30; *P*<.001), objective eHealth literacy (β=–.06; *P*=.03), performance expectancy (β=.55; *P*<.001), social influence (β=.37; *P*<.001), and facilitating conditions (β=.15; *P*<.001).

Conclusions: Findings from this pan-Canadian web-based survey on Canadian older adults suggest that their intention to use the eDA to make housing decisions is similar to the findings in other studies using UTAUT. The factors identified as influencing

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intention were mother tongue, objective eHealth literacy, performance expectancy, social influence, and facilitating conditions. These will guide future strategies for the implementation of the eDA.

(JMIR Aging 2023;6:e43106) doi:10.2196/43106

KEYWORDS

aged; intention; decision aid; decision support techniques; housing; unified theory of acceptance and use of technology; UTAUT; information technology; internet; shared decision-making

Introduction

Background

As in many other countries, older adults in Canada (ie, persons aged ≥65 years) are a rapidly growing segment of the population [1]. In Canada, the number of older adults increased by 18.3% between 2016 and 2021 to reach 7 million [2]. By 2030, it is estimated that older adults will account for 23% of the Canadian population [1]. As adults age, they are more likely to experience disabilities, leading to loss of autonomy [3]. For instance, in Canada, 19.5% of older adults reported that their health was perceived to be somewhat worse or much worse than 1 year ago and 16.5% had to receive assistance from family, friends, or neighbors for a health problem or disability. On the basis of the Instrumental and Basic Activities of Daily Living Classification, 93.9% of Canadian older adults experience a mild loss of autonomy [4].

To manage loss of autonomy, meet health care and social services needs, and ensure their safety and well-being, many Canadian older adults consider receiving home care, which typically includes nursing care, therapy (physical, occupational, and speech-language), and medical and social services [5]. Others consider assisted living or moving to residential health care facilities, such as nursing homes [6-8]. In this paper, all decisions about whether to stay home and age safely in place or to move out to a residential health care facility are referred to as “housing decisions” [9].

In Canada, housing decisions are considered the most frequent and difficult decisions for older adults receiving home care as well as for their caregivers [10,11]. The Ottawa Decision Framework identifies the factors influencing decisions as, in general, inadequate support and resources (or “decisional needs”) as well as personal characteristics such as gender, education, and ethnicity. In the context of housing decisions specifically, studies have shown that besides loss of autonomy, older adults in Canada consider moving for a variety of other reasons, such as caregivers’ opinions, proximity of services or relatives’ support, financial resources, and feelings of insecurity or fear at home [8,11]. One Canadian study showed that gender, age, household income, province, driving status, whether the current home met the older adults’ needs, and unmet heavy cleaning needs were all important influences on decisions to relocate [12].

Housing decisions and transitioning to long-term care can be experienced differently, depending on the sociocultural context. For instance, in Western cultures, some residential care facilities try to create a homelike atmosphere by allowing older adults to bring their furniture, pets, and family pictures to help ease the transition [13]. However, a meta-analysis showed that in the United States and Canada, older adults still experience transitioning to long-term care as a loss that requires a mourning process before coming to peace with the decision [14].

Amid the COVID-19 pandemic, housing decisions have become not only more frequent but also more painful and complicated for older Canadians [15]. The decision to relocate appears fraught with danger as long-term care homes and seniors’ residences were among the hardest-hit facilities in Canada in 2020 during COVID-19. Residents in nursing and senior homes accounted for >80% of all reported COVID-19 deaths [16].

To help older adults make informed decisions regarding the most appropriate housing option, shared decision-making (SDM) is advocated. SDM is the process of making a health care choice that involves patients, their relatives or family or both, and one or more health care professionals [17]. SDM is particularly appropriate for preference-sensitive decisions. The best housing decisions reflect older adults’ personal values and preferences, as well as those of their relatives [7,18]. As the need for self-management is increased by the cumulative effects of long-term conditions in older adults, SDM becomes more relevant, especially when it comes to housing. Besides, there is growing evidence that older adults and their caregivers would like to be more involved in decision-making [19]. Decision aids (DAs) can be used to facilitate SDM. DAs are evidence-based tools that support older adults in defining decisions, provide information regarding different options and outcomes, and help clarify personal values and priorities [20].

eHealth refers to health services and information delivered through the internet and related technologies [21]. According to recent studies, eHealth can empower older adults to manage their health by providing more accessible health information through educational and supportive web platforms and connection with others with shared health interests [22-25]. The use of eHealth has increased significantly since COVID-19. The accelerated digital transformation that has occurred [24] has encouraged older adults to use internet services to meet their needs in several aspects of life (eg, web-based groceries, web-based shopping, and health appointments). Because rapidly changing health conditions can quickly overtake older adults’ housing decisions [9], they need easily accessible web-based tools that can be updated to help them obtain the information they need to participate actively in SDM.

In a clinical setting, a DA is usually presented before the clinical encounter to prepare the patient for SDM with a health professional or during the encounter to prepare for a subsequent encounter. Few health professionals have the time to work through a DA with the patient and come to a conclusion on the

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spot [26]. We designed an electronic version of a paper-based DA [27,28] (electronic decision aid [eDA]) to help older adults choose the most appropriate housing option for them. Older adults can use the eDA alone or with their families to prepare for SDM with a health professional. The eDA can also be used in SDM training for health care professionals to help them understand the practical steps involved in the SDM process. The paper-based DA is already available on the website of the Canada Research Chair in SDM and Knowledge Translation [28]. The eDA will also be made available free on this website. Brief details of the conversion are provided in Multimedia Appendix 1 [7]. We also plan to register it on the Ottawa Decision Aids website [20] and will suggest that partnering organizations provide hyperlinks to the eDA (eg, Fédération de l'Âge d'Or du Québec and L'Appui for caregivers).

Objective

We hypothesized that older adults would find the eDA to be useful. To our knowledge, no study has yet investigated whether older adults would be willing to use the eDA for housing decisions. Therefore, our aim was to assess Canadian older adults' intention to use the eDA to make housing decisions and to identify the factors influencing their intention to use it.

Methods

Study Design

We conducted a cross-sectional web-based survey across Canada (including the 10 provinces and 3 territories) with older adults who had either made a housing decision in the past 12 months or were planning to make a housing decision the next year. We used the consensus-based Checklist for Reporting of Survey Studies (CROSS) to guide the reporting of our results [29] (Multimedia Appendix 2). This project is part of COORDINATEs (Technology to Support Decision Making About Aging at Home), an international study (Canada, Sweden, and the Netherlands), whose objective is to use technology to help older adults stay at home as long as possible in a safe manner and to assist them in making informed decisions about aging at home [9].

Ethics Approval

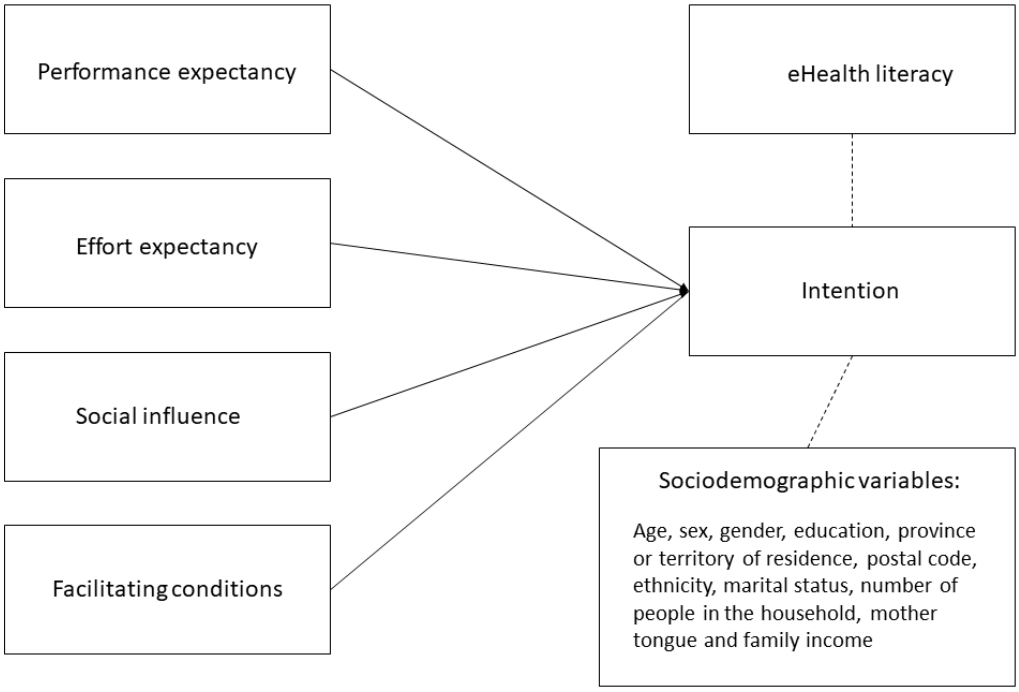
This project was approved by the Ethical Review Board of the Integrated University Health and Social Services Centre of the Capitale-Nationale, Quebec, Canada (#MP-13-2019-1519, 2019-1519_SPPL).

Theoretical Framework to Guide the Survey Development

Health-related behaviors are correlated with intention, which is defined as an individual's planned and rationalized decision to perform the behavior [30]. A meta-analysis of 10 meta-analyses showed that intention explained nearly one-third of the variance in behavior [31]. Using eHealth interventions to improve one's health first requires acceptance of technology and then the intention to use it. Several theoretical models have studied the intention (and its determinants) to use technology in health care. The Unified Theory of Acceptance and Use of Technology (UTAUT) is among the most widely used theoretical models for studying the intention to use technology in health care [32]. Developed by Venkatesh et al [32], UTAUT is an extension of several theoretical models that preceded it, such as the Technology Acceptance Model [33] and Ajzen's Theory of Planned Behavior [34]. UTAUT explains that behavioral intention to use technology is based on four constructs: (1) performance expectancy, defined as the degree to which individuals believe that using the system will help them gain advantages; (2) effort expectancy, defined as the degree of ease associated with the use of the system; (3) social influence, defined as the degree to which individuals perceive that their family, friends, and society in general would approve of them using the new system; and (4) facilitating conditions, defined as the degree to which an individual believes that an organizational and technical infrastructure exists to support the use of the system [32]. To achieve the aim of this study, we adapted this framework by adding variables that could have a direct influence on the intention to use the eDA. Therefore, we measured sociodemographic variables as well as eHealth literacy, defined as "the use of emerging information and communication technology to improve or enable health and health care" [35]. eHealth literacy combines different dimensions of literacy skills (traditional literacy, health literacy, information literacy, scientific literacy, media literacy, and computer literacy; Figure 1) [36].

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Figure 1. Adapted version of Unified Theory of Acceptance and Use of Technology.



Respondents and Recruitment

Respondents were eligible if they were Canadian adults aged ≥65 years, understood English or French, had access to an electronic device with an internet connection, and had made a housing decision in the past few months or were planning to make one in the coming year.

We recruited respondents through Leger Marketing, a market research and analytics company in Montreal, Canada. Leger Marketing is the largest private Canadian web-based panel (400,000 individuals) and claims to be representative of the entire population [37]. It adopts a hybrid recruitment approach using traditional and mobile telephone methodologies through call centers, panel websites, and social media. It also updates panelists' profiles every 6 months and controls the accuracy and quality of participants' answers using validation techniques (eg, username and strict restrictions on passwords, deduplication with existing panel, and simultaneous recruitment campaigns) from the beginning of the registration process [37]. Leger Marketing selected our sample from its panel of 400,000 individuals using a nonprobability sampling method. An electronic invitation was sent to 11,972 older adults to complete the closed survey. The sampling methods used were representative of the general Canadian population in terms of age, gender, region, and socioeconomic status. Upon obtaining consent, eligible respondents were able to complete the survey. The survey was conducted on a voluntary basis and compensation was offered to respondents in the form of Leger Points, which are redeemable for cash or gift cards.

Each respondent from the web-based panel received a personalized email invitation containing a unique URL link to access the nonopen survey. Respondents were then asked to answer the first questions about language preference, province or territory of residence, and eligibility. Leger Marketing sent reminders via email once a week, until the survey was closed. As respondents logged into the survey using their panel membership account, we had a unique response per member because it was not possible for the same member to have multiple submissions.

A minimum of 829 participants were required. The sample size was estimated using the central limit theorem formula [38]. This formula provides the recommended sample size to estimate the true population mean with the required margin of error and level of confidence. To determine the sample size, a similar study by Yousef et al [39] was chosen to estimate the SD of the mean intention score in the population (SD 0.56). The survey was closed once 1000 respondents had completed the survey. Recruitment took 4 weeks (April 5 to May 2, 2022).

Data Collection

Because no validated instruments that assess older adults' intention to use an eDA for housing decisions have been identified, we created a self-administered questionnaire based on the adapted UTAUT items. We measured our main outcome, intention, and its 4 determining constructs using the 17 UTAUT-based items. Each UTAUT construct (intention, performance expectancy, effort expectancy, social influence, and facilitating conditions) was measured using 3 or 4 items. Respondents indicated their agreement or disagreement levels with the corresponding items on a 7-point Likert scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). We calculated the final scores for each construct by averaging the scores of its corresponding items. In our UTAUT-based questionnaire, we replaced the word "technology" with "the web-based decision aid" and adapted the wording of each item to the context of our study. The UTAUT has good internal consistency and convergent and discriminant validity [32]. Cronbach α indicated good reliability of the multi-items measuring each construct (α range .9-.95).

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The survey also collected sociodemographic characteristics (ie, age, sex, gender, education, province or territory of residence, postal code, ethnicity, marital status, number of people in the household, mother tongue, and family income) using items based on Statistics Canada's 2021 census questionnaire [40].

We evaluated eHealth literacy using 2 scales. The first was the Electronic Health Literacy Scale (eHeals) [41], a validated scale that measures respondents' self-rated literacy level (referred to as "subjective scale"). eHeals was developed by Norman and Skinner [41] and is regarded as the "gold standard" for measuring eHealth literacy [41]. It is a validated 8-item scale with high internal consistency [42]. For each of the 8 items, respondents expressed their agreement or disagreement on a 5-point Likert scale (1=*strongly disagree* to 5=*strongly agree*), with higher scores reflecting better literacy skills. The eHeals scale generated a total score ranging from 8 to 40. On the basis of the different thresholds used in the literature to better classify literacy levels [43,44], eHealth literacy was considered high if the score was ≥26. We also used the Digital Health Literacy Instrument (DHLI) [45] to evaluate eHealth literacy. The DHLI (referred to as the "objective scale") is a measure of the actual performance of respondents when using internet web pages. The DHLI subscale, originally Dutch, measures health-related internet use skills using 7 items [45]. The DHLI consists of screenshots of web pages with questions that assess operational skills, navigation skills, evaluation of reliability, determination of relevance, information searching, addition of self-generated content, and protection of privacy [45]. For this project, we adapted the DHLI to the Canadian context. After discussion with our research team members, only 5 items were included in the questionnaire. The 2 items concerning content addition and privacy protection were not directly related to this project and were omitted. If the respondent gave the correct answer, they received a score of 1. Otherwise, they obtained a score of 0. Therefore, the maximum possible score was 5. Cronbach αs for eHeals and DHLI were, respectively, .91 and .35.

After completing the 2 eHealth literacy scales, the respondents were shown a 6-minute video vignette showing the use of the eDA in context. As mentioned by Godin et al [46], it is necessary to clearly define the targeted behavior (ie, use of the eDA for making housing decisions) before measuring the intention related to that behavior. The video was a demonstration of the SDM process regarding housing decisions and showed a situation where an autonomous older adult interacted with her caregiver who was concerned about her safety [47,48]. In the video, the older adult discussed the different housing options while using the eDA with her caregiver. All participants had to see the video to continue the survey and complete the UTAUT questions. The respondents were then asked to browse through the eDA [49]. Subsequently, UTAUT was used to evaluate respondents' intention (and its related constructs of performance expectancy, effort expectancy, social influence, and facilitating conditions) to use the eDA [32]. On the basis of the eDA, the survey ended with questions about the process of making housing decisions using the following variables: chosen housing decision ("Which option did you choose or do you consider choosing?"), preferred housing options ("Which option do you prefer?"), reasons for considering housing options ("What are your reasons for making this decision?"), support in the decision-making process ("Who had helped you or can help you to make this decision?"), and preferred role in the decision-making process ("If you had to make this decision, how would you prefer the decision to be made?"). We treated these decision-making process variables as descriptive variables and did not include them in the multivariable analysis.

The survey was 48 web pages long, took approximately 30 minutes to complete, and consisted of 50 closed-ended questions that were not randomized and appeared in the same order for all respondents. Each page included a "next" button for moving forward and a button with a list of older adult helplines for talking to a specialist who could support them mentally or emotionally if they were uncomfortable with any of the survey questions. Respondents could not move to the next page unless they had completed all the questions on the current page. Surveys were labeled as complete only if respondents had clicked on the "finish" button located at the end of the survey. Both English and French versions were pretested with a sample of 76 respondents to identify any possible ambiguity or technical problems, validate the clarity of the questions, and estimate the average completion time. No major revisions were made following the pretest.

Data Analysis

We determined the distribution of our population for sociodemographic variables, levels of eHealth literacy, UTAUT constructs, and decision-making process variables using descriptive statistics (means, SDs, and percentages). Because intention scores could vary between 1 and 7, we interpreted intention as a continuous variable. There is no definitive threshold for a clinically significant intention score in the literature. We used the Shapiro-Wilk test to verify whether the distribution of the dependent variable was normal.

We considered the "prefer not to answer" choice as missing data (1.8%, 18/1000) for bivariate and multivariable analyses, except for the income variable. We calculated the age of the respondents by considering their date of birth and date of survey completion. We performed a mixed linear regression model including all the independent variables, that is, age, sex, gender, education, province or territory of residence, postal code, ethnicity, marital status, number of people in the household, mother tongue, family income, eHealth literacy (objective and subjective), performance expectancy, effort expectancy, social influence, and facilitating conditions, using stepwise selection with the Bayesian Information Criterion [50]. We used an alternative variable selection approach to validate our model. We conducted a bivariate analysis using simple linear regressions on each variable to describe the associations between the dependent variable (intention to use the eDA for housing decisions) and the independent variables. Variables with *P* values <.10 were considered significant, a threshold more stringent than the usual .20. We then included the selected independent variables in a multivariable analysis model and identified the factors associated with intention. We checked collinearity using a correlation matrix of the continuous variables (age, number of people in the household, eHealth literacy, performance expectancy, social influence, and

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facilitating conditions; Multimedia Appendix 3). All analyses were performed using SAS (version 9.4; SAS Institute Inc) [51].

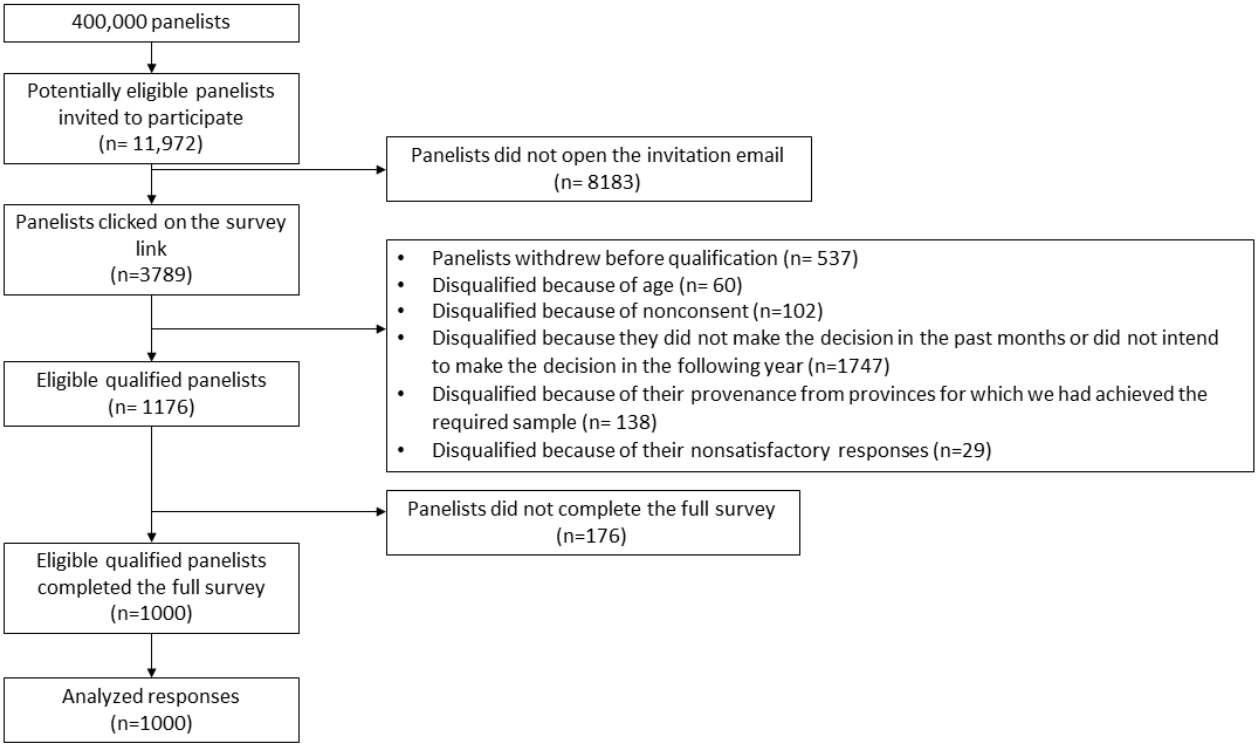
Results

Respondents' Characteristics

Of the 11,972 panelists who were invited to participate, 3789 (31.65%) panelists clicked on the survey link received by email; 1176 (31.04%) met the eligibility criteria; and 1000 (85.03%) respondents completed the entire survey and were included in the analysis (Figure 2). The response rate was 31.65% (ratio of 3789 users who clicked on the survey link to 11,972 invitations sent), and the completion rate was 85.03% (ratio of 1000 users who completed the survey to 1176 eligible users who participated).

The included respondent's characteristics are listed in Table 1. For the respondents who withdrew from the survey (14.97%, 176/1176), they had sociodemographic characteristics similar to those who fully completed the survey. Most respondents who withdrew were male (103/176, 58.5%) with a mean age of 73.9 (SD 6.0) years, White (160/176, 90.9%), living in Ontario or Quebec (101/176, 57.4%), and many were highly educated (64/176, 36.4% were university graduates). For the 1000 included respondents, the mean scores were 27.8 (SD 5.88) out of 40 for subjective eHealth literacy and 3.00 (SD 0.97) out of 5 for objective eHealth literacy. We consider that both scores represented high eHealth literacy levels. The subjective eHealth distribution was slightly skewed to the right in the direction of the highest score.

Figure 2. Flow of respondents.



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Table 1. Respondents' characteristics (n=1000).

	Respondents
Age (years), mean (SD)	72.5 (5.6)
Sex, n (%)	
Male	548 (54.8)
Female	452 (45.2)
Gender, n (%)	
Man	546 (54.6)
Woman	454 (45.4)
Level of education, n (%)	
A university certificate, diploma, or degree (eg, bachelor's degree, degree in medicine, dentistry, and veterinary medicine)	420 (42)
A college, CEGEP[a], or other nonuniversity certificate or diploma (other than trade certificates or diplomas)	264 (26.4)
A high school (secondary school) diploma or equivalent, a registered apprenticeship, or other trade certificate or diploma	286 (28.6)
Lower than a high school (secondary school) diploma or equivalent (eg, primary school)	25 (2.5)
I prefer not to answer	5 (0.5)
Province or territory of residence, n (%)	
Ontario	377 (37.7)
Quebec	251 (25.1)
Western Canada: British Columbia, Alberta, Saskatchewan, Manitoba, and Yukon	295 (29.5)
Eastern Canada: New Brunswick, Nova Scotia, Prince Edward Island, and Newfoundland and Labrador	77 (7.7)
Zone, based on postal code, n (%)	
Urban	850 (85)
Rural	141 (14.1)
I prefer not to answer	9 (0.9)
Ethnicity, n (%)	
White	906 (90.6)
Non-White	73 (7.3)
Indigenous peoples of North America (First Nations, Métis, or Inuk [Inuit])	18 (1.8)
I prefer not to answer	3 (0.3)
Marital status, n (%)	
Legally married (and not separated)	516 (51.6)
Divorced	152 (15.2)
Widowed	138 (13.8)
Never legally married	93 (9.3)
In a common-law union	81 (8.1)
Separated, but still legally married	19 (1.9)
I prefer not to answer	1 (0.1)
Number of people in the household, mean (SD)	1.80 (0.81)
Mother tongue, n (%)	
English	629 (62.9)
French	283 (28.3)
Other[b]	88 (8.8)
Aboriginal languages[c]	0 (0)

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	Respondents
Family income, n (%)	
CAD $100,000 (US $76.923) or more	172 (17.2)
CAD $75,000-$99,999 (US $57.700-US $76.922)	153 (15.3)
CAD $50,000-$74,999 (US $38.461-US $57.692)	221 (22.1)
CAD $25,000-$49,999 (US $19.230-US $38.460)	262 (26.2)
<CAD $25,000 (US $19.230)	114 (11.4)
I prefer not to answer	78 (7.8)
eHealth literacy (subjective)[d], mean (SD)	27.8 (5.88)
eHealth literacy (objective)[e], mean (SD)	3.00 (0.97)

[a]CEGEP: Collège d'enseignement général et professionnel.

[b]Other: Spanish, Mandarin, Arab, Cantonese, Dutch, Flemish, German, Greek, Gujarati, Hindi, Hungarian, Igbo, Indo, Italian, Lithuanian, Polish, Portuguese, Punjabi, Romanian, Russian, Serbian, Slovak, Slovenian, Tamil, Ukrainian, and Urdu.

[c]Aboriginal languages in Canada: Algonquian languages (eg, Cree, Ojibway, Innu or Montagnais, and Mi'kmaq), Inuit languages, Athabaskan languages, Salish languages, Siouan languages, Iroquoian languages, Tsimshian languages, Wakashan languages, Michif, Haida, Tlingit, and Kutenai.

[d]Sum of 8 items on a 1 to 5 Likert scale (1=strongly disagree and 5=strongly agree). Scores range from 8 to 40.

[e]Sum of 5 items (score 0 if wrong answer, score 1 if correct answer). Scores range from 0 to 5.

Intention and UTAUT Construct Scores

The UTAUT construct scores are shown in Table 2. The mean score of older adults' intention to use the eDA to decide about housing was 4.74 (SD 1.7) out of 7. We considered intention scores of ≥4 sufficient to assume that older adults would use eDA for housing decisions. As for the other UTAUT constructs, facilitating conditions had the highest mean score of 5.63 (SD 1.28) out of 7. Older adults seemed to believe that organizational and technical infrastructure existed to support the use of the eDA. The mean scores of performance expectancy, effort expectancy, and social influence were, respectively, 4.94 (SD 1.48), 5.61 (SD 1.35) and 4.76 (SD 1.59), that is, older adults believed that the eDA would help them to make better decisions and found it easy to use, and the eDA was approved by their relatives, so they would be more inclined to use it.

Cronbach α values are presented for each assessed construct and are a measure of internal consistency for each construct. This is considered to be a measure of scale reliability.

The intention scores associated with each decision-making process variable are listed in Table 3.

Table 2. Unified Theory of Acceptance and Use of Technology (UTAUT) construct scores (n=1000).

UTAUT construct[a]	Scores, mean (SD)	Cronbach α
Intention	4.74 (1.70)	.95
Performance expectancy	4.94 (1.48)	.94
Effort expectancy	5.61 (1.35)	.95
Social influence	4.76 (1.59)	.95
Facilitating conditions	5.63 (1.28)	.90

[a]Averaging the scores of the corresponding items on a Likert scale from 1 to 7. The scores range from 1 to 7.

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Table 3. Intention scores associated with decision-making process variables (n=1000).

	Respondents, n (%)	Intention scores, mean (SD)
Chosen housing option		
Only 1 chosen option		
Stay in your home	736 (73.6)	4.64 (1.7)
Move to a family member's home	17 (1.6)	4.29 (1.8)
Move to a private seniors' residence	78 (7.8)	5.25 (1.5)
Move to a public residential or long-term care center	16 (1.6)	5.37 (1.7)
2 chosen options	88 (8.8)	4.87 (1.7)
3 chosen options	14 (1.4)	5.30 (1.6)
4 chosen options	2 (0.2)	6.00 (0.0)
Other option, specify	49 (4.9)	4.8 (2.0)
Preferred housing option		
Stay in your home	843 (84.3)	4.67 (1.7)
Move to a family member's home	25 (2.5)	4.79 (1.6)
Move to a private seniors' residence	75 (7.5)	5.2 (1.6)
Move to a public residential or long-term care center	17 (1.7)	5.43 (1.8)
Other option, specify	40 (4)	4.9 (1.9)
Reasons for considering housing options		
Only one reason		
Someone else thinks you should move	26 (2.6)	4.93 (1.7)
You are concerned about your health	149 (14.9)	5.11 (1.5)
You are less able to walk or move around	44 (4.4)	3.95 (1.4)
You do not feel safe	8 (0.8)	5.08 (1.8)
You do not have enough help at home	21 (2.1)	5.23 (1.7)
You feel lonely	31 (3.1)	4.83 (1.6)
You have trouble doing your groceries, getting to the pharmacy, getting to the physician's office, etc	28 (2.8)	4.87 (1.5)
Your relatives can no longer give you the support you need	22 (2.2)	5.0 (1.8)
More than 1 reason	253 (25.3)	5.05 (1.6)
Other option, specify	418 (41.8)	4.42 (1.8)
Support in the decision-making process		
Spouse	271 (27.1)	4.44 (1.8)
Children	181 (18.1)	4.83 (1.6)
Grandchildren	5 (0.5)	4.13 (2.3)
Other family member	53 (5.3)	4.83 (1.6)
Friends	46 (4.6)	4.63 (1.6)
Physician	26 (2.6)	4.14 (1.7)
Social worker	11 (1.1)	4.82 (2.2)
Family and friends only	211 (21.1)	4.9 (1.6)
Health care team only	10 (1)	6.0 (0.9)
Both (family, friends, and health care team)	186 (18.6)	5.02 (1.6)
Preferred role in the decision-making process		

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	Respondents, n (%)	Intention scores, mean (SD)
Active ("I make the decision alone, I make the decision alone but consider the opinion of my relatives and/or health care providers, we decide together with my relatives and/or health care providers, equally")	973 (97.3)	4.73 (1.7)
Passive ("My relatives and/or health care providers make the decision but consider my opinion, my relatives and/or health care providers make the decision alone")	27 (2.7)	5.01 (1.6)

Factors Associated With Intention

Table 4 shows factors significantly associated with intention in the multivariable model. In order of importance, these factors were performance expectancy (β=.55; *P*<.001), social influence (β=.37; *P*<.001), mother tongue (β=.30; *P*<.001), facilitating conditions (β=.15; *P*<.001), and eHealth literacy (objective) (β=−0.06; *P*=.03). On the basis of these results, we proposed a modified parsimonious UTAUT model (Figure 3). Overall, our final model explained 73.3% of the total variance of our dependent variable.

The alternative variable selection approach (ie, the selection of independent variables in the bivariate analyses using the threshold of 0.1 before conducting the multivariable analysis) resulted in the same final model. In total, 9 variables were retained in the bivariate analyses (Multimedia Appendix 4).

Table 4. Multivariable factors significantly associated with older adults' intention to use the electronic decision aid.

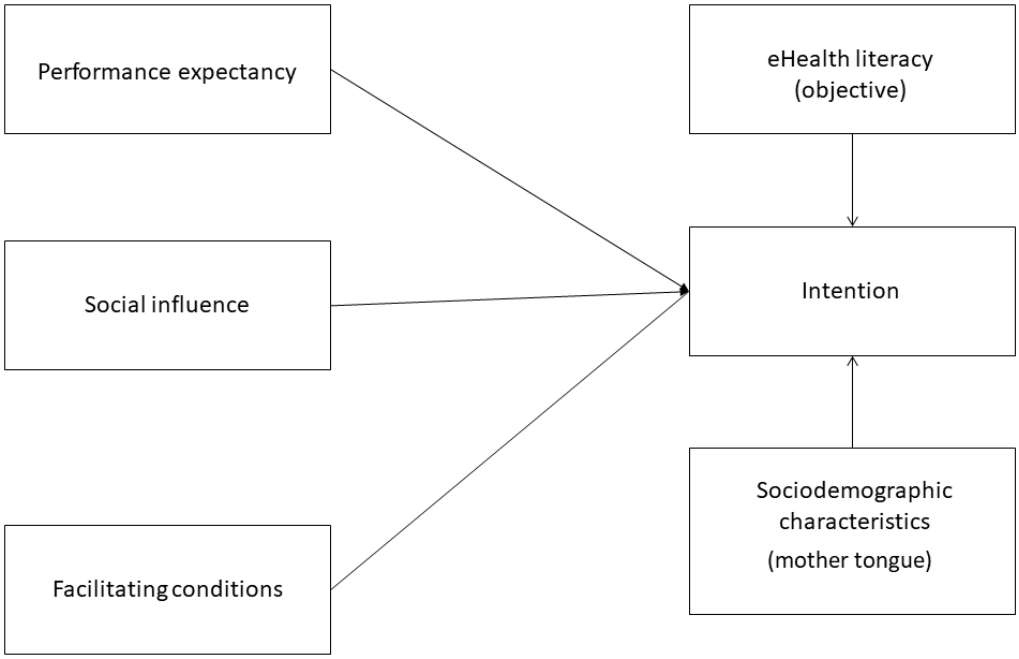
Variable	Respondents, n (%)	β (95% CI)[a]	*P* value
Mother tongue			
English (ref)[b]	629 (62.9)	N/A[c]	N/A
French	283 (28.3)	.30 (0.17 to 0.43)	<.001
Other	88 (8.8)	.06 (−0.11 to 0.28)	.57
eHealth literacy (objective)	1000 (100)	−0.06 (−0.1 to −0.005)	.03
Performance expectancy	1000 (100)	.55 (0.49 to 0.61)	<.001
Social influence	1000 (100)	.37 (0.32 to 0.43)	<.001
Facilitating conditions	1000 (100)	.15 (0.10 to 0.21)	<.001

[a]The estimated β for each variable and its 95% CI are presented in the table.

[b]Ref: reference category for the analysis.

[c]N/A: not applicable.

Figure 3. The final proposed model.



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Discussion

Principal Findings

To the best of our knowledge, this is the first web-based survey across the 10 Canadian provinces and 3 territories to investigate older adults' intention to use an eDA for housing decisions. The mean intention score was moderate. In addition, we found that older adults' most chosen and preferred housing option was to stay in their homes. Most participants had multiple reasons for this preference, which were largely related to their health conditions. Older adults were mostly supported by spouses or children in making their housing decisions, and the majority preferred to play an active role in the decision-making. We also found that intention varied across Canada according to the respondents' mother tongue. French native speakers were more likely to use the eDA for housing decisions than those with other mother tongues. In addition, objectively evaluated eHealth literacy was negatively associated with intention (ie, a lower level of eHealth literacy was associated with higher intention scores), whereas subjectively evaluated eHealth literacy was not. Finally, the UTAUT constructs of performance expectancy, social influence, and facilitating conditions were significantly and positively associated with intention. In other words, respondents with higher scores for performance expectancy, social influence, and facilitating conditions had a greater intention to use the eDA for housing decisions. These results allowed us to make the observations elaborated in the following sections.

Interpretation and Comparison With Prior Work

First, scores representing older adults' intention to use the eDA in this study were positive and similar to the scores in 3 studies using UTAUT model in the context of digital health care, which ranged from 2.8 to 4.42 [39,52,53]. The first study was a systematic review investigating the acceptance of web-based interventions for addressing various physical and mental health conditions among patients and health professionals [53]. The second study examined patients' intentions to use their eHealth records [39], and the third study examined older adults' intentions to use eHealth applications [52]. It is difficult to predict whether the intention score in our study is sufficient for older adults to adopt the targeted behavior (to use the eDA). As mentioned, there has been no definitive initiative to determine a cutoff point for clinically significant intention scores. All things considered, because there was no ceiling effect with regard to the intention score [54], suitable strategies and interventions should still be developed considering the factors influencing intention identified in our study to prompt older adults to use the eDA and thus make better informed housing decisions.

Second, our results suggest that older adults who are supported in their decision-making process by their family, friends, and health care team are more inclined to use the eDA to make housing decisions. Other studies have confirmed the importance of relatives in the decision-making process regarding housing options [10,11]. Therefore, it could be useful to add a section in the eDA to be filled in by caregivers who are involved in the decision. Comparing older adults' and caregivers' preferences could allow for a better understanding of each point of view and their respective needs, values, and priorities. This would better prepare older adults and their families for SDM discussions with each other and with their health professionals (eg, doctors, social workers, physiotherapists, and occupational therapists) and reduce the decisional regrets of older adults [11] and caregivers [10]. The eDA could thus be a useful tool in the implementation of an interprofessional SDM model, which stresses the importance of facilitating communication between different parties involved in the SDM process to reach common ground about the issues at stake, especially when it comes to sensitive topics such as housing decisions [55,56].

Third, contrary to our expectations, of the 11 sociodemographic variables in the study, only the mother tongue remained in the final model. Our results suggest that francophone Canadians are more inclined to use the eDA than anglophones. This might be because the province of Quebec, where most Canadian French native speakers live, has the highest percentage of older adults living in residential care in the country [57]. In 2021, 17% of Quebecers were aged ≥75 years and lived in senior residences, compared with only 5%-10% in the other provinces [57]. In addition to this cultural choice, Quebec dedicates a large share of its home care resources to tax credits, 83% of which are used to pay rent for older adults' private long-term care residences, instead of funding public services (eg, personal support workers) to enable people to stay in their homes [58]. Owing to these budgetary choices, the proportion of older people with access to publicly funded home care services has fallen sharply over the last years. Owing to such pressures and the growing rate of older adults, housing decisions are becoming more complex than ever before in Quebec; therefore, Quebecers would see more need for a tool that supports them in their housing decisions.

Quebec is considered as a "distinct society" whose culture and social values are different from those in English Canada [59,60]. A higher willingness to use the eDA in Quebec could also be attributed to the fact that the eDA was developed by a francophone research team affiliated with Université Laval, Quebec. Although the eDA was translated into English, it was originally designed in French, and the designers of the eDA may have unintentionally reflected Quebecers' interests and values more than those of other Canadian populations. In addition, a web-based survey assessing Canadians' health-related decision-making processes showed that being an older adult living in the province of Quebec decreased the level of SDM experienced [61]. This could explain why Quebecers are more eager to engage in SDM and use the eDA when presented with the possibility of doing so.

Fourth, even though eHealth literacy, whether measured objectively or subjectively, was associated with intention in the bivariate analysis, only the objective measure of eHealth literacy remained in the multivariable model and seemed to have had a stronger influence on intention. This result confirms the importance of measuring eHealth literacy both objectively and subjectively. Believing oneself to have high literacy levels is not sufficient and needs to be completed with objective performance measurements, which count more in terms of assessing behavioral intentions related to health [62]. Contrary

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to our hypothesis, we found a negative correlation between objective eHealth literacy and older adults' intention to use the eDA for housing decisions. The eDA was designed as a simple tool. As most respondents in our sample had high eHealth literacy scores, they might have expected a more sophisticated tool. This could explain their lower intention to use the eDA. Another possible explanation is that because eHealth literacy positively correlates with health literacy [36,63], respondents might have expected an eDA richer in content and information. Conversely, respondents with lower eHealth literacy scores were more inclined to use the eDA. This could be explained by the simplicity of the eDA. It is important to pay attention to those who have limited skills in using digital technologies. A study of low-income American older adults in 2020 showing that only half of the participants used the internet and of these, less than half had high eHealth literacy scores [44]. Older people are disproportionately affected by the "digital divide" [64]. Future research on eDAs could focus on the relationships among content, design, health literacy, objective eHealth literacy levels, and older adults' intention to use them.

Fifth, as expected, we found that the 3 UTAUT constructs (performance expectancy, social influence, and facilitating conditions) were significantly associated with intention. In other words, the more respondents believed that the eDA would improve the quality of their decision-making, that their social circle would approve of the use of the eDA, and that they had the necessary assistance for using web-based resources, the more they intended to use the eDA to decide about housing. Only the construct effort expectancy was excluded from the final model. Our results are congruent with those of other studies related to eHealth, except for effort expectancy, which was included in their models and not in ours [65,66]. As explained by Venkatesh et al [32], if the targeted behavior has not been experienced before by older adults (ie, the use of the eDA) and if effort expectancy is not present in the model, then facilitating conditions are expected to become the main predictor of intention. This was the case in this exploratory study. Moreover, Venkatesh et al [32] stated that according to the various models on which his theory is based, performance expectancy is the strongest predictor of intention of all the constructs, which was confirmed in our study. In contrast with our findings, de Veer et al [52] excluded social influence from their final model, although they found that family and friends influenced the intention to use eHealth. This might be because we operationalized social influence differently; de Veer et al [52] used only 1 item to measure social influence, whereas we used 3. Nonetheless, we too observed that respondents with higher-than-average intention scores benefited from social support (ie, family, friends, and health care team) in their decision-making process (Table 3).

Finally, our findings suggest that UTAUT constructs and behavior change methods [67] could be used to design strategies focusing on facilitating conditions and social influence that would enhance older adults' intention to use the eDA. For example, health and social care workers could be mobilized to promote the use of the eDA across different health care settings, in residential care facilities or when providing homecare services [67]. As also suggested by Bartholomew et al [67], mobilizing persuasive communication strategies and social networks could be helpful when disseminating the eDA. Members of social networks (eg, family members and relatives, caregivers, peers, and health care professionals) could help inexperienced older adults use eHealth resources [67,68].

Strengths and Limitations

The strength of our study was that this was a rigorous theory-based analysis of the intentions of older adults across Canada, a country that stretches 4700 miles coast to coast, to better support them in making one of their most difficult decisions. Furthermore, Leger Marketing, the survey firm, balanced our recruited sample across age, sex, gender, and socioeconomic status. In addition, the response rate in our study (3789/11,972, 31.65%) was higher than the average for web surveys, which usually ranges from 10% to 20% [69-71], and higher than the average response rate for the Leger panel.

Our study has a few limitations. First, our sample cannot be considered representative of all Canadian older adults because we excluded those with no internet access and most of our respondents were White, English speaking, highly educated, and male. Respondents may have been in a more privileged position than the average Canadian in terms of decisions about housing, that is, they could hire private home care workers or pay for private residential care [72]. A selection bias may have occurred because people with higher eHealth literacy are more likely to subscribe to private panels such as this one [70,73]. Rhodes et al [74] point out the pitfalls of collecting data electronically without considering the "digital divide," or with the inaccurate assumption that web access and use is equal among subgroups within a country's population. Second, in the Leger panel the percentage of respondents from the Canadian territories was lower than the percentage from the provinces, whereas the percentage of Indigenous people is higher in the territories (eg, 86% in Nunavut) than in the provinces. Thus, it is possible that Indigenous people were not adequately represented in our sample. Compounding this limitation, only 43.3% of households in the First Nations reserves have access to high-speed internet [75]. Third, our sample was limited to older adults who had made the decision to move in the past few months or were planning to make this decision in the coming year. This criterion was somewhat restrictive, as, according to Leger Marketing, some respondents from the territories screened out at this point in the survey. Fourth, we were able to measure older adults' intention to use eDA, but we cannot say that they will definitely use it. Studies that ask follow-up questions after a lapse of a few months can address this limitation. Finally, this study was conducted during the COVID-19 pandemic period. Although the pandemic affected housing decisions in older adults living in residential care [76], we did not include specific questions related to the pandemic; thus, our survey did not take this into account.

Conclusions

Our study is the first to assess Canadian older adults' intention to use an eDA to help them make housing decisions. This study makes both empirical and conceptual contributions to the field of eHealth behavior. We were able to provide a better understanding of the relationships between intention and its

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constructs and examine the effects of various variables on intention. In addition, we propose a modified parsimonious theoretical framework based on UTAUT, involving additional relevant concepts such as eHealth literacy. Research on older adults' decision-making about housing (eg, eDA development, assessment of intention to use it, and eventually its implementation and integration into various care trajectories) has become increasingly relevant. This study is a step forward toward facilitating eDA implementation and integration initiatives. Our findings and conclusions can be applied in similar sociodemographic contexts where older people are an increasingly large proportion of the population and need support to play an active decision-making role throughout their care continuum.

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Data Availability

The data sets used and analyzed during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

MF, KVP, VB, and FL contributed to study design. MF was responsible for data collection. MF, SG, AG, KVP, VB, and FL analyzed the data. MF, VB, AG, and FL contributed to manuscript writing. All authors were responsible for manuscript revision.

Conflicts of Interest

FL holds the Canada Research Chair in Shared Decision Making and Knowledge Translation.

Multimedia Appendix 1
Details of the conversion of the paper-based decision aid to electronic decision aid.
[DOCX File , 13 KB - aging_v6i1e43106_app1.docx]

Multimedia Appendix 2
Consensus-Based Checklist for Reporting of Survey Studies.
[DOCX File , 21 KB - aging_v6i1e43106_app2.docx]

Multimedia Appendix 3
Correlation matrix of the continuous variables (age, number of people in the household, eHealth literacy, performance expectancy, social influence, and facilitating conditions).
[DOCX File , 17 KB - aging_v6i1e43106_app3.docx]

Multimedia Appendix 4
Factors associated with older adults' intention to use the electronic decision aid in bivariate analyses.
[DOCX File , 19 KB - aging_v6i1e43106_app4.docx]

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Abbreviations

CROSS: Checklist for Reporting of Survey Studies
DA: decision aid
DHLI: Digital Health Literacy Instrument
eDA: electronic decision aid
eHeals: Electronic Health Literacy Scale
SDM: shared decision-making
UTAUT: Unified Theory of Acceptance and Use of Technology

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Original Paper

Understanding Older Adults' Experiences With Technologies for Health Self-management: Interview Study

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Abstract

Background: Many older adults now use technologies such as wearable devices and telehealth services to support their health and well-being while living independently at home. However, older adults vary in how they use these technologies, and there is a lack of knowledge regarding the motivations that influence their acceptance and use of health-related technologies in home environments.

Objective: This study aimed to understand the types of technologies that older adults use to support their health and the factors that motivate them to use their chosen technologies to support their health. In addition, we aimed to understand the factors that enable the effective use of technologies for health self-management and to identify the barriers that can negatively affect the adoption of technologies.

Methods: A total of 22 older adults participated in semistructured interviews regarding their experiences of using technologies for health self-management. Interview transcripts were analyzed through an in-depth thematic analysis.

Results: The interviews revealed that a range of technologies, such as videoconferencing software, fitness trackers, and other devices, were being used by older adults to support their health. Interviews showed that participants were motivated to use technologies to monitor health issues, to stay active and connected, and to record and change their behavior in the light of foreseen risks related to their future health status. Enablers that facilitated the effective use of technologies include social and organizational influence, convenient access to health care and safety provided by the technology, and easy setup and low cost of the technology. Barriers include information overload and a sense of futility about future health decline; telehealth being an inadequate substitute for in-person consultation; concerns about trust related to privacy and accuracy; and technologies being stigmatizing, uncomfortable to use, expensive, and unfamiliar.

Conclusions: This study suggested that older adults were using a variety of technologies to prevent or prepare for future health decline, evidencing a resilient attitude toward health and aging. In addition, older adults were willing to continue using the technology when there was a perceived need. The enabler mentioned by most participants was the social and organizational influence that included health care staff, family, friends, and organizations. This analysis provides a better understanding of how older adults use technologies to support their health and can guide the provision of appropriate health technologies for them.

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KEYWORDS

older adults; technology; health self-management; motivator; enabler; barrier

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Introduction

Background

Information and communication technologies have considerable potential to support older adults in accessing health care services and in self-managing their health. Recently, the COVID-19 pandemic has accelerated the interest in supporting older adults' health and has emphasized the critical importance of self-monitoring as a facet of public health [1]. Self-management refers to an individual's ability to manage symptoms; treatments; lifestyle adjustments; and the psychosocial, cultural, and spiritual consequences of health conditions, specifically chronic diseases, in collaboration with family, community, and health care professionals [2]. Examples of technologies for health self-management include wearable devices, telecare, sensor-based monitoring systems, and mobile apps. These technologies can help older adults to control their diet and physical activity or achieve emotional self-control [3-5]. Such technologies, if used effectively, could increase the efficiency of health care, reduce the workload for providers, reduce medical costs, and improve older adults' well-being [6]. Furthermore, these technologies can enable older adults to maintain their autonomy and independence as they age [7-9].

Recent research related to technology adoption among older adults has indicated that older adults are increasingly familiar with digital technologies [10-12] and are interested in using technology to manage their health, such as measuring heart rate, keeping an activity diary, and monitoring stressful situations [13,14]. However, older adults' experiences with technology can vary greatly, and many factors can influence whether an older adult successfully uses technologies for health self-management. This means that there is reason to be cautious about predicting the rising uptake of health technology by older adults. Previous quantitative studies have shown that older adults have reservations about using health-related technologies to obtain health information and advice [15,16]. However, these studies were conducted between 3 and 6 years ago, and the situation could have changed in recent years, as these technologies have become more commonplace.

Other studies suggest that there are a range of factors that affect the adoption of health technologies by older adults. Researchers have investigated older adults' use of activity trackers and sleep monitoring devices [13,14,17-20]. Although there is a positive interest in using such technologies, encouraging their ongoing use is a challenge [19], and social support has been identified as the main motivation for encouraging the use of these technologies in long-term users [14]. In addition, studies have concluded that the design and use of wearable devices and mobile apps must consider age-related cognitive, sensory, and motor function changes in the older generation to ensure the adoption of these technologies by them [13,20].

We also understand some of the potential applications of this technology. A key principle is supporting aging in place, where older adults are supported in living independently in their established home and community, rather than moving to specialist accommodation [21]. Previous studies have identified possible barriers to technology adoption for aging in place. These barriers include device usability, accessibility, reliability, affordability, and privacy [22,23]. Concerns about trust related to privacy and security, stigma, the lack of control over technology, the lack of human response, inaccuracy, need for training, and anxiety are further impediments [24,25]. A comprehensive review of smart residential environments added that security, the lack of interoperability, complexity, and the lack of perceived utility were concerns of older adults [7]. Almathami et al [26] conducted a systematic review of the factors that influence the use of web-based home health consultation systems or telemedicine health services. They identified internal factors, including users' behaviors and motivations while using and interacting with the system and patients' beliefs and perceptions of the relative advantages and disadvantages of the web-based home health consultation system.

The role of assistive technology in supporting the health of older adults has also received attention. Greenhalgh et al [27] conducted a study with 40 participants to develop a theoretical model of assistive technology use. They found that telehealth and telecare seldom met older adults' needs and did not assist them to live with an illness. Yusif et al [28] conducted a systematic review of factors that concern older adults in their decision to adopt assistive technology. They identified privacy as the main concern to older adults, followed by trust, the lack of functionality or added value, financial cost, and the ease of use. Other factors that negatively affect technology adoption included the suitability for daily use, perception of no need, stigma, fear of dependence, and lack of training.

These studies have collectively focused on why older adults have hesitated to or have been prevented from using technologies before or after they are familiar with them. However, the studies did not examine the motivations of older adults for using these technologies. This study closes this gap. It takes a broad perspective, looking at a variety of technologies that participants identify as relevant to their health self-management. This perspective provides a vital understanding of older adults' needs and, consequently, can improve the use of technologies and care for older adults.

Objectives

This study aimed to understand the technologies that older adults use to support their health and the factors that motivate them to use technologies to support their health. In addition, this study aimed to understand the factors that enable the effective use of technologies for health self-management and to identify the barriers that can negatively affect technology adoption. We adopted a qualitative approach involving semistructured interviews with 22 participants.

Understanding the motivators, enablers, and barriers that affect technology-based health management is essential to ensuring that future technologies are designed and deployed appropriately. To be effective, technologies must be designed to align with health self-management at a time of life when good health is not guaranteed.

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Methods

Ethics Approval

All procedures were approved by the Human Research Ethics Committee of The University of Melbourne (ID# 1955800).

Participants and Recruitment

We recruited participants by contacting organizations that provide services to older adults who live independently at home. The recruitment criteria included individuals who were aged >65 years; lived in Melbourne (Australia); used a device for their health care (eg, home blood pressure monitor, blood glucose monitor, fitness tracker, etc); and spoke English.

A total of 5 organizations distributed information about our research to their members. Respondents who registered their interest in the study were then contacted, and an interview was arranged. A total of 22 participants agreed to be interviewed. Drawing on the concept of "information power," this sample size was deemed sufficient [29]. Using information power as a guiding principle to assess the appropriate sample size in qualitative research gives weight to criteria such as clearly defined aims, sample specificity (eg, older adults who use technologies for health self-management), and the quality of conversations with interviewees. Our study met these criteria; therefore, we are confident that a sample size of 22 is sufficient to gain in-depth insights into the phenomenon studied. Furthermore, this sample size is in line with guidelines based on a meta-analysis of typical sample sizes required to reach theoretical "saturation" in qualitative data [30], and the study found that saturation is typically reached with between 8 and 17 interviews.

All the interviews were conducted from October 2020 to January 2021. To protect their anonymity, all the participants have been given a pseudonym and are referred to by their pseudonym in the *Results* section.

Procedure

Participation was voluntary, and the participants did not receive compensation in the study. Participants read a plain language statement and signed a consent form. All interviews were conducted by author EGR. The interviews were held via phone or videoconference, using WhatsApp (Meta Platforms Inc), FaceTime (Apple Inc), or Zoom (Zoom Video Communications), from October 2020 to January 2021. We conducted interviews to gain an in-depth understanding of older adults' motivations and experiences that affect their acceptance and use of technologies for health self-management. The interviewer asked questions related to the acquisition and use of technologies that participants used to manage their health, questions about participants' motivations for using these technologies, who influenced participants' decisions to use these technologies, and what they did not like about these technologies.

Data Analysis

Each interview was audio recorded following the participant's approval. Then, the interviews were transcribed verbatim and analyzed using thematic analysis [31]. The thematic analysis involved the following six stages: (1) becoming familiar with the data, (2) generating codes, (3) generating initial themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report. The data were coded by EGR using an inductive approach. Preliminary codes, subthemes, and key themes were refined through discussions among the research team. NVivo (version 12; QSR International) software was used to identify and categorize the codes and organize the data.

Results

Participants

A total of 22 people agreed to be interviewed, including 14 (64%) women and 8 (36%) men. Participants' age ranged from 65 to 87 (mean 73, SD 6) years. Most participants (n=20, 91%) were educated beyond secondary school. A total of 14 (64%) participants were living with their partner, and 8 (36%) participants were living alone. Additional demographics are summarized in Table 1. Multimedia Appendix 1 provides more details about the interviewees.

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Table 1. Participant demographics (N=22).

Demographics	Value
Age (years), mean (SD)	73 (6)
Sex, n (%)	
Female	14 (64)
Male	8 (36)
Highest level of education, n (%)	
Tertiary institution, university, or other higher educational institution	20 (91)
Secondary school	2 (9)
Marital status, n (%)	
Married	13 (59)
Widowed	4 (18)
Single	3 (14)
Divorced	1 (5)
Prefer not to answer	1 (5)
Employment, n (%)	
Retired	19 (86)
Semiretired	2 (9)
Working part time	1 (5)
Household composition, n (%)	
Live with his or her partner	14 (64)
Live alone	8 (36)
Need for help or supervision, n (%)	
No	17 (77)
Yes, sometimes	5 (23)
Reasons for help or supervision, n (%)	
No need for help or supervision	17 (77)
Long-term health condition	3 (14)
Short-term health condition	1 (5)
Other cause or community services come in to clean	1 (5)

Types of Technologies Used

Participants mentioned a range of technologies they used to support their health activities at home. These included videoconferencing software and phone devices to access health care services (telehealth), wearable devices to monitor activity and health status, personal alarm systems to alert carers in the case of emergencies, web-based sources for health information, and a range of other specific health technologies.

Telehealth, a remote health care service, was the technology used by most respondents (14/22, 64%). To access telehealth, the participants used videoconferencing software or phone calls.

Among the wearable devices mentioned by the 22 respondents were fitness trackers (n=8, 36%) and personal alarm systems such as pendant alarms (n=6, 27%). In addition, the participants mentioned using medical devices such as blood pressure monitors (n=9, 41%), blood sugar or glucose monitors (n=4, 18%), hearing aids (n=5, 23%), a pulse oximeter that measures blood oxygen level and pulse rate (n=1, 5%), a continuous positive airway pressure (CPAP) machine that treats sleep apnea disorders (n=1, 5%), an implantable cardiac defibrillator and pacemaker (n=1, 5%), and a pelvic floor stimulator that strengthens the pelvic floor muscles to reduce incontinence (n=1, 5%).

Some participants identified mobile devices (n=4, 18%) and personal computers or laptops (n=3, 14%) as technologies they used to look after their health. Moreover, 6 (27%) participants were using apps related to food and physical activities.

All the participants (22/22, 100%) had access to the internet, and 5 (23%) of them commented that they used the internet to search websites for information related to their health.

Other technologies mentioned by the participants included Google Calendar, used by 1 (5%) respondent as a diary to

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remember medical appointments and activities, and a customized spreadsheet, used by another participant (n=1, 5%) for health monitoring and tracking. A summary of these technologies is presented in Table 2.

Table 2. Types of technologies used to support participants' health activities at home (N=22).

Types of technologies	Participants, n (%)
Remote health care service	
Telehealth	14 (64)
Wearable devices	
Fitness tracker	8 (36)
Personal alarm system	6 (27)
Medical devices	
Blood pressure monitor	9 (41)
Hearing aids	5 (23)
Blood sugar or glucose monitor	4 (18)
Pulse oximeter	1 (5)
CPAP[a] machine	1 (5)
Implantable cardiac defibrillator and pacemaker	1 (5)
Pelvic floor stimulator	1 (5)
Others	
Apps related to food and physical activities	6 (27)
Mobile device	4 (18)
Personal computer or laptop	3 (14)
Google Calendar	1 (5)
Customized spreadsheet	1 (5)

[a]CPAP: continuous positive airway pressure.

Motivators: Factors That Motivate the Use of Technologies for Health Self-management

Overview

We present 3 themes that provide insight into why participants were using technology to manage their health. First, many participants were motivated by the need to keep track of health-related information to manage chronic health conditions, such as diabetes, and to stay independent. Second, participants were motivated to use technology to stay active and socially connected and saw this as an important part of their health self-management. Third, some participants were motivated to use technologies to monitor their health and change their behavior because of prior knowledge and awareness of personal risks related to their future health decline.

Theme 1: Monitoring Chronic Health Issues to Stay Independent

Of the 22 participants, 14 (64%) said that their main motivation for using technology was to monitor their health issues. Within this group, 12 (86%) participants reported that the technology was useful for monitoring or helping manage existing medical conditions or disabilities. For example, 1 (7%) participant used an app to track vital signs and blood pressure that could affect his health and to be in contact with his physician (general practitioner):

> *I have an app on my phone that is connected to my GP and so my cholesterol levels, my heart rate, my weight, blood pressure, are all communicated back to him. If I enter a value in here, it shows up on his screen and if he's concerned he will text me to come and see him or just...It will text me to make an appointment. In fact, I got one earlier this week where he said, it's time for your skin check. So, I get the skin check. I'll take that phone off.* [P2, Bob]

Furthermore, 3 (21%) participants commented that if they did not monitor their health issues, they would lose their capabilities and risk losing their independence, as described by Nancy:

> *I think I'm going to end up with knee surgery, probably a knee replacement. I've had minor knee surgery because I also tore a cartilage doing some stuff, but I think I'm going to end up with a knee replacement. Health, I'm going to have to keep control of diabetes because I know otherwise my independence, if I would lose my vision or if my kidneys start failing, that's going to really affect again my independence. So, I've got a handle on the diabetes so that the...That just gets harder as the*

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> *system gets older so I really, really got to work on that.* [P14, Nancy]

In addition, 3 (21%) participants wanted to be healthy to avoid being a burden to their family. A participant commented the following:

> *Some people would say money is more important. Some people would say family is more important, but I figure, no matter how wealthy you are, if your health is rotten, money means nothing. And if put family first and your healthy is no good, you are a burden on your family and they look after you. So you have to be healthy so you can do what your family might need regardless of your age.* [P11, Katy]

Participants reported that technologies such as telehealth and wearable and medical devices were useful for monitoring or assisting with medical conditions or disabilities. These findings suggest that these health technologies fulfill the purpose for which they are designed and help older adults maintain their independence by monitoring and managing their health.

Theme 2: Staying Active and Connected

Most of the participants performed technology-supported activities that helped them stay physically or mentally active and connected with family and friends. Overall, 14 (64%) of the 22 participants used technologies that were aligned to their objectives to stay active. For example, one participant commented as follows:

> *I have a Fitbit, which I carry in a pocket all the time. I aim for 10,000 steps, but don't often get there since I had the problem with the disk [back injury]. But I'm usually over 2000 or thereabouts. Sometimes higher. I do tend to sit. We also have weighing scales that are connected to the Fitbit. So I keep track of my weight, and also the percent body fat. And I think that's it.* [P13, Michael]

Of the 22 participants, 5 (23%) who were using apps related to fitness and food, videoconferencing software, and hearing aids mentioned that they shared information related to the progress and goals of their activities with relatives and friends. This helped them to stay socially connected:

> *The Strava app is a really good app because it links you with a group of friends, people you know who are also doing something similar so if you can't meet in person, you can sort of meet with your chat on the Strava app after you've recorded a ride. And, people give you positive comments, or they talk about the photos, or they say, well done for the distance or gee, that was a lot of mountain climbing you did today. So, you get a lot of positive feedback from your friends so I think that's a very positive thing.* [P7, Gwen]

One participant who had a hearing impairment and was using hearing aids to go out, talk to people, or watch television mentioned that hearing aids helped her avoid isolation:

> *Yes. I'd say that they're very important. The hearing aids are especially important, otherwise you're isolated from people and can't understand what they're saying…* [P3, Cyndi]

Of the 22 participants, 3 (14%) reported that these technologies helped them perform regular activities. One participant used a Google Calendar to plan his daily activities:

> *And I have diary that is on Google. I find that very useful to plan my appointments and things like that. Doctors' appointments, that sort of thing. And to make sure that I don't forget things that I need to do. I think that's pretty important.* [P6, Frank]

Theme 3: Knowledge of Risk of Future Health Decline

Of the 22 participants, 10 (45%) demonstrated an awareness of risk to certain diseases, especially because of known genetic traits in the family. On the basis of this knowledge, participants tried to prevent or monitor diseases they suspected were more likely to develop. One participant spoke about how his family history of stroke meant he had increased motivation to monitor his blood pressure, leading him to adopt a blood pressure monitor:

> *Well, currently, I'm undergoing no major medical treatment so that will be the first thing. I do take blood pressure medication and that type of thing, so my blood pressure is actually controlled, fortunately. Obviously that may have contributed to my father's, maybe even my grandfather's stroke. So it's been very important for me to keep my blood pressure under control. So that means taking the proper medication and getting it reviewed regularly.* [P6, Frank]

Within this group, 2 (20%) out of 10 participants reported familiarity with health self-management technologies because their close relatives used them to monitor their own medical conditions. For example, one participant commented as follows:

> *Well, I guess, my late wife had high blood pressure, and she had the monitor to keep a check on that, and so I'd use it [blood pressure monitor] occasionally, just more or less for a bit of fun and see what the readings were.* [P10, John]

In addition, 3 (30%) participants believed that they had a duty to know about their own health. A participant was motivated to use blood pressure and blood glucose monitors so that she could control her health:

> *Sometimes people get frightened because they think of bad news. I've heard of people who won't get tested for diabetes in case they have to stop eating cake. I think, would you rather be blind? So, yes, personally I like to know. The things I can control I would rather control, so I'd rather have the knowledge. That's important except, as I said, there's only so many things that you can twitch about.* [P14, Nancy]

Enablers: Factors that Enable the Use of Technologies for Health Self-management

Our analysis revealed 3 factors that enable the positive uptake of technologies for health self-management. These include social and organizational influence, convenient access to health care

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and safety provided by the technology, and easy setup and low cost of the technology.

Theme 4: Social and Organizational Influence on Decisions to Use Technology

Social and organizational influence was identified as an enabler in the use of technologies for health self-management. All 22 (100%) participants mentioned that health care staff, family, friends, or organizations influenced their use of technologies.

Health Care Staff

Of the 22 participants, 11 (50%) mentioned that health care staff recommended or suggested using technologies for health self-management to prevent, monitor, and treat health issues. The participants could monitor their health and report the readings from the device to the medical staff if the results were not within the normal range. A participant described several different technologies recommended by the medical staff:

> *Well, that [related to the CPAP machine] was a specialist recommendation. But I guess I use it differently to how some people might use it. I extract the card and I read the data on it and check the progress. I don't bother going back to the sleep physician. I've actually got training treatment of sleep disorders, so I know what the data means and if something's not looking right, then I've got a reasonably good idea about what I need to do about it. So that was that was specialist advice. Hearing aids, I've had a hearing impairment since childhood. But I only was aided once I was about 40. So again, that was kind of consultation with a health professional that says this could be helpful for you. Blood pressure monitor again,...I suppose, it's medical advice which says this would be a good idea, or I recommend this or something like that. Yeah.* [P15, Olivia]

Family and Friends

Overall, 3 (14%) participants reported that supportive family members helped them use the technologies. The family members made it easier for older adults to use technologies. A participant said that she received help from her family to use the blood pressure monitor:

> *My husband has to get it [blood pressure machine] out of the cupboard for me. He usually helps me put it on my arm. I can do that myself, but it's just easier if he does it, and he knows how to line it up or that sort of stuff. One of my daughters is a registered nurse and she lives not far from me. There have been times when I haven't been feeling good and she's come to my house. She can do those readings easily. It's generally family members who use the machines, but I will do it myself as long as I can get access to it, even if it's tucked away in a drawer or something, I can usually get it out when I need to.* [P17, Rita]

Furthermore, 3 (14%) participants received technologies as gifts from their families, and 5 (23%) participants acquired the technologies because their family or friends were using them. A participant started to use an app because her husband was using it:

> *Because he was already on Strava and I could see how much enjoyment he was getting out of it, and so after a little while I decided to join as well and I enjoy it so much that I probably do more recording than he does.* [P7, Gwen]

Another participant was influenced by her friends to obtain a fitness tracker because they used fitness trackers to monitor their activities:

> *I guess the Fitbit, friends had them. And I thought, 'Oh, that sounds like a good idea, to monitor your activity.' And it does give you encouragement. And I don't participate in groups, this is just me looking at what I do.* [P12, Linda]

Organizations

In addition, 5 (23%) participants were using technologies such as apps related to food, blood glucose monitors, hearing aids, or a pendant alarm based on information received from organizations. These were nonprofit organizations that cater to people aged >50 years and public and private organizations that provide assistance with conditions such as diabetes, tinnitus, hearing loss, or dementia. In some cases, these organizations allowed their clients to trial their technologies before purchasing them:

> *Well, with Academic Hearing, I went there, and they asked me if I'd trial their hearing aids, and I trialled them, and they said yes I could have them.* [P19, Tina]

Moreover, 7 (32%) participants had the cost of the devices subsidized by the government, care organizations, or health insurance companies. A participant said the following:

> *There's an organisation in Australia, Diabetes Australia and a lot of things are subsidised if you were a diabetic or if you have a record, medical diagnosis or diabetes. So, the test strips are heavily subsidised and that's where the companies make their big money so they're very, very interested in giving you the monitor so you would the test strips. Because if you bought them independently, I think they are 50, 60, maybe $70 a packet. And I get them for $5 something, $6 but they're getting 50, $60 a box of tests. So, they want you to use their things.* [P14, Nancy]

Furthermore, 8 (36%) participants received help or technical support for the technologies from government or technology providers. One participant stated the following:

> *Well, the hearing aids are the ones that the government provides for pensioners, so there's no financial support except I pay for batteries and having them checked up. Once a year I go for a checkup with them. The pendant is...What's it called? Well they do come, supposed to come once a year and check them, and once a month I ring the alarm just to see that it's working.* [P3, Cyndi]

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In addition, 2 (9%) participants mentioned that their living arrangements provided support for their needs that enabled independent living. That is, they saw the value of technologies for supporting independent living. One lived in a retirement village and the other in public housing (affordable government-owned homes that support older adults with accommodation issues). Both participants moved into homes that offered support and immediate assistance through technologies for health self-management. One participant who had a chronic illness and disability and lived in public housing said the following:

> *I love my little home and this chair and my computer and easy cooking and all of those things…And they did an upgrade of the units two and a half years ago, and they absolutely focused on my disability needs…I've got an oxygen concentrator here, I've got P2.5 masks and everything has been done to enable my functioning…all those fine details which the number of faxes and emails for my doctors to get everything that we reckoned, this was a one-off change to get this unit right for my aging, more assistive technologies [scooter, walking stick, pickup stick, orthopaedic lift up chair, and push along walker].* [P22, Zoe]

Another participant moved to a retirement village because of her husband's health issues and the need to access support:

> *The pendant alarm is part of being in the village, and that was one of the reasons we moved here, to have that sort of backup after my husband's brain tumor. We didn't know what the future meant for him, so that's been handy because he was recently ill, and pressed the pendant, and the ambulance was here straight away.* [P19, Tina]

Theme 5: Technology Provided Convenient Access to Health Care and Safety

In total, 13 (59%) out of the 22 respondents commented that technology such as telehealth was convenient and enabled prompt medical attention. The technology provided efficiency benefits because it reduced travel and wait times at hospitals for the participants:

> *It wasn't really very much available before, but I will continue to use it now, because there's no point driving out to the doctor if you don't need to see him. It takes less time for the doctor to see you on telehealth and less of your time as well.* [P1, Amy]

Furthermore, 3 (14%) participants who needed support mentioned that older adults who could not move easily or needed to stay home could benefit from telehealth because of its convenience and easy access to medical staff. As one participant noted, telehealth improved access to health services:

> *Telehealth, I think telehealth for some people is really good, and at times for old people because sometimes you just can't get somewhere. So being able to have sort of a consult with a doctor but not a situation where it's five minutes or 10 minutes and you're in and out, but a proper consult with your own doctor can be great at those times when people are housebound where they can't move easily and can't get out.* [P8, Helen]

Overall, 8 (36%) participants, including 3 (38%) of the 8 who were living alone and needed support, said that they used technologies such as pendant alarms because they offered safety and access to services and support. This enabled the participants to feel comfortable living independently:

> *The pendant because I live alone and I do a few risky things like climbing ladders, so in case I have a fall I've got someone I could contact. Otherwise, I'd be on my own without help.* [P3, Cyndi]

Theme 6: Easy Setup and Low Cost of the Technology

In addition, of the 22 participants, 7 (32%) commented that the technologies that they were using to monitor their health were easy to set up and use. A participant who was using apps related to fitness said the following:

> *No, there's nothing I don't like about it [related to the app]. I found it easy to use. No, there's nothing I don't like about it. It serves its purpose for me so I like it.* [P7, Gwen]

Of the 22 participants, for 4 (18%) of them, cost was not an issue to obtain and use technology. A participant commented that the price to buy technologies for health self-management such as blood pressure monitor, pendant alarm, pulse oximeter, and telehealth was affordable:

> *I haven't sought financial support, because they've all been within a reasonable price bracket.* [P17, Rita]

Barriers and Challenges: Factors that Discourage the Use of Technologies for Health Self-management

Overview

Our analysis identified 4 barriers and challenges that interviewees had encountered when using technologies for monitoring their health. Barriers include information overload and a sense of futility about future health decline; telehealth being an inadequate substitute for in-person consultation; concerns about trust related to privacy and accuracy; and technologies being stigmatizing, uncomfortable to use, expensive, and unfamiliar.

Theme 7: Information Overload and Sense of Futility About Future Health Decline

Of the 22 participants, 10 (45%) were motivated to manage their health because of the risk of developing certain conditions. There were 2 (9%) participants, however, who appeared to feel overwhelmed by gaining too much knowledge about their existing conditions from using the technologies. This caused them distress and anxiety. For example, a participant who was using devices such as a blood pressure monitor, blood glucose monitor, and a fitness tracker to control diabetes said the following:

> *You're a diabetic whose weight has got high glucose level but weight now follows your need to exercise more, but you've got this pain. So what can we do*

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> *first? Are there any signs that we need to change to diet? And what are you prepared to do? But it just gets more difficult the more things you have to think about.*
>
> *So I think people go for the easy stuff and I'm just trying to think, "All right. Try not to think about the cardiovascular stuff. I didn't need to know that. I really did not need to know that." The arthritis and the diabetes is enough, thank you and COVID made me very anxious, so I was very anxious.* [P14, Nancy]

Another participant, who had hyperacusis and was unable to tolerate loud sounds, commented that she received news about possible complications owing to the use of hearing aids and she had to decide whether she would be deaf or experience the complications of using hearing aids. This information caused her more distress because she had already been dealing with other health issues:

> *Well what are normal sounds for most people, cars going along the street and so on, or a dog barking. She [neurologist] said, 'I've had to set your hearing lower than I'd like because of all of that.' But the sound was too much. So we're in the trial stage and you know I might have to make the choice, okay I'm just going to get deaf and I might make the choice that I'm going to struggle with this. But I'm going to get brain symptoms if I use them [related to hearing aids]. My eyes are tearing up as I say all of that. It's very hard.* [P22, Zoe]

Of the 22 participants, 5 (23%) expressed a sense of futility about future health decline stating that no matter what they did, they could not avoid inherited or other diseases. One participant who used a blood pressure monitor and a fitness tracker said that she was concerned that she would still have cardiovascular disease, as her family members had before her:

> *Well, unfortunately my genetic background is full of heart trouble. So I presume I will end up with heart problems. Other than that, there has been cancer in the family, but not immediate family. So hopefully there would no problem there. And someone said as we get older, the worry is that you fall over and that could be a problem as well.* [P21, Whitney]

The participants commented that no matter what they did to be healthy, as they got older, they would become more fragile and more prone to disease, and something unexpected could happen:

> *And as you get older you're going to expect to get more frail, and you'll probably get cancer or something at some time, but that's life. Who knows what's going to front up, but when you get to 75, you've got max 25 years left, so you're going to pop off sometime.* [P10, John]

Theme 8: Telehealth Cannot Fully Replace In-Person Consultations

Some participants commented on the limitations of telehealth. In total, 4 (18%) participants communicated with physicians through phone calls, whereas others (5/22, 23%) communicated by Zoom. However, patients had to visit the hospital when physical examination or immediate attention was necessary. A participant who had osteoarthritis and mild sleep apnea and had consulted with the physician over the phone commented the following:

> *So, in the last nine months I would say, I've used a combination of...sometimes I've had to go to the doctor's in person for an injection right? You can't do that with Telehealth. But other times I've been able to have a consultation over the phone.* [P18, Sarah]

In addition, the participants mentioned that there was the lack of interaction and connection with the medical staff. The participants had used telehealth through their phones, and they could not interact with the physician. Therefore, they preferred face-to-face interactions:

> *But with telehealth, I understand that it's necessary to do because you can't have personal contact, but for me, if you can't have a personal dialog with your medical practitioner, it's not quite the same thing, I don't think…If you don't have that connection with the eyes that you understand exactly what they mean, because sometimes a doctor can say to you, 'That's really what I need you to do, do you understand?' And sometimes you do, but sometimes they may mean…something a little bit more dramatic that the very serious…So look, in the telehealth that I've been doing, it's been by phone…So there's been no visual…So that's been unsatisfactory. But I like the doctor and so I've still tried to do the best you can.* [P9, Isaac]

Theme 9: Concerns About Trust Related to Privacy and Accuracy

Security and privacy implications were mentioned by 4 (18%) of the 22 participants. The participants were concerned about privacy related to providing data for data collection, sharing information, and avoiding identity theft from technologies such as fitness trackers, apps, videoconferencing software, and messaging apps:

> *I guess the privacy concerns are just the suggestions are that the old people were worried about rumors and suggestions of people intruding on identity theft of getting knowledge about you in certain ways. And also of course, I imagine you understand the words, scams, the sort of…that sort of thing, yes.* [P16, Paul]
>
> *I don't join my Fitbit up to the…anything else. I refuse to give away my analog information. I don't know where it's going, so I don't have it joined up to the app. I've turned the app off so that it just gives me numbers and I charge.* [P14, Nancy]

In addition, 3 (14%) participants reported the inaccuracy of the measurement of the blood pressure monitor:

> *I am, just because of my physics background, suspicious of their accuracy, which as I said, I had three [related to blood pressure monitor], and I've taken measurements from using all three in quick*

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succession, or simultaneously, and then cross checked the results, so I always have a degree of skepticism about their precision. [P10, John]

Theme 10: Health Care Technologies Can Be Stigmatizing, Uncomfortable to Use, Expensive, and Not Familiar

Of the 22 participants, 2 (9%) participants expressed concerns about the visibility of the device and the stigma associated with using health care devices such as pendant alarms. The participants believed that they were wearing a technology that targeted older adults with frailty. By using these technologies, other people could perceive them as frail or with poor health condition. For example, one participant commented as follows:

> *I remember my late mum she used to have to wear something around her neck which she hated 24/7 and felt like a cow. She really hated that and I can totally relate now. So we were talking about devices that might help us, like something that we could wear on our wrist perhaps the Apple Watch for example or some other device that was on our wrist that was not intrusive and didn't look awful and identify us as being in a certain age group and having certain health problems and all of those types of things. So something like that definitely we would both look into it.* [P8, Helen]

Furthermore, 4 (18%) participants reported discomfort when using health-related technologies such as CPAP machine, blood pressure monitor, hearing aids, and implantable cardiac defibrillator. A participant who had sleep apnea mentioned that she felt uncomfortable while using it:

> *…And I mean, with things like C-PAP machine, no one in their right mind would get one if they didn't need one, because it's hideously, intrusive and uncomfortable. It's awful to have to use. So if I had a choice I wouldn't use it ever.* [P15, Olivia]

In addition, 1 (5%) participant expressed concerns about the cost of technologies:

> *So, for example, with a C-PAP machine, cause I've used one for about 10 years, I think and I'm on my second machine. They have a lifespan of about five, six years maybe. They're expensive. They're very expensive in Australia. If I lived in the US I'd get one for a third of the price, even from a company that's designed it in Australia. So really pisses me off that for some things where you really have little choice, you're not supported through Medicare [Australian public health insurance system], but you need these things and yet you're talking thousands of dollars. So if they need a service, that can be a thousand dollars. So I suppose like with any technology I suppose the thing that frustrates me with them is sometimes the need for maintenance is high and there's a cost associated with that.* [P15, Olivia]

Furthermore, 2 (9%) participants expressed an issue regarding the battery of the devices that drained quickly. A participant mentioned the following:

> *The costs of charging. You seem to always...have you got it charged, or haven't you got it charged, and that's probably the most annoying thing. And if you go anywhere, you seem to take more chargers than anything with you.* [P19, Tina]

In addition, 3 (14%) participants also shared concerns about their lack of familiarity with the technology:

> *The only thing I would say is, although most older people are quite tech savvy now, there's still a lot of people who don't have a computer. So there's still that gap…*
>
> *So, for example, I'm president of a group and there's about 15 people in it. And several of them I have to communicate with them either by going in person or by writing to them snail mail. Or by ringing them up because that's what I can do with them.*
>
> *And with others, I can quickly either send a text because lots of people got phones, but not everybody knows how to text.* [P18, Sarah]

Discussion

Principal Findings

This study aimed to understand what types of technologies older adults use to support their health, what motivates older adults to use technologies to support their health, and what factors enable the effective use of technologies for health self-management. Finally, this study investigated the barriers that negatively affect the adoption and use of technologies for health self-management.

A range of communication technologies such as videoconferencing software or phone calls were most commonly used to enable telehealth consultations. Wearable devices, medical devices, and web-based sources for health information were also discussed. Motivators that encouraged participants to use technology included a desire to monitor their health, stay active and connected, and monitor health signs, especially when they were already aware of a personal risk related to future health decline. Enablers that facilitated the positive uptake of technologies for health self-management included social and organizational influence, technology-enabled convenient access to health care and safety, and easy setup and low cost of the technology.

However, our findings showed that there are challenges that affect the use of technology by older adults. These include feeling overwhelmed by too much information; feelings of helplessness about future health decline; telehealth being a poor substitute for in-person consultation; concerns about trust in system privacy and accuracy; and technologies being stigmatizing, uncomfortable to use, expensive, and unfamiliar.

In the following sections, we discuss the importance of our findings in relation to previous work and present further interpretations.

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Motivators to Use Technology: Planning for Resilient Aging

We found 3 main motivators for using technologies for health management among our participants. Drawing on these findings, we argue that the knowledge of future adversities provided a sense of power and control for some of our participants. They expressed attitudes toward aging that demonstrated personal resilience and used technologies for health self-management to prevent or prepare for future health decline.

These findings can be interpreted using the lens of resilient aging. Resiliency is defined as the ability to recover from difficult situations, that is, "an extraordinary atypical personal ability to revert or 'bounce back' to a point of equilibrium despite significant adversity" [32]. Adversity can be viewed in terms of living conditions that lead to personal losses, inequalities, disabilities, and general challenges of aging [33].

Researchers have identified the ways in which systems can be designed for future resilience. Our findings suggest that participants have different approaches to preparing for future resilient aging. This points to a type of resilience that is related to the definition provided by Woods [34]: "to be resilient, a system looks ahead to read the signs that its adaptive capacity as it currently is configured and performs is becoming inadequate to meet the demands it will or could encounter in the future." According to Hollnagel [35], the fundamental functions for resilience include anticipating and monitoring changes and threats, being proactive, ensuring the ability to respond to interruptions, and learning from past experiences.

We observed this pattern of resilience in some of our participants. Knowledge of future adversities provided them with a sense of power and control, and knowledge about what to expect in the future meant that they knew what to do about their health and could make decisions with this knowledge in mind. For example, some participants, who monitored their health because of their family history, took early action and planned ahead to avoid or delay the appearance of hereditary diseases. Dismissing information about their health and not doing something about it could make them more susceptible to health decline and the loss of independence. A previous study reported that risk factors for the loss of independence in later life include poor mental and physical health, social isolation, the loss of mobility, inappropriate environment and living conditions, and the lack of resources [36]. Thus, older adults are likely to benefit from using technologies that allow them to maintain their independence; give them control and authority over the characteristics and functions of the technologies; and do not make them appear weak, dependent, or in need of special care [37].

In contrast, other participants showed less resilience. For these participants, this knowledge could cause anxiety and stress, as this information overwhelmed them and they did not know what to do. That is, information about the deterioration of their health created a feeling of helplessness in some participants. Previous research found that information overload creates stress, fatigue, burnout, and even interruption in the use of information sources [38,39]. In addition, information overload negatively affects psychological well-being and influences the intention to discontinue the pursuit of health information [39] and results in information avoidance [38].

We argue that participants who chose technology to track health and activity information were those who expressed a resilient attitude by preparing in advance to prevent or delay the onset of hereditary diseases. In contrast, those participants who said they felt overwhelmed with the information provided about their existing medical conditions were using technology to manage their health. This leads us to argue that the link between resilience and technology use for health self-management warrants further investigation.

Enablers to Use Technology: Social and Organizational Influence Is the Most Mentioned

This study identified 3 enablers in using technologies for health management among our participants.

First, our findings showed that social and organizational influence positively affected technology use. All the participants mentioned the influence of family and friends, health care staff, and organizations. In this study, social and organizational influence provided information about health-related technologies and helped in motivating the use of these technologies. In addition, some technologies were subsidized, and older adults received help or technical support from nonprofit organizations related to older adults; public and private organizations that research and assist people with diabetes, tinnitus, hearing loss, and dementia; or technology providers. Social and organizational influence became enablers and positively affected the use of technologies when they helped overcome technology barriers. In contrast to the Technology Acceptance Model [40] and the Unifying Theory of the Acceptance and Use of Technology [41], we observed clear evidence that social and organizational factors not only influenced the intention to use technologies but also shaped how they were used in practice. The influence of social context on actual use is not found in either model, so capturing this would be a vital element in a framework that captures the use of supportive technologies by older adults.

Previous research showed that older adults who received support in addressing technological challenges were more willing to use various products and devices in their daily lives [42]. Family members, friends, and medical staff often comment and recommend recent technology to older adults, and this influences older adults' technology use decisions [42]. According to Tseng et al [43], the opinions of other older adults can influence older adults' acceptance of the health monitoring system. On the basis of this finding, influential people such as health care professionals, family, and caregivers could be included in the design of the technologies for health self-management because they are familiar with the technology owing to the assistance they provide to older adults.

In addition, we found that organizational influence such as supported living arrangements influenced the participants' decisions about using technology. These accommodations offered support and prompt assistance to the participants through technologies for health self-management. Consistent with these findings, previous research has found that older adults at risk of losing their independence will try to adjust to their

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environment, such as finding suitable housing that will allow them to carry out the daily activities necessary to maintain their independence [36].

Focusing on the second enabler, we observed that our participants found technology such as telehealth to be convenient, enabling them prompt access to medical attention. In addition, participants who needed assistance mentioned that older adults who could not move around quickly or needed to stay at home might benefit from telehealth owing to its convenience and easy access to medical staff. In addition, the technology demonstrated efficiency benefits because it reduced travel and wait times at hospitals for the participants. Furthermore, participants who lived alone and required assistance mentioned using technologies such as pendant alarms because they provided safety and access to services and support. This finding supports the evidence from a previous study in which participants mentioned the benefits of telehealth, including convenience and cost [26]. In addition, participants reported that telemedicine health services were convenient because they eliminated travel and waiting times, saved money, and allowed them to complete the consultation from the comfort of their homes at any time [44]. In addition, results related to the safety provided by the technology are consistent with the studies in which participants reported a sense of safety and security because of using technologies, as well as a desire to use technologies to prevent or detect accidents and medical emergencies [45,46].

Finally, participants stated that the technologies that they were using to monitor their health were simple to set up and use and affordable. In a systematic review of web-based home consultation platforms, Almathami et al [26] found that the ease of use related to the ease of navigation and use of services and savings, based on the cost of mileage traveled per patient.

In this study, the enabler that was the most mentioned by the participants was the social and organizational influence. All the participants mentioned the influence of family and friends, health care staff, or organizations in their use of technologies. Therefore, we can conclude that social and organizational influence can play an important role in determining whether and how older adults will use health care technologies.

Perceived Need Trumps Barriers and Challenges

We found that our participants faced similar barriers to technology adoption as reported in previous studies related to using home health care technology such as wearable devices, smart home technologies, telemedicine, and other technologies that help older adults remain at home [24,47-56].

One of the barriers is that some participants felt overwhelmed by the information provided by the technologies related to their existing health conditions. This information overload caused anguish and anxiety. This finding broadly supports studies related to mobile health services and glucose monitoring, and they state that information and system feature overload increased older adults' fatigue and stress, thereby increasing their resistance to the adoption of these technologies [57,58].

One finding concerns the limitations of telehealth, such as the lack of physical examination or immediate attention and lack of interaction and connection with the medical staff. This finding accords with that of previous studies, in which participants expressed an interest in connecting with their health care provider for the want of human interaction [59] and a perceived lack of care integrity when care was delivered through video visits [60].

Our findings also highlighted older adults' concerns about trust related to privacy and accuracy. These results corroborate the findings of the previous work of LaMonica et al [61], who observed that data privacy and security risks were primary barriers to health technology use. If the digital technology is provided by reputable sources such as health organizations, universities and academics, and individuals with higher degrees or qualifications, these barriers could be mitigated. In addition, some studies related to monitoring systems or electronic health records have revealed that older adults have concerns about the privacy and confidentiality of their health information [49,50,62]. This is challenging to overcome, as the purpose of these systems is to collect and share their data, and these concerns could influence their willingness to adopt and use them.

In addition, some studies showed that older adults with greater concern for privacy will choose human support over health information technology when they are given the option, and older adults with disabilities are willing to give up their privacy for independence, but they need to make informed decisions [63].

Another barrier is that health care technologies can be stigmatizing. This finding was also reported by Mitzner et al [64] and Demiris et al [24] who showed that the fear of stigma can prevent older adults from embracing and using technology. According to Blythe et al [65], a design with the potential to stigmatize its users reinforces a particular view of older adults' place in society. For example, studies have revealed that wearable sensor devices or personal emergency alarms have a negative image among older individuals because they are conspicuous, identifiable as a care item, and even humiliating [66,67]. The fear of stigmatization or of being labeled as disabled or sick influences the adoption and use of health care devices. Stigma may become less of a concern for older adults when the need to use health care technologies becomes urgent [62]. Therefore, older adults are more likely to adopt technologies that they do not view as stigmatizing, such as smart watches, which are widely used and not immediately identifiable as a health care device.

Our result related to the cost of the technologies is consistent with that of previous studies that have mentioned cost as a barrier to overcome and affect the use of technologies to assist health care such as health information and assistive technologies [46,50,62,66,68]. It is important that technologies are affordable; otherwise, older adults would drive away from using technology [37].

The lack of familiarity is another barrier mentioned. These findings support evidence from a previous study on health information technologies such as telecare, electronic health record, decision support systems, and assistive information technologies, which found issues with familiarity as a barrier

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that older adults face when using technology [63]. In addition, some studies showed that some older adults with minimal technology experience prefer to rely on health care providers and carers for health tracking [69,70].

Our last finding related to perceived need supports evidence from previous studies, in which perceived need for the technology is a variable that could influence the adoption of new technologies [23,25,71-73], and it has been shown to be a significant factor in the acceptance of assistive technologies [74]. However, our findings do raise the question of why older people continue to use technology despite the presence of barriers. One reason is that the perceived need trumps the barriers to using technologies. Our participants were using health care technologies because there is a perceived need that motivates them to overcome perceived barriers. For example, even if they feel overloaded with information, they will continue to use technology because it helps manage their health. Although this suggests that older adults will tolerate these barriers if the need outweighs them, technology designers should focus on alleviating barriers to promote the uptake of technologies for health self-management by older adults.

Limitations and Future Work

One limitation of our study is the wide age range of the participants, spanning 20 years. This included, presumably, recent retirees (ie, those in their 60s) and those approaching advanced age. There is a significant difference between these 2 groups regarding needs and capabilities.

Second, most participants (20/22, 91%) had tertiary education, and this is not a representative sample. Previous studies have shown that a person's level of education was significantly associated with technology acceptance [75-77]

A third limitation is that this study provides an overview of factors but does not differentiate these factors between types of health self-management technologies. Therefore, the results may not be specific for each technology mentioned in this study.

Finally, the data for this study were collected during the COVID-19 pandemic. Owing to the restrictions imposed to prevent the spread of the virus, older adults had to access telehealth through videoconferences or consultation calls to access medical care [78]. Telehealth was the most common technology used by the interviewees, and some barriers related to the use of telehealth prevailed. Future studies could be carried out in nonpandemic times and could perhaps highlight other findings related to the barriers to using and accessing technologies other than telehealth.

Conclusions

This study investigated the use of digital technologies for self-management of health by older adults. On the basis of the range of technologies that support older adults' health, we argue that some participants showed a resilient attitude, taking early measures to monitor their health and stay active, for which they were more willing to use technology. In addition, we argue that older adults' perceived need outweighs technological barriers, so they will continue using the technology if it gives them value. We also found social and organizational influence to be one of the most mentioned enablers of the use of technologies.

The analysis of the interviews provides useful information for the design and implementation of future technologies for the self-management of health. Future studies could explore resilience, as this study shows evidence related to resilience that could influence the use of technologies for health self-management. In addition, we argue that it may be necessary to help people gain resilience in the face of future health decline before introducing health care technologies.

Finally, technology providers could investigate the social and organizational influence and incorporate their findings in technology design as this factor affects the adoption of technologies. They could also explore older adults' motivations to use technologies and reduce the barriers that they face.

Acknowledgments

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Authors' Contributions

This study was conceived by EGR, JW, and GB. EGR, JW, and GB designed this study. EGR collected the data. EGR conducted the data analysis. EGR, RMK, JW, and GB drafted the manuscript. All authors provided input to the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview participants.
[DOCX File , 20 KB - aging_v6i1e43197_app1.docx]

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Abbreviations

CPAP: continuous positive airway pressure

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Original Paper

Refined Analysis of Older eHealth Users From an Agency Perspective: Quantitative Telephone Interview Study

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Abstract

Background: Most studies on the eHealth divide among older people have compared users to nonusers and found that age, gender, and education were associated with eHealth misuse. They assumed that these characteristics were structural barriers to eHealth adoption. Furthermore, eHealth practices have been examined in a narrow and incomplete way, and the studies disagree about the association between health conditions and eHealth use. Using a more dynamic theoretical lens, we investigated the potential motivations driving older adults' agential adoption of eHealth practices despite their advanced age.

Objective: This study aimed to obtain a complete and detailed description of eHealth uses among older adults; examine whether demographic characteristics such as age, gender, and education (previously related to eHealth misuse) are still associated with the various eHealth clusters; and determine whether contextual factors such as changes in the health condition of older eHealth users or their loved ones are associated with older adult eHealth use.

Methods: We conducted a 30-minute telephone interview with a representative sample of 442 Israeli adults (aged ≥50 years) with a sampling error of 2.04%. The interviews were conducted in Hebrew, Arabic, and Russian. Using factor analysis with 21 eHealth use questions, we identified 4 eHealth clusters: instrumental and administrative information seeking, information sharing, seeking information from peers, and web-based self-tracking. In addition to age, gender, education, internet experience, frequency of internet use, perceived eHealth literacy, and self-rated health, we asked respondents to indicate how much they had used offline health services because of a health crisis in the past year.

Results: We found differences in the number of older eHealth users in the various clusters. They used instrumental and administrative information (420/442, 95%) and obtained information from peers (348/442, 78.7%) the most; followed by web-based self-tracking related to health issues (305/442, 69%), and only a few (52/442, 11.3%) uploaded and shared health information on the web. When controlling for personal attributes, age, gender, and education were no longer predictors of eHealth use, nor was a chronic ailment. Instead, internet experience, frequency of internet use, and perceived eHealth literacy were associated with 3 eHealth clusters. Looking for health information for family and friends predicted all 4 eHealth clusters.

Conclusions: Many older adults can overcome structural barriers such as age, gender, and education. The change in their or their loved ones' circumstances encouraged them to make deliberate efforts to embrace the new practices expected from today's patients. Seeking health information for family and friends and dealing with unexpected health crises motivates them to use eHealth. We suggest that health professionals ignore their tendency to label older people as nonusers and encourage them to benefit from using eHealth and overcome stereotypical ways of perceiving these patients.

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KEYWORDS

eHealth; health; internet; structuration theory; agency; digital divide; age; gender; education; information; health condition; self-rated health; SRH; health care services; surrogate; older adults; users; patient; Giddens; Archer; Bourdieu; capital

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Introduction

Background

Age is a well-known predictor of the eHealth divide [1-4]. However, there is mounting evidence that older people, particularly those in high-income countries, are among the fastest-growing users of eHealth [5-7]. Our study sought to portray a diverse range of eHealth uses among older adults; explain what trajectories might have led to this shift in eHealth use; and find out whether age, gender, and education (previously predicting non-eHealth use) will be associated with the amount of eHealth use among older adults. To that end, we proposed to rely on a different theoretical lens than the one used by most previous studies on the gray eHealth divide and conduct a study only among older eHealth users. Our study filled these gaps by addressing four objectives as follows: (1) to obtain a comprehensive and detailed description of eHealth uses among older adults and classify them into clusters; (2) to examine whether demographic characteristics such as age, gender, and education (previously associated with eHealth misuse) continue to be associated with the different eHealth clusters; and (3) and (4) to find out which contextual factors, such as older eHealth users' and their loved ones' changing health conditions, are associated with their use of eHealth in the different clusters.

Study Novelty and Knowledge Gaps

Most studies on the *eHealth divide* have explained why there are differences between older people who use eHealth and those who do not. However, they have ignored the possibility of a change in this practice trajectory. The Bourdieusian theoretical framework has been used in many studies to explain this divide [2,8-10]. However, this line of explanation has been criticized as being too deterministic and rigid [11,12]. We proposed that the structuration theory by Giddens [13,14] can explain this transition as he argues that social structure forces (such as belonging to the older age group [15] and being reluctant to use the internet) can be changed through a process of internal deliberation that people (agents) are doing when they face changes in their lives' contexts. They have the freedom to modify their own goals in relation to their changing context, choose projects, and translate them into new practices [16]. Bourdieu [8] and Giddens [13,14] differ in how they view social actors' conscious intentions. For Giddens [13,14], actors are reflexive; they can reflect on their actions and identities and act accordingly [17]. He defines *agency* as the ability and deliberateness to achieve goals through a conscious reflection on one's habitus [18-20]. In his view, context matters as it sets social expectations; makes agents reflect on their daily behavior; and may encourage them to modify their goals and embrace social expectations, especially in unforeseen situations [21]. Although this study is neither causal nor longitudinal, we explained the 2 things that have changed in the context of health service use in recent years: the social expectations regarding a patient's role [22] and pervasive internet access. Laypeople have gained technical and medical knowledge, skills, and expertise through the media and new technologies, resulting in *lay reskilling* encouraged by the availability of electronic information, policy makers, and institutions [23,24]. It reconstructed the new patient's identity [25] and set new social expectations for powerful autonomy. These changes were intertwined with internet penetration, suggesting that the first digital divide related to access has been closed [26], and thus, obtaining health information on the web became a proactive behavioral adaptation to later-life health challenges [27-29], representing an agentic approach to positive health behaviors and self-care [30]. To study the use of eHealth as an agentic behavior among older adults, we need a much more detailed and nuanced elaboration of the term *eHealth* as, although it is nearly 20 years old, we found a narrow operationalization and little consistency in how eHealth was defined and measured in the scientific literature on older adults' eHealth use.

Defining eHealth

We looked at quantitative studies published in the last 10 years that examined eHealth use among middle-aged and older adults using large, population-representative survey data sets (Multimedia Appendix 1 [1,3-6,31-38]). There were 77% (10/13) of the studies that examined eHealth use as a predicted variable and 23% (3/13) of the studies that examined it as a predictor variable. Most of the studies (9/13, 69%) in Multimedia Appendix 1 were conducted in the United States, with the rest being conducted in Poland, Israel, and Sweden. Most studies (10/13, 77%) measured eHealth as the predicted variable to identify its predictors, which explain its association with offline health service use [6], better self-care and users' empowerment [4], and medical satisfaction [31]. Some studies (2/13, 15%) defined eHealth use as "health information technology" [6,32], whereas others (1/13, 8%) defined it as "using social media for health-related activities" [33]. With some similarities, each study used 1 to 5 questions about eHealth use. In total, 77% (10/13) of the studies examined whether respondents looked on the web for general health information (about health or illness) [5]. The second most frequently asked eHealth use question (6/13, 46%) was whether respondents had used the internet to schedule a medical appointment [32], deal with health insurance [3], or refill a prescription [34] or whether they had contacted their medical provider directly [1]. Respondents were asked if they had sought health information [3], started or joined a health-related support group [35], or used chat groups to learn about health topics (3/13, 23%). Only 8% (1/13) of the studies examined whether participants kept a web-based diary or blog [35]. To conclude, recent research on eHealth use among middle-aged and older adults has revealed an incomplete and limited picture of the potential eHealth use. Thus, the first and second research questions of our study filled these gaps. First, we obtained a comprehensive and detailed description of the various eHealth uses among older adults. Second, we determined whether demographic characteristics such as age, gender, and education (previously related to non-eHealth users) continue to be associated with the use of eHealth in the different clusters. Notwithstanding, apart from the rich eHealth options available to users, there is another contextual factor that might facilitate nonusers' transition to become users—users' or their loved ones' unexpected changes in health condition.

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Measuring Health Condition Change Through Health Care Use

There was conflicting evidence related to the association between health status and eHealth use. People with chronic conditions, disabilities, or low self-rated health (SRH) were most likely to seek out and act on health news and information [39,40]. This was true for older participants as well [1,32,36,40]. In contrast, other studies found that web-based health information seekers were mostly healthy [2,41,42]. A study on older adults found no relationship between eHealth use and SRH [36]. A recent longitudinal, 2-cycle study explored the relationships among chronic conditions (representing health status), eHealth use, and health care use [6]. Both study cycles showed an association between eHealth use and physician visits (including emergency room or clinic visits); however, the association was stronger in the first cycle, when they were coterminous. The use of eHealth information was also linked to fewer physician visits among participants with 1 in 5 chronic conditions (diabetes). Wicks et al [43] found a negative relationship between eHealth use and physician visits. In total, 2 recent studies examined eHealth use before and after visiting a health care provider and health care use, which was not measured using physician visits. According to these studies, eHealth empowers patients and improves self-care and health perceptions [4,31]. In this study, we assumed that eHealth use can have a more crucial effect among those who experience a change in their own or a loved one's health [4], especially among the older population. As the focus of this study was on cases in which a change in one's own or a loved one's health condition served as a potential stressor [44], which facilitates the emergence of active eHealth users, it was important to conceptualize and measure changes in health status. The aforementioned studies used different health measures. Some studies used the total number of chronic illnesses diagnosed (followed by a list of the most common chronic illnesses), whereas others asked respondents to self-report activity restrictions and memory issues, among other things. It was suggested that the SRH responses may be sensitive to the wording of both the question and the response options [45]. It was not linked to eHealth after demographic variables were considered [33], and its measure may reflect a general estimation of one's health condition related to a given period, disregarding any coincidental or random episode of change in one's health condition that occurred during the research period but was resolved. Thus, although very popular, SRH may not reflect a recent health change. Chronic illness is an irreversible medical condition that may require lifelong adaptation and management, so treatment becomes part of one's daily routine. To capture major changes in health conditions during a certain period, we proposed using health care use as a proxy. In most cases, such a change requires using the multitiered health care system, such as seeing a general practitioner and a specialist or needing emergency services or hospitalization. Patients with major health changes quickly use the entire system's layered structures. Given that physicians cannot always satisfy patients' information needs [41] and that patient autonomy in making treatment decisions is encouraged, turning to eHealth resources may be a stress-buffering agent [44]. It transforms patients from passive health consumers into proactive health producers with knowledge [44]. To support our third research question, we suggested that recent health care use among old eHealth users can provide a thorough and detailed measure of health status change when studying eHealth uses and their relationship to changes in contextual factors of eHealth users that might turn them into active agents who use eHealth intensively.

Knowing Means Participating—Older Adults as Health Information Surrogates

People search for eHealth not only for themselves but also on behalf of others without being asked to do so, often initiating behavior change or influencing health-related decisions [46,47]. Lay information intermediaries, or health information surrogates (HISs), seek information in a self-generated (ie, internally motivated), nonprofessional, or informal capacity, anticipating another person's needs. These agents, also called *hidden patients*, are proxy searchers with purposeful, problem-driven behavior [48,49]. A possible motivation for this behavior is another contextual change for the seeker—a loved one's health change. In such situations, people seek health information on behalf of their family, friends, or colleagues as caregivers or significant others, sometimes at higher rates than they do for themselves [42]. Individuals who seek others' health-related information can promote better transmission of information and social support [50]. Cutrona et al [46] found that two-thirds (66.6%) of American respondents reported being HISs between 2011 and 2012. Surrogate seekers reported more eHealth activities requiring user-generated content, such as emailing health care providers, visiting social networking sites to read and share medical topics, and joining online health support groups. This number is higher than that of a 2012 Pew Internet Poll (54%) [51]. Europe had similar results. Data from the Flash Eurobarometer on 28 European Union member states showed that 61% of respondents searched for health-related information on behalf of someone else [52]. Middle-aged Europeans were the most likely to report being HISs, whereas the youngest and oldest were the least likely to do so. Despite these findings, the study suggests exploring HISs among older adults aged ≥50 years because of their varied family roles and social engagements. These engagements are part of the eHealth users' context. The group aged 50 to 64 years may be similar to the European middle-aged group with the most HISs. For users aged ≥65 years, this measure is also important as their generational identity is changing because of increased life expectancy and technology exposure. Most people will spend a longer period of their lives in a 3- to 4-generation family. This age group has considerable demographic and social weight as it can devote more time to intergenerational and friendship help [53-55]. Although studies have explored respondents' HIS behavior, most of them used general yes-or-no questions without specifying what kind of information they were looking for. Our study filled the gap in the literature by investigating which eHealth practices older adults use that are associated with their HIS behavior.

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Methods

Overview

This study used data collected through telephone interviews using a national random-digital dial-telephone household survey of Israeli adults (aged ≥50 years). The interviews lasted between 25 and 30 minutes. The interviews were conducted in Hebrew, Arabic, and Russian by professional interviewers who went through a special training session to familiarize themselves with the questionnaire's terminology. After a short introduction, each interviewee was asked whether they agreed to participate in the survey. Those who agreed were then interviewed. The interviewers conducted the telephone survey using computer-assisted telephone interviewing software.

Ethics Approval

This study was approved by the institutional review board of Ruppin Academic Center (2012-1-6). All respondents expressed consent before their participation. Respondents' anonymity was assured, and they were not asked for any identifying information during the phone survey.

Sample

Calls were placed to 1288 representative residential households, of which 128 (9.94%) were not relevant (eg, disconnected, business, or fax numbers). Of the remaining 1160 households, 603 agreed to be interviewed, representing a 51.98% response rate and a sampling error of 2.04%. The participation criterion for the first survey phase was the respondents' age (≥50 years). In this phase, there were 34.5% (208/603) of participants who did not use the internet at all, 28.5% (172/603) of participants who used the internet but not for health purposes, and 37% (223/603) of participants who used the internet for health purposes—the eHealth users. All 3 groups were interviewed. To focus on older eHealth users only and portray the extent and scope of eHealth activities on a larger sample, the data collection process followed a second phase using the same methodology as the one used in phase 1 except that the following 2 participation criteria were used: respondents' age (≥50 years) and respondents' use of the internet for health-related purposes. In phase 2, only participants who met the 2 criteria were interviewed. As a result, of the 1139 representative residential households that were contacted, an additional 219 (19.23%) eHealth participants were surveyed, resulting in a sample of 442 eHealth participants.

Design

The explained measures of eHealth activities included 4 clusters: instrumental and administrative information seeking, information sharing, seeking information from peers, and self-tracking. The explanatory variables included demographic variables such as age, gender, education, and marital status; health-related variables such as chronic ailments, seeking information for family and friends, and offline health care use; and internet use frequency, experience, and skills.

Measures

Clusters of eHealth Activities

eHealth activities were explored using 21 questions that examined participants' detailed engagement in web-based health-related activities. A total of 10 items were measured using a 5-point frequency scale (1=never; 5=several times a week) in response to the following question: "How often did you use the Internet for the following health issues?" A total of 11 items were measured using a dichotomous yes-or-no scale in response to the following question: "Did you engage in the following online health-related activities in the past twelve months?" Subsequently, using principal component analysis with varimax rotation, eHealth activities were clustered into 4 categories, which explained 33.9% of the variance. The 4 clusters of eHealth activities that emerged were instrumental and administrative information seeking (10 items; mean 1.53, SD 0.42; Cronbach α=.73; highest-loading item: "Sought information about long term care for an elderly or disabled person"), information sharing (3 items; mean 1.06, SD 0.19; Cronbach α=.74; highest-loading item: "Posted a review web-based of a particular drug or medical treatment"), seeking information from peers (5 items; mean 1.43, SD 0.32; Cronbach α=.68; highest-loading item: "Sought others who might have health concerns similar to mine"), and self-tracking on the web (3 items; mean 1.42, SD 0.36; Cronbach α=.57; highest-loading item: "Tracked my health indicators or symptoms online").

Demographic and Health-Related Variables

Participants were asked to provide their age, gender, education, and marital status. We have consistently reported on gender in the manuscript. The gender variable included 2 values. Offline health care use was measured by asking respondents whether they had experienced a major change in their health condition, seen their general practitioner, seen a specialist, sought emergency room services, or been hospitalized in the past year. Responses were provided using a 3-point response scale (1=no; 2=yes, once or twice; and 3=yes, 3 times or more). The possible response score obtainable for this independent variable was between 5 and 15 (mean 7.86, SD 1.86). The chronic ailments variable was measured using a 3-point response scale (1=no chronic ailment, 2=1 or 2 chronic ailments, and 3=3 or more chronic ailments). Health information seeking for family and friends was measured using a dichotomous yes-or-no scale in response to the following question: "For whom have you looked for health information online in the past year? (Yourself, your spouse, children, parents, relatives, friends)." The scale was scored by adding the answers, resulting in a score ranging from 6 to 12 (mean 8.13, SD 1.53).

Internet Use Frequency, Experience, and Skills

Participants' internet experience was measured by asking respondents to report the number of years since they first began surfing the web (mean 11.02, SD 5.93); the frequency of internet use was measured by asking respondents how often they generally used the internet. Responses were provided using a 7-point scale (1=very seldom; 7=every day, all day; mean 5.71, SD 1.02). eHealth literacy was measured using the eHEALS tool [56]. The scale comprises 8 items evaluated on a 5-point

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Likert scale (1=strongly disagree; 5=strongly agree; mean 3.1, SD 0.83; Cronbach α=.90; sample item: "I know how to find helpful health-related resources on the Internet"). The scale was previously translated into Hebrew [10].

Data Analysis

First, the sample's demographic and background characteristics and the eHealth cluster activities were described using descriptive statistics. Second, Pearson correlations between the 4 eHealth clusters of activities and all other variables were computed. Third, hierarchical multiple linear regression analyses were carried out on the 4 eHealth clusters of activities. Age, gender, education, and marital status were entered in the first step, and health-related variables, internet use frequency, experience, and skills were entered in the second step. Each step presents its contribution to the explained variance. The analyses were conducted using SPSS Statistics (version 23; IBM Corp).

Results

Sample Demographic and Background Characteristics

The characteristics of the participants are presented in Table 1. The sample comprised 63.1% (279/442) women and 95.2% (421/442) Jewish participants. Participants' age ranged from 50 to 87 years with a mean age of 61.05 (SD 8.23) years. The mean age of the men participants was considerably higher than that of women participants (mean 62.2, SD 8.85 vs mean 60.38, SD 7.77, respectively; $F_{1,439}$=5.07; P=.03). Approximately half (225/442, 50.9%) of the sample had postsecondary education, and 74.4% (329/442) were married. A total of 38% (168/442) of the participants reported one or more chronic ailments.

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Table 1. Demographic profile of older eHealth users (n=442).

Characteristic	Participants, n (%)
Gender	
Men	163 (36.9)
Women	279 (63.1)
Age (years)	
50-54	116 (26.2)
55-59	98 (22.2)
60-64	91 (20.6)
65-69	65 (14.7)
70-74	33 (7.5)
75-84	38 (8.6)
Education	
Secondary education	215 (48.6)
Postsecondary and tertiary education	225 (50.9)
Marital status	
Single, divorced, or widowed	96 (21.7)
Married	329 (74.4)
Ethnicity	
Jewish	421 (95.2)
Arabic	21 (4.8)
Health condition—chronic ailments	
No chronic ailments	262 (59.3)
One or more chronic ailments	168 (39)
Health condition—change in health condition in the past 12 months	
No	214 (48.4)
Yes	221 (50)
Internet use frequency	
Once a week or less	14 (3.2)
Several times a week	48 (10.9)
Once a day	49 (11.1)
Several times a day	261 (59)
All day, every day	69 (15.6)

Clusters of eHealth Activities

To obtain a comprehensive and detailed description of eHealth practices among older adults, we divided the sample into 6 age groups. As explained in the *Methods* section, different numbers of activities were classified into each of the 4 eHealth clusters. The clusters of eHealth uses and the amount of users in the various age groups are presented in Table 2.

For every cluster of eHealth practices, we calculated the percentage of participants of different age groups, and the mean percentage of all age groups is also displayed. Table 2 shows that, for *instrumental and administrative information seeking*, the practice rate was the highest, ranging from 88% (29/33) for the age group of 70 to 74 years to 97% (95/98) for the age group of 55 to 59 years, with a mean use of 94% (SD 3.20%). Next was the *seeking information from peers* cluster, ranging from 85% (28/33) for the age group of 70 to 74 years to the lowest percentage (27/38, 71%) for the oldest age group of ≥74 years (mean use 79%, SD 4.86%). The third cluster of use was *self-tracking on the web*, ranging from 74% (48/65) for the age group of 65 to 69 years to 63% (62/98) for the age group of 55 to 59 years. The mean use for this cluster was 69% (SD 4.83%). The least frequent uses of eHealth were in the *information-sharing practices* cluster, ranging from 13.8% (16/116) for the youngest age groups to 3% (1/38) for the oldest. Only a mean of 11% (SD 4.87%) of participants used eHealth in this cluster. We can see that there are few differences in the

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percentage of users between age groups within each cluster. However, there are significant differences in the percentage of users between clusters.

Table 2. Clusters of eHealth practices by different age groups.

Cluster	Age group (years), n (%)						Value (%), mean (SD)
	50-54 (n=116)	55-59 (n=98)	60-64 (n=91)	65-69 (n=65)	70-74 (n=33)	≥74 (n=38)	
Instrumental and administrative information	n (95)	95 (97)	n (96)	n (95)	29 (88)	n (95)	94 (3.20)
Seeking information from peers	n (78)	n (80)	n (77)	n (83)	28 (85)	27 (71)	79 (4.86)
Self-tracking on the web	n (66)	62 (63)	n (72)	48 (74)	n (73)	n (66)	69 (4.83)
Information sharing	16 (14)	n (14)	n (10)	n (8)	n (15)	1 (3)	11 (4.87)

Pearson Correlations Between the 4 eHealth Clusters and All Other Variables

The intercorrelations between the 4 clusters of activities and all independent variables are displayed in Table 3. We can see from the table that the 4 eHealth clusters are significantly associated with each other at moderate to high levels so that the more one engages in one cluster of activity, the more likely it is that one engages also in the other activities. Instrumental and administrative information seeking had significant positive correlations with the other 3 eHealth activities: information sharing (r=.31; P<.001), seeking information from peers, (r=.38; P<.001) and self-tracking (r=.48; P<.001). The correlations between information sharing and seeking information from peers and self-tracking activities were statistically significant but at a lower value (r=0.21 and P<.001 vs r=0.16 and P<.001, respectively). Seeking information from peers was also correlated with self-tracking at a moderate level (r=0.37; P<.001). Despite the large scale of the sample age, there were no significant correlations between age and the 4 eHealth activities, nor were they associated with gender, except for seeking information from peers. Women were found to use information from peers more than men (r=0.13; P=.01). Education was significantly correlated with 3 eHealth activities except for information sharing. Married respondents were significantly more likely to use information from peers (r=0.13; P=.01). Only 2 of the 3 health-related conditions were significantly correlated with eHealth activities such that health care use and health information seeking for family and friends were significantly correlated with the 4 clusters of eHealth activities and chronic ailments was not. The correlations for health care use were r=0.13 (P=.01) with instrumental information seeking, r=0.11 (P=.05) for information sharing, r=0.21 (P<.001) for seeking information from peers, and r=0.17 (P<.001) for self-tracking. The highest correlation of health information seeking for family and friends was with seeking information from peers (r=0.45; P<.001), followed by instrumental information seeking (r=0.39; P<.001), self-tracking (r=0.27; P<.001), and information sharing (r=0.12; P=.01). Offline health care use (which served as a proxy for health condition change) was also statistically significant and positive for all 4 eHealth activities but at a lower level. The highest correlation was between offline health care use and seeking information from peers (r=0.21; P<.001), followed by self-tracking activities (r=0.17; P<.001), instrumental information seeking (r=0.13; P=.01), and information sharing (r=0.11, P=.05).

The 3 variables related to internet use frequency, experience, and eHealth literacy were positively correlated with eHealth activities except for information sharing. eHealth literacy had the highest correlation with seeking information from peers (r=0.43; P<.001), followed by instrumental information seeking (r=0.40; P<.001), self-tracking activities (r=0.26; P<.001), and information sharing (r=0.10; P=.05). Internet use frequency was positively associated with instrumental information seeking (r=0.24; P<.001), followed by self-tracking activities (r=0.18; P<.001) and seeking information from peers (r=0.16; P<.001).

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Table 3. Correlation analysis (Pearson r and 2-tailed *P* value) between all the study variables.

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Instrumental information seeking													
r	1	0.31	0.48	0.38	−0.07	0.16	0.06	0.06	0.39	0.13	0.17	0.24	0.40
P value	—[a]	<.001	<.001	<.001	.12	<.001	.18	.25	<.001	.005	<.001	<.001	<.001
2. Information sharing													
r	0.31	1	0.21	0.16	−0.05	−0.01	−0.05	−0.03	0.12	0.11	0.05	0.08	0.10
P value	<.001	—	<.001	<.001	.31	.85	.34	.50	.01	.03	.34	.10	.03
3. Seeking information from peers													
r	0.48	0.21	1	0.37	−0.07	0.10	0.13	0.07	0.45	0.22	0.13	0.16	0.43
P value	<.001	<.001	—	<.001	.13	.03	.006	.14	<.001	<.001	.007	<.001	<.001
4. Web-based self-tracking													
r	0.38	0.16	0.37	1	0.02	0.18	−0.04	0.09	0.27	0.17	0.17	0.18	0.26
P value	<.001	<.001	<.001	—	.70	<.001	.48	.052	<.001	<.001	<.001	<.001	<.001
5. Age													
r	−0.07	−0.05	−0.07	0.02	1	−0.02	−0.11	0.24	−0.15	0.10	−0.16	−0.16	−0.18
P value	.12	.31	.13	.70	—	.65	.03	<.001	<.001	.04	<.001	<.001	<.001
6. Education													
r	0.16	−0.01	0.10	0.18	−0.02	1	0.01	−0.03	0.07	0.01	0.30	0.30	0.27
P value	<.001	.85	.03	<.001	.65	—	.79	.57	.15	.91	<.001	<.001	<.001
7. Gender													
r	0.06	−0.05	0.13	−0.04	−0.11	0.01	1	−0.02	0.17	0.08	−0.04	−0.04	0.06
P value	.18	.34	.006	.48	.03	.79	—	.72	<.001	.09	.38	.30	.24
8. Chronic ailments													
r	0.06	−0.03	0.07	0.09	0.24	−0.03	−0.02	1	−0.01	0.41	−0.02	−0.08	−0.03
P value	.25	.50	.14	.052	<.001	.57	.72	—	.85	<.001	.74	.09	.51
9. Information seeking for family and friends													
r	0.39	0.12	0.45	0.27	−0.15	0.07	0.17	−0.01	1	0.10	0.13	0.21	0.37
P value	<.001	.01	<.001	<.001	<.001	.15	<.001	.85	—	.03	.005	<.001	<.001
10. Offline health care use													
r	0.13	0.11	0.22	0.17	0.10	0.01	0.08	0.41	0.10	1	0.01	−0.06	0.06
P value	.005	.03	<.001	<.001	.04	.91	.09	<.001	.03	—	.80	.20	.23
11. Internet experience													
r	0.17	0.05	0.13	0.17	−0.16	0.30	−0.04	−0.02	0.13	0.01	1	0.28	0.34
P value	<.001	.34	.007	<.001	<.001	<.001	.38	.74	.005	.80	—	<.001	<.001
12. Internet use frequency													
r	0.24	0.08	0.16	0.18	−0.16	0.30	−0.04	−0.08	0.21	−0.06	0.28	1	0.27
P value	<.001	.10	<.001	<.001	<.001	<.001	.30	.09	<.001	.20	<.001	—	<.001
13. eHealth literacy													
r	0.40	0.10	0.43	0.26	−0.18	0.27	0.06	−0.03	0.37	0.06	0.34	0.27	1
P value	<.001	.03	<.001	<.001	<.001	<.001	.24	.51	<.001	.23	<.001	<.001	—

[a]Not applicable.

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Hierarchical Multiple Linear Regression Analyses on eHealth Clusters of Activities

Overview

Regression analysis of eHealth activities explored whether the health-related variables, internet use characteristics, and eHealth activities were associated with the 4 clusters of activities after controlling for the demographic variables age, gender, education, and marital status. The results are presented in Tables 4 and 5.

Table 4. Hierarchical regression analysis for variables predicting 2 clusters of web-based health activities (n=405).

Explanatory variables	Instrumental and administrative information seeking[a]		Information sharing (health Web 2.0)[b]	
	B (SE)	β	B (SE)	β
Age	0.001 (0.002)	−.012	0.000 (0.001)	−.01
Education	0.008 (0.014)	.027	−0.009 (0.007)	−.069
Gender (men)	0.002 (0.04)	.002	−0.03 (0.019)	−.073
Marital status (not married)	0.056 (0.05)	.057	0.011 (0.021)	.026
Offline health care use	0.021 (0.01)	.092[c]	0.02 (0.05)	.167[d]
Chronic ailments (none)	0.031 (0.033)	.045	−0.024 (0.016)	−.081
Information seeking for family and friends	0.073 (0.013)	.271[e]	−0.015 (0.006)	.13[d]
Internet experience	0.002 (0.003)	.024	0.001 (0.002)	.032
Internet use frequency	0.037 (0.019)	.093[c]	0.014 (0.009)	.083
eHealth literacy	0.126 (0.025)	.254[e]	0.001 (0.012)	.005

[a]R^2=0.26; $F_{10,395}$=14.08 (P<.001).

[b]R^2=0.6; $F_{10,394}$=2.59 (P=.005).

[c]P<.05.

[d]P<.01.

[e]P<.001.

Table 5. Hierarchical regression analysis for variables predicting 2 clusters of web-based health activities (n=405).

Explanatory variables	Looking for information from peers (health Web 2.0)[a]		Health-related web-based self-tracking[b]	
	B (SE)	β	B (SE)	β
Age	0.001 (0.002)	.028	0.003 (0.002)	.067
Education	−0.002 (0.010)	−.009	0.021 (0.013)	.081
Gender (men)	0.031 (0.028)	.047	−0.056 (0.036)	−.076
Marital status (not married)	0.112 (0.033)	.147[c]	0.033 (0.041)	.039
Offline health care use	0.030 (0.008)	.174[c]	0.027 (0.010)	.143[d]
Chronic ailments (none)	0.013 (0.024)	.024	0.024 (0.031)	.041
Information seeking for family and friends	0.061 (0.010)	.297[c]	0.047 (0.012)	.206[c]
Internet experience	−0.001 (0.002)	−.012	0.003 (0.003)	.056
Internet use frequency	0.011 (0.014)	.034	0.026 (0.018)	.077
eHealth literacy	0.117 (0.018)	.305[c]	0.041 (0.023)	.098

[a]R^2=0.34; $F_{10,395}$=19.91 (P<.001).

[b]R^2=0.15; $F_{10,395}$=6.91 (P<.001).

[c]P<.001.

[d]P<.01.

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Instrumental and Administrative Information Seeking Cluster

In Table 4, we see that the first step of the demographic variables predicted only 4% of the *instrumental and administrative information seeking* variance ($F_{4,401}$=3.93; *P*=.004). The health-related variables in the second step added 13% to the explained variance ($F_{7,398}$=13.86; *P*<.001), and the internet use characteristics in the third step added 7% to the explained variance ($F_{10,395}$=14.08; *P*<.001). The regression coefficients reported are those of the third step. Offline health care use (β=.09; t_{395}=1.91; *P*=.06), health information seeking for family and friends (β=.27; t_{395}=5.55; *P*<.001), frequency of internet use (β=.09; t_{395}=1.94; *P*=.05), and eHealth literacy (β=.25; t_{395}=5.00; *P*<.001) were found to be significantly associated with instrumental and administrative information seeking such that the more participants used offline health care services, looked for health information for family and friends, used the internet frequently, and had high eHealth literacy, the more they sought instrumental and administrative information.

Information Sharing Cluster

The first step of the demographic variables predicted only 1% of the *information sharing* variance ($F_{4,400}$=0.61; *P*=.65). The health-related variables in the second step added 3% to the explained variance ($F_{7,397}$=3.25; *P*=.002), and the internet use characteristics in the third step added 2% to the explained variance ($F_{10,394}$=2.59; *P*=.005). The regression coefficients reported are those of the third step. Only offline health care use (β=.17; t_{394}=3.05; *P*=.002) and health information seeking for family and friends (β=.13; t_{394}=2.32; *P*=.02) were found to be significantly associated with information sharing such that the more participants used offline health care services and looked for health information for family and friends, the more they shared health information on the web.

Information Seeking From Peers Cluster

Table 5 shows that the first step of the demographic variables predicted only 5% of the information seeking from peers variance (F4,401=5.35; *P*<.001). The health-related variables in the second step added 21% to the explained variance (F7,398=20.03; *P*<.001), and the internet use characteristics in the third step added 8% to the explained variance (F10,395=19.91; *P*<.001). The regression coefficients reported are those of the third step. Marital status (β=.15; t_{395}=3.49; *P*<.001), offline health care use (β=.17; t_{395}=3.80; *P*<.001), health information seeking for family and friends (β=.30; t_{395}=6.40; *P*<.001), and eHealth literacy (β=.31; t_{395}=6.32; *P*<.001) were found to be significantly associated with information seeking from peers such that married participants who more frequently used offline health care services, looked for health information for family and friends, and had a higher level of eHealth literacy sought information from peers to a larger extent.

Self-tracking Cluster

Finally, in Table 5, we see that the first step of the demographic variables predicted only 3% of the *self-tracking* variance ($F_{4,401}$=3.06; *P*=.02). The health-related variables in the second step added 10% to the explained variance ($F_{7,398}$=8.38; *P*<.001), and the internet use characteristics in the third step added 2% to the explained variance ($F_{10,395}$=6.91; *P*<.001). The regression coefficients reported are those of the third step. Only offline health care use (β=.14; t_{395}=2.75; *P*=.006) and health information seeking for family and friends (β=.21; t_{395}=3.92; *P*<.001) were found to be significantly associated with self-tracking such that the more participants used offline health care services and looked for health information for family and friends, the more they performed self-tracking activities.

Comparing the 4 Clusters

Instrumental information consumption was more prevalent among participants who had looked for health information for their relatives and friends and used the health care system in the past 12 months, especially among those with high eHealth literacy and frequency of internet use. These nonmaterial capitals helped users navigate the web and consume the information they needed to perform causal interventions for themselves or their loved ones, as opposed to the *information sharing* cluster (using Web 2.0 applications), which was the least prominent cluster of web-based health-related activities. The *seeking information from peers* cluster is a source of human capital as we exchange lay interpersonal knowledge and experience, which was also more prominent among participants who had used the health care system in the past 12 months with greater frequency and had high eHealth literacy. This activity is important as people are more likely to be receptive to information shared by others who are like them [57].

Participants used eHealth in the *web-based self-tracking* cluster to a lesser degree than in the previous 2 clusters, but it was more prominent among participants who had used the health care system in the past 12 months more frequently than their cohorts. The frequency of internet use and high eHealth literacy were found to have a positive impact on self-tracking on the web.

Discussion

Principal Descriptive Findings

Overview

Most studies on the eHealth divide among older adults in the past 10 years have compared users with nonusers [3,5]. We adopted the structuration theory and focused only on older eHealth users to explore the “full half glass” of internet use for health purposes. We wanted to understand the possible facilitators that encourage older adults’ agential adoption of eHealth practices despite their older age. Such findings are essential as older people, especially in high-income societies, constitute the fastest-growing internet user group.

First Research Question

Our descriptive statistics findings provided the answer to our first research question by obtaining a detailed description and portraying the diverse eHealth practices that older adults perform. Although previous studies used only 1 to 5 questions to measure eHealth practices among older adults [32,35], we

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used 21 questions. We created 4 eHealth clusters following a factor analysis procedure: instrumental and administrative information seeking, seeking information from peers who share the same health situation, web-based self-tracking, and uploading and sharing health information. These clusters served as the multipredicted variables in the multilevel analysis. Older adults used eHealth in the instrumental and administrative information cluster the most (29/33, 88% to 95/98, 97%), followed by 71% (27/38) to 85% (28/33) who obtained information from peers who shared the same health situation. Between 62% (61/98) and 77% (71/92) of the participants used eHealth in the third cluster, web-based self-tracking, whereas the least frequent cluster was uploading and sharing health information on the web (1/38, 3% to 5/33, 15%). The correlation analysis among the 4 eHealth clusters showed a small (r_{424}=0.16) to medium (r_{430}=0.48) association among the 4 eHealth clusters, suggesting that they are not entirely distinct.

Second Research Question

The second research question asked whether classic personal characteristics such as age, gender, and education were associated with older adults' use of eHealth in the different clusters. We answered this question by using descriptive, bivariate, and multilevel statistical analyses. As age was the most prevalent predictor of eHealth use or nonuse in most previous studies, we used descriptive statistics to compare each eHealth cluster across 6 age groups. Our comparison revealed that the differences in eHealth use among the 4 clusters were greater than the differences within each eHealth cluster, specifically among the 6 age groups. Age was not a significant predictor of any of the 4 eHealth clusters despite the sample's large age range. Gender was also insignificant except for the *seeking information from peers* cluster, which had more women than men participants. All clusters except for *information sharing* were significantly correlated with education (albeit at a very low value). In addition to the demographic variables, we checked the correlation between the 4 eHealth clusters and the 3 dimensions of internet use: frequency, experience, and eHealth literacy. We found that these variables were significantly associated with the eHealth clusters except for the *information sharing* cluster. This implies that the more experienced and confident the user is, the more they use most eHealth practices.

Third Research Question

To answer the third research question of whether changes in health circumstances are associated with older adults' use of eHealth in the different clusters, we correlated the 4 eHealth clusters with chronic ailments and recent offline health care use. In contrast to offline health care use, chronic ailments were not associated with any of the eHealth clusters, suggesting that offline health care use expresses a change in the respondents' health condition in the months that preceded the study. The more respondents used offline health care services, the more they used eHealth in the 4 clusters.

Fourth Research Question

The fourth research question was whether looking for health information for family and friends was associated with the 4 eHealth clusters. The literature suggests that, when family and friends experience changes in their health condition, their surrounding circles help them find more information even without being asked to do so. Such behaviors are referred to as HISs. The correlation between the 4 eHealth clusters and the variable "looking for health information online for respondents' spouses, other family members, and friends" was high and significant.

Multilevel Analysis Findings

The multivariate analysis revealed more distinct findings. In the first step, we found that the 3 classic background characteristics—age, gender, and education—were no longer significant predictors of the 4 eHealth clusters among eHealth users. Their contribution to the clusters' explained variance was meager. This finding answers our second research question. In the second step of the multilevel analysis, we found that 2 of the 3 health condition variables were significant predictors of using eHealth in the different clusters. Offline health care use and health information seeking for family and friends can be framed as contextual health situations. We found that these contextual health situations significantly predicted, across a diverse range, all 4 eHealth clusters after controlling for the demographic characteristics. They contributed the most (21%) to the *looking for information from peers* cluster, followed by the *instrumental and administrative information consumption* cluster (15%), the *web-based self-tracking* cluster (10%), and the *information uploading and sharing* cluster (3%). These findings suggest that changes in participants' and their loved ones' health conditions are strongly associated with the use of eHealth in 3 of the 4 clusters. The more they used offline health care services in the 12 months preceding the survey and the more they served as HISs, the more they used eHealth in the 3 clusters. These findings are in line with those of the longitudinal study by Shim et al [6]. They found that the use of web-based health information was positively associated with concurrent reports of physician visits but not over 2 years. Controlling for demographic characteristics and health context variables, we found in the third step of the multilevel analysis that internet frequency of use significantly predicted only instrumental and administrative information consumption. Internet experience did not predict any of the 4 eHealth clusters, and eHealth literacy was significantly associated only with instrumental and administrative information consumption and looking for information from peers. These variables contributed an additional 7% to 8% to the explained variance of the use of eHealth in the 2 clusters. We suggest that the low number of respondents who uploaded and shared information is associated with the more advanced skills needed to upload and produce content (Web 2.0). For late adopters, posting a review on the web of a particular drug or medical treatment is more challenging than lurking or retrieving information. In addition, sharing their own experience in a time of health crisis would be questionable. A recent study found that patient collaboration in a physician-patient forum depends on the disease type, time commitment, and incentives [15]. Thus, apart from the 2 contextual health conditions that significantly predicted the use of eHealth in the different clusters, all other variables were insignificant, resulting in an overall poor explained variance.

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The findings for research questions 1 and 2 suggest that many older adults can overcome structural barriers such as age, gender, and education. These findings are complemented with the results of research questions 3 and 4, suggesting that the context of our participants' actions matters. Becoming an HIS by seeking health information for family and friends and using offline health care services in the previous months suggests that an unexpected and unplanned change process occurred in older eHealth users' or their loved ones' lives. In a health crisis, patients seek professional support and depend on the structure of the health care system. As the health care system in Israel is public and there is no consideration of the cost of offline services, people do not hesitate to use them. As a result, we believe that increasing the use of public health services can serve as a proxy to measure the worsening of a participant's health condition. These changes in health condition coincide with new social expectations resulting from the role technology plays in patient-physician relationships, the expectation that patients will take increasing responsibility for their health-related decisions, and easy access to health information and services on the internet. Our study emphasized the need to trace potential change processes as, according to the structuration theory, the context of changes (in the health conditions of participants and their loved ones) matters. This establishes new social expectations that cause people to reflect on their day-to-day conduct. This ongoing reflection process might encourage people to make deliberate efforts to solve the demands of their lives [44] and embrace new practices expected from today's patients, especially when dealing with unexpected and unplanned contingencies. Although our study was neither longitudinal nor experimental, we suggest that these kinds of changes might explain what drove our participants to become eHealth users despite their old age, especially if they perceived themselves as having high eHealth literacy. The insignificant association between being chronically ill and using eHealth in the 4 clusters posits that monitoring and treating chronic illnesses has become part of daily routines for a long time, in contrast to a sudden change in health condition. We suggest that our findings align with findings that those with a particular chronic health condition using web-based health information were significantly associated with fewer physician visits at both time points of their study [6].

Limitations, Strengths, and Future Research

Our study is limited primarily because of its cross-sectional methodology. It is neither a longitudinal study nor experimental. Therefore, the associations reported previously might be bidirectional; however, as we asked respondents to describe their actual health circumstances in the previous year, we assume that eHealth use did not cause older eHealth users to feel a sudden change in their health condition followed by extensive use of offline health care services. We also do not believe that people will look for health information on the web for family and friends unless there is a good reason to do so. Despite including representative residential households, our sample limitations arise from our inclusion criteria. Older adults who experienced severe health decline or limitations in physical capacity and more substantial disabilities would not have participated in such a study. As a result, despite the sample's extensive age range, the participants' mean age was lower than the mean age of this group of users in the Israeli population. Multiple eHealth practice measures reflect a more fine-grained and detailed description of eHealth uses among older adults and show that, in certain circumstances, such as when confronted with a new health problem, older adults can reflect on their new situation and choose to adopt new practices and use eHealth to deal with offline challenges through an internal deliberation process. For instance, they can consult with peers with little or no effort to obtain advice and support despite their old age. Nevertheless, our study excluded the measurement of mobile technology uses, especially health apps that are very pervasive today, and opens up new opportunities for diagnosing, monitoring, and managing health problems. These findings have implications for potentially expanding the diverse uses of eHealth among older adults. This implies that health professionals should ignore their tendency to label older people as nonusers and encourage them to benefit from using eHealth by overcoming stereotypical ways of perceiving this population.

Future research should continue to explore eHealth use among the older population as technology constantly changes and evolves and pay attention to the unintended consequences of the digitalization of health and health care. Today, it becomes increasingly difficult for patients to resist the demands of being both reflexive and empowered to act. They need to engage with this new world, where patients are required to take increasing responsibility for health-related decisions or exercise agency in this dynamic technological environment that constantly evolves.

Conclusions

Belonging to age groups confers certain advantages and disadvantages through institutional, cultural, and interactional processes that produce and sustain age inequalities [15]. This study focused only on older eHealth users as they have crossed the chasm of being late technology adopters and overcome the structural barrier of belonging to an aged population. The structuration theory by Giddens [13,14] was a better choice to explain our findings as he posits that actors' reflexivity is a crucial and transformative social process and their agency is only meaningful as subjects. Today, it becomes increasingly difficult for patients to resist the demands of being reflexive and empowered to act. Engaging with this new world requires patients to take increasing responsibility for health-related decisions or exercise agency. That is the attribute that separates the passive patient of 1958 from the active one today. We propose viewing eHealth use among older adults as an important factor, in which people make deliberate efforts to solve problems in their lives. Using eHealth, they express their agency, which can sometimes be challenging for late adopters as the systems are not always user-friendly and fail to provide the needed tailored services, especially in times of pandemics. Health professionals can play a vital role in this change process by encouraging older adults to use eHealth, thus eliminating socially constructed practices that ignore this change and reinforce older adults' structural barriers.

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Acknowledgments

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Data Availability

The data set generated and analyzed during this study is available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
eHealth definition and operationalization in studies on older adults.
[DOCX File , 22 KB - aging_v6i1e40004_app1.docx]

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Abbreviations

HIS: health information surrogate
SRH: self-rated health

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Original Paper

Health-Seeking Behavior and Its Associated Technology Use: Interview Study Among Community-Dwelling Older Adults

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Abstract

Background: Understanding older people's health-seeking behavior (HSB) is crucial for uncovering their health needs and priorities and developing appropriate policies to address them and avert their disease progression. Technologies play an active role in our daily lives and have been incorporated into health activities to support the older population and facilitate their HSB. However, previous studies of HSB have mainly focused on behaviors during illness, and there are limited studies on how technologies have been used in older people's health-seeking activities.

Objective: This study aimed to investigate HSB and the associated technology use among the older population, ultimately proposing implications for practice to address their unmet health needs.

Methods: This paper presents partial data from a large qualitative study, which has been approved by the institutional review board and used a phenomenological approach. Semistructured interviews were conducted between April 2022 and July 2022, either via Zoom (Zoom Video Communications Inc) or face-to-face sessions. Inclusion criteria were being aged ≥50 years, long-term residence in Singapore, and being able to speak English or Mandarin. The interviews were manually transcribed verbatim, and thematic analysis was performed, with the individual as the unit of analysis to understand the patterns of behaviors.

Results: In total, 15 interviews were conducted to reach thematic saturation. We identified 5 main consequences of HSB, which were aligned with the original HSB model. Regarding technology use in health seeking, 4 themes were extracted: the most widely used digital technologies are the mobile health apps and wearable devices with the associated wellness programs launched by the government and local companies, and they have the potential to enhance health communication, promote health maintenance, and increase access to health services; information communication technologies and social media, though not primarily designed for health purposes, play a substantial role in easing the process of seeking health information and managing symptoms. Although the outbreak of the COVID-19 pandemic has resulted in some alterations to older adults' well-being, it has catalyzed the adoption of telehealth as a complement to access health care services, and older adults have different considerations when selecting technologies to facilitate their health seeking and fulfill their health needs. Moreover, 4 archetypes were proposed based on our findings and the insights gained from our participants' observations in their social networks. These findings led to several implications for practice regarding health communication and promotion, health education, technology design and improvement, telemonitoring service implementation, and solutions to address the needs of each proposed archetype.

Conclusions: Unlike the commonly held belief that older adults resist technologies and lack technological proficiency, our findings showed that technologies could play a promising role in facilitating older adults' health seeking. Our findings have implications for the design and implementation of health services and policies.

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KEYWORDS

health; health-seeking behavior; aging; technology; telehealth; mobile health; mHealth; eHealth; health access; qualitative study; mobile phone

Introduction

Background

Health-seeking behavior (HSB) is an important concept associated with a country's health status and economic development [1]. It also helps uncover the health needs and priorities of a population and informs the development of appropriate policies to address their needs and avert their disease progress [2]. In the literature, HSB has been studied with different scopes. The most commonly used definition is "any action or inaction undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy" [3], and studies adopting this definition always examined the formal health system use or the process of illness responses [2,4-6]. However, one could argue that this definition focuses mainly on illness behaviors [7] and ignores the importance of promoting overall health and well-being, as health is *not merely the absence of disease or infirmity* but rather *a state of complete physical, mental, and social well-being* [8]. Thus, HSB could be viewed in a broader sense. A more comprehensive definition proposed by Chinn and Kramer is *an individual's deed to the promotion of maximum well-being, recovery, and rehabilitation; this could happen with or without health concerns and within a range of potential to real health concerns* [9]. This definition encompasses practices for preserving optimal wellness, preventing illnesses, and addressing any deviation from good health [1,10], which aligns with the concept of universal health coverage [11].

Technologies have been seamlessly integrated into different aspects of people's life and reshaped people's health-seeking activities. For instance, smartwatches and wristbands with various sensors can collect continuous biological, behavioral, and environmental data; deliver health interventions; and measure users' health outcomes [12]. Mobile apps can keep people connected with their families and friends, disseminate health information [13], store and share health and lifestyle data [14], manage chronic diseases [15], and manage medical appointments [16]. Self-test kits, such as Antigen Rapid Test Kits, allow people to obtain results swiftly and conveniently at any location and time [17]. As another example, telemedicine services such as telephone calls and video consultations have also demonstrated their potential to be a cost-effective and efficient alternative solution to access quality health care during the COVID-19 pandemic, by reducing travel time and protecting users from disease transmission [18].

Singapore has one of the fastest-growing older populations in the world owing to the increasing life expectancy and low fertility rates [19,20]. Statistics showed that the proportion of the silver generation in Singapore has been rising from 3.4% in 1970 to 10.4% in 2011 and 17.6% in 2021 [21], and this number is anticipated to reach approximately 23.8% by 2030 [22]. To address this demographic shift, the Singapore government has been constantly exploring technological solutions and launching health initiatives to proactively meet the older population's health care needs. Some examples include HealthHub—the 1-stop *digital health care companion* to manage appointments and access personal medical records [23] and National Steps Challenge—the *world's first population-level and fitness tracker–based physical activity* that encourages Singapore residents to track their daily moderate to vigorous physical activities and get rewards [24]. Despite these efforts, there remains a scarcity of studies into the patterns of the older population's HSB and the potential of technologies in facilitating their health seeking and addressing their health needs.

Aim and Objectives

This study aimed to investigate HSB and associated technology use among older people in the Singapore community. We hoped to gain deep insights into how this population makes decisions when they engage with the health system and use technologies; identify any unmet needs; suggest ways in which technology can be leveraged to address these needs; and ultimately, propose recommendations for practical strategies that ensure they are not excluded from the efforts to build the *smart nation*. In particular, we would like to answer the following research questions:

1. What are the activities of HSB (consequences) in the context of aging in Singapore?
2. How have technologies been incorporated into older people's health seeking?
3. What considerations do older adults take into account when choosing technologies to meet their health needs?
4. What are the implications for practice?

Methods

This paper presents partial data from a large study that explored the potential of telehealth in addressing unmet health needs and the attitudes toward telehealth among older individuals in the Singapore community.

Study Design

We used a phenomenological approach to explore the lived experiences of older adults' HSB and associated technology use. The reporting of this study was guided by COREQ (Consolidated Criteria for Reporting Qualitative Research), a 32-item checklist [25].

Participant Recruitment

Inclusion criteria were (1) being ≥50 years old, (2) being Singapore citizens or foreigners who are dwelling in the Singapore community in the long term, and (3) being able to read and converse in English or Mandarin.

The study was planned during the *stabilization phase* [26,27] (with heightened COVID-19 safety management measures [SMMs] to slow down the rate of transmission), and participant recruitment started in January 2022, during the *transition phase*

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in Singapore (groups of up to 5 people were allowed in social gatherings) [28]. We aimed to recruit a diverse range of participants in terms of sociodemographic and socioeconomic characteristics such as age groups, ethnicities, education backgrounds, occupations, income levels, and housing types. To achieve this, we adopted convenience sampling with various recruitment strategies, considering the unpredictable SMMs imposed owing to the COVID-19 pandemic. Before data collection, we posted our study posters on social media platforms (Facebook and Instagram) and shared our study information with some chat groups for older adults. We then obtained referrals from our early participants and stopped recruitment until no new themes were identified. Subsequently, we reviewed the profiles of the interviewees and purposively recruited more participants of interest from the community centers and public areas during the *COVID-19–resilient nation phase* (the social distancing measures were relaxed, and the level of the Disease Outbreak Response System Condition was adjusted to yellow) [29]. We ceased the whole participant recruitment process in July 2022, as no new insights were obtained (thematic data saturation was reached).

Data Collection Tools

This qualitative study used 2 data collection tools—a web-based registration form and a semistructured interview guide.

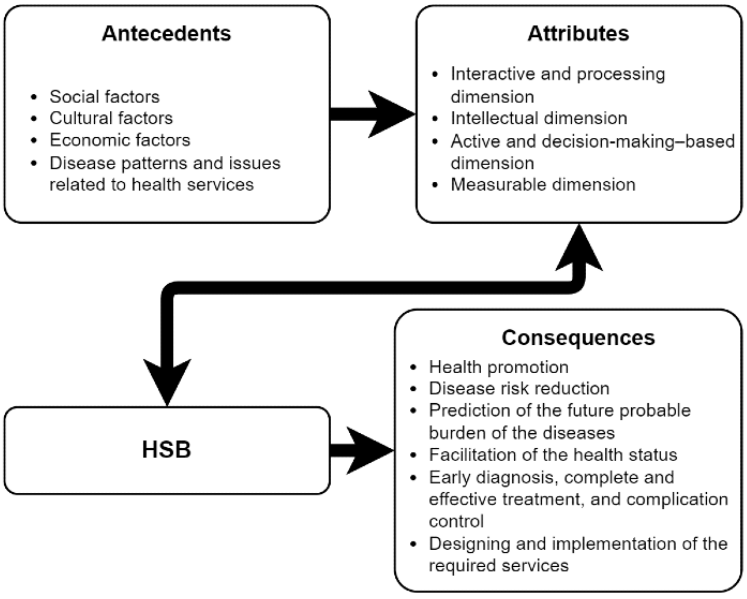
Web-Based Registration Form

The registration form was used to collect the participants' sociodemographic and socioeconomic characteristics, existing health conditions, ownership of mobile devices, access to Wi-Fi, and consent to participate in the subsequent interview.

Semistructured Interview Guide

The preapproved interview guide was developed by YZ and reviewed by WPT. In our study, we adopted the definition by Chinn and Kramer [9] and the evolutionary content analysis of HSB by Poortaghi et al [30] in the nursing setting. According to Poortaghi et al [30] HSB has 4 crucial attributes, namely, interactive and processing dimension, intellectual dimension, active and decision-making–based dimension, and measurable dimension (Figure 1). That is, HSB is an ongoing process involving a logical sequence from the symptom evaluation to the decision of using different care, the individual's efforts to pursue an acceptable level of well-being, the approach to acquiring health information, and the routine of constant health monitoring and behavior change to move toward high-level wellness [30]. The detailed list of guiding questions for the semistructured interviews can be found in Multimedia Appendix 1.

Figure 1. The health-seeking behavior (HSB) model by Poortaghi et al [30].



Data Collection Procedure

Data collection occurred from April 2022 to July 2022. Older adults who expressed interest in participating were invited to complete the web-based registration form and screened to check their eligibility for the interview. Eligible participants were then informed about the data collection procedure; recording of the interviews; and how the data would be analyzed, reported, and protected through written informed consent. Only those who gave their consent were scheduled for an interview. To comply with the SMMs, Zoom (Zoom Video Communications Inc) was chosen as the default interview medium, and a manual was provided to the participants whenever needed. Participants who had unresolvable difficulty with Zoom were offered the option of a face-to-face interview. YZ contacted all eligible candidates either via phone calls or WhatsApp to explain the study details again and scheduled the interviews at their convenience. Written informed consent and permission for interview recording were obtained in advance. Each participant was only required to attend 1 interview session. All interviews were conducted on a one-on-one basis and were video recorded with participants' consent.

At the beginning of each interview, the study details were explained again, and verbal consent was obtained and recorded. YZ conducted all the interviews. She documented her observations through field notes and confirmed important

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findings with the participants during the interviews to ensure accurate interpretations. The interview consisted of 3 sections: HSB, associated technology use, and how the participants selected technologies. Participants received shopping vouchers worth SG $20 (US $15) upon successful completion of the semistructured interview.

Data Analysis

Data analysis was performed after each interview. Each participant was assigned a unique identifier before data analysis, and all study data were deidentified during the transcription process. YZ manually transcribed all interviews verbatim in Word (Microsoft Corp) and transferred all text data to Excel (Microsoft Corp) for thematic analysis. Participants who preferred Mandarin had their transcripts translated by YZ and reviewed by WPT, to ensure the highest level of accuracy. The individual was chosen as the unit of analysis to identify the patterns of HSB and technology use in the older population. Next, YZ conducted inductive thematic analysis, in which a line-by-line coding approach was used while reading through the qualitative data. The codes were then categorized based on the research questions, and the generated pattern codes were used to identify themes. YZ and WPT met regularly to discuss the codes and themes until consensuses were reached, to enhance the validity of the analysis.

Ethics Approval

This paper presents partial data from a large study, which has been approved by the institutional review board of Nanyang Technological University Singapore (reference IRB-2021-797).

Results

Participant Recruitment and Characteristics

In the period from February 2022 to April 2022, 12 individuals signed up for our study after seeing our study poster on social media or in the chat groups for older adults, but only 2 (17%) met our inclusion criteria. Additional 8 participants were then recruited via the referral of the initial 2 eligible participants until no further new themes were generated. We subsequently visited different community centers and public areas and recruited 5 participants with low socioeconomic status or from other ethnicities before we reached thematic saturation. In total, we conducted 13 Zoom interviews where participants remained in their homes, and 2 face-to-face interviews were conducted at the community centers in close proximity to the participants' residences. The mean duration of the interviews in the larger study was 39 minutes (SD 15 minutes 26 seconds).

The 15 participants were aged between 55 and 73 (mean 65.8, SD 6) years, among whom 9 (60%) were women, 13 (87%) were Chinese, 6 (40%) were still working, and 8 (53%) had a personal monthly income of <SG $1000 (<US $752). All participants (15/15, 100%) owned a personal smartphone, but 13% (2/15) of them did not have Wi-Fi access at home. Their characteristics are summarized in Table 1, and detailed information can be found in Multimedia Appendix 2.

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Table 1. Summary of participants' characteristics (N=15).

Characteristics	Values, n (%)
Age range (years)[a]	
55-60	2 (13)
60-70	8 (53)
70-80	5 (33)
Sex	
Female	9 (60)
Male	6 (40)
Ethnicity	
Chinese	13 (87)
Indian	1 (7)
Malay	1 (7)
Number of known health conditions	
0	7 (47)
1	3 (20)
2	4 (27)
3	1 (7)
Highest education achieved	
Primary and secondary	5 (33)
Preuniversity	4 (27)
Degree and postgraduation	6 (40)
Employment status	
Homemaker	3 (20)
Retired	6 (40)
Employed part-time	4 (27)
Employed full-time	2 (13)
Estimated current personal monthly income, SG $ (US $)	
0 (0)	5 (33)
<1000 (<752)	3 (20)
1000-1999 (752-1503)	1 (7)
2000-2999 (1504-2255)	2 (13)
3000-3999 (2255-3006)	1 (7)
4000-4999 (3007-3758)	2 (13)
7000-7999 (5263-6014)	1 (7)
Housing type	
Rental flat[b]	1 (7)
4-room or 5-room HDB[c] flat[d]	4 (27)
Terrace house[e]	1 (7)
Semidetached house[f]	2 (13)
Condominium[g] (excluding executive condominium[h])	7 (47)
Ownership of a smart device	
Smartphone	15 (100)

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Characteristics	Values, n (%)
Tablet	7 (47)
Personal laptop (not for work purposes)	11 (73)
Access to Wi-Fi at home	
Yes	13 (87)
No	2 (13)

[a]Mean age 65.8, SD 6 years.

[b]An affordable housing rental option for Singaporeans with low income [31].

[c]HDB: Housing and Development Board.

[d]A public housing type in Singapore, which is affordable and can be easily purchased by the average Singaporean as they are subsidized by the government and are offered with housing grants (4-room HDB flat: 3 bedrooms and 1 living room; 5-room HDB flat: 4 bedrooms and 1 living room) [32].

[e]A dwelling house with its own land title that forms part of a row of at least 3 dwelling houses abutting the common boundary party walls [33].

[f]A single-family duplex dwelling house that shares a common wall with the next house [34].

[g]An apartment that is part of a development not managed by the HDB, owned by unit owners who share common areas and facilities with other unit owners within the development [35].

[h]A strata-titled property, with comparable designs and facilities to other condominiums [35].

Consequences of HSB in the Aging Context

Overview

Our interviews identified five main consequences of HSB, namely, (1) health information seeking, (2) health maintenance, (3) early diagnosis and complication control, (4) responses to symptoms, and (5) health service use.

Health Information Seeking

Health Education Participation

In total, 87% (13/15) of the participants have attended government, hospital, university, and other community health educational sessions or self-read the health information on mobile health (mHealth) apps, through which they could gain knowledge about various health topics:

> *I'm a volunteer with HPB, and we do conduct health talks. I'm interested in that and I'm still active with it. They have [the] War of Diabetes, [and] some [talks] focus on exercise and nutrition.* [Participant 2]

> *I attended the wellness and health [talk] held by Boon Lay CC last year on the 26th of December, the day after Christmas. I registered myself there to study health and wellness and they taught me to download some of the apps such as 365 [the Healthy 365 app]. I attended the health coaching course offered by NTU [Nanyang Technological University].* [Participant 13]

> *I attended one group education in KTPH [the Khoo Teck Puat Hospital].* [Participant 15]

Overall, 5 factors were identified to have an impact on the preference and judgment of health education, namely, the instructors' qualification, instructors' language or terminologies, usefulness and relevance of the content, cost, and personal interest. Sample responses are summarized in Multimedia Appendix 3.

Health Information Searching and Sharing

In total, 87% (13/15) of the participants actively searched for health information, and the most common information sources were the web (eg, Google, Wiki, and forums), mHealth apps, social networks (family members and friend groups), health professionals, and their fields of medicine expertise:

> *Yes, I will check online or ask friends...I [also] use the HealthHub app...I found it very useful. And it does have family program[s] and health tips that I can go to find out more.* [Participant 2]

> *Normally my friends and I will share health information in [the] WhatsApp group, we are in a retiree group.* [Participant 6]

> *I collect health information from the doctor.* [Participant 8]

> *Actually, I know all these investigations [that have been] done quite well because I worked in the hospital before, so I know all these tests, what they are for, and you must take some medication regularly.* [Participant 10]

Health Information Evaluation

Participants adopted multiple methods to evaluate the credibility of the health information: (1) relying solely on official sources, (2) seeking verification from health professionals, (3) checking the credibility of information sources, (4) searching for scientific evidence, (5) gathering information from individuals with similar experiences, and (6) self-experiment. Sample responses are summarized in Multimedia Appendix 4.

Participants shared that their health information searching and participation in health education could empower themselves with health-related knowledge. They have gained a deep understanding of well-being and diseases, and that has led them to better awareness of their bodies and a positive shift in their health behavior:

> *I become aware of the diseases, and for example, I know that if I eat a lot of fatty stuff, my cholesterol*

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will be affected, thereby when I choose the food I will read the label, so in my daily life in my choice of food and all those, I become educated. After I know all the knowledge but don't practice in my daily life, it's like zì jǐ zhǎo sǐ [killing myself] right? [Participant 5]

We all understand that exercise is good for our health which I'm doing every day. Moderation is the key for any food you take, and I never take excessive [but] just moderate and take what I need. And also need to keep your mental health good, and the more you use your brain the more you can keep your brain; [if] you don't use your brain, you may get dementia. Human beings need group activities like we walk together, and we go to the SACs [Senior Activity Centers] to talk to the elderly. And this way you need friends to be able to listen to your problems, and you don't separate from the society, and that might lead to some mental problems like depression and dementia. [Participant 6]

Health Maintenance

All participants (15/15, 100%) shared that they have been pursuing healthy lifestyles and strengthening social connections to maintain their physical, mental, and social capacities:

Enough sleep, proper diet, [and] regular exercise [help me maintain my health]. [I'm] getting myself active in daily activities, just to keep me mentally and physically engaged. [Participant 3]

I have several groups like my line dancing group, volunteering groups of a few institutions...These people really keep me mentally on the spot. [Participant 5]

Early Diagnosis and Complication Control

Health Screening and Follow-up Care

All participants (15/15, 100%) have been undergoing regular health screenings and follow-up care, with frequency varying from several months to several years, contingent on the purposes (eg, disease screening and chronic condition monitoring):

Once every three or four months I go for my health screening, once a year I get my flu injection, [and] once a year I also go [for] ultrasounds on my lungs, chest, and prostate. [Participant 8]

Self-measurement of Vital Signs

Vital signs are noninvasive objective measures of a person's physiological function using simple equipment, such as pulse, temperature, blood pressure, and respiratory rate [36]. They could serve as a basic means to communicate about a person's health status and keep track of both acute and chronic conditions [36]. In our study, only 7% (1/15) of the participants reverently measured his vitals at home and 60% (9/15) of the participants determined when to perform self-measurement based on the bodily symptoms or daily activities, whereas the rest did not practice self-measurement. Overall, four reasons were reported: (1) self-perceived good health, (2) inability to schedule, (3) lack of necessary equipment at hand, and (4) difficulty in obtaining accurate measurements. Sample responses are summarized in Multimedia Appendix 5.

Self-perceived Health and Responses to Symptoms

Despite the impacts of the COVID-19 pandemic on the participants' physical, mental, and social well-being (as seen in Multimedia Appendix 6), all participants (15/15, 100%) perceived their health to be good to excellent and stated that they rarely fell sick. In the event of any symptoms, three different actions were taken: (1) self-treatment; (2) seeking prompt professional medical attention; and (3) undergoing a logical process from self-treatment to seeking professional medical attention, depending on the severity of symptoms. Sample responses are summarized in Multimedia Appendix 7.

Health Service Use

Satisfaction With the Living Environment

All participants (15/15, 100%) were satisfied with their living and surrounding environments. They could easily access recreational spaces (eg, fitness facilities, parks and open spaces, and walking and cycling paths), amenities (eg, grocery stores and health stores such as Guardian), public transportation (eg, bus stops and Mass Rapid Transit stations), and health care services (eg, outpatient polyclinics, private general practitioners [GPs], and hospitals), and this could make their life more convenient and healthy:

My house is very accessible, and during COVID time we have walked to all the connectors, and we can also walk around within the whole estate. [Participant 7]

Good! It's within [a] 10-20 mins walk to the facilities. Every day I make the trip down to the mall with a library there and use the shopping mall and polyclinic. I also walk, it's like a form of exercise. [Participant 10]

Access—Cost

All participants (15/15, 100%) shared that various government subsidies, such as the Community Health Assist Scheme, Merdeka Generation Package, and Pioneer Generation Package, enabled them to access affordable medical services:

We have the CHAS [Community Health Assist Scheme] cards, we have the Pioneer Generation card, so the charge is minimal, I will say [it is] very affordable...[The health screening is] very affordable, there are two layers of subsidies. [Participant 10]

Access—Waiting Time

Most participants (11/15, 73%) reported that physicians' consultations were fast, but the waiting time could be hours, even with an appointment:

The consultation is very fast, but the waiting time to see the doctors can take hours. [Participant 1]

My appointment was set at 11:30 [am] in the morning [after a long weekend], but I did not see the doctor until 4:30 pm, that is unusual, and even the doctor

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said "today is unusual". The consultations are usually very fast. [Participant 6]

Interaction—Communication With Health Professionals

Our participants reported a general desire to engage in more health-related discussions with their physicians, but the physician-patient communications varied with health professionals and could affect patients' emotions:

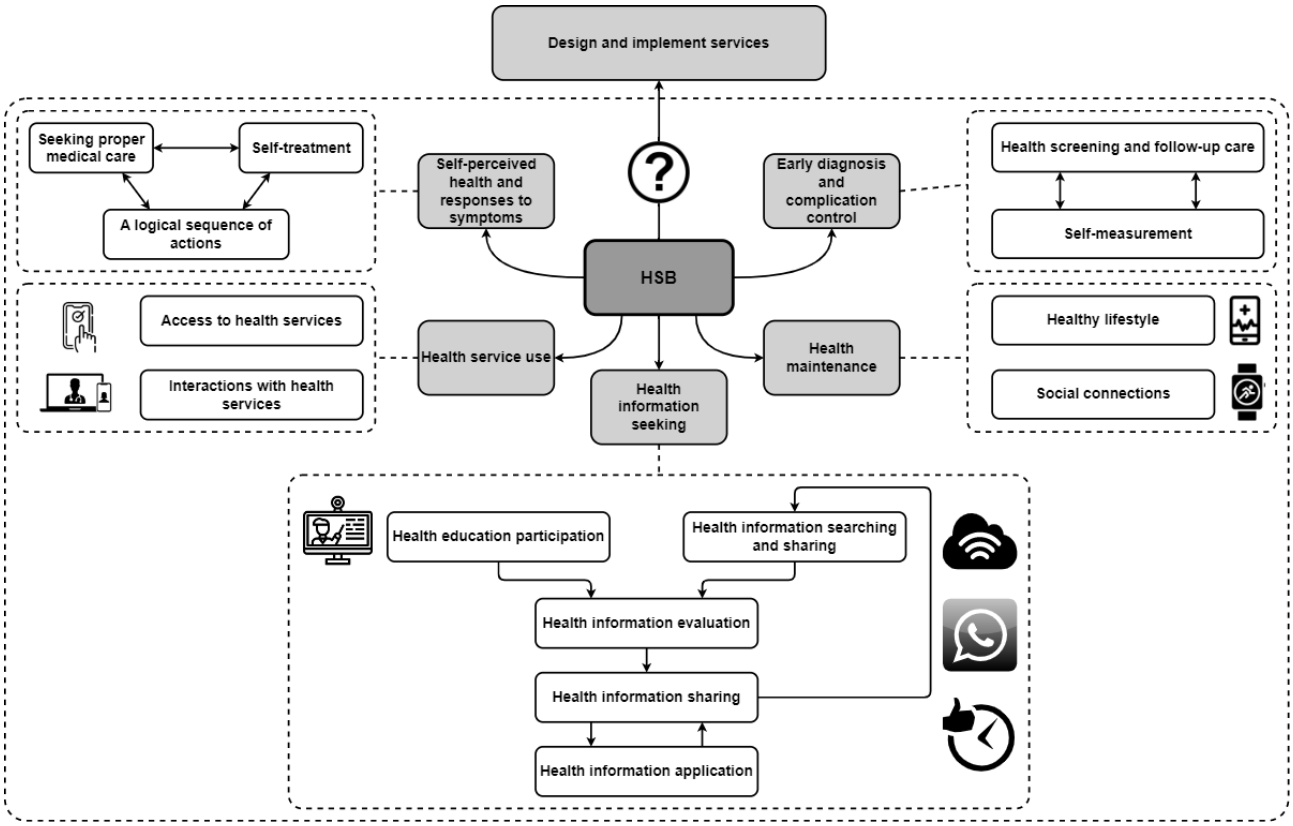
> *Very good because we have been seeing this family doctor for many many years, so we are very comfortable. The communication is very good.* [Participant 7]

> *I hardly see GP so I cannot comment on it. I only can comment [on] those doctors that I have seen in [the] polyclinic. These doctors keep on changing, it's not a specific doctor. I find it poor because sometimes I do feel that they are just doing their job only. Poor in the sense that I feel that sometimes they just do their job to move you away because they have so many patients. But sometimes there are some pretty good doctors, and they do try to explain, so I cannot generalize that. I will see 2 extremes: when I meet good doctors, I'm very happy, but when I meet these so-called poor doctors who are not with the patient, then I will say "okay lah I go polyclinic what do you expect."* [Participant 9]

Technology Use in Older Adults' Health Seeking

We explored the use of technologies in each consequence of the older adults' HSB (Figure 2) and extracted 4 main themes: theme 1—the most widely used digital technologies among the older population are mHealth apps and wearable devices with associated wellness programs launched by government agencies and local companies, and these technologies have the potential to enhance health communication, promote health maintenance, and increase access to health services; theme 2—information communication technologies (ICTs) and social media, although not primarily designed for health purposes, play a substantial role in easing the process of seeking health information and managing symptoms; theme 3—although the outbreak of the COVID-19 pandemic has resulted in some alterations to older adults' well-being, it has catalyzed the adoption of telehealth as a complement to access health care services; and theme 4—older adults have different considerations when selecting technologies to facilitate their health seeking and fulfill their health needs.

Figure 2. Summary of the use of technologies in older adults' health seeking. HSB: health-seeking behavior.



Theme 1—The Most Widely Used Digital Technologies in Health Seeking Among the Older Population

Health Communication

Health communication leverages technological innovations, such as mass media and multimedia to spread health information, enhance public understanding of health, educate the public about health concerns, and keep critical health issues on the public agenda [37]. Our participants shared that they were able to locate information about health programs and health tips through mHealth apps developed by the government:

> *I use the HealthHub app...I found it very useful. And it does have family program[s] and health tips that I can go to find out more.* [Participant 2]

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Health Maintenance

Most of the participants (10/15, 67%) reported using various mHealth apps and wearable fitness trackers, launched by either government or local companies, to track their daily physical activities and stay motivated toward achieving their health goals. They could also receive attractive incentives from the associated health campaigns:

> *I use it [Healthy 365 app] for step tracking. I participated [in] the [National] Steps Challenge as this is free money...I call it preventive medicine because they pay you to lose weight.* [Participant 9]

> *I use [the] SingTel StepUp program also, every month I can redeem at least 2 free Gigabytes for myself.* [Participant 14]

Overcoming Challenges in Health Service Use

Although most of the participants (11/15, 73%) expressed frustration with the long waiting time to see physicians, a few of them shared that mHealth apps such as the HealthHub app could offer them a platform to receive real-time updates about the waiting time and manage their nonurgent appointment bookings:

> *With the appointment on the HealthHub app, I can check how many more patients [are] ahead, then I hang out outside. It doesn't bother me if I have to wait very long.* [Participant 5]

> *I was using HealthHub to check the information about my appointment.* [Participant 14]

Besides managing appointments, participants said that they could also view test results and health reports on the mHealth apps:

> *I go there [the HealthHub app] to do [medical appointment] booking, checking my appointment, and checking my blood test results.* [Participant 9]

Theme 2—Application of ICTs and Social Media in Health Seeking

Health Information Seeking

Apart from health professionals, ICTs and social media were also the active sources of health information seeking and sharing for 87% (13/15) of the participants:

> *Google and read the review of the medicine, then go to some forum. I will check as many sources as I can.* [Participant 5]

> *Sometimes I check Facebook and YouTube.* [Participant 12]

> *From time to time we get [health information] from friends, we get the WhatsApp message to say "hey this is good, you can try this exercise...*" [Participant 8]

Responses to Symptoms

Among the participants who opted for self-treatment as their initial response to symptoms, web-based resources and peer sharing through ICT could provide them with relevant health information, especially from friends who have experienced similar symptoms:

> *Sometimes [I] can see [health information] from YouTube, like you press this pressure point, you massage this area, and your BP will be reduced; or you take some kind of herbal soup. Information is everywhere, so it depends on how you want to capture it. I check this info on YouTube and Facebook.* [Participant 14]

> *Sometimes, like when I had COVID, I shared with them [my friends in the WhatsApp group] the experience of the first few hours of having it, [how I felt after] three days of feeling about it and how I did the ART test, and the results. So it's the sharing of experiences and exchanging thoughts about what happened, are we [we are] facing the same issues or different [ones]*. [Participant 3]

Theme 3—Telehealth Adoption in Health Seeking

Telemedicine or Teleconsultation

During the COVID-19 pandemic, telemedicine served as an alternative way to access health care services. A few participants have tried teleconsultation when they were tested positive for COVID-19 and had to self-isolate:

> *I tried to do a virtual or teleconsult[ation] when I self-tested COVID...I talked to the app on my mobile phone, and I called in to schedule an appointment with the doctor. After the consult[ation], they sent the mediation in within 3 to 4 hours. The consultation, medication, and delivery were very reasonable, and it's cheaper than going to a GP.* [Participant 3]

Tele-Education

Several participants (5/15, 33%) shared that some of their regular health education sessions were adapted to a web-based format via Zoom amid the COVID-19 pandemic, and this allowed them to continue their learning journey with tele-education:

> *We had quite a number of Zoom lectures from HPB [the Health Promotion Board]*. [Participant 1]

> *365 [Cancer Prevention Society] sometimes has little talks about nutrition, I do go in and listen on Zoom.* [Participant 9]

Remote Health Tests

The COVID-19 pandemic did not eradicate the participants' regular health screenings, but the initial lockdown has caused some delays. Some participants chose to postpone their health screening to prevent possible infection and were offered self-tests as a substitute:

> *I didn't go for the blood test as my husband [who is a doctor] told me not to go. But I still did one free test which they sent to me, I collected the specimen and sent it back to them.* [Participant 5]

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Theme 4—Considerations When Selecting Technologies to Facilitate Health Seeking

When asked about how to select technologies, eight factors were reported by the participants, namely, (1) perceived usefulness, (2) comprehensiveness of features, (3) perceived ease of use, (4) performance and quality, (5) recommendation by the social network, (6) cost, (7) rewards, and (8) credibility. Sample responses are summarized in Multimedia Appendix 8.

Archetypes

The participants in our study exhibited a relatively consistent response pattern. However, our results, coupled with insights from our participants' observations within their social networks, have led us to propose 4 archetypes. These archetypes were designed based on factors such as the activeness level of their HSB, access to technologies, willingness to adopt technologies, and capability to use technologies (Textbox 1).

Textbox 1. The 4 proposed archetypes.

- Archetype 1
  - Inactive in health seeking
- Archetype 2
  - Proactive in health seeking but hesitant to adopt technologies
- Archetype 3
  - Proactive in health seeking and receptive to technologies but facing challenges in accessing or using technologies
- Archetype 4
  - Proactive in health seeking, receptive to technologies, and able to access and use technologies

Discussion

Principal Findings

This study expanded upon the literature by adopting the multidimensional model by Poortaghi et al [30] to explore the HSB of older adults in the Singapore community. Unlike previous studies that only focused on health system use and illness responses, our study explored older adults' health-seeking practices with a comprehensive approach, including health information seeking, health maintenance, early diagnosis and complication control, responses to symptoms, and access to and interaction with health care services. We also examined older adults' technology use and considerations for technology selection, and our results offered a different perspective from a previous qualitative study in Singapore, which found that older adults' HSB was technology independent [38]. Our findings suggested that technologies have been seamlessly integrated into older adults' health-seeking activities and have a promising capability of encouraging proactive HSB.

Consequences of HSB in the Aging Context

We identified a total of 5 major consequences of HSB, namely health information seeking, health maintenance, early diagnosis and complication control, responses to symptoms, and health service access and interaction, which are consistent with the model by Poortaghi et al [30]. Although we made an effort to recruit participants with varying sociodemographic and socioeconomic characteristics and observed relatively consistent patterns, the exploratory nature and limited sample size of qualitative research may restrict the generalizability of our findings. Future studies could expand on our study by incorporating the antecedents in the model by Poortaghi et al [30] and evaluating the impact of social, cultural, economic, and health-related factors on HSB, to uncover the unfulfilled needs of the older population.

Technology Use in Older Adults' Health Seeking

A key discovery was the older adults' wide engagement with technologies and associated health campaigns launched by the government and local companies. Supporting the findings by Low et al [38], most of our participants (10/15, 67%) were motivated to use wearable fitness trackers together with mHealth apps to keep track of their physical activities. These technologies could provide users with real-time feedback and motivate them to achieve the predetermined lifestyle goals [39]. Moreover, the financial incentives offered by these initiatives seemed to be an important motivator for older people to use such technologies and encourage positive changes and discourage negative ones in health behavior [40]. Future studies could further investigate the extent to which technology-driven behavior change techniques such as incentive schemes can alter users' behavior and improve their health outcomes. It would also be valuable to explore how such techniques can be integrated with policy tools to facilitate sustainable behavior change.

Technologies offer a solution to overcome the challenges in health service use and interaction. Although all our participants (15/15, 100%) were satisfied with their living and surrounding environments, were able to easily access primary care, and could enjoy affordable medical services through various government subsidies, they pointed out 2 challenges during the interaction with the current health systems. Similar to a theme in the findings by Lee et al [5], many of our participants (11/15, 73%) also shared their experience of waiting several hours for just a few-minute consultation, particularly after public holidays and during the COVID-19 pandemic. In addition, they also encountered communication barriers and even felt discouraged from engaging in further communication as they felt *pushed*

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away by their health professionals. These might be attributed to a shortage of health professionals in the country, as reported by the Ministry of Health that the physician-to-population ratio was 1:399 and there were only 2.5 physicians per 1000 population in 2019 [41]. In addition to incorporating self-service medical booths [42], the use of digital technologies such as the machine learning–based solution being developed by the Singapore National Eye Center, called Appointment Scheduling Optimizer, could reduce patients' waiting time [43]. Telehealth, which has the potential to reduce expenses and time spent on traveling and waiting [44], might offer another viable solution, but future studies are needed to further reaffirm the acceptability, effectiveness, and cost benefits of telehealth services.

ICT and social media expand people's alternatives in searching for health-related information; however, they are not tailored to health intentions and cannot alleviate, diagnose, or cure diseases. In contrast to the findings by Lin et al [45] that only a small portion of the participants searched for health information on the web using their mobile phone, a high percentage of older participants in our study used their smartphones for searching and sharing health information, via web-based resources, social media, mHealth apps, and messaging through social network communication tools. This difference may stem from the improved accessibility and easy sharing of information through mobile phones in recent years. Some of the government initiatives have also begun to harness these platforms, such as HPB's posting of health-related videos on YouTube for health promotion [46] and the launch of the official COVID-19 channels on Telegram and WhatsApp to broadcast news updates, deliver important announcements, and reduce the spread of misinformation during the COVID-19 pandemic [47]. An unexpected result was that almost all participants (14/15, 93%) made an effort to question and assess the credibility of the health information. They exhibited skepticism toward the health information encountered and used various means to verify its credibility. Our findings suggested that technologies have shaped health information seeking as a collective and collaborative effort—people first gather information; next, verify and circulate it through their social network; and then, apply it in their daily practice and provide feedback. Through this cyclic seeking-verifying-sharing-applying-feedback process, they can reaffirm the credibility and effectiveness of the information through firsthand experience.

Although the COVID-19 pandemic has brought some alterations to older people's well-being and disruptions to their lifestyle practices, it also catalyzed technological innovation and adoption. For example, telehealth, although not a novel concept [48,49], gained increasing attention amid the COVID-19 pandemic [50]. Our participants shared that different telehealth modalities could enable them to continue their access to health care services and health education. Future studies could further evaluate the role of telehealth in aging care.

Implications for Practice

This section serves as the last consequence in the HSB model by Poortaghi et al [30]—*design and implement needed services*.

Health Communication and Promotion

According to our findings, ICT and social media appeared to be promising channels for obtaining and exchanging health information. Previous studies also reported that many older citizens in the Singapore community are not resistant to technologies, and they spent more time on smartphones watching dramas, playing games, and chatting on messaging platforms [51,52]. Leveraging these platforms and launching eHealth communication and promotion campaigns could be a viable strategy to increase health awareness and encourage participation among the older population.

Health Education

Our participants shared that the overriding factors affecting their preference and evaluation of health education are the qualifications of and language used by the health instructors, usefulness and relevance of the content, cost, and personal interest. Although there is no *one-size-fits-all* solution, future health education programs could take these factors into consideration.

Technology Design, Improvement, and Implementation

Participants shared various factors in technology selection, but the results may be limited by the types of such technologies that they have used before. In contrast, this also implies that older adults might be granted access to a wider variety of digital technologies. Besides perceived usefulness, perceived ease of use, and financial cost found by Lin et al [45], our participants also shared that the comprehensiveness of features, quality of performance, recommendations by their social network, rewards, and credibility are the other overriding considerations. Taking these factors into consideration would be useful not only for technology developers when enhancing current technologies or creating novel ones to promote better user-centered designs but also for policy makers in the process of digital transformation and building the *smart nation*.

Clinical or Community-Based Telemonitoring Services to Support Older Adults' Self-measurement Practice

A possible gap we identified in the participants' HSB was a lack of self-measurement of their vitals, especially for those with chronic conditions. Single-point vital sign measurements have shown to be less sensitive in detecting disease processes as a result of the diverse but individual age-related physiological changes and comorbidities, whereas successive or serial measurements may enhance the sensitivity in detecting disease processes, especially when viewed in conjunction with individualized reference ranges [36]. In Singapore, some polyclinics have introduced telemonitoring services for patients with chronic health conditions, and such services have been well accepted [53,54]. Patients who rely solely on physical examinations, who do not own a personal device, and who are occupied with daily chores can get the necessary devices and benefit from such services for chronic disease management, as prompt measurements can be taken beyond the health care setting. Besides clinical approaches, community-based initiatives can be used to make technology more accessible to the public and aid those who have difficulty in obtaining accurate measurements. For example, telemonitoring kiosks with trained

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health ambassadors in the community can be set up to provide users with health tips and gather data to help health professionals make better decisions. By implementing these ground-up strategies, older individuals can enjoy better access to quality health care services and technologies; reduce expenses associated with travel and medical equipment purchases; take a more proactive role in managing their health; and ultimately, reduce health disparities. Future studies could further investigate the effectiveness of telemonitoring in detecting diseases and reducing complications, hospital readmissions, and mortality rates in aging care.

Possible Solutions to Facilitate the Health Seeking of the Proposed Archetypes

It is important to note that although technologies play a promising role in assisting older people's health seeking, they are not mandatory. People may have various reasons for using or not using technologies; therefore, it is crucial to uncover their specific health needs and ensure that no one is forced to use technologies or left behind in digital inclusion.

Archetype 1—Inactive in Health Seeking

For archetype 1, the priority might be identifying older people's unfulfilled needs and seeking tangible resources from both health care and community settings. Some possible strategies include educating them about the significance of proactive HSB through public health campaigns, providing regular updates about their health status, and ensuring that they are not left behind in digital inclusion.

Archetype 2—Proactive in Health Seeking but Hesitant to Adopt Technologies

For archetype 2, it might be helpful to work with health professionals and assess the need for incorporating technologies in their health seeking. Through this joint effort, they can determine the most suitable solutions to meet their specific needs. At the same time, they can be invited to attend health events or participate in awareness campaigns to gain firsthand experience regarding the benefits of technologies and make informed decisions.

Archetype 3—Proactive in Health Seeking and Receptive to Technologies but Facing Challenges in Either Accessing or Using Technologies

For archetype 3, the focus could be on lowering the barriers to using technologies. Some possible strategies might be introducing simple technologies in small steps, offering assistance and support to build people's technology skills (eg, the *Senior Go Digital* program [55]), encouraging social engagement and creating a supportive community, and improving both user-friendliness and accessibility of technologies for the older population.

Archetype 4—Proactive in Health Seeking, Receptive to Technologies, and Able to Access and Use Technologies

Archetype 4 might be the most suitable candidate for technology use and require the least amount of support. The focus could be on developing innovative technologies and policy solutions to sustain and enhance their HSB.

Strengths, Limitations, and Future Studies

This study had several strengths. Conceptually, we extended the literature by adopting a multidimensional model and assessed the older adults' HSB using a more comprehensive approach, and our findings further reiterated this model. Methodologically, we adopted multiple recruitment strategies to reduce selection bias, and we managed to get insights from older adults with varying sociodemographic and socioeconomic characteristics in Singapore. Despite these strengths, we acknowledge that our study also had some limitations. First, most participants (13/15, 87%) were Chinese, which might be because of the inclusion of only English and Mandarin speakers, considering the researchers' language proficiency. Future studies could be extended to Malay, Tamil, and Chinese dialect speakers. Second, owing to the COVID-19 pandemic restrictions, the main method of participant recruitment and contact was through social media and WhatsApp, which could have resulted in a possible bias toward individuals who were more technologically advanced and had better access to technologies. Future studies should attempt to reach out to individuals who are digitally illiterate or homebound. Finally, this was an exploratory qualitative study with a limited sample size, and the choice of the individual as the unit of analysis to understand group phenomena may overlook certain fine points and variations among individuals. Large-scale quantitative or mixed methods studies could further investigate the impact of social, cultural, economic, and health factors (the antecedents in the model by Poortaghi et al [30]) on older adults' HSB and how technologies can address these inequalities.

Conclusions

In conclusion, we have extended the literature and investigated older adults' HSB and associated technology use with a more comprehensive approach. Unlike the commonly held belief that older adults resist technologies and lack technological proficiency, our results showed that technologies could play a promising role in facilitating older adults' health seeking. Our findings have implications for the design and implementation of health services and policies.

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Data Availability

The data sets generated and analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Semistructured interview guide.
[DOCX File , 16 KB - aging_v6i1e43709_app1.docx]

Multimedia Appendix 2
Detailed participants' characteristics.
[DOCX File , 20 KB - aging_v6i1e43709_app2.docx]

Multimedia Appendix 3
Sample responses regarding the preference and evaluation of health education.
[DOCX File , 15 KB - aging_v6i1e43709_app3.docx]

Multimedia Appendix 4
Sample responses regarding evaluating the reliability of information sources.
[DOCX File , 16 KB - aging_v6i1e43709_app4.docx]

Multimedia Appendix 5
Sample responses regarding self-measurement.
[DOCX File , 16 KB - aging_v6i1e43709_app5.docx]

Multimedia Appendix 6
Sample responses regarding the impact of the COVID-19 pandemic on older people’s perceived health.
[DOCX File , 16 KB - aging_v6i1e43709_app6.docx]

Multimedia Appendix 7
Sample responses regarding health service use.
[DOCX File , 14 KB - aging_v6i1e43709_app7.docx]

Multimedia Appendix 8
Sample responses regarding the choice of health technologies.
[DOCX File , 15 KB - aging_v6i1e43709_app8.docx]

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Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research

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GP: general practitioner
HSB: health-seeking behavior
ICT: information communication technology
mHealth: mobile health
SMM: safety management measure

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Review

Older Adults and New Technology: Mapping Review of the Factors Associated With Older Adults' Intention to Adopt Digital Technologies

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Abstract

Background: Ongoing advancements in digital solutions support older adults' healthy aging and well-being. However, a unified synthesis of sociodemographic, cognitive, attitudinal, emotional, and environmental factors that influence older adults' intention to use these new digital technologies is still lacking. Understanding the salient factors that influence older adults' intention to use digital technologies will help to ensure that technology is developed appropriately and contextually. This understanding is also likely to contribute to developing technology acceptance models specifically for the aging generation, by reorganizing principles and constructing objectivity criteria for future research studies.

Objective: This review aims to identify the key factors associated with older adults' intention to use digital technologies and to provide a comprehensive conceptual framework to describe the relationships between these key factors and older adults' intention to use digital technologies.

Methods: A mapping review was conducted using 9 databases from inception to November 2022. Articles were selected for review if they had an evaluative component of older adults' intention to use digital technologies. Three researchers independently reviewed the articles and extracted the data. Data synthesis was performed via narrative review and quality appraisal was measured using 3 different tools based on each article's study design.

Results: We identified a total of 59 articles investigating older adults' intention to use digital technologies. The majority (40/59, 68%) of articles did not use an existing framework or model for technology acceptance. Studies mostly adopted a quantitative research design (27/59, 46%). We found 119 unique factors reported to influence older adults' intention to use digital technologies. These were categorized into 6 distinct themes: Demographics and Health Status, Emotional Awareness and Needs, Knowledge and Perception, Motivation, Social Influencers, and Technology Functional Features.

Conclusions: Given the importance of global demographic change toward an aging society, there is surprisingly limited research on the factors that influence older adults' intention to use digital technologies. Our identification of the key factors across different types of digital technology and models supports the future integration of a comprehensive perspective encompassing environmental, psychological, and social determinants for older adults' intention to use digital technologies.

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KEYWORDS

technology adoption; digital technology; older adults; seniors; intention to use digital technologies

Introduction

Technological innovation and the constantly increasing use of the internet are creating unique opportunities to assist older adults' (here defined as persons with a physical age of 65 years and above) health and well-being [1]. There is growing evidence of the benefits that older adults experience when they use digital technologies. These include improvements in their cognitive, social, and emotional well-being [2]. Technologies such as computers, the internet, and mobile phone apps have been found to be effective tools in managing health conditions and supporting well-being [3]. Although older adults' adoption rates of technology have traditionally been low, they are nowadays increasing and the gap toward the younger generations is closing significantly [4]. In this era of increased global aging, the World Health Organization estimates that by 2030, 1 in 6 people in the world will be aged 60 years or over [5], and that it is necessary that technological developments become more age-friendly and usable by older adults. However, the factors influencing older adults' intention to use digital technologies are not yet fully understood.

The information systems discipline has developed various models of technology acceptance to understand the factors leading to the acceptance, adoption, use, and continuous use of technology. Among the most widely used theoretical frameworks are the Technology Acceptance Model (TAM) [6] and the Unified Theory of Acceptance and Use of Technology (UTAUT) [7], which have been developed based on broadly defined adult populations with expansive age brackets [8].

Formulated by Davis [6], the TAM describes individuals' *acceptance* of technologies [9] and has been applied to a wide variety of contexts including the health care sector [10]. The TAM suggests that perceived usefulness (ie, whether the users perceive the technology as helpful to achieve the intended purpose) and perceived ease of use (ie, whether the users perceive the technology to be easy to use for them) explain an individuals' intention to use digital technology [6,11]. Based on the Theory of Reasoned Action [12], intention is regarded as a powerful predictor of actual use. However, the main points of criticism for the TAM are that its measurement relies on self-reported perceptions and that the dependent variable is behavioral intention, not the actual use of a technology [13]. Furthermore, the model does not consider factors including age and education, external variables which could influence willingness to use technology [14]. As such, more recent model developments have taken place.

The UTAUT model [7], developed by Venkatesh et al [7], combines and integrates 8 theories to explain human behavior with respect to technology adoption. It identifies 4 major constructs (performance expectancy, effort expectancy, social influence, and facilitating conditions), along with 4 moderators (age, gender, experience, and voluntariness) to predict individuals' use of technology [7,15]. In 2012, the UTAUT model was further developed into the UTAUT 2 model by Venkatesh et al [8]. The authors extracted factors for the consumer context and extended it by incorporating another 3 factors, namely, hedonic motivation, price value, and habit, which improved the prediction of behavioral intention to use behavior. The UTAUT 2 includes 3 moderators: age, gender, and experience [8]. The TAM and UTAUT received enormous attention in academia and practice, and probably belong to the most tested, adapted, and extended models in information systems research. However, both models share the same weakness that they were not developed with consideration of different application areas, which can be beneficial or detrimental. Furthermore, they do not incorporate the fact that technology acceptance may change over time [11].

In 2000, the original TAM was expanded by Venkatesh and Davis [16] with some elements and republished as TAM2, with further revisions made in 2008 to create TAM3 [17]. In TAM2, the input variables were differentiated into the groups of social influence and cognitive processes. TAM3 is based on the acceptance variables of the original TAM (ie, perceived usefulness, perceived ease of use, and intention to use) and TAM2 (ie, experience, voluntariness, subjective norm, image, workplace relevance, quality of outcome, and presentable results). This model is supplemented by the subcategories anchor and adjustment, which include computer self-efficacy, perception of external control, computer anxiety and computer playfulness, as well as perceived enjoyment and objective usability. The Senior Technology Acceptance Model [18] also describes a further development of the TAM and captures the context of the older mobile phone user. Here, intention to use is primarily determined by perceived usefulness and social influence (ie, children urging their parents to use the phone). The variables are social influence, intention to use, perceived usefulness, facilitating conditions, experimentation and exploration, confirmed usefulness, ease of learning and use, and actual use.

However, despite these adjustments, within gerontology and aging research fields, a widespread deficiency of the existing technology acceptance models is the neglect of biophysical factors (eg, cognitive and physical decline) and psychosocial factors (eg, social isolation and fear of illness) [19]. As such, extant theoretical models of technology acceptance are not fully applicable to members of the aging population [20].

This systematic mapping review is set to capture the diverse literature available on this topic and provide in-depth insights into overarching concepts to further advance this field. Furthermore, a framework that incorporates the most up-to-date evidence of how the key factors interact and their impact on older adults' behavioral intentions is yet to be produced. By tracking the flow of information through publications using a mapping review, linkages between core concepts related to the intended use of technology across disciplines can be identified [21,22].

This mapping review thus provides a synthesis of current research on older adults' intention to use digital technology and

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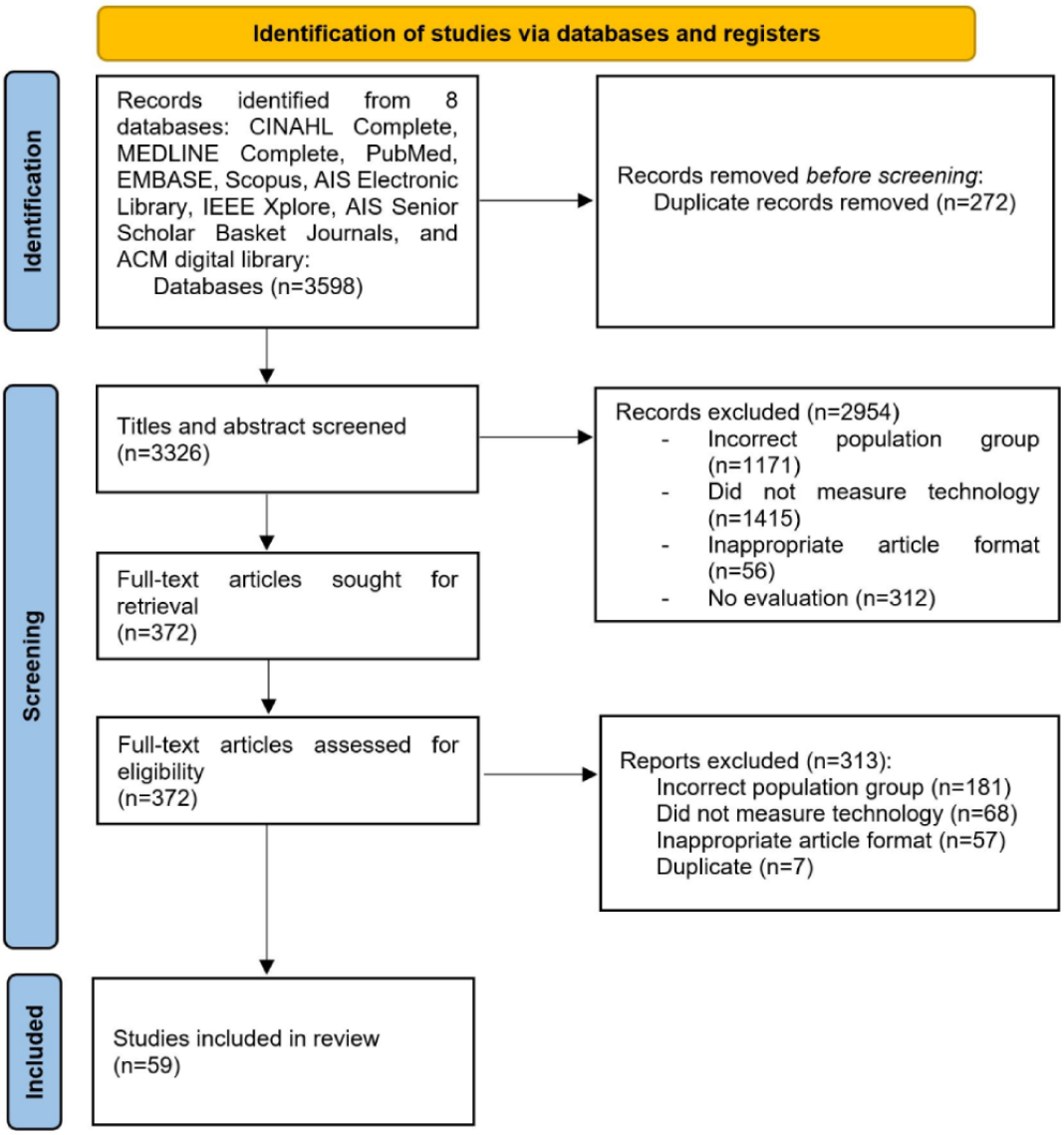
the corresponding salient factors. Our objective was 2-fold: (1) to identify the key factors associated with older adults' intention to use digital technologies, and (2) to provide a comprehensive conceptual framework to describe the relationships between these key factors and older adults' intention to use digital technologies. These findings will provide directions for further research addressing the specific user group of older adults.

Methods

Study Design

A systematic mapping review was used to identify the published original articles related to intention to use digital technology by older adults. The review protocol was registered with PROSPERO (International Prospective Register of Systematic Reviews; registration number CRD42022329705) and the selection process is outlined in Figure 1.

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



Search Strategy and Study Selection

A search was conducted from inception to November 15, 2022, in 9 databases including CINAHL Complete, MEDLINE Complete, PubMed, Embase, and Scopus, as well as in 3 information systems–focused databases, AIS Electronic Library, IEEE Xplore, and ACM Digital Library, and in the journals of the AIS Senior Scholar Basket. Broad keywords used were the following combination of 4 groups of keywords: older adults (eg, aged, older, senior, elderly) AND technology factor (eg, acceptance, adoption, use, adherence, rejection) AND influence (eg, behaviour, psychology, motivation) AND technology type (eg, technology, computers, eHealth, system, assistive technology, robotics, smart home, gerontechnology, telemonitoring). The full search strategy was updated on November 15, 2022 and is provided in Multimedia Appendix 1.

Inclusion Criteria

Original and peer-reviewed journal publications and conference proceedings written in English and using qualitative, quantitative, or mixed methods research were included. Studies had to include participants who were older adults (aged 65 years or older) and had an evaluative component of either

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demographic, cognitive, physical, or emotional factors that influenced the intention to use or actual use of digital technology.

All titles and abstracts of the identified studies were subsequently screened for eligibility by 3 reviewers (JS, LD, and TS) independently, applying the following inclusion criteria: (1) original and peer-reviewed research written in English with either a qualitative, quantitative, or mixed methods approach; (2) participants were older adults aged 65 years or more; and (3) research was aimed at investigating factors that influence the intention to use or the actual use of digital technologies for older adults. The 3 researchers then conferred to resolve any discrepancies on eligibility, and if an agreement could not be made, a fourth reviewer (AG) was consulted. The full text of the remaining studies was then checked and those that did not meet all inclusion criteria were excluded. The references of the selected studies were hand searched for other potential studies (snowballing method; Figure 1).

Assessment of Methodological Quality

Methodological quality was assessed using the Critical Appraisal Skills Program, the Cochrane Risk of Bias, and the Mixed Methods Appraisal Tool (MMAT) [23] which, in addition to specific criteria for qualitative and quantitative research, also contains specific criteria on the relevance of the use of a mixed methods design and the integration of different types of results. The researchers assessed the methodological quality of all included studies independently, followed by a discussion of their findings to determine the final rating for each study. It was decided not to exclude articles based on quality assessment because there is little empirical evidence on which to base exclusion decisions in mixed studies systematic reviews [23-25]. Instead, it was decided to report on the quality of the reviewed articles and to apply independent triangulation: at least two quality criteria had to be present in studies to be included in the results.

Data Extraction and Synthesis

As included articles ranged from qualitative to quantitative methods (or a combination of both), data extraction forms for both design types were designed. For qualitative articles and qualitative information from mixed methods articles, acceptance factors were coded and entered. For quantitative articles and quantitative information from mixed methods articles, variable/factor name and level of significance were entered into the data extraction form. Two authors (TS and JS) reached consensus on the data extraction form for each article.

Thematic synthesis [25] was used to synthesize qualitative data on technology use and intention to use factors. Multiple sessions in the research team were then held to group factors derived from articles into descriptive themes for acceptance in post-technology implementation. JS, LD, and TS each created a conceptual model of the relationships between themes, and through iterative discussions developed 1 final model. Factors derived from qualitative articles and mixed methods articles were compared with factors identified in quantitative articles. This allowed us to highlight which factors were statistically tested in quantitative research. Quantitative articles were summarized thematically. For this purpose, all factors examined were first extracted and compiled. We summarized thematically related factors into individual group categories to create a better overview. Cluster analysis was used as an explorative method to establish the group categories and to classify the individual factors by purpose and type. Subsequently, we also added the factors examined in the qualitative articles.

Results

Overview

The study characteristics of the 59 articles analyzed are shown in Table 1. Most articles (36/59, 61%) were written in the last 5 years, published in the United States (25/59, 42%), and conducted in a community-dwelling setting (23/59, 39%), with 39,153 older adults sampled (sample size ranged from 5 to 14,798).

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Table 1. Summary of the included articles.

Authors	Country	Study design	Setting	Sample size, n	Sample mean age (years)	Proportion of female, %	Technology type	Technology subtype	Purpose			Model used
									Health and safety	Social interaction	Independence	
Franks and Beckmann [26]	Canada	MM[a]	Other and home care	100	77.5	60	Remote or assistive care technologies	Hearing aids	✓	—[b]	✓	—
Billipp Heyn [27]	United States	E[c]	Home care	40	73	82	Everyday technologies	Computer	—	✓	✓	—
Jimison et al [28]	United States	E	Home care	15	79.5	—	Everyday technologies	A computer game	—	—	✓	—
Kurt et al [29]	United States	Q[d]	Other	240	77.5	—	Everyday technologies	Client-server computer application	—	—	✓	—
Horowitz et al [30]	United States	Q	Community center	438	80.4	—	Remote or assistive care technologies	Optical and adaptive device	✓	—	✓	—
Courtney et al [31]	United States	Q	Community dwelling	14	77.5	—	Remote or assistive care technologies	Smart home device	✓	—	✓	Health Belief Model
Demiris et al [32]	United States	O[e]	Home care	9	82.5	—	Remote or assistive care technologies	Smart home device	✓	—	✓	—
Chu et al [33]	United States	Q	Community center	137	77.5	72	Everyday technologies	Computer	—	✓	✓	Bandura's Self-Efficacy Theory
Beer and Takayama [34]	United States	E	Community dwelling	12	73.4	58.30	Everyday technologies	Mobile	—	—	✓	—
Chudyk et al [35]	Canada	Q	Primary care	28	71	50	Remote or assistive care technologies	Monitoring device	✓	—	—	—
Cornejo [36]	Mexico	E	Community dwelling	12	86.5	—	Everyday technologies	Sensors	—	—	✓	—
Aloulou et al [37]	Singapore	S[f]	Long-term care	8	85	100	Remote or assistive care technologies	Sensors	✓	—	✓	—
Choi and Dinitto Diana [38]	United States	Q	Community dwelling	6680	77.5	56	Everyday technologies	Internet	—	✓	✓	—
Demiris et al [39]	United States	E	Home care	27	86	27	Remote or assistive care technologies	A health management platform (CogniFit, GAITRite, and telehealth kiosk)	✓	—	—	Hoyman's Wellness Model
Baig et al [40]	New Zealand	E	Primary care	30	82.4	43	Remote or assistive care technologies	Monitoring system	✓	—	✓	—

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Authors	Country	Study design	Setting	Sample size, n	Sample mean age (years)	Proportion of female, %	Technology type	Technology subtype	Purpose			Model used
									Health and safety	Social interaction	Independence	
Colombo et al [41]	Italy	Q	Community dwelling	900	68.5	—	Everyday technologies	Smartphone, tablet, computer	—	✓	✓	—
Gellis et al [42]	United States	R[g]	Primary care	102	77.5	—	Remote or assistive care technologies	Telehealth	✓	✓	—	—
Aponte and Nokes Kathleen [43]	United States	Q and S	Community center	20	74	50	Everyday technologies	Internet	—	✓	✓	—
Jimison et al [44]	United States	O	Community dwelling	6	82.5	67	Everyday technologies	Video	—	—	✓	Trans-Theoretical Model of Behavioral Change
Neves et al [45]	Canada	MM	Long-term care	5	87.2	60	Everyday technologies	Mobile	—	✓	—	—
Chopik [46]	United States	Q and S	Community dwelling	591	68	56	Everyday technologies	Internet	—	✓	✓	—
Dupuy et al [47]	France	E	Community dwelling	34	85	—	Remote or assistive care technologies	Assistive device	✓	—	✓	Self-Determination Theory
Cajita et al [48]	United States	S	Primary care	129	71.3	26	Everyday technologies	Mobile	—	✓	✓	TAM[h]
Chang et al [49]	Taiwan	Q	Primary care	18	77.6	67	Remote or assistive care technologies	Telehealth	✓	✓	—	TAM2[i]
Chung et al [50]	United States	Q	Community dwelling	21	69.6	—	Remote or assistive care technologies	Monitoring systems	✓	—	—	TAM
Djabelkhir et al [51]	France	R	Primary care	20	76.7	45	Everyday technologies	Computerized cognitive stimulation	—	✓	✓	—
Irizarry et al [52]	United States	MM	Community dwelling	100	77.5	—	Remote or assistive care technologies	Patient portal	✓	—	—	—
Cajita et al [53]	United States	Q	Primary care	10	69.5	40	Remote or assistive care technologies	mHealth[j]	✓	—	—	TAM
Dugas et al [54]	United States	E	Primary care	27	67.6	—	Everyday technologies	A gamified mHealth Tool (DiaSocial)	✓	✓	—	Regulatory Mode Theory
Holgersson and Söderström [55]	Sweden	Q	Community dwelling	293	77.5	—	Everyday technologies	E-services	—	—	✓	—
Khosla et al [56]	Australia	MM	Home care	5	80	—	Remote or assistive care technologies	Social robot	✓	✓	✓	TAM
Mohlman and Basch [57]	United States	S	Community dwelling	85	77.2	60	Everyday technologies	—	—	✓	✓	—

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Authors	Country	Study design	Setting	Sample size, n	Sample mean age (years)	Proportion of female, %	Technology type	Technology subtype	Purpose			Model used
									Health and safety	Social interaction	Independence	
Kim et al [58]	Republic of Korea	S	Primary care	21	72	81	Everyday technologies	Mobile app	✓	✓	✓	—
Woo et al [59]	United States	Q	Home care	20	72.6	55	Remote or assistive care technologies	Telehealth	✓	✓	—	UTAUT[k]
Ali et al [60]	Australia	Q	Other/undefined[l]	14,798	—	52	Remote or assistive care technologies	E-services	✓	✓	—	—
Bernstein et al [61]	United States	S	Community dwelling	60	73.4	27	Everyday technologies	Computer and apps	—	✓	✓	—
Bevilacqua et al [62]	Italy	MM	Other/undefined	35	74	63	Remote or assistive care technologies	Robot	✓	✓	✓	—
Cohen-Mansfield et al [63]	Israel	Q	Home care	105	74	85	Everyday technologies	A gamified web-based activity program	—	—	✓	—
Doyle et al [64]	Ireland and Belgium	S	Home care	120	74.2	40	Remote or assistive care technologies	A digital health platform (ProACT)	✓	—	—	—
Ghorayeb et al [65]	United Kingdom	Q	Home care	13	77	54	Remote or assistive care technologies	Smart home devices	✓	—	✓	—
Harris et al [66]	United States	S	Community dwelling	70	71.1	73	Everyday technologies	Mobile	✓	✓	✓	—
Kalicki et al [67]	United States	S	Community dwelling	873	82.7	75	Remote or assistive care technologies	Telehealth	✓	✓	—	—
Klaver et al [68]	The Netherlands	S	Primary care	463	74	49	Remote or assistive care technologies	mHealth apps	✓	—	✓	TAM/UTAUT
Li et al [69]	United States	S	Primary care	2909	77.2	55	Everyday technologies	Information and communications technology	—	✓	✓	—
Marklund et al [70]	Sweden	Q	Primary care	16	72	75	Remote or assistive care technologies	eHealth	✓	—	—	Fogg Behavior Model
Nebeker and Zlatar [71]	United States	R	Other/undefined	41	71.6	76	Remote or assistive care technologies	mHealth	✓	—	✓	—
Pang et al [72]	Canada	MM	Community dwelling	42/27	69	43	Everyday technologies	Learning video prototype	—	—	✓	—

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Authors	Country	Study design	Setting	Sample size, n	Sample mean age (years)	Proportion of female, %	Technology type	Technology subtype	Purpose			Model used
									Health and safety	Social interaction	Independence	
Yachin and Nimrod [73]	Canada, Colombia, Israel, Italy, Peru, Romania, and Spain	S	Other/undefined[l]	184	71	100	Everyday technologies	Information and communications technology	—	✓	✓	—
Blavette et al [74]	France	S	Primary care	45	82	65	Remote or assistive care technologies	Robot	✓	✓	—	—
Choi et al [75]	United States	MM	Community dwelling	3257	—	56	Remote or assistive care technologies	Telehealth	✓	✓	—	Healthcare Utilization Model
Coley et al [76]	France	R	Community dwelling	2724	69	48	Remote or assistive care technologies	Internet-based intervention	✓	✓	✓	—
Domingos et al [77]	Portugal	S	Community dwelling	110	69	66	Everyday technologies	Activity tracker	—	—	✓	TAM3[m]
Gomez et al [78]	United Kingdom	O	Community dwelling	44	72	—	Remote or assistive care technologies	Hearing aid	✓	—	—	—
Krutter et al [79]	Germany	MM	Home care	20	65	—	Remote or assistive care technologies	Virtual avatar	✓	—	—	UTAUT
Özsungur [80]	Turkey	S	Home care	687	73	40	Everyday technologies	Online services and apps	✓	✓	✓	UTAUT 2[n]
Qin [81]	United States	S	Community dwelling	1769	—	55	Remote or assistive care technologies	Telehealth	✓	✓	—	—
Smrke et al [82]	Slovenia	S	Home care	185	81	66	Remote or assistive care technologies	Robot	—	✓	✓	—
Vailati Riboni et al [83]	Italy	Q	Community dwelling	68	72	71	Everyday technologies	App	✓	—	✓	—

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Authors	Country	Study design	Setting	Sample size, n	Sample mean age (years)	Proportion of female, %	Technology type	Technology subtype	Purpose			Model used
									Health and safety	Social interaction	Independence	
Van Elburg et al [84]	The Netherlands	S	Community dwelling	360	75	57	Remote or assistive care technologies	mHealth apps	✓	—	✓	TAM[o]

[a]MM: mixed methods study.

[b]Data not available.

[c]E: experimental study.

[d]Q: qualitative study.

[e]O: observation study.

[f]S: survey study.

[g]R: randomized control trial.

[h]TAM: Technology Acceptance Model.

[i]TAM2: Technology Acceptance Model 2.

[j]mHealth: mobile health.

[k]UTAUT: Unified Theory of Acceptance and Use of Technology Model.

[l]Others/undefined: The provided information does not fit in the settings (eg, free-living environment, Facebook group) or the information was not provided.

[m]TAM3: Technology Acceptance Model 3.

[n]UTAUT 2: Unified Theory of Acceptance and Use of Technology Model 2.

[o]Includes variables of TAM2 and the Senior Technology Acceptance Model, but we focused on the dominant model TAM.

Different types of technology were examined, ranging from mobile technologies and television-based to assistive technologies, with the most common technology type being technology devices. Based on the scope of functionalities, 2 main categories of technology were summarized [85]: (1) everyday technologies (including hardware devices, such as computers, smartwatches, tablets, computers, and services such as gaming, apps, and other technologies used to support daily living); and (2) remote or assistive care technologies, which were those that use information communication technology devices and networks to deliver health and social care technology. Remote or assistive care technologies were most commonly reported (32/59, 54%).

The purpose of technology was also defined. Technology that supports older adults' independence through activities of daily living or instrumental activities of daily living was the most common (40/59, 68%), followed by technology that aims to enhance safety (eg, such as monitoring or assistive technology; 36/59, 61%).

In a 2008 study [31], a model was used for the first time as a theoretical basis. Subsequently, studies from 2015 onward have used models for their studies. The studies did not show a trend in terms of setting, study design, technology type, and model use. Most study designs used were quantitative (27/59, 46%), followed by qualitative (21/59, 36%) and mixed methods (11/59, 19%).

Use of Theoretical Models

Only one-third (19/59) of the articles used 1 of the available theoretical models to explain older adults' intention to use digital technology. The remaining articles provided descriptive evidence to support, formulate, or extend a theoretical model. Table 2 provides an overview of the theories used, the research fields they derive from, and the articles that applied them to their research.

A classification of the 12 models based on academic discipline of their origin and the constructs applied by the corresponding research article is provided in Table 3. Table 4 presents a summary of the used constructs grouped into categories in articles that used and did not use a theoretical basis.

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Table 2. Use of theoretical models.

Model used	Research field	Total	Article(s)
Bandura's Self-Efficacy Theory	Psychology	1	[33]
Health Belief Model	Health	1	[31]
Hoyman's Wellness Model	Health	1	[39]
Healthcare Utilization Model	Health	1	[75]
Regulatory Mode Theory	Sociopsychology	1	[54]
Self-Determination Theory	Sociopsychology	1	[47]
Trans-Theoretical Model of Behavioral Change	Sociopsychology	1	[44]
Fogg Behavior Model	Sociopsychology	1	[70]
Technology Acceptance Model	Information systems	6	[48,50,53,56,68,84]
Technology Acceptance Model 2	Information systems	1	[49]
Technology Acceptance Model 3	Information systems	1	[77]
Unified Theory of Acceptance and Use of Technology	Information systems	3	[59,68,79]
Unified Theory of Acceptance and Use of Technology 2	Information systems	1	[80]
Articles using models	N/A[a]	19	N/A
No model used	N/A	40	N/A
Total articles	N/A	59	N/A

[a]N/A: not applicable.

Table 3. Classification of the used models.

Research field	Model	Constructs
Information systems	• Technology Acceptance Model • Technology Acceptance Model 2 • Technology Acceptance Model 3 • Unified Theory of Acceptance and Use of Technology • Unified Theory of Acceptance and Use of Technology 2	Computer anxiety; Computer playfulness; Computer self-efficacy; Confirmed usefulness; Ease of learning and use; Experimentation and exploration; Facilitating conditions; Habit; Hedonic motivation; Image; Job relevance; Objective usability; output quality; Perceived ease of use; Perceived enjoyment; Perceived usefulness; Perception of external control; Price value; Result demonstrability; Social influence; Subjective norm; User context
Health	• Hoyman's Wellness Model • Health Belief Model • Healthcare Utilization Model	Enabling factors (family support, access to health insurance); Mental and cognitive health; Perceived barriers; Perceived benefits; Perceived or actual needs; Perceived severity; Perceived susceptibility; Physical well-being; Predisposing factors (demographics); Social well-being; Spiritual well-being
Sociopsychology	• Fogg Behavior Model • Trans-Theoretical Model of Behavioral Change • Self-Determination Theory • Regulatory Mode Theory	Ability; Autonomy; Competence; Consciousness raising; Counter-conditions; Dramatic relief; Environmental reevaluation; Helping relationships; Locomotion and assessment; Motivation; Promoting value; Prompts; Reinforcement management; Relatedness; Self-liberation; Self-reevaluation; Social liberation; Stimulus control
Psychology	• Bandura's Self-Efficacy Theory	Emotional and physiological states; Performance outcomes (mastery experiences); Social persuasion; Social role models (vicarious experiences)

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Table 4. Summary of constructs grouped into categories[a].

Demographics and Health Status	Emotional Awareness and Needs	Knowledge, Competence, and Perception	Motivation	Social Influencers	Functionals features
• Age • BMI • Chronic disease • Cognitive impairment • Cognitive performance • Depression • Employer • Functional disability • Gender • Hearing ability • Linguistic problems • Marital status • Origin • Sensory perception • *Income* • *Existing disease* • *Medical history* • *Loneliness* • *Physical activity* • *Presence of dementia* • *Professional education* • *Quality of life* • *Religion* • *Cultural issues* • *Physical weakness*	• Anxiety • Application design • Self-determination • Self-efficacy • Self-esteem • *Confidence* • *Confidentiality* • *Emotional needs* • *Fear* • *Feelings* • *Intensity* • *Mood* • *Need for emotional support* • *Pain* • *Patience* • *Perceived loneliness* • *Resistance to change* • *Stigma consciousness*	• (Adequate) computer training • Education • (Previous) experience • Lack of knowledge • Perceived ease of use • Perceived privacy • Perceived risk expectancy • Perceived usefulness • *Beliefs* • *Digital literacy* • *Empowerment* • *Health literacy* • *(Medication) adherence* • *Memory* • *Misuse/overuse* • *Patients' choices* • *Perceived access barriers* • *Personal innovativeness* • *Previous experience* • *Privacy concerns* • *Satisfaction* • *Self-management* • *Trust in provider* • *Trust in system* • *Learning a new technology* • *Level of assessment/capability*	• Benefits • Habit • Perceived threat • *Attitude* • *Awareness* • *Curiosity* • *Equipment needs* • *Perception of need* • *Regularity* • *Rewards* • *Lack of need for technology* • *Willingness to learn* • *Reduced in-person health care* • *Engagement*	• Social influence • Subjective norm • *Interpersonal relationships* • *Learn with help* • *Social capital* • *Social isolation* • *Social participation* • *Social perceptions* • *Personal influence* • *Support* • *Social relationships* • *Physicians' recommendation*	• Cost • External influence • Facilitating conditions • Usability • User friendliness • Ease of use • Presence of useful features • *Accessibility* • *Assurances of technology* • *Compatibility* • *Feasibility* • *Impressions of technology* • *Inconvenience to wear* • *Information quality* • *Portal use* • *Self-perceived effectiveness of use* • *Service ability* • *Service quality* • *System quality* • *Utility of technology for health* • *Active versus passive communication* • *Ambiguous affordances* • *Poorly designed interface*

[a]Constructs not used in the models are given in italics.

The information systems field developed the TAM (n=6), TAM2 (n=1), TAM3 (n=1), UTAUT (n=3), and UTAUT 2 (n=1). These models focused on core constructs of perceived usefulness and perceived ease of use, attitude toward using, and intention to use the system (eg, TAM). The UTAUT also included the construct social influence and facilitating conditions. Both the TAM and the UTAUT were further developed, including TAM2 (n=1) and TAM3 (n=1), which highlighted trust and perceived risk on system use, and UTAUT 2 (n=1), which incorporated 3 other constructs including hedonistic motivation (eg, the pleasure of using a technology), price-performance ratio, and habits.

Three models had their origin in health-related research. Both the Health Belief Model [86,87] and Hoyman's Wellness Model [88] explored the multidimensional unit of health and wellness by emphasizing human health needs holistically within their environment by addressing 4 dimensions. Finally, Anderson's Healthcare Utilization Model [89] aimed to understand how and why people use health care services, assess inequalities in accessing health services, and aid in the creation of policies that will allow for equitable access to care. To predict or explain one's use of health care services, the model particularly focused on an individual's predisposition to use acute health care services, enabling factors that facilitate use and one's perceived or influenced need for care.

From the sociopsychological domain, the Trans-Theoretical Model of Behavioral Change [90] described an integrative theory of therapy that assesses an individual's readiness to act on a new healthier behavior, providing strategies or processes of change to guide the individual. The model is composed of constructs such as stages of change, processes of change, levels of change, self-efficacy, and decisional balance. The Regulatory Mode Theory [91] described how people approach situations to achieve their goals. Similarly, the Fogg Behavior Model [92] labeled main motivators (motivation), factors of simplicity (ability), and the types of prompts for goal acquisition constructs. The Self-Determination Theory [93] predicted health-related behaviors; however, the Health Belief Model focuses on the behavioral determinants influencing uptake of health-related behaviors, while the Self-Determination Theory

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explains behavioral motivation as dependent on whether basic psychological needs for competence, social inclusion, and autonomy can be satisfied.

From the research field psychology, the Self-Efficacy Theory [94] explained how well a person that can cope with the particular situation is dependent on the skills they have and the circumstances they face.

Technology Types and Purpose

Articles showed that older adults had varying acceptance levels to different forms of technology. Two different types of digital technologies were found that focused on (1) everyday technologies or (2) remote or assistive care technologies (Table 5). We further assigned these types by purpose using categories identified by Peek et al [11] that explored how the technology type supported the users' health and safety, social interaction, or independence.

Table 5. A summary of models identified through technology type and purpose.

Model used	Article(s)	Technology type		Technology purpose		
		Everyday technologies	Remote or assistive care technologies	Health and safety	Social interaction	Independence
Fogg Behavior Model	[70]	—[a]	1	✓	—	—
Health Belief Model	[31]	—	1	✓	—	✓
Hoyman's Wellness Model	[39]	—	1	✓	—	—
Healthcare Utilization Model	[75]	—	1	✓	✓	—
Regulatory Mode Theory	[54]	1	—	✓	✓	—
Self-Determination Theory	[47]	—	1	✓	—	✓
Bandura's Self-Efficacy Theory	[33]	—	1	—	✓	✓
Technology Acceptance Model	[48,50,53,56,68,84]	1	5	✓	✓	✓
Technology Acceptance Model 2	[49]	—	1	✓	✓	—
Technology Acceptance Model 3	[77]	1	—	—	—	✓
Trans-Theoretical Model of Behavioral Change	[44]	1	—	—	—	✓
Unified Theory of Acceptance and Use of Technology	[59,68,79]	—	3	✓	✓	✓
Unified Theory of Acceptance and Use of Technology 2	[80]	1	—	✓	✓	✓

[a]Data not available.

Models were more commonly applied to remote or assistive care technologies (15/19, 79%), with the TAM and UTAUT models identified in more than 1 article [68]. Other models were used less frequently. Similarly, only the TAM, UTAUT, and UTAUT 2 models were found in articles exploring all 3 technology purposes (eg, [59,68,79,80]).

Technology Types by Setting

The setting in which the research participants reside is expected to have a major influence on their intention to use digital technology. Thus, we analyzed which technology types were studied in what setting. Table 6 provides the corresponding overview.

The setting most studied was community dwelling (24/59, 41%), followed by primary care (13/59, 22%) and home care (12/59, 20%). Community dwelling refers to older people who live independently within the community. Primary care refers to health services that include a range of preventive, wellness, and treatment measures for common diseases. Primary care providers include doctors, nurses, nurse practitioners, and health care professionals. Home care refers to the nursing and domestic care of people in need of care outside of partial or full inpatient facilities in their home environment. Overall, technology types were relatively distributed between settings, although home care and primary settings tended to have more remote or assistive care technology types, while everyday technologies were more likely to be found in community dwelling and community centers.

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Table 6. Technology types studied in different settings by articles.

Setting	Technology type		Total (N=59)
	Everyday technology (n=27), n (%)	Remote or assistive care technology (n=32), n (%)	
Community center	2 (67)	1 (33)	3
Community dwelling	13 (57)	10 (43)	23
Home care	4 (33)	8 (67)	12
Long-term care	1 (50)	1 (50)	2
Primary care	5 (38)	8 (62)	13
Other/undefined	2 (33)	4 (67)	6

Factors Contributing to Older Adults' Intention to Use Digital Technology

Overview of Categories

Table 7 provides a list of the constructs used to explain and predict older adults' intention to adopt technology. To provide a meaningful analysis of the numerous constructs we grouped them into 6 categories: Demographics and Health Status, Emotional Awareness and Needs, Knowledge and Perception, Motivation, Social Influencers, and Technology Functional Features (for further information on these constructs, see Table 4 and Multimedia Appendix 1). Table 7 shows the number of articles that applied a specific category to a certain technology type.

Table 7. Articles reporting an intention to use technology by category and technology type.

Category	Articles that applied this category (N=59), n (%)	Technology type	
		Everyday technologies, n (%)	Remote or assistive care technologies, n (%)
Demographics and Health Status	37 (63)	15 (41)	22 (59)
Emotional Awareness and Needs	21 (36)	11 (52)	10 (48)
Knowledge, Competence, and Perception	40 (68)	15 (38)	25 (62)
Motivation	24 (41)	12 (50)	12 (50)
Social Influencers	22 (37)	11 (50)	11 (50)
Functional Features	36 (61)	16 (44)	20 (56)

The most commonly identified category was *Knowledge, Competence, and Perception* (40/59, 68%), which explored how education, privacy concerns, trust in the provider, and health literacy influenced behavioral intention. This was followed by *Demographics and Health Status* (37/59, 63%), which explored the concepts of age, gender, origin, as well as health status and medical history. *Functional Features* was also frequently described (36/59, 61%) and considered how technical capabilities and concepts such as better information quality, interoperability, and service and system quality affected behavioral intention.

Overall, technology types were relatively distributed between the categories. Remote or assistive care technologies were observed more frequently in the categories of Knowledge, Competence, and Perception (25/40, 63%) and Demographics and Health Status (22/37, 59%). More detailed descriptions of the categories and their direction of influence are described in the following sections.

Demographics and Health Status

Health limitations such as physical inability, presence of dementia, functional disabilities, and other diseases had a negative impact on the intention to use digital technology. By contrast, marital status, healthy BMI, and higher income were linked with higher behavioral intention. These individual factors as well as age were also considered moderators in other studies.

Emotional Awareness and Needs

This category explored the concepts of anxiety, fear, self-determination, self-efficacy, and pain, and was reported across the majority of technology types. Older adults' self-determination, stigma-consciousness, and self-efficacy were linked to increased behavioral intention. By contrast, resistance to change, fear, and anxiety were found to negatively impact on the intention to use digital technology.

Knowledge, Competence, and Perception

Older adults that had high perceived risk during technology use, privacy concerns, or lack of trust in the provider and the system, poor prior experience, low knowledge, and low health literacy had lower behavioral intentions. By contrast, if older adults could make their own choices, had prior computer training, had positive expectancy, and had prior strong satisfaction, they would be more likely to use the technology.

Motivation

This category reflected users' motives and intention. Concepts included perceived need for the technology, available rewards, attitudes, goals, and habits. Individuals were more likely to use

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technology when they set health goals and perceived a need to use a technology to support their goal.

Social Influencers

This category considered social determinants of general social pressure on a person to engage in a particular behavior and included factors such as isolation, participation, social capital, and network support. The presence of positive social support supported behavioral intention in 11 articles in each technology type.

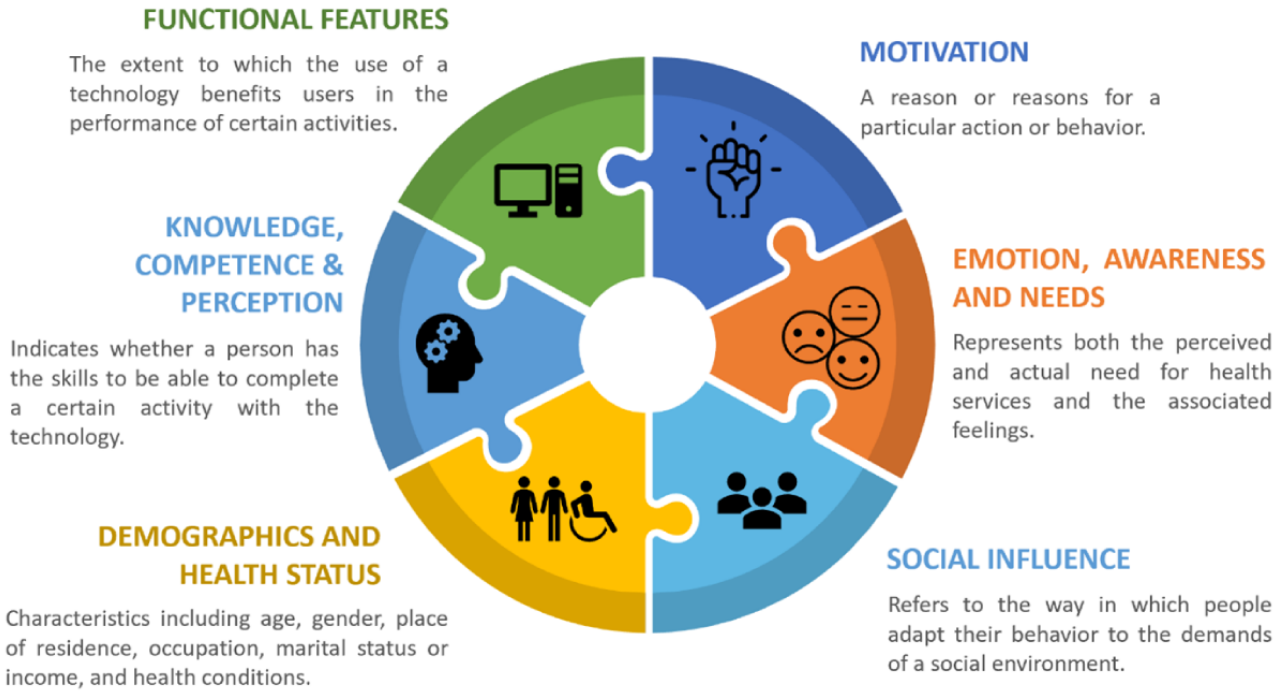
Functional Features

This category described the technical characteristics of a technology that fulfill a specific function. This included factors such as accessibility, usability, cost, system and service quality, and design. Users who could operate a technology better found the design more appealing, and were technically more capable and more likely to adopt the technology.

Conceptual Framework

Based on the information derived from our review, there were 6 clusters of influencing factors from sociopsychological, psychological, and health information fields, which describe older adults' intention to use digital technology. We have combined these to present a unified perspective, which provides a more comprehensive and collective view of the factors influencing older adults' behavioral intention across multiple disciplines (Figure 2). This framework emphasizes the interconnected role of the 6 constructs that influence older adults' intention to use technology across multiple technology types.

Figure 2. A collective framework of influencing factors.



Quality Appraisal

Overall, the quality of the studies was strong for qualitative and quantitative research designs, and moderate for mixed method designs (Multimedia Appendix 1). Most qualitative studies (17/21) had a clear research question, with 95% (20/21) of articles describing results appropriately. The qualitative articles that were screened using the Critical Appraisal Skills Program method largely met the requirements. One criterion for consideration of ethical issues was met by one-third of the articles examined [35,37,50].

The quantitative articles, which were examined with the MMAT and the Cochrane Risk of Bias screening criteria, were able to fulfil the criteria across the board. Most quantitative articles had a low bias. The MMAT criteria were largely met.

For mixed methods articles, the quality of 1 [46] out of 11 articles could not be fully assessed because we considered the research question of this article to be unclear. The remaining mixed method articles satisfied the majority of the criteria (10/11, 91%). One article [79] did not show exact outcomes; thus, the criteria could not be fulfilled unambiguously.

Discussion

Principal Findings

In our mapping review, we found that older 'adults' intention to use technology was driven by 6 different categories: Demographics and Health Status; Emotional Awareness and Needs; Knowledge, Competence, and Perception; Motivation; Social Influencers; and Actual Technology Features. These categories could be mapped to 2 different main technology types (everyday technologies and remote or assistive care technologies) and 3 purposes (health and safety, social interaction, and independence).

Our mapping review provides an overview of the application of existing theoretical models of technology acceptance while

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identifying additional key factors contributing to the intention to use digital technology among older adults. Most articles did not describe an existing technology adoption model. In the last 4 decades we found insufficient attention on research of technology adoption models specifically in the health sector, and more recent empirical research presenting major gaps in the actual application of theoretical models. Most articles lacked an explicit theoretical approach, which makes it difficult to interpret and compare the results of studies in this area.

New models incorporating constructs such as belief, resilience, and health status to facilitate the intention to use digital technology for older adults were found, alongside previous reports of individual influencing factors (eg, age, gender). Synonymous with previous reviews on the topic of technology acceptance and intention to use, our review suggests that despite 2 models being popularly used (TAM and UTAUT), older adults' acceptance of technology was influenced by factors beyond the key constructs of these models.

Existing reviews have investigated older adults' acceptance and intention to use technology across multiple phases of technology implementation [95-98]. Similar to the extrapolations of our mapping review, other reviews have found diversity in the variables influencing intention to use digital technology among older adults, with individual variables also being considered. This includes age (eg, older age); health status factors such as mobility issues (eg, fractured wrists and fingers) and vision discomfort; technology features; and support factors such as ongoing costs and accessibility of instructions and guidance [97]. A recent meta-analysis also highlighted that social influences (ie, conversations with family, friends, and professional caregivers) had a strong impact on the intention to use digital technology, especially when it is new and in the beginning of the adoption stages [96]. Factors including personality, beliefs, and resilience were found in our review, suggesting a dynamic influence of psychosocial traits on technology. These preferences and concerns adjust over the course of time and technology implementation [98,99].

There have been multiple studies exploring how existing technology models contribute to older adults' intention to adopt technology. However, research on technology adoption and older people should go beyond describing facilitators and barriers [100]. Instead, a better understanding of the environment of older people and their interaction with this environment should be developed [100]. We believe that uncovering the role of communication and interaction between older people and their environment should be a key health research concern, as a means of contributing to improved care for older people in the community.

Taken together, the findings from this mapping review have important repercussions on the validity and applicability of popular theoretical models of technology adoption and intention to use digital technology. Our findings correspond with those of previous research expressing concern about the impact of unexplored factors along with their potential interaction with key components of commonly used technology adoption models and their subsequent reduced predictive ability [95]. We have used the findings of previous research along with the additional constructs found in our mapping review to suggest contributions to the discourse around technology adoption and intention to use digital technology specifically in relation to older adults.

Implications for Research

Traditional models of technology adoption have been largely developed from information systems and health behavior models (eg, Table 3, Figure 2). However, factors from different disciplines have not been successfully combined so far. It has been shown that health-related and social-psychological factors also represent a major element in the adoption of technology, especially for older people. Our mapping review highlights that traditional information system models such as the TAM and UTAUT require the implementation of health and psychology constructs. Here, we identified a significant gap in the research. Furthermore, it is essential to note that existing models do not particularly focus on the age of technology users. The importance and awareness of the role of age in information systems were already highlighted by Tams et al [101]. They pointed out that future research needs to focus more extensively on cognitive age rather than on physical age, as older people show difficulties especially in dealing with complex and contemporary technologies. Perceived physical old age as opposed to cognitive old age, as well as perceived health status, constitutes further factors of investigation.

The advantage of this approach is that it emphasizes the relevant beliefs and antecedents for general intention to use digital technology and, consequently, provides more directive insights for the design of intention to use digital technology. Based on results, we underline the nature of personality (eg, attitude, self-efficacy expectation, resistance to change, resilience), emotions and social influences as well as the cognitive age, which are linked to health-promoting or health-damaging behavior and can have an activating effect on the intention to use digital technology [102,103]. Alternative factors including demographic and health data should be incorporated to ensure models can be applied appropriately (ie, at multiple stages of implementation), are flexible (ie, to account for different types of technology and changing older adult preferences), as well as being both individual- and context-dependent to assist with sustained intention to use digital technology (eg, inclusive of health status and disabilities). However, application of our framework should be considered in the context of the research objective and adapted accordingly. For example, while these constructs provide a basis for understanding early users' intention to use digital technology by specifically focusing on the attitudinal, social, and normative belief structure, functional features of the technology type need to be considered for the design, implementation, and intention to use digital technologies (eg, ease of interoperability, size of screen), as well as the research question.

Limitations and Further Research

Our review had a comprehensive search strategy covering social sciences, health care, and technology fields. However, it found a relatively small number of studies covering broad technology types and included limited theory-based studies as well as studies in conference proceedings. However, as ours is a mapping review, we focused mainly on identifying

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evidence-based gaps and trends across technology adoption in older adults more generally and the work was intended to be broad in scope. This may result in studies being overlooked (eg, from other databases and conference proceedings that are not peer-reviewed). Future studies should expand the scope to identify other factors and outcome variables, with more specific terms to capture wider forms of technology (eg, "digital assistants" or "bots"), as well as more inclusive eligibility criteria.

An additional limitation is that we discuss the stated theoretical models as equivalents without elaborating on their respective quality criteria. Previous research has already examined these models in the context of their research and shown variances, but there are considerably more opportunities to examine different age groups especially and to constantly include newly developed technologies. Future research could focus further on individual models in connection with specific categories of new and innovative technologies. Here, the focus should be on the health sector in particular. Existing studies were dominated by references to the TAM and UTAUT. Studies that pay more attention to interaction dimensions, emotional dimensions, and other resilience factors were lacking. Future research should bring these paradigms closer. While data on factors influencing use in the preadoption phase are extensive, findings on the postadoption phase were limited. To support the independence of community-dwelling older people over long periods, more research is needed to understand what influences the continued or sustained intention to use digital technologies after their introduction. Furthermore, additional quantitative research is required to understand which factors may have a greater impact than others and to examine the moderating or mediating relationships between factors.

Conclusion

Technology acceptance is influenced by numerous factors. Existing models of technology acceptance should be more intensively integrated and revised. However, there is limited research on technology acceptance among older adults. Further research targeting understanding of the complexity and timing of the acceptance process of different types of technology by older adults is warranted.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Additional details on data extraction and quality appraisal.
[DOCX File , 320 KB - aging_v6i1e44564_app1.docx]

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Abbreviations

mHealth: mobile health
MM: mixed method
MMAT: Mixed Methods Appraisal Tool
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
TAM: Technology Acceptance Model
TAM2: Technology Acceptance Model 2
TAM3: Technology Acceptance Model 3
UTAUT: Unified Theory of Acceptance and Use of Technology
UTAUT 2: Unified Theory of Acceptance and Use of Technology Model 2

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Original Paper

A Digital Tool for the Self-Assessment of Homes to Increase Age-Friendliness: Validity Study

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Abstract

Background: Age-friendly environments in homes and communities play an important role in optimizing the health and well-being of society. Older people have strong preferences for remaining at home as they age. Home environment assessment tools that enable older people to assess their homes and prepare for aging in place may be beneficial.

Objective: This study aims to establish the validity of a digital self-assessment tool by assessing it against the current gold standard, an occupational therapy home assessment.

Methods: A cohort of adults aged ≥60 years living in metropolitan Adelaide, South Australia, Australia, assessed their homes using a digital self-assessment tool with 89 questions simultaneously with an occupational therapist. Adults who were living within their homes and did not have significant levels of disabilities were recruited. Cohen κ and Gwet AC_1 were used to assess validity.

Results: A total of 61 participants (age: mean 71.2, SD 7.03 years) self-assessed their own homes using the digital self-assessment tool. The overall levels of agreement were high, supporting the validity of the tool in identifying potential hazards. Lower levels of agreement were found in the following domains: steps (77% agreement, Gwet AC_1=0.56), toilets (56% agreement, κ=0.10), bathrooms (64% agreement, κ=0.46), and backyards (55% agreement, κ=0.24).

Conclusions: Older people were able to self-assess their homes using a digital self-assessment tool. Digital health tools enable older people to start thinking about their future housing needs. Innovative tools that can identify problems and generate solutions may improve the age-friendliness of the home environment.

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KEYWORDS

age-friendliness; aging; home environment; self-assessment; digital; tool

Introduction

Background

Worldwide, people are living longer because of increased life expectancy and declining fertility rates [1]. Recent data show that the number of older people aged >60 years will increase from 1 billion in 2020 to 1.4 billion in 2030 [2]. By 2050, the number of older people aged ≥60 years will double, reaching 2.1 billion [2]. Aging leads to changes in intrinsic capacity (eg, physical and cognitive abilities) and functional ability. In turn, the environment in which the person lives may require adaptation. Over time, the home environment must be able to support a decline in both intrinsic capacity and functional ability [3].

The establishment of age-friendly environments in homes and communities will play an important role in optimizing the health and well-being of society [4]. Most people want to remain in their own homes as they age [5,6]. A survey of >10,000 Australians found that 80% of older people wanted to remain in their current homes [7]. Approximately 20% of older people

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preferred to live in long-term facilities [7]. In Canada, a population-wide survey of people aged 65 years found that >70% had not moved in the past 5 years [8,9]. In Hong Kong, research has found a strong preference among older people to stay at their homes, with family members, or in places that are familiar with their living environment [10]. Aging in place refers to the ability to remain at home for as long as possible, despite a decline in functional ability [11]. Supporting adults to age in place requires consideration of the house as not only a building but also a home [11]. Older people feel strongly connected with their homes and communities, as they provide security, comfort, and a place for self-reflection [5]. Homes are also considered a place to cherish memories and maintain a sense of belonging, which prevents loneliness [12,13]. The ability to age in place depends on the appropriateness of the home, the potential to make alterations to the home, cost and availability of suitable housing alternatives, and formal supports [14].

Occupational therapists often conduct home environment assessments and recommend modifications to improve safety and function in older people and reduce the risk of falls [15]. Examples of home modifications are the installation of grab rails in the shower, decluttering of overcrowded bedrooms, and installation of threshold ramps to eliminate trip hazards within the home [16]. Despite the proven benefits of home environment assessments, access is limited, particularly in rural areas, and assessments are usually available only after injury or illness [17-19]. Home environment assessments can take considerable time, averaging 80 minutes per home assessment [20]. Older adults have identified the potential benefits of adaptations and modifications earlier in the course of aging [21] and are receptive to more education about actions that can be taken to support aging in place [22].

To date, most home environment assessment tools have been developed for administration by occupational therapists [23]. Furthermore, most tools have been developed for use with older people with impaired functional ability, rather than those who are considering future needs to support aging in place [23]. A recent review of home accessibility assessment tools identified 7 home accessibility assessment tools that were considered promising; however, none of the tools had strong evidence supporting reliability and validity [24]. In recent years, home self-assessment tools have emerged. Ziebart et al [25] described the development of a self-assessment checklist that could be used by older adults to assess fall risks in the house [25]. The Home Safety Self-Assessment is another tool that includes a self-assessment checklist and has been shown to have good reliability and validity [26]. Further research aimed at developing and validating tools that can be used by older people to assess their homes to prepare for aging in place is required.

This Study

This project is part of a research program that seeks to develop a digital health tool to enable middle-aged and older people to self-assess their own homes to understand how to improve the accessibility and age-friendliness of the home environment. The tool was co-designed with older people and developed into a prototype. This study aimed to determine the validity of a home environment self-assessment tool and investigate the levels of agreement between completion by an occupational therapist and completion by an older adult. The research questions were as follows: (1) is it feasible for older people to self-assess their own home environment using a digital health tool? and (2) what are the levels of agreement between an occupational therapist and older person when using a home environment assessment tool?

Methods

Study Design

This study involved recruiting a cohort of older adults who completed the home environment self-assessment tool at the same time as an occupational therapist. The study design was used to establish the agreement (validity) of the self-assessment tool by assessing it against the current gold standard, an occupational therapy home assessment. This study was conducted across metropolitan Adelaide, South Australia, Australia.

Ethics Approval

This study was approved by the Flinders University Human Research Ethics Committee (project number 5303).

Participants

Participants were recruited if they met the following criteria: (1) being aged ≥60 years, (2) living within their own home either in a private dwelling or in a retirement village, (3) not having a significant level of disability (measured using the Modified Rankin Score, where people must score 2, which indicates that the participant is “able to carry out all usual duties and activities” or “unable to carry out all previous activities but able to look after own affairs without assistance”) [27]. Participants were included if they were aged ≥60 years. Although the ages of 60 to 65 years are not classified as older age, it is at these ages that many people plan retirement and consider longer-term living options [28].

Recruitment

The participants were recruited from June to November 2022 through local council newsletters, the research department’s registry of interested participants, and existing research networks. Individuals who expressed interest were contacted by the lead researcher (RD) via phone or email. They were provided with a copy of the participation information sheet and a written consent form. The included participants were offered an honorarium in recognition of their time (Aus $20; US $13) and a copy of their self-assessment results and the occupational therapy home assessment results at the end of the study.

Instrument

The self-assessment tool was specifically developed for this research program based on a review of existing tools and co-design workshops with older people [29]. In this study, the tool was made available via a website and displayed on a tablet computer (iPad; Apple, Inc). The self-assessment tool was developed using a co-design process led by an occupational therapist (KL) and built by a website designer. The tool contains 89 questions within the following domains: general safety,

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cleaning and maintenance, front entry and garden, hallways, kitchen, toilets, bedrooms, living rooms, bathrooms, laundry, backyard, internal steps, and neighborhood. Each question comprised the following possible responses: yes (satisfactory), no (needs improvement), and not applicable (not present). Participants also answered demographic questions related to their socioeconomic status; marital status; level of education; living status; housing type; ownership of housing; community services received; and whether they considered relocating in the future, which was recorded as a categorical variable, that is, as yes, no, or not applicable. In this study, a maximum of 2 of each area were assessed and data presented for ease of reporting (eg, 2 bathrooms and 2 bedrooms).

Data Collection

Potentially eligible participants were screened against the eligibility criteria by the lead researcher and occupational therapist, as mentioned earlier. Upon obtaining consent via phone or email, a time and date were scheduled for each participant to complete the self-assessment and receive the standardized occupational therapy home assessment. Before each visit, an offsite previsit risk assessment was completed to ensure that there were no specific safety risks to the therapist and research assistant (eg, COVID-19 infection).

Self-Assessment Procedure

At each visit, the occupational therapist demonstrated the use of the self-assessment tool using a study iPad with an inbuilt Wi-Fi card for internet access. The occupational therapist used an adapted version of the self-assessment program using a second iPad (which reflects that the therapist is the administrator, rather than the participant). A copy of the self-assessment tool is available on the internet [30]. The participant and occupational therapist simultaneously completed the self-assessment using the study iPads. The participant and the occupational therapist walked through the home together, did not discuss the content of the assessment, and scored each question independently. If 2 people were living in the same house, the occupational therapist and research assistant ensured that the 2 people were not sharing answers to limit bias.

Data Analysis

Data were entered into Microsoft Excel (Microsoft Corp) and exported to SPSS (IBM Corp) and Stata (StataCorp) software [31,32]. Descriptive statistics were used to report categorical and continuous variables, including the participants' demographic characteristics, responses to questions regarding the type of housing they lived in, the ownership of their home, formal services received, their postcode, whether they considered relocating in the future, and level of confidence using digital technology. Socioeconomic status was categorized according to the Australian Bureau of Statistics Index of Relative Socioeconomic Advantage and Disadvantage [33]. Each socioeconomic area was given a score (eg, Statistical Area Level 1). The scores ranged from a low index score (more disadvantaged, Statistical Area Level 1) to a high index score (most advantaged, Statistical Area Level 5) [33].

The rooms of each home were assessed using a series of questions related to home safety, which could be given a "yes/no" response. A total of 7 possible responses were developed: yes-yes, no-no, no-yes, yes-no, not applicable-not applicable, yes-not applicable, and no-not applicable. The κ statistic measure of agreement was used to examine the interrater reliability and level of agreement between the participant and occupational therapist using the same self-assessment tool. The level of agreement was determined through individual items. κ scores were presented to provide the agreement between the raters. κ scores ranged from 0, which represented no agreement beyond what can be expected by chance, to 1, which represented perfect agreement between the raters [34]. For this analysis, Cohen κ guidelines of interpretation were applied as suggested by McHugh [34]; values 0 to 0.20 indicated no agreement, 0.21 to 0.39 indicated minimal agreement, 0.40 to 0.59 indicated weak agreement, 0.60 to 0.79 indicated moderate agreement, 0.80 to 0.90 indicated strong agreement, and >0.90 indicated almost perfect agreement. This analysis interpreted any $\kappa < 0.60$, suggesting inadequate agreement between the 2 raters [34].

Variations of κ were used to assess validity. Where the results showed a high agreement but the κ value was low, Gwet AC_1 was applied. Dettori and Norvell [35] suggested that there are limitations to κ; high agreement can result in low κ [35,36], and κ values depend on sample sizes, the number of categories, and distribution of responses. Gwet AC_1 was used to overcome these problems [35]. Wongpakaran et al [37] recommended that Gwet AC_1 be considered for interrater reliability analyses alongside Cohen κ.

Results

Participants

A total of 61 participants completed the self-assessment tool. Table 1 presents the demographic characteristics of these 61 participants. The mean age of the participants was 71.2 (SD 7.03) years. The sample consisted of slightly more female participants (34/61, 56%) than male participants (27/61, 44%). Among the 61 participants, 39% (n=24) lived with a spouse or family member and conducted the self-assessment independently but within the same home at the same time. A total of 59 (97%) participants were assessed as having no disability, 1 (2%) participant had no significant disability despite symptoms, and 1 (2%) participant had a slight disability but was able to look after their own affairs without assistance [27]. All self-assessments were conducted in metropolitan Adelaide. Houses that were considered as "other" were homes built within retirement villages or were defined as apartments by the participant. Almost all the participants (60/61, 98%) did not use a mobility aid at home.

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Table 1. Demographic characteristics of the participants (N=61).

Demographics	Values
Age, mean (SD; range)	71.2 (7.03; 60-88)
Sex, n (%)	
Male	27 (44)
Female	34 (56)
Level of education, n (%)	
High school	9 (15)
Higher education	44 (72)
Other	6 (10)
Marital status, n (%)	
Married	40 (66)
Not married	21 (34)
Living status, n (%)	
Alone	15 (25)
Living with spouse	38 (62)
Living with family member	6 (10)
Other	1 (2)
Type of housing, n (%)	
House	50 (82)
Town house	1 (2)
Unit	4 (7)
Other	6 (10)
Ownership, n (%)	
Private owner	57 (93)
Private rental	1 (2)
Other	3 (5)
Services, n (%)	
Cleaning and gardening	2 (3)
Cleaning	3 (5)
Gardening	2 (3)
None	51 (84)
Socioeconomic status, n (%)	
SA[a]1 (most disadvantaged)	5 (8)
SA2	6 (10)
SA3	16 (26)
SA4	21 (34)
SA5 (least disadvantaged)	13 (21)
Considering relocation, n (%)	
Yes	2 (3)
No	49 (80)
Considering	10 (16)
Mobility aid use at home, n (%)	
Yes	1 (2)

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Demographics	Values
No	60 (98)

[a]SA: Statistical Area.

The average time taken to complete the self-assessment tool was 23 (SD 8.12) minutes. Table 2 shows the responses on the use and confidence in the use of the self-assessment tool. A total of 16 (26%) out of the 61 participants had minor technical difficulties with the use of the self-assessment tool on the iPad. These technical difficulties were due to accidentally exiting the self-assessment application and not knowing how to return to the original screen or being unable to scroll up or down the iPad. Despite technical difficulties, more than half (44/61, 72%) of the participants found the self-assessment tool easy to use.

Table 2. Responses to the questions on the self-assessment tool.

Responses to questions	Values
Time taken to complete the self-assessment tool (min), mean (SD; range)	23 (8.12; 11-60)
Was the self-assessment tool easy to use? (1: hard; 10: easy)	
10	44 (72)
9	14 (23)
8	1 (2)
7.5	1 (2)
7	1 (2)
Were there any technical difficulties?	
Yes	16 (26)
No	45 (74)

Levels of Agreement

Overview

Most participants (52/61, 85%) lived in homes with ≥2 bedrooms, 2 bathrooms, and 1 living room. In homes with >2 bedrooms, one of the bedrooms was used as a study room, for guests, for storage, or for grandchildren. Only 18% (11/61) of the homes had internal steps. Among the 61 participants, 11 (18%) had a 3-bedroom house, 7 (11%) had a 4-bedroom house, and only 2 (3%) had a 5-bedroom house. Most participants (60/61, 98%) had a backyard or shared outdoor space within a retirement village or an apartment.

An overview of the levels of agreement between each participant and occupational therapist is outlined in Tables 3 and 4. Overall, all the “general” and “neighborhood”-related questions demonstrated an almost perfect agreement, as all these questions became a point of discussion related to the opinion of the participant.

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Table 3. Agreement levels for cleaning, front access, hallways, and kitchen between the occupational therapist and participant.

Domain and questions asked between raters	Agreement (%)	Cohen κ	Gwet AC_1	95% CI
Cleaning				
1. Are clotheslines easy to access (height and location)?	85	0.34[a]	0.81	0.76-0.94
2. Is there an irrigation system in place with ease of watering?	93	0.89	0.91	0.87-1.00
3. Are there strategies to change lightbulbs, access high cupboards and clean gutters which don't require use of a ladder?	89	0.69[a]	0.86	0.80-0.97
4. Are long lasting lightbulbs (LED) installed to reduce the need for frequent changing?	97	0.66[a]	0.97	0.92-1.00
5. Is the home largely clutter free?	90	0.75	0.84	0.82-0.98
6. Is there a supportive step stool available to access items which are just out of reach	95	0.70	0.95	0.90-1.00
Front access				
1. Are paths relatively flat and approximately 1000mm wide?	72	0.19[a]	0.60	0.61-0.84
2. Do paths and driveways have a non-slip texture and are they free of moss?	79	0.24[a]	0.71	0.68-0.89
3. Is the gate easy to open?	85	0.68[a]	0.81	0.76-0.94
4. Are steps a suitable height (115-190mm) and depth (240mm-355mm) and stable?	79	0.51	0.73	0.68-0.89
5. Is it easy to unlock the front door and use the door handle?	89	0.33[a]	0.86	0.80-0.97
6. Is a lockable screen door in place to enable access to fresh air and maintain security?	87	0.57[a]	0.85	0.78-0.96
7. Is there space within the garage or carport to easily open the car door and get out?	93	0.57[a]	0.93	0.87-1.00
8. Is the letterbox easy to access and open?	75	0.00[a]	0.69	0.64-0.87
9. Is there at least one way to access the home without a step?	77	0.56	0.54	0.66-0.88
Hallways				
1. Are hallways free of clutter and unnecessary furniture?	87	0.50[a]	0.82	0.78-0.96
2. Are floor coverings secure and in good condition?	79	0.36[a]	0.74	0.68-0.89
3. Is the house free of internal steps?	97	0.91	0.95	0.92-1.00
Kitchen				
1. Is there room within the kitchen to easily manoeuvre?	100	1.00	1.00	1.00-1.00
2. Are benches clear?	82	0.38[a]	0.75	0.72-0.92
3. Are rugs and floor coverings secure and in good condition?	79	0.46	0.74	0.68-0.89
4. Are you able to easily reach or commonly used items without tiptoes, a stepladder, or bending too low?	92	0.40[a]	0.91	0.85-0.99
5. Are taps easy to turn on, off and adjust?	98	0.00[a]	0.98	0.95-1.00
6. Can appliance controls easily be accessed?	100	1.00	1.00	1.00-1.00
7. Is there space next to the microwave, oven, and stove top to place hot food?	80	0.46[a]	0.70	0.70-0.91
8. Is there a carbon monoxide detector installed to detect carbon monoxide and prevent poisoning?	93	0.48[a]	0.93	0.87-1.00
9. Is there a space in the kitchen areas where you could sit if needed to prepare food?	89	0.18[a]	0.87	0.80-0.97
10. Are stools a comfortable height and stable?	84	0.70	0.78	0.74-0.93
11. Are the oven and microwave located at a suitable height? With Access between knee and shoulder?	77	0.23[a]	0.68	0.66-0.88
12. Are bench tops a suitable height (850mm to 1050mm)?	100	1.00	1.00	1.00-1.00

[a]Where the results showed a high agreement but the κ value was low, Gwet AC_1 was applied.

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Table 4. Agreement levels for internal steps, bathroom, toilet, bedroom, lounge area, laundry, and backyard between the occupational therapist and participant.

Domain and questions asked between raters	Agreement (%)	Cohen κ	Gwet AC_1	95% CI
Internal step				
1. Do internal stairs have a sturdy rail in place?	91	0.62	0.88	0.71-1.00
2. Are doorways a minimum of 850mm wide?	100	1.00	1.00	1.00-1.00
3. Are door handles lever style?	82	0.68	0.75	0.55-1.00
4. Can doors and windows be easily opened to allow for fresh air?	73	−0.06[a]	0.68	0.41-1.00
Bathroom 1				
1. Is there room within the bedroom to easily manoeuvre?	78	0.29[a]	0.67	0.66-0.88
2. Are rugs or mats secure and in good condition?	64	0.46	0.48	0.52-0.76
3. Is there adequate ventilation with presence of a fan or easily opened window?	100	1.00	1.00	1.00-1.00
4. Is the transition between the floor and shower flat?	61	0.27	0.22	0.48-0.73
5. Is a shower hose in place?	82	0.84	0.89	0.85-0.99
6. Are taps easy to turn on, off and adjust?	66	0.08[a]	0.49	0.53-0.78
7. Is water thermostatically controlled to a delivery temperature of 45 degrees?	84	0.70	0.77	0.74-0.93
8. Is the floor surface non-slip?	67	0.33	0.38	0.55-0.79
9. Is the shower cubicle a minimum of 900×900mm?	92	0.70	0.90	0.85-0.99
Bathroom 2				
1. Is there room within the bathroom to easily manoeuvre?	56	0.14	0.25	0.42-0.71
2. Are rugs or mats secure and in good condition?	46	0.29	0.19	0.31-0.61
3. Is there adequate ventilation with presence of a fan or easily opened window?	94	−0.04[a]	0.93	0.86-1.00
4. Is the transition between the floor and shower flat?	54	0.20	0.11	0.39-0.69
5. Is a shower hose in place?	92	0.84	0.89	0.83-1.00
6. Are taps easy to turn on, off and adjust?	63	0.14[a]	0.40	0.48-0.77
7. Is water thermostatically controlled to a delivery temperature of 45 degrees?	90	0.80	0.86	0.80-1.00
8. Is the floor surface non-slip?	71	0.33	0.49	0.57-0.84
9. Is the shower cubicle a minimum of 900×900mm?	79	0.41	0.75	0.67-0.92
Toilet 1				
1. Is the toilet a suitable height (460mm-480mm)?	55	0.10	0.27	0.40-0.71
2. Are rugs or mats secure and in good condition and necessary?	70	0.53	0.58	0.59-0.82
3. Does the door swing outwards?	90	0.79	0.87	0.82-0.98
Toilet 2				
1. Is the toilet a suitable height (460mm-480mm)?	55	0.01[a]	0.27	0.40-0.71
2. Are rugs or mats secure and in good condition and necessary?	62	0.42	0.45	0.46-0.80
3. Does the door swing outwards?	89	0.79	0.86	0.78-1.00
Bedroom 1				

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Domain and questions asked between raters	Agreement (%)	Cohen κ	Gwet AC_1	95% CI
1. Is the bed a comfortable height to access and rise from?	93	0.31[a]	0.93	0.87-1.00
2. Is there space to easily manoeuvre within the bathroom?	75	0.16[a]	0.67	0.64-0.87
3. Is there access to light and phone next to the bed?	97	0.65[a]	0.96	0.92-1.00
4. Are floor covering secure and in good condition?	84	0.38[a]	0.81	0.74-0.93
5. Is there somewhere to sit while dressing and putting on shoes?	92	0.51[a]	0.91	0.85-0.99
6. Is it easy to access clothing and shoes without excessive reaching or bending?	93	−0.03[a]	0.93	0.87-1.00
7. Is it easy to open and close windows and blinds?	85	0.12[a]	0.82	0.76-0.94
8. Can the temperature in the bedroom be easily adjusted?	92	0.72	0.90	0.85-0.99
Bedroom 2				
1. Is the bed a comfortable height to access and rise from?	85	0.39[a]	0.83	0.74-0.95
2. Is there space to easily manoeuvre within the bedroom?	81	0.47[a]	0.77	0.70-0.92
3. Is there access to light and phone next to the bed?	90	0.41[a]	0.90	0.82-0.99
4. Are floor covering secure and in good condition?	90	0.58[a]	0.89	0.82-0.99
5. Is there somewhere to sit while dressing and putting on shoes?	94	0.65[a]	0.93	0.88-1.00
6. Is it easy to access clothing and shoes without excessive reaching or bending?	96	0.73[a]	0.96	0.91-1.00
7. Is it easy to open and close windows and blinds?	75	0.22[a]	0.64	0.63-0.87
8. Can the temperature in the bedroom be easily adjusted?	90	0.62	0.89	0.82-0.99
Living area 1				
1. Is there space to easily manoeuvre within the living area?	87	0.29[a]	0.84	0.78-0.96
2. Are floor covering secure and in good condition?	80	0.09[a]	0.78	0.70-0.90
3. Is there good storage so that all items have a spot?	95	0.38[a]	0.95	0.90-1.00
4. Is the room free of cords in walkways which may cause trips?	97	0.00[a]	0.97	0.92-1.00
5. Is it easy to access heating and cooling controls?	93	0.53[a]	0.93	0.87-1.00
6. Is it easy to open and close windows and blinds?	90	−0.03[a]	0.89	0.82-0.98
7. Are chairs in the room easy to get in and out of?	44	0.02	0.04	0.31-0.57
Living area 2				
1. Is there space to easily manoeuvre within the living area?	87	0.65	0.78	0.73-1.00
2. Are floor covering secure and in good condition?	73	0.13[a]	0.69	0.57-0.90
3. Is there good storage so that all items have a spot?	87	0.52[a]	0.84	0.74-1.00
4. Is the room free of cords in walkways which may cause trips?	90	0.37[a]	0.88	0.79-1.00
5. Is it easy to access heating and cooling controls?	100	1.00	1.00	1.00-1.00

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Domain and questions asked between raters	Agreement (%)	Cohen κ	Gwet AC_1	95% CI
6. Is it easy to open and close windows and blinds?	77	0.15[a]	0.73	0.61-0.93
7. Are chairs in the room easy to get in and out of?	53	0.07[a]	0.42	0.34-0.73
Laundry				
1. Is there adequate bench space in the laundry?	84	0.65	0.79	0.74-0.93
2. Can all appliances be easily accessed and plugged in when needed?	85	0.40[a]	0.83	0.76-0.94
3. Is there room in the house to hang small items of laundry to dry when needed?	97	0.78	0.96	0.92-1.00
4. Is the washing machine front-loading?	100	1.00	1.00	1.00-1.00
Back garden				
1. Are paths relatively flat and approximately 1000mm wide?	78	0.24[a]	0.75	0.68-0.89
2. Are doorways a minimum of 850mm wide?	100	1.00	1.00	1.00-1.00
3. Is it possible to access the clothesline without excessive reaching?	63	0.29[a]	0.52	0.51-0.76
4. Is the garden low maintenance in terms of watering requirements, lawn mowing and management of autumn leaves?	55	0.24	0.39	0.42-0.68
5. Are there shady areas outside to sit?	93	0.57[a]	0.92	0.87-1.00
6. Is outdoor furniture sturdy, comfortable and easy to get on/off?	83	0.40[a]	0.81	0.74-0.93

[a]Where the results showed a high agreement but the κ value was low, Gwet AC_1 was applied.

Among the 61 participants, the domains that demonstrated the lowest agreement levels between the occupational therapist and participant were the front garden and entry (72% to 93% agreement), bathrooms (46% to 100% agreement), toilets (54% to 92% agreement), and backyards (55% to 100% agreement).

Front Access

Items that showed a moderate level of agreement were paths being flat and wide (72% agreement, Gwet AC_1=0.60), paths and driveways having a nonslip texture and being free of moss (79% agreement, Gwet AC_1=0.71), and the letter box being easy to access and open (75% agreement, Gwet AC_1=0.69). Items with weak agreement were related to the front steps of the house. For example, steps being of a suitable height and depth and stable demonstrated 79% agreement (κ=0.51), and whether the home had at least 1 way to access it without a step demonstrated 77% agreement (Gwet AC_1=0.56). No participant assessed the front steps as being unsuitable and unstable, as opposed to the occupational therapist, who assessed 17 front steps as being unsuitable and unstable.

Hallways

The item that showed a strong agreement was the hallways being free of clutter and unnecessary furniture (87% agreement, Gwet AC_1=0.82). A total of 13 floor coverings within the hallways were assessed by the occupational therapist as being unsafe; by contrast, no participant assessed the floor coverings as being unsafe.

Kitchen

The responses to a total of 12 questions regarding the kitchen were compared for levels of agreement between the occupational therapist and participant. There was an overall weak to almost perfect level of agreement, as shown in Table 3. The occupational therapist assessed the oven and microwave to be at an unsuitable height on 14 (23%) out of 61 occasions; by contrast, no participant assessed the oven or microwave to be at an unsuitable height.

Bathroom 1

For the 9 questions regarding bathrooms, the levels of agreement varied from minimal to almost perfect, as shown in Table 4.

Both the occupational therapist and participant agreed (100% agreement, κ=1.00) that there was adequate ventilation with the presence of a fan or window. There was moderate agreement (78% agreement, Gwet AC_1=0.67) for bathroom 1 being easy to maneuver in and for the shower cubicle being a minimum of 900×900 mm in size (92% agreement, κ=0.70). There was a weaker level of agreement for rugs or mats being secure (64% agreement, κ=0.46) and for taps being easy to turn on, turn off, and adjust (66% agreement, κ=0.49). Moreover, there was minimal agreement for the transition between the floor and shower being flat (61% agreement, κ=.27) and for the floor surfaces being nonslip (67% agreement, κ=0.33). Most participants did not believe that “shower lips” and “shower alcove tracks” were home hazards and commonly considered these transitions to be flat.

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Toilet 1

For the 3 questions regarding toilets, the levels of agreement varied from no agreement to strong agreement, as shown in Table 4. Toilet 1's height had the lowest agreement (no agreement between the occupational therapist and participant; 56% agreement, κ=0.10) among the items. Both the occupational therapist and participant agreed that the toilet heights were suitable on 31 (51%) out of 61 occasions, whereas on 27 (44%) out of 61 occasions, the occupational therapist assessed the toilet height as being unsuitable. Participants commonly indicated the toilet height as currently manageable and not an area of concern.

Bedroom 1

For the 8 questions regarding bedrooms, the levels of agreement varied from moderate to almost perfect, as shown in Table 4.

The participants and occupational therapist both highly agreed that there was easy access to light and phone next to the bed (97% agreement, Gwet AC_1=0.96). Other items that indicated a high level of agreement were the bed being of a comfortable height to access and rise from (93% [almost perfect] agreement, Gwet AC_1=0.93), clothing and shoes being easy to access (93% [almost perfect] agreement, Gwet AC_1=0.93), having a place to sit when dressing and putting on shoes (92% [almost perfect] agreement, Gwet AC_1=0.91), and the temperature in the bedroom being easily adjustable (92% [almost perfect] agreement, κ=0.72). Although the participants were asked to assess bed heights, most participants (56/92, 61%) interpreted the bed height question as "was the bed comfortable," rather than whether the bed was at a "comfortable height."

Living Areas

Living areas 1 and 2 were classified by the participants as their main living areas where they watch television, rumpus rooms, or sitting areas.

For the 7 questions regarding living areas, the levels of agreement varied from no agreement to almost perfect agreement, as shown in Table 3.

An almost perfect level of agreement was evident for the following items: the walkways in the lounge area being free of cords (97% agreement, Gwet AC_1=0.97), the lounge area having good storage capacity (95% agreement, Gwet AC_1=0.95), and having easy access to heating and cooling controls (93% agreement, Gwet AC_1=0.93). A strong agreement level was illustrated for there being enough circulation space (90% agreement, Gwet AC_1=0.84) and for the windows or blinds being easy to open (90% agreement, Gwet AC_1=0.89) within the living area.

Floor coverings in the lounge area seemed to indicate "lower" levels of agreement (80% [moderate] agreement, Gwet AC_1=0.78). The occupational therapist disagreed with the participant and indicated that 8 (13%) out of 61 lounges had unsafe floor coverings.

Among the items assessing living area 1, the lowest level of agreement was for whether the chairs in the room were easy to get in and out of (no agreement between the occupational therapist and participant; 44% agreement, κ=0.02).

Backyard

For the 6 questions regarding the backyard, the levels of agreement varied from minimal agreement to almost perfect agreement, as shown in Table 3.

There was an almost perfect level of agreement between the participants and occupational therapist for whether the back garden doorway was a minimum of 850 mm wide (100% agreement, κ=1.00) and for whether there were shady areas outside to sit (93% agreement, Gwet AC_1=0.92). Whether the outdoor furniture was sturdy, comfortable, and easy to get on and off also had a high level of agreement (83% [strong] agreement, Gwet AC_1=0.81).

There was a moderate level of agreement for the paths being relatively flat and approximately 1000 m wide (78% agreement, Gwet AC_1=0.75). Here, the occupational therapist disagreed on 9 (15%) out of 60 occasions, and there was agreement between the raters on only 2 (3%) occasions. Among the items regarding the backyard, the lowest agreement levels were observed for whether it was possible to access the clothesline without excessive reaching (63% [weak] agreement, Gwet AC_1=0.52) and whether the garden was low maintenance (κ=0.24, minimal agreement with 55%).

Discussion

Principal Findings

In this study, a digital home environment self-assessment tool was tested with older people, and its validity was determined through an assessment of the levels of agreement between an occupational therapist and older person. The overall levels of agreement were high, supporting the validity of the tool in identifying potential hazards. Lower levels of agreement were found between the occupational therapist and older participants in the following domains: steps, toilets, bathrooms, and backyards. Items regarding the height of toilets; height of chairs in the lounge; loose rugs, mats, or floor coverings; height of kitchen appliances; and transition between shower alcoves and bathroom flooring also displayed lower levels of agreement. Lower levels of agreement likely occurred owing to (1) the subjective nature of some questions, such as "is there at least one way to access the home without a step?" and (2) the more critical lens through which an occupational therapist assesses the home environment. There were no items where participants were more likely to identify hazards than the occupational therapist.

Participants found the tool to be relatively simple and quick to complete, and overall, there were high levels of agreement. The study conducted by Ali and Kumar [38] also found that older people were able to self-assess potential risk factors at home. They also found that self-assessments led to older people being able to initiate minor modifications to their homes, including the removal of throw rugs and the reorganization of kitchen appliances. Other research has shown that older people prefer self-assessment approaches that go beyond identifying hazards

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and provide them with potential solutions to ensure that their home is safe and comfortable [39]. Checklists and recommendations for improving the age-friendliness of the home environment may also be useful for architects and designers to help them gain insights into the practical needs of older people.

Although older people were able to self-assess their homes, there were often occasions of disagreement between the perspective of the occupational therapist and that of the participant. In particular, the assessments of steps, toilets, bathrooms, and the backyard showed conflicting results. Occupational therapists have extensive training in environmental assessments with an emphasis on safety [29]. Another study has also shown that occupational therapists are more critical of the environment than other people [40]. Lower levels of agreement were commonly observed for items assessing bathrooms and toilets. These areas have been shown to be particularly hazardous for older people. Gell et al [41] found that bathroom modifications were common and usually increased after multiple falls. Similarly, Wellecke et al [42] found that bathroom modifications were frequently required to support aging in place. Their study also found that large step-free showers and bathrooms on the ground floor were beneficial [42]. It was clear from the participants in this study that bathrooms and toilets were not an area of concern for them yet. Bathroom and toilet modifications, such as the addition of grab rails, may be a key feature to consider in the design of new buildings in an age-ready city.

We also found a difference in agreement levels for items regarding the backyard, with many participants indicating that their gardens did not require high maintenance, despite the occupational therapist believing they did. Research shows that gardening stimulates a greater level of well-being, better physical and mental health, and better sleep quality among older people [43]. However, as aging takes place, older people have also described concerns about maintaining large gardens [44]. Suitable gardening solutions, such as landscaping options and irrigation systems for reducing maintenance, may facilitate age-friendly environments. Given that most older people experience a sense of connection with their homes [12,13], practical support for gardening or access to parks and gardens within walking distance can support the development of healthy aging cities.

Limitations

This study has several limitations that should be acknowledged. Participants were recruited through a variety of methods, and the use of convenience sampling may have influenced the results, as the population was not representative of the general population. Most participants (50/82, 61%) lived in metropolitan areas with high socioeconomic status. These living conditions may differ from those in other countries and those of other older populations. Further research should include participants with a lower socioeconomic status and those living in rural or remote areas.

The results may have been influenced by the variations in the interpretation of the questions. For example, some participants indicated that some questions were ambiguous. For example, the interpretation of the question “is the home largely clutter free?” depended on the person’s perception of clutter. Some of our participants (eg, spouses or family relatives) lived in the same house; however, the assessments were completed independently and without consultation between the cohabitants. Finally, our CIs may have been narrower with a larger sample size.

Conclusions

In conclusion, older people were able to self-assess their own homes using a digital health tool. The purpose of the digital tool was to enable people to start thinking about future housing decisions. This study showed that although agreement levels were generally high, older people and occupational therapists may still have different views on the safety of home environments. In particular, the items regarding steps, toilets, bathrooms, and backyards were subject to different perspectives. Following this research, the digital tool will be slightly modified to address questions for which there was a higher level of disagreement. Attempts will be made to reduce the ambiguity of some questions. Tools that identify potential problems and generate solutions are likely to be of value in supporting future housing decisions as populations age.

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Conflicts of Interest

None declared.

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Original Paper

Experiences of Patients With Chronic Obstructive Pulmonary Disease Using the Apple Watch Series 6 Versus the Traditional Finger Pulse Oximeter for Home SpO2 Self-Monitoring: Qualitative Study Part 2

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Abstract

Background: Amid the rise in mobile health, the Apple Watch now has the capability to measure peripheral blood oxygen saturation (SpO_2). Although the company indicated that the Watch is not a medical device, evidence suggests that SpO_2 measurements among patients with chronic obstructive pulmonary disease (COPD) are accurate in controlled settings. Yet, to our knowledge, the SpO_2 function has not been validated for patients with COPD in naturalistic settings.

Objective: This qualitative study explored the experiences of patients with COPD using the Apple Watch Series 6 versus a traditional finger pulse oximeter for home SpO_2 self-monitoring.

Methods: We conducted individual semistructured interviews with 8 female and 2 male participants with moderate to severe COPD, and transcripts were qualitatively analyzed. All received a watch to monitor their SpO_2 for 5 months.

Results: Due to respiratory distress, the watch was unable to collect reliable SpO_2 measurements, as it requires the patient to remain in a stable position. However, despite the physical limitations and lack of reliable SpO_2 values, participants expressed a preference toward the watch. Moreover, participants' health needs and their unique accessibility experiences influenced which device was more appropriate for self-monitoring purposes. Overall, all shared the perceived importance of prioritizing their physical COPD symptoms over device selection to manage their disease.

Conclusions: Differing results between participant preferences and smartwatch limitations warrant further investigation into the reliability and accuracy of the SpO_2 function of the watch and the balance among self-management, medical judgment, and dependence on self-monitoring technology.

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KEYWORDS

Apple Watch; chronic obstructive pulmonary disease; pulse oximeter; qualitative descriptive; self-monitoring; smartwatch

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Introduction

According to the World Health Organization, chronic obstructive pulmonary disease (COPD) is the third leading cause of death worldwide [1]. Unlike other types of lung diseases, COPD disproportionately afflicts older adults, contributing to a debilitating impact on their quality of life through decreased exercise performance and functional capacity, with the eventual requirement of supplemental oxygen therapy to prevent exacerbations requiring hospitalization [2,3]. Whether supplemental oxygen therapy is indicated or not, noninvasive pulse oximetry has become a critical component of self-management for those with respiratory conditions such as COPD, as they are known to experience chronic room air hypoxemia due to persistent airflow limitation and gas exchange abnormalities [4]. For these individuals, commercially available finger pulse oximeters have enabled out-of-hospital peripheral blood oxygen saturation (SpO_2) and heart rate (HR) monitoring and better home oxygen therapy management [5,6]. Moreover, the accessibility and portability of these devices have contributed to their prevalence for self-monitoring in individuals with COPD [7]. This has led to improved detection of acute hypoxemia events and prevention of exacerbations before the manifestation of visual cues such as cyanosis, thus reducing hospitalizations, particularly when used on a daily basis [8,9].

Pulse oximeters themselves have evolved significantly over the past decade, becoming increasingly integrated within the consumer wearable and mobile health market in the form of smartwatches, such as the Apple Watch Series 6, which provides several additional benefits beyond SpO_2 measurement [10]. With the advancement of optical sensors, accelerometers, and gyroscopes, as well as improvements to on-device hardware-accelerated artificial intelligence (AI) for analysis of raw biometric data, the Apple Watch Series 6 has become increasingly capable of compensating for limitations of traditional pulse oximeters such as low perfusion, skin pigmentation, movement artifacts, and systemic sclerosis [11]. Although strong correlations were observed for HR and SpO_2 measurements between the watch and the finger pulse oximeter, these findings were obtained under controlled conditions, and data were gathered at a single time point [11]. While results are promising, clinical trials that continuously monitor the SpO_2 values of patients with COPD using the Apple Watch in naturalistic settings are needed. Due to a lack of reliable clinical data and an understanding of the AI algorithms used for health monitoring [12], the medical community has reacted with reluctance and skepticism, and questions of accuracy and reliability have been raised [13].

Considering the fact that the US Food and Drug Administration (FDA) and Health Canada currently regulate medical devices similarly, whether "static," such as hip implants, or "dynamically updating," such as smartwatches, regulation has impeded emerging mobile health technologies, which have become increasingly sophisticated [10]. In 2018, Apple Inc. obtained the FDA's groundbreaking clearance for the Apple Watch, which was considered a Class II medical device with fall detection and advanced heart monitoring capabilities, such as low HR alert, irregular heart rhythm detection, and personal electrocardiogram monitoring [14,15]. The Apple Heart Study showed strong initial evidence that the Apple Watch might be a viable diagnostic tool in subclinical atrial fibrillation among relatively healthy young individuals [16,17]. Despite these promising results, researchers at the Mayo Clinic, who conducted a retrospective study, indicated that abnormal pulse readings resulted in an increased number of medically unnecessary emergency room visits [18], and the authors recommended that the FDA and Apple Inc. should carefully consider the unintended consequences of using the watch for asymptomatic atrial fibrillation.

Unlike the heart monitoring capabilities, Apple Inc does not have FDA clearance for their newly designed SpO_2 feature, which was introduced during the COVID-19 pandemic era [19]. Due to the lack of governmental approval, the Apple Watch SpO_2 feature should only be used for wellness and fitness purposes. Despite the fine print, consumers are using the device and considering it a medical tool [13]; often with limited knowledge about pulse oximetry in general [19]. Regardless of the need for reliable studies to validate smart wearable technologies, including the Apple Watch, it is imperative to understand the users' experiences of using the Apple Watch Series 6 versus the traditional finger pulse oximeter for home SpO_2 self-monitoring. Although the cognitive behavioral process underlying acceptance of the Apple Watch was explored in our previous study (add self-reference), we further elucidate the perceived differences in experience of using traditional finger pulse oximeters as compared with the Apple Watch. Therefore, the research question governing this qualitative descriptive study was: "Following the use of the Apple Watch and traditional finger pulse oximeter, how do patients with COPD compare their experiences monitoring their SpO_2 between both devices?"

Methods

Design, Sample, and Recruitment

This qualitative descriptive study represents a subsequent analysis of interview data that were collected within a larger mixed methods research project evaluating an integrated telehealth nursing system including traditional finger pulse oximeters and the Apple Watch Series 6, which features reflectance pulse oximetry at the wrist. Although the larger project started in June 2020, the integration of the Apple Watch for select participants occurred in June 2021, from which this study draws its data. The sociodemographic data were outlined in our previous study (add self-reference). All participants were previously familiar with the traditional finger pulse oximeter, as it is standard in the management of COPD; however, none had any significant previous experience with the Apple Watch or any other similar wrist-worn pulse oximeter. All participants owned electronic devices, either a single smartphone or a combination of smartphone and tablet or personal computer.

Data Collection and Analysis

Individual semistructured interviews were carried out through Zoom (Zoom Video Communications) with our participants after having experienced the Apple Watch for 5 months.

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Transcripts from the aforementioned interviews underwent primary open coding, then categories and themes relevant to device comparison, specifically around SpO_2 measurement, were isolated and subsequently analyzed qualitatively, as described in the previous study (add self-reference). Strategies to enhance the trustworthiness of the findings remain the same among studies [20].

Ethics Approval

Ethics approval was obtained from the research ethics committee of the Centre intégré universitaire de santé et de services sociaux de l'Ouest-de-L'Ile-de-Montréal (SMH #19-11) on August 16, 2019. All participants signed the consent form before the start of the larger study, and written information was provided explaining the study purpose, participant involvement, the right to withdraw at any stage, and data confidentiality. In June 2021, the 10 participants who agreed to use the Apple Watch were shown how to use the wearable and were monitored by the telenurse using the telemonitoring platform as described in the previous study (add self-reference).

Results

Overview

For accurate SpO_2 readings, the watch requires a person to remain at rest with a flat wrist and a steady arm for at least 15 seconds. However, respiratory distress among patients with COPD is accompanied by erratic movements from the use of accessory muscles, resulting in the inability to yield accurate SpO_2 measurements. This gap in the SpO_2 continuous monitoring is described in the first theme, "unveiled blind spots of the watch." Added to this measurement limitation, participants shared a discrepancy between their own subjective breathing problems and the associated O_2 saturation values monitored by the watch and the finger pulse oximeter. Although a decline in trust toward the watch was expected following the limitations, some participants reported confidence in the device, as illustrated in the second theme, "leniency toward the watch margin of error." The third theme, "perceived interdevice reliability," addressed participants' preferences for the traditional finger pulse oximeter, which was at arms' reach, and the watch, which is hands-free and collects all health data continuously and spontaneously. Nonetheless, regardless of participants' preferred device, they highlighted that the importance of recognizing, understanding, and acting upon their own COPD symptoms transcends the reliability of any monitoring device, as described in the fourth theme, "prioritizing personal health judgments." Finally, the fifth theme, "reliance on health care provider's medical judgment," defined participants needing the reassurance of a health care provider to interpret the numbers and, if needed, start their COPD action plan.

Unveiled Blind Spots of the Watch

Performing daily activities, according to participants P6-P10, can be exhausting and can trigger shortness of breath (SOB). For example, P6 shared: "I'm in the shower, washing up, and I'm getting really out of breath." Others (P7-P8) stressed that walking in the neighborhood, doing routine clean-up, or household tasks may cause respiratory distress. Moreover, the mandatory mask-wearing during the COVID-19 pandemic was challenging, as explained by P8: "I get in a panic, like in the store the other day, the first thing I wanted to do, was rip off that mask." In those moments of distress, P7 said: "When I experience SOB, I want to take it [O_2 saturation level]." Participant P8 needed a device that "give her immediate attention of what her body's going through." The Apple Watch requirements for accurate SpO_2 readings, such as being at rest and keeping the wrist in a stable position, are paradoxical with the capabilities of patients with COPD when experiencing dyspnea. Participant P7 explained the experience as follows:

> *When I am catching my breath, I make movements. Therefore, the watch is incapable of taking my measurements. I have to wait until I am calm.*

She continued:

> *You can try and hold onto the sofa arm, but you can't help but move when you are breathing hard. It shows a message: "Is your watch positioned properly," or something like it, just when I need it.*

Participant P6 pointed out that the "watch doesn't work" when in distress; however, by the time she calmed down and recovered from the exacerbation, she said: "my oxygen level had gone up because I am doing the breathing exercises, taking deep breaths." P6 questioned the necessity of having a watch for continuous monitoring and added: "Is it worth it? I don't know." Participant P7 made an interesting remark in terms of the added value of the continuous monitoring; saying:

> *I don't think there is any variation in my [SpO_2] data. My measurements at rest are never out of the normal range.*

These experiences unveiled a gap, or "blind spot" of the watch to monitor participants' SpO_2 values continuously. The inability to obtain readings when breathing heavily causes participants (P7-P10) to consider the finger pulse oximeter as a more reliable option for capturing their O_2 saturation levels. For example, P7 called the Apple Watch's blind spot a challenge, further adding that "it is a challenge for the watch because with the manual oximeter, it [blind spot in the device] was never a problem." P8 confirmed this behavior, saying, "If I feel bad, say I'm out of breath, I'll do it manually with the finger thing [oximeter] and then I just breathe, do my exercises."

Whether in respiratory distress or not, P10 found "the oximeter easier to use, it is easier to get your readings." She further explained:

> *It doesn't always work with the watch. I have to do it over and repeatedly whereas with the [traditional] oximeter I just take it on my finger, and it usually works right away.*

P8 was well aware of the Apple Watch instructions, saying, "The technology of the watch relies on its [wrist band] positioning in a certain way." Participant P9, however, had to "take her saturation level six or seven times before getting it properly fixed on her wrist." She said:

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> *It kept saying, "unable to read, make sure your watch is secure, comfortable," and I would move it and I would still get that [message], so I was annoyed by it.*

Although P9 was hopeful for the benefits of continuous monitoring, she left being very disappointed. She stated: "The watch was supposed to be easier and it's not." Additionally, for participants P5 and P10, whose wrists did not fit the standard bands, the difficulty collecting spot-check or continuous data is labeled a "blind spot of the device." For example, P10, who has congestive heart failure due to severe COPD, is edematous peripherally, and her wrists are so swollen that they don't fit any of 2 standard sizes available when purchasing the watch. She said: "If it had a more adjustable band, I wouldn't have to work so hard to get it to work." The wrist band fit so tightly that pitting marks remained after she removed the watch. These blind spots of the Apple Watch wearable form a gap in continuous data collection.

Leniency Toward Watch Margin of Error

Discrepancies in SpO_2 Measurements

The majority of participants (P1, P2, P5, P6, P8, and P10) noticed a significant discrepancy between the O_2 saturation values collected from their finger pulse oximetry and the watch. For instance, P5 stated:

> *It is a six-point difference, that is huge. If I am 88% maybe I should be looking to go to the hospital, but I am at 94 [with the finger pulse oximeter], I'm okay.*

Similarly, P1's experience also reflected a mismatch; he stated that "especially at the beginning of the project, the data were completely different […] at one time, the watch was at 96% and the [other] oximeter at 91%." Another participant, P8, indicated that the results reflected such big discrepancies that if you compare the watch and the finger pulse oximeter collected data, "you would think I'm collecting measurements from two different people, like the recordings of my husband and my recordings." Sporadic large discrepancies were experienced by P6, who stated that "at times I have experienced differences of over 10 points and other times none." With regard to the HR, P2 confirmed that "the difference [between the finger pulse oximeter and the watch] is contained between 1 or 2 units, never more." He continued:

> *The problem is mainly the saturation readings. Sometimes the watch shows 87%, whereas it should ideally show 90 to 95%. At the other times it gives 100%, which is not correct. Then I take the oximeter and my saturation is normal 94 or 95.*

Beyond the discrepancy between the watch and the traditional finger pulse oximeters, participants (P2, P5-P7, and P9) also noted variations between the devices and their own feelings. For example, P7 described that "sometimes the watch shows 100%; however, I do not feel like 100%." Similarly, P9 recalled an instance where the telenurse called, saying, "My nurse called me because [the watch] showed I think it was at 83%, and I didn't understand it either because I felt okay." P5 supported these experiences as she was "kind of surprised" of the differences and stated: "I felt well but my vital signs collected were critically low." These inconsistencies led participant P2 to have mistrust in the SpO_2 values monitored by the watch. He revealed:

> *If I was confident about the number on the watch, I would not need the oximeter. But at this moment, I am not. It's not complicated, I have seen a discrepancy in the numbers on the watch, I cannot trust those numbers alone. I cannot rely on it.*

Default Confidence in the Watch

Despite the inconsistencies between the devices and compared with their feelings, 6 participants (P1 and P4-P8) surprisingly expressed having confidence in the watch SpO_2 measurements. This confidence was rooted in having a default confidence in the watch due to distrust toward the manual oximeter. For example, P6 who experienced occasional discrepancies, when asked whether she lost confidence in the watch, replied: "No, not really, I still have confidence in the watch." Even participant P7, who experienced drastic differences between devices, stated:

> *It is difficult to know which one is saying the truth. I have less confidence in the manual oximeter because I am not sure the battery is still good.*

Other participants (P1, P4-P5, and P8) supported this statement. Participant P5 said:

> *The watch is much more reliable. I don't know if it's because the oximetry is now a year old, maybe the battery is becoming weaker.*

P8 continued:

> *When you change the battery [of the oximeter], you know the light is brighter and it gives a more accurate reading; whereas the technology of the watch relies on you positioning the watch*

which appears more reliable than dependence on batteries. The tech-savvy male participant (P1) had the impression that "the oximeter is less precise compared to the watch because we put it from finger to finger, hand to hand." Participant P4 summarized this leniency toward the Apple Watch as follows:

> *If I had a vote of confidence, it would be for the wristwatch, because it is connected to the pulse. Whereas for the oximeter, I could have dirty fingers, the battery could be weak. If the battery [of the watch] is well-charged, then it cannot make an error.*

An additional leniency toward the watch was rooted in the individual's interpretation of the numbers provided by the device. For example, P8 indicated: "Maybe I'm supposed to read it [discrepancy between both devices] that way, my range is between 92 and 96." P8 also added that there is leniency toward the Apple Watch because: "I'm not thinking this is curing my COPD. I'm thinking this as you're trying to find out the best way of controlling somebody's numbers." Overall, the findings of participants reflected higher forgiveness and confidence toward the Apple Watch's SpO_2 data.

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Perceived Interdevice Reliability

Traditional Oximeter at Arms' Reach

Due to its ease of use and availability, some participants (P2-P5) labeled the pulse oximeter as a reliable device. Participant P4 said:

> *I always have it in arms' reach. As soon as I need it, I take it and put my finger into it. It does not take more than 10 seconds and I receive a reading.*

Although this participant previously explained that his confidence in the accuracy of the results leans toward the watch, he clarified that in a situation of emergency, he would still prioritize the oximeter. This behavior was confirmed by P3:

> *If I was in distress, I would put my [Ventolin] puffer and I would take my oxygen level on the oximeter on my finger, I would not use the watch.*

Although P4 enjoyed using the watch, he emphasized not yet mastering its usage, saying,

> *I do not understand the watch well enough yet, the first thing I will get [in emergencies] is the [manual] oximeter.*

Another female participant, P5, shared:

> *I've used it [pulse oximeter] when my husband was not feeling well. I found that his heart was racing [...]. When we called the 911, I could give them that information, that was good.*

Following this incident, P5 realized that the watch is not rapidly shareable like the finger pulse oximetry, which made it more reliable than the watch. When asked about the reliability between the 2 devices used, P5 responded, "I will say the oximeter."

Hands-Free Continuous SpO_2 Monitoring

On the contrary, participants (P6 and P8-P9) labeled the watch as a reliable device due to its physical ease of access. For example, P6 stated: "I do not keep the manual oximeter next to me," therefore, she relied on the watch even during times of respiratory distress. Participant P8, however, anticipated that at the moment of sudden breathlessness crisis, first responders would "not dig in her drawer to get the finger thing," but could use the watch. She continued that wearing the watch led to spontaneity of measurements collection, which also increased her perceived reliability. In fact, she explained:

> *I'm aware of more things happening in my body [...] When I was at Costco the other day [experienced respiratory distress], I had my watch and was able to check this* [my saturation levels]

For the majority of participants (P1 and P5-P9) the continuous monitoring feature of the watch was seen as a characteristic of reliability. Participant P1, who is very tech-savvy, shared:

> *The oximeter takes it [vital sign measurements] whenever I decide to take them. With the watch, the information regarding my oxygen is continuous, and allows me to see the fluctuations.*

The watch's ability to collect continuous data was further compared to inpatient intensive care, as per P5, who stated: "It would do it automatically and it's like laying in an intensive care bed." Moreover, the hands-free experience of the watch's continuous monitoring ensured that the frequency of data collection no longer depends on manual initiation. P6 explained:

> *I find it interesting to have data more often. When I would take it on the finger, I would get one or two data entries. With the watch I have more details.*

Even the participants, such as P9, who trusted the manual oximeter, shared that with the continuous monitoring, she felt safer. She explained:

> *The watch is wonderful. But for me, for my COPD, the oximeter was fine, I felt just as reassured […] Except for the fact that it [watch] monitors saturation on its own. That makes me feel even safer. But I felt safe with the oximeter also.*

Above that, the nighttime continuous monitoring of the watch had allowed 2 participants (P1 and P6) to discover the nocturnal desaturations that they have been living with. P6 expressed:

> *I had a lot of difficulty sleeping. I would wake up questioning why is that? Then after I looked at the data collected overnight, I realised that my oxygen level was low at night.*

Similarly, P1 stated that with the use of the watch overnight, he noticed that "often during the night his oxygen level would go down below 90 and at times below 86," which gave him a clarification as to why he experienced difficulties sleeping.

Double SpO_2 Verification

Before being enrolled in the larger study, participant P9 did not have access to a device that measured her oxygen saturation levels. She shared:

> *I had no way of tracking my HR or my oxygen level before I got the oximeter, I will always keep the oximeter once the project is over. It gives me reassurance that I am doing better.*

Interestingly, for participant P2, having access to the largest quantity of health data possible was more important than the type of device used to measure her SpO_2 values, saying, "For sure I find the [manual] oximeter more accurate than the watch, but like I said, I take both measurements, that is what reassures me the most," in fact, "using both the watch and oximeter is a double verification." In the case of participant P3, for whom the watch is a "family affair," supported the statement that the device does not matter; however, she was open to any device as long as it prevents hospitalizations, saying,

> *The reason I am open to try a new device is the potential benefits it brings to my health since I don't want to return to the hospital nor return onto oxygen.*

Regardless of the device used, P3's husband added with laughter, "In a situation of distress, she would call for me and I would get up to go help her with it."

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Prioritizing Personal Health Judgments

Having access to reliable SpO_2 data was important for all participants with COPD; however, any device, either the finger pulse oximeter or the watch, are limited to providing numbers. Total reliance on numbers produced by the devices appeared to conflict with participants' (P1-P3, P5-P6, P8, and P10) self-perceived role in the management of their chronic condition. This was well said by participant P1:

> *Basically, there is a limit to what a computerized device can tell you. Devices do not have a judgment, even if algorithms are getting stronger.*

Furthermore, in situations where his respiratory symptoms were deteriorating, P1 explained:

> *It is not the watch that will tell me [that I am in respiratory distress], I will feel it myself. In fact, I will know that I am too out of breath or exhausted.*

He continued:

> *My first reflex is not to go see my blood oxygen level, but rather to decrease my activity, and to focus on the pace of my breathing to help calm myself.*

He further highlighted that his physical symptoms are signals to stop all triggering activities: "If I continue and I persist, I know I will have terrible secretions, I will get a runny nose and I will have an urge to urinate." In the same vein, P6, who had practically no concerns regarding the inconsistencies of the SpO_2 measurements on both devices as she knows "her body and symptoms," expressed: "It is not only about the numbers on the device but is about how I feel." She continued:

> *I do not get worried if there is a difference. I am so used to being in the 80% (O2 saturation level), so when I see 90%-100% on the watch I tell myself that it is impossible.*

For a person living with a chronic illness, having a baseline understanding of one's own health prevents them from feeling stressed by external false alarms. Furthermore, participant P10, who has lived with COPD since 2016, agreed that she has developed a knowledge base of her physical symptoms. She shared:

> *Depending on the weather and the barometer, you have good days and bad days […] So, you know, early on if your day is going to be a bad day or a good day, you know by the barometer, by the weather.*

Hence, in case of an emergency, P10 has learned to prioritize her physical symptoms above all numbers available, stating:

> *Number one for me is "I sit down" when I'm feeling uncomfortable, I'm having a hard time breathing, I sit down, and I breathe, I've learned how to breathe. And then I take my oxygen.*

She continued:

> *If I have the watch on or I have the oximeter with me. I don't always have both […] I go with whatever [device] is in hand.*

According to P2, "the watch gives her an idea of her saturation and HR but does improve her health." To conclude, P8 said:

> *I have the disease. There's nothing I can do about it, but I talk to my body, listen to my body.*

In contrast, for the female participant P5, the SpO_2 numbers on the monitoring device must match her physical symptoms and not the other way around. In the situation where she felt fine but the watch kept showing low O_2 saturation, P5 chose to repeatedly retake her vital signs until "she thought it was an accurate reading."

Reliance on Health Care Provider's Medical Judgment

Importantly, in addition to knowing their body and understanding their physical symptoms, participants (P3, P5, and P8) were also relying on the telenurse's interpretation of the submitted clinical data. Despite the new advanced digital health technologies, such as the Apple Watch Series 6, participant P5 verbalized: "I don't see technology ever being able to replace the personal care, either from the doctor or the nurse, that we need." P8 acknowledged this statement and added: "Technology is all these things, it's the helpline to get to the result," yet "I am not a medical expert. I can tell you how I feel but I'm not going to tell when to take my action plan. I want to speak to you [telenurse] first to reassure me that it's the time to do it [take the action plan]." Similarly, participant P3 emphasized that although she has an action plan in backup, she does not want to start it on her own, saying, "I prefer that the nurses give me the okay. It's not just some cough syrup, in the action plan there are antibiotics and cortisone. I prefer that a professional tells me when to start." These cases reflect the reliance on the health care professional's medical knowledge, assessment, and judgment also contribute to the patient's management of COPD.

Discussion

Overview

Despite the difficulties in obtaining accurate SpO_2 results when experiencing SOB and discrepancies between the watch and the traditional finger pulse oximeter, some participants had confidence and preference for the Apple Watch, as the device provided continuous passive measurements and other health-related data and allowed for meaningful feedback from a clinician. Interestingly, during exacerbations, participants would not rely on either reading but instead defaulted to their experienced physical symptoms and used their own judgment and health care providers' clinical guidance for decision-making. Consequently, some points warrant further discussion: (1) the inherent limitations of wrist-worn pulse oximeters; (2) the inherent benefits of the Apple Watch; (3) the level of reliance on the Apple Watch; and (4) the potential for future hardware and software improvements.

Inherent Limitations of Wrist-Worn Pulse Oximeters

When considering the blind spots we unveiled about the Apple Watch, an important distinction between all existing wrist-worn pulse oximeters is that they use reflectance pulse oximetry to obtain measurement, as opposed to the transmissive mode used

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by traditional finger-worn pulse oximeters [21]. Whereas transmissive pulse oximetry requires a light source and photodiode on either side of the measurement site (as with a finger probe), reflectance pulse oximetry is accomplished with both elements placed on the same side, allowing for measurement at many more sites, including the feet, forehead, chest, and wrist, as with the Apple Watch [21]. Unfortunately, this creates unique challenges, such as increased sensitivity to pressure and ambient light interference, requiring careful placement on the measurement site to maintain adequate contact [21]. The former challenge was borne out in our findings, with many participants having trouble measuring their SpO_2 when experiencing respiratory distress, which compromised their ability to maintain adequate contact between the probe and their wrist. For patients with COPD, who often experience instances of respiratory distress causing difficulty controlling arm movement, this limitation is particularly relevant, as the most important indication for pulse oximetry in this population is for detection of acute hypoxemia requiring intervention. Contrastingly, for devices using transmissive pulse oximetry, such as with the traditional finger probe, the opposing light source and photodiode remain aligned on either side of the measurement site, increasing reliability in instances of increased movement.

Inherent Benefits of the Apple Watch

As previously mentioned, the Apple Watch exemplifies a unique benefit of noninvasive wrist-worn pulse oximetry in providing an opportunity to track SpO_2 more consistently. This is particularly relevant overnight, where comorbid conditions such as obstructive sleep apnea and congestive heart failure may increase the risk of nocturnal hypoxemia. In this study, 2 out of 10 of our participants stated that the continuous monitoring allowed them to detect nocturnal desaturations. Hence, the Apple Watch has demonstrated the potential to facilitate the diagnosis of concurrent obstructive sleep apnea in patients with COPD (referred to as “overlap syndrome”) [22]. Although home nocturnal oximetry has been implemented for the diagnosis of such complications in patients with COPD, this often requires prolonged monitoring for the detection of apnea or hypopnea events with additional information about sleep duration and arousals that cannot be easily obtained from home studies, therefore often requiring laboratory-based polysomnography studies for a more accurate diagnosis [22]. The Apple Watch, in fact, has the added capacity to combine sleep data with nocturnal oximetry to meet this demand for more comprehensive data required to support a comorbid diagnosis of sleep apnea for these patients.

Level of Reliance on the Apple Watch

Despite this inherent advantage of the traditional finger pulse oximeter during events of respiratory distress, participants valued the passive nature of the Apple Watch for continuous self-monitoring. When compared with traditional finger pulse oximeters, the added convenience of the Apple Watch has led to preference over traditional devices for HR measurement [17], a phenomenon that appears to have carried over to SpO_2 measurement as well. Moreover, 6 out of 10 participants in this study indicated a tendency to trust the Apple Watch readings over the finger pulse oximeter due to the perceived objectivity of the device when manual initiation is not necessary. This represents the combined effect of automation complacency and automation bias, where monitoring and vigilance of the device decrease as suspicion of error decreases over time. Unfortunately, passive sensors fail to collect subjective data about a patient’s symptoms (eg, pain or SOB) and therefore only present an incomplete account of the patient’s health status. In addition to the inability of obtaining accurate and reliable measurements when patients are experiencing respiratory distress, this significantly limits the feasibility of using this device for diagnostic purposes in this patient population.

Unfortunately, with the iteration of the SpO_2 application installed on our test devices, the Apple Watch was unable to compensate for inadequate placement during respiratory distress events, rendering the device unusable for this purpose in naturalistic settings. This was surprising, given the lack of such challenges in the previous comparison carried out by Pipek et al [11] in a controlled setting. The accuracy and reliability resulting from a sterile and clinical setting contradict the purpose of self-monitoring devices, which are intended for noncontrolled home use. This study reveals the importance of taking into consideration the unique functional limitations of community-dwelling patients with COPD. In fact, weather-induced respiratory status changes, peripheral edema due to heart failure in severe COPD, and respiratory distress were all barriers to the successful use of the Apple Watch for continuous self-monitoring of SpO_2.

Potential for Future Hardware and Software Improvements

To address these limitations, one of the greatest advantages of smart wearables such as the Apple Watch is the possibility of dedicated hardware-accelerated machine learning to compensate for the wearer’s unique characteristics, including stability of placement on the wrist [10]. This feature allows for the combination of multiple data sources, such as integration with gyroscopes and accelerometers on the same device, and data from additional devices, such as the paired smartphone, to increase the signal-to-noise ratio and improve predictions through further aggregation and refinement [10]. Additionally, the Apple Watch incorporates the benefits of advanced mobile computing, such as over-the-air software updates and seamless integration with smartphone apps, empowering the end user through intuitive data visualization and meaningful alerts when biometric data exceeds predetermined thresholds [10]. For an increasingly smartphone-proficient older adult population, with 54% smartphone ownership in Canada according to most recent market research [23], these benefits are more likely to make meaningful impacts on their clinical outcomes by building from existing personal technology use and increasing engagement, leading to more timely therapy adjustment and intervention [24]. It remains to be seen if these iterative improvements to AI algorithms and onboard processing efficiency can overcome the challenges inherent in wrist-worn reflectance pulse oximetry and whether this will affect perceived accuracy and reliability for both patients with COPD themselves and their health care providers.

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Study Strengths and Limitations

This paper reinforced the importance of further exploration into the balance between the use of monitoring devices, self-management, and medical judgment. As our society faces increasing reliance on health monitoring devices, it needs to be acknowledged that it can be a double-edged sword. Although there are concerns for overreliance on technology reflected in the literature, there are also positive patient role changes related to the increased use of digital technologies. For example, it allows our health care system to increase remote monitoring, patient empowerment, and better consistency of care [9,10]. Furthermore, this qualitative research project conducted in a patient's natural setting revealed the importance of taking into consideration the unique limitations of community-dwelling patients with COPD in future research. An important limitation of this project is the sample size and population selection. This paper focused on the population with COPD, which does answer the literature gap, but is not completely accurate to the demographics in our community. Most patients with chronic illnesses have a more complex profile than a single diagnosis. In fact, many patients with COPD have comorbidities that are interrelated, and all contribute to their health status, which was not discussed in this paper. Following this project, more research is needed as questions remain unanswered, such as: "How should health care providers integrate SpO_2-enabled smartwatches like the Apple Watch into their treatment of community-dwelling older adults with COPD? How can we support patients in their adoption of new technologies while managing expectations about benefits and limitations?"

Conclusions

This study provides new insights on the experiences of patients with COPD using both the traditional finger pulse oximeter and the novel Apple Watch as vital signs monitoring devices. The results discussed physical limitations, the lack of reliable SpO_2 values, and the unexpected preference for the watch. Furthermore, the results covered how the health needs and their unique accessibility experiences impacted trust toward a device. The findings also unveiled a discussion on the significance of a device's accuracy in a sterile environment versus the patient's perspective on reliability in their natural setting and on the importance of clinical judgment as new technologies emerge. Within the participants' experiences, the findings show a contrast between preferences and perceived reliability.

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Data Availability

Data cannot be shared publicly as per the institutional review board–approved protocol and approved consent form. Our approved consent specifically states that participant data that are potentially identifiable will not be shared. Given the nature of our qualitative transcripts and coding sheets, although stripped of identifiers, such as names, they contain potentially identifiable and sensitive participant information in even the most aggregate form if shared with certain individuals who are familiar with the context. Some of the aggregated data may be available with approval from the Research Ethics Committee. For further questions regarding the approved protocol and consent, the office can be contacted at recherche.comtl@ssss.gouv.qc.ca.

Authors' Contributions

AA and ZD were responsible for conceptualization. AA conducted the methodology. YL, AA, DD, and PS were involved in formal analysis. AA, ZD, and SC were responsible for resources. YL, AA, DD, and PS performed data curation. AA, YL, DD, and PS were involved in writing, reviewing, and editing the manuscript. AA, ZD, SC were responsible for project administration. AA, ZD, and SC carried out funding acquisitions. All authors have read and agreed to the published version of the manuscript, and all authors contributed equally to the publication.

Conflicts of Interest

None declared.

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Abbreviations

AI: artificial intelligence
COPD: chronic obstructive pulmonary disease
FDA: Food and Drug Administration

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HR: heart rate
SOB: shortness of breath
SpO_2: peripheral blood oxygen saturation

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Original Paper

The Indirect Impact of Educational Attainment as a Distal Resource for Older Adults on Loneliness, Social Isolation, Psychological Resilience, and Technology Use During the COVID-19 Pandemic: Cross-Sectional Quantitative Study

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Abstract

Background: During the COVID-19 pandemic, government-mandated social distancing prevented the spread of the disease but potentially exacerbated social isolation and loneliness for older people, especially those already vulnerable to isolation. Older adults may have been able to draw from their personal resources such as psychological resilience (PR) and technology use (TU) to combat such effects. Educational attainment (EA) or early-life EA may potentially shape later-life personal resources and their impact on the effects of the pandemic lockdown on outcomes such as loneliness. The developmental adaptation model allows for the supposition that social isolation, TU, and PR may be affected by early EA in older adults.

Objective: This study examined the indirect impact of EA on pandemic-linked loneliness in a sample of older adults. The developmental adaptation model was used as the conceptual framework to view EA as a distal influence on loneliness, social isolation, PR, and TU. We hypothesized that EA would predict TU and PR and have a moderating impact on social isolation and loneliness. We also hypothesized that PR and TU would mediate the effect of EA on loneliness.

Methods: This was a cross-sectional observational study, in which data were gathered from 92 older adults aged ≥65 years in the United Kingdom from March 2020 to June 2021, when the country was under various pandemic-linked social mobility restrictions. The data captured demographic information including age, gender, ethnicity, and the highest degree of education achieved. The University of California Los Angeles Loneliness Scale, Connor–Davidson Resilience Scale, Lubben Social Network Index, and Technology Experience Questionnaire were used as standardized measures. Pearson correlation, moderation, and mediation regression analyses were conducted to investigate the hypotheses.

Results: We found a higher prevalence of loneliness in older adults than in prepandemic norms. EA was correlated with greater TU and PR and moderated the impact of social isolation on loneliness. PR mediated and TU partially mediated the relationship between EA and loneliness.

Conclusions: Early-life EA was confirmed as a distal resource for older adults and played an indirect role in affecting loneliness levels during the pandemic. It has an impact on present-day personal resources, such as PR and TU, which affect loneliness and also moderate the impact of social isolation on loneliness. Policymakers should be aware that older adults with low levels of EA may be more vulnerable to the harmful impacts of loneliness when isolated by choice.

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KEYWORDS

pandemic; educational attainment; isolation; loneliness; socioemotional needs; social engagement; technology use; older adults; psychological resilience

Introduction

Overview

The COVID-19 pandemic has been a severe health and socioeconomic crisis that created an immense amount of pressure with isolation, contact restrictions, and economic shutdown, transforming the psychosocial environment [1]. Public health responses focused on reducing community spread and increasing physical distance ("social distancing"). This helped reduce exposure to the virus and manage pressure on health care facilities. These measures included stay-at-home orders, cancellation of social activities and events, and limited to no visiting permitted.

The older adult population was disproportionately impacted by the pandemic. Older adults were particularly vulnerable to contracting COVID-19 and it progressing to a life-threatening state [2]. Age has also been strongly associated with the risk of fatality due to contracting COVID-19 [3] (eg, UK patients aged >80 years were found to be 20 times more likely to die from COVID-19 than those aged 50-59 years). Although social distancing measures during the pandemic may have been highly advantageous in reducing the spread of the disease, they did lead to an objective lack of interaction, particularly in older adults [4]. Being restricted physically in one location amplified negative outcomes for older adults and led to increased loneliness [5].

Before the pandemic, social isolation and its link to loneliness were well known as a severe public health concern for older adults with links to serious physical and mental health comorbidities [6-9]. Although social isolation may not be emotionally distressing for all, it is a known health risk factor comparable with smoking [10] and is linked to limited access to caregivers; the lack of financial, clinical, or emotional support; and exacerbating loneliness in older adults. Shelter-in-place and social distancing orders may have magnified the problem further, with older adults being restricted to their homes and not being able to see family and friends in person during the pandemic.

Several studies have examined loneliness and social isolation during the pandemic; however, this body of literature is still in its infancy, especially in relation to coping strategies among older adults [11,12]. Loneliness, already at high levels among the older adult population globally [13], is multifaceted and complex. Most studies examining loneliness during the pandemic have reported that loneliness levels in older adults were negatively affected by the COVID-19 pandemic compared with prepandemic norms [14-16]. Some causes identified for increased loneliness emanated from the inability to cope emotionally, social isolation resulting from stay-at-home orders or social distancing, insufficient social support, and inadequate access to communication technologies. Most older adults usually rely on a small number of informal support sources (eg, acquaintances, friends, and caregivers) to overcome hardship or adversity [17]. Limited exchanges with social network members may increase perceptions of stress, social isolation, and loneliness. Recent studies suggest that personal resources, such as technology use (TU) [18] and psychological resilience (PR) [19], may play a pivotal role in protecting older adults from isolation and loneliness. However, currently, there is very limited evidence on how educational attainment (EA) as a distal resource could have impacted these personal resources and whether past EA had an indirect impact on loneliness during the pandemic.

Successful aging is defined as high social, physical, and psychological functioning in old age [20]. The focus of the concept of successful aging is the expansion of healthy and functional years in the life span [21]. Previous studies have found that from a developmental perspective, successful aging results from satisfaction with increasing age-related demands for cultural input, where culture refers to the entirety of social, material, psychological, and symbolic (knowledge-based) resources and is known to reduce psychological vulnerability [22]. This posits the notion that individuals draw from and conserve personal (physical, material, social, and psychological) resources acquired during their life span and use them more as they age, especially in times of difficulty and stress to maintain or restore successful aging.

TU is a resource that could have mitigated the impact of the pandemic on loneliness, and social isolation is TU [11,12]. Previous studies have consistently highlighted the potential positive impact of TU on well-being, with a reduced probability of social isolation due to an increase in connections and a decrease in loneliness [23-26]. Videoconferencing apps (such as Microsoft Teams), instant messaging apps (such as WhatsApp), and services (such as Zoom) grew in popularity during the COVID-19 pandemic, for both social and business use [27]. Digital communication technology (DCT) can also increase social support from family, friends, social groups, and communities, which can be important when someone meets the criteria of being disconnected [28-31]. Recent studies that have examined TU in older adults during the pandemic have largely reported similar findings, for example, Yang et al [32] found that higher TU predicted lower levels of loneliness. Llorente-Barroso et al [33] reported that TU enabled closeness to family and friends. The use of such technology might have mitigated the impact of social isolation with it being used in place of previous in-person meetings among friends, family, and colleagues [29-31,34]. Group-based web-based meetings were being orchestrated through videoconferencing programs, as well as religious gatherings, yoga [18], or playing web-based games [35], all of which may have decreased feelings of loneliness.

Another resource that could have mitigated the impact of the pandemic on loneliness and social isolation is PR [36]. Psychologists have defined resilience as the ability to adapt well in the face of difficulties, tragedy, trauma, threats, or a

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significant source of stress [37] or as a resource that helps adapt successfully to any disturbances and shelter from significant challenges that threaten sustainability, stability, and growth [38]. PR can also be considered as either a process, outcome, or a trait acquired during one's lifetime [38]. As a process, it has been referred to as a dynamic process encompassing positive adaptation when facing significant adversity [39]. Resilience can be thought of as "bouncing back" from such difficult circumstances, and it can also involve personal growth and reflection [40]. Other studies that have demonstrated an increase in loneliness in older adults over time have consistently reported the need to improve the understanding of how PR could be an influencing factor, and there is good evidence that it can protect and even mediate relationships between health-related issues and loneliness [41-45]. Strong social ties have also been described as a key feature of PR [46], which may be improved through interventions [47]. Therefore, for older adults, PR represents an ability to return to equilibrium when they find themselves in difficult circumstances or situations [48-55]. Therefore, PR could have acted as a defense mechanism against increased loneliness and social isolation among older adults during the pandemic.

Factors that may enhance PR include concern for generativity (a concern in establishing and guiding the next generation), frequent religious attendance, and an ability to develop meaning in life when facing adversity [55]. Resilience could also be gained from one's social network and support, and perhaps the ability to remain connected with network members, potentially through technology, may have impacted resilience levels [56], indicating that those with higher PR may have used technology more.

However, despite EA being assumed as a resource acquired in the past for older adults, there is an expectation that this investment in knowledge and skills has long-term beneficial returns [57]. Dannefer [58] envisaged EA to be a mechanism of "cumulative advantage" across the life course, describing it as a process of "accentuation," that is, a process of accumulation throughout the life course. This hints at a potential pathway for early-life experiences shaping later psychosocial states including loneliness, in ways that also influence the acquisition of and the ability to use personal resources later in life. Studies have acknowledged that the association between distal experiences and better outcomes in older populations is mediated by psychosocial variables such as PR [59]. EA may also have an indirect effect on developmental outcomes later in life, including social isolation, how much older adults use technology, and how they draw upon PR to mitigate the circumstances of the pandemic. Therefore, in this study, we were particularly interested in EA as a distal resource in the past, which could have had a continued impact on present-day loneliness mediated by proximal personal resources in older adults.

EA is considered cognitively, socially, and physically stimulating, and has been selected as one of the most representative factors of cognitive reserve, which describes a person's PR and ability to withstand and adapt [60]. Mirowsky and Ross [61] argued that EA influences adults in ways that are diverse, omnipresent in adult life, cumulative, and positive. It creates desirable outcomes because it encourages individuals to evaluate, acquire, and use information and personal resources in effective ways to tap the power of knowledge and help develop the learned effectiveness that enables goal-orientated self-direction amplifying the impact of personal resources [62]. In a study on unmarried older adults, Bishop and Martin [63] found that EA had a negative indirect effect on loneliness (causing it to increase) through neuroticism. Other studies have provided evidence of a link between childhood EA and the development of emotional skills necessary to seek and maintain high-quality social relationships, both in childhood and adult life [64,65]. Kung et al [66], expanding on this, confirmed EA was strongly linked to a lower level of loneliness.

If EA as a distal resource is found to have a significant relationship with proximal personal resources impacting loneliness in older adults while also moderating the impact of social isolation, it may be considered a useful tool to identify older adults who may be more vulnerable to the negative impact of loneliness and isolation. Although there have been studies that have examined loneliness and social isolation in older adults during the pandemic, to the best of our knowledge, this is the first study to examine the impact of EA as a distal resource on levels of social isolation and loneliness during the pandemic, along with its impact on proximal resources such as TU and PR that could help mitigate their effect.

Although an explicit link between EA and PR in the literature is scarce, some studies have strongly hinted at its presence. For example, lower academic dropout rates have been associated with resilience [67], and there has been a consistent relationship between academic success and resilience [68,69]. Backmann et al [70] identified the link between positive outcomes in EA and PR through a link between positive personality traits such as emotional stability, openness, and conscientiousness being related to PR, and observed that EA and PR may modify each other's effects, hinting at a potential mediation pathway with other measures. An additional link connecting EA and PR and their impact on loneliness stems from studies that have found a link between EA and higher cognitive function later in life, which is necessary for PR [71].

EA could also be a bridge that enables older adults to navigate TU. Technology represents advances in skills, knowledge, and abilities that change the manner in which a person performs tasks. It can be considered an acquired personal resource that can make certain tasks easier, more efficient, safer, and perhaps pleasurable. Kämpfen and Maurer [72] in assessing early education of older adults on computer technology adoption and internet use found that 1 additional year of education resulted in almost 9% increase in the probability of having ever used the internet and in an increase of 12% in the probability of having at least "good" computer skills. Other studies noted that the quality of TU was also impacted by EA, although the causes have not been explored in detail [73-75]. This highlights the importance of EA as a distal resource for later-life TU and adoption, and the importance of bridging the knowledge gap about it and its influence on proximal factors.

Conceptual Framework

Studies that have examined stressful circumstances have discovered that personal resources (eg, resilience, self-efficacy,

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and perceived control) and social resources (eg, emotional support and social connectedness) can buffer against the negative impacts of stressful situations [76]. Older adults are generally a group of individuals that are under the increasing threat of actual or potential loss of resources over their life span (based on 5 dimensions including age-associated decline and loss of health resources, early cumulative factors, reduction and loss of economic resources linked to changes in job or retirement, loss of social support resources due to complexities revolving around access, and the personal experiences of losing friends and family members). Theories of aging such as the life course theory proposed by Elder [77] also reflect the age-linked loss of resources and perceived old age, emphasizing that one accumulates resources throughout one's life course, but there is a difference between people in how much they possess and use them depending upon the accessibility and availability of resources, resulting in differing levels [78]. When under threat or in a stressful environment such as the pandemic, individuals would feel encouraged to retain, protect, and foster valued resources for anticipated future requirements [57]. When investment in the acquisition of such resources fails in early life, vulnerability to stressors can lead to negative psychological outcomes such as loneliness [79]. Therefore, it can be argued that past life experiences and investment in resources can reduce vulnerability later in life.

Therefore, EA may be linked to the positive evaluation of contextually stressful or difficult circumstances and experiences and then adaptation to be able to deal with those circumstances. Adaptation is defined as a psychosocial adjustment to changing situations or circumstances [80]. The developmental adaptation model (DAM) by Martin and Martin [81] proposed a mechanism for how early-life experiences can be linked to current circumstances and the ability to adapt and cope with them. Their model synthesized a mechanism by which early experiences or distal influences could impact current outcomes through their action on proximal resources [82-84]. The DAM, with its pathways, can serve as the basis for the exploration of developmental trajectories based on life histories as well as present resources that play a crucial role in successful adaptation.

The model combines distal development influences with proximal influences, behavioral coping mediators, and developmental outcomes. The 2 central components are stress and ability to cope and life span and life course time frame. The model provides for the argument that distal resources influence long-term outcomes, such as loneliness, through action on proximal resources. It allows us to hypothesize the role that could be played by education on resilience and developmental outcomes (ie, loneliness) linking it to higher cognitive function later in life, which is necessary for increased resilience and TU. Essentially, the effect of distal, personal, social, and external resources may lead to an impact on later-life outcomes.

Incorporating DAM in this research allowed us to uncover indirect pathways of EA's impact on loneliness and mediating pathways proximal (social isolation, PR, and TU) variables relative to the current outcomes on loneliness during the COVID-19 pandemic.

Aims

We posit that early EA is a distal resource that affects present-day loneliness. PR and TU, both as personal resources that older adults potentially possess, surface as factors that could directly impact loneliness and potentially mediate the relationship between EA and loneliness. This study was conducted to answer the following research question: "How did past EA as an indirect distal resource influence loneliness through its relationship with social isolation, PR, and TU among older adults during the COVID-19 pandemic?"

To bridge this gap in the literature, we aimed to explore the findings and limits of current knowledge on the indirect impact of EA as a distal resource on loneliness in older adults. We expected EA to influence PR and loneliness, as well as PR and TU, to play a mediating role between EA and loneliness. Furthermore, we expected EA to play a moderating role between social isolation and loneliness. The direct impacts of PR and TU on loneliness were also explored.

We set out to test the following hypotheses:

1. Higher EA is correlated with higher PR and lower loneliness.
2. Higher PR predicts greater TU.
3. EA will predict greater TU after controlling for PR.
4. EA will moderate the impact of social isolation on loneliness.
5. TU will mediate the relationship between EA and loneliness.
6. PR will mediate the relationship between EA and loneliness.

Methods

Setting

This was a quantitative cross-sectional observational study. The STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) checklist was used [85].

Participants

Participants were recruited from England, United Kingdom, with a large majority (n=92, >80%) located in the northwest. The study was conducted during the mandated social distancing period of COVID-19 (March 16, 2020-June 21, 2021), with social mobility largely restricted.

Participants were required to be living in their own homes, be aged ≥65 years (age inclusion criterion specified by the American Psychological Association and APA, 2002) [85], and proficient in English. Participants living in nursing homes, living in care homes, or with a history of mental health issues were not considered eligible for this study.

Recruitment was conducted by advertising through resource centers for older adults, housing associations, third-sector organizations, social activity clubs, and local older adult groups via a personal approach and word-of-mouth recommendations from participants. Participants would either call and leave a voicemail or send an email if they wanted to participate. A call back would be made to determine eligibility, where participants were asked to complete the required informed consent process.

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To determine the minimum size of the research sample necessary for the empirical verification of the tested moderation model, G*Power software was used with an effect size of f_2=0.15, power=0.80, and 3 predictors, using the multiple regression design option for analyses. This resulted in a sample size of 87. A total of 110 participants were recruited for the study. However, 18 participants did not complete all the questionnaires and were excluded. The sample included 92 people aged between 65 and 92 (mean 74.6, SD 7.23) years. All participants were identified as either male or female, with more women (55/92, 60%) than men. More than 89% of the participants were White, with less than 11% from minority ethnicities (n=7 British Asian; n=3, British Black). In North West England, ≤1.4% of the older adult population is British Black, and less than 6.2% is British Asian [19] therefore, our sample seemed to be representative of areas from which participants were recruited. Having collated various demographic information such as age, gender, ethnicity, and education level, we were able to ascertain that the participants emanated from diverse sociodemographic backgrounds.

Variables and Measures

Participants completed a background health questionnaire that was developed based on the *SAGE Encyclopedia of Communication Research Methods* [86] and included capturing age, gender, ethnicity, sexual orientation, and EA.

Loneliness was measured using the 20-item University of California Los Angeles Loneliness Scale [87] with scores ranging from 20 to 80. Higher scores reflect higher loneliness (Cronbach α=.88).

PR was assessed using the 10-item Connor–Davidson Resilience Scale (CD-RISC) [88], in which items were rated on a 5-item scale ranging from 1 (strongly disagree) to 5 (strongly agree). The possible scores ranged from 0 to 60, with higher scores reflecting greater resilience (Cronbach α=.88).

The 12-item Lubben Social Network Index [89] was used to measure social network size and support, reporting on social isolation levels. The possible score range was 0 to 60, with a higher score indicating more social engagement and greater social connectedness (Cronbach α=.88).

TU was measured using the Technology Experience Questionnaire [90], in which participants were presented with a list of technologies (representing communication technology, computer technology, everyday technology, health technology, recreational technology, and transportation technology) and asked to indicate their familiarity with each on a 5-point scale. Scores ranged from 0 to 180, with higher scores indicating greater use of and familiarity with technology (Cronbach α=.84).

EA was defined as the highest level of academic achievement experienced by participants, and options included no formal education, high school equivalent (GCSEs and O-Levels), college or undergraduate degree, postgraduate degree, and advanced postgraduate degree (doctorate or equivalent).

Ethical Considerations

Participants received an information sheet before providing consent either via email or on the phone and were allowed to ask any questions. They were informed of their right to withdraw at any point in the research and given advice about anonymity. Ethical procedures aligned with the British Psychological Society guidelines and the study received ethical approval from the University Faculty Research Ethics Committee (FHMREC19121). Data were captured over the phone after the identity of the participant was confirmed and were recorded in spreadsheets and anonymized.

Procedure

The surveys were conducted over the telephone, gathering information on loneliness, social isolation, TU, and PR in addition to basic demographic information (age, education, and sex). Google Analytics was used to record and tabulate the data, with further analysis performed using SPSS (version 28; IBM Corp). Participants completed the assessments over 14 months, spanning various levels of COVID-19 pandemic–related lockdown measures.

Statistical Methods

All analyses were performed with a 95% probability and a minimum significance level of P<.05. There were no missing data identified among the observations. The variables EA, loneliness, TU, social isolation, and PR were screened for skewness and kurtosis to assess the deviation of their distributions from normality using a histogram with simulated overlapping normal curves. The homoscedasticity of the residuals was checked using standardized residual versus standardized predicted plots. Using the Mahalanobis distance (P<.001) and the Cook distance, we checked whether there was a linear relationship between the dependent variable and each of the independent variables using a scatterplot matrix of dependent and continuous independent variables to see if there were any significant outliers, high leverage points, or highly influential points. None of the patients were considered necessary for removal. Confirmation of the independence of observations and the assumption of no autocorrelation in residuals were checked using the Durbin-Watson d statistic.

The initial descriptive analyses included frequencies, means, and SDs. Pearson product-moment correlation coefficients were calculated to determine if there was an association between the dependent and continuous variables, which could further explain the relationships found in the proposed hypotheses. The same correlational analysis was used to determine whether EA was correlated with PR (hypothesis 1).

Simple linear regression models were built to evaluate whether PR predicts a greater TU to examine hypothesis 2. Whether EA predicts TU after controlling for PR (hypothesis 3) was assessed using hierarchical multiple linear regression analysis. TU was set as the dependent variable, EA was set as the independent variable, and PR was set as the control variable. The associated predictor variables were entered into the model, and a backward elimination approach was used, removing any variable with Cronbach α>.15.

The PROCESS macro for SPSS (version 3.2) by Hayes [91] essentially computes regression analyses containing various combinations of mediators, moderators, and covariates. With model 1, it was applied to investigate the moderating effects of

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EA on the relationship between social isolation and loneliness as per hypothesis 4. If the standardized coefficients of the interaction terms were significant (P<.05) or marginally significant (P<.09), we conducted a simple slope test to examine the interaction effect and further explain the moderating effect.

To test whether TU mediates the relationship between EA and loneliness (hypothesis 5) and whether PR mediates the relationship between EA and loneliness (hypothesis 6), we used the PROCESS macro model 4 by Hayes [91], which allows us to test the mediating relationship with bootstrap CIs for an indirect effect. We applied a bootstrapping approach to determine the indirect effect for each of the bootstrapped 5000 sample items from the original data set using stochastic sampling with replacement. As a nonparametric resampling procedure, bootstrapping is considered the most powerful method for small samples because it is the least vulnerable to type 1 errors. If the CIs did not include 0, the effects were considered significant (P<.05).

Results

Overview

The calculated means and SDs and the maximum and minimum as basic descriptive statistics are shown in Table 1.

Participants demonstrated moderate to high levels of loneliness with 44% of older adults demonstrating loneliness scores above 50 [87]. The Social Network Scale indicated by Lubben [89] that most participants reported good levels of social connectedness, with 82% scoring above 30 points. For PR, most participants (≥57%) scored above 25, demonstrating high levels of resilience [34]. Regarding TU, most participants scored ≥125 (n=92, 56%), demonstrating high use and familiarity with technology in general [90]. However, we noted a binormal distribution with a statistically significant number of participants at the end of the spectrum of low technology scores (n=92, 32%) lower than 120, which indicated low familiarity and use of technology [90]; 64% (n=92) of participants scored ≥2 as far as EA, indicating the completion of A-Levels or a high school equivalent, and almost 38% (n=92) of the participants had an undergraduate degree or higher.

Pearson correlation coefficients were calculated to examine the relationship among EA, loneliness, technology, PR, and social isolation. The results of the correlational matrix analysis are presented in Table 2.

Table 1. Descriptive statistics (n=92).

Scores	Minimum	Maximum	Values, mean (SD)
UCLA[a] Loneliness Score	20	80	47.49 (17.814)
Lubben Social Network Scale	1	49	26.91 (15.304)
Psychological resilience	5	36	21.76 (10.543)
Technology use	48	175	116.87 (40.951)
Educational attainment	0	4	N/A[b]

[a]UCLA: University of California Los Angeles.

[b]N/A: not applicable.

Table 2. Correlational analysis between variables (N=92).

	UCLA[a] Loneliness Score, *r*	Lubben Social Network, *r*	Psychological resilience, *r*	Technology experience, *r*	Educational attainment, *r*
UCLA Loneliness Score	1	−0.853[b]	−0.885[b]	−0.631[b]	−0.674[b]
Lubben Social Network	−0.853[b]	1	0.866[b]	0.557[b]	0.689[b]
Psychological resilience	−0.885[b]	0.866[b]	1	0.610[b]	0.773[b]
Technology use	−0.631[b]	0.557[b]	0.610[b]	1	0.588[b]
Educational attainment	−0.674[b]	0.689[b]	0.773[b]	0.588[b]	1

[a]UCLA: University of California Los Angeles.

[b]P<.01 (2-tailed).

Hypothesis 1: EA Is Correlated With Higher Levels of PR and Lower Loneliness

As shown in Table 2, EA and PR were statistically significantly and positively correlated (r=0.773; P=.007). EA and loneliness were statistically significantly and negatively correlated (r=−0.674; P=.006). This meant that higher EA correlated with higher PR scores and lower loneliness, thus supporting our first hypothesis.

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Hypothesis 2: PR Will Predict Greater TU

The results examining whether PR predicted TU (hypothesis 2) were checked using simple linear regression analysis. TU was set as the dependent variable, and PR was set as the independent variable. Table 3 presents the coefficient results of the simple linear regression analysis.

The results showed that PR (B=2.368, t_{90}=7.298, P<.001) was a significant predictor of TU. The results of the ANOVA test for the significance of the regression model showed that the whole model was significant ($F_{1,90}$=53.261; P<.001). PR accounted for almost 37.2% of the variance (R^2=0.372) of TU. Therefore, we can conclude that PR significantly predicted TU.

Table 3. Model output and coefficients of simple linear regression model on technology use.

Regression equation (dependent and independent variable)	Overall fit					Significance of regression coefficient	
	R	R^2	*F* test	*df1*	*df2*	B	*t* test (*df*)
Technology experience	0.61	0.37	53.26	1	90	N/A[a]	N/A
Intercept						65.33	8.33[b] (90)
Psychological resilience						2.37	7.30[b] (90)

[a]N/A: not applicable.

[b]P<.001.

Hypothesis 3: EA Will Predict TU After Controlling for the Impact of PR

The results examining whether EA predicts TU use after controlling for PR (hypothesis 3) were checked using hierarchical multiple linear regression analysis. TU was set as the dependent variable, EA was set as the independent variable, and PR was set as the control variable. Table 4 shows the coefficient results of the multiple regression analysis.

The results showed that both PR (B=1.501, t_{90}=3.001, P=.008) and EA (B=9.348, t_{90}=2.243, P=.04) were significant predictors of TU. The results of the ANOVA for the significance of the regression models showed that the combined effect of both predictors was significant ($F_{2,89}$=30.339; P<.001). EA alone in the model accounted for almost 34.5% of the variance (R^2=0.345). Adding PR to the multiple regression model changes the value of R^2 by 0.06 (P=.04). Therefore, we can say that after PR is controlled for and EA scores significantly predicted TU, thus confirming our third hypothesis.

Table 4. Model output and coefficients of multiple linear regression model on technology experience.

Model and regression equation (dependent and independent variable)	Overall fit					Significance of regression coefficient	
	R	R^2	*F* test	*df1*	*df2*	B	*t* test (*df*)
Technology use	0.59	0.35	47.45	1	90	N/A[a]	N/A
Intercept					90	83.80	14.14[b] (90)
Educational attainment					90	19.01	6.89[b] (90)
Technology use	0.64	0.40	30.34	2	89	N/A	N/A
Intercept					89	67.94	8.76[b] (90)
Psychological resilience					89	1.50	3.00[c] (90)
Educational attainment					89	9.35	2.24[d] (90)

[a]N/A: not applicable.

[b]P<.001

[c]P<.01.

[d]P<.05.

Hypothesis 4: EA Will Moderate the Impact of Social Isolation on Loneliness

Model 1 was used in the PROCESS 4.0 macro to examine the moderation effect of EA on social isolation for loneliness, as proposed in hypothesis 3 [92] and as shown in Figure 1.

All continuous variables were converted into *z* scores for use in the model; *z* scores describe the position of raw scores in terms of their distance from the mean when measured in SD units and standardize the distribution. As shown in Table 4, the unconditional interaction of EA and social isolation was not significant (β=.14, t_{90}=1.7926, P=.07), and EA did not seem to

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have a moderating effect on the impact of social isolation on loneliness.

To check whether there was any conditional interaction between EA and social isolation, we used the simple slope test to further analyze the moderation impact as can be seen in Figure 2.

When EA was high, social isolation and loneliness were significantly negatively correlated (βsimple(M+1SD)=−0.72, t_{90}=−6.05, P<.001). However, when EA was low, the correlation between social isolation and loneliness was not significant (βsimple(M-1SD)=−1.07, t_{90}=−1.88, P=.06). Thus, we can conclude that EA moderates the impact of social isolation on loneliness when EA is high but does not have an impact when EA is low. This confirms our third hypothesis and offers an explanation for why a moderation impact was not observed initially in the unconditional analysis, as only higher EA seems to have a moderating impact, and at lower levels, the impact is not discernible.

Figure 1. The moderating role of educational attainment on social isolation.

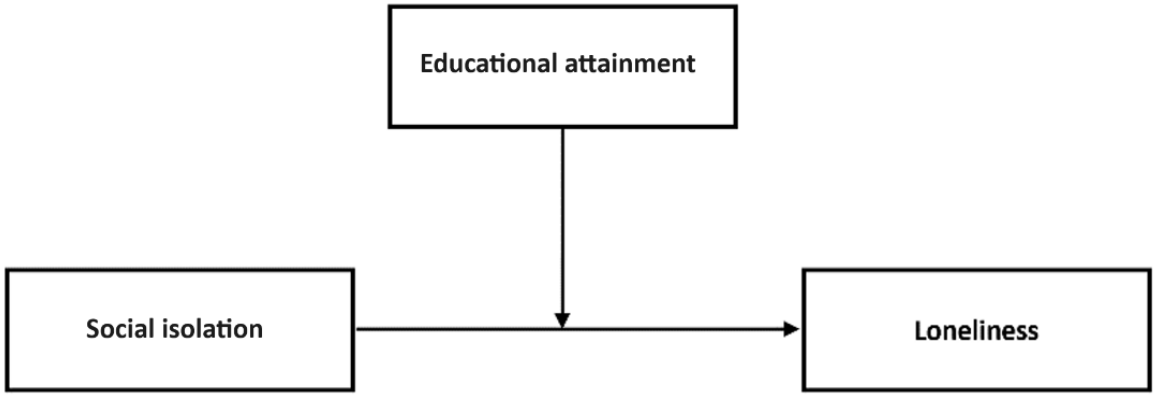
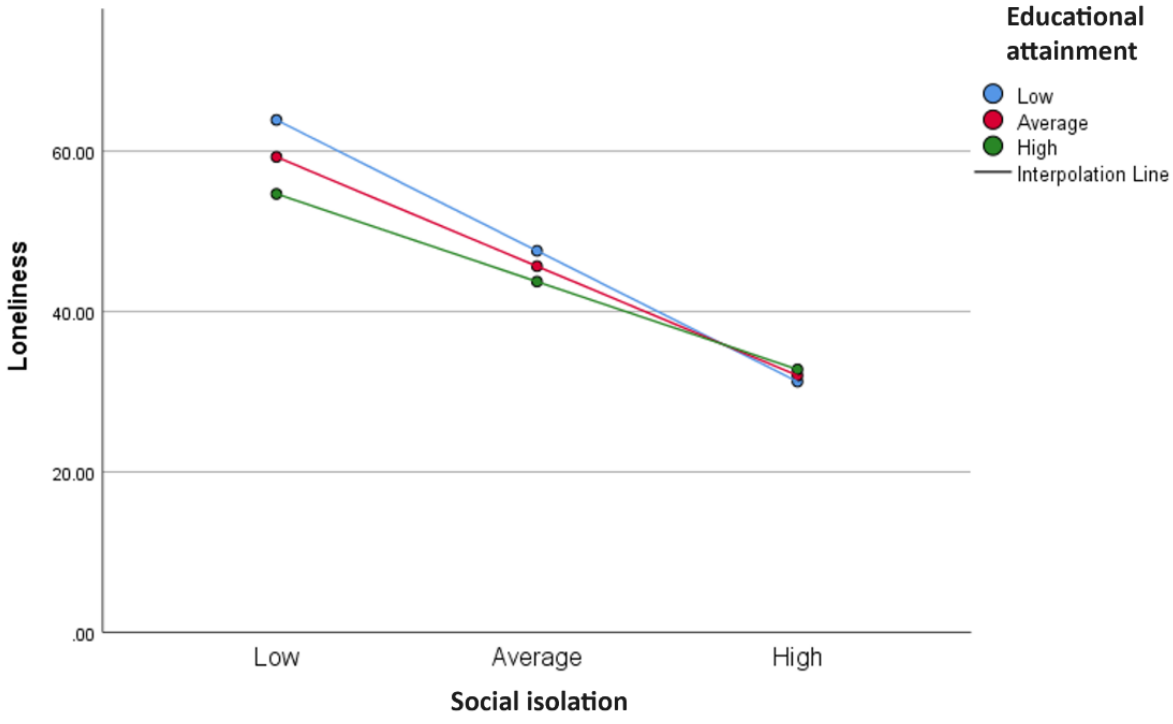


Figure 2. The moderating effect of educational attainment on social isolation. The graph shows the grouped scatter of average loneliness score by social isolation by education level.



Hypothesis 5: TU Will Mediate the Relationship Between EA and Loneliness

Using model 4 in the PROCESS macro 4.0 compiled by Hayes [93], we tested the mediating effect of TU between EA and loneliness, as shown in Figure 3, and the results are summarized in Table 5.

EA had a significant predictive effect on loneliness (path c; B=−0.67, t_{90}=−8.6616, P<.001), and when TU (the intermediary variable) was inserted, the direct predictive effect of EA on loneliness (Path c′) was still significant (B=−0.46, t_{90}=−5.2103, P<.001). The positive predictive effects of EA on TU (path a; (B=0.59, t_{90}=6.8884, P<.001) were significant, and the negative predictive effects of TU on loneliness were also significant (path b; B=−0.3588, t_{90}=−4.033, P<.001; Table 6).

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In addition, the direct effect of EA on loneliness was established (upper and lower limits of bootstrap at the 95% CI −9.01 to −4.04 did not contain 0), and the mediating effect of TU was also significant (upper and lower limits of bootstrap at the 95% CI −5.67 to −0.66 did not contain 0); the bootstrapped mediation indicates the presence of partial mediation of TU on the relationship between EA and loneliness (Table 7).

This intermediary effect accounted for 31.26% of the total effect. Therefore, we conclude that our fifth hypothesis is partially supported.

Figure 3. The mediating role of technology use between educational attainment and loneliness. Here, path a represents the effect of educational attainment on technology use, path b represents the effect of technology use on loneliness, and path c represents the total effect of educational attainment on loneliness. Path c' represents the direct effect of educational attainment on loneliness.

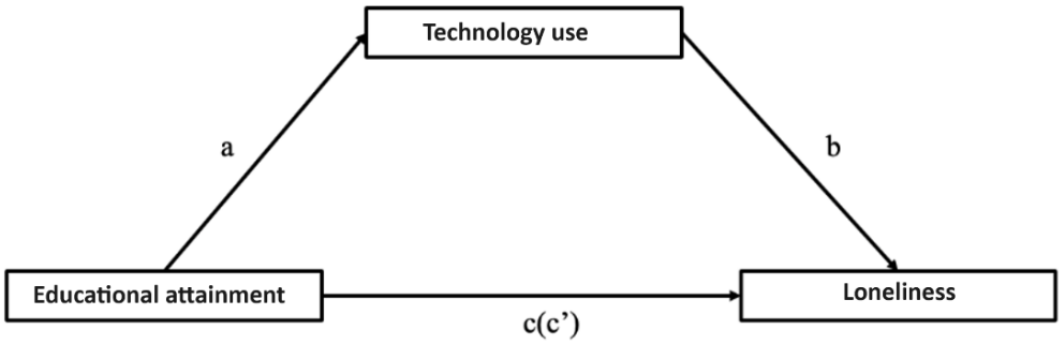


Table 5. Moderation analysis for the effect of social isolation on loneliness with educational attainment as a moderator.

	Overall fit					Significance of standardized coefficient	
	R	R^2	*F*	*df1*	*df2*	B	*t* test (*df*)
Independent variable	0.87	0.75	88.7417	3	88	N/A[a]	N/A
Social isolation (ZSI)						−.89	−10.26[b] (88)
Education (ZEA)						−1.52	−1.35 (88)
ZSI*ZEA						0.14	1.79 (88)

[a]N/A: not applicable.

[b]*P*<.001. All variables in the model were standardized and entered into the regression equation.

Table 6. Intermediary model test of technology use[a].

Regression equation (dependent variable and independent variable)	Overall fit					Significance of regression coefficient	
	R	R^2	*F* test	*df1*	*df2*	B	*t* test (*df*)
Loneliness	0.67	0.45	75.02	1	90	N/A[b]	N/A
Educational attainment (path c)						−0.67	−8.66[c] (90)
Technology use	0.59	0.35	47.45	1	90	N/A	N/A
Educational attainment (path a)						0.59	6.89[c] (90)
Loneliness	0.73	0.54	52.00	2	89	N/A	N/A
Technology use (path b)						−0.36	−4.03[c] (89)
Educational attainment (path c')						−0.46	−5.21[c] (89)

[a]All variables in the model are standardized and introduced into the regression equation.

[b]N/A: not applicable.

[c]*P*<.001.

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Table 7. Decomposition table of the total effect, direct effect, and indirect effect.

	Effect	Boot SE	Boot LLCI[a]	Boot ULCI[b]	Relative effect value (%)
Total effect	−9.4913	1.1	−11.67	−7.31	N/A[c]
Direct effect	−6.5240	1.25	−9.01	−4.04	68.74
Indirect effect	−2.9673	1.27	−5.67	−0.66	31.26

[a]LLCI: lower limit CI.

[b]ULCI: upper limit CI.

[c]N/A: not applicable.

Hypothesis 6: PR Will Mediate the Relationship Between EA and Loneliness

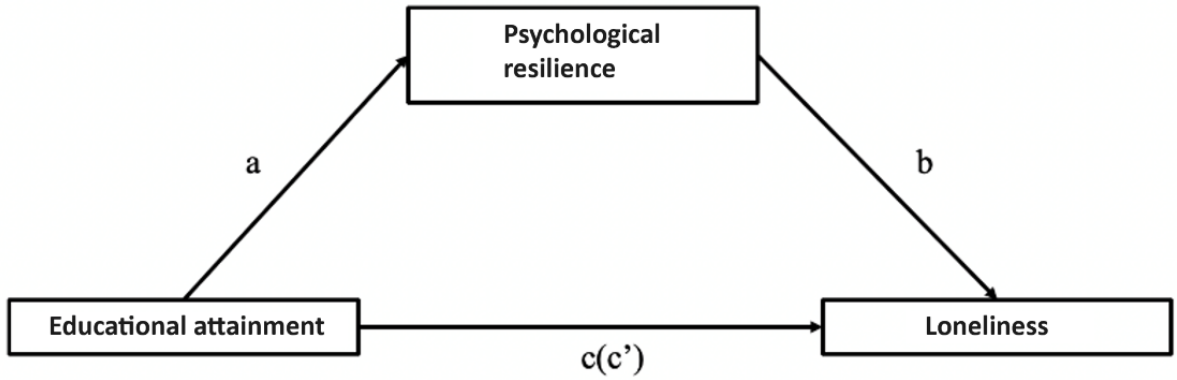
Using model 4 in PROCESS macro40 [93], we tested the mediating effect of PR between EA and loneliness, as seen in Figure 4; the results are summarized in Table 8.

EA had a significant predictive effect on loneliness (path c; B=−0.67, t_{90}=−8.6616, P<.001), and when PR (the intermediary variable) was included, the direct predictive effect of EA on loneliness (path c′) was not significant (B=0.02, t_{90}=0.3065, P=.06), indicating mediation. The positive predictive effects of EA on PR (path a; B=0.77, t_{90}=11.5513, P<.001) were significant, and the negative predictive effects of PR on loneliness were significant (path b; B=−0.9033, t_{90}=−11.6193, P<.001).

In addition, as shown in Table 9, the direct effect of EA on loneliness was not significant (upper and lower limits of bootstrap at the 95% CI −1.84 to 2.51 contained 0), while the mediating effect of PR was significant (upper and lower limits of bootstrap at the 95% CI −12.30 to −7.70 did not contain 0), the bootstrapped mediation indicates the presence of complete mediation of PR on the relationship between EA and loneliness.

This intermediary effect accounted for 96.47% of the total effect. Therefore, we conclude that our sixth hypothesis is supported.

Figure 4. The mediating role of psychological resilience between educational attainment and loneliness. Here, path a represents the effect of educational attainment on psychological resilience, path b represents the effect of psychological resilience on loneliness, and path c represents the total effect of educational attainment on loneliness. Path c' represents the direct effect of educational attainment on loneliness.



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Table 8. Intermediary model test of psychological resilience[a].

Regression equation (dependent variable and independent variable)	Overall fit					Significance of regression coefficient	
	R	R^2	*F* test	*df1*	*df2*	B	*t* test (*df*)
Loneliness	0.67	0.45	75.0230	1	90	N/A[b]	N/A
Educational attainment (path c)						−0.6743	−8.6616[c] (90)
Psychological resilience	0.77	0.60	133.4333	1	90	N/A	N/A
Educational attainment (path a)						0.7728	11.5513[c] (90)
Loneliness	0.89	0.78	160.8685	2	89	N/A	N/A
Psychological resilience (path b)						−0.9033	−11.6193[c] (90)
Educational attainment (path c')						0.0238	0.3065 (90)

[a]All variables in the model are standardized and introduced into the regression equation.

[b]N/A: not applicable.

[c]*P*<.001.

Table 9. Decomposition table of the total effect, direct effect, and indirect effect.

	Effect	Boot SE	Boot LLCI[a]	Boot ULCI[b]	Relative effect value (%)
Total effect	9.4913	1.1	−11.67	−7.31	N/A[c]
Direct effect	0.3354	1.09	−1.84	2.51	3.53
Indirect effect	9.8268	1.16	−12.30	−7.70	96.47

[a]LLCI: lower limit CI.

[b]ULCI: upper limit CI.

[c]N/A: not applicable.

Discussion

Principal Findings

This study set out to examine the indirect distal impact of EA on loneliness and whether its impact on loneliness is mediated by proximal personal resource predictors including TU and PR. We also examined whether EA moderated the effect of social isolation on loneliness. We used the DAM [81] as our conceptual model, which would allow us to explain how early experiences or distal influences could impact current outcomes through their action on proximal resources.

Our first observation was that we found higher levels of loneliness in this study than in other similar cross-sectional studies. In a recent analysis based on a review of the literature by Hawkley et al [94], the authors found prepandemic loneliness prevalence to be around 25% in older adults, compared with 44% in this study, raising an awareness that loneliness prevalence has been higher during the pandemic. The ability to use technology successfully to adapt to challenging experiences during the lockdown and to maintain social connectedness emerged unsurprisingly as a potential factor that reduced loneliness resulting from social distancing, as TU was correlated with lower loneliness. This was in line with our findings from the literature that highlighted the positive impact of TU on loneliness [23-25,31,32]. TU during the pandemic may have increased the ability of older adults to express themselves efficiently and easily, which has been linked to lower levels of perceived discomfort caused by a difficult situation, which is especially important in times of stress [26]. DCT may have also increased social support from family, friends, social groups, and the community, which can be important when someone meets the criteria of being disconnected [28].

In our first hypothesis, we examined the relationships among EA, PR, and loneliness. EA was found to be positively correlated to PR, that is, that higher attainment was linked to higher PR, and negatively to loneliness, that is, higher attainment was correlated with lower loneliness. Despite the scarcity of the literature exploring the connection between EA and PR, several explanations surfaced when applying the DAM. For example, positive personality traits such as emotional stability, openness, and conscientiousness have been found in people with both high EA and PR [70], showing that people with such traits may be more resilient to adverse circumstances and have good adaptive capabilities. Furthermore, EA may support the development of PR, and PR may help with better outcomes in EA [68,69]. In addition, EA is linked to higher cognitive function later in life, which is necessary for PR and may also impact loneliness [71]. The pandemic was a time when our participants may have been surrounded by a lot of negative stimuli, and therefore EA's indirect effect on loneliness through neuroticism may also have come into play, as higher EA and higher neuroticism lead to loneliness and the absence of neuroticism can predict lower loneliness [63]. To combat negative stimuli, older adults may

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have used emotional skills associated with EA and PR to maintain high-quality social relationships during the pandemic [50]. The ability to remain connected with friends and family through technology, sharing positive experiences, social solidarity, the ability to seek support, and generally having a positive mindset as well as applying previously learned skills may all have attributed to EA links with lower loneliness and higher PR [51-53].

Our second hypothesis confirmed the correlational link between PR and TU. Being able to maintain strong social ties has been known to be a key element in people with higher PR [46]. DCTs offer older adults the ability to maintain social connections; thus, older adults with higher PR may have been seeking out the use of technology more [47]. Older adults with a higher PR may also seek a return to equilibrium when facing difficult situations, which may further explain this link [48]. Further specific personality attributes linked to higher PR, such as seeking out meaning in life when facing adversity, may have encouraged older adults to seek out technologies [55]. For example, many church gatherings were web-based [18], and those seeking to find support from these would have to use technologies such as videoconferencing applications. Older adults with higher PR may have also used technology for "social exchange" having communicated with each other frequently to exchange opinions and information, especially on a subject such as the pandemic that was being covered and publicized heavily by media outlets.

EA also predicted greater TU after controlling for PR in our third hypothesis. Ross and Wu [95] suggested that education can provide students with the ability to communicate and analytical skills, gather and interpret information, and solve problems. Such skills increase older adults' ability to control certain life events and outcomes and may contribute toward the ability to use technology. Our results are also consistent with prior research where education was found to increase the use of technologies and improve the quality of use, allowing a person to carry out higher-order tasks, potentially giving older adults a personal resource to overcome difficulties in using technology [73-75]. EA could also be a bridge that enables older adults to navigate and use technology more effectively. Technology represents advances in skills, knowledge, and abilities that change the manner in which a person performs tasks. It can be considered an acquired personal resource that ideally makes performing certain tasks easier, more efficient, safer, and perhaps pleasurable. Early education is linked to better computer skills and the ability to learn complex technologies more easily [72]. Therefore, our study cemented the importance of EA as a distal resource in later-life TU.

Our fourth hypothesis explored whether EA would moderate the impact of social isolation on loneliness. The direct effects of social isolation on loneliness in older adults are well established in the literature [6,8,11,12] and were confirmed in this study. We also saw that despite EA being associated with events in the past, it continued to play a significant role in moderating the impact of social isolation on loneliness. The moderating impact of EA on the effect of social isolation could be connected to the concept that older adults were persistent in maintaining contact with earlier studies, noting that people with higher EA tend to maintain high-quality social networks later in life [64,65]. Social relationships can be challenging and complex, and it is not unsurprising that people who have demonstrated the ability to be persistent with life goals and have developed accompanying emotional skills would be more likely to be able to maintain and manage social relationships, demonstrating how the pathway of EA as a distal resource impacts social isolation. EA may also have allowed people to articulate experiences, engage in social solidarity, seek appropriate social support, maintain a positive mindset, and apply previously learned skills [51,52]. Although the literature has provided some knowledge on explaining this relationship, this aspect of EA's influence on social isolation requires further research.

The main principle of the DAM used in this study to structure our hypotheses highlights that resources shape risks and strengths to deal with difficulties [57] and indeed is an important consideration for successful aging [20,21]. We conjectured on this basis that EA could represent a type of distal resource that could dictate how susceptible older adults may be to loneliness because of its impact on proximal resources that were having a positive impact. To consider this, we examined whether EA would mediate the relationships between PR and loneliness and TU and loneliness. We found partial mediation by EA between TU and loneliness and complete mediation by EA between PR and loneliness. PR is known to be dependent upon high psychosocial functioning linked to EA [68], which allows older adults to maintain a positive disposition and achieve positive outcomes, despite the adversity of their circumstances. The strong link between higher cognitive function and EA later in life, which is essential to PR [71], may also explain the mediation effect. However, it should be noted that the unique circumstances of the COVID-19 pandemic may have amplified the impact of distal influences, as the immediate impact of the pandemic was overpowering, and other resources may have become diminished. Mirowsky and Ross [61] argued that the beneficial effect of a certain resource on another is greater when there is a situational context with resource limitation. They recognized that those with the fewest resources became more dependent on distal resources such as EA than those with more resources. Therefore, during the pandemic, when older adults' resources were severely limited owing to social distancing and other adverse effects associated with the pandemic, EA may have played the role of a compensatory leveling resource, thereby playing a mediating role in PR in the absence of other resources. Thus, we observed the complete mediation impact of EA on PR during the pandemic, which was a notable result. Older adults with lower EA could be provided with further training and support, thereby benefiting them with the same impact as distal EA.

The mediation impact of EA observed between TU and loneliness was partly in line with our expectations. The ability of older adults to use technology can be challenging and often difficult to navigate, as the technological landscape is ever-evolving, with needs being placed on older adults to learn new skills at all times. For older adults, EA may have helped with navigation and understanding of the information they had access to through technological means or given them further

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abilities to communicate and engage, mediating the positive impact of technology on loneliness, in line with the DAM framework. However, we only saw a partial mediation of TU between EA and loneliness. With the lack of qualitative data, we can only conjecture about the possibilities for this result. During the pandemic, older adults may have found technology to have both a positive impact and a negative impact, depending on the type of information they encountered. There was an immense amount of media coverage of the pandemic on social media, with potential health threats to older people being advertised, as well as discussions and interactions that may have been both positive and negative on the topic. Therefore, it is perhaps unsurprising that the mediation impact of TU between EA and loneliness was only partial. However, more light could be shed on this through a structured qualitative study that examines TU and older adults' perceptions of the information encountered and perceptions.

The indirect and direct effects of EA as a distal resource during the pandemic should be noted as a worthy outcome of our study and advance the knowledge associated with concepts behind successful aging. Previous research has focused on the influence of negative distal experiences such as family adversity and early traumatic events on developmental outcomes in older adults. However, EA in our study presented itself as a positive distal resource for older adults during the pandemic. EA is assumed to support increased mobility and opportunity (higher socioeconomic status) [96]; however, our study has shed new light on EA's influence of EA on other proximal resources. Our findings support both the direct and indirect benefits of past EA on loneliness among older adults during the pandemic.

Limitations

This study has several limitations. First, the sampling could have been predisposed to participants with access to or literacy in digital resources and potentially more socially connected individuals, at least virtually, owing to the recruitment process, which was largely coordinated on the web during the pandemic. These participants may have experienced less loneliness and may generally belong to a group with high EA. Second, a cross-sectional design cannot establish causality [97]. The absence of precise measures of PR, TU, loneliness, and social isolation from the period before the outbreak of the COVID-19 crisis for the same people precludes a comparison of the obtained data with prepandemic measures, which would also be useful in completing the picture.

The participants seemed to be representative of the age and gender distribution of the English population. Finally, one of the greatest weaknesses of the study was the lack of any measures of gross or adjusted household income or socioeconomic status based on occupational level (or previous occupational level for those who had retired), which could be linked to higher EA and potentially to higher availability and familiarity with technology. Higher household income would allow for affordability to access technologies and the internet and could add to the explanation of the impact of EA, leaving room for different interpretations and needs to be studied further.

Conclusions

Despite several limitations, our study has practical value for professionals. Gerontologists, counselors, education providers, and aging service providers can use the findings of this study to determine those who may be more vulnerable to adverse circumstances, such as those created by the pandemic. EA in early life could have continued to provide insulating benefits against loneliness when faced with an adverse set of circumstances related to the pandemic. Lower EA and older age can be both considered factors influencing the "digital divide," and this study demonstrates the importance of early-life education on later-life TU, suggesting that greater EA may help with technology adoption leading to the reduction of age-related gaps in the use of technologies. This, combined with EA's relationship with PR, demonstrates that early-life investment in education helps older adults keep up with the increasing speed of technological developments, reducing the risk of digital exclusion, and increasing social participation through digital means.

Finally, one recommendation from this study is that when considering technology interventions for older adults, the study design should consider the EA of participants, as those with lower levels of EA may require more support and training to fully use the benefits of the impact of technology on loneliness. When EA is low, participants could benefit from additional later-life training and knowledge exchange that may have a similar impact.

Suggestions for Future Research and Policy Implications

This study provides support for EA as an important resource for older adults. Our findings highlight the importance of EA in the early life course in influencing current resources. Education can help improve the older adult population's health and well-being, including their ability to deal with life course or pandemic-linked social isolation and loneliness. Our study has provided support for ensuring that EA is not forgotten as an important resource for older adults in times of stress and isolation. EA also plays an important role in combating loneliness and social isolation and older adult use of technology. The literature on later-life cognitive decline strongly suggests that mid- and later-life learning and occupational complexity can act in place of distal EA [98]; therefore, there is a possibility of continued learning as a potential solution to the absence of distal EA, requiring further research.

Our contribution to research related to successful aging included how distal (education) and proximal resources influence the present-day experience of loneliness in older adults, and it can serve as a catalyst in the investigation of the impact of EA on other resources (eg, coping strategies, perceived optimism, perceived control, stress, anxiety, and depression) in older adults. Researchers should further understand the additional impact of distal educational experiences, particularly the level of complexity of education in older adults. They can continue to test and model the mechanisms by which EA may influence psychological well-being and loneliness in older adults. Longitudinal changes in loneliness relative to aging and lifelong and later-life learning experiences may provide a more accurate

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picture of the results of this study. Larger sample sizes with additional parameters such as gender, household income, and ethnicity will help form a richer picture.

This study adds to the body of research calling for policymakers to focus on education in the early stages of the life course to prevent social inequalities, loneliness, and isolation and encourage EA trajectories. It is essential for policy makers to include EA as a vital component in planning for pandemics in the future and to insulate older adults who are vulnerable to their consequences. Further interdisciplinary research into how EA impacts other current resources of older adults and how it can play a role in balancing health disparities is required, as well as research into compensating proximal factors such as continued learning later in life, which need to be explored.

Conflicts of Interest

None declared.

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Abbreviations

DAM: developmental adaptation model
DCT: digital communication technology
EA: educational attainment
PR: psychological resilience
STROBE: Strengthening the Reporting of Observational studies in Epidemiology
TU: technology use

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Diabetes Life Expectancy Prediction Model Inputs and Results From Patient Surveys Compared With Electronic Health Record Abstraction: Survey Study

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Abstract

Background: Prediction models are being increasingly used in clinical practice, with some requiring patient-reported outcomes (PROs). The optimal approach to collecting the needed inputs is unknown.

Objective: Our objective was to compare mortality prediction model inputs and scores based on electronic health record (EHR) abstraction versus patient survey.

Methods: Older patients aged ≥65 years with type 2 diabetes at an urban primary care practice in Chicago were recruited to participate in a care management trial. All participants completed a survey via an electronic portal that included items on the presence of comorbid conditions and functional status, which are needed to complete a mortality prediction model. We compared the individual data inputs and the overall model performance based on the data gathered from the survey compared to the chart review.

Results: For individual data inputs, we found the largest differences in questions regarding functional status such as pushing/pulling, where 41.4% (31/75) of participants reported difficulties that were not captured in the chart with smaller differences for comorbid conditions. For the overall mortality score, we saw nonsignificant differences (*P*=.82) when comparing survey and chart-abstracted data. When allocating participants to life expectancy subgroups (<5 years, 5-10 years, >10 years), differences in survey and chart review data resulted in 20% having different subgroup assignments and, therefore, discordant glucose control recommendations.

Conclusions: In this small exploratory study, we found that, despite differences in data inputs regarding functional status, the overall performance of a mortality prediction model was similar when using survey and chart-abstracted data. Larger studies comparing patient survey and chart data are needed to assess whether these findings are reproduceable and clinically important.

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KEYWORDS

diabetes mellitus; patient-reported outcome measure; life expectancy; diabetes; diabetic; predict; model; mortality; chart review; chart abstraction; patient chart; prediction model; patient-reported outcome

Introduction

Prediction models are being increasingly used in many aspects of clinical practice to identify distinct patient subpopulations and to guide the selection of therapies for chronic disease management [1,2]. For instance, among older adults with diabetes, life expectancy prediction has become integral for determining individualized glycated hemoglobin (HbA_{1c}) goals [3]. The benefits of intensive glucose control (eg, HbA_{1c} level <7.0%) are not realized for 9 to 10 years, and the risks, such as hypoglycemia and falls, in patients with limited life expectancy generally outweigh potential benefits [4-6]. Based on this comparison of life expectancy and time to benefit from intensive glucose control, multiple diabetes care guidelines have recommended the individualization of HbA_{1c} goals by health status [4].

Many prediction models are designed to rely on readily available data from electronic health records (EHRs) and insurance claims [1,7-9]. However, major life expectancy prediction models for older patients require self-reporting of their ability to perform

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basic and instrumental activities of daily living [10,11]. Some of these variables may already exist in various structured or unstructured elements of the EHR, but prior studies have demonstrated that patient-reported outcomes (PROs) obtained via survey may differ from data obtained from the patient's EHR [12-15].

Despite increasing calls to use prediction models, the optimal approach to collecting the inputs for these models as part of clinical practice is unclear. An important question is whether we can rely solely on existing EHR data to populate these models or if we should expend additional resources to systematically collect PRO data. EHRs can be readily available for data extraction and analysis. In addition, EHRs have been designed to include fields for PRO data during the course of routine care. However, systematically collected PROs may reduce rates of missing data, have the benefit of coming directly from the patient, and can be tailored to the needs of the survey or model. Collecting the data often requires more time and effort due to tool development, management of patient follow-up times and nonresponse rates, and addressing of patient difficulties in responding due to cognitive, physical, technological, or other reasons [16]. Thus, it is important to determine the value of systematic data collection for PROs.

While conducting the My Diabetes GOAL (MDG) pilot trial, we systematically collected data for a prediction model via an electronic survey from older patients with diabetes. This created an opportunity to compare results from a life expectancy model using data from chart abstraction and data from patient surveys. The aims of this study were to (1) characterize the magnitude of variation in the availability of data from chart abstraction or survey for individual variables and (2) determine any difference in mortality risk score or life expectancy prediction for patients based on surrogate information from chart abstraction compared to survey.

Methods

Study Population

University of Chicago Medicine (UCM) is an urban academic medical center in Chicago, IL, serving a predominantly Black patient population. Study participants were recruited from UCM's primary care clinic from June 2018 to December 2019 to participate in the MDG pilot, which was a delayed comparator study that creates personalized goals using patient responses and a predictive model. All participants were ≥65 years of age, had a confirmed diagnosis of type 2 diabetes mellitus in the medical record, had attended at least 1 outpatient primary care clinic visit within the year prior to recruitment, and had an active online portal account through UCM. Throughout the MDG pilot, patients were surveyed via the portal about their health status. All participants who completed the initial survey, regardless of the MDG randomization arm to which they were allocated, were included in this study.

Ethical Considerations

The study protocol was approved by the institutional review board at UCM (number 18-0425), and all participants provided written informed consent.

Mortality Index Score

The mortality index deployed during this pilot study (hereafter referred to as the Lee Index) was developed and validated using data from the Health and Retirement Study [17]. The index has been widely used in other geriatric studies [18-22]. The index incorporates demographic characteristics (age, sex, and BMI), information about specific self-reported disease diagnoses (presence of cancer or malignant tumor, excluding skin cancer; presence of heart failure; an activity-limiting lung condition or home oxygen use; and recent cigarette smoker), and self-reported performance on a series of functional limitations (difficulty bathing or showering, difficulty managing money, difficulty ambulating several blocks, and difficulty pushing or pulling large objects). Points assigned to various answers to each question range from 1 to 7 out of a total of 26. The Lee Index calculation was performed twice for each patient: first using the information provided by the patient in their online portal survey and then using the data obtained retrospectively from the chart review described below. The scores were categorized into the following American Diabetes Association (ADA) classes for older adults with diabetes: participants with scores 0 to 7 were classified into class 1 with an HbA_{1c} goal <7.5%, scores 8 to 11 into class 2 with an HbA_{1c} goal <8.0%, and scores >12 into class 3 with an HbA_{1c} goal <8.5% [23,24]. These score cutoffs correspond with life expectancies of >10 years, 5 to 10 years, and <5 years.

Survey

As part of the enrollment and intervention for the larger MDG study, a comprehensive survey was sent to all study participants via an online patient portal in the EHR with questions about their individual health, diabetes management, treatment preferences, and adverse events. A subset of survey answers corresponded to the mortality index questions that were used to calculate the survey score.

Chart Review

A research assistant performed a retrospective chart review in UCM's EHR for all study participants over 6 months prior to and through enrollment. Relevant data were systematically obtained. The medical history and problem list sections were reviewed for relevant diagnoses. Demographic data were obtained from registration forms. Body measures were found in encounter flowsheets. Functional conditions, limitations, and any assessments or clarification of diagnoses were found by manually searching for keywords in a note search feature. All data obtained were recorded and coded into an electronic database. Differences between all survey responses and chart review were compared and frequencies were summed to determine which questions had the greatest diferences between the survey and the chart review.

Life Expectancy Prediction

Life expectancy predictions were calculated from the Gompertz-Predicted Median Life Expectancy data based on the Lee Index score calculated both from the survey and the chart review [11].

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Data Analysis

All quantitative outcomes were summarized with descriptive statistics. The McNemar test was used to evaluate the differences in patients' individual data inputs and ADA classes between chart abstraction and the survey. The Wilcoxon signed-rank test was used to evaluate the differences in patients' mortality index scores and life expectancy between chart abstraction and the survey. Linear regression was also used to model the correlation between the mortality index scores from chart abstraction and the survey. RStudio (version 4.1.0; Posit PBC) was used for data analysis.

Results

Survey

There were 75 participants who completed the survey through the larger MDG study. The majority of participants were female (n=50, 66.7%), identified as Black (n=49, 65.3%), and had a mean age of 72.5 (SD 5.3) years. Additionally, most participants (n=59, 78.7%) had an HbA_{1c} level ≤8%, while approximately a quarter (n=17, 22.7%) had an HbA_{1c} level <6.5% prior to enrollment (Table 1).

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Table . Participant characteristics from chart abstraction at 6 months prior to randomization (N=75).

Characteristic			Value
Age (years)			
	Mean (SD)		72.5 (5.3)
	Median (IQR)		72 (6)
Sex, n (%)			
	Female		50 (66.7)
	Male		25 (33.3)
Race, n (%)			
	Black		49 (65.3)
	White		22 (29.3)
	Other[a]		4 (5.3)
HbA_{1c}[bc]			
	Mean (SD)		7.1 (1.0)
	Median (IQR)		6.9 (1.2)
	Level, n (%)		
		<9%	65 (86.7)
		<8%	59 (78.7)
		<6.5%	17 (22.7)
Blood pressure (mm Hg)			
	Systolic		
		Mean (SD)	131 (16.7)
		Median (IQR)	130 (21)
	Diastolic		
		Mean (SD)	68 (10.2)
		Median (IQR)	67 (12)
BMI (kg/m^2)			
	Mean (SD)		32 (7.1)
	Median (IQR)		31 (8.7)
	<25 kg/m^2, n (%)		11 (14.7)
Use of diabetic medications, n (%)			
	Metformin		49 (65.3)
	Insulin		22 (29.3)
	Sulfonylureas		15 (20)
	GLP-1[d] agonists		12 (16)
	SGLT2[e] inhibitors		5 (6.7)
Other characteristics, n (%)			
	Statin use		63 (84)

[a]Participants identified as “Asian Indian” (n=3) and “More than one race; Hispanic” (n=1).

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

[c]No recent HbA_{1c} (n=8).

[d]GLP-1: glucagon-like peptide 1.

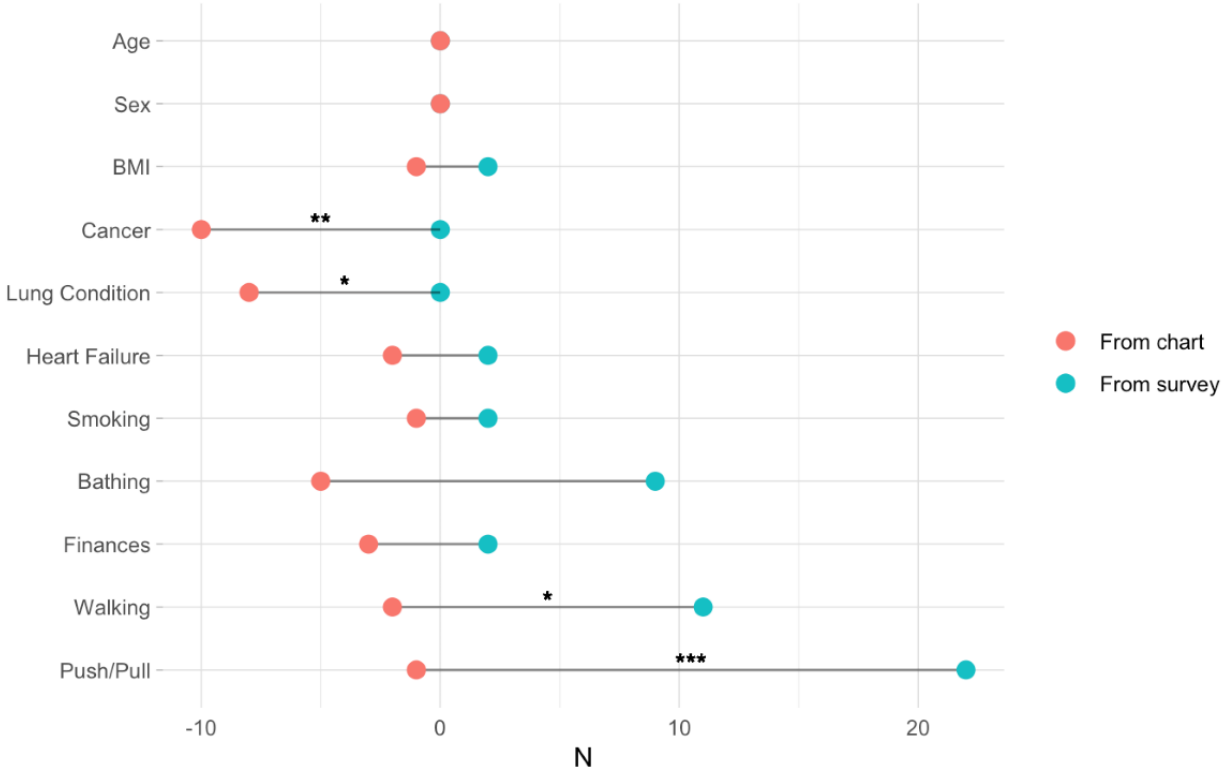
[e]SGLT2: sodium-glucose cotransporter-2.

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Individual Survey Data Inputs

Individual responses to questions were compared between the 2 methods and frequencies were summed to show notable differences across all questions except for demographics (Figure 1). Across questions, the largest differences in available data were related to physical function. A total of 31 (41.3%) individuals noted difficulty completing a task (ie, "bathing or showering," "walking a few blocks," and "pushing or pulling large objects") in the survey that was not captured in the chart review. A total of 23 (30.7%) participants had differences in their ability to push and pull; of these, 22 (95.7%) reported difficulties not found in the chart and only 1 had a reported difficulty in the chart that was not found in the survey. The last functional question, regarding difficulty with finances, differed for 5 participants where more disability was identified in the chart review compared to the survey.

Figure 1. Differences in Lee Index data inputs. The x-axis reflects the number of participants across the study with concordance or discordance across survey and chart-based data inputs. Zero represents agreement between individual inputs. "N" refers to the number of participants with a discordant response to a question. A positive N indicates that the response to the survey question was positive compared to the chart, and a negative N indicates that the response to the chart question was positive compared to the survey. Asterisks indicate a significant difference between the chart and the survey (*P<.05, **P<.01, ***P<.001).



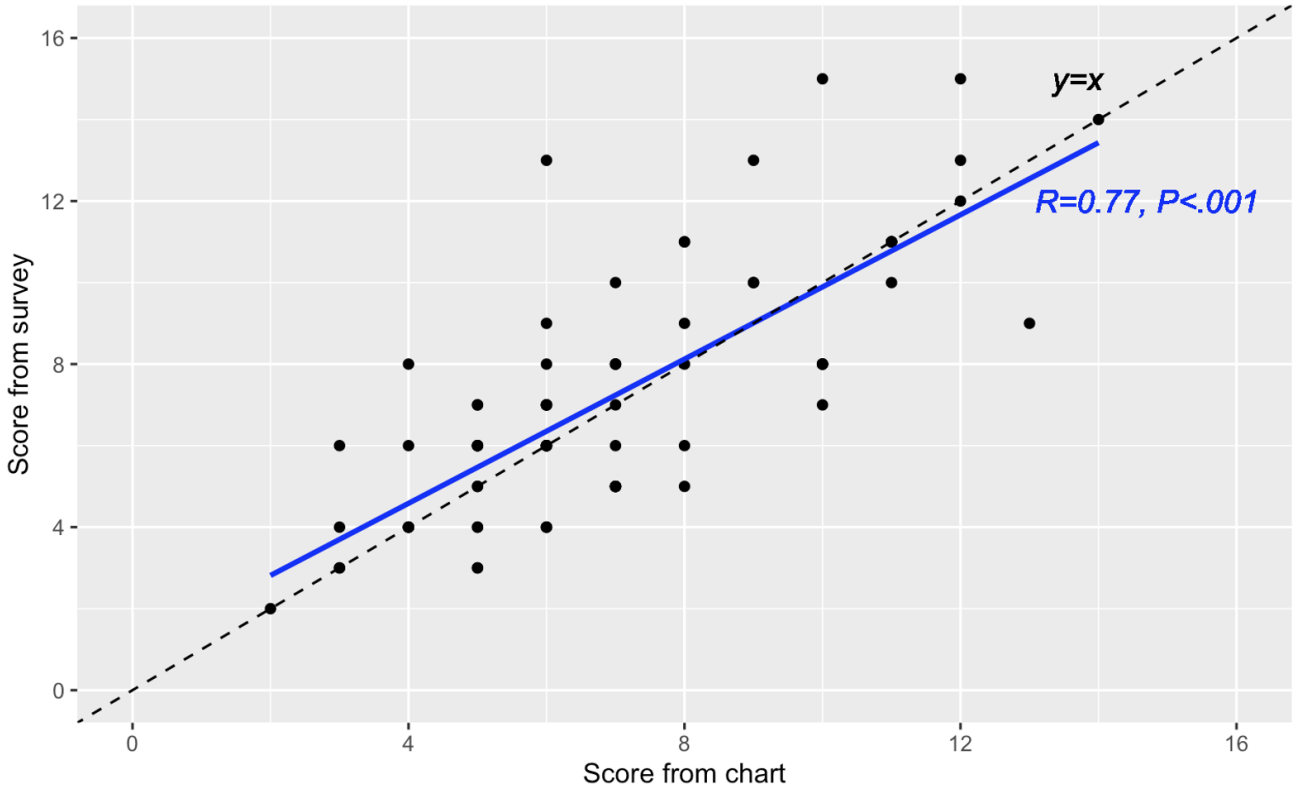
Additionally, 10 participants had a "cancer or a malignant tumor" identified by the chart review that was not reported in the survey, and 8 participants had "a lung condition that limits [their] usual activities" identified by their chart review that was not reported in the survey.

Mortality Index Score

The average mortality index score for all patients based on information from the self-reported MDG survey was 7.23 (SD 3.04, IQR 4), while the score calculated from the chart abstraction was 7.07 (SD 2.66, IQR 4). The difference between the Lee Index score assignment comparing survey and chart review was not statistically significant (P=.82). Comparing individual participants' scores, there was a significant positive correlation between the scores (R=0.77) (Figure 2).

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Figure 2. Mortality index score from the survey plotted against the abstracted score from the chart.



Life Expectancy Prediction

Using the mortality scores, the mean life expectancy prediction for all patients based on information from the MDG survey was 13.37 (SD 6.03, IQR 8.9) years compared to 13.40 (SD 5.53, IQR 8.9) years from the chart abstraction (*P*=.82).

ADA Class

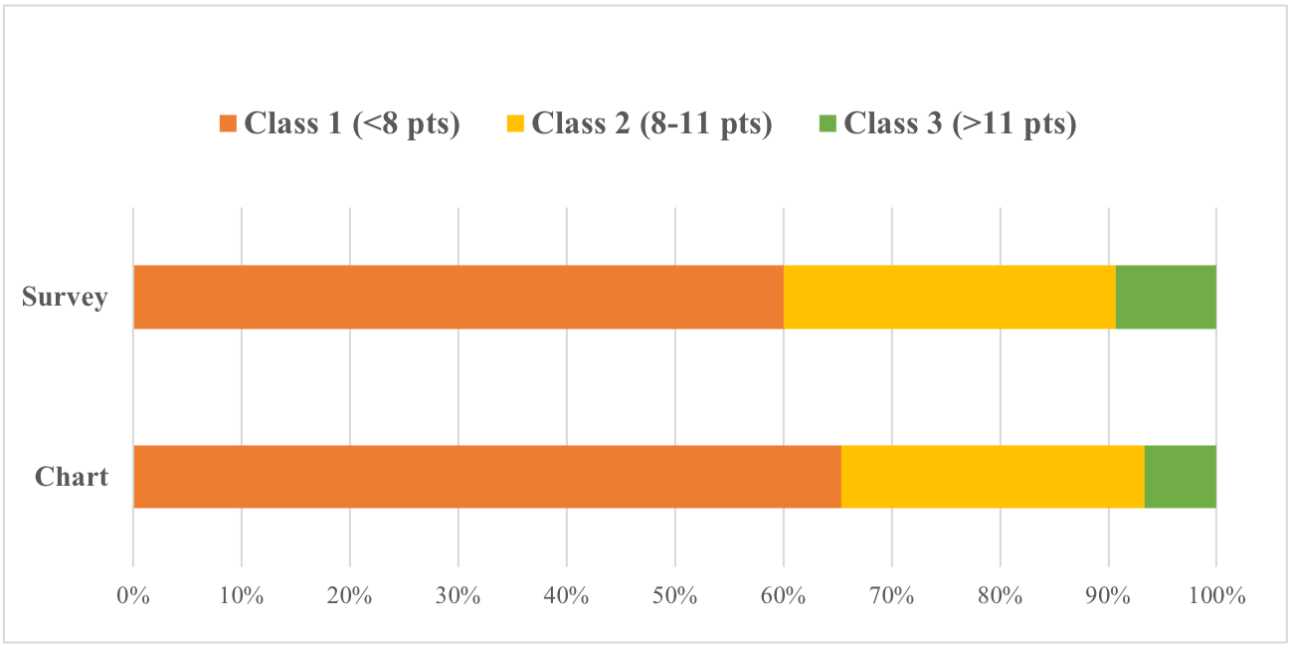
Of the 75 participants, 15 (20%) were placed in different ADA classes based on comparison of the survey and the chart review (*P*=.54; Table 2). The class distribution of the population was similar and not significantly different between the 2 class calculations (*P*=.74; Figure 3). From the survey, 60% (n=45) were in class 1, 31% (n=23) were in class 2, and 9% (n=7) were in class 3. The chart review percentages were 65% (n=49), 28% (n=21), and 7% (n=5), respectively.

Table . Class assignment based on the scores of the Lee Index from survey and chart review data.

Class assignment	Survey class 1, n	Survey class 2, n	Survey class 3, n
Chart class 1	41	7	1
Chart class 2	4	15	2
Chart class 3	0	1	4

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Figure 3. Class comparison. Class was calculated from the inputs for the Lee Index score as a distribution of the total population. Pts: points.



Discussion

Principal Findings

In this small exploratory study, we found differences in the reported functional status and disease history of patients when comparing data from chart reviews and surveys. Despite these differences in data inputs, the overall model life expectancy prediction was not significantly different across the chart review and the patient survey. It is not clear from this exploratory study whether the differences in data availability from the chart and the patient survey would actually lead to clinically significant differences in glucose control recommendations for older patients at scale. An alternative interpretation is that available data in the EHR performed reasonably well despite data limitations.

With the exception of demographics, other domains had differences between the chart review and the survey, the largest difference being in the functional status domains. The functional question related to having trouble pushing or pulling showed the largest difference between the 2 abstraction methods. The same question had the least predictive power in the calculations so it did not affect the overall score and subsequent class calculations significantly in this model. In models for other clinical conditions such as frailty, questions regarding functional status could have greater impact on the accuracy of predictions [25].

An additional area of difference was related to diagnoses. We found that many participants underreported temporally distant and low-stage cancers or early-stage chronic medical conditions such as heart failure or lung disease compared to what was documented in the chart.

A notable limitation in this study is the study size, which likely leaves the study underpowered to identify significant differences. Another is that our original study required patients to be able to use our patient portal application, MyChart. Thus, patients were excluded from recruitment if they did not have an active MyChart account. It is possible that patients who have an active patient portal are more engaged in care and have a more complete EHR than patients without an active portal.

We continued to see differences in several health domains as has been noted previously [15], with the largest differences observed in questions related to functional assessments. Since functional status is clinically important for an array of decisions, our study suggests the need to systematically capture functional status data in the EHR. As a health industry, we already collect responses to many social and behavior questions, like smoking status, to use in various models such as the ASCVD (Atherosclerotic Cardiovascular Disease) Risk Calculator [26], and effort should be made to collect more of these PROs. Our study shows that prediction models, such as the Lee Index, are incomplete without them. The overall impact of this incompleteness would be much more important for populations with significant functional impairments.

Conclusions

The future of health care will likely continue toward an increasing use of prediction models. As health care systems incorporate these models, there will be questions about whether or not to incorporate models that include PROs as inputs. Our study suggests that some of these models may actually already perform reasonably well with available EHR data despite some degree of missingness. Whether or not the degree of missing data leads to clinically important differences will require further study of the value of systematic PRO data collection. Tools such as MyChart open the door for routine collection of such patient-reported data at a reasonable cost to health systems. As systems become more experienced with systematically collecting PROs, these data become part of the EHR. Beyond the utility for predicting future outcomes, eliciting PROs may also have a benefit for patient engagement and health behavior change.

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Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

ADA: American Diabetes Association
ASCVD: Atherosclerotic Cardiovascular Disease
EHR: electronic health record
HbA_{1c}: glycated hemoglobin
MDG: My Diabetes GOAL
PRO: patient-reported outcome
UCM: University of Chicago Medicine

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Original Paper

A Novel Digital Digit-Symbol Substitution Test Measuring Processing Speed in Adults At Risk for Alzheimer Disease: Validation Study

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Abstract

Background: Assessing cognitive constructs affected by Alzheimer disease, such as processing speed (PS), is important to screen for potential disease and allow for early detection. Digital PS assessments have been developed to provide widespread, efficient cognitive testing, but all have been validated only based on the correlation between test scores. Best statistical practices dictate that concurrent validity should be assessed for agreement or equivalence rather than using correlation alone.

Objective: This study aimed to assess the concurrent validity of a novel digital PS assessment against a gold-standard measure of PS.

Methods: Adults aged 45-75 years (n=191) participated in this study. Participants completed the novel digital digit-symbol substitution test (DDSST) and the Repeatable Battery for the Assessment of Neuropsychological Status coding test (RBANS-C). The correlation between the test scores was determined using a Pearson product-moment correlation, and a difference in mean test scores between tests was checked for using a 2-tailed dependent samples *t* test. Data were analyzed for agreement between the 2 tests using Bland-Altman limits of agreement and equivalency using a two one-sided *t* tests (TOST) approach.

Results: A significant moderate, positive correlation was found between DDSST and RBANS-C scores (r=.577; P<.001), and no difference in mean scores was detected between the tests (P=.93). Bias was nearly zero (0.04). Scores between the tests were found to display adequate agreement with 90% of score differences falling between –22.66 and 22.75 (90% limits of agreement=–22.91 to 22.99), and the scores were equivalent (P=.049).

Conclusions: Analyses indicate that the DDSST is a valid digital assessment of PS. The DDSST appears to be a suitable option for widespread, immediate, and efficient PS testing.

Trial Registration: ClinicalTrials.gov NCT04559789; https://clinicaltrials.gov/ct2/show/NCT04559789

(JMIR Aging 2023;6:e36663) doi:10.2196/36663

KEYWORDS

Alzheimer disease; dementia; processing speed; digit-symbol substitution; aging; cognitive

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Introduction

Currently, Alzheimer disease (AD) affects more than 6 million Americans, and by the year 2050, this number is expected to rise to more than 13 million [1]. One in 3 seniors will die while experiencing AD or a related dementia, and the yearly deaths directly attributable to AD account for more than breast and prostate cancer combined [1]. AD and associated dementias also incur a substantial economic and social cost. It is estimated that in 2021, these cognitive diseases cost Americans US $355 billion; this figure is projected to rise to US $1.1 trillion by 2050. Socially, in 2020, more than 11 million unpaid caregivers worked 15.3 billion hours providing support for individuals with AD and related dementias—their time is valued at US $257 billion in lost wages [1]. Recognizing this dismal outlook, the research community has investigated many of the cognitive constructs associated with the disease in an effort to better understand the progression of the illness, detect signs earlier, and potentially develop methods to mitigate it [2].

One cognitive construct researchers have investigated in the context of AD is processing speed (PS). PS is defined as the rate at which an individual can analyze cognitive stimuli and complete cognitive tasks [3,4], and it has been shown to decrease significantly in individuals with mild cognitive impairment and further still in individuals with AD [3]. As such, PS is an important component in cognitive assessment protocols and AD-monitoring programs [5]. Several laboratory- and clinic-based assessments of PS have been developed [5], but the limited availability of these tests concerns researchers as neurobiological decline can occur 15 years before any cognitive deficits are measurable, indicating that testing should take place frequently and ubiquitously to ensure that cognitive decline is detected as early as possible [2,6,7]. More recently, to address the need for widespread, rapid testing, researchers have focused on the development of digital cognitive tests that can be taken quickly on a mobile device and demonstrate high scalability, efficiency, and convenience [6,8]. Although several digital PS tests have been developed and presented as valid assessments [9-11], the validation procedures followed in these studies only examined the linear relationship between novel test scores and a gold-standard test, not the *agreement* between individual scores as is required for proper validation [12]. The purpose of this study was to validate a novel PS task, a digital digit-symbol substitution test (DDSST), by examining its concurrent validity through comparison to a gold-standard test of PS. As tests of digit-symbol coding have been identified as gold-standard measures of PS [13], the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) coding test (RBANS-C) [14,15] was chosen as a comparison for its validity in the population analyzed in this study [15].

Methods

Study Design

This study implemented a cross-sectional design to evaluate concurrent validity between instruments. As a validation study, no random assignment was possible or required. Additionally, no form of blinding was used in this study design.

Participants

The goal sample size for this study was set at 200 participants to ensure adequate statistical power while allowing for potential attrition and incomplete data. Criteria for inclusion were adults aged between 45 and 75 years, BMI between 18.5 and 39.9 kg/m^2, and at least two of the following Alzheimer risk factors: high school education or less; BMI >25; and history of diabetes, hypertension, high cholesterol, or smoking. Participants were excluded if they had a diagnosed mental health condition, dementia, probable dementia, mild cognitive impairment, or other major health condition; a recent cardiovascular event; vision problems that would prevent viewing of a screen; learning disability; or more than one of the following Alzheimer protective factors: a high level of physical activity, a high level of fish consumption, or a high level of cognitive engagement. Participants were recruited in northwest Arkansas using local radio, emails, social media advertisements, news releases, and word of mouth.

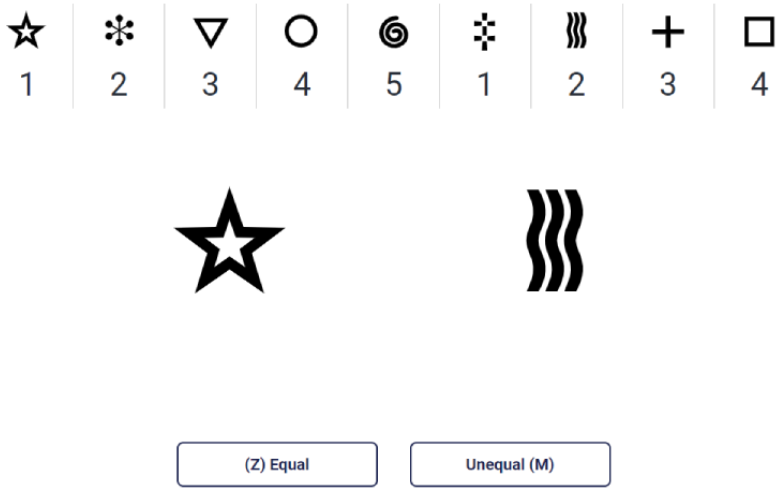
Procedure

Participants reported to the laboratory and completed the RBANS assessment with an experienced test administrator. RBANS assessment procedures are described in detail elsewhere [14], but briefly, the RBANS-C assessment asks participants to match sequential symbols with corresponding numbers from a key on the same page, writing the correct number below each symbol. The RBANS-C raw score is calculated as the number of correct numbers filled in within 90 seconds. Assessments were scored by an experienced test administrator in accordance with the RBANS Testing Manual [14].

After a minimum of 30 minutes of unrelated physical testing, participants were instructed to begin using the self-guided cognitive testing platform (Neurotrack Digital Testing Platform; Neurotrack Technologies Inc) containing the DDSST test. The DDSST is based on the Digit Symbol Substitution Test [16]. The assessment provided both written and visual step-by-step, on-screen instructions; asked participants to determine if 2 symbols were equal or unequal based on a legend with 9 number-symbol pairs (Figure 1); and was objectively scored based on accuracy and speed using Neurotrack's automated scoring algorithm. Specifically, raw scores were calculated as the number of correct responses given in 2 minutes. Data for this study were collected as part of an ongoing parent study (Digital Cognitive Multi-domain Alzheimer's Risk Velocity [DC MARVel] Study) that is longitudinally examining changes in cognition and AD risk measures in at-risk adults randomized into either a health education or health-coaching intervention [17]. Further information regarding other subtests found in the Neurotrack Digital Testing Platform can be found in the published protocol for the DC MARVel Study [17].

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Figure 1. DDSST testing screen seen by participants. In this example, the correct response would be that the star (value of 1) and wavy lines (value of 2) do not represent equal values based on the key. The participant would press the "M" key on their keyboard in this case. DDSST: digital digit-symbol substitution test.



Data Analysis

All statistical analyses were performed utilizing the *Analyse-It* extension for Microsoft Excel. The linear relationship between the RBANS-C and DDSST raw scores was calculated using a Pearson product-moment correlation. For tests of mean differences, agreement, and equivalency, the raw scores for both tests were scaled to a distribution with a mean of 100 and an SD of 15 to allow for the direct comparison of scores without impacting the distribution of scores or the appropriateness of the tests being used. In the case of scaling the RBANS-C score, the obtained score was converted to a *z* score based on the accepted population mean and SD for RBANS-C raw scores and then multiplied by 15, but as no accepted DDSST population mean and SD exists, those obtained from this study were used.

Differences between group means were assessed using a 2-tailed dependent samples *t* test. Agreement was assessed with a Bland-Altman limits of agreement (LoA) plot with a 90% LoA. The LoA cutoff was set at the mean bias plus or minus the minimum reliable change (RC) score for the RBANS-C test obtained from previous literature (z=1.53) [12]. Researchers have stressed that RC is a more appropriate metric for assessing minimum change in the RBANS test than the minimum clinically important difference or standard error of measure [18]. A mountain plot was also generated to assess the y-axis distribution of the mean-difference plot.

Equivalency was tested using a two one-sided *t* tests (TOST) analysis, and the equivalency upper and lower bounds were determined [19] using the RBANS RC score obtained from previous literature described above. An a priori α level of .05 was used for all appropriate analyses.

Ethics Approval

This study was approved by the Institutional Review Board at the University of Arkansas (protocol #2009280813).

Informed Consent

Participants were informed of their rights as research participants and clearly notified that their participation was voluntary and they could withdraw at any time. All participants signed an approved consent form in accordance with the ethical standards of Helsinki.

Results

Participants

In total, 210 participants were initially enrolled in this study. After prestudy attrition and adjusting the data set for incomplete testing data, a final sample of 191 adults (female: n=138; male: n=53) was analyzed. The average age of the sample was 62.2 (SD 8.27) years. Further descriptive statistics are presented in Table 1.

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Table 1. Participant descriptive statistics (n=191).

Measure	Value, mean (SD)	95% CI
Age (years)	62.2 (8.27)	63.4-61.0
Height (cm)	167.5 (9.13)	168.8-166.2
Weight (kg)	84.9 (18.23)	87.5-82.3
BMI (kg/m^2)	30.1 (5.22)	30.9-29.4
RBANS-C[a] score[b]	49.4 (8.09)	50.6-48.3
DDSST[c] score[b]	26.1 (6.57)	27.1-25.2

[a]RBANS-C: Repeatable Battery for the Assessment of Neuropsychological Status coding test.

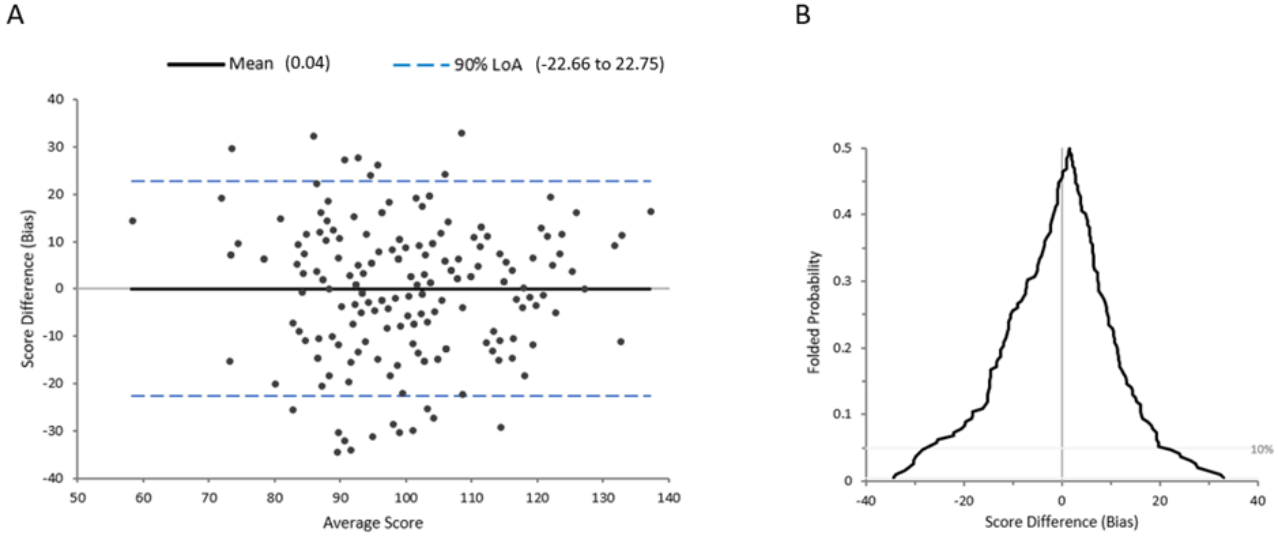
[b]RBANS-C and DDSST scores are presented as raw scores here.

[c]DDSST: digital digit-symbol substitution test.

Data Analysis

The moderately positive correlation obtained for the RBANS-C raw score and DDSST raw score was statistically significant (r=.577; P<.001). A 2-tailed dependent-samples t test showed no significant differences between the RBANS-C and DDSST scores within participants (t_{190}=–0.09; P=.93). Bland-Altman plots revealed the 90% LoA (–22.66 to 22.75) was within the a priori cutoff (–22.91 to 22.99), indicating that the scores for RBANS-C and DDSST were in acceptable agreement. Additionally, the mean bias score was near zero (0.04), indicating low systemic bias in scores, and there was no obvious linear pattern in the scatter plot distribution (Figure 2). The mountain plot distribution was roughly symmetrical, had a peak close to zero bias, and had no obvious tail skew (Figure 2). TOST analysis indicated that the scores for RBANS-C and DDSST were equivalent.

Figure 2. Bland-Altman plot (A) and mountain plot (B) comparing the novel DDSST test to RBANS coding test. DDSST: digital digit-symbol substitution test; LoA: limits of agreement; RBANS: Repeatable Battery for the Assessment of Neuropsychological Status.



Discussion

Principal Findings

The purpose of this study was to assess the concurrent validity of a novel DDSST test as compared to the RBANS-C, a gold-standard measure of PS. Results showed no statistically significant differences in mean test scores within participants; a significant, moderately positive correlation in individual test scores; and acceptable agreement and equivalency between the 2 assessments. These results indicate that the DDSST is a valid assessment tool for evaluating PS in the sample of middle-age and older adults.

Impact

The potential impact of an assessment such as the DDSST is greater when the efficiency, scalability, and convenience of a digitally enabled test is considered. Digital tests allow the instant reporting of results to the test taker and potentially clinicians; the immediate and ad hoc distribution of tests to any number of test takers; and the convenience of having the ability to take tests anywhere, at any time.

Compared to previous studies validating digital assessments of PS, the relationship between the novel test and gold-standard test was lower here (r=.577 vs r=.75-.8) [10,11]. Validation, however, should not be based upon correlation between scores as this does not accurately demonstrate agreement between individual scoring pairs but rather an overall linear relationship

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that minimizes residuals [12]. Of the previous studies of digital instruments evaluating PS reviewed by the authors, none analyzed or reported the agreement between paired measures from novel and gold-standard tests in their assessment of concurrent validity [9-11]. As such, this study conducted a more comprehensive analysis of concurrent validity through the additional examination of agreement and appears to be the first study of a digital PS test to base its validation on those criteria.

Limitations

First, this study may have been limited by its protocol. It was carried out as part of a larger trial, and the order of testing was not randomized in the protocol to minimize learning effects or cognitive fatigue effects. Second, the sampling procedure specifically excluded individuals with cognitive impairments. By excluding segments that exist in the general population, generalizability is reduced. Third, intrarater and test-retest reliability could not be assessed for the novel DDSST instrument as repeat trials were not conducted as a part of this data set.

Future Directions

Future studies should include individuals with cognitive impairments to assess validity in a broader population segment, as well as assess the ability of the DDSST to discriminate between levels of cognition. Although the test-retest reliability of the DDSST has been verified in a different sample [20], additional psychometric testing with a representative population is warranted to ensure the full utility of the measure.

Conclusion

Despite the study's limitations, the DDSST shows promising clinical utility. DDSST scores were in agreement with, and equivalent to, scores obtained from the RBANS-C, a gold-standard test of PS. Given its demonstrated concurrent validity, the DDSST appears to be a suitable option for widespread and rapid cognition testing. Further investigation, however, is required to assess the reliability of the instrument.

Data Availability

The data sets generated or analyzed during the current study are not publicly available due to the ongoing nature of the parent study, but aggregate data specific to the present study are available from the corresponding author on reasonable request.

Conflicts of Interest

ENM was an employee at Neurotrack Technologies while this work was completed and received salary and stock options. JM and JMG are employees at Neurotrack Technologies and receive salary and stock options as part of their employment.

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Abbreviations

AD: Alzheimer disease
DC MARVel: Digital Cognitive Multi-domain Alzheimer's Risk Velocity
DDSST: digital digit-symbol substitution test
LoA: limits of agreement
PS: processing speed
RBANS: Repeatable Battery for the Assessment of Neuropsychological Status
RBANS-C: Repeatable Battery for the Assessment of Neuropsychological Status coding test
RC: reliable change
TOST: two one-sided *t* tests

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Examining Public Awareness of Ageist Terms on Twitter: Content Analysis

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Abstract

Background: The World Health Organization, the Centers for Disease Control and Prevention, and the Gerontological Society of America have made efforts to raise awareness on ageist language and propose appropriate terms to denote the older adult population. The COVID-19 pandemic and older adults' vulnerability to the disease have perpetuated hostile ageist discourse on social media. This is an opportune time to understand the prevalence and use of ageist language and discuss the ways forward.

Objective: This study aimed to understand the prevalence and situated use of ageist terms on Twitter.

Methods: We collected 60.32 million tweets between March and July 2020 containing terms related to COVID-19. We then conducted a mixed methods study comprising a content analysis and a descriptive quantitative analysis.

Results: A total of 58,930 tweets contained the ageist terms "old people" or "elderly." The more appropriate term "older adult" was found in 11,328 tweets. Twitter users used ageist terms (eg, "old people" and "elderly") to criticize ageist messages (17/60, 28%), showing a lack of understanding of appropriate terms to describe older adults. Highly hostile ageist content against older adults came from tweets that contained the derogatory terms "old people" (22/30, 73%) or "elderly" (13/30, 43%).

Conclusions: The public discourse observed on Twitter shows a continued lack of understanding of appropriate terms to use when referring to older adults. Effort is needed to eliminate the perpetuation of ageist messages that challenge healthy aging. Our study highlights the need to inform the public about appropriate language use and ageism.

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KEYWORDS

social media; informatics; aging; ageism; public; COVID-19; disease; language; older adults; Twitter; elderly; term; terminology; pandemic; tweets

Introduction

Ageism has been defined as the "ideas, attitudes, beliefs, and practices on the part of individuals that are biased against persons or groups based on their age" [1] and "stereotyping and discrimination against individuals or groups based on their age" [2]. Ageism stems from everyday language that portrays older adults as a burden on society. Older adults are associated with the derogatory terms "geriatric," "geezer," and "senior citizen" while being inappropriately described as "adorable," "dried up," or "grumpy" [3]. This language perpetuates a stigma surrounding older adults in our society, such as the perspective that older adults are frail and incompetent [4] or that they are out of touch and burdensome [2]. Many perceive aging as a problem that needs to be fixed, leading to the segregation and social exclusion of older adults.

Ageism influences the physical and mental health of older adults [5]. Research has shown that internalized ageism is associated with a lower life expectancy, high blood pressure, reduced self-esteem, diminished risk taking, and decreased motivation [6]. Summers [1] further stated that the functional health of older individuals can worsen over time as a result of insults and negative images [1]. This is particularly detrimental considering the positive impact this population has on our society. For example, older individuals contribute significantly to the economy as they have additional free time and a more flexible income [7]. Furthermore, older adults stay active in their communities through volunteering, activism, advocacy, and nurturing [8].

The isolation of older adults from the rest of society has become more evident during the COVID-19 pandemic. Only 5% of Chinese people aged 60 years and older use the internet on a

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regular basis [9]. During a pandemic, older adults who do not know how to use technology to shop for groceries, socialize, order medications, or educate themselves about the virus may face difficulties [9]. Moreover, as governments try to establish a new "normal," older adults are being increasingly isolated. During the earlier part of the pandemic, the Chinese Center for Disease Control and Prevention cautioned older adults against traveling while the rest of the public was urged to "go out and resume spending" [9]. There is a false sense of security for younger members of our society because "COVID-19 is life-threatening, but mostly for the older adults and those with underlying conditions" [10]. This perspective propagates ageism, which impacts everyone in due time as no one can avoid aging.

Due to the negative impact caused by the public's use of ageist language, the editor of the *Journal of Gerontological Social Work* announced the replacement of "the elderly" with "older adults" when "vulnerable" is used [11]. The Gerontological Society of America has promoted the Reframing Aging Project's recommendations to use "older people" or "older adults" instead of "senior" and "the elderly" as well as inclusive "we" and "us" terms [12]. Current efforts to combat ageism from the World Health Organization and the Gerontological Society of America are examples of widespread campaigns to address this critical problem, with a target audience comprising largely researchers and those working in aging services. The American Association of Retired Persons (AARP) also created a public-facing effort to guide the public toward more inclusive language that does not segment older adults. Terms such as "older persons," "older people," "older adults," "older patients," "older individuals," "persons 65 years and older," and "the older population" are preferred. Terms such as "seniors," "elderly," "the aged," "aging dependents," and similar "othering" terms are not recommended because they connote a stereotype and suggest that older adults are not part of society but are a group apart [13,14]. The AARP has been promoting a campaign to "disrupt ageism" for at least 3 years now, with recommendations for employers, employees, and others to use language that is respectful and does not reinforce stereotypes and myths about older persons.

Studies on social media have successfully exposed societal norms and biases and have shown how social media may be influencing societal norms, social movements, and individuals' perceptions. Its large-scale ability to propagate ideologies has broad implications for creating and spreading harmful perceptions about racism, sexism, and ageism, often coupled with political influence [15]. Accordingly, researchers have used Twitter data to assess the propagation of ideologies related to health, wellness, politics, and public health at the societal and individual levels [16-19].

The impact of social media in a number of areas has been documented at the individual and societal levels: political influence [15,17,20,21], individuals' mental health affected by sexist and racist discourse online [16,22], and public health messages [19,23,24]. The prevalence of ageist content and the use of unsuitable language are troubling, not just for older adults but for everyone, given that we all age. The percentage of older adults (≥65 years) using social media has grown from 11% to 45% during the 2010-2021 period [25], and the negative public discourse will be harmful to those exposed to ageist content. Existing studies inform our understanding of public discourse and the ways through which we can move forward to resolve any conflicts and tensions.

Building on previous works, we investigated how the public used ageist language on Twitter, particularly during the COVID-19 pandemic, given the increases in ageist content observed during this time period [26]. We aimed to answer the following 2 research questions (RQs):

- RQ1: What is the prevalence of improper terms (eg, "old people" and "elderly") referring to older adults on Twitter?
- RQ2: How are the terms referring to older adults associated with ageist and antiageist content?

To answer these questions, we collected 60.32 million tweets with hashtags related to COVID-19. We then conducted a mixed methods study comprising a content analysis and a descriptive quantitative analysis.

Methods

Twitter Data Collection and Keyword Search

We collected Twitter posts between March and July 2020 that included these COVID-19–related hashtags: #COVID, #Sars-Cov, and #COVID19. We then subsampled posts that used ageist language as well as language that may indicate discussion on ageist discourse. To subsample Twitter posts that used ageist language, we identified a list of ageist language keywords aggregated from existing articles. In addition, research team members who are experts in ageism also brainstormed for keywords. We then searched these keywords on the Twitter website. Using the first 20 posts we retrieved, we assessed whether the posts referred to older adults. We then narrowed down the list of keywords, discarding those that resulted in irrelevant posts. The final keywords were "old people," "elderly," "older adult," "ageist," and "ageism." Other keywords, such as "senior," for instance, retrieved too many irrelevant posts, such as those related to "high school seniors." Thus, we excluded tweets that used such terms from the analysis.

Qualitative Analysis

With the collected data, we used two methods to address the two RQs. First, we developed a codebook for a qualitative content analysis based on an existing survey instrument that measures ageist perception or ageist content. Several instruments exist that measure ageism: the Ambivalent Ageism Scale [27], the Ageism Survey [28], the Fraboni Scale of Ageism (FSA) [29], and the Competence and Warmth Scale [30]. Among these scales, we used the FSA, given its high citation, comprehensiveness, and inclusivity of ageist concepts when compared to the other surveys. We thematized the FSA survey questions into three categories: (1) the perception that older individuals cannot make good decisions, (2) the perception that older individuals are a burden on society, and (3) the devaluing of older individuals' lives. We then applied these themes as codes for ageist content. We also included a theme to code antiageist content that criticizes ageist messages.

We randomly selected 150 tweets from the Twitter data. We randomly divided these tweets into 3 sets of 50 tweets and

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distributed the data to 3 coders. Using the codebook, 3 individuals coded 50 randomly selected tweets and 1 coder coded all 150 tweets. Given the implicit nature of the Twitter data (eg, posts can indicate sarcasm), it was challenging to establish high interrater reliability. Instead, we coded a common set of 20 tweets as a group, and using the agreed-upon codebook, we individually coded the assigned tweets. We then negotiated any disagreements.

Quantitative Analysis

For the descriptive quantitative analysis, we first counted the total posts that contained the keywords mentioned above. We also counted frequencies of ageist versus antiageist posts from the qualitative findings to understand the relationship between ageist content and terminology used to denote older adults. Specifically, we wanted to understand whether posts that included ageist terms were intended to be ageist and whether posts that included appropriate terms were nonageist.

Ethical Considerations

All data reviewed are publicly available and were collected through the Twitter API (application programming interface) and deidentified. Therefore, no ethical review or approval was deemed necessary.

Results

Use of Ageist Terms (RQ1)

As shown in Table 1, out of 60.32 million tweets, the term “elderly” occurred in 32,700 tweets (0.05%), “old people” occurred in 26,230 tweets (0.04%), and “older adult” occurred in 11,328 tweets (0.02%).

Table . The prevalence of terms referring to older adults on Twitter in tweets related to COVID-19 (N=60,320,000).

Keyword	Frequency[a], n (%)	Examples
“elderly”	32,700 (0.05)	• “Keep your elderly folks from flying. If the CDC advised the elderly population to try to stay indoors as much as possible the elderly should not be exposing themselves to airports filled with people or get on a plane where the air is recycled. This goes for (1 #CoronoaVirus)” • “It is but if ur elderly or got elderly family or existing diseases affected by flu or weak immune system then its bad”
”old people”	26,230 (0.04)	• “false alarm everybody turns out the coronavirus only kills old people” • “Young people on the ship MORE likely to have symptoms. We were fed another lie. More old people got infected because old ppl like cruises. #COVID19 #SARSCoV2 #coronavirus #outbreak #pandemic #USA #COVID19 #CDC #NYC #coronavirususa #Covid_19 #COVID2019 #COVID2019 #coronavirusus” • “Old people disproportionately die from #COVID19”
”older adult”	11,328 (0.02)	• “New CDC guidance says older adults should ‘stay at home as much as possible’ due to coronavirus” • “Advice from @WHO about keeping safe in older adults or at risk groups People, chat to your relatives now. Look after them. Wash your hands” • “Should older adults stay home to avoid coronavirus? Heres what health experts say - Macon Telegraph #news #feedly”

[a]Number of tweets that included the keyword.

Terms Referring to Older Adults and Ageist and Antiageist Content (RQ2)

Next, we investigated whether each term referring to older adults in tweets promoted or spoke against ageism. Table 2 describes the frequency results.

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Table . The qualitative coding results identifying ageist content.

Keywords	Code			Tweets, n		
	C1[a]	C2[b]	C3[c]	Ageist tweets	Tweets against ageism	Neutral tweets
Keyword against ageism, n (%)						
"ageism" (n=30)	0 (0)	0 (0)	0 (0)	0 (0)	23 (77)	7 (23)
"ageist" (n=30)	1 (3)	2 (7)	4 (13)	7 (23)	21 (70)	2 (7)
Proper term, n (%)						
"older adult" (n=30)	3 (10)	1 (3)	1 (3)	5 (17)	7 (23)	18 (60)
Improper term, n (%)						
"elderly" (n=30)	1 (3)	5 (17)	7 (23)	13 (43)	12 (40)	3 (10)
"old people" (n=30)	4 (13)	2 (7)	6 (20)	22 (73)	5 (17)	3 (10)

[a]C1: Does this tweet suggest older individuals cannot make good decisions?

[b]C2: Does this tweet suggest older individuals are a burden on society?

[c]C3: Does this tweet devalue older individuals' lives?

"Old People" Tweets

The majority of the tweets that contained the term "old people" were flagged as ageist (22/30, 73%), specifically in terms of devaluing older individuals' lives (16/30, 53%). These tweets included those linking the vulnerability of older adults to COVID-19 as a positive outcome of the pandemic. For instance, a tweet with "old people" as a keyword said, "how old is the editor/journalist. I heard the novel coronavirus love old people so hard. What I am hoping on top of my head is all old and old minded people be wiped out by this old-loving virus." Four tweets with the term "old people" suggested older individuals cannot make good decisions. These tweets criticized "old people" as being unable to make good decisions in terms of voting. Two tweets included content that suggested older adults are a burden on society.

"Elderly" Tweets

Of the tweets that included the term "elderly," 43% (13/30) were ageist whereas 40% (12/30) were against ageism. The majority of the ageist tweets with the term "elderly" included content that suggested older individuals are a burden on society (5/30, 16.7%) and devalued older individuals' lives (7/30, 23.3%). For example, extremely hostile tweets containing the term "elderly" were shared, including the following: "The elderly are a drag on the world economy. Covid19 preferentially kills the elderly. Illuminati developed Covid19 to prune the elderly population." On the other hand, antiageist tweets with the term "elderly" contained content that questioned how the threshold of "elderly" was defined and shared criticisms against ageist incidences around the world. An example tweet said: "ok so all these fucking attacks on elderly nfluen in San Francisco etc are disgusting. Ya'll need to sit your ass down, get re-educated and respect THE FUCKING ELDERLY. Not just elderly, but seriously. What gives you the RIGHT to assault, rob or humiliate a person. #COVID19."

"Ageism" and "Ageist" Tweets

The majority of the discourse that involved the terms "ageism" and "ageist" was about raising awareness of ageism. These tweets critiqued the widely circulating perspectives of COVID-19–related ageist tweets on the vulnerability of older adults and individuals with chronic illnesses and the reduced danger of COVID-19 given that it "only kills old people." Multimedia Appendix 1 provides frequencies and examples of Twitter content that included "ageism" and "ageist" terms in our data set.

"Older Adult" Tweets

While the term "older adult" is an aging-friendly term, we still observed a few tweets (5/30, 17%) associated with ageist content. For instance, themes seen in other ageist tweets were observed in "older adult" tweets (eg, older adults cannot make good political decisions: "You heard it here, folks. Let the young people handle voting. No need for older adults to risk it at their local polling location!"). The majority of the tweets were neutral, meaning that the tweet was neither ageist nor specifically arguing against being ageist. "Older adult" tweets were often retweets of news articles on older adults related to the COVID-19 pandemic (eg, "Older adults should 'stay at home as much as possible' due to coronavirus, CDC says").

Discussion

Principal Findings

We found that the use of ageist terms was prevalent on Twitter. Twitter users also used ageist terms to criticize ageist messages, showing a lack of understanding of the appropriate use of terms when referring to older adults. Highly hostile ageist content against older adults came from tweets that denoted older adults with derogatory terms.

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Comparison to Prior Work

Ageism has been heightened during the COVID-19 pandemic, and researchers have highlighted the hostile messages being propagated through social media against older adults and their role in society [31-34]. Accordingly, this was an opportune time for researchers to assess what language is being used and how this language is associated with ageist messages.

The terms "old people" and "elderly" were more prevalent than "older adult" in tweets. This finding shows a continued use of ageist terms despite the efforts of various organizations to raise awareness about not "othering" older adults. In addition, tweets with the term "elderly" showed a high percentage of antiageist content, which also suggests a lack of awareness of recommended terminology and of the derogatory nature of the term "elderly" as deemed by the AARP.

Strengths and Limitations

Our paper uniquely contributes to the field of aging using social media data and qualitative and quantitative methodologies to assess the public's use of common ageist terms. This study has a few limitations. First, the terms we used to assess ageist term use were not exhaustive. Such limitation came from the fact that the excluded terms were used in multiple ways depending on the context (eg, "senior" referring to senior housing rather than to older adults). Thus, we limited our use of the terms for analysis to those that were explicitly referring to older adults. Although using exhaustive terms would have generated more complete results, we were able to address our RQs with the terms we identified. Second, Twitter content can often convey sarcasm, which can result in interpretive errors. We engaged all coauthors of this manuscript to discuss and converge on the final interpretation. Lastly, the qualitative analysis was limited to a subset of the Twitter data set due to logistical feasibility (eg, time and resources needed for manual coding). However, this is a common practice in follow-up qualitative research to give richer nuance and context to quantitative results.

Future Directions

We suggest several future directions for this study. First, we can develop a training data set based on our qualitative research results to automate the identification of ageist terms on Twitter and perform a larger-scale study on the RQs. Second, a repeated follow-up study with post–COVID-19 Twitter data will help us understand how term usage has evolved over time. Third, using social network analysis, we can identify how influential Twitter users use ageist terms and how impactful their tweets are among their followers over nonageist content. Lastly, future work should examine how often ageist content is challenged and critiqued by antiageist responses. Public policies, organizations, and the technology industry should develop creative solutions to detect harmful content and educate the public on appropriate terminology use and how to change harmful perceptions of older adults.

Conclusions

The COVID-19 pandemic and older adults' vulnerability to the disease have perpetuated hostile ageist discourse on social media. This is an opportune time to understand the prevalence and use of ageist language and discuss the ways forward. From examining tweets related to COVID-19, we were able to uncover the prevalence of the ageist terms used and the contexts in which these terms were used. The findings showed a continued lack of understanding among the public on the appropriate use of terms that refer to older adults. This paper emphasizes the need to put more effort into eradicating the perpetuation of ageist messages that challenge healthy aging.

Acknowledgments

We acknowledge the $Cell_2$Society project members, especially Dr Rose Ann DiMaria-Ghalili, for kindly providing a venue in which the collaborators could come together and generate ideas for this project.

Data Availability

The data sets analyzed during this study are available from author CCY (ccy24@drexel.edu) upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Tweets that included the terms "ageism" and "ageist."
[DOCX File, 17 KB - aging_v6i1e41448_app1.docx]

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Abbreviations

AARP: American Association of Retired Persons
API: application programming interface
FSA: Fraboni Scale of Ageism
RQ: research question

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Original Paper

Individualistic Versus Collaborative Learning in an eHealth Literacy Intervention for Older Adults: Quasi-Experimental Study

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Abstract

Background: Older adults tend to have insufficient health literacy, which includes eHealth literacy—the ability to access, assess, and use digital health information. Interventions using methods such as collaborative learning (CL) and individualistic learning (IL) may be effective in addressing older adults' low eHealth literacy, but little is known about the short- and long-term effects of CL versus IL on older adults' eHealth literacy.

Objective: The objective of this study was to use a 3 × 2 × 3 mixed factorial design to examine older adults' learning with CL versus IL for eHealth literacy.

Methods: Older adults (N=466; mean age 70.5, SD 7.2; range 60-96 years) from diverse racial and ethnic groups were randomly assigned to either the CL or IL group (233/466, 50% in each). The intervention consisted of 4 weeks of training in 2-hour sessions held twice a week. Using ANOVA and multiple regression, we focused on the main effects of learning condition and interaction between learning condition and previous computer experience. Learning method (CL or IL) and previous computer experience (experienced, new, or mixed) were between-subject variables, and time of measurement (pretest measurement, posttest measurement, and 6-month follow-up) was the within-subject variable. Primary outcome variables were eHealth literacy efficacy, computer and web knowledge, basic computer and web operation skills, information-seeking skills, and website evaluation skills. Control variables were age, sex, education, health status, race and ethnicity, income, primary language, and previous health literacy.

Results: eHealth literacy efficacy, computer and web knowledge, basic computer and web operation skills, information-seeking skills, and website evaluation skills improved significantly (P<.001 in all cases) from before to after the intervention. From postintervention measurement to 6-month follow-up, there was a significant interaction between learning condition and previous computer experience based on 1 outcome measure, computer and web operation skills ($F_{2,55}$=3.69; P=.03). To maintain computer and web operation skills 6 months after the intervention, it was more effective for people with little to no previous computer experience to learn individually, whereas for people with more previous computer experience, it was more effective to learn collaboratively. From postintervention measurement to 6-month follow-up, statistically significant decreases were found in 3 of the 5 outcome measures: eHealth literacy efficacy, computer and web knowledge, and basic computer and web operation skills (P<.001 for all 3 cases).

Conclusions: Older adults' eHealth literacy can be improved through effective intervention, and the IL or CL condition may have little effect on short-term outcomes. However, to maintain long-term benefits, it may be best to learn collaboratively with others who have similar previous computer experience. eHealth literacy is multidimensional, with some components retained better over time. Findings suggest a need for resources to provide continuous training or periodic boosting to maintain intervention gains.

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KEYWORDS

eHealth literacy; digital literacy; older adults; eHealth; aging; web-based information; health information

Introduction

Background

Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand the basic health information and services needed to make appropriate health decisions [1]. Health literacy is important as those with below-basic levels of health literacy are at greater risk of lagging their peers across several health outcomes [1]. Older age is strongly associated with lower health literacy [2]. In fact, of all adult groups in the United States, the older adult population has the lowest health literacy level—a critical issue given the rapidly growing US older adult population [3-5]. Older adults often have multiple chronic health conditions that increase their interactions with health care providers, which in turn increases their need for sufficient health literacy [6]. However, only 3% of older adults in the United States have proficient health literacy [4].

Researchers continue to assess which components are critical for effective health literacy interventions and implementation strategies for older adults. A systematic review by Walters et al [7] highlighted the increasing attention of research on health literacy interventions in recent years, with just 5 studies published before 2017 and 17 studies published up to the first quarter of 2020. This review reinforces findings from various earlier reviews showing that few interventions have determined best practices for health literacy interventions, such as whether older adults learn better in groups or as individuals [7-12].

eHealth Literacy

Health literacy research continues to evolve as the conceptualization of health literacy evolves. As information and communication technologies become integral in delivering and receiving health care, areas such as eHealth literacy have emerged [13]. In 2006, Norman and Skinner [14] promoted the concept of eHealth literacy as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem." Norman [15] further pointed out that, as technology changes, so do the requirements for eHealth literacy skills. Health agencies such as the Centers for Disease Control and Prevention are increasingly providing health information on the web, making the internet an important and sometimes the main source of health information accessed via mobile phones and tablets [16].

This shift to electronic dissemination of health information has implications for health literacy interventions, suggesting that they should focus on eHealth literacy [17]. Such a focus is important as there is some evidence suggesting that older adults are interested in seeking health information on the web [18], yet older adults tend to have low digital literacy [19]. This can be addressed via eHealth literacy interventions that increase digital skills [20]. To address eHealth literacy challenges, it is essential to conceptualize health literacy as an active, dynamic process of lifelong learning [21], a process that goes beyond formal educational settings in early life and features continuous learning of new ways to find valid, reliable health information from trusted web-based resources [22]. This study is part of a series of projects that add to the health literacy literature by investigating the effectiveness of a theory-based intervention to contribute to the understanding of how different intervention strategies may affect older adults' acquisition of eHealth literacy.

Collaborative Learning in Community Settings

Collaborative learning (CL) refers to "any instructional method in which students work together in small groups toward a common goal" [23]. CL promotes engagement for both the individual and the group as students progress through the learning process [24]. Older adults value CL with and from their peers about important health issues such as diabetes and cancer [25]. Within the context of learning to use computers, CL has been found to be effective for both learning outcomes and social development in older adults [26-28], although an earlier study [29] found that older adults performed similarly in computer learning regardless of learning individually or in pairs. In the context of eHealth literacy, CL enables opportunities to learn new health information and skills to access such information on the web [21]. Similarly, Ahmad et al [26] have suggested that CL allows older adult learners to participate with peers and interact effectively to learn digital technology.

Health-related community-based research meets older adults in their communities to provide interventions in informal settings [30]. CL for older adults typically occurs in such settings as opposed to the formal educational settings that are more typical for younger people. The Electronic Health Information for Lifelong Learners (eHiLL) studies use community settings to integrate existing public infrastructure and resources such as public libraries and senior centers [31,32]. Existing and authoritative internet health information resources developed by the National Institutes of Health (NIH) enable this type of work to be replicable and accessible to all. A systematic literature review by Kim and Xie [9] revealed that interventions combined with educational programs at the community level can encourage target groups to use web-based health resources. Affirming the importance of informal learning environments for older adults' success in digital learning, a systematic review by Ahmad et al [26] found that, across study samples and settings, informal learning environments provided older adults with opportunities to share their experiences, options, and expectations with their peers, which encouraged them to learn.

Lifelong Learning

This study is part of the eHiLL research program, which aims to generate scientific knowledge of optimal learning conditions and strategies that can effectively and efficiently improve older adults' learning and use of eHealth applications [20,31,33-35]. Each eHiLL study builds on previous work to examine the

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effects of various learning conditions and strategies through the testing of hypotheses in rigorous theory-driven interventions. eHiLL studies are informed by social interdependence theory, which supports the superiority of CL over individualistic learning (IL) [36]. This theory emphasizes interdependence among group members by arguing that the group is a dynamic whole [36]. A meta-analysis of >300 studies has provided strong evidence that CL outperforms IL and competitive learning in postsecondary and professional settings [24]. However, less is known about CL's effectiveness among older adult eHealth learners in informal learning settings when learning computer skills. This eHiLL study was designed to address these gaps in the literature.

Earlier eHiLL Studies and Gaps in the Literature

The first eHiLL project was a pilot study (N=172) with 1 arm to assess the effectiveness of CL with no comparison [20]. This study found evidence to suggest that CL can be a useful method for improving older adults' eHealth literacy when paired with key elements of computer learning in older adults. The findings also indicated that social interdependence theory could be generalized beyond the younger population and formal educational settings. In a second study (N=124), we used a 2 × 2 × 2 mixed factorial design with learning method (CL and IL) and presentation (visual only and visual plus auditory) as between-subject variables and time of measurement (pre- and postintervention measurement) as the within-subject variable. The intervention, regardless of the specific combination of learning method and information presentation, was effective in improving eHealth literacy from before to after the intervention [34]. In a third study (N=146), we used a 2 × 2 mixed factorial design with learning method (CL and IL) as the between-subject variable and time of measurement (pre- and posttest measurement) as the within-subject variable to focus on CL versus IL in a new sample [21]. As in the second study, regardless of the specific learning method used, the eHealth literacy intervention significantly improved knowledge, skills, and eHealth literacy efficacy from before to after the intervention. However, CL did not differ from IL in affecting learning outcomes, suggesting that the previous widely reported advantages of CL over IL may not be easily applicable to the older population in informal settings. In all 3 studies, we used the same web-based learning modules and study protocols. Possible reasons that might have contributed to a lack of support for the superiority of CL over IL included relatively small sample sizes, underdeveloped CL strategies, potential confounding effects of various group compositions (eg, those based on sex and previous computer experience), and no follow-ups to examine potential longitudinal effects (because of a lack of resources for these pilot studies).

These earlier eHiLL studies [20,21,34], along with other studies reviewed by Ahmad et al [31], provide evidence that CL is effective for older adult populations even when using digital technologies. However, major gaps remain to be addressed, particularly with regard to longitudinal effects [20,37]. A systematic literature review by Manafo and Wong [37] found that, of 9 studies on health literacy programs for older adults, only 2 had a follow-up period, and neither of those studies reported any long-term outcomes. In addition, previous studies have identified differences in approaches to group composition in CL for older adults such that a heterogeneous group composition has been found to facilitate more successful CL than a homogeneous group composition [38,39]. Several studies have found that CL works better with either a female- or male-sex majority than in groups with equal sex composition [40,41], as well as with same-sex groups as opposed to mixed ones [41,42]. There is also some evidence suggesting that, for CL in older adults, it may be advantageous to form homogeneous groups based on previous computer experience [43]. Research is needed to address the implications of these findings in the literature.

This Study

In this study, we address the aforementioned gaps in the literature by (1) using a large randomized sample, (2) adding a 6-month follow-up to examine how gains might be maintained beyond the intervention period, (3) adding group composition based on previous computer experience as an independent variable to investigate the effects of group composition on learning outcomes, and (4) developing and implementing detailed instructions and procedures to ensure CL versus IL in the respective groups. Guided by social interdependence theory and our own previous eHiLL studies [20,21,34], in this study, we examined the research questions and hypotheses outlined in Textbox 1.

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Textbox 1. Research questions and hypotheses for this study.

Research questions (RQs)

- RQ 1
  - What are the differences between the main effects of the intervention (collaborative learning [CL] vs individualistic learning [IL]) on older adults' eHealth literacy from pre- to posttest measurement?
- RQ 2
  - Do the effects of CL interact with those of heterogeneous versus homogeneous computer-experience group composition?
- RQ 3
  - How are the effects of CL versus IL maintained beyond the training period?

Hypotheses

- Hypothesis 1
  - CL will be more effective than IL in improving older adults' eHealth literacy.
- Hypothesis 2
  - In the CL condition, the heterogeneous group composition (mixed users) will be more effective than either homogeneous group composition (experienced user–only and new user–only).
- Hypothesis 3
  - The effects of CL will be better maintained than those of IL.

Methods

Design

For this intervention, we used a 3 × 2 × 3 mixed factorial design, with group composition based on previous computer experience (experienced, new, and mixed) and learning method (IL and CL) as between-subject variables and time of measurement (preintervention measurement, postintervention measurement, and 6-month follow-up) as the within-subject variable.

Sample and Recruitment

Recruitment included the posting and distribution of flyers at the research sites and surrounding locations (eg, in grocery stores) as well as advertising in the research sites' newsletters and local newspapers. Recruitment continued until the target sample size was reached. The inclusion criteria were as follows: (1) age ≥60 years, (2) ability to go to and from a research site, (3) fluency in English, and (4) interest in learning about using computers to find health information. A total of 466 older adults aged 60 to 96 years participated (mean age 70.5, SD 7.2 years for all; 70.1, SD 6.7 years for the CL group; and 70.8, SD 7.6 years for the IL group).

Research Sites

Data were collected from 8 research sites: 2 public libraries in the greater Washington, District of Columbia, area; and 1 public library, 3 senior activity centers, 1 recreation center, and 1 senior living facility in the greater Austin, Texas, area. These sites were selected as they (1) served a large population of older adults of diverse ethnicities and socioeconomic status; (2) provided free networked computers, space, and staff support to facilitate the study's implementation; (3) were geographically convenient for potential research participants and the researchers; and (4) were accessible by car or public transportation, thus enabling us to reach a diverse range of older adults.

Ethics Approval

Before the intervention, participants signed a consent form approved by the institutional review boards of the authors' institutions, the University of Texas at Austin (2012-05-0049) and the University of Maryland (07-0264).

Procedure

The intervention consisted of 8 two-hour sessions: 1 preintervention test (session 1), 1 postintervention test (session 8), and 6 training sessions (sessions 2-7). Participants met twice a week for 4 weeks to complete the intervention.

Participants were randomly assigned to either IL classes or CL classes, with a maximum of 8 participants per class. In each training session, participants in both classes first watched the tutorial twice with a 5-minute break in between; then, they were given a handout to perform practice activities. A facilitator was available in each training session to set up the equipment, distribute handouts, and provide immediate help whenever needed.

In the IL classes, participants wore headphones and worked on their computers during the entire intervention to avoid interaction with peers. At the beginning of each session, the facilitator stated specifically that students should work independently and avoid interacting with peers. The tutorial in IL classes also reminded participants to learn and perform the activities independently throughout the session. Participants

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were encouraged to ask the facilitator for help whenever they had any questions.

In CL classes, to encourage collaboration, we asked groups of 2 or 3 participants to share a computer by using a multiheadphone splitter during the entire intervention. In this way, all members in a group could proceed at the same pace, and different groups would not interfere with each other. At the beginning of each session, the facilitator stressed that students in each group should learn together and work with their peers to perform the practice activities. The tutorial for the CL classes provided clear instructions throughout the session to encourage collaboration—for example, by taking turns or with group discussions and reflections. Multimedia Appendices 1 to 6 provide examples of IL and CL instructions as shown on participants' computer screens.

Instructional Materials

The instructional materials consisted of a series of web-based interactive tutorials developed for this study. The curriculum in the tutorials was guided by "Helping Older Adults Search for Health Information Online: A Toolkit for Trainers," developed by the National Institute on Aging of the NIH. This free toolkit [44] is designed to improve older adults' ability to find health information on 2 NIH websites: NIHSeniorHealth and MedlinePlus. The toolkit contains 9 modules: module 1 focuses on computer and internet basics, modules 2 to 5 introduce NIHSeniorHealth, modules 6 to 8 introduce MedlinePlus, and module 9 focuses specifically on improving one's ability to appraise health information. As the NIHSeniorHealth website was being retired at the time of this study, we adapted the content of modules 1 and 6 to 9 to make each module fit a 2-hour training session (Table 1). We then developed 10 web-based interactive tutorials based on the 5 learning modules using Adobe Captivate (Adobe Inc.): 5 for IL classes and 5 for CL classes. Specific instructions and activities were developed to ensure CL versus IL. The differences between the 2 tutorials are summarized in Table 2.

Table 1. Topics covered in the Electronic Health Information for Lifelong Learners tutorials used in this study.

Session number	Module number	Topic
Session 1	Module 1	Basic computer and internet terms
Session 2	Module 6	Introduction to MedlinePlus.gov and search for health topics on MedlinePlus.gov
Session 3	Module 7	Use of "Drugs and Supplement" on MedlinePlus.gov
Session 4	Module 8	How to find news, physicians, and hospitals and use multimedia on MedlinePlus.gov
Session 5	Module 8	How to find news, physicians, and hospitals and use multimedia on MedlinePlus.gov
Session 6	Module 9	How to identify the quality of health information on the internet

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Table 2. Differences between the individualistic learning (IL) and collaborative learning (CL) tutorials.

	IL	CL
At the beginning of each tutorial	The tutorial provides visual instructions and the following audio instructions reminding the students to work independently: "During today's lesson, you will work individually. This will include activities where we ask you to reflect on your own about what you have learnt. Please do not consult your fellow learners during this lesson. If you have any questions, consult the facilitator and they will answer any questions or concerns you might have."	The tutorial provides visual instructions and the following audio instructions about how to work together: "During today's lesson, you will work together with your group members to learn new skills and review the materials. Take turns completing the practice activities and moving the tutorials. If a group member has any difficulty, feel free to provide assistance. Think of yourself as a team that works together to help improve each other's learning."
Before performing each practice activity	The tutorial provides audio instructions to remind students to perform the practice activity individually, for example, "Now you are going to work individually to master the terms you just learnt."	The tutorial provides audio instructions to remind students to work together to complete the practice activity, for example, "Now you are going to work together to practice what you just learnt" or "Take the next few minutes to work together to follow the instructions on the screen to open the quiz on germs and hygiene. Each partner should take turns operating the tutorial. If you encounter any difficulties, consult your group members for assistance. After each partner has a chance to practice, press the 'Next' button to continue." Sometimes, the tutorial also provides visual instructions on how to practice together.
After completing each practice activity	The tutorial asks the students to try again or move on to the next practice.	The tutorial asks the students to restart the activity or try again until each group member has had a turn to practice.
At the end of each tutorial	The students review the lesson goals on their own.	Students review together the lesson goals covered in class. The following instruction is given: "Take the next few minutes to work together to review the following list of goals covered in today's lesson. Click on the check box next to each goal to confirm that all group members are comfortable that they have mastered it. If anyone has any difficulty, work together to come to a solution and refer to the handout for further clarification."
At the end of each learning goal in module 9	The students are reminded not to compare notes with anyone else.	In module 9, after students have accomplished each learning goal, they are asked to compare notes with their peers.

Measures

We used both objective and subjective measures to assess the learning outcomes or serve as control variables. The measures and data collection times are summarized in Table 3.

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Table 3. Measures used and time of measurement.

Category of measures and variable	Measure	Time[a]		
		1	2	3
Objective learning outcome				
Knowledge acquisition	• Objective tests of knowledge of computer components (eg, keyboard and mouse) and the web (eg, link and scroll bar). Computer knowledge and web knowledge were each measured using 10 items; each item was scored with 1 point if answered correctly and 0 points if answered incorrectly (scoring range 0-20).	✓	✓	✓

Skill acquisition	• 3 procedural tests required participants to carry out specific tasks on networked computers:
	  • Basic computer and web operation: participants performed 12 basic operations on the computer (eg, open a web browser and go to a website). Each task was scored with 1 point if performed correctly or 0 points if done incorrectly (scoring range 0-12).
	  • Information seeking: participants received 4 scenarios in which they were asked to find information about specific health topics on the internet (eg, find at least two treatments for breast cancer). Each scenario was scored from 0 to 2 (0 if no relevant information was found, 1 if some but not all the required information was found, and 2 if all the required information was found; scoring range 0-8).
	  • Website evaluation: participants were asked to visit and evaluate the reliability of 8 health information websites. Evaluations were recorded as "Yes" if a website was reliable, "No" if a website was not reliable, and "Can't decide" if the reliability of a website was unknown. Each website was scored with 1 if the evaluation result was correct or 0 if the evaluation result was incorrect or "Can't decide" (scoring range 0-8).
		✓	✓	✓

eHealth literacy				
eHealth literacy efficacy	• The 8-item eHealth literacy scale [14], which measures self-perceived skills and comfort with using IT for health information and decision-making. Items are scored on a 5-point Likert scale; higher scores indicate higher eHealth literacy efficacy (scoring range 8-40; Cronbach α=.89-.97, with good test-retest reliability) [15].	✓	✓	✓
Previous experience				
Previous experience with computers and the internet	• 6 items, 4 of which measured the duration and frequency of previous computer and internet use. Example question: "How long have you been using a computer?" In total, 2 items measured previous computer class experience. Example: "Have you taken our computer class previously?"	✓		
Control variables				
Familiarity with peers in the same class	• If and how participants may be related to or familiar with others in the same experimental condition (eg, spouse, sibling, friend, or acquaintance)	✓		
Standard health literacy test	• S-TOFHLA[b]; 2 subscales with 36 questions; scoring range 0 to 36; Cronbach α=.97 (reading) and .68 (numeracy) [45]	✓		
Demographic and health factors	• Age, sex, education, health, race and ethnicity, income, and primary language	✓		
Postintervention questionnaire				
Satisfaction	• How would you evaluate your entire experience in this computer class? ("Extremely dissatisfied," "Dissatisfied," "Neither satisfied nor dissatisfied," "Satisfied," and "Extremely satisfied")		✓	
Whom did participants learn from?	• During the past 4 weeks, while in class, from whom did you learn about computers? ("Peer student(s)," "Mostly the peer student(s)," "The tutorial and peer(s) equally," "Mostly the tutorial," and "The tutorial")		✓	
Interaction with peers	• During the past 4 weeks, how much in-class interaction have you had with your peer(s)? ("None," "A little," "Some," "A lot," and "Extensive")		✓	

[a]1: before the intervention; 2: after the intervention; 3: 6-month follow-up.

[b]S-TOFHLA: Short Test of Functional Health Literacy in Adults.

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Data Analysis

Trained graduate research assistants entered the data into SPSS (version 27.0; IBM Corp) for Windows, with the principal investigator monitoring data entry and cleaning by reviewing a random 10% of the data records. Before inferential analysis, the data were evaluated for accuracy, missing data, out-of-range values, and violation of the statistical assumptions. Background variables (demographics, previous experience, and language) were examined to detect potential differences between the 2 learning condition groups. Descriptive statistics were used to provide a statistical profile of the sample, with frequencies and percentages for categorical data and means and SDs for continuous data.

Mann-Whitney *U* tests and 2-tailed *t* tests were conducted to assess differences between participants who completed tests at all 3 time points and those who completed only the pretest measurement. A 3 (group composition based on previous computer experience: experienced, new, and mixed) × 2 (learning condition: IL vs CL) × 3 (time of measurement: pretest measurement, posttest measurement, and 6-month follow-up) mixed between-within univariate analysis of covariance was conducted on each of the dependent variables individually; the results for each outcome were of direct interest.

Using the 4 computer and internet experience variables, both factor analysis and cluster analysis were conducted. The factor analysis yielded one strong factor (eigenvalue 3.38 vs 0.38, 0.17, and 0.08), implying that the 4 variables are strongly related and could be used to define a continuum of computer and internet use that individuals have scores on. By contrast, the cluster analysis yielded a clean separation of 2-cluster solutions, which is characterized by mean comparisons that ranged between 1.28-1.95 (cluster 2) versus 4.38-5.08 (cluster 1). Cluster 1 is a group that has been using the computer and internet for 3 or more years and uses it at least weekly, if not more frequently. Cluster 2 is a group that has been using the computer or internet for less than a year and who typically accesses it less than once a month. This *computer and internet familiarity* dichotomous variable was used to further categorize the groups into 3 groups for group composition based on prior computer experience. The first grouping comprised of groups with <30% of participants being experienced (which we defined as the "new" user group composition in all subsequent analyses; 14/92, 15%). The second grouping comprised of groups with 30% to 70% of participants being experienced (the "mixed" group composition; 48/92, 52%). The third grouping comprised of groups with >70% of participants being experienced (the "experienced" group composition; 30/92, 33%).

The main outcome variables of interest were eHealth literacy efficacy, computer and web knowledge, and skill acquisition (3 measures: basic computer and web operation skills, information-seeking skills, and website evaluation skills). The Short Test of Functional Health Literacy in Adults (S-TOFHLA) was included as a covariate, as opposed to an outcome variable, as the intervention was not focused on the learning of outcomes measured by the S-TOFHLA. The S-TOFHLA was significantly correlated with all 5 outcomes, ranging from 0.11 (eHealth literacy efficacy) to 0.52 (computer and web knowledge).

To test the specific hypotheses of this study, we focused our analyses on the main effects of learning condition and on interactions between learning condition and previous computer experience. The main effects of previous computer experience were not a major focus as it is already well documented that previous computer experience is predictive of older adults' computer adoption and use [46-48]. Given the expected interactions, tests of simple effects within specific levels of the design were likely [49], such as those assessing the differential impact of learning condition within the experienced, new, and mixed levels of previous computer experience.

The models were conducted with and without control variables. A consistent pattern of seeing no differences with and without control variables was observed. The control variables included age, sex, education, health status, race and ethnicity, income, and primary language. The inclusion of these control variables could increase the statistical power of the design given that the variance in outcomes would likely be due, in part, to variability in one or more of these variables. Tests of the main effects were conducted in the absence of interactions involving the main effect variables. The resulting effect size estimates were calculated to compare the magnitude of change for the different types of dependent variables and between time points using η_p^2 [50].

Results

Participants

Participants' demographics and other background information are summarized in Table 4. Participants were randomized into the IL (233/466, 50%) or CL (233/466, 50%) group. Chi-square and *t* tests showed no significant differences in baseline characteristics between the IL and CL groups except in English as participants' primary language (χ^2_1=5.6; *P*=.02); English was the primary language of more participants in the IL group than in the CL group (211/233, 90.6% vs 194/233, 83.3%). A total of 85.4% (398/466) of the original sample completed the postintervention assessment, and 41% (191/466) completed the 6-month follow-up assessment.

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Table 4. Participant characteristics (N=466).

	All, n (%)	IL[a] group (n=233), n (%)	CL[b] group (n=233), n (%)	*P* value for chi-square or *t* test
Sex (female)	312 (67)	154 (66.1)	158 (67.8)	.69
Race and ethnicity				.10
African American	188 (40.3)	81 (34.8)	107 (45.9)	
White	153 (32.8)	84 (36.1)	69 (29.6)	
Latino	88 (18.9)	49 (21)	39 (16.7)	
Other	37 (7.9)	19 (8.2)	18 (7.7)	
Education				.99
Lower than high school	52 (11.2)	27 (11.6)	25 (10.7)	
High school	116 (24.9)	58 (24.9)	58 (24.9)	
Some college	159 (34.1)	80 (34.3)	79 (33.9)	
Bachelor's degree or higher	138 (29.6)	68 (29.2)	70 (30)	
Yearly household income (US $)				.12
<20,000	163 (35)	88 (37.8)	75 (32.2)	
20,000-29,000	86 (18.5)	38 (16.3)	48 (20.6)	
30,000-39,000	48 (10.3)	30 (12.9)	18 (7.7)	
40,000-99,000	91 (19.5)	37 (15.9)	54 (23.2)	
≥100,000	9 (1.9)	4 (1.7)	5 (2.1)	
Native English speaker (yes)	405 (86.9)	211 (90.6)	194 (83.3)	.02
Health status (excellent and very good)	123 (26.4)	65 (27.9)	58 (24.9)	.46
Frequency of computer use				.84
Never	151 (32.4)	75 (32.2)	76 (32.6)	
Less than once a month	54 (11.6)	29 (12.4)	25 (10.7)	
More than once a month	35 (7.5)	18 (7.7)	17 (7.3)	
Once a week	47 (10.1)	20 (8.6)	27 (11.6)	
Every 2-3 days	86 (18.5)	41 (17.6)	45 (19.3)	
Every day	93 (20)	50 (21.5)	43 (18.5)	
Length of computer use (years)				.86
Never	130 (27.9)	67 (28.8)	63 (27)	
<1	91 (19.5)	42 (18)	49 (21)	
1-3	51 (10.9)	27 (11.6)	24 (10.3)	
3-5	32 (6.9)	18 (7.7)	14 (6)	
5-10	64 (13.7)	29 (12.4)	35 (15)	
>10	96 (20.6)	49 (21)	47 (20.2)	
Frequency of internet use				.98
Never	196 (42.1)	98 (42.1)	98 (42.1)	
Less than once a month	53 (11.4)	27 (11.6)	26 (11.2)	
More than once a month	27 (5.8)	13 (5.6)	14 (6)	
Once a week	36 (7.7)	17 (7.3)	19 (8.2)	
Every 2-3 days	72 (15.5)	34 (14.6)	38 (16.3)	
Every day	81 (17.4)	43 (18.5)	38 (16.3)	
Length of internet use (years)				.84
Never	185 (39.7)	93 (39.9)	92 (39.5)	

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	All, n (%)	IL[a] group (n=233), n (%)	CL[b] group (n=233), n (%)	*P* value for chi-square or *t* test
<1	78 (16.7)	35 (15)	43 (18.5)	
1-3	50 (10.7)	27 (11.6)	23 (9.9)	
3-5	35 (7.5)	18 (7.7)	17 (7.3)	
5-10	62 (13.3)	29 (12.4)	17 (7.3)	
>10	56 (12)	31 (13.3)	33 (14.2)	
Familiar with other participants (yes)	126 (27)	68 (29.2)	58 (24.9)	.31

[a]IL: individualistic learning.

[b]CL: collaborative learning.

Participants Who Completed All 3 Time Points Versus Those Who Did Not

In *t* tests and Mann-Whitney *U* tests, no significant differences were found for baseline age (*P*=.623), education (*P*=.052), health (*P*=.090), language (*P*=.705), income (*P*=.893), computer and web knowledge (*P*=.453), basic computer and web operation (*P*=.731), and website evaluation (*P*=.929) between participants who completed all 3 time points and those who completed only the pretest measurement. There were no statistically significant differences in dropout rates between the IL and CL groups from baseline to postintervention measurement (*P*=.660) and from baseline to 6-month follow-up (*P*=.778).

Significant differences were found between those who completed all 3 time points and those who did not for sex (*P*=.009), race and ethnicity (*P*<.001), baseline computer use length (*P*=.001), internet use length (*P*<.001), computer use frequency (*P*=.004), internet use frequency (*P*<.001), eHealth literacy efficacy (*P*<.001), health literacy (*P*=.04), and information-seeking skills (*P*=.02). In comparison with participants who completed only the pretest measurement, there was a higher proportion of women (62% vs 74%), a lower proportion of African American individuals (51% vs 26%), and a higher proportion of those who reported more frequent and longer length of computer (17% vs 25%) or internet use (8% vs 17%) at baseline among participants who completed all 3 time points. Participants who completed all 3 time points also reported significantly higher scores on the eHealth literacy efficacy scale (mean difference=1.56), S-TOFHLA (mean difference=2.52), and information-seeking skill test (mean difference=1.27) at baseline.

Tests of Hypotheses

Examination of general linear models revealed 1 statistically significant model of interest (Table 5). The model with basic computer and web operation skills as the outcome resulted in a significant interaction that supported hypothesis 3. There was a significant interaction between learning condition and previous computer experience ($F_{2,55}$=3.69; *P*=.03). Simple effects were examined to decompose interaction results. Specifically, from postintervention measurement to 6-month follow-up, within the IL group, on average, being in a group with little or no previous computer experience (mean −0.59, SE 0.54) was more beneficial for retaining computer skills than being in a group with medium previous computer experience (mean −1.06, SE 0.25) or high previous computer experience (mean −1.65, SE 0.35). In comparison, in the CL group, on average, being in a group with high previous computer experience (mean −0.60, SE 0.35) was more beneficial for retaining computer skills than being in a group with medium previous computer experience (mean −0.64, SE 0.21) or little to no previous computer experience (mean −2.40, SE 0.82). Hypothesis 3 was partially supported; that is, the effects of CL were better maintained than those of IL for individuals in certain groups. Specifically, *for people with little to no previous experience, it may be better to learn individually, whereas for people with more previous experience, it may be better to learn collaboratively*. These results were specific to computer and web operation skills and maintenance of those skills at 6 months after the intervention.

No statistically significant differences were found in models examining the interactions between learning condition and previous computer experience for each of the following outcome measures: eHealth literacy efficacy, computer and web knowledge, information-seeking skills, and website evaluation skills (results not shown; available from the authors upon request). Hypotheses 1 and 2 were not supported.

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Table 5. General linear model results for retaining basic computer and web operation skills from postintervention measurement to 6-month follow-up.

	Basic computer and web operation	
	Wald *F* test (*df*)	*P* value[a]
IL[b] or CL[c] learning condition	0.09 (1)	.77
Computer familiarity	6.44 (1)	.01
Computer experience grouping	0.94 (2)	.40
IL or CL × computer familiarity	2.14 (1)	.15
IL or CL × previous experience grouping	3.69 (2)	.03
Computer familiarity × experience grouping	0.42 (2)	.66
IL or CL × computer familiarity × experience grouping	2.04 (2)	.14

[a]α=.05.

[b]IL: individualistic learning.

[c]CL: collaborative learning.

Main Effects

Univariate repeated-measure analyses revealed statistically significant differences between pretest measurement, posttest measurement, and 6-month follow-up for all 5 outcome measures (Table 6).

Follow-up comparison tests for these 5 outcome measures showed statistically significant improvements in mean scores from pre- to posttest measurement (*P*<.001 for all 5 cases). Follow-up comparison tests also showed statistically significant decreases in mean scores from posttest measurement to 6-month follow-up for 3 of the 5 outcome measures: eHealth literacy efficacy, computer and web knowledge, and basic computer and web operation skills (*P*<.001 for all 3 cases). There was no statistically significant difference in mean scores from posttest measurement to 6-month follow-up for the remaining 2 outcome measures—website evaluation (*P*=.774) and information-seeking skills (*P*=.365).

Table 6. Means, *F* test results, and effect sizes.

Dependent variable	Pretest measurement, mean (SD)	Posttest measurement, mean (SD)	6-month follow-up, mean (SD)	*F* test (*df*)[a]	η_p^2
eHealth literacy efficacy	19.86 (8.08)	33.37 (4.68)	32.06 (5.93)	373.82 (2)	0.676
Computer and web knowledge	12.59 (4.69)	16.44 (3.08)	15.66 (3.30)	89.60 (2)	0.334
Basic computer and web operation	6.29 (3.75)	10.17 (2.10)	9.44 (2.62)	167.92 (2)	0.484
Information-seeking skills	2.18 (2.63)	3.69 (2.63)	4.32 (2.56)	52.92 (2)	0.228
Website evaluation skills	4.02 (2.00)	5.04 (1.89)	5.24 (2.05)	35.80 (2)	0.167

[a]*P* value for all *F* test values is <.001.

Postintervention Questions

There were no significant differences in participants' satisfaction between the CL (100% satisfaction) and IL (99% satisfaction) groups (N=382, χ^2_1=1.1; *P*=.29). Overall, participants in both groups had satisfactory experiences with the intervention.

There were significant differences between the CL and IL groups for learning with peers versus tutorials (N=382, χ^2_4=29.2; *P*<.001) and for the amount of in-class interaction with peers (N=382, χ^2_4=84.3; *P*<.001). Demonstrating validity, individuals in the CL group reported learning from a combination of peers and the tutorial, whereas individuals in the IL group reported learning "exclusively" from the tutorial. Similarly, individuals in the IL group reported low interaction with peers, whereas individuals in the CL group reported high interaction with peers.

Discussion

Principal Findings

Older adults are less likely than younger adults to use the internet for tasks such as receiving test results, renewing prescriptions, and scheduling appointments, in part because of a low level of digital competence [51]. The COVID-19 pandemic has made accessing health information and services on the web a near necessity [52,53], exacerbating the need for eHealth literacy. Effective interventions are much needed to ensure the digital inclusion of older adults during and after the pandemic. This study's principal findings are as follows: (1) there are no major differences in older adults' eHealth literacy learning with regard to learning collaboratively versus individually when measured immediately after the intervention; (2) however, to maintain long-term benefits, it may be best to learn collaboratively with others that have similar previous computer experience; (3) regardless of the IL or CL method,

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this intervention was effective for increasing eHealth literacy in older adults; and (4) conducting periodic follow-up training (ie, booster sessions) may be important for improving the maintenance of gains over time. It is important to note that our sample included a large proportion of African American (188/466, 40.3%) and Latino (88/466, 18.9%) participants. The literature on eHealth interventions over the past 2 decades documents the lack of studies with racial and ethnic minority samples as well as the continued need to include these groups in studies [54-57]. This study's inclusion of a substantial proportion of participants from racial and ethnic minorities strengthens the evidence that our eHiLL intervention works for older adults from diverse groups.

CL Versus IL

In this study, we compared the impact of CL versus IL on older adults' learning of eHealth literacy and digital skills. Our data did not provide support for hypotheses 1 and 2. However, hypothesis 3 was partially supported. For participants in a group with medium or high previous computer experience, learning was maintained better at the 6-month follow-up in the CL condition, whereas in the IL condition, learning was maintained better for those in a group with low previous computer experience. Thus, previous computer experience may mediate the relationship between learning outcomes and learning methods.

We did not find any statistically significant differences from pre- to posttest measurement in the effects of CL versus IL on any of the outcome measures. This finding aligns with a previous study that used an earlier iteration of the intervention to test IL and CL [20]. The 5 principles of CL might shed light on why [36]. These principles are as follows: (1) to ensure that students understand that their scores are dependent on both their individual and group members' performances (eg, by giving bonus points to each student if all members of the group score at a certain percentage or higher on a test); (2) to structure individual accountability so that each student's individual contribution is assessed (eg, by giving individual tests, having each student explain their contribution to the group, or observing group interactions and documenting each student's contributions); (3) to ensure that students help, assist, support, encourage, and praise one another's learning efforts through face-to-face interactions; (4) to ensure that students have needed social skills (eg, communication and leadership) and use them properly in the group; and (5) to ensure that students have adequate time to engage in group interactions, reflect on what works and what does not, and make decisions about what actions to continue or change.

However, these principles have been developed for formal educational settings, and they are less applicable to informal settings [24,36]. Therefore, in this study, not all the principles were included. For example, the literature suggests that it is important to build dependency and accountability, which would work in formal educational settings [36]. In this study's context, individual success was not designed to be dependent on group success. Furthermore, this study, by nature, could not hold individual group members accountable for group success in any formal way. Each participant's individual contribution was not formally assessed, but it is plausible that having each participant explain their contribution to the group or observing group interactions and documenting participants' contributions might create a stronger sense of accountability within the group. Future research should assess creative ways to ensure dependency and accountability among older adult learners in informal settings.

The literature has found CL to work in informal settings with older adults [26], although this has not been supported with regard to computer training from pre- to posttest measurement [20,21,34]. Previous eHiLL studies [20,21,34] did not conduct follow-ups, so there was no evidence on the longitudinal effects of CL. In this study, which included a follow-up, CL did work better under certain conditions over the longer term.

Computer learning is more challenging than other subjects in informal learning [58]. An additional challenge is that CL research generally does not provide detailed instructions to ensure collaboration [59]. Therefore, in this study, we provided more detailed instructions for collaboration as the participants progressed through the modules. The participants' responses indicated that they did learn either collaboratively or individually in accordance with their group assignment; it is unlikely that our CL strategies were insufficient in soliciting CL.

Group Composition

Similar to hypothesis 1, hypothesis 2 was rejected, and no statistically significant differences were found between either learning condition and group composition. However, the partial support for hypothesis 3 may provide some insights into how group composition may affect learning outcomes over the longer term. Group composition appears to matter depending on the characteristic used to group participants. In this study, there were no differences between the CL and IL groups with regard to the familiarity of the participants within their groups. However, the literature has documented familiarity with group partners as a factor that may contribute to increased collaboration [40,41,60]. The relative benefits of CL versus IL among older adults—with familiar or unfamiliar partners—require further examination.

Our findings do indicate that grouping by previous computer experience may be particularly important for older adults' learning over the longer term. This study's findings are complemented by those from an earlier study with previous versions of the tutorial [20]. On the basis of information from the previous study, the differences in participants' previous computer experience might have at least partially affected their learning experience and outcomes. Xie [20] found that more experienced learners sometimes became frustrated and felt that they were not making the best use of their time when an instructor had to stop frequently to help less experienced peers keep up with basic procedures (eg, manipulating a mouse). The opposite happened as well: less experienced learners sometimes became embarrassed and frustrated and at times were intimidated by more experienced peers. These observations, in addition to guidance from the literature [43], support the change in this study to separate older adults into different groups based on their previous computer experience. This study's findings suggest that CL may be most beneficial for more experienced older adults when they are grouped with others who have similar

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levels of previous computer experience. Perhaps, when group members have already obtained sufficient previous experience, they can use their collective previous experience to learn from each other [61]. In comparison, CL groups with low collective previous experience may not have sufficient combined skills and knowledge to progress effectively. A recent systematic review also suggests that knowledge level and experience seems to be the most suitable and important attribute to form educational groups because of its effects on group outcomes [62]. Thus, IL may be better over the long term for older adult learners with low previous computer experience as each individual can move at a comfortable pace and may not be embarrassed to ask for help.

Overall Impact of the eHealth Intervention

In this study, we examined the intervention's effects on 5 outcomes: eHealth literacy efficacy, computer and web knowledge, basic computer and web operation, information-seeking skills, and website evaluation skills. Overall, the results show statistically significant improvements from before to after the intervention for all 5 outcomes (P<.001 in all cases). Thus, the intervention, with CL or IL, is effective in improving older adults' eHealth literacy. Effect sizes ranged from 0.167 to 0.676, suggesting that the magnitude of improvement was large for all 5 outcomes (according to the general guidelines used to interpret values for effect sizes: 0.01=small effect size, 0.06=medium effect size, and ≥0.14=large effect size) [50]. These results align with previous eHiLL studies, which included 3 of the same outcome variables (computer and web knowledge, computer and web skills, and eHealth literacy) also with large effect sizes [20,21,33,34]. The consistently large effects of the intervention in different populations and contexts highlight the potential generalizability of the intervention to improve older adults' eHealth literacy.

Longitudinal Effects

In this study, we included a follow-up at 6 months to assess how well improvements were retained. Overall, there was a decrease in scores from postintervention measurement to 6-month follow-up, with statistically significant decreases for 3 of the 5 outcomes (eHealth literacy efficacy, computer and web knowledge, and basic computer and web operation; P<.001 for all 3 cases). The decreases in information-seeking skills and website evaluation were not statistically significant. eHealth literacy is multidimensional, and some of its components may be retained better than others over time. However, it is possible that a worse long-term impact might have been observed overall if a longer follow-up was used, such as 1 year. A recent study assessing cognitive training for older adults found that little or no benefit remained 1 year after intensive initial training [63]. This study's findings suggest a need for resources to provide continuous training or periodic boosting given that benefits gained from pre- to posttest measurement dropped after 6 months. A study [64] assessing cognitive ability training with older adults that included long-term booster training (11 and 35 months after the intervention) and long-term follow-up tests (1, 3, and 5 years) found that the effects of the intervention were still present 5 years later. Further research is needed to understand how often such "booster" training is needed for this intervention to maximize resources (eg, every 1, 2, or 3 months). Another promising training component to consider for observing long-term effects might be frequent testing, which may lead to a practice-retrieval effect—there is some evidence suggesting that more frequent testing during an intervention phase is associated with long-term skill retention [65].

In addition to including the follow-up at 6 months, this study also addressed other limitations of previous eHiLL studies. We included a large sample size, a more even baseline group composition and group size because of randomization, and consistency of instructors. In earlier eHiLL studies, because of limited funding, it was not feasible to control for variation in instructors. Earlier eHiLL studies used many graduate students as instructors for the training classes, who were recruited through various mechanisms—some were part-time research assistants, some received course credits, and some were simply volunteers. These graduate students' enthusiasm speaks to the sustainability of the training program, but from the point of view of an intervention study, individual differences among such instructors (eg, personality, teaching style, experience, time commitment, and incentive) likely introduced unnecessary confounding variation into the previous studies. Therefore, in this study, we provided full-time support for a few instructors to minimize the potential impact of this factor. In short, compared with the earlier studies, this study provides stronger support for the effectiveness of the intervention overall and its various components. This evidence should enable other researchers to replicate this work using other samples, settings, learning conditions, or delivery methods.

Strengths and Limitations

First, this study's large sample size ensured sufficient statistical power for the findings; however, the sample may not be representative of the older adult population in general. Second, differential dropout by race and ethnicity, sex, and computer experience suggests that additional tailoring is needed to promote better adherence. For example, He et al [66] found evidence that machine learning–based approaches provided with individual characteristics and previous intervention data can provide useful information for predicting adherence, providing initial clues as to who to target with adherence support strategies and when to provide support. Further assessment of these types of innovations will be critical to strengthen an intervention's ability to support those at risk of poor adherence. Other researchers should replicate this study in other communities with different samples of older adults, which would help further strengthen the eHiLL intervention's generalizability.

Third, an inevitable limitation of any technology-related intervention is that technology evolves rapidly, rendering some intervention components (and corresponding outcome measures) outdated. Continuous updating of intervention components and outcome measures will be necessary for future interventions (eg, to be based on mobile devices and apps and voice-based web search enabled by new technology). Our findings suggest that eHealth literacy is multidimensional and that some of its components (eg, the ability to search for relevant information on the web to solve specific tasks, as measured in our information-seeking skill testing, and assess the quality of health

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information on websites, as measured in our website evaluation test) might be better retained than others (eg, eHealth literacy efficacy, computer and web knowledge, and basic computer and web operation) over time. This phenomenon is worth future systematic investigation, which might lead to the development of more granular interventions targeting specific dimensions or components of eHealth literacy.

Implications and Directions for Future Research

Given the context of this work in the larger program of work that has been carried out over a decade, there is strong evidence to suggest that older adults can increase their eHealth literacy via various learning conditions. This is important as increasing eHealth literacy for older adults can have substantial positive impacts on their health management in several ways. For example, those who are eHealth literate can take advantage of the many technologies that allow health care providers to monitor one's health remotely in real time. Older adults with diabetes may upload food logs, blood sugar levels, and drugs taken that providers can check daily and provide feedback on [67]. Also relevant for older adults are tools that can detect changes in daily activities, such as falls, and devices that send notifications to remind one to exercise or take drugs [67]. These technologies are only useful if one has the eHealth literacy to use them.

In addition, being able to incorporate eHealth into the management of their health can possibly help reduce other stressors. For example, knowing how to navigate a web-based health portal can help save time by allowing older adults to communicate with their providers through web-based messages as opposed to waiting on the phone just to pass their message along to someone who is not their physician. This could possibly reduce the stress associated with missing a phone call from their physician's office, knowing that they can check their message at any time as soon as it is available. Similarly, older adults can save time by making an appointment with their physician on the web. As telehealth becomes more common, when appropriate, older adults can take appointments in the comfort of their own homes, which can help reduce stress related to finding a date and time that works best for them to find transportation. eHealth has the potential to increase the health and well-being of older adults, and increasing eHealth literacy is one step toward helping them do so.

Further research should also examine how often booster training may be needed to maximize resources. Scalability should be of interest for future studies to assess the mass-scale impact this intervention can have. Future studies are being planned to assess the intervention's effectiveness with remote learning or hybrid modalities that may be better suited to a world coping with the COVID-19 pandemic. The finding that the intervention is effective with remote learning modalities will help strengthen the evidence that this intervention has the potential to be scalable at a national level. Finally, in this study, previous-experience group composition was a key factor; however, future research could assess if there are other, more effective group composition possibilities, such as groups based on self-assessed technology proficiency (ie, computer, mobile device, and networking proficiency). Tools assessing these proficiency levels [68-70] can be incorporated to assess whether composing groups based on overall high and low technology proficiency leads to more effective training, as suggested by the interactions found between group composition and learning condition.

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Data Availability

The data sets generated and analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Instructions at the beginning of the individualistic learning (IL) tutorial.
[PNG File , 75 KB - aging_v6i1e41809_app1.png]

Multimedia Appendix 2
Instructions at the beginning of the collaborative learning (CL) tutorial.
[PNG File , 68 KB - aging_v6i1e41809_app2.png]

Multimedia Appendix 3
Example of Instructions before practice activities in the collaborative learning (CL) tutorial (Step 1, Module 2).

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[PNG File , 95 KB - aging_v6i1e41809_app3.png]

Multimedia Appendix 4
Instructions before practice activities in the collaborative learning (CL) tutorial (Step 3, Module 2).
[PNG File , 105 KB - aging_v6i1e41809_app4.png]

Multimedia Appendix 5
Instructions after completing each practice activity in the collaborative learning (CL) tutorial.
[PNG File , 105 KB - aging_v6i1e41809_app5.png]

Multimedia Appendix 6
Instructions after completing each learning goal in the collaborative learning (CL) tutorial (Module 9).
[PNG File , 92 KB - aging_v6i1e41809_app6.png]

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Abbreviations

CL: collaborative learning
eHiLL: Electronic Health Information for Lifelong Learners
IL: individualistic learning
NIH: National Institutes of Health
S-TOFHLA: Short Test of Functional Health Literacy in Adults

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Original Paper

The Impact of Health Information Exchange on In-Hospital and Postdischarge Mortality in Older Adults with Alzheimer Disease Readmitted to a Different Hospital Within 30 Days of Discharge: Cohort Study of Medicare Beneficiaries

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Abstract

Background: Although electronic health information sharing is expanding nationally, it is unclear whether electronic health information sharing improves patient outcomes, particularly for patients who are at the highest risk of communication challenges, such as older adults with Alzheimer disease.

Objective: To determine the association between hospital-level health information exchange (HIE) participation and in-hospital or postdischarge mortality among Medicare beneficiaries with Alzheimer disease or 30-day readmissions to a different hospital following an admission for one of several common conditions.

Methods: This was a cohort study of Medicare beneficiaries with Alzheimer disease who had one or more 30-day readmissions in 2018 following an initial admission for select Hospital Readmission Reduction Program conditions (acute myocardial infarction, congestive heart failure, chronic obstructive pulmonary disease, and pneumonia) or common reasons for hospitalization among older adults with Alzheimer disease (dehydration, syncope, urinary tract infection, or behavioral issues). Using unadjusted and adjusted logistic regression, we examined the association between electronic information sharing and in-hospital mortality during the readmission or mortality in the 30 days following the readmission.

Results: A total of 28,946 admission-readmission pairs were included. Beneficiaries with same-hospital readmissions were older (aged 81.1, SD 8.6 years) than beneficiaries with readmissions to different hospitals (age range 79.8-80.3 years, $P<.001$). Compared to admissions and readmissions to the same hospital, beneficiaries who had a readmission to a different hospital that shared an HIE with the admission hospital had 39% lower odds of dying during the readmission (adjusted odds ratio [AOR] 0.61, 95% CI 0.39-0.95). There were no differences in in-hospital mortality observed for admission-readmission pairs to different hospitals that participated in different HIEs (AOR 1.02, 95% CI 0.82-1.28) or to different hospitals where one or both hospitals

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did not participate in HIE (AOR 1.25, 95% CI 0.93-1.68), and there was no association between information sharing and postdischarge mortality.

Conclusions: These results indicate that information sharing between unrelated hospitals via a shared HIE may be associated with lower in-hospital, but not postdischarge, mortality for older adults with Alzheimer disease. In-hospital mortality during a readmission to a different hospital was higher if the admission and readmission hospitals participated in different HIEs or if one or both hospitals did not participate in an HIE. Limitations of this analysis include that HIE participation was measured at the hospital level, rather than at the provider level. This study provides some evidence that HIEs can improve care for vulnerable populations receiving acute care from different hospitals.

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KEYWORDS

readmissions; care fragmentation; health information exchange; mortality; Alzheimer disease; electronic health information; information sharing; older adults; information exchange; hospital system; health informatics

Introduction

Hospitalizations frequently increase during the final months of an older person's life: two-thirds of Medicare fee-for-service beneficiaries are hospitalized in the final 6 months of life and 25% have multiple hospitalizations [1,2]. The transitions of care that occur at the end of life can lead to more readmissions [3], disruptions that may be further exacerbated by the presence of dementia. Previous work has shown that cognitive impairment is associated with decreases in both the quality of care a person receives in the hospital [4,5] and the patient's and their caregiver's ability to follow discharge instructions [6].

One underexamined factor that may worsen outcomes following hospitalizations in older adults is interhospital fragmentation of care, which occurs when an individual is readmitted to a hospital different than the one from which they were initially discharged. This happens in approximately 25% of all readmissions nationally and is associated with poor patient outcomes, including higher in-hospital mortality and longer lengths of stay [7-10]. Information discontinuity is one potential driver of poor outcomes in fragmented readmissions: because a patient's medical record may not be available at the readmission hospital, the care team may be making decisions with incomplete clinical information. Health information exchanges (HIEs), data systems in which health information is electronically shared between settings of care [11,12], are a potential solution to information discontinuity and associated challenges present in fragmented readmissions.

Previous work in general adult patient populations suggests that HIE availability in the inpatient setting may be associated with fewer readmissions [13,14], particularly fragmented readmissions [15], and may be associated with a reduction in repeat laboratory and imaging tests [16-20]. If the improvement in these metrics is due to improved care coordination attributable to information obtained from the HIE, we hypothesize that these positive impacts would extend to outcomes during and following hospitalizations as well. Those with cognitive impairment may be especially vulnerable in fragmented readmissions where outside clinical information is not available. The goal of this study was to measure the association between electronic information sharing, in-hospital mortality, and mortality in the 30 days following hospital readmission among Medicare beneficiaries with Alzheimer disease (AD) initially admitted for common conditions and then readmitted to a different hospital. This information will contribute to our understanding of the impact and limitations of HIEs as tools to mitigate information discontinuity across providers. HIEs have the potential to improve care for vulnerable populations, such as older adults with AD, but this potential is limited if the 2 hospitals do not share an HIE or if one does not participate.

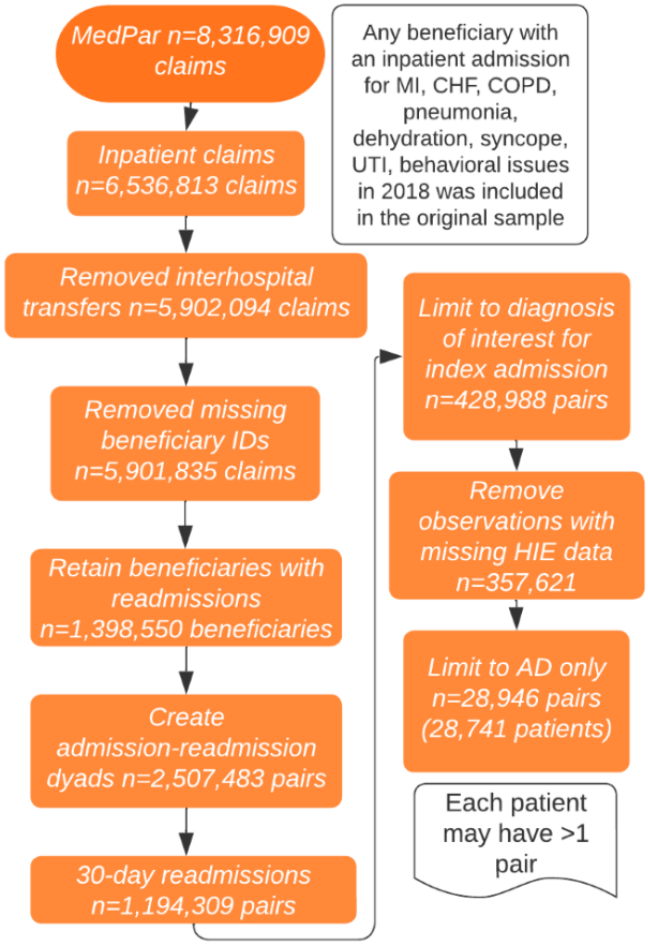
Methods

Study Design

We analyzed data from a longitudinal cohort of all Medicare beneficiaries in 2018 with a hospital admission for acute myocardial infarction (AMI), congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), pneumonia, dehydration, syncope, urinary tract infection (UTI), or behavioral issues and a subsequent readmission within 30 days for any reason (Figure 1). The objective of this study is to measure the association between electronic information sharing, in-hospital mortality, and mortality in the 30 days following hospital readmission to a different hospital than the beneficiary was previously discharged from.

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Figure 1. Sample development. AD: Alzheimer disease; CHF: congestive heart failure; COPD: chronic obstructive pulmonary disease; HIE: health information exchange; MI: myocardial infarction; UTI: urinary tract infection.



Data Sources

The primary data source for this analysis was the 2018 Medicare Provider Analysis and Review (MedPar) file, which includes inpatient Medicare claims. Additional clinical characteristics were obtained from the 2018 Medicare Master Beneficiary Summary and the Chronic Conditions Segment files. Hospital characteristics were obtained from the 2018 American Hospital Association (AHA) Annual Survey [21]. HIE participation was obtained from the AHA Information Technology (IT) Supplement from 2017 and 2018 [22,23].

Patients

Inpatient claims from Medicare beneficiaries who had a hospital admission for AMI, CHF, COPD, pneumonia, dehydration, syncope, UTI, or behavioral issues in 2018 were obtained from the Centers for Medicare and Medicaid Services (CMS). Multimedia Appendix 1 shows the International Classification of Diseases–10 codes and diagnosis related group codes used. These conditions were chosen because they are either conditions in the Hospital Readmissions Reduction Program (HRRP) [24]—conditions, including AMI, CHF, COPD, and pneumonia, identified by the CMS as having a high risk of readmission [25]—or are common causes of hospitalization among older adults, particularly those with AD [26,27]. While the index admission was for one of the above reasons, the readmission could be for any reason. We excluded beneficiaries who did not have a readmission in the data set, claims with missing beneficiary identification numbers, and claims that represented admissions resulting from an interhospital transfer. The unit of observation was transformed from a claim to an admission-readmission pair. If a beneficiary had more than 2 hospital admissions, multiple admission-readmission pairs were created (Multimedia Appendix 2 provides examples). We then removed all admission-readmission pairs in which the time from discharge to readmission was over 30 days. The analysis was limited to beneficiaries who were listed as having a diagnosis of AD in the chronic conditions segment; this data source includes diagnoses from 1999 onward [28].

Primary Exposure: Type of Information Sharing

We categorized electronic information sharing based on the availability of electronic information exchange between a beneficiary's admission and readmission hospitals based on the AHA Annual Survey and IT Supplement. The IT Supplement asks, "Please indicate your level of participation in a state, regional and/or local health information exchange or health information organization." Answers could be "do not know," "not operational," "operational...we are not participating," or "operational...we are participating and actively exchanging data." The IT survey additionally asks, "Which of the following national health information exchange networks does your hospital participate in?" Several options are provided, including "your [electronic health record] vendor's network which enables

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exchange with vendor's other users" and "other." If a hospital answered "other" and provided a free-text answer to describe the HIE they participated in, their answers were recoded to be comparable between admission and readmission hospitals. If a hospital had different or missing answers across the 2 years of data, we imputed the answer reflecting their highest level of participation. Hospitals that did not respond to the HIE survey in 2017 and 2018 or who did not respond to the participation in HIE questions were excluded from the analysis.

We classified information sharing into 4 distinct categories: same-hospital readmissions and 3 categories of information exchange between different hospitals with fragmented readmissions. The first type of information sharing was "same-hospital readmission." In this scenario, all the information from the initial admission should be readily available in the patient's medical record during their readmission, so there is no expectation that the hospital's HIE status would have an impact on the quality of care they received. Because these patients did not experience care fragmentation, this group served as the reference group for subsequent analyses. Second, patients could have a fragmented readmission to different hospitals in which both hospitals participate in the same HIE based on their answers to the AHA IT survey (ie, "fragmented/same HIE"). In this scenario, the information from the index admission is available to the readmission hospital via the HIE. The third type of information sharing was a fragmented readmission to different hospitals in which each hospital participated in an HIE, but the HIEs were different between the admission and readmission hospitals (ie, "fragmented/different HIE"). This category captures hospitals that participate in an HIE because they may be different than hospitals that do not participate in HIE, but in this scenario, there is no clear method of electronic information exchange between the admission and readmission hospitals, so information from the index admission is not available to clinicians at the readmission hospital. The final category was "no information shared": fragmented readmissions to different hospitals in which one or both hospitals indicated on the survey that they did not participate in an HIE (ie, "fragmented/no HIE"). Because a beneficiary could have multiple admission-readmission pairs in this analysis, they could have a pair in more than one category of information sharing. In both the fragmented/different HIE and the fragmented/no HIE categories, there is less expectation that participation in different HIEs by both hospitals or participation in an HIE by only one hospital would have an impact on the quality of care.

Outcomes: In-Hospital and 30-Day Postdischarge Mortality

The outcomes of interest for this study were all-cause in-hospital mortality and all-cause mortality in the 30 days following discharge from the readmission (among beneficiaries who survived their readmission). We used the death date of each beneficiary, where applicable, to determine vital status and when the beneficiary died.

Covariates

We included several beneficiary demographic and clinical characteristics, as well as hospital characteristics, in our models. Demographic characteristics included the beneficiary's age, sex, and race (White, Black, or other). Clinical characteristics included a frailty score, the number of chronic conditions, the reason for readmission to the hospital, and if the beneficiary was admitted to the intensive care unit (ICU) during the readmission. The frailty score ranges from 0 to 1, with a higher score indicating greater frailty; it was calculated using a deficit-accumulation model using 93 claims-based variables [29,30]. The number of chronic conditions was measured by counting the number of chronic conditions with which the beneficiary was ever diagnosed in the Chronic Conditions Supplement, which reports 27 chronic conditions [28]. Reason for readmission was divided into 9 categories, based on the 8 categories of interest identified for index admissions and 1 "other reason" category.

Hospital characteristics included hospital size (<500 or ≥500 beds), ownership (government, religious, nonprofit, or for-profit), hospital type (general medical/surgical, or other), urban/rural status of the hospital (metropolitan, micropolitan, or rural), and if the hospital was a teaching hospital or not. Urban/rural status was identified via the Rural Urban Commuting Area codes of the hospital [31]. Hospitals were classified as teaching hospitals if they reported that they had programs accredited by the American Council of Graduate Medical Education, the American Osteopathic Association, or the Council of Teaching Hospitals, or if they were affiliated with a medical school. Hospitals were categorized as either general medical/surgical or "other," which included specialty hospitals [21].

Analytic Approach

Univariate statistics were used to describe and compare clinical and demographic characteristics between admission-readmission pairs across categories of information sharing. Hospital characteristics by HIE status across all hospitals that responded to the AHA Annual Survey and AHA IT survey were also assessed.

To evaluate whether electronic information sharing via HIE between admission and readmission hospitals was associated with in-hospital or postdischarge mortality, we performed unadjusted and adjusted logistic regressions. Regression analyses were adjusted separately for patient demographics and clinical characteristics (age, sex, race, frailty score, number of chronic conditions, reason for readmission, and ICU use during readmission) and for readmission hospital characteristics (number of beds, ownership, hospital type, urban/rural location, and teaching status). Regressions included hospital fixed effects to adjust for unmeasured differences between hospitals. Robust standard errors clustered at the hospital level were used.

We also completed several sensitivity analyses. First, to test the influence of rural hospitals, which may have different market structures than micropolitan or urban hospitals, we removed readmissions to rural hospitals. Second, we limited the analysis to beneficiaries who did not have an ICU stay during their index hospital admission to select for patients at lower risk for death. Third, to determine if HIE use might have a stronger association with mortality in patients at higher risk for mortality, we calculated the probability of dying within 90 days following hospital discharge and analyzed only beneficiaries with a 90-day

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mortality probability of >0.25. We also created propensity-score matched cohorts on the odds of 30-day postdischarge mortality using optimal matching without replacement; this was done to balance the odds of dying across information-sharing categories. Finally, to test if patients who are frequently admitted to the same hospital had a disproportionate influence on the results of same hospital admission-readmission pairs, we limited the same-hospital category to only the first pair for each beneficiary. Analyses were completed in SAS (version 9.4; SAS Institute) and Stata (version 17; Stata Corp).

Ethical Considerations

This study was approved by the Institutional Review Board of Emory University School of Medicine (#00000108) and funded by the National Institute on Aging of the National Institutes of Health (K23AG065505).

Results

Participant Characteristics

The initial sample had 8,316,909 claims. We removed noninpatient claims, interhospital transfers, and observations missing beneficiary identification numbers. We then created admission-readmission pairs; after limiting the pairs to readmissions within 30 days, limiting the pairs to index admissions for the initial diagnoses of interest, and removing pairs in which the beneficiary was listed as deceased after their index admission, we had 428,988 pairs (including 279,729 unique patients). Next, we removed observations with missing HIE data due to nonresponse to the AHA IT survey or nonresponse to the HIE questions on the AHA IT survey (n=71,367, 16.6% of pairs were removed). Of the remaining 357,621 pairs, 8.1% were for beneficiaries with AD (n=28,946 pairs comprising 28,741 unique patients), representing the final sample. Full details of the sample development can be found in Figure 1.

Beneficiaries with same-hospital readmissions were older (aged 81.1, SD 8.6 years) than beneficiaries with readmissions to a different hospital (age range 79.8-80.3 years, $P<.001$; Table 1). There were no differences in frailty score or chronic condition count across the categories of information sharing. While 49.9% of hospitals that responded to the AHA and AHA IT surveys reported participating in an HIE (Multimedia Appendix 3), only 2.1% (601/28,946) of admission-readmission pairs were to hospitals that shared an HIE. Overall, 5.9% (1704/28,946) of beneficiaries died during their readmission, and 19.6% (5667/28,946) died in the 30 days following hospital readmission (Table 1).

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Table 1. Demographic and clinical information of admission-readmission pairs among Medicare beneficiaries with Alzheimer disease in 2018.

	Total (n=28,946)	Same-hospital readmission (n=24,952)	Fragmented readmission			*P* value
			Same HIE[a] (n=601)	Different HIEs (n=2105)	No HIE (n=1288)	
Age (years), mean (SD)	80.9 (8.6)	81.1 (8.6)	80.3 (8.7)	80.1 (8.6)	79.8 (8.4)	<.001
Sex, n (%)						.10
Female	16,163 (55.8)	14,004 (56.1)	329 (54.7)	1142 (54.2)	688 (53.4)	
Male	12,783 (44.2)	10,948 (43.9)	272 (45.3)	963 (45.7)	600 (46.6)	
Race, n (%)						<.001
White	24,097 (83.2)	20,976 (84.1)	467 (77.7)	1644 (78.1)	1010 (78.4)	
Black	3341 (11.5)	2692 (10.8)	111 (18.5)	335 (15.9)	203 (15.8)	
Other	1508 (5.2)	1284 (5.1)	23 (3.8)	126 (6)	75 (5.8)	
Urban/rural status, n (%)						<.001
Metropolitan	25,110 (87.1)	21,641 (87)	526 (87.8)	1878 (89.5)	1065 (82.9)	
Micropolitan	2748 (9.5)	2424 (9.7)	43 (7.2)	131 (6.2)	150 (11.7)	
Rural	985 (3.4)	797 (3.2)	30 (5)	89 (4.2)	69 (5.4)	
Frailty score, mean (SD)	0.20 (0.05)	0.20 (0.05)	0.20 (0.05)	0.21 (0.05)	0.20 (0.05)	.45
Chronic condition count, mean (SD)	20.7 (6.2)	20.7 (6.2)	20.4 (6.0)	20.5 (6.3)	20.7 (6.2)	.24
Reason for admission, n (%)						<.001
MI[b]	2451 (8.5)	2047 (8.2)	57 (9.5)	209 (9.9)	138 (10.7)	
CHF[c]	12,103 (41.8)	10,496 (42.1)	266 (44.3)	834 (39.6)	507 (39.4)	
COPD[d]	3916 (13.5)	3405 (13.6)	76 (12.6)	266 (12.6)	169 (13.1)	
Pneumonia	4716 (16.3)	4097 (16.4)	91 (15.1)	336 (16)	192 (14.9)	
Dehydration	1311 (4.5)	1101 (4.4)	33 (5.5)	112 (5.3)	65 (5)	
Syncope	459 (1.6)	364 (1.5)	13 (2.2)	54 (2.6)	28 (2.2)	
UTI[e]	3954 (13.7)	3411 (13.7)	65 (10.8)	290 (13.8)	188 (14.6)	
Behavioral issues	36 (0.1)	31 (0.1)	0 (0)	4 (0.2)	1 (0.01)	
Reason for readmission, n (%)						<.001
MI	651 (2.2)	516 (2.1)	29 (4.8)	63 (3)	43 (3.3)	
CHF	6362 (22)	5584 (22.4)	125 (20.8)	405 (19.2)	248 (19.2)	
COPD	1743 (6)	1551 (6.2)	27 (4.5)	97 (4.6)	68 (5.3)	
Pneumonia	1376 (4.7)	1238 (5)	18 (3)	74 (3.5)	46 (3.6)	
Dehydration	434 (1.5)	379 (1.5)	6 (1)	34 (1.6)	15 (1.2)	
Syncope	132 (0.5)	111 (0.4)	4 (0.7)	9 (0.4)	8 (0.6)	
UTI	936 (3.2)	838 (3.4)	8 (1.3)	55 (2.6)	35 (2.7)	
Behavioral issues	7 (0.02)	6 (0.02)	0 (0)	0 (0)	1 (0.01)	
Other	17305 (59.8)	14,729 (59)	384 (63.9)	1368 (65)	824 (64)	
ICU[f] stay admission	8651 (29.9)	7483 (30)	153 (25.5)	603 (28.6)	412 (32)	.02
ICU stay readmission	9727 (33.6)	8269 (33.1)	202 (33.6)	772 (36.7)	484 (37.6)	<.001
Readmission hospital number of beds, n (%)						<.001
<500 beds	21,789 (75.5)	18,909 (76.1)	401 (66.8)	1505 (71.7)	974 (76.1)	
≥500 beds	7051 (24.5)	5953 (23.9)	199 (33.2)	593 (28.3)	306 (23.9)	

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	Total (n=28,946)	Same-hospital readmission (n=24,952)	Fragmented readmission			*P* value
			Same HIE[a] (n=601)	Different HIEs (n=2105)	No HIE (n=1288)	
Readmission hospital ownership, n (%)						<.001
Government	2911 (10.1)	2483 (10)	63 (10.5)	204 (9.7)	161 (12.6)	
Religious	3444 (11.9)	2997 (12.1)	67 (11.2)	260 (12.4)	120 (9.4)	
Nonprofit	18,746 (65)	16,288 (65.5)	439 (73.2)	1271 (60.6)	748 (58.5)	
For-profit	3724 (12.9)	3080 (12.4)	31 (5.2)	363 (17.3)	250 (19.5)	
Readmission hospital type, n (%)						<.001
General medical/surgical	28,612 (99.3)	24,799 (99.8)	582 (97.2)	2026 (96.8)	1205 (94.4)	
Other	194 (0.7)	38 (0.1)	17 (2.8)	67 (3.2)	72 (5.6)	
Readmission hospital was a teaching hospital	20,937 (72.6)	17,959 (72.2)	469 (78.2)	1640 (78.2)	869 (67.9)	<.001
Died during readmission	1704 (5.9)	1459 (5.8)	29 (4.8)	130 (6.2)	86 (6.7)	.38
30-Day postdischarge mortality[g]	5667 (19.6)	4856 (19.5)	118 (19.6)	428 (20.3)	265 (20.6)	.62

[a]HIE: health information exchange.

[b]MI: myocardial infarction.

[c]CHF: congestive heart failure.

[d]COPD: chronic obstructive pulmonary disease.

[e]UTI: urinary tract infection.

[f]ICU: intensive care unit.

[g]Among beneficiaries who did not die during their readmission.

In-Hospital Mortality

Compared to same-hospital readmissions, older adults with AD admitted to a different hospital with a shared HIE had 39% lower odds of dying during their readmission (odds ratio [OR] 0.61, 95% CI 0.39-0.95; Table 2), accounting for readmission hospital fixed effects (not shown in table), demographics, clinical characteristics, and hospital characteristics. Beneficiaries with fragmented/different HIE readmissions had no statistically significant difference in the odds of dying during the readmission compared to same-hospital readmissions (adjusted odds ratio [AOR] 1.02, 95% CI 0.82-1.28). Beneficiaries with fragmented/no HIE had 33% increased odds of in-hospital mortality compared to same-hospital readmissions when adjusting for hospital characteristics only (AOR 1.33, 95% CI 1.01-1.75); however, the difference did not remain statistically significant when patient demographics and clinical characteristics were included (AOR 1.25, 95% CI 0.93-1.68).

Table 2. Unadjusted and logistic regressions for in-hospital mortality across categories of information sharing among Medicare beneficiaries with Alzheimer disease in 2018. All analyses are compared to same-hospital readmission pairs. Each model includes readmission hospital fixed effects; robust standard errors are clustered at the level of the hospital. Model 1: demographics (age, sex, race) and clinical characteristics (frailty score, chronic condition count, reason for readmission, intensive care unit stay during readmission); model 2: hospital characteristics (urban/rural, size, ownership, type, teaching status, each for readmission hospital); model 3: full model.

	Unadjusted OR[a,b] (95% CI)	Model 1 (n=18,072), adjusted OR (95% CI)	Model 2 (n=18,157), adjusted OR (95% CI)	Model 3 (n=18,036), adjusted OR (95% CI)
Fragmented/same HIE[c]	0.72 (0.47-1.12)	0.61 (0.39-0.95)	0.72 (0.47-1.12)	0.61 (0.39-0.95)
Fragmented/different HIEs	1.07 (0.87-1.33)	1.01 (0.80-1.27)	1.09 (0.88-1.34)	1.02 (0.82-1.28)
Fragmented/no HIE participation	1.31 (0.99-1.73)	1.24 (0.92-1.66)	1.33 (1.01-1.75)	1.25 (0.93-1.68)

[a]OR: odds ratio.

[b]n=18,196.

[c]HIE: health information exchange.

Thirty-Day Postdischarge Mortality

In unadjusted and adjusted regression models examining the odds of dying in the 30 days following hospital readmission compared to same-hospital readmission, no category of information sharing in fragmented readmissions was associated with postdischarge mortality (Table 3; hospital fixed effects not shown). However, admission-readmission pairs to different

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hospitals that participated in different HIEs trended toward significance when the model included hospital characteristics only (AOR 1.13, 95% CI 0.99-1.29; *P*=.06), but these results were not statistically significant.

Table 3. Unadjusted and logistic regressions for postdischarge mortality across categories of information sharing among Medicare beneficiaries with Alzheimer disease in 2018. All analyses are compared to same-hospital readmission pairs. Each model includes readmission hospital fixed effects; robust standard errors are clustered at the level of the hospital. Model 1: demographics (age, sex, race) and clinical characteristics (frailty score, chronic condition count, reason for readmission, intensive care unit stay during readmission); model 2: hospital characteristics (urban/rural, size, ownership, type, teaching status, each for readmission hospital); model 3: full model.

	Unadjusted OR[a,b] (95% CI)	Model 1 (n=25,668), adjusted OR (95% CI)	Model 2 (n=25,772), adjusted OR (95% CI)	Model 3 (n=25,569), adjusted OR (95% CI)
Fragmented/same HIE[c]	1.00 (0.78-1.28)	0.95 (0.73-1.22)	1.00 (0.78-1.28)	0.95 (0.74-1.23)
Fragmented/different HIEs	1.13 (0.99-1.29)	1.11 (0.97-1.27)	1.13 (0.99-1.29)	1.11 (0.97-1.27)
Fragmented/no HIE participation	1.12 (0.94-1.33)	1.09 (0.91-1.31)	1.12 (0.94-1.33)	1.09 (0.91-1.31)

[a]OR: odds ratio.

[b]n=28,874.

[c]HIE: health information exchange.

Sensitivity Analyses

When rural hospitals were removed to examine the effect of differences between metropolitan or micropolitan and rural market forces, the results of the analyses for both in-hospital and postdischarge mortality were similar to the primary analysis (Multimedia Appendix 4, Tables S1 and S2). When we removed beneficiaries with a probability of 90-day mortality <0.25, the association between fragmented/same HIE and lower odds of in-hospital mortality did not reach statistical significance, likely due to being underpowered (AOR 0.59, 95% CI 0.33-1.07; Multimedia Appendix 4, Table S5); all other associations were similar to the primary analysis (Multimedia Appendix 4, Tables S3-S10). Notably, when we created groups matched on the probably of mortality across information-sharing categories, the primary finding of lower in-hospital mortality remained (AOR 0.61, 95% CI 0.39-0.95; Multimedia Appendix 4, Table S7).

Discussion

Principal Findings

In this study, we sought to measure the association between HIE availability at the hospital level and in-hospital and postdischarge mortality following readmissions to a different hospital among older adults with AD. Compared to readmissions to the same hospital, a shared HIE during fragmented readmissions was associated with 39% lower in-hospital mortality. This benefit did not extend past the hospitalization, as there were no differences observed across the categories of HIE sharing for postdischarge mortality.

Comparison to Prior Work

There have been a limited number of previous studies examining the relationship between HIE presence and inpatient mortality [32]: one focused on patients admitted with acute myocardial infarction found no benefit of HIEs [15], while another focusing on HIE use in interhospital transfers found a 25% lower odds of inpatient mortality [33]. Our study advances the literature in two key ways: first, by focusing on a patient population that may stand to gain outsized benefit from information exchange, and second, by using a more focused definition of information exchange—namely, whether or not the admitting and readmitting hospital participated in the same HIE—to reduce misclassification bias.

Strengths and Limitations

This study has several limitations. First, one important unmeasured potential confounder of the relationship between electronic information exchange and mortality among older adults with AD is the presence of a caregiver. Because caregiver status and their presence during a hospital admission is not available in Medicare claims data, we were not able to assess whether caregivers were more or less likely to go to the hospital with their loved ones during fragmented or nonfragmented readmissions; and if they were present, it is unclear whether they might have served as a type of “human information exchange” for the care team. Qualitative data regarding patient and caregiver perceptions of fragmented versus nonfragmented readmissions, as well as patient and caregiver views on their role in transmitting information across fragmented settings of care, would help address this question.

Second, as with any study where HIE availability is used as a proxy for HIE use by providers, we do not know whether providers accessed the outside information, the quality or content of data shared via electronic information exchange, and, if providers accessed the data, when and how they incorporated the data into their clinical decision-making; this limitation is shared with many other studies of HIEs [13,15,33,34]. Previous work has suggested that providers do not often access HIEs [35,36], mainly because they do not perceive that HIEs contain clinically useful information [37]. Even if HIEs were accessed, we do not know how providers used the information obtained from the HIEs. Perhaps they accessed advance directives and adjusted their care plans to reflect patients’ wishes, or perhaps they reviewed old results and images that could lead to anchoring bias and potential missed diagnoses for the patient. Because the Office of the National Coordinator for Health Information Technology has made HIE availability a priority [38], HIE prevalence and use in clinical decision-making will likely grow over the coming years, and work should continue

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to understand how and when information contained within HIEs impacts patient outcomes. Further investigation into actual provider use of HIE at the point of care will allow researchers to go beyond HIE presence as a proxy for HIE use and will facilitate measurement of the association between how HIEs are used and patient outcomes.

Conclusions

Overall, this study contributes to our understanding of the impact and limitations of HIEs as tools to mitigate the information discontinuity present in fragmented readmissions. It also furthers our understanding of the impact of care fragmentation on older adults with AD and how we can harness existing systems within the health IT infrastructure to lessen the effects of interhospital fragmentation of care in this population.

Acknowledgments

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Data Availability

The data sets analyzed during the current study are not publicly available due to the data use agreement required by the Research Data Access Center/Centers for Medicare and Medicaid Services for use of identifiable Medicare data. Data are available from the corresponding author upon reasonable request and with permission of the Research Data Access Center.

Authors' Contributions

ST, CPV, SDC, KWH, KJR, MMP, CKC, and MKA contributed to conception, results interpretation, and editing the manuscript. ST and MKA contributed to data acquisition and data analysis. ST drafted the manuscript.

Conflicts of Interest

ST and MKA have received funding from Merck for research unrelated to this work.

Multimedia Appendix 1
ICD-10 and DRG Codes Used for Index Admissions.
[DOCX File , 19 KB - aging_v6i1e41936_app1.docx]

Multimedia Appendix 2
Illustration of Admission-Readmission Pairs.
[DOCX File , 36 KB - aging_v6i1e41936_app2.docx]

Multimedia Appendix 3
Characteristics of Hospitals by Availability of Health Information Exchange, 2018 American Hospital Association Annual Survey and 2017-2018 American Hospital Association Information Technology Supplement.
[DOCX File , 17 KB - aging_v6i1e41936_app3.docx]

Multimedia Appendix 4
Results of Sensitivity Analyses.
[DOCX File , 25 KB - aging_v6i1e41936_app4.docx]

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Abbreviations

AD: Alzheimer disease
AHA: American Hospital Association
AMI: myocardial infarction
CHF: congestive heart failure
CMS: Centers for Medicare and Medicaid Services
COPD: chronic obstructive pulmonary disease
HIE: health information exchange
HRRP: Hospital Readmissions Reduction Program
ICU: intensive care unit
IT: information technology
MedPar: Medicare Provider Analysis and Review
UTI: urinary tract infection

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Original Paper

Patient Perceptions of e-Visits: Qualitative Study of Older Adults to Inform Health System Implementation

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Abstract

Background: Electronic visits (e-visits) are billable, asynchronous patient-initiated messages that require at least five minutes of medical decision-making by a provider. Unequal use of patient portal tools like e-visits by certain patient populations may worsen health disparities. To date, no study has attempted to qualitatively assess perceptions of e-visits in older adults.

Objective: In this qualitative study, we aimed to understand patient perceptions of e-visits, including their perceived utility, barriers to use, and care implications, with a focus on vulnerable patient groups.

Methods: We conducted a qualitative study using in-depth structured individual interviews with patients from diverse backgrounds to assess their knowledge and perceptions surrounding e-visits as compared with unbilled portal messages and other visit types. We used content analysis to analyze interview data.

Results: We conducted 20 interviews, all in adults older than 65 years. We identified 4 overarching coding categories or themes. First, participants were generally accepting of the concept of e-visits and willing to try them. Second, nearly two-thirds of the participants voiced a preference for synchronous communication. Third, participants had specific concerns about the name "e-visit" and when to choose this type of visit in the patient portal. Fourth, some participants indicated discomfort using or accessing technology for e-visits. Financial barriers to the use of e-visits was not a common theme.

Conclusions: Our findings suggest that older adults are generally accepting of the concept of e-visits, but uptake may be limited due to their preference for synchronous communication. We identified several opportunities to improve e-visit implementation.

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KEYWORDS

e-visit; patient portal message; digital health tool; patient portal; perception; attitude; qualitative; e-consult; remote care; remote visit; remote consult; vulnerable; messaging; telehealth; telemedicine; eHealth

Introduction

Electronic visits (e-visits) allow patients to get web-based medical advice without the need for a face-to-face visit. They are billable, asynchronous patient-initiated messages that are sent through a patient portal and require at least five minutes of medical decision-making by a provider [1]. There are several benefits of e-visits to patients. They provide a flexible option for obtaining medical care that does not require travel or time off from work, which may save patients time and money [2,3].

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Studies have demonstrated improvements in access to care for patients in rural areas [4-6] and equivalent patient outcomes at a lower cost [7]. For physicians, e-visits are attractive because unlike other patient portal messages, they provide a mechanism for reimbursement [8], and therefore, may lead to direct compensation or credit toward productivity targets.

e-Visits have been used for the management of chronic conditions and for consultation on nonurgent acute health concerns [9,10]. The use and flexibility for reimbursement of e-visits has increased in recent years [11,12]. In 2020, the Centers for Medicare and Medicaid services began to cover e-visits in all types of locations, including the patient's home, and in all areas of the country, rather than just rural areas [12]. Particularly during the COVID-19 pandemic, e-visits have become an increasingly important means of providing virtual care [12].

e-Visits are only available to patients who use patient portals, creating the potential for health disparities. Specifically, older adults and those from minority backgrounds are less likely to enroll in patient portals [13-15]. Barriers to using digital tools like patient portals include limited internet access, low computer skills, and strong habits associated with face-to-face or phone scheduling [16]. As health systems shift toward providing more virtual care [17,18], it is crucial that we understand the interest and ability of vulnerable patient groups to use these digital tools so as to prevent worsening health disparities. Furthermore, when health systems begin to offer e-visits, they may see low uptake and dissatisfaction if key patient groups are uncomfortable with their use. Although several studies have evaluated the demographic characteristics of patients who use e-visits [9,10,19] and providers who offer them [4,7,20], little is known about how patients at risk of digital health disparities perceive this visit type, particularly compared to traditional, nonbillable patient portal messages. Therefore, in this qualitative study, we aimed to understand patient perceptions of e-visits, including their perceived utility, barriers to use, and care implications, with a focus on vulnerable patient groups.

Methods

Study Setting

We conducted this study at University of California, San Francisco (UCSF) Health, a large tertiary academic medical center that originally introduced e-visits in 2020 and was considering a change to how e-visits were offered to patients. UCSF uses a commercially available electronic health record from Epic Systems. Over 90% of patients empaneled to UCSF primary care were enrolled in the patient portal during the time of the study.

Study Design and Oversight

We conducted a qualitative study using in-depth structured individual interviews with patients from diverse backgrounds to assess their knowledge and perceptions surrounding e-visits as compared with portal messages and other visit types. We specifically explored their perceptions of the acceptability and usability of e-visits.

Ethical Considerations

This study was reviewed and deemed exempt by the University of California at San Francisco Institutional Review Board.

Study Recruitment

Potential participants were identified from among patients who received primary care at UCSF Health. To include patients with varying degrees of comfort using web-based patient portals for their care, we recruited half of the participants from among patients who had used a patient portal–based triage tool [21] and half of the participants from among patients who had used an identical telephone-based triage tool in the past 6 months. We hypothesized that patients who had opted to use the patient portal tool were more likely to be comfortable using other patient portal tools and that patients who had opted to use the more time-consuming telephone tool might be less comfortable or less preferential toward using other patient portal tools, such as e-visits.

To ensure representation from a diverse sample of patients, we then further identified those who met the following criteria: Latinx ethnicity, African American race, having MediCal (Medicaid) insurance, living outside of the 9 San Francisco Bay Area counties, and non–English speaking. We randomly selected at least two participants from each of these groups before recruiting a random selection of patients, regardless of their demographic characteristics, until we reached saturation of responses. Race and ethnicity were treated as social rather than biologic constructs and were included as a proxy for unmeasured factors experienced by socially marginalized populations that may predict their experience using e-visits. We used MediCal insurance as a proxy for low socioeconomic status. The researchers did not have previous treatment relationships with the participants.

On the initial phone call, the research coordinator described the study, and for those interested in participating, obtained informed consent and scheduled an interview. Participants were given a US $60 gift card for their participation, which was sent to them prior to completing the interview.

Participant Interviews

A trained service designer (JY) with extensive experience in human-centered design and qualitative research conducted an approximately 60-minute interview with each participant. Interviews were conducted by Zoom videoconferencing, if possible. If the participant was unable to use video, they were conducted by telephone. If patients preferred, they could invite a caretaker, such as an adult child, to join the interview. The service designer used a structured interview guide (Multimedia Appendix 1), which included the following domains: current methods of communicating with providers, perceptions of e-visits and patient portal messages, financial aspects of e-visits, naming conventions for e-visits, self-assessment of health technology literacy, and current health status. This interview guide, consisting of mostly open-ended questions, was developed after conducting a review of literature and lay press to identify potential risks and benefits of e-visits, particularly compared to other visit types. Certain questions were adapted from validated questionnaires [22,23]. Participants could elect

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not to answer any question. Patient interviews were digitally recorded and transcribed using the transcription service Tigerfish [24].

Transcription Review and Analysis

We used a combination of qualitative and quantitative content analysis to analyze interview data [25,26]. Transcripts were reviewed independently by 2 clinician investigators (TJJ and MS) under the guidance of a trained qualitative researcher (JDH). We organized data analysis around the study questions: acceptability, usability, as well as financial and care implications. We first used qualitative content analysis to systematically examine the transcripts to obtain a condensed understanding and description of content [25]. We used a data-driven (inductive) approach to analysis whereby open coding was performed to identify salient and elevated topics of importance within the data set. To ensure trustworthiness, throughout analysis, reviewers (TJJ, MS, and JDH) met to refine and define coding categories, and coding disparities were discussed and resolved by negotiated consensus [27]. Coding categories were then grouped into higher-order categories or themes.

Quantitative content analysis was then performed to count coding categories. This was conducted for the purpose of providing a more detailed assessment of how frequently certain themes or codes were mentioned. For each code, there was at least one corresponding question in the interview guide pertaining to that topic. For the purposes of determining the proportion of responses related to a particular code or coding category, we excluded participants from the denominator if they did not answer the pertinent question(s). We then did a secondary analysis comparing themes between patients who had used the patient portal tool in the past 6 months, compared to those who had not. We aimed to enroll until we reached saturation of responses, which we defined as having done at least 9-17 interviews [28] and observing the repetition of themes without significant new insights.

Sharing Findings With the Health System

After analyzing qualitative themes and identifying key patient responses, we shared findings with health systems leadership to inform informatics and operational changes related to the broader implementation of e-visits at the institution.

Results

From April 2021 to June 2021, we conducted qualitative interviews with a total of 20 adults (Table 1). The median age was 74 (IQR 68.5-77.8) years. Of 20 participants, 13 (65%) identified as male, and 7 (35%) identified as female; 10/20 (50%) participants identified as White or Caucasian, 5/20 (25%) as Asian, 2/20 (10%) as Black or African American, 1/20 (5%) as American Indian or Alaska Native, and 2/20 (10%) as a race not listed. Of the 20 participants, 3 (15%) identified as Latinx, and 2 (10%) patients had limited English proficiency. Most patients (14/20, 70%) had Medicare insurance. All patients had an active patient portal account. One of the interviewed participants reported having used an e-visit before.

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Table 1. Interview participants baseline characteristics.

Characteristics	Values (N=20)
Age (years), median (IQR)	74 (68.5-77.8)
Sex, n (%)	
Female	7 (35)
Male	13 (65)
Race, n (%)	
American Indian or Alaska Native	1 (5)
Asian	5 (25)
Black or African American	2 (10)
Other	2 (10)
White or Caucasian	10 (50)
Ethnicity, n (%)	
Hispanic or Latinx	3 (15)
Not Hispanic or Latinx	17 (85)
Limited English proficiency	2 (10)
County of residence, n (%)	
San Francisco	14 (70)
Other	6 (30)
Insurance, n (%)	
Medicare	14 (70)
Medicare advantage	2 (10)
Medicaid	3 (15)
Other	1 (5)

We identified 4 overarching coding categories or themes, comprising 7 codes (Table 2).

These themes stemmed from a combination of both prompted (in response to an interviewer question) and unprompted (ie, spontaneous) comments from participants. First, participants generally were accepting of the concept of e-visits and were willing to try them. For example, after hearing about the effort to make this visit type available to patients, one participant stated "I wholeheartedly endorse that. I think it's not just a good idea, it's essential." Participants voiced that e-visits may be most helpful to prevent office visits. For example, one participant stated, "the actual cost [of an in-person visit] is a lot more because of transportation…and lost opportunity to do something else." Participants also generally agreed with the idea that providers should be fairly compensated for time spent on medical decision-making, whether in a synchronous visit (eg, video visit) or asynchronous visit (eg, e-visit).

Second, nearly two-thirds (10/16) of the participants voiced a preference for synchronous communication. In many cases, in-person visits were preferred. These preferences stemmed from improved perceptions of communication and comprehension by both patients and physicians.

Third, some participants had specific concerns about e-visits. Many found the name confusing and thought they should instead have a more descriptive name, such as "online medical advice." Participants also voiced concern about choosing the right visit type in the patient portal and did not think it should be left up to the patient to determine whether they should submit a billable e-visit or nonbillable message. Participants also voiced discomfort expressing medical questions in writing. One participant stated, "You're relying upon your narrative. You have to express in [the patient portal] within a certain amount of words exactly what the issue is. And believe me, that sometimes can't be captured." Only 2 of the 7 participants who expressed this concern had limited English proficiency.

Fourth, 6/18 (33%) participants indicated discomfort using or accessing technology for e-visits. For example, the daughter of one participant stated "[My parents] don't have the computer skills. They are from the telephone era. They prefer talking to a human being and it makes sense to them versus typing."

Financial barriers were not a common theme, with only 3/18 (17%) patients expressing concern over increased out of pocket costs resulting from patient portal messages being converted to billable e-visits. Only 3/18 (17%) participants thought that precise out-of-pocket patient costs for e-visits need to be stated up front before a patient sends a message. However, participants did expect that the out-of-pocket costs for e-visits should be less than or equal to the costs for a synchronous visit. The most

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commonly quoted amount that participants reported they would pay out of pocket for an e-visit was US $20.

There were minimal differences in themes between participants who did or did not use the patient portal tool in the past 6 months. For example, 6/9 (67%) participants recruited from the patient portal group liked the idea of e-visits versus 5/10 (50%) participants recruited from the telephone hotline group. A total of 4 participants recruited from each group reported discomfort using technology.

Table 2. Summary of coding categories and codes describing patient perspectives of e-visits.

Higher-order coding category or theme	Code	Proportion[a], n/N	Sample quotation
Acceptance of the concept of e-visits	Favors the idea of e-visits	11/19	• "I wholeheartedly endorse that. I think it's not just a good idea, it's essential"
	Willing to try e-visits	14/18	• "All of sudden [if I] have sores in my mouth or something like that, I'm sure that could be handled through an e-visit."
	Thinks e-visits may help prevent office visits	11/16	• "The actual cost [of an in-person visit] is a lot more because of transportation…and lost opportunity to do something else"
	Thinks providers should be fairly compensated for their time	11/18	• "I am still using his time, so he definitely should get compensated for that because they are giving me medical advice"
Preference for synchronous communication[b]	Preference for synchronous communication[b]	10/16	• "[The patient portal] is not very effective because there's a lot of miscommunication and misunderstanding." • "I'm constantly having to ask for repetition. This is good because it helps me understand if the doctor is understanding me, as well as me understanding the doctor. In a text message you don't get that."
Concerns about e-visits	Naming convention is confusing	10/16	• "I don't know what it means…I think you would have to say something like an online visit, or online medical advice"
	Difficulty choosing right visit type within the patient portal	8/14	• "the doctor [should] make the call." • "if there were some guidelines, that could help the patient"
	Discomfort expressing medical questions in writing	7/18	• "You're relying upon your narrative. You have to express in [the patient portal] within a certain amount of words exactly what the issue is. And believe me, that sometimes can't be captured."
Discomfort using technology[b]	Discomfort using technology[b]	6/18	• "[My parents] don't have the computer skills. They are from the telephone era. They prefer talking to a human being and it makes sense to them versus typing…" • "I never could remember my password. Well, ok, that's because I'm old."

[a]We excluded participants from the denominator if they did not answer the pertinent question(s).

[b]Singular topics that were common within the data set are included as both a code and a theme.

Discussion

Principal Findings

The majority of participants in this study were accepting of the idea of e-visits—billable, asynchronous patient-initiated messages—and willing to try one, despite preferring synchronous visits. Most participants agreed that providers should be fairly compensated for medical decision-making. Although they opined that out-of-pocket costs should be similar to or less than the cost for synchronous visits, they did not voice major concerns over additional out-of-pocket spending. Few participants voiced the need to know the precise cost of the visit upfront. Major concerns about e-visits included naming conventions, difficulty choosing the right visit type, and discomfort expressing medical terms in writing. A minority of participants expressed technical barriers to use of e-visits, and these included both participants who had and had not recently used the patient portal to receive care.

Concern about potential out-of-pocket costs was not a common theme among the participants in this study, and participants

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generally agreed that providers should receive payment for providing medical advice via web-based messages. This finding is important because it differs from the concerns raised in recent media coverage of e-visits, which has emphasized the implementation of billable messaging causing possible financial harm to patients [29,30]. However, this study was limited to mostly patients with Medicare insurance, so the absence of concern about out-of-pocket costs of e-visits may not be generalizable to other patient groups with different health insurance cost sharing structures.

Over the past several years, there has been a major increase in the number of patient portal messages, leading to burnout among frontline nurses, physicians, and other staff who must respond to these messages, largely between or after their other clinical duties and without reimbursement [31,32]. Billable e-visits are one potential solution. By reimbursing providers for delivering medical advice outside of a visit, e-visits may allow them to schedule more protected time during the day for responding to messages, rather than doing so on nights and weekends. They may also encourage care delivery organizations to innovate alternate means of communicating with and engaging patients. However, there is a risk that if organizations replace patient-portal messaging with billable e-visits, it will create a financial disincentive for patients to seek help when they need it. Therefore, the findings of this study are important, as they suggest that the majority of older adults are receptive to the concept of e-visits and do not perceive major financial barriers to use.

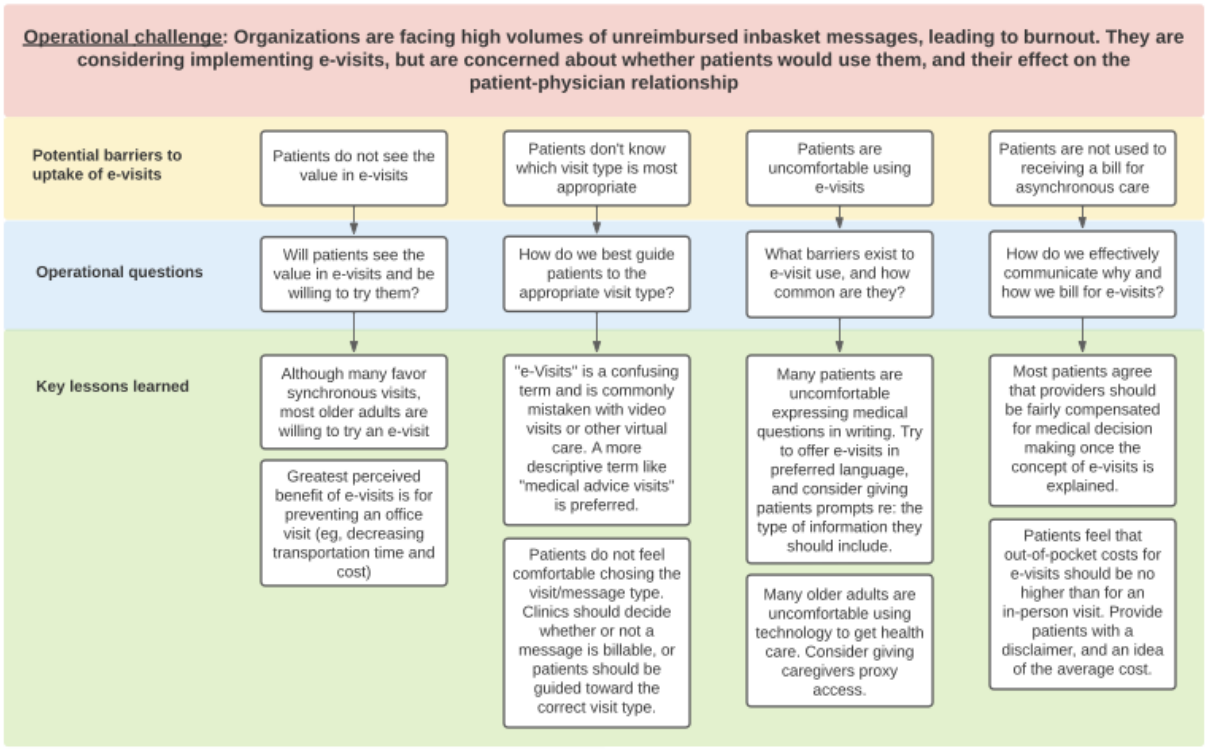
Older adults are at particular risk for facing health disparities as a result of decreased access to digital health technologies [33,34]. Our findings include perceptions of older adults and other groups at risk for health disparities, including those with limited English proficiency and of various races and ethnicities. Most participants in this study preferred synchronous communication over asynchronous methods like e-visits and unbilled patient portal messages, putting them at risk for ongoing disparities unless specific efforts are undertaken to make these tools attractive and accessible to them. Various interventions have been suggested for addressing the digital divide in general—for example, universal internet access, training in computer literacy, language concordant materials, and encouraging family or caregiver assistance in using digital tools [34]. In addition, we recommend several interventions below that are specific to e-visits.

Given recent changes in Centers for Medicare and Medicaid Services policy that allow for broader use of e-visits, many organizations may be considering implementing e-visits. However, there are several potential barriers to consider. The findings from our analysis, which includes the perspectives of a diverse group of older adults, may be generalizable to other institutions.(Figure 1). We identified several key lessons learned that may inform interventions to improve acceptability and usability of e-visits. First, patients may not know what e-visits are or how to choose between an e-visit and a traditional patient portal message or other visit type. To address this, we recommend that the patient-facing name for e-visits be something more descriptive, such as “medical advice message.” We also recommend that patients not be asked to determine whether their message clinically qualifies as a billable e-visit or a nonbillable patient portal message—rather, that there should be a single point of entry for patients and billing should occur only if the message meets criteria. Third, patients may have technical, language, or educational barriers to using e-visits. We found that few participants actually lacked access to the necessary equipment but that many expressed discomfort using technology or expressing medical questions in writing. For this reason, we recommend that patients be able to write e-visit queries in their preferred language and with prompts (eg, are you having pain? What medications have you tried?) to improve comfort with phrasing medical questions in writing. Patient caregivers (eg, adult children) should be given proxy access to patient portals to submit e-visits on their behalf. Finally, patients may have concerns about receiving a bill for patient portal messages that are classified as e-visits if their patient portal communications had all been unbilled in the past. We recommend that organizations include a disclaimer in plain language that requires the patient’s acknowledgement, describing that some messages may be billed and may generate out-of-pocket costs to the patient. Ideally, organizations should also provide patients with the range or average out-of-pocket cost of these visits, acknowledging that they will vary by insurance type.

Our results align with published literature on patient perceptions of use of other virtual care options, such as patient portals (secure websites giving patients access to personal health information, including the ability to communicate with their care team) and chatbots. For example, a 2018 National Poll by the University of Michigan determined that the technology gaps for older adults were rapidly narrowing, but nonetheless, respondents older than 65 years were more likely to report that they did not like using the computer to communicate about their health [35]. Similarly, a systematic review of perceptions of patient portals [36] determined that patient-provider communication was the most prevalent positive attribute, while concerns over security and user-friendliness were the most prevalent negative perceptions. This sentiment aligns with our findings that participants perceived a benefit of e-visits being the ability to communicate with their physician asynchronously to avoid a visit, while a commonly cited barrier to use was navigating the patient portal to choose the appropriate visit type. This insight also supports the conclusion of a study from Sweden [37] in which patients who used a chat-based, automated history-taking service appreciated the ability to communicate medical information asynchronously and potentially prevent an unnecessary visit.

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Figure 1. Recommendations for implementation of e-visits in practice.



Limitations and Strength

This study has several limitations. First, because e-visits were not being frequently used at the time of the study, very few of the participants had used an e-visit before, so their perceptions were based on the description of this new visit type by the interviewer. Patients who have used an e-visit to receive care in the past may have different perceptions. Second, we interviewed a relatively small sample size of 20 patients, and the majority were from the San Francisco Bay Area, where there are high rates of digital literacy. Our findings may therefore not be generalizable to very different patient populations. However, with this study's sample size and composition, we reached saturation of ideas in participants responses. Third, interpretation of transcription content may be biased due to individual reviewer's implicit biases. However, neither of the reviewers had a direct role in overseeing e-visit implementation and had no financial or other incentives for e-visits being successful. Fourth, participant responses could have been more favorable due to social desirability bias since the research team is affiliated with the health care system in which they receive care [38]. However, the researchers were not on the patients' treatment teams and explicitly stated prior to the interview that all responses would be anonymized and would in no way affect their care. Furthermore, gift cards to compensate participants' time were distributed prior to the interview to prevent any misperception that certain responses would be linked to reward. Fifth, because we used open-ended questions, more time may have been spent discussing certain themes or categories than others, which may have created a bias in quantitative analysis if participant responses were a reflection more so of the questions asked than of their opinions about e-visits. Finally, our study population was identified among UCSF primary care patients who had used a patient portal or telephone triage tool to seek an appointment, testing, or triage advice about COVID-19. It is possible that these patients differed in some way from the general population, though we have no reason to suspect that this group would have different perceptions about virtual care.

The study also had several strengths. We recruited a group of participants with diverse personal characteristics, including race, ethnicity, language, income, and geography, to capture of range of experiences. We allotted up to 60 minutes for each interview to provide time for open responses and for participants to elaborate on their responses. We also recruited patients who had variable historic use of the patient portal, to capture the perceptions of those who may be less technically savvy with digital health tools.

Conclusion

In summary, this is one of the first studies to report qualitative feedback on e-visits, and the first, to our knowledge, to do so since the start of the COVID-19 pandemic and reflecting the 2020 changes Centers for Medicare and Medicaid Services policy changes related to e-visits. Our evaluation is an important step toward understanding patient perceptions around e-visits, a relatively new asynchronous form of digital health care delivery. Our findings suggest that older adults are generally accepting of the concept of e-visits, but still prefer synchronous visit types. We identified opportunities to improve e-visit implementation and design. As telemedicine and virtual care continue to grow and occupy a greater part of the health care landscape, issues such as patient acceptance, digital health care access, and usability in provider workflows will become increasingly critical to the success of such programs.

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Authors' Contributions

TJJ, MS and JDH conceptualized the study. All authors contributed equally to the overall design of the study. TJJ and MS were responsible for the development of patient interview questionnaires. JY conducted the patient interviews. TJJ, MS, and JDH were involved in data analysis. TJJ and MS wrote the first draft of the manuscript, and all authors reviewed, edited, and contributed to subsequent revisions. Regarding data access, responsibility, and analysis, TJJ and MS had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Conflicts of Interest

TJJ receives consulting fees from the McKinsey Clinical Network and has received equity from Assure Health. MB receives University of California copyright royalties for Copyright SF2015-137 and Patent SF2016-239.

Multimedia Appendix 1
Structured interview guide.
[DOCX File , 18 KB - aging_v6i1e45641_app1.docx]

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Abbreviations

UCSF: University of California, San Francisco

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Evaluating the Acceptability and Appropriateness of the Augmented Reality Home Assessment Tool (ARHAT): Qualitative Descriptive Study

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Abstract

Background: The Augmented Reality Home Assessment Tool (ARHAT) is a mobile app developed to provide rapid, highly accurate assessments of the home environment. It uses 3D-capture technologies to help people identify and address functional limitations and environmental barriers.

Objective: This study was conducted to gain stakeholder feedback on the acceptability and appropriateness of the ARHAT for identifying and addressing barriers within home environments.

Methods: A qualitative descriptive study was conducted because it allows for variability when obtaining data and seeks to understand stakeholders' insights on an understudied phenomenon. Each stakeholder group (occupational therapists, housing professionals, and aging adult and caregiver "dyads") participated in a 60-minute, web-based focus group via a secure Zoom platform. Focus group data were analyzed by 2 trained qualitative research team members using a framework method for analysis.

Results: A total of 19 stakeholders, aged from 18 to 85+ years, were included in the study. Of the occupational therapists (n=5, 26%), housing professionals (n=3, 16%), and dyads (n=11, 58%), a total of 32% (n=6) were male and 68% (n=13) were female, with most living in the Midwestern United States (n=10, 53%). The focus group data demonstrate the acceptability and appropriateness of the workflow, style, measurement tools, and impact of the ARHAT. All stakeholders stated that they could see the ARHAT being used at many different levels and by any population. Dyads specifically mentioned that the ARHAT would allow them to do forward planning and made them think of home modifications in a new light.

Conclusions: Stakeholders found the ARHAT to be acceptable and appropriate for identifying and addressing functional limitations and barriers in the home environment. This study highlights the importance of considering the workflow, style, measurement tools, and potential impact of home assessment technology early in the developmental process.

(JMIR Aging 2023;6:e44525) doi:10.2196/44525

KEYWORDS

technology; aging in place; augmented reality; home modification; mobile; assessment; mobile application; qualitative study; environmental barrier

Introduction

Nearly 90% of adults wish to age independently or remain in their home and community as long as possible [1,2]. Yet as people age, they are more likely to experience physical and cognitive declines and symptoms associated with chronic health conditions, which result in functional impairments that can impact their safety and ability to age independently [3]. Evidence demonstrates that addressing aging adults' functional limitations in their home environment enables people to continue living at home instead of moving into an institutional care facility [4]. However, there are relatively few standardized mobile apps on the market that help people identify and address functional limitations and barriers in the home environment [5,6]. This is problematic because environmental barriers increase the risks of functional limitations and reduce the level of independence one has when choosing to age in place safely.

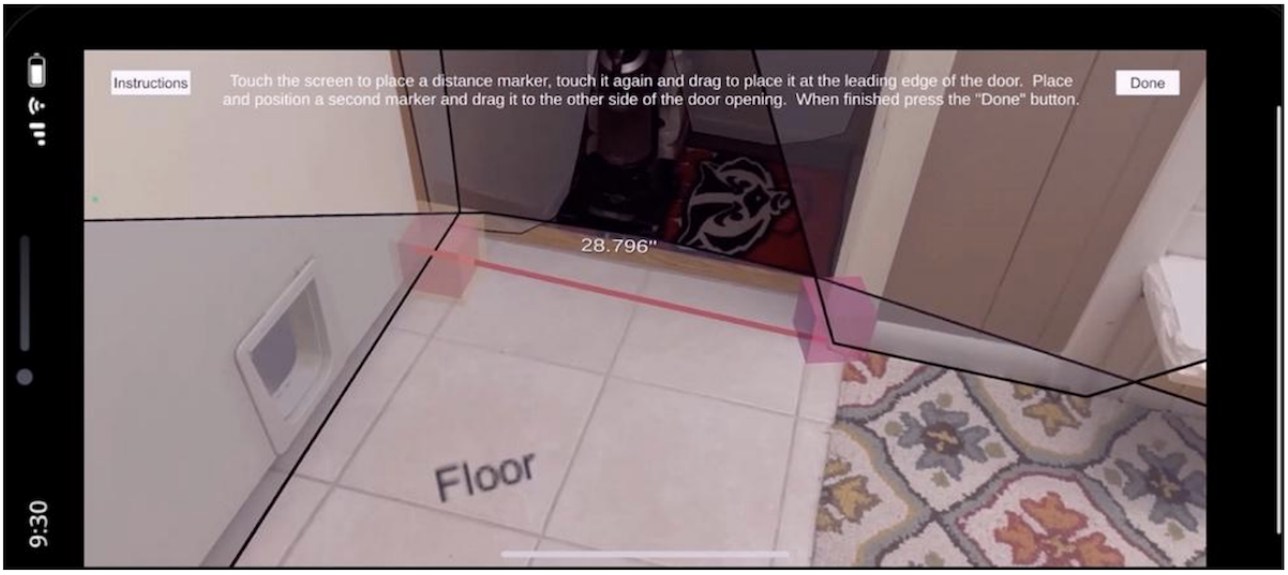
The Augmented Reality Home Assessment Tool (ARHAT) is a new tool aiming to address these problems. This mobile app helps people identify and address functional limitations and

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environmental barriers in their home and environments. In comparison to other mobile apps, the ARHAT is guided by the Housing Enabler (HE) [7] and the 2010 American Disability Act (ADA) [8] and provides rapid, highly accurate assessments of home environments by using 3D-capture technologies. The HE provides equal emphasis on the functional limitations of the individual and housing configurations based on the Ecological Theory of Aging and its foundational concept of the Person-Environment fit [9]. The HE uses 14 different types of functional limitations, focusing on the symptoms rather than a diagnosis of disease. Additionally, the ADA provides guidelines to ensure all spaces promote accessibility and usability for individuals with disabilities [8]. Together, the HE and ADA provide a solid foundation for guiding the ARHAT's approach to assessment.

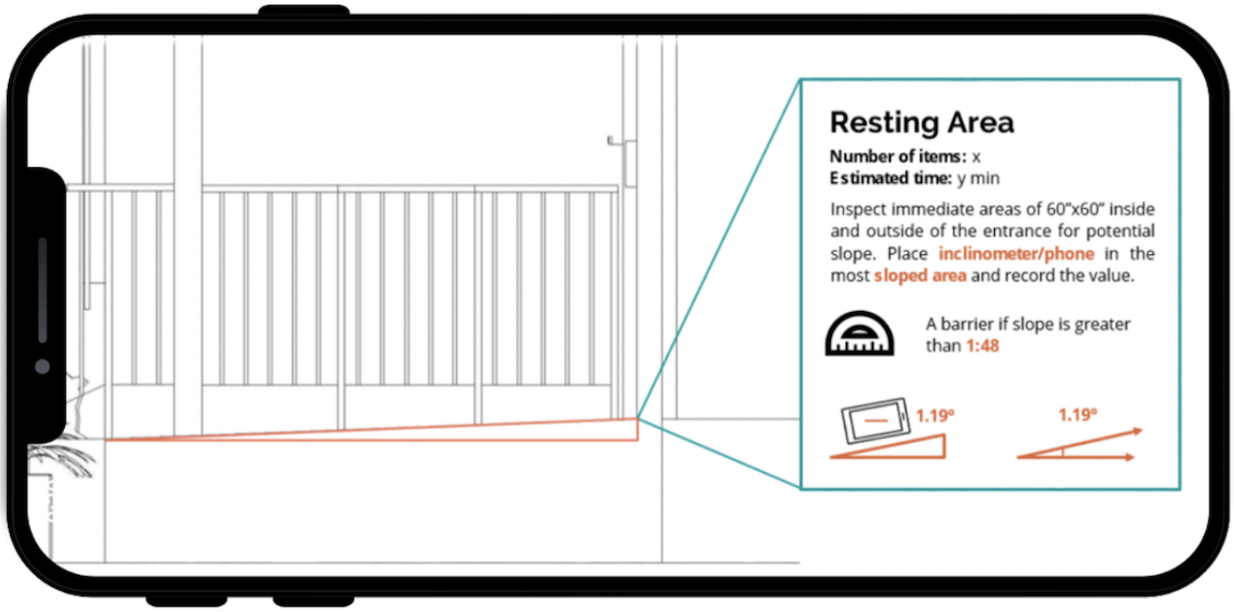
The ARHAT is comprised of 3 unique approaches to assess the home environment: by selecting either a functional limitation (eg, vision impairment), a space (eg, the bathroom), or the whole house. Through each approach, users are prompted to learn about and use many augmented reality (AR) measurement tools, including tools for measuring distance, incline, illumination, radius, and maneuverable space. As individuals use these measurement tools in the ARHAT, they are provided information on whether their home is compliant with the ADA guidelines. Distance measurements are performed when the user touches areas on the screen they would like to measure. Two or more end points can be adjusted to measure both vertical and horizontal distances, for example, as shown in Figure 1 when performing a doorway measurement.

Figure 1. Distance tool.



Resting areas are traditionally measured using inclinometers to assess the slope of a resting area for accessibility. The ARHAT uses sensors inside the phone to measure slope when the phone is set on the ground (Figure 2).

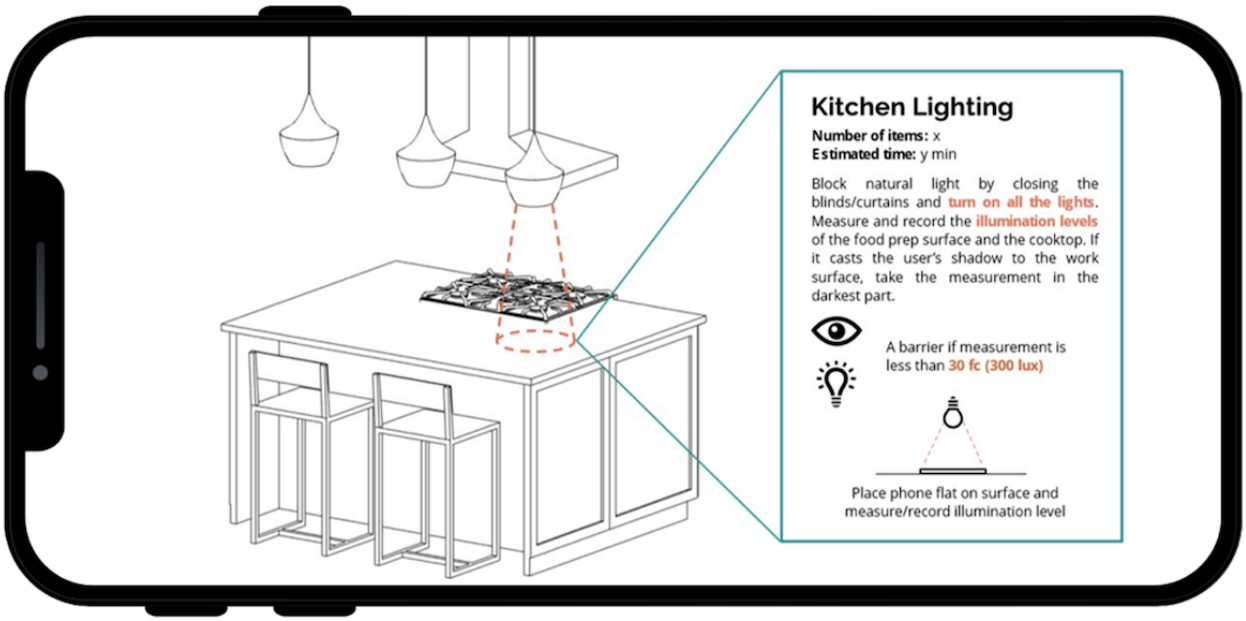
Figure 2. Incline tool.



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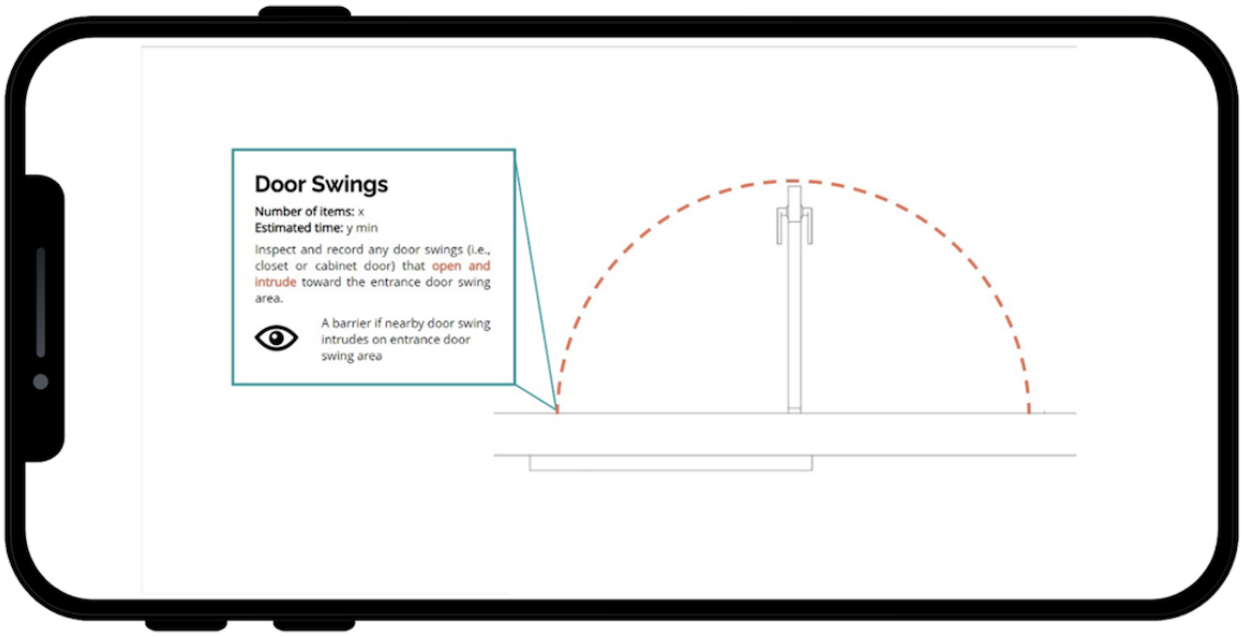
The ARHAT adds an objective way to measure whether illumination is sufficient for accessibility in an area; otherwise, it may become a safety concern. The ARHAT uses light sensors embedded in the phone to perform a similar assessment when placed on critical work surfaces (Figure 3).

Figure 3. Illumination tool.



The radius tool allows for direct visualization of the radius of a door swing, for example, to aid in the visual inspection of obstructions (Figure 4).

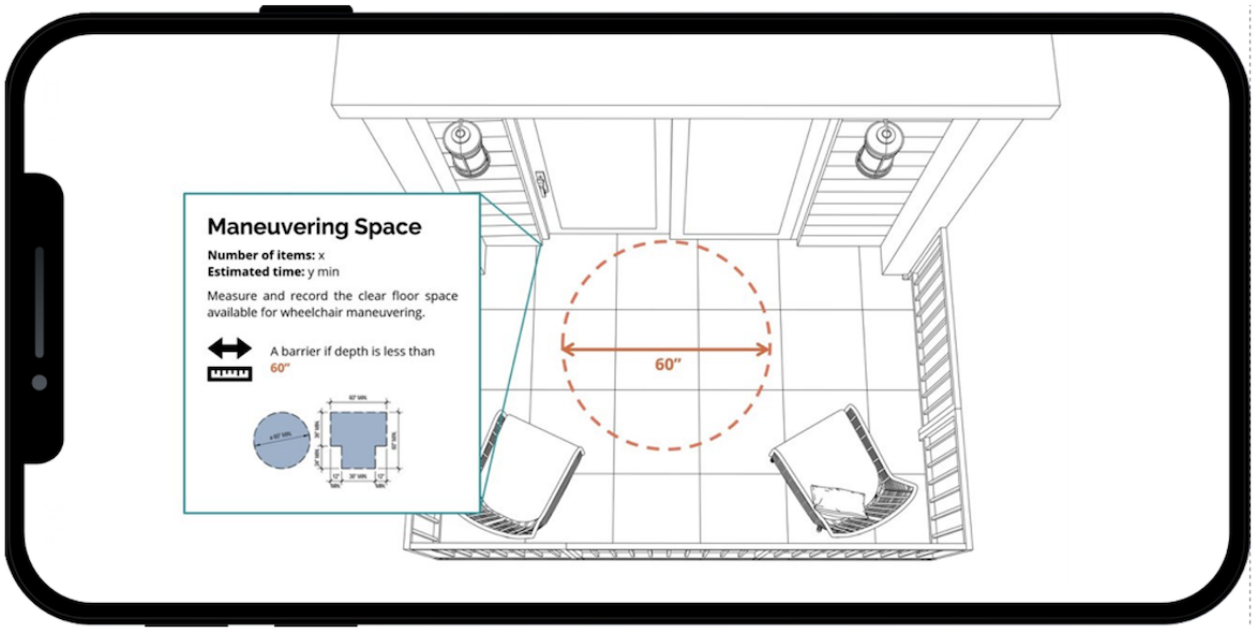
Figure 4. Radius tool.



Lastly, the maneuvering visualization tool allows the user to see a colored area on the floor that represents the measured maneuvering area for a wheelchair user (Figure 5).

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Figure 5. Maneuvering visualization tool.



Despite the promising utility for the ARHAT, the appropriateness and acceptability of the tool must be examined before implementation in the home environment. Appropriateness is defined as "the perceived fit, relevance, or compatibility of the innovation to address a current issue," and acceptability is defined as "the perception among implementation stakeholders that a given treatment, service, practice, or innovation is agreeable, palatable, or satisfactory" [10]. These constructs are important to consider early in the ARHAT development process, as they serve as indicators of implementation success. Therefore, the purpose of this study was to assess the appropriateness and acceptability of the ARHAT. As a result of this study, the ever-growing number of people wanting to safely age in place will have a mobile app to help them identify and address barriers within their home environment.

Methods

Design

A qualitative descriptive study [11] was conducted. This design was selected because it allows for variability when obtaining data and seeks to understand stakeholders' insights on an understudied phenomenon [11].

Stakeholders

We purposely recruited occupational therapists (OTs), housing professionals (HPs), and aging adult and caregiver ("family members or friends") dyads through social media sites and email listservs, including Twitter, Facebook, caregiving and aging networks (ie, Center for Aging Research and Education), and national organization community boards (ie, American Occupational Therapy's Productive Aging Group). These 3 stakeholder groups were targeted because of their expertise in home assessments, home modifications, functional limitations, and aging in place. Inclusion criteria for OTs were having had 5 years of professional experience in their respective positions and speaking English. Inclusion criteria for HPs were having had 5 years of professional experience in their respective positions, having earned the Certified Aging-In-Place Specialist designation, and speaking English. Inclusion criteria for aging adults were being at least 60 years or older, speaking English, and living at home. Inclusion criteria for caregivers were being at least 18 years of age and providing unpaid care to a relative or partner aged 60 years or older to assist them in taking care of themselves. No stakeholders were excluded based on their sex, gender, race, ethnicity, or socioeconomic status.

From the recruitment materials, stakeholders interested in the study were directed to either email or call the research team. Research team members then followed up with interested stakeholders to share more study details, go over consent, and confirm next steps. All stakeholders were informed that the study was completely voluntary and that they could withdraw at any time.

Ethical Considerations

Based on the study procedures, the Institutional Review Board at the University of Wisconsin-Madison (#2021-0856) determined this research to be no more than minimal risk and qualified as exempt from ethics approval. For these reasons, verbal consent was received from all stakeholders in this study.

Data Collection

Each stakeholder group participated in a 60-minute, web-based focus group via a secure Zoom platform (Zoom Video Communications). Stakeholders were emailed a Zoom link, an agenda, and a demographic survey 1 week prior to the focus group. Demographics that were collected included gender, education, geographic location, age, occupation, and race and ethnicity. Each focus group was led by a trained qualitative research member (BF). Two other members of the research team (LK and MF) were responsible for taking notes during each

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focus group. During each focus group, stakeholders first introduced themselves. They then viewed a demonstration video of the ARHAT that walked them through the use of the AR technologies. After the demonstration video, the stakeholders were asked open-ended questions to learn their perspectives on the ARHAT's acceptability and appropriateness [10]. For example, stakeholders were asked how they could see the ARHAT being used within their occupation or which color scheme was preferred. See Multimedia Appendix 1 for the focus group guides. All focus groups were recorded, transcribed, and checked for accuracy prior to data analysis.

Data Analysis

Focus group data were analyzed by 2 trained qualitative research team members (LK and MF). The research team selected a framework method for analysis [12] because coding was guided by the overall organization of the focus groups. Specifically, the team members completed the following three steps: (1) read transcribed interviews, (2) applied existing categories to the data using the focus group guides, and (3) condensed codes into themes. All stakeholder interviews were transcribed and coded using NVivo 12 Pro (Lumivero). To ensure the reliability of coding, research team members performed a reliability check by comparing coding in a one-on-one meeting. Data were then summarized and discussed with the research team (LK, MF, BF, JHS, KP, RT, BS, and JL) to understand the strengths and areas for improvement of the ARHAT.

Results

Stakeholder Demographics

A total of 19 stakeholders, aged from 18 to 85+ years, were included in the study. Of the OTs (n=5, 26%), HPs (n=3, 16%), and dyads (n=11, 58%), a total of 32% (n=6) were male and 68% (n=13) were female, with most living in the Midwestern United States (n=10, 53%). Other stakeholders resided in the Northeastern (n=4, 21%), Western (n=1, 4%), Southeastern (n=2, 11%), and Southwestern (n=2, 11%) United States. Stakeholders were predominantly White (n=17, 89%), with 1 (5%) American Indian or Alaska Native and 1 (5%) African American stakeholder. The education of the 19 stakeholders varied, as 16% (n=3) held a doctorate-level degree, 26% (n=5) had obtained their master's degree, and the majority (n=18, 94%) reported attending some college.

Data demonstrate the acceptability and appropriateness of the ARHAT and are organized around the focus group guides: workflow, style, measurement tools, and impact. To illustrate the acceptability and appropriateness of the ARHAT, direct quotes are provided for each stakeholder group.

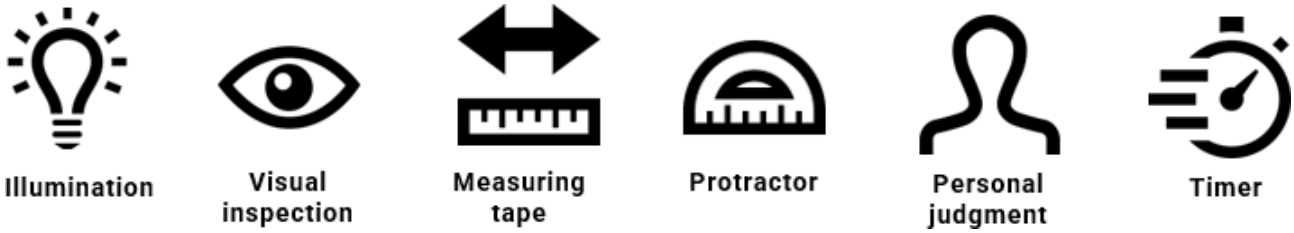
Workflow

To increase workflow usability, all stakeholder groups stated that they would like to see more prompting and call-out boxes within the ARHAT for further clarification. Moreover, during each focus group, stakeholders sparked questions about what the output data would look like from the ARHAT. They also inquired about how they would be able to use the information collected through the mobile app. Stakeholders recommended inserting a screen at the beginning of the ARHAT to describe how the data could be used, a preview of what the data would look like after measurements were taken, and how to export the data after completing an assessment. Demonstration videos within the ARHAT were suggested, as stakeholders thought this would be useful to all users. Dyad 1 stated that "I think it would be helpful if you're going to do a measurement you could have an option to click a quick tutorial…then you know exactly what to do and then you do it yourself." Stakeholders specifically mentioned a drop-down screen with a list of video tutorials would be the easiest to navigate, allowing users to stay within the ARHAT and not seek out resources outside of the mobile app. Overall, all stakeholder groups appreciated the simple to complex design and thought that it would be user-friendly for people of any age. For example, HP1 stated that "it's pretty straightforward and seems easy to use with a swipe."

Style

All stakeholder groups provided feedback on the ARHAT's use of font, icons, and color. The font pairing throughout the ARHAT consists of Roboto Bold and Open Sans. In addition, 6 measurement icons are used throughout the ARHAT that guides the assessment process. These 6 icons are illumination, visual inspection, measuring tape, protractor, expert judgment, and timer (Figure 6).

Figure 6. Measurement icons.



Dyads reported that the font size was too small throughout the ARHAT, especially for a user that may have a vision impairment. Dyad 2 stated that "on any given screen or slide, the font looks very little." Additionally, the bold font used throughout was difficult for some stakeholders to read. An area of confusion across all focus groups was the "expert judgment" icon. All stakeholders needed clarification on whether this icon was supposed to represent the user using their judgment or if it was prompting the user to seek out an expert opinion. OTs recommended that the ARHAT could use "personal judgment" as the title for this icon to avoid confusion. HPs also mentioned how enabling a 2-finger zoom-in feature on the app would be beneficial for users of the ARHAT. They recognized that this

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feature is allowed in some apps and thought that this could be useful for small font sizes or images throughout the ARHAT.

Stakeholders were shown a colored version of the ARHAT, along with a black-and-white version. Each stakeholder group was fond of the use of color throughout the ARHAT, as long as a specific color was not implying importance. OT1 stated that "I don't know if color sometimes alarms you to something that you may think this is more important for me to assess." All stakeholders were able to view 3 different color palettes, and collectively, they all agreed that the color palette consisting of teal, tan, and orange was the easiest to see throughout (Figure 7).

Figure 7. Color palette.



Dyad 3 stated that "I think this is a good example of using color to illustrate exactly what you're trying to get to in a very quick way," and D4 stated that "I think contrast is important." Additionally, all stakeholder groups found all the functional limitation icons to be easily recognizable and, overall, liked the integration of the functional limitation icons throughout the ARHAT.

Measurement Tools

One limitation that was discussed by OTs and dyads was that all users might not be able to perform all the measurements within the ARHAT independently. For example, some OTs shared that aging adults may not be able to bend over to place their phone on the ground to measure the slope of a ramp. Dyad 3 further clarified that someone with a "physical limitation" may not be able to "get down on their knees to put the camera on the porch just to see the angle." Additionally, the distance tool used to measure the width of doors and entryways was critiqued, as 3D blocks (as seen in Figure 1) are used to line up this measurement. All stakeholder groups thought that the 3D blocks might be challenging for users because the 3D blocks may be difficult to align to get an accurate measurement. Instead of using 3D blocks, HPs recommended pinpoints, as they thought that it would be easier to get an accurate measurement by placing the points on specific areas. OTs critiqued the call-out boxes that are used within each measurement tool and suggested incorporating the ADA guidelines into the call-out boxes. They also mentioned the possibility that users of the ARHAT may not be familiar with the ADA, and it was suggested that explaining the guidelines somewhere within the tool could be helpful for further clarification for all users. Lastly, all stakeholder groups liked the lumen measurement but thought that the correct amount of light is different for everyone, especially those with visual impairments. OT3 stated that "people's vision skills, vision abilities, are so variable." Dyads were also curious if any settings on the user's mobile device would need to be enabled before using the app to access the ARHAT, or if all capabilities needed for the measurement tool would be automatically turned on.

Impact

All stakeholder groups stated that they could see the ARHAT being used at many different levels and by any population. Dyads specifically mentioned that the ARHAT would allow them to do forward planning and made them think of home modifications in a new light. OTs suggested that the ARHAT would be a great resource for people living in rural areas with limited resources. OT2 stated that "our county it's very rural, it's very sparsely populated, it's a long drive to a healthcare facility or for the practitioner to go to the home." The ARHAT could provide those with limited access to health care services the opportunity to complete in-home assessments, such as those conducted by OTs. The ARHAT could also be beneficial for individuals who are discharged from medical care and need to make their homes accessible but do not know where to start. OT3 stated that "rehab centers being able to say you can get this app and figure out if you think mom's wheelchair will work in your house" is just one example of how the ARHAT may impact patient discharge planning.

OTs enjoyed the possibilities of this tool, as it would allow for a quicker evaluation and measurement process, as well as allowing them to record their measurements within a mobile app rather than on paper. They liked the ability to show clients a tool such as this and then have clients report back their information to provide modification suggestions without having to go into the home. The HPs identified the measurement tools as a beneficial aspect of the ARHAT. They stated that these tools would allow for easy assessment within the home. Dyads enjoyed the overall style of the tool, noting the clear layout and flow of the ARHAT. Dyad 10 shared that "I think it would be pretty easy for aging adults to use, even those who may not be familiar with AR technology."

Discussion

Principal Findings

This study was conducted to gain stakeholder feedback on the acceptability and appropriateness of the ARHAT for identifying and addressing barriers within home environments. Three main findings were revealed from the stakeholders in this study: (1) more guidance is needed on how to use data collected from the ARHAT and ADA guidelines, (2) additional resources such as videos demonstrating the AR tools would increase the usability of the ARHAT across age groups, and (3) the ARHAT is an acceptable and appropriate tool for helping people safely age in place. The research team is using these findings to revise the ARHAT and improve future usability and adoption.

The ARHAT has the potential to provide individuals with an easy-to-use tool for assessing the home and identifying barriers in the environment. The ADA guidelines are a major component to the app development and key to understanding the data the

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ARHAT collects. We found that users of the ARHAT may benefit from learning the ADA guidelines directly through the mobile app itself. The ADA guidelines were developed to protect individuals who have one or more "major life activities" (eg, caring for oneself, walking, lifting, and bending) limited due to a physical or mental impairment [13]. The ARHAT would aid in the home assessment process of those seeking to age in place while managing their major life activities. Furthermore, we found that users may also benefit from knowing what the output data will look like before beginning an assessment and how they are able to disperse this information to potential home contractors, OTs, or family members.

Since AR is relatively new and constantly evolving, many people, especially older adults, may not be familiar with the technology or feel confident when using it for a home assessment. For example, intelligent display technology, 3D registration technology, and intelligent interaction technology are all versions of AR that allow for a magnitude of benefits for various applications [14]. One potential solution to account for differentiating skill levels in the realms of technology is to embed demonstration videos within the mobile app itself. OTs, HPs, and dyads all emphasized the impact that including demonstration videos would have on making the ARHAT user-friendly across all populations. According to Seifert and Schlomann [15], "developers, practitioners, and researchers in the field must acknowledge digital inequalities and provide older adults with training tools, support services, and digital solutions that consider their heterogeneous backgrounds and needs." The addition of resources within the tool may also be less time-consuming for users, as information would be readily available to them. This would also aid in mitigating the limited knowledge of AR for some populations who are less familiar with technology [16].

According to Ahn et al [2], "prior research on gerontology and housing has frequently adopted a perspective that aging in place is the goal," yet hiring a professional to conduct a home assessment to support aging in place can be time-consuming, expensive, or out of one's comfort zone [17]. The ARHAT is an innovative tool that can provide people the opportunity to conduct their own home assessment, eliminating the need to hire or bring a professional in. As there is a growing acceptance of technology among the aging population, the ARHAT can help alleviate the common concerns of aging in place by providing further insight on whether their homes are compliant with the ADA guidelines [18]. Frequently, aging adults are unaware of their housing limitations [17]. The AR measurement tools embedded in the ARHAT will allow aging adults and others to identify limitations they may previously have not been aware of.

Strengths and Limitations

There were many strengths to this study. Two trained qualitative research team members coded and analyzed data to verify the accuracy of the themes yielded from the focus groups. Additionally, purposeful sampling techniques were used to gain broad insight from diverse stakeholder groups. Expert knowledge from OTs, HPs, and aging adults and caregivers was gleaned to address potential challenges and solutions to increase the future usability and adoption of the ARHAT. All focus groups were held on the web, allowing stakeholders from across the United States to participate in this study. Furthermore, stakeholders who participated in this study were aged from 18 to 85+ years, contributing a wide range of personal experiences, knowledge, and perspectives to the findings.

This study is not without limitations. This study only included 19 stakeholders, with most stakeholders being female (n=13, 68%). The stakeholder group lacked diversity, as 89% (n=17) of the stakeholders were White. Furthermore, because of the web-based nature of the focus groups, the observation of nonverbal communication was difficult to obtain. Lastly, stakeholders were only shown a demonstration video of the ARHAT, which limits the research team's ability to understand the usability features of the mobile app (eg, an older adult may have difficulty using the ARHAT due to their digital literacy level or deterioration of fine motor skills).

Future Research

The research team is revising the ARHAT based on the focus group findings. Following these revisions, smartphones with the ARHAT installed will be disseminated to recruited stakeholders to gain feedback on their experience of using the mobile app in a real-world context. An electronic survey will be distributed to stakeholders to obtain their perceived usefulness and satisfaction of the ARHAT. They will also be able to provide insight on the workflow, style, and measurement tools through open-ended questions embedded in the survey. The team also recognizes that the goals and motivations for using the ARHAT may be different for each stakeholder group. A qualitative comparison analysis of focus group and survey data will be completed to better understand these potential differences.

Conclusion

From the perspectives of the stakeholders in this study, the ARHAT is acceptable and appropriate for identifying and addressing functional limitations and barriers in the home environment. This study highlights the importance of considering the workflow, style, measurement tools, and potential impact of tools early in the developmental process. The feedback and areas for improvement received by a wide range of stakeholders involved in this study shed light on ways the ARHAT can reduce risk and improve the level of independence among people who wish to safely age in place.

Acknowledgments

The authors acknowledge and thank the stakeholders who participated in this study and the RRF Foundation on Aging (2021058) for supporting this work.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Focus group guides.
[DOCX File, 21 KB - aging_v6i1e44525_app1.docx]

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Abbreviations

ADA: American Disability Act
AR: augmented reality
ARHAT: Augmented Reality Home Assessment Tool
HE: Housing Enabler
HP: housing professional
OT: occupational therapist

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Original Paper

Factors Predicting Older People's Acceptance of a Personalized Health Care Service App and the Effect of Chronic Disease: Cross-Sectional Questionnaire Study

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Abstract

Background: Mobile health (mHealth) services enable real-time measurement of information on individuals' biosignals and environmental risk factors; accordingly, research on health management using mHealth is being actively conducted.

Objective: The study aims to identify the predictors of older people's intention to use mHealth in South Korea and verify whether chronic disease moderates the effect of the identified predictors on behavioral intentions.

Methods: A cross-sectional questionnaire study was conducted among 500 participants aged 60 to 75 years. The research hypotheses were tested using structural equation modeling, and indirect effects were verified through bootstrapping. Bootstrapping was performed 10,000 times, and the significance of the indirect effects was confirmed through the bias-corrected percentile method.

Results: Of 477 participants, 278 (58.3%) had at least 1 chronic disease. Performance expectancy (β=.453; P=.003) and social influence (β=.693; P<.001) were significant predictors of behavioral intention. Bootstrapping results showed that facilitating conditions (β=.325; P=.006; 95% CI 0.115-0.759) were found to have a significant indirect effect on behavioral intention. Multigroup structural equation modeling testing the presence or absence of chronic disease revealed a significant difference in the path of device trust to performance expectancy (critical ratio=–2.165). Bootstrapping also confirmed that device trust (β=.122; P=.039; 95% CI 0.007-0.346) had a significant indirect effect on behavioral intention in people with chronic disease.

Conclusions: This study, which explored the predictors of the intention to use mHealth through a web-based survey of older people, suggests similar results to those of other studies that applied the unified theory of acceptance and use of technology model to the acceptance of mHealth. Performance expectancy, social influence, and facilitating conditions were revealed as predictors of accepting mHealth. In addition, trust in a wearable device for measuring biosignals was investigated as an additional predictor in people with chronic disease. This suggests that different strategies are needed, depending on the characteristics of users.

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KEYWORDS

environmental risk factor; personalized health care service app; chronic disease; unified theory of acceptance and use of technology; structural equation modeling; older adult; acceptance; adoption; technology use; mHealth; mobile health; mobile app; health app; gerontology; personalized; health care service; intention to use

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Introduction

Background

New medical strategies that aim to change individual behaviors and lifestyles are being introduced. These medical strategies are based on information and communications technology and the internet of things. Among these, mobile health (mHealth) apps are one type of strategy that allows us to perform tasks such as modernizing data acquisition analysis for clinical trials, facilitating behavior change among users, disease management, self-diagnosis, improving patients' confidence and satisfaction, and reducing health care costs [1-4].

Several studies have examined the use of mHealth for environmental health impact assessments—assessment of health-related problems deriving from the environment, such as chemical hazards, environmental contaminants, and other aspects of the ambient and living environment [5]. For example, Karagiannaki et al [6] deployed mHealth to monitor environmental factors affecting maternal health remotely. Honkoop et al [7] predicted the onset of asthma according to physiological, behavioral, and environmental data obtained by mHealth and home-monitoring sensors. Another study emphasized the importance of integrating location-based services into mHealth platforms to evaluate exposure to air pollutants [8]. As these examples show, mHealth is being actively used to promote human health in the context of environmental risk.

Using mHealth alongside medical prescriptions for older adults is more effective than traditional methods of managing their health [9]. mHealth positively influences health behavior, including improving physical activity, normalizing BMI, and decreasing sedentariness [10-12]. Although older people know the benefits of improving health behaviors, they tend not to pursue such improvements. In such cases, mHealth can facilitate older people's healthy behavior through notifications that serve as reminders [13,14]. Furthermore, older people need to extend their health span through continuous and systematic health management [15]; managing chronic diseases is the most important and fundamental aspect in this regard. mHealth is also effective for people with chronic diseases [16,17]. One study proved that mHealth was useful in meeting older people's information needs, especially concerning health, and was entirely accepted as a tool for monitoring health status and changing behavior [18]. Clearly, the evidence suggests that mHealth is an effective means of health management for older people and that the efforts should be focused on increasing its usage. Thus, studying the acceptability of mHealth usage among older people is important. In this study, we examine the acceptability of a personalized health care service app that we are currently developing.

Research on technology acceptance commonly uses the technology acceptance model (TAM) and the unified theory of acceptance and use of technology (UTAUT). TAM [19] is widely used in research that primarily addresses the intention to use information and communications technology; it assesses a person's attitude toward using the system, its perceived usefulness (PU), and its perceived ease of use (PEOU). Attitude directly affects behavioral intention to use the system, and PU and PEOU indirectly affect behavioral intention by directly affecting attitude. UTAUT [20] is a model developed by analyzing and comparing 8 models related to behavioral intention; in this model, performance expectancy, effort expectancy, and social influence affect behavioral intention, whereas behavioral intention and facilitating conditions affect use behavior. Unlike TAM, the UTAUT does not include "attitude" in the model.

Personalized Health Care Service App

The personalized health care service app we are developing aims to facilitate early identification and management of the health effects of exposure to real-time environmental risk factors. It provides health status reports and hospital visit recommendations based on the user's biosignals and surrounding environment information. Biosignals such as electrocardiograms and heart rates are measured by wearable devices and linked with the app. Our app also assesses concentrations of hazardous substances in the air as environmental risk factors. It contains the values for particular matter ($PM_{2.5}$, PM_{10}), ozone, nitrogen dioxide, carbon monoxide, and sulfur dioxide. Instead of individually measuring the concentration of environmental risk factors, our design measures concentration data every minute using real-time personal location information based on the global positioning system combined with information from environmental harmful factor concentration stations in Korea. The app also provides information about health risks by considering individual health status (sociodemographic variables, individual medical checkups, diagnostic records, etc) and identifying correlations between environmental exposure and health effects. Furthermore, the app provides regular health analysis reports, information about nearby hospitals, recommendations for appropriate actions in the event of a health hazard, and so forth.

Objective

This study aims to identify predictors of older people's intention to use the personalized health care service app and to verify whether chronic disease moderates the effect on behavioral intentions using the extended UTAUT model.

Methods

Research Model and Research Hypotheses

We used the latent variables of performance expectancy, effort expectancy, social influence, and facilitating conditions from UTAUT [20]. UTAUT addresses actual use behavior; thus, facilitating conditions are set as variables that affect use behavior but not behavioral intention. However, since the app in this study is in the development stage and has not been released, use behavior cannot yet be measured. In the later UTAUT2 model developed by Venkatesh et al [21], facilitating conditions are extended to include factors affecting behavioral intention and use behavior. To receive customized services through the app, it is essential to use a wearable device to measure biosignals. Therefore, we also included device trust in our research model.

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Performance expectancy is defined as "the degree to which individuals believe that using the personalized health management service app will help improve their health" [20]; this construct is similar to PU in the TAM [19]. Many previous studies on accepting health care services have demonstrated that performance expectancy is a good predictor of behavioral intention [22-35]. Thus, we proposed the following hypothesis.

H1: Performance expectancy will have a significant positive influence on behavioral intention.

Effort expectancy is also an essential predictor of behavioral intention; it refers to "the degree of ease associated with the use of the personalized health management service app" [20] and is similar to PEOU in the TAM [19]. The relationship between effort expectancy and behavioral intention has been confirmed in many studies [24-33,36]. Although the UTAUT model differs from TAM, assuming that effort expectancy does not affect performance expectancy, we can intuitively say that user-friendly and accessible services feel more useful. Indeed, consistent evidence shows a significant relationship between effort expectancy and performance expectancy [23-26,34,37,38]. Accordingly, we hypothesized the following.

H2: Effort expectancy will have a significant positive influence on behavioral intention.

H3: Effort expectancy will have a significant positive influence on performance expectancy.

Facilitating conditions are defined as "the degree to which an individual believes that an organizational and technical infrastructure exists to support the use of the personalized health management service app" [20]. In some cases, facilitating conditions are divided into resource and technological aspects [26]. In this study, we considered technological facilitating conditions at the organizational level. Particularly, older people unfamiliar with the new technology are more likely to try to use it if they have the support of a service provider. Previous studies have shown that facilitating conditions may affect behavioral intention [26-31,34]. Additionally, from the perspective of gerontechnology—which helps older people lead a consistently healthier, more independent, and more socially engaged life—a study predicted that facilitating conditions will affect performance expectancy [38]. From the health management perspective, some studies showed that facilitating conditions can influence performance expectancy [26,32,34,38]. Taking these points together, we proposed the following 2 hypotheses.

H4: Facilitating conditions will have a significant positive influence on behavioral intention.

H5: Facilitating conditions will have a significant positive influence on performance expectancy.

Social influence refers to "the degree to which an individual perceives that important others believe he or she should use the personalized health management service app" [20]. If people who are important to target users want them to use particular services, their usage likelihood increases. In particular, this influence may be more decisive when their knowledge about the service is insufficient or when the service is unfamiliar. Many studies have shown that social influence can be one of the good predictors of behavioral intention [25-29,32-34,37]. Accordingly, we hypothesized the following.

H6: Social influence will have a significant positive influence on behavioral intention.

Device trust is defined as "the degree to which individuals believe that they are confident in the quality and reliability of wearable devices" [39]. Although many studies have verified the accuracy and reliability of wearable devices from the perspective of precision medicine, there are relatively few studies on their technological acceptance [36]. Considering the technology behind wearable medical devices has reached a certain level of maturity, we need to pay attention to other aspects. In particular, if users can trust the measurement function and security of wearable devices, their intention to use the health care service will increase. Several studies have shown that trust in products or services has a positive effect on behavioral intention toward new technology [24,27,37]. Our app will provide personalized services based on biosignals measured by wearable devices. Therefore, those who trust wearable devices should be more likely to evaluate this service model as useful [40]. Several similar studies have found positive relationships between trust and performance expectancy [25,37,41]. Accordingly, we hypothesized the following:

H7: Device trust will have a significant positive influence on performance expectancy.

H8: Device trust will have a significant positive influence on behavioral intention.

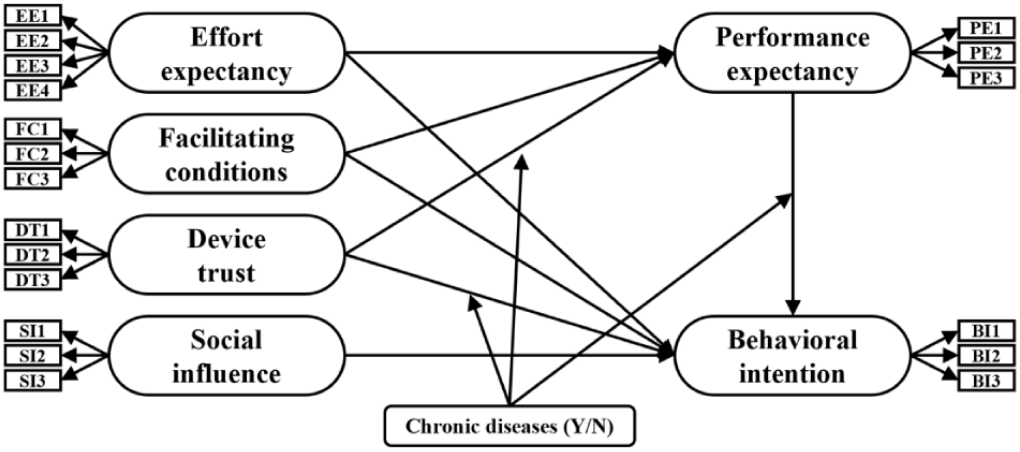
It is widely known that people with chronic diseases are more vulnerable to environmental risk factors such as air pollution [42,43]. Furthermore, patients with chronic disease are more likely to use health system portals and to track health indicators [44]. Therefore, we assumed that patients with chronic disease would show more interest in using health care services for health management than other patients. Moreover, since patients with chronic disease periodically measure and manage their biosignals, such as blood pressure and blood sugar, they would be more accustomed to biosignal measurement. Accordingly, we hypothesized the following:

H9-H11: The influences of performance expectancy on behavioral intention (H9), device trust on behavioral intention (H10), and device trust on performance expectancy (H11) are moderated by the presence or absence of chronic diseases, such that the influences will be stronger for people who have chronic diseases.

In summary, the proposed research model is shown in Figure 1.

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Figure 1. Research model. BI: behavioral intention; DT: device trust; EE: effort expectancy; FC: facilitating conditions; PE: performance expectancy; SI: social influence.



Data Collection

The web-based survey was conducted from June 27 to July 4, 2022, by the survey company dataSpring. The sample size was calculated using an a priori sample size calculator for structural equation modeling (SEM) [45]. The minimum recommended sample size was 200 cases based on 6 latent and 19 observed variables, with an anticipated effect size of 0.3, a desired statistical power level of 0.9, and a probability level of .05.

The study's target group comprised people aged between 60 and 75 years and who are vulnerable to environmental risk factors. We recruited a sample of 500 participants to perform a multigroup analysis. The survey was first conducted on 290 people with chronic diseases, recruited using convenience sampling; subsequently, 210 people without chronic diseases were surveyed by matching the intergroup gender and age ratios as much as possible.

Only individuals who read the description of the research before the survey and voluntarily agreed to participate were selected as study participants. Before answering the questionnaire, they watched a video explaining the functionality of the personalized health care service app, which took about 4 minutes.

Ethics Approval

This study was conducted after receiving ethical approval from the institutional review board of Yonsei University Wonju Severance Christian Hospital (CR322027).

Questionnaire Development

All questionnaire items were constructed based on previous studies (see Multimedia Appendix 1). The measurement variables used in the research model were scored on 5-point Likert scales ranging from 1="strongly disagree" to 5="strongly agree." Additionally, information about gender, age, residential area, final educational background, and presence of chronic disease were collected. Residential areas were divided into metropolitan areas (Seoul, Incheon, and Gyeonggi) and others. A person with chronic disease was defined as "someone who has been diagnosed by a doctor and has been regularly under treatment or taking medication for at least three months"; participants were asked to self-report the presence of chronic diseases.

Statistical Analysis

First, the general characteristics of the survey respondents were confirmed through frequency analysis. Subsequently, we verified the research model's convergent and discriminant validity. Convergent validity was confirmed using factor loading, average variance extracted (AVE), and construct reliability values obtained through confirmatory factor analysis. Two methods were used to test the model's discriminant validity. The first involved testing whether the construct's square root value of AVE was greater than its correlation with any other constructs [46]. The second involved testing whether the range of adding or subtracting the SE of covariance multiplied by 2 to the correlation coefficient between 2 latent variables did not include 1 [47,48]. Additionally, to verify the cross-validation between the chronic disease and nonchronic disease groups, an analysis of measurement equivalence was conducted.

Then, SEM—a method used to statistically verify relationships defined in a theoretical framework using the covariance or correlation matrixes of the data—was performed to verify the research hypotheses. The analysis was performed using maximum likelihood estimation, and the model fit was confirmed through the absolute and incremental fit indexes. For the former, normed chi-square, goodness-of-fit index, and root-mean-square error of approximation were used. For the latter, Tucker-Lewis index, comparative fit index, and normed fit index were used. Subsequently, the critical ratio for differences was confirmed by restricting each pathway to verify the moderating effect of chronic diseases. Bootstrapping using the maximum likelihood method was repeated 10,000 times to confirm the statistical significance of the model's indirect effects. Finally, statistical significance and confidence limits were obtained with the bias-corrected percentile method [49]. All statistical analyses were performed using SPSS Statistics 26.0 and SPSS Amos 28.0 Graphics (IBM Corp).

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Results

General Respondent Characteristics

The descriptive statistics for respondents' characteristics are shown in Table 1. Among 500 participants, the responses of 23 participants were discarded due to poor data quality, such as straight-lined answers. Given the methodological procedure described above (in which nonchronic disease participants were recruited after those with chronic diseases and were matched for gender and age), there were no statistically significant differences between the 2 groups according to gender or age. Additionally, we found no statistically significant differences between the groups in terms of residential area and educational background.

Table 1. Descriptive statistics for respondents' characteristics.

Characteristics	Total	CD[a]	No CD	P value
Total, n (%)	477 (100)	278 (58.3)	199 (41.7)	N/A[b]
Sex , n (%)				.55
Male	276 (57.9)	164 (59.4)	112 (40.6)	
Female	201 (42.1)	114 (56.7)	87 (43)	
Age (years)				.63
60-64, n (%)	280 (58.7)	159 (56.8)	121 (43.2)	
65-69, n (%)	150 (31.4)	89 (59.3)	61 (41)	
70-75, n (%)	47 (10)	30 (63.8)	17 (36)	
Continuous mean (SD)	64.31 (3.42)	64.46 (3.47)	64.09 (3.36)	.23
Residential area, n (%)				.92
Metropolitan areas	308 (64.6)	180 (58.4)	128 (41.6)	
Others	169 (35.4)	98 (58)	71 (42)	
Educational background, n (%)				.69
High school or lower	152 (31.9)	91 (59.9)	61 (40)	
College or university	274 (57.4)	160 (58.4)	114 (41.6)	
Graduate school	51 (11)	27 (53)	24 (47)	
Chronic diseases , n (%)				N/A
Yes	278 (58.3)	N/A	N/A	
No	199 (41.7)	N/A	N/A	

[a]CD: chronic diseases.

[b]N/A: not applicable.

Validity Analyses

Convergent Validity

The results of the confirmatory factor analysis are shown in Table 2. According to Hulland [50], the value of standardized factor loading is recommended to be 0.7 or higher. Bagozzi and Yi [51] suggested that the construct reliability and AVE values should be greater than or equal to 0.7 and 0.5, respectively. With these criteria, confirmatory factor analysis confirmed the convergent validity of our model.

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Table 2. Confirmatory factor analysis.

Variables	β	Estimate	SE	Critical ratio	P value	AVE[a]	CR[b]
PE[c]						0.74	0.89
PE1	.70	1.00	—[d]	—	—	—	—
PE2	.82	1.30	0.08	16.19	<.001	—	—
PE3	.84	1.21	0.07	16.67	<.001		
EE[e]						0.68	0.89
EE1	.69	1.00	—	—	—	—	—
EE2	.80	1.39	0.09	15.49	<.001	—	—
EE3	.79	1.41	0.09	15.39	<.001	—	—
EE4	.79	1.40	0.09	15.41	<.001	—	—
FC[f]						0.68	0.86
FC1	.70	1.00	—	—	—	—	—
FC2	.78	1.21	0.08	15.34	<.001	—	—
FC3	.80	1.27	0.08	15.70	<.001	—	—
SI[g]						0.67	0.86
SI1	.71	1.00	—	—	—		
SI2	.75	1.15	0.08	15.16	<.001	—	—
SI3	.81	1.27	0.08	16.10	<.001		
DT[h]						0.62	0.83
DT1	.69	1.00	—	—	—	—	—
DT2	.71	1.29	0.10	13.18	<.001	—	—
DT3	.79	1.35	0.10	14.16	<.001	—	—
BI[i]						0.77	0.91
BI1	.83	1.00	—	—	—	—	—
BI2	.83	1.09	0.06	19.56	<.001	—	—
BI3	.79	1.02	0.06	18.62	<.001	—	—

[a]AVE: average variance extracted.
[b]CR: construct reliability.
[c]PE: performance expectancy.
[d]Not available.
[e]EE: effort expectancy.
[f]FC: facilitating conditions.
[g]SI: social influence.
[h]DT: device trust.
[i]BI: behavioral intention.

Discriminant Validity

The discriminant validity was tested in 2 ways. Table 3 shows the results of the first method, which compares the correlation coefficient of the latent variables and the square root of AVE. Although discriminant validity was generally satisfied, we found that some correlation coefficients were higher than the square root of AVE. Next, discriminant validity was reconfirmed by the second method, using performance expectancy and social influence, which had the highest correlation coefficients. The correlation coefficient between them was 0.866, and the SE of covariance was 0.024; therefore, we confirmed that the range of adding or subtracting the SE multiplied by 2 to the correlation coefficient did not include 1.

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Table 3. Discriminant validity analysis.

	PE[a]	EE[b]	FC[c]	SI[d]	DT[e]	BI[f]
PE	1					
EE	0.75	1				
FC	0.87	0.76	1			
SI	0.87	0.71	0.85	1		
DT	0.73	0.64	0.76	0.78	1	
BI	0.72	0.53	0.65	0.77	0.65	1
Sqrt of AVE[g]	0.86	0.83	0.82	0.82	0.79	0.88

[a]PE: performance expectancy.

[b]EE: effort expectancy.

[c]FC: facilitating conditions.

[d]SI: social influence.

[e]DT: device trust.

[f]BI: behavioral intention.

[g]Sqrt of AVE: square root of average variance extract.

Cross-Validity

The verification of measurement equivalence was performed through multigroup confirmatory factor analysis. To confirm the difference between the unconstrained and factor-loading constrained models, we used the difference between their chi-square values. The chi-square value of the unconstrained model was 591.4, and the degree of freedom was 274; for the factor loading constrained model, the values were 603.9 and 287, respectively. Since the threshold of the chi-square value at the degree of freedom of 13 was 22.4, there was no statistically significant difference in factor loading between the 2 groups for the measurement tool.

Hypotheses Testing

We performed SEM to test our research hypotheses. Table 4 shows that H1, H5, and H6 were supported. That is, participants who stated that performance expectancy and social influence were important were more likely to have behavioral intentions to use mHealth, and people who thought that facilitating conditions was important were more likely to believe performance expectancy was also important. Bootstrapping was performed 10,000 times to check whether there was an indirect effect, whereby facilitating conditions affected behavioral intention through performance expectancy. Assessing the statistical significance using the bias-corrected percentile method showed that the standardized indirect effect of facilitating conditions on behavioral intention was 0.325, the significance probability 0.006, and the 95% CI of 0.115-0.759, confirming a significant indirect effect.

The model fit of SEM was confirmed through normed chi-square, goodness-of-fit index, and root mean squared error of approximation (absolute fit index), Tucker-Lewis index, comparative fit index, and normed fit index (incremental fit index). Therefore, we confirmed that the recommended values suggested in previous studies were generally satisfied (Table 5).

The results of multigroup SEM analysis are shown in Table 6. The significance of the path difference between groups can be confirmed by looking at the critical ratio for differences. If the absolute value of the critical ratio is 1.965 or higher, there is a statistically significant difference in the path coefficients between groups. As the critical ratio for differences in hypothesis 11 was –2.165, there is a statistically significant difference between the 2 groups in the effect of device trust on performance expectancy. Whether there was an indirect effect of device trust on behavioral intention through performance expectancy in the chronic disease group was also confirmed through bootstrapping. Results found that the standardized indirect effect of device trust on behavioral intention was 0.122, the probability of significance 0.039, and 95% CI of 0.007-0.346, confirming that device trust has a significant indirect effect on behavioral intention in the chronic disease group.

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Table 4. Verification of the research hypotheses.

Hypothesis	Path	β	Estimate	SE	P value
H1	PE[a]→BI[b]	.453	0.538	0.179	.003
H2	EE[c]→BI	–.097	–0.118	0.097	.23
H3	EE→PE	.116	0.120	0.070	.09
H4	FC[d]→BI	–.338	–0.385	0.265	.15
H5	FC→PE	.716	0.686	0.099	<.001
H6	SI[e]→BI	.693	0.776	0.197	<.001
H7	DT[f]→BI	.089	0.107	0.114	.35
H8	DT→PE	.122	0.123	0.074	.10

[a]PE: performance expectancy.
[b]BI: behavioral intention.
[c]EE: effort expectancy.
[d]FC: facilitating conditions.
[e]SI: social influence.
[f]DT: device trust.

Table 5. Model fit.

Model fit measure	Value	Recommended value	Results	Reference
Normed χ^{2a}	3.4	≤3	Acceptable	Hair et al [52]
GFI[b]	0.9	>0.90	Acceptable	Hair et al [52]
RMSEA[c]	0.1	<0.08	Good	Hair et al [52]
TLI[d]	0.9	>0.90	Good	Bentler et al [53]
CFI[e]	0.9	>0.90	Good	Hair et al [52]
NFI[f]	0.9	>0.90	Good	Bentler et al [53]

[a]χ^2_{138}=463.3.
[b]GFI: goodness-of-fit index.
[c]RMSEA: root mean squared error of approximation.
[d]TLI: Tucker-Lewis index.
[e]CFI: comparative fit index.
[f]NFI: normed fit index.

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Table 6. Verification of the research hypotheses on the moderating effect.

Hypothesis (path) and group	β	Estimate	SE	*P*-value	Critical ratio for differences
H9 (PE[a]→BI[b])					–0.934
CD[c]	.438	0.516	0.188	.006	
No CD	.429	0.508	0.393	.429	
H10 (DT[d]→BI)					0.780
CD	.060	0.069	0.146	.060	
No CD	.215	0.277	0.224	.215	
H11 (DT→PE)					–2.165
CD	.278	0.272	0.083	.001	
No CD	–.100	–0.107	0.154	.487	

[a]PE: performance expectancy.

[b]BI: behavioral intention.

[c]CD: chronic disease.

[d]DT: device trust.

Discussion

Principal Results

This study identified the predictors of acceptance of a personalized health care service app by conducting SEM on questionnaire survey data collected from older adults aged 60 to 75 years. Performance expectancy (β=.453; P=.003) and social influence (β=.693; P<.001) were identified as significant predictors. Furthermore, bootstrapping analysis confirmed that facilitating conditions (β=.325; P=.006; 95% CI 0.115-0.759) had an indirect effect on behavioral intention. Differences between groups according to the presence or absence of chronic diseases were confirmed through multigroup SEM. Additionally, device trust (β=.122; P=.039; 95% CI 0.007-0.346) was found to have a significant indirect effect on behavioral intention in patients with chronic disease.

Comparison With Prior Work

As expected, performance expectancy was a significant predictor of the intention to use the personalized health care service app. These results were in line with many previous studies on the intention to use health care–related services [22-35]. Performance expectancy can be increased if it is possible to integrate mHealth services, with an existing health tracking app or a health information app that includes medication, treatment, and health checkup histories or hospital information such as the nearest hospital or reservation service. Park et al [29] emphasized the importance of effectively expressing the causal relationship between personal health records and physiological conditions and providing immediate feedback from health experts for encouragement to use a health care app. Another study suggested that mHealth apps should be integrated with other applications [28]. Notably, the results of a previous study indicate that performance expectancy has an important effect on the behavioral intention of people who have never used the service [54].

In line with several studies [22,23,35,37,41], we could not find evidence for effort expectancy's effect on behavioral intention. The lack of direct effect might be because our survey design targeted people in the preuse stage [23,35]. Another study that found no effect of effort expectancy suggested the following explanation: their study sample was already familiar with the service, so variance according to effort expectancy was minimal [37]. In this study, although the service was explained through a description of the research and an introductory video, it may have been difficult for respondents to judge how much effort would actually be required.

Facilitating conditions were not a predictor of behavioral intention but did affect performance expectancy. We confirmed that facilitating conditions have an indirect effect on behavioral intention through performance expectancy. Some studies have revealed that facilitating conditions have an indirect effect on behavioral intention through performance expectancy [26,32,34]. In other words, if there is support from the service provider, the user may feel that the service is more useful. Since the participants in this study are older people who are unfamiliar with new technology, the facilitative infrastructure of service providers is important. One study showed that performance expectancy was relatively more important than facilitating conditions in a group that had not yet experienced the service [54]. However, in the case of the group with experience in using the service, the importance of facilitating conditions was relatively high. With the previous study's results in mind, it would be interesting to investigate any changes in our results after our mHealth app has been put into actual use.

Social influence was also an essential predictor of the intention to use the service model; this supports previous studies dealing with similar topics to ours, which have reported that social influence positively affects behavioral intention [22,30,31,35]. There are several possible explanations, though 1 important reason could be the cultural context. Older people's decisions regarding health care may be more influenced by their families than by themselves; the influence of the family is particularly

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prominent in Confucian culture [55]. For this reason, the personalized health care service app will need to be promoted at the family and community levels in such cultures especially.

Finally, we confirmed that trust in wearable devices affects performance expectancy in the group with chronic diseases. Through this, we proved that device trust could be one of the predictors that indirectly affected behavioral intention. Artificial intelligence–based health care management services using biosignal measurement and wearable devices are known to be safe and cost-effective for managing chronic diseases [56]. Thus, in the early stage of service introduction, the project should specifically target older people with chronic diseases vulnerable to environmental risk factors. Improving their performance expectancy would be helpful, highlighting the accuracy and reliability of wearable devices.

Limitations

In this study, discriminant validity was verified in 2 ways. There were some ambiguities in comparison with the correlation coefficient between latent variables and the square root of AVE. These can be solved by merging the corresponding latent variables or removing some [57]; however, this method is not desirable when the research model is built based on a particular theory [48]. Since UTAUT is a very widely used theory, we decided to accept the conclusion gained using the second method of testing discriminant validity used in this study. In future studies, better results could be obtained to reduce measurement errors.

The mHealth app, which we are developing, does not target a specific chronic disease. Therefore, in this study, the definition of “chronic disease” has been set broadly. There are various types of chronic diseases, and the methods and levels of their management are also different. More detailed research can be done on mHealth for the management of specific chronic diseases.

Additionally, since this study was designed as a cross-sectional survey and random sampling was not applied, the generalizability of the results is limited. The personalized health care service app introduced in this study is currently under development; the goal is to develop it into a more user-friendly service through continuous research on the attitudes of potential users. Furthermore, continuous research, which can better represent the population, will further strengthen the explanatory power of the model proposed in this study.

Conclusions

Performance expectancy, social influence, and facilitating conditions are predictors of the intention to use mHealth among older people vulnerable to environmental risk factors. It is important to demonstrate and highlight the benefits of personalized health care services for health management to encourage older people to use them. The awareness of people around the target users also plays an important role. In particular, it is necessary to promote such services at the family and community levels; this aspect is critical in the Confucian culture. In addition, support from service providers should be strengthened so that older people can trust that they have consistent access to technical support. Furthermore, our findings suggest that different strategies should be used depending on the presence or absence of chronic disease. The reliability of biosignal measurements made by wearable devices should be emphasized to achieve a higher usage rate among older people with chronic diseases.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Overview of the instrument.
[DOCX File , 25 KB - aging_v6i1e41429_app1.docx]

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Abbreviations

AVE: average variance extracted
mHealth: mobile health
PEOU: perceived ease of use
PU: perceived usefulness
SEM: structural equation modeling
TAM: technology acceptance model
UTAUT: unified theory of acceptance and use of technology

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Original Paper

Co-Creating a Digital Life-Integrated Self-Assessment for Older Adults: User Experience Study

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Abstract

Background: Older adults are at increased risk of developing health disorders and functional decline. However, owing to time constraints and considerable effort, physicians rarely conduct comprehensive assessments to detect early signs of negative trajectories. If designed properly, digital technologies could identify health risks already at a preclinical stage, thereby facilitating preventive efforts and targeted intervention. For this purpose, a Life-integrated Self-Assessment (LiSA) tablet system will be developed through a structured co-creation process.

Objective: This study aims to investigate older adults' perceptions of different self-assessment domains, components affecting user experience, risks and benefits associated with LiSA, characteristics of potential LiSA users, and the LiSA concept in general.

Methods: A total of 10 community-dwelling older adults aged ≥70 years were recruited. In total, 6 co-creation workshops were held and started with expert input followed by semistructured discussion rounds. Participants performed hands-on activities with a tablet, including testing of preinstalled self-assessment apps. All workshops were audio recorded and additionally documented by the researchers using flipcharts, notes, and photos. Qualitative content analysis was used to analyze the data following a deductive-inductive approach guided by the Optimized Honeycomb Model for user experience.

Results: The group (mean age 77.8, SD 5.1 years) was heterogeneous in terms of previous technology experience and health status. The mean workshop duration was 2 hours (122.5, SD 4.43 min), and an average of 8 (SD 1.15) participants attended each workshop. A total of 11 thematic categories were identified, covering results on all research questions. Participants emphasized a strong interest in conducting a digital self-assessment of physical activity and function and sensory and cognitive functions and requested additional features such as recommendations for actions or reminders. LiSA was perceived as empowering and a motivator to engage in active health care planning as well as enabling shared and informed decision-making. Concerns and barriers included the lack of technical competence, feelings of frustration, and fear of being left alone, with negative assessment results. In essence, participants expressed a positive attitude toward using LiSA repeatedly and identified it as an option to increase the chances of maintaining independence when growing older.

Conclusions: The co-creation participants supported the LiSA approach and were interested in performing regular self-assessments on a long-term basis. In their opinion, LiSA should include relevant assessments capturing physical activity and function and sensory and cognitive functions as well as recommendations for actions. It should be customizable to individual needs. These

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results will form the basis for a prototype. Iterative development and validation will aim to make LiSA accessible in the public domain as a reliable tablet-based system for self-assessment.

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KEYWORDS

aged; self-assessment; mobile apps; mobile health; mHealth; community-based participatory research; co-creation; comprehensive geriatric assessment; mobile phone

Introduction

Future Challenges for Health Care

By 2027, the old age–to–working age demographic ratio in Organisation for Economic Cooperation and Development countries will be almost 40%, and it will be >50% by 2050 [1]. The aging of the baby boomer generation will lead to health care needs that will most probably not be met by a shrinking workforce of health care professionals (HCPs) unless major changes are implemented in the health care system [2]. Older adults aged >70 years have an increased risk of developing health disorders. Approximately 30% to 40% will follow accelerated functional decline trajectories [3]. Cognition, mood, social contact, sensory function, and mobility often deteriorate gradually. In general practice offices, older patients often present with discrete functional impairments, which may hamper the early identification of risks [4]. To meet the challenges of an aging global population, health care delivery processes may benefit from digital technologies.

Starting Points for Self-Assessment in Health

The World Health Organization *Integrated care for older people* guidelines stress the importance of health assessments and support for older adults' self-management to prevent premature decline and foster healthy aging [2]. A comprehensive geriatric assessment (CGA) is a multidimensional process usually conducted by a multidisciplinary team (ie, physicians, nurses, social workers, and other HCPs) in hospitals, residential care homes, or community settings [5]. The current literature defines CGA as determining an older person's medical, psychosocial, functional, and environmental risks and resources [6]. It goes beyond a disease-oriented medical assessment and allows for a more individualized and comprehensive care planning and follow-up [7]. Over the past 2 decades, numerous studies have shown that a CGA can benefit patients, society, and the health care system by identifying the early signs of negative trajectories [8-11]. Despite the positive effects of a CGA, there remains a *know-dogap* in most settings [11-13]. Implementation barriers include poor acceptance of preventive work [14], the lack of guidelines and professional interactions, and time and economic factors [12,13]. A promising solution to facilitate the scaled-up implementation of regular CGAs may be the integration of digital and patient self-service technologies into medical practice.

Digital Technology and Older People

Owing to the COVID-19 pandemic and social isolation, the willingness of older people to use wireless information and communications technology (ICT) has further increased [15]. Smartphones are owned by >70% of people aged ≥70 years in the United States, and tablets are owned by almost 60% [15]. Nevertheless, the target group of older adults has specific usability requirements, and sovereign operation is particularly important for health apps to be used without supervision. Therefore, involving end users in the co-creation of health interventions is imperative. The literature now provides guidelines to support the usability of mobile health apps for older users [16], systematic reviews on factors influencing their acceptance of technologies are available [17], and tools such as those from the HEALTH CASCADE project for evidence-based co-creation of public health interventions [18] can be used.

Current State of the Art in Digital Self-Assessment

In 2021, a total of 350,000 fitness, health, and medical apps were available for download in the Apple Store and Google Play Store [19]. This is comparable with approximately 160,000 in 2015, indicating a high interest in and demand for digital health apps. Compared with this enormous growth, the provision of apps as medical devices has been very slow owing to high authorization burdens [19]. Many countries are working to set up regulatory pathways [20]. Using activity trackers and wearables for heart rate, glucose, or oxygen saturation monitoring, citizens have started to collect their own health data, sometimes on a daily basis. However, currently, these data are often not factored in by HCPs. The development of digital self-assessment of cognitive, sensory, and physical functions is a rapidly developing process [21-27]. Recently, there have been some attempts using a comprehensive assessment approach [28,29]. The current landscape of digital health technologies reveals a market in which technologies are often developed commercially and rapidly but often at the expense of regulated medical product design, safety, and clinical validation [30].

Proposing the Life-Integrated Self-Assessment to Address Problems and Potentials

We aimed to develop a *Life-integrated Self-Assessment* (LiSA) providing self-screening and monitoring for older adults to identify health risks early and facilitate efficient and targeted health care. LiSA is to be performed on a regular basis at home by people aged >70 years independently living at home. To our knowledge, this is the first approach toward a superordinate, tablet-based system for evidence-based, predictive self-assessments that provides users with individual, outcome-oriented, and scientifically sound recommendations for actions. LiSA's development is designed as a process of co-creation, which we define as "an evidence-based methodology for the development, implementation and evaluation of innovations through continuous, open collaboration, interactional knowledge production and shared decision-making among key stakeholders, directed at improving

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public health" [31]. By using a co-creation approach, we aim to gain a deeper understanding of the target group's needs regarding LiSA to develop a tailored and valuable solution with maximum user experience (UX). UX has become increasingly important in recent years. Research has focused on UX components that go beyond instrumental needs; include affective and emotional aspects of interaction; and understand the encounter with technology as subjective, contextual, dynamic, and complex [32].

In this study, we report the first step of the iterative LiSA co-creation process, which aimed to answer the following research questions (RQs):

1. RQ 1: Which assessments should or should not be part of LiSA?
2. RQ 2: Which components would affect the LiSA UX?
3. RQ 3: What benefits and risks do older adults expect regarding LiSA?
4. RQ 4: What characteristics might distinguish potential LiSA users from nonusers?
5. RQ 5: What do participants think about the LiSA concept in general?

Methods

Overview

In April 2022 and May 2022, we conducted a series of 6 workshops with older adults at the study center (Network Aging Research, University of Heidelberg, Germany). The co-creation process is described following the evidence-based co-creation guideline (PRODUCES+ [Problem, Objective, Design, [End-] Users, Co-creators, Evaluation, Scaling]) [33], which extends the previous PRODUCES framework [34]. The PRODUCES+ reporting checklist can be found in Multimedia Appendix 1 [33-41].

Participant Recruitment

Convenience and stratified sampling methods were adopted to facilitate participant engagement [34]. We aimed to identify a diverse sample of older adults with sufficient heterogeneity in age, gender, health status, previous experience, and competence regarding ICT use. Participants who took part in a previous study [35] were contacted by mail. Those who agreed to participate were screened via phone. Inclusion criteria were age of ≥65 years, living at home, internet access at home, previous experience using ICT (eg, tablets, smartphones, or computers), and absence of acute or severe illnesses (eg, cardiac arrhythmia or planned surgery). Further exclusion criteria were subjective hearing or vision impairment leading to limitations in everyday life and inability to walk without assistive devices to ensure participants' capability to fully participate in workshop content and discussions. To ensure accessibility to the study center in compliance with SARS-CoV-2 regulations, full vaccine protection was required. A total of 10 participants were included and provided informed consent to take part in the study.

Co-Creation Workshops

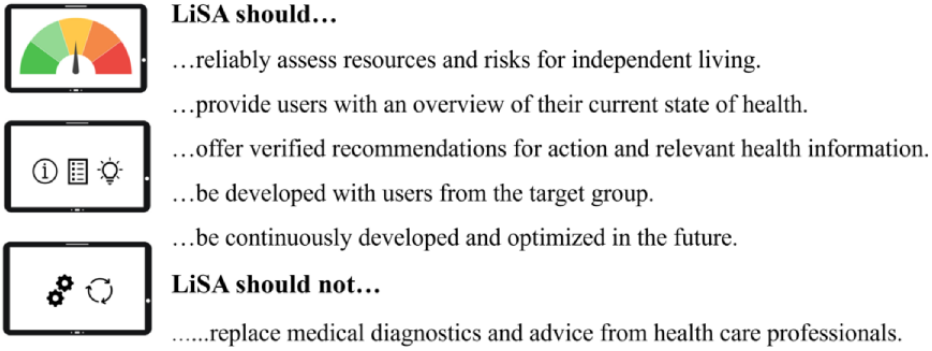
Overview

The workshops were conducted by an interdisciplinary research team consisting of a geriatrician (CB), 2 physiotherapists (MJB and KG-O), a sports scientist (C-PJ), 2 psychologists (EL and CM), a sociologist (NM), a software engineer (LR), and an optometrist (MV). MJB moderated the workshops and was accompanied by 2 to 3 other members of the team, who contributed by giving short expert presentations, taking notes, and being available to support and answer questions during individual and group work. A brief description of the content of each workshop is provided in the following sections. Multimedia Appendix 2 contains a more detailed content and material description of the workshops.

Workshop 1

Workshop 1 started with a round of introductions and information on the background and the concept of LiSA as well as the aims and agendas of the workshop sessions (Figure 1 and Multimedia Appendix 2) to ensure transparency with the participants [34]. To explain the term *digital self-assessment*, an example app for a fall risk self-assessment was shown to the participants (Table 1). A joint understanding of roles in the co-creation process was discussed in plenary to ensure that all co-creators had equal status within the group and responsibility to contribute their ideas [33]. After participants' agreement on the agenda and roles was obtained, workshop 1 continued with participants sharing their first thoughts about the LiSA idea in plenary (RQ 5). In the next step, the card sorting technique was used to categorize and prioritize possible self-assessment contents (RQ 1). At the end of workshop 1, all participants were handed a tablet (Lenovo Tab M10 FHD Plus) and given the homework to test an app (Table 1), which should invite participants to be introduced to the basic tablet functions.

Figure 1. Life-integrated Self-Assessment (LiSA) concept presented to the participants.



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Table 1. Self-assessment apps and materials used during the workshops.

Number	Type of material and name (translation)	Goal	Home page; download; and scientific publication
1	Smartphone app: Aachener Sturzpass (fall risk prediction tool)	Fall risk self-assessment	Home page [42]; publication [43]
2	Tablet and smartphone app: starthilfe digital (digital starter kit)	Introduction to basic tablet functions	Home page [44]; download from the Google Play Store [45]; download from the Apple App Store [46]
3	Smartphone app: Up &Go	Instrumented Timed Up and Go test—measure functional mobility	We used a previous version of the app; download of the current version from the Google Play Store [47]; publication [27,48]
4	Print brochure: Bewegungspass (mobility passport)	Self-assess fitness and exercise	Download [49]; balance and mobility self-assessment based on the studies by Guralnik et al [50], Rikli and Jones [51], Howe et al [52], Berg [53], Tinetti et al [54], and Clemson et al [55]
5	Tablet app: TUCAN[a]	Cognitive assessment	Home page [56]; publication [23]
6	Print brochure: LUCAS[b] Navigator	Self-test of functional competence	Download [57]; publication [58]
7	Web-based application: ZEISS Online Vision Screening	Self-assessment of visual function	Home page [59]
8	Tablet and smartphone app: Mimi Hearing Test	Self-assessment of hearing function	Home page [60]; download from the Google Play Store [61]; download from the Apple App Store [62]
9	Tablet app: smartVERNETZT (PRISM[c])	Reduce social isolation and loneliness	Home page [63]; we used the currently developed German version of the PRISM system [64]
10	Tablet app: KOKU[d]	Home-based strength and balance exercise	Home page [65]; download from the Google Play Store [66]; download from the Apple App Store [67]; we used the German version of the KOKU app [68]

[a]TUCAN: Tuebingen Cognitive Assessment for Neuropsychiatric Disorders.

[b]LUCAS: Longitudinal Urban Cohort Aging Study.

[c]PRISM: Personal Reminder Information and Social Management.

[d]KOKU: Keep On Keep Up.

Workshops 2 to 5

Workshops 2 to 5 followed a similar agenda. After a short wrap-up of the last workshop, participants were invited to share their experiences with the homework. Each workshop contained a short expert presentation on the main topic of each workshop: *physical activity* (workshop 2; C-PJ), *physical function* (workshop 2; C-PJ), *cognition* (workshop 3; CM), *vision* (workshop 4; CB), *hearing* (workshop 4; MV), and *social and contextual factors* (workshop 5; NM). Each presentation was followed by participants sharing their knowledge and experiences of each topic to create a common understanding of each domain. In the next step, participants tested selected self-assessments, both analog and digital, in group or individual work mode (Table 1). This method was applied to stimulate participants' thoughts about components that would affect the LiSA UX positively or negatively (RQ 2). Participants shared their experiences from these *try-out sessions* in plenary. The suitability of these self-assessments to be part of LiSA was also discussed (RQ 1). In workshop 5, a total of 2 apps currently under development [64,68] were presented to the participants to provide an outlook on possible follow-up interventions (Table 1). Between workshops, participants were asked to test further preselected self-assessments and complete questionnaires addressing their technology commitment and affinity. These are described in detail in the *Data Collection* section.

Workshop 6

In workshop 6, the card sorting of self-assessment domains (workshop 1; RQ 1) was repeated to ensure informed decision-making and gain information on participants' awareness of the relevance of the suggested LiSA contents for the early identification of health risks. The differences between the card sorting results from workshops 1 and 6 were discussed in the group afterward. To stimulate discussion about user types (RQ 4), participants were presented with 4 fictional profiles representing older adults with different attitudes toward health and technology use (Multimedia Appendix 3). Working in tandems, participants were invited to become familiar with one persona and note their thoughts on whether and why this persona would be a LiSA user or nonuser. The results were shared and discussed in the group. The last part of workshop 6 focused on benefits and risks regarding LiSA (RQ 3). After a short expert input on data security (LR), participants discussed the benefits and risks they expected as a result of using LiSA. Workshop 6 concluded with participants sharing their thoughts about the LiSA idea in general (RQ 5) and feedback on the workshops.

Data Collection

All workshops were audio recorded. During group discussions, researchers (MJB and EL) documented the discussion results on a flipchart and created a workshop protocol from an observer perspective. The group work processes and results were

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photographed. Participants provided written consent for the photos and audio recordings.

Before workshop 1, data on participant characteristics were collected using a paper-based questionnaire specifically designed for this study. The following data were obtained to verify the inclusion criteria and for sample description: sociodemographics (ie, age and gender), SARS-CoV-2 vaccination status, lifestyle (ie, living at home, living alone or not, former employment, participation in voluntary work, and physical activity level), health status (ie, hearing or vision impairment and acute or severe illnesses), and previous experience with technology use (ie, use of devices and fitness apps).

In total, 3 questionnaires on affinity and commitment toward technology and UX were used. The Affinity for Technology Interaction (ATI) scale [36] was handed out to the participants after workshop 1 to quantify their tendency to actively engage in technology interaction. The ATI has been demonstrated to be a reliable, valid, and economic tool for research applications, such as the characterization of user diversity. It contains 9 items rated on a 6-point Likert scale from 1 (*completely disagree*) to 6 (*completely agree*).

The Technology Commitment Short Scale [37] was filled out by the participants after workshop 2. It is a 12-item questionnaire using a 5-point Likert scale (1=*completely disagree*; 5=*completely agree*). It identifies 3 determinants of readiness to use technology: technology acceptance, technology competence, and technology control convictions. The Technology Commitment Short Scale has been developed to study the use of new technologies in older age for both research and practice and has good psychometric properties.

The short version of the User Experience Questionnaire (UEQ-S) [38] was filled out by participants for each self-assessment app they tested in workshops 2 to 5. The UEQ-S is the 8-item short form of the original User Experience Questionnaire (UEQ) and measures the subjective impression of users regarding the UX of products. This questionnaire was chosen as it is available in Germany, and the underlying UEQ has shown sufficient reliability and good construct validity [69]. Each item of the UEQ-S consists of a pair of terms with opposite meanings and can be rated on a 7-point Likert scale. The UEQ-S contains 2 subscales with 4 items each: pragmatic quality (eg, complicated—easy) and hedonic quality (eg, boring—exciting), with a total value reflecting the overall UX.

Data Analysis

Quantitative data were analyzed descriptively using SPSS Statistics (version 27.0.1.0; IBM Corp). The mean, SD, minimum, maximum, median, range, and Cronbach α values were calculated. UEQ data were analyzed using the UEQ Data Analysis Tool (UEQ Team) [38,69]. MAXQDA Plus 2022 (version 22.3.0; VERBI GmbH) was used for verbatim transcription of the workshop audio recordings and qualitative content analysis [39] to answer RQs 1 to 5.

For qualitative data analysis, the Optimized Honeycomb Model for UX [40,41] (Figure 2) served as a basic structure to categorize the components affecting the LiSA UX thematically (RQ 2). This model has been successfully applied in other UX studies in health research [70] and in a recent co-creation study aimed at improving the UX of a self-test app to assess balance function [26].

Before starting the data analysis, researchers (MJB and CB) agreed on the definitions of each Honeycomb Model category, oriented toward the original description [40,41] (Textbox 1).

Figure 2. The Optimized Honeycomb Model for user experience (adapted from Karagianni [40], with permission from Katerina Karagianni and Morville [41], with permission from Peter Morville.)



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Textbox 1. Agreed upon definitions for each Honeycomb Model category.

- Usable: *What does the Life-integrated Self-Assessment (LiSA) need to be used with effectiveness, efficiency, and satisfaction?*
- Useful: *Which LiSA functions would be helpful to meet user needs?*
- Findable: *How does LiSA have to be set up and structured so that people can navigate it easily?*
- Credible: *What must LiSA be like to be safe, credible, and trustworthy?*
- Accessible: *How can access to LiSA be enabled?*
- Desirable: *What components could make LiSA emotionally attractive?*
- Valuable: *What higher goal and benefits should LiSA fulfill?*

The subsequent process followed a deductive-inductive approach to content analysis [39,71,72]: (1) reading and understanding all transcripts; (2) identifying meaning units according to RQs 1 to 5; (3) deductively sorting the meaning units into the 7 Honeycomb Model categories (findable, accessible, usable, desirable, credible, useful, and valuable); (4) inductively creating further categories and allocating meaning units to these categories regarding RQ 1, RQ 3, RQ 4, and RQ 5; (5) creating subcategories within all categories; and (6) viewing and assigning data from flipcharts, photos, and researchers' notes to the categories.

Ethics Approval

This study was approved by the University of Heidelberg Medical Faculty ethical committee (S-110/2022).

Results

Participant Characteristics

A total of 10 community-dwelling older adults aged between 68 and 85 years (n=6, 60% female and n=4, 40% male; mean age 77.8, SD 5.1 years) with previous experience using ICT and access to the internet at home were included. A total of 60% (6/10) of the participants lived alone, and 60% (6/10) of the participants had spent more than 2 and a half hours per week doing moderate or vigorous physical activities (eg, brisk walking) during the last 3 months. All participants were retired and formerly employed in tourism (1/10, 10%), fashion (1/10, 10%), banking law (1/10, 10%), health care (1/10, 10%), public service (1/10, 10%), armed forces (1/10, 10%), and the education system (4/10, 40%), suggesting a high level of education among the participants. In total, 20% (2/10) of the participants regularly engaged in volunteer work. None of the participants reported any acute or severe illnesses or subjective visual impairment; 40% (4/10) reported perceived hearing limitations. Participants had previous experience using a computer (10/10, 100%), smartphone (9/10, 90%), tablet (4/10, 40%), and smartwatch (2/10, 20%). In total, 90% (9/10) reported knowing how to open and send messages (eg, email) and search for information on the internet. A total of 20% (2/10) used fitness tracking apps.

The group's mean ATI score over the 9 items was 3.20 (SD 0.84; Multimedia Appendix 4 [36,37]), indicating that the group had neither a very high nor a very low tendency to actively engage in intensive technology interaction. The wide distribution of values on the 6-point Likert scale shows diversity regarding affinity for technology within the group.

Mean scores on the Technology Commitment Short Scale were 3.22 (SD 0.43) over all 12 items, 2.89 (SD 0.89) for technology acceptance, 3.44 (SD 0.74) for technology competence, and 3.33 (SD 0.55) for technology control convictions (Multimedia Appendix 4 [36,37]), showing that the group's readiness for technology was moderate. The range of values on the 5-point Likert scale indicated diversity regarding the participants' readiness to use technology.

The UEQ-S was filled out by participants for each app they tried during the workshops. The results of the UEQ-S showed positive overall UX evaluations as well as high pragmatic quality scores for 86% (6/7) of the tested apps. Hedonic quality was rated positively for all the apps. The hearing test app yielded neutral evaluations regarding pragmatic quality and overall score. Multimedia Appendix 5 [38] shows in detail how the apps were rated on the UEQ-S.

Owing to vacation and illness, an average of 8 (SD 1.15) people were present at each workshop. A total of 10% (1/10) of the participants were excluded from the study after workshop 1 because of noncompliance with the workshop ground rules. A substitute participant was recruited, who then took part in workshops 3 to 6. The duration of the workshops ranged from 117 to 130 (mean 122.5, SD 4.43) minutes.

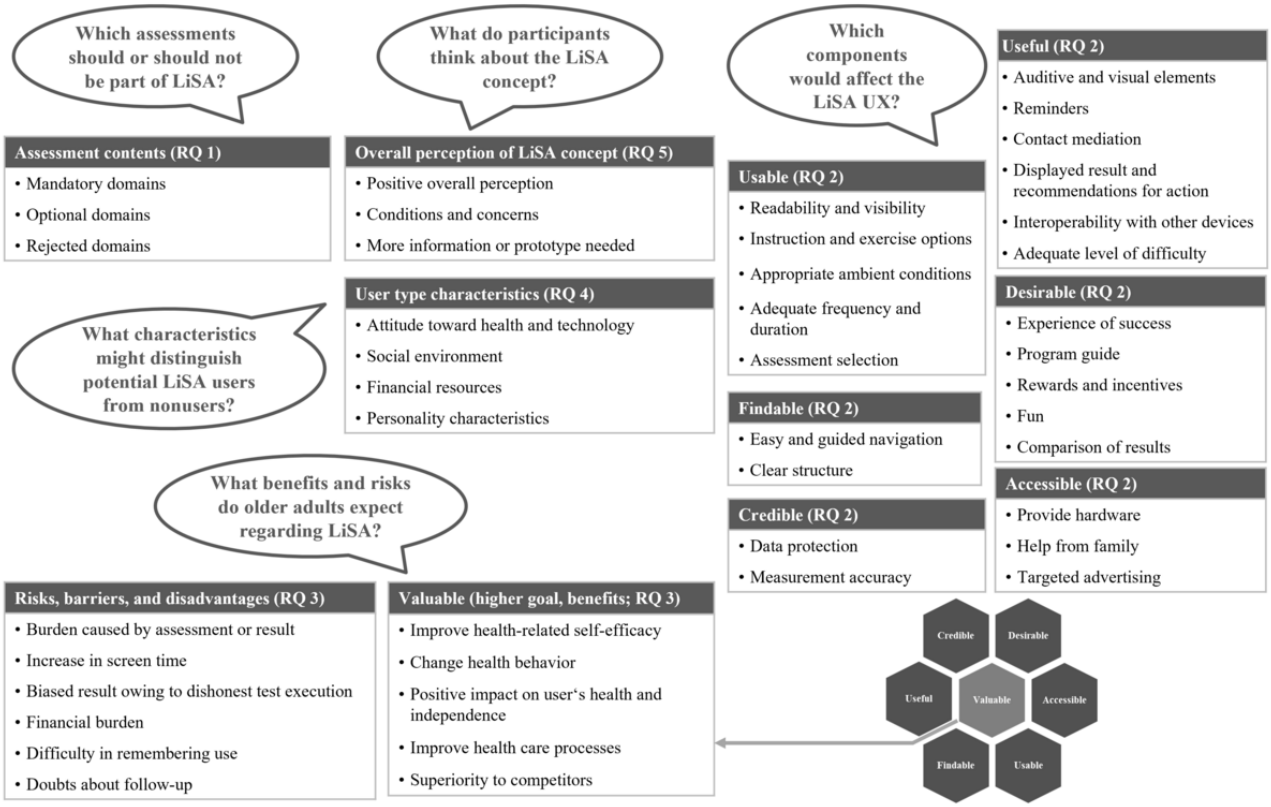
Co-Creation Results for RQs 1 to 5

Overview

The deductive-inductive data analysis resulted in 11 thematic categories covering results on all RQs. The category *assessment contents* was inductively generated to answer RQ 1. In total, 6 of 7 Honeycomb categories—*findable*, *accessible*, *usable*, *desirable*, *credible*, and *useful*—were deductively created to address RQ 2. The seventh Honeycomb category, *valuable*, targets RQ 3 together with the inductively created category *risks, barriers, and disadvantages*. The categories *user type characteristics* and *overall perception of LiSA concept* were also inductively generated to answer RQ 4 and RQ 5, respectively. Within these 11 categories, 44 subcategories were created, as shown in Figure 3.

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Figure 3. Categories and subcategories created to answer research questions (RQs) 1 to 5. LiSA: Life-integrated Self-Assessment; UX: user experience.



RQ 1: Which Assessments Should or Should Not Be Part of LiSA?

Overview

Participants' opinions on self-assessment contents within LiSA were obtained in workshops 1 and 6 by asking them to sort prepared cards with standard CGA domains [5] and further assessments (eg, physical activity) into columns depending on whether they should be included in LiSA or not (Textbox 2). The results of the group work in workshop 6 were assigned to 3 subcategories within the category *assessment contents* during qualitative content analysis and will be described in the following sections.

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Textbox 2. Life-integrated Self-Assessment contents—results from card sorting technique in workshop 6.

Mandatory domains

- Physical activity (eg, steps/d)
- Physical function (eg, strength, balance, and fall risk)
- Cognitive function (eg, memory)
- Sensory function (eg, hearing and vision)

Optional domains

- Vaccination status
- Medication
- Comorbidities
- Home environment
- Affective function (eg, mood and depression)
- Nutrition
- Social environment (eg, loneliness)
- Pain
- Sleep

Rejected domains

- Incontinence
- Sexuality
- Financial situation

Mandatory Domains

The physical activity and cognitive and sensory function domains were perceived as necessary and important components of LiSA in workshops 1 and 6. Physical function (eg, strength) was not desired to be part of LiSA in workshop 1; however, participants considered physical function to be an essential part of LiSA in workshop 6 as they then discovered the strong connection between physical muscle strength and health:

> *Probably because the connection with health [and muscle strength] was not there. When you think of strength, you think of the gym. And that's not the primary topic when you're old and sick.* [75 years; workshop 6]

Optional Domains

When discussing the topics of vaccination, medications, and comorbidities, participants were unsure of whether this would be out of scope. They suggested capturing these domains in LiSA at the beginning. LiSA should then regularly remind people to attend medical checkups, but it should not include medical assessments:

> *But that's a huge field when you're sitting there in front of it, and you have to fill it all out. Will that be too much?* [73 years; workshop 1]

Assessments regarding home environment, nutrition, and affective function were initially rather unfamiliar or unknown to the participants in workshop 1. Then, in workshop 6, they emphasized that it would be important to assess and monitor these aspects, especially as they are often not considered in a physician's visit. However, they were unsure of whether this would be feasible and appropriate as a self-assessment. Social environment, pain, and sleep were also seen as important aspects, but participants were not sure what a self-assessment in these domains would yield:

> *But, that there is the possibility [occupational therapist analyzing the home environment] that someone comes and looks at it, that makes sense. I would never have thought of that.* [77 years; workshop 5]

> *When it comes to financial status, what should the poor doctor say? Or nutrition. But there are also quite other things in the social environment, like contact, loneliness, and we know that the people are sicker there. And all this does not take place there at all.* [73 years; workshop 1]

> *I wonder what the app can do there, regarding loneliness.* [77 years; workshop 6]

Rejected Domains

Regarding incontinence, sexuality, and financial status, participants agreed in both workshop 1 and 6 that these domains should not be part of LiSA as they thought that people would not want to disclose information on these topics:

> *Of course, there are data that no one wants to give.* [75 years; workshop 6]

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RQ 2: Which Components Would Affect the LiSA UX?

Overview

The results on RQ 2 were obtained both from aspects derived from other apps tested during the workshops and from participants' own suggestions and ideas about the LiSA UX components. Multimedia Appendix 5 shows in detail the *dos and don'ts* derived from each app. All results on components affecting the LiSA UX were assigned to the following 6 Honeycomb categories and 23 subcategories.

Usable: What Does LiSA Need to Be Used With Effectiveness, Efficiency, and Satisfaction?

Readability and Visibility: This subcategory captures the participants' needs for large font sizes and images as well as good visibility of app contents:

> *I would have preferred the symbols to be a bit larger because I had difficulty looking at them.* [78 years; workshop 3]

Instruction and Exercise Options: Participants desired to be introduced to the handling of the program as part of LiSA and stated that they would need to practice to successfully complete the self-assessments:

> *I thought it needs to be well explained. But I personally need more time to practice.* [81 years; workshop 4]

Appropriate Ambient Conditions: The need for appropriate lighting and a noise-free environment to perform the self-assessments was mapped to this subcategory:

> *I was very irritated by the conversations. A quiet place is certainly appropriate.* [77 years; workshop 4]

Adequate Frequency and Duration: Participants expressed different time specifications, ranging from 15 to 60 minutes per session and from daily to twice a year. At the same time, the participants noted that the appropriate frequencies can vary according to the content of the assessments:

> *No, you don't do a hearing test every day. It's different with physical exercises, which you do more often. You have to take that into account.* [77 years; workshop 6]

Assessment Selection: Participants had different opinions on whether the selection of assessments should be predetermined or self-decided. Some preferred to be flexible regarding when to perform which assessment and wanted the opportunity to decide that for themselves, as well as to avoid having to repeat assessments that had been recently completed with their HCPs. Others wanted LiSA to provide clear guidance on assessment performance:

> *You could make a selection at the beginning, where you say I'd like to try these areas now.* [81 years; workshop 6]

> *But also, not to have the feeling what I do today with LiSA that is up to me alone. So based on a certain randomness, but that LiSA then takes me by the hand a bit and says, so, this and that is on the agenda today.* [68 years; workshop 6]

Useful: What LiSA Functions Would Be Helpful to Meet User Needs?

Auditive and Visual Elements: Participants suggested integrating auditive and visual elements such as instructional videos, a voice assistant, or a reminder sound:

> *Via an acoustic signal. And maybe add a voice assistant to the whole app.* [78 years; workshop 6]

Reminders: A reminder function for the use of LiSA and for other appointments (eg, preventive care or HCP appointments) was desired by participants:

> *Maybe it should always remind you. That there is a pling sound and then LiSA is active and that means for the user, ah now I have to open it again and look.* [78 years; workshop 6]

> *And then, at the appropriate time, the app reminds you when which preventive checkup is due again.* [75 years; workshop 1]

Contact Mediation: Participants wished for LiSA to provide contact with technology counseling (eg, via senior citizen meetings) as well as with medical counseling (eg, physicians) to make appointments. There was also interest in a LiSA hotline and in having the possibility to share experiences and contact other users:

> *Such a hotline sign where you can inquire under a certain number. If you don't know what to do, I think that would also be necessary. A direct one, without a waiting loop.* [81 years; workshop 3]

> *To get an idea of what helped others. When you're in such a difficult situation and can't see beyond it, then you do get a suggestion.* [77 years; workshop 5]

Displayed Results and Recommendations for Action: Participants wished to see not only the results after the assessment but also individual recommendations for actions to support daily health-conscious life:

> *I think what also plays a role, is that you get suggestions afterwards what you should do. I think that's a very difficult step, because sometimes you know that there's something wrong. And what should you do then? To find a solution.* [73 years; workshop 2]

Interoperability With Other Devices: Participants liked the idea of being able to connect LiSA with already available devices (eg, smartwatches), but they also feared increased complexity:

> *It would be nice [to use available devices]. Yes, but maybe that will make it too complicated.* [78 years; workshop 2]

Adequate Level of Difficulty: Participants agreed that the assessment tasks should not be too easy, and they expressed the idea of offering different levels:

> *But if it's too easy, it's not a test. Then you don't see where you might have weaknesses. If I'm great everywhere, then I don't need that.* [80 years; workshop 4]

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Desirable: What Components Could Make LiSA Emotionally Attractive?

Experience of Success: Participants found that LiSA should be designed in such a way that users can experience a sense of achievement, for example, through the independent installation and operation of LiSA or the possibility to improve on assessment results over time. From the participants' point of view, an experience of success feels motivating, encourages ambition, and causes a sense of pride. In contrast, being overchallenged by technology or assessments that are too difficult would lead to frustration and anger:

> *And then I'm really proud when I can say the next day, wow, it worked today. And that motivates me to try and do it again and again.* [80 years; workshop 6]

Program Guide: Participants liked the idea of an entertaining guiding element such as an animated character or avatar. They suggested that real people could act as ambassadors and program guides within LiSA. Participants were ambivalent about the extent to which this program guide should or should not be more senior oriented:

> *I am actually very happy when it is presented very senior-like, very detailed.* [81 years; workshop 2]
>
> *What I didn't like was the speech, the way it was addressed. That was too senior-like for me.* [78 years; workshop 2]

Rewards and Incentives: This subcategory includes participants' ideas on nonmaterial and material rewarding elements and incentives within LiSA. For example, insurance companies could provide a tablet device for free under the condition of using LiSA on it. In addition, rewards such as a point system or vouchers were suggested to increase adherence:

> *Maybe a reward system at the end of the week. That counts the number of points and then says here you have now reached 100 points. See if you can get 200 next week. A little incentive.* [78 years; workshop 5]

Fun: Participants wanted LiSA to be enjoyable as having fun with it would increase adherence and help them remember to use it:

> *For me, it would make sense in the first place if I enjoyed it. Then I do it voluntarily, then no one needs to remind me. The tests simply must be interesting and fun.* [78 years; workshop 3]

Comparison of Results: The participants had different opinions on the possibility of comparing results with those of other users. On the one hand, it could be competitive, fun, and stimulating. In contrast, it could also feel discouraging. Therefore, participants suggested that the possibility to compare results with those of others should be offered as an optional component:

> *I think it would drag me down. To be the worst of all the others I think I would give up.* [80 years; workshop 3]

Accessible: How Can Access to LiSA Be Enabled?

Provide Hardware: Participants had different ideas on how to access the LiSA tablet. They were in disagreement on whether the users themselves should bear the costs. It was suggested that insurance companies could offer the tablets to their customers:

> *It must be provided, only then it will work out.* [78 years; workshop 6]
>
> *And if you need a tablet to use it, you have to say, ok I'll go for it and buy a tablet.* [80 years; workshop 6]

Help From Family: Being supported by family is an important factor in the use of LiSA. Most participants had received help from family members in the past in dealing with technology. However, they were unsure of the extent to which families could also help with a new program such as LiSA. Furthermore, there was a desire to be able to use technology successfully on their own in the future:

> *I actually want to be able to do it on my own.* [81 years; workshop 3]

Targeted Advertising: Participants felt that it was difficult to develop a *one-size-fits-all* approach. To enable widespread access to LiSA, participants believed that target group–specific advertising and communication are needed. They mentioned senior centers, television, and word-of-mouth recommendations as possible advertising channels, especially for older adults without internet access. It was suggested that different LiSA versions be gradually developed and offered to better address the different target groups:

> *There are many different people who will use it. And I think you can't develop something optimal for everyone.* [80 years; workshop 5]
>
> *It would also be possible to set up LiSA courses in senior centres.* [77 years; workshop 4]

Credible: What Must LiSA Be Like to Be Safe, Credible, and Trustworthy?

Data Protection: Participants expressed a lack of knowledge on this topic. From their viewpoint, data protection was an illusion, and one simply must accept that there is no absolute guarantee of security. They had different opinions on the consequences that might occur if LiSA were to collect and share data with HCPs or other third parties. They did not want the data to be sold to insurance companies. From the participants' point of view, there should be education in LiSA about data protection to provide transparency and overcome possible concerns:

> *Either you are not on the internet at all, or you have some risks.* [78 years; workshop 6]

Measurement Accuracy: The participants had a critical attitude toward the objectivity of the self-report assessment. Regarding mood or loneliness, they considered the comparison between self- and external assessment by another person to be helpful. In the case of the hearing and vision tests, the participants found it convincing and face-valid if the tests were structured similarly to those used by HCPs and if the goal behind the tasks within the assessment was recognizable for users. Participants' thoughts

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on reliability and validity included that LiSA measurements must consider the placement of the device, the time of day, and the individual form on the day:

> *Or maybe I would ask other people. How do you feel about me? Because some say, listen, you're always just sitting there in your apartment. And you're totally happy about it. And the others say, no and that's really bad and that's already depression.* [78 years; workshop 5]
>
> *If I do this three times a day, and then the result is not the same.* [68 years; workshop 4]

Findable: How Does LiSA Have to Be Set Up and Structured So That People Can Navigate It Easily?

Easy and Guided Navigation: Clearly labeled buttons would help participants navigate and be guided within LiSA. Furthermore, participants liked the possibility to continue where they left off. Assessments that have already been completed should be deactivated within LiSA:

> *That should be easy, that you click on Done or Back or so. That you also find back.* [73 years; workshop 3]
>
> *I would like that the tests that I have already done are no longer accessible. I don't want to do it twice and get different results. That would then have to be locked.* [78 years; workshop 4]

Clear Structure: Participants had several ideas on how to provide a clear higher-level structure by integrating different assessment domains into LiSA. A possibility would be to create links within LiSA that lead to other assessment apps or websites. However, participants were afraid that this could also be confusing. Another suggestion was to embed all individual assessments as modules in LiSA so that users would only need to use 1 program. Participants saw it as important that assessments be presented in a structured and clear overview:

> *It's all interesting for sure, all the possibilities. But I think as an older person, clarity should have priority. If there is too much on offer and you can't cope with it, then you don't do it.* [81 years; workshop 3]

RQ 3: What Benefits and Risks Do Older Adults Expect Regarding LiSA?

Overview

The aspects from the workshops that relate to the higher goals, opportunities, and benefits of LiSA were assigned to the Honeycomb category *valuable* and thematically assigned to 5 subcategories. A separate category was created for the anticipated risks, barriers, and disadvantages that were expressed by participants. Within this category, 6 subcategories were created during qualitative content analysis.

Valuable: What Higher Goal and Benefits Should LiSA Fulfill?

Improve Health-Related Self-Efficacy: Participants perceived benefits of using LiSA to self-assess and monitor their own health status. They liked the idea that LiSA provided information on their health status and gave them a better self-estimation. They hoped to achieve more self-control regarding health decisions and appreciated the opportunity to perform the assessments in LiSA first instead of going straight to the physician:

> *A certain awareness of your estimation of yourself would not be wrong.* [85 years; workshop 1]
>
> *Well, I must say, I am someone who never goes to the doctor. Otherwise, I find something like that [LiSA] always better than going to the doctor. Because when I see, oh that was better last time, then I go to the doctor or somewhere.* [81 years; workshop 4]

Change Health Behavior: From the participants' perspective, the displayed results and recommendations for action could help change their health behavior for the better:

> *So, I think that's not bad if you get feedback on how bad you are, for example. Then I have to do something in that direction.* [73 years; workshop 3]

Positive Impact on User's Health and Independence: This category includes participants' reflections regarding the fact that LiSA could positively affect their own health and independence in old age:

> *This is really an interesting thing and I already think that this will help me in terms of health.* [75 years; workshop 6]
>
> *And this is where I see the benefit now. I want to be independent of the help from children for as long as possible.* [81 years; workshop 6]

Improve Health Care Processes: Participants stated that LiSA could empower users to prepare for physician visits, help physicians make diagnoses, and support patient education. They imagined that users would visit the physician earlier if necessary and would be more likely to attend preventive care appointments because of the LiSA results:

> *Something I can present that he [the doctor] can then review and get an idea that will help him make a diagnosis. A service that also forces the individual [doctor] to explain something. That is often missing in the medical examination. That would be a goal.* [85 years; workshop 1]
>
> *To say I'll see what preventive checkups I need to attend. Did I think of everything? Preventive checkups at 70, preventive checkups at 80.* [73 years; workshop 6]

Superiority to Competitors: More generally, participants emphasized that the user should benefit from LiSA being superior to other digital offerings:

> *It must be better than what I already have.* [78 years; workshop 6]

Risks, Barriers, and Disadvantages: What Risks Do Older Adults Expect Regarding LiSA?

Burden Caused by Assessment or Result: The participants expressed concern that an overdemanding test procedure or a poor test result could cause a burden for users:

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> *If you would score now very badly, and then you sit alone at home. I don't know what to do then. I just imagined that there could also be a senior citizens' meeting place and that there could be such a contact point.* [73 years; workshop 3]

Increase in Screen Time: The presumption that LiSA leads to more screen time was pointed out as a possible negative consequence:

> *The fact that you're even more stuck to the screen is a disadvantage, of course.* [77 years; workshop 6]

Biased Results Owing to Dishonest Test Execution: It was mentioned that users would cheat on self-assessments to obtain a better result:

> *So, I don't know if I would be so honest with myself if I were tested on that. I don't know.* [78 years; workshop 5]

Financial Burden: If the data were passed on to insurance companies, LiSA could lead to financial disadvantages for every user from the participants' perspective. The health care system could also be affected by additional costs if LiSA resulted in more medical consultations:

> *So, the insurance companies, they're always mentioned there. That if you do that [LiSA], then the insurance company says, oh God, now he's sick, he has to pay more for insurance.* [73 years; workshop 6]

> *Either we assume that someone who uses LiSA is already a health-conscious or illness-conscious person. And they will go to the doctor more often than others. So, they will cause more costs than someone who does not use LiSA.* [75 years; workshop 6]

Difficulty in Remembering Use: A possible barrier to long-term and regular LiSA use according to the participants could be forgetting to use LiSA:

> *My only concerns are that hopefully my memory will also allow me to remember to check something. For example, if it says daily or once a week, that I really remember it too.* [80 years; workshop 1]

Doubts About Follow-Up: Concerns were raised about the extent to which follow-up after LiSA could be ensured. Participants doubted that they could discuss LiSA outcomes with physicians or that it might take too long to obtain an appointment with an HCP after identifying emerging problems in LiSA. In addition, there are domains for which the ability of LiSA to make recommendations to improve is restricted, such as social contacts:

> *Taking that to the doctor, that doesn't work at all, I assume that already. That doesn't work.* [75 years; workshop 6]

> *I find it quite difficult, for example, with contacts. If someone has few social contacts, how does he change that?* [80 years; workshop 5]

RQ 4: What Characteristics Might Distinguish Potential LiSA Users From Nonusers?

Overview

The following results are derived from the findings of the tandem work with the personas in workshop 1 as well as the spontaneously expressed thoughts of the participants regarding possible LiSA users and nonusers during the other workshops. Multimedia Appendix 3 provides a description of the 4 personas and the results of the tandem work on why these personas would be users or nonusers. All results regarding RQ 4 were assigned to 4 subcategories within the category *user type characteristics* during qualitative content analysis.

Attitude Toward Health and Technology

The participants felt that it would be easier to reach people who are already motivated to care about their health, who already use a tablet, or who are interested in engaging with technology. Even though it was considered difficult, they found it crucial to reach people with little health motivation and technology competence so that these individuals, as well as the health care system, could benefit from the advantages:

> *I think Anita [persona with negative attitude toward health and technology], we would have to include her absolutely, because probably this group of people are the most expensive for the health care system.* [78 years; workshop 6]

Social Environment

Participants saw difficulties for users who could not expect support with technical issues from friends or family. However, these users should still be reached through training:

> *There you have to try to fix that [lack of skills] with training.* [68 years; workshop 6]

Financial Resources

As financing of the LiSA hardware was not predefined at the time of the workshops, the participants considered whether LiSA would then only be usable by people who owned a tablet or could afford to purchase one:

> *But if you have financial worries, you don't use a LiSA app, I would say. Yes, the hardware must be there first.* [78 years; workshop 6]

Personality Characteristics

Another decisive criterion for LiSA use from the participants' point of view was personality. They explained that some older people who are anxious or hesitant in general or have a change-averse personality would not use LiSA:

> *But there will certainly be those who say, I don't need that, I have enough friends, I have way too much, I don't know how I'm going to manage that with my schedule. That also exists. But they probably wouldn't do that.* [80 years; workshop 5]

> *Sometimes people want to stay in their current state, they don't want to be motivated. And in my experience, older people in particular don't always want to hear, do this, from younger people, because*

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> *they're not in that situation. I think that people would like to stay more among themselves in the same generation.* [81 years; workshop 6]

RQ 5: What Do Participants Think About the LiSA Concept?

Participants' overall perceptions and thoughts on the LiSA concept were summarized in the category *overall perception of LiSA concept* and were thematically assigned to 3 subcategories.

Positive Overall Perception

Participants were mostly positive and interested in using LiSA at home on a regular basis:

> *I find that interesting, I would certainly like to use that.* [80 years; workshop 1]
>
> *I hope that I still live to see the LiSA project and that it does not last too long, because I am one of the older ones and would actually like to use this for a few more years.* [81 years; workshop 6]
>
> *I think I could do this well on my own at home.* [81 years; workshop 4]

Conditions and Concerns

Overall conditions that must be met for LiSA to be used were expressed by participants and described in the results section for RQ 2 (UX) and RQ 3 (risks and benefits):

> *However, it would also have to be user-friendly.* [80 years; workshop 6]
>
> *So I'm open-minded, but at the same time I'm a little afraid of whether I'll be able to cope with the whole thing when I'm on my own.* [81 years; workshop 3]

More Information or Prototype Needed

For some participants, it was too early to form an opinion on the LiSA concept as LiSA was not entirely predefined by the research team at the time of the workshops. Participants expressed the need for a prototype to better evaluate LiSA:

> *I still have no real idea what would be possible with the program.* [68 years; workshop 1]
>
> *I would have to try it and then try it again a few days later and then see the result.* [78 years; workshop 5]

Discussion

Principal Findings

The co-creation process was a mutual learning experience toward the development of LiSA. Overall, the participants in this co-creation process had a positive attitude toward the regular use of LiSA. The main expectations of the participants from LiSA were to collect valid and relevant data to have a better control of their health status, be better prepared for visits to their physicians, and be able to identify and respond earlier to risks. Their overall goal was to improve or maintain their own health status for as long as possible, thereby keeping their independence and autonomy.

Participants favored the ability to individually determine the frequency, duration, and scope of LiSA. Consistent with the recommendation of another study examining the usability of mobile health apps for older adults [16], LiSA should include a default selection of mandatory domains and the possibility to enable more functionality (ie, optional assessment domains). This would also be consistent with the personalized and iterative nature of a CGA [73]. The domains of physical activity and capacity as well as sensory and cognitive function were prioritized by the participants and, therefore, should be integrated into LiSA. However, it may be that participants prioritized these above all other assessment domains mainly because they already knew the assessments in these areas from their own experience or because they most likely noticed physical, sensory, or cognitive deterioration in their peer groups and were worried about becoming affected themselves. In contrast, participants may have rejected the domains of sexuality and incontinence out of embarrassment or because they believed that incontinence is a natural and inevitable consequence of aging [74]. Therefore, a balanced approach to user preference and medical expertise should be followed to define mandatory and optional assessments within LiSA. This will not only facilitate the integration of all relevant domains for risk identification into LiSA but also ensure a positive UX.

The participants highlighted that the identification of risk factors was relevant, but they expected problem-solving suggestions and a timely follow-up. LiSA should not be reduced or limited to an alarm function, leaving the participant alone with it. Another study on a self-test app to assess balance function showed similar results. Participants wanted not only to be notified when physical function was declining but also to receive guidance on how to exercise [26]. The provided information (eg, pointing out opportunities for social interaction, such as senior centers in the area) and recommendations for actions (eg, recommending consulting an appropriate expert or referring to a training intervention) within LiSA should be evidence-based and precise to ensure that they do not cause unnecessary medical visits. For people with physical or social access barriers to medical care (eg, remote rural areas), further digital interventions such as video consultation or training apps could also be offered as a follow-up to LiSA assessments.

The setting in which LiSA could be used was left open on purpose by the research team at the beginning of the workshops. The participants discussed that LiSA could be used solely as a private self-assessment or as a preclinical tool to prepare for a physician's visit. The transfer of data to physicians (either electronically or independently brought along by the patient) has the potential to promote CGA implementation as reliable data would then already be available as a basis for further, specific assessments. However, the transfer of data to third parties such as physicians or health insurance companies was viewed with skepticism. In accordance with the participants' opinions as well as a guideline to support mobile health app design for older users [16], LiSA should ensure transparency and users' autonomy and control over their own data. Providing offline access would ensure data security and also avoid interruptions because of poor internet connectivity.

The level of technological competence as well as the type and number of available technical devices can vary greatly in the target group of older adults. Therefore, LiSA should allow for

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the interoperability of different devices such as smartphones, step counters, and tablets to exploit users' existing individual resources and skills. Low technological competence and a negative attitude toward health and technology were the main characteristics of potential nonusers mentioned by participants. Other nonuser characteristics were a low level of social support, lack of financial resources, and anxious and change-averse personality traits. Workshop participants felt that no one should be excluded from the LiSA target group. However, realistically, there are criteria that may prevent the regular use of LiSA (eg, significant cognitive or visual impairment). To achieve accessibility and acceptance among different user types, personalized LiSA versions could be offered in perspective, such as a single-device version for people who own only one technical device. Possible further strategies to overcome user barriers are presented in Multimedia Appendix 3.

As in our group, there will be selective users in the population of older adults who like to compare apps and then select the best one. This means that development and subsequent maintenance must also consider the comparison with competitor apps to meet the disparate expectations and wishes of users. The integration of incentives into LiSA to increase attractiveness was proposed by participants but must be critically considered. Offering financial incentives such as vouchers or rebates might undermine intrinsic motivation and lead to a greater likelihood of disuse or manipulation of test results. However, cognitive evaluation theory predicts that, if such a reward is perceived as confirming an individual's autonomy rather than controlling behavior, it would enhance intrinsic motivation [75].

Strengths and Limitations of the Co-Creation Process

The main strength of this study lies in the high engagement of the participants, which is also shown by the high adherence rate and time they invested without any financial compensation. The 6 co-creation workshops were carried out as planned, and the atmosphere during the workshops was characterized by appreciation, trust, and constructivism. Participants engaged in the interaction with the research team as well as with the group, which is reflected in the depth and scope of the results. Different approaches were adopted throughout the co-creation process and reporting to strengthen the study's validity and trustworthiness and increase the impact of the results [39]. During the group discussions, methods for securing results [34] were used to ensure a correct understanding of the participants' comments. In addition, regular participant evaluations [33] were conducted to assess satisfaction with the co-creation process. The presentation of methods and results was guided by current guidelines [33,34]. Workshop contents and analysis procedures were described transparently to enable the comprehensibility of the methodological procedure. The use of quotations shows the connection between the data and the results, indicating the richness and diversity of the material. The UX Honeycomb Model proved to be an appropriate and helpful framework for categorizing our findings, and we recommend it for use in further UX research.

It should be noted that the results may have been biased by participants being similar in terms of ethnicity, cultural background, and high educational level. This makes it difficult to transfer the results to other contexts with more diversity. More multilayered data could have been obtained through the additional collection and analysis of video data, especially during small-group work. Another limitation of this study is that the qualitative content analysis was conducted by 1 person. Owing to the limited sample size and cultural setting, the results are not directly transferable to the general population of older adults.

Future Perspectives

As suggested by the participants, the next step is to develop a LiSA prototype building on the findings from the co-creation process. From the participants' perspective, this prototype is needed to thoroughly evaluate LiSA. In a follow-up study with the prototype, all components of UX (UX before, during, and after use) will be investigated further. The participants found that a one-size-fits-all approach should not be aimed for. As a possible first step into the consumer market, it might make sense to start with a version for users with few barriers. This version could then be iteratively tested, developed, and expanded to overcome barriers gradually and to be able to offer LiSA to a larger target population in the long term.

The following relevant stakeholders should be involved in future co-creation processes. Focus groups with general practitioners and other HCPs (eg, physiotherapists and optometrists) should be held to discuss readiness and potential barriers to integrating data collected in LiSA into appointments with HCPs. In addition, data privacy experts should be involved to ensure the security of user data within LiSA. Health insurance companies should also be considered as stakeholders to discuss possible funding opportunities, such as the provision of hardware to their policyholders. Finally, family members should also be involved to capture their perspective and needs to support older family members in their use of LiSA.

Further research steps will be the examination of the test quality criteria (ie, test-retest reliability and cross-validation) to verify whether LiSA provides comparable data with those of a standard CGA.

Conclusions

We co-created the LiSA concept with 10 older adults, an approach toward LiSA to identify risks early and facilitate the targeted management of older adults' health. The study design and chosen co-creation methods promoted an intensive discussion and differentiated insights into the ideas, expectations, and concerns of the target group. The co-creation participants supported the general concept and ascribed a high value and great interest to LiSA. The core assessments identified were physical activity and capacity and sensory and cognitive function. Customizable scope and content, as well as recommendations upon assessment results, were requested. On the basis of this study, a prototype will be designed, validated, and iteratively developed, including further co-creation processes with different stakeholders and including older adults with a lower educational level. Five take-home messages from this co-creation study are listed in Textbox 3.

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Textbox 3. Take-home messages.

- *Carry on*: the participants confirmed that the Life-integrated Self-Assessment would be relevant to them; further developments were recommended.
- *Repeat*: participants were interested in performing self-assessments on a regular basis and in the long term.
- *Less is more*: the scope should not be too extensive but focus on the most important assessments (physical activity and capacity as well as sensory and cognitive function).
- *Individualize*: content and scope should be customizable to the user's needs.
- *Think ahead*: clear recommendations derived from assessment results were expected.

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Authors' Contributions

MJB, CB, and EL conceptualized the study. MJB, CB, EL, KG-O, C-PJ, NM, CM, and LR took part in the co-creation workshops. MJB, EL, and CB took part in the data analysis phase. MJB drafted the manuscript and visualizations, and EL and CB took part in a preliminary process of reviewing and editing the manuscript. All authors participated in the subsequent editing process, read the entire manuscript, and agreed to the published version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
PRODUCES+ (Problem, Objective, Design, [End-] Users, Co-creators, Evaluation, Scaling) co-creation reporting checklist.
[DOCX File , 59 KB - aging_v6i1e46738_app1.docx]

Multimedia Appendix 2
Overview of the workshop contents.
[DOCX File , 28 KB - aging_v6i1e46738_app2.docx]

Multimedia Appendix 3
Description of personas, results from the tandem work, and strategies to overcome potential user barriers.
[DOCX File , 243 KB - aging_v6i1e46738_app3.docx]

Multimedia Appendix 4
Results from the Affinity for Technology Interaction and Technology Commitment Scale.
[DOCX File , 29 KB - aging_v6i1e46738_app4.docx]

Multimedia Appendix 5
Participants' ratings of the tested apps on the short version of the User Experience Questionnaire and dos and don'ts regarding the Life-integrated Self-Assessment.
[DOCX File , 32 KB - aging_v6i1e46738_app5.docx]

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Abbreviations

ATI: Affinity for Technology Interaction
CGA: comprehensive geriatric assessment
HCP: health care professional
ICT: information and communications technology
LiSA: Life-integrated Self-Assessment
PRODUCES+: Problem, Objective, Design, (End-) Users, Co-creators, Evaluation, Scaling
RQ: research question
UEQ: User Experience Questionnaire
UEQ-S: short version of the User Experience Questionnaire
UX: user experience

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Review

Key Features of Smart Medication Adherence Products: Updated Scoping Review

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Abstract

Background: Older adults often face challenges in self-managing their medication owing to physical and cognitive limitations, complex medication regimens, and packaging of medications. Emerging *smart* medication dispensing and adherence products (SMAPs) offer the options of automated dispensing, tracking medication intake in real time, and reminders and notifications. A 2021 review identified 51 SMAPs owing to the rapid influx of digital technology; an update to this review is required.

Objective: This review aims to identify new products and summarize and compare the key features of SMAPs.

Methods: Gray and published literature and videos were searched using Google, YouTube, PubMed, Embase, and Scopus. The first 10 pages of Google and the first 100 results of YouTube were screened using 4 and 5 keyword searches, respectively. SMAPs were included if they were able to store and allowed for the dispensation of medications, tracked real-time medication intake data, and could automatically analyze data. Products were excluded if they were stand-alone software applications, not marketed in English, not for in-home use, or only used in clinical trials. In total, 5 researchers independently screened and extracted the data.

Results: This review identified 114 SMAPs, including 80 (70.2%) marketed and 34 (29.8%) prototypes, grouped into 15 types. Among the marketed products, 68% (54/80) were available for consumer purchase. Of these products, 26% (14/54) were available worldwide and 78% (42/54) were available in North America. There was variability in the hardware, software, data collection and management features, and cost of the products. Examples of hardware features include battery life, medication storage capacity, availability of types and number of alarms, locking features, and additional technology required for use of the product, whereas software features included reminder and notification capabilities and availability of manufacturer support. Data capture methods included the availability of sensors to record the use of the product and data-syncing capabilities with cloud storage with short-range communications. Data were accessible to users via mobile apps or web-based portals. Some SMAPs provided data security assurance with secure log-ins (use of personal identification numbers or facial recognition), whereas other SMAPs provided data through registered email addresses. Although some SMAPs were available at set prices or free of cost to end users, the cost of other products varied based on availability, shipping fees, and subscription fees.

Conclusions: An expanding market for SMAPs with features specific to at-home patient use is emerging. Health care professionals can use these features to select and suggest products that meet their patients' unique requirements.

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KEYWORDS

technology; medication; aging; adherence; smart medication; digital technology; self-management; older adult; mobile health; mHealth; apps; digital health; geriatrics; older adults; mHealth app; application; management; scoping review; medication adherence; consumer; use; mobile phone

Introduction

Background

As of July 2022, Canada's older adults aged ≥65 years comprised 18.8% of the total population [1]. The number of centenarians per 100,000 persons has also increased from 20.5 (2001) to 34.6 [1]. This can be attributed to the baby boomers, the largest generation in Canadian history, reaching this age group between 2031 and 2036, as well as the gradual rise in life expectancy, which is projected to continue to increase [2]. Older adults are frequently diagnosed with multiple comorbidities, including cardiovascular diseases, diabetes, arthritis, and respiratory disorders [3]. In Canada, 1 out of 3 older adults aged 65 years is reported to have at least 2 chronic medical conditions [4].

Medications are the mainstay of treatment to manage chronic medical conditions. Despite the evidence that shows that medication adherence is vital for managing chronic diseases, medication nonadherence is common among older adults. This can be attributed to a variety of factors, such as cognitive impairment, polypharmacy, multimorbidity, drug-related adverse effects, and storage or formulation issues with medications [5]. Furthermore, older adults often face certain cognitive, physical, or both types of limitations that make daily medication management a difficult and demanding task. Inadequate medication adherence is associated with worsened clinical outcomes, decreased quality of life, and frequent hospitalizations. A retrospective cohort study addressing geriatric nonadherence among patients with heart failure reported that, with every 10% increase in medication adherence, there was a consequent 11% decrease in emergency room visits, 6% decrease in hospital admissions, and 9% reduction in mortality [6]. Similarly, medication nonadherence has been shown to have a negative impact on health care system costs. A literature review conducted by Cutler et al [7] estimated that 10% of hospitalizations occurred because of adherence issues. A nonadherent patient on average requires 3 more medical visits per year, which is typically a US $2000 increase in yearly health care costs [7]. Thus, medication nonadherence can be considered a critical clinical and economic problem.

Numerous interventions have been identified and used to support medication management in older adults [8]. One such intervention is the use of smart technology-based adherence products, otherwise called smart medication dispensing and adherence products (SMAPs) [9,10]. SMAPs contain sensors and processors that allow them to track real-time medication intake and record medication events such as the date and time of medication administration [11]. These products capture medication intake data through a human-initiated action such as opening a pill bottle, puncturing a blister pack, or pressing a button on an automated dispensing device. SMAPs allow for the communication of adherence information to patients, caregivers, and health care providers through the remote upload of data via various means of connectivity, including Wi-Fi, Bluetooth, long-term evolution, and near-field communication [11]. In 2020, our research team systematically searched for and identified 51 products, of which 38 were available for patients to purchase for in-home use [11]. In another recent review, 79 different technologies were found to be available for medication adherence, such as electronic pill boxes, pill bottles, blister packages, and various other products that can track medication intake in real time [12]. Although the rapid development of these technologies is intended to address medication nonadherence, it is not clear whether all of these products positively affect medication taking. For example, the results of a previous scoping review examining the usability, acceptability, and functionality of smart oral multidose dispensing systems indicated that the impact of these systems on medication adherence was inconsistently defined, measured, and reported in the studies [13]. In addition, although acceptability and usability were reported by the studies included in the scoping review, the details of why a product was usable or acceptable were not specified. The use of these SMAPs may be driven by user experience with the features offered by specific products. For example, a usability study conducted by Patel et al [14] reported that the usability of different electronic medication adherence products was highly variable. The variability in the usability of these products may be dependent on their features as well as the medication management capacity of the individuals using these products. Previous qualitative research indicates that older adults, caregivers, and health care providers identified simplicity, availability and usability of alarms, portability, restricted access to medications, and storage capacity as some of the product features that may drive their decision-making regarding the use of a product to support medication management [15]. The same study also highlighted user factors that may drive the appropriate use of these technologies, including sentiment, privacy, user frustration, affordability, physical and cognitive capacity, and technology literacy and learnability. Medication adherence technologies that are not usable by patients may negatively affect medication adherence (ie, worsen medication nonadherence rather than improve it). However, the features of different medication adherence technologies that may drive the usability of these products have not been previously outlined.

Objectives

Given the rapid development of such technology and how features of different products may need to be considered by clinicians when recommending smart medication adherence technologies, we sought to update a previous review of the features of new SMAPs available for in-home use [16,17]. Information on the available features of SMAPs is especially important to clinicians addressing medication nonadherence among their patients and can assist with the selection of the best-suited product. Therefore, the primary objective of this

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review was to identify SMAPs available worldwide and describe and compare their features to assist clinicians in recommending products that suit their patients' needs, expectations, and capacity to improve adherence.

Methods

A systematic approach was used to search for and maximize the number of products identified. The search encompassed both published and gray literature to identify the maximum number of SMAPs available.

Search Strategy for Published Literature

Published literature was searched using 3 databases: PubMed (MEDLINE), Ovid Embase, and Scopus. The search strategy was developed by consulting a librarian. Keywords and Medical Subject Heading terms, including "medication," "adherence," "smart," and "dispensing," were used to search the databases. The Boolean operators AND/OR were used to combine the search terms. Multimedia Appendix 1 provides the detailed search strategy for the databases. The searches were limited to between January 2019 and August 2022 to identify the scholarly articles published since our last review. One researcher (SF) conducted the searches. The final search was conducted on September 29, 2022. All citations were imported to Mendeley Desktop (version 1.19.4; Elsevier Ltd), and duplicates were removed. The titles and abstracts of the search results were reviewed by 1 researcher (SF) to identify all potential SMAPs. A full-text review of potentially relevant citations was completed by a single researcher (SF) to extract the product information. We used the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines for reporting the studies.

Search Strategy for Gray Literature

Gray literature was searched using the Google and YouTube search engines with the keywords "smart medication dispensers," "smart medication device," "smart dispensing delivery," "smart blister pack," and "smart medication vial." Multimedia Appendix 2 provides the detailed search strategy for YouTube and Google. In total, 2 researchers (HP and SP) conducted the Google and YouTube searches independently. The researchers searched the first 10 pages of Google and the first 100 YouTube videos using each search strategy to identify products that met the inclusion criteria. In total, 2 other researchers (YA and DS) reviewed the included products and extracted the product details.

Inclusion and Exclusion Criteria

Products were included in this review if they (1) were smart, defined as "products that are embedded with processors or sensors that allow data to be exchanged between the products and its environment, manufacturer, user and other product systems automatically via various means of connectivity" [18]; (2) had a mechanism to either dispense or organize medications; and (3) were able to track real-time medication intake via mobile apps or web-based portals.

Products were excluded if (1) they were not available for in-home patient use, (2) the product information was not available in English, (3) they were stand-alone mobile apps, or (4) were used only in clinical trials.

Data Extraction

The assessment criteria developed by Mason et al [12], in addition to features assessed in our previous review, were used to extract data related to the SMAPs. The assessment criteria developed by Mason et al [12] included technology hardware and software features, development information, data collection and management, feasibility and implementation, and acceptability and usability. Data related to the products and their features were independently extracted by 4 researchers (SF, BB, HP, and SP) and reviewed and discussed within the team. The following features were extracted: (1) type of products based on their design; (2) developer information, including region or country of product availability, development stage, regulatory approval status, and commercial availability; (3) technological features, including hardware (size, battery life, product storage capacity, alarms, secure medication storage, portability, and additional technology needed to use the product) and software (reminders, notifications, available customer support for users, and ability to integrate with other clinical systems) features; (4) data collection and management; and (5) other features, including product adoption or social engagement via the product.

Results

Overview

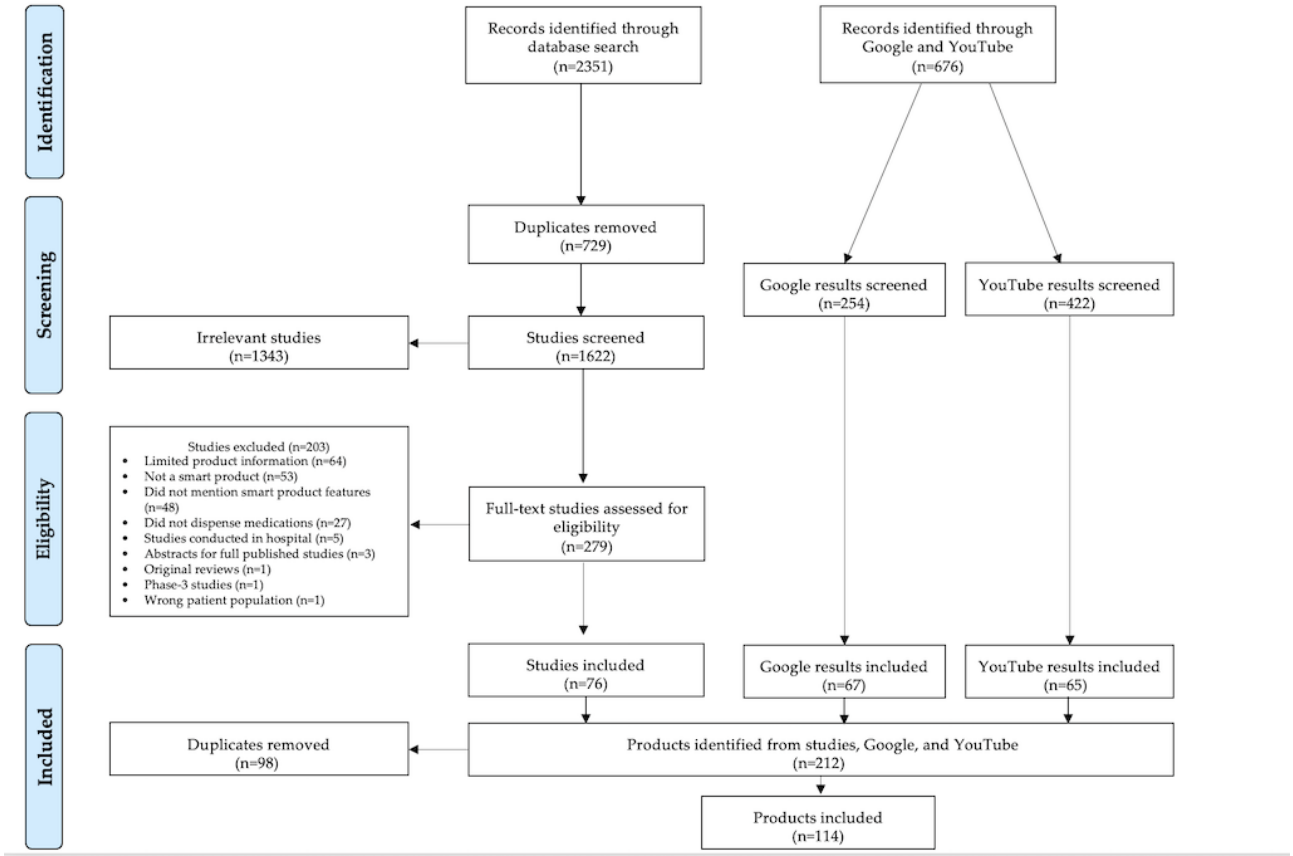
The published literature search identified 2351 studies from the databases—PubMed (n=1169, 49.72%), Embase (n=722, 30.71%), and Scopus (n=460, 19.57%)—and an additional 676 records were identified from Google (n=254, 37.6%) and YouTube (n=422, 62.4%). Figure 1 shows the PRISMA flow diagram.

From these searches, we identified a total of 212 products, including 80 (37.7%) products identified from 76 research studies, 67 (31.6%) from Google, and 65 (30.7%) from YouTube. After removing 98/212 (46.2%) duplicates, the final review, the final review included 114 products. The products were grouped into 15 categories. The definitions of the different types of products are outlined in Textbox 1.

The review included 114 products, of which 34 (29.8%) were prototypes and 80 (70.2%) were marketed. Prototypes were defined as preliminary models of a product that were not fully developed, and marketed products were defined as fully developed products that were available for purchase. Tables 1-5 provide the lists of the marketed and prototype SMAPs that were included in this review.

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Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram.



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Textbox 1. Definitions.

Product type

- Automated dispenser: medication dispensers that provide access to a controlled number of medications at specific time intervals via human-initiated actions and record dispensation or retrieval of medications
- Blister pack: plastic packaging that holds medications in individual pockets or compartments and is sealed using adhesive-coated paper or aluminum that incorporates electronic circuitry or conductive wiring
- Blister pack add-on sensor: sensors that can be attached to a traditional blister pack and record the puncturing of different blisters or compartments in the pack
- Blister pack holder: a box or case that allows for the storage of blister packs or blister cards and records the time at which the box is opened
- Inhaler: electronic inhaler with built-in sensors that automatically records use
- Inhaler add-on sensor: a sensor that can be attached to an inhaler device and track the date and time of inhaler use; some inhalers have the ability to track other respiratory parameters such as inhalation duration or flow rate
- Inhaler holder: a stand or holder that is designed for the purpose of holding or storing 1 or more inhalers and automatically records data when the inhaler is used
- Injectors: electronic injector with built-in sensors that automatically records use
- Injector holder: a stand or holder that is designed for the purpose of holding or storing 1 or more injectables and automatically records data when the injector is used
- Medication tray: multicompartment medication organizers for storing medications, with built-in sensors that automatically record the date and time of opening the compartment
- Medication tray holder: a box or case that allows for the storage of medication vials or a medication tray and records the time at which the box is opened
- Pill bottle: a vial that can store medication and automatically records the date and time when the lid is opened
- Pill bottle holder: a stand or holder that is designed for the purpose of holding or storing 1 or more pill bottles and automatically records the date and time when a pill bottle is removed from the holder
- Pill box: a box that can contain medications in their original packaging and that have not been repackaged into pouches, blisters, or compartments and automatically records the date and time when it is opened
- Vial caps: sensors on the vial cap that record the date and time when the vial is opened

Product features

- Alarm: use of visual or auditory signals produced by the device to alert the user to the time of dosing
- Reminder: a written or audio message that reminds users to perform an activity, such as medication taking
- Notification: an alert (typically a pop-up or other message) generated by an application to notify the user of a new message, update, social media post, missed dose, or wrong dose
- Accessibility: design of products, devices, services, or environments for people who experience disabilities
- Single-medication storage: a product that can only store 1 type of medication
- Multimedication storage: a product that can store >1 type of medication
- Ability to integrate with clinical platforms: for example, pharmacy software, electronic medication administration records, and hospital records
- IT support: for example, phone number, email, web-based forms, and web-based chats for customer inquiry about any technical difficulties with the product

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Table 1. Marketed and prototype smart medication adherence products—automated dispensers.

Product type and product name	Manufacturer or supplier	Products, n (%)
Marketed (n=80)		
Automated dispenser		24 (30)
EMMA [11]	EMMA Health Technologies	
e-Pill MedSmart PLUS [19]	e-Pill	
Evondos [20]	Evondos	
Hero pill dispenser [21-26]	Hero Health	
Home8 Medication Dispensing System [27-29]	Visiotech	
Karie [30-32]	AceAge Inc; Karie Health	
LiveFine [33,34]	LiveFine	
Livi [35,36]	PharmRight Corp	
MedaCube [37,38]	PharmAdva	
Medido [39]	Innospense BV	
MedReady [40,41]	MedReady, Inc; TabTimer	
Mymemo [42]	Studio Volpi	
Philips Medication Dispenser [17,22,43,44]	Philips Lifeline	
Pill Connect [45-50]	eLucid mHealth Ltd	
Pivotell Advance GSM [51]	Pivotell	
Pria [52,53]	Black & Decker	
RxPense Care [54]	Medipense	
DoseControl Smart Automatic Pill Dispenser—Model 2021 [55-57]	MedControl	
Smart medication dispenser [58,59]	As Directed TLC[a]	
Smart Pillbox medicine management system [60]	BlueStar SeniorTech	
Spencer [61-67]	Custom Health Inc	
TabSafe [68]	Medication Solutions	
The Kindo [69]	KIN	
Voice Pro (e-Pill MedSmart PLUS) [19,70]	e-Pill	
Prototypes (n=34)		
Automated dispenser		5 (15)
e-pill smart medication dispenser [71]	CybernetX	
ReX [13,72]	Dosentrx Ltd	
Smart medicine dispenser [73]	—[b]	
Smart pill dispenser [74]	—	
Smart pill expert system [75]	Unknown	

[a]TLC: Total Linked Care.

[b]Not available.

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Table 2. Marketed and prototype smart medication adherence products—blister packs.

Product type and product name	Manufacturer or supplier	Products, n (%)
Marketed (n=80)		
Blister pack		6 (8)
Popit [76]	Popit	
Electronic blister pack (Med-ic) [77]	IMC[a]	
SMART Blister Pack [78]	Wellness Pharmacy	
Smart Clinical Support Package [79]	ECCT B.V.	
Smart Polypharmacy Card [80]	ECCT B.V.	
Time4Med [81]	Adherence Innovations	
Blister pack holder		2 (3)
Aavia smart birth control pill case [82]	Aavia	
Sensemedic Blister Dispenser [83,84]	Evalan	
Blister pack sensor		1 (1)
CueSticker [85,86]	CuePath Innovation	
Prototypes (n=34)		
Blister pack		4 (12)
CpaX [87,88]	Jones Healthcare Group	
Electronic medication blister [89]	DSM TCG B.V.	
SmartBlister [90]	ECCT B.V.	
Smart blister [91]	Unknown	

[a]IMC: Information Mediary Corp.

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Table 3. Marketed and prototype smart medication adherence products—eye drops, glasses, inhalers, and injectables.

Product type and product name	Manufacturer or supplier	Products, n (%)
Marketed (n=80)		
Inhaler		12 (15)
Digihaler (ProAir, AirDuo, and ArmonAir) [92-94]	Teva Pharmaceutical Industries	
Enerzair Breezhaler [94,95]	Novartis Europharm Limited	
FindAir ONE [96]	FindAir	
Hailie sensor [92,93,97-99]	Adherium	
Propeller [92,93]	Propeller Health (ResMed)	
Respiro device [92,94,100,101]	Amiko	
SmartDisk [92,94]	Nexus6 Ltd	
SmartMat [92,102]	Nexus6 Ltd	
SmartTouch [92]	Nexus6 Ltd	
SmartTrack [92]	Nexus6 Ltd	
SmartTurbo [92,94]	Nexus6 Ltd	
Turbu+ V2.1 [103]	AstraZeneca UK Ltd	
Inhaler add-on sensor		2 (3)
FindAir (pMDI[a], Turbuhaler, Ellipta, and Easyhaler) [96]	FindAir	
HeroTracker [104]	Aptar Pharma	
Injector		4 (5)
BETACONNECT autoinjector [105]	Bayer	
Easypod [106-110]	Merck Serono International S.A.	
InPen [111,112]	Medtronic	
RebiSmart [105]	Merck KGaA	
Injector holder		1 (1)
SmartSyringe [113]	ECCT B.V.	
Prototypes (n=34)		
Eye drop device		2 (6)
KaliDrop device [114]	Kali Care	
Smart electronic eye drop bottle [115]	—[b]	
Glasses		1 (3)
MedGlasses (smart glasses-based pill recognition system) [116]	—	
Inhaler		2 (6)
SmartTrack device [117]	Shanghai Sonmol Internet Technology Co, Ltd	
VHC[c] [118]	InspiRx, Inc	
Inhaler add-on sensor		2 (6)
BreatheMate [119,120]	AstraZeneca	
FindAir (Diskus; capsules) [96]	FindAir	

[a]pMDI: pressurized metered dose inhaler.

[b]Not available.

[c]VHC: valve-holding chamber.

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Table 4. Marketed and prototype smart medication adherence products—medication trays and pill boxes.

Product type and product name	Manufacturer or supplier	Products, n (%)
Marketed (n=80)		
Medication tray		5 (6)
Ellie [121]	EllieGrid	
MedMinder Maya [122,123]	MedMinder	
MedMinder Jon [11,122,124-126]	MedMinder	
MED-TIMER [127]	Arthritis Supplies	
SimpleMed+ [128,129]	Vaica Medical	
Medication tray holder		2 (3)
Sensemedic Pill Dispenser [83,84]	Evalan	
Wisepill RT3000 [130]	Wisepill Technologies	
Pill box		9 (11)
CleverCell [131]	Compliance Meds Technologies	
CYCO [132]	Qualife	
evriMED1000 [133]	Wisepill Technologies	
iLidRx [134,135]	iRxReminder LLC	
Pillgo [136]	Pillgo	
Pletaal Assist System [137]	Otsuka Pharmaceutical	
Smart narrowband-IoT[a] Pillsure Pocket [138,139]	1NCE	
Wisepill 2G (model RT2000) dispenser [13,130,140-148]	Wisepill Technologies	
Wisepill 4G LTE[b] (model RT2000) medication dispenser [130]	Wisepill Technologies	
Prototypes (n=34)		
Medication tray		4 (12)
EDossette [13,149]	McMaster University	
mHealth[c] system [150]	MedMinder	
SMSS[d] [13,151]	—[e]	
Smart pill box [152]	—	
Pill box		5 (15)
iMedBox [153]	—	
IoT device [154]	—	
KaliJAR [155]	Kali Care	
OnDosis [156]	—	
Smart pill box [157]	—	

[a]IoT: Internet of Things.

[b]LTE: long-term evolution.

[c]mHealth: mobile health.

[d]SMSS: smartphone-based medication self-management system.

[e]Not available.

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Table 5. Marketed and prototype smart medication adherence products—pill bottles and vial caps.

Product type and product name	Manufacturer or supplier	Products, n (%)
Marketed (n=80)		
Pill bottle		7 (9)
Aidia [158-169]	AdhereTech	
CleverCap Lite [170]	Compliance Meds Technologies	
SmartBottle [171]	ECCT B.V.	
eCAP [172]	IMC[a]	
Nomi Bottle [173,174]	SMRxT Inc	
Pilleve [175,176]	Pilleve Inc	
Pillsy Smart Cap [177,178]	Pillsy Inc	
Pill bottle holder		1 (1)
Sensemedic Pill Bottle Dispenser [84]	Evalan	
Vial cap		4 (5)
SmartCap [171]	ECCT B.V.	
CleverCap Pro [131]	Compliance Meds Technologies	
Smart Med Reminder System [179]	Concordance Health Solutions	
SmartVial [180]	ECCT B.V.	
Prototypes (n=34)		
Pill bottle		5 (15)
Electronic pill bottles [181,182]	Digital Media Technologies and AdhereTech	
EVE smart bottle [183]	—[b]	
MotionDx [184]	—	
Smart pill bottle [185]	—	
Smart pill bottle [186]	Pfizer	
Pill bottle holder		2 (6)
NVOLVE [187]	NVOLVE	
SMRT[c] bottle [188]	Amcor and Confrérie Clinique	
Vial cap		2 (6)
BETR-Cap [189]	Pacific Life Technologies	
Pill-safe digital health system [190]	ModoScript	

[a]IMC: Information Mediary Corp.

[b]Not available.

[c]SMRT: separate, monitor, release, and track.

Consumer Availability

Among the 80 marketed products (Table 6), 54 (68%) were available for consumer purchase, whereas the remaining 26 (33%) were available to patients through partner organizations or for clinical research purposes only (Table 6 and Figure 2).

Of the products available for consumer purchase, 26% (14/54) were available worldwide, 78% (42/54) were available in North America, 30% (16/54) were available in South America, 44% (24/54) were available in Europe, 30% (16/54) were available in Australia, 35% (19/54) were available in Africa, and 44% (24/54) were available in Asia.

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Table 6. Marketed smart medication adherence product features.

Product feature	Products, n (%)
Consumer availability (n=54)	
Africa	19 (35)
Asia	24 (44)
Australia	16 (30)
Europe	24 (44)
North America	42 (78)
South America	16 (30)
Worldwide	14 (26)
Hardware features (n=80)	
Battery life	
≤1 y	33 (41)
>1 y	9 (11)
Not reported	38 (48)
Storage capacity	
Single-medication storage	21 (26)
Multimedication storage	57 (71)
Not reported	2 (3)
Alarm	
None	4 (5)
Audio only	10 (13)
Visual only	5 (6)
Both audio and visual	44 (55)
Not reported	31 (39)
Locking feature	
Available	19 (24)
Not available	22 (28)
Not reported	39 (49)
Installation and setup	
Additional app required	61 (76)
No additional app required	13 (16)
Not reported	6 (8)
Software features (n=80)	
Reminders	60 (75)
Notifications	50 (63)
Available IT support	35 (44)
Ability to integrate with other clinical platforms	5 (6)
Ability to capture other data or metrics	15 (19)
Data accessibility	
Patient only	8 (10)
Patient and CPs[a] only	22 (28)
Patient and HCPs[b] only	12 (15)

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Product feature	Products, n (%)
Patient, CPs, and HCPs	28 (35)
Data security	
Secure log-in	26 (33)
Not reported	54 (68)
Connectivity	
Built-in SIM	8 (10)
Cellular data, Wi-Fi, or Ethernet required	72 (90)
Bluetooth	11 (14)
NFC[c]	8 (10)

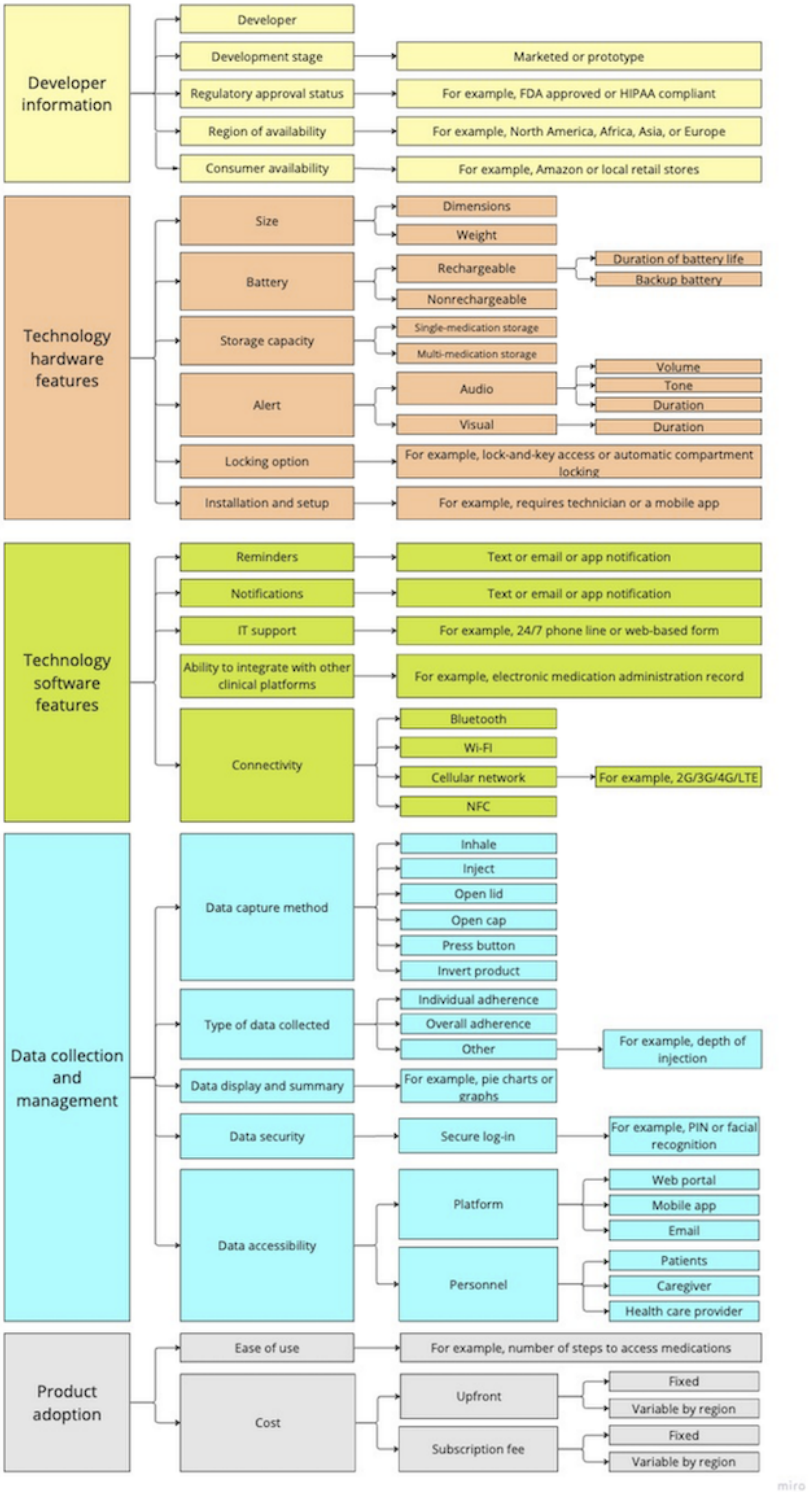
[a]CP: care provider (or caregiver).

[b]HCP: health care provider.

[c]NFC: near-field communication.

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Figure 2. Smart medication adherence product features. eMAR: electronic medication administration record; FDA: Food and Drug Administration; HIPAA: Health Insurance Portability and Accountability Act; LTE: long-term evolution; NFC: near-field communication; PIN: personal identification number.



Regulatory Approval

Regulatory approval (Table 6) refers to any authorization by the government or health authorities required to market a product in a given country. Examples of the types of regulations considered include the US Food and Drug Administration, Australian Quality Care Pharmacy Program, and Health Insurance Portability and Accountability Act compliance. There were 18.4% (21/114) of identified marketed products that had one or more of the described regulatory approvals, whereas 81.6% (93/114) of the marketed products' regulatory approval status was not stated or indeterminate.

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Hardware Features

Battery Life

The hardware features are outlined in Tables 6 and 7 and Figure 2. Battery life is defined as the duration for which the product can be used after the battery is fully charged. Our review found that some products used single-use batteries that could not be recharged. Some products (4/114, 3.5%) were equipped with a battery level display to inform users of low battery before depletion, which allowed for a timely replacement (eg, Pivotell Advance GSM) [51]. However, some products (29/114, 25.4%) did not have this feature, which may cause them to stop working before users become aware that the battery needs replacement. For products using rechargeable batteries, a full charge could sustain function for up to 1 week, as in the case of Ellie, or up to 3 years (eg, Pill Connect) [45-50,121]. Other products may require an uninterrupted connection to a power outlet to function, which highlights concerns in case of a power outage or lack of access to power during travel (eg, Hero pill dispenser) [21-26]. However, some products may be equipped with a backup power supply to maintain their function for an additional 4 (eg, Pria) to 48 hours (eg, MedReady) in case of a power outage [40,41,52,53].

Table 7. Prototype smart medication adherence product features (N=34).

Product feature	Products, n (%)
Hardware features	
Storage capacity	
Single-medication storage	5 (15)
Multimedication storage	19 (56)
Not reported	10 (29)
Alarm	
None	1 (3)
Audio only	2 (6)
Visual only	0 (0)
Both audio and visual	10 (29)
Not reported	21 (62)
Locking feature	
Available	5 (15)
Not available	3 (9)
Not reported	26 (76)
Software features	
Reminders	34 (100)
Notifications	12 (35)
Data accessibility	
Patient only	1 (3)
Patient and CPs[a] only	5 (15)
Patient and HCPs[b] only	6 (18)
Patient, CPs, and HCPs	8 (24)
Not reported	14 (41)

[a]CP: care provider (or caregiver).

[b]HCP: health care provider.

Medication Storage Capacity

Single-medication storage products are designed to only store one type of medication (eg, pill bottles), as opposed to their counterpart, multimedication storage, which can store ≥2 types of medications (eg, automated dispensers). More than two-thirds of the currently marketed SMAPs (62/80, 78%) are multidose, 15% (9/62) hold a single type of medication whereas the remaining 85% (53/62) support multiple (≥2) medications storage capabilities. The number of prescriptions per dose, doses per day, and duration of the supply cycle can differ across products. For instance, LiveFine and Home8 Medication Dispensing System can supply medication for 28 days, storing up to 6 doses per day, whereas Livi has the capability to store 15 medications for a duration of 90 days, enabling the dispensing of a maximum of 24 doses each day [27-29,33-36].

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Alarms

A total of 68% (54/80) of the marketed SMAPs were equipped with an alarm feature that reminded users to take the medication when scheduled doses were due. Of these 54 SMAPs, 10 (19%) provided only audio alarms that included beeping or chiming, 5 (9%) were equipped with only visual alarms (eg, a flashing light), and 44 (81%) were reported to have both audio and visual alarms. Some products (4/54, 7%) allowed for recurrent alerts before the dose was due, at the time of the dose, and after the dose. These alerts could continue up to a specified amount of time or until the dose was taken. At each alert, certain products may require users to click a button to confirm the number of pills to be dispensed and initiate dispensation (eg, Livi), whereas others (2/54, 4%) gave the option to receive a dose early or a missed dose (eg, MedaCube) [35-38]. Other information may also be present on the screen interface of the SMAP during dosage events, such as medication name, medication dose, and quantity of pills left (eg, Livi) [35,36].

Locking Feature

Approximately one-quarter of the products (24/114, 21.1%) were equipped with a locking mechanism through either lock and key–protected access to medication storage compartments (eg, MedaCube, e-pill MedSmart PLUS, and LiveFine) or automatic locking of upcoming dose compartments, permitting access only to compartments for doses that were due (eg, MedMinder Jon, Pill Connect, Pilleve, and Pria) [11,21,33,34,37,38,45,50,52,53,70,121-126,175,176]. Some locking mechanisms did not permit access on a scheduled dose basis; however, they did offer a child-resistant feature (eg, eCAP and Spencer), whereas some products (23/114, 20.2%) did not have any locking features (eg, MedMinder Maya). SMAPs that come with a locking feature may prevent users from accessing the wrong pills at the wrong time and may be used to prevent unauthorized or accidental access to medications (eg, child safety or limiting access to medications with high misuse potential) [61-67,122,123,172].

Additional Technology Required to Use the Product

SMAPs track and record real-time adherence data on an external web- or cloud-based platform. In most cases, the data recorded are accessible via a dashboard; thus, it may require the installation of additional software apps on mobile devices such as smartphones or tablets or on a computer or logging in through a web-based portal to complete the setup. There were 16% (13/80) of products that did not require any additional software installations, and they reported adherence through other means such as SMS text messaging or email.

Software Features

Reminders and Notifications

The software features are outlined in Tables 6 and 7 and Figure 2. Approximately 75% (60/80) of the marketed SMAPs were equipped with the functionality of sending reminders, and 62% (50/80) were equipped with notifications. Reminders were written or spoken messages that reminded individuals to take their medications. In contrast, notifications were alerts (typically a pop-up or other message) generated by an application to notify the user of a new message regarding events other than taking medication, such as missed dose alerts, wrong-dose alerts, or other suggestions to help improve medication adherence. Most products (59/114, 51.8%) included both alerts and reminders. In addition to notifying patients, some products (6/114, 5.3%) provided the option of notifying care partners in cases of a missed dose or double dose (eg, Pillsy Smart Cap) [177,178,191-193].

Available Manufacturer Support Related to the Product

IT support refers to the ability of users to directly contact customer services for technical support—this does not include noninteractive user guide pamphlets that are presumed to come with the SMAPs. IT support is offered by the manufacturers to their consumers through a 24/7 phone line, email, SMS text messaging, or web page chat or form. This review identified 44% (35/80) of products that came with IT support. Other accessibility services included certified health care providers available on standby who could provide internet-based advice and home office support when needed. For instance, the Smart Pill Box Medicine Management Systems provide access to licensed nurses, whereas the Karie Pharmacy Home Monitoring Program provides access to licensed pharmacists, and nurses are available as support for users [30-32,60].

Data Collection and Management

Data Capture Method

The data collection and management features are outlined in Tables 6 and 7 and Figure 2. SMAPs automatically record the date and time of use in response to a human-initiated physical action. For example, data capture occurs when a user opens the lid of a medication tray, opens vial caps or pill bottles, presses a button, or inverts the product. Some other methods for data capture included actuation of the inhaler or injector, opening the medication box, punching a blister, or pulling the tab in a blister pack. Depending on the product type, sensors were designed to automatically record the use of the product as an indicator of the dosage being taken. To be able to synchronize the collected data with cloud storage, SMAPs without a built-in SIM require one or more of the following short-range communications: wireless near-field communication, which was available on 10% (8/80) of the SMAPs in this review; Bluetooth (11/80, 14%); and cellular data (eg, 2G, 3G, or 4G and long-term evolution), Wi-Fi, or Ethernet on 90% (72/80) of the SMAPs in this review. SMAPs with a built-in SIM, which was available in 10% (8/80) of the products in this review, may require an additional subscription fee; however, they do not require wireless short-range communication (eg, Mymemo or Philips Medication Dispenser) [17,22,42-44].

Adherence Data Captured by the Product

SMAPs vary in their method of recording the date and time of medication taking. SMAPs may be designed to report periodic (ie, weekly, monthly, and annual) medication adherence history. Individual or overall adherence may be reported as percentages or presented in graphical form (eg, calendar view and pie charts).

Other Data Captured by the Product

A total of 19% (15/80) of the products were also designed to record other data in addition to medication adherence. For

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instance, the FindAir inhaler was able to capture pollutant levels in the surrounding environment at the location of use [96]. Similarly, Propeller was able to capture the location of use, and BETACONNECT autoinjectors could capture the depth of the injection [92,93,105]. Some products had the ability to capture one or more types of biometric data, such as blood pressure, blood glucose, heart rate, respiratory rate, and weight (eg, Pillgo, Respiro device, and Smart Pillbox Medicine Management System) [60,92-94,100,101,136].

Data Security and Accessibility

The medication adherence reports were accessible to patients through mobile apps (eg, Pletaal Assist System, Popit, Propeller, and RebiSmart), web-based portals (eg, Pivotell Advance GSM), or both mobile apps and portals (eg, RxPense Care). In total, 32% (26/80) of the SMAPs provided data security assurance for mobile apps and web-based portal access via secure log-ins (ie, personal identification number or facial recognition). For products that did not have application installations or portals in the initial setup, medication adherence reports were sent to registered email addresses (eg, Wisepill) [11,51,54,76,92,93,105,130,137,140-148]. Currently, only 6% (5/80) of the SMAPs automatically integrate adherence data into other clinical platforms such as pharmacy software or electronic medical records. Adherence reports could be accessed only by the patient in 10% (8/80) of the SMAPs, whereas 28% (22/80) permitted access by the patient and their caregivers; 15% (12/80) permitted access by the patient and their health care provider or providers; and 35% (28/80) permitted access by the patient, caregiver or caregivers, and health care provider or providers.

Cost

There was a diverse range of prices for the different SMAPs. With suitable health insurance coverage, some products (2/114, 1.8%) could be free of cost (eg, Aidia and Medido) to the end user, whereas others (4/114, 3.5%) were available at discounted prices (eg, InPen) [39,111,112,158-169]. Some products (2/114, 1.8%) were offered at no cost if specified conditions were met—for instance, SMART Blister Packs were available free of cost for Wellness Pharmacy patients [78]. In contrast, Pria, along with Voice Pro (e-pill MedSmart PLUS), cost up to US $300 [19,52,53,70]. The cost of a product may also vary by region owing to a variety of factors, such as availability in the region or shipping fees (eg, LiveFine) [33,34]. In some cases (8/114, 7%), providers required users to directly contact them for more purchase information (eg, Livi and Nomi Bottle) [35,36,173,174]. In addition to the upfront cost of the product, some products (8/114, 7%) required monthly or annual subscription fees. Among these products, some (2/114, 1.8%) offered a free trial period before the subscription started (eg, Time4Med and TabSafe) [68,81].

Discussion

Principal Findings

This scoping review provided a summary of emerging SMAPs, including both prototypes and marketed products. This review also provided detailed descriptions of their features, including product type, hardware features (battery life, storage capacity, alarms, and locking ability), software features (ie, reminders, notifications, IT support, and integration with other clinical platforms), data collection and management, and product cost. A comprehensive comparison of the product features can inform patients, their care partners, and clinicians as they assess the benefits and challenges of using such a product to support self-management of medications. For instance, a product with multimedication storage capacity and an audio alarm may be more suitable for patients with visual impairment who are self-managing a complex medication regimen with multiple medications. Similarly, the ability to limit access to medications using locking features may be essential for patients with cognitive impairments to limit overadherence or in homes where children may be cared for. Reminders and alarm functions are important features of SMAPs that can help improve medication adherence [194]. SMAPs with audio or visual alarms or reminders inform users when a scheduled dose is due, and for some products, the alarm will continue until the dose is taken (ie, MedReady) [40,41]. This feature can be valuable for forgetful older adults.

The availability of SMAPs with a variety of features provides end users with a range of products to choose from when deciding on a device to support medication self-management. However, for these products to be adopted by older adults, several factors need to be addressed. Product design and cost were identified as barriers to use by older adults in a qualitative study investigating the integration of a prototype smart blister pack among older adults with chronic diseases [11]. Product design affects usability, and it is vital to determine whether these products are usable. A previous study examining the usability of 21 electronic medication adherence products demonstrated that their usability varied widely [14]. Although SMAPs provide the ability to monitor medication taking in real time, if older adults are not able to appropriately use these products, it may worsen medication taking rather than improve adherence. An important feature identified in this review is the offer of additional IT support or 24/7 customer service. This factor can improve the usability of the product to accommodate a wider range of users, including those who lack confidence with technology.

Our review identified that these products ranged variably in terms of cost, from a few to a few hundred dollars, whereas others were available without cost to the end user. Still, financial consideration is important as many older adults live on limited income [12].

SMAPs record medication intake in real time and transmit these data to a mobile app or portal. These apps display and summarize the adherence data and allow for remote access, which provides not only the ability for patients to be aware of their medication taking but also the opportunity for caregivers and health care providers to conveniently access an overview of patients' adherence history. Research has reported that health care providers value the availability of real-time medication-taking data and perceive that access to medication adherence data can help make clinical decisions in a timely manner, thus improving health-related outcomes for patients [13,15]. However, although SMAPs can track real-time data,

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they do not ensure that the patient ingested, inhaled, or injected the medication and only provide surrogate markers for adherence. Hence, there is room for discrepancy between the adherence data recorded and patients' actual adherence. The ability of SMAPs to integrate with other clinical platforms such as pharmacy software, electronic medication administration record, or hospital records is also highly valued by stakeholders, especially pharmacists and physicians, as it allows them to access adherence data in a seamless manner and may reduce their workload [15].

In our previous review, published in 2021, we identified 51 SMAPs. This scoping review identified a total of 114 SMAPs. Over a period of 4 years, the number of SMAPs has doubled, providing users with more options and variability in the products they can use. The increase in the number of products underlines the importance of addressing the declining capacity of older adults to self-manage their medications, which has downstream effects on medication adherence, medication errors, clinical outcomes, and hospitalizations.

The major strength of this review is the use of both published and gray literature to identify the products as well as using a comprehensive search strategy to capture the products available worldwide. Although this review has its strengths, it is important to acknowledge its limitations. One limitation is that the search was limited to products available in English; thus, it may not be representative of all SMAPs currently available in the global market. Another limitation is that the features identified for each product were limited to resources available on the web; the products were not purchased for testing by our research team. Although this review provides a detailed summary of the features associated with each of the 114 identified SMAPs, it did not evaluate the usability of the products; therefore, it cannot comment on how usable these products are for older adults.

Conclusions

SMAPs can vary greatly in the features they possess. With an increasing number of SMAPs being introduced into the market, it can be challenging for patients, care partners, and clinicians to determine which is the most appropriate product for medication management. This review can potentially serve as a useful resource for clinicians to become familiar with the essential features of SMAPs, facilitating their ability to recommend a SMAP that aligns with their patients' specific needs related to medication management.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Databases search strategy.
[PDF File (Adobe PDF File), 67 KB - aging_v6i1e50990_app1.pdf]

Multimedia Appendix 2
Google and YouTube search strategy. A detailed list of the features of each product is available on our website.
[PDF File (Adobe PDF File), 10 KB - aging_v6i1e50990_app2.pdf]

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Abbreviations

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SMAP: smart medication dispensing and adherence product

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Tablet-Based Puzzle Game Intervention for Cognitive Function and Well-Being in Healthy Adults: Pilot Feasibility Randomized Controlled Trial

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Abstract

Background: Promoting cognitive health is key to maintaining cognitive and everyday functions and preventing the risk of cognitive impairment or dementia. Existing scientific evidence shows the benefits of various training modalities on cognition. One way to promote cognitive health is through engagement in cognitive activities (eg, board and video games).

Objective: This study aims to investigate the benefits of dynamic adaptive casual puzzle games on cognitive function and well-being in healthy adults and older people.

Methods: A total of 12 adults and older people (female participants: n=6; mean age 58.92, SD 10.28 years; range 46-75 years) were included in this pilot randomized controlled trial. This study used a crossover design with two phases (8 weeks each) and three measurement waves (pretest, midtest, and posttest). The participants were randomly allocated either to the control or experimental group. In the control group, participants read newspapers between the pre- and midtest, then switched to cognitive training with puzzle games. In the experimental group, the interventions were reversed. Baseline measurements (pretest) were collected before the intervention. The interventions were delivered on tablet computers and took place unsupervised at participants' homes.

Results: The outcome measures included global cognitive function, higher cognitive function, and emotional well-being at 3 time points (pretest, midtest, and posttest) using standardized neuropsychological tests. The participants showed improvements in their visual attention and visuospatial measures after the puzzle game intervention.

Conclusions: The study showed that digital games are a feasible way to train cognition in healthy adults and older people. The algorithm-based dynamic adaption allows accommodations for persons with different cognitive levels of skill. The results of the study will guide future prevention efforts and trials in high-risk populations.

Trial Registration: ClinicalTrials.gov NCT03139799; https://clinicaltrials.gov/study/NCT03139799

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KEYWORDS

puzzle games; aging; cognitive assessment; visual attention; adults; elderly; well-being; randomized controlled trial; RCT; older adult

Introduction

The world's older adult population is increasing in both size and proportion. By 2050, the world's population of older people will nearly double [1]. The aging population inevitably requires better health care services for age-related diseases and the prevention of physical and cognitive health decline. Age-related cognitive decline affects memory, attention, orientation, perception, and executive and motor function that impact everyday activities and quality of life [2,3]. Considering population aging as a dominant worldwide phenomenon, preventing or reversing cognitive decline are clinical and public health priorities [3].

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The use of video games for training in strategic control in structured conditions may enhance the cognition of both adults and older people [4-7]. Ample research suggests that playing video games enhances a variety of cognitive skills such as visual selective attention, speed of processing, memory, reasoning, problem-solving, learning, and executive functioning [8-13]. The use of video games for cognitive assessment may facilitate reliable, personalized, and cost-effective tests [14]. Video games provide a variety of performance data (eg, number of errors, reaction time, and other task-based measures) that can make cognitive function assessments more accurate [15].

Traditional cognitive training programs require an in-person meeting, which entails setting a meeting location, traveling, and scheduling an appointment. For traditional training programs, recruiting older adults who are homebound or live in assisted living is more challenging. Computer-based cognitive interventions are potentially a more efficient alternative to traditional training programs that enhance their users' accessibility, affordability, and applicability. Computerized training provides real-time feedback and can be personalized, restoring users' activity engagement and motivation for the program [16,17] and eliminating staff load and training requirements, as well as errors and deliverer and observational biases in patient performance and performance anxiety. For a long-term effect (improvement in a broad range of cognitive domains), it is important to maximize player engagement.

Computerized training can be deployed either as virtual reality games, augmented reality games, serious games, or casual video games (CVGs). CVGs are primarily designed for entertainment [18] and share features that closely match recommendations for video games for older adults [19]. CVGs have simple and minimized game elements, rules, and goals (simplicity); can easily be stopped and replayed, are error-forgiving, and use flexible difficulty levels (flexibility); and allow players to quickly learn the game (accessibility). One of the main advantages of using CVG-based tools is in their motivational properties, which are crucial in making the interaction enjoyable and engaging [20]. Previous studies have demonstrated artificial intelligence (AI)–based interventions as a promising tool for enhancing cognition, quality of life, or well-being among older adults [21-23]. A recent large-scale study showed that regular engagement in Sudoku and similar puzzles represent a cognitively enriching leisure activity that prevents and delays age-related cognitive decline [24]. Several studies have suggested puzzle video games are sensitive to the cognitive or motor alternations of normal aging [25,26]. In particular, the mazelike numberlink and match-3 puzzle video games' performance was shown as a strong predictor of assessing cognitive or motor variabilities in older adults [25,27]. These games can be varied in difficulty to match the user's level of cognitive ability and can help prevent practice effects during repeated administration and reduce ceiling and flooring effects by continuously matching the task difficulty to the participant's cognitive ability [28,29].

The study aimed to conduct a pilot randomized controlled trial (RCT) to evaluate the potential benefits of the puzzle game intervention in healthy adults including older adults. The primary objective was to examine whether a puzzle game supported by AI personalization significantly improves attentional function (visual search attention) and leads to in-game learning effects. Other secondary objectives were to investigate improvements in further cognitive outcome measures proposed to be engaged by the puzzle game (attention, processing speed, working memory, and spatial reasoning) and the efficacy of the puzzle game intervention in reducing symptoms of depression, anxiety, and stress and improving everyday function and quality of life. First, we expected significant improvement in attentional and executive function (near transfer) and other cognitive functions engaged by the game (far transfer). Second, we generalized that well-being (mood and stress) will show significant improvement.

Methods

Ethical Considerations

Ethics approval was granted by the University of Bern Ethics Committee and the Ethics Committee Northwest/Central Switzerland (ID 2016-01281). The study was carried out following the current version of the Declaration of Helsinki and the Good Clinical Practice guidelines. A written informed consent form was sought from each participant.

Participants

The sample included healthy adults and older adults (N=12; female: n=6, 50%; mean age 58.92, SD 10.28 years; range 46-75 years) recruited from the local community. The inclusion criteria for participation were adults aged between 45 and 75 years and with a Montreal Cognitive Assessment (MoCA) score ≥24. The exclusion criteria for participation were any previous history of comorbid neurological or psychiatric deficits; any previous diagnosis of mild or major neurocognitive disorder; and insufficient coordinative, motor, and perceptual ability to handle a tablet computer. All participants had normal or corrected-to-normal vision.

The data of a participant (ID 09) was excluded due to the incomplete measurement of the participant's cognitive function and emotional well-being at the 3 time points (pretest, midtest, and posttest).

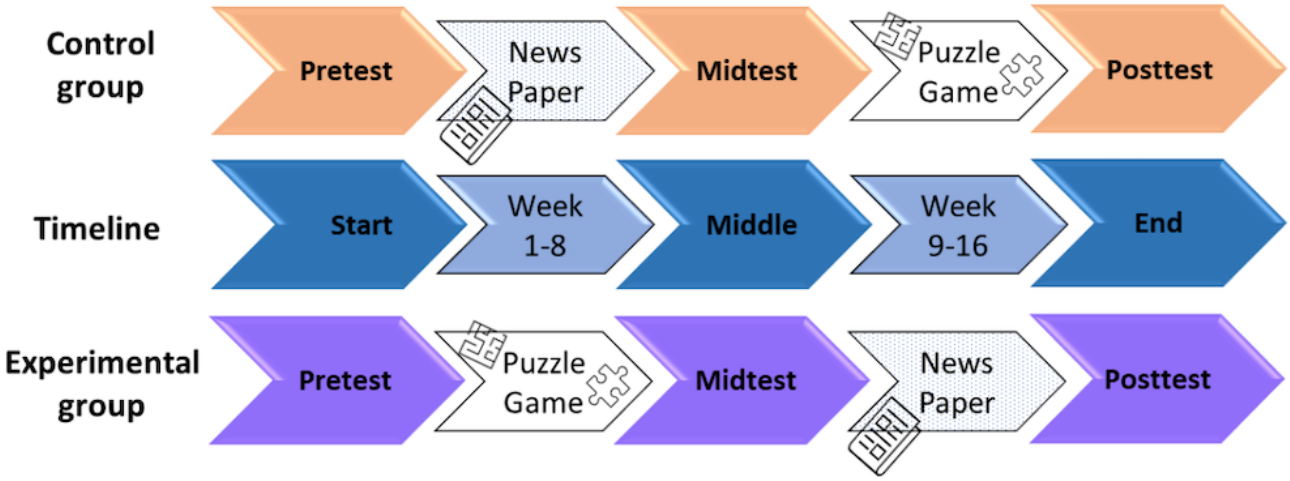
Study Design

The pilot was designed as a 16-week randomized controlled trial using a crossover design with two phases (8 weeks each) and three waves (pretest, midtest, and posttest) of measurement. The participants were randomly allocated either to the control or experimental group. Baseline measurements (pretest) were collected before the intervention. In the control group, participants read newspapers at least 3 times a week for 8 weeks between the pre- and midtest, then switched to cognitive training with puzzle games after the midtest. In the experimental group, the interventions were reversed compared to the control group. The interventions were delivered on tablet computers (10.2" Apple iPad 2019 model, 32 GB, 4G edition [for SIM card], Apple Inc., Cupertino, CA) and took place unsupervised at participants' homes (Figure 1). After completing recruitment formalities, participants were given an introduction to the study followed by a training session of both games consisting of 4 trials each of three grid sizes (4 × 4, 5 × 5, and 6 × 6). In

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addition, a manual/handbook was given to each of the participants.

Figure 1. Study timeline. Participants were randomly allotted either to the control or experimental group. To test the baseline, a pretest was conducted for each participant; after 8 weeks, a midtest was conducted; and then after 8 weeks of the second intervention, a posttest was performed. In the experimental group, interventions were reversed.



At 3 time points (pretest, midtest, and posttest), global cognitive function, higher cognitive function, and emotional well-being were assessed using standardized neuropsychological tests (computerized visual-scanning Test of Attentional Performance [TAP] task [30], MoCA [31], Trail Making Test [TMT] [32], and Snellgrove Maze Test [33]) and questionnaires (Profile of Mood States [34-36], State-Trait Anxiety Inventory [37,38], and a quality of life questionnaire [39]). To remove bias in too-close measurements, alternative versions of MoCA were used for the pretest, midtest, and posttest. Additionally, information on the cognitive load (NASA Task Load Index [40]), motivation (adapted version of Intrinsic Motivation Inventory [IMI] [41]), and familiarity with using a tablet (adapted Tablet Familiarity Questionnaire [42]) was collected at the end of the study. All assessments were administered in paper-and-pencil format except for the computerized visual-scanning TAP task presented on a laptop. In the visual-scanning TAP task, participants actively scanned a 5 × 5 matrix and indicated whether a specific target stimulus (square with a top opening) was present among 3 types of similar distractor stimuli (squares with openings on the left, right, or bottom).

Newspaper-Reading Task

The participants were instructed to read a newspaper on the iPad for about 8 weeks at least 3 times a week for about 20 minutes a day. Some of the locally known news apps (BBC, Tages-Anzeiger, 20 Minuten, NZZ, etc) were preinstalled, and participants were free to choose a news app of their choice.

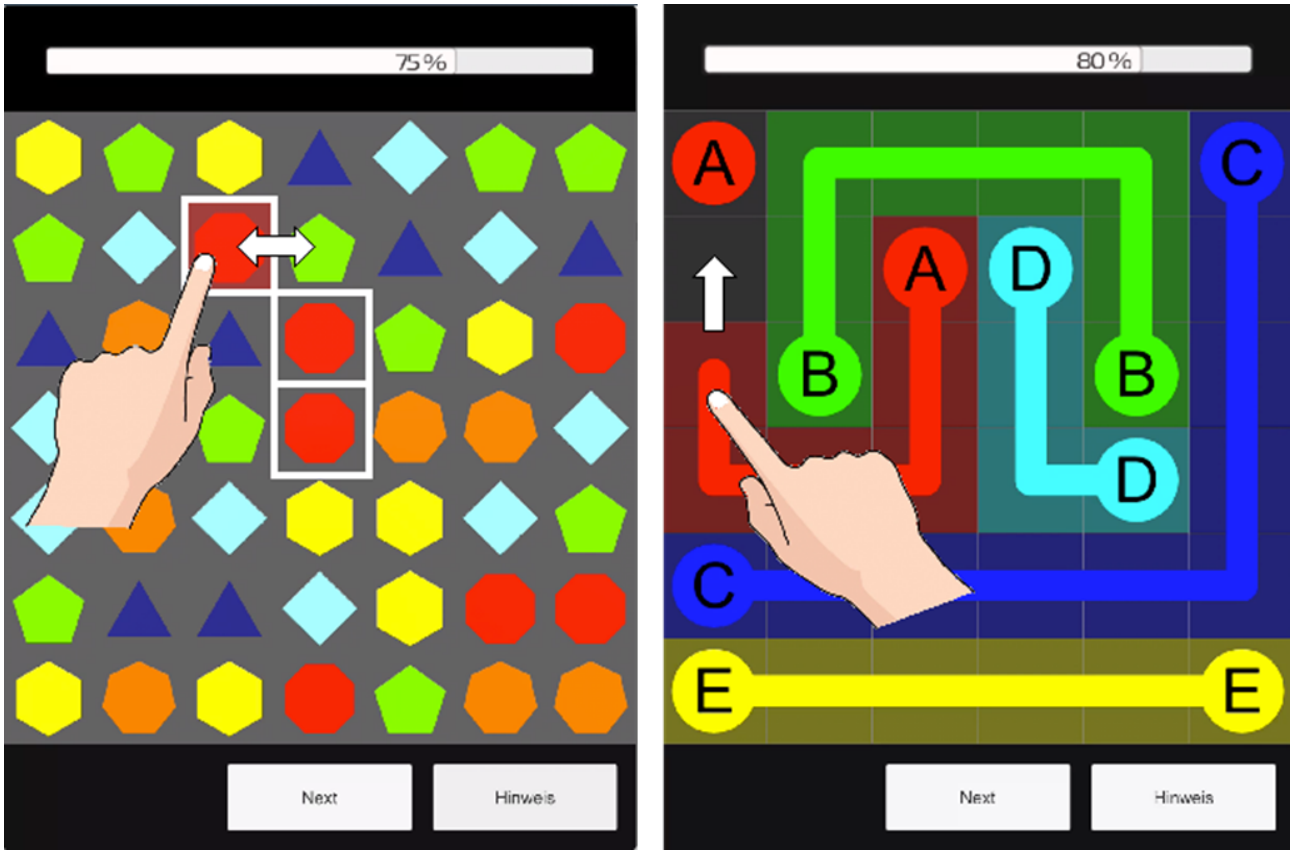
Puzzle Game Task

Participants were instructed to play both puzzle games (numberlink and match-3), delivered to them on an iPad, a minimum of 3 times per week (maximum of 10 min/game). A time tracker in the game limited the participants' daily training time to 20 minutes, while a scoreboarder displayed stars corresponding to the number of levels completed by the participants. The training duration of 20 minutes a day was selected to avoid any fatigue or complaints of addiction. We also hypothesized that playing for shorter sessions over a longer study duration had better transfer effects and avoided early ceiling effects. Previous studies on game interventions in adults also used a similar training duration [43,44]. To begin with, participants were assigned an initial difficulty level depending on their scores from the pretest. The difficulty level for the next day was updated depending on the game performance of the participants on the previous day by the AI-based method.

The match-3 puzzle [27] (Figure 2 left) requires visual search, visuospatial working memory, and pattern recognition skills to swap game objects into a row of three identical objects. The numberlink puzzle [25] (Figure 2 right) requires visuospatial, visuo-constructional, and executive (planning, foresight, and reasoning) functions to find paths between identically colored pairs of game objects, filling all empty cells. A range of difficulty levels for both games was implemented using the height and width of the puzzle board (from 4 × 4 to 8 × 8) and the number of unique game objects (from 4 to 8).

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Figure 2. Left: A match-3 puzzle is played by swapping objects to make a row of three identical objects. Right: A numberlink puzzle is played by finding paths to connect pairs of objects [45].



Puzzle Game Difficulty

To dynamically adjust the puzzle game difficulty during the cognitive intervention, an AI-based method was developed. We hypothesized that the AI method could continuously model the participant's ability through a multidimensional combination of puzzle difficulty parameters (ability assessment) and could adjust the puzzle difficulty as the participant progresses within the intervention (adaptivity assessment). To begin with, the participant's initial level is set using predefined variables collected at the pretest before the game intervention. When a puzzle level is solved, the AI service receives the solving time (state, t_m) and decides whether this lies within a threshold (reward). The AI agent then learns whether to increase or decrease the puzzle's difficulty.

The model is built on a database of input features, a regressor, the time predictor, and the level predictor. The end points are *match_three/ putInitialLevel*, *match_three/ putNextLevel*, *number_link/ putInitialLevel*, and *number_link/ putNextLevel*. The database of input features is a collection of sorted participant training data and difficulty level (determined by the set size and the number of gems/tiles) data for the two games. The participants' data were cleaned and prepared with pandas 1.0.3 and numpy 1.18.1. The regressor was selected depending on the adjusted R^2 value on the training data set. Accordingly, a voting regressor was chosen for the match-3 puzzle and an MLPRegressor for the numberlink puzzle. The features of just completed or played levels are sent to a timing predictor to calculate the predicted time t_p. The level predictor uses solved time t_m and predicted time t_p as inputs to provide an output of –1 (retreat one level), 0 (stay on the same level), or 1 (advance one level).



where c is a constant between 0 and 1, and σ is the SD of all the games played on the given difficulty level in the data set.

Implementation

The AI service was implemented in Python 3.8.2 (Python Software Foundation) and deployed on a CentOS cloud instance. Every entity in the architecture of the AI service corresponds to a Python file. The AI service is queried via a representational state transfer (REST) application programming interface (FastAPI 0.52.0 and uvicorn 0.11.3). The pilot RCT tablet computers were equipped with SIM cards to ensure a continuous connection with the AI server. A mail-alerting service using the free tier of Mailgun was implemented to follow up with the daily progress of the participants' gameplay.

Data Analysis

Time-based performance indicators such as overall solving time (minutes), average target search time (seconds), and processing time per item (seconds) were calculated from the files stored on the tablet computer. The improvement in the match-3 puzzle was calculated as the slope of the search time over the intervention period; similarly, the slope of path completion time was used for the numberlink puzzle.

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Statistical analysis was performed in SPSS v20.0 (IBM Corp). The normality of all values of interest was checked using the Shapiro-Wilk test [46]. An α value of .05 was used to determine significance. To evaluate the intervention effect on participants' cognitive function and emotional well-being at 3 time points (pretest, midtest, and posttest), repeated-measure ANOVA was performed. Paired *t* tests were used to compare the visual search attention task (visual-scanning TAP) before and after the intervention wave. Correlation analyses were used to examine the intervention performance and efficiency and the cognitive and emotional measures.

Results

The demographics and characteristics of the participants included in this pilot study are shown in Table 1.

Table . Participant demographics and characteristics.

Group and subject ID	Age (years)	Gender	Handedness	MoCA[a]	TMT[b]-A (s)	TMT-B (s)	SMT[c] (s)
Control group							
01	75	Male	Right	26	38	119	27
02	51	Female	Left	28	29	67	13
03	46	Female	Left	29	23	46	10
04	66	Female	Right	29	43	95	31
05	53	Female	Right	30	18	43	13
06	56	Male	Left	28	45	71	11
07	74	Male	Right	25	51	268	34
Experimental group							
08	48	Female	Right	29	29	49	13
10	59	Male	Right	24	22	122	18
11	72	Male	Right	25	41	120	29
12	52	Female	Right	28	20	45	15
13	55	Male	Right	30	28	57	16

[a]MoCA: Montreal Cognitive Assessment (score: 1-30).

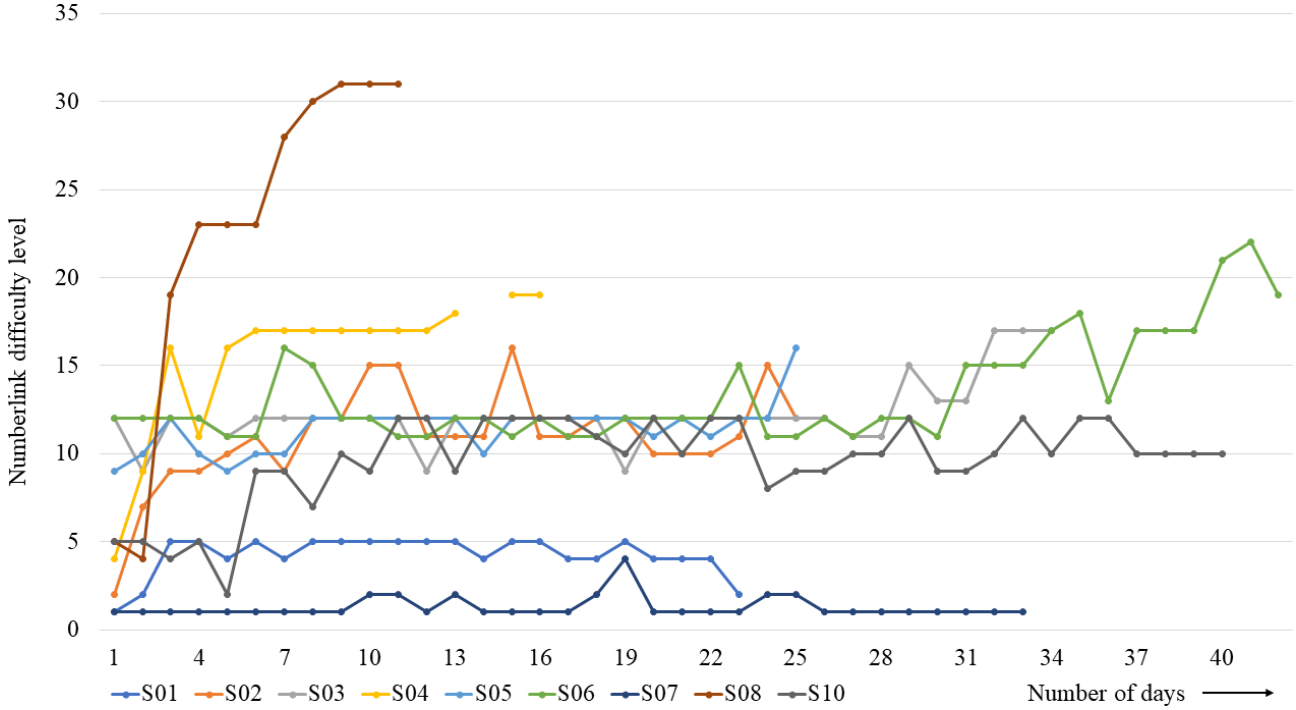
[b]TMT: Trail Making Test. TMT-A is the selective attention test set. TMT-B is the divided attention test set.

[c]SMT: Snellgrove Maze Task.

The participants assigned to the control group read newspapers (20 min/d) between the first and second waves of assessments, then switched to cognitive training with the match-3 (10 min/d) and numberlink (10 min/d) puzzles after the second wave of assessments. In the experimental group, the interventions were reversed compared to the control group. The AI server logged every request sent from the iPad to the server. Figure 3 shows the duration of the game training intervention for the numberlink puzzle and the progress in the difficulty level.

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Figure 3. Numberlink difficulty level of subjects S01 to S10 over intervention duration.



There was a significant difference between the pre- and postintervention primary outcome measure (visual-scanning TAP; total trials: mean 5.04, SD 0.82 vs mean 4.41, SD 0.63; t_{11}=3.5; *P*=.005; trials with targets present: mean 4.98, SD 0.76 vs mean 4.41, SD 0.73; t_{11}=4.23; *P*=.001). No significant differences were found with the measures of global cognition (MoCA), selective (TMT-A completion time) and divided (TMT-B completion time) attention, mood disturbances, anxiety, and quality of life when compared between the 3 time points (pretest, midtest, and posttest), as shown in Table 2. However, there was a significant difference in the MoCA visuospatial executive subscore for the midtest and posttest (mean 3.83, SD 1.03 vs mean 4.58, SD 0.67; *P*=.04).

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Table . Neuropsychological, emotional, and quality of life scores.

Variables and time point	Score, mean (SD)	*P* value[a]
Montreal Cognitive Assessment (score: 1-30)		.40
Pre	27.58 (2.06)	
Mid	26.92 (2.43)	
Post	27.58 (2.64)	
Trail Making Test–A[b] (s)		.44
Pre	32.25 (10.96)	
Mid	31.50 (12.99)	
Post	30.08 (10.88)	
Trail Making Test–B[c] (s)		.13
Pre	91.83 (63.43)	
Mid	63.75 (30.36)	
Post	66.75 (27.48)	
Snellgrove Maze Task (s)		.02
Pre	19.17 (8.59)	
Mid	19.75 (9.55)	
Post	16.50 (8.12)	
Total mood disturbance (from Profile of Mood States)		.35
Pre	47.58 (7.34)	
Mid	47.25 (6.05)	
Post	43.42 (10.83)	
Trait anxiety		.51
Pre	30.48 (17.11)	
Mid	27.46 (14.94)	
Post	24.53 (11.76)	
State anxiety		.99
Pre	26.11 (14.38)	
Mid	25.68 (18.04)	
Post	25.72 (22.77)	
EQ-5D-L–health		.38
Pre	90.42 (5.42)	
Mid	86.33 (9.95)	
Post	88.75 (6.78)	
Test of Attentional Performance (total)		.005
Pre	5.04 (0.82)	
Post	4.41 (0.63)	
Test of Attentional Performance (positive)		.001
Pre	4.98 (0.76)	
Post	4.41 (0.73)	
Test of Attentional Performance (negative)		.71
Pre	5.44 (2.47)	
Post	5.19 (1.53)	

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[a]*P* value <.05 is significant.

[b]Trail Making Test–A is the selective attention test set.

[c]Trail Making Test–B is the divided attention test set.

Correlation analyses showed a significant positive association between participants' fondness to read computer magazines and the search time slope (r=0.97; P<.001) and the slope of path time (r=0.75; P=.01). Both the search time slope (r=−0.83; P=.003) and the slope of path time (r=−0.78; P=.007) were found to be negatively correlated with the IMI subscale "pressure/tension."

Of the 12 participants, 8 reported that they had used tablet computers before and could perform tasks successfully with them (Figure 4). Participants rated the IMI subscale "interest/enjoyment" with the highest score, while the "value/usefulness" was scored the lowest (Table 3). Participants scored physical demand the lowest compared to the other task load domains for the game intervention (Table 4).

Figure 4. Overview of the tablet computer familiarity scores.

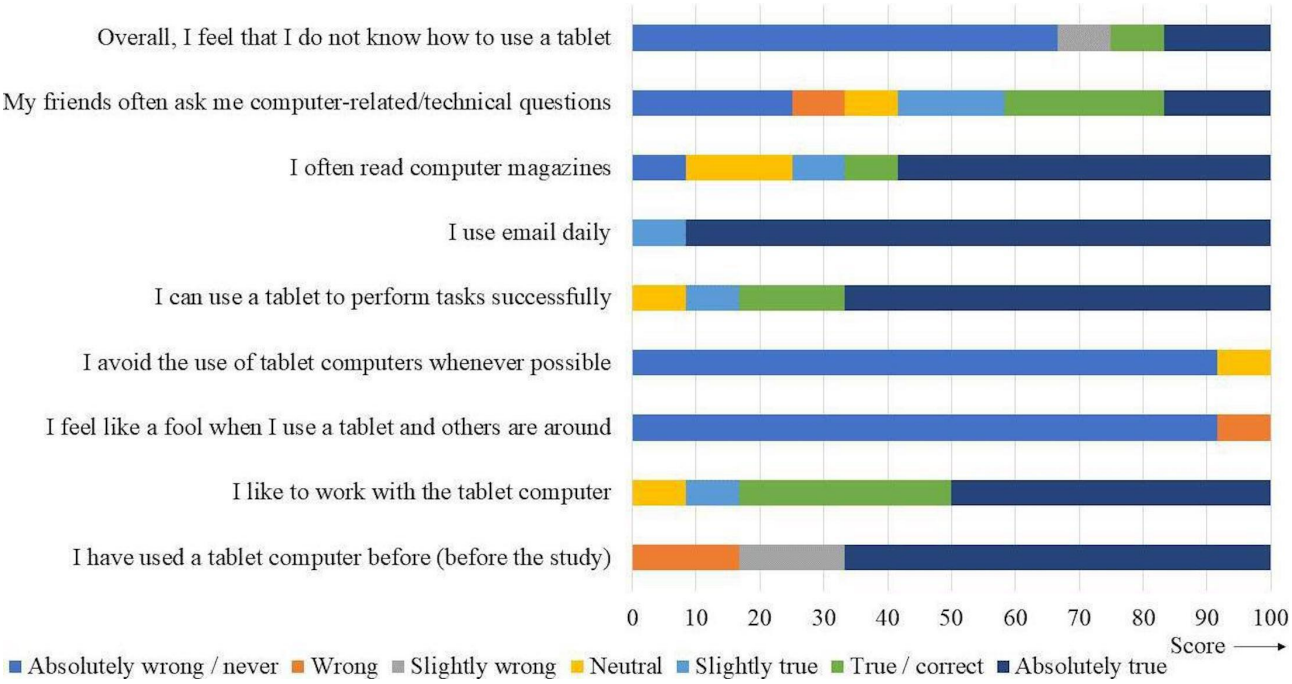


Table . Intrinsic Motivation Inventory subscale scores reported by the participants.

Participant ID	Competence/effort	Interest/enjoyment	Value/usefulness	Pressure/tension
01	13	45	13	21
02	13	41	9	19
03	8	32	2	21
04	14	41	5	19
05	11	29	3	21
06	10	40	11	19
07	13	42	12	20
08	13	40	5	14
10	13	38	9	18
11	14	44	13	21
12	13	43	4	18
13	13	37	4	14

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Table . Task Load Index subscale scores reported by the participants.

Participant ID	Mental demand	Physical demand	Temporal demand	Performance	Effort	Frustration
01	6	1	1	2	1	3
02	6	1	3	4	2	3
03	4	1	18	0	7	9
04	8	1	4	2	3	5
05	10	2	6	4	4	2
06	12	3	12	2	14	3
07	14	2	4	2	4	2
08	5	1	2	1	4	3
10	7	1	3	4	4	3
11	15	1	1	5	11	1
12	2	1	5	20	1	1
13	10	1	10	15	8	2

Discussion

Principal Findings

Puzzle games have the potential to target the following cognitive domains: learning and memory (working memory), attention (visual search), executive functions (inhibition and flexibility), and perceptual motor function (visuospatial ability). This study aimed to assess the feasibility of using a tablet-based puzzle game intervention to improve cognitive function and well-being.

We focused on associations between attention executive functions and game performance measures. The results of this pilot study show improvements in visual attention and visuospatial measures after the intervention.

Limitations

The main limitation is the small sample size, which poses a risk of providing false significant results. If rigorously tested and evaluated in larger cohorts, it will help to increase the methodological rigor, amplify the transferability, and thereby enhance the specificity and sensitivity of the puzzle game as a diagnostic tool. The other limitation was the duration of our pilot study, which was not long enough. The successive study should be longer to measure a far transfer as well as minimize novelty effects in the data. The IMI scale was assessed at posttest (in the control group after the puzzle game intervention and in the experimental group after the newspaper-reading task) and might be a potential bias in the study. The carryover design and having no washout period owing to a carryover bias can be a possible shortcoming. Although reading a newspaper is a good control for cognitive tasks, it can be counterintuitive, thereby increasing anxiety about mental health outcomes. Therefore, it would be advisable to have an alternate control group engaged in other control activities such as playing games, which are readily accessible on various tablet applications and easily downloadable.

Comparison With Prior Work

Visuospatial reasoning has been reported as a marker of Alzheimer disease and mild cognitive impairment [47]. Our results of improvement in the visual-scanning attentional and visuospatial measures also align with earlier studies where video games have been shown to benefit fluid cognitive abilities [48]. Fluid cognitive abilities are subject to age-related cognitive decline and crucial in activities of daily living, and hence need to be a focus in cognitive studies aiming for quality of life improvements [49].

However, most RCTs only investigate improvements in cognitive function. In our pilot study, we have attempted to evaluate the efficacy of training on cognition, emotional well-being, and quality of life.

A key aspect of motivational and enriching gameplay is the ability to continuously learn and adapt to new challenges. Dynamic adjustment systems can help to adapt to higher levels or to predict when the player is failing repeatedly to avoid such states. Random difficulty adjustment does not consider the player and can lead to unbalanced and unpredictable difficulty. Much of the existing dynamic level adjustment systems rely upon prediction. AI-based algorithms are used to follow these trends in predicting the time and level. The dynamic and personalized adjustment used in this study also uses a data-driven behavior that emerges from interaction with the game. The agent uses previous participant training data to learn and work out the prediction strategy. By using a person-centric adaption of the difficulty level, we were able to not only accommodate the heterogeneity in cognitive ability between participants but also continuously match the game difficulty to the skill level of the participant, thus benefitting the training effect and long-term motivation. Based on our results, it was also shown that participants with good visual search and executive skills progress faster to higher levels. Previous studies have demonstrated the effectiveness of video games for promoting multiple cognitive domains [5,50-53], quality of life [54], and emotional skills [55,56]. However, in our study, we didn't find any significant difference in quality of life and well-being. The possible reason could be a small sample size, and future studies on a larger cohort might show significant changes in these variables.

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A significant positive association between the participant's fondness for reading computer magazines and puzzle game improvement indicates a high level of interest in technology and gaming. When individuals engage in reading computer magazines, they are exposed to similar cognitive challenges such as understanding technical concepts or following complex instructions. This mental exercise can transfer to puzzle games, improving their ability to think critically, solve puzzles more efficiently, and adapt to different game scenarios. When individuals are passionate about a subject, they tend to invest more time and effort into it. Consequently, the more engaged individuals are, the more opportunities they have to practice and improve their puzzle-solving skills, which can lead to better performance over time.

Research is lacking evidence of the long-term effects of such interventions, particularly if learning and improvement are meant to be lasting. The crossover design of this study minimizes the possibility of a carryover effect being a possible avenue of exploration. The sample size was heterogeneous, meaning the game applications were tested on a broad group of users. Previous studies have suggested cognitive decline begins at the age of 45 years [57,58]. Therefore, including a broader age range of adults (aged ≥45 years) in our study allowed for a better understanding of cognitive decline across different age groups and enhanced the research findings' applicability to a wider range of individuals.

Conclusions

Digital games are a feasible way to train cognition while allowing additional data for assessment and monitoring progress. Gameplay can induce neuroplastic reorganization that leads to long-term retention and transfer of skill. However, the two games used in the training intervention targeted different cognitive domains. Some participants can have excellent spatial navigation skills, while others are good at visual divided attention tasks. The benefit of games on players who are already good in the domains targeted by the game is questionable. Future studies should be longitudinal and target dedicated domains to avoid ceiling effects.

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Conflicts of Interest

None declared.

Checklist 1
CONSORT-eHEALTH checklist (V 1.6.1).
[PDF File, 96 KB - aging_v6i1e46177_app1.pdf]

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Abbreviations

AI: artificial intelligence
CVG: casual video game
IMI: Intrinsic Motivation Inventory
MoCA: Montreal Cognitive Assessment
RCT: randomized controlled trial
REST: representational state transfer
TAP: Test of Attentional Performance
TMT: Trail Making Test

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Lexical Speech Features of Spontaneous Speech in Older Persons With and Without Cognitive Impairment: Reliability Analysis

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Abstract

Background: Speech analysis data are promising digital biomarkers for the early detection of Alzheimer disease. However, despite its importance, very few studies in this area have examined whether older adults produce spontaneous speech with characteristics that are sufficiently consistent to be used as proxy markers of cognitive status.

Objective: This preliminary study seeks to investigate consistency across lexical characteristics of speech in older adults with and without cognitive impairment.

Methods: A total of 39 older adults from a larger, ongoing study (age: mean 81.1, SD 5.9 years) were included. Participants completed neuropsychological testing and both picture description tasks and expository tasks to elicit speech. Participants with T-scores of ≤40 on ≥2 cognitive tests were categorized as having mild cognitive impairment (MCI). Speech features were computed automatically by using Python and the Natural Language Toolkit.

Results: Reliability indices based on mean correlations for picture description tasks and expository tasks were similar in persons with and without MCI (with *r* ranging from 0.49 to 0.65 within tasks). Intraindividual variability was generally preserved across lexical speech features. Speech rate and filler rate were the most consistent indices for the cognitively intact group, and speech rate was the most consistent for the MCI group.

Conclusions: Our findings suggest that automatically calculated lexical properties of speech are consistent in older adults with varying levels of cognitive impairment. These findings encourage further investigation of the utility of speech analysis and other digital biomarkers for monitoring cognitive status over time.

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KEYWORDS

Alzheimer's disease; cognitive dysfunction; early diagnosis; psychometrics; speech; technology assessment

Introduction

Use of Digital Biomarkers as a Method for Cognitive Monitoring

Much like monitoring cardiac rhythm through smartwatches, the integration of smart technology into the daily lives of older adults creates new opportunities for the remote monitoring of cognitive function. Researchers have started to use *digital biomarkers*, which are defined as "objective, quantifiable, physiological, and behavioral data that are collected and measured by means of digital devices, such as embedded environmental sensors, portables, wearables, implantables, or digestibles," to help identify and track symptoms in persons with dementia [1].

Speech Analysis Data as Digital Biomarkers

A growing number of digital biomarkers have been examined in persons with Alzheimer disease and related dementias (ADRD), such as home-based motion sensors and systems that monitor driving performance. Spontaneous speech appears particularly promising, presumably because the declarative memory system that supports some aspects of language [2] changes dramatically in persons with ADRD. Technological advances now allow commonly observed language changes in persons with ADRD (eg, wording-finding problems and empty speech) to be automatically computed from transcripts of spontaneous speech, and the resulting indices appear sensitive to early cognitive dysfunction. For example, lexical frequency, which quantifies an individual's ability to access more versus fewer common words, has been shown to predict current and future cognitive status [3,4]. Other studies suggest that indices from spontaneous speech may be even more sensitive to ADRD

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than traditional neuropsychological language tests of confrontation naming or semantic fluency [5].

Study Aims

Though such findings are encouraging, many practical questions remain regarding the feasibility of using spontaneous speech analysis to monitor cognitive function. A key concern is the limited investigation of the psychometric properties of speech features. Put simply, whether an individual's spontaneous speech is internally consistent enough to be used as a marker of cognitive function has yet to be determined. Many person- and environment-based factors are known to influence spontaneous speech production (including age, sex, task demands, nativeness, and proficiency, among others [6,7]), and the degree to which a short sample of spontaneous speech reflects an individual's general speech has not been previously examined. This study aims to provide a preliminary examination of the reliability of lexical features calculated from the spontaneous speech produced by older adults. That is, we were interested in determining how much variability or consistency was exhibited within and across these features. In effect, our analysis is analogous to examining the test-retest reliability of a traditional neuropsychological test. We hypothesized that speech features would be consistent both between multiple instances of a similar speech elicitation task and across different types of speech elicitation tasks in persons with and without mild cognitive impairment (MCI). In combination, these analyses provide critical insight into the appropriateness of using spontaneous speech indices to predict cognitive status in older adults.

Methods

Participants

Data from 39 participants (female: n=27; age: mean 81.1, SD 5.9; range 69-90 years) with complete data were extracted from a larger, ongoing project [3]. All participants' demographic and medical data were obtained through self-report, and no medical records or neuroimaging studies were available. For inclusion, participants were required to be English speakers and have no reported history of neurological conditions or severe psychiatric conditions. MCI status was determined by using criteria from past studies, namely, scoring ≥1 SD below the normative mean on 2 or more tasks within the same cognitive domain [8]. Following this criterion, 26% (10/39) of the participant sample were classified as having MCI; the remaining 29 participants were classified as cognitively intact. Table 1 presents summary statistics of the demographic and neuropsychological characteristics of the sample.

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Table . Demographic characteristics and neuropsychological test performance of the study sample.

		Full sample (N=39)	Cognitively intact participants (n=29)	Participants with MCI[a] (n=10)
Demographic characteristics				
	Age (years), mean (SD)	81.15 (5.95)	81.07 (5.84)	81.40 (6.59)
	Women, n (%)	27 (69)	18 (62)	9 (90)
	Men, n (%)	12 (31)	11 (38)	1 (10)
	Racial and ethnic minority participants[b], n (%)	17 (44)	12 (41)	5 (50)
	Participants with depression, n (%)	3 (8)	3 (10)	0 (0)
Neuropsychological test performance[c], mean (SD)				
	Mini-Mental State Exam (raw score)	28.85 (1.79)	29.17 (1.26)	27.90 (2.69)
	Digit Span Forward (T-score)	51.10 (9.79)	52.69 (9.25)	46.50 (10.34)
	Digit Span Backward (T-score)	52.51 (10.74)	54.55 (10.67)	46.60 (8.98)
	Trail Making Test A (T-score)	52.49 (8.69)	54.17 (6.11)	47.60 (12.92)
	Trail Making Test B (T-score)	51.72 (10.02)	52.96 (8.97)	48.50 (12.27)
	Frontal Assessment Battery (T-score)	47.36 (14.76)	51.21 (13.27)	36.20 (13.63)
	Controlled Oral Word Association Test (T-score)	56.97 (10.73)	58.59 (9.31)	52.30 (13.65)
	Animal Naming Test (T-score)	48.54 (11.27)	51.90 (7.83)	38.80 (14.28)
	Boston Naming Test–Short Form (T-score)	55.67 (11.00)	58.69 (8.16)	46.90 (13.72)
	Complex Figure Test–Copy (T-score)	41.67 (12.48)	43.55 (12.15)	36.20 (12.43)
	Complex Figure Test–Delayed Recall (T-score)	51.17 (18.76)	59.41 (12.81)	27.25 (10.94)
	HVLT[d] (sum of trials 1-3; T-score)	52.18 (10.88)	55.79 (6.68)	41.70 (14.05)
	HVLT–Delayed Recall (T-score)	49.18 (13.23)	52.76 (9.71)	38.80 (16.89)
	HVLT Discrimination (T-score)	49.26 (12.03)	51.83 (9.61)	41.80 (15.53)

[a]MCI: mild cognitive impairment.

[b]The participants were African American, Asian, or Hispanic or Latino.

[c]With the exception of the Mini-Mental State Exam, of which the results are presented here as raw scores, all neuropsychological test scores were transformed to T-scores based on normative data.

[d]HVLT: Hopkins Verbal Learning Test.

Ethical Considerations

This study was approved by the Kent State University Institutional Review Board (#20–300), and all procedures were completed in accordance with the ethical standards outlined in the Declaration of Helsinki. Upon entry into the study, all participants completed an informed consent process. Individuals demonstrating intact comprehension of study activities provided written consent and those with cognitive dysfunction provided assent and consent provided by a trusted other. Participants were assigned a randomly generated study identification number to protect confidentiality and privacy, and all materials were protected through multiple security measures. At the completion

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of the study assessment, participants were compensated with a gift card for their time.

Neuropsychological Test Battery

To promote generalizability, participants completed a collection of commonly used neuropsychological tests of global functioning (Modified Mini-Mental State Exam [9]), attention (Digit Span Longest String Forward and Backward [10] and Trail Making Test A [11]), executive function (Trail Making Test B [11] and Frontal Assessment Battery), language (Controlled Oral Word Association Test [12], Animal Naming Test [12], and Boston Naming Test–Short Form [13]), visuospatial skills (Complex Figure Test–Copy [14,15]), and memory (Hopkins Verbal Learning Test–Revised [16] and Complex Figure Test–Delayed Recall [14,15]). Raw test scores were converted to T-scores using normative data to facilitate comparison to past work.

Speech Tasks

Participants completed 3 picture description tasks and 2 expository tasks as part of the study protocol. Speech from these tasks was audio-recorded and then transcribed manually. Picture description tasks included the Cookie Theft task from the Boston Diagnostic Aphasia Exam [17], which depicts 2 children reaching into a cookie jar and a mother washing dishes. The other two pictures were drawn in a similar style, with one showing a man changing a lightbulb [18] and the other showing a kitten in a tree [19]. Expository tasks asked participants to describe an important person in their life (expository task 1) and a meaningful location or place (expository task 2). Importantly, the inclusion of a multiple categories of speech prompts (picture description tasks vs expository tasks) allowed us to examine whether different speech features can be reliably elicited across different types of tasks (eg, providing semantic structure in the form of a picture versus requiring memory retrieval and content generation).

A total of 16 lexical and semantic features were calculated based on the spontaneous speech generated from each task and were used as features in the analyses for word count, filler words, empty words, lexical frequency, the type-token ratio, the Honoré statistic, the Brunet index, speech rate, filler rate, definite articles, indefinite articles, pronouns, nouns, verbs, determiners, and content words. These features were chosen based on prior studies and clinical work that showed that these properties of speech production are often affected in persons with dementia or MCI [3]. All features were calculated automatically from transcripts of the participants' speech, using Python (version 2.7.17) and the Natural Language Toolkit (version 3.2.1; Bird et al [20]). Table 2 shows the list of speech features and how they were defined; Table 3 shows the between-participant mean values for each linguistic feature that was computed from each speech sample.

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Table . Operationalization of the speech features computed for each spontaneous speech task.

Speech feature	Operational definition
Word count	Total number of words spoken by the participant
Fillers	Number of filler words (eg, *um*, *uh*, and *hmm*) spoken by the participant; scaled by total word count
Empty words	Number of empty words (eg, *thing*, *place*, and *stuff*); scaled by total word count
Definite articles	Number of definite articles (*the*); scaled by total word count
Indefinite articles	Number of indefinite articles (*a* and *an*); scaled by total word count
Pronouns[a]	Number of pronouns; scaled by total word count
Nouns[a]	Number of nouns; scaled by total word count
Verbs[a]	Number of verbs; scaled by total word count
Determiners[a]	Number of determiners; scaled by total word count
Content words	Number of content words (defined as the words not in Natural Language Toolkit's list of stop words); scaled by total word count
Frequency	Mean of the log of the frequency of all the words spoken by the participant
Type-token ratio	Ratio of unique words (types) to total words (tokens) spoken; used as a measure of lexical diversity
Honoré statistic	A measure of lexical richness based on the number of words that are produced exactly once
Brunet index	A measure of lexical diversity and richness that is less biased by the length of the text
Speech rate	Speech rate was computed as words per second, counting all words, nonwords, and partial words the speaker produced divided by the total elapsed time of the speech
Filler rate	Filler rate was computed as words per second, counting all filler words (as defined above) divided by the total elapsed time of the speech

[a]Computed using the Penn Treebank part of speech tags within the Python Natural Language Toolkit module (Bird et al [20]).

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Table . Mean values for the computed speech features across the five speech tasks for the full sample.

Speech feature	Value, mean (SD)				
	Expository task 1 (person)	Expository task 2 (place)	Picture description task 1 (cookie theft)	Picture description task 2 (lightbulb)	Picture description task 3 (cat in tree)
Word count	632.18 (316.32)	531.64 (412.87)	290.82 (172.77)	233.92 (117.47)	222.69 (106.25)
Number of fillers	1.23 (0.61)	0.98 (0.57)	0.63 (0.47)	0.54 (0.36)	0.43 (0.33)
Number of empty words	0.20 (0.16)	0.51 (0.36)	0.18 (0.12)	0.28 (0.18)	0.15 (0.14)
Number of definite articles	0.60 (0.36)	1.00 (0.51)	1.38 (0.45)	0.94 (0.3)	1.35 (0.33)
Number of indefinite articles	0.79 (0.29)	0.69 (0.33)	0.86 (0.3)	1.19 (0.36)	0.84 (0.28)
Number of pronouns	3.29 (0.95)	2.19 (1.1)	1.18 (0.6)	1.15 (0.54)	0.94 (0.54)
Number of nouns	5.26 (1.49)	4.80 (1.66)	4.14 (1.2)	3.69 (0.92)	3.38 (0.79)
Number of verbs	5.15 (1.47)	4.18 (1.57)	3.42 (1.07)	3.22 (0.91)	3.03 (0.87)
Number of determiners	1.84 (0.69)	2.15 (0.87)	2.54 (0.7)	2.46 (0.56)	2.44 (0.43)
Number of content words	11.89 (3.04)	10.31 (3.53)	8.28 (2.55)	7.44 (1.97)	7.04 (1.84)
Frequency[a]	5.68 (0.41)	5.80 (0.49)	5.32 (0.43)	5.54 (0.46)	5.76 (0.55)
Type-token ratio	0.41 (0.08)	0.43 (0.09)	0.48 (0.09)	0.50 (0.08)	0.48 (0.05)
Honoré statistic	5.16 (3.15)	6.29 (3.78)	7.85 (2.42)	8.40 (2.49)	9.48 (3.16)
Brunet index	13.14 (1.13)	12.98 (1.4)	12.23 (1.22)	11.92 (1.15)	12.11 (0.79)
Speech rate[b]	2.20 (0.37)	2.35 (0.37)	2.31 (0.35)	2.31 (0.33)	2.53 (0.39)
Filler rate[c]	0.11 (0.05)	0.10 (0.06)	0.09 (0.06)	0.08 (0.05)	0.07 (0.06)

[a]Mean of the log of the frequency of all the words spoken by the participant.

[b]Words per second, counting all words, nonwords, and partial words the speaker produced divided by the total elapsed time of the speech.

[c]Words per second, counting all filler words divided by the total elapsed time of the speech.

Procedures

Participants completed all neuropsychological tests and speech elicitation tasks during a single study visit that lasted approximately 75 minutes. After providing written informed consent, participants were administered the neuropsychological test battery in a fixed order, under the supervision of a licensed clinical neuropsychologist. The aforementioned spontaneous speech tasks were then completed. The session concluded after participants were provided with a debriefing statement and compensated for their time.

Data Analyses

Overview

As several of the speech features were measured on different scales (eg, lexical frequency was computed as number of words per million, parts of speech features were scaled by the total word count, the total number of words was a raw count, etc), the raw values for each speech feature were converted to *z*-scores to enable interfeature comparisons. The *z*-scoring of each participant's speech feature values was performed separately for each speech feature, by task (eg, picture description task 1, picture description task 2, expository task 1, etc) and cognitive status group (ie, MCI vs cognitively intact). The *z*-scored values for each speech feature were then used in the following analyses.

Intraindividual Variability Across Instances of the Same Speech Task

To assess the degree to which a given speech feature remained consistent for each participant across multiple instances of the same speech elicitation task, pairwise Pearson *r* correlations were computed between each feature and itself within each task type. Afterward, to examine the influence of cognitive dysfunction on these indices, correlations were computed separately for participants with MCI and cognitively intact participants. For example, a paired correlation was computed, for all participants in the MCI group, between the *z*-scored word count values for expository task 1 and the *z*-scored word count values for expository task 2. For the picture description tasks, the correlations were averaged over the three pairwise correlations of picture description tasks (task 1–task 2, task 1–task 3, and task 2–task 3). All averaging of correlation values was performed after the Fisher *z* transformation of the Pearson *r* correlation coefficients [21]. After averaging was completed, Fisher *z* values were back-transformed to Pearson *r* values for reporting.

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In order to determine whether these mean correlations were significantly larger than what would be expected for any two given measurements of the same linguistic feature, we used resampling methods. Null distributions of correlations were created for each task type by randomly pairing each participant's speech feature values with values for the same speech features from a different, randomly selected participant within the same group (MCI or cognitively intact group). These correlations show how much a participant's value for one feature correlates with a different person's value for the same feature and thus can be used as a baseline for the expected size of within-feature correlations, if there is no additional effect from within-participant reliability. This resampling procedure was repeated 10,000 times for each of the four null distributions, which were then used as the distribution against which the true correlation values were compared to compute their *P* value.

Intraindividual Variability Across Multiple Speech Tasks

Intraindividual variability was calculated for each speech feature by computing the SD of a participant's *z*-scores for a given speech feature across all 5 tasks (eg, the SD of a participant's *z*-transformed word count values across expository task 1, expository task 2, picture description task 1, picture description task 2, and picture description task 3). Weighted averages of the variance of these SDs were then computed as an index of intraindividual variability. These SD values were then averaged over participants for each of the 16 speech features, as shown in the following formula (larger values reflected greater intraindividual variability):



Results

Intraindividual Variability Across Instances of the Same Speech Task

In the picture description tasks, the mean within-participant correlation between the 16 speech features and themselves across the three possible pairwise comparisons (task 1–task 2, task 1–task 3, and task 2–task 3) was high (MCI group *r*: mean 0.6555, SD 0.2867; cognitively intact group *r*: mean 0.6440, SD 0.2997). The strength of the correlation was not statistically different between the two cognitive status groups (t_{30}=0.4351; *P*=.66; 95% CI −0.17 to 0.26).

In the expository tasks, the mean within-participant correlation between the speech features and themselves was similarly high for the MCI group (*r*: mean 0.6101, SD 0.3679) but lower for the cognitively intact group (*r*: mean 0.4971, SD 0.3586), although this between-group difference did not reach statistical significance (t_{30}=1.363; *P*=.18; 95% CI −0.09 to 0.45).

We then examined whether these correlations were significantly different from what might be expected between any two given linguistic measures, using the resampling procedure described in the *Methods* section. The average correlation for each of the null distributions was extremely close to 0 (MCI group picture description task: *r*=0.0022; cognitively intact group picture description task: *r*=−0.0002; MCI group expository task: *r*=0.0004; cognitively intact group expository task: *r*=0.0002), and all 4 true within-participant correlations were significantly larger than what was expected by chance based on these null distributions (all *P* values were <.001).

Notably, mean correlations varied substantially across different speech features (Table 4). Some speech features showed consistently strong correlations, suggesting high reliability (such as speech rate, Brunet index, and number and rate of filler words), while others showed lower reliability (such as empty words, definite and indefinite articles, determiners, and pronouns).

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Table . Reliability values for the speech features.

	Total words	Fillers	Empty words	Definite articles	Indefinite articles	Pronouns	Nouns	Verbs	Determiners	Content words	Frequency	Type-token ratio	Honoré statistic	Brunet index	Speech rate	Filler rate
Reliability analysis of each task type[a]																
Expository tasks																
Full sample	0.581	0.75	0.372	0.188	0.499	0.566	0.580	0.614	0.368	0.667	0.480	0.720	0.325	0.748	0.895	0.769
MCI[b] group[c]	0.728	0.782	0.676	0.285	0.321	0.607	0.740	0.705	0.313	0.807	0.601	0.814	–0.04	0.817	0.884	0.721
Cognitively intact group[d]	0.382	0.714	–0.039	0.087	0.643	0.521	0.357	0.503	0.421	0.455	0.337	0.587	0.613	0.659	0.905	0.809
Picture description tasks																
Full sample	0.814	0.756	0.422	0.461	0.545	0.674	0.722	0.746	0.647	0.870	0.774	0.721	0.245	0.784	0.79	0.73
MCI group	0.823	0.746	0.557	0.513	0.626	0.521	0.689	0.753	0.661	0.907	0.835	0.691	0.271	0.763	0.798	0.72
Cognitively intact group	0.805	0.765	0.265	0.406	0.452	0.785	0.752	0.739	0.631	0.821	0.696	0.749	0.218	0.803	0.782	0.74
Reliability analysis of all tasks[e]																
Full sample	0.712	0.616	0.881	0.848	0.817	0.727	0.754	0.734	0.762	0.71	0.809	0.685	0.723	0.755	0.721	0.488
MCI group	0.647	0.641	0.754	0.777	0.775	0.806	0.693	0.65	0.696	0.61	0.679	0.63	0.596	0.593	0.573	0.497
Cognitively intact group	0.733	0.607	0.921	0.871	0.831	0.698	0.774	0.761	0.783	0.741	0.850	0.702	0.762	0.804	0.765	0.485

[a]This section reports the mean within-participant correlations between each speech feature and itself for each task type and group. All averaged correlations were converted to Fisher *z* values before averaging and back-transformed to Pearson *r* values for reporting.

[b]MCI: mild cognitive impairment.

[c]The MCI group includes persons diagnosed with MCI.

[d]The cognitively intact group includes persons diagnosed as not having MCI.

[e]This section reports the SDs of *z*-scored values for each speech feature computed over all 5 tasks, which were averaged across participants within each group. Larger values reflect more intraindividual variability.

Intraindividual Variability Across Multiple Speech Tasks

The amount of variability in each speech feature for each participant additionally varied as a function of speech feature and group (Table 4). The lowest amount of intraindividual variability was exhibited by speech rate and filler rate for the cognitively intact group and by speech rate for the MCI group. The largest amount of intraindividual variability differed somewhat between the MCI and cognitively intact groups; for example, definite and indefinite articles showed high between-participant variability for both groups, whereas empty words showed numerically higher variability for the cognitively intact group and pronouns showed numerically higher variability for the MCI group.

Discussion

Some evidence suggests that there is greater variability in performance on traditional cognitive screening measures (eg, Mini-Mental State Exam, Clock Drawing Test, etc) among persons with MCI [22]. Although such variability itself can be a useful marker of MCI [23], variability can also make results harder to replicate and lower statistical power. Given that spontaneous speech (1) is affected in MCI and (2) may be useful for distinguishing healthy controls from individuals with MCI and ADRD [3,4,24,25], it was therefore important to establish the degree of variability (or stability) of spontaneous speech in

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individuals with and without MCI. The results from this preliminary study demonstrate that spontaneous speech is generally consistent in both individuals with MCI and cognitively intact older adults, as individuals maintained their lexical-semantic characteristics of speech across multiple tasks. Such findings provide initial evidence that properties of an individual's spontaneous speech are sufficiently "reliable" to be viewed as trait-like features and encourage continued investigation into the validity of speech analysis data as digital biomarkers of cognitive status.

Given the importance of the early detection of cognitive decline, future studies may be enhanced by examining the potential value in using a combination of indices from spontaneous speech to predict cognitive status—not just lexical-semantic features. For example, acoustic-phonetic aspects of speech, such as prosodic measures, pause duration, or loudness, are also impacted by ADRD and can distinguish healthy groups from clinical groups [26,27]. Changes in the syntax and coherence of speech are found in persons with advanced ADRD and can be reliably detected [28,29]. There is also evidence that subtle changes in extrapyramidal function predict incipient MCI and Alzheimer disease [30], and recent technological advances can automatically quantify these changes in short video clips of an individual, suggesting the possibility of extending this work into measuring behavior in video calls or videoconferencing (eg, FaceTime and Zoom) or via mobile apps [31]. It is possible that a combination of multiple speech features and video analysis may prove more sensitive to early cognitive decline than a single category of linguistic features; thus, further work in this area is needed. More research should also be directed at determining the reliability of such features in other neurological brain disorders for which some aspects of language have been shown to be associated with decline, such as Parkinson disease [32].

Despite encouraging findings, this study is limited in several important ways. The sample size was modest, the analysis was cross-sectional in nature, and we only assessed speech and cognitive function during a single testing session. Although several findings were statistically significant despite the modest sample size, the nonsignificant group difference in intraindividual variability across instances of the same speech task type (expository tasks; P=.18) may have been underpowered due to the small sample. Therefore, future research on the consistency of speech tasks for assessing MCI should ensure sufficient power. Furthermore, prospective studies with larger and more diverse samples are needed to clarify the feasibility of using automated speech analysis (Soroski et al [33] used such analyses in research settings and for at-home monitoring of cognitive function), though several studies on automatic speech analysis have shown such analyses to be promising [5,34,35]. Such findings will provide key insight into the stability of spontaneous speech over longer intervals (eg, weeks to months). It is also possible that the prospective monitoring of speech changes may help to overcome some of the limitations (ie, higher rates of misclassification of cognitive status) found in existing cognitive screening instruments for diverse populations [36,37] and facilitate early identification. This study is also limited in that effects of depression were not able to be explored. Future studies should examine the possible contributions of depression and anxiety to spontaneous speech in older adults, given that mental health conditions are common in older adults [38] and that depression may also alter speech content [39] and vocal features [40]. Finally, an important limitation of this study is that participants' cognitive status (MCI and cognitively intact), as well as other potentially relevant medical conditions (eg, depression), was based on a self-report of their history of diagnosed neurological conditions. Detailed information regarding specific etiology was not available or objectively assessed, limiting the strength of our conclusions (including the possibility that MCI was not due to Alzheimer disease). Future studies on the reliability of speech as a marker of MCI should incorporate more comprehensive neurological evaluations to ensure that the assessment of speech reliability is valid (eg, neuroimaging and other biomarkers).

In summary, our findings suggest that lexical-semantic aspects of spontaneous speech are similarly reliable in older adults with and without MCI. This finding is an essential first step toward the widespread use of speech biomarkers as a low-burden method for cognitive monitoring and the facilitation of the early detection of neurodegeneration in persons at risk for ADRD.

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Data Availability

Due to internal review board limitations, which consider our human subjects data to be highly sensitive, we are not permitted to share any data other than those already presented within this paper.

Conflicts of Interest

None declared.

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Abbreviations

ADRD: Alzheimer disease and related dementias
MCI: mild cognitive impairment

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Original Paper

Web-Based Cognitive Behavioral Therapy for Depression Among Homebound Older Adults: Development and Usability Study

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Abstract

Background: Homebound older adults are a high-risk group for depression. However, many of them face barriers to accessing evidence-supported mental health treatments. Digital mental health interventions can potentially improve treatment access, but few web-based interventions are explicitly tailored for depression in older adults.

Objective: This paper describes the development process of Empower@Home, a web-delivered intervention for depression in homebound older adults that is based on cognitive behavioral therapy, and reports on the outcomes of usability studies.

Methods: Empower@Home was developed in collaboration with community agencies, stakeholders, and older adults, guided by user-centered design principles. User needs were assessed through secondary data analysis, demographic and health profiles from administrative data, and interviews and surveys of community partners. A comparative usability evaluation was conducted with 10 older adults to assess the usability of Empower@Home compared to 2 similar programs. Field testing was conducted with 4 end users to detect additional usability issues.

Results: Feedback and recommendations from community partners heavily influenced the content and design of Empower@Home. The intervention consists of 9 sessions, including psychoeducation and an introduction to cognitive behavioral therapy skills and tools through short video clips, in-session exercises, an animated storyline, and weekly out-of-session home practice. A printed workbook accompanies the web-based lessons. In comparative usability testing (N=10), Empower@Home received a System Usability Scale score of 78 (SD 7.4), which was significantly higher than the 2 comparator programs (t_9=3.28; P=.005 and t_9=2.78; P=.011). Most participants, 80% (n=8), preferred Empower@Home over the comparators. In the longitudinal field test (n=4), all participants reported liking the program procedures and feeling confident in performing program-related tasks. The single-subject line graph showed an overall downward trend in their depression scores over time, offering an encouraging indication of the intervention's potential effects.

Conclusions: Collaboration with community stakeholders and careful consideration of potential implementation issues during the design process can result in more usable, engaging, and effective digital mental health interventions.

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KEYWORDS

internet-based cognitive behavioral therapy; usability; geriatric depression; community-engaged research; web-based; geriatrics; geriatric; depression; psychotherapy; mental health; older adults; older adult; cognitive behavioral therapy; CBT; design; development; community; user centered design; digital health; aging; old age; digital mental health; web-based health; internet

Introduction

Being homebound is often linked with socioeconomic disadvantages, including low income, racial minority status, and high levels of disability. Studies have shown that half of homebound older adults exhibit clinically significant symptoms of depression, with 14% meeting the criteria for current major depression [1,2]. This starkly contrasts the 2% prevalence of major depression in nonhomebound older adults [3]. When left untreated or insufficiently treated, depression can reduce quality of life and increase hospitalizations and early mortality [4]. Despite the availability of evidence-based treatments, traditional office-based services often remain out of reach for homebound older adults due to access barriers such as cost, transportation, and stigma [5]. Insurance coverage options for minor depression are also limited, and few mental health clinicians have received specialized training in working with older adults. It is crucial to find innovative ways to provide evidence-supported psychosocial treatments that are both accessible and cost-effective while reducing reliance on highly trained professionals and ensuring scalability.

Digital mental health interventions (DMHIs) are behavioral and psychological intervention strategies that use technology, such as websites, mobile apps, and other mobile devices, to improve mental health. Internet-based cognitive behavioral therapy, or iCBT, is one of the most studied DMHIs. iCBT is an automated psychotherapy based on cognitive behavioral therapy (CBT) principles delivered via dedicated websites or apps [6]. Patients receive psychoeducational materials through a web platform or a dedicated app and are exposed to the same core components as conventional CBT (eg, behavioral activation and cognitive restructuring). At a reduced marginal cost, iCBT can be used repeatedly with different patients without losing its therapeutic power, making it particularly useful for reducing health disparities in underresourced settings [7]. Studies have shown that iCBT is as effective as face-to-face CBT in treating depression in mixed-age samples [8]. Emerging evidence also supports the potential benefits of iCBT in older adults, including those with a heightened risk of depression [9,10].

However, most iCBT programs have not been specifically tailored to meet the needs of older adults, with only a few exceptions [11-14]. For older adults, this includes procedural and content modifications to CBT that address differences in thinking styles and age-related adjustment [15]. In addition, the user interface (UI) in web-delivered interventions may need to be adjusted to fit the preferences, needs, and capabilities of older adults [16]. Furthermore, we are unaware of such programs in the US market tailored explicitly for homebound older adults. Generic DMHIs can benefit older adults, but we have found that those with complex interfaces often result in low adherence and engagement, limited effects, and a myriad of usability issues among low-income, homebound older adults [10,17]. These individuals are typically less tech-savvy and more sensitive to usability problems.

Our team developed Empower@Home, a web-based psychosocial depression intervention explicitly designed for homebound older adults, to address the shortage of DMHIs tailored to this high-need and underserved population. Empower@Home is a 9-session iCBT program that aims to prevent and reduce the symptoms of depression. The target population is homebound adults aged >60 years (ie, those with mobility difficulties). The intervention development process involved significant stakeholder input and user-centered design principles and occurred alongside academic-community partnership development. In this paper, we describe the process of developing Empower@Home, report on its feasibility and usability evaluation outcomes, and discuss its implications for designing DMHIs that are attuned to the needs of individuals and the characteristics of implementation settings.

Methods

The Empower@Home Intervention

Empower@Home includes 9 web-based lessons, each featuring didactic content, in-session exercises, motivational quotes, and an engaging animated story driven by human characters. Table 1 presents an overview of each session. Each lesson is presented in brief videos (less than 2 minutes) to lessen cognitive load (Multimedia Appendix 1). The lessons are arranged in a specific sequence, and each concludes with instructions for home practice. During home practices, users apply the skills they have learned using various program tools. These tools focus on fundamental CBT skills and are grouped into categories: doing tools for behavioral activation and problem-solving, thinking tools for cognitive restructuring, feeling tools for relaxation and mood monitoring, and communication tools for fostering effective communication. In addition, participants do a mood self-check by filling out the Patient Health Questionnaire-9 (PHQ-9) in every other session (sessions 1, 3, 5, 7, and 9) to track their symptoms [18].

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Table 1. Empower@Home session-by-session overview[a].

Session	Session content	CBT[b] elements	Home practice
Session 1: Ready, Set… Go!	Session 1 orients the user to the program, delivers psychoeducation about depression and aging, and gently introduces CBT in jargon-free language. The session also includes content to motivate the user to engage with the program and introduces BA[c], which is referred to as a doing tool.	• Psychoeducation • Doing tools: activity monitoring	Activity monitoring form
Session 2: Doing Tools	Session 2 is a continued exploration of BA using the value-based BA approach. Major in-session activities include reviewing the activity monitoring form from the last session, charting the depression downward spiral, filling out the values and activities inventory, and creating the "my desired activities" master list. The first mindfulness exercise—Body Scan—is also introduced in this session.	• Doing tools: value-based behavioral activation; activity scheduling • Feeling tools: body scan	Body scan and activity scheduling
Session 3: Working with Barriers	Session 3 continues the focus on BA skills by addressing common barriers to BA for older adults. Major in-session activities include practicing breaking things down into small steps, completing the "my desired activities" master list by adding the names of supportive people, and turning "you statements" into "I statements." This session also discusses the characteristics of effective communication.	• Doing tools: break down tasks; activity scheduling • Communication tools: effective communication and I statements	Activity scheduling
Session 4: Keep Doing	Session 4 continues to address common barriers to BA, including unhelpful thoughts (eg, "I can't do anything") and physical barriers to doing things. The user learns about adaptive behaviors and behavioral modification methods. Issues like independence and getting help are also discussed. Major in-session exercises include adaptive behavior quizzes, identifying inner strengths, and making adjustments to the "my desired activities" master list. The second mindfulness exercise, called mind-calming, is introduced.	• Doing tools: adaptive behaviors • Thinking tools: unhelpful thoughts related to BA • Feeling tools: mind-calming exercise	Mind-calming exercise and activity scheduling
Session 5: Problem Solving	Session 5 provides a 5-step problem-solving technique. The user follows along to practice the technique using their own problem, concluding in an action plan. The second communication tool—active listening—is introduced.	• Doing tools: 5-step problem-solving • Communication tools: active listening	Problem-solving and activity scheduling
Session 6: Unhelpful Thinking	Session 6 is the first of two sessions on cognitive restructuring—another core CBT skill. The user learns about common unhelpful thinking patterns and is asked to identify them in case stories and reflect on their experience. Core beliefs are also introduced.	• Thinking tools: ABC model; identify unhelpful thoughts and core beliefs.	Thought record and activity scheduling
Session 7: Thinking Tools	Session 7 is the second session on cognitive restructuring and moves from identifying thinking errors to challenging them. The "7-column thought record" is introduced to continue tracking thinking errors and practicing challenging methods.	• Thinking tools: challenge unhelpful thoughts	Thought record and activity scheduling
Session 8: Feeling Tools	Session 8 discusses various forms of self-care and addresses physical activity and nutrition. The second half of the session introduces mindfulness and walks the users through a guided breathing exercise. Another mindfulness exercise—the senses exercise—is also introduced.	• Feeling tools: self-care; mindfulness	Breathing exercise and activity scheduling
Session 9: Putting It All Together	As the last session of the program, Session 9 reviews the core techniques taught and addresses relapse prevention. The user follows along to create their empowerment guide. The user also learns about other treatment options like medication, one-on-one therapy, and other therapies.	• Program review and relapse prevention	Relapse prevention plan

[a]The list of sessions and content presented in this table is the most updated version and is being tested in an ongoing pilot randomized controlled trial.

[b]CBT: cognitive behavioral therapy.

[c]BA: behavioral activation.

The web-based sessions are enriched with an animated case story series featuring a 74-year-old homebound woman named Jackie (Multimedia Appendix 2). The animated story series is embedded within each session, similar to a television show episode, to reinforce and further illustrate the application of core CBT skills and techniques. The inclusion of an animated case story aligns with persuasive design and uses entertainment to elicit strong emotional responses [19].

The web-based program is accompanied by a printed user workbook in large print, containing session summaries, in-session exercises, directions and forms for home practices, inspirational quotes, and wellness resources (Multimedia Appendix 3). Typically, iCBT programs offer web-based worksheets or workbooks. However, we provided a printed workbook considering the target population's likely familiarity with print media and the commonly reported issues regarding text entry from other iCBT studies involving older adults [20].

Using agile, state-of-the-art development processes, we built the web platform as a custom learning management system and made it accessible across various devices. The main interface

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features large buttons, icons with text descriptions, high-contrast color schemes, and intuitive navigation, all of which follow the current best practices for creating age-friendly UIs [16]. In addition, we designed a provider dashboard that allows providers to review patients' progress, enabling them to readily access easily digestible data for quality improvement and evaluation purposes (Multimedia Appendix 4).

Design Overview

The intervention development followed a user-centered design process and involved 3 iterative steps: elicitation, design, and usability testing, as outlined by Kruzan et al [21]. In the elicitation phase, we drew on multiple data sources to inform our understanding of end user needs, preferences, and requirements.

In the design phase, we used a co-design approach to create the treatment manual, case stories, and media design in collaboration with community stakeholders. These stakeholders included older adult advisors, geriatric mental health professionals, and aging services providers from 14 community organizations in Michigan. Over 100-plus meetings, the team iteratively refined the scripts of web-based sessions, voice-over actors, animated character designs, media designs, workbook designs, and other program elements based on stakeholder input. The core research team worked with a user experience designer to develop a wireframe, followed by a low-fidelity prototype. This prototype was tested by researchers and older adult stakeholders and refined based on their feedback.

In the usability testing phase, the ready-to-release version of Empower@Home underwent a heuristic evaluation by researchers and User Experience designers, followed by an in-home comparative usability study involving think-aloud exercises and longitudinal field testing with end users. Design needs and refinements to both the treatment manual and the web interfaces were made after each evaluation.

We assembled a multidisciplinary team to support our design activities, including mental health researchers, gerontologists, human-computer interaction researchers, user experience designers, web developers, and community stakeholders. We used recommended eHealth development strategies, such as heavy stakeholder participation, an iterative design process, continuous evaluations, and integration of implementation issues and concerns into the design process [22].

Elicitation

Multiple data sources informed our understanding of the needs, preferences, and requirements of end users and the community settings that are likely to implement the intervention. First, we reanalyzed qualitative data from 21 homebound older adults who had participated in our prior study on a generic iCBT program. We applied a deductive coding approach guided by the efficiency model of support [23] to identify issues surrounding usability (ease of use), engagement (motivation), fit (meeting user's needs), knowledge (how to use a tool), and implementation (how to apply the tool into user's life). The procedures of the prior study are detailed elsewhere [17]. We edited the transcripts, preserving only text relevant to our research question. A priori codes were developed based on the efficiency model of support and codes from our prior work. New codes were inductively added as we analyzed the transcripts. After the codes were finalized, we then identified patterns and categorized the initial codes into a smaller number of groups, themes, and concepts.

Our second data source was summary statistics of participants in Michigan's 1915(c) MI Choice Waiver program, generously shared by colleagues. This program caters to our target demographic of low-income homebound older adults.

In addition, we established partnerships with social service agencies that serve many homebound older adults. We conducted semistructured interviews and a web-based survey with these organizations to identify potential barriers to implementing DMHIs at both the provider and organization levels. Each organization was profiled, and common barriers to implementation were identified through a descriptive analysis of the survey data and a text analysis of the qualitative data.

Design

The design process primarily used co-design meetings and passive storyboarding techniques. Given that CBT is considered gold standard psychotherapy for depression, the core session elements were informed by widely used, evidence-supported CBT manuals [24-27]. In our regular meetings with community stakeholders, we shared each session's content by reading it aloud, thus soliciting immediate feedback and stimulating discussions on potential improvements to both content and delivery. Revisions, guided by meeting notes, were typically integrated within a day or two. Frequent meetings were held with stakeholders from various organizations each week. The revised content would then be tested in subsequent meetings with different stakeholder groups, an iterative process that continued until the core development team was satisfied that all feedback had been addressed. This labor-intensive co-design process served to not only craft the intervention but also foster partnerships with community organizations. Given that these activities unfolded amidst the COVID-19 pandemic, individual co-design meetings over Zoom (Zoom Video Communications, Inc) were deemed the most viable way to garner feedback from each stakeholder group.

While social service providers, many of whom are social workers, significantly influenced the psychoeducational content of the program, the development of the character-driven animated story heavily relied on input from homebound older adults. These senior advisors contributed to weekly small group discussions, guiding the development of characters, plot, script, and visual design. Each story episode was role-played during these meetings to obtain feedback on tone, dialogue, and alignment with the educational objectives of the sessions. Following each meeting, the core development team convened for a debrief, and revisions were promptly implemented. This iterative process of presenting revised scripts and design elements continued until no further feedback was forthcoming.

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Usability Testing

In-Home Comparative Usability Evaluation

In a single in-home session, we conducted a comparative usability evaluation of 3 different DMHI programs, including Beating the Blues, MoodGym, and Empower@Home. Ten homebound older adults were recruited through UMHealthResearch, a volunteer registry maintained by the University of Michigan. Participants were eligible if they were at least 60 years old and homebound. Homebound status was broadly defined as self-reported difficulty with outdoor mobility or receipt of in-home care or home-delivered meals. Prior computer experience was not required. A diagnosis of depression or elevated depressive symptoms was not required.

Beating the Blues was selected due to a solid body of evidence supporting its effectiveness [28,29] and core features shared with Empower@Home, including using a mix of audio and video-based content to teach CBT techniques, case examples, in-session exercises, and homework practice. Unlike Empower@Home, Beating the Blues uses real actors in its case examples. MoodGym, which has no audio or video material, was also included in the evaluation. MoodGym is a popular iCBT program and has been shown to reduce depressive symptoms [30]. Of the 3 programs, Empower@Home was the only program specifically designed for older adults.

The order of trials was based on a predetermined random sequence to reduce the influence of learning effects. Participants spent up to 20 minutes per program and were asked to think aloud as they performed tasks such as reviewing information on the web pages, advancing to the next page, navigating between program components, and completing in-session exercises. After each trial, participants completed the System Usability Scale (SUS), followed by open-ended questions to probe their experiences, likes, and dislikes. After participants tried all 3 programs, they were asked to select their favorite program and explain their choice.

The SUS is a 10-item scale commonly used in evaluating the usability of websites, software, and other human-machine systems [31]. Scoring the SUS involves reverse coding the negatively worded statements and summing up all 10 item scores. The sum was then multiplied by 2.5 so that the total SUS score ranged from 0 (very poor perceived usability) to 100 (excellent perceived usability) in 2.5-point increments. A SUS score above 68 is considered above average. The SUS is a valid measure to compare systems [32] and has excellent internal consistency in the study sample (Cronbach α=.92).

Data were collected at each participant's home, and all participants engaged with the 3 programs on a 10.5-inch tablet provided by the study team. Participants' interactions with the screen were recorded using a screen recording app. One researcher with user experience design training took detailed notes of participants' interactions with each program.

Descriptive statistics were conducted to describe the study sample and the SUS scores. Paired sample 2-tailed *t* tests were used to compare the SUS scores of Empower@Home and those of the 2 comparator programs. The user experience designer coded the responses to open-ended questions, field notes, and observations and generated a 1-page report, which aided in the interpretation of the SUS scores and their differences.

Longitudinal Field Testing

We conducted longitudinal field testing with low-income homebound older adults through a small open-pilot trial. Participants in the field test were recruited via community partner agency referrals. Participants needed to (1) read and speak English, (2) be at least 60 years old, and (3) have at least mild depressive symptoms at screening (≥5 on the PHQ-9) [18]. Individuals were ineligible if they had (1) probable dementia based on the Blessed Orientation, Memory, and Concentration test (score>9) [33]; (2) elevated suicide risk based on the Columbia-Suicide Severity Rating Scale [34]; (3) a terminal illness or unstable physical health conditions; or (4) severe vision impairment. Device ownership, prior computer use, or internet access were not required.

A 10.5-inch tablet with cellular data was provided to participants without technology access. Participants were given 10 weeks to complete the program with minimal support from project staff in the form of a brief weekly check-in that typically lasted between 5 and 10 minutes. Participants were invited to complete a short survey before the start of the program and then again at the end of the 10-week trial. Participants also completed up to 5 in-app assessments based on the PHQ-9.

Descriptive statistics were conducted to describe the study sample. Given the small sample size, inferential statistics were not computed. Instead, a single-subject line graph was used to visualize the changes in the PHQ-9 scores over time. Furthermore, participants' feedback and field notes were coded and consolidated to uncover any additional usability concerns.

Ethics Approval

The University of Michigan Institutional Review Board approved the usability study and the field-testing study (HUM00207612). Written informed consent was obtained at the start of the home visit for the usability study. Verbal informed consent was obtained from each participant before the start of the program for the field-testing study.

Results

Elicitation

Secondary data analysis of qualitative data from our previous project revealed various user needs and potential failure points to address. The key problems identified were usability issues that frustrated older participants. These included hard-to-read text, small clickable areas, perplexing navigation pathways, complex menu options, excessive information, and difficulties with text entry. One particular feature of the DMHI evaluated in our previous study demanded users input text. This aspect proved to be challenging for most participants. The contributing factors included a small text entry field, minimized text size when entered, unfamiliarity with on-screen keyboards, lower literacy levels, and potential website bugs, such as misleading error messages indicating omitted entries when users had filled them in. Underscoring the importance of design that accounts for age, the same program was highly regarded as

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"straightforward" and "easy-to-use" when tested by research assistants, most of whom were in their 20s.

In terms of engagement, participants appreciated the characters and their stories, the digestible module format, and the in-session exercises throughout the sessions. However, some activities, especially those requiring considerable cognitive flexibility, posed a challenge for them. Regarding issues surrounding fit, some participants noted that it occasionally used complex or sophisticated language that was difficult to comprehend. A primary concern was the program's lack of age-appropriate stories and case examples, leading to a perception that it was "not for someone like me." Another recurrent complaint was the excessive length of some sessions. Despite being broken down into shorter segments or pages, these sessions sometimes required 2 to 3 hours or more, imposing a considerable burden on the users. In terms of knowledge, external support could enhance comprehension of session content. Finally, concerning implementation, participants welcomed the opportunity to apply the skills learned beyond the web-based sessions.

Based on the summary statistics of participants in Michigan's 1915(c) MI Choice Waiver program, the typical profile of a low-income, homebound older adult is as follows: female (68%), White (75%), living alone (34%), aged between 65 and 79 years (36%), and experiencing diabetes (39%), and pain-related issues (44%).

Additional insights for the design were gleaned from semistructured interviews (n=14) and the web-based survey (n=17) conducted with social service agencies. At the client level, the primary barriers to DMHI implementation identified by social service providers were limited access to technology (n=17, 100%), low technology literacy (n=16, 94%), the stigma associated with mental illness (n=12, 71%), and cost constraints (n=10, 59%). Provider-level barriers included limited knowledge of geriatric depression, high caseloads, and competing demands. At the organizational level, potential barriers included a lack of financial incentives, reimbursement restrictions, and staff shortages.

Design

The design of Empower@Home, based on insights from our elicitation phase, addressed the identified failure point with various features. We created a streamlined UI to enhance usability, incorporating intuitive navigation, clear call-to-action prompts (eg, "Press NEXT"), and large buttons, text, and print. Our design avoids complex menu options and information overload on any page, focusing on a responsive web layout where each page fits within a single screen of a 10-inch tablet or larger, thus eliminating the need for scrolling. Most exercises are implemented via a printed workbook, making on-screen text entry optional. The sessions are brief (20-25 min) and divided into short videos and occasional voice-over instructional pages. A video tutorial to familiarize users with the system and on-demand technical support is also available.

For engagement, our program uses video-based learning featuring diverse older adults and an overarching character-driven narrative featuring a homebound older adult named Jackie. The inclusion of in-session exercises throughout the sessions aims to maintain user involvement.

Regarding fit, we used plain language, age-appropriate case stories, and examples. Case stories and additional workbook information support knowledge acquisition. Finally, weekly home practices and modeling behavioral changes in the character-driven story are designed to aid the implementation of the CBT tools.

To further enhance our program, we introduced "Empower Coaches," laypersons trained to provide weekly support calls to users, thereby addressing potential technical difficulties. This addition stemmed from user preferences for real-time support from a human over a fully automated system. Such external support is vital for populations with lower educational attainment and health or technology literacy, as it can bolster knowledge and implementation. While clinicians or therapists could fulfill the coaching role, we opted for laypersons or agency staff without specialized mental health training, such as caseworkers or community health workers. This decision considered the shortage of mental health professionals and the staffing structure of social service agencies serving older adults identified through our elicitation phase.

Stakeholder input influenced every aspect of the program design. To illustrate, input from older adult advisors informed the selection of the narrator's voice, with a preference for lower-pitched voices with neutral American accents and slightly slower pacing. We also avoided using background music during voice-over narrations to prevent comprehension difficulties for those with age-related hearing loss [35]. Additionally, 1 group of social service providers identified the lack of diversity among inspirational quotes, leading to a more diverse selection in our program.

Jackie, the central character in the animated story series, was modeled on the typical profile of the Michigan's MI Choice Waiver participants. Jackie is portrayed as a 74-year-old White female living by herself, similar to the typical participant profile. She also shares their health challenges, specifically diabetes and arthritis-related pain. The decision to animate the Jackie story was informed by small group discussions, in which older adult advisors unanimously preferred animated story series over those performed by actors. Animation also provided an opportunity to incorporate visual storytelling elements that deepened the Jackie narrative without overrelying on lengthy narration or dialogue. When the visual design of characters was presented to stakeholders for feedback, a strong preference was shown for designs that did not rely on stereotyped representations of older people as disabled or frail. The initial character designs were revised based on additional stakeholder feedback. Multimedia Appendix 2 shows example video frames from various episodes of the Jackie story.

Development Cost

Excluding research staff time, replicators can expect a platform development cost near US $20,000 and monthly maintenance costs of around US $100. Our initial intervention development cost was US $10,125, supplemented by US $8700 for iterative refinements, totaling US $18,825. Regular upkeep, including

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server hosting with 2 central processing units, 4 GB RAM, 50 GB storage, and automated backups costs US $37 per month, plus US $50 per month for a dedicated database that is compliant with the Health Insurance Portability and Accountability Act. The University of Michigan Information and Technology Services provides the hosting service.

Additional expenses to consider are content creation costs, which can significantly differ based on creative requirements and chosen vendors. In our case, the animated story series "Jackie" cost US $32,900 to produce. The storyline, crafted by a freelance writer with a master of social work degree, incurred a cost of US $3000. In addition, voice-over recordings, performed by Fiverr-sourced artists who took on the roles of narrator, mindfulness exercise guide, and characters from the animated story series, added US $5000 to our expenses, making the total cost for the animated story series US $40,900.

Usability Testing

In-Home Comparative Usability Evaluation

The in-home visits lasted between 90 and 120 minutes. Table 2 shows descriptive statistics of the 10 participants from the in-home usability evaluation. They were aged 71.4 years on average, and primarily identified as female (n=6, 60%). In total, 8 had at least a college degree (80%), and 5 (50%) had a household annual income of over US $50,000. They all owned a laptop or a computer and had internet access at home. All agreed or strongly agreed that they felt confident working on computers.

Table 2. Descriptive statistics of the in-home comparative usability study participants (N=10).

Characteristics	Values
Age (years), mean (SD)	71.4 (6.4)
Gender, n (%)	
Male	4 (40)
Female	6 (60)
Race or ethnicity, n (%)	
Non-Hispanic White	9 (90)
Hispanic	1 (10)
Education, n (%)	
Some college, no degree	2 (20)
Bachelor's degree	3 (30)
Graduate degree	5 (50)
Marital status, n (%)	
Married or partnered	3 (30)
Divorced or separated	3 (30)
Widowed	3 (30)
Never married	1 (10)
Household income (US $), n (%)	
$10,000-$20,000	1 (10)
$20,001-$30,000	1 (10)
$30,001-$40,000	1 (10)
$40,001-$50,000	2 (20)
$50,001+	5 (50)
Regularly used devices, n (%)	
Tablet or iPad	8 (80)
Laptop or computer	10 (100)
Smartphone	9 (90)

Table 3 shows the SUS scores by program tested. Normality tests were conducted to check the distribution of SUS scores, using the Stata commands *swilk* (the Shapiro-Wilk test for normality) and *sktest* (for skewness and kurtosis). All tests resulted in *P* values exceeding .05. These results failed to reject the null hypothesis, suggesting that the SUS scores followed a normal distribution. The average SUS score was 78 for Empower@Home, 55.8 for Beating the Blues, and 57.5 for MoodGym. SUS scores for Empower@Home had the smallest range and SD (score 78, SD 7.4), suggesting consistency in

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perceived usability across participants. In contrast, the SUS scores for Beating the Blues (55.8, SD 24.4) and MoodGym (57.5, SD 20.1) had large ranges and SDs. Results from paired 2-tailed *t* tests showed a significantly higher SUS score for Empower@Home compared to Beating the Blues and MoodGym, suggesting the superior perceived usability of Empower@Home over the 2 comparable programs.

Table 3. Usability statistics by programs tested during in-home evaluation.

Program tested	System Usability Scale[a] score			
	Mean (SD)	Range (min-max)	Paired 2-tailed *t* test[b] (df)	*P*(T>t) values
Empower@Home	78.0 (7.4)	65-87.5	Comparator	Comparator
Beating the Blues	55.8 (24.4)	2.5-87.5	*t*=3.28 (9)	.005
MoodGym	57.5 (20.1)	22.5-90	*t*=2.78 (9)	.011

[a]Higher total score indicates better usability.

[b]Paired 2-tailed *t* test compared the total SUS scores between Beating the Blues and Empower@Home, and between MoodGym and Empower@Home. Applying the Bonferroni correction, a 1-tailed *P* value of <.025 is statistically significant.

Of the 10 participants, 80% (n=8) preferred Empower@Home, reporting that they liked the mix of audio, video, and visual materials, and reported it being easy to use and engaging. Half of the users liked the narration and the animated story and said the story felt "real." Most users felt that the look and feel of Empower@Home was neutral and had a clear layout. Two participants preferred Beating the Blues, liking its pacing, use of real actors, case examples, and in-session exercises. However, most participants, including the 2 who preferred Beating the Blues, reported that it was difficult to navigate its homepage, densely presented information, long loading time, and distracting "Urgent Support" button. Most users preferred a mix of audio, video, and visual materials, which were present in both Empower@Home and Beating the Blues. Most participants did not favor MoodGym for being text-heavy and having poor readability (small font and occasionally confusing terms or jargon). One participant shared a positive impression of MoodGym and liked it because they loved reading (however, this participant chose Empower@Home as their favorite).

Usability problems were found, particularly with the touch registration of the "Back" and "Next" buttons. The buttons, created with HTML's tag, function like hyperlinks requiring close pressing to the text. This issue is accentuated in older adults unfamiliar with touchscreens, who often apply long, hard presses, which capacitive touchscreens might not recognize. To address this issue, we replaced the with the <button> tag to create an actual button that allows the entire button area to be clickable. Second, we implemented a dual color scheme to signal when a click command is registered. Third, we provided tips on interacting with a touchscreen in a short navigation tutorial played at the beginning of the program. Finally, we offered a stylus pen to participants to reduce problems caused by dry fingertips.

Longitudinal Field Testing

Four participants provided posttest data for the longitudinal field testing. They were all low-income homebound older adults enrolled in the Medicaid MI Choice Waiver program. Table 4 shows descriptive statistics of the participants. None of the 4 participants had a 4-year college degree. Two used the program on their own devices, and the other 2 used a 10.5-inch tablet provided by the study team. All participants had elevated depressive symptoms on the PHQ-9 before the start of the program (mean 12.75, SD 3.6).

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Table 4. Descriptive statistics of the longitudinal field testing (n=4).

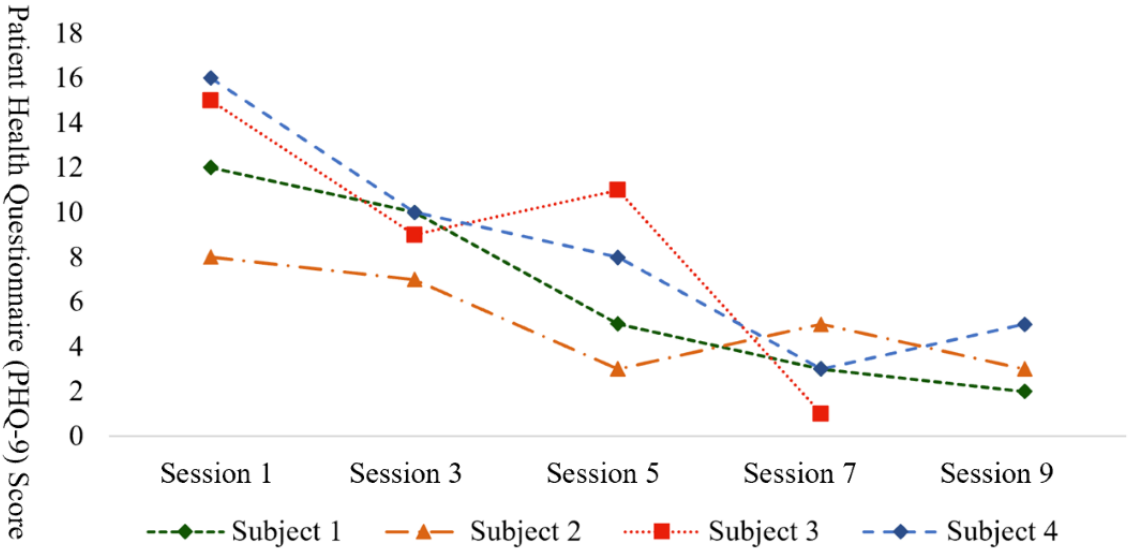
	Values
Age (years), mean (SD)	64.3 (3.4)
Gender, n (%)	
Male	1 (25)
Female	3 (75)
Race or ethnicity, n (%)	
Non-Hispanic White	4 (100)
Hispanic	0 (0)
Education, n (%)	
High school	2 (50)
Some college, no degree	2 (50)
Marital status, n (%)	
Married or partnered	2 (50)
Divorced or separated	1 (25)
Never married	1 (25)
Household income (US $), n (%)	
$10,000-$20,000	2 (50)
$20,001-$30,000	2 (50)
Device ownership, n (%)	
Tablet, iPad, laptop, or computer	2 (50)
No device ownership	2 (50)
Pretreatment PHQ-9[a] score, mean (SD)	12.75 (3.6)

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

At the end of the 10 weeks, 3 participants completed all 9 sessions, and 1 completed 8 sessions, suggesting excellent adherence rates. All participants agreed or strongly agreed that they liked the procedures used in this program and felt confident in their ability to perform the tasks required to participate in this program. The single-subject line graph (Figure 1) shows an overall trend of decreasing PHQ-9 scores over time.

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Figure 1. Single-subject line graph showing Patient Health Questionnaire-9 scores from in-app assessments.



Discussion

Principal Findings

Through a collaborative design process involving various stakeholders, we developed a DMHI incorporating CBT principles, age-related themes, engaging content, and an accessible UI. The in-home comparative usability evaluation results suggested that Empower@Home had higher perceived usability than Beating the Blues and MoodGym, 2 established iCBT programs. Most participants preferred Empower@Home over the other programs, citing its engaging multimedia content, clear layout, and relatable animated story. The longitudinal field testing results showed that low-income homebound older adults could adhere to the program with minimal support, suggesting the potential feasibility of the intervention.

Although the benefits of involving stakeholders in designing eHealth interventions, such as enhanced acceptability and engagement, are well discussed and acknowledged [36], members of some social groups continue to be excluded from full participation in the digital health ecosystem [37]. One such group is homebound older adults, who experience multiple social vulnerabilities and have limited technology literacy. Working with older adults with varying needs and technology literacy levels, we identified and addressed potential usability issues, such as touchscreen navigation difficulties, by refining the design and providing additional support and guidance to users. The program's character-driven story was also developed in close collaboration with older adult advisors and drawing on the profile of low-income homebound older adults to ensure that the central character, Jackie, was representative of the population likely to receive the program as part of routine practice.

The COVID-19 pandemic has accelerated the use of web-based applications across multiple areas of health care, including mental health services [38]. The trend toward using DMHIs as part of routine care for those seeking treatment for mental health concerns is expected to continue. DMHIs that are cost-effective, scalable, ecologically responsive, and tailored have the potential to significantly expand treatment access, improve treatment outcomes, and support equity in mental health care. Researchers and clinicians developing DMHIs can learn from our experiences, which included close collaboration with community agencies and care recipients, an iterative design process, and close attention to user experience.

Limitations

Although our results are promising, there are some limitations to consider. First, participants of the in-home usability evaluation were predominately non-Hispanic White and college-educated, which may not represent those likely to receive Empower@Home as part of routine practice. This may have resulted in overlooking UI challenges faced by other groups. Additionally, the in-home comparative usability evaluation involved a single session with each program, which may not fully capture the user experience throughout the intervention. Furthermore, although our longitudinal field testing was conducted with chronically ill, low-income homebound older adults, the sample size was small and lacked diversity. As our development process continues, we will continue to integrate feedback from participants from more diverse backgrounds and determine the efficacy of the intervention [39,40]. While we proactively considered implementation challenges during the design phase, future studies should systematically investigate implementation. Issues like coaching training and fidelity require further exploration to ensure the intervention is delivered as intended.

Conclusions

In conclusion, the development of Empower@Home provides a valuable example of how DMHIs can be designed and developed through close collaboration with stakeholders, iterative design processes, and attention to user experience.

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DMHIs have the potential to significantly expand access to mental health care and improve treatment outcomes, and future research should continue to explore the efficacy and implementation of these interventions.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Empower@Home session content example web pages. From left to right: video, text with voice-over, and mood self-check score page.
[DOCX File , 502 KB - aging_v6i1e47691_app1.docx]

Multimedia Appendix 2
Example video frames from the animated story of Jackie.
[DOCX File , 1371 KB - aging_v6i1e47691_app2.docx]

Multimedia Appendix 3
Empower@Home user workbook example pages. From left to right: session summary, in-session exercise, home practice, and inspirational quote.
[DOCX File , 1819 KB - aging_v6i1e47691_app3.docx]

Multimedia Appendix 4
Empower@Home user interface example pages. From left to right: program homepage, video page, and provider dashboard.
[DOCX File , 371 KB - aging_v6i1e47691_app4.docx]

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Abbreviations

CBT: cognitive behavioral therapy
DMHI: digital mental health intervention
iCBT: internet-based cognitive behavioral therapy
PHQ-9: Patient Health Questionnaire-9
SUS: System Usability Scale
UI: user interface

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Identifying Predictors of Nursing Home Admission by Using Electronic Health Records and Administrative Data: Scoping Review

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Abstract

Background: Among older adults, nursing home admissions (NHAs) are considered a significant adverse outcome and have been extensively studied. Although the volume and significance of electronic data sources are expanding, it is unclear what predictors of NHA have been systematically identified in the literature via electronic health records (EHRs) and administrative data.

Objective: This study synthesizes findings of recent literature on identifying predictors of NHA that are collected from administrative data or EHRs.

Methods: The PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) guidelines were used for study selection. The PubMed and CINAHL databases were used to retrieve the studies. Articles published between January 1, 2012, and March 31, 2023, were included.

Results: A total of 34 papers were selected for final inclusion in this review. In addition to NHA, all-cause mortality, hospitalization, and rehospitalization were frequently used as outcome measures. The most frequently used models for predicting NHAs were Cox proportional hazards models (studies: n=12, 35%), logistic regression models (studies: n=9, 26%), and a combination of both (studies: n=6, 18%). Several predictors were used in the NHA prediction models, which were further categorized into sociodemographic, caregiver support, health status, health use, and social service use factors. Only 5 (15%) studies used a validated frailty measure in their NHA prediction models.

Conclusions: NHA prediction tools based on EHRs or administrative data may assist clinicians, patients, and policy makers in making informed decisions and allocating public health resources. More research is needed to assess the value of various predictors and data sources in predicting NHAs and validating NHA prediction models externally.

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KEYWORDS

prediction model; nursing home admission; electronic health record; EHR; administrative claims data; administrative data; claims data; health record; medical record; long-term care; nursing home; elder care; geriatric; gerontology; machine learning; PRISMA; scoping review; search strategy; aging; older adult

Introduction

Aging is one of the most impactful medical and social demographic challenges across the globe [1]. By 2050, with the older population projected to reach 1.5 billion people, the proportion of older adults will be approximately 16% of the world's total population [1,2]. In response, many countries have implemented long-term care within their health systems. Long-term care, which is defined as a variety of individualized, well-coordinated services that promote independence for people with functional limitations, is provided over an extended period

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in both community settings and institutional settings, including nursing homes [3].

Among older adults, nursing home admissions (NHAs) are a major driver of costs and are extensively studied along with other adverse outcomes, such as hospitalization and mortality [4,5]. Identifying the common predictors of NHA is considered a key factor in delaying the entry into long-term care services [2] and in enhancing the development and application of preadmission assessments for managing long-term care utilization among older adults [6]. Furthermore, identifying predictors of NHA among older adults can increase the understanding of modifiers for functional status, dependency, and utilization of health services for older patients [7,8]. As Gauler et al [9] reported, NHA can be considered as "less of an endpoint and instead as an important transition where associated factors operate to influence outcomes after admission" [9]. As choosing NHA is a crucial and challenging decision for both patients and caregivers, it may require additional tools to facilitate shared decision-making. Therefore, a model that can predict an individual's risk of admission based on NHA predictors can help improve communication with patients and the implementation of clinical and policy preventive measures.

Clinical data sources, such as administrative data and electronic health record (EHR) technology, have become central in developing digital health tools throughout the health care spectrum [10]. Electronic data, including administrative claims and EHR data, are widely available across large populations, including older adults. These data sources can offer information across expanded follow-up periods, thereby improving the quality of study findings [11]. Predictors extracted from insurance claims or EHR data can be particularly useful for predicting NHA among older adults on a population scale, including the development of risk prediction models.

Administrative data are commonly leveraged to study health care delivery, benefits, harms, and costs [11]. Among these data, claims data have been increasingly used and are reported to be more structured and consistent, while EHR data have more in-depth information on each patient. Most notably, EHRs can contain a wide range of clinical data and narrative clinical notes that provide important information about a patient's medical history, symptoms, and the clinical reasoning that underpins treatment decisions. Both data sources cover a different range of factors and are often complementary to each other [12].

It is unclear what NHA predictors have been systematically identified in the literature via EHRs and administrative claims data. To address this gap in knowledge, this study aimed to conduct a scoping review to map the recent evidence on assessing predictors of NHA among older adults. This review aimed to address the following research questions: (1) what were the predictors or associated factors of NHAs among past studies, and (2) what prediction models were constructed or validated to predict NHA?

Methods

This scoping review was conducted per the Arksey and O'Malley framework [13] and the Joanna Briggs Institute methodology [14]. To report the study selection process, the extended PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) guidelines were used [15].

Identifying Relevant Studies

The electronic databases used in this review included the PubMed and CINAHL databases. Table S1 in Multimedia Appendix 1 provides additional information about the search terms used for this review.

Search Strategies

Inclusion Criteria

As shown in Table 1, this review included studies that (1) were peer reviewed, (2) researched long-term care, (3) were authored in English, and (4) were deemed original research. Search terms were selected based on the following elements: population, concept, and context [16]. Each element was further refined, as follows: the population of interest was older adults at risk of NHA; the concept studied was the prediction of health, health care utilization, or health expenditure; and the studied context was the use of EHRs, electronic medical records, or administrative claims data. We limited the studies to those published after 2011, as the last review of similar studies already included publications published by the year 2011 [17]. More specifically, studies were limited to those published between January 1, 2012, and March 31, 2023.

Table . Eligibility criteria used in this review.

	Inclusion criteria	Exclusion criteria
Article type	Peer-reviewed studies deemed original research	Studies that were not peer reviewed, as well as reviews, abstracts, commentaries, editorials, letters to the editor, study protocols, and gray literature
Language	English	Languages other than English
Population characteristics	Older adults at risk of NHA[a]	Older adults who already reside in nursing homes, skilled nursing facilities(SNFs), or hospices
Predictor characteristics	At least 1 predictor related to NHA	No predictor reported related to NHA

[a]NHA: nursing home admission.

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Exclusion Criteria

The following studies were excluded from this review: (1) studies with patients who were already residing in nursing homes and were thus missing NHA data; (2) studies that reported predictors of adverse outcomes among older adults but not predictors of NHA (eg, studies that only reported hospital or hospice admission); and (3) studies that only focused on SNFs, as our review focused on longer-term residence (typically longer than 1 y) rather than on short-term rehabilitation environments [2]. Reviews, abstracts, editorials, letters to the editor, and study protocols (with no outcome results) were also excluded (Table 1).

Selection of Sources of Evidence, Data Charting, and Synthesis of Results

All authors participated in the planning of screening and data extraction, as well as in the construction of search strategies. One author (EH) evaluated the titles, abstracts, and full texts of all publications identified through systematic searches.

A data charting form was developed and refined, incorporating the final variables, such as study sample, country, the dependent variables used in the study, the independent variables used in the study, data source, statistical analysis, findings or conclusions, settings, and implications. Key study characteristics and detailed information were extracted from eligible studies and recorded, using the charting form. Furthermore, we categorized and synthesized the sources of evidence that contained explicit information on leveraging electronic data and addressing the practical implementation of the outcome of NHA risk prediction. The study selection and data charting processes were amended, with any disagreements among the authors being addressed and resolved consensually.

Based on the results obtained from data extraction and charting, we found that the identified studies covered varying health care settings and timings of nursing home utilization. Accordingly, we established distinct phases to differentiate the timings and settings of risk prediction (Figure S1).

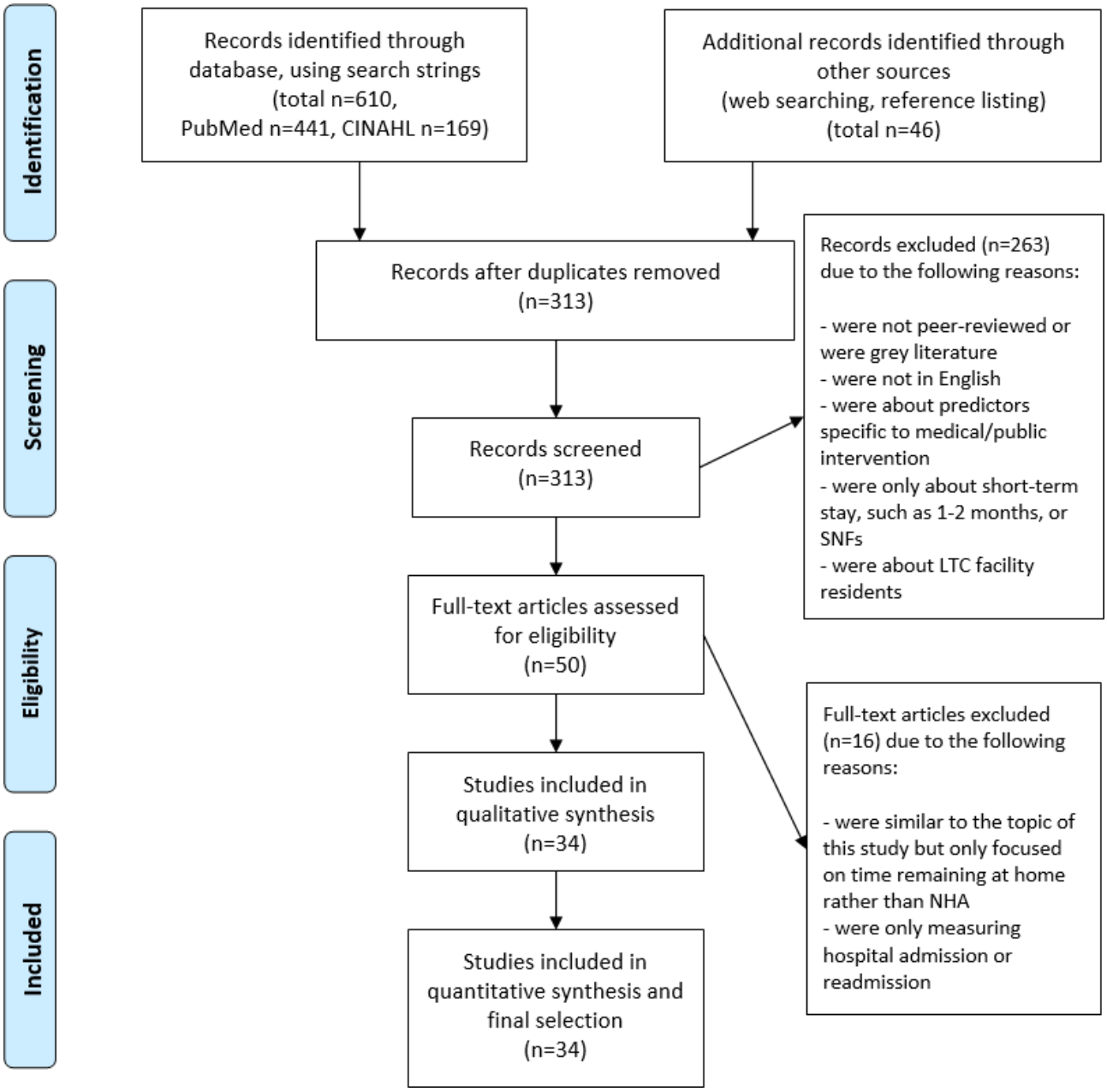
Results

Selection of Sources of Evidence

The initial search identified 610 articles across all search engines. Searching through the references of past reviews provided an additional 46 articles. A total of 313 articles remained after removing the duplicates. Screening the titles and abstracts of the 313 articles resulted in the exclusion of 263 articles. The full texts of the remaining 50 publications were reviewed, which resulted in the exclusion of 16 articles. A total of 34 peer-reviewed original research publications were selected for final inclusion in this review (Figure 1). Tables S1-S4 in Multimedia Appendix 1 [8,18-50] present the search strings and the comprehensive characteristics of the sources of evidence included in this study.

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Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram [51]. LTC: long-term care; NHA: nursing home admission; SNF: skilled nursing facility.



Results of Individual Sources of Evidence

Patient Population

Different patient populations with various (typically chronic) conditions (eg, dementia [18-22], Alzheimer disease [23], depressive burden [24], stroke [25,52], hip fracture [26], frailty [8,27-29], and traumatic brain injury [30,31]) and specific insurance or socioeconomic statuses (eg, Medicare [24,32,33,35], Medicaid [34,36], or special social support beneficiaries [37]) were reported. The categorization of older adult populations was not limited to disease categories alone but also included factors related to medical service use and socioeconomic status. It was observed that the diseases affecting the study participants predominantly fell within the *noninfectious disease* category.

NHA Definitions and Other Outcomes

NHA was defined in different ways across the studies; 6 studies defined *admission* based on a time period after the receipt of acute care (ie, admission to long-term care at 1 y after first-ever ischemic stroke or intracerebral hemorrhage [25]; admission to a nursing home within 1 y of discharge from hip fracture surgery [26]; NHA at 90 d outside of acute care [38]; 1-y home time, which was defined as the number of days spent outside of a nursing home after stroke [52]; and 90 or 100 d of NHA after a traumatic brain injury experience [30,31]). Further, 1 study [39] used a distinctive outcome measure to define NHA, which was "whether the subject was recommended by healthcare experts to live in residential care."

Several studies used other outcome measures in addition to NHA (Table 2). All-cause mortality (studies: 16/34, 47%), as well as hospitalization and rehospitalization (studies: 11/34,

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32%), was frequently used. In other studies, discharge from home and home-based services or recommendations to live in the community were compared to NHA (studies: 4/34, 12%). Further, of the 34 studies, 4 (12%) used 1 or more functional measures, including quality of life, activities of daily living (ADL), and mental well-being. Other measures were discharge to any health care institutions other than a nursing home (eg, rehabilitation center), other long-term care service use, an emergency department visit, the onset of important chronic conditions, fall incidence, time of death, and health and social service costs.

Table . Outcome measures used in the selected studies beyond nursing home admission (N=37[a]).

Secondary outcome	Outcome reported, n (%)
Mortality	16 (43)
Hospitalization or rehospitalization	11 (30)
Discharge from home and home-based services or recommendations to live in the community	4 (11)
Functional measures (quality of life, activities of daily living, and mental well-being)	4 (11)
Discharge to any health care institutions other than a nursing home (eg, rehabilitation center)	2 (5)
Other long-term care service use	1 (3)
Emergency department visit	1 (3)
Disability	1 (3)
Onset of 5 important chronic conditions	1 (3)
Nursing care needs	1 (3)
Time of death	1 (3)
Fall incidence	1 (3)
Health and social service costs	1 (3)

[a]More than 1 outcome measure was reported from individual studies. Therefore, N was greater than the number of selected studies.

Predictors of NHA

A wide range of predictors was identified across the reviewed studies (Table 3). Some studies used sociodemographic predictors, such as age, sex, residence, marital status, migration status, household income, preferential status in public health care insurance, and living alone. Caregiver factors were measured in 4 studies, including the type of informal care [21,23,39,40]. Health-related factors included cognitive function and dementia (eg, cognitive ability, dementia severity, cognitive dysfunction [41], and presence of dementia [26]), falls [20,36], behavioral symptoms at baseline [23], Parkinson disease [26], physical comorbidities [26], stroke [25], depression [20,26], quality of life measured by the EuroQol EQ-5D-3L [20], and the Cumulative Illness Rating Scale [26]. Medication-related variables included the Medication Appropriateness Index [20], the use of antipsychotics [19], dementia medication [22], and medication adherence [42]. Polypharmacy was used to predict NHA in 2 studies [22,43]. On the other hand, frailty was used in 8 studies. Among these 8 studies, 5 reported the development and validation of prediction models using different frailty index scores [27,28,33,35,44]. Another structured score that was used to predict NHA was the Identification of Seniors at Risk score, which is a standardized, comprehensive geriatric assessment tool administered at admission to a hospital [38]. Social service use predictors included short-stay service use, social care type, care needs, the intensity of formal home support [41], and preinjury home care [26]. Additionally, 1 study included the different patterns of use of home- and community-based social services [37].

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Table . Identified predictors of nursing home admission.

Predictors		Items
Sociodemographic factors		• Age, sex, residence, marital status, migration status, household income, preferential status in public health care insurance, and living alone
Caregiver factors		• Caregiver distress, caregiving coresidence, type of informal care, and relationship with the main caregiver
Health status		
	Frailty	• Presence of frailty and structured frailty index
	Geriatric conditions (other than cognitive function and dementia)	• Presence of 1 or more geriatric syndromes (fall-related fractures, incontinence, and pressure ulcers) and number of previous falls • Combined index of geriatric conditions (falls, difficulty in walking, malnutrition, weight loss, vision, decubitus ulcer, severe issues with bladder control, and absence of fecal control), and standardized comprehensive geriatric assessment results
	Cognitive function and dementia	• Cognitive ability, dementia severity, decline in dementia severity, cognitive dysfunction, and presence of dementia
	Other diseases and morbidities	• Behavioral symptoms, stroke type, depression, Parkinson disease, experience of traumatic brain injury, disease count, and Cumulative Illness Rating Scale
	Quality of life	• EuroQol EQ-5D-3L instrument
Health use and medication		• Medication Appropriateness Index, medication adherence, use of antipsychotics, dementia medication, polypharmacy, and quality of primary care experience
Social service use		• Use of short-stay services, social care type, care needs, intensity of formal home support, preinjury home care, and different patterns of use of home- and community-based services

Administrative claims data were used in 20 (59%) of the 34 studies to capture the predictors of NHA. Only 3 studies explicitly reported the utilization of EHRs as their data source. Predictors were used to predict risk scores for NHA, but none of the studies reported whether the prediction models were implemented in the real world to influence older adults' decision-making regarding NHA.

Modeling Methods Used to Predict NHA

Of the 34 selected studies, 35% (n=12) reported Cox proportional hazards models for their primary modeling method, while 26% (n=9) reported logistic regression models. Further, 6 (18%) studies used both Cox proportional hazards models and logistic regression models. Other regression models used included the Fine-Grey regression model, the subdistribution hazards model, the generalized linear model, and survival analysis using the competing risk method. (Table 4).

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Table . Modeling methods used in the risk prediction of nursing home admission (N=34).

Modeling methods	Method reported, n (%)
Cox proportional hazards model	12 (35)
Logistic regression model	9 (26)
Cox proportional hazards and logistic regression model	6 (18)
Other regression models (Fine-Grey regression model, subdistribution hazards model, GLM[a], and survival analysis using the competing risk method)	5 (15)
Linear and logistic regression models	1 (3)
Receiver-operator curve analysis	1 (3)

[a]GLM: generalized linear model.

Location of Studies

The United States was the country with the highest number of studies (8/34, 24%). In Europe, 9 countries published 12 studies, including studies conducted in Germany (4/34, 12%). Further, of the 34 studies, 4 (12%) were conducted in Asia. Additionally, 1 (3%) study was conducted in Australia, and 1 (3%) study was conducted in more than 1 continent (Table 5).

Table . Countries and regional distribution of selected studies (N=34).

Regions and countries		Studies, n (%)
United States and Canada		
	United States	8 (24)
	Canada	4 (12)
Europe		
	Germany	4 (12)
	United Kingdom	2 (6)
	Spain	1 (3)
	Denmark	1 (3)
	Ireland	1 (3)
	Finland	1 (3)
	The Netherlands	1 (3)
	Belgium	2 (6)
	Italy	2 (6)
	Switzerland	1 (3)
Asia		
	South Korea	2 (6)
	Japan	1 (3)
	Taiwan	1 (3)
Australia		
	Australia	1 (3)
>1 continent		
	Italy, Spain, Germany, the Netherlands, France, Czech Republic, and Australia	1 (3)

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Major Findings of Studies on NHA Prediction

A total of 5 studies included validated frailty indexes as predictors (Table 6). Studies that used a frailty assessment to develop a risk index exhibited similarities in terms of objectives, variables, and outcome measures when compared to studies that reported a distinct, heterogeneous set of predictors. According to the reviewed studies, a frailty index could be adapted for use with EHR data or claims data to predict NHA. According to Clegg et al [44], the primary aim of an electronic frailty index is to identify categories of frailty; therefore, the assessment of utility should be based primarily on the predictive validity of frailty categories for adverse outcomes. Kinosian et al [33] reported that the area under the curve for predicting NHA based on the JEN frailty index was 0.781, although it discriminated less well than an ADL-based model. Segal et al [35] reported that a claims-based frailty indicator significantly predicted NHA in an adjusted model (odds ratio 1.45, 95% CI 1.04-2.01). Clegg et al [44] reported that an EHR-based frailty index identified older people with severe frailty and showed robust predictive validity for outcomes of NHA (hazard ratio 4.76, 95% CI 3.92-5.77).

Table . Studies that included validated frailty prediction models in NHA[a] predictions.

Study (author, year)	Prediction model	Data source	Sample size for NHA prediction, n	Area under the ROC[b] for NHA
Amuah et al [28], 2023	FRM[c]	Clinical administrative data	788,701	0.81
Le Pogam et al [27], 2022	eFS[d]	Clinical administrative data	469	0.71
Kinosian et al [33], 2018	JFI[e]	Administrative claims (Medicare)	12,563	0.78
Segal et al [35], 2017	CFI[f]	Administrative claims (Medicare)	4454	0.75
Clegg et al [44], 2016	eFI[g]	EHR[h] (primary care setting)	931,541	0.74

[a]NHA: nursing home admission.

[b]ROC: receiver-operator curve.

[c]FRM: frailty risk measure.

[d]eFS: electronic frailty score.

[e]JFI: JEN Frailty Index.

[f]CFI: claims-based frailty indicator.

[g]eFI: electronic frailty index.

[h]EHR: electronic health record.

A total of 3 studies reported the usefulness of calculating a risk index or predicting NHA. Kan et al [32] reported that the odds ratio estimates for their geriatric risk index were statistically significantly associated with increased health care utilitzation, including NHA in the first year of study. Pilotto et al [45] reported that a higher Multidimensional Prognostic Index value was associated with NHA and other negative outcomes. Müller et al [20] reported a comparison between claims data–based and trial data–based prognostic models to predict negative health outcomes in older patients with multimorbidity and polypharmacy.

Predictors that were identified to decrease the risk of NHA included the receipt of higher-quality primary care, the receipt of coresident care, integrated medical care and other types of long-term care services, intense formal home support, and short-stay service use (Table S5 in Multimedia Appendix 1).

Discussion

Principal Findings

In this study, we reviewed 34 studies that either assessed the association between predictors and outcomes or reported the development and validation of predictors of NHA via observational studies based on EHR or administrative data. These predictors were further categorized into sociodemographic, caregiver support, health status, health use, and social service use factors, consistent with previous studies [9,18-22,24,26,34,39,40,43,46,52,53]. Most studies (23/34, 68%) included multiple outcome variables in addition to NHA. All-cause mortality, hospitalization, and rehospitalization were frequently used as outcome measures. Cox proportional hazards models, logistic regression models, and a combination of both were frequently used to predict NHA. In terms of data sources, administrative claims data and EHRs were jointly used, rather than each source being used alone.

Overall, studies did not fully leverage the data sources of our interest. Administrative claims and EHRs may have strengths, including the abilities to help with recruiting larger sample sizes, incorporate expanded types of predictors or outcome variables, enable short-term prediction, and facilitate easy implementation in practice [54]. For instance, routinely coded EHR data can be used to establish a frailty index, thereby allowing for the classification of subtypes of frailty. These data can be readily integrated into clinical computer systems, automatically populated, and made available without requiring additional resource input [44]. Further, although we found some studies that used large sample sizes comprised of more than 200,000 participants [18,20,28,31,43,44,47], this did not necessarily

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mean that the predictors or outcome variables were distinctive. In addition, although many studies used administrative claims data, the use of billing information or the construction of cost predictors was rarely observed. Discussion on enhancing the quality of data source utilization was limited. For instance, only 1 study reported the variation in outcomes based on the use of structured EHRs versus nonstructured EHRs [32].

Developing a validated risk prediction model that is expressed as an index or score is one option to effectively leverage electronic data sources. Such a model would serve as a convenient tool for preplacement assessments and help address the challenges posed by big data sources, which often contain excessive information that may be disorganized or lack systematic summarization. As international guidelines recommend the routine identification of frailty to provide evidence-based treatment [44], several studies tried to identify frailty from routinely available electronic health data, which showed fair predictive value. Despite the identified NHA predictors, the development of a predictable index from routine data sources needs further exploration, as the predictive value of the identified factors was limited.

Although many of the reviewed studies included clinical predictors, social determinants of health, such as education, economic hardships, food security, and community factors [55], were used in a limited fashion. The limited use of social determinants of health might be partly due to the complexities of extracting such data from EHRs and the limited capture of these data in insurance claims [56]. Similarly, caregiving, which is an important aspect of social support for patients, was used as the predictor of NHA in a few of the reviewed studies. One study [21] collected information on a caregiver's formality and qualitative characteristics of caregiving (eg, value of caregiving to and impact of caregiving on care recipients). In another study [40], a comprehensive assessment survey, which included the caregiver distress factor, was conducted and included as a predictor of NHA.

The study findings have implications for the development of prevention strategies in communities. Several studies reported the utilization of home care to delay NHA [8,36-39,41,48,49]. Prediction models for older adults may play a distinctive role in screening the at-risk population or assessing the need for home services in primary care settings. Efficient NHA prediction may involve making the short-term decision of whether a person is suited for living in the community or for institutionalization and applying this approach to a specific population instead of applying it broadly to all community-dwelling older adults. In addition, such complex decision-making may require informed communication among older adults, caregivers, and care providers about resource allocation between community-based care and institutional care. Therefore, NHA prediction in communities should be in alignment with the continuum of care, considering the benefits and costs of institutionalization.

Comparison to Prior Work

Unlike other recent studies that primarily targeted risk prediction for nursing home residents [57,58], this study examined the preplacement status of individuals, with many of the study samples residing in communities. Our focus was on exploring how the study results could assist in developing prevention strategies at the population health level within these communities.

The main findings of this study are consistent with a previously conducted meta-analysis [9] and cohort study [53], which identified predictors of NHA, specifically ADL dependency, cognitive decline, and prior NHA. Studies on the predictors of readmission to nursing homes also showed similar trends [59]. Nevertheless, in comparison to these prior studies, our study revealed an expansion in the types of predictors reported since 2010, including frailty and geriatric syndromes.

Previous studies on risk prediction via EHR data or administrative claims data discussed various strengths and challenges [48,54,60,61]. EHRs may provide an alternative to the longitudinal cohort studies that are traditionally used to construct risk models [60]. In this regard, clinically available risk prediction models for the early prevention of NHA that are based on EHRs are more appropriate for a clinical context than those based on other types of electronic data sources [44]. However, variations in EHR implementations and data standards across health care systems may limit the practical adoption of EHR-based NHA prediction models [62]. Future research should pay attention to the development and use of predictors of NHA across different electronic data, health systems, and patient populations.

Strengths and Limitations

To our knowledge, this is the first study to systematically review existing evidence on identifying predictors of NHA based on administrative claims or EHRs. Since NHA is a considerable burden to health care delivery systems, identifying and developing NHA prediction models can enable health systems to both reduce overall health service utilization and improve health care outcomes among older adults. We reported distinctive characteristics of existing predictors and prediction models, including how they leveraged specific data sources. These findings have implications for delaying NHA in communities.

This review has several limitations. First, this review is limited to the literature on EHRs and administrative data concerning the older adult population and NHAs. Therefore, the findings from the literature on EHRs and administrative claims data may not be generalizable to other data sources. Second, this review only included studies that researched potential factors or predictors of NHA in a retrospective manner. Thus, studies that evaluated a specific program for reducing NHAs were excluded in this study. These studies may have included predictors that could have been added to the list of predictors found in this review, although such predictors are often not available in routine EHR data or claims data sources. To mitigate this limitation, we searched and reviewed the list of excluded studies during the multiple stages of the final selection process. Third, we limited this review to studies that used administrative data or EHR data as their primary sources of data to assess predictors of NHA. However, the differences between administrative data, administrative claims data, and EHR data are not always clear in different clinical settings. Future studies may refine data sources beyond EHRs and claims data, although the application

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of such data sources in population health management efforts should be further evaluated. Finally, our review followed a scoping review guideline and thus may have inadvertently excluded a few relevant studies. A systematic review of relevant studies is recommended to provide a comprehensive list of predictors for NHA among older adults.

Future Directions

Considering that NHA is not an end point but rather a transitional point [9] in the care continuum, an NHA prediction model can be used in a risk prediction and prevention framework (Figure S1 in Multimedia Appendix 1). In the first phase of preventing NHA, adults may undergo routine screenings while maintaining independence in their communities. If they experience functional decline or reach a certain level of dependency, preventive interventions can be implemented based on the results of prediction models to delay NHA timing in the second phase of prevention. Even after NHA occurs, prevention strategies to reduce the risk of other adverse outcomes during nursing home residency are still important. During this phase of prevention, we believe that NHA risk prediction models can evaluate whether an individual is prepared to return to the community, if relevant. Thus, risk scores calculated by using a frailty index or a comprehensive geriatric assessment index can also be used for newly admitted nursing home residents. In future studies, other factors may be controlled to examine the impact of using NHA prediction scores (Figure S2 in Multimedia Appendix 1).

Of note, some studies focused on continuous care and primary care qualities [8,44,55]. As prevention programs for delaying NHA at earlier stages can be implemented in primary care settings, further studies are warranted on this topic.

Conclusions

Several studies have investigated the potential predictors of NHA by using EHRs or administrative data. Frequently used predictors included sociodemographic factors, caregiver factors, health-related factors, medications, and medical and social service utilization. The most frequently used models for predicting NHAs were Cox proportional hazards models and logistic regression models. Prediction tools based on EHR data or administrative claims data may assist clinicians, patients, and policy makers in making informed decisions and allocating public health resources.

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Data Availability

All data generated or analyzed during this study are included in this published article and its supplementary information files.

Authors' Contributions

EH conceptualized and conducted the data collection, investigation, and data synthesis processes. HK developed the search strings and supervised the data analysis. EH and HK wrote the manuscript. LS reviewed the manuscript and provided supervision throughout the process from conceptualization. All authors reviewed the manuscript and agreed to the amendments.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary materials, including those regarding eligibility criteria, search terms, data charting results, predictors of nursing home admission (NHA), an NHA framework, and the utilization of NHA risk scores.
[DOC File, 305 KB - aging_v6i1e42437_app1.doc]

Checklist 1
PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) checklist.
[PDF File, 511 KB - aging_v6i1e42437_app2.pdf]

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Abbreviations

ADL: activities of daily living
EHR: electronic health record
NHA: nursing home admission

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PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews
SNF: skilled nursing facility

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Review

Robots in Assisted Living Facilities: Scoping Review

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Abstract

Background: Various technological interventions have been proposed and studied to address the growing demand for care of residents in assisted living facilities, in which a preexisting shortage of professional caregivers has been exacerbated by the COVID-19 pandemic. Care robots are one such intervention with the potential to improve both the care of older adults and the work life of their professional caregivers. However, concerns about efficacy, ethics, and best practices in the applications of robotic technologies in care settings remain.

Objective: This scoping review aimed to examine the literature on robots used in assisted living facilities and identify gaps in the literature to guide future research.

Methods: On February 12, 2022, following the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) protocol, we searched PubMed, CINAHL Plus with Full Text, PsycINFO, IEEE Xplore digital library, and ACM Digital Library using predetermined search terms. Publications were included if they were written in English and focused on the use of robotics in assisted living facilities. Publications were excluded if they did not provide peer-reviewed empirical data, focused on user needs, or developed an instrument to study human-robot interaction. The study findings were then summarized, coded, and analyzed using the Patterns, Advances, Gaps, Evidence for practice, and Research recommendations framework.

Results: The final sample included 73 publications from 69 unique studies on the use of robots in assisted living facilities. The findings of studies on older adults were mixed, with some studies suggesting positive impacts of robots, some expressing concerns about robots and barriers to their use, and others being inconclusive. Although many therapeutic benefits of care robots have been identified, methodological limitations have weakened the internal and external validity of the findings of these studies. Few studies (18/69, 26%) considered the context of care: most studies (48/69, 70%) collected data only on recipients of care, 15 studies collected data on staff, and 3 studies collected data on relatives or visitors. Theory-driven, longitudinal, and large sample size study designs were rare. Across the authors' disciplines, a lack of consistency in methodological quality and reporting makes it difficult to synthesize and assess research on care robotics.

Conclusions: The findings of this study call for more systematic research on the feasibility and efficacy of robots in assisted living facilities. In particular, there is a dearth of research on how robots may change geriatric care and the work environment within assisted living facilities. To maximize the benefits and minimize the consequences for older adults and caregivers, future research will require interdisciplinary collaboration among health sciences, computer science, and engineering as well as agreement on methodological standards.

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KEYWORDS

robotics; long-term care; nursing home; residential care; scoping review; review method; robot; aging; elder; older adult; gerontology; geriatric; senior living

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Introduction

There is a severe need to provide quality care for the world's growing population of older adults and to improve the work environments of their professional caregivers. In the United States, the population aged ≥65 years is projected to increase from 49 million in 2016 to 95 million in 2060 [1], and adults in the United States aged >65 years have a 70% chance of eventually requiring some type of long-term care [2]. A study conducted since the start of the COVID-19 pandemic found that 99% of nursing homes and 96% of assisted living facilities in the United States are facing staffing shortages [3]. With >14% of their workforce lost since February 2020, nursing homes have been forced to limit new patient admissions, thus preventing older adults from accessing care [4]. The growing population of older adults, coupled with current caregiver shortages, has led to a severe mismatch between the individuals who need care and those who provide it.

Much effort has been devoted to developing technological interventions to ameliorate the mismatch between care needs and the capacity and quality of care for older adults. An increasing number of robotics and gerotechnology researchers are designing, developing, and evaluating care robots to provide physical assistance and social support to older adults and their caregivers [5]. Countries such as Germany, the United Kingdom, the United States, and Japan have provided economic support to care robotics research [6-8]. Care robots are increasingly highlighted as an innovative way to provide geriatric care, and in a recent European Commission report, 20% of the most influential information technologies for aging projects included care robots [9,10]. Preliminary evidence suggests that care robots have the potential to improve the health of older adults, improve their general well-being and social interactions, and reduce their loneliness [11,12].

Despite these potential benefits, ethical concerns regarding the adoption of robots in aged care remain, including questions about autonomy, deception, and safety [5]. Barriers to the implementation of care robots include technical difficulties, limited capabilities, and negative perceptions [13]. With respect to caregivers, robots have both positive and negative effects on the work environment [14]. Together, these factors present a substantial headwind for both researchers and practitioners as they attempt to develop effective robotic interventions and understand related effects and best practices.

Nevertheless, the implementation of robots in care settings will have profound effects on health care delivery and work environments. As a result of the potential for these wide-ranging effects, several prior literature reviews have focused on care robotics. Existing reviews have examined in-home use of robots to promote aging in place [15-17], specific robotic applications (eg, telepresence robots) [18], relevant ethical issues [5], factors that affect the acceptability or implementation of care robots [13,19], and the impact of robots on caregivers [14]. We aimed to expand upon previous research by focusing our review within the context of assisted living facilities specifically. In addition, our review encompasses all types of robotic applications. Prior literature reviewing research on robots for older adults tends to focus specifically on social robots and on psychological or cognitive outcomes [20-24]. In comparison, our review encompasses a broader picture of robotic research, interventions, and outcomes relevant to caregivers and patients in this setting.

Instead of focusing on quality assessment and synthesis of a well-defined research question, scoping reviews map the current state of knowledge on a topic and identify gaps for future research [25-28]. This form of the review is thus appropriate to our broad research questions: (1) What is known about robots used in assisted living facilities? (2) What research methods, designs, and populations were used in this research? and (3) What gaps exist in the literature and warrant future research?

Methods

This study adhered to the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) protocol [29]. The PRISMA-ScR checklist is provided in Multimedia Appendix 1 [29].

Round 1: Keyword Search

As the subject under investigation was interdisciplinary—the use of robots in assisted living facilities—we searched databases in engineering, computer science, and health sciences: PubMed, CINAHL Plus with Full Text, PsycINFO, IEEE Xplore digital library, and ACM Digital Library. On February 12, 2022, we searched PubMed for titles and abstracts using the following sets of terms: ("robot*") AND ("senior living facilit*" OR "residential facilit*" OR "independent living" OR "assisted living" OR "senior living center*" OR "nursing home*" OR "skilled nursing facilit*" OR "intermediate care facilit*") AND ("aged" OR "older" OR "elderly"). These search terms were developed from the authors' previous experience and by examining prior literature reviews in the field. To retrieve a full scope of the literature on our topic of interest, we imposed no time limit on years of publication. Then, we searched CINAHL Plus with Full Text and PsycINFO by titles and abstracts using the same sets of search terms. We then excluded duplicate publications using an electronic screening tool.

In addition, on February 12, 2022, we searched the IEEE Xplore digital library and ACM Digital Library (ACM Full-Text Collection) using the same sets of search terms. We searched IEEE by metadata (titles, abstracts, and indexing terms) and used the 2012 ACM Computing Classification System with the filter "Robotics" to search the ACM Digital Library. Duplicate publications were removed using an electronic screening tool. The publications identified from PubMed, CINAHL, and PsycINFO were combined with the publications from the ACM and IEEE databases, and additional duplicates were removed. A detailed search strategy for each database is provided in Multimedia Appendix 2.

Round 2: Screening of Titles and Abstracts

Next, the first author (KT) screened each of the nonduplicate papers by title and abstract using predetermined inclusion and exclusion criteria. The results were cross-examined by the other 3 authors, and disagreements were resolved through discussion. Inclusion criteria were as follows: (1) full text written in English and (2) focus on the use of robotics in assisted living facilities.

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We used the National Library of Medicine's Medical Subject Headings definition of robotics: "the application of electronic, computerized control systems to mechanical devices designed to perform human functions" [30]. Smart assistive devices (eg, walkers, canes, and transfer devices) and ambient assisted living technologies without a robotic platform were thus excluded from the review. *Assisted living facility* was defined as any residential setting that provides long-term care to older adults, consistent with prior literature reviews [11]. Studies on the in-home use of robots to promote aging in place were excluded. Projects that did not study the robot in a real-world setting were also excluded (eg, those that studied the robot in a laboratory environment or studied the infrastructure behind the robot). Publications were excluded if they (1) did not provide peer-reviewed empirical data (eg, literature reviews, opinion pieces, system architectures, and dissertations), (2) focused on user needs to guide future robot development, or (3) developed an instrument to study human-robot interaction.

Round 3: Screening of Full Text

The remaining papers were screened by full text using the same predetermined inclusion and exclusion criteria.

Round 4: Coding and Analysis of Full Text

Data from each of the papers in our final sample were then coded by publication year, study aim, research method, participants' characteristics, sample size, country and setting where data collection took place, specific robot studied, outcome measures, length of study, and key findings. Two reviewers (KT and RT) completed the coding independently; disagreements were resolved through discussion.

Our data analysis, presentation, and discussion of results follow the PAGER (Patterns, Advances, Gaps, Evidence for practice, and Research recommendations) framework [28], identifying 5 key patterns in the reviewed literature, along with advances, gaps, evidence for practice, and research recommendations for each. Following the PAGER framework [28], the 5 patterns were identified through a patterning chart analysis of the study findings. The patterning chart displays key themes and how they are distributed across publications, which is then used to highlight important patterns and gaps in the included literature (Multimedia Appendix 3 [31-104]).

Results

Overview

In this section, we first describe the results of our search and screening process. We then report the key descriptive characteristics of the studies in our final sample. Finally, we describe the 5 key patterns identified from the findings of the final studies.

Search and Screening Results

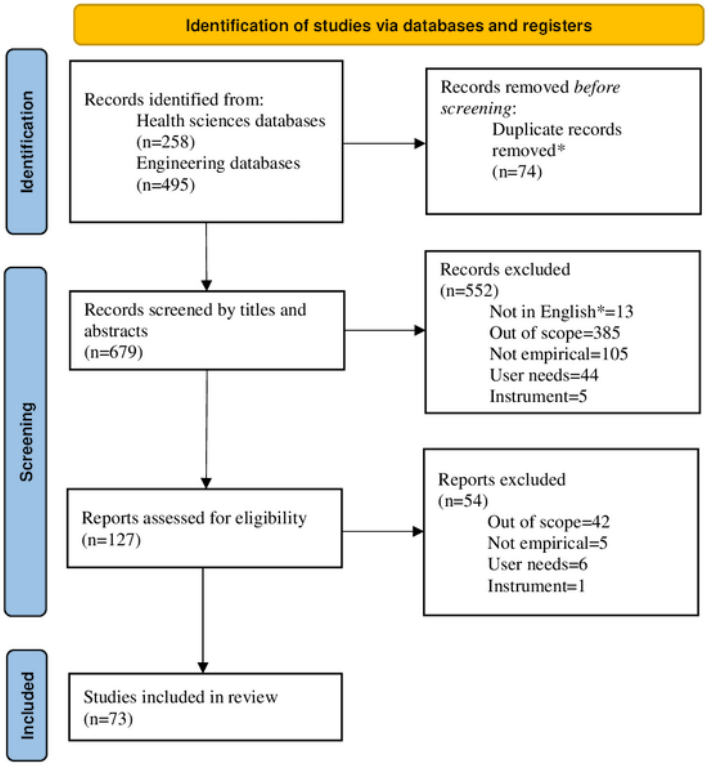
During round 1, keyword search, our PubMed search yielded 108 publications. Our CINAHL search yielded 75 publications including 37 duplicates, and PsycINFO search yielded 75 publications including 31 duplicates. Excluding the 68 duplicates, 190 papers remained from the health sciences databases. For the engineering and computer science databases, IEEE Xplore digital library yielded 437 publications and ACM Digital Library yielded 58 publications. Two duplicates were removed from the ACM and IEEE databases, resulting in a total of 493 publications. Combining these with the 190 papers from PubMed, CINAHL, and PsycINFO revealed 4 additional duplicates, resulting in a total of 679 nonduplicate results.

During round 2, screening of titles and abstracts, a total of 552 publications were excluded (refer to Figure 1 for details), resulting in 127 publications.

Round 3, screening of full text, resulted in the exclusion of 54 papers. A total of 73 papers remained in the final sample. Figure 1 presents the full search and screening process [105].

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Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram. *Records that were excluded by automation tools.



Descriptive Results Based on the Coding of Full Text

The 73 publications included in our final sample reported 69 unique studies; 8 of the publications [31-38] reported on the same 4 studies. Key characteristics of the 73 publications are summarized in Multimedia Appendix 4 [31-104]. The publications were published between 2002 and 2022; >50% (41/73) were published in the last 6 years, suggesting a growing interest in our research topic. Furthermore, 3 studies were inspired by challenges related to the COVID-19 pandemic [39-41]. The studies were conducted in 17 countries—in Asia (22/69, 32%), North America (20/69, 29%), Europe (16/69, 23%), and Oceania (11/69, 16%). On the basis of the authors' academic disciplines, 33% (23/69) of studies were identified as computer science or engineering oriented, 42% (29/69) were multidisciplinary, and the remaining were from health sciences (15/69, 22%) or social sciences (2/69, 3%).

The included studies were primarily designed to test the feasibility of a robot-based intervention. Feasibility studies assess whether an intervention is relevant and sustainable, and they can include limited efficacy testing [106]. Most of the studies (41/69, 59%) used quasi-experimental designs; the remaining studies were either case studies (21/69, 30%) or randomized controlled trials (7/69, 10%). Overall, 12 studies did not report the study duration; of those that did (57/69, 83%), the majority (37/57) lasted no longer than 6 months. Furthermore, 10 studies lasted <1 week, and 1 study [42] lasted 4 years. Only a few studies (6/69, 9%) [37,42-46] have reported the use of a theoretical or conceptual framework; the majority (63/69, 91%) lacked theoretical guidance. In addition, only a few studies (8/69, 12%) were user informed [47-51] or consulted clinical experts [33,52,53]; the remaining studies (61/69, 88%) lacked users' or experts' perspectives.

All studies used convenience samples, ranging from 3 older adults [31,54] or 3 recreational therapists [55] to 245 older adults in the largest study [38]. Five studies did not report the sample sizes [43,47,56-58]. Of the 64 studies that reported the sample sizes, 42 (66%) had no more than 25 participants. Most of the studies (48/64, 75%) collected data only from older adult recipients of care. Overall, 15 studies collected data on staff (eg, caregivers, therapists, board members, management, and preschool staff) [38,48,51,55,59-69], and 3 studies collected data on relatives or visitors [61,64,68]. One study [59], which examined the use of social robots for intergenerational activities, included 30 preschool children, and another study [70] used 6 young adults as a control group. The age of the older adult participants ranged from 55 to 104 years. Of the studies that reported demographic information, all but one [71] included >50% women participants. Of the 69 studies, 27 (39%) reported that they included older adults with cognitive impairments [31,41,42,45,52,53,69,70,72-90].

The studies examined a wide variety of robotic platforms and applications. The most commonly studied robot was PARO (n=22), followed by aibo (n=7) and NAO (n=7). Both PARO and aibo are pet-like robots, whereas NAO is a humanoid robot. The most common application of the robots was to provide social interaction or companionship to older adults (ie, social robots; 60/69, 87%). Less common uses were to assist caregivers with tasks related to their jobs (ie, assistive robots; 6/69, 9%) or to allow relatives and caregivers to provide remote presence to the older adults (ie, telepresence robots; 3/69, 4%).

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Outcome measures, both objective and subjective, varied widely across studies. Observations, interviews, and surveys were the 3 most common methods of data collection. Observations were made by the research team, by caregivers employed at facilities, or via the robots' software. Common observational measures included the number of interactions with robots, time spent interacting with robots, and emotional responses to robots. Observational measures collected by the robots included reaction time [31] and audio and facial tracking [88]. Three studies collected information on medication use [76,79,86]. More than 20 different questionnaires were used, but the most common were the validated and widely used Geriatric Depression Scale (n=4), the face scale mood evaluation (n=3), and the University of California Los Angeles Loneliness Scale (n=3). Furthermore, 4 studies collected physiological data, including blood pressure and heart rate [91], electroencephalogram [70], sleep-wake patterns obtained via wrist actigraphy [83], and salivary chromogranin [92]. Owing to the participants' cognitive impairments, 3 studies [49,79,86] relied on proxy assessments of quality of life or pain.

Patterns of Research Findings

In addition to these key characteristics of the studies included in our final sample, we identified 5 key patterns of research findings.

Effects, Perceptions, and Experience of Care Robots

The overall findings were mixed; some studies suggested therapeutic effects of the robots, whereas others were neutral or inconclusive. The most commonly reported benefits of the social robots were improved mood and emotional states [33,41,42,44,49,52,55,72,74,76,78,80,81,84,85,87,92-94] and an increase in social interaction between the residents and other human interactors [31,36,41,42,52,55,58,59,63,69,72,75,81,82,95-98], including caregivers [69] and preschoolers [59]. Other commonly reported benefits of the robots were reduced loneliness [36,92,99], evoked positive memories of pets [59,65,85,96,100], improved quality of life [53,79] and well-being [65], reduced pain and pain medication use [85,86], cognitive stimulation [31,59,78], and improved behavior [49,55,80]. Several robots promoted movement [50,62,72,100,101], and 1 robot prevented unexpected falls [69]. Four studies [45,51,69,71] investigated robots that assist with medication administration, and in 1 study [69], the robot successfully prevented a medication error. Less frequently cited but objectively measured benefits included improved neuroactivity [70], reduced stress [92], decreased blood pressure [91], and improved sleep [83]. Several studies have investigated whether robotic pets could achieve the same benefits as traditional animal-assisted therapy. Three studies found that these robots were able to reduce loneliness [99] and stimulate interaction [75,82], with no differences between the robot and a live dog. One study [89] found that attention toward the robot decreased with time but remained stable with a live dog, whereas another study [35] found that the interaction was statistically significantly greater with the robot than with a live dog.

Residents and caregivers primarily reported positive experiences of using the robots and had positive attitudes toward the robots. However, a few studies [36,41,55,66,68,77,87,96] reported disapproval, and 3 studies [36,65,78] found that human companionship or human-facilitated interventions were preferred by the older adults. In 2 studies, the older adults perceived the robots to be dependent on them, which resulted in a sense of unwanted responsibility [41,96]. In 2 other studies, the older adults were not interested in interacting with the robots because they perceived the robots as toys [36,77]. In 1 study [66], the staff's perception of the robots' agency decreased over time.

Our review illuminated several concerns related to care robots as well as barriers to their use. Ethical concerns regarding privacy [54,64,69,95], maintaining autonomy [68,95], and age appropriateness of the robots [36,77] were common themes. One study illuminated safety concerns regarding relatives responding to emergencies via a telepresence robot instead of caregivers [64]. Barriers to use included technical difficulties [38,45,51,54,57,64,77,84,95], difficulty hearing [64,85,88,102] and seeing [48] the robots, and physical limitations [48,51,85,96,100]. However, other studies found the robots easy to use despite cognitive impairments and technological illiteracy [45,57,67,68,102].

Factors Influencing the Effects of Care Robots

Several factors have been repeatedly identified as possibly influencing the impact of care robots on older adults living in assisted living facilities. Gender was one such factor, although the results were inconsistent. For example, one study [102] found no differences between men and women participants, but another study found that robot interactions tended to follow socially constructed gender norms: men participants were primarily interested in the robot's technical functions ("engineer-style" interaction), whereas women participants interacted with the robot as if it were alive [61]. The results were also mixed with respect to how participants' age and level of cognitive decline affected robot-based interventions' efficacy. Some studies found better results with younger participants [90] and those with milder cognitive decline [88,90], whereas others found better results with older participants [53] and those with more advanced cognitive decline [53,70,79,84]. Another potential factor that could have influenced the results of the studies was whether the robots spoke the participants' native languages. In 3 studies, the robots did not speak the participants' native language or use an appropriate accent, which may have contributed to reduced participation [66] and reduced satisfaction [34] as well as increased staff involvement for translation services [84].

In several studies, the robots' limited capabilities reduced their efficacy or reduced the older adults' interest in the robots [45,51,85,86,96,100,101]. For example, 1 robot's [101] small size contributed to a reduced range of motion during physical therapy sessions. Another robot [45], which assisted older adults with medication administration, required caregiver presence because it lacked the essential capabilities for medication administration such as offering a glass of water. In 2 studies, the older adults wished that the robot had a companion element [51] or was more human like [100].

Novelty effects were a potential factor that may have affected the effects of care robots. Novelty effects are caused by the initial reaction to a new technology, as opposed to the effects

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of long-term use once the technology is no longer perceived as new [103]. In 5 studies, the initial positive effects of the robots decreased or were no longer significant by the end of the study [80,84,86,89,91]. However, other studies have demonstrated that engagement with and benefits of the robots increased over time [38,42,44,60,62,98,104]. Although many of these studies were not long enough to refute novelty effects, 1 study [98] demonstrated an increase in interactions over a 7-week period; 1 study [62] demonstrated an increased willingness to interact with the robot over 8 weeks; 1 study [38] found that robot use increased from year 1 to year 2; and a 4-year-long study [42] demonstrated significant improvements in emotional, visual, and behavioral engagement from baseline.

Robots' Impact on Caregivers and the Care Environment

Many studies (27/69, 39%) relied on facilitation of robots by researchers, nursing staff, or relatives [35,38,42-45,48,52,58,59,61,62,67,72,75-77,79-81,83,84,89,90,96,98,101]. Four of these studies [38,52,62,101] suggested one-on-one sessions or groups of <3 to maximize the benefits of robots, but one-on-one sessions were time intensive for caregivers [38]. Of the few studies that compared mediated and nonmediated interventions, 2 studies [43,59] found better results with less staff mediation, and 3 studies [61,72,96] found that the interventions were more effective with staff mediation.

Caregiver shortages have been repeatedly cited as a rationale for studying robots in assisted living facilities, but few studies have addressed the impact of robots on professional caregivers and their work environments. In studies that explored the impact of robots on professional caregivers, robot use was associated with nursing staff's attitude toward the robot [65], caregivers' high workload was identified as a barrier to incorporating the robots into care [65,96], and operating the robots was found to be a burden and increased workload for the staff [84,88]. One study [38] reported that caregivers desired more preprogrammed activities to reduce the workload associated with using a care robot, and another study [81] addressed this need by systematizing the use of a recreational robot, significantly increasing participation. Another study presented a system that allowed caregivers to teach a robot how to facilitate a game with residents and allowed caregivers to personalize the robot's behavior [67]. Several studies emphasized that care robots were not meant to replace nurses, but instead they should be treated as an adjunct method of providing care [43,52,65]. One robot that played games with the residents freed caregivers to perform other tasks [33], caregivers in 1 study appreciated the help of a medication delivery robot [51], and another robot demonstrated the potential to reduce caregiver burden by responding to nurse calls and collecting real-time patient information [69]. The only study to compare job satisfaction before and after a robot intervention found a significant increase for the control group only, which received no robot intervention [66].

Comparisons of Robot- and Human-Facilitated Interventions

Instead of comparing robot-facilitated interventions with human-facilitated control groups, most studies (68/69, 99%) either had no control group or compared robot interventions with control groups that received treatment-as-usual. The studies that used treatment-as-usual control groups provided little to no description of usual care or how it was controlled for. This makes it impossible to determine whether the benefits discovered were because of the robot itself or because of the increased attention from being in a research study. Only 1 study in our review directly compared the effects of a robot-facilitated intervention with a comparable human-facilitated intervention [39]. The results of that study indicated that the therapeutic effects of occupational therapist–led sessions were significantly greater than those of robot-directed sessions. The authors concluded that robot-facilitated sessions cannot replace sessions with occupational therapists; however, they suggested that in settings with limited human resources, robots could be an appropriate alternative to occupational therapists [39].

Methodological Approaches to Care Robotics in Assisted Living Facilities

Several methodological limitations were noted throughout the final sample of studies included in our review. All studies in this literature review relied on convenience samples, and 5 studies lacked reporting on participant characteristics [43,47,56-58]. Observations, interviews, and surveys were the 3 most common methods of data collection. Observations were made by the research team, by caregivers employed at facilities, or via the robots' software; however, little to no information was provided on how the assessors were trained. Finally, >20 different questionnaires were used, and there was little discussion about the reliability and validity of these measurement tools.

Discussion

Overview

This review examined 73 publications from 69 unique studies on the use of robots in assisted living facilities. The findings of studies on older adults were mixed, with some studies suggesting positive impacts of robots, some expressing concerns about robots and barriers to their use, and others being inconclusive. Although many therapeutic benefits of care robots were identified, methodological limitations weakened the internal and external validity of the findings of the studies. Few studies (18/69, 26%) considered the context of care: most studies (48/69, 70%) collected data only on recipients of care, 15 studies collected data on staff, and 3 studies collected data on relatives or visitors. Theory-driven, longitudinal, and large sample size study designs were rare. Across the authors' disciplines, a lack of consistency in methodological quality and reporting makes it difficult to synthesize and assess research on care robotics.

Using the PAGER framework [28], we synthesized our findings into five patterns: (1) effects, perceptions, and experiences of care robots; (2) factors influencing the effects of care robots; (3) robots' impact on caregivers and the care environment; (4) comparisons of robot- and human-facilitated interventions; and (5) methodological approaches to care robotics in assisted living facilities. Table 1 presents an overview of the analysis of these patterns. We discuss the implications of each in detail in the following sections.

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Table 1. PAGER (Patterns, Advances, Gaps, Evidence for practice, and Research recommendations) framework.

Pattern	Advances	Gaps	Evidence for practice	Research recommendations
1. Effects, perceptions, and experience of care robots	Evidence shows mixed effects (positive, neutral, or inconclusive) and mostly positive perceptions and experiences of robots.	Further systematic research is needed to fully understand the effects, perceptions, and experiences of robot use.	There is growing evidence of the potential of robots to improve the health of older adults living in assisted living facilities.	Continue developing innovative robots to meet the needs of older adults and caregivers. Continue investigating the effects, perceptions, and experiences of robots.
2. Factors influencing the effects of care robots	Evidence suggests that a user's age, cognitive decline, gender, and culture impact the effect of robots.	Further study is needed to confirm and understand the factors that influence effects of care robots to inform personalization of robot interventions.	To develop effective robots, it is important to consider the factors that influence a person's attitude and response to robots.	Collaborate with interdisciplinary teams to develop personalized robotic interventions, achieve representative samples, and explore novelty effects.
3. Robots' impact on caregivers and the care environment	Evidence shows that human mediation affects the efficacy of robots. Evidence also shows that robots can increase workload for caregivers, which is a barrier to use.	Further study is needed on how human mediation affects robot efficacy. Evidence on how robots will be implemented into busy workloads is lacking.	It is crucial for caregivers to be considered in the design of robots.	Study the impact of human mediation on the efficacy of robots. Study how robots impact caregivers. Involve caregivers directly in the design of robot interventions.
4. Comparisons of robot- and human-facilitated interventions	Growing evidence supports the benefits of robot-facilitated interventions compared with treatment-as-usual, but when compared with equivalent human-facilitated interventions, the robot is less effective.	Research that compares robot-facilitated interventions and human-facilitated interventions is limited.	Growing evidence supports the benefits of robot-facilitated interventions, but there is little evidence that robots can provide the same quality of care as a human can.	Future research should carefully consider whether a robot-facilitated intervention is appropriate instead of a human-facilitated alternative. Future robot-based interventions should be designed to support human caregivers.
5. Methodological approaches to care robotics in assisted living facilities	A lack of consistency across disciplines in methodological quality and reporting makes it difficult to synthesize care robotics research and perform quality assessments.	Further systematic research is needed on the use of robots in assisted living facilities, with increased control and quality of reporting.	Methodological limitations reduce internal and external validity, making it difficult to make claims about the efficacy or best practices of care robots.	Develop interdisciplinary guidelines for conducting and reporting high-quality studies. Consult content experts to select appropriate and valid measurement tools. Use theory to guide studies.

Effects, Perceptions, and Experience of Care Robots

Various robotic platforms were presented in the reviewed studies; social robots were the most common (60/69, 87%), with PARO being the most frequently studied (22/69, 32%). Less commonly studied robots were assistive (6/69, 9%) and telepresence robots (3/69, 4%). The studies' findings were mixed: some suggested therapeutic effects of the robots, but others were neutral or inconclusive. The most commonly reported benefit of the robots was improved mood and emotional states [33,41,42,44,49,52,55,72,74,76,78,80,81,84,85,87,92-94]. Other commonly identified benefits were increased social interaction [31,36,41,42,52,55,58,59,63,69,72,75,81,82,95-98], reduced loneliness [36,92,99], evocation of positive memories [59,65,85,96,100], cognitive stimulation [31,59,78], improved quality of life and well-being [53,65,79], reduced pain and medication use [85,86], improved behavior [49,55,80], and increased movement [50,62,72,100,101]. Similar findings were identified by other literature reviews [11,12]. In addition, there is some evidence that robotic pets could be a feasible alternative to animal-assisted therapy [35,75,82,99].

For the most part, participants accepted the robots and reported positive experiences of using the robots. The most common concerns related to the adoption of robots in the assisted living facilities were privacy [54,64,69,95], autonomy [68,95], age appropriateness of the robots [36,77], and safety [64]. Common barriers to use included technical difficulties [38,45,51,54,57,64,77,84,95], hearing and vision impairments [48,64,85,88,102], and physical limitations [48,51,85,96,100]. Similar concerns and barriers were noted in other literature reviews [5,13]. Although there is growing evidence of the potential for robots to improve the health of older adults, further research is needed to systematically explore the efficacy of care robots as well as participants' perceptions and experiences of their use.

Factors Influencing the Effects of Care Robots

The impact of age and cognitive decline on the efficacy of care robots remains inconclusive. Some interventions appeared to be better suited for younger participants with milder cognitive decline [88,90], whereas others might be better suited for older participants with more advanced cognitive decline [53,70,79,84]. The impact of gender on the efficacy of care robots was also inconclusive (all but 1 study included in our review had a majority of women participants). The use of convenience samples makes it difficult to gain the perspectives of those who are resistant to care robots. Future studies should include study samples representative of assisted living facilities to fully

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understand the key factors that influence geriatric robotic care. Further research is also needed to examine whether and how novelty effects might affect residents' and staff's responses to care robots. Existing robots tend to have limited functions, which may have contributed to a novelty effect. Prestudy exposure to robots might be an effective way to reduce the impact of novelty effects [95].

These findings also suggest a need to personalize robot-based interventions rather than adopt a one-size-fits-all approach. The nursing discipline has a long tradition of valuing person-centered care [107]. Instead of standardizing care to a whole group of people, person-centered care is holistic, individualized to the unique needs of the person, respectful, and empowering [108]. With a person-centered approach, care robots will be more effective and will better meet the needs of older adults living in assisted living facilities. It is worth noting that 2 studies in this review attempted to personalize robot services, which evoked positive memories and engaged the older adults [34,42].

In addition to personalization based on age, level of cognitive decline, and gender, robots should be tailored to other important factors such as cultural backgrounds. This includes, but is not limited to, using the native language of users. A prior integrative review found that a person's culture influences their attitudes, engagement, likeability, and perceptions toward a robot [109]. Further studies are required to understand the key factors that influence individuals' attitudes and responses to care robots. The care robotics field will benefit from partnering with nurse researchers and others in the health sciences discipline who have experience in developing and implementing person-centered care.

Robots' Impact on Caregivers and the Care Environment

Caregiver shortages have been repeatedly cited as a rationale for studying robots in assisted living facilities, but few studies have investigated the impact of robots on professional caregivers. Caregiver involvement was essential to the success of many robotic interventions, but few studies considered how robots would be implemented within an already heavy workload. Sharkey [110] argued that the benefits of robots are likely the result of skilled and careful use by caregivers and family members. Our findings support this claim and suggest that human mediation plays an important role in the efficacy of care robots; however, further research is needed to fully understand the impact of robot adoption and use on staff and family members. Knowing whether and how much human mediation is required to achieve the full benefits of care robots is essential because if the use of a robot is burdensome for caregivers, caregiver burnout will worsen or robots will not be used to their full potential.

The few studies in our review that focused on caregivers suggest that robots have the potential to increase the capacity for care by freeing caregivers to perform more meaningful tasks; however, robots also have the potential to increase workload, which is a barrier to their use. One study successfully increased participation by systematizing a robotic program to reduce barriers for caregivers [81]. It is crucial for researchers to carefully consider caregiver needs when designing robots; otherwise, the benefits identified in this literature review will not be achieved. Furthermore, future studies should address how robots will be implemented into an already busy workload.

Comparisons of Robot- and Human-Facilitated Interventions

Instead of comparing the robots with an equivalent human-facilitated control group, most of the studies (68/69, 99%) included in our review either had no control group or compared the robots with treatment-as-usual. Furthermore, these studies provided little to no description of usual care or how it was controlled for. This makes it impossible to determine whether the benefits discovered were because of the robot itself or because of the increased attention from being in a research study.

In a systematic review on the use of robot-assisted therapy for upper limb recovery after stroke, the authors emphasized that there is no reason to believe that robot-facilitated therapy would have better results than human-facilitated therapy if all other variables were the same [111]. The same is true for care robots in assisted living facilities, as evidenced by the studies that showed better results from human-facilitated interventions or preference for human-facilitated interventions [36,39,65,78,88]. Despite the limitations of using treatment-as-usual control groups, high-quality studies that compare robot-led interventions and usual care can be helpful for determining the benefits of care robots in comparison with the current state in assisted living facilities. With a growing gap between the number of older adults needing care and the number of professional caregivers, it might be unrealistic to expect assisted living facilities to implement additional human-facilitated interventions. Therefore, robots may be a more practical alternative. Either way, it is crucial to carefully consider whether a robot-facilitated intervention is appropriate instead of a human-facilitated intervention. More importantly, it may be necessary for researchers to recognize that robots should not fully replace humans and that robot-based interventions should be designed with the goal of supplementing humans.

Methodological Approaches to Care Robotics in Assisted Living Facilities

Although this review identified many reported benefits of using care robots, these findings should be interpreted with caution. The research practices and methods currently used in the development and evaluation of robotic systems fall short of those expected by the medical informatics and health technology research communities. Methodological limitations in studies on care robotics have been noted in several other scoping reviews [20-22,112,113]. Establishing standards in research design and in the reporting of study findings is urgently needed for this emerging interdisciplinary work, and it will increase the mutual contribution of caregivers and technologists as the field of robotics moves from the laboratory into its application in care settings.

Many of the studies (15/69, 22%), especially those identified in the engineering databases, lacked reporting on methods and participants' characteristics. This echoes a similar finding of a literature review that examined the use of artificial intelligence

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for caregivers of individuals with Alzheimer disease [114]. The lack of consistency across disciplines for what is considered high-quality research makes it difficult to synthesize care robotics research and perform quality assessments. As health care technology continues to advance and as disciplines further merge, it is increasingly important for interdisciplinary criteria to be established for studies and publications.

Observations, interviews, and questionnaires were the 3 most common methods of data collection in the reviewed studies; however, the specifics of these methods varied greatly among studies. More than 20 different questionnaires were used, which makes it difficult to compare the results of the studies, and few studies described the reliability and validity of their measurement tools adequately. Future researchers should consult content experts to ensure that appropriate and valid measurement tools are selected for the setting and population. Studies that relied on researchers' or caregivers' observations and assessments (ie, most of the studies) provided little to no information on how assessors were trained, which weakens the internal validity of the findings. Furthermore, serious concerns about bias arise from the widespread use of caregivers, who have prior relationships with residents, to observe and assess the residents. Although proxy measures are often appropriate and necessary for assessing participants with cognitive impairments and can sometimes be an efficient method of longitudinal data collection, no reliability assessments of these measures were conducted, and the studies did not supply information on the training of proxy raters.

The methodological limitations of the reviewed studies reduced their internal and external validity, making it difficult to make claims about clinical efficacy or best practices. To improve the level of evidence, attention should be given to developing interdisciplinary guidelines for conducting and reporting on high-quality studies as well as prioritizing theory-driven research. Although the methods used in these studies are commonly accepted for developing, demonstrating, and assessing novel robotic *functionality*, the responsible and successful application of robotic technology in care settings demands an evolution toward the standards of evidence and validity developed within health research broadly.

Limitations

Our scoping review had several limitations. First, it is possible that important and relevant studies were missed as only 5 electronic databases were searched. To mitigate this possibility, we chose a broad range of databases representing engineering, computer science, and health sciences. Second, we included only publications with full text written in English; therefore, it is possible that we missed important relevant studies written in other languages. Third, our search terms were not exhaustive, and we may have missed important relevant studies that used different terms for "assisted living facility" or "older adults." To mitigate this possibility, we reviewed the search terms of prior literature reviews in the field and consulted an information science librarian. Fourth, owing to overlaps between robotic platforms and their uses, we did not further categorize the robots by type. Future work should focus on creating clear definitions of the different categories of care robots to facilitate clearer distinctions and comparisons.

Conclusions

The implementation of robots in assisted living facilities has profound implications for both older adults and professional caregivers. Care robots have the potential to improve the lives of older adults and the work lives of professional caregivers; however, concerns about their efficacy, ethics, and best practices remain. Despite the prevalence of research on this topic, relatively little work has been conducted with a specific focus on assisted living facilities and determining gaps in understanding how robots impact assisted living facilities. Previous research also overrepresents social robots relative to other types of assistive robots [115] and future research should ensure a more holistic approach going forward.

This scoping review identified 5 patterns of existing research (Table 1). Although existing knowledge, gaps, and recommendations for research vary across patterns, there are commonalities across them. Overall, we found a relative lack of systematic research methods commonly accepted in medical informatics to determine the feasibility and efficacy of robots in assisted living facilities. Research on how robots will change both geriatric care and the work environment of assisted living facilities is lacking, limiting our understanding of how robotics might impact the fuller context of care within which it will operate.

Interdisciplinary collaboration among health sciences, computer science, and engineering as well as agreement on methodological standards will be essential to enable care robotics research to realize its potential benefits and minimize its detriments to older adults and their caregivers. Although many approaches should be investigated, we suggest that formal categorizations of care work are a particularly promising artifact that can be used to strengthen the emerging collaborations that constitute care robotics for older adults and their caregivers.

A more holistic categorization of care interventions would provide a promising vantage point for the interdisciplinary negotiations needed to advance care robotics in a way that augments the skills and knowledge of care workers. The scope of care interventions provided by existing care robotics systems is very narrow, as evidenced in this study and elsewhere [116]. A more encompassing sense of what nurses and other care workers actually *do* could greatly inform the science of care robotics. Could nursing ontologies of interventions and outcomes help care robotics research be more accountable to care professionals and their patients? Could a sociological understanding of how nurses provide care inform the development of robotic technology designed to assist caregivers, rather than patients?

These questions and others must be fully explored so that robotic interventions can be appropriately oriented within the full context of care. Only by understanding patient needs and acknowledging existing care professionals' knowledge and skills can robots assume a contributing role on care teams.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) checklist.
[DOCX File , 108 KB - aging_v6i1e42652_app1.docx]

Multimedia Appendix 2
Detailed search strategy.
[DOCX File , 14 KB - aging_v6i1e42652_app2.docx]

Multimedia Appendix 3
Patterning chart analysis.
[XLSX File (Microsoft Excel File), 48 KB - aging_v6i1e42652_app3.xlsx]

Multimedia Appendix 4
Summary of the 73 papers in the final sample.
[DOCX File , 56 KB - aging_v6i1e42652_app4.docx]

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Abbreviations

PAGER: Patterns, Advances, Gaps, Evidence for practice, and Research recommendations
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews

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Review

Monitoring the Well-being of Older People by Energy Usage Patterns: Systematic Review of the Literature and Evidence Synthesis

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Abstract

Background: Due to the aging population, there is a need for monitoring well-being and safety while living independently. A low-intrusive monitoring system is based on a person's use of energy or water.

Objective: The study's objective was to provide a systematic overview of studies that monitor the health and well-being of older people using energy (eg, electricity and gas) and water usage data and study the outcomes on health and well-being.

Methods: CENTRAL, Embase, MEDLINE (Ovid), Scopus, Web of Science, and Google Scholar were searched systematically from inception until November 8, 2021. The inclusion criteria were that the study had to be published in English, have full-text availability, target independent-living people aged 60 years and older from the general population, have an observational design, and assess the outcomes of a monitoring system based on energy (ie, electricity, gas, or water) usage on well-being and safety. The quality of the studies was assessed by the QualSyst systematic review tool.

Results: The search strategy identified 2920 articles. The majority of studies focused on the technical algorithms underlying energy usage data and related sensors. One study was included in this review. This study reported that the smart energy meter data monitoring system was considered unobtrusive and was well accepted by the older people and professionals involved. Energy usage in a household acted as a unique signature and therefore provided useful insight into well-being and safety. This study lacked statistical power due to the small number of participants and the low number of observed events. In addition, the quality of the study was rated as low.

Conclusions: This review identified only 1 study that evaluated the impact of an energy usage monitoring system on the well-being and safety of older people. The absence of reliable evidence impedes any definitive guidance or recommendations for practice. Because this emerging field has not yet been studied thoroughly, many questions remain open for further research. Future studies should focus on the further development of a monitoring system and the evaluation of the implementation and outcomes of these systems.

Trial Registration: PROSPERO CRD42022245713; https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=245713

(JMIR Aging 2023;6:e41187) doi:10.2196/41187

KEYWORDS

smart energy meter; healthy aging; activities of daily living; independent living; monitoring; older adults; devices; risk; well-being; effectiveness; design; safety

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Introduction

The number of older people is increasing worldwide due to a global increase in life expectancy [1]. Between 2015 and 2050, the percentage of "older people," in this study defined as those 65 years and older, will nearly double as a proportion of the global population, from 12% to 22%, respectively [2]. As a result, the old-age dependency ratio (ie, the ratio of people aged 20-64 years to people 65 years and older) has declined from around 4 working adults for every person older than 65 years in 2001 to fewer than 3 in 2020 [3]. This means that roughly 1 adult older than 65 years is financially dependent on less than 3 working adults (aged 20-64 years) at present [4]. In addition, the proportion of single-person households in the European Union increased as well, from 25% in 2010 to 35% in 2017 [5]. Meanwhile, more and more older people live independently—the "aging in place" trend [6,7]. Independent living means noninstitutionalized living, with the possibility of extra professional help if needed [8].

Technologies are being developed within the health care sector to enable older people to live independently for longer. There is a wide variety of health technologies available to monitor symptoms of chronic disease; in the World Health Organization report on digital health, a complete overview is provided [9]. Technologies include the Internet of Things, virtual care, remote monitoring, artificial intelligence, big data analytics, blockchain, and smart wearables, but also platforms and tools enabling data exchange and storage and tools enabling remote data capture [9]. These technologies aim to provide the necessary tools to monitor the symptoms of chronic conditions like dementia. Research by Brownsell et al [10] showed that an individual's health status can be determined based on simple interactions between an individual and their immediate environment. This determination is the premise of activities of daily living (ADL) monitoring technologies, which aim to support the safety of the older person and enable both formal and informal caregivers to check in with the older person. For example, sensors are placed inside the homes of older people to detect movement, sleep patterns, occupancy, living conditions, or appliance usage [10]. There is a vast amount of literature available describing the potential of smart homes [10-12]. For example, a longitudinal study by Kaye et al [12] showed that the placement of infrared motion sensors could monitor walking speed and other in-home activity metrics. These solutions, however, require the installation and maintenance of specific hardware and software in the house or apartment of the older person. Additional sensors in the house or apartment, such as cameras, motion detectors, or heart rate monitors, can also be considered obtrusive, expensive, and violate the resident's privacy [11,13].

A potential low-intrusive system for monitoring may be designed using smart energy meter data. Smart energy meters are increasingly present in houses and apartments worldwide, automatically measuring and recording energy usage. A smart energy meter is a meter that keeps track of the energy supply and sends meter readings to the energy supplier automatically [14]. A study by Berg Insight [15] reported that the expectation is to reach 72% of smart electricity meter coverage in Europe by 2026. In 2024, in the EU, more than 100 million smart meters for electricity and over 50 million for gas will be rolled out [16]. This increase in coverage provides an opportunity for this type of research. The growing availability of smart energy meters and the relative simplicity of recording, storing, and transmitting data have created a potential opportunity to monitor activity among older people to support well-being and safety.

Specifically, age-related diseases, such as cognitive decline, have a direct impact on ADLs [17,18]. Based on the disaggregation of energy usage, ADL patterns can be established in a simple, unobtrusive, and inexpensive way [19]. By disaggregating the total energy load, it is possible to determine which appliances are being used on a certain day [20-23]. This technique, also known as nonintrusive load monitoring, makes it possible, by using algorithms, to infer the fine-grained energy usage patterns of different appliances in the household [20,24-26]. This energy usage pattern could be linked to health-related activities, such as cooking, which can therefore be used as a proxy for the general health and safety of the persons living in this household and possibly anticipate accidents or hospitalization [27].

The aim of this review was 2-fold. The first aim was to provide an overview of existing evidence describing initiatives that developed a monitoring system for the well-being and safety of independent-living older people using energy (ie, electricity and gas) and water usage data. For the remainder of the paper, we will use "energy" to refer to electricity, gas, and water. The second was to provide an overview of the outcomes of these systems on the well-being of older people. Moreover, if implementation outcomes were described, these were also reported.

Methods

Search Strategy

This systematic review was registered at PROSPERO (ID 245713). The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement was used as a guideline (Multimedia Appendix 1) [28]. A systematic literature search was conducted within the databases CENTRAL, Embase, MEDLINE (Ovid), Scopus, Web of Science, and Google Scholar in November 2021 to identify relevant studies. The following keywords were included in the search: "smart meter," "energy meter," "electric meter," "gas meter," "water meter," "independent living," "monitoring," "support," "activity recognize," "anomaly," "daily life activity," and "community-dwelling." The search strategy was determined in collaboration with a medical information specialist; the full search strategy can be found in Multimedia Appendix 2. Additional articles were added via a manual search for eligible articles based on the reference lists of the included articles.

Inclusion and Exclusion Criteria

Language

The inclusion criteria included studies published in English. Non-English studies were excluded from the study.

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Article Availability

Only full articles were included. Conference abstracts and proceedings were excluded; for conference abstracts, corresponding authors were contacted for full text; these articles were excluded if they were unavailable.

Target Population

The study is based on independent-living people 60 years and older from the general population. Studies recruiting only clinical populations (eg, patients diagnosed with dementia) and studies among nonhumans were excluded.

Type of Study

Studies with an observational design (ie, a design where the participant is observed and analyzed in their natural or real-world setting) and that assessed the outcomes of a monitoring system based on energy usage on outcomes regarding the well-being and safety of the older people were included. Studies assessing only feasibility were excluded.

Study Focus

Studies that evaluated the monitoring system based on energy usage, including electricity, gas, or water were included. Studies using only wearable appliances to determine the well-being of the study participants (eg, heart rate appliances and movement sensors) were excluded.

Study Selection

All references were exported and managed using EndNote (version X9; Clarivate Analytics). After duplicate records were removed, title and abstract screening were performed independently by 2 reviewers (SK and YF), based on the predetermined inclusion and exclusion criteria described above. Relevant articles were retrieved for full-text reading and further review by 2 reviewers (SAK and YF). The 2 reviewers discussed disagreements until they agreed. The remaining disagreements were discussed with a third author (AvG) until a consensus was reached.

Data Extraction

A predetermined data extraction form was filled in with the extracted data from the included studies. Extracted information included the first author, year of publication, country, population and characteristics (ie, number of participants, type of population, and age of population), study design, study period, type of monitoring system, health-related outcomes, and effect size. This process was conducted by 2 researchers (SK and YF) independently. Discrepancies were resolved through discussion.

Quality Appraisal

The quality of the included study was assessed with the QualSyst (standard quality assessment criteria) systematic review tool of Kmet et al [29]. This checklist contains 10 items, which were scored from 0 points (no), 1 point (partial), to 2 points (yes). All scores were summed and consequently divided by the total possible sum score to calculate the quality score per study. With this final score, the quality of the study was then rated as high (≥0.75), medium (≥0.55 and < 0.75), or low (<0.55) [29]. This process was performed independently by 2 researchers (SAK and YF). Discrepancies between the researchers were discussed until a consensus was reached.

Results

Search Results

The search strategy identified 2920 articles in the selected databases. After deduplication, 1876 articles remained for the title and abstract screening. Based on the reference lists of the included articles and screened on title and abstract, 52 articles were added via a manual search for eligible articles. After title and abstract screening, 844 articles remained. After screening the remaining full-text articles for eligibility, 41 articles were eligible for inclusion in this systematic review. Finally, 1 article was included; in this article, 2 substudies were reported [27]. The PRISMA flow diagram is presented in Figure 1. The characteristics of the included study are described in Table 1.

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Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram.

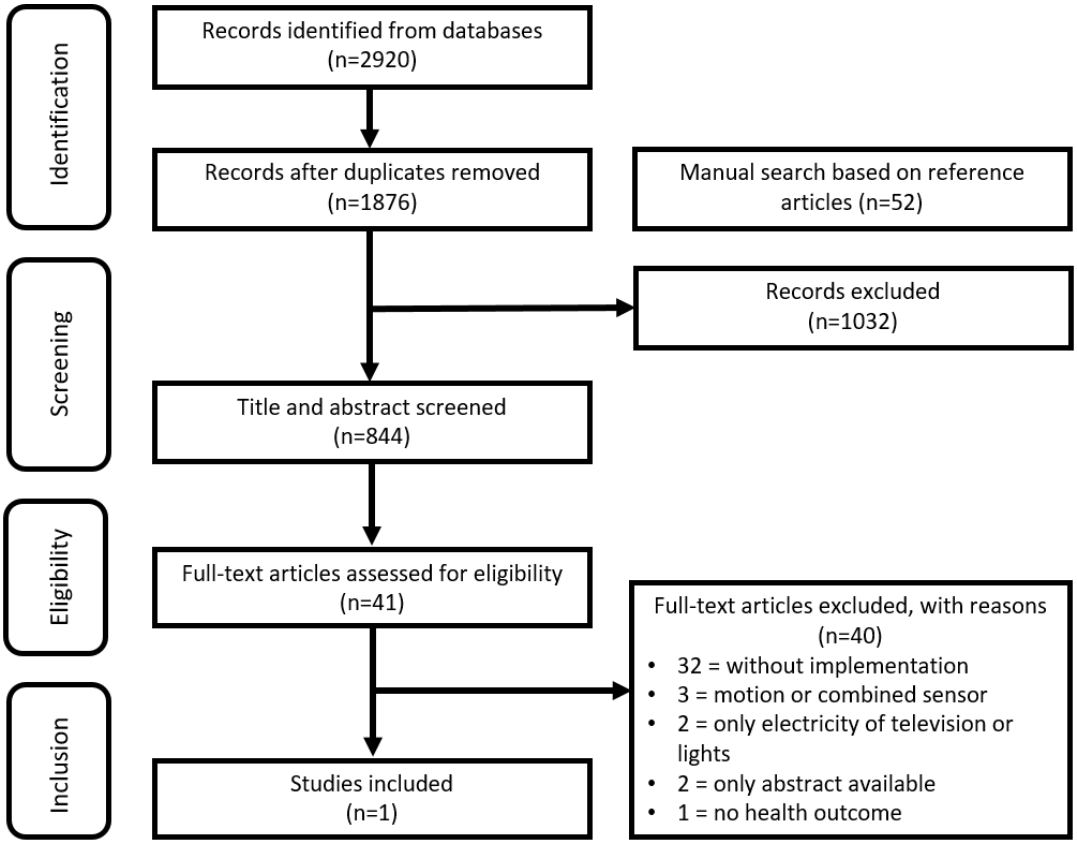


Table 1. Characteristics of the included study.

First author (year of publication)	Country	Participants included, n		Study period		Type of study population	Study design		Age at participation (years)		Determinants or outcome	Level of quality
		Study 1	Study 2	Study 1	Study 2		Study 1	Study 2	Study 1	Study 2		
Noury et al [27] (2011)	France	13	12	Before 2008	2008	Community-dwelling older citizens (1-person household)	Single-arm trial	Single-arm trial	Unknown	80.5	Detection of ADL[a], validity of energy use (daily index of activity), acceptability of the monitoring system	Low[b]

[a]ADL: activities of daily living.

[b]Low quality as rated with the QualSyst systematic review tool by Kmet et al [29].

Study Characteristics and Results

We included 1 article that included the report of 2 substudies. In this study, Noury et al [27] aimed to develop a system for the remote monitoring of large populations of older people living independently at home. In addition, they developed an ADL index and evaluated the relevance and acceptability of the monitoring system as a whole. They used electricity data to study ADLs. They built a unique referential (ie, individual energy use pattern) for each subject, constructed from the mean energy usage of the selected ADLs: food preparation and eating, hygiene, and turning off appliances during diurnal and nocturnal periods. A unique ADL index was computed for each ADL and compared to the corresponding mean value in the referential. The data was obtained by a detector on the residential power line to monitor the energy usage of each electrical appliance in a home [30]. This electricity usage monitoring system could memorize a "signature" for each appliance during a learning phase. Noury et al [27] referred to both ADLs and instrumental ADLs (IADLs). IADLs include housekeeping tasks such as "turning off appliances." For the remainder of the paper, we will use ADLs to refer to both ADLs and IADLs [31].

The study consisted of 2 experiments, both conducted with older people living in single-person households [27]. The first experiment was conducted in 2005 with 13 participants from the LI2G lab (Laboratoire Interuniversitaire de Gérontologie de Grenoble) in Grenoble, France. The second experiment was

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conducted with 12 participants, aged 80.5 (SD 3.2) years, in Sable-sur-Sarthe and Chatillon, France, in 2008. In this study, 3 ADLs (food preparation and eating, hygiene, and turning off appliances) in 4 time periods (morning, afternoon, evening, and night) were studied. Two additional activity levels (diurnal and nocturnal) were also studied, and an ADL index was built, which was validated by a social worker involved with the participants. The results of the study showed that electricity usage data could be a useful method to monitor independent-living older people's ADLs. In addition, they tested this in 2 separate experiments in the population and showed that ADLs can be detected through electricity usage monitoring. They also showed that deviations from the normal 24-hour pattern could be linked to older people's ADL patterns, which were subsequently linked with their health status and interpreted by a social worker. Furthermore, the study was well-accepted by both the participants and the social workers involved, and it was considered a little intrusive. However, participants were afraid of the costs involved in data transfer communications.

Quality Appraisal

The quality of the study, measured with the QualSyst systematic review tool of Kmet et al [29], was rated as low (<0.55). Overall, the QualSyst systematic review tool rated the quality of the evidence in this study as low, as it only included a small number of participants (n=25), and the objective, connection to the theory, data collection, data analysis, and outcomes were incompletely reported. Furthermore, no information on sampling strategy, verification, or reflexivity was reported. Moreover, the conclusion was only partially supported by the results. Next to that, participants self-reported their ADLs, and the questionnaires were not well described [27].

Discussion

Principal Findings

With this systematic review, we aimed to provide an overview of existing initiatives using energy data to monitor the well-being and safety of older people and to describe the outcomes of these energy data monitoring systems. Only 2 substudies were identified in the literature and reported in 1 article [27]. This 1 article was rated as low quality. Moreover, the outcomes for the well-being of older people were not visible. However, it did indicate that independent-living older people and social workers who participated in the study considered the energy usage monitoring system to be a little intrusive and a reliable and potentially beneficial solution for the time management of professionals involved in older persons' care.

Implementation of Monitoring Energy Usage to Support Independent Living

Monitoring energy usage to support independent living requires a process of step-by-step evaluation and testing. It can be described as consisting of 3 elements: monitoring energy usage, appliance and activity recognition, and implementing the system in practice. Figure 2 illustrates the elements that are involved in studying the feasibility of energy usage monitoring.

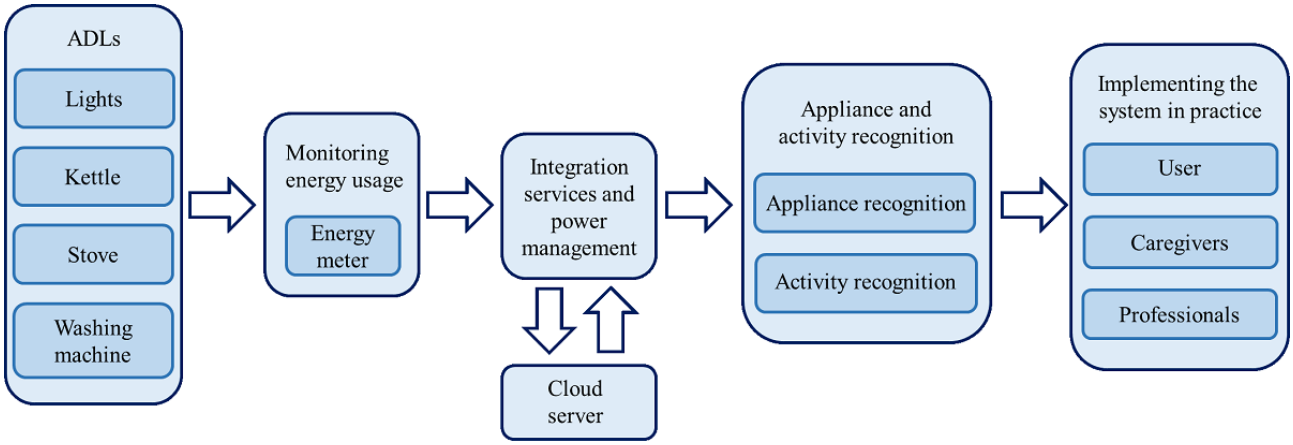
First, regarding the ways of monitoring energy usage, there are 2 main ways of data collection: overall data from all appliances, via, for example, the smart energy meter, or data from just a single appliance. Both approaches have their advantages. Data from a single appliance does not need to be disaggregated; it is already known where the energy usage comes from. For data from the smart electricity meter, however, all electrical activity within the household is included, which requires disaggregation. The Noury et al [27] study described placing a detector on the residential power line, placed inside the main electrical supply cabinet, which monitored electricity usage and acted as a sensor for the total household consumption.

Second, regarding appliance and activity recognition, energy usage monitoring enables the identification of appliances through their energy usage patterns [17]. Subsequently, this pattern can then be used to identify ADL patterns. One way is appliance detection, whereby a pattern of a specific appliance can be recognized within the total energy usage; another way is historical ADL pattern recognition, whereby current energy usage is compared to historical energy usage [17]. Potentially, problems that have a rising prevalence with age, such as insomnia and possibly cognitive decline, can cause problems in ADLs [27]. Energy usage monitoring may, for example, detect deviations from the "normal" 24-hour pattern such as activity during the night [27].

The next step in appliance and activity recognition would be verifying the algorithms with real-life data. The studies identified in this review focused on testing algorithms mainly on already existing energy data or computer-generated energy data. These studies reported a reasonable (50%) to good (84%) accuracy for recognizing (kitchen) appliances [21,32-34].

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Figure 2. Energy usage monitoring elements. ADL: activities of daily living.



Comparison to Prior Work

However, few studies were conducted to test the accuracy and outcomes of an energy usage monitoring system in real-life settings [17]. Billis et al [35] used smart television data to extract meaningful information about television usage patterns and subsequently associate them with the clinical findings of experts. Another study by Franco et al [36] tested the feasibility of a system for noninvasive monitoring of subjects at home by recording electrical activity from room lighting and other electrical domestic appliances. This type of monitoring—monitoring by specific types of appliances—is less sensitive to deviations from the average 24-hour energy usage pattern compared to an energy usage monitoring system operating via the smart meter because these particular appliances do not include the total activity of a household. However, the advantage of this system is that the collected data does not need to be disaggregated; it is immediately clear which appliance was used [35,36].

Lastly, it is needed to implement the system in practice and collect information on the impact on well-being, safety, and usability. The only article included in this review, by Noury et al [27], included energy usage monitoring, appliance and activity recognition, as well as testing the system in practice. Although the article of Noury et al [27] concluded that such a system is promising and appreciated by users, more research is needed to further confirm and elaborate on these findings. Moreover, to implement a monitoring system in practice, studies are needed to evaluate the design and usability of the system, for example, the client interface and communication.

Challenges to Implementing Energy Use Monitoring

Although energy usage monitoring is a promising method, some challenges should also be mentioned. We divided the challenges according to the levels of the socio-ecological framework [37]. First, on a personal level, energy usage monitoring is considered unobtrusive; however, privacy-related issues are still involved [32]. A study by Kolter and Johnson [32] reported that sharing real-time energy usage data can potentially be harmful since these data can easily be linked to being at home or not. During the rollout of smart energy meters on an international level, concern has been expressed within the population about the possibility of privacy breaches [38]. These discussions and issues should be considered in future studies evaluating the potential of smart-energy monitoring systems. Therefore, separating real-time energy usage data from identifiable personal data is essential. Furthermore, older people's attitudes toward technology are relatively mixed [39]. Those who fear technology use are generally afraid of privacy breaches, loss of self-determination, and the replacement of human contact [39,40]. Others embrace technology and are more dependent on it, consequently more easily accepting possible negative side effects [39,40]. Counterintuitively, longer independent living can be supported by technologies and, therefore, might protect against a certain loss of privacy that will be in place when living in an institution [41].

Second, on a community and structural level, data collection from a smart energy meter can be easily achieved with a reliable internet connection, yet even in Europe, not everyone has access to the internet [42]. In addition, ADL patterns in older people are not always stable. It is relatively easy to detect deviations in ADL patterns; however, a deviation is not necessarily related to a change in health and could also mean that this person does not have a regular lifestyle [10]. Therefore, it can be challenging to relate deviations from normal ADL patterns to changes in well-being [10]. Discovering deviations in the lifestyle or ADL pattern would require longer-term monitoring. A potential advantage of monitoring electricity consumption by smart meters is that smart meters can perform this sort of long-term monitoring.

Strengths and Limitations

To the best of our knowledge, this is the first systematic review addressing ways to monitor the well-being and safety of older people using energy use data and describing their outcomes. Furthermore, we used a broad search strategy, including electricity, gas, and water, to identify all potential studies on this topic.

First, the main limitation of this systematic review is the lack of studies that could be included after screening—only 1. Overall, the QualSyst systematic review tool rated the quality of evidence in this study as low, as it only included a small number of participants (n=25), and the objective, connection to the theory, data collection, data analysis, and outcomes were incompletely reported. Furthermore, no information on sampling strategy, verification, or reflexivity was reported. Moreover,

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the conclusion was only partially supported by the results. Next to that, participants self-reported their ADLs, and the questionnaires were not well-described [27]. The lack of studies might have induced selection bias. Second, another methodological consideration of this review is that publication bias cannot be ruled out as only peer-reviewed articles in the English language were included. Third, this review studied older people 60 years and older; there is no set age limit to define "older" [2,43]. In general, with age and decreasing mobility, the chances of unsafe situations increase. For example, adults older than 60 years endure the greatest number of fatal falls [44]. Nevertheless, implementing an energy-based monitoring system may also be useful for other subgroups, independent of age. If an age limit had been set, the conclusions of the review could have better suited a defined age group; now, they are better suited for various subgroups. Fourth, there are several ways, technically, to monitor energy data. However, in this review, we aimed to evaluate the impact of energy monitoring on the well-being and safety of independent-living older people. So, we have limited ourselves to the broad outlines of all technical energy activity monitoring possibilities.

Future Directions

The findings from this study indicate that energy usage monitoring may have the potential to aid in monitoring independent-living older people. Currently, the care for older people is organized more and more at home in Western countries [7]. Consequently, there will be relatively less capacity within high-need facilities for the rising numbers of older people [7].

First, further investigation of energy usage monitoring and the recognition of appliances and activities is required. Specifically, research is needed to examine whether, how, and for which subpopulations energy usage monitoring has potential. Heterogeneity between people increases with age, with an observed peak at 70 years; independent-living older people are therefore not a homogeneous group [45]. Furthermore, there are many levels of activity within a population, making it harder to build one system for the general population [46]. In line herewith, investigating the combination of electricity usage monitoring with other types of monitoring, such as via smart gas or water meters, could have great potential for increasing accuracy [47], especially as not all ADLs can be monitored by electricity usage, such as using the toilet or getting dressed. In addition, not all household appliances can be detected reliably yet [24]. Currently, smart electricity meters are the most installed; smart gas and water meters are less common but are also projected to increase shortly [15,48]. Household water usage can be disaggregated in various ways to produce similar data to electricity usage [49,50]. Smart water meters are at present mostly used for leakage detection and diminishing water use, but this information could also be used for ADL detection [51].

Second, it is recommended to implement the system in practice. Moreover, it is recommended that future studies apply a longitudinal study design with a larger sample size and longer study duration. Noury et al [27] included only 25 participants, who were followed up for 6 months. Since energy usage patterns are unique, it is important to include enough participants to have a representative sample of the target population [21]. Energy usage monitoring relies on energy pattern detection. Since energy usage is highly dependent on external factors like weather conditions, temperature, and the available appliances in a household, it is useful to follow a household for a longer period to take these factors into account and detect changes in 24-hour patterns.

Studies will also benefit from better measurement of well-being and safety outcomes. Since it is an emerging field, there have not been many scientific trials conducted in this field yet. The well-being and safety outcomes of energy usage monitoring and setting up a monitoring system based on this have not been well described yet. Noury et al [27] do mention health outcomes; however, it was not described which specific health outcomes were examined or how these health outcomes were measured. The other screened articles have not mentioned health outcomes at all.

Conclusions

In this systematic review, we aimed to provide an overview of existing evidence describing initiatives that developed and tested the outcomes of a system that monitors the well-being and safety of independent-living older people using energy usage data. Although only 1 article was included, which described 2 substudies that did not have sufficient power for definitive guidance for research and practice, this review has provided an overview of the current literature on energy usage monitoring systems for the well-being and safety of independent-living older people. The absence of reliable evidence impedes any definitive guidance or recommendations for practice. Future studies are recommended to further gain insight into both the technical development of a smart-energy usage monitoring system as well as the implementation of a system and its outcomes for older people and their caregivers.

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Data Availability

Data sharing is not applicable to this study as no data sets were generated or analyzed during this study.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement.
[PDF File (Adobe PDF File), 73 KB - aging_v6i1e41187_app1.pdf]

Multimedia Appendix 2
Full search strategy.
[PDF File (Adobe PDF File), 592 KB - aging_v6i1e41187_app2.pdf]

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Abbreviations

ADL: activities of daily living
IADL: instrumental activities of daily living
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QualSyst: standard quality assessment criteria

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Review

Domains, Feasibility, Effectiveness, Cost, and Acceptability of Telehealth in Aging Care: Scoping Review of Systematic Reviews

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Abstract

Background: Aging is becoming a major global challenge. Compared with younger adults, the older population has greater health needs but faces inadequate access to appropriate, affordable, and high-quality health care. Telehealth can remove geographic and time boundaries, as well as enabling socially isolated and physically homebound people to access a wider range of care options. The impacts of different telehealth interventions in terms of their effectiveness, cost, and acceptability in aging care are still unclear.

Objective: This scoping review of systematic reviews aimed to provide an overview of the domains of telehealth implemented in aging care; synthesize evidence of telehealth's feasibility, effectiveness, cost benefits, and acceptability in the context of aging care; identify gaps in the literature; and determine the priorities for future research.

Methods: Guided by the methodological framework of the Joanna Briggs Institute, we reviewed systematic reviews concerning all types of telehealth interventions involving direct communication between older users and health care providers. In total, 5 major electronic databases, PubMed, Embase (Ovid), Cochrane Library, CINAHL, and PsycINFO (EBSCO), were searched on September 16, 2021, and an updated search was performed on April 28, 2022, across the same databases as well as the first 10 pages of the Google search.

Results: A total of 29 systematic reviews, including 1 post hoc subanalysis of a previously published large Cochrane systematic review with meta-analysis, were included. Telehealth has been adopted in various domains in aging care, such as cardiovascular diseases, mental health, cognitive impairment, prefrailty and frailty, chronic diseases, and oral health, and it seems to be a promising, feasible, effective, cost-effective, and acceptable alternative to usual care in selected domains. However, it should be noted that the generalizability of the results might be limited, and further studies with larger sample sizes, more rigorous designs, adequate reporting, and more consistently defined outcomes and methodologies are needed. The factors affecting telehealth use among older adults have been categorized into individual, interpersonal, technological, system, and policy levels, which could help direct collaborative efforts toward improving the security, accessibility, and affordability of telehealth as well as better prepare the older population for digital inclusion.

Conclusions: Although telehealth remains in its infancy and there is a lack of high-quality studies to rigorously prove the feasibility, effectiveness, cost benefit, and acceptability of telehealth, mounting evidence has indicated that it could play a promising complementary role in the care of the aging population.

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KEYWORDS

telehealth; telemedicine; telecare; telemonitoring; aging care; health care access; scoping review; digital health; mobile health; mHealth; eHealth

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Introduction

Background

According to the World Health Organization (WHO) statistics, there were 1 billion people aged ≥60 years in 2020, and this number is projected to reach 1.4 billion by 2030 and double to 2.1 billion by 2050 [1]. The shift in population demographics has substantially contributed to the rising demand for and cost of medical care [2], but many older people are still facing inadequate access to appropriate, affordable, and high-quality health care. In a 2010 survey across 32 countries in Africa, Asia, Eastern Europe, Western Europe, and the Caribbean, 63% of the 1265 respondents aged ≥60 years reported that access to health care when required was a challenge [3].

Telehealth, *the delivery and facilitation of health and health-related services including medical care, provider and patient education, health information services, and self-care via telecommunications and digital communication technologies* [4], is one of the many new possibilities that made health care more accessible and has been widely believed to bring various benefits in aging care settings. First, it can expand health services by removing geographic and time boundaries [5] and enabling socially isolated and physically homebound individuals access to a wider range of care options [6]. Second, it can minimize the risk of direct transmission of infectious agents from person to person [7], especially during the recent COVID-19 pandemic [8]. Third, it redefines health care by engaging the patients' familiar settings, so that both the patients and the health care providers can put greater emphasis on the intervention itself, which in turn results in improved efficiency and quality of care [9]. Furthermore, as hospitals and medical providers are under increasing pressure to provide quality care at lower costs, telehealth has been accepted and successful across a variety of medical specialties and settings [9], such as dentistry [10], psychiatry [11], dermatology [12], and COVID-19 consultation [13].

The impacts of different telehealth interventions in terms of their effectiveness, cost, and acceptability were studied; however, the results were not consistent [14-16]. For instance, a systematic review of reviews by Ekeland et al [14] in 2010 showed that 21 of the 80 included reviews concluded the effectiveness of telemedicine, 18 found incomplete evidence, the remaining 41 reviews found limited and inconsistent evidence, and the costs of these interventions were not well understood. In 2021, Snoswell et al [16] revisited the meta-analyses from 2010 to 2019 and discovered that telehealth across a range of modalities could be clinically equivalent or more effective than usual care in cardiovascular disease, dermatology, endocrinology, neurology, nephrology, obstetrics, ophthalmology, psychiatry and psychology, pulmonary, and multidisciplinary care. In the same year, Goharinejad et al [15] conducted a review of systematic reviews in the field of telemedicine, in which the 191 included reviews covering different telehealth modalities (eg, telemedicine, telerehabilitation, tele-diabetes, telecardiology, home telecare, telepsychiatry, teledermatology, and teleneurology) and outcomes (eg, clinical outcomes, cost-effectiveness, and user satisfactions) revealed inconsistent evidence regarding the effectiveness (101 positive, 22 unclear, and 1 negative), cost benefits (42 positive and 20 unclear), and satisfaction (47 positive and 9 unclear). In view of the lack of synthesized evidence, particularly in aging care, and the increased demand for telehealth services since the COVID-19 pandemic [17], we would like to extend the literature by including the latest evidence and focusing on the applications of telehealth for the older population.

Objective

A scoping review generally aims to identify and map the evidence available on a certain topic [18-20]. It is an ideal tool for indicating the volume of literature available and provides a general or detailed overview of the topic's focus [20]; identifying gaps in the research bases; and evaluating future research priorities in a formal, systematic, and transparent manner [21]. Considering the high heterogeneity of telehealth interventions, we sought to conduct this scoping review to identify the domains in which there is evidence for telehealth's feasibility, effectiveness, cost benefits, and acceptability in the context of aging care; discover gaps in the literature; and determine the priorities for future research.

Methods

Review Methodology

This scoping review of systematic reviews was guided by the methodological framework of the Joanna Briggs Institute [22]. The study selection followed the PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analyses) flow diagram, and the reporting and mapping of the body of literature followed the PRISMA-ScR (Preferred Reporting Items for Systematic Review and Meta-Analyses extension for Scoping Reviews) guidelines [23]. The review protocol was registered in the Open Science Framework [24].

Selection of the Reviews

The eligibility criteria were established a priori [22]. We included different types of systematic reviews (eg, rapid reviews, narrative reviews, integrative reviews, systematic literature reviews, and systematic reviews with meta-analysis) that analyzed telehealth interventions involving older users or subgroup analysis of older users with or without known health conditions, including those residing in hospitals, nursing homes, and their homes. The intervention could be any form or subgroup analysis of telehealth intervention involving direct communication between older adults and health care providers. No restrictions were placed on the date and location of publications for this review. Only full-text reviews in English were included, considering the language proficiency of the reviewers, to ensure the quality of study selection and data extraction.

The systematic reviews were excluded if (1) the population did not consist of older adults or the reviews did not perform a subgroup analysis of older adults; (2) the reviews solely focused on the design or algorithm of telehealth interventions, policies, or experts' opinions; (3) the reviews included a broader range of digital health or eHealth interventions but did not present a

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subgroup analysis of telehealth interventions; (4) the language was not in English; or (5) full texts were not accessible.

Search for Relevant Studies

Source of Studies

In total, 5 electronic databases were searched to ensure comprehensiveness: PubMed, Embase (Ovid), Cochrane Library, CINAHL, and PsycINFO (EBSCO). Reference lists of the included systematic reviews were manually searched to identify potentially relevant reviews.

Haddaway et al [25] recommended Google Scholar search to identify gray literature in evidence reviews; however, Google Scholar is an "academic version of Google" [26] and only consists of a "scholarly" subset of the larger Google search index [27]. Therefore, we decided to use Google to identify any new relevant reviews, to ensure the completeness of the search. As Google's search algorithm considers multiple factors and signals, we followed the procedure by Piasecki et al [28] and logged out of all Google accounts during the search to avoid personalized search results. Although we were unable to locate any more relevant results on the fifth and sixth pages, we continued browsing and stopped on the 10th page to ensure that there were no further relevant results.

Search Strategy

The search strategy for this scoping review used a 3-step search strategy. In the initial step, a limited search was undertaken in Embase (Ovid) for relevant systematic reviews, followed by an analysis of the index terms used to describe the articles and the text words contained in the title and abstract of retrieved papers. This step helped us identify two concepts for the search strategy: (1) aging and (2) telehealth. These two concepts and the choice of databases were discussed and agreed upon in consultation with an experienced librarian (YLM) and all team members. In the second step, all identified keywords and index terms were used to develop our final search strategy, which had been consulted with the librarian (YLM) and compared with the published literature to ensure comprehensiveness. As a result of the preliminary search, some of the possible relevant systematic reviews identified did not include the term "review" in their titles or abstracts; therefore, adding the third concept "review" might result in such reviews being excluded. The detailed search strategy and results across all the included databases are provided in Multimedia Appendix 1. Finally, the reference lists of all identified systematic reviews in the included full texts were searched for additional articles.

Selection of Studies

The study selection consisted of two levels of screenings: (1) title and abstract screening and (2) full-text screening, and the reasons for all excluded full texts were recorded. In the first level of screening, 2 independent reviewers (YZ and JSPL) first screened the titles and abstracts of a random sample of 10% (620/6198) of the retrieved articles to ensure consistency in the interpretation of the inclusion and exclusion criteria, while discussions were conducted to reach a consensus in case of any discrepancies. Subsequently, they independently screened the remaining articles, and any study with unclear eligibility was conservatively included in the next step of the full-text screening. Only accessible full-text reviews were considered, and all attempts were made to access full-text copies of the selected articles, with the help of the librarian (YLM) or by directly contacting the author via email.

In the second step, 2 reviewers (YZ and JSPL) independently assessed the full-text articles of all selected reviews. When discrepancies in the assessment were encountered, reviewers discussed among themselves, or with a third reviewer (WPT) acting as a mediator, to achieve consensus.

Data Charting

YZ extracted the characteristics of the included systematic reviews using a data charting form, which included the following items: article title, country of the authors, publication year, type of review (with a reason for not conducting a meta-analysis, if applicable), review aim, number of articles included, conceptual and operational definitions of the terms related to telehealth, inclusion and exclusion criteria, outcomes with main findings, quality of evidence, limitation of the reviews, and future practice and research recommendations. Data were manually copied and pasted wherever possible to avoid any potential misinterpretation.

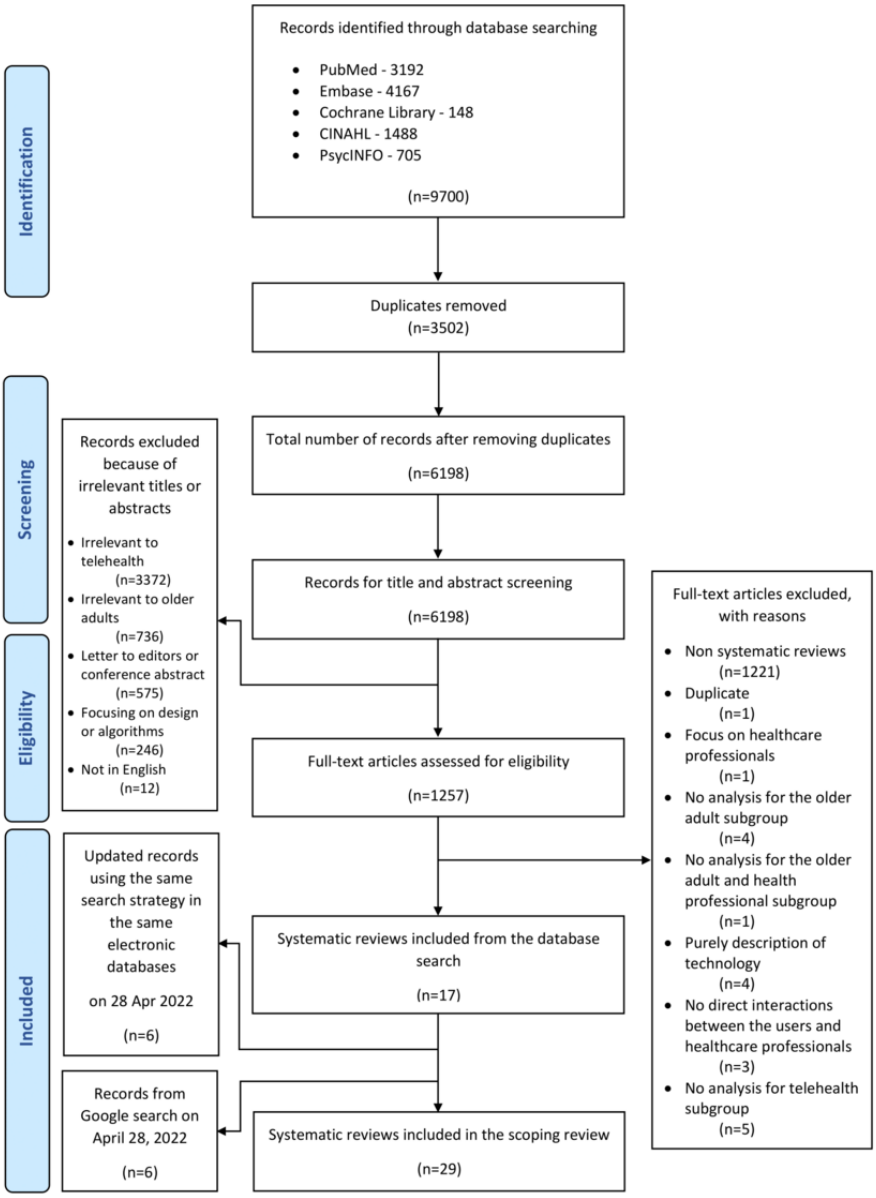
Results

Search Results

Figure 1 illustrates the preferred reporting items for the PRISMA flowchart of the study selection process. The initial database search conducted on September 16, 2021, identified 9700 articles, and 6198 (63.9%) were included in the title and abstract screening stage after 3502 (36.1%) duplicates were removed. In the full-text screening, 1257 articles were assessed for eligibility, and 17 systematic reviews were found to be relevant, including 1 post hoc subanalysis of a previously published large Cochrane systematic review with meta-analysis [29]. We performed another updated search on April 28, 2022, in the same databases as well as the first 10 pages of the Google search and identified another 12 relevant systematic reviews. As a result, 29 systematic reviews were included for data extraction in this scoping review.

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Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2009 flowchart of the scoping review's inclusion.



Characteristics of the Included Systematic Reviews

The characteristics of the included studies are summarized in Multimedia Appendix 2 [30-61].

Of the 29 reviews, 2 (7%) were published before 2010 [62,63], 15 (52%) were published between 2010 and 2019 [29,64-77], and 12 (41%) were published between 2020 and April 2022 [78-89]. A total of 19 reviews provided details on the locations of the included studies [63,68-78,80,81,83,84,86,88,89], with the most prevalent being in North America (the United States and Canada) [63,68-77,80,83,86,88,89], Europe (the United Kingdom, France, Italy, Sweden, the Netherlands, etc) [63,68-71,73-78,80,83,86,88,89], and Australia [68-71,77,78,80,81,86].

The majority of the reviews were narrative, except for 4 that included a meta-analysis [65,74,84,86]. Among the remaining 25 narrative reviews, 5 explained that a meta-analysis was not carried out given the heterogeneity of design, participants, and intervention types [63]; data reporting with the variability of methodology in the studies [67,81]; low quality of the included articles [68]; and high selection and publication bias [78].

A total of 24 reviews presented either a conceptual definition (a working definition in terms of its abstract concept [90,91]) or an operational definition (specific process, events, or activities that the researcher used in the measurement to determine the concept [92]) of at least 1 of the 15 terminologies used (ie, telehealth, telemedicine, telecare, structured telephone, telepsychiatry, remote patient monitoring, teledentistry, telemonitoring, health information technology, remote care programs, telephone only support, remote activity monitoring, telenursing, decision support systems, and health coaching systems), and a summary table can be found in Multimedia Appendix 3.

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Domains of Telehealth Use in Aging Care

Population of Interest

Of the 29 included reviews, the population of interest comprised older patients with at least 1 health condition in 17 (59%) reviews [29,62-64,66-69,71-74,78,80,82-84]. Among all these health conditions, the most prevalent ones are cognitive impairment (eg, dementia [82,83] and mild cognitive impairment and Alzheimer disease [66,69]), heart failure [29,80], and prefrailty or frailty [63,74], followed by leg and foot ulcers [72], chronic obstructive pulmonary disease [64], unipolar depression [68], hypertension [84], and oral health [78].

The remaining 12 reviews targeted the general older population, regardless of health conditions. Ten reviews set age cut-offs of 50 [77,79], 55 [87], 60 [70,75,86,89], and 65 years [65,85,88]. Three reviews focused on telehealth services during the COVID-19 pandemic [81,83,88].

It was also reported in several reviews that older adults were not able to participate in telehealth research because of the following factors: sensory change (eg, visual or auditory impairment) [70,82,83], negative affect [83], cognitive impairment [68,70,74,75,82], and communication barriers [70,82].

Interventions of Interest

The most prevalent modalities of telehealth interventions in the included reviews focused on remote consultation via mobile phones or video calls [29,64,65,67-69,72,76,77,81], remote monitoring or telemonitoring with synchronous or asynchronous data transmission [64,70-72,85], home-based telecare services [63,66,73,75], and nurse-led telecare services [62,66]. Tam et al [84] examined text messaging in hypertension management; Markert et al [85] investigated remote monitoring combined with health coaching; and the other reviews did not differentiate the different telehealth modalities, with aims including, but not limited to, screening, diagnosis, support, consultation, and education.

According to WHO, universal health coverage is the idea that everyone can access a full range of essential and quality health services, including promotive, preventive, curative, rehabilitative, and palliative care [93]. Most included reviews focused on curative and rehabilitative care (28/29, 97%), and health education interventions were excluded from 3 reviews [29,64,67].

The detailed inclusion (population, intervention, and comparator) and exclusion criteria of the 29 reviews can be found in Multimedia Appendix 4.

Outcomes With Findings

Outcomes of interest in this review included the effectiveness in individual outcomes (clinical benefits, health literacy, and behavioral outcomes) and system outcomes (efficacy and impact on health system use), feasibility and cost benefits of telehealth interventions or programs, and older people's acceptance of telehealth with factors affecting their telehealth use.

Effectiveness of Telehealth

Individual Outcomes: Clinical Benefits

In total, 17 reviews have documented the clinical benefits of telehealth interventions for older adults, in which a clinical benefit is defined as "a favorable effect on a meaningful aspect of how a patient feels (e.g., symptom relief), functions (e.g., improved mobility) or survives as a result of treatment" [94]. In the included reviews, such outcomes included self-reported or clinically assessed health outcomes [62,63,65,66,68-70,72,74,77-79,84,86,87], hospitalization rate [29,81], the mortality rate [29,65], and quality of life [65,77,79,86].

All these reviews have suggested a promising impact of telehealth interventions on the clinical benefits for older adults. Post hoc analysis of a previously published systematic review with meta-analysis by Inglis et al [29] showed that remotely monitoring older patients with heart failure using structured telephone support or telemonitoring could reduce mortality rates and all-cause hospitalization. Likewise, Tam et al [84] performed a meta-analysis to assess the effectiveness of text messaging interventions in hypertension management and concluded that text messaging could substantially reduce systolic blood pressure in older adults. However, there is a lack of rigorous evidence to further support the clinical benefits of these telehealth interventions.

Individual Outcomes: Health Literacy

Two reviews reported an improvement in older adults' health literacy, which is "the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions" [95]. Santana et al [66] reported a better understanding of the basic pathology and comorbidities among older adults with Alzheimer disease and an improvement in older adults' behavior management skills via the use of telecare. Similarly, according to Constanzo et al [69], all included studies concluded that participants with cognitive deficits were able to relearn everyday skills by using different technological tools, particularly when learning methods with error reduction were used.

Individual Outcomes: Behavioral Outcomes

The effects of telehealth interventions on various behavioral outcomes of older adults were studied in 3 reviews. van den Berg et al [70] found that regular personal monitoring and individual support by a health care provider or in the form of telemedical measurements seemed to have a positive influence on the adherence to behavioral changes (eg, adherence to medication, diet, physical activity, daily life activities, self-efficacy, and disease management compared with the other outcome categories). Tam et al [84] found a moderate effect on improving medication adherence by integrating telemedicine interventions. Finally, Rush et al [87] presented the use of telehealth as a possible solution to modify older adults' unhealthy behaviors (eg, smoking) that are higher in rural and remote areas than in urban areas.

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System Outcomes: Efficacy of the Telehealth Intervention or System

In total, 8 reviews explored the efficacy of telehealth interventions and reached inconsistent conclusions. Jones and Brennan [62], Barlow et al [63], Gentry et al [77], and Markert et al [85] found some evidence of the efficacy of telehealth interventions, although more rigorous evidence is needed. In contrast, Marx et al [65] and Costanzo et al [69] did not find a difference between telemedicine and in-person diagnosis and home visits, and Sekhon et al [82] found inconsistent results on the reliability of telemedicine caused by the testing conditions and the accessibility of telemedicine. In addition, Markert et al [85] reported that the presence of humans in the interventions might influence the outcomes. Jones and Brennan [62] revealed that the use of telehealth for clinical assessment has shown great promise in the nursing process; however, it was not ready for wide-scale clinical deployment.

System Outcomes: Impact of Telehealth on the Health Care System Infrastructure

In total, 7 reviews included the impact of telehealth on health care system use as an outcome. Barlow et al [63] showed that telephone follow-ups after hospital discharge were associated with reduced health service use (eg, lower hospital admissions and costs), Franek [64] reported that home telemonitoring could reduce the use of other health care services with a need of further confirmation with more randomized controlled trials (RCTs) of high quality, and Murphy et al [81] demonstrated that a telemedicine-based geriatric clinic model of care had the potential to reduce acute hospitalization and shorten the waiting times. The other 4 reviews demonstrated the potential benefits of telehealth services in improving older adults' access to health care [68,83,88] and extending existing health services from the health care facilities to home and community [86].

A summary of the effectiveness outcomes and findings can be found in Multimedia Appendix 5.

Feasibility of Telehealth

To measure the feasibility of telehealth, earlier studies used different indicators, such as use [96], adherence [97], dropout rates [98], technical errors [98], specialist consultation time [98], perceived feasibility [99], delivery mode [100], and social accountability [100]. Considering the lack of details in the included reviews, we opted to use adherence and attrition rates as proxy measures.

Three reviews reported on older users' adherence to telehealth interventions. In the review by Sekhon et al [82], mixed results were reported on the actual rate of adherence to telehealth and the implementation of telemedicine specialists' recommendations. In addition, Rush et al [87] also indicated that half of the studies reported low adherence and modest attrition rates because of technology failure and not achieving behavioral goals, and the adherence rates were found to vary according to the nature of telehealth interventions. Santana et al [66] reported an improvement in adherence to treatment, an increase in the number of older adults accompanied by health providers, and an improvement in the quality of care. The review with meta-analysis by Marx et al [65] found that more than half of the studies (7/9, 78%) found a much lower attrition rate among those who used telephone consultations (0%-31%) than those who used telemonitoring devices (50%-61%). A summary of the feasibility outcomes and findings can be found in Multimedia Appendix 6.

Cost Benefits

In total, 6 reviews examined the cost benefits of the telehealth interventions. Marx et al [65] concluded that telehealth interventions were cost-effective compared with no intervention, but the cost-efficacy compared with home visits was not yet established. Peretz et al [73] found no reliable cost estimates for remote patient monitoring program implementation, but it appeared that the cost of remote patient monitoring programs was dependent on the number of vital signs monitored, the complexity of the health condition monitored, and the geographic locations of the programs. Among the studies included in the review by Gentry et al [77], only 1 found no health care cost difference between virtual consultation and in-person treatment, whereas the other studies on memory disorder clinics via telemedicine only supported cost benefits to patients and caregivers but found no evidence of cost-effectiveness for health care organizations. In dentistry, Aquilanti et al [78] found that telehealth interventions tended to be less costly than face-to-face oral examinations. In the review by Murphy et al [81], virtual geriatric clinics were likely to be more cost-effective, but substantial discrepancies were noted in 2 studies because they used different costing models. The review by Rush et al [87] included studies of medium to high quality and observed direct cost savings for the health care system and rural older adults; however, many of the cost savings resulted from the savings on travel expenses. A summary of the cost-benefit outcomes and findings can be found in Multimedia Appendix 7.

Acceptance of Telehealth

A summary of the acceptance outcomes and findings can be found in Multimedia Appendix 8.

Satisfaction, Acceptability, Attitude, Experience, and Usability

In total, 12 reviews reported users' attitudes, satisfaction, or acceptance of telehealth services. Narasimha et al [76] reported that 65% of the geriatric population has shown a strong will to keep abreast of current advances, despite the stereotype that older people may be more averse to using technology for health care. Positive attitude toward telehealth was also reported in other reviews [62,66-68,77,78,81-83]. If the attrition rate could be used as a proxy for older users' acceptance, Marx et al [65] found that among the geriatric population, acceptability was good for telehealth consultation but less desirable for asynchronous approaches that relied on computerized devices. Moreover, Costanzo et al [69] discovered that younger caregivers seemed more comfortable and capable of using the internet and were more motivated to use the service.

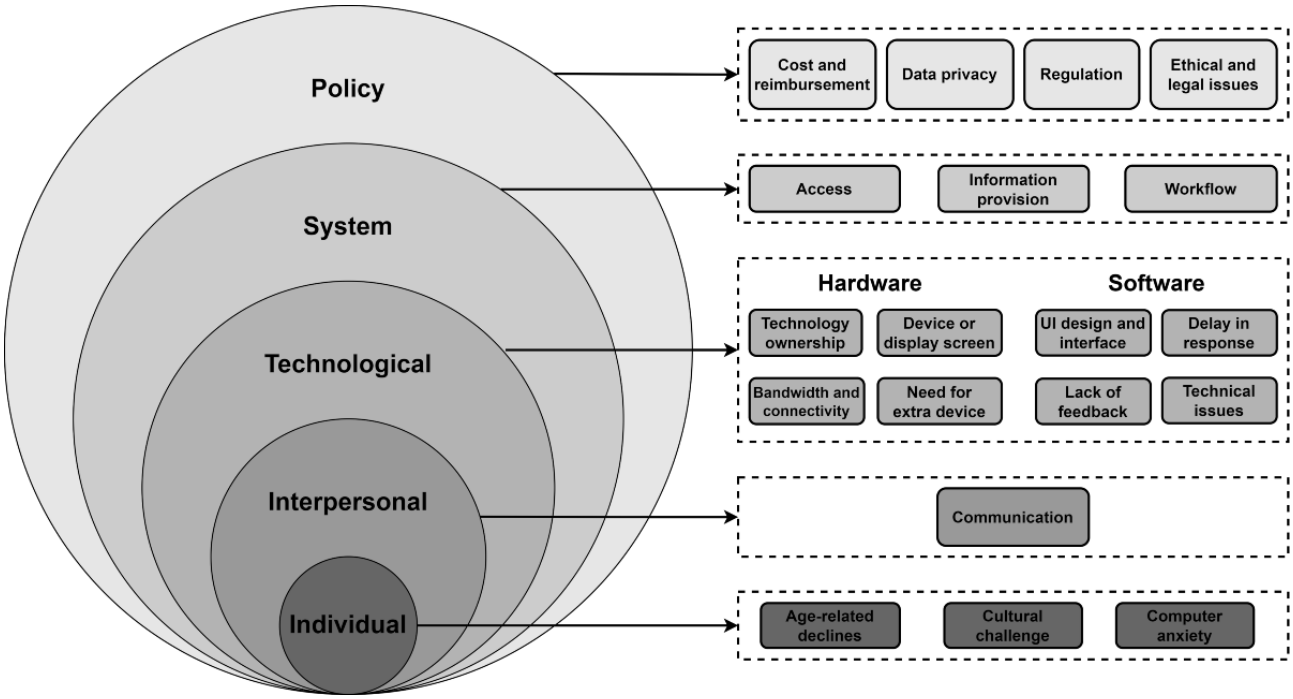
Factors Affecting Older Adults' Use of Telehealth: Overview

In the 1970s, Urie Bronfenbrenner developed the social ecological model as a conceptual model to understand human development. It consists of nested circles centered at individuals

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and contains microsystem, mesosystem, exosystem, macrosystem, and chronosystem levels [101]. In this review, we adapted the social ecological model as a framework to guide the classification of the factors affecting older adults' telehealth use, namely, individual, interpersonal, technological, system, and policy levels (Figure 2 [101]).

Figure 2. Illustration of our model, which was adapted from the social ecological model [101]. UI: user interface.



Factors Affecting Older Adults' Use of Telehealth: Individual Level

At the individual level, aging-related declines in vision, perception, hearing, motor, and cognitive functions adversely affected older adults' ability to carry out tasks, thus increasing the challenge of telehealth use and the inaccuracy of assessment [67,68,76,77,79]. For older adults who are unfamiliar with technologies, telehealth may bring technical difficulties and cultural challenges [71,83], and some even dropped out of the studies [70]. Such factors may lead to resistance to technology use [68].

Factors Affecting Older Adults' Use of Telehealth: Interpersonal Level

Some health care providers reported difficulty in communicating and conducting proper physical examinations via telehealth owing to older patients' possible age-related declines and technological incapability [67,68,83]; therefore, they were reluctant to recommend technologies. Moreover, it was recommended that more communication between patients and staff as well as between peers could create a feeling of more involved care [80].

Factors Affecting Older Adults' Use of Telehealth: Technological Level

At the technological level, both hardware and software factors have been reported to affect telehealth use in the older population.

Regarding hardware factors, ownership of technology [79], an effective device or display screen [71,76], bandwidth, and connectivity [77,83], along with a need for devices with widgets or multiple screens [71], could influence older users' ability to accomplish the final goal. For example, some patients with hearing disabilities reported interference between a videophone and their hearing aids [76]. The convenience of technology use can improve comfort and efficiency.

Regarding software factors, several reviews identified barriers in terms of the software and user interface design, such as inappropriate font size, unusual characters, bland graphics, poor color contrast, and complicated menu designs [76,79]. A simple and intuitive interface that requires little or no technical knowledge would better reflect normal daily activities and allow a more seamless transition toward its use [80], whereas a delay in responses, lack of feedback, and technical issues may lead to frustration for older users, which may lower their motivation to continue telehealth use [71].

Factors Affecting Older Adults' Use of Telehealth: System Level

An important factor regarding older adults' telehealth use is access, which may be limited by age-related sensory impairment [67,68] and unfamiliarity with technology [68], as reported at the interpersonal level. Sekhon et al [82] also reported that gaining a referral to a specialist who uses telemedicine was another barrier, although all physicians claimed future use of telehealth. In addition, skepticism about the telehealth benefits [68] and information loss owing to the inability to properly examine patients [83] were other 2 barriers reported by health care providers.

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Factors Affecting Older Adults' Use of Telehealth: Policy Level

At the policy level, several reviews reported that the cost of using telehealth and reimbursement from the government or insurance companies were barriers to telehealth adoption [77,79]. Other barriers reported at the policy level are regulations (eg, state law and licensure) as well as ethical and legal issues (liability, malpractice, and safety) [77,89].

Data privacy was a contradictory factor in these reviews. In the review by Karlsen et al [75], possible privacy issues caused by the use of cameras and video recording tools were not seen as a problem by most older adults because the technologies were supposed to help them live safely in their own homes. In contrast, the reviews by Pool et al [89] and Kruse et al [79] reported that the privacy issue had an impact on user attitudes, intentions to adopt, and their actual use of telehealth.

Quality of the Evidence Included in the Reviews and Limitations of the Reviews

Most of the included reviews reported that the literature did not meet orthodox quality standards because of the study design in the lower tiers of the hierarchy of evidence [63,69,71,72,79,81]; small sample size [63,65,68,69,71,82,86]; short follow-up period [63]; small number of studies [63,65,66,68,79,81,84]; high risk of bias [67,71,72,74,84]; high heterogeneity of interventions and outcomes [64,67,69,78,81,86,87]; insufficient and partly inadequate reporting of predefined outcome values and few participants, especially in the intervention group [72]; and inconsistent measurement of the outcomes [67,69,87]. The included studies of all the reviews were conducted in a limited number of locations (Multimedia Appendix 2), and the interventions used different telehealth modalities in different settings; hence, generalizability was attenuated [64,68,75,81], and the findings might not be generalizable to the entire older population group.

Discussion

Principal Findings

This scoping review synthesized the evidence from past research on telehealth in aging care and summarized the findings of 29 systematic reviews regarding telehealth interventions in aging care. Although telehealth has garnered attention since before 2010, it was in the spotlight during the COVID-19 pandemic when >40% of the included reviews were published. The present evidence shows promising evidence regarding the feasibility, costs, and acceptability of telehealth for screening, diagnosing, supporting, and consulting in aging care. However, some discrepancies were observed because of differences in telehealth modalities, health conditions, definitions of outcomes and measurements, and costing models. In addition, we summarized and categorized various factors affecting older people's telehealth use into individual, interpersonal, technological, system, and policy levels to provide a pathway for collaborative efforts to better prepare the older population for digital inclusion.

A large proportion of the evidence focused on curative and rehabilitative care (28/29, 97%), and there is scarce evidence on promotive, preventive, and palliative care, which is consistent with the scoping review in 2013 that the largest number of studies primarily focused on chronic disease management and symptom management [102]. Despite the importance of health education and promotion for the whole population, older adults have long been left out of health promotion activities until after 2001 when WHO experts declared that a healthy lifestyle should be emphasized for all ages [103]. Evidence has indicated that a healthy lifestyle, such as quitting smoking, limiting alcohol consumption, and increasing physical exercise, can help delay the development of many diseases, prevent the loss of functional capacity, improve the quality of life, and extend life expectancy [103]. Palliative care is another important public health issue as a consequence of the aging population, which focuses on improving the quality of life and dignity of people facing the end of their lives as well as the support and care of their loved ones [104]. For most patients in need of palliative care, the most preferred place of care is at home [105]. Nevertheless, some unmet in-home palliative care needs, such as the lack of communication among health care providers and patients' uncertainty about the urgency of their problem, have also been reported [106]. Future research could investigate how telehealth can address these gaps and the role of telehealth in universal health coverage.

In comparison with usual care, different modalities of telehealth have demonstrated remarkably promising effectiveness in improving both individual outcomes and system outcomes. As Russell et al [107] stressed that it is important to ensure that telehealth is not inferior to usual care, our results support past reviews [14-16] that telehealth could be a viable alternative to traditional clinical practice in selected domains and further highlight that telehealth could be effectively used in a broad range of clinical disciplines. However, we should be cautious about possible biases in the literature that may limit the generalizability of the results. For instance, most empirical studies in the included reviews were conducted in countries with higher incomes, and older adults with chronic or aging-related conditions were excluded in some studies if they were not part of the target population. Moreover, our findings also reiterate the inconsistent quality of evidence reported in other reviews [14,108]. The included reviews were predominantly narrative (25/29, 86%), and most reported that the literature was not up to orthodox standards. The evidence base needs to be strengthened through additional studies on the top tiers of the hierarchy of evidence (eg, RCTs or cluster RCTs) with larger sample sizes, longer follow-up periods, and consistent definitions and outcome measures coupled with good reporting methodologies.

In terms of the feasibility of telehealth in aging care, we used users' adherence and attrition as proxy measures and found mixed results, varying by different telehealth modalities and subpopulation types. Indeed, suboptimal adherence and substantial attrition are common in digital health intervention studies among the older population [109,110], and some contributing factors include personal choices, technical difficulties, physical and cognitive impairments, and concerns regarding the security of digital health interventions [110]. Low engagement continues to plague the internet-based studies [111], results in a study cohort not being representative of the

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demographics and disease status of the originally recruited study population [109], thereby threatening the validity of the findings [112]. Meanwhile, other factors such as referral by a clinician to the study, compensation for participation, having a clinical condition of interest in the study, and an older age [109] have been revealed to be associated with increased participation retention. Future research could further explore how older users' adherence and retention rates could be improved to advance the current telehealth practices and how this could impact the effectiveness, costs, and acceptability of telehealth interventions.

Similar to the systematic review of reviews by Ekeland et al [14], several reviews in our study also reported promising benefits of telehealth in terms of cost, and we also observed some discrepancies in implementation cost savings and cost-effectiveness in different studies owing to heterogeneity in comparator care delivery modes [65], the complexity of health conditions [73], geographic locations [73], and cost models used [77,81]. A common obstacle in most published economic evaluations of digital health interventions is reliance on standard methodological recommendations for assessing health care technologies, but such methodological assumptions may not fully reflect the nature of digital health interventions, especially complex ones [113]. Moreover, the cost benefits of digital health interventions may vary over time as well as the degree to which users use them, making their impact more likely to be heterogeneous [113-115]. Further research could overcome these challenges by streamlining the methodologies. For example, as recommended by Gomes et al [113], researchers should carefully choose comparators, determine the scope of cost and effects to be considered, and identify the effects of the interventions with appropriate measurements as well as the cost of other resources before the economic analysis.

In contrast to other studies indicating that older adults have not been fully ready for telehealth [116,117], all our included reviews that assessed the participants' experiences with and attitudes toward telehealth interventions have demonstrated good acceptance of telehealth among the older population. This difference might be explained by the use of different telehealth modalities in different studies as well as the prescreening process in some studies that excluded older adults who may have difficulty using telehealth. We identified a similar set of factors affecting older adults' telehealth use as other reviews [118,119], and further categorizing these factors into individual, interpersonal, technological, system, and policy levels could assist in understanding the needs of the older population in this process and identify the potential collaborative efforts that individuals, health care providers, developers of telehealth applications, government and community organizations, and policy makers can make to prepare the older population for digital inclusion. To help older individuals cope with the cultural and psychological challenges associated with digital health technologies, training programs could be offered to both the older population and health care providers to improve their digital literacy as well as skills in interpersonal communication and rapport building. Although there is no "one-size-fits-all" solution, developers of telehealth applications could engage older people, especially those with special needs (eg, those with physical immobility, sensory change, negative affect, cognitive impairment, low digital literacy, or communication barriers), in the user-centered design, testing, and evaluation of telehealth technologies and keep their needs in mind. Health systems should be responsible for ensuring a smooth and continuous clinical workflow with telehealth, along with providing the latest guidelines and health information to health care providers and older patients. Policy makers could enhance clinical guidelines and policies to regulate the design and implementation of telehealth, address privacy concerns, bridge the digital divide, and improve the current payment models so that telehealth could be offered to users with better security, accessibility, and affordability.

Strengths and Limitations

We chose to conduct a scoping review to comprehensively cover a wide range of older subpopulations, telehealth interventions, outcome measures, and types of systematic reviews. Our choice of only including systematic reviews was in response to the rapid growth of telehealth studies and the heterogeneous aims of the systematic reviews of telehealth interventions in the aging care context. Nonetheless, this choice may have neglected the details of the included telehealth interventions as well as the exclusion of some pertinent studies in consideration of their methodology and design. Although we adopted a systematic approach guided by the methodological framework of the Joanna Briggs Institute [22], there might be undetected relevant systematic reviews. The inclusion of only full-text systematic reviews in English may also lead to the loss of sight of those reviews without full-text accessibility. In addition, the low number of systematic reviews with meta-analyses also limits the robustness of the conclusions that can be drawn.

In addition to the methodological limitations, we identified limitations regarding the generalizability of the results. First, most of the studies in the included reviews were conducted in North America, Europe, and Australia, which may limit the generalizability of our findings to the global telehealth market. Second, several reviews have reported that the prescreening process has excluded the older users with special needs (eg, physical immobility, sensory change, negative affect, cognitive impairment, and communication barriers); hence, the results may not be generalizable to these vulnerable groups. Third, we identified different definitions of the population (older adults), interventions (telehealth, telemedicine, and telecare), and outcome measures, which might be because of different search terms, research settings, and geographic locations. This makes it difficult to compare the feasibility, effectiveness, cost, and acceptability of the interventions. Therefore, it is important to standardize and carefully define the terminologies and assessment tools in future research to reduce bias and draw robust and reliable conclusions.

Conclusions

The development and implementation of telehealth have been further catalyzed by the COVID-19 pandemic, and this scoping review has identified considerable evidence of the effectiveness, feasibility, cost benefits, and acceptability of telehealth applications in aging care. Although telehealth remains in its infancy and there is a lack of high-quality studies to draw robust conclusions, mounting evidence indicates that telehealth plays

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an important complementary role in the care of the aging population. It is imperative for older individuals, health care providers, developers of telehealth applications, government and community organizations, and policy makers to make a collaborative effort. This could help gain deeper insights into the multifaceted needs of and challenges faced by the older populations; facilitate a user-centered approach in the design and testing of telehealth technologies; and improve the security, accessibility, and affordability by enhancing the existing clinical guidelines and regulations. More high-quality studies are also required to provide a robust evidence base for aging care.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategy and results.
[DOCX File , 32 KB - aging_v6i1e40460_app1.docx]

Multimedia Appendix 2
Characteristics of the included reviews.
[DOCX File , 41 KB - aging_v6i1e40460_app2.docx]

Multimedia Appendix 3
Summary of the conceptual and operational definitions of the terminologies.
[DOCX File , 39 KB - aging_v6i1e40460_app3.docx]

Multimedia Appendix 4
Inclusion and exclusion criteria of the included reviews.
[DOCX File , 43 KB - aging_v6i1e40460_app4.docx]

Multimedia Appendix 5
Summary of the effectiveness outcomes of telehealth.
[DOCX File , 38 KB - aging_v6i1e40460_app5.docx]

Multimedia Appendix 6
Summary of the feasibility outcomes of telehealth.
[DOCX File , 24 KB - aging_v6i1e40460_app6.docx]

Multimedia Appendix 7
Summary of the cost-benefit outcomes of telehealth.
[DOCX File , 27 KB - aging_v6i1e40460_app7.docx]

Multimedia Appendix 8
Summary of the acceptance outcomes with factors affecting telehealth use.
[DOCX File , 33 KB - aging_v6i1e40460_app8.docx]

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Abbreviations

PRISMA: Preferred Reporting Items for Systematic Review and Meta-Analyses
PRISMA-ScR: Preferred Reporting Items for Systematic Review and Meta-Analyses extension for Scoping Reviews
RCT: randomized controlled trial

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WHO: World Health Organization

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Review

Adapting Transportation Planning e-Tools to Older Adults' Needs: Scoping Review

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Abstract

Background: Aging is often accompanied by a decrease in physical and sensory capacities and financial resources, which makes travel and the use of public transport a big challenge for older adults. These mobility limitations may prevent them from going out for groceries, medical appointments, or entertainment, which increases the risk of social isolation. A key element in helping older adults to maintain healthy aging and social engagement is to foster autonomy, freedom, and active mobility. A transportation planning e-tool can provide older adults with information about transport and trip options. There are many transportation planning e-tools, but little is known about whether and how their characteristics and functionalities address older adults' needs and preferences.

Objective: This study aims to map existing transportation e-tools and identify gaps to be filled in order to match their functionalities with older adults' needs and preferences.

Methods: A scoping review of existing transportation planning e-tools was conducted based on the approach developed by Arksey and O'Malley. A search in the scientific literature (Academic Search Complete, MEDLINE, CINAHL, SocINDEX, and ERIC) as well as gray literature (TRID Database, Google Scholar, Proquest, Google Play, etc) was conducted in June 2020 and updated 3 times; in September 2021, December 2021, and May 2022. After the studies were selected, a comparative analysis was performed by 2 evaluators; an occupational therapy student and a computer science student. These e-tools were analyzed with respect to some characteristics (eg, tool's development status, target customers, and geographic coverage) as well as 10 functionalities (time autonomy, walkability, crowd avoidance, incline avoidance, weather consideration, dark avoidance, winter obstacles avoidance, amenities inclusion, taxi driver's information, and support affordance) that we defined based on older adults' needs and preferences (mainly Canadians). These needs were identified from a literature review and confirmed by workshops (focus groups).

Results: The scientific and gray literature search yielded 463 sources, and 42 transportation e-tools were included. None of the e-tools reviewed addresses all 10 functionalities. More specifically, functionalities such as dark avoidance and support affordance were not addressed by any of the included e-tools.

Conclusions: Most of the e-tools currently available to plan trips do not address older adults' needs and preferences. The results of this scoping review helped fill this gap by identifying functionalities to include in transportation planning e-tools designed to

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promote active aging. The findings of this study highlight the need to use a multicriteria optimization algorithm to address older adults' mobility needs and preferences.

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KEYWORDS

active aging, transportation; e-tool; user-centered; review; Canadian mobility experience

Introduction

Background

According to the World Health Organization [1], the percentage of the population made up of older adults has grown continuously over the years. The Canadian population aged 60 years or older is estimated to be 26% of the total population in 2022 and to reach 31.2% by 2030. Aging is often associated with frailty-related difficulties, including slower walking speed and poorer balance, increasing the risk of falling on icy sidewalks or not having enough time to cross at a traffic light or climb a steep hill [2]. It is challenging for many older adults to use public transport, as they may be reluctant to get on a crowded bus or have difficulty getting on and off the bus [3]. Vision loss may prevent older adults from feeling safe when driving [4,5] while having fewer financial resources often limits the use of taxis [5,6]. As their social network is often restricted, many older adults do not have anyone to help them, for example, to go shopping [5]. In addition, a lack of digital literacy increases their difficulty planning their trips and finding public transportation options [7]. These difficulties and barriers affect older adults' ability to move around safely and independently and prevent them from maintaining social life as actively as they would like, which is often considered essential to maintaining social connectedness, independence, and a sense of well-being [8,9]. Thus, there is a need to provide accessible and affordable transportation options and support older adults in transportation planning and selecting the means of transport that best fit their needs and preferences [10].

Transportation planning e-tools have become increasingly popular around the world, providing information about different means of transport and helping people get to their destinations quickly and easily [11]. These transportation e-tools may be helpful for basic uses, such as giving directions from a departure point to a destination or identifying the shortest and fastest route or the route with the fewest connections [11]. They can also provide real-time data (eg, bus current location and arrival time), traffic congestion, and route changes. However, little is known about the extent to which existing planning e-tools are tailored to older adults' unique values surrounding mobility issues and whether they provide safe, independent, and pleasant trips [12,13]. Therefore, there is a need to identify gaps to be filled for e-tool functionalities to be tailored to older adults' special needs and preferences and, by fostering their mobility, contribute to healthy aging.

Context and Objectives

This scoping review was embedded in the first phase of a larger project named Mobilaînés. This project aims to implement a Mobility as a Service (MaaS) e-tool, or, in other words, a 1-stop platform transport service combining different means of transport and various forms of transport services to help older adults move around where, when, and how they want [14]. The Mobilaînés project is supported by LIPPA (Laboratoire d'innovations par et pour les aînés), a laboratory of innovations by and for older adults [14]. Mobilaînés is based on a living laboratory research approach, in which stakeholders from various sectors and fields collaborate to create, validate, and test new technologies, services, products, and systems in real-life contexts [14]. The ultimate aim of Mobilaînés is to promote active aging by helping older adults plan their trips and guiding them to use routes adapted to their needs (eg, avoid hills and snowy sidewalks) and preferences (pass by toilets or benches to take a rest). The aim of this scoping review was to (1) identify existing transportation e-tools designed to help with trips and that provide useful information about the various means of transportation available, (2) evaluate the extent to which their characteristics and functionalities are tailored to older adults' needs and preferences emerging from the first phase of Mobilaînés [14], and (3) pinpoint research gaps that need to be filled in order to develop an e-tool that supports active, healthy aging.

Methods

Study Design

The approach used follows the five stages described by Arksey and O'Malley [15]: (1) phrasing the research questions, (2) identifying relevant libraries and sources, (3) selecting interesting transportation e-tools based on defined inclusion and exclusion criteria, (4) charting the data, and (5) summarizing the data and synthesizing the results.

Phrasing the Research Questions

This scoping review aimed to answer the following questions:

1. What are the current local, national, and international transportation planning e-tools? What are their characteristics and functionalities?
2. To what extent do these transportation planning e-tools take older adults' needs and preferences into consideration in order to enhance their independence, sense of well-being, and safety when moving around?

Identifying Relevant Libraries and Sources

Relevant libraries and sources were identified by an occupational therapy student and a computer science student involved in the Mobilaînés study. The search included the scientific literature (2015–2022) in 5 databases (Academic Search Complete, MEDLINE, CINAHL, SocINDEX, and ERIC) using the

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following keywords: (transport* OR "public transport*" OR travel OR "public transit" OR "active transport*" OR "alternative transport" OR paratransit OR bus* OR carpool*) AND ("integrated service" OR "mobility as a service" OR "MaaS" OR "mobility information system*" OR "technology as a service" OR "TaaS" OR "intermodal mobility" OR "intermodal transportation").

To ensure the most up-to-date review of the data, we limited our search to the scientific and gray literature (books, memoirs, and government publications) published in French or English since 2015. Our search was extended to the TRID (Transportation Research International Documentation) Database, Google Scholar, Proquest, Google, and Google Play to identify interesting mobile apps related to transport. Keywords were adapted to each source based on iterative search processes to pinpoint the most accurate and appropriate results. The keywords used for each source are shown in Table 1. Results from the databases and grey literature were exported to a reference manager (Zotero), and duplicates were eliminated.

Table 1. Keywords used for each source.

Source	Keywords
TRID[a] Database	"integrated service" OR "mobility as a service" OR "MaaS" OR "mobility information system" OR "technology as a service" OR "TaaS" OR "intermodal mobility" OR "intermodal transportation"
Google Scholar	"Outil planification déplacement" (French), "Mobility as a service"
Proquest	"Mobility as a service" AND "Canada" AND ("transport" OR "public transport" OR "mobility" OR travel OR "public transit" OR "active transport" OR "alternative transport" OR "paratransit" OR "bus" OR "carpool") AND ("integrated service" OR "mobility as a service" OR "mobility information system" OR "technology as a service" OR "intermodal mobility" OR "intermodal transportation").
Google	"Outil planification déplacement" AND "Aide déplacement" AND "Outil aide mobilité" AND "Assistance déplacement" AND "Transport personnes âgées" (French) AND "Mobility as a service" + "for seniors" AND "Dial a ride" AND "Mobility on demand"
Google App Store or Play	"Déplacement" AND "Mobilité" (French) AND "Transport" AND "Assistive technology"

[a]TRID: Transportation Research International Documentation.

Selecting Interesting Transportation e-Tools—Inclusion and Exclusion Criteria

Relevant sources were selected by 2 research assistants from different disciplines (occupational therapy and engineering). First, sources were screened by title and included if they (1) introduced a transportation tool or included a state-of-the-art section about transportation e-tools or (2) combined different available means of transport. Sources were then screened by abstract when available. The initial search yielded 463 sources: Academic Search Complete (n=215), MEDLINE with full text (n=30), CINAHL Plus with full text (n=14), SocINDEX with full text (n=3), ERIC (n=2), Transportation Research Board (n=104), Google Scholar (n=10), Google (n=18), Google App Store or Play (n=61), and scientific papers and conference proceedings recommended by team members (n=6). After removing duplicates, 421 publications remained, of which 379 did not meet the inclusion criteria according to title and abstract screening. Ultimately, 42 sources met the criteria defined above and were included in the full-text analysis.

Charting the Data

The transportation planning e-tools selected were then charted in an Excel (Microsoft Corp) sheet by 2 research assistants (students in computer science and occupational therapy), according to the following characteristics: (1) transportation tool name, (2) tool's development status, (3) tool's interface, (4) target customers, (5) geographic coverage, and (6) cost for users. To achieve our objectives, we evaluated the selected e-tools according to a set of 7 values related to older adults' mobility. This set of 7 values was determined by the research team (see protocol [14]) based on (1) an inventory of core values [16], and (2) older adults' mobility needs and preferences, identified from the literature review and 6 individual phone interviews conducted during the first phase of Mobilaînés in Sherbrooke, Quebec, Canada. The following are the seven values:

1. Eco responsibility and environmental preferences: they have a great impact on older adults' choice of means of transport. In this context, Vredin Johansson et al [17] maintained that "*…environmental preferences increase the likelihood of choosing an environmentally friendly mode over a less environmentally friendly mode.*"
2. Health: it is viewed by older adults as a state of physical, mental, spiritual, and social well-being. Daily mobility is a kind of exercise for older adults that helps them maintain an active and healthy lifestyle [14,18].
3. Safety: it is the protection of older adults' physical, emotional, and psychological integrity. Safety concerns can create a fear of crime [19], accidents, harassment, and so on, as well as misbehavior by staff [20]. This anxiety prevents older adults from using public transportation.
4. Quality of life: a lack of transportation has a major impact on older adults' satisfaction and sense of personal well-being. According to Kim and Ulfarsson [21], "*…mobility is significantly associated with quality of life among older people.*" Metz [18] highlighted the destination-dependent and psychological benefits of mobility.
5. Equality: it is vital to give the same consideration to promoting the mobility of all older adults. Bourgault-Brunelle [22] showed that there is a diversity of

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transportation services in administrative regions (of Quebec in our case), and these services are not accessible to everyone; it seems that some regions or subregions are not served as well as others. Fiedler and Consult [20] also proved that language and cultural barriers often prevent older adults from suitably using public transportation.

6. Functional autonomy: this refers to older adults' ability to carry out their daily activities in their physical, social, institutional, and cultural environments.
7. Decision-making autonomy: this refers to older adults' involvement in decisions that affect them. In this context, Shrestha et al [23] maintained that public transport plays a crucial role in older adults' freedom and independence, and *"access to public transport can help older adults to avail themselves of goods, services, employment, and other activities."*

These 7 values were then translated into 9 statements that an adapted transportation system for older adults should ideally satisfy (Table 2). To do so, 6 phone interviews with frailer older adults were conducted in order to identify facilitators and barriers to mobility (when planning trips and moving around) and document previous experiences. These phone interviews were transcribed and coded, and later on, the outcome was classified into mobility facilitators and barriers by 2 project team members and then covalidated by 2 researchers [24]. Emerging themes were compared with data from 2 workshops on mobility facilitators and barriers (see research protocol) [8]. Recurrent themes were finally analyzed by the research team to generate the Mobilaînés statements (Table 2).

A survey was sent to the steering committee members (stakeholders from the public, scientific, and community sectors who work with or study the older adult population) [8] and LIPPA's older adults committee to validate and classify these statements according to their importance and impact on promoting active aging. Gaps between the 2 group classifications were discussed during a steering committee meeting to decide the final classification: 9 statements were classified as important, recommended, or not important. The resultant statements and the corresponding values, as well as the steering committee members' and older adults' classifications of these statements, are presented in Table 2.

The survey results support the relevance of co-designing a transportation tool that would offer a safe journey and routes and interfaces adapted to the physical, sensory, and cultural needs of older adults. Interactions with older adults through co-design workshops highlighted the importance of providing an easy-to-use platform and considering key elements such as the weather, especially for trips that require you to arrive at a specific time. Exploration of new travel experiences was identified as not important by both partners and the older adults committee.

To translate these statements into more technical and measurable functionalities, 2 "in-person" workshop sessions with transportation service providers and 2 others with older citizens (n=8) were conducted. In total, 10 relevant functionalities (see Table 3) were kept after the research team's analysis and after discussion and validation by the steering committee members. These 10 functionalities are considered to be what an ideal transportation tool should provide to address older adults' needs and preferences.

Table 2. Statements that a transportation tool should ideally satisfy.

Statement: Transportation tool should…	Values	Partners' classification	Older adults' classification
Consider the values of sustainable and eco-responsible mobility	1	Recommended	Recommended
Suggest a route adapted to older adults	3,6	Important	Important
Suggest a pleasant route	4	Important	Recommended
Be adapted and accessible to people with limitations (hearing, visual, cognitive, reading difficulties or facing linguistic or cultural barriers)	5,6	Important	Important
Foster active mobility	2,4	Recommended	Recommended
Suggest a safe journey	3,4,6	Important	Important
Be useful for more rural communities	5,6	Recommended	Recommended
Consider travel costs to support decision-making	3,5,6	Recommended	Important
Encourage the exploration of new travel experiences	4,6	Not important	Not important

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Table 3. Relevant functionalities an ideal transportation tool should provide.

Number	Functionalities	Older adults' interpretation
1	Time autonomy	I want to go out whenever I want (now, tomorrow, etc)
2	Walkability	I want to avoid walking or take my walking speed into account when planning trips
3	Crowd avoidance	I want to avoid crowded routes and places
4	Incline avoidance	I want to avoid hills
5	Weather consideration	I want to avoid going out when the weather is hot or wet
6	Dark avoidance	I want to avoid going out when it's dark
7	Winter obstacle avoidance	I want to avoid icy sidewalks or icy roads
8	Amenities inclusion	I want information about relevant amenities on my route (toilet, bench, bus shelter, public telephone, etc)
9	Taxi driver's information	I want to know who is going to pick me up, what type of car, especially for a taxi
10	Support affordance	I need some support (providing company, helping with bags and to get into, onto, and out of or off vehicles)

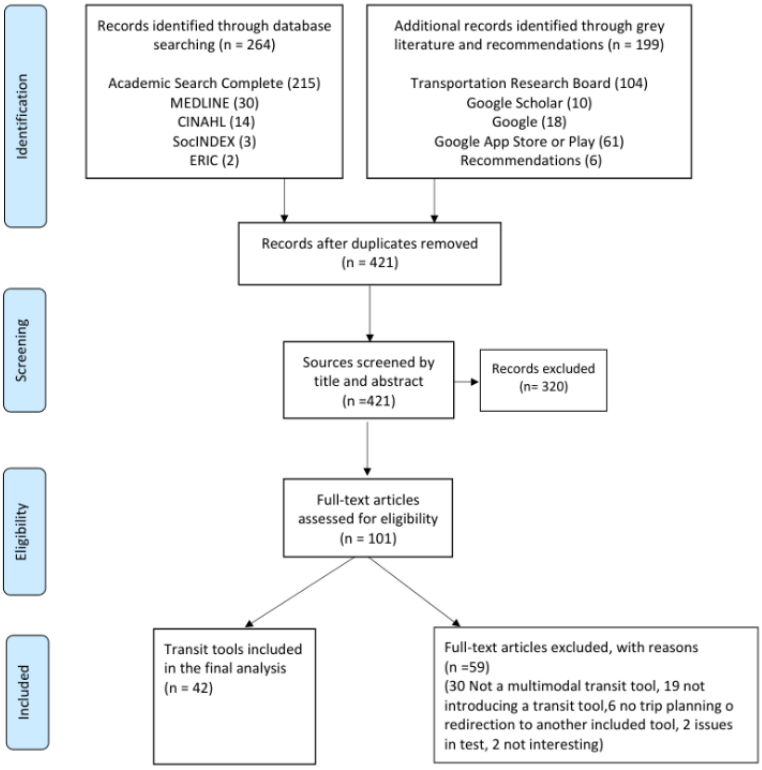
Results

Characteristics of the e-Tools

A total of 42 transportation e-tools were included in this scoping review: 37 are accessible via mobile apps (Android or iOS) and web platforms, along with 4 prototypes and 1 web platform (Figure 1). The e-tools included did not target a specific population, except for 3 of the prototypes, namely Path2.0 [25], mPASS [26], and Mobility in Later Life [27], which were designed for people with disabilities, pedestrians, and older adults, respectively. Two e-tools (STS [28] and Embarque Estrie [29]) cover the region where the study took place (the city of Sherbrooke, Quebec, Canada), while 4 e-tools cover other cities in Quebec (the Montreal area for Chrono [30], STL Synchro+ [31], and TripGo [32], the province of Quebec for Exo Quebec [33]), and 2 cover cities in another Canadian province, Ontario (OC Transpo [34] in Ottawa and Triplinx in Toronto). While 27 e-tools are for use in different cities and countries in Europe, 6 e-tools (Transit [35], Moovit [36], CityMapper [37], GoogleMaps [38], HERE WeGo [39], and Transperth [40]) can be used in different cities around the world. Most of the e-tools reviewed (n=38) consider public transport: 7 consider only bus while others consider rail, tramway, and bus. All of the e-tools reviewed suggest walking paths, 29 suggest bike paths, 8 suggest bike sharing, and 10 e-tools redirect users to ride-sharing websites or apps for ride-sharing routes. The same is true for taxi routes, which are included in 4 of the e-tools reviewed. Three e-tools redirect people to Uber for rides. Twenty e-tools suggest riding (car) paths. Five e-tools suggest paths for kick scooters, but only 1 tool suggests paths for motorbikes. All the transportation e-tools reviewed are free to install and use, except for Transit [35] and Whiz [41], which charge fees for additional personalization and more functionalities.

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Figure 1. Flowchart of sources screened and included in the scoping review.



Functionalities of the e-Tools

Following is our analysis of the e-tools in relation to the 10 functionalities.

- Functionality 1 (Time autonomy): all of the e-tools reviewed, except for 5 [25–27,29,42], which do not give any details about time, allow users to set a departure time and depart whenever they want. Embarque Estrie [29] does not give a choice of departure time (it shows alternate routes without further details about time), while no details were given for this functionality in the 4 prototypes examined (mPASS [26], Path2.0 [25], Sway [42], and Mobility in Later Life [27]).
- Functionality 2 (Walkability): twelve of the e-tools provide the option of minimizing distance or walking. Eleven e-tools ask users to choose their walking speed or to set the maximum walking distance tolerated, or both (walking speed and maximum walking distance tolerated). Path2.0 [25] is a prototype that stores accessible routes for people with disabilities so these routes could be recommended for the next trip; this could also be applied to walking speed.
- Functionality 3 (Crowd avoidance): five of the e-tools reviewed give information about road traffic. Three e-tools give real-time data about free parking places or an estimate of the crowd on the bus, while only one, Google Maps [38], provides an estimate of available seats in addition to estimated traffic for bus and road trips.
- Functionality 4 (Incline avoidance): inclines were not considered by most of the e-tools reviewed, except for Transp'Or [43], which suggests balanced and bike-adapted paths. Martinique mobilités [44], Irigo [45], and Tac mobilités [46] show the bike path's elevation. Additionally, Irigo [45] and Tac mobilités [46] show the percentage of cyclable, normal, and dangerous lanes in bike paths. The prototype mPASS [26] provides personalized maps and adapted routes that consider users' needs. For example, inclines can be considered a barrier about which data will be collected through sources (crowdsourcing, sensing, and expert data), so they can be considered when route planning. Stairs were considered in the case study of testing the prototype. Sway [42] considers the criterion of comfort when planning a route through incline avoidance.
- Functionality 5 (Weather consideration): most of the e-tools reviewed do not consider the weather, except for 4 e-tools [27,34,42,47] that give the temperature.
- Functionality 6 (Dark avoidance): this functionality was not considered by any of the e-tools reviewed.
- Functionality 7 (Winter obstacle avoidance): similar to Functionality 4, icy sidewalks were not considered by any of the e-tools reviewed, except for mPASS [26], a prototype that provides personalized maps and adapted routes that consider users' needs. For example, icy sidewalks can be considered a barrier about which data will be collected through sources (crowdsourcing, sensing, and expert data), so they can be considered when route planning. Stairs were considered in the case study of testing the prototype. Sway [42] considers the criterion of comfort when planning a route through incline avoidance.
- Functionality 8 (Amenities inclusion): relevant amenities and services (eg, bus stations, parks, hospitals, universities, and parking) available near a given address are provided by 7 e-tools, while Embarque Estrie [29] gives relevant places near the departure and arrival addresses. Toilets and benches were not considered by any of the e-tools reviewed, except for mPASS [26], where toilets and benches can be considered facilities to take into account in route planning.

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Ramps and curb cuts were considered in the case study of testing the prototype.

- Functionality 9 (taxi driver's information): none of the e-tools reviewed includes this information, except for 3 e-tools (Transit [35], OiseMobilité [48], and Go!Vermont [49]) that redirect users who choose ride-sharing to another app that gives details about the carpooler, and Mobility in Later Life [27], which shows the carpool route and details about the carpooler.
- Functionality 10 (Support affordance): none of the e-tools reviewed has the option of getting support (providing company, helping with bags, and to get into, onto, and out of or off vehicles).

Table 4 summarizes further details.

Table 4. Operationalization of defined functionalities by the e-tools reviewed.

Functionality and how this is addressed by the e-tools in this scoping review	Tool references
Time autonomy: provide the option of choosing a departure date and time	[27,28,30-66]
Walkability	
Provide the option of minimizing distance or walking	[31,33,35,36,38,41,48,52,59,62,65,66]
Store accessible routes for people with disabilities so these routes could be recommended for the next trip	[25]
Consider the maximum distance tolerated by the user	[28,40,47,51,52,57,66]
Consider the walking speed indicated by the use in route planning	[28,40,44-48,52,56,57,63,66]
Crowd avoidance	
Provide information about road traffic or parking	[38,39,47,49,50,54]
Provide an estimate of the crowd on the bus	[38,61,63]
Provide an estimate of the crowd at the destination	[38]
Incline avoidance	
Consider inclines a barrier to avoid; data about inclines could be collected through crowdsourcing, available data provided by experts	[26]
Provide balanced and adapted routes for biking	[37,43]
Consider the criterion of comfort	[42]
Show the bike path's elevation	[44-47,52,54,59]
Show the percentage of cyclable, normal, and dangerous lanes in bike paths	[45,46,52,54]
Weather: display information about the temperature	[27,34,39,42,47]
Dark avoidance: none	None
Winter obstacle avoidance: consider icy sidewalks a barrier to avoid; data about icy sidewalks could be collected through crowdsourcing, available data provided by experts	[26]
Amenities inclusion	
Have the option next to the user that gives relevant amenities (bus stations, parking, hospitals, universities, parks, administrations, etc) near the address given	[28,48,53,55,59,60]
Show users relevant amenities (bus stations, bike stations, parking, etc) within 500 m of departure and destination locations	[29]
Consider toilets and bench facilities to take into account; data about toilets could be collected through crowdsourcing, and available data provided by experts	[26]
Taxi driver's information: in the case of ride-sharing, redirect users to the ride-sharing app containing further details about the carpooler, such as the person's name and type of car	[35,48,49]
Support affordance: none	None

Discussion

Principal Findings

The aim of this scoping review was to explore the scientific and gray literature in order to identify existing transportation planning e-tools and evaluate the extent to which their characteristics and functionalities are tailored to older adults' needs and preferences. Although many transportation planning e-tools have been developed to help people reach their destination using different means of transport (car, taxi, bus, car sharing, bicycle, walking, etc) and to give them various details about the trip (eg, directions, which bus to take, and which station), most of the existing e-tools focus on the functionalities for the shortest or fastest route or the route with the fewest transfers and consider only 1 criterion (distance, time,

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or the number of transfers). However, based on the Mobilainés project workshops, older adults did not find these functionalities (shortest or fastest route) to be very important. Furthermore, older adults' needs with respect to avoiding winter obstacles and inclines were not taken into consideration in most of the e-tools reviewed. In general, workshop results show that weather conditions are considered by older adults when making decisions about transportation means, the time of the day, and the reason they travel. This finding is consistent with those of Stein et al [27]. Incline avoidance was considered only for bike paths by 8 e-tools. The only exceptions are mPASS [26], which considers icy sidewalks and inclines as barriers to avoid in route planning, and Sway [42], which considers the criterion of comfort. Moreover, few e-tools provide functionalities that might help older adults who have difficulty walking. Transit [35] proposes routes without stairs, while VaNavigo [56], RATP [61], and Path2.0 [25] suggest accessible routes for people with reduced mobility using wheelchairs. In this context, TripGo [32] provides 6 alternatives (recommended, greenest, easiest, fastest, healthiest, and cheapest) (see Multimedia Appendix 1 for further details).

To foster older adults' mobility, identified gaps (eg, help to get into or onto, and out of or off vehicles and with bags or a walker), awareness of accessible amenities (eg, toilets and restaurants) as brought up by Stein et al [27], and information about whether it will be dark during the return trip) should be considered in the Mobilainés platform to fulfill their needs and preferences. Furthermore, since older adults' needs and preferences may differ from one person to the next, multicriteria optimization algorithms may be a promising way to personalize mobility [27]. To contribute to healthy aging, there is a great need for a transportation planning tool that provides personalized maps with textual and graphic presentation and routes adapted to older adults' physical and sensory impairments and cognitive capacities [5].

Limitations

This study has some limitations; for example, some articles may not have been retrieved (due to the chosen keywords). Including prototypes in our scoping review is also a limitation of our analysis because these e-tools are not accessible and could not be tested. Furthermore, not including transportation planning e-tools that use only one mode may be a limitation because they may have some interesting functionalities for an e-tool involving only one mode of transport.

Conclusions

This scoping review identified gaps that should be addressed to produce transportation planning e-tools that aim to promote active and independent aging. The results of this scoping review will be useful in designing a personalized multimodal planning tool, such as Mobilaînés, to help older adults select a route that takes their needs and preferences into account. Further research is needed to determine whether data related to the functionalities identified are available or must be created to develop a transportation planning tool in line with older adults' values. Challenges that remain concerning include which approaches to take in terms of routing algorithms, optimization criteria, and the importance of each of the criteria considered in order to find suitable routes for older adults and make these e-tools readily accessible to users with limited digital literacy.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Functionalities of the reviewed e-tools.
[DOCX File , 57 KB - aging_v6i1e41938_app1.docx]

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Abbreviations

LIPPA: Laboratoire d'innovations par et pour les aînés
MaaS: Mobility as a Service

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Review

The Experiences of Informal Caregivers of People With Dementia in Web-Based Psychoeducation Programs: Systematic Review and Metasynthesis

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Abstract

Background: Informal caregivers of people living with dementia experience a higher level of physical and mental stress compared with other types of caregivers. Psychoeducation programs are viewed as beneficial for building caregivers' knowledge and skills and for decreasing caregiver stress.

Objective: This review aimed to synthesize the experiences and perceptions of informal caregivers of people with dementia when participating in web-based psychoeducation programs and the factors that enable and impede informal caregivers' engagement in web-based psychoeducation programs.

Methods: This review followed the Joanna Briggs Institute protocol of systematic review and meta-aggregation of qualitative studies. We searched 4 English databases, 4 Chinese databases, and 1 Arabic database in July 2021.

Results: A total of 9 studies written in English were included in this review. From these studies, 87 findings were extracted and grouped into 20 categories. These categories were further synthesized into 5 findings: web-based learning as an empowering experience, peer support, satisfactory and unsatisfactory program content, satisfactory and unsatisfactory technical design, and challenges encountered in web-based learning.

Conclusions: High-quality and carefully designed web-based psychoeducation programs offered positive experiences for informal caregivers of people living with dementia. To meet broader caregiver education and support needs, program developers should consider information quality and relevancy, the support offered, individual needs, flexibility in delivery, and connectedness between peers and program facilitators.

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KEYWORDS

informal caregivers; dementia; psychoeducation; online; web based; qualitative research; systematic review; metasynthesis

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Introduction

Dementia is a major cause of disability among older adults worldwide [1]. People living with dementia have complex care needs and are often highly dependent on others to care for them [2]. Most people living with dementia are cared for by unpaid informal caregivers who are their family members or friends. Worldwide, in 2019, informal caregivers spent approximately 5 hours per day per person with dementia assisting in daily living activities [2]. They experienced a higher level of physical and mental stress compared with other types of caregivers; showed increased caregiver burden, anxiety, and depression; and showed decreased quality of life [3-5]. Such caregiving situations directly impact the caregiver's ability to provide quality care.

Early educational interventions to prepare informal caregivers for their caregiver role are crucial [2,6]. However, the educational interventions offered do not always meet their needs. Informal caregivers often feel that they lack knowledge of dementia progression and symptom management and the skills for providing daily care [7,8]. They also expressed the need for more support at home from trained health professionals [9] that could foster knowledge sharing; build skills, such as symptom management and physical care; and provide emotional support [10,11].

Psychoeducation programs are viewed as beneficial for meeting caregivers' expectations and learning needs through knowledge and skill building, while encouraging positive thoughts, decreasing caregiver stress, and improving caregivers' psychological well-being and quality of life [12]. According to Cheng et al [12], psychoeducation programs usually incorporate theoretical, psychological, and behavioral training components relevant to dementia care to achieve these benefits. Traditionally, psychoeducation programs are delivered face-to-face in small groups [12]. Web-based psychoeducation programs have been widely used in recent years to offer convenience and flexibility to increase caregivers' participation and retention [13-15]. However, many informal caregivers reported a lack of time or flexibility to commit to these programs because of care responsibilities [16].

Despite the known advantages of web-based psychoeducation for caregivers, underutilization and a lack of program trustworthiness have been identified [2]. Furthermore, studies have revealed a high dropout rate among caregivers in web-based psychoeducation programs [17]. The reasons for the high dropout rate varied across studies and programs. For example, the low recruitment and retention rates reported in a study by Baruah et al [18] indicated a need for further adaptations to the program to improve acceptability and accessibility. Whereas, other studies have indicated that gender [19], program length [20], and uncertain factors [21] contributed to the dropout rate. There is a need to synthesize studies on caregivers' experiences of using web-based psychoeducation programs to gain further insights into their experiences and facilitators affecting participation in a global context. This review addresses this gap in the literature.

This review aims to synthesize (1) the experiences and perceptions of informal caregivers of people with dementia when participating in web-based psychoeducation programs and (2) the factors that enable and impede informal caregivers' engagement in web-based psychoeducation programs.

Methods

Inclusion and Exclusion Criteria

This review included studies that reported components of the experiences of informal caregivers of people living with dementia when using web-based psychoeducation programs in a home care setting. The review included qualitative studies and mixed methods studies that included qualitative components. The following studies were excluded from the review: (1) quantitative design; (2) web-based programs without an educational component, such as social support groups (ie, singing group) and telehealth; (3) non–internet-based programs, such as a DVD or booklet; (4) the population of interest in the study was people with dementia in residential care or hospital settings, rather than home care settings; and (5) not written in English, Chinese, or Arabic (because of team members' backgrounds).

Search Strategy and Screening Method

Keywords were identified according to the study's population (informal caregivers of people living with dementia), interest (web-based psychoeducation program), and context (home care setting; Multimedia Appendix 1). A Boolean search was conducted by combining keywords. The following English databases were searched in July 2021: CINAHL, Web of Science, MEDLINE, and Scopus (Multimedia Appendix 2). Keywords were translated into Chinese (by YY) and Arabic (by FS) by the review team. The Chinese databases searched included the China National Knowledge Infrastructure, Wang Fang Data, Weipu Data, and Chaoxing Data. We also manually searched the *Academic Journal of the Middle East* for articles written in Arabic. No time limit was applied to the search. All retrieved records were imported into EndNote 20 [22] and Covidence [23] to remove duplicate studies. In total, 4 reviewers (YY, LX, CM, and SU) screened the English titles and abstracts. In addition, 2 reviewers (YY and JW) screened the Chinese titles and abstracts to identify studies that met the inclusion criteria, and 2 reviewers (YY and LX) reviewed the full text retrieved. The reference list of each selected article was scanned manually.

Assessment of Methodology

The methodology of all selected papers was assessed using Joanna Briggs Institute (JBI) critical appraisal instruments for qualitative research [24]. The review team decided to include only those studies that satisfied >5 appraisal questions. The main findings from each paper were critiqued by 2 reviewers to evaluate the level of credibility (ranked as unequivocal, credible, or not supported) according to JBI [24]. The final synthesized findings were derived from unequivocal (findings and supporting data are beyond reasonable doubt and therefore not open to challenge) and credible (findings and supporting data lack clear association and are therefore open to challenge)

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findings. Throughout the quality assessment process, disagreements between any 2 reviewers were resolved either through comparison and discussion between the reviewers or through a third reviewer.

Data Extraction

Qualitative data were extracted by 2 reviewers (anonymized for peer review) using the standardized data extraction tool from JBI Qualitative Assessment and Review Instrument [24]. The tool includes (1) author, publication year, and country; (2) participants' characteristics and sample size; (3) web-based education or training program details, including duration, facilitator details, and theoretical framework; (4) study setting, design, and methods; and (5) main findings. The main findings from each study were extracted with an illustration to evaluate the credibility of the findings (Multimedia Appendix 3) [25-33].

Data Synthesis and Reporting

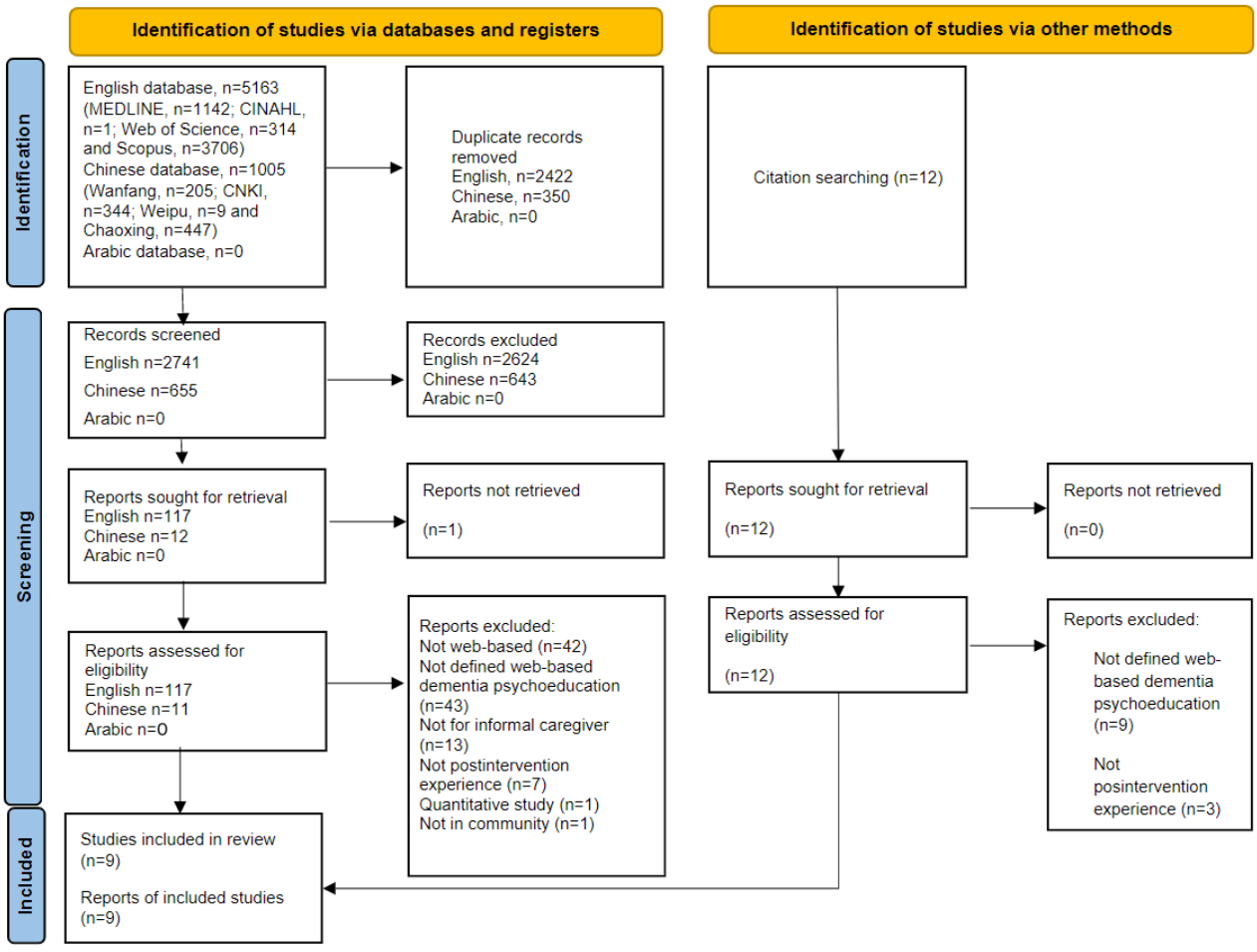
Data synthesis in this review followed the JBI protocol of meta-aggregation of qualitative studies [24], with the following three steps: (1) the main findings from each study were reviewed by 2 reviewers to evaluate the level of credibility, with unequivocal and credible findings included in the data synthesis and meta-aggregation; (2) similar findings were grouped into categories; and (3) categories were refined and synthesized into final findings. The final findings were reported following PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 [34] (Multimedia Appendix 4).

Results

Study Inclusion

A total of 6168 articles were initially identified from database searches and uploaded to Covidence [23] (English databases, n=5163; Chinese databases, n=1005; and Arabic database, n=0). Covidence automatically removed duplicates (n=2422). Duplicates were manually removed from the Chinese database (n=350). After a title and abstract screening (English, n=2721; Chinese, n=655; and Arabic, n=0), 128 (English, n=117 and Chinese, n=11) full-text articles were retrieved. An additional 12 articles were identified from the searching the reference list of the included articles. After assessing the eligibility of full-text articles, 9 studies written in English met the inclusion criteria and were included for methodology assessment. No articles written in Chinese or Arabic met the inclusion criteria. The study selection process is illustrated in Figure 1.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram. CNKI: China National Knowledge Infrastructure.



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Methodology Quality

The methodological quality of the 9 selected studies was assessed and is presented in Table 1. Of the 9 studies reviewed, 5 (56%) were mixed methods studies and 4 (44%) were qualitative studies. Only 1 study indicated the philosophical perspectives underpinning the methodology [25]. In total, 3 studies were not clear about the cultural and theoretical orientations of the researcher [26-28], and 5 studies did not address the researchers' influence on the study [26,27,29-31]. Moreover, 1 study only selected 2 cases to represent the qualitative data collected [30]. Therefore, the adequate representation of the participants in that study is questionable. All studies, except 1, indicated participation in an ethics review [27]. No studies were excluded from this review based on the methodological quality assessment.

Table 1. Quality appraisal for qualitative studies.

Study	Q1[a,b]	Q2[c]	Q3[d]	Q4[e]	Q5[f]	Q6[g]	Q7[h]	Q8[i]	Q9[j]	Q10[k]
Brennan et al [29]	U[l]	Y[m]	Y	Y	Y	Y	U	Y	Y	Y
Duggleby et al [33]	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
Fowler et al [30]	U	Y	Y	Y	Y	Y	U	U	Y	U
Gaugler et al [26]	U	Y	Y	Y	Y	U	U	Y	Y	Y
Halbach et al [27]	U	Y	Y	U	Y	U	U	Y	U	Y
Hattink et al [28]	U	Y	Y	Y	Y	U	Y	Y	Y	Y
Kovaleva et al [31]	U	Y	Y	Y	Y	Y	U	Y	Y	Y
Lewis et al [32]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Ploeg et al [25]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

[a]Q: question.

[b]Q1: Is there congruity between the stated philosophical perspective and the research methodology?

[c]Q2: Is there congruity between the research methodology and the research question or objectives?

[d]Q3: Is there congruity between the research methodology and the methods used to collect data?

[e]Q4: Is there congruity between the research methodology and the representation and analysis of data?

[f]Q5: Is there congruity between the research methodology and the interpretation of results?

[g]Q6: Is there a statement locating the researcher culturally or theoretically?

[h]Q7: Is the influence of the researcher on the research, and vice versa, addressed?

[i]Q8: Are participants, and their voices, adequately represented?

[j]Q9: Is the research ethical according to the current criteria or, for recent studies, and is there evidence of ethics approval by an appropriate body?

[k]Q10: Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

[l]U: unclear.

[m]Y: yes.

Characteristics of the Included Studies

The included studies were published between 1991 and 2019 and were conducted in the United States (n=5), Canada (n=2), the Netherlands (n=1), and Norway (n=1; Table 2). A total of 367 people participated in the qualitative component of these studies. Among the included studies, 5 used a mixed methods design and 4 applied a qualitative study design. The methodologies used in those studies included case studies [27,30], qualitative descriptions [25,31], content analysis of open-ended questions in the survey [26,29,31,32], and secondary analysis of telephone interviews [33]. The data collection methods used in these studies included focus group interviews [27], semistructured interviews either via telephone or face-to-face [25,30,31], or surveys with open-ended questions [26,29,31,32].

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Table 2. Characteristics of the included studies.

Study, country	Study design	Program	Participants in the qualitative study	Method	Findings

Brennan et al [29], United States	Mixed methods	ComputerLink	Family caregivers of PwD[a] (n=22)	• Data collection:
				  • Messages posted on the discussion forum were collected
				• Data analysis:
				  • Qualitative content analysis of collected messages
					• Pros:
					  • The forum and questions and answers section served as emotional support and social interaction opportunities for caregivers of PwD
					  • The public communication section allows participants to control the discussion focus and address the issue in a timely manner
					  • Self-paced learning provided more flexible learning for caregivers without time and space restraints
					• Cons:
					  • Findings do not represent a diverse population (ie, different age groups and cultural backgrounds)

Duggleby et al [33], Canada	Secondary analysis of a mixed methods study	MT4C[b]	Family caregivers of PwD (n=92)	• Data collection:
				  • Telephone interviews
				• Data analysis:
				  • Qualitative content analysis
					• Pros:
					  • Improved PwD's self-efficacy
					• Cons:
					  • Poor internet connectivity and low computer literacy were the barriers to accessing MT4C
					  • Reasons for not using the program also included caregiver demands and preference for a paper or a face-to-face interaction

Fowler et al [30], United States	Case study	Virtual health care neighborhood technology	Family caregivers of PwD used the program (n=28)	• Data collection:
				  • Interviews
				• Data analysis:
				  • Qualitative descriptive
					• Pros:
					  • Provided social support and information sharing using the blog section. The blogs included safety, sleep issues, memory, social engagement, enjoyment, and suggestions.
					  • Participants have opportunities to interact with health professionals from different disciplines
					• Cons:
					  • Only reported 2 cases

Gaugler et al [26], United States	Mixed methods	CARES Dementia Care for Families	Family caregivers of PwD (n=41)	• Data collection:
				  • Survey
				• Data analysis:
				  • Qualitative content analysis of open-ended questions in the survey
					• Pros:
					  • Comprehensive content
					  • Use of real individuals with dementia in videos
					  • The video shows the stages/progression of dementia
					  • The flexibility of web-based delivery
					• Cons:
					  • The video segment was too small
					  • Some audio segment was incomplete

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Study, country	Study design	Program	Participants in the qualitative study	Method	Findings

Halbach et al [27], Norway	Qualitative case report	Mobile app mYouTime	Relatives and staff of PwD (n=17)	• Data collection:
				  • Focus group interviews
				• Data analysis:
				  • Qualitative descriptive
					• Pros:
					  • Well-structured learning units
					  • Large font size
					  • Contains videos
					  • Contains basic and in-depth information
					• Cons:
					  • The quiz section was the least attractive
					  • Need more local information rather than be redirected to another web page

Hattink et al [28], the Netherlands	Mixed methods	The Digital Alzheimer Center	Family caregivers of PwD (n=6), PwD (n=6), and professional staff (n=6)	• Data collection:
				  • Observations
				  • Web-based survey
				  • Semistructured interviews
				• Data analysis:
				  • Thematic analysis
					• Pros:
					  • Clear layout, calm background, large font, and contrasting color
					  • Comprehensive and well-written information
					  • Helped caregivers of PwD with understanding and dealing with dementia
					  • Information can be accessed anytime and anywhere (flexibility in delivery)
					• Cons:
					  • Posting a message on the forum, finding information on driving, and watching videos appeared difficult to some participants
					  • Small sample size

Kovaleva et al [31], United States	Qualitative description	Tele-Savvy	Family caregivers of PwD (n=36)	• Data collection:
				  • Interviews
				• Data analysis:
				  • Qualitative content analysis	

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Study, country	Study design	Program	Participants in the qualitative study	Method	Findings

					• Pros:
					  • Provided opportunity for caregivers to connect with others via videoconferences (peer support and learning from others)
					  • The web-based program promoted access for those who need to travel
					  • Videoconferencing was facilitated by a health professional
					  • Contains prerecorded expert-delivered lessons
					  • Provided caregiver manual
					• Cons:
					  • Information needs to be more relevant to stage-specific caregiving
					  • Need more videos to cover more complex situation and represents more diverse cultural backgrounds
					  • The program needs to be longer
					  • Videoconferences need to be longer
					  • Videoconferencing needs to be more engaging
					  • Technical issues (poor internet connection)
					  • Insufficient instructions on how to join videoconferences
					  • Need more detailed written and illustrated instructions for video viewing
					  • The web-based program may not be suitable for some people. The study only included people who have internet access

Lewis et al [32], United States	Mixed methods	The internet-based Savvy Caregiver program	Family caregivers of PwD (n=47)	• Data collection:
				  • Survey with open-ended questions
				• Data analysis:
				  • Constant comparative analysis
					• Pros:
					  • Information and caregiving strategies were relevant and interesting to participants
					  • Videoclips of professionals, caregivers, and PwD
					  • The convenience of the internet program
					  • Presentation of the program
					• Cons:
					  • Spelling errors
					  • Technical difficulties (difficulty in navigating the website)
					  • Repetition of information
					  • Length of the program
					  • Did not provide an opportunity for participants to interact with other people
					  • Need a hard copy workbook

Ploeg et al [25], Canada	Qualitative	MT4C	Family caregivers of PwD (n=56)		

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Study, country	Study design	Program	Participants in the qualitative study	Method	Findings

				• Data collection:
				  • Semistructured, open-ended, and telephone interviews
				• Data analysis:
				  • Qualitative content analysis
					• Pros:
					  • Easy to navigate
					  • Provided the opportunity to reflect on and share their caregiving experiences
					  • Information was relevant and applicable to the individual caregiver's situation
					  • Provided affirmation of their caregiving experiences through the content of the website and linked videos
					• Cons:
					  • MT4C did not apply to the caregiver's current situation or suit their current needs because of their stage in the caregiving journey
					  • Technical issues and security concerns
					  • Writing or sharing their thoughts and experiences in MT4C
					  • Need a directory of services searchable by postal code
					  • Not having a person available to answer caregivers' questions
					  • Not having a navigator to help the caregiver identify and access resources that meet their specific needs

[a]PwD: people with dementia.

[b]MT4C: My Tools 4 Care.

Content of the Psychoeducation Programs

A total of 8 programs were reported in 9 studies (Table 3). In total, 2 studies reported the same program from different perspectives [25,33]. For example, Duggleby et al [33] only reported the reasons of nonusers in the web-based MT4C program, whereas Ploeg et al [25] reported users' experiences in the same program. All programs were asynchronized web-based psychoeducation programs and had a clear indication of the educational component [25-33]. A total of 4 programs offered peer support functions [28-31]; of these 4 programs, 3 used asynchronized discussion forums or blogging [28-30] and 1 applied a synchronized method such as videoconferencing [31]. Health professionals' involvement in the programs was reported in 4 studies [28-31]. Moreover, 1 study reported a program in a mobile app format, with limited details of psychoeducational content [27]. The duration of the psychoeducation programs ranged from 7 weeks [31], 2 months [28], 3 months [25,30,33] to 12 months [29]. Overall, 3 studies did not specify a time frame for participants to view or test the program [26,27,32].

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Table 3. Details of the psychoeducation programs.

Study	Program and duration	Delivery format	Program content
Brennan et al [29]	ComputerLink; 12 months	Asynchronized, web based	• Content: dementia care information, decision support, and communication • Theoretical framework: multiattribute utility theory • Theoretical training: yes • Psychological training: unclear • Behavior training: unclear • Peer support: using private email and discussion forum • Facilitator: discussion forums were facilitated by health professionals.
Duggleby et al [33] and Ploeg et al [25]	My Tool 4 Care; 3 months	Asynchronized, web based	• Content: each web page contains frequently asked questions, resources, and a calendar. An electronic copy of the Alzheimer Society's Alzheimer disease booklet was available. • Theoretical framework: Meleis' theory of transition • Theoretical training: yes • Psychological training: yes • Behavior training: yes • Peer support: not offered • Facilitator: not offered
Fowler et al [30]	Virtual Health Care Neighbourhood; 3 months	Asynchronized, web based	• Content: information relevant to caring for people with dementia at home • Theoretical framework: not indicated • Theoretical training: yes • Psychological training: yes • Behavior training: yes • Peer support: using Question and Answer and Social Support forums • Facilitator: the blogging section was supported by health professionals.
Gaugler et al [26]	The CARES for Families; the duration was not indicated	Asynchronized, web based	• Content: information on understanding memory loss, living with dementia, and using the CARES Approach • Theoretical framework: not indicated • Theoretical training: yes • Psychological training: yes • Behavior training: yes • Peer support: not offered • Facilitator: not offered
Halbach et al [27]	mYouTime mobile app; the duration was not indicated	Asynchronized, web based	• Content: lectures, videos, and hyperlinks about dementia care. Details were not discussed in the paper. • Theoretical framework: not indicated • Theoretical training: unclear • Psychological training: unclear • Behavior training: unclear • Peer support: not offered • Facilitator: not offered
Hattink et al [28]	The Digital Alzheimer Center; the duration was not indicated	Asynchronized, web based	• Content: information about dementia, an overview of appointments, community sections, news, and upcoming events • Theoretical framework: not indicated • Theoretical training: yes • Psychological training: yes • Behavior training: yes • Peer support: using the forum • Facilitator: participants can privately email health professionals or make an appointment.

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Study	Program and duration	Delivery format	Program content
Kovaleva et al [31]	Tele-Savvy; 7 weeks	Hybrid, asynchronized, web-based information with synchronized videoconferencing for peer support	• Content: prerecorded expert-delivered lessons about dementia care • Theoretical framework: social cognitive theory and stress and coping theory • Theoretical training: yes • Psychological training: yes • Behavior training: yes • Peer support: weekly instructor-facilitated videoconferences • Facilitator: health professionals
Lewis et al [32]	Internet-based Savvy Caregiver program; the duration was not indicated	Asynchronized, web based	• Content: information on (1) the effects of dementia on thinking, (2) taking charge and letting go, (3) providing practical help, and (4) managing daily care and difficult behavior • Theoretical framework: stress and coping theory • Theoretical training: yes • Psychological training: yes • Behavior training: yes • Peer support: not offered • Facilitator: not offered

Synthesized Findings

Overview

A total of 87 findings were extracted and grouped into 20 categories based on similarities and differences. These were further synthesized into five findings: (1) web-based learning as an empowering experience, (2) peer support, (3) satisfactory and unsatisfactory program content, (4) satisfactory and unsatisfactory technical design, and (5) challenges encountered in web-based learning (Multimedia Appendix 5). These synthesized findings are built on evidence rated as moderate to high confidence, which is outlined in the ConQual summary of findings in Multimedia Appendix 6. Multimedia Appendix 7 presents the meta-aggregation flowchart.

Synthesized Finding 1: Web-Based Learning as an Empowering Experience

This synthesized finding was based on 9 findings from 7 studies [26-32]. Caregivers who used web-based psychoeducation programs had a sense of empowerment through the knowledge they gained, and activities were undertaken [28-30]. For example, 1 participant stated the following [30]:

> *Being a part of the study at that time in my life really helped me cope with difficult family issues and decisions.*

Caregivers welcomed topics on caregiver coping skills, which helped them develop strategies to deal with everyday challenges [29,32]. One participant stated the following [32]:

> *It is a gentle reference vehicle to understanding Alzheimer's changes. It won't smack you in the face with the fear of what is coming but will prepare you for techniques to cope.*

Caregivers perceived that the knowledge they learned through real-life stories enabled them to understand the disease, which improved their self-efficacy [26-28]. One participant stated the following [26]:

> *The examples and the stories of families who live with Alzheimer's were very informative and gave me comfort that I, too, can do this.*

Some programs encouraged participants to complete their behavioral appraisal and develop a long-term plan [25]:

> *It [MT4C] made me even realize somebody else needs a list of doctors and [chuckles] you know, things like that... It made me think about personal care in the future because that's long-term care.*

Some caregivers were initially intimidated by web-based learning, but their experience in a well-run web-based classroom encouraged them to engage with the program [31]:

> *At first I was... this is not gonna work; I'm 60 years old. It really worked, I loved going to school online, I thought I was in a real class—I'm talking a real classroom.*

Similarly, another participant indicated the following [30]:

> *I was a little intimidated with it at first but then I got on and it worked very smoothly, you know, the way it was supposed to and it made the experience kind of fun.*

Participants expressed that having a program facilitator to answer their questions may further enhance their experience [25]. For example, 1 participant commented the following [25]:

> *Having a person available to answer caregivers' questions by telephone and having a navigator to "be that bridge" to help the caregiver identify and access resources that meet their specific needs.*

Overall, web-based psychoeducation programs empowered participants by enhancing their self-efficacy, skill building, knowledge sharing, and self-reflection, which contributed to a positive learning experience.

Synthesized Finding 2: Peer Support

This synthesized finding was based on 9 findings identified from 6 studies [25,28-32]. Peer interactions were important factors that influenced caregivers' experiences in the web-based

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psychoeducation program. Asynchronized peer support included web-based forums for participants to exchange information and was perceived positively by participants [28-30]. One participant stated [29]:

> *There are frequent statements of encouragement and support among caregivers for example "My husband is in the middle stages of the disease and I would like some suggestions on how to occupy his time..." "Dorothy I also have a problem with my wife who likes to walk and gets bored..." "Hi this is Sue. I noticed a reply to idle Time,..."*

Reading fellow caregivers' stories provided an opportunity for caregivers to share, reflect on, and have a better understanding of dementia care. For example, 1 participant wrote the following [30]:

> *Oh, I'm not out here alone, kind of thing but just to be able to see what other people's stories were like, how others were handling things and seeing how people interacted with each other. That medium was really valuable.*

Encouragement and support from synchronized online peer support groups were also considered helpful [31]. However, not all peer support was positive. Issues identified in synchronized online peer support groups were more apparent. Poor group interactions were reported in 1 study that used videoconferences and negatively influenced caregivers' experience. Group members were not focused on the topic, and a lack of equal opportunity to contribute to the group meeting and a desire to have more interactions were reported [31].

When the program did not offer a peer support function, participants specifically commented on the value of connecting and sharing experiences with others [25,32]. For example, 1 participant commented the following [32]:

> *I don't have the option of sharing or interacting with others. The opportunity for questions related to my situation are not possible.*

Caregivers also suggested the following [25]:

> *Adding a feature to MT4C to enable caregivers to connect with one another to share information, experiences, and caregiving strategies would be helpful.*

Caregivers perceived that a facilitator played a crucial role in motivating them and clarifying the issues discussed in peer support groups [31]:

> *One of the very helpful parts of the chats was to have positive feedback from the teachers. I don't think caregivers get very many "good job on that" ... comments. It is easy to know when we mess up ... hard to know that we did it well.*

Peer support during the program reduced caregivers' feelings of isolation, and many participants expressed a desire to stay connected after the program ended [31]:

> *For me it was a lifesaver... seeing all those people from all around the country... they are not really handling it any better than I ... I don't feel so alone in spirit.*

Synthesized Finding 3: Satisfactory and Unsatisfactory Program Content

This synthesized finding was based on a total of 17 findings identified from 7 studies [25-29,31,32]. The program content aspects considered in this finding include program components, such as video, and the information presented in the video or text format, such as different topics covering dementia caregiving strategies. No content was delivered in a synchronized format in the included studies.

A video component was welcomed by most participants, especially when a real person with dementia and their caregivers were featured in the video [32]. Videos enhanced caregivers' understanding of dementia progression and care needs at different stages [26,27,31]. One caregiver stated [26]:

> *I really liked the videos that showed the progression of the disease in the early, middle, and late stages of the disease. For example, the making coffee and taking a bath example. I also liked the driving example, too, about the different parts of the brain and how they are affected.*

Other caregivers echoed similar comments [32]:

> *Person with dementia was very interesting and I felt like I could connect with them.*

The video structure and content also contributed to caregivers' experiences. Although some programs' videos were well structured [27], in other programs, the video display was too small [26], had poor audio quality [27], and content lacked cultural diversity [31]. Additional videos to highlight more challenging situations were requested by participants in 1 study [31]; for example:

> *The Caucasian daughter (age 61) suggested the vignettes did not portray the "messiness of life"—times when a care recipient may not follow caregiver's guidance, multiple family members involved in caregiving, and families with limited resources: I would have liked to see a daughter or son single caregiver with just a parent, try to make it more identifiable and inclusive.*

Caregivers perceived that the information provided in the web-based psychoeducation program was important. They welcomed information that accommodated their individual learning needs [27,28,31]. One caregiver stated [32]:

> *Good information, I found myself surprised at being able to relate to a lot of it.*

Participants also perceived that the information provided should be relevant to the individual caregiver's needs and their caregiving journeys [26] and detailed and practical [25]. One participant stated the following [25]:

> *I feel like I'm not there yet; Mom's still early, so some of the things are a bit more advanced...*

They particularly liked the information presented by both caregivers and experts [32]. The participants also noted that

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some programs missed important topics [25,27,31]. One participant stated [27]:

> *It was a known issue that the 23 lectures were not covering the entire area, and this was also remarked on with several participants mentioning missing topics and in-depth information*

Most participants in this review were satisfied with the video content and written information included in web-based psychoeducation programs.

Synthesized Finding 4: Satisfactory and Unsatisfactory Technical Design

This synthesized finding came from a total of 23 findings identified from 6 studies [25-28,31,32]. The program design aspects considered in this finding include structure, language, functionality, accessibility, and supplementary material.

Participants liked a clear page layout with a large font size for the content [27,28,32]. A lack of systematic layout was reported in 1 study [31]:

> *Participants suggested that the [printed] manual be laid out more clearly (e.g., include a table of contents and a glossary) and be more precisely coordinated with the videos, videoconference "lectures," and "homework" assignments.*

Participants identified grammar and spelling errors in 2 programs [27,32]. There were also concerns about the literacy level of 1 program [25]:

> *It is a lot of text and the literacy level. Oh, the other thing is it's only in English... you need to make the language a bit simpler.*

One caregiver suggested that the case scenario presented needed to be positive to provide a better learning experience [26]:

> *I found it very sad to be left with the vision of the dear man peeling bananas. You could have chosen something a bit more uplifting.*

Caregivers in 1 program considered quizzes to be the least helpful component [27]. Participants in another program experienced information overload and were frustrated by lengthy, repetitive, and missing content [32].

Caregivers especially welcomed the flexibility, convenience, and easy navigation of psychoeducation programs delivered on the web [28]:

> *You can check this information anytime, even in the middle of the night.*

These features were extremely helpful for caregivers who lived far from the place where a face-to-face program might be delivered [31]:

> *I live forty miles from everywhere; it was wonderful... It was good to be able to do it online rather than trying to get in the car, considering the traffic situation here.*

The caregivers expressed that the program website should have a bookmark function [32]. Supplementary materials, such as instruction manuals, were also suggested by the participants when they were not provided [31,32]. Caregivers would also like ongoing access to the program after completion for various reasons [26,30,31]. One caregiver stated [31]:

> *Caregivers could not access the videos after Tele-Savvy conclusion; however, many stated that they would be willing to rewatch videos, share them with family members, and rewatch them when their care recipient is in a later dementia stage.*

Synthesized Finding 5: Challenges Encountered in Web-Based Learning

This synthesized finding was based on a total of 7 findings identified from 4 studies [25,28,31,33]. Technical issues such as problems with accessing and poor internet connection were a great challenge in using 2 web-based programs [31,33], which did not differentiate between asynchronized programs (information accessing) and synchronized online peer support. One participant commented the following [33]:

> *My internet connection at home is poor—I live in a rural area.*

Others experienced problems during synchronized videoconferencing; or example [31]:

> *Problems during videoconferences (e.g., poor Internet connection, slow sound and video transmission, and insufficient instructions on joining videoconferences) affected connectedness.*

A low level of computer literacy among the participants also contributed to access difficulties [31,33]. One participant commented the following [31]:

> *Some caregivers noted that others struggled to follow some directions... and needed to be better aligned relative to their webcam and sit in a position with good lighting.*

Caregivers who struggled with the technology seem to prefer hard copy information [33]:

> *Sometimes, you actually have to have something printed in front of you, uh, and I'm better off—I'm better with paper.*

Time was another challenge in this regard. Caregiving demands prevented some from participating in web-based psychoeducation programs [25,28,33]. One participant commented the following [33]:

> *[I] work full-time early morning to late evening... and at the end of the day, I don't have the energy or time to go on the computer.*

Similarly, another carer stated [25]:

> *The more time I spend on the computer, the more [name of spouse] approaches me and saying "What are you doing? Why aren't you sitting with me?"*

Other caregivers preferred learning through actual social contact [31]:

> *It would have been better to absorb the content in a group setting, person to person... very difficult to have a personal connection with a computer screen.*

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Discussion

Principal Findings

Our review revealed that the empowerment caregivers experienced from participating in a web-based psychoeducation program was built on knowledge sharing, individualized support from the program facilitator, and skill building to foster positive thoughts. This empowerment enables the active management of care activities. Our findings support previous studies that define empowerment for caregivers as a learning process that enables them to improve their coping capabilities by enhancing self-efficacy and self-determination, thereby creating more constructive relationships with the people surrounding them [35-37]. Self-efficacy is the belief that a person can complete tasks effectively when faced with stressors [38]. A positive outcome of self-efficacy is associated with cultivating positive thoughts and self-control [39]. According to the self-determination theory introduced by Ryan and Deci [40], people are motivated to learn to achieve their goals when they have a sense of self-control and self-efficacy and feel connected to other people. The carefully designed programs identified in our review reflect the development of these capabilities that empower caregivers in their caregiving role. Our finding on empowering learning is also in line with the study by Sakanashi and Fujita [36], in which empowering education programs for caregivers of people living with dementia included coping strategies, understanding the caregiver role, self-reflection, and quality information to enable the person to find autonomy and the capacity to take on the role.

We found that peer support through psychoeducation programs has a positive impact on caregivers' experiences. Caring for people living with dementia is associated with social isolation because of demands from caregiving and dementia stigma [41]. Peer support provides caregivers with opportunities to communicate with others and share their experiences, which can potentially help them acquire new knowledge, build skills, develop resilience, and reduce caregiver burden [42-45]. The caregivers in this review valued peer support experiences, reflecting on the benefits they received. Research also shows that knowledge exchange through peer interactions can improve caregivers' sense of self-efficacy [46] and reduce depressive symptoms [47]. In contrast, the absence of group learning and support may be associated with a low level of self-efficacy [48].

Our review revealed the caregivers' preferences regarding the content of web-based psychoeducation programs. From our review, video components were preferred by caregivers as a means to facilitate a better understanding of the information presented. We found that caregivers were particularly touched by videos that portrayed real-life stories. The findings of our review also indicated that the relevance of information presented in pictures and text influenced caregivers' experiences. This finding could be explained in the context of human cognitive function in processing information, in which visual stimuli, such as pictures, text, and videos, during focused attention are useful for learners to attain new knowledge [49,50]. However, the cognitive learning process is based on the condition that the information, or learning content, is relevant to learners [49]. A study that explored caregivers' information needs and information-seeking behaviors indicated that the most frequently requested information was general information on dementia, care provision, self-care, and how to use available services [51]. A caregiver's decision to access information depends on the quality and trustworthiness of the source [52]. Caregivers in this review valued learning content that facilitated reflection on their role and promoted self-care. In addition, our review found that caregivers' learning needs were influenced by the stages of their dementia journey. Caregivers requested that information should be tailored to accommodate their differences, thereby enhancing their learning experience while avoiding mismatches between information and learning content. The information included in web-based programs should be tailored to the individual's situation and address the individual's needs, while simultaneously preventing information overload.

In this review, we identified that the technical design of a web-based psychoeducation program is another factor that influences caregivers' learning experiences. The visual layout, structure, language used, functionality, and accessibility of the web-based program were important to the caregivers. Caregiver expectations in these aspects of program design within this review can be explained by how people sense and perceive the information displayed in a web-based program. The first step in human cognitive functioning for information processing occurs via the sensory system (ie, visual and audio), which filters out irrelevant information, notes the information that is of interest and relevance via short-term memory, and then lays down long-term memories [53]. According to Vu et al [50], website design needs to consider the user's cognitive and physical capabilities. For example, older people will see contents on the screen more easily when the program design avoids the use of blue or green colors from the short-wavelength end of the visual spectrum and increases the resolution of screen contents [50]. The caregivers' feedback on the web-based psychoeducation program design noted in our review reflects these recommendations.

Our review also identified various challenges for caregivers when using web-based psychoeducation programs and learning on the web. These challenges included, but were not limited to, caregiving demands, especially for those in the workforce, technical issues, and program design. In contrast to previous studies, our review did not identify caregivers' concerns about the privacy and confidentiality of their information [54,55]. We found that although caregivers, especially those living in remote areas, perceived web-based psychoeducation programs as flexible, caregiving demands precluded many working caregivers from participating. Previous studies have found that web-based programs can support working caregivers to achieve a balance between work and caregiver demands, supporting them through web-based peer interactions that save both time and money [55,56], but this does require an individual's resolution. According to West and Hogan [57], regular support group attendance was associated with members' perception of support from the group, subjective well-being, compromises they made, and care responsibilities. Moreover, according to our review, using a web-based program depends on an individual's perception of how useful it is to address their needs.

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Research has identified that working caregivers report lower carer confidence compared with nonworking caregivers, indicating the need for additional support to build their skills and confidence [58]. However, the educational support programs reviewed here do not necessarily reflect this. A flaw noted in this review was that most programs were not available after the completion of the study, despite participants wanting to revisit some of the information. A previous study suggested that program usefulness depended on whether the function and cost met individual needs [59]. These factors potentially influence caregivers' feelings about web-based programs' usefulness in the long term.

It is important to consider group dynamics if peer interactions are included in a program. Previous studies have focused more on the positive aspects of support groups, with negative experiences rarely discussed. A forum was convened in 1 study to ascertain barriers to successful web-based group meetings and made recommendations, for example, that groups be arranged according to the similarity of caregivers' experience, have clear meeting agendas, and consider participants' diversity [60]. Other studies showed that the positive impact of support groups depended on peer interactions and how well groups were organized [57,61]. The caregivers in our review expressed concerns about poor peer interaction, lack of discussion topics, and lack of equal opportunities to contribute during group meetings. This highlights the importance of a trained facilitator leading a caregiver support group.

As identified in multiple studies [55,60], technical difficulties accessing a program, such as a poor internet connection, challenge the use of web-based programs, as does an individual's confidence and computer skills [62,63]. In our review, most participants felt positive about web-based psychoeducation programs; but to meet a broader audience, programs must consider the caregiver population that may not be technically savvy.

Recommendations

High-quality and carefully designed web-based psychoeducation programs offer positive experiences to informal caregivers of people living with dementia. To meet broader caregiver education and support needs, program designers should consider the following recommendations (Multimedia Appendix 7). First, the learning content and information provided must be tailored to caregivers' learning needs. This can be achieved by encouraging caregivers to self-diagnose their learning needs and select relevant sections. Second, web-based psychoeducation programs should include components to facilitate social connectedness among caregivers so that they can share their experiences and help each other. Third, having program facilitators who are trained health or social care professionals is imperative for engaging caregivers in the program and providing individualized support. Fourth, programs should integrate multimodality teaching materials, such as text, videos, discussion boards, and supporting group meetings, to attract learners at the cognitive information processing level. Fifth, asynchronized web-based learning and teaching are recommended to accommodate a broader audience, especially working caregivers. Sixth, the program content should be developed based on an education needs analysis of caregivers. Program providers should conduct ongoing evaluations of the quality and relevance of the information presented to ensure caregivers' confidence in the program, thereby enhancing its utilization. Seventh, initial training and ongoing technical support for caregivers are required when implementing web-based psychoeducation programs. A program should be accompanied by hard copy instructions to support caregivers when technical issues arise. Finally, most psychoeducation research has focused on program effectiveness. Future research should also focus on informal caregivers' experiences of using web-based psychoeducation programs to increase utilization.

Limitations

The main strength of this review is the rigorous adherence to the JBI systematic review and meta-aggregation protocol to minimize bias during the process. However, this review has a few limitations. First, only 9 articles were included; this is an indicator that research evidence from qualitative studies is limited. Second, this review was based on database searches in 3 languages: English, Chinese, and Arabic. Therefore, a bias exists in the selection of studies. Despite the primary effort to review studies in Chinese and Arabic, the lack of diverse evidence from different contexts in non-English studies is apparent. The caregivers' experiences identified in this review may not be representative of a wider culturally and linguistically diverse population. Transferability to similar contexts in qualitative research needs to be confirmed by the reader.

Conclusions

This is the first comprehensive systematic review to synthesize qualitative studies on dementia caregivers' experiences in web-based psychoeducation programs in a global context. The findings contribute to new knowledge about caregivers' learning experiences, including interactions with peers, learning content, program technical design, and challenges encountered in web-based programs. The synthesized findings confirmed that multiple factors affected informal caregivers' experiences. The enabling factors most often mentioned included the programs' quality and relevancy, support received, relevance to individual caregivers' needs, flexibility in delivery, and ability to connect to other caregivers and program facilitators without time and space restrictions. The impeding factors included caregiving demands, poor program performance (eg, internet connection), and the inability to meet individual caregiver's needs (eg, their caring situation) or preferences (eg, for a paper-based program).

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Keywords.
[DOCX File , 14 KB - aging_v6i1e47152_app1.docx]

Multimedia Appendix 2
Search strategies.
[DOCX File , 32 KB - aging_v6i1e47152_app2.docx]

Multimedia Appendix 3
Findings and illustrations.
[DOCX File , 41 KB - aging_v6i1e47152_app3.docx]

Multimedia Appendix 4
PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 item checklist.
[DOCX File , 21 KB - aging_v6i1e47152_app4.docx]

Multimedia Appendix 5
Table results of metasynthesis.
[DOCX File , 19 KB - aging_v6i1e47152_app5.docx]

Multimedia Appendix 6
The ConQual summary of findings.
[DOCX File , 15 KB - aging_v6i1e47152_app6.docx]

Multimedia Appendix 7
The meta-aggregation flowchart.
[DOCX File , 24 KB - aging_v6i1e47152_app7.docx]

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Abbreviations

JBI: Joanna Briggs Institute
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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Review

Older Adults' Pain Outcomes After mHealth Interventions: Scoping Review

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Abstract

Background: Pain is prevalent and poorly managed in older adults. Although pain self-management strategies are helpful, adoption and access are limited; thus, technology provides an opportunity for intervention delivery. Mobile health (mHealth) is feasible to use in older adults; however, we have yet to understand the effect of mHealth pain self-management interventions on pain outcomes in older adults.

Objective: The purpose of this scoping review is to examine the characteristics of mHealth interventions and their efficacy on pain outcomes in older adults with musculoskeletal pain.

Methods: With the assistance of a medical librarian, keywords and subject headings were generated, including but not limited to mobile health application, mHealth, digital, pain, pain management, and older. A search was conducted for papers in journal databases, including PubMed, Embase, CINAHL, Scopus, and IEEE Xplore, between 2000 and 2022. Papers were screened according to predetermined inclusion and exclusion criteria, and reference lists were reviewed for additional paper inclusion. Three authors appraised the methodology of papers independently, then collaboratively to synthesize the evidence.

Results: Six publications were included in the scoping review. The design and methodology ranged widely from pilot studies to a comparative effectiveness trial. Older participants in the studies reported a variety of musculoskeletal conditions. Delivery of the mHealth pain self-management interventions incorporated mobile devices, such as a smartphone or tablet. Most mHealth-delivered interventions were multicomponent and incorporated elements of in-person and telephone access to an interventionist. The findings suggested mHealth interventions may reduce pain intensity; however, pain interference and other pain-related conditions did not have a statistically significant reduction.

Conclusions: Research that has explored mHealth for pain self-management is beginning to move beyond feasibility. The few experimental studies conducted in older adults are heterogeneous, and the interventions are mostly multicomponent. It is premature to conclude the interventions' significant effect on pain or pain-related symptoms. As technology continues to integrate into health care, more experimental research is warranted to examine the efficacy of mHealth interventions on a variety of pain outcomes in older adults.

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KEYWORDS

mHealth; older adults; pain; self-management; pain management; mobile health; musculoskeletal pain; scoping review; pain outcomes; mobile phone

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Introduction

The population of older adults in the United States is expected to reach 80.8 million by 2040. Along with the population increase, it is likely that the number of individuals with chronic conditions and symptoms, such as chronic pain, will grow [1]. The prevalence of pain in adults 65 years of age and older is higher than in the general adult population globally and in the United States [2].

The concept of "pain self-management" has not been well-defined in the literature. Some researchers have defined self-management as a behavior that helps patients maintain wellness through several tasks: condition management, creation of new meaningful behaviors, and emotion management [3]. Researchers have also postulated that the term "self-management" is often used interchangeably with terms such as "self-help," "guided self-help," "self-management strategies," "self-management interventions," "coping strategies," and "self-care." It remains unclear whether pain self-management presumes a collection of strategies for patients or packaged interventions and treatments [4]. Since pain self-management has not been consistently defined in the literature, this variation can influence studies exploring this concept.

Pain self-management has been historically encouraged among older adults with chronic pain [3,5]. For example, yoga, tai chi, qigong, massage, cognitive behavioral therapy, and music therapy are self-management interventions that have been reported to improve musculoskeletal pain in older adults [5-7]. To improve accessibility and adoption, pain self-management interventions have also been developed and delivered using technology. In fact, mobile health (mHealth) software apps are a modality that has gained popularity to promote pain self-management interventions [8-10].

While definitions of mHealth vary, it is often defined as the use of mobile phones, tablets, sensors, and other wireless devices to help accomplish health objectives [11,12]. mHealth software apps are typically task-specific, health-related computer programs that can be downloaded on the internet for use on a personal mobile device. Not only may mHealth apps track health and lifestyle [13], but these apps may also facilitate symptom and disease management among older adults [14]. In the pain realm, the function of mHealth may support an older adult's remote pain monitoring and reporting, improve patient–health care provider communication, and promote therapeutic pain treatment delivery and pain research access [15].

The possibilities are numerous for mHealth and older adults who have pain. In total, 28% of older adults currently use at least one mHealth app, and 49% of those between the ages of 50 and 64 years were more likely to have used an app than 38% of older adults between 65 and 80 years of age [16]. Although there are usability barriers with devices that deliver mHealth, pain management via mHealth is feasible and acceptable for older adults [17]. Among older adults with minimal prior use of mHealth, most report willingness to try mHealth to help manage pain symptoms and pain medications. Older adults also appreciate the potential benefit of being able to contact their health care provider and safely manage their pain [18]. Given the acceptability and potential usefulness of mHealth pain self-management interventions for older adults, a review of the evidence is warranted. This scoping review was guided by the following research questions: What are the characteristics of the mHealth pain interventions that have been used in older adults? What effect do mHealth interventions have on pain outcomes in older adults?

Methods

Study Design

The aim of a scoping review is to conduct a broad analysis of available evidence to answer a research question [19] and demonstrate the range of evidence pertinent to the research question [20]. The methodology used in this review is based on the Arksey and O'Malley [19] framework. This scoping review involved five steps: (1) formulating the research questions, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarizing, and reporting the results [19,20].

Search Strategy

To obtain a comprehensive review of the literature, the research team performed a search across multiple bioscience and biomedical databases, including MEDLINE via PubMed, Embase, CINAHL, Scopus, and IEEE Xplore for pertinent papers. The results were limited to peer-reviewed papers published in English between 2000 and 2022. The search was performed in accordance with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines. The search strategy, designed by an experienced academic medical librarian (KH), combined controlled vocabulary terms and free-text words on the concepts of mobile apps, pain management, and adults aged 60 years or older. The full search strategy is included in Multimedia Appendix 1. The systematic search was last run in September 2022. To minimize bias, the researchers used a broad search strategy to be inclusive across gender, sex, orientation, race, ethnicity, ability, literacy, socioeconomic status, and comorbidity. We solely focused on interventions for noncancer chronic pain among older adults. The search resulted in 1840 unique papers. The research team used the citation manager, RefWorks, to remove 4 duplicate papers. This resulted in 1838 unique papers. These papers were then screened and ascertained for relevance to the inclusion and exclusion criteria.

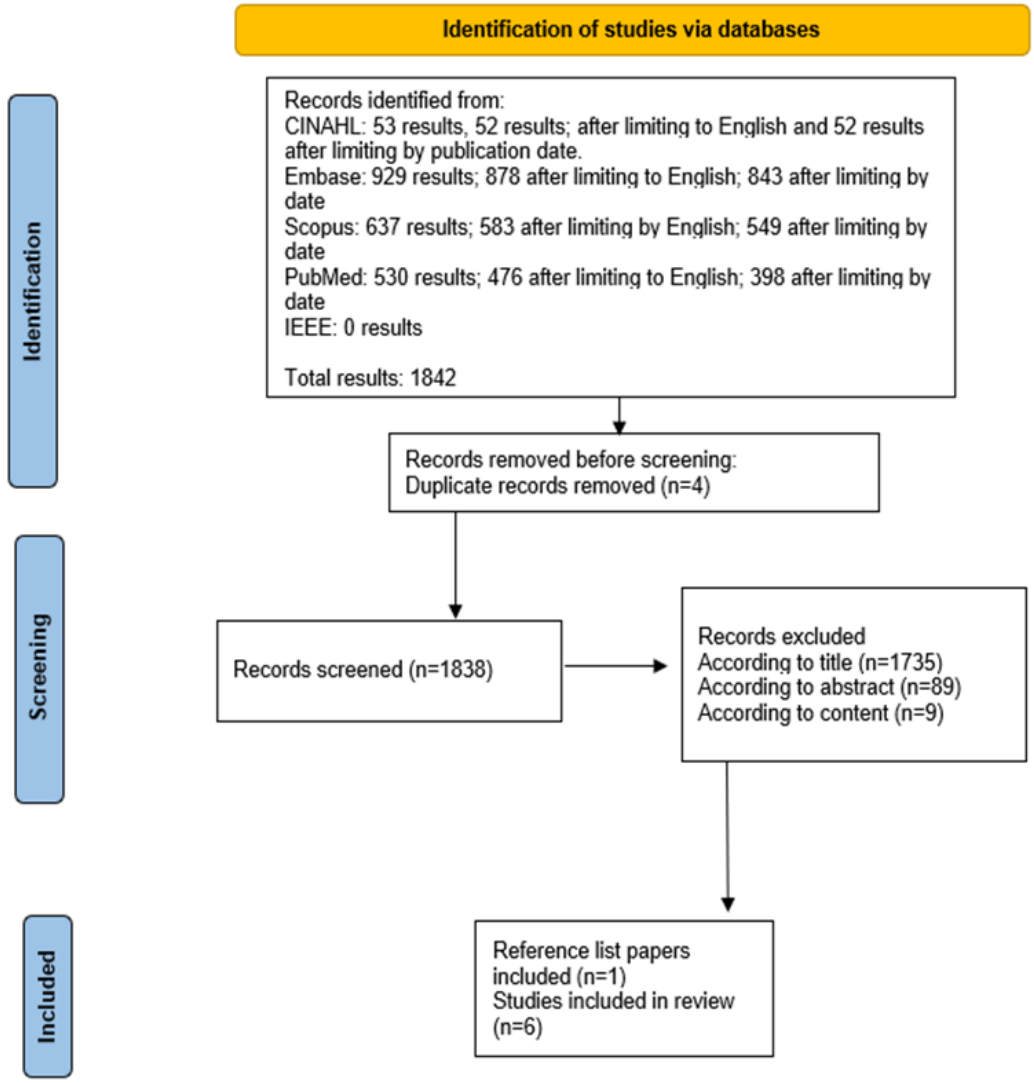
Eligibility Criteria

Studies were included in this review if they aimed to explore the outcomes of using mHealth pain interventions in older adults. Older adults were defined as those individuals 60 years of age or older as characterized by the World Health Organization [21]. Studies were included if the mean age of study participants was 60 years or older. We included intervention and cohort studies published in English. Studies were excluded if the pain intervention was delivered on a personal desktop computer (ie, nonmobile device) or if participants did not report musculoskeletal pain. Study protocols, opinion and editorial papers, reviews, case studies, abstracts,

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position statements, dissertations and theses, guidelines, book chapters, conference proceedings, and solely qualitative studies were excluded. The flowchart [22] of the database search and screening process is shown in Figure 1. Papers were evaluated according to study methodology.

Figure 1. Scoping review flowchart mHealth interventions for pain outcomes in older adults.



Charting the Data

Three authors (MS, AMH, and MK) selected the final set of studies. Two authors (MS and MK) reviewed and organized the data that pertained to research questions. The data included country, median or mean age, sample size, race or ethnicity, clinical pain diagnoses or conditions that were the subject of treatment, devices used to deliver mHealth, mHealth intervention characteristics, and pain outcomes. Six papers were included, and the data are summarized in Multimedia Appendix 2 [23-47].

Results

Overview

In total, 4 of the selected studies were conducted in the United States, 1 study was conducted in Sweden, and 1 in the United Kingdom. The study designs varied; 2 studies were randomized controlled trials [48,49]. Other designs included a mixed methods exploratory within-subject pre- and posttest study [50], longitudinal cohort study [51], a phased randomized wait list control trial [52], and a randomized noninferiority comparative effectiveness trial [53].

The papers included men and women (mean age range 63-70 years; 45%-91.7% White). Sample sizes of the studies ranged from 12 [50] to 499 participants [51]. The study participants' clinical pain diagnoses included those commonly associated with chronic musculoskeletal pain. Pain and corresponding diagnoses included knee or hip pain from osteoarthritis [48,51], back pain [53], multiple pain locations [52], musculoskeletal and neurological pain [50], and chronic noncancer pain [49].

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Devices Used for Intervention Delivery

In 3 studies, a smartphone or tablet were used to deliver a downloaded software app or stream content as an mHealth intervention [48,49,51]. Another study incorporated a wrist-worn activity monitor with a software app delivered using a smartphone or tablet [52]. One study incorporated an artificial intelligence engine that delivered the mHealth intervention using an interactive voice response via telephone [53]. One study used a virtual reality (VR) headset to deliver the mHealth intervention [50].

mHealth Pain Self-management Intervention Characteristics

Despite the similarity in using mHealth, the interventions varied widely in the structure, content, and duration. Overall, the structure of the intervention components varied. Interventions incorporated a mixture of mHealth along with in-person and access to other interventionalists such as a coach or therapist. An in-person component was present in one study [52]. By contrast, in another study [52], an initial phase of the intervention included group sessions led by interventionists. In 4 studies, telephone access to an interventionist was offered [48,49,51,53].

The studies also varied in content and duration. In 2 studies, exercise and osteoarthritis education were the main intervention components [48,51]. In the VR study, distraction was used for coping and relaxation as the main intervention component. Older adults played games or interacted for 15-45 minutes, with virtual activities focused on pet engagement, animals, music, and travel [50]. In one study, pain and coping skills training were used. The pain and coping skills training was web-based and included group videoconferencing led by expert facilitators. An app was used as part of the intervention to help tailor pain management goals for 12 weeks. Although it was in the first 3 weeks of the intervention, this was the only study with in-person groups [52]. One study included a multicomponent intervention to encourage behavioral activities for symptom monitoring. Behavioral activities included the daily entry of pain symptoms, diet, and behavior tracking. Older adults received weekly health telecoaching sessions with tailoring of lifestyle adjustments to manage pain symptoms [49]. One study used cognitive behavioral therapy delivered by artificial intelligence, and the intervention incorporated daily interactive voice feedback [53].

Pain and Pain-Related Outcomes

In each study, the intervention's efficacy for decreasing pain intensity was measured. In 5 studies [48-51,53], pain intensity was measured using the numeric rating scale [23,27]. Fanning and colleagues [52] used the Patient-Reported Outcomes Measurement Information System (PROMIS) 3-item pain intensity scale [29]. In 2 studies where the numeric rating scale was used, pain intensity was measured within the past week [48,51]. In one study, current pain intensity was measured [49]. In 2 studies, a time-framed measure of the pain outcome was undefined [50,53]. In the study that used the PROMIS tool, pain intensity was measured in the previous week [52]. A decrease in pain intensity after the delivery of the mHealth interventions was reported in all studies.

Pain interference was measured in 2 studies. In one study [53], the items on the Brief Pain Inventory were used [44,45], and in another study [52], the PROMIS pain interference scale was used [29]. A statistically significant difference was not found in pain interference after the use of an mHealth intervention in one study [52]. In the other study [53], it was not reported whether pain interference had a statistically significant change after the mHealth intervention.

Additional pain-related outcomes were measured in the selected papers. Depressive symptoms were measured in 2 studies [50,53] and did not improve after the mHealth interventions. A nonsignificant decrease in anxiety and emotional affect was found in one study [49]. Similarly, in the 2 studies that measured quality of life, no change was found [49,50]. Pain-related disability was measured in 2 studies and did not demonstrate a statistically significant improvement after implementing mHealth interventions [49,53].

Discussion

Principal Findings

A scoping review was conducted to examine the characteristics of mHealth interventions and their efficacy on pain outcomes in older adults. Consistent with the purpose of a scoping review, we demonstrated the breadth of evidence on a topic [19]. The main findings of our review were (1) mHealth interventions varied widely in structure, content, duration, and target audience in terms of pain diagnoses; (2) there was a statistically significant reduction in pain intensity in all studies; and (3) varied results were attained regarding other pain-related outcomes, with no consensus possible, due to the small number of studies to date.

The number of studies that focus on measuring pain or pain-related outcomes in older adults is sparse. Most studies where mHealth for pain was explored were excluded due to participants having a mean age of less than 60 years old. The sample sizes of the studies varied, which may be attributed to usability barriers in the oldest old of adults, leading to challenges in recruiting older participants for mHealth pain intervention studies. Many excluded studies also focused on usability, acceptance, and design of mHealth pain interventions, and yet while important for aiding adoption, many of these studies did not measure an effect on pain outcomes.

There were a variety of devices used to deliver mHealth interventions, including smartphones or tablets. The use of smartphones would be the most logical device to deliver mHealth interventions due to the availability and increased use by older adults. Despite the common assumption that older adults do not use technology, many have adopted mobile devices, which is consistent with Pew research describing older adult's use of smartphones has grown [54]. VR is gaining momentum for use in treatment and intervention delivery. VR has not routinely been included in mHealth interventions; however, a wireless VR headset (with or without a smartphone) may be transformed for a therapeutic treatment by virtue of the intended use of the software it is running [55]. Thus, VR was included in this review based on the definition of mHealth used

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in this scoping review and to explore the broad range of evidence. Although VR was used in one study [50], most of the literature on VR is focused on factors related to attitudes and usability in older adults [56,57], as opposed to the effect on pain outcomes. Other emerging devices, such as smart speakers (eg, Amazon Alexa and Google Home) and wearables (eg, Apple Watch and Fitbit), have yet to be widely explored for the delivery of mHealth pain interventions.

Most pain self-management strategies incorporate content elements of pain education, training or coaching to strengthen relaxation skills, coping, problem-solving, and communication [5]. In this review, the mHealth pain interventions varied and combined multiple approaches to affect older adults' pain. The structure of the interventions varied, with most interventions incorporating access to in-person [52] or telephone or chat [48,49,51,53] interventionist. One perspective on this incorporation of a human component to mHealth interventions is that older adults may be unable or unwilling to partake in mHealth interventions remotely without access to an interventionist. It may be necessary to include interventionist access to help ease anxiety, assist older adults, or ensure proper intervention delivery. It is also fair to propose that mHealth delivery can be used to complement in-person care or support traditional interventions (eg, offer mHealth intervention between traditional in-person physician's appointments). The characteristics of the interventions discussed in the studies are consistent with the evidence associated with pain management strategies that need to be promoted in older adults. A multimodal approach to pain is encouraged to manage pain in older adults, and what works for one person may not work for someone else. Although it is unclear from the review, mHealth interventions may need to incorporate a variety of strategies for tailoring and tangible support for older adults.

Pain is a biopsychosocial symptom, and several instruments were used to assess pain outcomes. Pain intensity was a universal outcome, but measurement occurred at different time points. For example, it is not clear if mHealth interventions affect the older adult's current pain intensity or pain that occurred within the past week. Surprisingly, pain interference was only measured in 2 studies [52,53] and did not improve. Pain interference is defined as the degree to which pain prevents an individual's participation in physical, cognitive, emotional, sleep, recreational activities, and experiencing enjoyment [58]. Contingent on the evidence presented in this review, even if pain intensity decreases, pain may continue to interfere with aspects of the older adult's life. Therefore, a reduction in pain intensity may not capture an outcome that is meaningful to patients, particularly if pain continues to hinder activities. Self-reported pain interference needs to be measured in future studies using mHealth interventions for pain in older adults. Also, based on the heterogeneity and small number of studies in this review, it is unclear whether incorporating mHealth pain interventions significantly affects pain-related conditions, such as mental and emotional symptoms and disability. Future studies need to measure the biopsychosocial elements of pain and consistently use validated and reliable instruments to give direction and support for interventions.

More experimental studies are needed with large and culturally diverse samples to examine the efficacy of mHealth pain interventions on pain outcomes. Recruitment strategies must be such that older adults will be assured that training and assistance with technology will be provided to help alleviate apprehensions associated with usability. One example of assistance would be "navigators" that help older adults become acclimated with and troubleshoot the technology [59,60]. It is important to continue examining the role and outcomes of mHealth interventions for pain management in older adults. With the growing adoption of mobile devices, older adults have greater opportunities to use mHealth for pain management as a nonpharmacologic strategy, which may improve health outcomes and quality of life. Additionally, pragmatic issues of mHealth use among older adults such as cost and internet access may be examined.

Limitations

There are some limitations in this scoping review. The search identified few papers that focused on mHealth interventions for pain in older adults. As this is a rapidly growing body of research, other relevant papers could have been missed. For example, we did not include conference proceedings or abstracts from human-computer interaction databases, which may include additional experiments of mHealth pain interventions in older adults. The mental and behavioral health database, PsycInfo, was eliminated during the medical librarian's preliminary search due to zero returns on the search terms combining keywords and controlled vocabulary for the concepts of mobile apps and chronic pain. Publication bias may have also caused us to miss papers with a negative or poor pain outcomes associated with mHealth interventions. Additionally, we only selected papers published in English.

Conclusions

This scoping review was conducted to examine the characteristics of mHealth interventions and pain outcomes in older adults. Although the research is beginning to move beyond usability and acceptance, few experimental studies have been conducted in older adults that focus on improving pain outcomes. The studies that have been conducted vary in design, sample size and diversity, measured outcomes, and interventional approach. As technology continues to integrate into health care, more research is warranted to examine the efficacy of mHealth interventions on pain outcomes in older adults.

Conflicts of Interest

None declared.

Multimedia Appendix 1

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Search strategy.
[DOCX File , 23 KB - aging_v6i1e46976_app1.docx]

Multimedia Appendix 2
Mobile health intervention characteristics and outcomes.
[DOCX File , 22 KB - aging_v6i1e46976_app2.docx]

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Abbreviations

mHealth: mobile health
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROMIS: Patient-Reported Outcomes Measurement Information System
VR: virtual reality

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Review

Usability and Acceptability of Clinical Dashboards in Aged Care: Systematic Review

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Abstract

Background: The use of clinical dashboards in aged care systems to support performance review and improve outcomes for older adults receiving care is increasing.

Objective: Our aim was to explore evidence from studies of the acceptability and usability of clinical dashboards including their visual features and functionalities in aged care settings.

Methods: A systematic review was conducted using 5 databases (MEDLINE, Embase, PsycINFO, Cochrane Library, and CINAHL) from inception to April 2022. Studies were included in the review if they were conducted in aged care environments (home-based community care, retirement villages, and long-term care) and reported a usability or acceptability evaluation of a clinical dashboard for use in aged care environments, including specific dashboard visual features (eg, a qualitative summary of individual user experience or metrics from a usability scale). Two researchers independently reviewed the articles and extracted the data. Data synthesis was performed via narrative review, and the risk of bias was measured using the Mixed Methods Appraisal Tool.

Results: In total, 14 articles reporting on 12 dashboards were included. The quality of the articles varied. There was considerable heterogeneity in implementation setting (home care 8/14, 57%), dashboard user groups (health professionals 9/14, 64%), and sample size (range 3-292). Dashboard features included a visual representation of information (eg, medical condition prevalence), analytic capability (eg, predictive), and others (eg, stakeholder communication). Dashboard usability was mixed (4 dashboards rated as high), and dashboard acceptability was high for 9 dashboards. Most users considered dashboards to be informative, relevant, and functional, highlighting the use and intention of using this resource in the future. Dashboards that had the presence of one or more of these features (bar charts, radio buttons, checkboxes or other symbols, interactive displays, and reporting capabilities) were found to be highly acceptable.

Conclusions: A comprehensive summary of clinical dashboards used in aged care is provided to inform future dashboard development, testing, and implementation. Further research is required to optimize visualization features, usability, and acceptability of dashboards in aged care.

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KEYWORDS

dashboard; visualization; usability; acceptability; user interface design; health information technology; aged care; clinical; database; development; aged care

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Introduction

Health information technologies are increasingly being used in the health care sector, including in aged care, due to their capacity to improve workflow efficiencies and quality of care [1,2]. A technology rapidly gaining momentum in health is electronic clinical dashboards. These typically provide a summary of vital clinical data relating to individual patients to increase users' understanding of their health care needs and care, display trends in patient-reported clinical outcomes, and support decision-making [3,4]. Limited examples of clinical dashboards currently exist within aged care [5,6].

Aged care has a diverse workforce with varying levels of health and digital literacy. In order to address the needs of older adults (defined as individuals aged 65 years and older) in care, their families, and the workforce, dashboards ideally should be designed to support the perspectives and requirements of all relevant stakeholders in aged care. However, there is limited research on how best to present data to support the interpretation of resident outcomes [7]. Furthermore, while the use of visual information can help reduce information overload and improve understanding of data for users in general [4], it is unclear how different types of visual displays used in dashboards may affect comprehension and decision-making for aged care users.

It has been shown that the way in which information is presented (eg, icon displays vs tables, pie charts, and bar graphs) can impact the accuracy of decisions taken by health professionals [4], but limited work has examined whether interpretation of the visual information is dependent upon the expertise, knowledge, and experience of various dashboard users. Aged care organizations are being encouraged to adopt dashboards to improve the quality of care and resident safety [8]; however, dashboards can be used to communicate information to different users, including patients, clinicians, or others.

The aim of this review was to thus identify the visual features of clinical dashboards that are usable and acceptable to the varied number of users in aged care settings in order to help guide future development, design, and implementation of dashboards in aged care.

Methods

Search Strategy

Adhering to recommended procedures for systematic reviews (ie, PRISMA [Preferred Reporting Items for Systematic Reviews and Meta-Analyses] guidelines) [9], we conducted a literature search for peer-reviewed empirical studies until April 27, 2022, using a predefined search strategy in the following databases: MEDLINE, Embase, Scopus, PsycINFO, and CINAHL. Primary search terms were dashboard, aged population, aged care, acceptability, and usability; papers were limited to 2000 to April 2022, human subjects, and in English (see search strategy in Table S1 in Multimedia Appendix 1). To increase the comprehensiveness of the search, we scanned the reference lists and cited documents of included peer-reviewed articles (ie, snowballing) to identify any relevant articles missed by the searches.

Inclusion and Exclusion Criteria

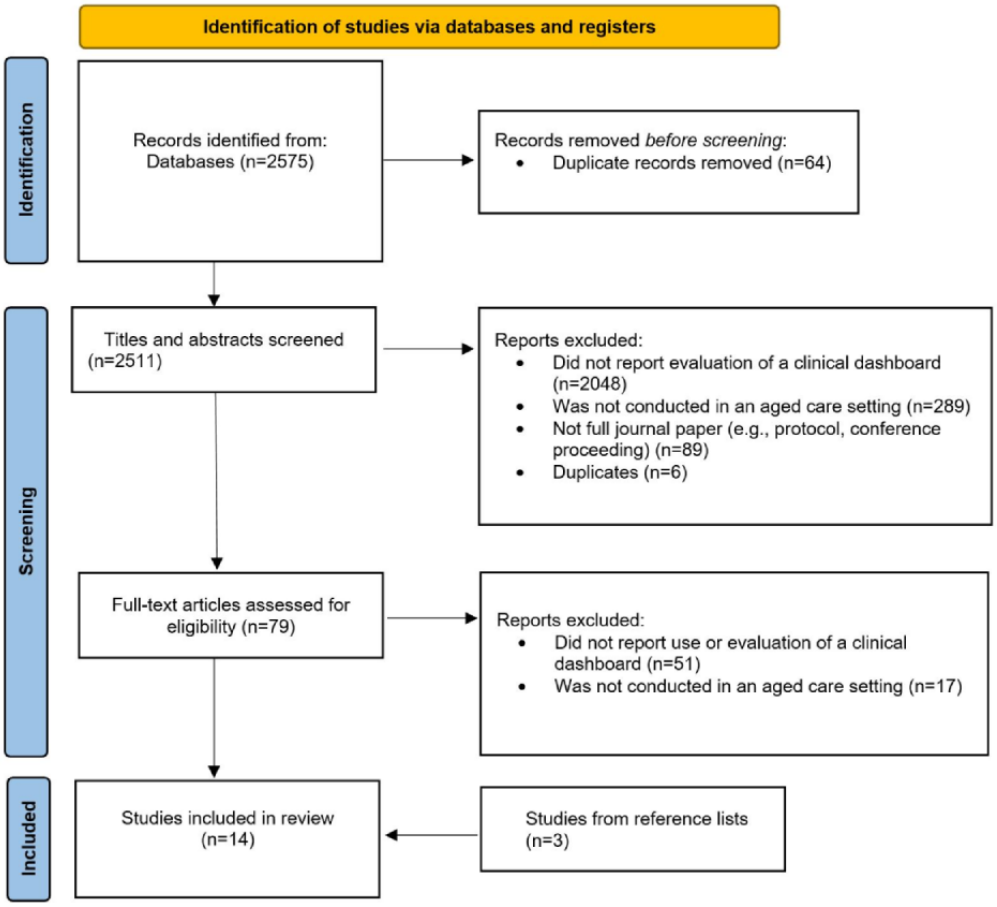
We included peer-reviewed primary studies reporting a usability or acceptability evaluation of a clinical dashboard for use in aged care environments, including home-based community care, retirement villages, and long-term care (Table S2 in Multimedia Appendix 1). All study designs were included.

Study Selection

All potential studies were exported into a reference citation manager and duplicates were removed. The primary author (JS) removed additional duplicates. A random selection of 10% of the abstracts (n=200) was then screened by the 2 authors (JS and FS). An interreviewer agreement was high (100%), with no disagreement on which papers should proceed to full-text screening. FS conducted the remainder of the abstract review. Full-text articles were then obtained for screening by JS and FS, with AN moderating the final list of articles. Please see PRISMA diagram for a detailed summary (Figure 1).

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Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram.



Data Extraction

Overview

Data extraction was completed independently by 2 reviewers (JS and LD) and checked by an additional reviewer (AN). The data extraction tool was piloted to ensure complete documentation of the qualitative and quantitative components of the included studies. Once finalized, data were extracted on study general characteristics (eg, year, country, type of dashboards, participants, and study design), sample characteristics (eg, age and gender), dashboard visual features (eg, charts), acceptability and usability ratings, study findings, and recommendations.

Acceptability

Acceptability was defined as the users' judgement on the appropriateness of the dashboard and its design features, which included sensitivity to their needs as well as usage levels and utility [10]. Adopting the theoretical framework of acceptability [11], perceived user acceptability was explored for the overall dashboard as well as specific design features as described by the study (eg, bar charts). Detailed examples of acceptability scoring are shown in Table 1.

Briefly, acceptability was categorized according to technology acceptability statements in validated technology usability tools or through other in-house developed surveys that were focused on users' responses to acceptability. For example, statements such as "I found the system unnecessarily complex" in the System Usability Scale [12]; "I think the visual perception of the dashboard is rich" in the Questionnaire for User Interaction Satisfaction [13-15]; and "Using this dashboard would enable me to accomplish tasks more quickly" in the Technology Acceptance Model (TAM) [16] were used to rate acceptability of the dashboards or its features. Acceptability was scored according to the confirmed metrics of these tools and were classified as low, medium, or high, for each scale. For example, with the TAM model, acceptability was defined as low (<50% agreement), medium (50%-70% agreement), and high (>70% agreement) [16].

In-house surveys typically used a 5-point Likert scale of agreement (1=highly disagree to 5=highly agree) to specific statements on the usefulness of the dashboard, its value, and its necessity (eg, Lee and Huebner [17]) and was scored as low (1-2), medium (2-4), and high (4-5) acceptability.

For qualitative articles, general and specific dashboard features that were perceived positively by all stakeholders in a single study were coded as high acceptability, features that included a mix of both positive and negative stakeholder feedback were coded as medium acceptability, and features that were perceived to provide minimal to no added value for stakeholders (eg, low staff engagement [18] or required significant improvements [19]) were categorized as having low acceptability.

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Table 1. Scoring system for acceptability and usability of articles.

Study design and measurement	Low	Medium	High
Acceptability			
Quantitative[a]			
System Usability Scale [12]	<25	25-35	>35+
Questionnaire for User Interaction Satisfaction [15]	<5	5-7	>7+
Technology Acceptance Model [16]	<50% agreement	50%-70% agreement	>70% agreement
In-house survey on the overall dashboard (eg, "the anticoagulation dashboard is necessary for high-quality home health patient care" [17]) and specific dashboard features (eg, "The graph combining edema status and weight is useful [17])	<50% agreement	50%-70% agreement	70%-100% agreement
Qualitative			
Participant feedback	Negative appraisals (eg, "The tablet is extra work, and for people with dementia, it's very important for me to give them extra time." [19])	Containing a mix of both negative and positive comments (eg, "On the right track but not quite there." [20]; "Whether the system really works remains to be seen. At least it is [better] than nothing." [21])	• Positive appraisal for overall dashboard use (eg, "I find this to be a very helpful tool in a team approach working together with the physician and other team members for the best possible outcomes for our patients" [17]) • Positive appraisal for specific dashboard feature (eg, "I have just received one alert, a yellow one, I contacted the older adult the day after...she was happy that it works, and it really works." [22])
Usability			
Quantitative			
System Usability Scale [12]	<50 (low)	50-70 (medium)	70+ (high)
Technology Acceptance Model [16]	<50% agreement	50%-70% agreement	>70% agreement
In-house survey (eg, "The CHF dashboard provides the ease of reviewing necessary patient information at one time." [17])	<50% agreement	50%-70% agreement	80%-100% agreement
Qualitative			
Participant feedback	Negative appraisals (eg, "there are no options that we might like to have clicked, that the clients are, for example, chronically or acutely confused." [19]; "The staff struggled with the challenge of responding to acute events versus detecting trends and patterns of behavioural decline and determining how to integrate such monitoring into their daily schedules" [18])	Mix of appraisals (eg, "We had difficulty logging into the system in the beginning." [18]; "The system has a learning curve, so training is necessary" but "we can identify fixable usability challenges using scenario based training" [23])	Positive appraisals (eg, "Oh, I love it. I have a sense of being cared for!" [21]; "The electronic form flows nicely. It is set up just like the paper form, is easy to follow and is one less thing on my desk." [23])

[a]Acceptability subscores of the quantitative scales were used to compute the overall acceptability of the dashboards.

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Usability

Usability was defined as the extent to which the dashboard could be used by the specified users to achieve their goals effectively, efficiently, and with satisfaction [24,25]. Usability was also rated for overall dashboard use and specific dashboard features using previously described methods focused on usability items in the tools (eg, System Usability Scale, Questionnaire for User Interaction Satisfaction, and TAM) for assessing low, medium, and high usability (eg, Dowding et al [26], Lanzarone et al [27]). These items typically focused on the dashboard's effectiveness (ie, can stakeholders achieve their goals) and efficiency (ie, amount of effort and resources required to achieve their goal) metrics. For further information, refer to our scoring system described in Table 1.

Data Synthesis

Qualitative Data

For qualitative studies, acceptability and usability were synthesized using a thematic analysis [28] where main themes regarding the acceptability or usability of the dashboard (including its individual visual features) were first identified independently by JS and LD. Any discrepancies that arose were solved through discussion with the third member of the review team (AN). Themes were reviewed and amended by the review team and were subsequently organized into overarching topics for clarity and conciseness. A similar process was also adopted identifying the recommendations to improve acceptability and usability. Where possible, synthesis was made according to different dashboard user types (eg, resident, caregiver, health care professional).

Quantitative Data

A narrative synthesis of quantitative articles was used to specify whether clinical dashboards and their features were considered acceptable and usable. Interreviewer disagreement on data extracted was resolved through discussion among the research team. The review team included academics with backgrounds in psychology (JS), aged care (LD and KS), public health (FS and MR), epidemiology (JW, MR, and KS), digital health (JW, AN, MR, and MB), pharmacy (KS, MR, and NW), human factors (MB), and data science (NW). The results were synthesized as a narrative review.

Quality Assessment

Study quality was assessed using the Mixed Methods Appraisal Tool (MMAT) [29] by three authors (JS, KS, and MR). This tool allows the appraisal of the methodological quality of 5 categories of studies: qualitative research, randomized controlled trials, nonrandomized studies, quantitative descriptive studies, and mixed methods studies. Each study category has 5 assessment criteria, which are scored as either "yes—criterion met," "no—criterion not met," or "unclear/can't tell whether criterion met" [29]. Mixed methods studies are assessed against the relevant study categories, as well as the mixed methods studies category.

Two reviewers independently scored each study, and disagreements were discussed with a third reviewer to come to a consensus on the rating. An overall quality score was assigned to each study following the method described by MMAT [29]. The score was the overall percent of quality criteria met for an individual study. For multimethod studies, the overall quality score was the score for the lowest-scoring component.

Results

Overview

After excluding duplicates, our search strategy identified 2575 potentially relevant articles (Figure 1). After excluding articles that did not meet our inclusion criteria, a total of 14 peer-reviewed articles were included, although 2 articles were reported on the same dashboard [26,30,31] and were described collectively. Articles were most frequently excluded because they did not report an evaluation of a clinical dashboard.

Study Quality Assessment

The quality of studies ranged from 20% (n=3) to 100% (n=6) on the MMAT checklist (Table S3 in Multimedia Appendix 1) [18-20,22,23,26,27,30-35]. Although more than half of the studies (n=8) received scores greater than 60%, over a third of the studies (n=5) had scores less than 40%, indicating a mix of low, moderate, and excellent quality.

Characteristics of Studies

Study characteristics are summarized in Table 2. Studies were conducted mostly in the United States (6/12) [17,18,20,23,26,30-32], with 1 study conducted in Australia [33], China [34], Sweden [22], Italy [27], Canada [35], and Europe [19]. The majority of studies adopted a mixed methods design (8/12) [17,18,22,23,26,27,30,35], followed by a quantitative approach (3/12) [20,31,32] and 2 used a qualitative design [19,33]. Studies were carried out mostly in a home care setting (6/12) [17,18,20,22,26,27,30,31], which encompasses domiciliary care, community care, or other social care provided within the home in which the older adult is living or long-term care (6/12) [19,23,32-35], which refers to individuals in residential aged care, nursing homes, or other care facilities that provide permanent accommodation for persons who require consistent and ongoing services to assist with activities of daily living. Studies had varied sample sizes of users (median 32, range 3-292 [22,30]). Most studies described the experiences of health professionals including nurses (9/12) [17,22,23,26,30-35], aged care staff (5/12) [18,19,27,33,35], physicians (3/12) [20,32,35], with 5 studies including a mix of older adults in home or community care, respite care, and long-term care; staff; and health care professionals [18,22,27,32,35].

A summary of the methodological frameworks and theories used to develop or evaluate the dashboards is provided in Table S4 in Multimedia Appendix 1 [16,17,30,32,35-46]. Most dashboards (8/12) used a developmental framework [17,20,22,23,26,27,30,34,35], including feedback intervention theory [47], and most also used an evaluation framework (7/12) [19,22,23,26,27,30,34,35], with the most common being the TAM [16] and the UK's Medical Research Council complex intervention evaluation framework [48].

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Table 2. Characteristics of included studies (n=14).

Author (year), country	Study design[a]	Dashboard type	Platform	Software used	Focus[b]	Study setting				System users		
						HC[c]	R[d]	LTC[e]	O[f]	Sample size, n	Age (years), mean (SD)	Sex (female), %
Algilani et al [22] (2016), Sweden	MM	Clinical	ICT[g] application	In-house	Health status	✓						
										Older adults: 8	77.6 (—[h])	60
										Nurses:3	—	100
Bail et al [33] (2022), Australia	Qual	Clinical	ICT application	Humanetix	Administrative, health status			✓		Staff: 65	—	—
Bell et al [32] (2020), USA	Quant	Clinical	Web-based	Unclear	Medication and prescribing practices		✓	✓	✓[i]			
										Older adults: 112	83[j] (—)	0
										Physician: 6	—	—
										Nurse: 1	—	—
Cui et al [34] (2018), China	Quant	Clinical prototype	Mobile app	Unclear	Administrative, health status			✓	✓[k]	Nurses: 18	—	100
Dowding et al [30] (2018), USA	Quant	Clinical prototype	Paper-based	In-house	Administrative, health status	✓				Nurses: 195	49 (11)	89.7
Dowding et al [31] (2018), USA	MM	Clinical prototype	Computer	Morae software (Techsmith)	Health status	✓				Nurses: 292	—	—
Dowding et al [26] (2019), USA	MM	Clinical prototype	Web-based	Morae software (Techsmith)	Health status	✓				Nurses: 32	51[l] (10)	91
Kramer et al [20] (2016), USA	Quant	Clinical simulation	Computer	In-house	Medication and prescribing practices	✓				Physicians: 19	39.8 (6.1)	57.9
Lanzarone et al [27] (2017), Italy	MM	Administrative	Diamond-Touch table	Geodan	Administrative	✓				Staff/other[m]	—	—
Lee and Huebner [17] (2017), USA	MM	Clinical prototype	Computer	MS Excel	Administrative, health status	✓				Nurse: 14	—	—
Mei et al [23] (2013), USA	MM	Clinical	Computer	MS InfoPath, Sharepoint	Adverse events			✓		Nurse: 4	—	—
Papaioannou et al [35] (2010), Canada	MM	Clinical, MEDeINR[n]	Web-based	In-house	Medication and prescribing practices			✓				
										Older adults: 128	85.9 (8)	75

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Author (year), country	Study design[a]	Dashboard type	Platform	Software used	Focus[b]	Study setting				System users		
						HC[c]	R[d]	LTC[e]	O[f]	Sample size, n	Age (years), mean (SD)	Sex (female), %
										Physician: 4	—	—
										Nurse: 8	—	—
Shiells et al [19] (2020), Belgium, Czech Republic, and Spain	Qual	EHR[o]	Computer, tablet	Unclear	Administrative, health status			✓		Staff (21)[k]	—	90.5
Wild et al [18] (2021), USA	MM	Clinical, ambient	Web-based	ZigBee	Administrative	✓						
										Older adults: 95	86.4 (7.4)	80
										Staff: 25	—	—

[a]Study design (MM: mixed methods; Quant: Quantitative; Qual: Qualitative).

[b]Focus of dashboard (Health status: vital signs, physiological, and functional status, eg, weight, blood pressure; Medication and prescribing practices: medication discrepancies, appropriate prescribing practices; administrative includes care pathways and changes to services/care an older adult is receiving; Falls refers to the incidence of older adult falls).

[c]HC: home or community care. Refers to in-home care, domiciliary care, community care, and social care provided within the home in which the older adult is living compared to care provided in group accommodation, clinics, and nursing homes, and also 3 independent living retirement communities.

[d]R: respite care. Refers to planned or unplanned short-term care for older adults to provide a temporary break for caregivers.

[e]LTC: long-term care. Refers to those in residential aged care, nursing homes, or long-term care facilities who provide permanent accommodation for those who require consistent and ongoing services to assist with activities of daily living.

[f]O: other.

[g]ICT: information and communication technology.

[h]Not available.

[i]Refers to short stay/transitional care and palliative care.

[j]Only at-risk older adults receiving care (n=21) data were reported.

[k]Refers to a community hospital.

[l]Age reported for usability component only.

[m]Including home care planners, experts, and nonexperts of home care providers. Sample size is not provided.

[n]MEDeINR: an electronic decision support system based on a validated algorithm for warfarin dosing.

[o]EHR: electronic health record.

Dashboard Purpose and Features

An overview of dashboard type and purpose are shown in Table 3. Dashboards were either already established in existing information systems (8/12) [18,19,22,23,27,32,33,35] or were prototypes (4/12) [17,20,26,30,31,34]. Most dashboards were accessed through a computer (5/12) [17,19,20,23,26] or specialized hardware (eg, DiamondTouch table [27]) or a web-based platform (4/12) [18,26,32,35] (Table 2).

The main purpose of dashboards was grouped into four categories: (1) health status (8/12) [17,19,22,26,30,31,33,34], which included monitoring of vital signs, physiological, and functional status such as weight and blood pressure; (2) medication and prescribing practices (3/12) [20,32,35], which referred to medication discrepancies and appropriate prescribing practices; (3) administrative (7/12) [17-19,27,31,33,34], which included exploring and viewing older adult care pathways as well as changes to services or care that the older adult is receiving; and (4) adverse events (1/11) [23], which refers to the specific incidence of falls or other behavior-related events.

Dashboard features are described in Table 3 and were broadly categorized into information, analytic capability, and other functionalities. Most *information* depicted on dashboards included health conditions prevalence and incidence (9/12) [17,18,22,23,26,30-33] and medication use patterns (6/12) [17,18,20,32,33,35], which could be displayed over time (8/12) [17,18,22,26,27,30,32,33]. Other information included geographical location (2/12) [18,27], hospitalization data (2/12) [18,31], and linkage to additional resources of complementary information and guidelines (2/12) [27,32].

Analytic capability referred to the dashboard's ability to display data in a meaningful way (eg, wound record, medical status, and medication administration and use) either through descriptive analysis (12/12) [17-20,22,23,26,27,30-32,34,35], predictive ability (7/12) [17,18,22,26,30,32,35], or prescriptive capability (7/12) [17,18,26,30,32,33,35] (ie, predicting what action should be completed according to available guidelines),

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which was supported by a visual exploration of the data through charts or other graphical means (6/12) [17,18,20,26,30,31].

Other functionalities included interactive forms dedicated to client assessment and service planning (11/12) [17,19,20,22,23,26,27,30,32-35], which included initial assessments, transitions in client care, client-level monitoring (eg, vital signs), as well as the management and coordination of aged care service operations to suit clients' needs. The ability for stakeholders to communicate and interact was also described (6/12) [17,18,20,23,27,32].

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Table 3. Summary of dashboard features and functionalities including visual application and analytic capabilities.

Author (year)	Visual representation of information						Analytic capability				Features		
	General			Specific			Descriptive	Predictive[a]	Prescriptive[b]	Visual exploration[c]	Epidemiologic monitoring or surveillance	Client assessment and service planning[d]	Stakeholder communication and interaction[e]
	Prevalence/incidence[f]	Spatial[g]	Resources[h]	Events over time[i]	Medication use patterns	Hospitalization							
Algilani et al [22] (2016)	✓			✓			✓	✓				✓	
Bail et al [33] (2022)	✓			✓			✓		✓			✓	
Bell et al [32] (2020)	✓		✓[j]	✓	✓		✓	✓	✓		✓	✓	✓[k]
Cui et al [34] (2018)							✓					✓	
Dowding et al [30] (2018)	✓					✓	✓			✓			
Dowding et al [31] (2018)	✓			✓			✓	✓	✓	✓		✓	
Dowding et al [26] (2019)	✓			✓			✓	✓	✓	✓		✓	
Kramer et al [20] (2016)					✓		✓					✓	✓
Lanzarone et al [27] (2017)		✓	✓	✓			✓			✓		✓	✓[l]
Lee and Huebner [17] (2017)	✓			✓	✓		✓	✓	✓	✓		✓	✓
Mei et al [23] (2013)	✓						✓					✓	✓
Papaioannou et al [35] (2010)					✓		✓	✓	✓			✓	
Shiells et al [19] (2020)							✓					✓	
Wild et al [18] (2021)	✓	✓		✓	✓	✓	✓	✓	✓	✓			✓

[a]Refers to dashboard/application capability of predicting what could happen (eg, dashboard triggers alerts on older adults with high risk based on risk assessment modeling of older adult health concerns).

[b]Refers to dashboard/application capability of recommending what should be done according to guidelines (eg, decision support).

[c]Refers to any graphical representation of data (eg, charts, graphs, and maps).

[d]Includes initial assessment and transitions in older adult care, monitoring (eg, vital signs), and the management and coordination of aged care service operations to suit older adult needs.

[e]Includes capability of communicating between users of the dashboard and data sharing.

[f]Refers to whether the dashboard/tool provided prevalence or incidence data or indicated the potential to compute these data for reporting purposes.

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[g]Refers to visual applications that directly or indirectly provide geographical area or location (eg, of staff and clients).

[h]Refers to whether the dashboard/application provided links to additional physical resources or complementary information, guidelines, and recommendations outside that of the information within the dashboard/application (eg, through links to external websites/files).

[i]Refers to whether the dashboard/application had the capability to display changes in events over time.

[j]Physical resource was a pharmacist to prescribe or deprescribe based on evidence-based guidelines.

[k]Advised the pharmacist of "actionable older adults receiving care" and recommended appropriate prescribing with the provider.

[l]Involved reorganization and allocation of staff and dispatch of emergency vehicles.

Overall Acceptability and Usability of Dashboards

A summary of the users' overall perceived acceptability and usability of the dashboards is presented in Table 4. Using the criteria described in the methods, perceived usability was mixed, with 4 studies reporting low [18,19,22,32], 5 medium [20,23,26,27], and 4 high usability [17,30,34,35]. Discrepancies between studies related to whether the dashboard was easy to learn, operate, and navigate, with some stakeholders feeling very confident using the dashboard [34] and others reporting difficulties with dashboard functionalities [17,23,27,33].

In terms of acceptability, most studies reported medium to high acceptance (10/11), with only 1 study revealing low acceptance [19]. While most respondents were willing to use the dashboard in their workplace (eg, 94.4% agreement [34]), uptake was low (eg, across 3 years, more than half of staff members logged in less than once [18]) and initial enthusiasm declined over time (eg, [18]).

There was no distinct pattern of dashboard type (eg, clinical and administrative), platform (eg, ICT application and computer), or focus area (eg, health status, administration, and medication) on reported dashboard usability or acceptability. Older adults tended to report usability as low (3/4 studies) [18,22,32], while other user groups (eg, aged care staff) reported dashboard usability as medium to high (8/9) [17,20,23,26,27,31,33,34]. There were no noticeable differences between users on dashboard acceptability.

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Table 4. Summary of overall usability and acceptability of dashboard.

Author (year)	Dashboard type	User group (n)	Usability[a]	Key findings	Acceptability[b]	Key findings
Algilani et al [22] (2016)	Clinical	• Older adults in-home care (8) • Nurses (3)	Low	Interviews: Barriers to navigation and access, documentation and monitoring, and subject matter.	High	Interviews: Reported acceptability and management of own care.
Bail et al [33] (2022)	Clinical	• Staff (65)	Medium	Interviews, focus groups, and survey[c]: Users reported positively on the application across multiple devices, ease of access, scheduling and documentation of information at point-of-care (formatting and structure of alerts), and instantaneity of changes to care plan (rather than waiting hours to weeks). Some users felt that the app interfered with the rhythm of care (eg, repetitive information), lacked training and login for agency staff, resulting in workarounds and missing data, and offering different styles of alerts and flagging (eg, different adverse events and health conditions).	High	Interviews, focus groups and survey[c]: Users reported reduced time spent on information retrieval and documentation; reduced errors by omission and missed documentation; improved staff and resident satisfaction; built consistency working with clinical treatment protocols; assisted management decisions and allocation of resources.
Bell et al [32] (2020)	Clinical	• Older adults in respite/long-term/other care (112) • Physician (6) • Nurse (1)	Low	Survey[c]: Little preference for using dashboard to receive prescribing notifications over traditional methods; user satisfaction, tool integration, and interface intuitiveness.	Medium	Survey[c]: Percentage of time of prescribing recommendations accepted by skilled nursing facilities was adequate (66% uptake).
Cui et al [34] (2018)	Clinical prototype	• Nurses (18)	High	Survey: TAMM[d] found a large proportion of participants who found the dashboard easy to learn, use, and navigate (89%), and were satisfied with the component (100%).	High	Survey: TAMM results highlighting considerable perceived usefulness of the dashboard in improving assessment quality, collecting data, and standardizing information (100% of users).
Dowding et al [30] (2018)	Clinical prototype	• Nurses (292)	Medium	Survey[c]: Large percentage of users who were able to use the dashboard immediately (91%) and use icons to switch between data types (96%). Heuristic evaluation and task analysis: Time taken to complete tasks differed (eg, 5.7 minutes for nurses vs 1.4 minutes for expert users).	High	Survey: High SUS[e] (73.2) and QUIS[f] (6.1) scores for overall user reactions.

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Author (year)	Dashboard type	User group (n)	Usability[a]	Key findings	Acceptability[b]	Key findings
Dowding et al [26] (2019)	Clinical prototype	• Nurses (32)	Medium	Survey[c]: >50% of participants had difficulty navigating dashboard and interpreting data in the dashboard due to interoperability.	High	Survey: High SUS (73.2) scores. Interviews: users valued the ability to see trends for vital signs over time.
Kramer et al [20] (2016)	Clinical simulation	• Physicians (19)	Medium	Survey: High SUS (86.5) scores, however, reported improvements in accuracy (ie, number of medication reconciliation discrepancies using electronic dashboard vs paper) and amount of time to complete cases (ie, efficiency; reported similar completion time for paper-based process vs electronic dashboard) was mixed.	High	Survey[c]: Majority preferred the electronic module compared to paper-based processes (89.5% of users).
Lanzarone et al [27] (2017)	Administrative	• Staff/other (-)	Medium	Survey[c]: Low completion times for task completion, increased distance traveled; however, there was minimal change in nurse allocated to visits (ie, good satisfaction among older adults receiving care) and low numbers of overloaded nurses.	Medium	Survey[c]: Mixed reports on the satisfaction of older adults receiving care, applicability of tool integration, and visualization of the information, with multiple recommendations.
Lee and Huebner [17] (2017)	Clinical prototype	• Nurse (14)	High	Interviews: Users provided positive responses regarding the module's ability to locate laboratory findings quickly, review information easily, and access decision support.	High	Survey[c]: High user ratings of clinical dashboard usefulness and necessity data (100%) particularly for supporting high-quality home health care.
Mei et al [23] (2013)	Clinical	• Nurse (4)	High	Survey: High TAM[g] scores (reported on system usability (eg, time taken to complete, the proportion of participants reporting ease of use) (100%).	High	Survey[c]: High user agreement for improving job performance and accomplishing more work following system implementation.
Papaioannou et al [35] (2010)	Clinical, MEDeINR	• Older adults (128) • Physician (4) • Nursing staff (8)	High	Survey[c]: 100% of users found the platform was easy/very easy to use with improvements in therapeutic range and time in sub/supratherapeutic ranges.	Medium to high	Survey[c]: 75% of users agreed platform decreased workload and 92% felt communication was better. Interviews: feedback found decreased anxiety around prescribing and emphasized improvements for training.
Shiells et al [19] (2020)	EHR[h]	• Staff (21)	Low		Low	

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Author (year)	Dashboard type	User group (n)	Usability[a]	Key findings	Acceptability[b]	Key findings
				Interviews: Users reported the absence of core assessment scales in the records, systems being not interoperable, and frustration with organizational support for system access and training.		Interviews: Users reported a low preference for the device (preferring traditional methods of a desktop computer and paper) and its functionality, perceiving it as more work.
Wild et al [18] (2021)	Clinical, ambient	• Older adults in-home care (95) • Staff (25)	Low	Survey[c]: Low proportion of users who logged into the dashboard (44%). Interviews: users reported technical difficulties and continued unfamiliarity with the system.	Medium	Interviews: Users reported some enthusiasm about interest areas (eg, sleep and medication adherence) and appreciated real-time metrics (eg, sleep duration) being captured.

[a]Usability refers to the extent to which the dashboard could be used by the specified users to achieve their goals effectively and efficiently.

[b]Acceptability refers to the satisfaction with the dashboard and future adoption by specified users.

[c]Survey developed in-house by researchers.

[d]TAMM: Technology Acceptance Model for Mobile.

[e]SUS: System Usability Scale.

[f]QUIS: Questionnaire for User Interaction Satisfaction.

[g]TAM: Technology Acceptance Model.

[h]EHR: electronic health record.

Dashboard Features

An overview of the key dashboard features and their perceived acceptability is provided in Figure 2. The median number of features used in the dashboards was 6 and ranged from 4 [32] to 11 [27]. Displaying an alert (10/13) [17-20,22,23,26,27,30,32-35] was the most common, followed by customizable displays (8/12) [17-20,26,27,30,33] and the presence of color coding (7/12) [17,18,20,22,26,27,30,33]. One-third of the dashboards used symbols and icons (4/12) [17,18,26,27,30]. Visual graphs such as bar charts (2/12) [17,26,30,31] and line graphs (3/12) [17,18,26,30,31] were less frequently used in the dashboards. Functional aspects, including radio buttons (4/12) [20,23,26,27,30] and checkboxes (2/12) [23,34], were not used frequently.

The ability to update, alert, and generate reports for primary stakeholders was the most frequently used feature and was reported to be highly acceptable across all dashboard types. In general, features with high acceptability were bar charts, tables, icons, symbols, images, and color coding to organize and display information, as well as the use of radio buttons, the ability to expand and collapse information, and multiple displays to facilitate easy customization of the dashboard for different users. A small number of studies also described positional coding, checkboxes, and a completeness bar, which had high acceptability. One study of 195 nurses used a dashboard with spider and radar graphs, and these were reported as too complex [31].

There was only 1 study in-home care exploring older adults' acceptability for line graphs, icons, and displays, all which were rated as medium. Nurses tended to report communication features (eg, ability to converse with other users in the system) as low to medium [27,32], whereas older adults report it as high [22]. Compared to other user groups, older adults' acceptability of alert features was variable, ranging from low to high acceptability.

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Figure 2. Summary of perceived acceptability to key dashboard features.



Feature	Algiliani	Bali	Bell	Cui	Dowding	Dowding	Dowding	Kramer	Lanzarone	Lee	Mei	Papaioannou	Shiells	Wild	Total
Bar charts	-	-	-	-	H	H	H	-	-	M	-	-	-	-	4
Tables	-	-	-	H	H	-	-	-	-	H	-	H	H	M	6
Line graph	-	-	-	-	M	H	H	-	-	M	-	-	-	M	5
Spider/radar graph	-	-	-	-	L	-	-	-	-	-	-	-	-	-	1
General graph	H	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Radio buttons	-	-	-	-	-	H	H	H	H	-	M	-	-	-	5
Check boxes	-	-	-	H	-	-	-	-	-	-	M	-	-	-	2
Icons/symbols/images	-	-	-	-	-	H	H	-	H	H	-	-	-	M	5
Positional coding[a]	-	H	-	-	-	-	-	H	H	-	-	-	-	-	3
Colour coding	H	H	-	-	-	M-H [b]	H[c]	H	M-H[d]	H	-	-	-	M	7
Shape coding	-		-	-	-	-	-	-	H	-	-	-	-	-	1
Completeness bar	-		-	H	-	-	-	-	-	-	-	-	-	-	1
Expand/collapse[e]		H		H	-	-	-	-	H	M	M	-	H	-	6
Displays[f]	-	H	-	-	-	H	H	H	M[g]	H	-	-	H	M	8
Alerts	H	M	M[h]	H	-	H	H	H	H	-	M	-	H	L	11
Additional resources[i]	M	-	M	H	-	H	H	-	-	M-H[j]	M	H	-	M	9
User communication[k]	H	-	M	H	-	-	-	-	L	-	M	-	-	-	5
Reporting[l]	H[m]	H	H[n]	?	-	H	H	-	H	H	-	H	-	?	9
Training	?	L[o]	L[p]	H	-	M	M	-	H	?	H	H	H		9
Total	6	7	5	8	4	10	10	5	11	9	7	4	5	7	

H/Green=high acceptability; M/Pink=medium acceptability; M-H/Orange=medium to high acceptability, L/Red=low acceptability; ?

[a] Refers to using numbers or positioning to indicate level of priority (ie, 1= highest priority; top of page=highest priority).
[b] Recommended contrasting color for the icon indicating which graph is selected.
[c] When older adult receiving care has a vital sign measure outside recommended guidelines.
[d] Colors should be used to indicate higher importance rather than referring to streets on the map. Use of border color alone to indicate type of care patient receiving not enough.
[e] Refers to functions that enable users to expand and hide information (eg, expansion under headings, filters, hover, plus or minus icon, drop -downs).
[f] Refers to multiple displays or customizable interfaces (eg, using radio buttons to switch between data, alternative tabs).
[g] Filters was a recommendation for improvement to choose which older adults and nurses to display.
[h] Upon prescribing change in risk to older adult receiving care.
[i] Refers to additional physical resources or complementary information, guidelines, and recommendations (eg, self-care advice or prescribing guidelines included in predictive algorithm).
[j] Varied depending on condition the dashboard was reporting on (eg, values of edema status and weight gain that should be reported to a doctor not as useful as providing the values of vital signs and pain ratings that should be reported to a doctor).
[k] Refers to ability to communicate with staff through dashboard (eg, registered nurse, general practitioners, pharmacist, older adult receiving care). Includes ability to data share.
[l] Refers to frequency of dashboard updates/alerts (report generation, sending updates to key stakeholders).
[m] Twice a week for staff and 1-3 times a week for older adults' self-assessment.
[n] Preferred pharmacist notification rather than dashboard.
[o] Issues with on-the-job training, new staff accessing training and log-ins.
[p] No formal training required.

Problems Identified With Dashboard Acceptability and Usability

Thirteen studies described problems hindering user acceptability and usability of dashboards. The main issues that decreased the overall acceptability and usability of the clinical dashboards included hardware problems, display options, and training. For older adults in home, respite, and long-term care, accessibility of a smart tablet was hindered by locking the tablet, having the incorrect pin code, and forgetting to charge the device [22]. Older adults within each care setting also appreciated a larger text display size and found the 3-step question design difficult when inputting information for a dashboard (eg, yes/no and subsequent questions as they have to recall the previous answer) [22]. For registered nurses, the existing workload prevented daily log-ins despite instructions [18,22]. Similarly, reliance on agency or outsourced workers meant that many staff did not have log-ins and prevented the use of the dashboard [33].

Training on how to use and navigate the dashboard was provided for most dashboard users; however, participant feedback on training ranged from low [32,33] to high satisfaction across studies [19,23,27,34,35]. In some papers, 3 training classroom sessions were sufficient [23], and in others, "on-the-job" training was preferred as an alternative to classroom-based learning [19]. In 1 study, more training was requested by new staff with suggestions for a designated nursing staff member to lead the training session, which could be a recorded session to enable easy dissemination [35].

Suggested areas for improvement across papers mostly related to reducing user workloads, ensuring the security and privacy of resident data, and strengthening decision support and communication features. Ensuring data remain private, particularly data on medication and prescribing patterns, was an emerging area for improvement, with a focus on having data available only to the relevant user [20,32]. Furthermore, inputting reasons for medication use would support nurses' and clinician' decision-making on medication administration, identification of discrepancies, and reconciling errors.

Although dashboards could be used to support interactions between different users (eg, staff, providers, and older adults), in 1 study, it was shown that users valued traditional methods of communication, particularly in relation to medication practices (eg, receiving pharmacist notifications separately)

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rather than logging into the dashboard [32]. This was because users reported spending more time searching for appropriate medication-related information on the dashboard compared to routine practice (ie, predashboard) [20,32] and thus preferred alternative mediums (eg, sourced from electronic notes [32], phone calls [20], and face-to-face conversations [32]) to clarify discrepancies. Suggestions for dashboard functionalities to improve communication and reduce workload included (1) easy-to-navigate workflows [22,27,30]; (2) visual features that allow for better interpretability and usefulness (ie, simple graphs, customizable alerts, and appropriately positioned icons) [19,20,22,31,33]; and (3) timely responses between users to facilitate efficiency and confidence in medication reconciliation and management [20,23,32,35].

Discussion

Principal Findings

The aim of this review was to assess current evidence about the acceptability and usability of clinical dashboard features and functionalities in aged care environments. In general, users had high acceptability but mixed opinions on usability, with dashboards focused on administration activities having high acceptability. Dashboards that featured an update, alerts, and reports and those with simple visual elements (eg, bar charts, tables, and symbols) were considered highly acceptable, while those with complex features (eg, spider and radar graphs) had low acceptability.

Clinical dashboards are relatively new in aged care settings, despite these apps being used widely within population health and health services [49]. In our review, dashboards were developed to support a wide range of clinical and administrative purposes and had no distinct pattern of usability and acceptability on dashboard type or platform. Rather, our results suggest that the capabilities of the dashboards and how information is displayed to end users are more likely to influence the acceptability and usability of dashboards.

Previous studies reporting on the usefulness of other dashboard visualization features in health care settings may inform future dashboard design in aged care. For instance, clinicians prefer data tables as they perceive numbers as less “biased” than data that are presented in graphics [50-53]. Although not explored in the studies included in this review, visual aids such as league charts, caterpillar plots, or funnel plots can offer substantial benefits particularly if the purpose of the dashboard includes institutional performance comparisons (eg, comparing several aged care facilities in certain adverse health events). League charts are often desired because of their familiarity and simplicity [50,51]. Caterpillar plots and funnel plots, types of statistical process control techniques, are widely used visual aids for comparing the performance of institutions in certain performance indicator against a benchmark value [54]. Research shows that health care providers prefer caterpillar and funnel plots once they are taught how to read them [52]. A dashboard that includes specific values, as well as organizational comparisons in certain performance indicators may improve service processes and improve delivery of aged care quality [53]. Thus, when designing dashboards, data visualization approaches need to consider the target audience as well as dashboard purpose.

The perceived usefulness and acceptability of dashboards and their features may differ between end users. For instance, in this review, there were differences between older adults and other end users on the perceived usefulness of dashboards, with older adults likely to report usability as low, while other users reported it as medium-high. Such variability in the perceived usefulness of dashboards across end users can be minimized through *customizable design* [55], that is, engaging and considering the need of end users (eg, clients, staff members, and family) in the dashboard development process. A *user-centered design* approach would enable designers to gain an in-depth understanding of end user experiences, expectations, and needs for clinical dashboards, which are critical to addressing usability and acceptability issues and enhancing the likelihood of having an impactful and sustainable dashboard [56,57].

Implications and Recommendations for Future Dashboard Development

The findings of this study have important implications to guide future dashboard development. Dashboards often focused on 1 aspect of care (eg, clinical or administrative). While clinical outcomes are an important aspect of aged care quality, there is increasing understanding that a holistic resident or client trajectory should be key to understanding quality [58]. Future dashboards thus need to consider and construct an inclusive picture of resident or client needs to support the care continuum from entry in the system.

Our results found that dashboards typically used in-house collected data, with some using real-time reporting of information [18,27,30,35]. As reporting of quality indicators becomes mandatory in aged care sectors in many countries, the use of a dashboard makes it potentially possible to streamline and automate this process. This may relieve aged care staff of the significant time burden in collating and reporting these data [59]. It could also mean that reported data are more accurate as it removes some opportunities for human error and reports in real time.

Given that dashboards present data visually and aim to support users’ decision-making, the use of in-built decision support within a dashboard provides another opportunity for improved quality care. Recommendations in response to information presented in the dashboard could prompt end users to take appropriate actions to improve clinical care [17,26,30,32,35,60]. This review suggests that certain dashboard features are associated with increased usability and acceptability. For example, reduce user workload through customizability and interoperability of the dashboard, provide visual features to support timely interpretation and response, and include links to complementary information to strengthen confidence in clinical decision-making. Extending such decision support to enhance quality care could include alerts for allergies or special care needs, links to published guidelines to make users aware of appropriate care pathways, and medication errors such as duplications and interactions. Implementing evidence-based decision support to inform better care could be seen as highly

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beneficial within the aged care sector where health literacy levels vary greatly [61,62].

Limitations

There are several limitations to our review. The exclusion of gray literature, small number of studies fulfilling the inclusion criteria, and poor quality of the included studies are current drawbacks. Furthermore, most of the studies included in the current review did not explore the potential effect of their dashboards on outcomes and care processes (eg, documentation of care processes and better health outcomes). Due to the nature of reporting in each of the study's findings and the variation in type and size of end user groups, it was not feasible to determine the differences in usability and acceptability between individual groups; thus, our findings are a summary of all respondents. Future research should focus on how the introduction of different types of clinical dashboards could support adherence to quality guidelines and understand dashboard design and usability in terms of mixed versus specific user groups. Identification of areas where dashboards should be most appropriately introduced to target specific initiatives should also be considered (eg, older adults with dementia and home care) to help improve the quality of care. Further work is needed to explore how users understand and interpret dashboard features, their preferences for information presentation, and how the information is used to support care or service planning, decision support, and user behavior.

Conclusions

Users found dashboards in aged care generally highly acceptable, particularly those with simple visual elements and features such as an update, alerts, and reporting functionalities. This review highlights the variability in the usability of dashboards and identified certain design features of dashboards, which are associated with increased usability and acceptability. Four possible advantageous features and functionalities for future dashboard developments within aged care are emphasized. Specifically, customizability and interoperability to account for different end user preferences; incorporating numerical (tables) and graphical (league and caterpillar charts) presentations of data to facilitate accurate individual assessment and comparison (benchmarking) respectively; integrating changes to client care preferences with real-time clinical outcomes for a holistic representation of the care journey; and building in recommendations and alerts for best practice clinical decision-making to reduce error and support appropriate care pathways. However, further research on the development, testing, and implementation of visualization dashboard solutions to support outcome improvement for older adults is required.

Authors' Contributions

All authors contributed to the conception of the review. JS led the design of the review, with input from all authors. JS, FS, and LD reviewed the retrieved references, with AN acting as fourth reviewer. Papers were retried by JS, with assistance from LD and AN. JS reviewed the full-text papers, with LD and AN acting as second reviewers. JS, KS, and MR conducted the risk of bias assessment. Data extraction and quality assessment were undertaken by JS and LD. JS led the writing of the manuscript, with all authors contributing or providing feedback and approving the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary material.
[DOCX File , 24 KB - aging_v6i1e42274_app1.docx]

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Abbreviations

ICT: information and communication technology
MMAT: Mixed Methods Appraisal Tool
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
TAM: Technology Acceptance Model

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Viewpoint

Pioneering the Metaverse: The Role of the Metaverse in an Aging Population

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Abstract

Amid a worldwide pandemic in the setting of an era of rapidly developing technologies, we turn now to the novel and exciting endeavor of pioneering the metaverse. Described as the conglomeration of augmented reality, virtual reality, and artificial intelligence, the metaverse has widespread applications in multiple settings, including revolutionizing health care. It also holds the potential to transform geriatric medicine, introducing new dimensions through which we can prevent social isolation, encourage health and well-being, and offer a new dimension through which we manage chronic disease. Although it is still a futuristic and novel technology, the metaverse's realization may indeed be closer than we think.

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KEYWORDS

metaverse; older adult; aging in place; dementia; gerontology; geriatric; digital health; digital technology; computer generated; artificial intelligence; virtual reality; mixed reality; augmented reality; aging; mental health

Since the introduction of the World Wide Web, possibilities and imaginations have proliferated and expanded, and they have revolutionized the dissemination and sharing of information, communication, and connectedness through social media, videoconferencing, and gaming platforms. The *metaverse*, a term symbolizing the intersection of physical, augmented, and virtual reality in a shared web-based arena, was originally coined from the 1992 sci-fi novel *Snow Crash* [1], and it has now eerily become a tangible reality of the near future.

Technologies over the years have included many advances in virtual reality, augmented reality, artificial intelligence, and now the metaverse. The ability for people's avatars to interact in real time with each other, much like what we see in the gaming industry with games like *Roblox* (Roblox Corporation) and *Animal Crossing* (Nintendo Co, Ltd), will soon become prevalent on social media and videoconferencing platforms—a virtual teleportation into digital space that will enable the transcendence of space and time.

The surge in technology, further bolstered by the COVID-19 pandemic, has transformed our videoconferencing platforms to enable work-from-home meetings, medical appointments via telehealth, and education across all levels. In the scientific community, conferences turned to virtual reality, using surprisingly interactive and advanced technologies, thereby enabling personal interaction via avatars among professionals across the globe. Virtual workspaces are currently being prototyped by companies like Microsoft. Facebook's recent announcement, in which they pledged their pursuit of such future capabilities and stated that they were officially changing their name to *Meta*, set the stage for the next generation of technology [2].

Already, many have surmised the role of the metaverse in transforming health care in cardiovascular medicine, spine surgery, gynecology, behavioral and mental health, and even dentistry [3-8]. Such a novel concept opens possibilities for far-reaching applications, including using the metaverse to transform care for the aging population. With so many now

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interested in pioneering the metaverse, we can also take part in exploring what the metaverse can implicate in the lives of the older adult population. Digital presence in a time when physical presence is becoming less common and more difficult, such as during the current COVID-19 pandemic, makes us wonder whether the metaverse can truly be used toward promoting a society of intergenerational connectedness.

The COVID-19 pandemic has certainly highlighted the impact of social isolation on psychosocial health not only in the older adult population but also across all ages [9]. Fostering socialization through the use of technologies during this time has been an all too welcome solution. Older adults already experience the highest rates of social isolation and loneliness [10]. Combating this by facilitating socialization among loved ones already helps to decrease one of the leading causes of mortality in this population. Videoconferencing technologies enable social interaction with loved ones across the globe. The ability to interact with avatars or digital twins of loved ones in a virtual space will ultimately enhance the notion of *presence* when otherwise physically impossible [11].

These so-called *digital twins* provide yet another way through which medical visits may be augmented in the metaverse. Essentially virtual representations using real-time data that enable the running of endless simulations and extend to the human being, digital twins have the potential to guide disease management and become a tool for personalized and directed health care. Already, companies like Philips are developing technologies for creating digital twins of human hearts to help guide personalized medical decision-making and treatment [12]. Telehealth provides people living in remote areas or people who are otherwise unable to physically present to a clinic with the ability to carry out health care visits in virtual reality—another dimension that can enhance virtual diagnoses and care.

The use of such technologies can however prove challenging in older persons with reduced visual acuity, reduced manual dexterity, and cognitive impairment. Technological advancements have overcome some of these barriers, serving to improve functioning, tracking, and mobility, and have the potential to not only alleviate caregiver burden but also enable individuals to successfully age in place [13]. Alternately, there exist multiple forms of computerized cognitive training programs, or *serious games* (named as such due to their primary purpose being other than pure entertainment), that have been shown to help improve verbal, nonverbal, and working memory and therefore potentially have a role in slowing or preventing cognitive decline [14,15]. Incorporating cognitive training strategies is another application of the metaverse for this population.

The metaverse also holds the potential to address aspects of well-being, such as exercise and fitness. Much like the Wii Fit (Nintendo Co, Ltd) did for encouraging engaging in at-home workouts, nowadays apps like Supernatural (Within Unlimited, Inc) and FitXR (FitXR Limited) provide a means to exercise via virtual reality. Studies on virtual exercise via virtual reality applications and games have shown that these are viable modes of exercise that are able to elicit exercise intensities matching those in recommended guidelines and are being further studied to help inform developers about integrating exercise in the metaverse [16,17]. Integrating metaverse fitness into at-home exercises targeted toward older adults can help them to enhance their fitness in the comfort of their own homes. With the help of virtual reality, at-home exercise also can prove to be a means of helping someone to exercise when otherwise unable.

The first dementia villages were built in the Netherlands and Germany and introduced a novel concept of communal care, focusing on the psychological and emotional needs of those with dementia [18]. In the United States, the first dementia village—Glenner Town Square, San Diego, California—was built in 2018, using the setting of a 1950s town, and such villages are now being franchised and recreated around the country [19]. These villages build on the concept of reminiscence therapy and its potential benefit on cognition and mood in individuals with dementia [20]. Now, we can extend the creation of dementia villages into the metaverse by creating a digital "virtual playground," so to speak. Individuals would be able to transcend time by going back to any time and any town of their choosing and enjoy the things with which they are familiar. Such reminiscence therapy can help individuals with dementia age with dignity by allowing them to find comfort in the memories of their past.

Through the metaverse, loved ones separated by physical distance may be able to interact within a virtual space in real time. Perhaps soon we will be able to create virtual spaces filled with specific memories of our own childhoods and store these memories to be able to share them with our future generations, so that they may be able to catch a glimpse of the world in which we once lived. As Amazon recently announced its current endeavor to develop artificial intelligence technology to enable Amazon Alexa to mimic voices of deceased loved ones, the capability to preserve or leave behind a piece of what was lost hints at the endless innovations to come [21]. The thought of this all too attainable future sounds like an episode from *Black Mirror*. Indeed, we are finding ourselves in a "digital catch-22" in which the potential benefits of virtual reality, augmented reality, and artificial intelligence technologies are ultimately dependent on having the desire to use these technologies and the knowledge and access to do so [22].

In pioneering the metaverse, future studies should focus on amplifying the potential of this virtual world in directly improving the mental health, and even indirectly improving the physical health, of the aging population. With the current paucity of evidence and developed technologies, there exists an urgency to invest resources to develop and apply such technologies for the care and well-being of our aging population. A once far-fetched, science-fictional imagination is now within our grasp.

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Conflicts of Interest

None declared.

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Viewpoint

Proactive and Ongoing Analysis and Management of Ethical Concerns in the Development, Evaluation, and Implementation of Smart Homes for Older Adults With Frailty

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Abstract

Successful adoption and sustained use of smart home technology can support the aging in place of older adults with frailty. However, the expansion of this technology has been limited, particularly by a lack of ethical considerations surrounding its application. This can ultimately prevent older adults and members of their support ecosystems from benefiting from the technology. This paper has 2 aims in the effort to facilitate adoption and sustained use: to assert that proactive and ongoing analysis and management of ethical concerns are crucial to the successful development, evaluation, and implementation of smart homes for older adults with frailty and to present recommendations to create a framework, resources, and tools to manage ethical concerns with the collaboration of older adults; members of their support ecosystems; and the research, technical development, clinical, and industry communities. To support our assertion, we reviewed intersecting concepts from bioethics, specifically principlism and ethics of care, and from technology ethics that are salient to smart homes in the management of frailty in older adults. We focused on 6 conceptual domains that can lead to ethical tensions and of which proper analysis is essential: privacy and security, individual and relational autonomy, informed consent and supported decision-making, social inclusion and isolation, stigma and discrimination, and equity of access. To facilitate the proactive and ongoing analysis and management of ethical concerns, we recommended collaboration to develop a framework with 4 proposed elements: a set of conceptual domains as discussed in this paper, along with a tool consisting of reflective questions to guide ethical deliberation throughout the project phases; resources comprising strategies and guidance for the planning and reporting of ethical analysis throughout the project phases; training resources to support leadership, literacy, and competency in project teams for the analysis and management of ethical concerns; and training resources for older adults with frailty, their support ecosystems, and the public to support their awareness and participation in teams and ethical analysis processes. Older adults with frailty require nuanced consideration when incorporating technology into their care because of their complex health and social status and vulnerability. Smart homes may have a greater likelihood of accommodating users and their contexts with committed and comprehensive analysis, anticipation, and management of ethical concerns that reflect the unique circumstances of these users. Smart home technology may then achieve its desired individual, societal, and economic outcomes and serve as a solution to support health; well-being; and responsible, high-quality care.

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KEYWORDS

ethics; older adults; frailty; smart home; assistive technology; aging in place; ethical concerns; implementation; bioethics; technology ethics; autonomy; privacy; security; informed consent; support ecosystem

Introduction

Population aging, along with chronic disease and disability among older adults, are increasing challenges for supporting a high quality of life and sustaining services in health and social care systems. The COVID-19 pandemic has highlighted the many limitations of multiple health systems worldwide whose delivery models struggled to keep up with service demands. With widespread calls for physical distancing to limit COVID-19 transmission, the existing social isolation of older adults [1,2] has been exacerbated. However, the pandemic has enabled an unprecedented surge in the use of new technologies in all parts of society, particularly in health systems. Nevertheless, some solutions are slow to be adopted, particularly those based on smart home technology. Often situated in a private home, a smart environment "adopts ICT [information and communication technology] to collect and share information, analyze and monitor residents' behavioral patterns, and improve residents' quality of life" [3]. Smart homes entail a combination of products and services that make up a smart environment (also referred to as active and assisted living systems). In addition to being, for the most part, at a low level of maturity and with little strong evidence of effectiveness [4-7], smart home technology may be slowly adopted because of unmitigated ethical concerns [4].

This viewpoint paper has 2 aims in the effort to facilitate the adoption and sustained use of smart home technology: (1) to assert that proactive and ongoing analysis and management of ethical concerns are crucial to the successful development, evaluation, and implementation of smart homes for older adults with frailty and (2) to present recommendations to create a framework, resources, and tools to manage ethical concerns with the collaboration of older adults; members of their support ecosystems; and the research, technical development, clinical, and industry communities.

The paper is structured as follows. We begin by explaining the nature of frailty and the importance of addressing it. We discuss smart home technology and its potential to support older adults with frailty. Our work summarizes key anthropological concepts that are relevant to smart homes when managing frailty in older adults and how these concepts can lead to ethical concerns. Thus, we discuss the rationale for proactive and ongoing analysis and management of these ethical concerns from development to sustained use. Finally, we present recommendations and opportunities for collective action to create and implement a framework, resources, and tools.

Background

Older Adults With Frailty

Approximately 32 million Europeans [8] and 1.6 million Canadians [9] are estimated to experience frailty. Frailty is an umbrella term that encapsulates a constellation of conditions with varying severity and consequences for individual older adults. It presents with poor health and function and heightened vulnerability to incidental adverse health events and deteriorating quality of life [10]. The integrated model consensually developed by Gobbens et al [11] highlights 3 major components of frailty—physical, psychological, and social—that dynamically interact to create this situation of vulnerability. For example, a diagnosis of frailty may be assigned if physical conditions (eg, malnutrition or mobility restrictions because of arthritis) that may affect or be affected by psychological capacity (eg, cognitive decline caused by Alzheimer disease or low mood because of depression) co-occur with an unsupportive social situation (eg, poor social relations or isolation). In such a scenario, an adverse event such as a fall is more likely to occur and may cause an older adult to reduce social activities and self-isolate at home. A vicious cycle may thereby be created and further increase the risk of falls and physical, psychological, and social vulnerability. Without intervention, interactions between these frailty components may lead to the following: (1) disability or difficulties performing self-care and household management activities, creating dependency; (2) falls and mobility reduction; (3) hospitalizations; (4) changes in living situations (eg, moving to a long-term care home); and (5) death. However, frailty, depending on the modifiability and interactions of the diseases and conditions, may be preventable and reversible with appropriate interventions [12].

Research suggests that frailty may be viewed as progressive alterations in an older adult's intrinsic capacities (ie, motor skills, cognition, and sensory functions), suggesting reversibility through strengthening of these altered capacities with health and social interventions (eg, physical and cognitive rehabilitation and participation in valued social and community activities) [13]. As such, it is imperative to identify frailty (or the risk of frailty) and implement early intervention. However, with persistent impairments, support strategies may be based on compensation for the loss of capacity and function to reduce dependency [14]. Social support and technology may be crucial environmental elements in early detection and intervention [5,15]. Digital solutions such as smart home technology may play key roles in mitigating some of the causes and consequences of social isolation and frailty [16] while respecting older adults' right to self-determination.

Smart Homes

Smart homes may be interventions to address pressing concerns about supporting the high quality of life of older adults, relieve stressors on informal supports, and mitigate the challenges of health and social system sustainability with population aging. Users of smart homes may include older adults and members of their support ecosystems (ie, family or friends in caregiving roles, physicians, therapists, social workers, nurses, and home support workers) [17]. (Additional users necessarily include the

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research, technical development, and industry communities as they are responsible for data maintenance and support for use.) The combination of smart home technology and human support constitutes a powerful environmental support strategy. Indeed, these homes may be viewed as an embodiment of the collective human intelligence. This collective intelligence may support shared goals and respect the older adult and members of their support ecosystem. This may be done by supporting decision-making processes and affording efficient, personalized, and adaptive management of frailty in older adults living at home.

Smart home technology may assist with daily activities in various ways. Broad functions may include home environment or appliance automation (eg, thermostat control and stove shutoff), health or activity tracking for self-management purposes, monitoring and alerting for safety or emergency situations, and supporting social connectedness [17,18]. Sensors embedded in a home may collect longitudinal data to monitor a resident's health status, behaviors, and activities. Important frailty-related information regarding cognition, mobility, and daily activity performance status may be monitored and inferred through activity patterns and indicators [5,15]. Data integration and analysis using artificial intelligence (AI) approaches such as machine learning may allow for the creation of tools that predict or detect events. The detection of adverse events such as falls or concerning trends in health, such as a routine disruption that may suggest the occurrence of a delirium, may expedite access to intervention from caregivers and health care providers. Reminders or stepwise assistance to perform daily activities may be delivered based on the system's input, observed, or learned knowledge of residents' behaviors, activity patterns, and preferences. Residents may interact with a smart home through various interfaces involving voice, touch, motion, or gestures [19]. Although many specialized smart home products and services are in development for older adults with health needs [4], there is also a proliferation of technology for general consumers that offers desirable functions for older adults to enhance environmental comfort (eg, automated control of lights or thermostat), safety (eg, home security systems and automated door locks), and daily activity performance (eg, kitchen appliances).

Despite innumerable smart home projects at various phases of development and implementation worldwide, the vast majority are not realized into commercial products and services, and mainstream technology on the market has not been widely adopted by older adults [18,20]. Ethical challenges have been reported to influence the successful adoption and sustained use of smart homes [21]. There is also increased focus on systematically considering ethics as part of the Health Technology Assessment that supports policy recommendations for available technology [19,22,23]. Nevertheless, little attention has been paid to ethical evaluation during the design of intelligent assistive technology such as smart homes [24,25]. Few researchers have highlighted the imperative for comprehensive inclusion of ethical considerations across processes for development, evaluation, implementation, and the sustained use of smart home technology. As such, we assert that proactive and ongoing analysis and management of ethical concerns are crucial to the successful development, evaluation, and implementation of smart homes for older adults with frailty.

Concepts and Ethical Challenges

Overview

Ethical challenges and the need for deliberation arise when anthropological concepts such as values conflict with other values that are considered equally important. Applied ethics is the field that examines real-world applications of this deliberation and action. We bring together concepts from often-siloed fields of bioethics, such as principlism and ethics of care, and technology ethics to highlight ethical challenges to be deliberated with respect to smart home technology.

Principlism

Principlism by Beauchamp and Childress [26] refers to a dominant framework in bioethics that outlines 4 key principles—respect for autonomy, beneficence, nonmaleficence, and justice. Although the latest edition of Beauchamp and Childress [26] includes discussions of moral virtues and features of the professional-patient relationship, such as veracity, privacy, confidentiality, and fidelity, the 4 principles remain pillars of bioethics. Autonomy is the fundamental right to make decisions about oneself and to do what one chooses within one's own life. A distinction can be made between being autonomous and independent. Being autonomous means being able to express and act in terms of one's own free will, which may include choosing to receive assistance from others. Being independent means not requiring assistance from others. Beneficence relates to the responsibility to act in ways that benefit others overall, which may include preventing, mitigating, and removing harm to others and promoting benefits. Nonmaleficence refers to the responsibility to abstain from or avoid actions that cause or may cause harm to others. Justice is the principle that is concerned with fairness (treating everyone with the same concern and respect) and equity (seeing that benefits and harms are distributed across people as equals) [27].

Ethics of Care

Although ethics of care, or care ethics, may be positioned as an alternative to the rationalist principle-oriented perspective of principlism [28], it is valuable to consider both approaches as they are complementary when examining the management of frailty in older adults. Maio [28] concentrates on the core ideas of care ethics without invoking the historical gendered view of care and ethics. Fundamentally, the ethics of care deals with the asymmetric nature of care relationships and the potential dependency and vulnerability that can result. Furthermore, assuming that care relationships are, to varying degrees, asymmetrical does not deny the equality of people in care-associated relationships and the sovereignty of individuals to determine their life and care goals. On the contrary, it requires all participants to appraise this vulnerability to offer adequate support. In this way, according to Maio [28], ethics of care must be situation-oriented; responsive; and informed by knowledge from experiences, relationships, and the situation at hand.

In details, according to the revised version of the 4-phase model of care by Tronto [29], ethics of care leads to acceptance of

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fundamental dependency on and need of mutual support (Conradi, 2001, as cited in Maio [28]). Attentiveness is the first step to be able to care about someone else. Keeping in mind the concern for the other leads to an inclination to respond to their needs. This response to another's needs is grounded in a sense of responsibility and translates into direct action or chains of action depending on the competencies of caregivers and singularities of each situation and relationship. Individual competency and the ability to initiate the required chain of action to manage the situation are key. The ability to provide a solution or initiate a chain of solidarity to support an identified need is the basis of ethics of care.

Technology Ethics

There is currently no dominant or unified approach to technology ethics. Ethical issues, implications, and decision-making practices arising from the design, use, and spread of different technologies are much-discussed topics in different fields and referred to using various terms (eg, technoethics, ethics of technology, computer ethics, AI ethics, and machine ethics). Consistent across these fields is the need to examine ethical, social, and legal implications, and there is often an orientation toward supporting citizens' rights [30]. Many concerns are based on the rapid evolution of digital technology and AI, which raise new questions, possibilities, and challenges that require careful deliberation. Technological developments may have a range of intended and unintended uses and outcomes or may amplify existing societal problems. Indeed, care ethics, with its emphasis on personal relationships, may rightly or wrongly subordinate care delivered through technical means in relation to human care [30]. These developments require us to continuously reflect on and modify our individual and collective values and practices.

Concepts in technology ethics are numerous and often include those of bioethics. Friedman and Kahn [31] in the field of human-computer interaction outline 12 human values they consider to be ethically important in computer ethics. The 12 values are human welfare, ownership and property, privacy, freedom from bias, universal usability, trust, autonomy, informed consent, accountability, identity, calmness, and environmental sustainability. In the Institute of Electrical and Electronics Engineers Global Initiative on Ethics of Autonomous and Intelligent Systems, 5 general ethical principles were identified as critical in the design, development, and implementation of technology: human rights, well-being, accountability, transparency, and awareness of misuse [32].

Ethical Challenges Related to Smart Homes for Older Adults With Frailty

Overview

Bioethics and technology ethics concepts are salient but intersecting. Examining these concepts in relation to smart homes for use by older adults and in the management of frailty can lead to ethical challenges. We describe in depth 6 key conceptual domains that need to be analyzed for smart homes but that can lead to ethical tensions.

Privacy and Security

Privacy and security concerns are multidimensional and often interrelated. There are 2 dimensions of privacy that warrant examination: privacy of personal information (ie, identity) and physical privacy (ie, related to one's body and the activities and routines being carried out in different spaces) [24]. Security may refer to information security or the safeguarding of data from unauthorized access. In addition, security may pertain to the experience of safety or trust in someone or something in a situation.

Information privacy and security are linked as maintaining privacy necessitates the security of information. Ethical concerns relate to the vast amount of sensitive information (eg, personal, medical, physiological, behavioral, and locations) that may be collected from users, how and for what purposes the information may be used, and who has and should have access to the information (eg, family, friends, health care providers, insurers, and manufacturers). Furthermore, the loss of private and confidential information to crime or unauthorized or wrongful access and use may lead to safety concerns and loss of the feeling of security [19]. Of particular importance to older adults with cognitive impairments or who are dependent on others are the experiences of uncertainty regarding what information is being collected, who has access (both intentional and unintentional in the case of an information breach), whether access may be controlled by users or others, and how reliable and trustworthy are those who have access. In such cases, harm may be inflicted without the older adult's knowledge or control.

Privacy concerns are commonly voiced by older adults when considering smart homes and their adoption [18,20,33]. Facilitating personal safety and feelings of security is important for living at home autonomously and may be a strong motivator for adoption. There may need to be a trade-off between gaining security (and, thereby, freedom) and the loss of privacy if activities or routines in the home are monitored [19]. When older adults and those in their support ecosystems are trying to enhance safety and security with remote monitoring (eg, installation of cameras or other sensors in the bathroom to alert for assistance after a fall), a balance needs to be created when setting up systems to see that older adults' privacy rights and personal wishes are respected. Older adults with cognitive impairments may need more monitoring as they may be at greater risk of harm [19] but less able to express their wishes.

Issues of privacy loss may be mediated by perceptions of the smart home technology's usefulness. If the functions or services provided by the technology are perceived to be beneficial, older adults may elect to disregard some privacy concerns [24,33]. Some studies have reported that people with better health prioritize privacy protection more than those with poorer health and that those with poorer health prioritize the potential benefits of technology use [18]. However, there may be a tendency for older adults to favor conservative options when presented with novel, uncertain, or even risky situations [34]. That is, in making decisions, they may elect to implement strategies aimed at avoiding losses rather than optimizing gains. This prospect may need to be accounted for in decision-making regarding the adoption and use of smart home technology. There may also be

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scenarios in which older adults with cognitive impairment do not perceive a risk and feel safe despite the heightened risk related to frailty. In such cases, they may reject technological assistance based on its perceived nonusefulness. These trade-offs among the need to maintain privacy standards, minimize losses, and accept benefits necessitate heightened awareness to ensure that older adults who may be vulnerable are not exploited and able to make the best decision for their situation.

Individual and Relational Autonomy

An important dimension of autonomy involves older adults' relationships with others in their support ecosystems, as underscored in care ethics. Individual autonomy is the right of individual older adults to make choices about their lives and act freely without external influences [26]. However, in care contexts, relational aspects are critical, whether they are with other people or environmental elements such as smart homes [35,36]. In relational autonomy, dynamic interactions between individuals and others around them cocreate an individual's identity, interests, and needs. The reality when considering respect for autonomy is that decisions of older adults regarding how they are supported (eg, by other people, technology, or a combination of these), what support they accept and when, what benefits are desirable, or what risks or harms are acceptable are affected by and will affect those around them. For instance, in cohabitation situations where remote home monitoring is considered, decisions affect others directly, so collective privacy needs to be discussed [30].

Some research has identified that caregivers perceive the benefits of technology use more than older adults who feel they may do without technological support [18]. Family members have reported feeling trust in the technology and that it would help their older relatives carry out more activities on their own, whereas older adults felt that smart homes may help in emergency situations but reported feeling more secure with another person present [17]. Overemphasis on either individual or relational perspectives has been critiqued as one may risk neglecting collective decision-making to benefit individuals and the other may neglect individual older adults' needs over those of others. The relational influences of ethical import on the adoption and use of smart homes for older adults with frailty and enhanced vulnerability may include positive and negative social pressure, persuasion, or even coercion from family, friends, or other social forces [18].

Beyond autonomy in care relationships with other people, ethical concerns have been raised regarding relationships with technology in the management of health and social needs. Concerns have been identified over the loss of individual autonomy with technology use in circumstances where it is perceived to control what older adults do or provide too much assistance [19]. Fears may be experienced by older adults and those in their support ecosystems that they may become overreliant on technology or automation [19].

Respecting the autonomy of older adults and their support ecosystems individually and within relationships may necessitate the adoption of the tenets of care ethics and the application of a support ecosystem–centered approach. Information about and experience with using smart home systems needs to be personalized to support their collective goals and informed decision-making about use. Notably, older adults with cognitive impairments may require additional considerations for making their needs known and support in shared decision-making [37]. The original theory of discourse ethics by Habermas [38], which emphasized the imperative for intersubjectivity in arriving at moral standards [39], may be pertinent to decision-making in relational autonomy. The theory with key concepts adapted by Frantik [40] to be inclusive of people with dementia may be particularly useful as it affirms their rights and empowers them through practical strategies to participate equally in negotiations that result in decisions affecting their lives.

Informed Consent and Supported Decision-making

Informed consent may only occur when people have knowledge and understanding of technology, their intended purposes and uses, and the potential benefits and harms the technology may create for them and their situations. A lack of awareness, familiarity, knowledge, and skills associated with smart home technology undermines consent capacity. This may have implications for adoption and use, the selection of options or features to maximize benefits and minimize risks during use, and consent to terms of service or data use [20,25,33]. These gaps may lead users to distrust technology or reject its use as they experience a loss of autonomy. Users may not even be aware of or comprehend the fact that these are ethical concerns [24].

Requirements for informed consent become more complex and unfeasible with the addition of AI to smart home technology because of limitations in the transparency and traceability of algorithmic decisions [25,30,41]. Transparency issues relate to how well users may understand how decisions are being made. With AI, large data sets are processed continuously and used to autonomously learn about users and make decisions to eventually carry out a desired action. Decision-making opportunities are not presented to users, so they do not have explicit choices, and it is unrealistic for users to make all these decisions. Algorithms tend to be opaque such that the decisions of the system cannot be explained [30]. Furthermore, algorithms evolve over time, whereby the functions and abilities of algorithms may no longer be consistent with those that users granted their consent for [25]. Although users are asked to consent to sharing a lot of their data, it may be challenging for users to assess benefits and harms. Indeed, developers who use the data and algorithms cannot adequately assess the benefits and harms as the exact ways in which decisions or actions are determined from the algorithms may be unknowable. Traceability refers to whether the cause of harm may be identifiable in situations where multiple actors are involved in the creation or implementation of an algorithm and who may be accountable and liable for harms [41].

Informed consent by older adults also depends on the availability of high-quality information. The proliferation of misinformation creates challenges in disentangling information and finding information from trustworthy and reliable sources. Unscrupulous or unknowledgeable individuals may also sell products or services targeted at older adults that overemphasize benefits and minimize potential harms. Considering older adults'

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tendency to select options that minimize losses in novel circumstances, how or by whom information is presented may be more important than what is presented. Older adults, especially those with cognitive impairments or who are socially isolated, may be particularly vulnerable to mistreatment related to the trustworthiness of information.

Without accessible information or appropriate learning opportunities that are oriented to enhance understanding by older adults who may be unfamiliar with technology or have cognitive limitations, informed consent and decision-making may not be possible. The information offered to older adults may be overly simplistic (ie, merely asking for agreement to use a service) or complicated (ie, detailing specifics of terms of service) [24]. Even in the absence of disease, cognitive aging is associated with a decline in information-processing speed. As such, the ability to make decisions is preserved only when enough time and explanations are provided in an environment where distractions are minimized [34]. For some older adults with cognitive impairments, the availability of ongoing decision-making support may be essential across the spectrum of cognitive abilities. For example, trained and trusted family members, health or social care professionals, or substitute decision makers may be essential to explain information in understandable ways or grade decision-making to match the abilities of the older adult. Determining advanced directives for older adults with cognitive impairments may be a possible solution, although assent will continue to be required by assessing older adults' verbal or nonverbal signs of agreement or disagreement in specific situations [25].

Social Inclusion and Isolation

Commonly discussed functions of smart homes are to enhance social connectedness, support, and inclusion; reduce isolation through remote communication with caregivers or health care providers; and offer ready access to assistance in emergency situations. Given the anticipated shortage of health care providers and working-age caregivers and changes in family living arrangements, with younger generations living further away from senior family members, care from a distance through technology is increasingly the reality [42,43]. However, older adults have voiced concerns over the potential loss of social contact and human touch when care technologies such as smart homes are suggested [18-20,33]. With the capabilities of AI, there may be the added threat of replacing care providers and further compromising relationships [44].

Considering care ethics, relationships and experiences of empathy and responsiveness to needs are critical. As such, technology serves as an augmentative tool and one of several elements of personalized care. Overreliance on technology-based care, whereby technology is applied as a substitute for in-person interactions, may have detrimental effects in situations involving older adults with frailty. Nevertheless, a possibility may be that some older adults wish to include technology in their health management to limit social contact, preserve private time, or protect privacy [19]. Considering the social needs of older adults and members of their support ecosystems relates back to respecting autonomy in the management of frailty. Beneficence and maleficence also need examination to balance the overall benefits and harms of the use of smart homes as components of health and social care for those involved.

Stigma and Discrimination

Stigma and discrimination are concerns that may vary across sociocultural contexts and result in considerable harm. These concerns are pertinent to older adults' adoption and use of smart home technology and are important in the development and implementation of potentially beneficial technology. Stigma may be defined as "a set of negative and often unfair beliefs that a society or group of people have about something" [45]. Stigma is associated with being an older adult (ie, being *elderly* and senile) or having a disability and the perception of being a burden. Older adults have expressed concerns over the stigma associated with the technology used to support health and social care [18,33]. The use of such technology may be perceived to reflect diminished health and increased frailty and disability—characteristics with which older adults may not personally identify. The obtrusiveness of technology (eg, whether installed components or functions are clearly visible or audible to others and call attention to personal problems) has an influence on its adoption by older adults [20]. The perception and experience of stigma with the use of smart homes may result in older adults' rejection of potentially useful tools to support their goals.

Discrimination is "the practice of unfairly treating a person or a group differently from other people or groups of people" [46] and is often the result of unfair and negative beliefs. Ageism (negative attitudes toward aging or older people), ableism (negative attitudes toward people with disabilities and their potential achievements), and mentalism (negative attitudes toward people with mental health or cognitive disorders) are all causes of discrimination. Discrimination may negatively influence what and how smart home technologies are developed. The choice of technology functions to create or the goals achievable by the technology may be informed by unfair beliefs about older people or people with disabilities. The lack of available data sets representing diverse age groups and abilities to inform AI development for these applications may be reflective of negative attitudes and contribute to the considerable problem of AI bias. What is considered normal or healthy may be determined by a small subset of people and their biases (eg, industry) [41]. Consequently, the developed functions or applications may not work for older adults with disabilities, or the decisions made by AI algorithms may not reflect the decisions of these users [41]. The inclusion of AI may not make decision-making more objective, and thus, predictions or recommendations should be used as guidance rather than as definitive decisions. Furthermore, even if technology is available, it may not be offered to older adults. This may be because caregivers, health care providers, or others may believe that older adults are not interested in it, are incapable of learning to use it, or will not benefit as much from it as younger people.

Equity of Access

Equity of access to beneficial support that may enable health and well-being is a concern of justice. Being equitable may involve "treating people or distributing resources differently, when people are in different situations and unequal treatment

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or distribution creates an equal outcome" [27]. A concern is whether the availability of smart home technology with its associated costs will only benefit people who can afford to pay for it [19,25,33]. Inequitable access may result in older adults who are unable to pay (or without family support to pay) being excluded from the benefits of smart homes, experiencing poorer health and well-being, and being further socially excluded. At a societal level, this may deepen the existing digital divide, whereby only privileged groups benefit from the use of digital tools and broad adoption is restricted. Nonetheless, the cost of smart home technology is anticipated to be driven down as it becomes more available and prevalent (though initially for those who can pay) and technology production costs decrease. In recent years, technology to support health and social care for the growing older adult population has become an important development topic for industry.

Government policy makers have also considered the topic critical in policy actions to ensure the health and well-being of citizens and the sustainability of funding to support care systems. In managing resources and spending priorities, there is a need for consideration and evaluation of the cost-effectiveness of smart home implementation for older adults with frailty and the intended goals [19]. Policies that allow for faster uptake of smart home technology by everyone may require more insurance-based reimbursements in health care plans [25]. Notably, smart home technology was determined to be more acceptable to older adults if they were paid for by family or the government [18].

Proactive and Ongoing Ethics Analysis and Management

Overview

Consideration of ethical issues and ethical practices is increasingly viewed as core in development, evaluation, and implementation activities for assistive and rehabilitation technology, which includes smart homes [47]. Ethics is relevant to the (1) development (including conception) and implementation of smart homes to align outputs and outcomes with our ethical, social, and cultural values and (2) processes for development, evaluation, and implementation of smart homes. Existing processes entailing ethical considerations that are relevant to smart homes include approvals for ethical research conduct and regulatory approvals addressing safety, effectiveness, and standards compliance for product and service transfer to market. These processes are highly focused and may not thoroughly reflect the broader questions of what we develop and implement; whether these innovations align with our values; and the ethical implications of innovations (as in 1) and how we develop, evaluate, and implement smart homes and whether our processes are consistent with these values (as in 2).

The success of smart home technology will ultimately be adoption, sustained use that facilitates health and well-being outcomes of older adults and caregivers, and increased sustainability of health and social care systems. The concepts within the 6 domains presented have been shown in research to influence adoption and use of smart homes. Smart homes may have a greater likelihood of success with committed proactive and comprehensive analysis, anticipation, and management of ethical concerns. For users with frailty, these processes need especially to reflect and accommodate their unique circumstances throughout the course of projects. Older adults with frailty may require more nuanced consideration with regard to technology use owing to their heightened vulnerability resulting from limitations in physical and cognitive abilities, experiences of mental health concerns and isolation, and reliance on others. Frailty is a complex condition necessitating management through an interdisciplinary clinical approach alongside older adults and their caregivers. This scenario leads to greater complexity in ethical analysis. Development and implementation may be enhanced through ethically aligned practices that place users and their contexts and usability goals at the center of activities such that outputs are usable and accessible by users in various living situations and market and funding systems. We emphasize ongoing analysis and management as the conditions and information related to previous decisions may change over time. A mindset that embraces potential unknowns and promotes reevaluation and course correction if circumstances change may enable better outcomes.

A lack of consideration and mitigation of ethical issues may result in several negative outcomes. Unfavorable perceptions from the public regarding technology and its potential uses and benefits may lead to the rejection of technology-based solutions or the removal of public resources for future research and development. This may result in the loss of opportunities for future implementation to benefit users. Errors or differences in understanding or expectations with AI and other technologies may result in inappropriate policies and legislation and again halt potentially important progress [41]. The adoption of appropriate measures for oversight of technology using AI requires ethical considerations and should be established before implementation and use [44]. There may be amplification of stigma and discrimination related to older people, disability, or assistive technology use, which may result in harm or unrealized opportunities. Negative perceptions of technology from poor consideration of ethical issues may result in a lack of investment from business developers who may be needed to commercialize technology or lack of funding from public funders or private insurers to support access for use [48].

Recommendations

To facilitate proactive and ongoing analysis and management of ethical concerns, we recommend collaboration among all stakeholders. This includes older adults; members of their support ecosystems; and the research, technical development, clinical, and industry communities in the field of smart home technology. This collaboration may be achieved through their inclusion in workshops and project teams. It is essential to cocreate a framework and associated resources and tools to support its implementation. The framework may include 4 elements to be discussed and elaborated on (Textbox 1).

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Textbox 1. Elements of a framework to facilitate the proactive and ongoing analysis and management of ethical concerns.

- A set of conceptual domains, such as those discussed in this paper, along with a tool consisting of reflective questions to guide the ethical deliberation of these domains

Systematic and standardized consideration of these domains across stages of a project from conception, development, evaluation, and implementation to sustained use is recommended as part of a comprehensive strategy. Reflective questions, potentially applying a Socratic approach for analyzing ethical implications [19,22], may be compiled as a tool. The tool may be used to examine ethical values for the technology and functions offered, what the technology may be used for or how it may be used, what is required for use, and the potential expected and unexpected outcomes. The analysis may cover personal, interpersonal, group, institutional, and societal levels of implications [41].

- Resources comprising strategies and guidance for the planning and reporting of ethical analysis throughout project phases

These resources may outline detailed strategies and guidance to be used at the start of and throughout projects to reflect on, anticipate, identify, define, deliberate, and mitigate real and potential ethical issues before and if they arise. New methods, guidelines, and checklists to support planning and reporting to enable transparency of ethical analyses during development, evaluation, and implementation processes, especially as they relate to decisions made throughout project phases, may need to be developed.

- Training resources to support leadership, literacy, and competency in teams for the analysis and management of ethical concerns

Leadership, collective team responsibility, and a culture that values the analysis and management of ethical concerns need to be promoted. Cross-disciplinary knowledge and skill development for researchers and practitioners in the clinical and technical sciences, industry members, and others may be essential to support literacy and competency in ethical analysis and management as part of smart home development, evaluation, and implementation. Contributing to the collaborative process, team members also need to develop knowledge and skills to meaningfully engage with older adults, their support ecosystems, and the public to fully include them in teams.

- Training resources for older adults with frailty, their support ecosystems, and the public to support their awareness and participation in teams and ethical analysis processes

These stakeholders are essential team members and prospective users of smart homes, and therefore, commitment and strategies to ensure their full inclusion are critical. Raising awareness of smart homes and their potential benefits and harms and enhancing knowledge and skills regarding ethics and ethical analysis are important to support critical and realistic assessment of technology for adoption, use, and provision of feedback to developers or providers. For older adults and their support ecosystems, knowledge and skill development may focus on strategies to communicate and advocate for their needs. Resources on technology and ethical analysis need to be easy to understand to promote knowledge exchange and learning.

Conclusions

Successful adoption and sustained use of smart homes in the management of frailty in older adults have thus far been limited. Older adults with frailty require nuanced consideration when incorporating technology into their care because of their complex health and social status and vulnerability. Unmitigated ethical concerns are important factors restricting older adults and their support ecosystems from benefiting from the use of smart home technology. Applying a proactive and ongoing ethics analysis and management approach from development, evaluation, and implementation to sustained use is important for success. We recommend the development of a framework along with educational resources and analysis tools, cocreated by older adults, members of their support ecosystems, and other stakeholders, to support the implementation of this approach. Within this framework, consideration of a range of conceptual domains derived from bioethics and technology ethics is key: (1) privacy and security, (2) individual and relational autonomy, (3) informed consent and supported decision-making, (4) social inclusion and isolation, (5) stigma and discrimination, and (6) equity of access. Smart homes may have a greater likelihood of accommodating users and their contexts with committed and comprehensive analysis, anticipation, and management of ethical concerns that reflect the unique circumstances of these users. Smart home technology use may then achieve its desired individual, societal, and economic outcomes and serve as a solution to support health; well-being; and responsible, high-quality care.

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Authors' Contributions

RHW conceived and designed the work and drafted and substantively revised the manuscript. TT, NB, MC, and RA conceived and substantively revised the work. All authors read and approved the final manuscript.

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Conflicts of Interest

None declared.

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Abbreviations

AI: artificial intelligence

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Viewpoint

Developing a Memory and Communication App for Persons Living With Dementia: An 8-Step Process

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Abstract

According to the 2022 Alzheimer's Association Facts and Figures, more than 6 million Americans have Alzheimer disease and related dementias. They are cared for by millions of family members, friends, or other unpaid caregivers. Communication deficits are common among persons with Alzheimer disease and related dementias and pose challenges to caregiving and clinical care, which is already complex. An interdisciplinary team developed a mobile app prototype to improve communications between people living with dementia and their caregivers and providers and to promote person-centered care. This viewpoint paper provides a road map for how the interdisciplinary team worked together to develop and plan for the implementation and evaluation of a new evidence-based app. In our paper, we provide an 8-step process used by a team of clinicians, researchers, and software engineers to develop a new app to meet the needs of people living with dementia and their caregiver(s). The planned clinical trial has been registered at ClinicalTrials.gov (NCT04571502; https://clinicaltrials.gov/ct2/show/NCT04571502).

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KEYWORDS

health technology; interdisiplinary team; older adults; dementia; communication; communication aids for disabled persons; communication boards; app; Alzheimer disease; family; caregiver; clinical care; development; speech; psychosocial intervention; software design

Introduction

Background

People living with dementia often experience communication deficits due to a variety of symptoms associated with Alzheimer disease and related dementias, including memory loss, primary progressive aphasia, decreased attention span, and word-retrieval anomia [1-6]. These deficits can have a negative impact on caregiving and clinical care for people living with dementia while also resulting in negative physical and mental health outcomes for their caregivers [6-8].

Prior research has found that augmentative and alternative communication (AAC) devices can effectively support people living with dementia in communicating [9]. However, many of these AAC devices are limited in their ability to customize content and have been criticized for their limitations in

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addressing the personhood of people living with dementia and targeting the family as a unit in communication support [9,10]. Specifically, most of these technology-based devices are not designed to support people living with dementia in communicating their daily and changing preferences and needs [9-19]. This paper describes the first phase of a clinical trial, where a team of interdisciplinary researchers applied a multistep framework for user interface (UI) development [20] to develop an electronic AAC device, the My Person Assisted Touchscreen Interface (*My PATI*) for people living with dementia.

The My PATI for People Living With Dementia

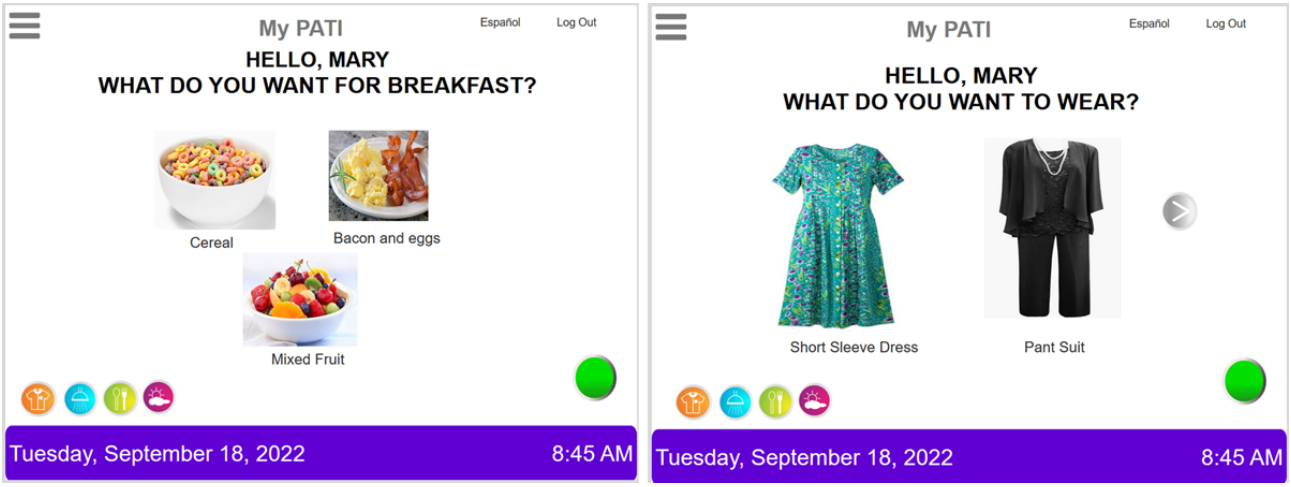
The focus of this overall project was to develop an electronic AAC device for people living with dementia that aims to (1) support them in communicating their daily care preferences and needs with caregivers; (2) communicate their everyday experiences and behaviors with caregivers; (3) share information about these experiences and behaviors with providers involved with their care; and (4) provide the caregivers with the ability to easily update information, with internet access.

The newly developed *My PATI* provides structure and prompts and serves as a tool for ongoing engagement between people living with dementia and their caregivers. Similar to traditional paper AAC devices, *My PATI* uses graphic images and text that people living with dementia can point to when trying to communicate. Unlike traditional AAC devices, these graphic images can be customized. For example, rather than a generic icon of a shirt or dress, *My PATI* can be populated with images of the care recipient's actual clothing to make *My PATI* more relevant to the person living with dementia when communicating about getting dressed for the day (see an example in Figure 1).

It also differs from traditional AAC devices in that its features are organized by activities of daily living (ADL; ie, basic self-care tasks, such as eating and grooming) and instrumental ADL (IADL; ie, more complex activities, such as preparing meals and maintaining schedules). *My PATI* is designed to support the autonomy and life participation of people living with dementia, by allowing them to make selections about their care preferences during ADL and IADL throughout the day. For example, *My PATI* provides personalized touchscreen selection options for grooming and dressing (ie, ADL) and prompts the user to communicate, manage, and engage in their surroundings (ie, IADL). The people living with dementia can use *My PATI* alone (when able to) or in partnership with a family caregiver, another family member, or a paid caregiver involved with their care.

My PATI has features that allow the caregiver to continually update content as the care recipient's needs and preferences evolve, which is not easily done with a paper version of an AAC device. The caregiver UI of *My PATI* is designed to allow the caregiver to upload, add, or change graphics and functions that reflect the care recipient's unique preferences and memorabilia. For example, images of clothing may be updated to reflect a change in the season, or a change of diet may necessitate the need for different food choices. This feature of updating graphic images and the ability to access the app from anywhere with internet connectivity is novel. Textbox 1 features the fictitious case of Mary, an older adult with dementia, demonstrating an example of the potential use of *My PATI*. Figure 1 provides a screenshot from *MY PATI*, displaying options Mary is offered regarding her breakfast preferences and what she would like to wear.

Figure 1. Screenshots of Mary's preferences for breakfast and clothes. My PATI: My Person Assisted Touchscreen Interface.



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Textbox 1. Example use case of Mary.

Mary is 80 years old, has multiple medical problems, and was diagnosed with vascular dementia 6 years ago. Mary is often confused and anxious and does not sleep well. Her family, including her live-in son, makes every effort to let the daily paid nursing assistants know Mary's care preferences (eg, types of food, clothing, and grooming), interests (eg, preferred TV shows, music, daily walks, and manicures), and abilities (eg, able to select her clothing and style her hair). Mary has significant verbal communication deficits. Therefore, she often communicates through single words or short phrases, which frequently results in family members and in-home caregivers not giving Mary a choice on what to wear, eat, or do for her daily activities, despite their good intentions for her daily care. Sometimes Mary exhibits care-resistant behaviors (eg, aggression and lack of cooperation) when she seems unhappy with food or clothing suggestions. Using *My PATI*, Mary's caregivers are able to communicate with Mary about what she wants to eat or wear by using pictures, and Mary can select them using the touchscreen rather than having to verbally communicate about them. This reduces the frequency of Mary's behavioral disturbances, and Mary is more frequently alert and engaged during mealtimes and dressing. Essentially, *My PATI* is a tool that compensates for Mary's communication deficits and provides a method for her to make choices that facilitates involvement in her care.

My PATI is grounded in evidence from low-technology versions of AAC devices [21]. In the mid-1980s, when dementia was a new diagnosis, there were no known interventions for its accompanying memory and communication problems. Bourgeois [22] developed the *Memory Wallet*, a collection of 30 pages of personal information, one photograph per page captioned with a 5- to 7-word declarative sentence, to provide prompts for desired conversation topics. Persons with midstage dementia used the wallets to read the sentence and comment about the photograph, increasing the overall number of on-topic statements made during conversations with the wallet compared to those without the wallet; they also decreased the number of ambiguous, repetitive, and erroneous utterances made during conversations with the wallet. In the following years, Bourgeois [23] systematically replicated the effects of the 1990 study with individuals across the continuum of dementia severity using various sizes of memory books and demonstrated similarly positive effects, as long as the size of the font was large enough to be read easily, and the content of the pages was personally relevant. Caregivers reported serendipitous effects of the memory aids on other challenging behaviors, including the reduction of repetitive questioning when the person was shown the page in the aid that answered the question [22-24]. The effects of memory aids were also evaluated in conversations and care interactions between people living with dementia and nursing aides [25-27] and spousal caregivers [28,29]. The overall conclusion of these studies was that reading is believed to be an overlearned behavior and a preserved skill and that personalized text has the potential to moderate the effects of memory loss [30]. Therefore, *My PATI* features incorporate individualized text and content to support meaningful engagement for the person living with dementia and their caregiver [31].

From the perspective of a speech-language pathologist, *MY PATI* clearly provides an approach to treatment that is rehabilitative in nature. Communication rehabilitation for people living with dementia encompasses all treatments geared toward providing the client with the skills or access to strategies that will assist them to regain or compensate for what has been disrupted [32,33]. A major objective of *MY PATI* was to compensate for communication functions to the greatest extent possible about daily preferences. This is instrumental for facilitating person-centered care (PCC) for people living with dementia. PCC in dementia care stems from the groundbreaking work of Kitwood [31], *Dementia Reconsidered the First Comes First*, which asserts that people living with dementia need to be involved in decision-making about their care whenever possible. It also posits that care for people living with dementia should emphasize their preferred needs, values, and life history. This is facilitated by knowing the person receiving care, which requires interpersonal relationship and communication between people living with dementia and their care providers [34-36].

As PCC has become the gold standard of care, an increasing number of technologies that support the autonomy of people living with dementia have emerged, including monitoring technologies for the safety of people living with dementia, robotics, therapeutic technologies, and various apps to support brain and mental health [37]. Hence, *My PATI* is part of a larger trend in IT to support this population. Unfortunately, there currently lacks a consensus on standards or guidelines for delivering PCC to inform technology development [34-37]. However, the development of *My PATI* has been informed by the definitions and conclusions reported by the American Geriatrics Society Expert Panel on PCC [36].

An 8-Step Process for Developing My PATI

Overview

Moving from the traditional paper format of an AAC device or memory aid for people living with dementia to an electronic version requires experts from multiple disciplines, including nursing, social work, physical therapy, speech therapy, and software engineering. Interdisciplinary development teams can sometimes encounter challenges when health and social scientists collaborate with engineers. For example, health and social scientists may not understand the capabilities or limitations of technologies, and engineering members may not understand the context of health and social problems being addressed. There are no easy answers on how to address these barriers. Still, an agreed-upon stepwise process that allows for regular opportunities for groups to talk about issues and share progress is helpful.

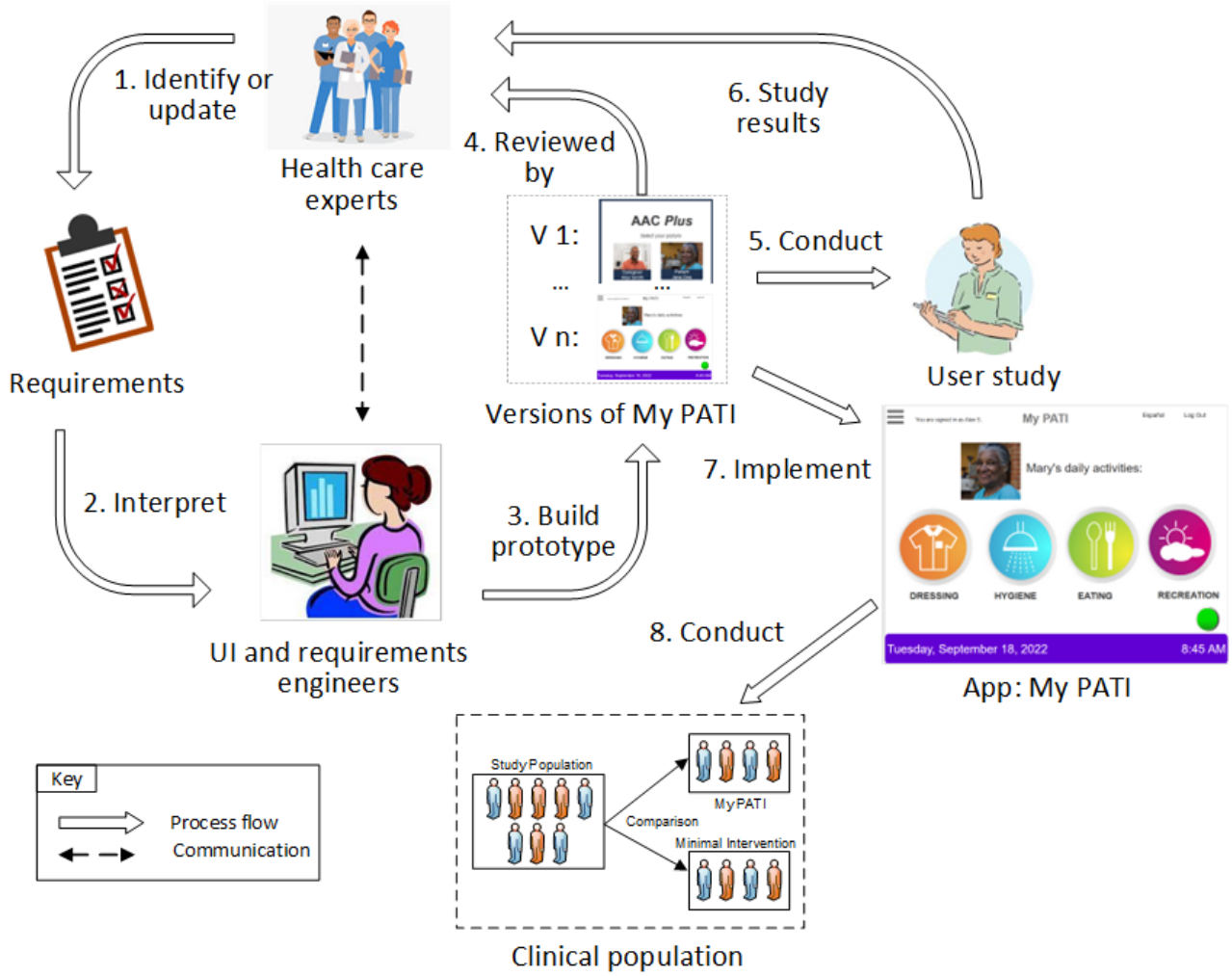
To develop *My PATI*, our team developed and implemented an 8-step process (see Figure 2). The diagram provides a proposed communication flow for information throughout the 8 steps. The ongoing communication between the software engineers and the clinical and research team members was critical. This was a challenge as this development work was primarily done remotely during the COVID-19 pandemic. Ongoing communication occurred primarily with the use of web-based meetings, emails, and phone calls. Additionally, in-person interactions with research subjects were not permitted for a

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period of time due to the pandemic, which posed challenges for obtaining feedback from potential end users. Web-based focus groups and interviews were used. Beginning in the next section of this paper, we describe our multistep process that has been implemented to develop and evaluate *My PATI*.

The underlying principle for developing *My PATI* in steps 1 through 4 in Figure 2 is based on 3 software process models. These models included the incremental, throwaway prototype, and agile (a combination of incremental and prototyping, see Textbox 2 for definitions) models [38,39]. *My PATI* is a research app, thus making the requirements, by definition, inherently vague. Further adding complexity to the development process is the fact that the research team is highly interdisciplinary. The overall approach to developing the app involved first defining the software requirements using a throwaway prototype, then applying an agile approach to implement the app based on the requirements produced by the team. The throwaway prototype was critical to getting the UI correct before any implementation activities of the app starts. The agile approach (see Textbox 2) was the most suitable for the implementation stage since the health care experts and potential users (ie, customers) were frequently consulted during the implementation of *My PATI*. The approach we used for the project is supported by Dawson and Dawson [39], based on their analysis of various software process models using functionality-time graphs and combined functionality-time/cost/benefit graphs.

Figure 2. Multistep process used to develop and evaluate My Person Assisted Touchscreen Interface (My PATI).



Textbox 2. Software engineering definitions.

- An *incremental software model* produces successive increments of working, deliverable software based on partitioning of the software requirements to be implemented in each of the increments [40].
- *Software prototyping* is an activity that generally creates incomplete or minimally functional versions of a software application, usually for trying out specific new features, soliciting feedback on software requirements or user interfaces, further exploring software requirements, or gaining some other useful insight into the software [40].
- *Agile software methods* are considered lightweight methods in that they are characterized by short, iterative development cycles; frequent customer (ie, health care experts and potential users) involvement; and an emphasis on creating a demonstrable working product with each development cycle [40].

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Step 1: Identification of My PATI Requirements by Clinical Experts

The development and decisions regarding *My PATI app features* were guided primarily by the work of Bourgeois and theories on PCC, as described earlier. Early in the process, a goal of the social scientist members of the team was to provide the software engineering team with a background in PCC. This was essential as the common understanding of the challenges and strategies for promoting evidence-based PCC provides a road map and common language for our work. The engineering team was provided with articles and related videos to assist them in developing a greater understanding of the uniqueness and routine daily needs of people living with dementia. Clinical team members provided insights into functional and cognitive impairments that provided the foundation for *My PATI* features and navigation based on their experiences with patients and families. The decision to use touchscreen technology was evidence based, as touchscreens are the optimal mechanism for delivering *My PATI* to people living with dementia. The use of touchscreen technology by people living with dementia has been the focus of 2 systematic reviews [16,17], which established that people living with dementia can use personalized touchscreen technology independently and engage with touchscreen technology to improve interactions, supporting relationships and fostering PCC.

Step 2: Requirements Interpreted by the Software Engineers

The design of the *My PATI* prototype incorporated a goal-directed and user-driven design process. In this approach, the main focus of planning and developing the system was on the goals and needs of the primary user population for each functional component or interface of the system. This resulted in providing enhanced usability and ubiquitous user experiences (UXs) for the targeted users [41]. The UI/UX experts on the software engineering team began this process by working closely with the entire team, assessing the purpose, scope, and goals for creation of the *My PATI* design. It was determined that there were 2 functional components of the system, namely (1) the capabilities of people living with dementia for communicating their preferences and feelings about their daily care activities and experiences; and (2) the capabilities of caregivers for set-up and the available customization functions of the app.

For the more detailed design, the UX experts incorporated UX design best practices, including conducting in-depth formative and substantive UX research throughout the development process [20]. For the UX research, the clinical experts of people living with dementia were the participants of the studies. This was important as it is the clinical experts who are the most knowledgeable about the primary users of the interface for people living with dementia, particularly their special cognitive and functional needs. UX research included contextual inquiries using a think-aloud protocol, clinical expert focus groups, persona and scenario creation, user case studies, and workflow analysis. The design and development studies were conducted separately with the clinical experts, caregivers, and people living with dementia. The methodologies used included participatory design using paper prototyping, wireframing and interactive prototyping, heuristic evaluation, and usability testing.

Step 3: Engineers Built a Prototype

As described above, the software engineering team built the prototype using the requirements provided by the health care experts and interpreted by the UI/UX experts. The requirements were captured using structured natural language as use cases. The *My PATI* prototype was built using Axure [42]. Axure is a wireframing and prototyping tool that allows UI/UX designers to quickly create interactive interfaces for an app without writing a line of program code. Figure 2 shows the cycle used to develop the *My PATI* prototype, which involved steps 1, 2, 3, and 4 in the cycle. The software engineering team developed at least five versions of the prototype, with the health care and UI/UX experts reviewing each version and providing feedback to the engineering team. These versions are shown in the box labeled "Version of *My PATI*" between steps 3 and 4 and were built using the best practices in UI/UX development [20]. The first and last versions of the *My PATI* prototype are shown in Figure 2. Additional screenshots of *My PATI* are shown in Figure 1, showing how Mary and her caregiver are able to select her daily activities, such as what Mary would like for breakfast and what she would like to wear for the day.

Step 4: Prototype Evaluated by Clinical Experts Followed by Repeating Steps 1-4

The research team then had the clinical experts review the prototype. It was initially determined that the graphic icons used for the app may not adequately reflect the feature or function that the icon represented (eg, music library and video library). The research team then consulted with an artist with UI/UX experience. The clinical team then engaged in a series of meetings with the artist to provide their clinical input about the various aspects of the icon (eg, the significance of the icon and its appropriateness for people living with dementia). The artist then redesigned the icons, which were integrated into the prototype. When this process was complete, the team continued steps 1 through 4 until consensus was reached on icon design.

Step 5: User Study Conducted With a Person Living With Dementia and a Caregiver

User studies with both people living with dementia and caregivers have been conducted following approval from an Institutional Review Board (IRB-21-0527). For potential end user feedback, we implemented a participatory research design with persons with moderate cognitive impairment (defined as a recent Montreal Cognitive Assessment score of 10-17 or Mini-Mental State Exam score of 13-20) and caregivers at a collaborating memory clinic. The provided data revealed potential navigation issues, and our team made modifications to simplify navigation based on these findings. The protocol was structured and developed jointly by clinicians, researchers, and software engineers, and interviews were audio recorded. During the interview of the person living with dementia, we evaluated if the *My PATI* app's features could be accessed by the participant without difficulty. Finally, we validated whether the participant's selections were valid and reflected the true preference of the person living with dementia (as opposed to

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random touches on the screen). The team worked together to develop a methodology to gain insight into the validity of the person's true preference. Our approach was to compare the selected iPad choice (in the *My PATI app*) to the actual item. See Textbox 3 for an example of how the protocol validated respondent food choice.

To date, for these participants, there was agreement between the snack choice made with the *My PATI* interface and the snack choice made when the person living with dementia was presented with the actual snack by the interviewer. There was agreement for the majority of validation tests. More data from more participants are needed and are planned. To date, 5 participants—3 caregivers and 2 people living with dementia—have been able to navigate through the app and perform tasks with ongoing guidance and support. A barrier to this usability testing has been that the information in the current *My PATI* prototype is not "personalized" (eg, generic pictures of food, clothing, and activities). A pilot is planned to test *My PATI* with personalized information (step 7).

Textbox 3. Instructions on the interview protocol for user study.

Interviewer: "Now I am going to ask you about things you ordinarily like to eat and drink."

- Show the person living with dementia the 2 snack options, pointing to each but not touching the iPad.

Interviewer: "What do you ordinarily like to eat?"

- Hold the iPad while the participant selects their choice or if the participant verbally states their response, select their response for them. Once a selection is made, put the iPad down and bring out the physical snacks (ie, identical to images on the iPad) while stating the following.

Interviewer: "I have a couple of snacks. Which of these snacks do you prefer?"

- Document the selected snack.

Step 6: Results Interpreted by Experts and Updated

This step is similar to step 4, where the clinical experts will review the results from the user study and make recommendations for interface revision (if deemed necessary), which would be followed by steps 1-4 again.

Step 7: My PATI Pilot Implementation

A small pilot will be conducted in preparation for the planned clinical trial (see step 8). These findings will be used to make necessary changes to *My PATI* and inform the design of a subsequent clinical trial (step 8). The team recognized from previous research [43-46] that the implementation and use of an app can present challenges. As a component of implementation, a decision was made that materials are needed to both educate the participants on technology and guide them in the use of *My PATI*; these materials will be evaluated in the pilot. Central to these implementation materials will be audiovisual presentations (available on the web) for the *My PATI* app described below. A decision was made, based on our previous research [44,46], that the technology needs to be seamlessly integrated into daily life, or it will not be viewed as helpful and be underused. It is for this reason that the "*A Day in the Life with My PATI*" implementation video is being developed. Textbox 4 provides a condensed version of the script from the video, which portrays a common daily interaction between Grandma Mary (person living with dementia) and Samantha (her granddaughter).

Textbox 4. Condensed script excerpt from the My Person Assisted Touchscreen Interface (My PATI) implementation video.

Samantha: "Good Morning, Grandma. How are you feeling today?"

Grandma Mary: (smiles at Samantha)

Samantha: "Grandma, we have a doctor's appointment later this morning. What would you like to wear today?"

- Samantha shows Mary photos of her clothes displayed on *My PATI*. Mary looks over her choices and touches the icons on the screen picturing her pink blouse and white slacks.

Samantha: "Nice choice, Grandma! You will look very pretty for the doctor. Let's get ready."

- Samantha helps her grandmother stand up, and they move off together to get dressed.

Step 8: Conduct a Clinical Trial of My PATI

A trial is planned to commence in the spring of 2024 with triads of people living with dementia, caregivers, and their health care providers [47,48]. The study will investigate the impact of using *My PATI* on a number of outcomes. Two clinical sites (Miami, Florida, and Birmingham, Alabama) are collaborators for the project, and the study will enroll 60 triads at each site. The trial consists of 2 arms, where participants in both arms will continue receiving regular health care services at their respective clinics. Participants in the treatment (*My PATI*) group will receive training on how to use the device and then be asked to use the device as part of their regular daily caregiving routine for a period of 12 months. Outcome measures will be assessed at baseline, 6 months, and 12 months over the phone. Primary outcome variables include improving the quality of life for people living with dementia and their caregiver. Secondary outcome measures include depression, positive aspects of

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caregiving, caregiver burden, and overall health for the caregiver; depression, memory, and behavioral problems; functional linguistic communication for people living with dementia; engagement of people living with dementia and their caregivers; and provider perceptions of the intervention. All user data for *My PATI* by all participants will be tracked and analyzed. Full details about the outcome variable measures to be used and the research design can be accessed at ClinicalTrials.gov (NCT04571502). Results are anticipated to be available in 2025.

Limitations

There are several limitations of the 8-step approach presented in this paper and adjustments that should be made if the process was repeated. First, most the team had previously worked together on the development and testing of another dementia caregiver app before developing *My PATI* [44]. It is suspected that clinical and engineering teams working together for the first time would need more time to progress through the early stages of the 8-stage process. Second, due to the COVID-19 pandemic, our development process included limited collaboration with people living with dementia and their caregivers. Ideally, collaboration with these stakeholders would occur from the outset and for as often as needed. It should be noted that multiple members of the research team had experience with caregiving for someone living with dementia, concurrently or previously. These experiences were often included in the team discussions.

Conclusions

This paper provides a road map for implementing an interprofessional practice approach to developing an evidence-based app, *My PATI*, designed for older adults diagnosed with dementia and their caregivers. An interdisciplinary team of clinicians, researchers, and software engineers collaborated to develop *My PATI* to improve the quality of life of a person diagnosed with dementia by increasing their independence and participation. *My PATI*'s 8-step developmental process is described along with hypothetical scenarios demonstrating its use. The authors of this paper are planning to initiate the trial in the winter of 2024. This study will investigate the effectiveness of using *My PATI* in improving the quality of life of people with Alzheimer disease and related dementias and their caregivers. The results of this study are anticipated to be available in 2025.

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Conflicts of Interest

None declared.

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Abbreviations

AAC: augmentative and alternative communication
ADL: activities of daily living
IADL: instrumental activities of daily living
My PATI: My Person Assisted Technology Interface
PCC: person-centered care
UX: user experience
UI: user interface

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Original Paper

Understanding the Connection Among Ikigai, Well-Being, and Home Robot Acceptance in Japanese Older Adults: Mixed Methods Study

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Abstract

Background: Ikigai (meaning or purpose in life) is a concept understood by most older adults in Japan. The term has also garnered international attention, with recent academic attempts to map it to concepts in the Western well-being literature. In addition, efforts to use social and home robots to increase well-being have grown; however, they have mostly focused on hedonic well-being (eg, increasing happiness and decreasing loneliness) rather than eudaimonic well-being (eg, fostering meaning or purpose in life).

Objective: First, we explored how Japanese older adults experience ikigai and relate these to concepts in the Western well-being literature. Second, we investigated how a home robot meant to promote ikigai is perceived by older adults.

Methods: We used a mixed methods research design—including 20 interviews with older adults, a survey of 50 older adults, and 10 interviews with family caregivers. For interviews, we asked questions about older adults' sources of ikigai, happiness, and social support, along with their perception of the robot (QT). For surveys, a number of well-being scales were used, including 2 ikigai scales—ikigai-9 and K-1—and 6 Patient-Reported Outcomes Measurement Information System scales, measuring meaning and purpose, positive affect, satisfaction with participation in social roles, satisfaction with participation in discretionary social activities, companionship, and emotional support. Questions related to the perception and desired adoption of the robot and older adults' health status were also included.

Results: Our results suggest that health is older adults' most common source of ikigai. Additionally, although self-rated health correlated moderately with ikigai and other well-being measures, reported physical limitation did not. As opposed to social roles (work and family), we found that ikigai is more strongly related to satisfaction with discretionary social activities (leisure, hobbies, and friends) for older adults. Moreover, we found that older adults' sources of ikigai included the eudaimonic aspects of vitality, positive relations with others, contribution, accomplishment, purpose, and personal growth, with the first 3 being most common, and the hedonic aspects of positive affect, life satisfaction, and lack of negative affect, with the first 2 being most common. However, the concept of ikigai was most related to eudaimonic well-being, specifically meaning in life, along the dimension of significance. Finally, we found that Japanese older adults have high expectations of a home robot for well-being, mentioning that it should support them in a multitude of ways before they would likely adopt it. However, we report that those with the highest levels of meaning, and satisfaction with their leisure life and friendships, may be most likely to adopt it.

Conclusions: We outline several ways to improve the robot to increase its acceptance, such as improving its voice, adding functional features, and designing it to support multiple aspects of well-being.

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KEYWORDS

ikigai; meaning in life; purpose; well-being; eudaimonic; hedonic; happiness; home robots; social robots; human-robot interaction; Japan

Introduction

Study Overview

Ikigai, a Japanese term, roughly translates to "that which most makes one's life seem worth living" [1], "meaning in life" [2], or "reason for living" [3]. Having ikigai has been associated with numerous health benefits among older adults, such as reduced risk of developing depression [4], dementia [4], disability [4,5] and cardiovascular disease [6,7]. Furthermore, it is associated with lowered all-cause mortality [6,8,9]. Ikigai is essential for older adults to lead fulfilling and independent lives [10] and is associated with increased mental well-being and life satisfaction [4].

Emerging technologies with artificial intelligence may be able to support and even expand people's experience of ikigai by providing activity suggestions and opportunities for people to connect with others. Several recent review papers suggest that for older adults, social robots might be particularly appropriate for providing social, cognitive, and behavioral interventions through home use, as they show positive effects on the physical, social, and mental health of older adults [11-14]. However, it is important to understand who to design for—both in terms of who might receive the most benefit from the technology and who might be most accepting of it.

In this paper, we explored (1) how Japanese older adults define and experience ikigai and (2) how a home robot meant to promote ikigai is perceived by older adults. We achieved these 2 aims by conducting 20 in-depth interviews with older adults, collecting 50 survey responses from older adults, and conducting 10 interviews with family caregivers. We focus on older adults because ikigai often declines in old age [9,15], as individuals experience changes in social roles [16] and autonomy, caused by factors such as retirement [17], reduced social interaction [18], and declining physical health [19].

As some ambiguity exists over how to translate the conceptual essence of "ikigai" to a Western audience, we start by using a mixed methods approach to consider how ikigai maps to other concepts in the well-being literature (eg, eudaimonic well-being [EWB], hedonic well-being [HWB], meaning, and vitality), analyze older adults' sources of ikigai along with their sources of concern, and consider how ikigai relates to satisfaction with social roles (work and family) and discretionary activities (leisure and friendships).

In addition, we analyze how an "ikigai" robot—showcased to participants via video—is viewed by older adults and might further be developed to support their ikigai. Previous studies with older adults in the United States have suggested that robots may be beneficial in helping older adults maintain and enhance their ikigai [20]. In addition, feedback obtained via interviews with ikigai experts, both academic scholars and those running ikigai centers in Japan, has been largely positive about the idea of using robots cross-culturally to support ikigai [21]. Therefore, this paper presents the next step in answering if and how robots might support Japanese older adults' ikigai. This also entails exploring which older adults may be most open to having QT, a humanoid desktop robot, as an "ikigai" robot in their homes. Our study advances the human-robot interaction and social robotics fields by (1) contributing to knowledge about robot design for meaning and purpose in life, an area little represented in the field and (2) contributing additional knowledge about the individual characteristics that are associated with home robot acceptance.

There are several reasons why we studied ikigai, instead of only studying the perception and design of QT for this application. First, owing to differences in the definition of the term *ikigai* in literature, we needed a better understanding of exactly what we would be designing the robot to do and which of the existing ikigai scales to use to measure changes in ikigai. Second, as there is a large body of research on using robots to support HWB (eg, decreasing loneliness and increasing positive affect) in the United States, we needed to determine whether this existing body of literature might be directly applicable to the development of this robot. Third, the goal of our larger research project is to design such a robot for cross-cultural deployment between the United States and Japan, where the word "ikigai" is not understood by those in the United States. Thus, we needed to clarify how best to translate this term for the US population during testing. Therefore, we explored 4 main research questions (RQs):

- RQ1—What are older adults' self-reported primary sources of ikigai, and how do these relate to eudaimonic and hedonic sources of well-being?
- RQ2—How does ikigai correlate with scales of well-being common in the Western well-being literature, such as scales of meaning and purpose, positive affect, social support, and related concepts such as satisfaction with social roles and discretionary activities?
- RQ3—How do older adults envision a social home robot supporting their ikigai and overall well-being?
- RQ4—Are there certain characteristics of older adults that lead to more positive perceptions or acceptance of a social robot for supporting ikigai and well-being?

What Is Ikigai?

The Japanese term, ikigai, consists of 2 Japanese (Kanji) characters: "iki (生き)," which means life, and "gai (甲斐)," which means value or worth. Therefore, broadly speaking, ikigai means that which makes one's life seem worth living [22]. However, it also refers to a range of additional concepts including purpose and meaning of life; self-actualization [23]; psychological well-being [24]; or at a smaller scope, the joy a person finds in living day to day [25]. In fact, there are still considerable differences in definitions of ikigai, as found in a systematic review [26].

Despite the diversity and broadness in the interpretation of the concept, what seems to be accepted across different

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interpretations is that ikigai is individual to everyone, and ikigai is a familiar concept deeply rooted in the daily lives of Japanese people. Miyako Kamiya—who is often described as the mother of ikigai research—suggested a distinction to address 2 aspects of ikigai—"ikigai-kan," meaning the feeling of ikigai, and "ikigai tai-sho," meaning the object or the source of ikigai [23]. It is also described as having 3 "levels"—first person (personal; eg, hobbies), second person (interpersonal; eg, family), and third person (community; eg, volunteering) [27]. In Japan, the concept of ikigai is pervasive to the extent that many individuals possess an abstract idea of what it is without thinking about it [25].

Issues arise as the concept garners broad international interest, including the publication of several popular English-language books and efforts by Japanese scholars and practitioners of ikigai to make the concept and related practices more available to a non-Japanese audience [25,28-30]. When translating ikigai as a concept from Japan to international audiences, it is clear that ikigai is not the same as HWB or subjective well-being (SWB; defined as positive affect, negative affect, and life satisfaction [31,32]). However, whether it is largely equivalent to EWB [24,33] or comprises aspects of both EWB and HWB [6,34,35] has been a point of divergence among some researchers. This is an important distinction, as it facilitates the understanding, adaptation, and comparison of decades of accumulated ikigai studies in Japan with well-being studies in the West.

What Is Well-Being?

There are 2 different but complementary aspects of well-being [36,37]. The first, HWB, is typically measured by 3 constructs: positive affect, negative affect, and life satisfaction [38]. In this way, it is synonymous with SWB. The word happiness is often used interchangeably with both HWB and SWB. Of the 3 constructs, life satisfaction results from a cognitive appraisal of one's life as a whole, whereas positive and negative affect are affective components of HWB. It has been shown that positive affect is responsible for 75% of the variation in HWB [36].

In contrast, EWB is often defined by what it is not (ie, not mere affect, pleasure, or happiness) [39]. It encompasses many important aspects of one's experiences, including meaning in life, vitality, personal growth, spiritual transcendence, accomplishment, engagement, and self-acceptance. However, most scholars agree that if a single construct is to be associated with EWB, it is meaning. In fact, meaning has been found to capture 70% of the variance in EWB and is often used as its proxy [36].

Researchers now define "meaning" as referencing 3 different dimensions—coherence, purpose, and significance [33]. *Meaning as coherence* refers to one's cognitive ability to make sense of the experiences one has in life. *Meaning as purpose* is future oriented, providing a sense of direction, and it refers to one's goals and aims in life. *Meaning as significance* is an evaluation that life or one's life is significant—that one has a "life worth living." This assessment involves taking into account our past, present, and future. It can also overlap with many of the EWB concepts mentioned previously, as to come to the decision that one has a life that is significant and worthwhile, consideration might be given to one's accomplishments, goals, vitality, and so on. HWB, similar to these EWB concepts, can even become a part of one's meaning (significance) if it is assessed as part of what makes one's life worth living. Though these may lead some individuals to feel they have meaning, they are still conceptually separate, distinguished as a "source of meaning rather than a part of meaning" [33].

Ikigai Scales

Japan experienced a "Renaissance of ikigai research [26]" in the 2000s, especially regarding older adults' ikigai, owing to its relevance to social concerns about the rapid aging of the population [2]. Therefore, various ikigai models and scales to conceptualize and measure ikigai were developed during the period. Although early Japanese researchers adopted and modified the scales made in the West to quantify ikigai, including the Philadelphia Geriatric Center, Morale scale [40], and Purpose in Life test [41], new scales were developed for the Japanese concept specifically including: the K-1 scale by Kondo and Kamada [42], the ikigai model by Hasegawa et al [2], and the ikigai-9 scale by Imai [43].

The K-1 scale measures older adults' ikigai using 16 items across four categories: (1) self-realization and motivation, (2) sense of fulfillment in life, (3) motivation to live, and (4) sense of existence [42]. The ikigai-9 is a 9-item scale developed with Japanese older adults aged >60 years, designed as a tool to measure their sense of ikigai across three different aspects: (1) optimistic and positive emotions toward life (eg, "I often feel that I am happy"), (2) active and positive attitudes toward one's future (eg, "I would like to learn something new or start something"), and (3) acknowledgment of the meaning of one's existence (eg, "I believe that I have some impact on someone") [28,43]. The reliability of both scales has been validated with Japanese populations [43,44] (and international populations for the kigai-9 [28]), and they have been used as valid tools to investigate older adults' ikigai [20,28,45].

Ikigai Interventions

Previous studies have examined the effects of various interventions on older adults' ikigai. For example, Ohashi and Katsura [46] designed a behavior program to enhance older adults' ikigai, a series of participatory workshops focusing on themes including improving relationship skills and reflecting on their life and goals. Using the K-1 scale [42] as a validation tool and 32 female older adults as their study participants, the authors reported the program's effectiveness in increasing the sense of ikigai for older adults. Similarly, using a combination of self-evaluation scales, including the K-1, Shitakura and Murayama [47] suggested the success of using a program consisting of goal-oriented activities (eg, exercise sessions) with older adults to maintain and improve their self-reported physical health and sense of ikigai. Iwahara et al [48] used the Japanese version of the Philadelphia Geriatric Center morale scale [49] to suggest the positive effect of their intervention (ie, college students spending a couple of days doing various activities with older adults) on the ikigai of older adults living alone.

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Ikigai and Health

Health is often discussed as inseparable from ikigai and frequently cited as an indicator that correlates with a high sense of ikigai for older adults [2] or as a precondition or a means to support older adults' pursuit of activities [27]. The Japanese government discusses the promotion of ikigai and health together, encouraging and supporting national-level and municipal-level projects to improve older adults' health and ikigai—for example, senior citizen's club, national senior sports festival event called "Nen-rin pics," and exercise programs conducted at local ikigai centers [50]. One of the aims of such promotion of health and ikigai for older adults through national policy is to improve the health expectancy of older adults, which leads to the prevention of care needs and therefore the reduction of costs for older adults' care at the national level, which is a pressing societal issue for the aging society [50]. On the basis of a survey-based study to investigate regional differences in ikigai, Hasegawa et al [51] suggest a strong positive correlation between older adults' sense of ikigai and their self-rated level of health, for older adults in both rural and suburban areas. Shirai et al [35] also found that subjective assessments of health (but not number of hospitalizations) contributed to having ikigai; however, it did not influence how much ikigai one had. Similarly, studies such as those by Okamoto [52] and Harada et al [53] report a strong correlation between sports and exercise and a high sense of ikigai in older adults.

In contrast, for those with declining health, maintaining or increasing social ties, both strong and weak, is associated with a protective effect against the decline in ikigai that often occurs in old age [19]. Other research indicates that physical decline does not directly lead to loss of ikigai but rather that overlaps in "frail" categories do—that is, having issues with ≥2 of the following health indicators: physical health, cognitive health, or social health [54]. In addition, causative modeling has found involvement in social activities to be predictive of ikigai, whereas physical functioning was not [55]. Studies have also suggested that the benefits of health to ikigai are, at least partially, a consequence of participation in the leisure activities they allow [56].

Social Robots for Older Adults' Well-Being

As aging has become a prominent challenge in many parts of the world, robot designers and researchers have explored the potential of social robots to support older adults' well-being and quality of life [57,58]. For instance, it is possible for social robots to enhance older adults' well-being by enabling fun, engagement, and calming interactions [59]. Social robots might also enhance social bonds and self-reflection [20]. Furthermore, robots can increase older individuals' perceived emotional support and social connection for a better quality of life [12]. These robots might resemble a pet, such as AIBO or Paro [12], or be more humanlike, such as the telenoid [59]. For example, Paro, a baby seal–like robot, was shown to stimulate engagement by older adults when applied in a multisensory behavior therapy session in a nursing home [60]; when used in a public space in the nursing home for voluntary interactions, it acted as a social mediator between the participants and other people [61].

Among the many countries that have robots, Japan is prominent in the variety and public pervasiveness of social robot designs and applications for everyday consumer use [62]. Many such robots are developed to support the health and well-being of older adults, including the previously mentioned Paro [12]. Another example of a social robot for well-being developed and studied in Japan is Kabochan Nodding Communication ROBO [63], a humanoid robot developed as an intervention for older Japanese women living alone; it was found to improve cognitive abilities that could be helpful for other aspects of well-being.

As the concept of ikigai has broad personal and societal significance in Japan and people in Japan are likely to be aware of the potential social and health applications of robots, we were particularly interested in exploring perceptions about the potential use of robots to support ikigai among Japanese older adults.

However, despite the high interest in robotic technology, social barriers to designing and implementing social robots for older adults cannot be ignored. Older adults tend to distance themselves from being the prospective robot user because they believe users are lonely, needing care and companionship [64]. In a study conducted with older adults in the United States, older adult participants framed robots designed specifically for older adults as not being for them, despite an otherwise positive view about such robots in general [65]. Older adults more generally tend to avoid situating themselves in relation to aging-related technologies, owing to the associated negative aging stigma [66]. For example, older adults will avoid using personal call alarms to prevent serious injury unless they live alone or are very old [67]. Therefore, there may be resistance among some older adults to using robots, even if they see their benefits.

Methods

Overview

Our mixed methods design included 20 interviews with older adults, a survey of 50 older adults (about ikigai and related measures and perceptions of the QT robot [68]), and 10 interviews with family caregivers. Both interviews and surveys were conducted over the internet, with interviews conducted using videoconferencing software. Survey and interview participants were recruited in collaboration with a market research company in Japan. They were residents of the greater Tokyo area.

Ethics Approval

The study (IRB# 11960 and 11026) was approved by Indiana University's research ethics board.

Participants and Study Setting

Recruitment

Recruiting guidelines specified that older adult participants should be aged at least 65 years, reside in single-family homes, and be residents of the greater Tokyo area of Japan. Demographic details about the participants in the various components of the study are given in Table 1.

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Table 1. Participants' demographics.

Characteristics	Interview with older adults (n=20)	Surveys with older adults (n=50)	Interview with family caregivers (n=10)
Gender, n (%)			
Men	10 (50)	26 (52)	5 (50)
Women	10 (50)	24 (48)	5 (50)
Age (years), mean (SD)	71.0 (3.1)	71.9 (4.8)	57.6 (7.5)

Interviews With Older Adults

For web-based interviews with older adults (Multimedia Appendix 1), we recruited 20 participants. Participants were chosen such that they had various degrees of ikigai, based on a screening questionnaire assessing their ikigai. Specifically, according to the K-1 scale [69], of the 20 individuals, 4 (20%) had low or very low ikigai, 6 (30%) had neither high nor low ikigai, and 10 (50%) had high or very high ikigai. In addition, participants were recruited such that half (10/20, 50%) needed support by a family caregiver, whereas the other half (10/20, 50%) performed daily activities independently. Interviews lasted approximately 1 hour. Participant ages ranged from 66 to 78 years, with mean of 71 (SD 3.1; median 72) years. There was an equal (men and women) gender split. Of the 20 participants, 16 (80%) participants lived with family members and 4 (20%) lived alone.

Surveys With Older Adults

In total, 50 survey responses were collected. Only 50 were collected because our study was somewhat exploratory in nature. There was no overlap between survey and interview respondents. Nearly all participants (42/50, 84%) reported some use of data communication technologies (eg, mobile phones and internet), and half (25/50, 50%) had seen at least one robot before (eg, robot toy, robot vacuum, and factory robot). However, only 14% (7/50) had reported previous use of one. Average age of participants was 71.9 (SD 4.75; range 65-80) years. Of the 50 participants, 26 (52%) were men and 24 (48%) were women. Of the 50 participants, 41 (82%) lived with family members and 9 (18%) lived alone.

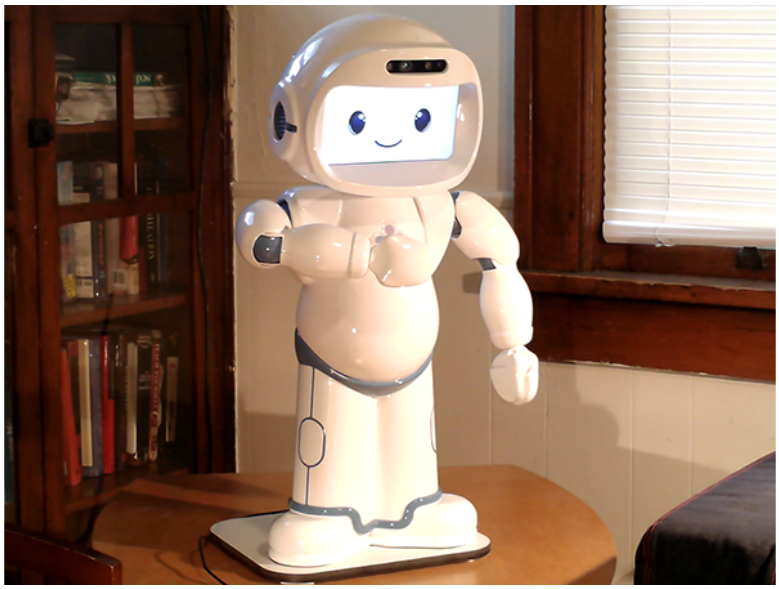
Interviews With Family Caregivers

In addition to surveys and interviews with older adults, 10 interviews were conducted with family members who identified themselves as providing informal support to older adults. Of the 10 participants, 8 (80%) were children of older adults, 1 (10%) was a spouse, and 1 (10%) was an in-law. There was an equal (men and women) gender split. The older adults they provided care for were aged between 75 and 93 years.

Video of the QT Robot

Older adult participants (in both surveys and interviews) and family caregivers were introduced to the QT robot (Figure 1) via a video. LuxAI's QT is a programmable humanoid robot. QT was chosen because it is a commercial robot with a rich software development kit, making it more robust for in-home use and widely adaptable by researchers.

Figure 1. QT robot.



The capabilities and activities presented in the video of QT were based on literature related to ikigai and well-being. The video showed social engagement prompting (eg, QT: "Maybe you should call Mary later to share what happened?"), storytelling prompting, emotion mirroring (eg, QT: "I'm feeling low today. Exercise always cheers me up. How about doing some exercises together?"), exercise, skill and cognitive development, game play, personalization through user programming, and reflection prompting (eg, QT: "You've done well today. Before you go to bed, reflect on one thing you were proud of today and one thing you could do tomorrow to help increase your sense of meaning."). These interactions exemplified how QT might help

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improve older adults' source and sense of ikigai through activities and self-awareness. We also showed the robot being proactive (initiating conversations and offering activity suggestions). The video mentioned the ability of QT to make suggestions for increasing meaning-making activities or social interaction at personal, interpersonal, and community levels. The video was recorded in a naturalistic, home-like environment to show QT in its potential context of use. Only the robot was shown. The narrator both described the robot and acted as its interlocutor. The video was 4 minutes and 30 seconds long.

Data Collection

We deployed a concurrent triangulation design [70], collecting interviews and surveys within the same study stage. This included interviews with older adults, surveys with older adults, and interviews with family caregivers.

Interviews With Older Adults

Web-based semi-structured interviews were conducted with participants to identify their sources of ikigai, happiness, and social support. The open-ended questions were based on those suggested by Mitsuhashi [71]. We also asked participants to describe what occupies their mind and allocate percentages to these items. Following the well-being–related questions, participants were briefly introduced to 3 robots: Lovot, Qoobo, and QT, via pictures. The 3 robots were shown to collect information about design elements that the older adults thought to be useful, so that we could use this information to determine how to update QT in the future. Moreover, showing diverse robots to older adults is likely to prompt more design ideas [72]. Then, they saw the QT video, described previously, which showcased ikigai and well-being–related behaviors. Finally, they answered questions regarding their perceptions of QT and its potential use in their home. All interviews were audio and video recorded.

Surveys With Older Adults

The web-based survey collected rating scale data and written responses to open-ended questions. A component of this survey was meant to measure the aspects of well-being (subjective happiness, meaning, ikigai, and social support), whereas the other other component determined perceptions toward QT, based on the video described previously.

The first half of the survey included validated scales measuring ikigai and related concepts. The included *K-1 scale* [42] is widely used with older adults in Japan, whereas the *ikigai-9 scale* [28] is frequently used in surveys conducted by the municipal and regional governments in Japan. We included 6 *PROMIS scales* selected from the National Institute of Health's *Patient-Reported Outcomes Measurement Information System (PROMIS)* to measure meaning and purpose, positive affect, satisfaction with participation in social roles, satisfaction with participation in discretionary social activities (DSA), companionship, and emotional support [73-77]. The PROMIS Meaning and Purpose scale contains questions measuring meaning along 2 of its dimensions: purpose and significance. The PROMIS Satisfaction with Social Roles 4a measures satisfaction with family and work responsibilities (eg, "I am satisfied with my ability to work [include work at home]" and "I am satisfied with my ability to do regular personal and household responsibilities"). The PROMIS Satisfaction with Discretionary Social Activities 7a is a 7-question scale measuring satisfaction with leisure activities and friendships (eg, "I am satisfied with the amount of time I spend doing leisure activities," "I am satisfied with my ability to do things for fun outside my home," and "I am satisfied with my current level of social activity."). We used these scales to empirically explore the relationship between the PROMIS measures developed in the United States and the ikigai measures developed in Japan.

In the second half of the survey, participants watched the video demonstrating QT's general well-being–related and ikigai-related features and interaction capabilities before answering the QT perception questions. These included the *Almere scale* [78], developed to measure older adults' acceptance of social robots. We included a *technology familiarity scale* [79] and questions about social interaction frequency, demographics, and health. In addition, we included questions about feelings toward home use of the robot and comfort with discussing experiences, memories, strengths, and goals with it. Finally, there were questions regarding the robot's perceived intrusiveness and feelings about its proactivity and open-ended questions about daily activities that participants might do with the robot.

Interviews With Family Caregivers

Family caregivers were interviewed about what occupies their mind, their feelings and tasks as caregivers, interactions with the older adults they cared for, and perceptions of older adults' health and fulfillment. In addition, they were briefly introduced to 3 robots: Lovot, Qoobo, and QT, via pictures. Then, they were introduced to the QT robot (Figure 1) via a video.

Data Analysis

Interviews With Older Adults

Interviews were translated into English from Japanese and coded using MAXQDA (VERBI Software). The same codebook developed for US interviews was used [20]; however, approximately 20 additional codes were added to capture unique responses from the Japanese data. In total, 3 authors, including the first author who was involved in the development of the original code book, were involved in the manual coding and thematic analysis of interview data, based on the "coding reliability approach" [80,81]. Several rounds of discussions occurred to promote similar understanding and application of the codes. Approximately 15% of the data were coded to measure interrater reliability, with a resulting κ of 0.88.

Surveys With Older Adults

For the surveys, we analyzed all 6 *PROMIS scales* by calculating raw scores and then converting these scores to *T* scores according to their respective conversion charts [76,82-86]. As these were developed in the United States, these standardized scores are based on the general US population. The average has been set to a score of 50, and a 10-point derivation is equivalent to a 1 SD difference. We analyzed the *ikigai-9 scale* by calculating raw scores. For the *K-1 scale*, raw scores were calculated and level of ikigai was determined according to the

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guidelines outlined in a previous study [69]. Scores correspond to ikigai levels as follows: 0 to 12 indicates very low, 13 to 16 indicates low, 17 to 23 indicates neither high nor low, 24 to 27 indicates high, and 28 to 32 indicates very high. Written answers to open-ended survey questions about robot use were coded using inductive coding. Interest in robot adoption was calculated as a composite of how interested they were in the robot and how much they wanted to use the robot, each on a scale of 1 to 5. Perception of the robot was calculated as a composite of five 5-point semantic differential questions, with older adults rating their perception of the robot along the following adjectives: good to bad, favorable to unfavorable, positive to negative, calm to worried, and excited to fearful. Self-rated health was determined by their response to the question, "In general, how would you rate your current health condition on the scale below?" from poor to excellent. Physical limitation was determined by asking participants about their degree of limitation when performing activities of daily life, from bathing to bending to exercising (3-point scale ranging from "Not limited" to "Limited a lot").

Interviews With Family Caregivers

Interviews were translated into English from Japanese and coded in MAXQDA. In total, 2 authors, including the first author with a background in human-robot interaction, were involved in inductive coding and thematic analysis of interview data, based on the "coding reliability approach" [80,81]. Several rounds of discussions occurred to develop the initial code book, which was then revised throughout the coding process. Approximately 20% of the data were coded to measure interrater reliability, with a resulting κ of 0.91.

Data from all sources were categorized into 6 themes, as discussed in the following sections.

Results

Health as Primary Concern and Source of Ikigai

We describe 2 subthemes related to this larger theme: *health as primary concern* and *health as a component of ikigai*. The first subtheme describes how older adults' and family caregivers' primary concern was older adults' health, whereas the second subtheme finds that health does not just support ikigai but is also a source of ikigai in itself.

Health as Primary Concern

Both thoughts about family (eg, children and grandchildren; 10/20, 50%) and self (eg, own health, hobbies, and work; 20/20, 100%) occupied most of the older adults' minds. This reflects that both spheres were important to older adults. However, it was more common for older adults to focus first on the self, which was sometimes described as a reordering of priorities with older age:

> *Of course, up until 55, the most important thing in my life was my family but now, to be honest, it's me.* [Participant 1]

In fact, *health concerns dominated* older adults*' minds*, both in terms of breadth (number of older adults reporting) and depth (most persistent thoughts older adults had). Overall, 60% (12/20) of the older adults reported health as occupying their thoughts, and 67% (8/12) of these individuals identified it as the most recurrent thoughts they had:

> *As I said, 55% of my thinking is regarding my health; I just want to be well. I think I'm going to become much more concerned about my health and more likely worry about dementia as well as my physical well-being.* [Participant 1]

> *Recently, my brain is shrinking, I think, and I am not thinking so much, but health—health is always on my mind. That is about it actually, my own health, and my life after retirement.* [Participant 13]

Health-related concerns spanned both the physical and mental aspects, with concerns about longevity (7/20, 35%) and dementia (6/20, 30%) being common. In addition, more than half (11/20, 55%) of all participants described some physical limitation. Thus, older adults talked about many negative aspects of the aging process, as these issues were beginning to affect functioning in their daily lives (5/20, 25%). Other older adults described feelings of being a burden to others around them owing to their physical decline (5/20, 25%), even if it had not reached the point of eroding their ability to perform activities of daily life:

> *Well, I can't really do anything for anybody right now physically; instead, people are doing all these things for me.* [Participant 8]

They pointed out that this dynamic made them experience negative emotions, such as guilt.

Similarly, family caregivers also described ways in which physical limitations caused by health problem, especially mobility issues, were a persistent source of stress for older adults (3/10, 30%). However, unlike older adults, they did not discuss their perception of concerns related to mental decline. Instead, they discussed loneliness as a stressor for them, which arose from other life changes, such as less frequent interaction owing to physical issues, the COVID-19 pandemic, or changing social roles (4/10, 40%):

> *I think going out to the day service is her ikigai because I feel that on Sundays when she does not go, she would ask me, "hey, isn't there anything going on today" And I would say "no, there isn't."...Before she would go out with her friends and have lunch, when she was able to ride buses, she would go out to have lunch and go shopping with her friends. I think she really loved that.* [Participant 23]

Health as a Component of Ikigai

Older adults mentioned 4 primary sources of ikigai—health (11/20, 55%), relationships with family (10/20, 50%), happiness (9/20, 45%), and helping others (6/20, 30%). To a lesser extent, goal pursuit and a sense of accomplishment (4/20, 20%) was also discussed. Health was described as a source of ikigai related to having health or being healthy:

> *Ikigai, well, being able to live without any problems and in a healthy way every single day. It's nothing*

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> *that proactive in a way, you know, and to do that in peace.* [Participant 4]

Referring to a time she felt a lack of ikigai, a participant stated the following:

> *I felt rather meaningless. I think that was maybe when I was ill, because up till then, I was very healthy and well.* [Participant 15]

Therefore, health was often described as a passive source of ikigai, something one had or possessed but could also lose. In this way, it was separate from the actions that might normally be associated with its attainment (eg, exercise). As many participants had experienced or were currently experiencing major health issues, which were strongly associated to the aging process itself and not necessarily the result of an unhealthy lifestyle, health may have been seen as something that they received rather than something they had complete influence over:

> *I suffered a major disease, so living every day feeling fulfilled would be my purpose [of] living. Living life without injuries and not suffering any illness [is what makes me fulfilled]. Being able to look back on your day and say it was a good day.* [Participant 27]

Their mindset was one where simply being healthy had become a source of ikigai, without any specific experience needed to obtain it. They also viewed their health as giving them the capacity to do basic activities of daily life (eg, clean and cook) and a certain sense of freedom. Therefore, the absence of issues or just "having wellbeing and health without troubling anyone" (Participant 10) is likely to have also led to an enhanced sense of autonomy.

Although *health was a major source of ikigai* among participants, it was never their only source. It always occurred with sources from more active pursuits—joyful experiences such as being creative, traveling, and participating in pleasurable meals—or from emotionally fulfilling social interactions—such as through relationships with loved ones and helping others. In fact, sometimes the 2 aspects were explicitly linked, and health was valued because it allowed for the derivation of ikigai from other sources:

> *Being healthy and being able to take care of myself and being actually in a position where you can care for others, that would be good.* [Participant 11]

As directly stated by one participant:

> *If you don't have health, you can't have happiness.* [Participant 5]

In contrast, *health was not a precondition for ikigai*, as those who did not have it were still able to obtain it from other sources. On the basis of survey data, there was a significant and moderate association between self-reported health and ikigai-9 scores (r=0.347; P=.01), suggesting that views about one's health likely contribute to ikigai, but other factors may be just as, if not more, important. In addition, there was *no statistically significant association between actual limitation* owing to health and ikigai-9 scores (r=0.227; P=.11). This pattern was also apparent given the positive association between self-assessed health rating and several other scales, including K-1 (r=0.298; P=.04), PROMIS Positive Affect (r=0.307; P=.03), PROMIS Satisfaction with Social Roles (r=0.435; P=.002) and PROMIS Satisfaction with Discretionary Social Activities (r=0.392; P=.005). However, as with the ikigai-9, reported limitation owing to health was not significantly correlated with any of these measures. Although the lack of statistical significance should be interpreted with caution owing to the small sample size, the effect size was also small, suggesting that one's self-assessment of their overall health is more important to ikigai than the objective challenges that declining health may cause.

Ikigai Sources Relate to EWB and HWB

As mentioned, participants discussed relationships and helping others as 2 primary sources of ikigai, corresponding with its second and third levels. They also discussed aims and accomplishments (4/20, 20%):

> *When [my children] have more kids in the future, I can help take care of them.* [Participant 11]
>
> *I have to keep up the effort to determine my ikigai and take action right away in that direction.* [Participant 6]

Describing how she felt after harvesting what was in her garden and how it connects with her ikigai, a participant revealed the following:

> *I feel a very strong sense of achievement and accomplishment then.* [Participant 9]

Rarely, personal growth was also discussed (2/20, 10%):

> *To be creative, creating things, making things using my past experiences.* [Participant 7]

These, along with health, all correspond with the first level of ikigai, which is the personal level (ie, anything involving the self).

Taken together, *these are consistent with both meaning as purpose and significance*. Specifically, participants discussed their ikigai as related to the EWB concepts of *vitality* (eg, feeling physically and mentally energized) [87], *positive relations with others* [88], *contribution* [89,90], *accomplishment* [36], *purpose* [88], and *personal growth* [88]. Vitality, relations with others, and contribution were the most frequently discussed aspects. These are mostly consistent with sources of meaning along the *meaning as significance* dimension. That is to say that significance (ie, having a life worth living) likely captures the essence of ikigai for older adults considerably more than purpose.

In addition, participants described their ikigai as "living life, enjoying every single day" (Participant 11), "being more positive-minded" (Participant 10), "being able to look back on my day and say it was a good day" (Participant 27), and "being able to live without any problems" (Participant 4). These were discussed as a cognitive appraisal of one's life as satisfying and positive emotions derived from momentary experiences or a positive mindset. Therefore, these reflect moments of joy that are consistent with HWB:

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> *Well, my ikigai is just to enjoy myself. I like to do all sorts of things.* [Participant 11]

Many participants (9/20, 45%) discussed momentary states such as these as contributing to or forming their ikigai. Their descriptions are reflective of all the aspects of HWB, that is, increased *positive affect* and *life satisfaction* and *decreased negative affect*.

Overall, of the 20 participants, 4 (20%) participants discussed ikigai in terms of HWB only and 5 (25%) participants described it as a mix of HWB and EWB. Most (11/20, 55%) described it in terms of EWB only. This suggests that although older adults may have ikigai sources comprising both components of well-being and differing components depending on the individual, *ikigai (and its sources) is likely more strongly linked to EWB*. It may also suggest a temporal component, in which sources of ikigai become more strongly associated with HWB as one ages:

> *I think I'm fine as long as each day is fulfilling and I'm sure I won't be able to do anything major. When you get older, your world becomes smaller, and you can't help that.* [Participant 27]

Survey data are supportive of ikigai being more closely connected to EWB than HWB, based on the 2 scales designed to measure it. Both the ikigai-9 and K-1, common scales for measuring ikigai in Japan, were more highly correlated with the PROMIS Meaning and Purpose scale (which measures meaning as a single facet; r=0.70; P<.001 and r=0.77; P<.001, respectively) than the PROMIS Positive Affect scale (which measures positive affect; r=0.64; P<.001 and r=0.69; P<.001, respectively). It is worth noting that the PROMIS Meaning and Purpose and PROMIS Positive Affect scales correlated at r=0.67 (P<.001) and that meaning and happiness have been shown through previous studies to exhibit a high degree of correlation [91]. Relative to each other, it appears that the K-1 better reflects meaning as the underlying conceptual understanding of ikigai than the ikigai-9, which makes sense given that its 4 composite factors are eudaimonic in nature.

Older Adults' Well-Being Is More Strongly Related to Discretionary Activities Than to Social Roles

The PROMIS Satisfaction with Discretionary Social Activities measures satisfaction with leisure and relationships with friends. This scale exhibited a moderate to large correlation with most other well-being measures of interest. This included the 2 ikigai scales, ikigai-9 (r=0.435; P=.002) and K-1 (r=0.591; P<.001); the PROMIS Meaning and Purpose scale (r=0.465; P<.001); and the PROMIS Positive Affect scale (r=0.589; P<.001). Traveling (17/20, 85%), walking (13/20, 65%), volunteering (7/20, 35%), and reading (7/20, 35%) are some of the leisure activities mentioned by participants, with traveling (and creative activities) also being mentioned as sources of ikigai. The PROMIS Satisfaction with Discretionary Social Activities scale also measures satisfaction with friendships. Although only 5% (1/20) of the participants in the interviews mentioned friends directly as a source of ikigai, nearly all participants (18/20, 90%) mentioned them as a source of social connection.

The PROMIS Satisfaction with Social Roles, in turn, measures satisfaction with work and family responsibilities. The association between social roles and ikigai was comparatively much weaker. This includes its correlation with the ikigai-9 (r=0.290; P=.04) and K-1 (r=0.412; P=.003). In addition, its correlation with the PROMIS Meaning and Purpose scale was not significant (r=0.278; P=.05), and it was only weakly correlated with the PROMIS Positive Affect scale (r=0.296; P=.04). None of the interview participants mentioned work as a source of ikigai, with few mentioning it as a current activity, as most older adults (15/20, 75%) were retired. Although half (10/20, 50%) of our participants mentioned family directly as a source of their ikigai, it is reasonable to assume that these relationships had changed over time, with their role shifting within the home and the family structure:

> *When I'm in my house with my family, although we don't really meddle in one another's affairs; it's kind of like the ikigai that I have.* [Participant 1]

That their previous social roles (eg, as worker or child rearer) started to fill less of their time may have influenced the shift in fulfillment from family to self:

> *The ikigai is my grandchildren and also thinking about what I can do, yeah, on my own in the future.* [Participant 12]

High Expectations About Robot Features

Older adults expected the robot to be able to *support their cognitive* (11/20, 55%) *and physical* (8/20, 40%) *health*, consistent with their main concern, as outlined in theme 1. Regarding cognitive health, this could either be via brain training (eg, with quizzes) or by offering in-the-moment reminders. Participants saw the benefits these would provide in stalling issues with forgetfulness or dementia, either those they were currently experiencing or future, anticipated issues:

> *Well, then it might prevent aging. Because yes, as I am aging, I just end up watching TV a lot when there is nothing more to do. So, I think, in terms of my brain work, it is much slower compared to before and I am much more forgetful.* [Participant 14]

Regarding physical health, they described a desire for a robot to be able to help by providing hands-on assistance, by being able to determine health status, or by encouraging exercise. Although the first was seen as something illogical for QT's embodiment, participants envisioned QT as being able to help in the other 2 areas:

> *Well, it would detect a lot of different things about you. If it finds you sitting too long, it will prompt you to move. So, for me, I think that would be really helpful.* [Participant 11]

> *If it can automatically do those kinds of things, such as to measure your temperature, just like that, if you can just show it your wrist, and it can detect your pulse and blood pressure, and if it's too high or something, it could give you tips to go to the doctor that day or something. So, I wish they could notice those little things for me.* [Participant 10]

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In addition to their main concerns, older adults also wanted the robot to *support their emotional well-being* (7/20, 35%). This was expressed as the robot being empathetic when they were experiencing negative emotions:

> *And also, it will console you when you're feeling lonely and sad.* [Participant 3]

This was either seen as initiated by them—by telling the robot that they were feeling down—or detectable by the robot—through the reading of facial expressions. This was also described as a feeling of "warmth" or "heart" the robot would impart. In the latter case, this would not occur just when they were feeling down but rather be integrated into the design itself.

The older adult participants described *rich conversational ability* as a fundamental feature the robot should have (18/20, 90%). They wanted the ability to have dynamic conversations with the robot, feeling as if they had a real conversational partner in the room:

> *There is Aibo type small size pet-like robot. I have not bought one yet because I think the current level of conversation is very boring.* [Participant 15]

> *It'll ask you about how you're doing, and it's not just you asking it questions, it asks you questions. So that would make me happy, I think.* [Participant 2]

They also wanted it to be a confidant that they could confide their concerns or express their complaints to:

> *I would have him in the living room and I just say everything that have in my mind that I cannot tell others.* [Participant 14]

> *Well, it could be someone I could, yeah, nag to, yeah.* [Participant 12]

These conversations were also best if they were adaptable, occurring in response to information the robot learned about them. This necessitated that the robot be able to remember past conversations that occurred between the two of them. Similarly, caregivers also believed that QT's conversational ability was the most critical feature (9/10, 90%), as it would provide an intuitive form of interaction for supporting the use of other features and would support older adults emotional well-being:

> *Talking I think, having a conversation with it because she is alone during the daytime.* [Participant 18]

They wanted the robot to be able to learn about their older family members' preferences, likes, and dislikes, to make appropriate recommendations (7/10, 70%). This also required the ability to remember previous discussions the two had. To support older adults' ikigai, many (6/10, 60%) wanted QT to be able to connect older adults to other people. This could be family members or friends, but they also saw the appeal in connecting them to their broad community:

> *For example, if it could read in information of events, you know, in the community and if it could suggest to her "oh, there is an event happening in your neighborhood on this day, how about going?" If it could make suggestions like that, that would be good.* [Participant 22]

> *And so, if you set the local area and the area information is all incorporated, and if there is like a chorus group, maybe it can give suggestions like "why not go to this new chorus group." As I said, my mother was feeling down and lonely. And that is because she is not talking to other people. That is my personal understanding.* [Participant 20]

These are opportunities that older adults may not always proactively seek out on their own:

> *Well, my mother is always the type to wait until she is invited. She never initiates.* [Participant 23]

Therefore, the robot can serve as an intermediary to connect friends, family, or the broader community together, as there may sometimes be hesitancy among older adults to do it themselves.

To support first-person ikigai, family caregivers also described ways in which QT could talk to older adults about their hobbies, such as calligraphy, cooking, or music, or give them suggestions for when and how to engage (4/10, 40%). Similarly, they believed that QT could support older adults' physical health, by showing moves that older adults could mimic (4/10, 40%). Caregivers believed that older adults would likely imitate the robot's movements, and it would also be a source of enjoyment. Moreover, as older adults also expressed, they also wanted QT to offer various types of reminders (eg, medication and appointment).

In addition, older adults wanted QT to be *more humanlike*. This mainly related to notes that its voice was very robotic (5/20, 25%):

> *I wished that it talked a little more like humans.* [Participant 11]

> *It sounded very robotic.* [Participant 27]

Participants wanted the voice to sound more natural, which seemed to be inclusive of not only the sound of the voice used but also its vocal inflections, variations, and pauses. Similar to older adults, caregivers felt that QT was too robot like (4/10, 40%), instead liking the pet-like nature of Qoobo (4/10, 40%). Improvements to its speech were also desired. In addition, some expressed doubts similar to older adults regarding whether older adults would like it (3/10, 30%) or consider it useful (3/10, 30%). On the other hand, some older adults wanted QT to be less humanlike and *more pet like* in both appearance and interaction. In part, they felt that this was necessary, so that the interaction could also be a physical one:

> *Right, like if it is a pet, then you can feel closer to it...I should not say it feels cold, but there is no point of physical contact.* [Participant 11]

> *So, if it is a cat or dog, it approaches you, comes near you? And I can touch them and, well, robot can do that too, but with the robot image, I just do not feel that comfortable.* [Participant 13]

In fact, what participants liked the most about Qoobo (a robot presented via pictures) was that it was pet like. Participants' desire for QT to be more pet like was also a response to concerns about lack of warmth and the belief that having an interaction

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closer to that with a human or pet would help them form a closer connection to it.

In addition, older adults believed that the robot should also be equipped with *many functional features* (18/20, 90%), such as offering meeting and appointment reminders, serving as a memory aid, providing information at their request, being able to clean, and offering home security. Typically, only after older adults outlined the many ways in which QT could be upgraded did they see it as something relevant and highly desirable to have in their homes. Survey data additionally supported that QT is not for everyone, with equal numbers reporting that they would either like QT developed for conversational use (15/50, 30%) or would not use it at all (15/50, 30%).

Caregivers also believed that QT could support *their* ability to ensure that the older adult was well and therefore suggested a safety feature (5/10, 50%). Using the frequency of conversation and skeletal tracking was believed to be a good way to remain cognizant of potential issues, and receiving an alert when something might be wrong was described as providing them with more peace of mind. In addition to improving QT's speech, caregivers were also concerned with QT's ability to detect older adults' speech, which had deteriorated in recent years (4/10, 40%). Some caregivers also specifically noted that they felt their parents would not like using QT in practice (3/10, 30%) and might get bored of using QT over time (3/10, 30%).

QT Is Perceived as for Those Who Live Alone

Several older adults expressed that although QT could be valuable to others, they did not see themselves as in need of it currently. In fact, QT was perceived by many (11/20, 55%) as a robot for those who live alone. A participant explained the following:

> *If this is available for a low price, and it comes into different people's homes, especially for people who live alone, it might be good because they'll have something to talk to ... Well, currently I don't need it. I have my wife.* [Participant 5]

In contrast, another participant expressed her preference of human companionship over robot companionship:

> *I am amazed by the technology, but I guess I would rather speak to a human. It is better to be talking to real people.* [Participant 30]

Moreover, some (6/20, 30%) viewed QT as being suitable for people older than themselves or for use when they themselves were older. As 1 participant stated:

> *Right now, I'm very active, and having this around would be a little bit annoying, but maybe, I don't know, 20 years from now, I would have a totally different way of thinking.* [Participant 1]

Meanwhile, several older adults (3/4, 75%) expressed eagerness to adopt QT because they lived alone. A participant explained:

> *It'll be great if I could because I spend a lot of hours alone. So, if there's somebody there that I can talk to, that'll be great, I think.* [Participant 8]

QT Is Better Accepted by Those With High Meaning and DSA

Survey participants' ikigai-9 scores averaged 28.38 (SD 6.08; range 13-44). Although the ikigai-9 scale does not specify the determination of ikigai levels based on score, previous literature found the average ikigai-9 scores for a sample of Japanese older adults to be 29.7 (SD 6.3) [55], whereas another found it to be 33.9 for a "high life purpose" group of community-dwelling older adults in Japan [92]. Scores here, therefore, are likely consistent with those of "average" Japanese older adults and represent participants having a wide range of ikigai. K-1 scores support that these older adults had varying amounts of ikigai, with scores that were, on average, neither high nor low. As classified according to guidelines, of the 50 respondents, 20 (40%) had high or very high ikigai, 15 (30%) had low or very low ikigai, and 15 (30%) had ikigai that was "neither high nor low." On the PROMIS Meaning and Purpose scale, 58% (29/50) of the participants had meaning scores falling within 1 SD of the average of the general US population (scores between 40 and 60), 40% (20/50) had scores below average, and only 2% (1/50) scored 1 SD above average. With an average score of 42.32 (SD 8.36) on this scale, we see that meaning and purpose scores were lower than the average of the general US population (the PROMIS scores are created based on US population data). Average scores on the PROMIS Positive Affect scale were similar (42.32; SD 8.36) with slightly higher levels of reported companionship (45.134; SD 10.46) as based on the PROMIS Companionship scale.

We then explored whether those with lower levels of ikigai, meaning, affect, satisfaction with participation in social roles, satisfaction with participation in DSA, or companionship may be more willing to adopt QT. It was thought that those who would benefit most from using QT might be more interested in its adoption. However, for meaning and satisfaction with DSA (leisure and friendships), we found the opposite trend—*with those with the greatest meaning and satisfaction reporting higher willingness to adopt*. Specifically, the correlation between the *PROMIS Meaning and Purpose* scale and interest in adoption was as follows: r=0.387; P=.005 and that between the *PROMIS Satisfaction with Discretionary Social Activities* scale and interest in adoption was as follows: r=0.391; P=.005. All other correlations (between interest in adoption and the abovementioned well-being constructs) were small and nonsignificant. Although positive perceptions of QT were also correlated with the *PROMIS Satisfaction with Discretionary Social Activities* scale (r=0.375; P=.007), it was not correlated with meaning.

In addition, interest in adoption and a positive perception of QT positively correlated with greater degrees of previous exposure to robots (r=0.315; P=.03 and r=0.387; P=.006, respectively) but not to technology use more generally.

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Discussion

Comparison With US Findings

Comparison of Well-Being Scales

Randall et al [20] explored ikigai and well-being with older adults in the United States. Compared with the data presented in this paper, US participants scored markedly higher on all well-being metrics. However, this likely reflects a difference in survey response styles, rather than any difference in the level of well-being between the 2 groups. Japanese participants have a propensity to display a midpoint response style (selecting items in the middle of the scale) [93,94] or "nay-saying" (responding more negatively) [95]; meanwhile, American participants are more likely to exhibit acquiescence response style (providing positive answers regardless of content) [94] and social desirability bias (responding how they believe others want them to respond) [96]. Therefore, the scores presented are not directly comparable. To directly compare survey results in the future, it would be advisable to use scales with Japanese participants that do not have a midpoint or strongly worded end points [93] or standardize scores [97], when direct comparison between countries is the desired outcome.

However, considering the correlation between various scales, we find that the K-1 and PROMIS Meaning and Purpose scales and the ikigai-9 and PROMIS Meaning and Purpose scales show similar associations between the United States and Japan. That is, for the K-1 and PROMIS, Pearson correlation coefficient was 0.79 in the United States and 0.77 in Japan. For the ikigai-9 and PROMIS, Pearson correlation coefficient was 0.67 in the United States and 0.70 in Japan. However, for the 2 ikigai measures developed in Japan—ikigai-9 and K-1—the correlation was much higher in Japan compared with the United States (r=0.78 vs r=0.69). It was originally thought that this might have been explained by a stronger association between meaning and affect in Japan compared with the United States in our sample, but the opposite was actually true (r=0.67 in Japan vs r=0.75 in the United States). Therefore, it is not clear why this is the case, even though it may indicate that particular aspects of well-being captured by these scales are more strongly related in Japan than in the United States. Outside Japan, the ikigai-9 has been described as a 1-factor solution only [28,98], indicating some country-level differences. That said, the correlation between the 2 scales indicates that the constructs they measure better aligns in Japan than in the United States. The association between the K-1 and PROMIS Meaning and Purpose scales indicates that they may be capturing similar constructs in both Eastern and Western populations, strongly associated with meaning in life (and EWB).

Expectations of Robots

Participants in the United States [20] had a much more positive view of QT than participants in Japan, based on both interview and survey results. Participants living independently in their homes in the United States described functional uses (eg, informational assistant, exercise coach, and performer of domestic tasks) as key to their imagined use of the robot. Desired use as a conversational partner was secondary. However, this varied according to living condition, with approximately 40% of those who lived with others wanting to use it for conversation and few people who lived alone desiring to use it for this purpose. Although participants in the United States desired its use for various aspects of health, their discussions about how the robot could perform these tasks were not as involved as those of Japanese participants. Although participants in assisted living were most positive about conversations, they also mentioned that there were limits to what they would want the robot to discuss, indicating that it should not give feedback about a healthy diet and lifestyle, as a person was better for such tasks. Overall, participants in the United States seemed more accepting of the robot at its level of presented capability.

However, participants in Japan had much higher expectations of what they expected the robot to be capable of doing. This is likely owing to the overall higher exposure to robots in Japan than in the United States. In Japan, they described numerous ways to improve the robot, wanting it to be almost human in some respects (ease of conversation, voice, and broad range of abilities) and be capable of providing them with various types of support. They also described ways it could detect their environment or their current state (emotions, idleness, etc) to further support them.

Living Situation and Desired Adoption

In the United States, it was found that those who live alone are less likely to adopt the QT robot than those who live with others [20]. The opposite may be true in Japan, with interview results showing that QT is perceived as being for those who live alone. Although more studies should confirm these findings using larger samples, we speculate that there are 2 reasons why this may be the case. First, this may be cultural, and second, this may be related to health.

In the United States, where independence is valued, living alone is a decision made, at least partly, to maintain one's autonomy and privacy [99-101]. Therefore, QT may be viewed as an unwanted social entity invading their personal space, which is consistent with survey data showing that QT was viewed as more intrusive by those who lived alone [20]. In Japan, where interdependence is valued, it may be less common to make a decision to live alone based on values of autonomy and privacy. This may instead be the result of life circumstance (eg, being widowed as some of the participants in our interviews) [102]. Regardless, the percentage of Japanese older adults living alone is skyrocketing, going from 19.7% in 2000 to 26.4% in 2017 [103]. This is only expected to further increase as a result of aging in Japan's society [104]. However, living alone in Japan has been consistently associated with a decrease in well-being, both for younger [105] and older [104,106,107] adults. This is also contrary to the United States, where the effects of living alone on well-being have been mixed (with some studies showing neutral, some showing positive, and some showing negative effects) [108-111].

In addition, in our US sample, older adults were quite healthy. Those who lived alone in this study (interview participants) reported more health problems. Therefore, they may have fewer opportunities to be active outside the home and to obtain the

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companionship desired. This may also have contributed to the potential differential effects of living situation on desired robot adoption.

Ikigai Sources as EWB and HWB

Some scholars have suggested that ikigai is akin to EWB [24,33,112], whereas others have suggested that it has elements of both EWB and HWB [6,34,35]. Although Kono et al [34] suggested that their findings may be owing to the fact that they used a student population, our results reveal that ikigai sources are not viewed as purely eudaimonic, even in older adult populations. However, specifically, we find that *sources* of ikigai can be eudaimonic or hedonic. Whether ikigai is conceptually equivalent to EWB only or both EWB and HWB is another question, one that may be analogous to the assertion that, although a source of meaning can be happiness, happiness is not conceptually a part of meaning [33]. As Yamamoto-Mitani and Wallhagen [113] put it, "ikigai assumes the presence of a value judgment that a certain life experience is meaningful," and this value judgment may be sufficient to differentiate it from mere HWB. Therefore, ikigai does not lie in any experience but in the interpretation of an experience and thus may also be derived from joyful moments, depending on how they are perceived. This may also explain the difference in the findings of Kumano [24], as their methods were apt to explore the conceptual foundation of ikigai, instead of its sources.

Summarizing sources of ikigai, we found that most participants (11/20, 55%) had sources that were consistent with EWB only. Sources comprised various EWB aspects such as vitality, positive relations with others, contribution, accomplishment, purpose, and personal growth. Sources consistent with HWB were also common; however, only 20% (4/20) reported sources consistent with happiness only. Sources of ikigai in the HWB sphere of well-being were positive affect, lack of negative affect, and life satisfaction, with positive affect and life satisfaction being the most discussed. This reflects a diversity of sources, wide in scope, though ones more consistent with EWB. Moreover, survey results revealed that the ikigai-9 and K-1 were somewhat more strongly correlated with meaning than affect (as measured by the corresponding PROMIS scales). Therefore, *ikigai is at least better described by and more heavily related to EWB than HWB*. In this way, our findings support that of Kumano [24]. We further clarify ikigai and its relation to EWB by stating that it is strongly related to the concept of meaning as significance, at least for older adults. This finding is similar to that proposed by Martela and Steger [33], although, we do not state that ikigai is necessarily *only* "having a life worth living."

The K-1 scale measures ikigai as a completely EWB facet of well-being, whereas the ikigai-9 reflects both EWB and HWB aspects. This results from some ambiguity in its definition, along with its individualistic nature. Specifically, the K-1 seems to reflect ikigai as meaning as significance, meaning as purpose, and positive relations with others. The ikigai-9 measures it as personal growth, positive affect and life satisfaction, and satisfaction with social roles. They both offer advantages and disadvantages in measuring ikigai. Although the ikigai-9 spans both broad areas of well-being and may thus better capture population variation and diversity than the K-1, the K-1 scale may be better at capturing the conceptual core of ikigai along with older adults' most common sources of it.

Ikigai as Internal Versus External

On the basis of our study, *ikigai may come from internal (mindset) or external (material) sources* (Figure 2). Regarding internal sources (mindset), ikigai was obtained from having a positive view of one's life that did not arise from a particular experience or person. Instead, this was experienced as gratitude for lack of issues, having their health, or just appreciating their daily life. External sources of ikigai were relationships with family, accomplishments, engaging in creative endeavors, traveling, and enjoying a good meal. These, therefore, were obtained through interaction with the world, rather than arising from a mental process alone.

Ikigai can thus be obtained from appreciating one's life or the *absence* of things in it (eg, problems). Therefore, it is possible to increase people's ikigai without having older adults make changes to the content of their lives (similar to fostering "ikigai-kan") or even without focusing on a specific object of ikigai. This is consistent with findings from other well-being literature showing that gratitude or mediation practices can increase meaning in life.

Consistent with this view, we found that subjective ratings of health status were associated with a number of well-being constructs (ikigai, meaning, positive affect, and satisfaction with roles and activities). However, the extent of reported limitation owing to health was not correlated with any well-being measures. Although these results should be interpreted with caution owing to our limited sample size, they suggest that perceived health status or satisfaction with health may be more important to well-being than any resulting physical limitations. This is consistent with previous literature showing that self-assessments of health, but not hospitalizations, were associated with ikigai. It is also consistent with studies showing that other sources of ikigai (eg, social relationships) can offer a protective effect against declines in ikigai that otherwise occur owing to physical decline [19]. Furthermore, outside the ikigai literature, studies have shown that self-rated health is not determined by health alone but also by economical, psychological, and social factors—with actual health only accounting for 35% to 40% of the variance in self-ratings of health [114]. Depressive symptoms, age, work status, and even life satisfaction have further been associated with self-ratings, with physical functioning only explaining 33.9% of the variation in self-rated health in Japan [115]. Therefore, helping to foster an optimistic mindset or an attitude of gratitude among older adults could potentially also offset the loss of ikigai owing to declining health.

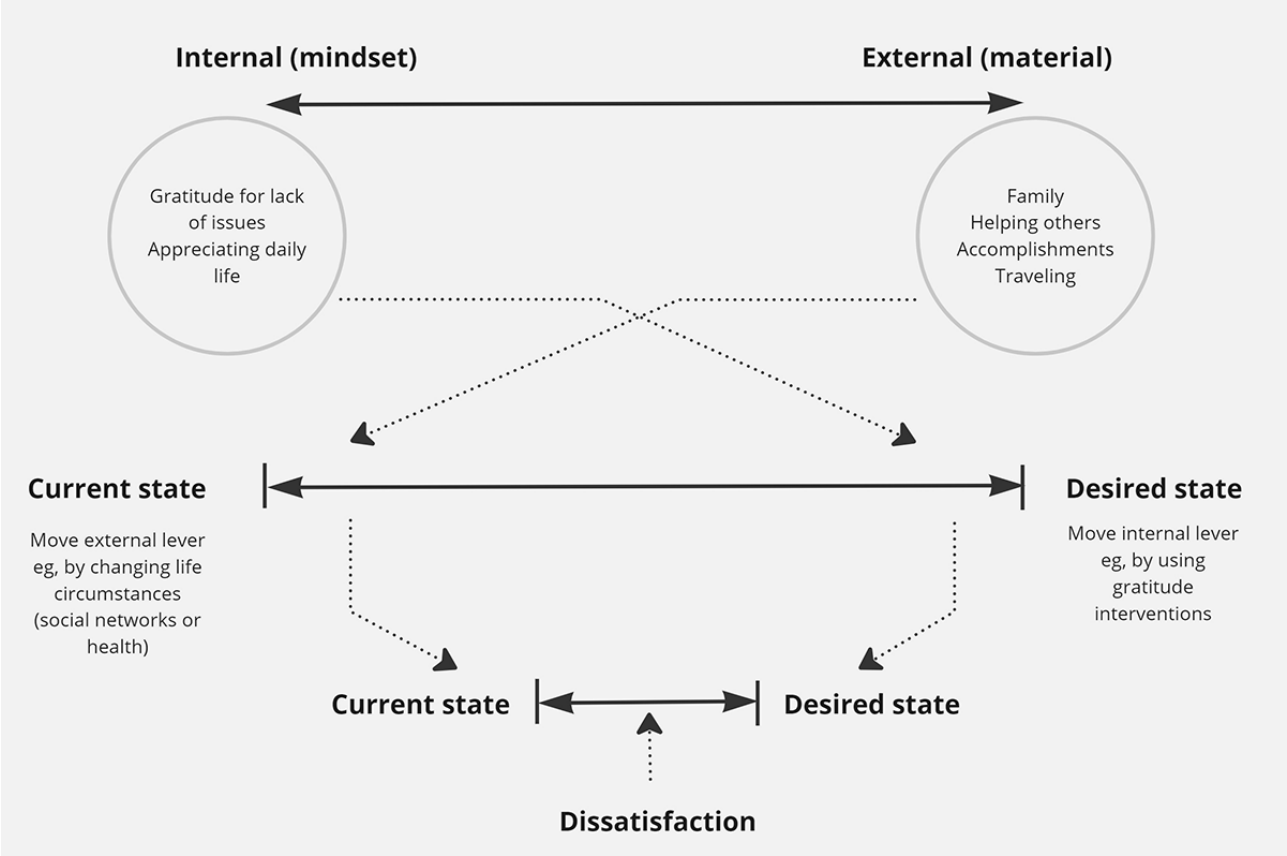
In the well-being literature, gratitude is recognized as an especially powerful intervention. In a review about gratitude by Wood et al [116], the authors determine that "gratitude is strongly related to well-being, however defined, and this link may be unique and causal." It has been positively and strongly correlated to many facets of well-being—including positive affect, happiness, personal growth, purpose in life, life satisfaction, autonomy, environmental mastery, and

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self-acceptance [117-119]. It has also been shown to reduce negative affect, anxiety, and depression [117,118]. Therefore, it positively affects both hedonic and eudaimonic aspects of well-being. Both these types of well-being are captured by ikigai, as discussed previously. Gratitude is often more effective than other interventions for increasing well-being, such as recalling memorable experiences and re-experiencing related emotions [120]. In addition, gratitude has been shown to positively affect many aspects of health and social functioning—strengthening relationships [121-123] and objective indicators of health (eg, better subjective sleep quality, increased motivation to seek care, and less illness [119,124,125]).

As dissatisfaction with one's life is largely a measure of the distance between where one is (actual or real self) and where one wants to be (ideal or ought self) [126-130], external sources of ikigai are likely to bring older adults' current state closer to their desired state, whereas internal sources of ikigai may move their desired state closer to their current state (Figure 2). Especially in old age, when it can be more difficult to change one's actual state (ie, health and work), it may be especially useful to *use interventions that encourage acceptance and gratitude*, alongside other interventions that improve their social network, health, and other external sources of ikigai. It is also a relatively simple way to increase well-being.

Figure 2. Proposed relationship between sources of ikigai and perceived well-being (ikigai).



Ikigai and Leisure

Some commonly cited sources of ikigai are work, family, and leisure activities [17,24,35,131,132]. For men, work has especially been associated with ikigai, whereas family and child-rearing has been found as prominent for women [17,35]. *As opposed to social roles* (work and family), we find that *ikigai is more strongly related to satisfaction with DSA* (leisure, hobbies, and friends) for older adults. This may be a product of changing social roles, as older adults experience retirement and changing family dynamics. As their children grow up, they can become caregivers to their parents, further shifting social roles. Research by Mathews [16] is also evidence that ikigai changes with age; however, this work focused on the shift from ikigai as centered on the future, then present, and then past as one ages.

The relation of ikigai and DSA is also consistent with studies showing that maintenance of and increases in the number of weak and strong social connections is protective against potential declines in ikigai, along with studies causally linking the number of social activities to ikigai (but not physical functioning) [55]. Furthermore, there are several studies exploring the positive effects of leisure on ikigai. This connection has been drawn in both students [131,133,134] and older adults [5]. Studies have also revealed that certain types of leisure promote eudaimonic aspects of well-being, such as meaning in life [34].

Although we are unaware of studies comparing the influence of social roles and discretionary activities on ikigai, our findings are consistent with studies in the SWB literature. A meta-review by Kuykendall et al [135] about leisure concluded that "leisure engagement appears to be at least as strongly related to SWB as occupational status, income, and social activities."

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Furthermore, they found that the association between leisure and SWB was stronger for retired individuals than working individuals [135]. In addition, satisfaction with leisure can, in turn, affect satisfaction with family relationships, physical health, and mental health [136-140]. Thus, if older adults experience declining physical health that may preclude them from the same level of involvement in their previous leisure activities, it is paramount to identify how to support their engagement in alternative activities.

Acceptance of Robots for Well-Being

Personality, Well-Being, and Acceptance of Robots

Personality is a robust correlate of well-being. Various studies have found that, among the Big Five personality traits, extroversion, openness to experience, agreeableness, and conscientiousness positively relate to well-being, whereas neuroticism negatively and significantly correlates [141-146]. In particular, neuroticism, extroversion, and conscientiousness seem to be the most strongly related to SWB (HWB) [141,144,147,148], whereas openness to experience, neuroticism, extroversion, and conscientiousness seem to be robustly associated with meaning (EWB) [149-152]. Other personality traits outside the Big Five, such as optimism [144] and proactiveness [153], also seem to contribute to life satisfaction.

Many of these same personality traits are also linked to robot acceptance. In a meta-review by Esterwood et al [154], they found that 3 of the Big Five personality traits—extroversion, openness to experience, and agreeableness—all correlated positively with intention to use, perceived usefulness, and other acceptance metrics. They also note that there is an absence of adequate research on the effects of conscientiousness to conclude how that affects acceptance [154]. In addition, although not studied, it seems reasonable that other *personality traits found to be influential in well-being* (eg, proactiveness) *may also play a role in desire to adopt a robot* to improve well-being specifically.

These findings may explain why those with the highest levels of meaning and life (leisure) satisfaction were most interested in adopting QT as an "ikigai" robot. In addition, studies show that personality predicts sources of meaning, that is, different personalities derive meaning in different ways [152,155]. This may also have influenced individuals' perception of QT, if the robot was not seen to adequately address their preferred ways of deriving meaning in the world. If those with the most need for a well-being robot are, in fact, the least likely to adopt it, the question then becomes "how can willingness to adopt be increased among these individuals, or are other interventions more appropriate?" Further studies should directly explore these connections.

Robot Exposure, Living Situation, and Acceptance of Robots

Besides meaning, we found that increased robot exposure and living alone may positively influence adoption. We have discussed the negative effects of living alone in Japan on well-being in the Living Situation and Desired Adoption section. Therefore, robots for those living alone may be particularly beneficial, as increased social interaction can counteract some of the negative effects of this living arrangement [107]. This suggests that this population might see a need for an "ikigai" robot while also being a population that would benefit from its use. This may also present fewer technological and interaction challenges, as the robot would only need to be designed to interact with 1 user.

Regarding exposure to robots, this lends itself to the idea that owing to Japan's rapid integration of social robots into various stores and cafes [156,157], acceptance of QT is likely to increase over time. This is consistent with previous studies showing that acceptance and use of socially assistive robots by older adults are strongly related to technophobia, even more than levels of system trust [158]. Exposure may also decrease any stigma associated with using such devices, as social acceptability has been found to decrease the stigma related to assistive technology use among older adults [159]. Direct exposure to the robot through use, rather than through video presentation, may also increase acceptance, as benefits become more apparent. Although Mara et al [160] found that there was no difference in the intention to use a robot based on video and live presentations, participants only watched the robot in the live condition and did not interact with it directly. Therefore, synchronous communication and perceived benefit may increase positive perceptions.

Improving QT for Acceptance

To improve QT as a robot for ikigai and well-being, the following recommendations can be made. First, fluid and fulfilling conversation is perhaps the most important feature the robot should have. This includes a more natural sounding, less robotic voice. Second, some form of physical interaction is a key interaction element that will likely engender a feeling of warmth between the older adult and robot. Therefore, fur or clothing is a possibility to support this, and the addition of tactile sensors is another. These tactile sensors would allow the robot to respond to the older adult when touched. Third, functional features (eg, reminders and information assistance) are somewhat of an expectation for most home robots. Moreover, the robot can provide a more intuitive interface for older adults to use these features than smartphones or other nonconversational and nonrelational technology. Although these features fall somewhat outside the purview of tasks for an "ikigai" robot, they are likely to increase acceptance and desired adoption. This is also consistent with past studies showing that companionship is often not sufficient for the adoption of home robots by older adults, and more functional features are required [132]. Fourth, the robot should ideally support all facets of well-being. We consider 4 facets: social, emotional, cognitive, and physical. These factors are either directly related to ikigai, are protective factors against ikigai loss, or support other sources of ikigai. This is also consistent with feedback obtained from ikigai experts, suggesting that a holistic, multidimensional approach should be taken to support older adults' ikigai, as these factors are often interconnected [21].

Limitations

Our study adds to the research community's understanding of what ikigai is and is the first to explore how to design a robot

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to support ikigai in Japan. However, we note several limitations in our study. First, our study is largely exploratory. Confirmatory, hypothesis-driven research, with larger sample size, is necessary. Moreover, further design research is needed, as updates to QT are integrated into its design, to determine whether these are perceived as expected.

In addition, we used a video to introduce older adults to the robot versus a copresent robot. This video included the robot only, with no interlocutors present. Whether initial self-reported acceptance based on this video translates into positive perception and actual use after in-home deployment is another question, which is not explored here. Chosen stimuli can affect an individual's perceptions of robots [160,161]; thus, QT may be more or less accepted after an actual interaction occurs. In addition, perception after extended use is another question requiring further research, as the novelty effect can result in declining positive perceptions and use intentions.

Finally, all participants in this study were from the Tokyo area of Japan. Therefore, results may be more applicable to residents of urban areas of Japan, as there exist some differences in ikigai sources and correlates between residents of urban and rural areas [51].

Conclusions

Our results suggest that health is a prominent factor in older adults' ikigai. Although self-rated health correlated moderately with ikigai and other well-being measures, reported physical limitation did not. This suggests that perception of health is more important to ikigai than the resulting restriction to activities of daily life that declining health may cause. As opposed to social roles (work and family), we find that ikigai is more strongly related to satisfaction with DSA (leisure and friendships) for older adults. This may be a change that individuals experience as they move into older adulthood, as a result of retirement and having adult children who no longer share the same home.

We report that QT was perceived as a robot for those who live alone; however, further studies are needed to confirm whether those who live alone are more likely to adopt an "ikigai" robot. Moreover, those with the highest levels of meaning and satisfaction with leisure and friendships may be most likely to adopt a robot for well-being, and we suggest personality as the moderator of this relationship. In addition, we outline a number of ways to improve the QT robot to increase its acceptance, such as improving its voice and conversational ability, including many functional features, adding a form of physical interaction or softening the robot's appearance to engender warmth, and designing the robot to support 4 facets of well-being—social, emotional, cognitive, and physical.

Conflicts of Interest

KMT receives a small monetary incentive for publication from Toyota Research Institute.

Multimedia Appendix 1
Interview questions for older adults.
[PDF File (Adobe PDF File), 272 KB - aging_v6i1e45442_app1.pdf]

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Abbreviations

DSA: discretionary social activity
EWB: eudaimonic well-being
HWB: hedonic well-being
PROMIS: Patient-Reported Outcomes Measurement Information System
RQ: research question
SWB: subjective well-being

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Review

Contextual Factors That Impact the Implementation of Patient Portals With a Focus on Older People in Acute Care Hospitals: Scoping Review

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Abstract

Background: Older people are the highest users of health services but are less likely to use a patient portal than younger people.

Objective: This scoping review aimed to identify and synthesize the literature on contextual factors that impact the implementation of patient portals in acute care hospitals and among older people.

Methods: A scoping review was conducted according to the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) guidelines. The following databases were searched from 2010 to June 2020: MEDLINE and Embase via the Ovid platform, CINAHL and PsycINFO via the EBSCO platform, and the Cochrane Library. Eligible reviews were published in English; focused on the implementation of tethered patient portals; included patients, health care professionals, managers, and budget holders; and aimed at identifying the contextual factors (ie, barriers and facilitators) that impact the implementation of patient portals. Review titles and abstracts and full-text publications were screened in duplicate. The study characteristics were charted by one author and checked for accuracy by a second author. The NASSS (Non-adoption, Abandonment, Scale-up, Spread, and Sustainability) framework was used to synthesize the findings.

Results: In total, 10 systematic reviews published between 2015 and 2020 were included in the study. Of these, 3 (30%) reviews addressed patient portals in acute care hospitals, and 2 (20%) reviews addressed the implementation of patient portals among older people in multiple settings (including acute care hospitals). To maximize the inclusion of the literature on patient portal implementation, we also included 5 reviews of systematic reviews that examined patient portals in multiple care settings (including acute care hospitals). Contextual factors influencing patient portal implementation tended to cluster in specific NASSS domains, namely the condition, technology, and value proposition. Certain aspects within these domains received more coverage than others, such as sociocultural factors and comorbidities, the usability and functionality aspects of the technology, and the demand-side value. There are gaps in the literature pertinent to the consideration of the provision of patient portals for older people in acute care hospitals, including the lack of consideration of the diversity of older adults and their needs, the question of interoperability between systems (likely to be important where care involves multiple services), the involvement of lay caregivers, and looking beyond short-term implementation to ways in which portal use can be sustained.

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Conclusions: We identified important contextual factors that impact patient portal implementation and key gaps in the literature. Future research should focus on evaluating strategies that address disparities in use and promote engagement with patient portals among older people in acute care settings.

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KEYWORDS

patient portal; tethered personal health records; acute care hospitals; implementation; scoping review

Introduction

Background

Patient portals (also known as tethered personal health records) consist of an internet-based application that accesses the electronic health record of a health care organization and provides timely access to medical records, laboratory results, appointment bookings, repeat prescriptions, and secure messaging with health care professionals, among other content and functionality [1]. Patient portals aim to engage patients and carers in managing their care, which has been found to improve health outcomes, the quality of care, and patient safety [2]. Patient portals are well established in UK family practice, with electronic health records being commonplace in 96% of general practices for almost 3 decades [3]. In UK acute care hospitals, the use of handwritten inpatient records remains widespread [3], and as such, patient portals are less common. Global Digital Exemplar (GDE) trusts are internationally recognized providers of exceptional and efficient National Health Service (NHS) care via world-class digital technology and information and are committed to sharing best practices and supporting the widespread adoption of patient portals [4]. The future vision of the NHS is to create a single access point to acute care hospitals with integrated systems that share and exchange data securely with other health and care providers [5]. However, the integration of portals with the existing systems is currently a barrier to their adoption, in addition to clinical engagement, information governance, low patient awareness, and resources [6]. Furthermore, among the patients who currently access portals, engagement or meaningful use is often limited.

The greatest benefit to patients and the health service can be achieved by optimizing portal use among older people [7]. Older people (aged ≥65 years) are less likely to use a patient portal than younger people (86% of adopters are aged <65 years) [8], yet they are the highest users of the health service, with more than half (54%) of them experiencing multimorbidity [9]. Older people are more at risk of serious complications and hospital-acquired infections, and they may experience frailty and other mobility problems that hinder their access to health centers. Moreover, older age is the greatest risk factor for mortality from COVID-19 [10]. Barriers are exacerbated when older patients lack access to and experience of using technology, have lower levels of education, and have low health literacy [11-13]. However, older people have been found to express interest in using a patient portal independently or with a carer, irrespective of their health literacy level, previous portal use, or experience seeking health information over the internet [11]. The COVID-19 pandemic has accelerated the rate of adoption of digital technologies in health care settings by necessitating remote visits, communication, and monitoring, which are especially important for people managing long-term health conditions [14]. The need and demand for more flexible access to health services are unlikely to diminish.

There are numerous reviews of patient portal features, functionality, adoption, and implementation, with the vast majority focusing on family practice settings. A review examining portal use in multiple health care settings was published by Antonio et al [14]. This umbrella review explored the current state of evidence for patient portals, with a specific focus on portal technology. It identified several factors that influence portal adoption, including patient circumstances, interest, and satisfaction; portal usability; provider attitudes; and service use [14]. Another review across multiple health care settings reported a range of patient characteristics that impact portal use, such as age, ethnicity, education, health literacy, health status, and carer role [7], and factors that impact patient portal engagement, such as provider endorsement and portal usability. The authors argue that future research should aim to boost portal engagement among specific populations most likely to benefit from its use [7]. This review set out to scope the literature on older people and acute care settings to inform the broader aim of our research program—to develop an evidence-based implementation strategy for portal use and engagement among older people in acute care settings. Despite efforts toward the widespread uptake of and engagement with patient portals across acute NHS trusts, there is limited research into evidence-based strategies for successful engagement [15]. Engagement strategies, such as advertisement campaigns or training for patients, carers, and staff, must be tailored to the targeted population groups and the local context to be effective [16]. Tailoring can improve equity within the patient group. Identifying contextual factors that impact the routine implementation of patient portals in acute care hospitals is the first step toward developing an evidence-based implementation strategy for older people.

Aim

The aim of this scoping review was to identify and synthesize the literature on contextual factors that impact the implementation of patient portals in acute care hospitals and among older people.

Our primary interest was to improve the engagement with patient portals among older people in acute care hospitals. However, we needed a broad scope of the literature to capture learning from studies in multiple settings (family practice and acute care hospitals) and patient groups (general population and older people), given the potential generalizability of the findings across settings.

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Methods

Reporting Guidance and Theoretical Framework

This scoping review followed the methodological framework described by Arksey and O'Malley [17] and the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) reporting guidelines [18]. The framework was selected to achieve our broad aim of summarizing what is known about our primary area of interest, to synthesize findings, and to highlight key gaps in the literature.

Non-adoption, Abandonment, Scale-up, Spread, and Sustainability Framework

To build on the existing literature, we used a theoretical framework to provide a semantic structure to the synthesis of our findings. The NASSS (Non-adoption, Abandonment, Scale-up, Spread, and Sustainability) framework [19] provided the basis for summarizing the results. This framework was developed to analyze the varied outcomes of technological innovations in health and social care and to help inform the implementation of such technologies. The NASSS framework comprises 7 domains: (1) the condition or illness, (2) the technology, (3) the value proposition, (4) the adopter system (intended users), (5) the organization, (6) the wider system (especially regulatory, legal, and policy issues), and (7) a final cross-cutting domain that considers adaptation and embedding over time. Each of the 7 domains can be "simple" (ie, few components and predictable), "complicated" (ie, many components but still largely predictable), or "complex" (ie, many components interacting in a dynamic and unpredictable way). Crucially, NASSS surfaces factors that are often unacknowledged in technology implementation programs, helping to move beyond the identification of individual barriers and enablers in recognition of the dynamic interactions between the domains, for example, the relationship between the individual adopter and the organizational or wider system context.

Search Strategy

A search strategy was developed in collaboration with an academic librarian. As a preliminary examination of the literature indicated that only a few reviews focused solely on acute care hospitals or older adults and because the specific health care setting was not always immediately clear, we decided not to include filters for population or health care setting in order not to exclude potentially relevant publications.

The full search strategy is shown in Textbox 1. Search terms related to patient portals and systematic reviews were used. The search strategy used a combination of medical subject headings and free-text words. Searches were restricted to 2010 to account for the pace of development in portal technology. Searches were conducted on June 16, 2020, and included the following databases: MEDLINE and Embase via the Ovid platform, CINAHL and PsycINFO via the EBSCO platform, and the Cochrane Library. Reference lists of the included reviews were screened for additional literature.

To generate sufficient breadth of coverage for the scoping review, inclusion criteria were defined to capture maximum learning with respect to the implementation of tethered patient portals among older people and in acute care hospitals. Specifically, 3 categories of reviews were eligible for consideration:

1. Systematic reviews of patient portals in acute care hospitals
2. Systematic reviews of reviews (with both primary studies and reviews) of patient portals in multiple settings, including acute care hospitals
3. Systematic reviews of patient portals for older adults in multiple settings, including acute care hospitals

The inclusion criteria were as follows: reviews published since 2010 in English; reviews focused on the implementation of tethered patient portals (as defined in the *Introduction* section); reviews focused on patient portals for older adults (in settings that include acute care hospitals); reviews focused on patient portals for patients, health care professionals, managers, and budget holders in acute care hospitals; reviews of reviews of patient portals in settings that include acute care hospitals; reviews focused on contextual factors (ie, barriers and facilitators) that impact the implementation of patient portals; systematic reviews; scoping reviews; narrative reviews; qualitative meta-syntheses; meta-ethnographies; and reviews of reviews.

The exclusion criteria were as follows: reviews published before 2010; reviews not in English; reviews not focused on the implementation of tethered patient portals; reviews focused on the technical aspects of patient portals; reviews in family practice settings only; nonsystematic reviews; secondary analyses of the existing data sets; discussions of literature for theory building or critique; summaries of literature for information or commentary; editors' discussions; letters; conference abstracts; and theses; and reviews whose full text was not available.

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Textbox 1. Search strategy by database.

Search terms for MEDLINE and Embase (via OVID)

1. Exp Patient Portals/
2. Health Records, Personal
3. Patient ADJ2 Portal*.mp
4. Electronic ADJ2 Portal.mp
5. (personal adj2 (health or medical) adj2 (record* or info*)).mp
6. Patient accessible record*.mp
7. PHR.mp
8. ePHR.mp
9. or/1-8 (MEDLINE) or/3-8 (EMBASE)
10. Meta analysis/
11. Meta-analysis.ti,ab,pt.
12. Meta-ethno*.ti,ab,pt.
13. Review.ti,ab.pt.
14. or/10-13
15. and/9,14
16. Limits – English Language, 2010-current, humans

Search terms for CINAHL and PsycINFO (via EBSCO)

1. MH “Patient Portals”
2. MH “Medical Records, Personal”
3. Patient n2 Portal*
4. Electronic n2 Portal
5. Personal n2 (health or medical) n2 (record* or info*)
6. Patient accessible record*
7. PHR
8. ePHR
9. or/1-8 (CINAHL) or/3-8 (PsycInfo)
10. MH Meta analysis
11. Meta-analysis
12. Meta-ethno*
13. Review.ti,ab.pt.
14. or/10-13
15. and/9,14
16. Limits – English Language, 2010-current

Search terms for Cochrane Library

1. Exp Patient Portals
2. Health Records, Personal
3. Health Records, Electronic

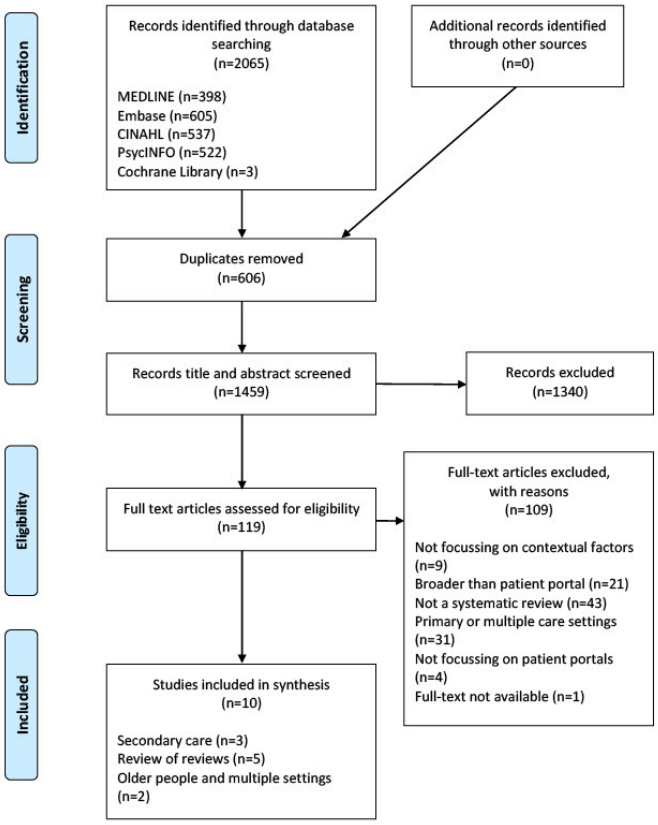
Study Selection

Search results were imported into EndNote reference management software (Clarivate Analytics), and duplicates were removed automatically and double checked manually. Two reviewers (JH and ZK) independently screened titles and abstracts. Any discrepancies in the articles identified for full-text screening were discussed, and consensus was reached. Full-text

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articles of potentially eligible reviews were assessed independently by 2 reviewers (JH and ZK) against the prespecified inclusion and exclusion criteria. Discrepancies were resolved through discussion. The reasons for exclusion were recorded and included in the PRISMA diagram (Figure 1).

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram.



Data Charting

In accordance with the Arksey and O'Malley framework for scoping reviews [17], a data charting form was compiled in Microsoft Excel (Microsoft Corp), which contained a row for each included study and columns to record general study information, namely authors, publication date, country of origin, review aim, health care setting, participants, definition of patient portal, theoretical framework, database searches, inclusion and exclusion criteria, data extraction method, quality assessment method, method of analysis or synthesis, and the number of included studies. The included studies were examined to determine the extent of study overlap between the included reviews. The data charting form was also used to extract data on the contextual factors (barriers and facilitators) that impacted the implementation of patient portals in accordance with the 7 domains of the NASSS framework (refer to the *NASSS Framework* section), together with the authors' recommendations for future research. The form was piloted on 4 studies. A single reviewer (JH) read each study and extracted the study characteristics and data on contextual factors from the results and discussion sections. The discussion sections were included in the charting process, as they often provide additional material to enhance the interpretation of review findings. The data extraction for each of the 4 articles was cross-checked by another team member (TJB, ZK, JL, and FS) to verify whether data charting was performed in accordance with the 7 NASSS framework domains. Data charting was then completed by a single reviewer (JH) and independently verified by another member of the team (ZK).

Summarizing the Results

A narrative approach was used to summarize the results of the scoping review. In line with the usual practice for scoping reviews [17], no attempt was made to assess the quality of the included reviews or the weight of the evidence with respect to the implementation of patient portals.

Results

Search Results

A total of 2065 references were identified (Figure 1). After the removal of duplicates (n=606, 29.35%), another 1340 (64.9%) records were excluded based on the title and abstract, leaving 119 (5.76%) full-text articles to be assessed for eligibility. Of the 119 full papers assessed, 10 (8.4%) met the criteria for inclusion in this scoping review. Scrutiny of the reference lists of the included reviews did not generate additional literature for inclusion. Multimedia Appendix 1 provides details on the characteristics of the included reviews [15,20-28].

Description of the Included Reviews

The reviews were published between 2015 and 2020. Of the 10 included reviews, 4 (40%) originated from the United States [15,20-22], 2 (20%) each from the United Kingdom [23,24] and the Netherlands [25,26], and 1 (10%) each from Australia [27]

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and Iran [28]. Overall, 3 (30%) systematic reviews addressed patient portals in acute care hospitals [15,20,23], 5 (50%) systematic reviews of reviews examined patient portals in both acute care hospitals and other care settings [24-28], and 2 (20%) systematic reviews addressed the implementation of patient portals among older adults (in multiple settings, including acute care hospitals) [21,22].

Of the included reviews, 7 (70%) did not specify a particular framework for the analysis of the results [20-24,27,28], 1 (10%) used the System Engineering Initiative for Patient Safety model to categorize interventions [15], 1 (10%) used the Clinical Adoption Framework [25], and 1 (10%) applied the Problem Solving Cycle [26]. Reviews in which no framework was specified considered portal design, use, and usability [20]; input, process, and output factors [27]; content and capabilities [28]; impact on outcome measures [24]; barriers to and facilitators of adoption and user experience [21]; characteristics of older users, evaluation of outcome measures and results, and barriers to and facilitators of use [22]; and impact on trust and communication and consideration of ethical issues [23].

Study Overlap

To establish the breadth of coverage of this scoping review, an indication of the extent of overlap of studies in the included reviews was determined. The included reviews contained 206 studies (156 primary studies, 75.8%, and 50 reviews, 24.3%), excluding the 109 references of Otte-Trojel et al [26], which, unfortunately, we were not able to obtain for scrutiny. Table 1 provides a summary of the extent of study overlap. Only 19 studies appeared in >1 included review, suggesting limited duplication in the scoping review.

Table 1. Overlap of studies[a].

	Acute care hospitals, n			Multiple settings (review of reviews), n					Older adults (aged >60 years), n	
	D'Costa et al [23], 2020	Grossman et al [15], 2019	Kelly et al [20], 2018	Dendere et al [27], 2019	Aslani et al [28], 2020	van Mens et al [25], 2019	Otte-Trojel et al [26], 2016[b]	Jilka et al [24], 2015	Sakaguchi-Tang et al [21], 2017	Kneale and Demiris [22], 2017
D'Costa et al [23], 2020	N/A[b]	0	3	3	0	0	N/A	0	0	0
Grossman et al [15], 2019	0	N/A	0	1	0	0	N/A	0	0	0
Kelly et al [20], 2018	3	0	N/A	6	0	0	N/A	0	0	0
Dendere et al [27], 2019	3	1	5	N/A	1	6	N/A	2	0	2
Aslani et al [28], 2020	0	0	0	1	N/A	0	N/A	0	0	1
van Mens et al [25], 2019	0	0	0	6	0	N/A	N/A	0	0	0
Otte-Trojel et al [26], 2016[c]	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Jilka et al [24], 2015	0	0	0	2	0	0	N/A	N/A	0	0
Sakaguchi-Tang et al [21], 2017	0	0	0	0	0	0	N/A	0	N/A	1
Kneale and Demiris [22], 2017	0	0	0	2	1	0	N/A	0	1	N/A

[a]Overlap tracked in 156 primary studies and 50 reviews.

[b]N/A: not applicable.

[c]Not able to obtain reference list.

Narrative of Results by NASSS Framework Domains

Overview

The results and discussion sections of the included studies were successfully mapped to the NASSS framework domains and subdomains. The findings for each domain are presented and a summary is provided in Table 2. The headings for the domains and subdomains are taken directly from the NASSS framework. Although each domain is commented on in turn, there are interrelationships between the findings that are highlighted in the text and addressed at the end of this section.

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Table 2. Non-adoption, Abandonment, Scale-up, Spread, and Sustainability (NASSS) framework: contextual factors that influence the implementation of patient portals.

NASSS domain and subdomain and contextual factors (namely, facilitators and barriers)	Acute care hospitals	Mixed health care setting	Older adults (aged >60 years)
1. Condition			
What is the nature of the condition or illness?			
Facilitators			
Greater disease severity	—[a]	[24]	—
Chronic disease (and associated well-established case management programs)	—	[21,23]	—
Barriers			
Severity and circumstances of illness (eg, reduced involvement in decision-making and fewer questions)	[20]	[24]	—
Relevant sociocultural factors and comorbidities			
Facilitators			
Higher socioeconomic status, female sex, younger age, White ethnicity, and younger senior citizens	—	[23,24]	[18]
Disease-specific portal	—	[24]	—
Barriers			
Lower socioeconomic status, male gender, older age, and non-White ethnicity (impacts enrollment and engagement)	[12,20]	[24]	—
Diversity of older adults (not well understood)	—	—	[19]
Low health literacy and numeracy (and understanding of health literacy)	—	[23,24]	[19]
Lack of digital access	—	[23]	[18]
Insurance status	[12]	—	—
Comorbidities such as vision and hearing loss, decreased dexterity and mobility, and declining cognitive function	—	—	[18,19]
2. Technology			
Key features			
Facilitators			
Information and identity authentication and protection	—	[23,25]	—
Usability (eg, set-up, interface design, simple displays, text visibility, buttons, patient-friendly content, ease of navigation, personalized interface, and reminders to view)	[12,17,20]	[21,24,25]	[18]
Functionality (eg, communication with providers; access to reliable, timely and comprehensive personal medical information; content in minority languages; and inbuilt system alerts)	[17]	[23,24]	[18]
Accessibility (eg, adding mobile access and providing on-site kiosks)	[12]	[21,23]	—
Participatory and iterative design approaches	—	[23,24]	—
Iterative user evaluation (eg, patients and providers)	[12]	—	—
Definition of minimum data set to plan care and continuously evaluate treatment	—	[25]	—
Barriers			
Patients' security and privacy concerns (eg, control over access)	[17,20]	[21-24]	[18]
Providers' concerns about sharing patient information	—	[21,25]	—
Usability (eg, interface design, technical glitches, log-on, navigation, accessibility of information for patients, and printing and using information)	[17]	[21,23,24]	[18,19]
Establishing a trade-off among security measures, user friendliness, and flexibility	—	[23]	—

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NASSS domain and subdomain and contextual factors (namely, facilitators and barriers)	Acute care hospitals	Mixed health care setting	Older adults (aged >60 years)
Functionality (eg, differing information needs of patients and providers; differing patient preferences over data content and input; diversity of health data types and formats and portal ability to handle the diversity of health data types and formats; data transparency—what data are released and to whom and how they are released; language used; and level of features [eg, reminders, dictionary, lifestyle advice, print capability, and user voice command])	[17]	[23-25]	[18]
Accessibility (eg, computer and internet access and secure and stable infrastructures)	—	[21-23]	[18]
Type of knowledge in play			
Facilitators			
Data set is comprehensive, reliable, complete, understandable, and valid	—	[25]]	—
Audit trail for revisions to data	—	[23]	—
Barriers			
Concerns about patients' ability to interpret test results and deal with sensitive information without professional support or interpretation	[17,20]	[21,23,24]	[18]
Real-time (release of) information without real-time support	[20]	—	—
Providers' concerns about the reliability of patient-generated data (as basis for clinical decisions)	[20]	[23]	—
Knowledge to use			
Facilitators			
Patient training and technical support (eg, videos, handbooks, hotline, and workshops)	[12]	[23]	[18]
Training for providers	—	[23]	—
Barriers			
Quality of patient training	[12]	—	—
Patients' level of technology literacy (eg, perceived and actual skill and computer anxiety)	[12]	—	[18]
Technology supply model			
Facilitators			
Portals that integrate into preexisting systems	[17]	—	—
Interoperability (eg, information exchange and sharing)	—	[25]	—
Barriers			
Interoperability (eg, achieving appropriate data exchange among systems)	—	[21,23]	—
3. Value proposition			
Supply-side value			
Facilitators			
Facilitates the processing of payments by insurance companies	—	[25]	—
Trial period before purchase (ie, to test usability and estimate financial and organizational impact)	—	[23]	—
Positive return on investment and impact on charges and costs	—	[21]	—
Barriers			
Trade-off among the type of architecture, responsiveness to local needs, and implementation time and cost (ie, decentralized and more expensive but more responsive and shorter implementation time)	—	[25]	—
Establishing sound business case (eg, no standardized evaluation frameworks, no reimbursement structures for electronic services, lack of evidence of cost savings, and lack of financial sustainability)	—	[23,24]	—
Demand-side value			
Facilitators			

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NASSS domain and subdomain and contextual factors (namely, facilitators and barriers)	Acute care hospitals	Mixed health care setting	Older adults (aged >60 years)
Satisfies patients' need for information; facilitates knowledge retention, understanding, and engagement in care by patient; sense of empowerment and control; feeling of being better prepared; and perceived usefulness (eg, aids self-management, utility features, and information in one place)	[17,20]	[21,22,24,25]	[18,19]
Provide communication route with professionals between clinic rounds (eg, patient driven communication)	[17]	[21,24]	[18]
Assists (verbal) interactions or appointments with professionals and patient-provider communication	[17,20]	[21,22,24,25]	[18]
Access to information facilitates the development of trust in diagnosis, investigations, treatment, and professionals (eg, relationships)	[20]	[21]	[19]
Helps inaccuracies in EHR[b] to be identified (eg, detection of errors and patient safety)	[17,20]	[24]	—
Contributes to enhanced discussions with patients and aids communication	[17]	[21,24,25]	—
Prevents misunderstandings and builds trust (ie, careful and clear recording of information)	[20]	[21]	—
Usefulness and time efficiency (ie, clear recording prevents the need to repeat information and aids interprofessional communication)	—	[21,25]	—
Helps improve care (eg, planning and continuous evaluation of treatment, adherence, patient satisfaction and engagement, reduced patient anxiety, timely decision-making)	—	[24,25]	—
Barriers			
Patients perceive extra responsibility for finding errors or poor outcomes	[20]	—	—
Patients' concern about threat to face-to-face communication with professionals	[20]	—	[18]
Patients' do not see value or usefulness (eg, lack awareness of features)	[12]	[21,23,24]	[19]
Patient views about "user fee for use"	—	—	[19]
Professionals' concern that messaging may adversely impact verbal communication	[17]	—	—
Professionals do not perceive usefulness	—	[21]	—
4. Adopter system			
Changes in staff roles, practices, and identities			
Facilitators			
Accepting of collaborative versus expert-led care	[20]	—	—
Professionals' positive level of engagement, knowledge, and confidence in portal systems	—	[24]	—
Barriers			
Less accepting of collaborative versus expert-led care and do not wish to cede autonomy to patients	[20]	[23]	—
Professionals need to support patients to interpret and emotionally deal with the information in portals	[20]	—	—
How is responsibility for the release of test results managed? (eg, who takes responsibility and editing before release)	[20]	—	—
Professionals' level of engagement, knowledge, skills, and confidence in portals	—	[2,21,23]	—
What is expected of patients?			
Facilitators			
Professionals support and encourage patients' use of portals (eg, endorsement, reminders, and materials)	—	[22-24]	—
Patients' willingness to enter basic information into portals or manage records	—	—	[18,19]
Barriers			
Patient preferences regarding the entry of data into portals, increased knowledge, and managing records	[20]	[24]	[18,19]
Professionals or providers do not encourage patients' use of portals	—	[23]	—

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NASSS domain and subdomain and contextual factors (namely, facilitators and barriers)	Acute care hospitals	Mixed health care setting	Older adults (aged >60 years)
What is assumed about the network of lay care givers?			
Facilitators			
None identified	—	—	—
Barriers			
Patients lack help or support to access portals	—	—	[18]
5. Organization			
Organization's capacity to innovate			
Facilitators			
Leadership involvement in portal design and development of policies for user training and the integration of patient portals into workflows	—	[24]	—
Communication around technical, interpersonal, and workflow aspects of portals	—	[23]	—
Organizational interpretation of government legislation related to portals	—	[24]	—
Barriers			
Constrained financial context (eg, small or rural hospitals)	[20]	[24]	—
Organizational interpretation of government legislation	—	[24]	—
Lack of leadership support (fear and hesitancy in implementation)	—	[25]	—
Is the organization ready for technology-supported change?			
Facilitators			
Policies in place to support portals (eg, universal access policy, security protocols, adherence audits, data availability, and timing)	[12]	[23]	—
Barriers			
Lack of support for new forms of communication between patients and professionals	—	[24]	—
Lack of policies on access rights and authorization process (including proxy access and access for minors)	—	[23]	—
Ease of funding and adoption decision			
Facilitators			
Internal and external exchange of information to improve the quality, safety, and effectiveness of care	—	[25]	—
Barriers			
Providers' concerns about diverting resources to the less disadvantaged (ie, those who can read and ask questions)	[20]	—	—
Integrating patient portal use across care transitions (ie, with other organizations) to improve care	[17]	[25]	—
Deciding on the balance between IT structure and implementation time and cost		[25]	
Changes needed in team interactions and routines			
Facilitators			
Integrating data release with workflow (ie, to facilitate professionals' follow-up with patients)	—	[23]	—
Workload and work routines not adversely impacted or positively impacted (eg, time efficiencies)	—	[21]	—
Barriers			
How to organize the release of results to patients without professionals' help with interpretation and support (eg, real-time release or delayed released)	[20]	—	—
Professionals' concerns about the impact of increased level of patient questions, patient overuse of messaging, increase in documentation time, and portals on workflow	[17]	[21,23,24]	—
Work involved in implementation and who will do it			

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NASSS domain and subdomain and contextual factors (namely, facilitators and barriers)	Acute care hospitals	Mixed health care setting	Older adults (aged >60 years)
Facilitators			
Involvement of professionals in workflow engineering and the evaluation of the impact of portal use on workload and processes	[17]	[23]	—
Barriers			
None identified	—	—	—
6. Wider context			
What is the political, economic, regulatory, professional, and sociocultural context of program rollout?			
Facilitators			
Aspects of culture (doctors from English-speaking countries), including the coverage of portals, PHRs[c], and EHRs in medical and nursing school curricula	[20]	[23]	—
Health professionals' liability concerns	[20]	—	—
Health systems with a transactional component	[20]	—	—
Resource for policy makers, health care specialists, and stakeholders to improve care and the quality of treatment	—	[25]	—
National and international information exchange (interoperability) and other standards (eg, Health Insurance Portability and Accountability Act, International Health Level 7, regional health information exchanges, and key public infrastructures)	—	[23,25]	—
Appropriate reimbursement mechanisms	—	[23]	—
Barriers			
Reimbursement structures for electronic services	—	[23]	—
Providers' liability concerns (eg, breached privacy or patients' harmful behaviors)	—	[23]	—
Nonstandardized rules for developing and managing health information infrastructures	—	[23]	—
Relationship between macrolevel and mesolevel (eg, organization) factors was not well explored	—	[22]	—
Regulations (eg, Health Insurance Portability) do not cover portal developers and hosting organizations	—	[23]	—
7. Embedding and adaptation			
Scope for adapting and coevolving technology and service			
Facilitators			
None identified	—	—	—
Barriers			
Concern that medical record maintains integrity as a working document that facilitates the transfer of knowledge between health professionals	[20]	—	—
How portals can be extended beyond a single organization (ie, particularly in fragmented care delivery contexts)?	—	[23]	—
Organization resilience to critical events			
Facilitators			
None identified	—	—	—
Barriers			
None identified	—	—	—

[a]Not available.

[b]EHR: electronic health record.

[c]PHR: personal health record.

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Domain 1: The Condition

What Is the Nature of the Condition or Illness?

The included reviews documented patient portals that are open to individuals with a variety of health conditions, including acute and chronic diseases and high-risk conditions. Reviews focusing on patient portals in acute care hospitals included adult patients with acute medical conditions [23], inpatients and outpatients classified as vulnerable (including those with cardiovascular diseases, those with HIV, those with ophthalmic conditions and those with chronic or unspecified conditions) [15], patients who have had cardiac surgery, patients who were in an intensive care unit, patients with cancer, parents of patients who were in a neonatal intensive care unit, and caregivers or patients who underwent bone marrow transplant. Reviews focusing on multiple care settings included patients with multiple sclerosis [28], patients in any medical domain [25], adult patients with chronic diseases, patients in family practice settings [24], and patients with unspecified conditions [26,27]. The reviews focused on older patients aged ≥60 years did not specify an illness or medical domain.

There was limited consideration of how clinical characteristics played a role in patient portal use. An examination of inpatient portals [27] highlighted patients' desire to be able to view their daily schedule, view information on medications and test results, and learn about care and preparations for discharge. This review acknowledged how the nature of an individual's condition (eg, severe illness or intense pain) could affect their ability or desire to interact with the functionality of a patient portal, as well as their capacity to be involved in decision-making about their care and to formulate and ask questions to health professionals [23,27].

A total of 3 (30%) reviews suggested that patients with greater disease severity [27] or with chronic disease [24,26] may engage more with a portal. Patients with chronic diseases (such as diabetes, hypertension, or depression) have the benefit of well-established case management programs [24]. Although this may facilitate the adoption of a portal, the authors noted that concomitant case management programs will also be a factor impacting disease outcomes (separate from any impact on patient outcomes from the portal), making the findings of disease-specific studies of patient portal implementation difficult to extrapolate across non–disease-specific populations [24].

What Are the Relevant Sociocultural Factors and Comorbidities?

The NASSS framework considers how complexity occurs when a condition or an illness is associated with sociocultural factors (eg, poverty or social exclusion) and comorbidities (eg, loss of function and multimorbidity of older age). The impact of these factors on patient portal adoption received more extensive coverage in the included reviews, along with concerns about the potential for the exacerbation of health inequalities owing to disparities in engagement, as outlined subsequently.

The included reviews suggested that portal adoption is associated with having a higher socioeconomic status, being female, being of White ethnicity, being younger, and being a younger senior citizen [21,26,27].

Low health literacy and numeracy in patient groups [21,22,27] as well as a lack of digital access [21,26] were identified as barriers to portal use. Vulnerable groups [15], those with lower socioeconomic status [15,23,27], and those with less favorable health insurance status [15] are less likely to be enrolled in or engage with patient portals. In addition, increasing age, male sex, and non-White ethnicity were identified as factors associated with low adoption [15,23,27].

Certain comorbidities, such as vision and hearing loss, decreased dexterity and mobility, and declining cognitive function, were identified as barriers to portal use [21,22]. These factors may be associated with the aging process; however, 1 (10%) review highlighted that the diversity of older adults and their needs relative to patient portals are not well understood [21].

Domain 2: The Technology

Material and Technical Features

The included reviews did not outline the technology in detail but identified several material and technical features that promote patient portal adoption and user satisfaction, including a well-designed interface [20,28], ease of setup and access [21], straightforward navigation [20] and information transfer [21], simple formats [20,23] and buttons [23], text visibility [28], user-friendly content [20], error messages [28], real-time [20] or disease-specific information [27], email reminders to view content [15], and a personalized interface [20].

Conversely, poor usability features, such as poor interface design [24,26,27], technical glitches [27], log-on [21] or navigation difficulties [21,22], and difficulties with printing and using information [22] were reported to have a negative impact on users' experience, and satisfaction, with patient portals [20-22,24,26,27]. Moreover, 1 (10%) review suggested that if patients perceive the access to their personal health records as useful, they are more willing to overcome the technical barriers of engaging with the patient portal [22]. This is linked to domain 3 (the value proposition) in terms of the desirability or value of the portal technology for patients.

The reviews suggested that participatory and iterative design [26,27] and iterative user evaluation [15], including both patient and health professional users, at the planning and development stage of a patient portal are ways to overcome usability issues. Such inclusive and consultative design approaches also allow the functionality of patient portals to be addressed [20,26-28]. Reviews reported that patient engagement with portals can be facilitated by offering desired features, including communication with health professionals [20]; access to reliable, timely, and comprehensive personal medical information [27]; and content in minority languages [26]. The reviews also pointed to the benefits for health professionals from their involvement at the design stage, including the specification of a minimum data set for care planning and for the continuous evaluation of treatment [28], and from inbuilt system alerts (eg, if a patient does not open an email or to signal a medical emergency) [26].

Several reviews highlighted potential difficulties in defining the functionality of a patient portal system, including the differing information needs of patients and health professionals [20], differing patient preferences regarding data content and

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data input [27], the diversity of health data formats [28], the language to be used (ie, designing content for lay and professional audiences) [26], the level of features (eg, reminders, dictionary of medical terms, lifestyle advice, and print and user voice command capability) [21], and data transparency (ie, deciding what data to release to patients and when and how to make them available) [26].

The information privacy and security aspects of patient portals were reported to be an area of concern. This could be patients' concerns regarding their personal health information [20,21,23-27] or health professionals' concerns about sharing patient information [24,28]. Measures such as robust identity authentication and information protection [26,28] were suggested as mechanisms to address such concerns, with the observation that there can be a trade-off between security measures and user friendliness [26].

Accessibility of the technology for patients [24], including computer [21] and internet [21,25] access, was highlighted as another barrier to the implementation of patient portals. This may be because of cost issues [21]. Suggested mechanisms to promote accessibility were making mobile as well as computer access available [15] and providing on-site kiosks [26]. Establishing secure and stable technical infrastructures on which portals can operate was reported to be a challenge for providers [26].

Type of Data Generated or Knowledge in Play

In terms of the data held in the patient portal, 1 (10%) review suggested that the data set needed to be comprehensive, reliable, complete, understandable, and valid [28], with another (10%) recommending the inclusion of an audit trail so that the revisions made to the data are visible [26].

Several reviews raised the issue of health professionals' concerns about patients' access to health information via portals, particularly sensitive information, with questions about how patients can deal with the information without professionals' help with interpretation and support [20,21,23,24,26,27]. This concern particularly revolved around the issue of the real-time release of data or test results without real-time support [23] and is linked to domain 5 (the organization), whereby health professionals need to adapt to patient portal technology and incorporate it into their practice. Patient portals providing opportunities for patients to enter data about their condition raised additional questions about knowledge in play; 2 (20%) reviews reported that health professionals can have reservations about the reliability of patient-generated data in a portal and whether these data should form the basis of clinical decisions [23,26].

Knowledge Needed to Use

The reviews suggested that training and support can help portal use [15,26] and the use of specific features [15], helping to overcome the barrier of patients' technology literacy [15,21,26], including perceived and actual computer and internet skills [21]. However, 1 (10%) review reported that it is possible for training to have unintended consequences (ie, decreased intention to use) [15]. The training of health professionals must also be addressed [26]. It was posited that various tools and aids can facilitate the understanding of portal concepts and navigation, health information, and health management tasks (eg, videos, user handbooks, hotlines, and workshops) [21].

Technology Supply Model

Although the included reviews did not address how the patient portal technology was procured, the lack of interoperability for achieving appropriate data exchange between systems was identified as a barrier to adoption [24,26]. Portals that can be integrated into preexisting systems or offer data sharing and exchange are identified as facilitators [20].

Domain 3: The Value Proposition

What Is the Developer's Business Case for the Technology (Supply-Side Value)?

The reviews did not address the issue of the business case for patient portals from the developer's perspective but did examine it from the health care system's point of view, primarily with respect to the difficulties in establishing such a case [23,24].

Uncertainty around cost savings and financial sustainability, as well as reimbursement models for electronic services [26], contributes to complexity in this situation. The absence of standardized evaluation frameworks means that evidence of benefits (such as administrative efficiency or better-managed patients) is lacking. In addition, 1 (10%) review highlighted the challenge of deciding on a balance between technology architecture (ie, centralized or decentralized), its responsiveness to local needs, ease of implementation, and cost when compiling a business case; decentralized architectures are reportedly more compatible with local needs and can be implemented more quickly but have higher costs [28].

A recommendation for ensuring a sustainable business case was to have a trial period before committing to the purchase of a portal [26]. This allows the testing of usability and provides an opportunity to estimate the likely financial and organizational effects [26], such as the facilitation of the processing of payments [28]. It was suggested that determining a positive return on investment and the potential for lower hospital costs will support implementation [24].

What Is the Desirability, Efficacy, Safety, and Cost-effectiveness (Demand-Side Value)?

The reviews suggested that patient portals do satisfy patients' need for information (eg, about hospital schedule, medication, test results, and discharge planning) [20-22,27,28], helping with knowledge retention [23] and interactions with professionals [20,21,23-25,27,28] and providing a communication channel between clinic rounds [20,21,24,27]. These features support patients' understanding of their condition [22,24,25] and engagement in care or self-management [21,22,24,25,27], leading to a greater sense of empowerment and control [25,27] and feeling of being better prepared (ie, for appointments, emergencies, and discharge) [20,21]. In addition, the reviews indicated that access to information via the portal also facilitated the development of trust in health professionals [22-24], with patients feeling reassured by shared information [23].

Professionals valued patient portals as a mechanism for enhancing patient care [27] through timely decision-making

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[28], planning and continuous evaluation of treatment [28], and building trust [23,24] and as a mechanism that leads to improved patient engagement, adherence to treatment, and satisfaction with care [27,28]. Portals are also regarded as an aid to communication with patients [20,24,27,28] and as a tool to enhance interprofessional communication [24,28]. The clear recording of data in a portal was found to help efficiency by reducing the need to repeat information [24,28] and to contribute to patient safety by allowing inaccuracies and errors to be identified [20,23,27].

As indicated under domain 2 (the technology), where patients perceive portals as useful, they are prepared to overcome the technical barriers to portal use [22]. However, some reviews identified a lack of perceived usefulness from the patient perspective as a barrier to engagement with a portal [15,22,24,26,27], together with patient views about "fee for use" [22]. Some patients regarded portals as a threat to valued face-to-face communication with health professionals [21,23] or felt an additional (and unwelcome) burden of responsibility with respect to their care (eg, for finding errors or for poor outcomes) [23]. Some health professionals also did not see the usefulness or value of patient portals [24] or felt that they would adversely impact face-to-face communication with patients [20].

Domain 4: The Adopter System

What Changes in Staff Roles, Practices, and Identities Are Implied?

The reviews highlighted that the adoption of patient portals can raise questions regarding health professionals' scope of practice and professional identity. There are implications in terms of health professionals' confidence and ability to interact with the technology [24,26,27]; their need to incorporate the technology into their work practices [23]; and the potential for patient portals to alter the balance of the professional-patient relationship, shifting to more collaborative, rather than expert-led, working [23,26]. These elements are linked to considerations in domain 2 (the technology) regarding the involvement of health professionals at the portal design stage, as well as the provision of training and ongoing support for portal use, and to domain 5 (the organization) regarding the potential impact of patient portals on the workflow and workload of professionals and models of care and service delivery.

Moreover, 1 (10%) review suggested that when health professionals advocated collaborative working with patients and had confidence in using patient portals, this acted as a facilitator of implementation [23]. Conversely, where professionals were reluctant to cede professional autonomy and work more collaboratively with patients [23,26] or had concerns about their capacity and skills to engage with portal technology [24,26,27], this acted as a barrier to the implementation of patient portals. Examples of implications for practice included being able to support patients to interpret and emotionally deal with the information contained in the portal and deciding who takes responsibility for the release of information into the portal and whether the information needs to be edited before release [23].

What Is Expected of the Patient (or Immediate Caregiver) and Is This Achievable by, and Acceptable to, Them?

Professionals' support and encouragement of patients' use of portals were identified as mechanisms to facilitate the adoption of portals among patients [25-27]. Both (20%) the reviews that focused on older adults suggested that patients may be willing to enter basic data into the portal [21,22]. Patient engagement with portals is impacted by different preferences: some patients may not wish to have the responsibility of increased knowledge afforded by the portal [23] and do not wish to enter data [21,22,27] or be responsible for managing records [21].

What Is Assumed About the Extended Network of Lay Caregivers?

The included reviews did not directly address expectations of the involvement of the wider care network or lay caregivers in the adoption of patient portals, although it is acknowledged that older patients may lack help or support to access a portal [21]. This subject is linked to the information security and privacy concerns raised in domain 2 (the technology) and to the questions about policies on access (including proxy access) and security in domain 5 (the organization).

Domain 5: The Organization

What Is the Organization's Capacity to Innovate?

The included reviews highlighted the importance of organizational leadership support in promoting portal adoption [27,28] through actions such as working with developers on portal design [27] and developing policies for user training (both patients and health professionals) and integrating portals into clinical workflows, as well as organizing communication around the technical, interpersonal, and workflow aspects of patient portals [28]. A lack of executive leadership support can lead to hesitancy with portal implementation [28].

One (10%) review pointed to the potential for variability in portal implementation (eg, content made available to patients) in situations where providers have the discretion to interpret government legislation [27]. This is connected with the issue of internal and external information exchange; domain 6 (the wider context); and the extent to which there are standardized, nationally mandated regulations for developing and maintaining health information technologies. This may also influence the value proposition for patients (domain 3).

A constrained financial context will impact the implementation of portal technology [23,27]. One of the included reviews highlighted resource constraints at small or rural hospitals [27] as a situation likely to make the adoption of patient portals more difficult.

How Ready Is the Organization for Technology-Supported Change?

The included reviews highlighted the range of preparatory work that organizations need to do to support portal implementation. Organizational policies such as universal access [15]; security protocols, including those related to proxy access and access for minors [26]; adherence audits [26]; and data availability and timing will facilitate portal development and implementation. One (10%) review pointed to the necessity for sufficient

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organizational support for new forms of communication between patients and health professionals afforded by patient portals [27].

How Easy Will the Adoption and Funding Decision Be?

The challenges of making decisions on adoption and funding were highlighted by the included reviews. Organizations need to decide on the balance between costs, implementation time, and the flexibility of the portal architecture [28], including the ability to integrate portal use across care transitions (ie, interoperability with other organizations) [20,28]. There may be concerns that portals divert scarce resources to those who are *less* disadvantaged (ie, those who can read and have the confidence to ask questions) [23]. However, enhanced communication through internal and external exchange of information may offer positive advantages for the quality, safety, and effectiveness of patient care [28].

What Changes Will Be Needed in Team Interactions and Routines?

Concerns among health professionals regarding the potential impact of patient portals on workload and workflow were identified in the reviews [20,24,26,27], including the possibility of an increased level of patient questions [20], the potential for patient overuse of portal messaging functions [20], the question of how to respond to patient inquiries in a timely manner [26], and an increase in documentation time [24]. A related concern was how to manage and organize the release of results to patients without the presence of a health professional to offer help with interpretation and support [23].

Some solutions addressing workflow concerns were presented, including integrating data release to patients with workflow patterns to facilitate health professional follow-up with patients when the results are made available [26] and providing evidence for a positive impact on workflow and workload (eg, time efficiencies) [24].

These issues are linked to the involvement of health professionals at the technology design stage (domain 2), where concerns about the potential impact on workflows can be raised, and to the points raised earlier about the development of policies around integration by organizational leadership and proactive communication around the integration of portals into workflows.

Domain 6: The Wider Context

What Is the Political, Economic, Regulatory, Professional, and Sociocultural Context for Program Rollout?

The included reviews suggest the development of national and international information exchange (ie, interoperability) and other standards (eg, security) as a facilitator of portal implementation [26,28].

One (10%) review identified health professionals' liability concerns as a factor that will promote patient access to records (eg, in countries such as Norway and the United States) [23]. For countries with health systems that have a transactional component (eg, the United States), it is posited that portals can act as a mechanism for helping patients understand their health care costs and that this will encourage the provision of the technology [23]. Other cultural components identified as important for adoption included the coverage of portals in medical and nursing school curricula [26] and the perceived benefit of portal data sets as a resource for policy makers, health care specialists, and stakeholders to evaluate and improve care [28].

Barriers to portal implementation identified in the reviews included nonstandardized rules for developing and managing health information infrastructures (ie, for interoperability) and regulations for data protection and management (eg, Health Insurance Portability and Accountability Act in the United States) that do not cover portal developers or hosting organizations, creating uncertainty about appropriate data governance [26]. In addition, it was pointed out that providers may have liability concerns about privacy breaches or patients' harmful behaviors [26].

One (10%) review pointed to inadequate or contradictory reimbursement structures for electronic services as a wider contextual barrier to the implementation of patient portals [26], inhibiting the development of a sound business model (link to domain 3). This review cited the Meaningful Use program in the United States as an example of a national initiative for patient portal adoption that was hampered by modest incentives and high thresholds, which impeded the development of an adequate business case [26].

Domain 7: Embedding and Sustaining

How Much Scope Is There for Adapting and Coevolving the Technology and Services Over Time?

In the included reviews, there was little consideration of the long-term adaptability and sustainability of the patient portals. The focus of attention was on development and short-term implementation issues.

Two long-term considerations were mentioned in the literature. The first was a general concern that the medical record maintains its integrity as a working document that facilitates the transfer of knowledge among many health professionals [23]. The second was related to the fact that most portals are implemented within a single organization or organized care delivery system, which limits their relevance to other organizational contexts [26]. Portal implementation will be more challenging across organizational contexts or in fragmented care delivery contexts, which are situations that are likely to feature in older people's care.

How Resilient Is the Organization to Handling Critical Events and Adapting to Unforeseen Eventualities?

There was no coverage of organizational resilience to critical or unforeseen events and ability to adapt to them.

Coverage and Interactions Between NASSS Domains

Table 2 shows that the contextual factors influencing implementation identified in the included reviews tended to cluster in specific domains: (1) the condition, (2) the technology, and (3) the value proposition. Certain aspects within these domains received more coverage than others, such as sociocultural factors and comorbidities, the usability and functionality aspects of the technology, and the demand-side value. The included reviews that used a theoretical framework

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[15,26,28] pointed to a focus on a narrow range of components of patient portal adoption, usually people and use factors.

There are links among the different domains. For example, the severity of an individual's illness can affect their ability to interact with portal technology, raising questions about expectations of the involvement of lay caregivers (domain 4: the adopter system), organizational policies on proxy access (domain 5: the organization), privacy and security features (domain 2: the technology), and information governance (domain 6: the wider context). Similarly, organizational leadership and support (domain 5: the organization) for the development and implementation of portals can ensure inclusive and iterative portal design (domain 1: the technology), addressing not only usability and functionality issues but also the perceived value (domain 3: the value proposition) of the technology, as well as concerns about the impact of portals on health professional roles and identities (domain 4: the adopter system) and workload and workflow (domain 5: the organization).

There are gaps in the literature pertinent to the consideration of the provision of patient portals among older people in acute care hospitals, including the lack of consideration of the diversity of older adults and their needs, the question of interoperability between systems (likely to be important where care involves multiple services), the involvement of lay caregivers and looking beyond short-term implementation to ways in which portal use can be sustained.

Discussion

Summary of Key Findings

This scoping review provides an overview of the contextual factors that impact the implementation of patient portals through an exploration of the emerging literature on patient portal use and engagement in acute care hospitals and among older people. Patients with chronic disease or greater disease severity were found to engage more with portals; however, comorbidities associated with the aging process were identified as barriers to portal use (domain 1: the condition). Perceived benefits from the supply side supported the adoption of portals, such as the potential for lower hospital costs, as did benefits from the demand side, such as engagement in care or self-management (domain 3: value proposition). Training for patients and staff should address technology literacy, the use of portal features, capacity-related concerns (integration of portals into workflows), and perceived value among health care professionals (domain 2: the technology). Older patients may lack help or support to access a portal; however, expectations of the involvement of lay caregivers in the adoption of patient portals were not reported (domain 4: the adopter system). Organizational leadership facilitates portal adoption, such as working with developers on portal design, developing policies for user training, and integrating portals into clinical workflows (domain 5: the organization). The development of national and international information exchange (ie, interoperability) and other standards (eg, security) was as a facilitator of portal implementation within the wider context (domain 6: the wider context). The reviews did not report on the long-term adaptability or sustainability of patient portals or organizational resilience. There were concerns that most portals are implemented within a single organization and that implementation across organizational contexts or in fragmented care delivery contexts would be challenging. This is important for the care of older people (domain 7: embedding and sustaining).

Older People and Inequalities

The diversity of older adults and their patient portal needs are not well understood. Older patients are more likely to experience chronic disease or greater severity of disease, and patients with chronic illness and greater severity of disease were found to engage more with portals owing to the perceived benefits of self-management, empowerment, and enhanced patient care. However, comorbidities related to age, such as vision and hearing loss, decreased dexterity and mobility, and declining cognitive function impede portal use. Variability in portal use and engagement among older people will, in part, be linked to the reasons for variability in internet use. Low income is the largest impediment to internet use among older people, followed by being aged >75 years, living alone, mobility, and memory or concentration problems [29]. This scoping review found that lower socioeconomic status, increasing age, male sex, and non-White ethnicity were factors associated with low adoption. People of lower socioeconomic status, older people, and people with mobility and memory or concentration problems are regular users of acute care services, making it an ideal setting to address these inequalities in patient portal access and engagement. Training programs and other engagement activities must directly target these inequalities to prevent any unintended exacerbation of the gray digital divide caused by the introduction or widespread use of a patient portal.

Adopter System

An important gap in the literature identified by this review was the lack of consideration of the involvement of the wider care network or lay caregivers in the adoption of patient portals. Many impediments to internet use among older people are linked to the increased likelihood of receiving care, for example, older age, mobility, and memory or concentration problems [29]. Older people are found to value proxy access to patient portals [30], with motivators including help to manage care, in the event of an emergency and lack of technology experience [31]. However, older patients express concerns when portals contain access to stigmatized conditions and financial commitments [32]. A review of 20 US health systems found that half of them had proxy access functionality, although only a few allowed the patient to specify role-based privileges [33]. The provision of separate proxy access should be accompanied by the provision of more control for patients over the information they wish to share [34]. This review found that organizational policies such as universal access; security protocols, including proxy access; adherence audits; and data availability and timing will facilitate portal development and implementation. To further aid the organizational readiness for technology-supported change, wider contextual factors must be considered at the planning stage in the form of policy shifts and patient developer specifications regarding the facility for internal and external information

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exchange. There is a need to engage with new ways of managing and talking about people's data, which may require a different skill set, that is, different stakeholders round the table.

Technology Supply Model

None of the included studies addressed the procurement process for patient portals. In the United Kingdom, there are a handful of providers that offer patient portals to acute care hospitals, such as Epic and Cerner. Patient portals differ in the extent to which they provide an off-the-shelf product or a tailored product with features that can be switched on or off depending on organizational readiness and capacity to facilitate them, such as patient-clinician communication. This review found that decentralized architectures were more compatible with local needs and implemented more quickly but were associated with higher costs [28]. Furthermore, there is no information on the level of support provided by the technology suppliers for the use of their products. This is anticipated to be a major organizational level barrier to implementation, which needs to be promptly addressed to facilitate the scale-up of portal use in acute care hospitals across the United Kingdom. Portals that can integrate into preexisting systems or offer data sharing and exchange were identified as facilitators [20]. Interoperability of health and care systems and other community services, such as the police and social services, is placed high on the NHS agenda [5], but although organizations may desire data sharing among themselves, the loss of control over shared data may serve as a barrier to portal adoption and highlights the complexity of this approach.

Strengths and Limitations

This scoping review used a comprehensive set of search terms to identify literature from electronic databases and followed robust procedures for citation and full-text screening in duplicate. Study overlap is a recognized limitation of reviews of reviews, where the primary studies may be reported in >1 systematic review and hence findings are overemphasized. This review included 156 primary studies and 50 reviews. We found that 19 (9.2%) of these 206 studies appeared in >1 review, indicating that study overlap was minimal, although we did not track overlap in the reference lists of all the included reviews. The NASSS framework provides a semantic structure by which to explore multilevel contextual factors impacting the implementation of digital health interventions. NASSS has largely been used to predict and evaluate implementation programs, but more recently, the framework has been used to synthesize review findings [35,36].

The number of reviews that focused exclusively on acute care hospitals (3/10, 30%) and older people (2/10, 20%) was low, which led to a broader scope of the extensive literature, primarily conducted in family practice and other patient groups, to capture learning and potential generalizability of the findings across settings and patients. In broadening the scope of the review, there were similarities with the umbrella review conducted by Antonio et al [14], who used a similar search strategy and a knowledge translation tool to present their findings. Our review was designed and our searches were conducted before the publication of the review conducted by Antonio et al [14]. We believe these similarities reinforce our robust approach to reviewing and synthesizing the literature, particularly as our design aimed to scope and map the literature rather than to systematically review it. The key differences between the reviews include our focus on older people and acute care hospitals; our review design aimed to scope rather than systematically review and appraise the literature; and our application of the NASSS framework. The NASSS has been referenced in >70 JMIR published studies since its publication in 2017, enabling easy comparison with the wider literature.

Papers were selected in accordance with our definition of a patient portal, and we were guided by the authors' description of a patient portal. Multimedia Appendix 1 shows the definition of patient portals in each of the included studies. The use of the NASSS framework is concerned with the complexity of the use of portals; therefore, all data were considered according to the framework to produce a "big picture" aggregation of what is known about the implementation of patient portals. The included reviews were limited to those published in English; however, we did not exclude reviews that included non-English studies.

Recommendations for Research

There is substantial literature on the contextual factors impacting patient portal use, with approximately 200 studies identified by the included reviews. However, there are few studies that evaluated interventions to address disparities in the use of patient portals [15]. As highlighted in a systematic review on the implementation of complex interventions in family practice [37], implementation studies exploring contextual factors tend to focus on surveys and qualitative studies, which are valuable in providing individual stakeholder perspectives but need triangulation with other methods. Observation and document analysis should accompany interviews to capture a more complete picture of the contextual factors at play, in particular, the wider context. As with any study exploring or evaluating the determinants of implementing a complex intervention, the features and functionality of the portal should be described in detail using established guidance [38] to enable reflection on the transferability of the findings to other settings. Finally, where interviews are used to explore the determinants of implementation among patients and staff, portal use data could be used to prompt further examination of use and sustained use.

Recommendations for Practice

This review provides implications for portal adoption and implementation that can inform current practice. This review found that cost, interoperability, trialability, and adaptability were all facilitators of portal adoption. Among hospitals in England deciding which portal product to adopt, GDE trusts play an important role in sharing detailed journeys through a digital technology via GDE blueprints, which are intended to promote scale-up, spread, and sustainability. To maximize the impact of GDE blueprints, they must be reported in an honest and transparent manner, with details on the challenges as well as the benefits of portals' adoption, engagement, and sustained use. Descriptions of portal implementation must clearly delineate implementation strategies, such as detailed information on training for staff and patients (ie, content, frequency, and format) and communication strategies for the technical, interpersonal, and workflow aspects of patient portals. NHS Digital has created

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a Personal Health Records adoption toolkit, which offers generic support to organizations looking to implement a patient portal [39]. Furthermore, GDE trusts act as buddy sites to support other trusts, known as "Fast Followers," for example, by sharing software, IT teams, standard processes, and could possibly assist with the selection and implementation of a patient portal; this approach is a powerful knowledge mobilization strategy enabling successful models to be scaled-up across the NHS [4].

Conclusions

This scoping review found that contextual factors influencing patient portal implementation tended to cluster in specific domains: (1) the condition, (2) the technology, and (3) the value proposition. Certain aspects within these domains received more coverage than others, such as sociocultural factors and comorbidities, the usability and functionality aspects of the technology, and the demand-side value. There are gaps in the literature pertinent to the consideration of the provision of patient portals for older people in acute care hospitals, including the lack of consideration of the diversity of older adults and their needs, the question of interoperability between systems (likely to be important where care involves multiple services), the involvement of lay caregivers, and looking beyond short-term implementation to ways in which portal use can be sustained. There is substantial literature on the contextual factors impacting patient portal use. Future research should focus on evaluating strategies that address disparities in use and promote engagement with patient portals among older people in acute care settings.

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Conflicts of Interest

HJ is a member of the digital management team at a Global Digital Exemplar National Health Service trust and has management responsibility for the implementation of a patient portal (Oracle Cerner HealtheLife). She has presented at Cerner conferences and received travel and hospitality reimbursement from Cerner.

Multimedia Appendix 1
Characteristics of included reviews.
[DOCX File , 32 KB - aging_v6i1e31812_app1.docx]

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Abbreviations

GDE: Global Digital Exemplar
NASSS: Non-adoption, Abandonment, Scale-up, Spread, and Sustainability
NHS: National Health Service
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews

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Correction: Identifying Predictors of Nursing Home Admission by Using Electronic Health Records and Administrative Data: Scoping Review

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In "Identifying Predictors of Nursing Home Admission by Using Electronic Health Records and Administrative Data: Scoping Review" (JMIR Aging 2023;6:e42437) the authors noted one error.

In the originally published manuscript, some percentage values in Table 2 were listed incorrectly. The corrected version of Table 2 appears as follows:

Table . Outcome measures used in the selected studies beyond nursing home admission (N=37[a]).

Secondary outcome	Outcome reported, n (%)
Mortality	16 (43)
Hospitalization or rehospitalization	11 (30)
Discharge from home and home-based services or recommendations to live in the community	4 (11)
Functional measures (quality of life, activities of daily living, and mental well-being)	4 (11)
Discharge to any health care institutions other than a nursing home (eg, rehabilitation center)	2 (5)
Other long-term care service use	1 (3)
Emergency department visit	1 (3)
Disability	1 (3)
Onset of 5 important chronic conditions	1 (3)
Nursing care needs	1 (3)
Time of death	1 (3)
Fall incidence	1 (3)
Health and social service costs	1 (3)

[a]More than 1 outcome measure was reported from individual studies. Therefore, N was greater than the number of selected studies.

The originally published version of Table 2 is included as Multimedia Appendix 1.

The correction will appear in the online version of the paper on the JMIR Publications website on December 19, 2023, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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Multimedia Appendix 1
Originally published Table 2.
[DOCX File, 188 KB - aging_v6i1e54952_app1.docx]

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Offering Outworld Experiences to In-Patients With Dementia Through Virtual Reality: Mixed Methods Study

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Abstract

Background: Research has suggested that institutionalization can increase the behavioral and psychological symptoms of dementia. To date, recent studies have reported a growing number of successful deployments of virtual reality for people with dementia to alleviate behavioral and psychological symptoms of dementia and improve quality of life. However, virtual reality has yet to be rigorously evaluated, since the findings are still in their infancy, with nonstatistically significant and inconclusive results.

Objective: Unlike prior works, to overcome limitations in the current literature, our virtual reality system was co-designed with people with dementia and experts in dementia care and was evaluated with a larger population of patients with mild to severe cases of dementia.

Methods: Working with 44 patients with dementia and 51 medical experts, we co-designed a virtual reality system to enhance the symptom management of in-patients with dementia residing in long-term care. We evaluated the system with 16 medical experts and 20 people with dementia.

Results: This paper explains the screening process and analysis we used to identify which environments patients would like to receive as an intervention. We also present the system's evaluation results by discussing their impact in depth. According to our findings, virtual reality contributes significantly to the reduction of behavioral and psychological symptoms of dementia, especially for aggressive, agitated, anxious, apathetic, depressive, and fearful behaviors.

Conclusions: Ultimately, we hope that the results from this study will offer insight into how virtual reality technology can be designed, deployed, and used in dementia care.

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KEYWORDS

virtual reality; dementia; patient-centered design; psychophysiological responses; behavioral and psychological symptoms; in-patient; VR; symptom management; quality of life; intervention; mental health; mental disorder; dementia care

Introduction

Globally, there are estimated to be 55 million patients with dementia [1]; therefore, the World Health Organization set out a global action plan to improve these patients' quality of life [2,3]. Dementia refers to a set of conditions that affect memory, thinking, and orientation and is often accompanied by behavioral and psychological symptoms (BPSDs), which are characterized by aggressive behaviors toward oneself and others, restlessness, irritability, depression, apathy, and lack of motivation [1,4-7].

The majority of interventions designed to prevent or reduce BPSDs in patients with dementia are based on pharmacological medications and physical barriers that are linked to adverse effects; the worsening of the patient's condition; and increases in anxiety, distress, and aggressive behaviors [8-12]. Meanwhile, there is a growing body of evidence demonstrating positive outcomes from nonpharmacological interventions for people with dementia that do not cause any of the aforementioned adverse effects [13-16]. Among the most common practices is sensory stimulation (eg, aromatherapy, music, and massages), as well as exposure to interesting and alternative environments, art, and reminiscence therapy. Therefore, in accordance with the World Health Organization's global action plan [3], best practices should reflect the use of pharmacological interventions and physical restraints only when nonpharmacological interventions have failed to be effective in treating complex cases.

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The use of computer technology and, in particular, virtual reality (VR) has enabled the use of nonpharmacological interventions, as a result of their ability to immerse the person with dementia in interesting and alternative environments that offer feedback based on multisensory stimulations [17,18]. According to recent studies, VR can serve as a viable and acceptable method for enhancing the engagement and enjoyment of patients with dementia [18,19]. A number of recent studies have also explored the effectiveness of VR in alleviating BPSDs and improving the quality of life of patients with dementia, with inconclusive results [11,20-23]. Specifically, some results have suggested a reduction in agitated, apathetic, and depressive responses but no improvements in cognitive function [20-22], while others have demonstrated that when VR is administered, it can preserve cognitive function [21].

Building on the above findings, to examine if VR can play a fundamental role in the reduction of BPSDs and the enhancement of quality of life for patients with dementia, we co-designed a VR system, reflecting on comments from 44 patients with dementia and 51 medical experts, to improve the symptom management of patients with dementia residing in long-term care services. We then evaluated the effectiveness of the system with 20 patients with dementia.

Methods

Ethics Approval

Patients diagnosed with dementia were recruited from a national Alzheimer disease and dementia hospital, in which they were residing and receiving care. Ethical approval was obtained from the National Bioethics Committee (approval number: Eebk ep 2022 56). All participants signed a consent form before this study. The patients' capacity to consent to participate was established with a capacity assessment, which was conducted by a registered clinical psychologist who was not part of this study.

Participants

A total of 60 patients with dementia were screened for inclusion. A history of severe motion sickness, vertigo, or impaired vision was set as an exclusion criterion. Patients confined to bed were also excluded. Per these exclusion criteria, 47 participants were eligible for participation. A total of 27 patients with dementia were deemed capable of consenting to participate in this study, of whom 20 consented and 7 declined. Therefore, this study included 20 patients with dementia.

In total, 20 in-patients with mild to severe dementia (male: n=7; female: n=13; age: mean 73.15, SD 16.17 years) participated in this study. The diagnosis was confirmed by using the Mini-Mental State Examination (MMSE) [24]. Our participants had a mean MMSE score of 15.10 (SD 6.16), ranging from 3 to 24 (mild: n=6; MMSE score: mean 22.17, SD 1.52; moderate: n=8; MMSE score: mean 15.25, SD 1.67; severe: n=6; MMSE score: mean 7.83, SD 3.82). Participants had no prior experience of using VR. All participants had normal or corrected vision and no history of severe motion sickness.

A total of 16 health care professionals (HCPs; male: n=2; female: n=14; age: mean 27.5, SD 5.89 years) were recruited to evaluate the system's usability and to identify the design challenges and opportunities. Their professions included caregiving or nursing (n=10), as well as occupational and speech therapy (n=6).

Instruments

To overcome the communication difficulties associated with dementia, patients were escorted during the data collection process by their caregivers. The data were also collected by a psychologist with experience in working with patients with dementia.

Heart Rate

Previous research has suggested that heart rate provides a valid and reliable measure of the psychophysiology of emotions [25]. Therefore, we measured the participants' heart rate every second to identify emotional anticipation. The heart rate was measured through optical heart rate monitoring, using photoplethysmography. This method uses light and the changes in the amount of light absorbed by the skin to measure changes in blood volume.

Eye-Tracking Data

The technology used in this study allowed for the analysis of the behavior and gaze patterns of patients with dementia, thus providing the opportunity to gain a better understanding of what they were experiencing. Specifically, we collected data on which objects they were looking at over time and how long they spent looking at these objects.

Time

Patients with dementia could spend up to 15 minutes exposed to VR. The time exposed to VR was measured in minutes and seconds. This time was measured in order to determine the patients' interest in VR and to record the side effects.

Overt Aggression Scale-Modified for Neurorehabilitation

The Overt Aggression Scale-Modified for Neurorehabilitation (OAS-MNR) [26] allows for the continuous direct observation and assessment of antecedents, contexts, behaviors, and interventions. It records the type and severity of aggression, using the following four categories: verbal aggression, physical aggression against objects, physical aggression against self, and physical aggression against others. The scale was administered to the patients with dementia before, during, and after the VR session to evaluate their aggressive responses.

Observed Emotion Rating Scale

The Observed Emotion Rating Scale (OERS) [27] allows for the direct observation of the time spent expressing the following five affect types: pleasure, anger, anxiety, sadness, and general alertness. For patients with dementia, this time was measured in minutes and seconds (1=never; 2=less than 16 s; 3=16-59 s; 4=1-5 min; 5=more than 5 min) before, during, and after the VR session in order to assess the presence of BPSDs.

Visual Analog Scale

A visual analog scale (VAS) [28] was used to obtain data on the emotional reactions toward each virtual environment. The patients with dementia were asked to point to the emoji

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(0=happy; 5=sad) that matched their emotional state before, during, and after the VR session.

Slater-Usoh-Steed Questionnaire

The Slater-Usoh-Steed Questionnaire [29] assesses the level of presence and immersion through questions rated on a 7-point Likert scale (eg, 1=being somewhere else; 7=being in the virtual environment). The scale was administered after VR exposure to both the patients with dementia and the HCPs in order to assess the level of presence and immersion and to inform the design of the VR system.

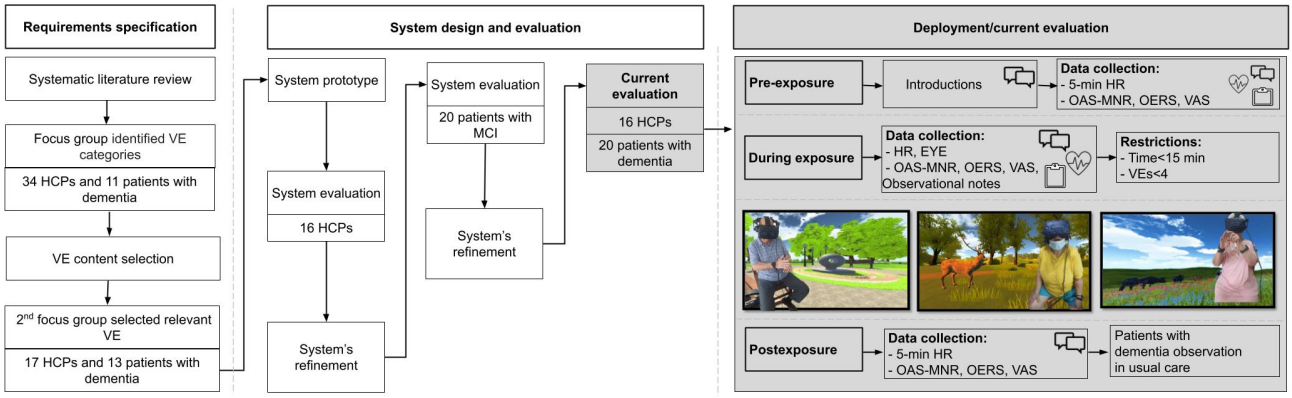
System Usability Scale

The System Usability Scale [30] evaluates a system's usability by using questions rated on a 5-point Likert scale (1=strongly disagree; 5=strongly agree). The scale was administered to the HCPs after the use of the VR system, to inform the design of the system.

Study Design and Procedure

The study design emerged from a systematic review that examined the feasibility of VR for people with neurological disorders and dementia, as well as discussions with experts in the field [31]. Data were collected within a 3-month period and included data on interviews, quantitative subjective responses, and physiological reactions. These data were obtained from HCPs, older adults with mild cognitive impairment (MCI), and patients with dementia (Figure 1). Specifically, first, we identified the VR system's requirements and developed an initial prototype (further details can be found in the *Affective Experiences in VR* and *Virtual Environment Selection Process* sections). Second, we evaluated the system's usability and sense of presence with 16 HCPs. Each HCP used the system as a user and as an administrator. Third, we refined the system based on the HCPs' comments, and we conducted a pilot study with 20 older adults with MCI to inform the design of the system. Based on the feedback we received from the older adults with MCI, we refined the system again and re-evaluated it with the 16 HCPs. Finally, we evaluated the final product with patients with dementia. All aspects of the design process are documented and published [32].

Figure 1. Study design and procedure. EYE: eye-tracking data; HCP: health care professional; HR: heart rate; MCI: mild cognitive impairment; OAS-MNR: Overt Aggression Scale-Modified for Neurorehabilitation; OERS: Observed Emotion Rating Scale; VAS: visual analog scale; VE: virtual environment.



Trials in the final evaluation started with the recording of pre-exposure measures before the VR session. This included recording the heart rate for 5 minutes, completing the VAS questionnaire, and recording responses to the OAS-MNR and OERS. Participants were then provided with an A3-sized sheet of paper presenting a "menu" with pictures of the available virtual environments to choose from. Each participant could choose up to 3 virtual environments to experience. Afterward, VR was introduced to the participants. To prevent adverse effects, such as dizziness associated with VR, a maximum duration of 15 minutes was suggested. However, during the exposure, some patients with dementia refused to remove the headset, so 5 more minutes were offered to them. During the VR session, various during-exposure measures were taken. This included recording the heart rate and eye-tracking−related metrics, filling in the VAS questionnaire after experiencing each virtual environment, and recording OAS-MNR and OERS responses and observational notes. As part of the postexposure measures, participants completed a semistructured interview and filled in quantitative data (ie, VAS, Slater-Usoh-Steed Questionnaire, and System Usability Scale questionnaires). The heart rate was also recorded for a 5-minute period after exposure. On average, each session lasted 40 minutes.

Apparatus

The VR system for this study was developed by the authors, using the Unity3D (Unity Technologies) [33] game engine, and the 3D models were retrieved from the Unity Asset Store and repurposed to run on a VIVE Pro Eye VR system (HTC Corporation) [34]. The VR content was streamed on a laptop screen, mirroring the real-time views of patients with dementia. The gazes of patients with dementia were tracked through the head-mounted display's eye tracker and visualized by using a ray that was only visible on the laptop screen. The ray, which was based on the direction of the gaze of the patient with dementia and their position, could indicate where the patients were looking. By casting the ray toward the virtual environment, we were able to identify which object in the virtual world patients with dementia were looking at, via collision detection with the various points of interest in the environment. Finally, a Samsung Galaxy Active 2 (Samsung Electronics) [35] smartwatch was worn by the participants and tracked their heart

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rate. For this purpose, a smartwatch-based app was developed by using Tizen Studio (Tizen Project), which communicated (via Bluetooth) with a paired mobile device that recorded the heart rate data every second via a mobile app that was developed by using Eclipse (IBM Corporation).

Data Analysis

An analysis of presence and exposure time data was conducted, using descriptive statistics. Further, an analysis of system usability was performed based on ratings, which ranged from 0 to 100. The ratings were calculated by subtracting 1 from participants' responses to positive statements and subtracting 5 from participants' responses to negative statements. The resulting values were then added and multiplied by 2.5 to yield the final rating. The heart rate data followed a normal distribution; thus, a repeated measures ANOVA was performed. For the eye-tracking data, descriptive statistics were run to identify the virtual environments that were of interest to patients with dementia and determine the amount of time patients with dementia spent looking at different groups of objects within the virtual environments. Finally, frequencies were used to report on the OAS-MNR, and Friedman tests were performed to report on the VAS and the observed emotions (pleasure, anger, anxiety, sadness, and general alertness), which were compared before, during, and after VR exposure. Means and SDs were reported. For statistical tests, an α of .05 was used to test significance.

Results

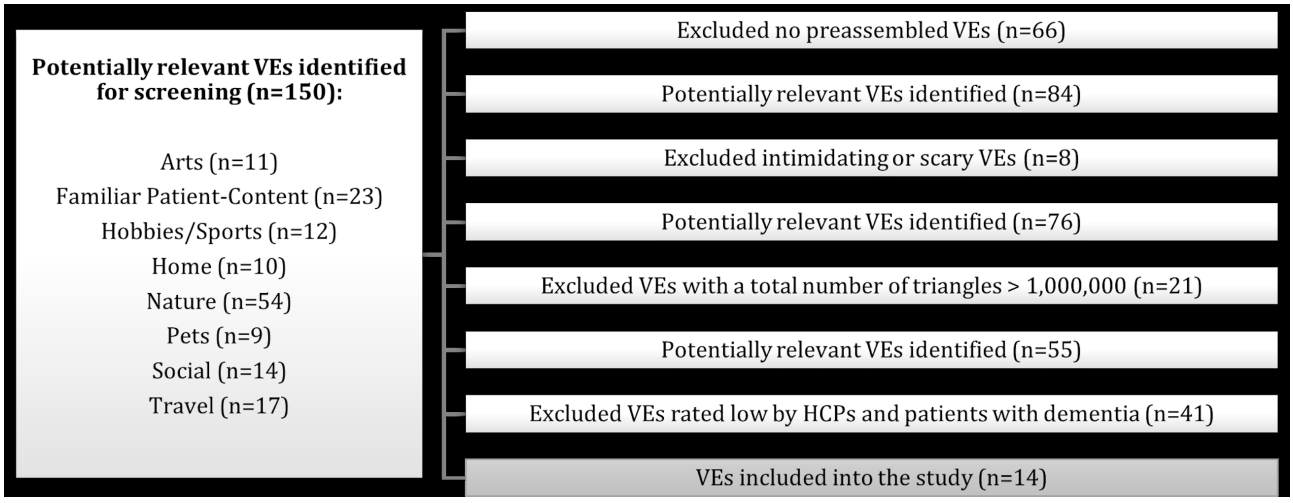
Virtual Environment Selection Process

The virtual environments that were used in the developed system were selected by using a multistep process. First, a 2-hour workshop was conducted with 34 specialists in dementia care and 11 patients with dementia. During the workshop, attendees were asked to brainstorm the types of VR content that patients with dementia would like to receive as interventions. Attendees suggested the following categories: (1) *Travel*, (2) *Nature*, (3) *Arts Experience*, (4) *Hobbies and Sports*, (5) *Social*, (6) *Home*, (7) *Pets*, and (8) *Familiar Patient-Content*.

After the conclusion of the workshop, we systematically searched the Unity Asset Store, using the human-computer interaction Bargas-Avila and Hornbæk methodology [32], for all the relevant assets and environments. Overall, we identified 150 potentially relevant assets and environments. Exclusion criteria were then applied, which narrowed down the available content to 55 virtual environments. We excluded (1) nonpreassembled virtual environments (eg, we excluded packages that only included individual models or did not include already designed virtual environments) to provide the patients with dementia with the sense of being in the environment; (2) intimidating or scary content (eg, we excluded animals or people that were close to the user); and (3) virtual environments with a total of >1,000,000 triangles to avoid simulator sickness and long loading times.

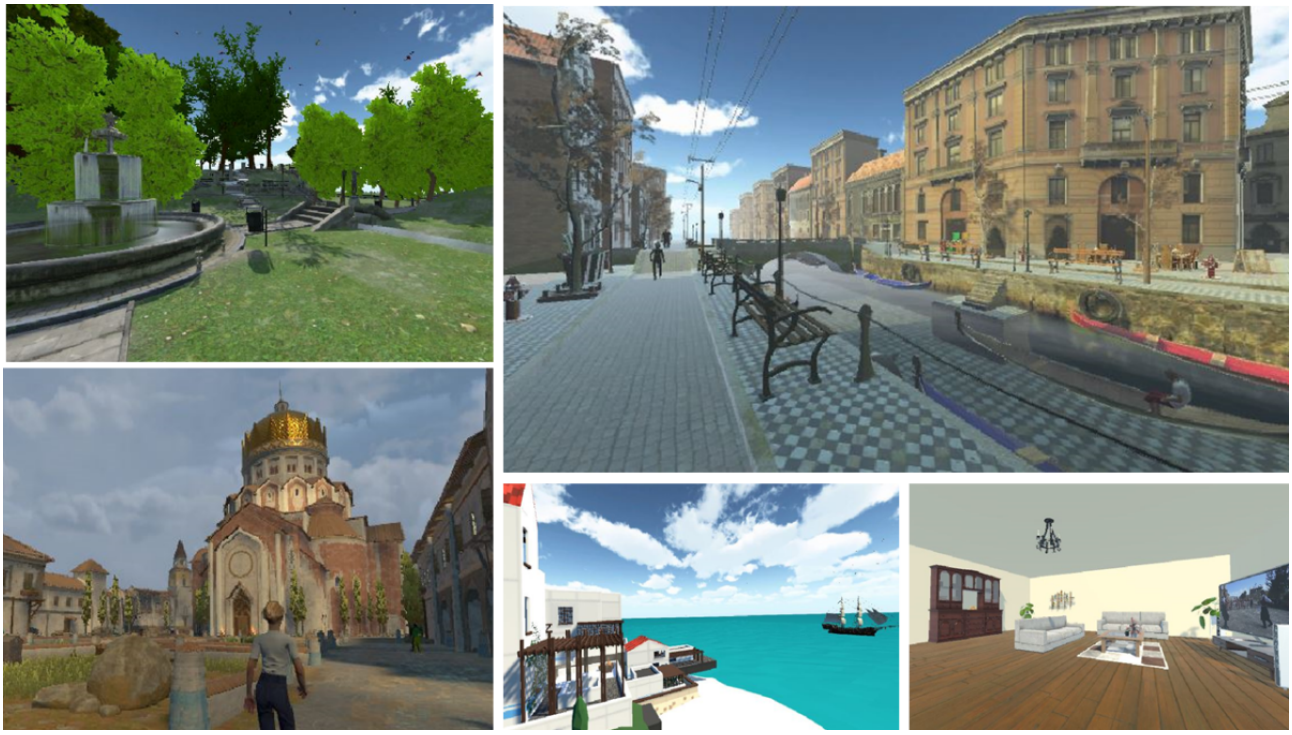
Two focus groups with 17 specialists (group 1) and 13 patients with dementia (group 2) were then conducted to rate the available virtual environments. Through this process, 14 virtual environments were selected for final inclusion, as can be seen in Figure 2, which presents the identification and selection process. All of the virtual environments were enhanced with sounds (eg, sounds of nature and traditional music), videos (eg, traditional dancing, cooking shows, and movies), animals (eg, birds, cats, cows, and deer), people, and other elements. Snapshots of some of the virtual environments that were included in this study are displayed in Figure 3.

Figure 2. Identification and selection process for the VEs included in the virtual reality system. HCP: health care professional; VE: virtual environment.



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Figure 3. Snapshots of 5 of the 14 virtual environments that were offered to the patients with dementia.



System Usability and Presence

High ratings for presence (maximum score of 7) were reported by both patients with dementia (mean 6.4, SD 0.92) and HCPs (mean 4.82, SD 1.49). HCPs reported high ratings for system usability, with an average score of 71.63.

Exposure Time

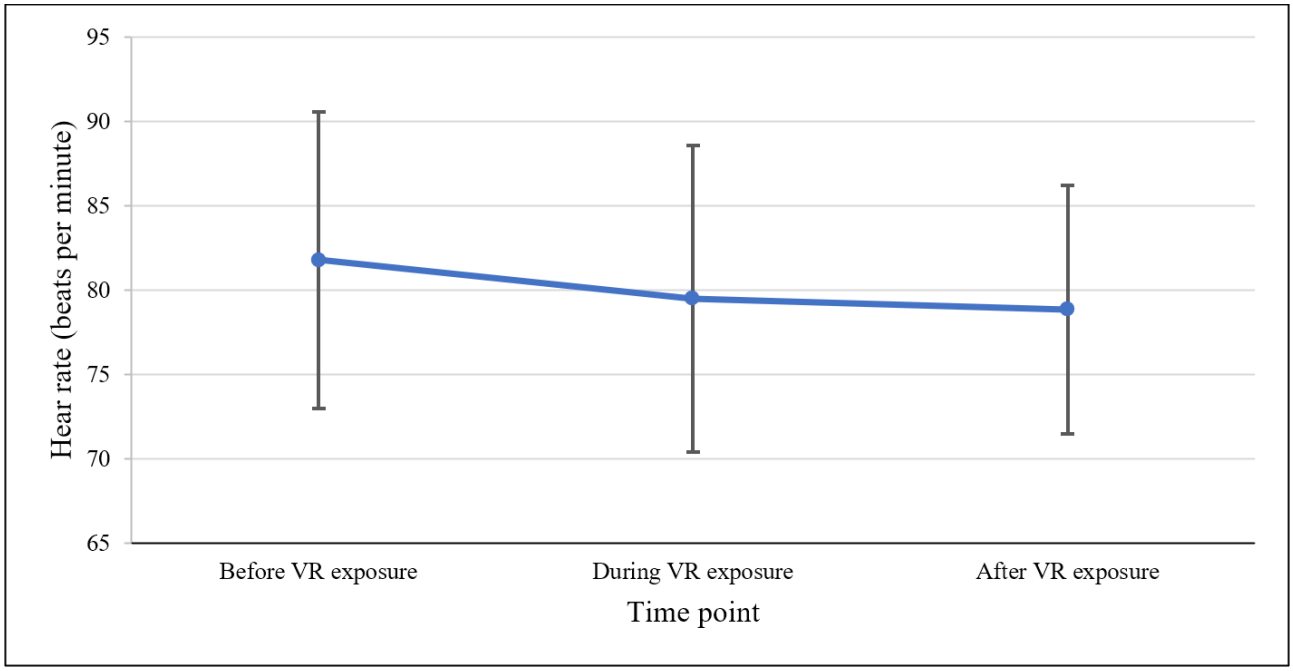
Our findings suggested that 17 of 20 patients with dementia completed the 15-minute VR session, and almost all (n=15) requested a longer exposure time; some of the participants refused to remove the headset, and up to 5 more minutes were offered to them (exposure time: mean 16.08, SD 1.63 minutes). Only 3 out of 20 patients with dementia requested to limit the exposure time due to the headset's properties (eg, the headset was too heavy for them and blocked their normal breathing; exposure time: mean 4.79, SD 2.52 minutes). The overall average exposure time was 14.38 (SD 4.47) minutes. No adverse effects, such as motion sickness or dizziness, were reported by the patients with dementia during or after VR use.

Heart Rate

The heart rate measurements of patients with dementia before, during, and after VR exposure were compared. The repeated measures ANOVA indicated that heart rates were significantly different among the three measurement time points ($F_{2,17}$=5.86; P=.007). A post hoc pairwise comparison with Tukey correction showed a significant decrease in heart rate from before to during VR exposure (Z=2.76; P=.03) and a significant decrease from before to after VR exposure (Z=2.65; P=.04). No significant difference was found between heart rate during VR exposure and heart rate after VR exposure (Z=0.88; P=.66). These findings indicate the ability of VR to reduce the heart rates of patients with dementia (Figure 4).

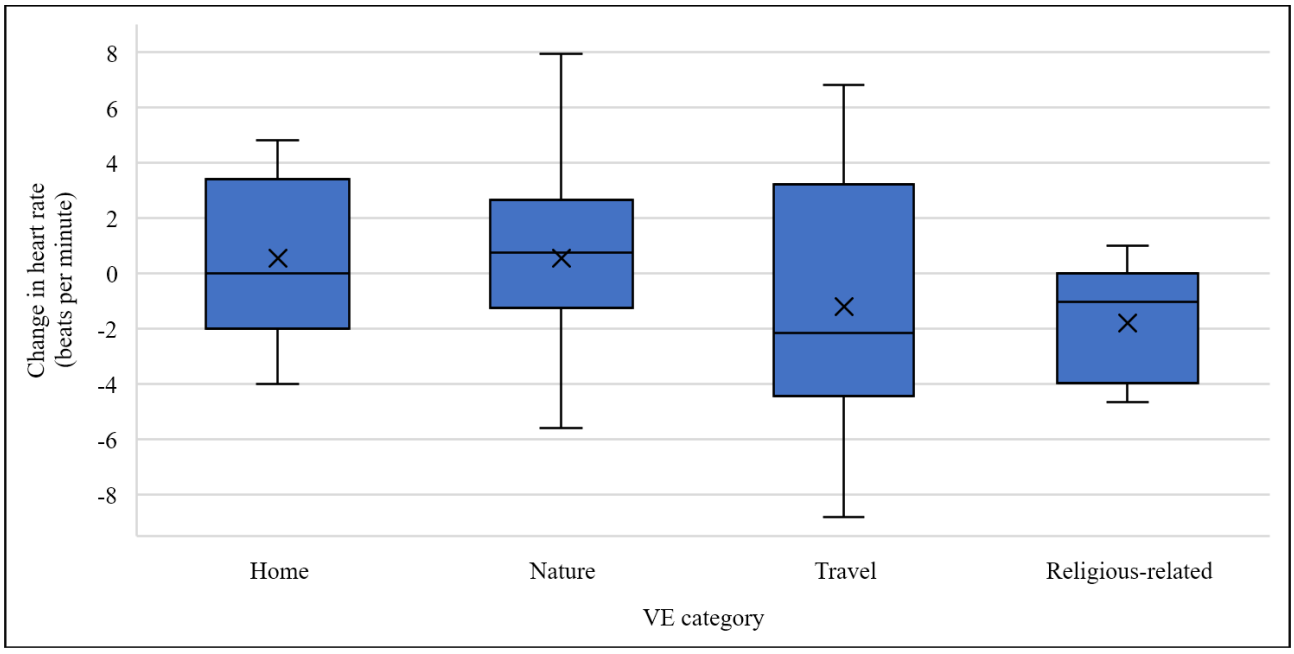
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Figure 4. Heart rate before, during, and after VR exposure. VR: virtual reality.



The 14 virtual environments were grouped into different categories based on their context (eg, nature scenes, travel destinations, etc). Figure 5 shows the change in heart rate from the start of VR exposure to the end of VR exposure for the virtual environment categories to which at least two patients with dementia were exposed. The categories that resulted in the highest decrease in heart rate measures were religious-related content (mean −1.81, SD 2.1 beats per minute) and travel (mean −1.22, SD 5.25 beats per minute).

Figure 5. Box and whisker plot showing the change in heart rate from before virtual reality exposure to after virtual reality exposure for each thematic category of VEs. VE: virtual environment.



Eye Tracking

As previously mentioned, patients with dementia were provided with an A3-sized sheet of paper presenting a “menu” with pictures of the available virtual environments to choose from. Each patient with dementia could choose up to 3 virtual environments (n=60). Descriptive statistics indicated that patients with dementia viewed a total of 52 different environments. Most patients with dementia requested to be exposed to environments relevant to nature (30/52, 58%). This was followed by familiar places, such as home environments (10/52, 19%), environments related to traveling (6/52, 12%), and religious places (4/52, 8%). It is worth noting that during their exposure to religious places, the patients with dementia reacted as if the virtual place was a real holy place (eg, patients with dementia crossed themselves while entering the temple environment). These reactions indicate high levels of immersion

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and presence. Patients with dementia showed limited interest in sport-related virtual environments (2/52, 4%).

Table 1 presents the amount of time patients with dementia spent looking at different groups of objects within the virtual environments, based on the total time they were exposed to VR. Almost 33% of the time was spent looking at background elements, such as the atmosphere (eg, the sky, clouds, etc) and the ground (eg, grass and floor). Various naturalistic elements were also widely looked at (eg, 13.93% of the time was spent looking at trees, plants, etc; around 6% of the time was spent looking at water, hills, etc). Patients with dementia were also attracted to moving and active objects within the virtual environments, spending 9.22% of the time looking at them. For example, these included cars racing, boats sailing, and content playing on a television. Further, relative to their sparsity within the virtual environments, the time patients with dementia spent looking at animals was also noteworthy.

Table . The percentage of time people looked at different categories of objects within the virtual environments.

Object category	Viewing time, %[a]
Atmosphere	16.65
Ground	16.14
Flora	13.93
Motion/active objects	9.22
Water	6.52
Nature	5.97
Wall	5.65
Religious place	5.07
Building	4.56
Furniture	4.2
Animal	3.87
Item	3.1
Human	1.6
Art	1.47
Decoration	0.8
Other	1.25

[a]Amount of time spent looking at an object over the total time of virtual reality exposure.

Affective Experiences in VR

A range of data sources was analyzed to identify the affects experienced by patients with dementia in VR. As can be seen from the following results, VR usage was associated with many positive emotions.

The OAS-MNR

Overall, 6 of 20 in-patients presented aggressive behaviors (verbal aggression: n=3; physical aggression toward self: n=3). There was a reduction in the frequency and severity of overt aggression before the VR exposure compared to those during and after the VR exposure. The aggregate aggression score was calculated by multiplying frequency by the mean weighted severity. An aggregate aggression score of 9 was calculated before VR exposure, which decreased to 0 during and after VR exposure.

The OERS

The Friedman test indicated that ratings of pleasure before, during, and after VR exposure significantly differed (χ^2_2=25.200; *P*<.001). Wilcoxon signed-rank tests revealed a significant increase in pleasure from before to during VR exposure (*Z*=–3.755; *P*<.001), from before to after VR exposure (*Z*=–3.140; *P*=.002), and from during to after VR exposure (*Z*=–2.683; *P*=.007). These findings suggest that patients with dementia feel pleasure and have positive emotions when they are immersed in VR. These findings also suggest a reduction in positive emotions once patients return to reality, but in comparison to the pre-exposure reports, pleasure was still significantly high.

Ratings of anger before, during, and after VR exposure significantly differed (χ^2_2=31.902; *P*<.001). Wilcoxon signed-rank tests revealed a significant decrease in anger from before to during VR exposure (*Z*=–3.873; *P*<.001) and from before to after VR exposure (*Z*=–3.637; *P*<.001). There was no significant difference between anger during VR exposure and anger after VR exposure (*P*=.40).

The Friedman test indicated that ratings of anxiety and fear before, during, and after VR exposure significantly differed (χ^2_2=25.750; *P*<.001). Wilcoxon signed-rank tests revealed a significant decrease in anxiety and fear from before to during VR exposure (*Z*=–3.579; *P*<.001) and from before to after VR exposure (*Z*=–3.453; *P*=.001). No significant differences were

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reported between anxiety and fear during VR exposure and those after exposure (P=.76).

Similarly, the ratings of sadness before, during, and after VR exposure were significantly different (χ^2_2=18.746; P<.001). Wilcoxon signed-rank tests revealed a significant decrease in sadness from before to during VR exposure (Z=–3.367; P=.001) and a significant increase in sadness from during to after VR exposure (Z=–3.015; P=.003). There was no significant difference between sadness before VR exposure and sadness after VR exposure (P=.07).

Finally, ratings of general alertness before, during, and after VR exposure significantly differed (χ^2_2=36.701; P<.001). Wilcoxon signed-rank tests revealed a significant increase in general alertness from before to during VR exposure (Z=–3.931; P<.001), from before to after VR exposure (Z=–3.834; P<.001), and from during to after VR exposure (Z=–3.517; P<.001). These findings suggest that patients with dementia reacted with alertness (ie, participated in the VR interactions, maintained eye contact with and followed objects like animals and persons in the virtual environment, looked around the room, turned their body to have a better view, and talked about and described the virtual environment) and had positive emotions when they were immersed in VR. These findings also suggest that alertness persisted after the VR exposure (Table 2).

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Table . Observed ratings of emotions before, during, and after virtual reality (VR) exposure from the Observed Emotion Rating Scale.

Affect and VR exposure time point	Rating, mean (SD)	Rating, median	Phase	*P* value
Pleasure				<.001
Before VR exposure	1.80 (0.95)	2.00	Before VR exposure to during VR exposure	<.001
During VR exposure	3.55 (0.94)	3.00	Before VR exposure to after VR exposure	.002
After VR exposure	2.80 (0.41)	3.00	During VR exposure to after VR exposure	.007
Anger				<.001
Before VR exposure	2.35 (1.04)	2.00	Before VR exposure to during VR exposure	<.001
During VR exposure	2.19 (0.51)	2.00	Before VR exposure to after VR exposure	<.001
After VR exposure	1.28 (0.33)	1.25	During VR exposure to after VR exposure	.40
Anxiety and fear				<.001
Before VR exposure	2.65 (2.00)	1.23	Before VR exposure to during VR exposure	<.001
During VR exposure	1.25 (1.00)	0.44	Before VR exposure to after VR exposure	.001
After VR exposure	1.20 (1.00)	0.52	During VR exposure to after VR exposure	.76
Sadness				<.001
Before VR exposure	2.40 (1.09)	2.00	Before VR exposure to during VR exposure	.001
During VR exposure	1.23 (0.38)	1.00	Before VR exposure to after VR exposure	.07
After VR exposure	1.77 (0.41)	1.71	During VR exposure to after VR exposure	.003
Alertness				<.001
Before VR exposure	1.35 (0.49)	1.00	Before VR exposure to during VR exposure	<.001
During VR exposure	4.03 (0.74)	4.00	Before VR exposure to after VR exposure	<.001
After VR exposure	3.04 (0.90)	3.00	During VR exposure to after VR exposure	<.001

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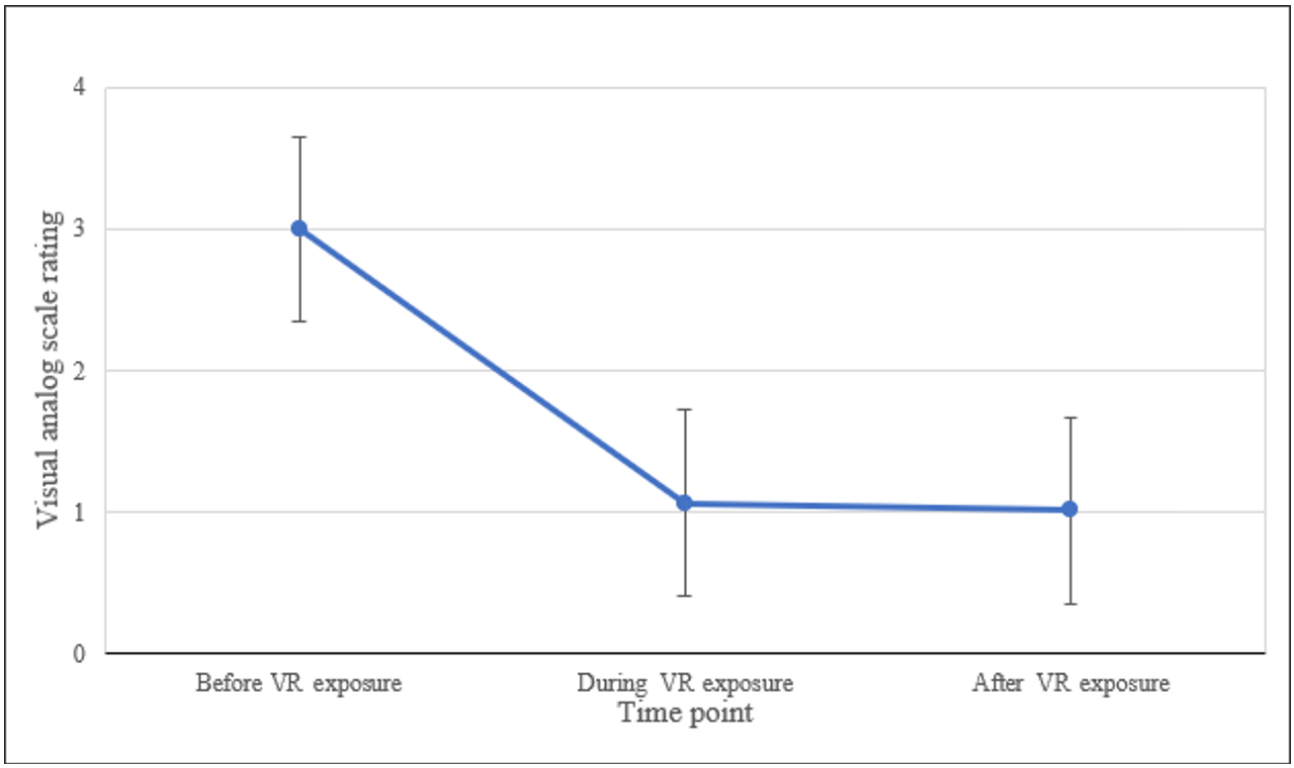
The VAS

The Friedman test indicated that the negative emotions before, during, and after VR exposure were significantly different (χ^2_2=31.66; *P*<.001). Wilcoxon signed-rank tests revealed a significant decrease in negative emotions (and a significant increase in positive emotions) from before to during VR exposure (*Z*=–3.735; *P*<.001) and from before to after VR exposure (*Z*=–3.836; *P*<.001). However, there was no significant difference between the emotional state of the person during the VR exposure and that after the VR exposure (*P*=.64; Table 3, Figure 6).

Table . Emotions before, during, and after virtual reality (VR) exposure (measured using a visual analog scale).

		Rating, mean (SD)	Rating, median	Phase	*P* value
Emotional state					<.001
	Before VR exposure	3.00 (1.45)	2.50	Before VR exposure to during VR exposure	<.001
	During VR exposure	1.07 (1.19)	0.83	Before VR exposure to after VR exposure	<.001
	After VR exposure	1.01 (1.22)	0.83	During VR exposure to after VR exposure	.64

Figure 6. Emotions before, during, and after VR exposure (measured using a visual analog scale). VR: virtual reality.



Discussion

Principal Findings and Implications for Design

The importance of supporting the health-related quality of life of patients with dementia, including mental health and well-being, is undoubted. Current research suggests that VR can be a reliable, feasible, and acceptable solution that can promote engagement and provide an enjoyable experience for patients with dementia [18,19]. This paper describes how 24 patients with dementia, 20 patients with MCI, and 51 medical experts co-designed a VR system for reducing BPSDs among patients with dementia residing in long-term care. This paper also presents the evaluation of the system, which was carried out with 20 patients with dementia and 16 medical experts. Our findings suggest that VR encompasses several therapeutic benefits for patients with dementia. Particularly, it was shown that VR can be very effective for the reduction of BPSDs and, especially, the reduction of aggressive, agitated, anxious, apathetic, depressive, and fearful behaviors.

The results validated that VR could result in a significant improvement in BPSDs, which are highly associated with poor well-being for patients with dementia residing in long-term care [36-38]. As we have shown in the *Results* section, the recording and analysis of physiological data allow for a better understanding of the emotional states of patients with dementia during VR exposure. Earlier research has shown that stress can affect heart rate [39]; therefore, particularly promising results from our study were the heart rate data collected before, during, and after VR session. The analysis revealed a significant

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decrease in heart rate from before to during (P=.03) and after (P=.04) VR exposure, validating that VR can significantly reduce stress levels for patients with dementia. Therefore, these findings are especially important, since they triangulate the validation of the effectiveness of VR for patients with dementia.

To reduce BPSDs, exposure to outworld and low-stimulus experiences have been suggested in the general literature [40-42]. We support this suggestion and recommend that VR environments incorporate out-of-reach experiences that are enhanced by animals, artistic content, natural environments, and travel destinations.

In particular, we found that animals, such as cows, donkeys, birds, and cats, among others, can benefit patients with dementia, and this is in line with previous research suggesting that watching animal content can reduce cardiovascular responses, stress, and anxiety and can generally benefit the health of patients with dementia [43-45].

We also included music and dancing festivals as part of our VR content. We found that such content, within VR, can replicate the findings of the existing literature, as it can create meaningful experiences, reduce stress and anxiety [46,47], and increase communication between caregivers and patients with dementia [48]. Similarly, consistent with previous studies, we found that patients with dementia reminisced when they were exposed to environments with which they were familiar [49]. This is an important finding, since reminiscence therapy is recommended as a person-centered approach for treating dementia [50]. Even though the system was not fully personalized, we managed to use familiar bodies (eg, traditional dancing festivals and older-style homes) that closely matched the memories of patients with dementia. Therefore, to successfully design a VR system for patients with dementia, the use of elements that patients are familiar with is essential, since such elements trigger memories of their past.

Per our findings, we also advise adding naturalistic environments. Based on previous research, nature viewing can enhance emotional well-being and aid recovery from stress [51,52]. Indeed, nature-related environments were the most commonly chosen virtual environments among our patients with dementia, and based on our findings, nature was able to enhance emotional well-being and aid recovery from stress. 53,54

Conclusions, Limitations, and Future Directions

This paper describes a study that examines the design and development of a VR system for patients with dementia. In contrast to prior works, to overcome limitations in the current literature, the system was co-designed with a total of 24 patients with dementia, 20 patients with MCI, and 51 experts in dementia care and was evaluated with a larger population (compared to other relevant studies) of patients with mild to severe cases of dementia. Based on our findings, VR can enhance the health-related quality of life of patients with dementia, as it encompasses a wide range of therapeutic benefits. VR was shown to be especially effective in reducing heart rate and aggressive, agitated, anxious, depressive, and fearful behaviors associated with BPSDs.

A major limitation of this study is that we evaluated the system only in a single trial. In the future, it will be necessary to conduct a longitudinal study to determine whether the positive results are sustainable and determine the clear benefits of the permanent deployment of VR in health care. Another limitation of this study is that the focus was exclusively on evaluating the VR solution in health facilities, and help was provided to the patients when administering the VR system. In recent years, low-cost, immersive VR consumer systems have been developed and released. Therefore, we suggest that future studies evaluate the use of an affordable, home-based VR solution for patients with dementia. Additionally, while this study provides the basis for conducting the first trial to evaluate the effect of VR therapy on BPSDs validated by physiological responses (eg, heart rate and eye tracking) in care hospitals, a limitation of this study is that it did not correlate the heart rate data with the gaze data. We, therefore, suggest that future studies correlate heart rate with what patients with dementia are looking at within the virtual environment and use this information for the creation of more personalized experiences. Further research is also warranted on the analysis of the gaze behaviors of patients with dementia for diagnostic purposes and for understanding their affective states during VR exposure. Ultimately, we hope that the results from this study will offer insight into how VR technology can be designed, deployed, and used in dementia care.

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Conflicts of Interest

None declared.

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Abbreviations

BPSD: behavioral and psychological symptom
HCP: health care professional
MCI: mild cognitive impairment
MMSE: Mini-Mental State Examination
OAS-MNR: Overt Aggression Scale-Modified for Neurorehabilitation
OERS: Observed Emotion Rating Scale
VAS: visual analog scale
VR: virtual reality

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Joint Modeling of Social Determinants and Clinical Factors to Define Subphenotypes in Out-of-Hospital Cardiac Arrest Survival: Cluster Analysis

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Abstract

Background: Machine learning clustering offers an unbiased approach to better understand the interactions of complex social and clinical variables via integrative subphenotypes, an approach not studied in out-of-hospital cardiac arrest (OHCA).

Objective: We conducted a cluster analysis for a cohort of OHCA survivors to examine the association of clinical and social factors for mortality at 1 year.

Methods: We used a retrospective observational OHCA cohort identified from Medicare claims data, including area-level social determinants of health (SDOH) features and hospital-level data sets. We applied k-means clustering algorithms to identify subphenotypes of beneficiaries who had survived an OHCA and examined associations of outcomes by subphenotype.

Results: We identified 27,028 unique beneficiaries who survived to discharge after OHCA. We derived 4 distinct subphenotypes. Subphenotype 1 included a distribution of more urban, female, and Black beneficiaries with the least robust area-level SDOH measures and the highest 1-year mortality (2375/4417, 53.8%). Subphenotype 2 was characterized by a greater distribution of male, White beneficiaries and had the strongest zip code–level SDOH measures, with 1-year mortality at 49.9% (4577/9165). Subphenotype 3 had the highest rates of cardiac catheterization at 34.7% (1342/3866) and the greatest distribution with a driving distance to the index OHCA hospital from their primary residence >16.1 km at 85.4% (8179/9580); more were also discharged to a skilled nursing facility after index hospitalization. Subphenotype 4 had moderate median household income at US $51,659.50 (IQR US $41,295 to $67,081) and moderate to high median unemployment at 5.5% (IQR 4.2%-7.1%), with the lowest 1-year mortality (1207/3866, 31.2%). Joint modeling of these features demonstrated an increased hazard of death for subphenotypes 1 to 3 but not for subphenotype 4 when compared to reference.

Conclusions: We identified 4 distinct subphenotypes with differences in outcomes by clinical and area-level SDOH features for OHCA. Further work is needed to determine if individual or other SDOH domains are specifically tied to long-term survival after OHCA.

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KEYWORDS

out-of-hospital-cardiac arrest; machine learning; social determinants of health; SDOH; cluster; cardiac; heart; cardiology; myocardial; phenotype; phenotypes; subphenotype; subphenotypes; mortality; death; survive; survival; survivor; survivors; retrospective; observational; cohort; algorithm; algorithms; k-means; clustering; association; associations

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Introduction

More than 400,000 incidents of out-of-hospital cardiac arrest (OHCA) occur each year in the United States, with low rates of survival [1-4]. Despite poor outcomes, there have been noted improvements in rates of survival over the last decade, leading to a renewed focus on postdischarge longitudinal trajectories. Drivers of disparities in long-term outcomes after OHCA are not well understood and are potentially affected by nonclinical factors. Social determinants of health (SDOH) represent key social, living, and environmental conditions where people reside and work [5]. SDOH are linked to racial, ethnic, and socioeconomic disparities in health outcomes for multiple chronic health conditions [6-9]. Several of these SDOH domains are noted to be important factors in short-term OHCA survival, but the relationships with longer-term outcomes and area-level SDOH have not been deeply explored [10-12]. While individual-level SDOH information provides granular patient-level information, screening and collection of this data can be resource intensive and has been inconsistently collected by health systems and organizations [13]. Area-level SDOH data derived from the US Census at the neighborhood, census tract, zip code, or regional level is highly accessible; linkages to existing health care data sets can provide insight into the association of key social and living environments with clinical outcomes.

Unsupervised machine learning cluster analysis is a methodologic approach that seeks to discover hidden patterns in unlabeled data and can be used to identify distinct subgroups of patients that share certain characteristics that can be tied to specific clinical end points. The primary objective of this approach is to group observations that share similarities in their features or characteristics, allowing the identification of distinct subgroups of patients with similar traits. These subgroups can then be correlated with specific clinical end points, providing valuable insights into disease pathogenesis and potential therapeutic targets. This can function to further elucidate specific clinical subphenotypes of patients and better understand the interactions of complex variables. Prior clustering methods have successfully identified subphenotypes of COVID-19 patients in the intensive care unit, disparities in Black kidney transplant recipients' outcomes, and clusters of patients with high mortality in sepsis [14-16]. Differences in outcomes might be better captured through clustering methodology that could reveal similarities or differences in subgroups of patients to better understand this interaction between SDOH factors and health outcomes. By jointly modeling features, a comprehensive model can account for multiple data sources or features, improving performance over separate models.

The complex interaction between community-level SDOH and clinical factors has undergone limited study in OHCA, and prior work examining outcomes for Medicare beneficiaries has not been explored deeply. Because of this, we undertook an analysis of a Medicare OHCA cohort who survived to discharge using unsupervised machine learning clustering approaches to examine if clinical, demographic, and important SDOH domains are associated with differences in mortality at 1 year.

Methods

Study Population

For this analysis, we used a retrospective observational cohort of age-eligible (≥65 years) Medicare fee-for-service claims data from the Medicare Provider Analysis and Review (MedPAR) and outpatient research identifiable files (RIFs) for January 2013 through December 2015. We identified individual patient demographics, including race and ethnicity, sex, and age from the Medicare Beneficiary Summary file. We included beneficiaries with emergency department (ED)–treated OHCA using claims with *International Classification of Diseases, Ninth Revision, Clinical Modification* (*ICD-9-CM*) codes 427.5, 427.4, 427.41, and 427.42; we mapped *ICD-10-CM* codes I46, I49.0, I49.01, and I49.02 as the primary or admitting diagnosis based on prior approaches used for identifying OHCA patients [17-20]. Beneficiary zip code–level residence was determined from the primary claim present at index admission for OHCA.

Features of Interest

We included a total of 28 continuous and categorical features that were incorporated into our models (Table S1 in Multimedia Appendix 1). These features were selected based on prior OHCA research conducted using Centers for Medicare and Medicaid Services (CMS) data [21] and variables closely aligned with OHCA outcomes. Medicare beneficiary demographics were abstracted from the index hospital claim: age category, sex, and race and ethnicity. Race and ethnicity were classified as Black, White, or "other." The "other" category included CMS-defined racial and ethnic groups: Hispanic; Asian, Native Hawaiian, or Pacific Islander; and American Indian or Alaska Native. Beneficiary comorbidities were identified from the MedPAR or outpatient RIFs and summarized using the Agency for Healthcare Research and Quality Elixhauser Comorbidity Index that were present on admission [22,23]. We also identified beneficiaries who underwent cardiac catheterization and implantable cardioverter defibrillator placement at the index hospitalization for OHCA using documented procedure codes. We determined beneficiaries who underwent interhospital transfer at index hospitalization and those with a prior claim at a skilled nursing facility (SNF) or inpatient stay prior to index OHCA hospitalization. We calculated total length of stay (LOS) for each beneficiary and if they were discharged to a SNF after index hospitalization for OHCA.

For hospital-level variables, we selected key hospital-level characteristics from the American Hospital Association Survey data set that could impact care. Hospital characteristics included total number of hospital beds and hospital teaching status (major academic teaching, minor academic teaching). We also estimated the driving distance to the nearest hospital for each beneficiary based on primary zip code–level residence (<8.0 km, 8.0 km-16.1 km, >16.1 km). The driving distance was calculated using the Open-Source Routing Machine (OSRM) library [24].

We used the US Census Bureau American Community Survey 5-year estimates to identify key zip code–level SDOH domains. These domains were selected based on expert consensus and from prior research using claims data [25]. We mapped selected SDOH features to the residential zip code documented on the

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index OHCA claim. For SDOH features, we included the following at the zip code level: (1) median household income (HHI), (2) percentage unemployed, (3) percentage below the poverty line, (3) percentage with a high school education or higher, (4) percentage with a bachelor's degree or higher, and (4) percentage who drive alone. To characterize urban-rural status, the 2013 National Center for Health Statistics (NCHS) urban-rural classification was used, using the residential zip code identified on the first claim of each encounter. We classified urban-rural status into three categories: (1) large metropolitan urban, (2) small/midmetropolitan, and (3) nonmetropolitan.

Study Outcomes

Our primary outcome was mortality at 1 year from index OHCA. Beneficiary date of death was determined from the Vital Status File, including validated dates of death up to June 2019.

Data Processing and Subphenotype Development

We applied several preprocessing steps to our data set to address outliers, including 95% Winsorization and log transformation of features with skewed distributions, using a total of 28 features for clustering analysis. We selected Winsorization over other approaches given extreme values within the SDOH data set. Beneficiaries that had any missing features of interest were excluded from the final analytic data set.

Cluster Analysis

We used k-means clustering to extract subphenotypes. The final optimal number of clusters was determined from the results generated from the NbClust package in R (version 4.04; R Foundation for Statistical Computing) [26]. We evaluated the robustness of the subphenotypes by rederiving them from hierarchical clustering, assessing the consistency of the subphenotypes from both the k-means and hierarchical approaches visually on uniform manifold approximation and projection (UMAP) spaces (Figure S1 in Multimedia Appendix 2 and Figure S2 in Multimedia Appendix 3). We also numerically examined the agreement of the subphenotype membership using Sankey diagrams and multiclass area under the receiver operating characteristic (ROC) curves.

Statistical Analysis

Descriptive statistics were reported for continuous variables as means with SDs or medians with IQRs, and frequencies with percentages for categorical variables. For the outcome of mortality at 1 year, we first determined time to event with Kaplan-Meier estimation for each subphenotype. We then fitted Cox proportional hazards models to ascertain hazard ratios and 95% CIs for each subphenotype compared to reference. For reference categories, we used all other subphenotypes compared to each selected subphenotype. These models were adjusted using 21 total features: beneficiary demographics (age, sex, race), beneficiary-level cardiac procedures (implantable cardioverter defibrillator, cardiac catheterization), hospital academic status, hospital number of beds, hospital travel distance, complete area-level SDOH factors, and NCHS urban/rural status (Table S2 in Multimedia Appendix 2). Features were selected for the models based on prior OHCA literature and those that more closely aligned with our outcome of survival at 1 year [2,3,11]. To account for the inclusion of multiple predictor variables, we used a linear predictor as an offset in these models. Statistical analyses were performed using R and Python (vesrion 3.9.3). This study was completed in accordance with the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines [27].

Ethical Considerations

The study was reviewed and approved by the Institutional Review Board at the Icahn School of Medicine at Mount Sinai (21-00976).

Results

Overall Cohort

After excluding beneficiaries with missing data, we identified 27,028 unique individuals who survived to discharge after OHCA. Overall, the cohort was 40.1% (n=10,831) female; 15% (n=4055) identified as Black, 79.2% (n=21,407) as White, and 5.8% (n=1566) as "other" beneficiaries (Table 1). For age, 15.4% (n=4156) of the cohort included beneficiaries older than 85 years. Among area-level SDOH, the median HHI by zip code was US $49,720.50 (IQR US $39,893.25-$64,233.25), and the median percentage living below the poverty level at the zip code level was 10.4% (IQR 6.0%-16.4%). Overall mortality at 1 year was 45.1% (n=12,191).

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Table . Overall characteristics by subphenotype.

Features		Subphenotype 1 (n=4417)	Subphenotype 2 (n=9165)	Subphenotype 3 (n=9580)	Subphenotype 4 (n=3866)	Total (n=27,028)	*P* value
Beneficiary-level demographics							
Sex, n (%)							
	Male	2080 (47.1)	5577 (60.9)	6057 (63.2)	2483 (64.2)	16,197 (59.9)	<.001
	Female	2337 (52.9)	3588 (39.1)	3523 (36.8)	1383 (35.8)	10,831 (40.1)	
Age category (years), n (%)							
	65–74	2310 (52.3)	4414 (48.2)	4810 (50.2)	2173 (56.2)	13,707 (50.7)	<.001
	75–84	1344 (30.4)	3169 (34.5)	3321 (34.7)	1331 (34.4)	9165 (33.9)	
	≥85	763 (17.3)	1582 (17.3)	1449 (15.1)	362 (9.4)	4156 (15.4)	
Race, n (%)							
	Black	2631 (59.6)	448 (4.9)	504 (5.3)	472 (12.2)	4055 (15)	<.001
	White	1327 (30)	8234 (89.8)	8729 (91.1)	3117 (80.6)	21,407 (79.2)	
	Other	459 (10.4)	483 (5.3)	347 (3.6)	277 (7.2)	1566 (5.8)	
Elixhauser Comorbidity Index, median (IQR)		14.000 (4.000–23.000)	13.000 (4.000–23.000)	14.000 (4.000–24.000)	14.000 (4.000–24.000)	13.000 (4.000–23.000)	<.001
Beneficiary-level hospital procedures and dispositions							
Cardiac catheterization at index hospitalization, n (%)		843 (19.1)	1767 (19.3)	2937 (30.7)	1342 (34.7)	6889 (25.5)	<.001
Implantable cardioverter defibrillator placement at index hospitalization, n (%)		351 (7.9)	653 (7.1)	1192 (12.4)	347 (9)	2543 (9.4)	<.001
Interhospital transfer at index hospitalization, n (%)		107 (2.4)	6 (0.1)	11 (0.1)	3849 (99.6)	3973 (14.7)	<.001
From skilled nursing facility prior to index OHCA[a] hospitalization, n (%)		559 (12.7)	531 (5.8)	828 (8.6)	226 (5.8)	2144 (7.9)	<.001
Inpatient hospital stay prior to index OHCA, n (%)		114 (2.6)	120 (1.3)	285 (3)	155 (4)	674 (2.5)	<.001
Discharged to skilled nursing facility after index OHCA, n (%)		879 (19.9)	981 (10.7)	1594 (16.6)	1412 (36.5)	4866 (18)	<.001
Total hospital length of stay in days, median (IQR)		5.000 (1.000–12.000)	5.000 (1.000–12.000)	5.000 (1.000–12.000)	5.000 (1.000–12.000)	5.000 (1.000–12.000)	<.001
Total number of interhospital transfers mean (SD)		0.024 (0.156)	0.001 (0.026)	0.001 (0.034)	1.135 (0.362)	0.167 (0.424)	<.001
Travel distance to index OHCA hospital from residence (kilometers), n (%)							
	<8.0	2566 (58.1)	6049 (66)	73 (0.8)	1510 (39.1)	10,198 (37.7)	<.001
	8.0-16.1	1182 (26.8)	2639 (28.8)	1328 (13.9)	851 (22)	6000 (22.2)	<.001
	>16.1	669 (15.1)	477 (5.2)	8179 (85.4)	1505 (38.9)	10,830 (40.1)	<.001
Hospital-level characteristics, n (%)							
Minor academic teaching		1406 (31.8)	471 (5.1)	1541 (16.1)	431 (11.1)	3849 (14.2)	<.001
Major academic teaching		3011 (68.2)	8694 (94.9)	8039 (83.9)	3435 (88.9)	23,179 (85.8)	<.001
Total number of beds[b], median (IQR)		7.000 (5.000–8.000)	5.000 (4.000–6.000)	6.000 (4.000–8.000)	5.000 (4.000–7.000)	5.000 (4.000–7.000)	<.001
Area-level social determinants of health							

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Features		Subphenotype 1 (n=4417)	Subphenotype 2 (n=9165)	Subphenotype 3 (n=9580)	Subphenotype 4 (n=3866)	Total (n=27,028)	*P* value
	Household income (US $) at zip code level, median (IQR)	$36,462 ($29,648-$45,309)	$54,375 ($44,320-$72,394)	$50,818 ($41,825.50-$63,549.25)	$51,659.50 ($41,295-$67,081)	$49,720.50 ($39,893.25-$64,233.25)	<.001
	Percentage unemployed at zip code level, median (IQR)	8.4 (6.8–10.4)	5 (3.9–6.2)	5.15 (4–6.6)	5.5 (4.2–7.1)	5.5 (4.2–7.2)	<.001
	Percentage below poverty level at zip code level, median (IQR)	22.1 (16.5–29)	8.4 (4.9–12.8)	9.2 (5.5–14)	9.8 (5.7–15.7)	10.4 (6–16.4)	<.001
	Percentage high school education or higher at zip code level, median (IQR)	79 (72.3–84)	90.5 (85.9–93.9)	88.5 (83.2–92.6)	88.4 (81.8–92.9)	88 (81.6–92.6)	<.001
	Percentage bachelor's degree or higher at zip code level, median (IQR)	16.9 (11.6–24.6)	28.3 (19.2–43)	21 (14.7–31.3)	24.2 (16.3–36.4)	22.8 (15.5–34.7)	<.001
	Percentage who drive alone at zip code level, median (IQR)	72.9 (58.5–79)	81 (76.8–84.3)	82.3 (78.5–85.6)	80.6 (75.8–84.4)	80.6 (75.4–84.4)	<.001
	NCHS[c] large metropolitan urban classification, n (%)	3223 (73)	4776 (52.1)	3373 (35.2)	2095 (54.2)	13,467 (49.8)	<.001
	NCHS small/mid metropolitan classification, n (%)	1028 (23.2)	2599 (28.4)	3561 (37.2)	1143 (29.6)	8331 (30.8)	<.001
	NCHS nonmetropolitan classification, n (%)	166 (3.8)	1790 (19.5)	2646 (27.6)	628 (16.2)	5230 (19.4)	<.001
Outcomes							
	1-year mortality	2375 (53.8)	4577 (49.9)	4032 (42.1)	1207 (31.2)	12,191 (45.1)	<.001

[a]OHCA: out-of-hospital cardiac arrest.

[b]Number of beds: 1=6-24 beds, 2=25-49 beds, 3=50-99 beds, 4=100-199 beds, 5=200-299 beds, 6=300-399 beds, 7=400-499 beds, 8=500 or more beds.

[c]NCHS: National Center for Health Statistics.

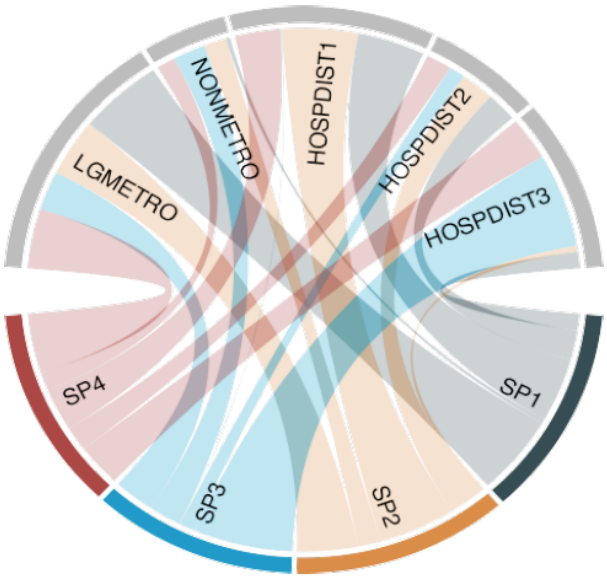
Characteristics of Subphenotypes by K-Means

We identified 4 distinct subphenotypes that were statistically and significantly different based on distributions of features. Distributions can be seen in the chord diagrams in Figure 1, and the relationship of normalized features and cluster membership is shown in Figure 2.

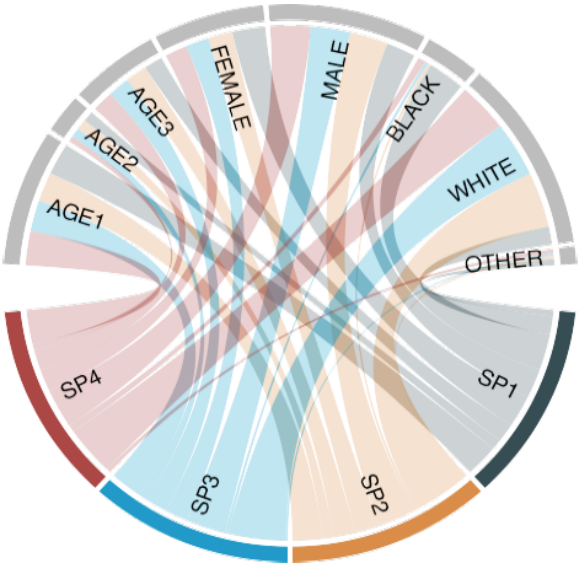
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Figure 1. Chord diagrams demonstrating grouped characteristics for each of 4 out-of-hospital cardiac arrest (OHCA) subphenotypes. The diagrams demonstrate the grouped characteristics by each subphenotype. Each chord diagram includes key grouped features and their relationship with each subphenotype. The size of each chord (or arc) is representative of the proportional relationship between each feature and subphenotype. (A) Urban/nonurban and driving distance by subphenotype. (B) Beneficiary-level demographics by subphenotype. (C) Hospital characteristics and procedures by subphenotype. (D) Beneficiary disposition by location for each subphenotype. AGE1: beneficiary level—age category 65-74 years; AGE2: beneficiary level—age category 75-84 years; AGE3: beneficiary level—age category >85 years; BLACK: beneficiary level—Black race; CATH: beneficiary level—cardiac catheterization at index hospitalization; DRIVE: area level—percentage who drive alone at zip code level; ELX: beneficiary level—Elixhauser comorbidity index; FEMALE: beneficiary level—female sex; FROMSNF: beneficiary level—from skilled nursing facility prior to index OHCA; HOSPBEDS: hospital level—total number of beds; HOSPDIST1: beneficiary level—distance to travel to hospital from residence <8.0 kilometers; HOSPDIST2: beneficiary level—distance to travel to hospital from residence 8.0-16.1 kilometers; HOSPDIST3: beneficiary level—distance to travel to hospital from residence >16.1 kilometers; ICD: beneficiary level—implantable cardioverter defibrillator placement at index hospitalization; INPATIENT: beneficiary level—inpatient hospital stay at index OHCA; LGMETRO: area level—National Center for Health Statistics large metropolitan urban classification; LOS: beneficiary level—total hospital length of stay in days; MAJOR: hospital level—major academic teaching; MINOR: hospital level—minor academic teaching; NONMETRO: area level—National Center for Health Statistics nonmetro classification; OTHER: other beneficiary race/ethnicity (Centers for Medicare and Medicaid Services–defined categories Hispanic, Asian, Native Hawaiian or Pacific Islander, American Indian, or Alaska Native); SP1: subphenotype 1; SP2: subphenotype 2; SP3: subphenotype 3; SP4: subphenotype 4; TOSNF: beneficiary level—to skilled nursing facility after index OHCA; TRNSFR: beneficiary level—interhospital transfer at index hospitalization; TRSNFRTOT: beneficiary level—total number of interhospital transfers; WHITE: beneficiary level—White race.

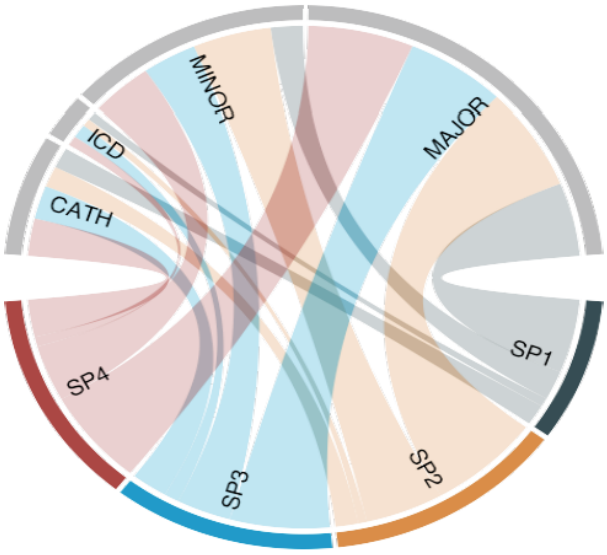
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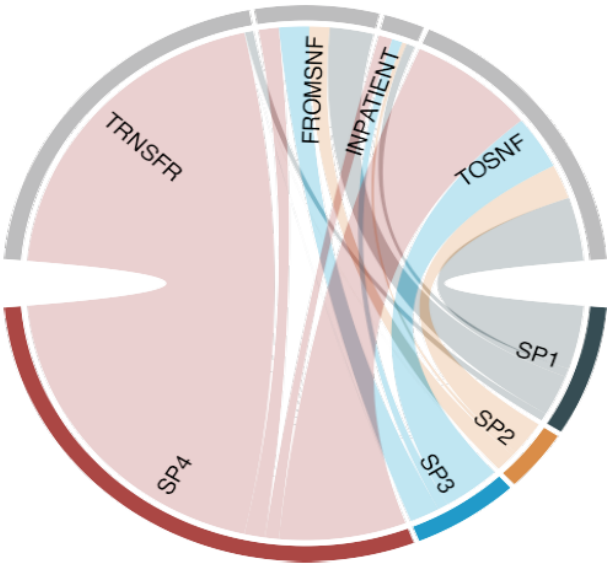
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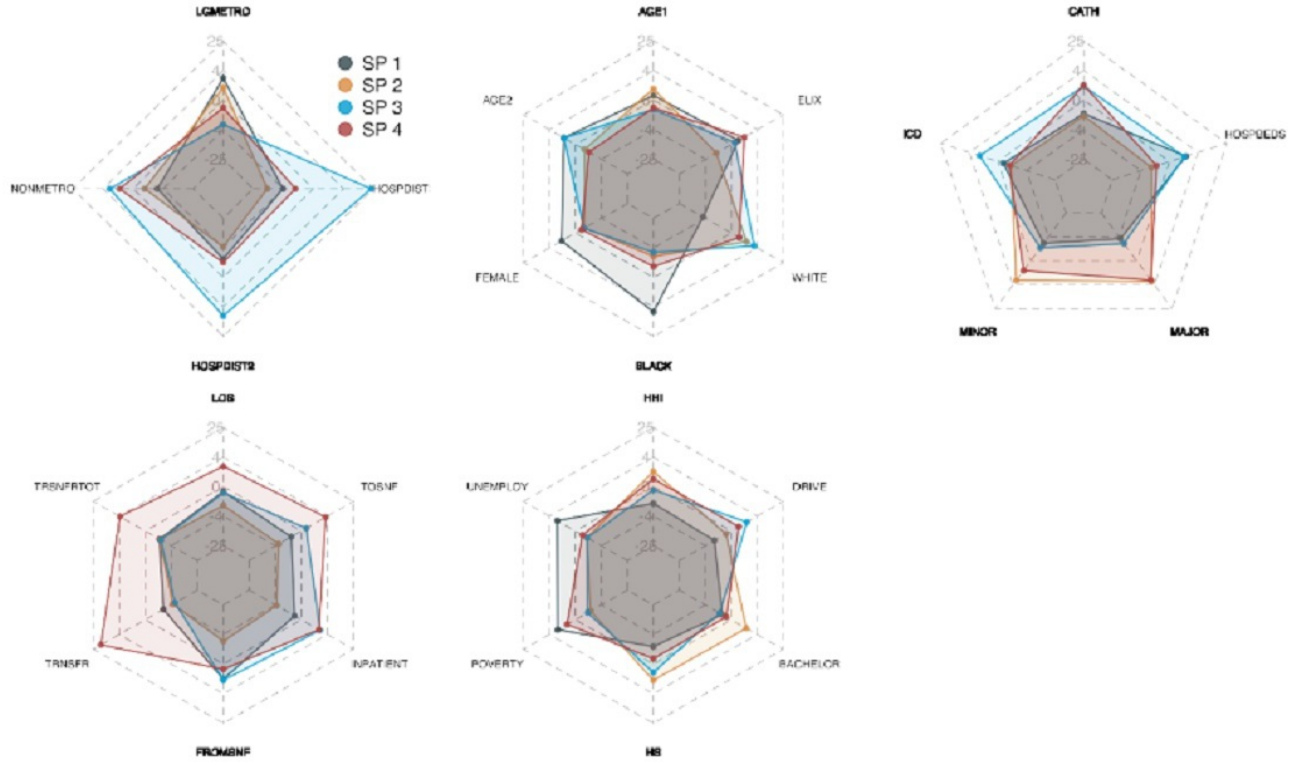
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Figure 2. Radar plots demonstrating the degree of association between normalized features and cluster membership. The radar plots represent the degree of association between normalized features and cluster membership. Each point represents a coefficient from the multinomial regression model for subtypes using normalized features (note that we do not normalize binary features), and each grid line represents −25, −4, 0, 4, and 25, respectively, where axes are scaled with squared root. As an example, a 1 unit increase in normalized household income (HHI) increases log odds of subtype 1-4 by −2.0, 1.6, −0.1, and 0.4. AGE1: beneficiary level—age category 65-74 years; AGE2: beneficiary level—age category 75-84 years; BLACK: beneficiary level—Black race ; CATH: beneficiary level—cardiac catheterization at index hospitalization; DRIVE: area level—percentage who drive alone at zip code level; ELX: beneficiary level—Elixhauser comorbidity index; FEMALE: beneficiary level—female sex; FROMSNF: beneficiary level—from skilled nursing facility prior to index OHCA; HOSPBEDS: hospital level—total number of beds; HOSPDIST1: beneficiary level—distance to travel to hospital from residence <8.0 km; HOSPDIST2: beneficiary level—distance to travel to hospital from residence 8-16 kilometers; ICD: beneficiary level—implantable cardioverter defibrillator placement at index hospitalization; INPATIENT: beneficiary level—inpatient hospital stay at index OHCA; LGMETRO: area level—National Center for Health Statistics large metropolitan urban classification; LOS: beneficiary level—total hospital length of stay in days; MAJOR: hospital level—major academic teaching; MINOR: hospital level—minor academic teaching; NONMETRO: area level—National Center for Health Statistics nonmetro classification; SP1: subphenotype 1; SP2: subphenotype 2; SP3: subphenotype 3; SP4: subphenotype 4.; TOSNF: beneficiary level—to skilled nursing facility after index OHCA; TRNSFR: beneficiary level—interhospital transfer at index hospitalization; TRSNFRTOT: beneficiary level—total number of interhospital transfers; WHITE: beneficiary level—White race.



Subphenotype 1

Subphenotype 1 (n=4417) included the largest distribution of female and Black beneficiaries, 52.9% (n=2337) and 59.6% (n=2631) respectively, as well as Other benefciaries at 10.4% (n=459), who resided in more NCHS urban-classified zip codes (n=3323, 73%). A greater proportion were transferred from a SNF prior to index hospitalization for OHCA. Compared to other subphenotypes, beneficiaries in this group had the lowest rates of cardiac catheterization at index hospitalization, at 19.1% (n=843). Subphenotype 1 had, notably, several of the least robust area-level SDOH measures: the lowest median HHI at US $36,462 (IQR US $29,648-$45,309), highest unemployment at 8.4% (IQR 6.8%-10.4%), and highest percentage living below the poverty level at 22.1% (IQR 16.5%-29%). For outcomes, this subphenotype had the highest 1-year mortality at 53.8% (n=2375).

Subphenotype 2

Subphenotype 2 (n=9165) was characterized by a greater distribution of White and male beneficiaries, the smallest distribution of Black beneficaries, and had the strongest zip code–level SDOH measures. This included the highest median HHI at US $54,375 (IQR US $44,320-$72,394), highest median percentage high school education or higher at 90.5% (IQR 85.9%-93.9%), highest median bachelor's degree or higher at 28.3% (IQR 19.2%-43%), and the lowest median unemployment at 5% (IQR 3.9%-6.2%). For subphenotype 2, 1-year mortality was 49.9%(n=4577).

Subphenotype 3

This subphenotype (n=9580) included the largest demographic representation of White beneficiaries and had the highest rate of cardiac catheterization at 34.7% (n=1342), the greatest distribution with a driving distance to index OHCA hospital from primary residence >16.1 kilometers at 85.4% (n=8179), and the highest rate of discharge to a SNF after index hospitalization at 36.5% (n=1412) compared to the other subphenotypes. One year mortality was 41.2% (n=4032).

Subphenotype 4

Subphenotype 4 (n=3866) was characterized by the greatest distribution of the beneficiaries undergoing interhospital transfer at index hospitalization at 99.6% (n=3849) and included a large

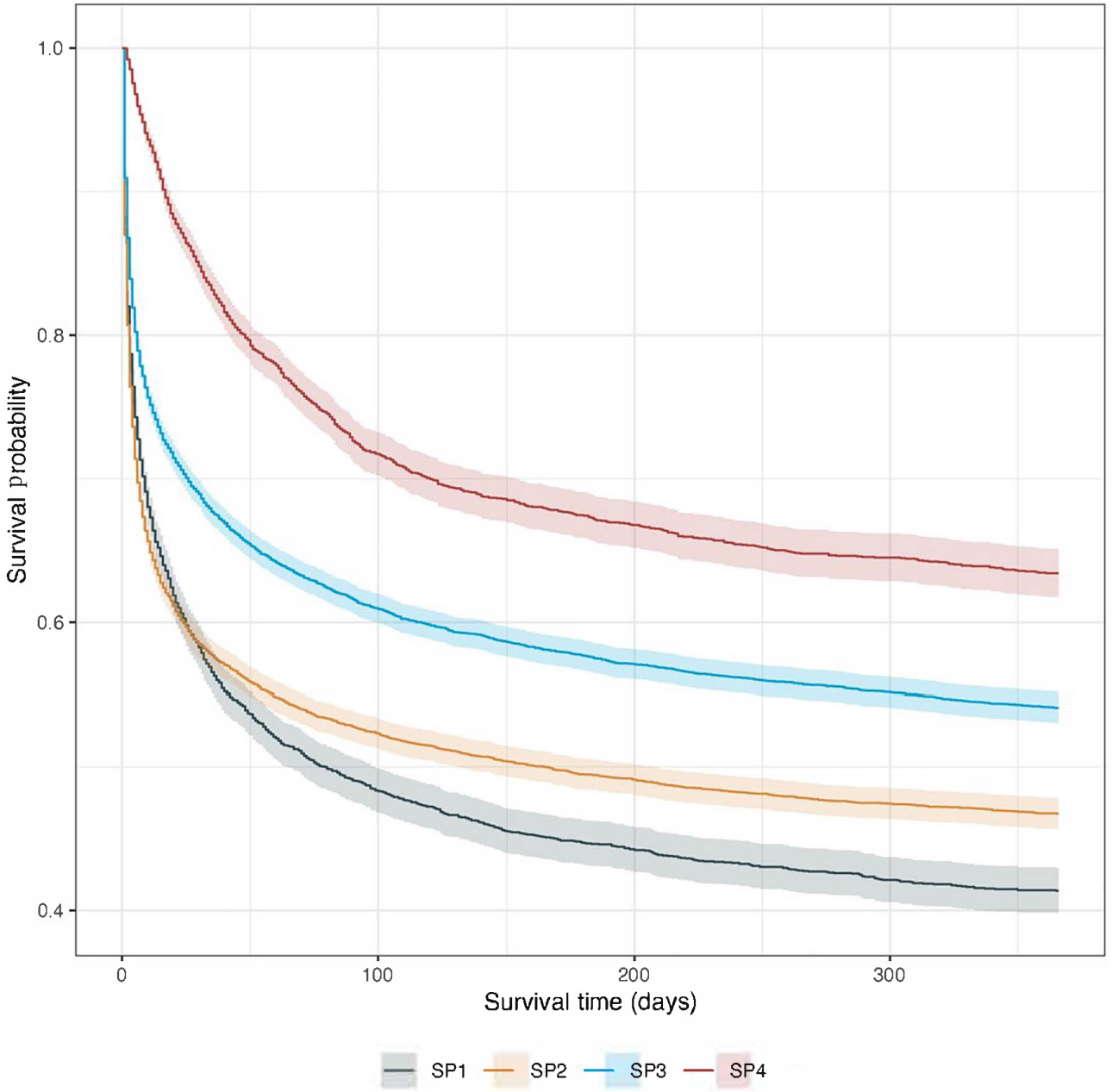
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distribution of male (n=2483) and White (n=3117) beneficiaries. Among zip code–level SDOH measures, beneficiaries in subphenotype 4 had moderate median HHI at US $51,659.50 (IQR US $41,295-$67,081) and moderate to high median percentage unemployed at 5.5% (IQR 4.2%-7.1%) compared to other subphenotypes. This subphenotype had the lowest 1-year mortality at 31.2% (n=1207).

Association of Subphenotypes and Primary Outcomes

One year survival by Kaplan Meier estimation is shown in Figure 3 and Table 2. Subphenotype 1 demonstrated the steepest mortality, with a median survival of 80 days (95% CI 64-99 days) and subphenotype 4 had the highest probability of survival at one year. In fully adjusted models evaluating the primary outcome of mortality at 1 year, subphenotype 4 had a decreased hazard of death at 1 year (hazard ratio [HR] 0.53, 95% CI 0.50-0.57) compared to reference (all other subphenotypes) (Figure 4). For all other subphenotypes (1-3) we found an increased hazard of death compared to reference (subphenotype 1: HR 1.07, 95% CI 1.02-1.12; subphenotype 2: HR 1.19, 95% CI 1.15-1.23; subphenotype 3: HR 1.11, 95% CI 1.07-1.15).

Figure 3. Survival by Kaplan Meier estimation for 1-year mortality for each of the 4 out-of-hospital cardiac arrest subphenotypes. SP1: subphenotype 1; SP2: subphenoytype 2; SP3: subphenotype 3; SP4: subphenotype 4.



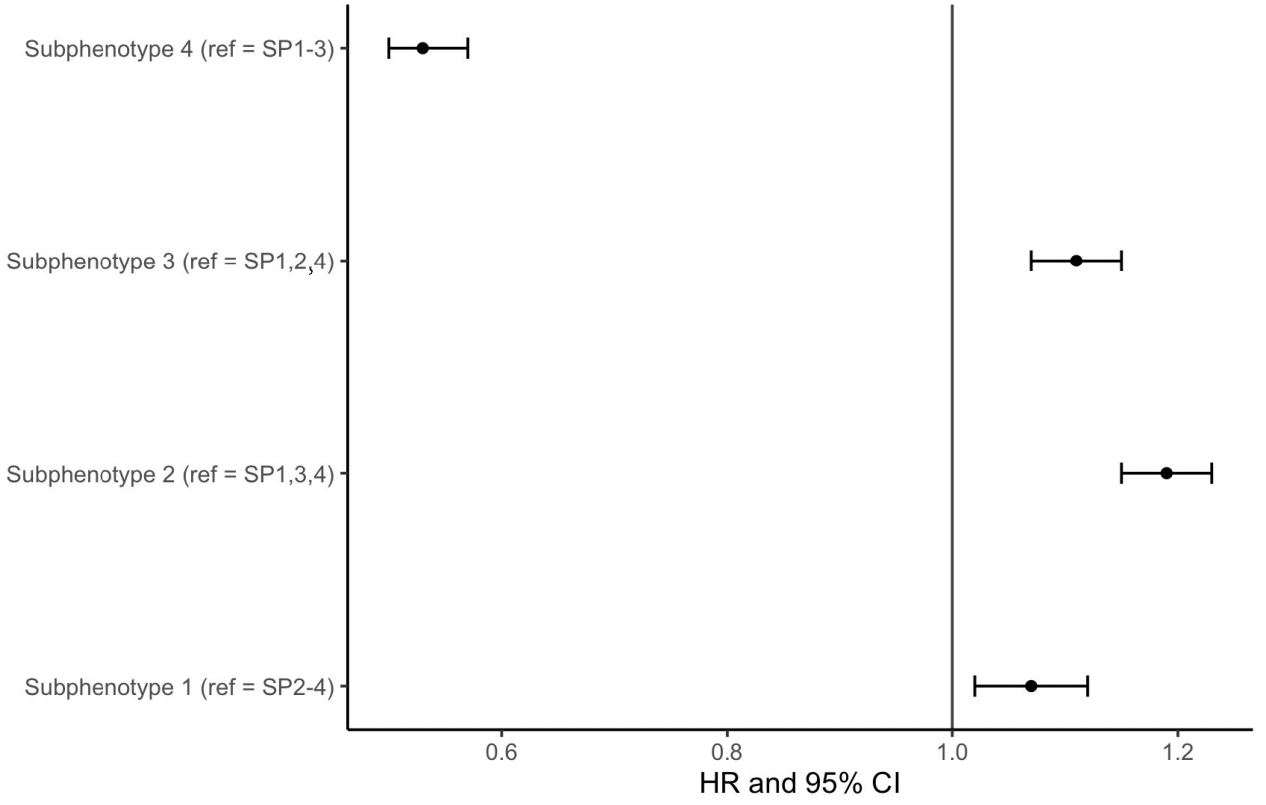
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Table . Time to event for Kaplan-Meier estimation.

	At risk, n	Events, n	Days, mean	Median (95% upper, lower confidence limit)
Subphenotype 1	4417	2375	173.3	80 (64, 99)
Subphenotype 2	9165	4577	187.9	131 (131, 207)
Subphenotype 3	9580	4032	218.4	N/A[a]
Subphenotype 4	3866	1207	257.8	N/A

[a]N/A: not applicable.

Figure 4. Forest plot of Cox proportional hazards models for each subphenotype for outcome of mortality at 1 year using a linear predictor as an offset. Models are adjusted for 21 total features, including beneficiary demographics (age, sex, race), beneficiary-level cardiac procedures (implantable cardioverter defibrillator, cardiac catheterization), hospital academic status, hospital number of beds, hospital travel distance, complete area-level social determinant of health factors, and National Center for Health Statistics urban/rural status (Table S2 in Multimedia Appendix 4). Each subphenotype model is compared to reference (ie, all other subphenotypes). HR: hazard ratio.



Discussion

Principal Findings

In this unsupervised machine learning cluster analysis, we identified 4 unique and distinct OHCA subphenotypes among Medicare beneficiaries using multi-modal data. The characteristics of these subphenotypes are distinguished by both beneficiary demographics and area-level SDOH such as zip code–level HHI, poverty, education, and unemployment. For subphenotype 1, we found high 1-year mortality was tied to poor area-level SDOH factors and subphenotype 4 was tied with moderate SDOH factors and lowest unadjusted 1-year mortality. After complete adjustment and joint modeling of these features, we noted an increased hazard of death for subphenotypes 1 to 3 but not for subphenotype 4 when compared to reference (ie, all other subphenotypes). This exploratory work provides further insight into the complex interaction of nonclinical factors in health outcomes and has identified potential methodological approaches for other patient populations or data sets.

Research using machine learning or clustering approaches and incorporating SDOH factors for predictive modeling of OHCA outcomes is limited, with most prior work using individual-level clinical or prehospital features for outcome prediction, and none using Medicare data [28-31]. Of note, one recent study used the city of Chicago Cardiac Arrest Registry to Enhance Survival (CARES) data merged with multi-modal community-level data to evaluate if social and environmental factors can increase predictive accuracy of models. The authors found, compared to base models using registry data alone, that model accuracy was significantly improved when including important community and social determinants to predict neurological outcomes [32]. A prior study of OHCA patients with nonshockable rhythms using a machine learning latent class

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approach identified 4 clinically distinct subphenotypes associated with neurological and mortality outcomes at 30 days, finding that arterial partial pressure of oxygen, patient age, and serum potassium had the highest discriminatory power; however, this study did not examine area- or individual-level SDOH. Several studies have also found contrasting results, with area-level SDOH factors not demonstrating strong associations with outcomes. In a non-OHCA study specifically assessing the predictive performance of neighborhood-level SDOH for risk prediction, the authors found that SDOH data did not improve models beyond baseline electronic health record data [33].

Our work has identified 4 unique Medicare beneficiary subphenotypes tied to long-term OHCA outcomes in the context of several SDOH domains. Descriptively, we identified important characteristics among our subphenotypes, including differences in distributions across race, sex, key hospital cardiac procedures, rates of interhospital transfer, and zip code–level SDOH factors, such as poverty, HHI, and unemployment. Overall, in models that included adjustment for SDOH, clinical, and demographic factors, the hazard of death at 1 year persisted and was increased across subphenotypes 1 to 3 but decreased for subphenotype 4. This mortality risk was notably highest among subphenotypes 2 and 3 compared to other subphenotypes. This suggests that certain SDOH domains may not modify mortality risk and clinical and demographic factors are drivers of differences in survival. The decreased risk of morality at 1 year for subphenotype 4 was also potentially modified by more robust SDOH factors, but likely represents attributes unique to this subphenotype. The majority of subphenotype 4 underwent interhospital transfer at index OHCA. This could have potentially incurred a survival benefit due to escalation of care at the receiving hospital. Additionally, subphenotype 4 had the smallest distribution of patients aged older than 85 years and high rates of implantable cardioverter defibrillator and cardiac catheterization, potentially leading to differences in outcomes. This could reflect the high morbidity and mortality in OHCA at the extremes of age, as well as improved survival and clinical outcomes for select patients undergoing cardiac catheterization or implantable cardioverter defibrillator placement at index hospitalization.

The results of this study have implications for future work, which could explore if our identified subphenotypes are associated with other OHCA outcomes such as readmission and health care expenditures, as well as their place in the context of broader SDOH domains. This approach could serve to better identify groups of beneficiaries who are at risk for worse postdischarge trajectories after OHCA. Further work is needed to elucidate our findings and examine actionable and modifiable social factors tied to OHCA survival. However, we believe our proposed approach is scalable and feasible and could be applied to emergency care conditions and health outcomes in the context of SDOH factors.

Limitations

There are several limitations to this work that should be noted. Because we are using claims and not cardiac arrest registry data, identification of the cohort may lack similar sensitivity and specificity for OHCA. This could result in potential misclassification of OHCA cases. Additionally, using zip codes as our geographic unit of analysis as opposed to smaller areas, such as census tract or neighborhood level, and using individual-level SDOH data may have limited our ability to identify a robust association with SDOH and clinical outcomes after OHCA. Overall, some of our results could be potentially attributable to the SDOH domains we selected for this study. These domains were not comprehensive and did not include other important SDOH (food insecurity, housing insecurity). Also, it is important to note that the racial composition of Medicare data included more than 75% of beneficiaries who identified as White and 10% of beneficiaries who identified as Black in 2013 [34]. This limits our ability to closely examine outcomes across a robust population that includes representative races and ethnicities for the United States. Despite these limitations, this exploratory research has identified important subphenotypes of beneficiaries linked to SDOH factors who may be at risk for poor long-term outcomes. These areas could be targets for improved in-hospital care or discharge planning to improve long-term survival.

Conclusions

In this machine learning cluster analysis examining the association of area-level SDOH factors with long-term outcomes for a cohort of Medicare beneficiaries who experienced an OHCA, we identified 4 distinct clusters and important associations with SDOH measures and mortality at 1 year. After adjustment, we found an increased hazard of death at 1 year for subphenotypes 1 to 3 and decreased hazard for subphenotype 4 when compared to reference (all other subphenotypes). These results suggest that area-level SDOH measures may be associated with OHCA outcomes, but further work is needed to determine if other individual- or area-level SDOH domains are more closely tied to long-term survival.

Acknowledgments

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Authors' Contributions

EEA and WO contributed equally to study design and intellectual content and are co–first authors. EEA, WO, YD, and LC participated in the design of the study and analysis of the data. EEA drafted the manuscript. All other authors made substantial intellectual contributions to the manuscript and approved the latest version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Table S1. Complete list of proposed features.
[DOCX File, 17 KB - aging_v6i1e51844_app1.docx]

Multimedia Appendix 2
Uniform manifold approximation and projection of k-means clustering (panel 1) vs hierarchical clustering (panel 2).
[DOCX File, 216 KB - aging_v6i1e51844_app2.docx]

Multimedia Appendix 3
Comparison of subphenotypes using k-means and hierarchical clustering algorithms. KM: k-means; HC: hierarchical clustering; SP: subphenotype.
[DOCX File, 138 KB - aging_v6i1e51844_app3.docx]

Multimedia Appendix 4
Features included for cox proportional hazard regression models by subphenotype.
[DOCX File, 13 KB - aging_v6i1e51844_app4.docx]

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Abbreviations

CARES: Cardiac Arrest Registry to Enhance Survival
CMS: Centers for Medicare and Medicaid Services
ED: emergency department
HHI: household income
HR: hazard ratio
***ICD-9-CM*:** *International Classification of Diseases, Ninth Revision, Clinical Modification*
LOS: length of stay
MedPAR: Medicare Provider Analysis and Review
NCHS: National Center for Health Statistics
OHCA: out-of-hospital cardiac arrest
OSRM: Open-Source Routing Machine
RIF: research identifiable file
ROC: receiver operating characteristic
SDOH: social determinants of health
SNF: skilled nursing facility
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
UMAP: uniform manifold approximation and projection

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Original Paper

How Older Persons and Health Care Professionals Co-designed a Medication Plan Prototype Remotely to Promote Patient Safety: Case Study

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Abstract

Background: Harm from medications is a major patient safety challenge. Most adverse drug events arise when a medication is prescribed or reevaluated. Therefore, interventions in this area may improve patient safety. A medication plan, that is, a plan for continued treatment with medications, may support patient safety. Participation of patients in the design of health care products or services may improve patient safety. Co-design, as in the Double Diamond framework from the Design Council, England, can emphasize patient involvement. As the COVID-19 pandemic brought restrictions to face-to-face co-design approaches, interest in remote approaches increased. However, it is uncertain how best to perform remote co-design. Therefore, we explored a remote approach, which brought together older persons and health care professionals to co-design a medication plan prototype in the electronic health record, aiming to support patient safety.

Objective: This study aimed to describe how remote co-design was applied to create a medication plan prototype and to explore participants' experiences with this approach.

Methods: Within a case study design, we explored the experiences of a remote co-design initiative with 14 participants in a regional health care system in southern Sweden. Using descriptive statistics, quantitative data from questionnaires and web-based workshop timestamps were analyzed. A thematic analysis of the qualitative data gathered from workshops, interviews, and free-text responses to the survey questions was performed. Qualitative and quantitative data were compared side by side in the discussion.

Results: The analysis of the questionnaires revealed that the participants rated the experiences of the co-design initiative very high. In addition, the balance between how much involved persons expressed their wishes and were listened to was considered very good. Marked timestamps from audio recordings showed that the workshops proceeded according to the plan. The thematic analysis yielded the following main themes: *Everyone's perspective matters*, *Learning by sharing*, and *Mastering a digital space*. The themes encompassed what helped to establish a permissive environment that allowed the participants to be involved and share viewpoints. There was a dynamic process of learning and understanding, realizing that despite different backgrounds, there was consensus about the requirements for a medication plan. The remote co-design process seemed appealing, by balancing opportunities and challenges and building an inviting, creative, and tolerant environment.

Conclusions: Participants experienced that the remote co-design initiative was inclusive of their perspectives and facilitated learning by sharing experiences. The Double Diamond framework was applicable in a digital context and supported the co-design process of the medication plan prototype. Remote co-design is still novel, but with attentiveness to power relations between all

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involved, this approach may increase opportunities for older persons and health care professionals to collaboratively design products or services that can improve patient safety.

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KEYWORDS

co-design; remote; older people; medications; medication plan; patient safety; patient experience; participatory; engagement

Introduction

Harm caused by medications, often known as adverse drug events (ADEs) [1], is recognized by the World Health Organization as 1 of the 3 greatest patient safety challenges [2]. The older population, defined here as those aged ≥75 years, tends to be more prone to ADEs due to a higher prevalence of illness and multiple medications [3]. Errors related to ADEs tend to arise when medications are prescribed or reevaluated [4]. Therefore, interventions in these areas may improve safety. Safe clinical management of medications in older persons may be supported by a plan for continued treatment [5]. Such a plan, a medication plan, articulating what to observe when using medications (expected and adverse effects), when to act, and who should take the initiative when needed, may facilitate resilient performance, that is where a system adjusts to maintain a desired level of performance [6].

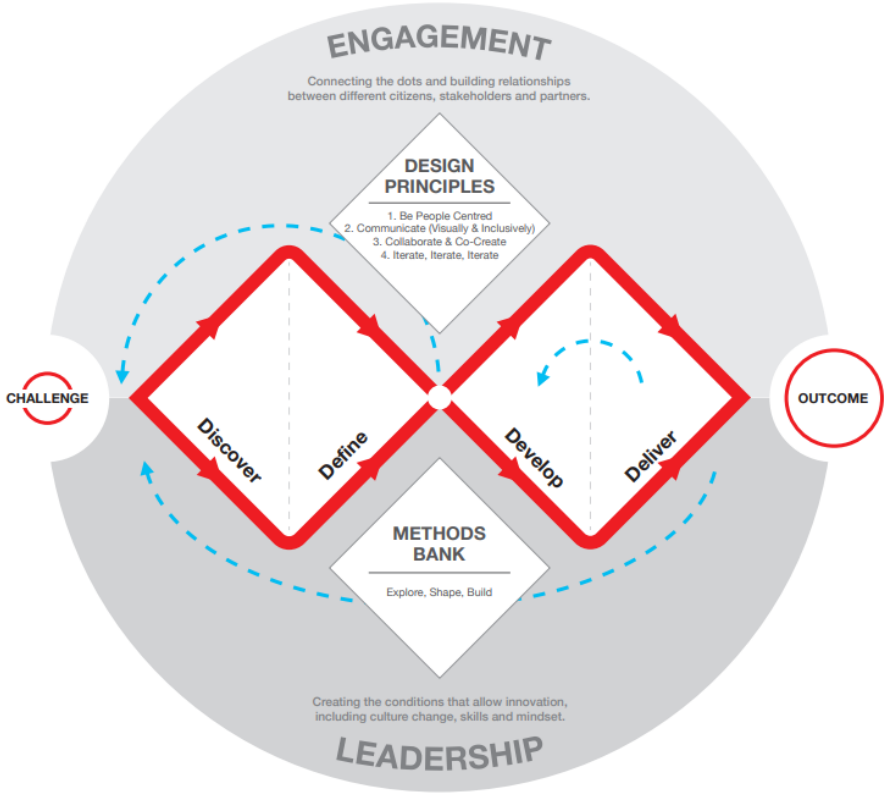
Having patients participate in the design of health care processes can improve patient safety [7]. In Sweden, as in many other countries, regulations and national policies strengthen and clarify patients' position and promote their integrity and participation in health care [8]. Furthermore, persons invited to participate in initiatives aimed at improving patient safety are generally willing to do so [9]. There is still a lack of methods for patients to be involved in efforts to improve patient safety [10]. O'Hara and Lawton [11] outline opportunities to improve patient involvement in design and improvement initiatives for patient safety, highlighting the need to explore ways to engage susceptible patients, such as older persons, on their terms, as they tend to be at the highest risk for adverse events. If they are not involved, it may limit the generalizability of improvement efforts, as they may not reflect the reality of older people. So far, the dominant approaches to involving patients in patient safety initiatives include making them more aware of risks and comfortable with giving feedback about safety concerns rather than having them participate in improvement initiatives [12].

Co-design is an approach that emphasizes patient involvement in the improvement of health care services [13]. It enables participants to share experiences, where each participant's experience is considered their expertise [14]. A co-design process is powerful, yet challenging, as both patients and health care professionals need to negotiate their roles and balance power between them [15]. Co-design is now an established approach in health care [16]. Even so, initiatives involving older persons are scarce, but some initiatives have addressed the development of different electronic health care tools [17,18] or improvement of specific health care services [19]. There are different frameworks for co-design in health care [16,20], including the Double Diamond from the Design Council, England [21]. The Double Diamond has 4 phases: Discover, Define, Develop, and Deliver (Figure 1). The Discover phase explores the problem space from a service user perspective, whereas the Define phase synthesizes insights to understand how service users are affected by the problem. The Develop phase encourages the exploration of potential solutions to the problem, which in the subsequent Deliver phase are tested and improved before they are incorporated into daily practice.

Although co-design approaches are increasingly common in health care, they are criticized for a lack of evaluation of their effectiveness and cost-effectiveness [22] and are seen as challenging to implement in a busy health care environment. Therefore, the application of any co-design framework must be adapted to the contextual needs of the health care system. The COVID-19 pandemic brought restrictions to co-design approaches, which are usually performed face-to-face with users. Remote co-design may have both limitations and strengths, but it seems possible to perform with similar outcomes and quality as face-to-face co-design efforts [23,24]. Remote co-design initiatives including older persons and health care professionals to support patient safety seem rare, and their potential and limitations are not fully understood. Therefore, we report the experiences of such an initiative concerning patient safety. This study aimed to describe how remote co-design was applied to create a medication plan prototype and to explore participants' experiences with this approach.

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Figure 1. Design Council Double Diamond, created in 2004 (reproduced from Ball et al [21], with permission from The Design Council).



Methods

Study Design

We report on the co-design initiative using a case study design [25]. Case study methods are useful when exploring efforts to improve patient safety in complex systems such as health care [26]. Qualitative and quantitative data were first analyzed separately and then included in a side-by-side comparison in the discussion.

Participants and Setting

The co-design initiative was part of a large national initiative introducing Patient Contracts, aiming to strengthen patients' role in health care [27]. A Patient Contract is an agreement, documented in the electronic health record, intended to strengthen the relationship between a patient and caregivers by promoting care coordination, accessibility, and predictability. To achieve a variety of perspectives and experiences [28], we sought a balanced group composition with an equal number of older persons (aged >75 years), next of kin, general practitioners, and nurses working in municipality-based home health care. Participants were recruited through existing contacts within the initiative Patient Contract in 1 regional public health care system in southern Sweden, serving a population of 350,000 residents [27]. Inclusion required availability to participate in all 3 parts of the initiative, adequate communication capability in Swedish, and access to and comfort in using the internet. There were no explicit exclusion criteria for this study. Gender, age, and number of medications were noted for older persons; for health care professionals, gender and years in the profession were noted.

The initiative included 14 participants (Table 1): 3 general practitioners who had worked for 5-39 years as physicians, 6 nurses who had worked for 4-35 years as registered nurses, and 5 older persons aged 72-82 years and using 3-8 medications daily. One of the older persons also reported having the experience of being next of kin to a person taking medications.

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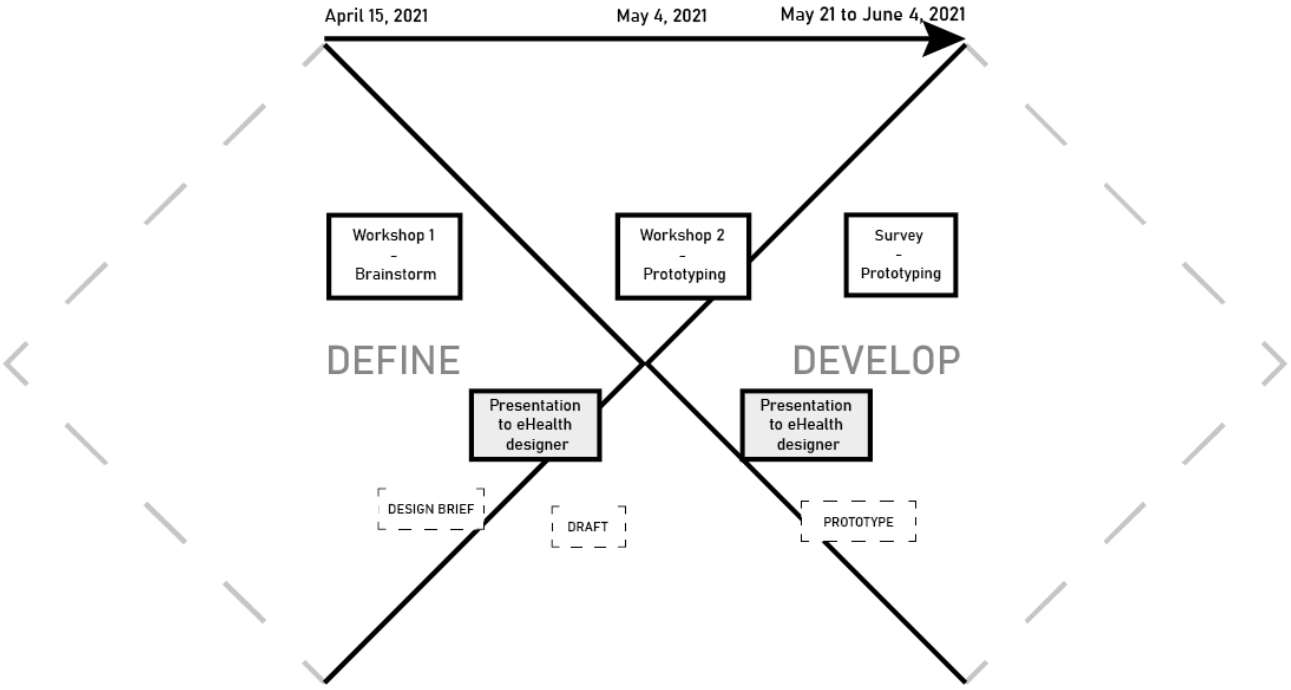
Table 1. Number of participants and data collected at each step of the study (N=14).

Session	Participants, n (%)			Data collected
	Older persons, n (%)	General practitioners, n (%)	Nurses, n (%)	
Workshop 1 (n=14)	5 (36)	3 (21)	6 (43)	Audio recording with timestamps, Zoom Polls
Workshop 2 (n=14)	5 (36)	3 (21)	6 (43)	Audio recording with timestamps, Zoom Polls
Survey (n=13)	5 (38)	3 (23)	5 (38)	Digital questions, closed and in free-text form
Interviews (n=7)	4 (57)	1 (14)	2 (29)	Audio recordings

The Co-design Initiative

The co-design initiative (Figure 2) aimed to create a prototype, that is, a model of a proposed solution, for a medication plan incorporated in the electronic health record to support older persons and health care professionals jointly in using and monitoring medications. This initiative focused on the Define and Develop phases in the Double Diamond framework and was informed by the guide "Design methods for developing services" by the Design Council [29]. The first phase of the Double Diamond, Discover, has been performed before [30,31], and the last phase, Deliver, will be performed later. This co-design initiative was performed over a 2-month period and included 3 sessions: 2 workshops via the web-supported Zoom (Zoom Video Communications) videoconferencing software and 1 survey session (Multimedia Appendix 1).

Figure 2. The structure of the co-design initiative.



Two facilitators, the first author and one quality improvement adviser, guided the participants through the co-design initiative. Two additional persons provided technical support, collected notes on the Padlet Web platform (a digital notice board), recorded audio, and encouraged collaboration during the workshops.

The workshops lasted for 2 hours each and were guided by a minute-by-minute timetable. The timetable was set up by the first and third author (with experience in co-design), together with the quality improvement adviser, detailing all planned activities (Multimedia Appendix 2). The setup for the workshops was pilot-tested to identify and resolve challenges to the digital collaboration. One week before each session, all participants received general information about the session along with specific input: before workshop 1, insights generated in the Discover phase and before workshop 2, the design brief and medication plan drafts and along with the survey, the medication plan prototype. To ensure that everyone received the information, it was sent out by both postal mail and email. Between the 3 sessions, facilitators presented data from the co-design initiative to eHealth designers in the regional public health care system where the initiative was performed, which informed their prototype design.

In the Define phase, including the first workshop, participants were invited to analyze the findings from the Discover phase, when insights about the evaluation of medications were gathered from older persons, nurses, and general practitioners [30,31] along with information from research studies and regulations related to the initiative. Furthermore, they were asked to synthesize their analysis into a number of opportunities for a medication plan. Brainstorming was used to gather ideas and build a shared understanding of the orientation of the group. After the session, the first author formed a design brief, that is, a core reference point based on gathered data produced during

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the session, and presented it to the eHealth designers, who used it to assist in preparing medication plan drafts, that is, preliminary prototypes.

In the Develop phase, including the second workshop and the concluding survey, participants were invited to develop the drafts further into 1 prototype by designing components in detail and iteratively refining the draft. Experience Prototyping, a way to test and refine a solution in feedback loops with potential users, with made-up fictitious patient cases, was used to enable participants to gain first-hand understanding of the drafts and gather feedback from them. After the second workshop, the first author gathered data produced during the session and presented it to the eHealth designers, further informing the design of the medication plan prototype. This prototype was sent out to all participants together with a survey, open for 2 weeks, to collect final feedback on the prototype.

Data Collection

This case study of the co-design initiative draws on quantitative and qualitative data (Table 1).

Audio recordings of the workshops were transcribed verbatim and marked with timestamps. Zoom Polls (ie, questions) about the participants' experience of the workshop, with fixed response options on a 4-grade Likert scale, ended each workshop. A survey, created in the web-based survey tool esMaker NX3, was sent out to all participants to collect feedback and reflections related to the co-design activities, participation in the activities, and practicalities of participating. It consisted of 7 questions with answers on a 10-grade Likert scale and with a possibility to add free-text comments, 1 yes or no question, and 7 additional free-text questions. The participants had 2 weeks to respond and received 2 reminders, after 1 week and on the last day for completion. All participants were invited to participate in an individual semistructured interview on Zoom. The interview guide (Multimedia Appendix 3), developed by the research team based on the findings from the survey, included questions about the prototype and the co-design process. The interviews were audio recorded, transcribed verbatim, and lasted between 21 and 46 minutes (30:37 SD 9:13).

Data Analysis

Quantitative data from the Zoom Polls and survey were analyzed using descriptive statistics. Marked timestamps in the workshop audio recordings were compared with the original timetable.

Qualitative data from the free-text responses in the survey and the transcribed audio recordings from workshops and interviews were analyzed together through thematic analysis, as outlined by Braun and Clark [32,33]. An inductive approach was applied to look for patterns, that is, to identify themes addressing the underlying meanings of data. To support the analysis, transcriptions and free-text responses were gathered using the NVivo software (QSR International). Initially, the material was read and reread to strengthen familiarity with data. The first author generated the initial codes and gathered them into potential themes. Then, the first and last authors reviewed the initial codes and themes and presented them to the entire research group to define the final themes. The entire research team contributed to writing and rewriting the descriptions of the themes and to generating the report.

Ethics Approval

This study was approved by the Swedish Ethical Review Authority (dnr 2020-04781) and adhered to the Declaration of Helsinki [34]. All participants received written information regarding the aim and arrangement of the study and provided written consent before the first session. Data were deidentified to maintain confidentiality and were presented so that no individual could be identified. Data from the study were kept secure at Region Jönköping County.

Results

Quantitative Data Regarding Experiences of the Remote Co-design Initiative

Using Zoom Polls, participants (13/14, 93%) assessed the first workshop as good (9/13, 69%) or very good (4/13, 31%). The participants' (12/14, 86%) experience after the second workshop was fairly good (2/12, 17%), good (5/12, 42%), or very good (5/12, 42%). For the yes or no question in the survey, they (11/12, 92%) responded that the initiative corresponded to the aim, that is, to develop a medication plan prototype together; 1 respondent did not know. On the following survey questions, participants (13/14, 93%) responded with answers on a 10-grade Likert scale (Table 2). They reported being able to speak to the extent they wanted (median response 9) and that the views they expressed were considered when developing the prototype (median response 9). On a scale of 1 being very bad and 10 being excellent (Table 3), participants' overall experiences of participating in the co-design initiative, the balance between how much all involved expressed their wishes, and the information provided to facilitate participation were close to excellent (median response 9). On the same scale, the participants indicated that the practical parts of the workshops facilitated participation and that the balance between how much all involved were listened to was almost excellent (median response 8).

Marked timestamps from the workshop audio recordings showed that both workshops ended according to the schedule (Multimedia Appendix 2). Presentations of activities took in general less time than planned in both workshops. The background introduction in the first workshop took longer than planned. In the second workshop, the introduction to and test of the digital notice board took longer than planned. The time for individual reflections was shorter than planned, whereas prioritizing the requirements for the medication plan took more time than planned.

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Table 2. Answers from the survey (Q=question number) on a 10-grade Likert scale (13/14, 93%)[a].

Item	1	2	3	4	5	6	7	8	9	10	Do not know	Median
Q4. In the workshops I was allowed to speak to the extent that I wanted	0	0	0	0	0	0	1	3	4	5	0	9
Q2. The views I expressed in the workshops were taken into account in developing the medication plan prototype	0	0	0	0	0	0	1	3	4	3	2	9

[a]1=do not agree to 10=totally agree.

Table 3. Answers from the survey (Q=question number) on a 10-grade Likert scale (13/14, 93%)[a].

Item	1	2	3	4	5	6	7	8	9	10	Do not know	Median
Q1. What is your overall experience of participating in the work of creating a medication plan prototype?	0	0	0	0	1	0	1	4	5	2	0	9
Q6. How did you experience the balance between how much older persons, general practitioners and nurses expressed their wishes?	0	0	0	0	1	2	0	3	3	4	0	9
Q7. How did you experience the balance between how much the views of older persons, general practitioners and nurses were listened to?	0	0	0	0	1	0	2	3	4	1	2	8
Q8. How did you perceive that information provided before, during, and after the workshops facilitated your participation?	0	0	1	0	0	0	2	3	5	2	0	9
Q9. How did you experience that the practical parts of the workshops (that is, use of the digital platform, the facilitators' actions) facilitated your participation?	0	0	0	0	1	2	1	3	4	2	0	8

[a]From 1=very bad to 10=excellent.

Qualitative Data Regarding Experiences of the Digital Co-design Initiative

Thematic analysis included interviews, workshops, and free-text responses to questions in the survey. A total of 3 main themes and 11 associated subthemes were identified, which described the experiences of the approach (Textbox 1). The main themes *Everyone's perspective matters*, *Learning by sharing*, and *Mastering a digital space* encompass conditions of importance for establishing a permissive, dynamic, and appealing remote co-design process, as described in the following text.

Everyone's perspective matters reflects the experiences of a permissive environment during the co-design process, which allowed the participants, especially older persons, to be involved and share viewpoints that were taken into account when developing the prototype.

On the basis of their different perspectives and backgrounds, the participants experienced that they were *contributing from multiple viewpoints* to the design of the prototype. The purpose, that is, to improve medication safety, seemed to be important when participants decided to participate, as it was something worthwhile for them to affect. Contributing with different viewpoints in the workshops was considered to add broader input to the prototype, something not possible to extract from the existing literature. With different perspectives, both as individuals and as representatives of a group of people, the participants complemented each other, which means that the prototype was created collaboratively:

> *I think that…what I heard from the nurses in other municipalities as well, it is pretty much the same thoughts as we shared. But I think we complemented each other quite well.* [Interview—nurse]

The atmosphere in the workshops was *inviting to dialog*. Together, facilitators and participants created opportunities for the exchange of perspectives by inviting all participants, regardless of who, to provide input and by allowing everyone to speak:

> *Yes, but I think we had the opportunity to speak, especially at the group meetings.* [Survey—older person]

Participants' viewpoints were taken into consideration in the development of the prototype, meaning that everyone counted. Even so, concerns were raised that some people, regardless of their roles, occupied more space than others. At the same time, different ways to inform the development of the prototype during the process, that is, by dialog, Zoom Polls, and note boards were appreciated as they gave participants opportunities to provide input into the process, including ideas that popped up between sessions

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Textbox 1. Themes and subthemes.

Everyone's perspective matters

- Contributing from multiple viewpoints
- Inviting to dialog
- The voice of medication users

Learning by sharing

- Acknowledging each other's daily life
- Creating shared understanding
- Reaching coherence

Mastering a digital space

- Meeting remotely is the future
- Building relationships remotely
- Structuring the work
- Digital hassles
- Allocating time

The voice of medication users stood out and was considered to be of extra importance, meaning that services in health care must be adjusted to make sense for both patients and health care professionals. Some health care professionals even highlighted that older persons should have had even more impact than they had in the co-design initiative. In contrast, the older persons thought that health care staff's requirements must outweigh, as medication plans mainly concerned their way of working in daily practice. They also stated that they as patients had a responsibility to contribute to improving health care:

> *And I think so…patient's own responsibility. I would like to mention that. You cannot be passive in healthcare. Because then you are gone very quickly. You have to be…uh, at the forefront, updated, inquisitive. Ask uncomfortable questions. And you want an answer.* [Interview—older person]

Although it was emphasized by the health care professionals that the older persons in this initiative were particularly knowledgeable, that is, "expert patients," there were also concerns that the balance between patients and health care professionals might be to the disadvantage of the patients. Older persons might be frail, and medical terms and jargon in discussions can make it difficult for them to be completely involved.

Learning by sharing highlights the dynamic process of learning and understanding by sharing daily life experiences and realizing that despite different backgrounds, participants could reach consensus about the requirements for a medication plan.

Gaining knowledge about how things work out in different contexts and to *acknowledge each other's daily life* was experienced as fruitful, meaning that the participants may not normally be aware of the situations of other patients or health care professionals:

> *You get an insight into each other's practice and can jointly reach something that works for everyone.* [Survey—nurse]

The fictitious cases used in the workshops, whether the participants considered them familiar or not, worked out well for participants to reflect upon. The sharing of each other's everyday practices contributed to individual learning and showed how other participants looked at the difficulties associated with medications. This learning provided insight into the desirable requirements for the medication plan and also into the challenges to come, such as medication prescribers having enough time when introducing a new way of working together.

Having a 2-way dialog with the possibility of providing direct responses to one another helped in *creating shared understanding.* The participants saw creating something together as valuable and good, meaning that it supported the development of the prototype:

> *Yes, it [cocreation] is that people with different experiences, different lengths of experience, get the opportunity to work together and learn from each other. And build…build something together with…the platforms you have.* [Interview—older person]

Participating in a dialog appeared to increase interest in the topic itself, generating increased curiosity about medication treatment in general. This approach was also considered worth applying to other improvement initiatives. However, concerns about missing out on the perspectives of groups other than those included, such as homecare staff and pharmacists, were raised, meaning that home health assistants (who were not represented in the co-design initiative) have valuable additional insights into everyday practice close to older persons.

The participants were *reaching coherence* for the final prototype, meaning that they seemed to empathize with each other's needs to make the prototype applicable:

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> *There was consensus around it. And I think that is also a very good thing about co-creation, that…just that we realize that there is a consensus.* [Interview—older person]

The prototype corresponded well with participants' needs and expectations. They stated that it also seemed to live up to the requirements of the group as a whole. Understanding that different visions are not always profession related but person related was another experience the participants seemed to gain, as they observed that there appeared to be no "us and them." Similarities in how to manage things applied to people, not profession.

Mastering a digital context focuses on the balance between opportunities and challenges the digital platform offers, such as building an inviting and creative environment for co-design in a web-based context.

Participants argued that *meeting remotely is the future*, as easy access from home or the workplace leads to efficient meetings:

> *Yes, many times, you have slightly more pithy comments and you listen a little more to others as well.* [Interview—general practitioner]

The digital platform made it possible to join without losing valuable working hours traveling. The accessible platform was considered a proper alternative even after meeting restrictions, imposed during the COVID-19 pandemic, were lifted. The digital space provided ample room for reasoning and possibilities to interact in other ways, for instance, via digital chat.

At the same time, *building relationships remotely* seemed to be more difficult, as the context challenges the way we normally build relationships. For example, the participants commented that informal chats during a coffee break, which help people get to know each other, were hard to imitate digitally. Moreover, having all faces side by side on a screen made it difficult to remember who was who and what role the person had (Textbox 2).

Knowing if someone was behind a "black screen"; the interpretation of silence in the digital room; and etiquette, such as knowing when to speak or not, seemed to be more complicated remotely, thereby hampering social interaction.

Structuring the work, such as moderating and giving clear instructions before and during each session, was desirable according to the participants and something they reported experiencing. The structure and quality of the workshops seemed to be related to the facilitators' ability to provide guidance and instructions to the participants, for example, how to mute the microphone, answer Zoom Polls, or get in and out of breakout rooms. At the beginning of the process, some participants experienced that they did not know what was expected of them, which created uncertainty, but the support they received at the start made them feel comfortable and on track.

Technical problems, such as not being able to connect to workshops in time, not being able to present the right screen, or not understanding how to manage the digital room, contributed to *digital hassles* (Textbox 3).

Textbox 2. Transcription from a breakout room in workshop 2 (P=older person and F=facilitator)

P: Question from X [name]. I wonder, how many of us are in our group?
F: You are four in your group.
P: There are four of us? Yes, that is good. It is a new outfit today, so you never know…
F: Exactly. Y [name] is a nurse. Z [name] is a doctor. And X [name] and W [name] are users of medications.

Textbox 3. Transcription from a breakout room in workshop 1 (P=older person and F=facilitator)

F: Well I think…he probably managed to press 'Join' there. So we will…we will wait…we are waiting for some more to come. It is two more…
P: Yes.
F: We will see if she succeeds with that…Or what happens. But we can start a little bit then…There comes x [name] too. Welcome.

Some participants had more problems than others, and guidance was often required to resolve these situations. This could take extra time and contribute to some participants missing parts of the workshop.

Allocating time for cocreation was experienced as essential, meaning that during the workshops time seemed to pass quickly, whereas having time for discussion and reflection was considered important for the outcome. Worries were raised that time was hardly ever adjusted for difficult issues such as those in this initiative. Some participants also argued that more time would have helped older persons to provide input.

Discussion

Principal Findings

User involvement in initiatives aiming at supporting patient safety is novel. Therefore, this study describes a remote co-design initiative, including both older persons and health care professionals, and highlights the experiences of the approach. Our findings indicate that remote co-design can be a complement or substitute for face-to-face co-design sessions but requires careful planning and adjustments in action throughout the process to allocate sufficient time for cocreation. Even so, the approach allowed an accessible environment for the participants, and the chosen co-design framework seemed to work well in a digital context. The participants had a positive

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experience of participating in the co-design initiative and thought it allowed a permissive environment where everyone's perspectives mattered. Sharing of everyday life created learning and resulted in the participants gaining awareness of possible risks and strategies that could contribute to safer medication treatment.

Comparison of Data and Comparison With Previous Work

In the quantitative results, participants rated the overall experience of the second workshop lower than the first, and the time for individual reflections in the second workshop was shorter than planned. In addition, the thematic analysis identified that participants considered time for dialog important and that lack of time could be a limitation, especially for older persons. To the best of our knowledge, the optimal duration of a co-design session is unknown. The time frames for these workshops were therefore a prediction, limiting the risk of digital fatigue [23], while allocating enough time for interaction and achieving adequate input on the prototype. The participants in this study experienced that they had the opportunity within the given time frame to hear and respond to others' input directly. To find time for co-design is a matter of discussion, as co-design generally requires more time compared with top-down approaches, such as individual or group interviews, used to inform the design of a service [20,35]. Using participants' time efficiently is advantageous, especially because a high workload makes it difficult to engage health care professionals in co-design initiatives [36]. The remote approach made it possible to participate without spending time on travel. Apart from saving time, remote initiatives may broaden participant groups, inviting those who really want to participate instead of only those who have the capacity and time to attend physical meetings [23,24]. Previous studies have shown that remote co-design has pros and cons [23,24], and this study revealed that digital hassles took time and adversely affected the timetable. Even so, managing new technology is not limited to aspects of age [37]. Individual user perspectives are more important to address than chronological age and are worth paying attention to in future remote co-design initiatives.

Even if the time allocated for cocreation might have been short, participants reported that they had opportunities to speak as much as they wanted. The workshop structure, guided by the Double Diamond framework, and the digital context seemed to form a welcoming environment, where facilitators and participants together created a space for the exchange of perspectives and ideas where everyone was empowered to speak and provide input. This mirrors another co-design study from Australia [23], suggesting that the web-based meeting space may break down power imbalances and establish equal participation. Facilitators can balance power between participants and encourage vulnerable members in a group to express their opinions [38]. As in many other co-design activities [39], the facilitators and participants in this initiative had no specific training in co-design. Nevertheless, our findings show that the participants were satisfied with the facilitation both during workshops and in between.

Both health care professionals and older persons in this study emphasized the importance of considering the views of patients when creating new services or products. However, the findings included statements that health care staff's requirements must be more important than those of patients and also revealed concerns that building relationships remotely can be more challenging than face-to-face meetings. To constantly reflect on power relations in co-design initiatives is therefore essential to empower a balanced relationship between involved persons [15,40]. Future remote co-design initiatives conducted in the context of patient safety need to anticipate this, as an imbalance between patients and health care professionals may threaten the outcome. If health care organizations invite patients to co-design, health care professionals must share power with them and work responsibly to overcome barriers on equal terms [41].

On the basis of the results of this study, we cannot determine whether a remote co-design initiative with older persons supports patient safety. The participants experienced individual learning during the initiative, and by allowing patients, together with health care professionals, to address safety concerns, they might gain higher awareness of risks in their everyday life [42]. Other studies have shown that patients actively involved as cocreators of resilience at the micro, meso, and macro levels develop their own strategies to reduce harm and use their capabilities to contribute to safer care [43,44]. Patient participation in initiatives aimed at improving patient safety is still insufficiently explored, possibly because of challenges that arise when trying to involve patients in the complexity of health care processes [11]. Sharing of everyday practice provided the participants with insights into why special requirements were called for in the medication plan and also revealed possible challenges for future implementation. In approaches aimed at improving health care quality and patient safety, it is important to address organizational human factors and encourage the active and adaptive role of users [45]. The Systems Engineering Initiative for Patient Safety is a human factors systems approach to patient safety, which acknowledges the importance of considering the whole system for an intervention to have a sustainable impact on patient safety [45,46]. The participants in this initiative, representing different parts of the health care system, experienced that they contributed to the development of the prototype from multiple perspectives, such as patients and health care professionals. Their shared understanding, developed through this process, contributed to their common view of what was needed for the prototype to work well for everyone. Therefore, we conclude that co-design initiatives that include everyone's perspectives and create learning for those involved may, also in a remote approach, inform the development of new products or services to improve patient safety.

Strengths and Limitations

We aimed to ensure trustworthiness, credibility, confirmability, dependability, and transferability were considered throughout this case study [47]. The case study design, with a thorough description of the initiative and using well-known qualitative and quantitative methods, contributed to *dependability* of the results. To ensure consistency, a pilot test of the setup for the workshops was conducted and evaluated, resulting in some

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minor adjustments in the timetable. The first author performed all interviews with a semistructured interview guide to promote consistency.

Owing to the broad approach to recruiting participants, it is unknown how many people choose not to participate and why. We aimed for a mix of older persons, next of kin, and health care professionals [28], which was achieved, except that no persons participated solely as next of kin. The participants were recruited within the initiative Patient Contract and may therefore be prone to working together to strengthen the patients' role in health care. In addition, older persons may be considered extra knowledgeable, and they had previous experience with digital meetings. Persons unable to communicate in Swedish or use a computer were therefore not included in this initiative, and concerns that digital initiatives may exclude some people have been raised before [23]. Consequently, the inclusion criteria used in this initiative need to be considered when interpreting the results, as they may affect *transferability* to other co-design initiatives with older persons.

Objectivity is important when considering the *confirmability* of data. The first author and one quality improvement adviser guided and facilitated the co-design initiative. Both had met some of the participants before in other projects, meaning they were known to each other. To ensure objectivity in the study findings, peer debriefing was used in the thematic analysis, where the first and last authors first reviewed themes together and then presented them to the author group to rewrite the final descriptions. The quality improvement adviser was not involved in the data analysis.

We believe that the multidisciplinary author group, with different experiences in patient safety and co-design, contributed to the study's *credibility*, as preunderstanding is helpful in case studies and when interpreting if the findings are real and accurate. Linking and comparing our findings with each other and prior research also ensured the accuracy of our findings.

Future Directions

This remote co-design initiative has resulted in a medication plan prototype. A future study could address the last phase in the Double Diamond framework, the Deliver phase, and evaluate the medication plan prototype according to usability and safety.

Future studies could also expand on the remote co-design approach's possibilities to broaden the participant group and increase opportunities for older people and health care professionals to meet and collaboratively improve patient safety.

The web-based meeting space seems to support an inviting environment and establish equal participation, which allows participants to address safety concerns and contribute to safer care. Therefore, research to increase knowledge on how patients can be further involved in remote co-design initiatives aimed at improving patient safety would be helpful.

Conclusions

Participants experienced that the remote co-design initiative was inclusive of their perspectives and facilitated learning by sharing experiences. The Double Diamond framework was applicable in a digital context and supported the co-design process of the medication plan prototype. Remote co-design is still novel, but with attentiveness to power relations between all involved, this approach may increase opportunities for older persons and health care professionals to collaboratively design products or services that can improve patient safety.

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Data Availability

The data generated during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

All authors contributed to the design of the study and the discussion of the results and approved the final manuscript. MH and BL arranged the setup for the co-design initiative together with a quality improvement adviser in Region Jönköping County. MH participated in the workshops, performed the interviews, analyzed the data, and drafted and revised the manuscript. LJ supervised and helped with the analysis and interpretation of the data and reviewed the manuscript. JT, AR, and BL helped with the interpretation of the data and reviewed and edited the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey.
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Multimedia Appendix 2
Timetable with planned activities.
[DOCX File , 29 KB - aging_v6i1e41950_app2.docx]

Multimedia Appendix 3
Interview guide.
[DOCX File , 22 KB - aging_v6i1e41950_app3.docx]

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Abbreviations

ADE: adverse drug event

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Original Paper

The Changes in Levels and Barriers of Physical Activity Among Community-Dwelling Older Adults During and After the Fifth Wave of COVID-19 Outbreak in Hong Kong: Repeated Random Telephone Surveys

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Abstract

Background: COVID-19 has had an impact on physical activity (PA) among older adults; however, it is unclear whether this effect would be long-lasting, and there is a dearth of studies assessing the changes in barriers to performing PA among older adults before and after entering the "postpandemic era."

Objective: The aim of this study was to compare the levels and barriers of PA among a random sample of community-dwelling older adults recruited during (February to April 2022) and after the fifth wave of the COVID-19 outbreak (May to July 2022) in Hong Kong. In addition, we investigated factors associated with a low PA level among participants recruited at different time points.

Methods: This study involved two rounds of random telephone surveys. Participants were community-dwelling Chinese-speaking individuals aged 65 years or above and having a Hong Kong ID card. Household telephone numbers were randomly selected from the most updated telephone directories. Experienced interviewers carried out telephone interviews between 6 PM and 10 PM on weekdays and between 2 PM and 9 PM on Saturdays to avoid undersampling of working individuals. We called 3900 and 3840 households in the first and second round, respectively; for each round, 640 and 625 households had an eligible older adult and 395 and 370 completed the telephone survey, respectively.

Results: As compared to participants in the first round, fewer participants indicated a low level of PA in the second round (28.6% vs 45.9%, *P*<.001). Participants in the second round had higher metabolic equivalent of tasks-minutes/week (median 1707.5 vs 840, *P*<.001) and minutes of moderate-to-vigorous PA per week (median 240 vs 105, *P*<.001) than those in the first round. After adjustment for significant background characteristics, participants who perceived a lack of physical capacity to perform PA (first round: adjusted odds ratio [AOR] 3.34, *P*=.001; second round: 2.92, *P*=.002) and believed that PA would cause pain and discomfort (first round: AOR 2.04, *P*=.02; second round: 2.82, *P*=.001) were more likely to have a low level of PA in both rounds. Lack of time (AOR 4.19, *P*=.01) and concern about COVID-19 infection during PA (AOR 1.73, *P*=.02) were associated with a low level of PA among participants in the first round, but not in the second round. A perceived lack of space and facility to perform PA at home (AOR 2.03, *P*=.02) and unable to find people to do PA with (AOR 1.80, *P*=.04) were associated with a low PA level in the second round, but not in the first round.

Conclusions: The level of PA increased significantly among older adults after Hong Kong entered the "postpandemic era." Different factors influenced older adults' PA level during and after the fifth wave of the COVID-19 outbreak. Regular monitoring of the PA level and its associated factors should be conducted to guide health promotion and policy-making.

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KEYWORDS

COVID-19; physical activity; older adults; barriers; changes; repeated random telephone survey; China; aging; elderly population; community-dwelling older adults; health promotion; telehealth

Introduction

Hong Kong has a rapidly aging population. By 2030, 22% of Hong Kong residents will be ≥65 years old [1]. Recent data show that 75% of older adults in Hong Kong are suffering from one or more chronic diseases [1]. This situation has already created a huge burden on the local health system [1]. Physical activity (PA) is defined as any bodily movement produced by the skeletal muscles that results in an expenditure of energy, and is widely recognized as an effective intervention for reducing mortality and the risk of dependence-inducing diseases in older adults [2]. Systematic reviews have shown that sustainable PA improved cognitive functions, frailty symptoms, body composition, and physical functions among older adults [3,4]. Therefore, the World Health Organization (WHO) recommends that older adults without any contradiction to PA should perform at least 150 minutes of moderate-intensity aerobic PA, at least 75 minutes of vigorous-intensity aerobic PA, or an equivalent combination of moderate-to-vigorous PA (MVPA) every week [2]. Local health authorities follow the same recommendation.

Physical inactivity remains a global phenomenon and increases significantly with age. A systematic review showed that 43.4%-78.0% of older adults across countries could not meet the WHO-recommended PA level [5]. In Hong Kong, the prevalence of physical inactivity was 13.5% among people aged 65-74 years, 22.4% among those aged 75-84 years, and 42.8% among those aged 85 years or above in 2019 [6]. Another study conducted in Hong Kong oHbefore the COVID-19 outbreak reported that 20% of individuals aged ≥60 years had a low PA level [7]. Globally, the COVID-19 pandemic has negatively affected PA levels among older adults [8]. As compared to the time before COVID-19, studies consistently observed a decline in PA level among older adults after the COVID-19 outbreak [9-18]. Similar trends were observed in Hong Kong. As compared to the PA situation in 2019, two studies found a decline in the frequency of walking and moderate- and high-intensity sports among the general population, and in the overall PA level among men aged ≥60 years after the COVID-19 outbreak [10,19]. Therefore, there is an urgent need to improve PA among older adults in Hong Kong, especially considering the negative impact of COVID-19.

Several different facilitators and barriers affect the participation of PA among older adults. A systematic review suggested that lack of knowledge, skills, capacities, and support from peers or family members related to PA; perceived cons of PA (causing pain, risk of injury, and fear of falling); and environmental barriers (access to facilities and transportation, bad weather) were the main barriers of performing PA among community-dwelling older adults [20]. Perceived benefits of PA (improved physical and mental health, fun and enjoyment), perceived self-efficacy, and suggestions from health professionals were highlighted as facilitators [20]. Similar facilitators and barriers applied to Hong Kong older adults before the COVID-19 outbreak [7]. During the outbreak, COVID-19 control measures (closure of exercise facilities, social distancing) significantly increased older adults' difficulties in accessing sports facilities and reduced support from peers [8]. An increase in caring responsibility during the pandemic due to school closure further reduced the availability for PA [21]. Moreover, concerns about the risk of COVID-19 infection reduces older adults' motivation, and increases fear and anxiety related to PA [8,16,18]. Achieving "zero-COVID" is difficult. Instead, most countries have started to relax COVID-19 control measures and "return to normal" with high COVID-19 vaccination coverage. In Hong Kong, the government lifted its strict COVID-19 control measures (eg, closure of schools and sports facilities, prohibiting group gatherings) when the number of daily new cases dropped to about 300 (April 2022) [22]. Despite an increasing trend of daily confirmed COVID-19 cases (from <300 in May 2022 to over 3000 in July 2022), the government did not tighten up COVID-19 control measures again [22]. The changing pandemic and its control measures might influence barriers to performing PA among older adults. To our knowledge, it remains unclear whether the impact of COVID-19 on PA among older adults would be long-lasting, and there is a dearth of studies assessing the changes in barriers to performing PA among older adults before and after entering the "postpandemic era."

To address the above-mentioned knowledge gaps, we analyzed the data of two rounds of cross-sectional random telephone surveys among community-dwelling older adults in Hong Kong, China. We compared levels and barriers to performing PA between rounds. In addition, we investigated the factors associated with a low PA level among participants of different rounds. We hypothesized that less participants would have a low PA level in the second round of the survey compared to the first round. Associated factors of low PA level were also expected to be different between the two rounds of the survey.

Methods

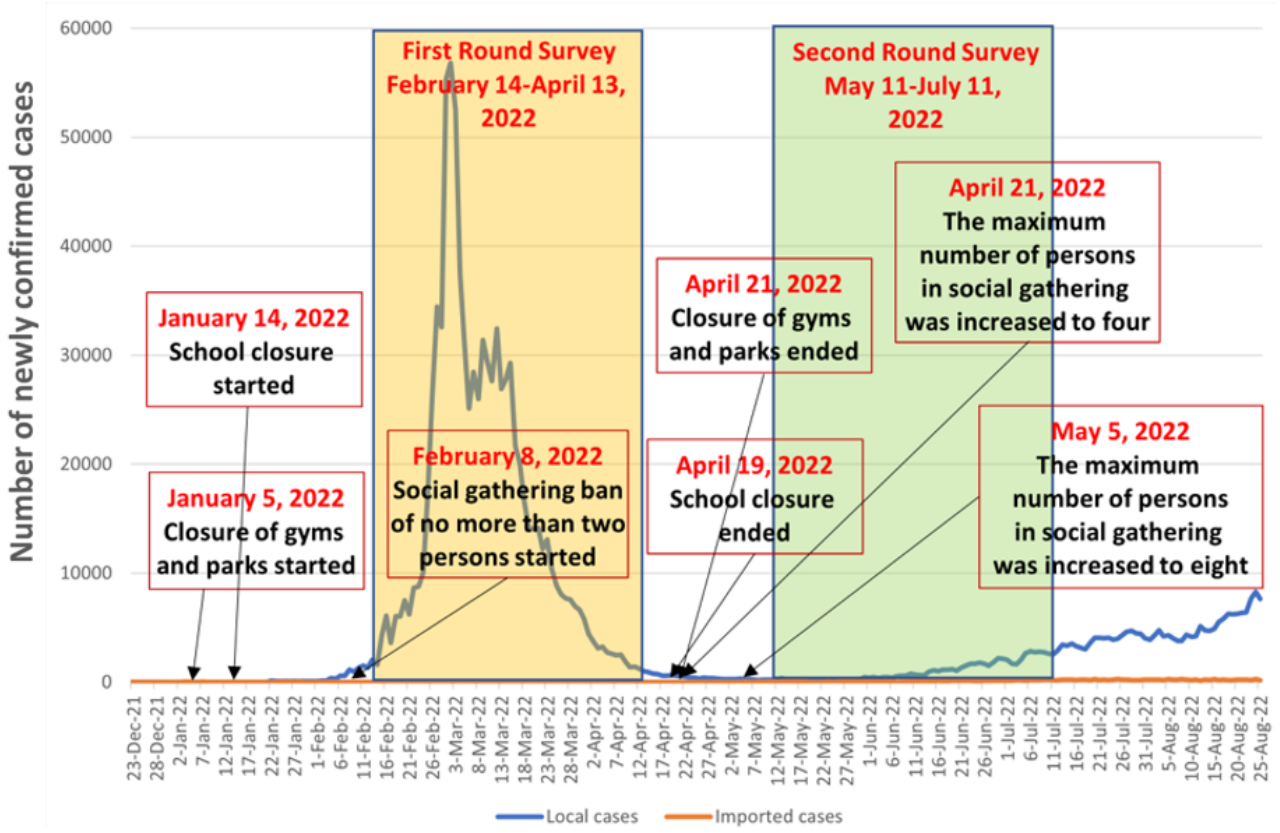
Study Design

This study was a secondary analysis of two rounds of random telephone surveys investigating COVID-19 vaccination uptake among community-dwelling Chinese-speaking individuals aged 65 years or above in Hong Kong, China [23]. STROBE checklist for cross-sectional study was shown in Multimedia Appendix 1. The first round was conducted during the fifth wave of the COVID-19 outbreak between February 14 and April 13, 2022. During the first round, strict COVID-19 control measures were implemented [24], including (1) closure of all playgroups, kindergartens, and primary schools (between January 14 and April 19, 2022); (2) closure of fitness centers, swimming pools, and sports premises (between January 5 and April 21, 2022);

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and (3) prohibition of social gatherings involving more than two persons (between February 8 and April 21, 2022). The number of daily confirmed COVID-19 cases reached its peak on March 2, 2022 (n=56,827) and dropped to 1043 on April 13, 2022. The second round of telephone surveys was conducted between May 11 and July 11, 2022. The number of daily confirmed COVID-19 cases increased slowly from 294 on May 11, 2022, to 2769 on July 11, 2022. A summary of the COVID-19 situation and its control measures in Hong Kong during the study period is presented in Figure 1.

Figure 1. The COVID-19 situation and its control measures in Hong Kong during the study period.



Participants and Data Collection

Inclusion criteria of the participants were: (1) community-dwelling Chinese-speaking individuals aged 65 years or above and (2) having a Hong Kong ID card. The exclusion criterion was not able to communicate effectively with the study interviewers. We used the same data collection methods in both rounds of surveys and reported these details previously [23]. First, we input all household telephone numbers listed in the most updated telephone directories (approximately 350,000) into an Excel file. We then randomly selected 4000 numbers by using the function "select random cells." Experienced interviewers carried out telephone interviews between 6 PM and 10 PM on weekdays and between 2 PM and 9 PM on Saturdays to avoid undersampling of working individuals. We considered a household to be nonvalid (one without an eligible participant) if no one answered five calls made at different time slots. If there was more than one individual in the household who was 65 years or above, the interviewers invited the person whose last birthday was the closest to the survey date to join the study. This practice was adopted to avoid clustering effects (ie, older adults living in the same household sharing a similar PA level and determinants of PA). Interviewers screened prospective participants for eligibility; briefed them about the study; and made guarantees of anonymity, their right to quit at any time, and that refusal to participate would have no consequences. Verbal informed consent was obtained. The interviewers also signed a form pledging that the participants had been fully informed about the study. The telephone interview took approximately 20 minutes to complete. No incentives were given to the participants.

Ethics Approval

Ethics approval was obtained from the Survey and Behavioral Research Ethics Committee of the Chinese University of Hong Kong (SBRE-19-187).

Measures

Background Characteristics

The English and Chinese versions of the questionnaires are provided in Multimedia Appendix 2. Participants reported sociodemographic characteristics (eg, age, sex assigned at birth, relationship status, education level, employment status, income, and living arrangement), presence of chronic diseases, and history of COVID-19 and COVID-19 vaccination.

PA Assessment

The interviewers assessed participants' PA in the past week using the validated Chinese version of the 7-item International Physical Activity Questionnaire-Short Form (IPAQ-SF) [25]. The IPAQ-SF was validated in Chinese older adults [26,27]. The questionnaire assessed the walking, and moderate- and

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vigorous-intensity activities of an individual in the past week. We computed the metabolic equivalent of tasks (MET) minutes per week and minutes of MVPA per week, and categorized the PA levels into high, moderate, and low based on the protocol of IPAQ-SF [25]. A high level of PA was defined as (1) vigorous-intensity activity on at least 3 days achieving a minimum total PA of ≥1500 MET-minutes/week or (2) ≥7 days of any combination of walking or moderate- or vigorous-intensity activities achieving a minimum total PA of ≥3000 MET-minutes/week. A moderate PA level was defined as: (1) ≥3 days of vigorous-intensity activity of at least 20 minutes per day, (2) ≥5 days of moderate-intensity activity and/or walking of at least 30 minutes per day, or (3) ≥5 days of any combination of walking and moderate-intensity or vigorous-intensity activities achieving a total PA of 600 MET-minutes/week. Participants who did not meet the criteria of a moderate or high level of PA were considered to have a low PA level.

Barriers to Performing PA

Nine items were constructed for this study to assess barriers to performing PA (response categories: 1=disagree, 2=neutral, and 3=agree). They were: (1) do not have time, (2) lack of interest, (3) cannot find people to do PA with, (4) lack of physical capacity to do PA, (5) PA will cause pain and discomfort, (6) lack of space and facility to do PA at home, (7) concern about COVID-19 infection during PA, (8) closure of facilities due to COVID-19 and its control measures, and (9) peers refused to do PA with you due to COVID-19. Responses to these items were dichotomized ("disagree/neutral" vs "agree") for analysis.

Sample Size Determination

The target sample size for each round of the survey was 400. The sample size planning for the original study was explained in a previous publication [23]. In brief, assuming the proportion of participants having a low PA level of 30%-70% in the first round, this sample size was determined to be sufficient to detect a minimum between-round difference of 8.6% (power=0.80, α=.05; calculated with PASS 11.0 software).

Statistical Analysis

There were no missing values in either round of survey. The differences in background characteristics between participants in the first and second rounds were assessed using χ^2 tests. After controlling for background variables with significant differences between rounds, the differences in the level of PA, MET-minutes/week, minutes of MVPA per week, and barriers to performing PA were compared using ordinal, logistic, or linear regression models. The level of PA, MET-minutes/week, and minutes of MVPA per week between rounds were further compared in subgroups of participants with and without a specific barrier to performing PA (ie, lack of physical capacity to perform PA or perception that PA would cause pain and discomfort). The subsequent analysis was performed among participants in the same round of the survey. Using a low level of PA as the dependent variable and background characteristics as independent variables, crude odds ratios were obtained using logistic regression models. The associations between barriers to performing PA and the dependent variable were then obtained by fitting a single logistic regression model involving one of the independent variables and all significant background characteristics. Adjusted odds ratios (AORs) and respective 95% CIs were obtained. SPSS version 26.0 (IBM Corp, Armonk, NY, USA) was used for data analysis, with P<.05 considered as statistically significant.

Results

Background Characteristics

We called 3900 and 3840 households in the first and second rounds, 640 and 625 households had an eligible older adult, 245 and 255 refused to participate in the study, and 395 and 370 completed the telephone survey, respectively. The response rate was 62% and 59% in the first and second round, respectively. The characteristics of the participants are presented in Table 1. Approximately half of the participants were aged 70 years or above (first round, 50.1%; second round, 50.8%) and female. Most of the participants were married or cohabited with a partner, did not receive tertiary education (first round, 89.9%; second round, 89.2%), without full-time/part-time employment, and with a monthly household income lower than HK $20,000 (US $2580). Approximately one-fifth of the participants had at least one chronic condition (first round, 19.2%; second round, 18.9%). There was no difference in these characteristics between participants in the first and second rounds (P values ranged from .68 to .98). As compared to participants in the first round, more participants in the second round reported a history of COVID-19, completed the primary COVID-19 vaccination series (92.1% vs 78.7%, P<.001), and had received COVID-19 vaccine booster doses (58.9% vs 31.6%, P<.001).

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Table 1. Background characteristics of the participants.

Characteristics	Round 1 (n=395), n (%)	Round 2 (n=370), n (%)	*P* value
Sociodemographic characteristics			
Age group (years)			.98
65-69	197 (49.9)	182 (49.2)	
70-74	132 (33.4)	125 (33.8)	
75 or above	66 (16.7)	63 (17.0)	
Sex assigned at birth			.88
Male	157 (39.7)	145 (39.2)	
Female	238 (60.3)	225 (60.8)	
Relationship status			.79
Currently single	97 (24.6)	94 (25.4)	
Married or cohabiting	298 (75.4)	276 (74.6)	
Education level			.94
Primary or below	167 (42.3)	157 (42.4)	
Secondary	188 (47.6)	173 (46.8)	
Tertiary or above	40 (10.1)	40 (10.8)	
Current employment status			.88
Unemployed/retired/homemaker	339 (85.8)	319 (86.2)	
Full-time/part-time	56 (14.2)	51 (13.8)	
Monthly household income, HK $ (US $)			.99
<20,000 (2580)	292 (74.3)	273 (74.2)	
≥20,000 (2580)	53 (13.5)	49 (13.3)	
Refuse to disclose	48 (12.2)	46 (12.5)	
Receiving Comprehensive Social Security Assistance (CSSA)			.88
No	364 (92.2)	342 (92.4)	
Yes	31 (7.8)	28 (7.6)	
Living alone			.75
No	328 (83.0)	304 (82.2)	
Yes	67 (17.0)	66 (17.8)	
Medical history			
Presence of chronic conditions, yes			
Hypertension	188 (47.6)	173 (46.8)	.82
Chronic cardiovascular diseases	43 (10.9)	40 (10.8)	.97
Chronic lung diseases	8 (2.0)	6 (1.6)	.68
Chronic liver diseases	8 (2.0)	8 (2.2)	.90
Chronic kidney diseases	2 (0.5)	2 (0.5)	.95
Diabetes mellitus	76 (19.2)	70 (18.9)	.91
Any of above			
History of COVID-19			<.001
No	353 (89.4)	276 (74.6)	
Yes	42 (10.6)	94 (25.4)	
Number of doses of COVID-19 vaccination received			<.001
0	32 (8.1)	16 (4.3)	

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Characteristics	Round 1 (n=395), n (%)	Round 2 (n=370), n (%)	*P* value
1	52 (13.2)	13 (3.5)	
2	186 (47.1)	123 (33.2)	
3	125 (31.6)	205 (55.4)	
4	0 (0.0)	13 (3.5)	

Changes in PA

The changes in PA are presented in Table 2. As compared to participants in the first round, fewer participants had a low level of PA in the second round. Participants in the second round had higher MET-minutes/week and minutes of MVPA per week than those in the first round. Subgroup analysis showed that older adults with some specific barriers to performing PA (ie, lack of physical capacity or perceived that PA would cause pain and discomfort) had a significantly lower PA level, MET-minutes/week, and minutes of MVPA per week compared to those of participants without such barriers (see Multimedia Appendix 3).

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Table 2. Physical activity and barriers to performing physical activity.

Variables	Round 1 (n=395)	Round 2 (n=370)	*P* value	
			Unadjusted	Adjusted
Physical activity				
Level of physical activity, n (%)			<.001	<.001[a]
Low	170 (45.9)	106 (28.6)		
Moderate	147 (39.7)	161 (43.5)		
High	53 (14.3)	103 (27.8)		
MET[b]-minutes/week, median (IQR)	840.0 (371.3-1834.3)	1707.5 (716.6-3395.0)	<.001	<.001[c]
Minutes of moderate-intensity or vigorous-intensity physical activity (MVPA) per week, median (IQR)	105 (0-315)	240 (67.5-600)	<.001	<.001[c]
Barriers to performing physical activity, n (%)				
Do not have time			.18	.08[d]
Disagree/neutral	368 (93.2)	353 (95.4)		
Agree	27 (6.8)	17 (4.6)		
Lack of interest			.08	.12[d]
Disagree/neutral	342 (86.6)	303 (81.9)		
Agree	53 (13.4)	67 (18.1)		
Cannot find people to do physical activity together			.73	.29[d]
Disagree/neutral	287 (72.7)	273 (73.8)		
Agree	108 (27.3)	97 (26.2)		
Lack of physical capacity to do physical activity			.58	.47[d]
Disagree/neutral	355 (89.9)	328 (88.6)		
Agree	40 (10.1)	42 (11.4)		
Physical activity will cause pain and discomfort			.98	.83[d]
Disagree/neutral	335 (84.8)	314 (84.9)		
Agree	60 (15.2)	56 (15.1)		
Lack of space and facility to do physical activity at home			.04	.02[d]
Disagree/neutral	274 (69.4)	281 (75.9)		
Agree	121 (30.6)	89 (24.1)		
Concern about COVID-19 infection when doing physical activity			<.001	<.001[d]
Disagree/neutral	118 (29.9)	189 (51.1)		
Agree	277 (70.1)	181 (48.9)		
Closure of facilities due to COVID-19 and its control measures			.26	.046[d]
Disagree/neutral	232 (58.7)	232 (62.7)		
Agree	163 (41.3)	138 (37.3)		
Peers refused to do physical activity with you due to COVID-19			.10	.01[d]
Disagree/neutral	238 (60.3)	244 (65.9)		
Agree	157 (39.7)	126 (34.1)		

[a]*P* values obtained from multivariate ordinal logistic regression after adjusting for history of COVID-19 and number of doses of COVID-19 vaccination received.

[b]MET: metabolic equivalent of tasks.

[c]*P* values obtained from multivariate linear regression models after adjusting for history of COVID-19 and number of doses of COVID-19 vaccination

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received.

[d]*P* values obtained from multivariate logistic regression models after adjusting for history of COVID-19 and number of doses of COVID-19 vaccination received.

Changes in Barriers to Performing PA

The changes in barriers to performing PA are also presented in Table 2. As compared to participants in the first round, fewer participants in the second round reported lack of space and a facility to do PA at home or being concerned about COVID-19 infection when doing PA. Fewer participants had experienced the closure of facilities and refusal by peers to do PA with them due to COVID-19 compared to those in the first round.

Factors Associated With Having a Low PA Level

In univariate analysis, participants who completed the primary COVID-19 vaccination series and/or booster dose were less likely to have a low PA level in both rounds (Table 3). After adjustment for these significant characteristics, participants who perceived a lack of physical capacity to do PA and believed that PA would cause pain and discomfort were more likely to have low level of PA in both rounds. Do not have time and concern about COVID-19 infection during PA were associated with a low level of PA among participants in the first round, but not in the second round. Perceived lack of space and facility to do PA at home and cannot find people to do PA together were associated with a low PA level in the second round, but not in the first round (Table 4).

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Table 3. Associations between background characteristics and low physical activity level.

Characteristics	Round 1 (n=395)		Round 2 (n=370)	
	OR[a] (95% CI)	*P* value	OR (95% CI)	*P* value
Age group (years)				
65-69 (reference)	1.0	__[b]	1.0	—
70-74	1.40 (0.90-2.19)	.14	0.96 (0.57-1.62)	.88
75 or above	1.32 (0.75-2.31)	.33	1.96 (1.08-3.58)	.03
Sex assigned at birth				
Male (reference)	1.0	—	1.0	—
Female	0.86 (0.58-1.29)	.48	0.98 (0.62-1.55)	.92
Relationship status				
Currently single (reference)	1.0	—	1.0	—
Married or cohabiting	1.13 (0.71-1.79)	.61	1.55 (0.89-2.68)	.12
Education level				
Primary or below (reference)	1.0	—	1.0	—
Secondary	0.86 (0.57-1.31)	.48	1.26 (0.78-2.04)	.36
Tertiary or above	0.80 (0.40-1.61)	.54	1.58 (0.75-3.31)	.23
Current employment status				
Unemployed/retired/homemaker (reference)	1.0	—	1.0	—
Full-time/part-time	0.74 (0.42-1.32)	.31	1.16 (0.61-2.21)	.64
Monthly household income, HK $ (US $)				
<20,000 (2580) (reference)	1.0	—	1.0	—
≥20,000 (2580)	0.86 (0.47-1.54)	.60	0.86 (0.43-1.70)	.66
Refuse to disclose	0.67 (0.36-1.26)	.21	0.66 (0.31-1.39)	.27
Receiving CSSA[c]				
No (reference)	1.0	—	1.0	—
Yes	0.64 (0.30-1.36)	.24	0.39 (0.13-1.16)	.09
Living alone				
No (reference)	1.0	—	1.0	—
Yes	1.11 (0.66-1.88)	.69	0.92 (0.51-1.67)	.79
Presence of any chronic conditions				
No (reference)	1.0	—	1.0	—
Yes	0.87 (0.58-1.30)	.49	1.13 (0.71-1.79)	.62
History of COVID-19				
No (reference)	1.0	—	1.0	—
Yes	0.99 (0.52-1.87)	.96	1.23 (0.74-2.05)	.42
Number of doses of COVID-19 vaccination received				
0-1 (reference)	1.0	—	1.0	—
2	0.59 (0.35-0.99)	.048	0.43 (0.19-0.99)	.049
3-4	0.50 (0.29-0.88)	.02	0.48 (0.22-1.05)	.07

[a]OR: odds ratio.

[b]Not applicable.

[c]CSSA: Comprehensive Social Security Assistance.

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Table 4. Associations between perceived barriers to performing physical activity and low physical activity level.

Perceived barriers[a]	Round 1 (n=395)		Round 2 (n=370)	
	AOR[b] (95% CI)	*P* value	AOR (95% CI)	*P* value
Do not have time	4.19 (1.54-11.40)	.01	0.99 (0.33-2.92)	.98
Lack of interest	1.06 (0.59-1.90)	.85	0.91 (0.50-1.66)	.75
Cannot find people to do physical activity together	1.07 (0.68-1.67)	.78	1.80 (1.03-3.16)	.04
Lack of physical capacity to do physical activity	3.34 (1.61-6.94)	.001	2.92 (1.48-5.76)	.002
Physical activity will cause pain and discomfort	2.04 (1.15-3.61)	.02	2.82 (1.55-5.16)	.001
Lack of space and facility to do physical activity at home	0.74 (0.48-1.14)	.17	2.03 (1.11-3.72)	.02
Concern about COVID-19 infection when doing physical activity	1.73 (1.10-2.72)	.02	0.75 (0.48-1.19)	.23
Closure of facilities due to COVID-19 and its control measures	0.97 (0.66-1.48)	.95	1.12 (0.69-1.80)	.65
Peers refused to do physical activity with you due to COVID-19	1.45 (0.96-2.19)	.08	0.78 (0.48-1.29)	.33

[a]Responses were categorized into disagree/neutral (reference category) and agree.

[b]AOR: adjusted odds ratio; adjusted for significant background characteristics listed in Table 3.

Discussion

Principal Findings

This was one of the first studies to track changes in the levels and barriers to performing PA among older adults before and after entering the "postpandemic era." One of the strengths of this study is that it was based on a random and population-based sample. In response to the fifth wave of the COVID-19 outbreak, the Hong Kong government closed all sports centers and venues, and advised older adults to stay at home and limit their outdoor activities due to their vulnerability to COVID-19 [24]. Therefore, it was not surprising to observe that a sizeable proportion of older adults had a low PA level (over 40%), which was much higher than that reported at the time before COVID-19 (about 20%) [6,7]. Despite an increasing trend in daily confirmed cases, we observed a significant increase in PA level among older adults in the second round of the survey. However, the proportion of older adults having a low PA level (27.8%) was still higher than that reported at the time before COVID-19 (20%) [6,7]. Therefore, efforts are needed to facilitate older adults to resume and increase PA in the "postpandemic era."

Comparison With Prior Work and Implications for Health Promotion

As compared to those in the first round, participants in the second round reported a much higher completion rate of the primary COVID-19 vaccine series (94% vs 78.7%) and the booster dose (58.9% vs 31.6%). Completing the primary COVID-19 series and/or the booster dose was associated with a higher PA level in both rounds. An increase in COVID-19 vaccination coverage might contribute to the increasing PA level in the second round. Vaccinated older adults might feel they are protected against COVID-19 and hence have fewer concerns to resume outdoor activities (eg, PA). Promoting COVID-19 vaccination and the booster dose might be useful strategies to improve PA among older adults in the future.

Our findings suggested some different barriers to performing PA applied to older adults in Hong Kong before and after the fifth wave of the outbreak. First, a higher proportion of older adults agreed that they did not have time for PA in the first round compared to those in the second round. Those who lacked time for PA were more likely to report a low PA level in the first round, but not in the second round. In Hong Kong, grandparents are the main caregivers of children [28,29]. A qualitative study suggested that the increased caring responsibility due to school closure and lack of childcare during the pandemic was a barrier to performing PA among older adults in the United Kingdom [21]. During the fifth wave of the COVID-19 outbreak, the Hong Kong government closed all playgroups, kindergartens, and primary schools between January 14 and April 21, 2022. During the same period, the Hong Kong government directed civil servants to work from home. However, most private organizations did not follow the work-from-home policy. Since civil servants only account for less than 2% of the entire working population in Hong Kong, most parents had to work as usual and could not take care of their children during school closure. As a result, the childcare responsibility suddenly increased among many grandparents, which reduced their availability to perform PA. Second, there was a significant decrease in concerns about COVID-19 infection over time. Such concern was associated with a lower PA level during the pandemic, but not in the "postpandemic era." A decrease in daily confirmed cases and an increase in COVID-19 vaccination coverage might have reduced their concerns about COVID-19 infection. Third, lack of space and facilities for home fitness was a significant barrier to performing PA in the "postpandemic era," but not in the first round of the survey. One possible explanation was that lack of time to perform PA caused by a sudden increase in childcare responsibility during school closure was an overwhelming barrier to performing PA during the outbreak. Therefore, although more participants indicated lacking space and a facility for home fitness in the first round of the survey, they might not consider it as a significant barrier. Health promotion in the "postpandemic era" should encourage older adults to perform

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home-based PA without extensive requirement of space or facilities, such as stationary aerobic exercise or weight/strength training. Although the Hong Kong government used a series of exercise videos on television to promote PA at home for older adults living in public housing estates during the pandemic [30], the efficiency of such programs in promoting PA for older adults should be further explored. In addition, facilitating older adults to form peer support groups is a useful strategy to promote PA in the "postpandemic era." Forming such peer support groups was less feasible during the pandemic when group gatherings were prohibited [24]. Since the government already lifted the restriction on group social gatherings, health promotion in the "postpandemic era" should consider using such a strategy [31].

Some similar barriers have hindered older adults to perform PA both before and after the fifth wave of the COVID-19 outbreak. In this study, concern about PA capacity and that PA would cause pain and discomfort were associated with a lower PA level. These concerns were also barriers to performing PA in this group before the time of COVID-19 [7,20]. Sport scientists should introduce feasible options of PA suitable for older adults. Testimonials of older adults on how they overcome these physical and environmental barriers and stay active might also be useful. Studies suggested that communication among Chinese older adults is very effective due to the high level of rapport among people of similar age [32]. Chinese older adults prefer to seek information and opinion from their peers, which are considered to be more credible than other information sources [32].

In contrast to our hypothesis, the closure of facilities due to COVID-19 and its control measures were not significantly associated with the PA level in the first or the second round. A previous study suggested that older adults in Hong Kong changed their mode of PA to cope with the COVID-19 control measures. For example, older adults reduced swimming or going to the gym for exercise, but increased stretching, brisk walking, or other activities that rely less on access to sports facilities [10]. Such adaptations might have mitigated the impact caused by the closure of sports facilities.

Limitations

This study had some limitations. First, it was a major limitation that we did not assess the functional limitations of the participants. In Hong Kong, 16.3% of community-dwelling older adults had a functional limitation [33]. Older adults with functional limitation had lower PA levels. Second, we did not gather more information on family members of the participants due to the limited length of the questionnaire. Family members would have an influence on participants' PA level (eg, whether family members can share the childcare responsibility during school closure). Third, PA was self-reported. We did not use accelerometers or wearable devices to assess PA due to feasibility and resource constraints. This raised concerns about reliability and recall bias. Fourth, due to the limited length of the questionnaire, some determinants of PA among older adults were not covered by the study (eg, perceived benefits and self-efficacy of PA). Fifth, we did not measure participants' physical capacity to perform PA. Sixth, compared to census data, people who were 75 years or above were undersampled in this study [34]. However, the distributions of gender and age were similar to those of recent random telephone surveys among community-dwelling older adults [35]. Furthermore, nonresponses would cause selection bias. We were not able to obtain characteristics of those who refused to participate, which might be different from those of the participants. Our response rate was comparable to those of previous random telephone surveys targeting older adults in Hong Kong [32,35,36]. Last but not least, this was a cross-sectional study and could not establish causal relationships.

Conclusion

The level of PA increased significantly after the drop of daily confirmed COVID-19 cases and the relaxation of COVID-19 control measures among older adults in Hong Kong. Different factors influenced older adults' PA level during and after the fifth wave of the COVID-19 outbreak. Barriers to performing PA, such as perceived lack of space and a facility to perform PA at home, concerns about COVID-19 infection during PA, closure of facilities, and refusals made by peers to perform PA reduced significantly over time. Regular monitoring of the PA level and its associated factors should be conducted to guide health promotion and policy-making. Sport scientists should introduce suitable options for older adults with inadequate physical capacity or having functional limitations. In the "postpandemic era," reactivating peer support groups and promoting home-based PA may increase the PA level among older adults. Health authorities should be aware of the negative impact of school closure on PA among older adults. If school closure has to be implemented in future waves of a COVID-19 outbreak, introducing PA options suitable for older adults to perform with their grandchildren may be helpful to alleviate its negative influence.

Acknowledgments

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Data Availability

The data sets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
STROBE checklist for cross-sectional study.
[DOCX File , 33 KB - aging_v6i1e42223_app1.docx]

Multimedia Appendix 2
The English and Chinese versions of the questionnaires used in the telephone survey.
[DOCX File , 38 KB - aging_v6i1e42223_app2.docx]

Multimedia Appendix 3
Changes in physical activity among subgroups of participants.
[DOCX File , 25 KB - aging_v6i1e42223_app3.docx]

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Abbreviations

AOR: adjusted odds ratio
IPAQ-SF: International Physical Activity Questionnaire-Short Form
MET: metabolic equivalent of tasks
MVPA: moderate-to-vigorous physical activity
PA: physical activity
WHO: World Health Organization

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Original Paper

Pandemic-Related Changes in Technology Use Among a Sample of Previously Hospitalized Older Adult New Yorkers: Observational Study

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Abstract

Background: The COVID-19 pandemic increased the importance of technology for all Americans, including older adults. Although a few studies have indicated that older adults might have increased their technology use during the COVID-19 pandemic, further research is needed to confirm these findings, especially among different populations, and using validated surveys. In particular, research on changes in technology use among previously hospitalized community-dwelling older adults, especially those with physical disability, is needed because older adults with multimorbidity and hospital associated deconditioning were a population greatly impacted by COVID-19 and related distancing measures. Obtaining knowledge regarding previously hospitalized older adults' technology use, before and during the pandemic, could inform the appropriateness of technology-based interventions for vulnerable older adults.

Objective: In this paper, we 1) described changes in older adult technology-based communication, technology-based phone use, and technology-based gaming during the COVID-19 pandemic, compared to before the COVID-19 pandemic and 2) tested whether technology use moderated the association between changes in in-person visits and well-being, controlling for covariates.

Methods: Between December 2020 and January 2021 we conducted a telephone-based objective survey with 60 previously hospitalized older New Yorkers with physical disability. We measured technology-based communication through three questions pulled from the National Health and Aging Trends Study COVID-19 Questionnaire. We measured technology-based smart phone use and technology-based video gaming through the Media Technology Usage and Attitudes Scale. We used paired *t* tests and interaction models to analyze survey data.

Results: This sample of previously hospitalized older adults with physical disability consisted of 60 participants, 63.3% of whom identified as female, 50.0% of whom identified as White, and 63.8% of whom reported an annual income of $25,000 or less. This sample had not had physical contact (such as friendly hug or kiss) for a median of 60 days and had not left their home for a median of 2 days. The majority of older adults from this study reported using the internet, owning smart phones, and nearly half learned a new technology during the pandemic. During the pandemic, this sample of older adults significantly increased their technology-based communication (mean difference=.74, *P*=.003), smart phone use (mean difference=2.9, *P*=.016), and technology-based gaming (mean difference=.52, *P*=.030). However, this technology use during the pandemic did not moderate the association between changes in in-person visits and well-being, controlling for covariates.

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Conclusions: These study findings suggest that previously hospitalized older adults with physical disability are open to using or learning technology, but that technology use might not be able to replace in-person social interactions. Future research might explore the specific components of in-person visits that are missing in virtual interactions, and if they could be replicated in the virtual environment, or through other means.

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KEYWORDS

older adults; technology; COVID-19; well-being; elderly population; technology use; physical disability; virtual health; social interaction; digital gaming; digital learning

Introduction

Beginning with New York City as the COVID-19 epicenter in the United States (March-May 2020) [1,2], the pandemic generated morbidity and mortality numbers that had been unseen for a century. By the end of 2020, the Centers for Disease Control and Statistics ranked COVID-19 as the third leading cause of death, second only to heart disease and cancer [3]. Older adults, especially those with multimorbidity or existing deconditioning, have shouldered a disproportionate burden of the illness and death caused by COVID-19 [4-10].

In response to the COVID-19 pandemic, the first major public health strategy for disease containment was physical distancing, defined as maintaining space from others who are not within one's household [8,11,12]. People who were aged 70 years and older or perceived themselves at an increased health risk reported greater adherence to physical distancing during the pandemic [13]. Numerous research studies have documented the psychosocial impact of such physical distancing measures for older adults such as increased depression, increased anxiety, increased loneliness, and decreased well-being [14-18].

In an effort to buffer the effects of COVID-19 distancing restrictions, many people maintained active lifestyles and social communication with others through technology-based platforms [19,20]. Examples of technology that were used to maintain activity engagement or social connection during the pandemic include web-based communication such as "video chat," smartphone use such as reading the news, and web-based gaming. Historically, older adults have used novel technology less than younger populations [21-25]. However, the COVID-19 pandemic increased the importance of technology for all Americans, including older adults [26]. Although a few studies have suggested that older adults might have increased their technology use during the COVID-19 pandemic, further research is needed to confirm these findings, especially among different populations, and using validated surveys [26-31]. In particular, research on changes in technology use among previously hospitalized community-dwelling older adults, especially those with physical disability, is needed because older adults with multimorbidity and hospital-associated deconditioning were a population greatly impacted by COVID-19 and related distancing measures [4-10]. Obtaining knowledge regarding previously hospitalized older adults' technology use, before and during the pandemic, could inform the appropriateness of technology-based interventions for vulnerable older adults.

For the purposes of this study, well-being was defined as a combination of emotional experiences (both positive and negative) of a person, as well as their life satisfaction [32]. Prior to the pandemic, research evidence on the association of technology use and the well-being of older adults had been inconsistent. Some studies indicated that novel technologies could help support the well-being of the aging population through facilitating social connection and optimizing their daily activities (eg, information gathering and health maintenance) [33-36]. Alternatively, other studies have suggested that such conclusions are overgeneralizations based on scarce evidence and poor study methodology [37,38]. Although further research is needed to examine this association, researchers must consider that the simple association of technology use and well-being could offer misleading findings when using data from the pandemic [28]. For example, older adults who had more stress and anxiety related to the pandemic were more likely to decrease their in-person visits with family and friends, and older adults who were more likely to decrease their in-person visits with family and friends were more likely to use technologies to maintain that connection [28]. Thus, examining a cross-sectional association between technology use and well-being, while not taking into account pandemic-related changes in in-person visits, might overstate the negative effects of technology use on older adults. Instead, research is needed to examine if older adults' technology use changed the relationship between fewer in-person visits and well-being. Obtaining knowledge regarding the role of technology in buffering the emotional impact of distancing restrictions for previously hospitalized community-dwelling older adults is important because such research can inform future interventions that increase their technology use and access [39].

This study had two aims: (1) to describe changes in older adults' technology-based communication, technology-based phone use, and technology-based gaming during the COVID-19 pandemic, compared to before the COVID-19 pandemic, and (2) to test whether technology use moderated the association between changes in in-person visits and well-being, controlling for demographics such as age, gender, income, and living alone status. For this study, we applied Galappatti and Richardson's [40] Well-being Conceptual Framework, which describes the linkage between well-being and disaster risk reduction. According to this framework, disaster events can deplete the resources that help a person maintain their well-being. Elements that bolster well-being during a disaster are (1) social ecological factors, which include maintaining relationships and venues for engagement, (2) human capacity, which includes maintaining skills, knowledge, and a sense of identity, and (3) the material

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environment, which includes infrastructure and physical safety and comfort [40]. Consistent with this conceptual framework, older adults might have increased their technology use during the pandemic to maintain social ecological factors and human capacity. Additionally, those older adults who had high technology use during the COVID-19 pandemic, and thus bolstered their social ecological factors and human capacity, might have experienced higher well-being. Informed by Galappatti and Richardson's [40] Well-being Conceptual Framework, we hypothesized that previously hospitalized older adults with physical disability increased their technology use during the pandemic, and that this technology use buffered the negative impact of decreased in-person visits on older adults' well-being.

Methods

Sampling

CAPABLE (Community Aging in Place–Advancing Better Living for Elders) is a home-based intervention that addresses function through personalized goal-setting to improve the health and safety of older adults. We recruited participants from a research study based in New York City, conducted in collaboration with the Center for Home Care Policy & Research at VNS Health, testing whether CAPABLE decreases posthospitalization disability. Participants were eligible for the CAPABLE parent study if they were (1) aged 65 years or older, (2) within a 60-74–day period post hospital discharge, (3) discharged from postacute home health services, (4) able to stand up with or without assistance, (5) experiencing physical disability as determined by patient verbalization of difficulty with at least one activity of daily living (eg, difficulty walking or difficulty dressing), (6) not actively receiving radiation treatment or chemotherapy, (7) hospitalized 3 times or less in the last 12 months, (8) living in New York City for the next 5 months, and (9) cognitively intact, as determined by a score of ≥5 on the Callahan 6-item screener [41]. Participants were eligible for this substudy if they (1) were participants in the CAPABLE parent study and (2) received a score of ≥5 on the Callahan 6-item screener [41] at the time of the substudy's interview survey. At the time of the substudy's interview survey, participants were in a period between 13 and 28 months post hospitalization. In the order of participation in the CAPABLE parent study, we included the first 60 older adults who passed the cognitive screen and agreed to participate in this substudy.

Data Collection

We collected data between December 2020 and January 2021, which was shortly after the peak of the COVID-19 pandemic in New York City. Considering the physical distancing measures instituted during this period, and some older adults' reticence with computer use, we used a telephone-based objective survey. The researchers who surveyed participants (BFD and JWL) were trained in proper techniques for conversing with those with hearing impairment (eg, talking slower not louder and rewording). The survey contained 50 items, most of which were multiple-choice questions, and took approximately 40 minutes to complete. We audio-recorded all calls, which the first author (BFD) checked for accuracy.

Ethical Considerations

The Johns Hopkins University's institutional review board and VNS Health's institutional review board approved this study (E17-002). Prior to participation, a research assistant (BFD or JWL) informed participants that the study participation was voluntary, and if they chose not to participate, their care at VNS Health would not be affected. All participants provided verbal informed consent and all participant data were deidentified. Participants were mailed a US $25 gift card for their study participation.

Survey Measures

Technology Use

Although data for this study were collected at one time point, we asked participants about their technology use currently, as well as (retrospectively) prior to the pandemic, which allowed for the examination of changes in older adults' technology use during the pandemic. Similar to the National Health and Aging Trends Study COVID-19 Questionnaire [28,42], we established March 2020 as the time point in which "the effects of the outbreak first began." For the 2 time frames "before the pandemic" and "during the pandemic," we measured 3 types of technology: technology-based communication, technology-based smartphone use, and technology-based video gaming. These 3 measures of technology use are described below.

We measured technology-based communication through 3 questions extracted from the National Health and Aging Trends Study COVID-19 Questionnaire and described by Drazich et al [28] and Freedman Vicki and Kasper [42]. These items assess the frequency of social communication with family and friends through various forms of technology: (1) telephone calls, (2) emails, texts, and social media, and (3) video calls. For each item, participants reported their weekly frequency using a 5-point scale from 0="never" to 4="at least daily." Summed responses ranged from 0 to 12, with higher scores indicating the highest frequency of technology-based communication. These 3 technology-based communication questions were asked in relation to the period "during the COVID-19 pandemic" and (retrospectively) "before the COVID-19 pandemic."

We measured technology-based smartphone use through the 9-item "Smartphone Usage Sub-Scale" within the Media Technology Usage and Attitudes Scale [43]. The Smartphone Usage Sub-Scale has a Cronbach α of .93 [43]. These items assess how often a participant uses his/her smartphone for 9 purposes: reading emails, getting directions, browsing the web, listening to music, taking pictures, checking the news, recording a video, using apps, or searching for information. For each item, participants respond using a 10-point frequency scale from 1="never" to 10="all the time." Summed responses ranged from 9 to 90 with higher scores indicating the highest frequency of smartphone use. These 9 technology-based smartphone questions were asked in relation to the time period "during the COVID-19 pandemic" and (retrospectively) "before the COVID-19 pandemic." Of note, the Smartphone Usage Sub-Scale was only administered to participants who responded "yes" to owning a smartphone.

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We measured technology-based video gaming through the 3-item "Video Gaming Sub-Scale" within the Media Technology Usage and Attitudes Scale [43]. The Video Gaming Sub-Scale has a Cronbach α of .83 [43]. These items assess how often a participant plays games on his/her computer, video game console, or smartphone (1) by him-/herself, (2) with other people in the same room, and (3) with other people on the web. Again, for each item, participants respond using a 10-point frequency scale from 1 "never" to 10 "all the time." For the Video Gaming Sub-Scale, summed responses ranged from 3 to 30, with higher scores indicating the highest frequency of video gaming. These 3 technology-based video gaming questions were asked in relation to the period "during the COVID-19 pandemic" and (retrospectively) "before the COVID-19 pandemic."

For descriptive purposes, we asked whether participants had access to the internet (yes/no), owned a smartphone (yes/no), and whether they learned a new technology during the COVID-19 pandemic (yes/no) and why (open answer).

Change in in-Person Visits

We measured change in in-person visits through a question that asked, "In a typical week, how often have you been in contact through in-person visits with family and friends not living with you?" Participants reported 0="never," 1="less than once a week," 2="about once a week," 3="a few times a week," or 4="at least daily." We asked this question for 2 periods: "before the pandemic" (retrospective report) and "during the pandemic." We then subtracted responses "before the pandemic" from "during the pandemic" to obtain the "change in in-person visits" score. This "change in in-person visits" score ranged from –4 to +4, with negative numbers indicating a decrease in in-person visits during the pandemic and positive numbers indicating an increase in in-person visits during the pandemic. For descriptive purposes, we also asked the participants to report the number of days since they last had physical contact with a person (friendly hug or kiss), and the number of days since they had left their house for any reason (walk, grocery store, and pharmacy).

Well-being

We measured well-being through the 4-item Personal Well-being Scale [44]. The Personal Well-being Scale has an interitem correlation coefficient of 0.77 and Cronbach α of .9 [44]. These items assess both the emotional components ("I was happy yesterday" and "I was not anxious yesterday") and the life satisfaction components ("I am satisfied with my life" and "What I do in my life is worthwhile") of well-being [32,44]. Participants responded using a 4-point Likert scale from "disagree" to "strongly agree." "I was not anxious yesterday" was reverse coded and all items were summed for a range between 0 and 16, with higher scores indicating better well-being.

Covariates

We included 4 covariate variables that are associated with older adult technology use and were collected through self-report: age, gender, living alone status, and income. We measured age on a raw continuous scale (see Table 1). Gender and living alone status consisted of 2 nominal categories (male/female; lives alone/lives with others). We measured income through interval data with six categories ranging from US $5000-$9999 annually to US $100,000 or above annually, with higher scores indicating greater income.

Statistical Analysis

We first conducted descriptive analyses for each variable, assessed measures of central tendency and outliers, as well as model assumptions. To fulfill the first study aim, which was to describe changes in technology use due to the COVID-19 pandemic, we performed paired *t* tests. To fulfill the second study aim, to test whether technology use significantly changed the relationship between changes in in-person visits and well-being, we tested an interaction model with technology use as the moderator. We considered a 1-sided *P* value of <.05 as statistical significance and performed statistical analyses using SPSS (version 26; IBM Corp).

Results

Sample

Our sample consisted of 60 participants, 63.3% of whom identified as female, and 50.0% of whom identified as White (see Table 1). The participants reported various chronic conditions, with a total of 14 (23.3%) reporting a history of heart attack, 24 (40%) reporting a history of asthma or wheezing, 16 (26.7%) reporting a history of colitis, and 13 (21.7%) reporting a history of cancer. The majority of participants (63.8%) had an annual income of US $25,000 or less and 46.7% of participants reported living alone. On a scale from 0-4, with 4 indicating the highest score for in-person visits, participants decreased their in-person visits from a score of 2.19 before the pandemic to a score of 1.49 during the pandemic (mean difference –70, *P*<.001). At the time of the survey between December 2020 and January 2021, participants reported that they had not had physical contact (such as friendly hug, kiss, or handshake) for a median of 60 days and had not left their home for a median of 2 days. A total of 10 (17%) participants in this sample reported that they had not left their home for more than 20 days. Approximately 54 (90%) participants reported having access to the internet and 40 (66.7%) participants reported owning a smartphone. A total of 28 (46.7%) participants reported "learning a new technology during the pandemic." The most common type of technology learned was videoconferencing software for the purpose of socialization, health (eg, telehealth), or activity engagement (eg, religious service). The average well-being score, which ranges 0-16 with higher scores indicating higher well-being, was 11.03 (SD 3.4).

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Table 1. Participant characteristics (N=60).

Characteristics	Value
Age (years), mean (SD)	75.9 (7.1)
Age (years), n (%)	
65-69	12 (20)
70-74	16 (27)
75-79	12 (20)
80-84	15 (25)
85-89	4 (7)
≥90	1 (2)
Sex, n (%)	
Women	38 (63)
Men	22 (37)
Race or ethnicity, n (%)	
White	30 (50)
African American	21 (35)
Other	9 (15)
Hispanic	8 (14)
Income[a] (US $), n (%)	
5000-9999	10 (17)
10,000-14,999	11 (19)
15,000-24,999	16 (28)
25,000-34,999	7 (12)
≥35,000	14 (24)
Live alone status, n (%)	
Live alone	28 (47)
Live with others	32 (53)
Education[a], n (%)	
More than high school	6 (10)
High school	19 (33)
Technical degree	5 (9)
Associate's or bachelor's degree	16 (28)
Graduate school	12 (21)

[a]A total of 2 participants refused to report their income and educational attainment.

Aim 1: Change in Technology Use

Fulfilling aim 1, we first tested if older adults' technology-based communication, technology-based smartphone use, and technology-based gaming increased during the COVID-19 pandemic, compared to before the COVID-19 pandemic. We found that our sample of 60 previously hospitalized older adults with physical disability significantly increased their technology-based communication (*P*=.003), smartphone use (*P*=.02), and technology-based gaming (*P*=.03) during the pandemic, compared to those before the pandemic (see Table 2). On a scale from 0 to 12, with higher scores indicating the highest frequency of technology-based communication, older adults increased their technology-based communication from 6.4 points to 7.1 points. In particular, older adults who responded "never" to frequency of video calls changed from 63.3% before the pandemic, to 44.1% during the pandemic. On a scale from 9 to 90, with higher scores indicating the highest frequency of smartphone use, older adults increased their smartphone use from 27.0 points to 30.0 points. On a scale from 3 to 30, with higher scores indicating the highest frequency of technology-based gaming, older adults increased their technology-based gaming from 5.2 points to 5.7 points.

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Table 2. Change in technology use.

	Participants, n	Before the pandemic, mean (SD)	During the pandemic, mean (SD)	Change, mean (SD)	*P* value
Technology-based communication	57	6.4 (3.1)	7.1 (2.9)	.74 (2.0)	.003
Smartphone use	39	27.0 (11.3)	30.0 (12.4)	2.9 (8.1)	.02
Technology-based gaming	59	5.2 (3.5)	5.7 (3.6)	0.52 (2.1)	.03

Aim 2: Moderation Effects of Technology Use

Fulfilling aim 2, we then tested whether technology use during the pandemic moderated the association between changes in in-person visits with family and friends and well-being, controlling for age, gender, income, and living alone status. We found that technology-based communication (b=–0.19, *P*=.17), technology-based smartphone use (b=–0.0002, *P*=.99), and technology-based video gaming (b=–0.03, *P*=.82) during the pandemic did not moderate the association between changes in in-person visits and well-being, controlling for covariates. Thus, the relationship between change in in-person visits and well-being is the same, regardless of level of technology use.

Discussion

Principal Findings

This sample of 60 previously hospitalized older adults with physical disability significantly increased their technology-based communication, smartphone use, and technology-based gaming during the pandemic, compared to before the pandemic. This finding complements previous research, which indicated that older adults increased their technology use during the pandemic [27,28,45]. This finding is distinct from previous findings in that it specifically examined smartphone use and web-based gaming using surveys with tested psychometric properties, and was in a sample of vulnerable older adults [43]. This study also found that technology use during the pandemic did not significantly moderate the association between changes in in-person visits and well-being.

The finding that previously hospitalized older adults with physical disability increased their technology use during the pandemic has research and clinical implications. First, although older adults use technology less than other age cohorts, this study suggests that older adults should not be thought of as non–technology users [21-25]. The majority of previously hospitalized older adults from this study reported using the internet and owning smartphones, and nearly half of them learned a new technology during the pandemic. Thus, researchers should consider that many older adults are open to using technology, and this should, therefore, be considered in the design and implementation of technology-based health interventions. Second, the finding that nearly half of this sample of previously hospitalized older adults with physical disability learned a new technology during the pandemic indicates that many vulnerable older adults might be open to learning new technology-based interventions.

This study was guided by Galappatti and Richardson's [40] Well-being Conceptual Framework, which suggests that the following elements bolster well-being during a disaster: (1) social ecological factors, (2) human capacity, and (3) the material environment. Consistent with this framework, we hypothesized that older adults who had high technology use during the COVID-19 pandemic, and thus bolstered their social ecological factors and human capacity, would have higher associated well-being. The framework's third element that contributes to well-being, the "material environment," was not explored in this study, but might help explain our finding that technology use did not buffer the effects of changes in in-person visits on older adults' well-being. The "material environment" includes infrastructure and the degree of physical safety and comfort. In this study, older adults who used technology could have had financial concerns related to data usage, internet security concerns, stress due to technology use confusion, or addictive technology tendencies. Greater research is needed to investigate the potential negative effects of technology on older adults such as problematic technology use and technostress [46,47].

The findings that technology use did not significantly buffer the effects of changes in in-person visits on older adults' well-being was a surprising finding and can have implications far beyond the pandemic. Older adults are often unable to experience in-person interaction due to a variety of reasons, such as mobility limitations, transportation inaccessibility, or income restraints. This study indicates that technology might not provide or supplement the full benefits of in-person visits. Future research might explore the specific components of in-person visits that are missing in digital interactions, and if they could be replicated in the digital environment, or through other means. In particular, greater investment in social or "cuddly" robotics might be warranted in the field of geriatrics, especially robots with high usability and safety, and those that are designed to support the values of the individual users [48-51].

Limitations

Given the small sample size of 60 participants, this study might not have been powered to find statistical differences. Additionally, this sample was drawn from a population of older adults who live in New York City and had already received the CAPABLE intervention, which addresses physical function through goal-setting. Thus, this sample might be different form the general population of recently hospitalized older adults with functional disability who have not received the CAPABLE intervention or who live in different geographic regions. Another study limitation was the data collection at one time point. Participants might have had difficulty retrospectively reporting on their technology use prior to the COVID-19 pandemic (recall bias). Conversely, a strength of this study was the inclusion of older adults who are underrepresented in geriatric research, such

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as adults older than 75 years, Black older adults, and low-income older adults.

Conclusions

This study found that previously hospitalized older adults significantly increased their technology use during the pandemic, compared to before the pandemic, but this technology use did not significantly moderate the association between changes in in-person visits and well-being. These study findings suggest that older adults are open to using or learning technology, but that technology use might not be able to replace in-person social interactions. These findings can guide researchers and clinicians in the postpandemic environment for the planning of technology-based health interventions.

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Data Availability

The data sets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

Conflicts of Interest

None declared.

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Abbreviations

CAPABLE: Community Aging in Place–Advancing Better Living for Elders

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Original Paper

COVID-19 Infodemic and Impacts on the Mental Health of Older People: Cross-sectional Multicenter Survey Study

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Abstract

Background: The COVID-19 pandemic received widespread media coverage due to its novelty, an early lack of data, and the rapid rise in deaths and cases. This excessive coverage created a secondary “infodemic” that was considered to be a serious public and mental health problem by the World Health Organization and the international scientific community. The infodemic particularly affected older individuals, specifically those who are vulnerable to misinformation due to political positions, low interpretive and critical analysis capacity, and limited technical-scientific knowledge. Thus, it is important to understand older people’s reaction to COVID-19 information disseminated by the media and the effect on their lives and mental health.

Objective: We aimed to describe the profile of exposure to COVID-19 information among older Brazilian individuals and the impact on their mental health, perceived stress, and the presence of generalized anxiety disorder (GAD).

Methods: This cross-sectional, exploratory study surveyed 3307 older Brazilians via the web, social networks, and email between July 2020 and March 2021. Descriptive analysis and bivariate analysis were performed to estimate associations of interest.

Results: Major proportions of the 3307 participants were aged 60 to 64 years (n=1285, 38.9%), female (n=2250, 68.4%), and married (n=1835, 55.5%) and self-identified as White (n=2364, 71.5%). Only 295 (8.9%) had never started or completed a basic education. COVID-19 information was mainly accessed on television (n=2680, 81.1%) and social networks (n=1943, 58.8%). Television exposure was ≥3 hours in 1301 (39.3%) participants, social network use was 2 to 5 hours in 1084 (32.8%) participants, and radio exposure was ≥1 hour in 1223 (37%) participants. Frequency of exposure to social networks was significantly associated

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with perceived stress (*P*=.04) and GAD (*P*=.01). A Bonferroni post hoc test revealed significantly different perceived stress in participants who were exposed to social networks for 1 hour (*P*=.04) and those who had no exposure (*P*=.04). A crude linear regression showed that "some" social media use (*P*=.02) and 1 hour of exposure to social media (*P*<.001) were associated with perceived stress. Adjusting for sociodemographic variables revealed no associations with this outcome variable. In a crude logistic regression, some social media use (*P*<.001) and 2 to 5 hours of exposure to social media (*P*=.03) were associated with GAD. Adjusting for the indicated variables showed that some social network use (*P*<.001) and 1 hour (*P*=.04) and 2 to 5 hours (*P*=.03) of exposure to social media were associated with GAD.

Conclusions: Older people, especially women, were often exposed to COVID-19–related information through television and social networks; this affected their mental health, specifically GAD and stress. Thus, the impact of the infodemic should be considered during anamnesis for older people, so that they can share their feelings about it and receive appropriate psychosocial care.

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KEYWORDS

information dissemination; health communication; COVID-19; COVID-19 pandemic; public health; health of older people; mental health

Introduction

The COVID-19 pandemic has been described as the greatest health crisis of the 21st century and is recognized as a public health emergency of international importance [1,2]. COVID-19 is a highly contagious infectious disease. Its main symptoms are coughing, sore throat, runny nose and nasal congestion, fatigue, anosmia, ageusia, diarrhea, headache, and skin rashes. Other symptoms are more severe, such as severe acute respiratory syndrome, shock, and multiple organ dysfunction. In Brazil, the disease caused more than 700,000 deaths [3].

Due to the novelty of the diagnosis, the initial lack of information, and the rapid dissemination of the disease worldwide, as well as the number of deaths and symptomatic cases, the COVID-19 pandemic quickly received wide media coverage. Excessive information related to the disease caused problems secondary to the pandemic, constituting an "infodemic" that impacted the lives of individuals. The World Health Organization and the scientific communities of different countries consider infodemics a serious public health problem [4].

Infodemics are defined by the volume of information associated with a specific subject multiplying quickly in a short time [4]. In this context, Wardle and Derakshan [5] described different terms related to the disclosure of information, constituting what the authors call "an ecosystem of disinformation."

This ecosystem is composed of 3 large groups: "misinformation," "malinformation," and "disinformation." Misinformation refers to false information disseminated without the primary intention of causing harm. Malinformation is based on legitimate content but is used to cause harm; information is taken out of context or manipulated to achieve the goal of causing harm [5]. By contrast, disinformation is the creation of false information designed specifically for a harmful purpose [5,6].

In Brazil, the political context added to the COVID-19 infodemic and led to the emergence of conspiracy theories and misinterpretations of data and scientific research that were grounded in denialism, which requires the acceptance of interventions without scientific validation. Denialist perspectives on COVID-19 are at the heart of antiscientific and even antihistorical thinking, with the rhetoric of the antivaccine movement being an example. This discourse is characterized by being cyclical and permeated by ethical-political and ideological issues, in which actions are intentional [7,8].

Among all age groups, the infodemic has had the greatest impact on the lives of older individuals. In addition to their political positions and behavior, older people who have low interpretive and critical analysis capacity and limited technical-scientific knowledge tend to generate more misinformation and be exposed to more misinformation, which can impact their mental health. Older individuals represent the largest proportion of functionally illiterate individuals in Brazil, and the illiteracy rate in people aged 60 years or older reaches 10.3% among White people, increasing to 27.5% among other racial groups; moreover, 53% of people aged between 50 and 64 years are considered functionally illiterate, which makes them vulnerable to being targets of misinformation, as well as being its main propagators [9].

Older people are not digital natives but are increasingly active and, consequently, are gradually starting to use computerized media and gain access to other media. Internet use has grown most rapidly among older people over the years, increasing by 56% between 2015 and 2017 [10] and by 97% by 2021 [11].

Given the above, it is important to understand how older people react to information about COVID-19 disseminated by the media, what effects this information has on their lives, and how it can affect their mental health. Thus, we conducted this study, which is derived from an international multicenter study titled "COVID-19 infodemic and its repercussions on the mental health of the elderly during and postpandemic: A multicenter study Brazil/Chile/Peru/Colombia/Mexico and Portugal." We aimed to describe the profile of exposure to information on COVID-19 among older Brazilian individuals and determine the mental health repercussions of this exposure by screening for perceived stress and generalized anxiety disorder (GAD). The following hypothesis guided the collection and analysis of quantitative data: There are associations between variables

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related to the COVID-19 infodemic, GAD, and perceived stress among older Brazilian people.

With regard to screening for perceived stress and GAD, it is necessary to understand aspects of these conditions that are accentuated in the context of an infodemic and pandemic.

Stress has multiple etiologies and can be understood as the result of exposure to events considered stressful that exceed the body's ability to control or manage them; this generates important behavioral symptoms, such as fear, avoidance behaviors, irritability, and repetitive nightmares. Stress is also a symptom of several mental disorders [12].

The diagnosis of GAD is based on excessive anxiety, worry, and apprehensive anticipation that occur on most days for at least 6 months and are related to a variety of events or activities that the individual finds it difficult to control. Anxiety and worry are generally associated with signs and symptoms of restlessness, fatigability, difficulty concentrating, irritability, muscle tension, and sleep disturbance; these signs and symptoms persist and cause clinically significant distress or impairment in social and professional functioning [12].

Methods

Overview

This paper is derived from an international multicenter study that is still ongoing, titled "COVID-19 infodemic and its repercussions on the mental health of the elderly during and postpandemic: A multicenter study Brazil/Chile/Peru/Colombia/Mexico and Portugal," which seeks to analyze the COVID-19 infodemic and its repercussions on the mental health of older individuals.

This is a cross-sectional, quantitative, exploratory study conducted among people aged 60 years or older in several Brazilian municipalities. Participants eligible for this study were older Brazilians who had access to the internet and social networks.

The data collection instruments were delivered through a web-based survey between July 2020 and March 2021. The access link was sent by email and through social networks; up to 3 attempts were made over 3 months. Mediation with older people was performed in collaboration with scientific societies for geriatrics and gerontology, health care units, and associations of retirees; direct contact was also made with older people who were already being monitored through research and outreach activities at the collaborating research centers.

When they first accessed the link, the participants were directed to a digital informed consent form where they either accepted or refused to participate in the study. The choice to participate or not participate in the study was automatically recorded in a database generated by the web-based survey. Those who chose to continue participating in the study gained access to the research questions.

The data collection instrument was adapted from studies by Ahmad and Murad [13] and Gao et al [14] and measured demographic and socioeconomic variables. In addition, it included variables related to the COVID-19 infodemic that measured types of media accessed, including social networks, radio, and television, and the time of exposure to these media as frequency and hours. The Perceived Stress Scale (PSS) was used to screen for perceived stress and was analyzed as a continuous variable [15]. The Geriatric Anxiety Inventory (GAI) was used to screen for GAD and was analyzed according to studies validated and conducted in Brazil; a cutoff score of 13 indicated the presence of GAD [16].

The final version of the database was transferred from Microsoft Excel (Microsoft Corp) to SPSS (version 23.0; IBM Corp). The treatment and descriptive analysis procedures were performed through sociodemographic characterization of the participants and with reference to variables related to exposure to COVID-19–related news and information in the media. For the qualitative variables, the absolute and relative frequencies were estimated. For the quantitative variables, measures of position (mean and median) and dispersion (SD, IQR, and minimum and maximum) were estimated according to data distribution (symmetric or asymmetric).

Responses to the PSS questionnaire were analyzed by calculating position and dispersion measures. The estimated prevalence of GAD among the population was determined according to a cutoff point adopted for the analysis of the GAI.

A 1-way analysis of variance (ANOVA) was used to determine differences in mean perceived stress in the participants based on infodemic exposure and sociodemographic characteristics using the Bonferroni post hoc test and a significance level of $P<.05$. Multiple linear regression analysis was performed to estimate the crude and adjusted regression coefficients with 95% CIs for the association between the independent variables of interest and the perceived stress outcome.

The associations between infodemic variables and outcomes related to the geriatric anxiety screening were assessed using the chi-square test. Subsequently, crude and adjusted multiple logistic regression analyses were performed to identify associations between the independent variables of interest and the GAD outcome with the 95% CI. The significance level adopted in all tests was 5%.

Ethical Considerations

The study was approved by the Brazilian National Research Ethics Committee (Comissão Nacional de Ética em Pesquisa) on March 7, 2020 (CAAE 31932620.1.1001.5147; opinion 4.134.050). Data collection was initiated after approval.

This study complied with all ethical and legal requirements specific to investigations involving human beings, in line with the regulatory provisions of Brazilian Resolution No 466/12 of the National Health Council. The interviewees were guaranteed anonymity and codenames were used to represent them in the study. The participants were informed about the study's objectives, its justification, and the research procedures, and it was explained to them that participation was voluntary, without financial advantages or expenses. Findings will be disclosed only at scientific events or in journals.

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The data and instruments used in the research will be archived with the responsible researcher for a period of 5 years and will be destroyed after that period. Authorizations were requested from the institutions involved to carry out the research. The consent to said documents relies on the performance of the study, description of the methods, and the dissemination of results exclusively in events or journals of a scientific nature.

Results

A total of 3307 older individuals participated in the study, of whom 2250 (68.4%) were female, 1285 (38.9%) were aged between 60 and 64 years, 1835 (55.5%) were married, and 2364 (71.5%) were White. Housing data showed that 3160 (95.6%) lived in an urban area and 1886 (57%) lived in homes with 1 or 2 people. Only 295 (8.9%) had not started or completed basic education, while 645 (19.5%) had completed higher education. The majority, 1343 (40.6%), used free and paid health services. In addition, 2437 (73.8%) responded that the pandemic did not affect their monthly income (Table 1).

The most used resources to access news and information about COVID-19 during the day among the 3307 participants were television, used by 2680 (81.1%), and social networks, used by 1943 (58.8%); only 876 (26.5%) used the radio. Participants also self-reported their frequency of exposure to information and news about COVID-19 over a period of 1 week (ie, 7 days), ranging from “no exposure” to “frequent exposure.” Television was reported as a frequent source by 1473 (44.5%) participants, while social networks were reported as sometimes being a source by 1464 (44.3%) patients. In contrast, the radio was not a source of exposure for the majority of participants (n=1956, 59.1%). Television exposure was 3 hours or more for 1301 (39.3%) participants, social network exposure was 2 to 5 hours for 1084 (32.8%) participants, and radio exposure was 1 hour or more for 1223 (37%) participants (Table 2).

An ANOVA testing the association of perceived stress with infodemic variables showed a significant association between perceived stress and frequency of exposure to social networks (P=.04). It is also noteworthy that the mean score for perceived stress was higher (mean 20.84, SD 9.55) among those who had no exposure to social networks. The Bonferroni post hoc test revealed that the perceived stress of participants who were exposed to social networks for 1 hour (P=.04) and those who had no exposure to social networks (P=.04) differed significantly. There was also a significant association with hours of exposure to news and information about COVID-19 on social networks (P=.02; Table 3).

Approximately 143 of 822 (17.4%) of participants who were not exposed to social networks and 173 of 1021 (16.9%) who were frequently exposed to social networks had a GAI score that indicated GAD (P<.001). A significant association was found between geriatric anxiety and hours of exposure to news and information about COVID-19 on social networks (P=.01). Among the participants, 73 of 395 (18.5%) who were frequently exposed to radio as a means of information and 105 of 560 (18.8%) who were exposed to social networks for 6 hours or more had a GAI score that indicated GAD (Table 4).

Logistic regression analyses were performed a GAI score indicating GAD as the outcome variable, and linear regression was used for perceived stress to estimate the raw and adjusted regression coefficients for the predictor variables (ie, the sociodemographic variables: age group, gender, education, cohabitation status, and income changes) and the infodemic variables.

The crude linear regression showed that some frequency of exposure to social networks (P=.02) and 1 hour of exposure to social networks (P<.001) were associated with perceived stress. In the analysis adjusted for the sociodemographic variables, no associations were found with the outcome variable. In the crude logistic regression, some frequency of exposure to social networks (P<.001) and 2 to 5 hours of exposure to social networks (P=.03) were also associated with GAD. In the adjusted analysis for the indicated variables, some frequency of exposure to social networks (P<.001), 1 hour of exposure to social networks (P=.04), and 2 to 5 hours of exposure to social networks (P=.03) were associated with a GAI score indicating GAD (Table 5).

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Table 1. Sociodemographic profile of participants in this study (n=3307).

Variables	Participants, n (%)
Gender	
Female	2250 (68.4)
Male	1039 (31.6)
Prefer not to declare	18 (0.5)
City	
Other	544 (16.4)
Juiz de Fora, Minas Gerais	470 (14.2)
São Paulo, São Paulo	412 (12.5)
Porto Alegre, Rio Grande do Sul	397 (12)
Divinópolis, Minas Gerais	381 (11.5)
Rio de Janeiro, Rio de Janeiro	352 (10.6)
Viçosa, Minas Gerais	335 (10.1)
Ribeirão Preto, São Paulo	251 (7.5)
Brasília, Distrito Federal	165 (5)
Age group (years)	
60 to 64	1285 (38.9)
65 to 69	921 (27.9)
70 to 74	503 (15.2)
75 to 79	334 (10.1)
80 or older	264 (8)
Marital status	
Married or living together	1835 (55.5)
Widowed	598 (18.1)
Separated	509 (15.4)
Single	365 (11)
Race	
White	2364 (71.5)
Non-White	943 (28.5)
Cohabitation	
Living alone	587 (17.8)
Living with 1 or 2 people	1886 (57)
Living with 3 or more people	834 (25.2)
Own residence	
Yes	2756 (83.3)
No	551 (16.7)
Area of residence	
Urban	3160 (95.6)
Rural	147 (4.4)
Maximum education	
Did not complete basic education	295 (8.9)
Basic or elementary education	713 (21.6)
Secondary education	718 (21.7)

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Variables	Participants, n (%)
Completed higher education	645 (19.5)
Specialization	512 (15.5)
Master's, doctoral, or postdoctoral degree	424 (12.8)
Health services used	
Only paid health services (including health insurance)	1133 (34.3)
Both (free and paid)	1343 (40.6)
Only free health services	814 (24.6)
None	17 (0.5)
Receives retirement or pension income	
Yes	2565 (77.6)
No	740 (22.4)
Pandemic altered income	
No	2437 (73.8)
Yes, my income decreased	787 (23.8)
Yes, my income increased	80 (2.4)

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Table 2. Characteristics of the methods most commonly used to access news and information about COVID-19 and the frequency and hours of exposure (n=3307).

Characteristics	Participants, n (%)
Social network exposure (n=3303)	
Yes	1943 (58.8)
No	1361 (41.2)
Frequency of exposure	
None	822 (24.9)
Sometimes	1464 (44.3)
Often	1021 (30.9)
Hours of exposure to news and information about COVID-19 on social networks	
None	848 (25.6)
1	811 (24.5)
2 to 5	1084 (32.8)
6 or more	560 (16.9)
Television exposure (n=3304)	
Yes	2680 (81.1)
No	624 (18.9)
Frequency of exposure	
None	394 (11.9)
Sometimes	1440 (43.5)
Often	1473 (44.5)
Hours of exposure to news and information about COVID-19 on television	
None	431 (13)
1	884 (26.7)
2	685 (20.7)
3 or more	1301 (39.3)
Radio exposure (n=3304)	
Yes	876 (26.5)
No	2429 (73.5)
Frequency of exposure	
None	1956 (59.1)
Sometimes	956 (28.9)
Often	395 (11.9)
Hours of exposure to news and information about COVID-19 on the radio	
None	2083 (63)
1 or more	1223 (37)

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Table 3. Differences in mean Perceived Stress Scale score and infodemic variables (n=3307).

Variables	Perceived Stress Scale score, mean (SD)	*P* value[a]
Frequency of exposure to social networks		.04
None	20.84 (9.55)	
Sometimes	19.89 (9.27)	
Often	20.61 (9.82)	
Frequency of exposure to television		.33
None	20.03 (9.51)	
Sometimes	20.16 (9.38)	
Often	20.62 (9.65)	
Frequency of exposure to radio		.89
None	20.36 (9.57)	
Sometimes	20.40 (9.33)	
Often	20.13 (9.72)	
Hours of exposure to news and information about COVID-19 on social networks		.02
None	20.92 (9.46)	
1	19.68 (9.53)	
2 to 5	20.11 (9.41)	
6 or more	20.91 (9.77)	
Hours of exposure to news and information about COVID-19 on television		.6
None	20.05 (9.67)	
1	20.07 (9.42)	
2	20.50 (9.84)	
3 or more	20.54 (9.38)	
Hours of exposure to news and information about COVID-19 on the radio		.60
None	20.28 (9.53)	
1 or more	20.46 (9.50)	

[a]One-way ANOVA between groups with Bonferroni correction and a significance level of $P<.05$.

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Table 4. Association between infodemic variables and screening for geriatric anxiety (n=3307).

Variables	Presence of geriatric anxiety (participants), n (%)		*P* value[a]
	Yes	No	
Frequency of exposure to social networks			.008
None (n=822)	143 (17.4)	679 (82.6)	
Sometimes (n=1464)	194 (13.3)	1270 (86.7)	
Often (n=1021)	173 (16.9)	848 (83.1)	
Frequency of exposure to television			.15
None (n=394)	66 (16.8)	328 (83.2)	
Sometimes (n=1440)	202 (14)	1238 (86)	
Often (n=1473)	242 (16.4)	1231 (83.6)	
Frequency of exposure to radio			.13
None (n=1956)	302 (15.4)	1654 (84.6)	
Sometimes (n=956)	135 (14.1)	821 (85.9)	
Often (n=395)	73 (18.5)	322 (81.5)	
Hours of exposure to news and information about COVID-19 on social networks			.01
None (n=848)	145 (17.1)	703 (82.9)	
1 (n=811)	112 (13.8)	699 (86.2)	
2 to 5 (n=1084)	148 (13.7)	936 (86.3)	
6 or more (n=560)	105 (18.8)	455 (81.2)	
Hours of exposure to news and information about COVID-19 on television			.62
None (n=431)	69 (16)	362 (84)	
1 (n=884)	127 (14.4)	757 (85.6)	
2 (n=685)	102 (14.9)	583 (85.1)	
3 or more (n=1301)	212 (16.3)	1089 (83.7)	
Hours of exposure to news and information about COVID-19 on the radio			.13
None (n=2083)	306 (14.7)	1777 (85.3)	
1 or more (n=1223)	204 (16.7)	1019 (83.3)	

[a]Chi-square test.

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Table 5. Crude and adjusted logistic regression models for the Geriatric Anxiety Inventory score and crude and adjusted linear regression models for the Perceived Stress Scale score (n=3307).

Variables	Geriatric anxiety (logistic regression), OR[a] (95% CI)		Perceived stress (linear regression), OR (95% CI)	
	Crude analysis	Adjusted analysis[b]	Crude analysis	Adjusted analysis[b]
Frequency of exposure to social networks				
None	1	1	1	1
Sometimes	0.72 (0.57 to 0.91)	0.69 (0.53 to 0.90)	–0.94 (–1.76 to –0.13)	–0.54 (–1.44 to 0.35)
Often	0.96 (0.75 to 1.23)	0.92 (0.70 to 1.22)	–0.22 (–1.10 to 0.64)	0.25 (–0.73 to 1.23)
Frequency of exposure to television				
None	1	1	1	1
Sometimes	0.81 (0.59 to 1.09)	0.81 (0.59 to 1.10)	0.13 (–0.93 to 1.19)	0.04 (–1.02 to 1.10)
Often	0.97 (0.72 to 1.31)	0.97 (0.72 to 1.31)	0.59 (–0.46 to 1.65)	0.49 (–0.57 to 1.56)
Frequency of exposure to radio				
None	1	1	1	1
Sometimes	0.90 (0.72 to 1.12)	0.88 (0.71 to 1.11)	0.03 (–0.69 to 0.77)	0.00 (–0.73 to 0.75)
Often	1.24 (0.93 to 1.64)	1.24 (0.93 to 1.65)	–0.23 (–1.26 to 0.79)	–0.26 (–1.31 to 0.77)
Hours of exposure to news and information about COVID-19 on social networks				
None	1	1	1	1
1	0.77 (0.59 to 1.01)	0.73 (0.55 to 0.99)	–1.23 (–2.15 to –0.32)	0.89 (–1.88 to 0.11)
2 to 5	0.76 (0.59 to 0.98)	0.74 (0.56 to 0.98)	–0.80 (–1.66 to 0.04)	–0.43 (–1.36 to 0.49)
6 or more	1.11 (0.84 to 1.47)	1.10 (0.81 to 1.49)	–0.00 (–1.02 to 1.01)	0.43 (–0.65 to 1.53)
Hours of exposure to news and information about COVID-19 on television				
None	1	1	1	1
1	0.88 (0.64 to 1.21)	0.87 (0.63 to 1.20)	0.01 (–1.07 to 1.11)	–0.72 (–1.17 to 1.03)
2	0.91 (0.65 to 1.28)	0.92 (0.65 to 1.28)	0.45 (–0.69 to 1.60)	0.37 (–0.78 to 1.52)
3 or more	1.02 (0.75 to 1.37)	1.02 (0.75 to 1.39)	0.49 (–0.54 to 1.53)	0.33 (–0.72 to 1.39)
Hours of exposure to news and information about COVID-19 on the radio				
None	1	1	1	1
1 or more	1.16 (0.95 to 1.41)	1.16 (0.95 to 1.42)	0.17 (–0.49 to 0.85)	0.12 (–0.56 to 0.80)

[a]OR: odds ratio.

[b]Adjusted for gender, age group, education, cohabitation status, and income changes during the pandemic.

Discussion

Principal Findings and Comparison to Prior Work

This study found that older people, especially older women, were often exposed to information related to COVID-19 through television and social networks and that this had repercussions for their mental health, specifically GAD and stress.

The participants in this study were mostly White educated women aged 60 to 64 years who cohabited with 1 or 2 people in their own residence, received retirement income, and had no change in income due to the pandemic.

We hypothesize that our findings may be related to the income status of the study population, as this is a limitation for many older people. A lack of financial support and purchasing power limits access to the internet and to electronic devices. Social exclusion from internet access is considered one of the most important markers of socioeconomic inequality [9]. Moreover, the persistence of ageism can make older people digitally invisible, supporting the idea that older people do not have the necessary skills to make use of all the functions of technology [9,17].

One study inferred that older adults with 9 or more years of education are more likely to maintain internet use than older adults who had less education or who did not have access to school [18]. The proportion of internet users is higher among people with more education, those with a higher monthly family income, and those who are younger, which is in line with the results of this study. Older individuals with a lower educational level may have greater difficulty using and manipulating computers and cell phones and therefore use the internet less [17,18].

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In line with this study, data from the Continuous Pesquisa Nacional por Amostra de Domicílios (National Household Sample Survey) [11] show that there are more women than men in Brazil. The Brazilian population is composed of 48.2% men and 51.8% women, and among older individuals, the percentage of women reaches 56%. In addition, women show greater receptivity, which ensures greater agreement and participation in opinion studies and interviews [19]. Media consumption increased during the period of social distancing, and although older people are part of the population with the lowest level of internet and digital media use, their access to and use of such media also increased during the pandemic [20,21].

Some studies indicate that social distancing and anxiety further increased digital screen time [20-23]. The use of the internet was promoted by video calls, which allowed greater contact between older people and their family and friends, and by apps that allowed delivery of food and medicine. These contacts, in addition to acting directly on health by promoting well-being and quality of life, helped reduce feelings of loneliness [22]. On the other hand, the continuous use of the internet and other means of communication contributed to increasing access to ill-organized information and continuous information overload [23].

This study found that television was the most used means of accessing information, followed by social networks. Older people reported that they were frequently exposed to information about COVID-19 on television and that their daily exposure was 3 hours or more.

Television is a medium that allows access to content produced by journalists, which suggests a certain level of confidence from the social point of view, although television may also promote content that is biased in favor of business, political, and even economic interests. During the pandemic, television briefly acquired centrality in Brazilian homes, because older people gathered around televisions in search of information about the disease. In emergency situations, social media is another useful channel for news, due to its rapid, real-time dissemination of specific, objective content [18,20].

Similarly, the literature shows that social networks and television are the main means of access to information in the pandemic [17,23-26]. A cross-sectional study conducted in Brazil with data from a virtual health survey revealed an increase in television-watching among adults during the pandemic [17].

A Brazilian study reported that during the pandemic television use averaged 3.31 hours, representing an increase of 1 hour and 45 minutes compared to the average time dedicated to television before the pandemic. Among the participants, those aged 60 years or older were the group who spent the longest average time watching television, which corroborates the data found in this study. The average time of use of computers or tablets was more than 5 hours during the pandemic, representing an average increase of 1 hour and 30 minutes compared to before the pandemic [27].

The hours and frequency of exposure to information are important data, because they can be indicative of information-seeking behavior, and they can potentiate infodemic content in the social context and the possible impacts of the infodemic on the mental health of the individual. Additionally, when investigating factors that increase protection and well-being regarding the use of the media, it is important to weigh the time spent in hours and the frequency of exposure to the media [6,28].

We found a significant association between infodemic variables, perceived stress, GAD, and the frequency of exposure to social networks. This suggests that exposure time and the source of information used by older people can impact their levels of anxiety and stress.

A recent German study reinforced the idea that the information conveyed by digital social media and traditional media, including broadcast television and radio, are linked to increased anxiety [28]. Conversely, the information provided by official sources and government websites is related to a decrease in anxiety [29]. Another study, conducted with 4872 adult Chinese citizens, found that older individuals who were frequently exposed to social media had a prevalence of anxiety of 22.6% and a prevalence of depressive disorders of 16.6% [14].

Research shows that in the context of the pandemic, being frequently exposed to alarming information about sick or deceased individuals increases the risk of mental disorders such as depression and anxiety [14,24,30]. Sensationalist content and misinformation generate a large supply of ideas that are difficult to process, causing symptoms of anguish and mental confusion.

In this study, mean perceived stress and GAD were higher among older participants who had no exposure to social networks. This agrees with studies [28-30] that point out that avoiding information can be an attempt at a defensive response and a form of emotional coping with infodemic stressors [28]. On the other hand, avoiding information can lead people to worry that they are missing important new information, generating stress and anxiety and showing that avoidance is a poor adaptive coping attitude [31].

The abovementioned German study showed that the choice to avoid information may be linked to a feeling that there is nothing that can be done to prevent the negative consequences of COVID-19. Participants who were “very concerned” about the risks to mental and physical health were also more likely to avoid or ignore the media. That analysis also revealed that a higher level of stress was associated with less access to social networks, especially among those who did not consider themselves to have good mental health [29].

Individuals tend to avoid exposing themselves to information when they associate it with aversive emotions or when the information might make it necessary to perform unwanted actions [31]. Indeed, the COVID-19 infodemic provoked thoughts about human mortality, sequelae of the disease, progression to the severe stage of the disease, and involved biosafety guidelines and recommendations that imposed new habits, including social distancing, to which a significant proportion of older people objected.

Thus, it is necessary to develop health education strategies appropriate to older individuals to respond to the infodemic and provide clear, specific, and objectively necessary information.

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In addition, it is important to investigate health literacy (ie, the ability to access and use information to make appropriate health decisions) and digital literacy (ie, the ability to locate information in digital media, select it, access it, and use it to acquire knowledge) [32,33].

The media constitute an important element in the construction of an informative discourse, distributing information about diseases and their methods of transmission, prevention, treatment, and immunization, as well as reporting on the most recent research [19]. Reliable and accessible information is important to increase the population's awareness of preventive measures, the importance of immunization, and the fight against disease progression [19,32].

Given the above, we emphasize the importance of public health policies on infodemic management that encourage social education among older people on how to seek and interpret information. A past study that discussed the public health research agenda for managing infodemics suggested that public health authorities should develop, implement, validate, and adapt tools to manage infodemics at acute public health events, taking into account the country-specific context, and invest and foster policy makers in the scientific community [34].

Limitations

A limitation of this study is the use of a web-based survey. This tool, which was chosen due to COVID-19 restrictions, limited the participation of many older people who do not have access to the internet or social networks, causing sample bias.

Another limitation was the profile of the participants, who were predominantly female, White, had completed elementary or higher education (even graduate education), lived in urban areas, cohabited with 1 or 2 people, had fixed incomes, and had incomes that were unaffected by the pandemic. These characteristics, which do not correspond exactly to the general Brazilian population, might have been protective against mental illness.

Conclusions

Excessive information can affect mental health, cause feelings of stress and anxiety, and affect the quality of life of older individuals. In a pandemic context, the severity of these effects may be magnified by obstacles to sociable behavior and health service and support networks.

Investigation of the infodemic and its impacts on mental health should be part of the anamnesis of older people, so that they can share their feelings about this phenomenon and receive appropriate psychosocial care.

The management of excessive information should be a subject of debate in public health. The infodemic phenomenon is complex, because it is centralized, multifactorial, and cross-cut by important political and sociocultural issues.

This study contributes to the scientific community by presenting quantitative data that demonstrate the association between infodemic variables and mental health. This study also helps fill a knowledge gap in an important thematic axis and represents an original investigation into the impacts of the infodemic on GAD, perceived stress, and major depression in the older Brazilian population.

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Data Availability

The data sets generated and/or analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

None declared.

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Abbreviations

ANOVA: analysis of variance
GAD: generalized anxiety disorder
GAI: Geriatric Anxiety Inventory
PPS: Perceived Stress Scale

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Original Paper

Older Adults' Trust and Distrust in COVID-19 Public Health Information: Qualitative Critical Incident Study

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Abstract

Background: The COVID-19 infodemic has imposed a disproportionate burden on older adults who face increased challenges in accessing and assessing public health information, but little is known about factors influencing older adults' trust in public health information during COVID-19.

Objective: This study aims to identify sources that older adults turn to for trusted COVID-19 public health information and factors that influence their trust. In addition, we explore the relationship between public health information sources and trust factors.

Methods: Adults aged 65 years or older (N=30; mean age 71.6, SD 5.57; range 65-84 years) were recruited using Prime Panels. Semistructured phone interviews, guided by critical incident technique, were conducted in October and November 2020. Participants were asked about their sources of COVID-19 public health information, the trustworthiness of that information, and factors influencing their trust. Interview data were examined with thematic analysis.

Results: Mass media, known individuals, and the internet were the older adults' main sources for COVID-19 public health information. Although they used social media for entertainment and personal communication, the older adults actively avoided accessing or sharing COVID-19 information on social media. Factors influencing their trust in COVID-19 public health information included confirmation bias, personal research, resigned acceptance, and personal relevance.

Conclusions: These findings shed light on older adults' use of information sources and their criteria for evaluating the trustworthiness of public health information during a pandemic. They have implications for the future development of effective public health communication, policies, and interventions for older adults during health crises.

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KEYWORDS

health information; information-seeking behavior; COVID-19; qualitative research methods; communication; media and networks; aging; older adults; elderly population; mass media; public health information; trust

Introduction

Older adults have been disproportionately affected by the COVID-19 pandemic [1] and by the resulting infodemic of rapidly spreading misinformation and disinformation about it [2-4]. Finding credible, trustworthy public health information about COVID-19 can be daunting for anyone, but it has been especially difficult for older adults who tend to face challenges

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in using digital technology to access information and services [3]. Preliminary evidence suggests that older adults may be more susceptible to misinformation [5], and older adults can lack confidence in assessing the quality of health information on the web [6]. More research is needed in order to understand the sources and factors that influence older adults' trust in public health information during a pandemic.

Compared with younger adults, who tend to rely on health information found on the internet [7,8], older adults are more likely to experience difficulties in sifting through the large quantities of health information on the web [9-11]. Older adults use social media to stay in touch with family and friends [12,13], and, increasingly, to locate or share health information as well [14]. Yet they still turn to health care providers as a foundational source for health information, and they still rely on direct personal contacts such as friends and family for help in obtaining and interpreting health information from web-based sources [15]. Researchers have identified differences in how older adults understand web-based information and how this impacts their trust in it [16]. For example, increased exposure to and repetition of information over time can increase trust in that information; this has been called a repetition-induced truth effect [16,17]. Similarly, how people choose to share health education is affected by the tendency to select information that aligns with established beliefs, or confirmation bias [18,19].

Uncertainty, fear, and social isolation associated with COVID-19 can not only hinder the integration of information from trusted sources but also increase one's susceptibility to misinformation and disinformation [20,21]. During the pandemic, older adults may have felt overwhelmed by the quantity of information about COVID-19 available [3,22]. Whereas younger adults turn to social media platforms such as Facebook, Twitter, or YouTube for COVID-19 public health information, older adults often rely on traditional mass media such as television, radio, and newspapers [20], as well as on their personal contacts with family and friends [22,23].

Beyond accessing and assessing sources for COVID-19 public health information, people must also evaluate the information itself. One way to do so is to seek and compare information across multiple sources [24]. Older adults seem to be more likely than younger people to fact-check or research new information that they have heard about COVID-19, which includes drawing upon their previous life experiences to help determine the information's trustworthiness [25]. Nevertheless, people across age groups tend to seek information that confirms their existing political beliefs [26], and the politicization of information about COVID-19 represents a danger to individuals' willingness to fact-check information.

Personal criteria for assessing information's trustworthiness can vary, but little is understood about older adults' criteria for vetting COVID-19 public health information and the interplay among those criteria. Our multiphase research project, funded by the National Science Foundation, is intended to address these gaps in the literature. Here, we report findings from phase 2 of the study, in which we conducted semistructured in-depth interviews to further understand factors that might influence older adults' trust in information sources as well as the information itself. Our research questions (RQs) were as follows:

1. RQ1: From what information sources do older adults seek, receive, evaluate, and use information about COVID-19?
2. RQ2: What factors might influence older adults' trust in the COVID-19 information that they obtain from various information sources?

To answer our RQs, we used the critical incident technique (CIT) [27,28] to develop an interview guide for our interviews. As a qualitative interview method, the CIT allows participants to self-identify and reflect on significant events. We chose to use the CIT to inductively identify COVID-19 public health information sources and the factors that influenced older adults' trust. At the time of the interviews, information about a possible COVID-19 vaccine was beginning to circulate in the media. Through the CIT, we were able to gain a snapshot of older adults' perspectives of trust in COVID-19 public health information at a critical moment during the pandemic.

Methods

Design

In semistructured interviews, we used the CIT [27,28] to engage participants in recalling and discussing specific examples of COVID-19 public health information. For example, we asked participants to recall the most recent health information about COVID-19 that they had heard (see Multimedia Appendix 1).

Participants and Recruitment

Participants were a purposive sample of 30 US older adults aged 65 to 84 (mean age 71.6, SD 5.57) years interviewed in October and November 2020. They were recruited from a pool of 123 older adults from phase 1 of our study who indicated a willingness to participate in a follow-up interview. We used Prime Panels for all recruitment. Of 123 older adults contacted, 48 (39%) responded. Those in our final sample of 30 were chosen to best reach a balance of political inclination (Democrat: n=11, 37%; Independent or other: n=8, 27%; and Republican: n=11, 37%), education (with degree: n=16, 53% and without degree: n=14, 47%), and self-identified gender (female: n=19, 63% and male: n=11, 37%). However, we were unable to balance participants on the basis of race or ethnicity (Black or African American: n=1, 3% and White: n=29, 97%).

Materials and Measurements

A list of predetermined questions guided each interview (see Multimedia Appendix 1). The CIT informed the development of our interview guide, such that questions focused on the most recent COVID-19 public health information that participants had encountered as well as specific examples of COVID-19 public health information that they found trustworthy or untrustworthy. To begin each interview, we elicited their recollection of critical incidents by asking the following question: "From what source did you first learn about COVID-19?" Additional follow-up questions facilitated clarification and provided additional depth as needed to obtain insight into individuals' personal motivations and to understand unique situations [29]. For example, after asking about specific

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examples of information that participants trusted or distrusted, we asked them "Why did you trust/distrust this information?" "What was the information source?" and "Has your trust/distrust in this information changed over time?"

Ethical Considerations

A total of 2 team members conducted telephone interviews with each participant, with 1 serving as the interviewer and the other taking notes. At the start of each phone call, the interviewer obtained verbal consent to audio record the interview. At the beginning of the audio recording, the interviewer read a brief consent statement to the participant, answered any of the participant's questions, and asked for verbal informed consent to proceed. The interviews were recorded with AISense, Inc's Otter.ai transcription software, with Apple's QuickTime as a backup. Each interview lasted approximately 1 hour. At the conclusion of each interview, the participant received a US $20 Amazon eGift card. This study's procedures were approved by the institutional review board of The University of Texas at Austin (IRB study #2020-03-0080).

Data Analysis

The interview transcriptions automatically generated by Otter.ai were reviewed and manually corrected as necessary by the interviewer and the notetaker to ensure accuracy. The interviewer then uploaded each transcription into Dedoose's web-based qualitative data analysis software, and both the interviewer and the notetaker independently coded the data in Dedoose using inductive thematic analysis [30]. The goal was to identify themes or patterns in the participants' responses that reflected their beliefs about COVID-19, as well as trusted and distrusted sources of public health information. First, we (the interviewer and the notetaker) familiarized ourselves with the interview data through multiple readings of the transcripts. In this step, both researchers noted initial ideas, highlighting passages in which participants spoke about COVID-19 public health information, trusted or distrusted sources of COVID-19 information, and personal impacts of the pandemic on their lives. Second, through iterative rereading and discussion, we developed initial codes for the interview data. For example, the code "information source" identified instances in which participants discussed using a specific resource for COVID-19 public health information. Next, we collated the coded data, assessed the data for themes, and developed initial themes; examples included "active avoidance of social media," "human versus digital sources of information," and "common sense as a factor in trust." A third team member then reviewed the data as a separate coder, and the research team met as a group to discuss that coder's findings and establish agreement on initial themes. We reviewed the initial themes in relation to both the coded extracts and the data set as a whole, and we discussed, revised, and finalized the themes as a team.

Results

Overview

The data revealed 2 main themes. The first theme, "Sources of COVID-19 Public Health Information," represents sources to which participants turned for public health information about COVID-19. Under this theme, we identified 3 subthemes: mass media, known individuals, and the internet. The second theme, "Older Adults' Criteria for Trusting COVID-19 Public Health Information," represents the factors that participants discussed in assessing the trustworthiness of their public health information sources. Under this theme, we identified 4 subthemes: personal relevance, personal research, confirmation bias, and resigned acceptance.

Sources of COVID-19 Public Health Information

Overview

The older adults in the study turned to mass media, individuals with whom they shared personal relationships (ie, known individuals), and the internet to access COVID-19 public health information. They turned to mass media not only for national news but also for local and regional information about COVID-19's impact on their communities. Years of reliance on mass media were often given as a reason for trusting such sources to provide reliable COVID-19 public health information. The participants also placed trust in information obtained directly from known individuals, and often, they did not think it was necessary to verify such information. When participants did feel a need to verify COVID-19 public health information, they used the internet to fact-check it.

Although the older adults reported using social media to connect with others or for entertainment, they were adamant about not using social media to access important public health information about COVID-19. Of the 70% (21/30) of participants who said that they had used social media, 16 (53%) said that they avoided seeking COVID-19 public health information from social media. Participants found social media posts to be unverifiable and had a general distrust of using social media for health information. Some even considered social media to be sinister or dangerous.

Given the breadth of these 3 categories of information sources (mass media, known individuals, and the internet), we subsequently identified subcategories under each. Mass media included information sources such as television news, radio programs, podcasts, and newspapers. Known individuals included friends, family, and personal doctors. As for the internet, participants typically consulted websites maintained by authoritative health organizations or simply used search engines such as Google.

Mass Media

Participants used mass media such as television, newspapers, radio, and podcasts as sources of information. Some had a generalized trust in certain mass media sources: "Fox, NBC, CBS, any of them...I really don't distrust them. Because they have to maintain a level of believability in anything to be believable in all things." Others expressed preferences for specific cable networks or programs: "CNN, my best friend," or "I love my 60 Minutes." Some said that they accessed COVID-19 information from radio stations: "I do listen to conservative talk radio at least once a day." Participants also discussed mass media personalities as trusted individuals. One participant discussed a favorite newscaster: "He [Don Lemon] just seems trustworthy; he seems to report it as it is." Other trusted mass media personalities were medical experts such as

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Dr Sanjay Gupta: “Dr. Gupta from CNN...I like him when he’s on. I think he is excellent, and he presents everything objectively.”

Known Individuals

For trusted COVID-19 public health information, participants relied on people with whom they shared personal relationships, such as family, friends, and their own doctors. Family members were frequently mentioned: “My daughter follows something and gets alerts constantly on the phone, so she’s always updating me with everything.” Others spoke of their friends: “My ex-husband’s wife is a nurse and we’re good friends. And she says they are fudging the numbers.” Some received COVID-19 public health information directly from their doctors: “Well, this is from...not on a news source. I just happened to go for an annual checkup 2 days ago and just said to the doctor, ‘Hey, what’s going on with this?’”

Internet

Participants also searched the internet for information from websites maintained by authoritative health organizations. One referred to using these websites as a source for fact-checking: “If I had doubts, I would go to a website like...the World Health Organization website, CDC website, something like that.” Others did not recognize specific websites as information sources but instead spoke of search engines such as Google or Bing: “I go to Bing.com every morning...That’s where I get most of my stuff, on the internet.”

Participants discussed using the internet to verify information obtained from mass media: “At this point, when I hear something on CBS, I go out on the internet and see what the health organizations are saying about it, to back up what I’m hearing.” They also used the internet to verify the credentials of medical experts seen on mass media: **“**One or two [experts] I looked up on the internet just to confirm my own reasoning, to find out what their credentials were.”

Participants also used the internet to access and share COVID-19 public health information with individuals. This could include sharing information with one’s personal doctor: “[My doctor] was sort of fascinated by it too, so we went online and we were talking about the information.” One participant thought that the internet was where a health professional would go for information, so the internet must be a good source: “I think people in the medical field go to those websites [CDC]...I feel more comfortable in knowing the facts, and then I make my own decision.”

Older Adults’ Criteria for Trusting COVID-19 Public Health Information

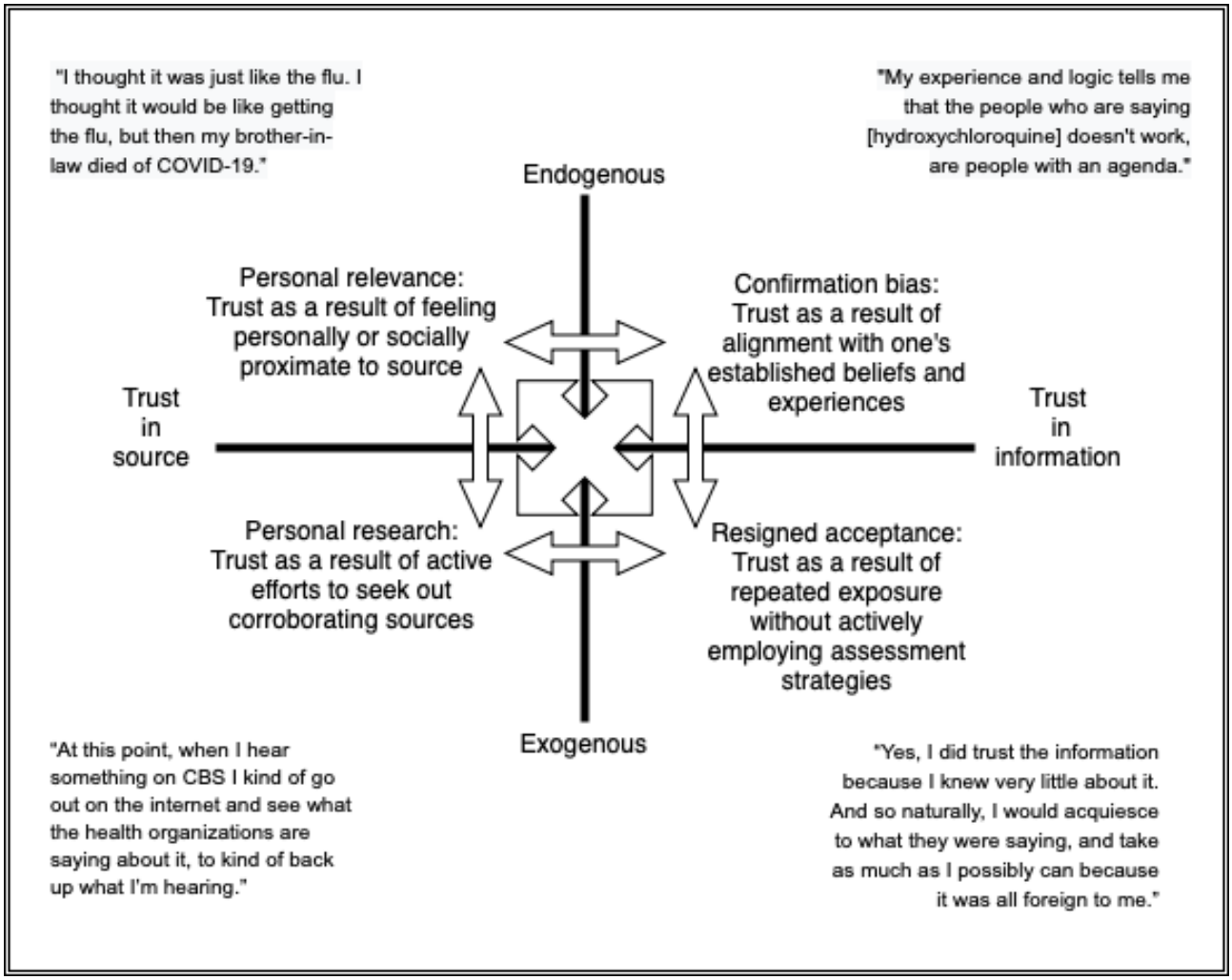
Overview

In assessing the trustworthiness of public health information about COVID-19, participants relied on 4 personal criteria: personal relevance, personal research, confirmation bias, and resigned acceptance. Each of these criteria was situated either endogenously (as an internal factor) or exogenously (as an outward factor). In addition, these personal criteria were used to assess trust in either the information itself or the information’s source.

The semiotic square in Figure 1 illustrates the relationships among these 4 criteria acting as factors, along with how they influenced participants’ trust in COVID-19 public health information. Each personal criterion is situated as an endogenous or exogenous factor as well as according to whether trust is attributed to the information source or to the information itself. Thus, Figure 1 illustrates relationships among opposing concepts. Personal relevance and research are based on trust in the information source, whereas confirmation bias and resigned acceptance are based on trust in the information itself. Personal relevance and confirmation bias are both endogenous, generated from within the individual; personal research and resigned acceptance are exogenous, depending primarily on information and experience external to the individual.

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Figure 1. Personal criteria for trusting information.



Personal Relevance

Personal relevance, the degree to which participants felt personally or socially proximate to an information source, was 1 criterion in trusting new COVID-19 public health information. Personal relevance is an endogenous criterion in which one uses one's unique life experience to assess an information source's trustworthiness.

Although international and national news may have been difficult to believe early on during the COVID-19 pandemic, as information grew personally or socially proximate, participants began to believe in it. State and local authorities were often mentioned as proximate trusted sources: "Our governor did come on TV every day at 2:30 pm for about a month straight to give us information about what we had to do as a state. And that was very, very helpful." Similarly, another participant's trust in the governor was based on what could be seen in the local community: "So far I have not heard anything from [the governor] that I would lose trust in because it seems to fit in with everything around my community." Others expressed trust in local health authorities: "I trust everything that's coming out of the Oregon Health Authority."

The more local the information was, the more the participant trusted that information source: "I'll get [my information] locally from the emergency management, see where they're coming from. At least there are people there we can trust." Another participant who resided in an assisted living facility said "[They] send memos and notes and emails from time to time. They provide a lot of information. It's very helpful." COVID-19 had to become socially proximate before some could trust the reported severity: "I thought it would be like getting the flu, but then my brother-in-law died of COVID-19."

Personal Research

Another criterion that contributed to trust in COVID-19 public health information was personal research, which varied in style and level of detail. Personal research, or the active seeking of corroborating sources of information, was a frequent intentional strategy among the participants. Because personal research necessitates searching for information that reaches beyond one's prior understanding, it is an exogenous criterion for assessing trust in information sources.

Some participants compared emerging COVID-19 information from 1 source with that from another: "Nothing they've said disagrees with everything else I've heard." Others reported actively checking various television sources in an attempt to gather bipartisan information:

> *When I watch the news, I don't just watch one network … Because I know one's supposed to be very liberal. One's supposed to be very conservative. One's*

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> *supposedly pro-White House. So I try to take a little bit of each, so it will be more than one source.*

Some participants used multiple subcategories of mass media to cross-reference information: "I wanted to get more information, so I did check other channels like NBC, ABC, and CNN. And also we get 2 daily newspapers." Personal research became a part of an information-seeking routine for some: "When I hear something on CBS I kind of go out on the internet and see what the health organizations are saying about it, to kind of back up what I'm hearing."

Besides traditional mass media sources, the internet offered a source for further research on emerging COVID-19 information: "I put in [Google] 'What types of death qualifies as COVID deaths?' I did actually find a CDC article that said that if someone dies with the COVID virus, it should be counted as a cause of death." Personal research also included going to fact-checking websites: "I usually go to one of those fact-finding sites like Snopes.com. Usually they're a pretty reliable source to find out whether something is an actual fact or if it's false." Participants often defended their use of internet sources as part of due diligence; as one said, "I know that sounds silly—'on the internet.' But I go to decent news sources. And when I do read them, I try to look up corroborating testimony."

Confirmation Bias

Participants also exhibited confirmation bias in their decisions regarding what COVID-19 information to believe, choosing to trust information that matched their prior beliefs. Confirmation biases are generated endogenously from within as the individual draws from lived experience, relationships, the environment, and unique situations, in an attempt to determine the trustworthiness of emerging pieces of information.

Confirmation bias is often referred to as "common sense," because it results from one's lived experience. The lived experience of a lawsuit against a pharmaceutical company, for example, left 1 participant especially distrustful of COVID-19 vaccine makers: "I have a generalized distrust of pharmaceutical companies. They're in it for the money, not to help people." Common sense was also reflected in a prior understanding of how diseases spread indoors: "Yes [I trusted the information from CBS] because it made sense to me. Because we're now gonna be indoors, it makes sense that's what their cases look like [higher]." One participant demonstrated confirmation bias in discussing how to decide which information to trust and which to ignore:

> *I believe what I think is correct based on my past knowledge and experience from what I've seen from other sources and read in the newspapers. And ones in conflict with those, I just ignore.*

Although some individuals gave the reasoning behind or specific examples of their lived experience, others stated their reliance on common sense proudly, without justification: "Partly I go by my gut—what strikes me as logical, reasonable, possible, probable." One participant distrusted information in order to debunk the wisdom of wearing a mask: "I believe with my whole power of reasoning and my gut feeling and perceptions. I just didn't buy it." Another participant simply stated that information could be trusted "if it makes sense. Sometimes things don't make sense, and I know they're not true, so I just ignore it." In explaining the trustworthiness of information from the cable network One American News, 1 participant said:

> *The first test is common sense, The second test is, does it square with my experience?...My experience and logic tells me that the people who are saying [hydroxychloroquine] doesn't work, are people with an agenda.*

Thus "common sense" could explain almost any position regarding what information should be trusted or believed.

Resigned Acceptance

The feeling that one has no other choice but to trust information that one is exposed to repeatedly, or a resigned acceptance of information, was another important criterion for trusting COVID-19 public health information. As an exogenous criterion, resigned acceptance consists of an outward reliance on repeated information as presented, without actively using strategies to assess its trustworthiness. For some, resigned acceptance relied on professional sources on television shows: "I would like to think that the information that's provided on the television shows are truthful...they're provided by professionals and I have no reason not to trust them." The lack of knowledge was given as a reason for resigned acceptance of mass media: "Yes, I did trust the information [from Fox News] because I knew very little about it. And so naturally, I would acquiesce to what they were saying, and take as much as I possibly can because it was all foreign to me."

Others thought that repeated corroborating information left them with no choice but to believe it: "I guess if you hear it over and over again from enough sources, you're going to trust it. I don't have anything else to go by." Another participant began to pay attention to public health information from mass media only after hearing about repeated, increasingly deadly cases:

> *I really wasn't paying attention to [the information from CNN] at first. They were saying in NYC all these people were dying. At first I said nah, it's a bunch of baloney to that. But then you know, as days went on, weeks went on, months went on and it's getting worse and worse and worse, I had to trust it.*

Information Sources, Trust, and Personal Criteria

Personal criteria for trusting COVID-19 public health information can be situated between a person's trust in the source of the information and trust in the information itself. For example, personal relevance is invoked when information is trusted because the source of the information is more personally or socially proximate to the individual. Similarly, personal research is tied to trust in sources of information that the individual has sought in order to gather additional information, rejecting unreliable sources and accepting those that they trust. Personal relevance and personal research are based on trust in the information source. Yet personal relevance is an endogenous criterion, meaning that the trust is based on one's own understanding or experience, whereas personal research is an exogenous criterion and garners trust from outside sources.

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On the other hand, both confirmation bias and resigned acceptance are more closely tied to trust (or lack of trust) in particular pieces of information. Confirmation bias is seen when individuals automatically trust information because it confirms their preexisting beliefs, and resigned acceptance may be seen when individuals decide to accept information based on hearing it repeatedly from multiple sources. Confirmation bias is an endogenous criterion in that it relies on trust developed through preexisting beliefs, whereas resigned acceptance is an exogenous criterion because it relies on trust that comes from repeated exposure to external information sources.

Discussion

Principal Findings

In this interview study, we have identified sources that older adults turned to for trusted COVID-19 public health information and the factors that influenced their trust. We have also identified and examined 4 key criteria that influenced older adults' trust in information sources for COVID-19 public health information. In Figure 1, we illustrate the relationships among these key criteria: the criteria are either endogenous or exogenous, and the trust in the information is based on either the source of the information or the information itself. Although other COVID-19 research has focused on individual criteria that influence trust, to the best of our knowledge, this is the first attempt to demonstrate the interplay among criteria.

The participants in this study relied on information sources such as mass media, known individuals, and the internet for COVID-19 public health information. The subcategories of individual sources that older adults trusted included media such as television news and newspapers; individuals such as friends and family; and internet sources such as websites maintained by authoritative health organizations, as well as search engines themselves. These information sources echo the findings of earlier work exploring older adults' trust in COVID-19 public health information [6,20,31]. In addition, echoing the findings of earlier studies [12-14], participants reported using social media for social interactions and entertainment. However, the participants in our study did not trust social media for reliable information and adamantly refused to use social media to obtain COVID-19 public health information.

Prior research has examined how older adults consider the ways in which information is presented on the web and their resulting perceptions of trust [16]. The pandemic offers an opportunity to extend the current understanding of older adults' trust and distrust of public health information during an unprecedented, fast-paced, and evolving public health crisis. Negative cognitive and emotional responses to COVID-19 have been found to decrease the integration of information from trusted sources and increase susceptibility to misinformation [5,21]. Participants in this study were perceptive to and leery of potential COVID-19 misinformation. They recognized that COVID-19 public health information changed quickly and was often contradictory. Although we did not use the word "misinformation" in our interview guide, we did ask participants to share a piece of information that they distrusted and where they had found it. Participants were adamant that the COVID-19 public health information found on social media was not trustworthy.

In total, 4 factors affected how older adults determined trust in information sources. First, participants indicated that the personal relevance of information was key to determining its reliability and trustworthiness. When a participant received information from a close social connection or witnessed it as physically or socially proximate, the participant was more likely to trust the information. Many spoke of trusting COVID-19 public health information from their local news, state health organizations, and others in their community, as well as of witnessing the pandemic's effects themselves. This finding aligns with previous research in which individuals considered COVID-19 information most helpful when it was directly relevant to their own lives [31]. Chen et al [22] found that older adults weighed the trustworthiness of COVID-19 public health information on the basis of their evaluation of the source. As in our findings, older adults considered socially and physically proximate information to be more helpful and trustworthy [22,23].

Second, our participants relied on personal research to verify new information and determine its veracity. They reported different approaches to performing their own research on the trustworthiness of information. Some fact-checked multiple mass media sources against each other. Others used the internet to do research on information that they acquired from mass media. These findings echo prior research on trust in information [24], including research on older adults' information-seeking during a pandemic. Moore and Hancock [25] found that, given the proper resources, older adults fact-checked more often than their younger counterparts did. They also found that older adults could combine modern information resources with their life experiences in judging the veracity of COVID-19 public health information. Although research has previously suggested that older adults are challenged by sifting through large quantities of health information on the web, the older adults in our study used web-based sources such as the World Health Organization (WHO) and Centers for Disease Control and Prevention (CDC) websites as a means to fact-check the information that they received from mass media. The older adults in our study also suggested that personal research was only 1 way to determine their trust in information.

Third, the older adults exhibited confirmation bias when they justified their trust in COVID-19 information, echoing previous studies [19,26]. Zhao et al [19] found that confirmation bias was an influencing factor in the propensity to share information. However, their sample did not consist of older adults exclusively, and the study focused on sharing health information via social media, which our participants actively avoided. Older adults tend to prefer health care providers as their main sources of health information while relying on friends and family to provide and interpret information from web-based health sources [6,15]. Similarly, the participants in our study relied on their direct personal contacts, such as friends and family, for trustworthy health information, and they were less likely to fact-check information given to them by direct personal contacts. Turner et al [15] suggested that older adults lacked confidence in assessing the quality of web-based health information, but

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our participants did not. A likely reason is that our participants were recruited from cloud platforms, so these older adults may have been more experienced with technology than the general older adult population or the sample in Turner et al [15].

Fourth, participants reported a resigned acceptance of COVID-19 public health information, reluctantly trusting it only after they had received it from multiple sources over time. The work of Unkelbach et al [17] on repeated exposure and repetition-induced truth indicates that the quantity of information and the hearing of the same information repeatedly over time affects individuals' tendency to trust it. For our participants, repetition increased the perception of truth more than the information itself did. However, we also found that repeated exposure was only 1 factor. Both repeated exposure to information and confirmation bias were key to resigned acceptance of COVID-19 public health information. Our findings suggest that confirmation bias, the lack of viable alternate explanations, and repetitions of information all shape trust. The study of Unkelbach et al [17] was not focused on COVID-19 public health information, but the authors did discuss the implications of their findings within interventions to change false beliefs such as those of the antivaccination movement.

The results depicted in the semiotic square in Figure 1 reflect the dichotomy between trust focused on sources and trust focused on the information itself, as well as the relationships between them. Among the older adult participants in this study, personal relevance and confirmation bias were endogenous factors of trust; personal research and resigned acceptance were exogenous factors of trust. Simultaneously, personal relevance and personal research are factors in which older adults rely on their trust in particular sources of information, whereas confirmation bias and resigned acceptance depend on trust in the information itself. The evaluation of each of these criteria does not always occur independently; the criteria often overlap and influence each other. This complex interplay reflects the multifaceted nature of the personal and social factors in older adults' navigation of COVID-19 public health information as they attempt to make sense of their world.

Limitations and Future Directions

This study has some limitations. The study sample was from a pool of older adults for our earlier web-based survey study, so the results may not be representatively applicable to the general older adult population. Although Prime Panels allowed us to rapidly recruit and collect data from older adults (who might otherwise have been difficult to reach because of pandemic-related constraints [32]), older adults who use a web-based crowdsourcing platform may have higher digital literacy than those who do not. In addition, all but 1 of our research participants reported their race as White. Future work should focus on underrepresented subgroups of older adults.

It is critical to understand older adults' trust in information during health crises in order to develop strategies for successful public health dissemination. In this CIT study, we have investigated older adults' trust in new, rapidly changing public health information. A critical incident interviewing technique allowed participants to identify salient topics from which we could develop a framework for trust in COVID-19 public health information. Our qualitative approach ensured that participants' own perspectives and experiences were represented without deductive, researcher-directed categories. However, future studies should also examine relationships between information sources and personal criteria using quantitative methods.

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Conflicts of Interest

The author BX is an editorial board member of *JMIR Aging*. The other authors declare no conflicts of interest.

Multimedia Appendix 1
Interview Guide.
[DOCX File , 16 KB - aging_v6i1e42517_app1.docx]

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Abbreviations

CDC: Centers for Disease Control and Prevention
CIT: critical incident technique
RQ: research question
WHO: World Health Organization

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Original Paper

Use of a Data Repository to Identify Delirium as a Presenting Symptom of COVID-19 Infection in Hospitalized Adults: Cross-Sectional Cohort Pilot Study

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Abstract

Background: Delirium, an acute confusional state highlighted by inattention, has been reported to occur in 10% to 50% of patients with COVID-19. People hospitalized with COVID-19 have been noted to present with or develop delirium and neurocognitive disorders. Caring for patients with delirium is associated with more burden for nurses, clinicians, and caregivers. Using information in electronic health record data to recognize delirium and possibly COVID-19 could lead to earlier treatment of the underlying viral infection and improve outcomes in clinical and health care systems cost per patient. Clinical data repositories can further support rapid discovery through cohort identification tools, such as the Informatics for Integrating Biology and the Bedside tool.

Objective: The specific aim of this research was to investigate delirium in hospitalized older adults as a possible presenting symptom in COVID-19 using a data repository to identify neurocognitive disorders with a novel group of *International Classification of Diseases, Tenth Revision* (ICD-10) codes.

Methods: We analyzed data from 2 catchment areas with different demographics. The first catchment area (7 counties in the North-Central Florida) is predominantly rural while the second (1 county in North Florida) is predominantly urban. The Integrating Biology and the Bedside data repository was queried for patients with COVID-19 admitted to inpatient units via the emergency department (ED) within the health center from April 1, 2020, and April 1, 2022. Patients with COVID-19 were identified by having a positive COVID-19 laboratory test or a diagnosis code of U07.1. We identified neurocognitive disorders as delirium or encephalopathy, using ICD-10 codes.

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Results: Less than one-third (1437/4828, 29.8%) of patients with COVID-19 were diagnosed with a co-occurring neurocognitive disorder. A neurocognitive disorder was present on admission for 15.8% (762/4828) of all patients with COVID-19 admitted through the ED. Among patients with both COVID-19 and a neurocognitive disorder, 56.9% (817/1437) were aged ≥65 years, a significantly higher proportion than those with no neurocognitive disorder (P<.001). The proportion of patients aged <65 years was significantly higher among patients diagnosed with encephalopathy only than patients diagnosed with delirium only and both delirium and encephalopathy (P<.001). Most (1272/4828, 26.3%) patients with COVID-19 admitted through the ED during our study period were admitted during the Delta variant peak.

Conclusions: The data collected demonstrated that an increased number of older patients with neurocognitive disorder present on admission were infected with COVID-19. Knowing that delirium increases the staffing, nursing care needs, hospital resources used, and the length of stay as previously noted, identifying delirium early may benefit hospital administration when planning for newly anticipated COVID-19 surges. A robust and accessible data repository, such as the one used in this study, can provide invaluable support to clinicians and clinical administrators in such resource reallocation and clinical decision-making.

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KEYWORDS

COVID-19; delirium; neurocognitive disorder; data repository; adults; pilot study; symptom; electronic health record; viral infection; clinical; patient; research; diagnosis; disorder; memory; covid; memory loss; old; old age

Introduction

Delirium, an acute confusional state highlighted by inattention [1,2], has been reported to occur in 10% to 50% of patients with COVID-19 [3,4]. People hospitalized with COVID-19 have been noted to present with or develop delirium and neurocognitive disorders [5,6]. Delirium has been noted as a common presentation to emergency departments (EDs) during the current pandemic but is an atypical symptom of COVID-19 in hospitalized patients [6]. Recognizing delirium as a possible presenting symptom of COVID-19 may decrease the effects on the patient and the health care system.

Delirium has been found to be the most common neurocognitive syndrome in the acute hospital setting and is a condition of particular concern due to its association with multiple adverse outcomes, including increased critical care use and costs, prolonged length of stay, increased rate of discharge to skilled nursing facilities, long-term cognitive decline, greater functional impairment, increased numbers of readmission, and increased mortality [7-12].

Caring for patients with delirium is associated with more burden for nurses, clinicians, and caregivers [13,14] and poorer clinical outcomes for patients [15]. Fortunately, delirium has been able to be managed through multicomponent interventions including nonpharmacologic ones [16-18]; however, the cost and personnel required for these multicomponent prevention programs can be prohibitive and requires a way of identifying patients at the greatest risk for developing delirium [19].

The COVID-19 pandemic has increased demands on nurses and other hospital clinical resources and intensified the possible consequences of delirium in hospitalized people. Additional infection control precautions, isolations, and personal protective equipment conservation efforts have only amplified the difficulty of delivering multicomponent interventions that have been shown to reduce delirium risk [20,21]. This combination of circumstances, which developed during care of the various surges of patients with COVID-19, increased the urgency to develop alternate means of determining delirium risk through new advances in technologies and data science.

Using information in electronic health record (EHR) data to recognize delirium and possibly COVID-19 could lead to earlier treatment of the underlying viral infection and improve outcomes in clinical and health care systems cost per patient. However, clinical EHR data are largely inaccessible due to data sensitivity, ethical issues, and data complexity [22], hindering the rapid discovery necessary to recognize health trends and generate knowledge during emergent situations such as a pandemic. Clinical data repositories or data warehouses address part of this issue by integrating and organizing information from EHR systems. While EHR systems are mainly optimized for clinical transaction processing and intramural systems communication, a clinical data repository allows information to be organized in a database form that can be tailored for retrieval and analysis. Clinical data repositories can further support rapid discovery through cohort identification tools, such as the Informatics for Integrating Biology and the Bedside (i2b2) tool. The National Institute of Health funded the i2b2 National Center for Biomedical Computing to provide an open-source framework for informatics tools that facilitate clinical data analysis and integration [22,23]. The tool can support self-service and custom queries on deidentified data, protecting patient privacy without requiring a lengthy scientific review process for each query. Information accessible through i2b2 has been reported to provide more realistic cohort identification for clinical trials, expose a new data source for hypothesis generation, and provide a foundation for vendor neutral interinstitutional research [23,24]. Less attention has been devoted to the potential utility of cohort identification tools such as i2b2 for clinicians and hospital systems to identify trends, generate knowledge to improve care, or inform resource allocation.

It has been noted that delirium is often underdiagnosed and undercoded. However, EHR data have shown to be valid to study occurrence of delirium [25-28]. Documentation and data from the EHR during routine care have been used and validated in developing clinical prediction models of delirium risk prior

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to and during this pandemic [28-31]. Using cohort identification tools for rapid detection and exploration of trends could enable the mitigation of pandemic-related stressors on health systems and improve treatments and outcomes. The specific aim of this research was to investigate delirium in hospitalized older adults as a possible presenting symptom in COVID-19 using a data repository (i2b2) to identify neurocognitive disorders with a novel group of *International Classification of Diseases, Tenth Revision* (ICD-10) codes.

Methods

Ethics Approval

The University of Florida's institutional review board approved this cross-sectional exploratory retrospective study using secondary data analysis (IRB-201900208).

Data Collection

Our data were extracted from a HIPAA (Health Insurance Portability and Accountability Act) limited repository of EHR data, i2b2 [22], and supplemented by counts provided by an honest broker team at a large comprehensive academic health center serving diverse communities across North and Central Florida. The health system serves more than 2 million patients from all 67 counties in Florida.

In this study, we analyzed data from 2 catchment areas with different demographics. The first catchment area (7 counties in North-Central Florida) is predominantly rural and consists of approximately 906,697 people (n=144,867, 16% Black; n=679,582, 75% White; and n=82,248, 9.1% other, including n=26,043, 2.9% Asian). The Hispanic or Latino population in this catchment area is estimated to be 108,462 (12%). The second catchment area (1 county in North Florida) is predominantly urban and consists of approximately 857,191 people (n=276,791, 32.3% Black; n=498,033, 58.1% White; and n=82,367, 9.6% other, including n=47,888, 5.6% Asian). The Hispanic or Latino population in this catchment area is estimated to be 100,564 (11.7%).

The i2b2 data repository was queried for patients with COVID-19 admitted to inpatient units via the ED within the health center during the period between April 1, 2020, and April 1, 2022. Patients with COVID-19 were identified by having a positive result of a COVID-19 laboratory test or having a diagnosis code of U07.1. Further, the data repository was queried for a subset of patients with COVID-19 diagnosed with neurocognitive disorders during their hospitalizations. We identified neurocognitive disorders as delirium or encephalopathy, using the following ICD-10 codes: R41.0, R41.82, R41.9, F05, and F44.89 for delirium and G92, G92.8, G92.9, G93.40, G93.41, and G93.49 for encephalopathy. We further distinguished between diagnostic codes present on admission (PoA) that were defined as patients' condition on admission to the hospital; discharge diagnosis that was defined by hospital coder; and any diagnosis that included discharge diagnosis, physician billing diagnosis, and problem list diagnosis. All queries included demographics (ie, age, gender, race, and ethnicity).

Due to limited data availability in the i2b2, data were augmented by counts provided by an honest broker team at our institution. While the i2b2 data repository contains only a subset of data elements from the EHR, the honest broker team has access to the entire EHR system. The additional data included average length of stay and mortality rate for each cohort that we considered in this study.

We used the obtained data to produce descriptive statistics, including frequencies and percentages, and examined the data by individual diagnoses, as well as within time intervals corresponding to the national peaks of the Alpha (March 27, 2021, to June 12, 2021), Delta (July 3, 2021, to September, 30, 2021), and Omicron (December 1, 2021, to April 1, 2022) variants. We defined peak as an interval when at least 50% of national cases belonged to a specific variant. We used the i2b2 tool for counts of unique patients satisfying the inclusion diagnoses. This approach resulted in each patient being counted only once within a specific time interval even if the patient met the inclusion criteria during multiple hospital encounters. Bivariate associations were analyzed using an "N-1" chi-square test [32,33] or a 2-tailed Welch *t* test (used for length of stay) [34]. Bivariate associations were considered statistically significant with a *P* value of .05 or less. Statistical tests were performed using *R* (version 4.2.0; *R* Foundation for Statistical Computing).

Results

A total of 4828 patients were hospitalized with COVID-19 through the ED during this study's period. Table 1 displays the descriptive characteristics of these patients. Adults aged 65 years and older constituted 39.1% (n=1886) of the COVID-19 hospitalizations, and 50.7% (n=2449) of patients hospitalized with COVID-19 were male. Black patients represented 29.7% (n=1432) of all COVID-19 hospitalizations; additionally, 6.6% (n=318) of patients were Hispanic or Latino. The average length of stay was 9.6 days. The admission ended in death for 10.5% (n=507) of patients hospitalized with COVID-19 through the ED during this study's period.

Slightly less than one-third (n=1437, 29.8%) of patients with COVID-19 were diagnosed with a co-occurring neurocognitive disorder, that is, delirium or encephalopathy. Among patients with both COVID-19 and a neurocognitive disorder, 56.9% (817/1437) were aged 65 years or older, a significantly higher proportion than those with no neurocognitive disorder (*P*<.001). There was also a significantly higher proportion of male patients in this group, compared to those with no neurocognitive disorder (*P*=.02). Just under a third (418/1437, 29.1%) of patients with both COVID-19 and a neurocognitive disorder expired during their hospital stay, which is a significantly higher proportion than among those with COVID-19 and no neurocognitive disorder (*P*<.001). The length of stay in this group was also substantially higher (20.8 days).

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Table 1. Patient characteristics.

Characteristics	All patients with COVID-19 (N=4828), n (%)	Patients with COVID-19 and neurocognitive disorder (n=1437), n (%)	Patients with COVID-19 but no neurocognitive disorder (n=3391), n (%)	*P* value
Age group[a] (years)				
<65	2942 (60.9)	620 (43.1)	2322 (68.5)	<.001
≥65	1886 (39.1)	817 (56.9)	1069 (31.5)	<.001
Sex[a]				
Female	2379 (49.3)	669 (46.6)	1710 (50.4)	.02
Male	2449 (50.7)	768 (53.4)	1681 (49.6)	.02
Race				
Black	1432 (29.7)	409 (28.5)	1023 (30.2)	.24
White	2981 (61.7)	916 (63.7)	2065 (60.9)	.07
Other	415 (8.6)	112 (7.8)	303 (8.9)	.21
Ethnicity				
Hispanic	318 (6.6)	80 (5.6)	238 (7)	.07
Non-Hispanic	4437 (91.9)	1322 (92)	3115 (91.9)	.91
Other	73 (1.5)	35 (2.4)	38 (2.2)	.67
Expired[a]	507 (10.5)	418 (29.1)	89 (5.3)	<.001
Length of stay (days)[a], mean (SD)	9.6 (13.5)	20.8 (24.3)	4.9 (6)	<.001

[a]Indicates that the variable was statistically significant at the .05 significance level.

A neurocognitive disorder was PoA for 15.8% (762/4828) of all patients with COVID-19 admitted through the ED. Table 2 shows a comparison of sample characteristics for patients with COVID-19 where the co-occurring neurocognitive disorder was PoA versus diagnosed later during the hospitalization. Among the 1437 patients with both COVID-19 and a neurocognitive disorder, just over half (762/1437, 53%; *P*<.001) had the neurocognitive disorder PoA. Significantly higher proportion of patients with COVID-19 and a neurocognitive disorder PoA were aged 65 years or older (485/762, 64%; *P*<.001) and Black (238/762, 31.2%; *P*=.01), compared to those whose neurocognitive disorder was not assigned as PoA (171/675, 25.3%). Contrastingly, significantly lower proportions of patients with COVID-19 and a neurocognitive disorder PoA identified as other race (49/762, 6.4% vs 63/675, 9.3%; *P*=.04) and Hispanic (33/762, 4.3% vs 47/675, 7%; *P*=.03). A significantly higher proportion of patients whose neurocognitive disorder was not assigned as PoA expired during their hospitalization (*P*<.001).

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Table 2. Comparison of patient characteristics between those with neurocognitive disorder PoA[a] versus those diagnosed later during the hospitalization.

Characteristics	Patients with COVID-19 and a neurocognitive disorder PoA (n=762), n (%)	Patients with COVID-19 and a neurocognitive disorder not PoA (n=675), n (%)	*P* value
Age group[b] (years)			
<65	277 (36.4)	343 (50.8)	<.001
≥65	485 (63.6)	332 (49.2)	<.001
Sex			
Female	361 (47.4)	308 (45.6)	.49
Male	401 (52.6)	367 (54.4)	.49
Race			
Black[b]	238 (31.2)	171 (25.3)	.01
White	475 (62.3)	441 (65.3)	.24
Other[b]	49 (6.4)	63 (9.3)	.04
Ethnicity			
Hispanic[b]	33 (4.3)	47 (7)	.03
Non-Hispanic	709 (93)	613 (90.8)	.13
Other	20 (2.6)	15 (2.2)	.62
Expired[b]	177 (23.2)	241 (35.7)	<.001
Length of stay (days)[b], mean (SD)	15.1 (19.3)	27.2 (26.2)	<.001

[a]PoA: present on admission.

[b]Indicates that the variable was statistically significant at the .05 significance level.

Among the 1437 patients with COVID-19 and a neurocognitive disorder, 290 (20.2%) of them were diagnosed with delirium only, 470 (32.7%) were diagnosed with encephalopathy only, and 677 (47.1%) were diagnosed with more than 1 neurocognitive disorder. The proportion of patients younger than 65 years (239/470, 50.9%; *P*<.001) was significantly higher among patients diagnosed with encephalopathy only compared with patients diagnosed with delirium only (103/290, 35.5%; *P*<.001) and both delirium and encephalopathy (278/677, 41.1%; *P*<.001; Multimedia Appendix 1).

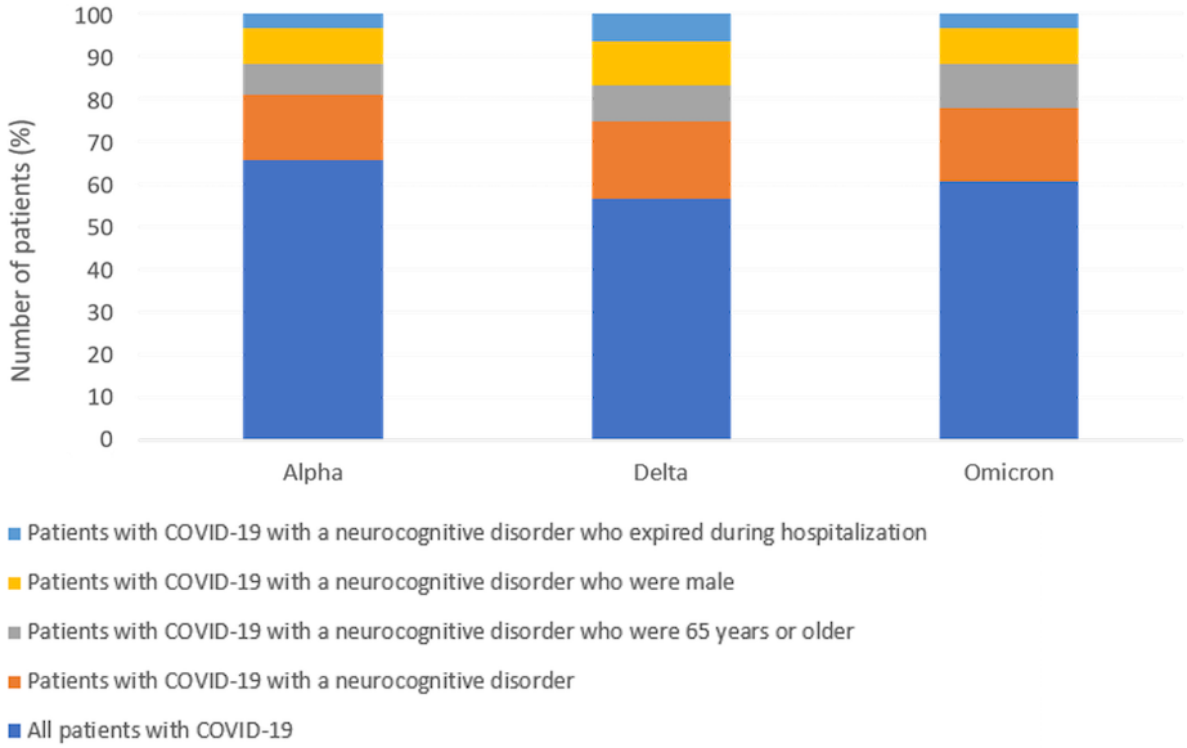
Significant differences were observed in the proportion of patients who expired during their hospitalization. Among the 418 patients with COVID-19 and neurocognitive disorders who expired during their hospitalization, half (209/470, 44.5%) of them were diagnosed with only encephalopathy. For comparison, 28.2% (191/677) of those diagnosed with more than 1 neurocognitive disorder and 6.2% (18/290) of those diagnosed with delirium alone expired during their hospitalization. In terms of length of stay, patients diagnosed with more than 1 neurocognitive disorder had the longest average length of stay at 23.4 days, followed by patients diagnosed with encephalopathy alone at 18.9 days. The average length of stay for patients diagnosed with delirium alone was 12.1 days.

Most (1272/4828; 26.3%) patients with COVID-19 admitted through the ED during our study period were admitted during the Delta variant peak. Among the 1437 patients with COVID-19 and neurocognitive disorder, 71 (4.9%) were admitted during the Alpha variant peak, 403 (28%) were admitted during the Delta variant peak, and 317 (22.1%) were admitted during the Omicron variant peak.

A significantly higher proportion of those admitted during the Omicron variant peak were aged 65 years or older (191/317, 60.3%), compared to both Alpha and Delta variants (33/71, 47%; *P*=.03 and 191/403, 47.4%; *P*<.001, respectively). A significantly higher proportion of patients admitted during the Delta variant peak were male (229/403, 56.8%), compared to the Omicron variant peak (154/317, 48.6%; *P*=.03). In addition, a significantly higher proportion of patients admitted during the Delta variant peak expired during their hospitalization (147/403, 36.5%), compared to both Alpha and Omicron (16/71, 23%; *P*=.02 and 64/317, 20.2%; *P*<.001, respectively). Finally, the average length of stay was the shortest (15.8 days) among patients admitted during the Omicron variant peak (Figure 1).

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Figure 1. Counts across the 3 variant peaks for patients admitted through the emergency department who had COVID-19, COVID-19 and a neurocognitive disorder, COVID-19 and a neurocognitive disorder who were aged 65 years or older, COVID-19 and a neurocognitive disorder who were male, and COVID-19 and a neurocognitive disorder who expired during their admission.



Discussion

Principal Findings

The data collected demonstrated that an increased number of older patients, 65 years and older, with neurocognitive disorder PoA were infected with COVID-19.The presence of delirium or neurocognitive disorder was shown to be more than twice as high in this group than what normally is found in emergency departments and acute care settings (485/1437, 33.7%; *P*<.001) compared to the incidence rate of 9% to 14% in emergency departments that has been reported in the literature by Kennedy et al [35]. Furthermore, the average length of stay in patients with COVID-19 and delirium was shown to be 4 times as long. Of note, a much higher and statistically significant number of people with neurocognitive disorder and COVID-19 died than those with only COVID-19 (*P*<.001).

The data repository review showed that just over a third (103/290, 35.5%) of the cases of delirium and COVID-19 were in people younger than 65 years. While a higher number of patients over 65 years old had delirium PoA (in the ED), there was a higher percentage of patients younger than 65 years who developed delirium while in the hospital. Unfortunately, not all the admitted patients were tested for COVID-19 on admission, particularly in the early part of the pandemic. Nevertheless, this suggests that it may be beneficial to adopt delirium prevention protocols for all patients with COVID-19 upon admission.

Social isolation among individuals aged 65 years and older has been associated with future ED use and poorer health outcomes [36]. However, Falcão et al [37] showed that the number of visits to ED per day decreased by 45% during lockdown and nonelective hospital admissions decreased by 50% during periods of social isolation. One possible explanation of the prevalence of delirium PoA, particularly among older adults, is the social isolation people experienced during the pandemic. This may have led to people waiting longer before presenting to the ED due to the fear of going to the hospital. The psychosocial implications of social isolation during a pandemic warrant further study.

Our data show that approximately 23.9% (421,658/1,763,888) of the patients in our catchment areas are Black, yet 29.7% (1432/4828) of the patients being admitted were Black. Our data also show a higher proportion of Black patients being admitted for COVID-19. These results coincide with past research that describes racial disparities in COVID-19 cases. Black and Hispanic patients were shown to be disproportionately affected by COVID-19 [38] in both hospitalizations and deaths rates. Moreover, this further validates the use of a data repository to investigate health care disparities.

A data repository to review incidence of delirium coinciding with COVID-19 may help hospitals align resources to COVID-19 units to decrease strain on an already stressed system with limited resources. Currently, the data repository we used refreshes i2b2-accessible data every 90 days, which can provide

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useful information for hospital or health systems for quarterly planning of staffing and resource reallocation. However, the fast-paced environment of modern health care requires more current data, particularly in a rapidly evolving public health emergency such as the COVID-19 pandemic. Future research is needed to explore and develop the technical infrastructure required to provide real-time or near real-time data to support resource allocation and clinical decision-making, as part of a learning health care system.

Furthermore, future studies should examine the role of any neurocognitive symptoms on presentation to the ED in diagnosing COVID-19. Further, 1 hypothesis to explore is whether neurocognitive symptoms on presentation to the ED should be considered COVID-19 unless ruled out by testing. Finally, length of stays related to delirium and allocation of resources can be investigated to discover more efficient use of hospital resources. With a robust data science infrastructure, innovative artificial intelligence solutions can be implemented to address these issues and improve care for patients having COVID-19 and delirium, as well as emerging future health care threats.

Limitations

A limitation of this study is that not all the admitted patients were tested for COVID-19 on admission. Therefore, the entry to the ED as a variable to developing delirium was not available. Another limitation is the lack of documentation for the presence of a preexisting neurocognitive disorder or a baseline mental status of the patients. An additional limitation is that our research did not attempt to factor in any vaccine effect during the different variant surges due to the lack of data on vaccination status. Further, a limitation is that the cause of death may not be easily available through data extraction with i2b2 and caution must be exercised when interpreting such data. These limitations highlight the trade-offs inherent in the use of cohort identification tools, as the ability for quick and direct queries without additional scientific review necessitates that the data available through such tools be limited to protect data privacy and confidentiality.

Conclusions

Identifying delirium as a presenting sign of COVID-19 may be beneficial to better develop care plans for patients and resource planning for hospitals. Knowing that delirium increases the staffing, nursing care needs, hospital resources used, and the length of stay as previously noted, identifying delirium early may benefit hospital administration when planning for newly anticipated COVID-19 surges. During COVID-19 surges, it is imperative to use hospital resources efficiently and effectively to better meet the demands of patients in need of a higher level of care. If the length of stays related to delirium can be decreased, there exists the potential to reallocate resources where they are the most needed. A robust and accessible data repository, such as the one used in this study, can provide invaluable support to clinicians and clinical administrators in such resource reallocation and clinical decision-making.

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Authors' Contributions

LMS, JJD, TM, BC, NR, CRP, RL, RIB, EMD, and TD contributed to this study’s concept and design, acquisition of subjects or data, analysis and interpretation of data, and preparation of this paper. UAS, SES, MB, and CB contributed to the acquisition of subjects or data, analysis and interpretation of data, and preparation of this paper.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Comparison of patients with COVID-19 who have delirium only, encephalopathy only, and more than 1 neurocognitive disorder.
[PNG File , 93 KB - aging_v6i1e43185_app1.png]

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Abbreviations

ED: emergency department
EHR: electronic health record
HIPAA: Health Insurance Portability and Accountability Act
i2b2: Integrating Biology and the Bedside
***ICD-10*:** *International Classification of Diseases, Tenth Revision*
PoA: present on admission

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A Machine Learning–Based Preclinical Osteoporosis Screening Tool (POST): Model Development and Validation Study

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Abstract

Background: Identifying persons with a high risk of developing osteoporosis and preventing the occurrence of the first fracture is a health care priority. Most existing osteoporosis screening tools have high sensitivity but relatively low specificity.

Objective: We aimed to develop an easily accessible and high-performance preclinical risk screening tool for osteoporosis using a machine learning–based method among the Hong Kong Chinese population.

Methods: Participants aged 45 years or older were enrolled from 6 clinics in the 3 major districts of Hong Kong. The potential risk factors for osteoporosis were collected through a validated, self-administered questionnaire and then filtered using a machine learning–based method. Bone mineral density was measured with dual-energy x-ray absorptiometry at the clinics; osteoporosis was defined as a *t* score of −2.5 or lower. We constructed machine learning models, including gradient boosting machines, support vector machines, and naive Bayes, as well as the commonly used logistic regression models, for the prediction of osteoporosis. The best-performing model was chosen as the final tool, named the Preclinical Osteoporosis Screening Tool (POST). Model performance was evaluated by the area under the receiver operating characteristic curve (AUC) and other metrics.

Results: Among the 800 participants enrolled in this study, the prevalence of osteoporosis was 10.6% (n=85). The machine learning–based Boruta algorithm identified 15 significantly important predictors from the 113 potential risk factors. Seven variables were further selected based on their accessibility and convenience for daily self-assessment and health care practice, including age, gender, education level, decreased body height, BMI, number of teeth lost, and the intake of vitamin D supplements, to construct the POST. The AUC of the POST was 0.86 and the sensitivity, specificity, and accuracy were all 0.83. The positive predictive value, negative predictive value, and F_1-score were 0.41, 0.98, and 0.56, respectively.

Conclusions: The machine learning–based POST was conveniently accessible and exhibited accurate discriminative capabilities for the prediction of osteoporosis; it might be useful to guide population-based preclinical screening of osteoporosis and clinical decision-making.

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KEYWORDS

osteoporosis; machine learning; screening tool; older people; health care; Hong Kong

Introduction

Osteoporosis is a systemic skeletal disease characterized by low bone mass and microarchitectural deterioration of bone tissue, leading to enhanced bone fragility and a consequent increase in fracture risk [1]. Over 200 million people worldwide are affected by osteoporosis [2]. In Hong Kong, about 300,000 postmenopausal women and 100,000 men aged older than 50 years had osteoporosis in 2009, and the number of individuals with low bone mass is expected to double by the year 2030 [3]. The acute hospital care cost of hip fractures amounted to 1% of the total hospital budget in Hong Kong [3]. Individuals with an osteoporotic fracture may experience long-term chronic pain and disability, loss of independence, and negative psychosocial impact, resulting in decreased quality of life [4,5]. Even upon

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recovery, the irreversible structural loss in bone microarchitecture makes the restoration of full bone strength unlikely. Therefore, identifying persons at the highest risk of developing osteoporosis and preventing the occurrence of the first fracture is a health care priority.

The gold standard for the diagnosis of osteoporosis is the measurement of bone mineral density (BMD) with dual-energy x-ray absorptiometry (DXA) at the anteroposterior spine (lumbar 1 to 4) and left proximal femur. Unfortunately, BMD testing of an entire aging population is impossible, and DXA machines are not readily available in all lab settings due to the cost and space requirements. In Hong Kong, DXA is generally done only with a doctor's referral for those who have a significant risk of developing osteoporosis. Moreover, the cost of a DXA scan is not generally covered by the health checkup package. These factors often lead to referrals for DXA scans being highly selective and sometimes lacking, resulting in underdiagnosis and delayed treatment of osteoporosis in affected adults. Thus, implementing early preclinical screening for targeted DXA testing for those who are at risk of osteoporosis is needed, as this would enhance timely treatment and improve the cost-effectiveness of DXA use [6]. In fact, screening for osteoporosis to reduce bone fractures is recommended by many national clinical practice guidelines [7].

Hong Kong, as a special administrative region of China, is one of the world's most prominent financial centers, with a unique cultural background that blends Chinese and Western influences. Although several preclinical screening tools have been developed for predicting low BMD or osteoporosis [8-17], accurate preclinical prediction of osteoporosis for the Hong Kong Chinese population still represents an unmet need. Most existing preclinical screening tools are derived from ones used in Western countries [8-15], limiting the applicability to the Chinese population. Furthermore, most tools have high sensitivity but with the trade-off of relatively low specificity [8-12,16,17], which might lead to the unnecessary cost of DXA tests that return false positives. In addition, most osteoporosis predictor selection and prediction model construction has been conducted with traditional statistical techniques (eg, linear regression, logistic regression) which are constrained by the need to meet assumptions such as normal distribution and linearity. Machine learning is a method of big data analysis that automates analytical model building. It is a branch of artificial intelligence based on the idea that computers can learn from data, identify patterns, and make decisions with minimal human intervention [18]. Machine learning methods could overcome some of the limitations of traditional statistical techniques by applying computer algorithms to large, multidimensional data and can enable more precise predictor selection and improve the performance of osteoporosis risk screening tools. However, most current machine learning–based osteoporosis predictive models for the Chinese population have been built based on clinical characteristics, such as computed tomography images, radiographs, ultrasound radiofrequency signals, and molecular and genetic biomarkers [19-26], limiting their use in daily self-assessment and preclinical conditions. Therefore, in this study, we aimed to apply machine learning algorithms for osteoporosis predictor selection and prediction model construction to develop and validate an easily accessible and high-performance tool, the Preclinical Osteoporosis Screening Tool (POST), for the Hong Kong Chinese population.

Methods

Study Design and Setting

This study had 3 parts. First, we developed a questionnaire for data collection of potential risk factors for osteoporosis. Second, we conducted a cross-sectional study to collect data on osteoporosis as measured by BMD and potential risk factors in a sample of Chinese participants in Hong Kong. Third, we used machine learning algorithms for predictor selection and model construction and selected the best-performing model. This cross-sectional study was conducted by the Family Planning Association of Hong Kong (FPAHK) between December 2018 and December 2019. The FPAHK is a nonprofit organization in Hong Kong that provides medical and counseling services for Hong Kong residents. It offers bone health consultation, bone density measurement, laboratory tests, and treatment for men and women. Six FPAHK clinics located in Wanchai, Ma Tau Chung, Yuen Long, Tai Wai, Tsuen Wan, and Wong Tai Sin in the 3 main districts of Hong Kong provided a relatively representative sample for this study.

Ethical Considerations

The study protocol was approved by the Ethics Committee of FPAHK and Hong Kong Polytechnic University (HSEARS20180315010). Written informed consent and permission for accessing DXA data were obtained from all participants.

Participants

People who received the services of FPAHK were invited to participate in this study. Interested persons were screened according to the inclusion and exclusion criteria. The inclusion criteria were (1) being aged 45 years or less; (2) being a Chinese person who can speak, read, and write Chinese; (3) having had a DXA scan done at FPAHK in the past year, or planning to have one done within the next 1.5 years (DXA scans are mostly done once a year); (4) having an accessible email address for contact; (5) being willing to participate in the study and provide informed consent; and (6) providing written permission for accessing DXA data. Exclusion criteria were (1) currently being pregnant; (2) having a history or evidence of metabolic bone disease (including, but not limited to, Paget disease, osteomalacia, renal osteodystrophy or osteogenesis imperfecta); (3) having cancer(s) with known metastasis to bone.

Questionnaire for Risk Factor Identification

A self-administered questionnaire was designed to measure osteoporosis-associated risk factors among the study population. Risk factors that were reported to have significant associations with BMD, fractures, osteoporosis, or osteopenia were collected in the preliminary version of the questionnaire [8-13,16,17,27-31]. To validate the questionnaire, 20 experts, including 6 epidemiologists, 6 doctors, 4 senior nurses, and 4 senior researchers, with rich experience in osteoporosis treatment and research were invited to rate the relevance of all

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the questionnaire items on a 4-point scale: 1=not relevant, 2=somewhat relevant, 3=quite relevant, and 4=highly relevant. The Content Validity Index for Items (I-CVI) was computed as the number of experts giving a rating of 3 or 4, divided by the total number of experts. The optimal value of I-CVI ranges from 0.78 to 1.00 [32]. To identify more possible risk factors for osteoporosis in our study, items with I-CVI values that were equal to or greater than 0.50 were retained in the questionnaire.

In total, 138 items were selected for the measurement of initial potential risk factors for BMD, fractures, osteoporosis, or osteopenia. Of these items, 103 had an I-CVI that was equal to or greater than 0.78. Among these 103 items, 3 were excluded because of the difficulty in obtaining answers, leading to 100 items being retained in the questionnaire. Of 35 items with an I-CVI less than 0.78, 20 were excluded directly from the questionnaire, and 15 were amended and then retained in the questionnaire according to the suggestions of the experts. Finally, 115 items were identified as potential risk factor measurements in the questionnaire.

The final questionnaire was composed of 8 sections, including (1) sociodemographic information (eg, gender, age); (2) anthropometric variables (eg, height, weight, height loss); (3) personal characteristics (eg, tooth loss); (4) reproductive health information (eg, menstruation, menopausal stage, pregnancy history, estrogen use); (5) medical and health information (eg, chronic disease, long-term medication use, surgical history, previous bone fracture); (6) lifestyle factors (eg, smoking, alcohol consumption, physical activity, sedentary behavior, sun exposure level); (7) dietary intake (eg, calcium-rich food frequency; calcium supplementation, if any; caffeine intake); and (8) family history (eg, osteoporosis among blood relatives) (Table S1 in Multimedia Appendix 1).

Osteoporosis Identification

The BMD data were obtained from FPAHK's medical record databases. BMD was measured with the QDR 4500 W bone densitometer (Hologic) at the lumbar spine (L2-L4) and left femoral neck. A World Health Organization study group [33] has defined osteoporosis as a *t* score (a comparison of a subject's BMD to that of a healthy young man or woman at the particular anatomic site) more than 2.5 SD below the mean for typical young adults (*t* score ≤−2.5).

Data Analysis Strategy

Predictor Selection

Predictor selection was conducted to optimize the number of predictors included in the osteoporosis prediction models. We used a 3-step strategy to select the optimal predictors. In the first step, univariate logistic regression was used to perform a preliminary screening of all variables collected from the questionnaire. Variables with *P* values less than .10 in the univariate logistic regression were selected as the initial predictors for the next step. This more liberal *P* value threshold allowed for a wider inclusion of potential predictors [34]. The random forest imputation method was used to impute the missing values in the filtered predictors in this step [35]. The percentages of missing values ranged from 0% to 13.2% (Table S2 in Multimedia Appendix 1). In the second step, a machine learning–based variable selection algorithm called Boruta was used to confirm the significantly important predictors. The algorithm is designed as a wrapper around a random forest classification algorithm that can output variable importance, which is a metric that indicates how much each variable contributes to the model prediction. Boruta iteratively compares the importance of variables with the importance of shadow variables created by shuffling the original ones. Variables that have significantly worse importance than shadows are considered unimportant variables and are consequently dropped. On the other hand, variables that are significantly better than shadows are considered important variables [36]. The important predictors confirmed by the Boruta algorithm were used to construct the full models. In the third step, we further selected the predictors based on their accessibility and convenience for daily self-assessment and health care practice. These artificially selected variables were used to construct the simplified models in the study. Considering the model complexity and practical applicability, the best-performing model was chosen from the simplified models.

Model Development and Validation

The data set was randomly split into a training set (70%) and a testing set (30%). The training set was used to train the prediction models and tune the parameters, while the testing set was used to test the performance of the developed models. We used several algorithms to construct the prediction models for osteoporosis, including the following machine learning models: gradient boosting machine (GBM), support vector machine (SVM), and naive Bayes (NB) (Multimedia Appendix 1)**,** as well as a commonly used algorithm, logistic regression, for comparison. The area under the receiver operating characteristic (ROC) curve (AUC) of the testing set was used to measure the model discrimination. Sensitivity, specificity, positive predictive value, negative predictive value, accuracy, and F_1-score were calculated based on the optimal point of the ROC curves that had the maximal sensitivity and 1–specificity. This cutoff point was used for osteoporosis risk stratification, with those having scores above the cutoff point being classified as high risk and those below as low risk. The metric calculation formulas are provided in Multimedia Appendix 1. The best-performing model, which optimized the AUC, sensitivity, and specificity from the simplified models, was selected as the POST, whose output is a risk score for osteoporosis. Additionally, we merged the training and testing sets into a single pooled data set of 800 participants. Calibration was evaluated graphically by plotting the observed and predicted probability stratified by the deciles of the predictive risks in the pooled data set.

Statistical Analysis

Continuous variables are presented as mean and SD, while categorical variables are reported as numbers and percentages. A 2-tailed *t* test was used to examine difference between continuous variables and chi-squared test was used for categorical variables. All the statistical analyses were conducted using R (version 4.2.1; R Foundation for Statistical Computing). A 2-sided $P<.05$ was considered statistically significant.

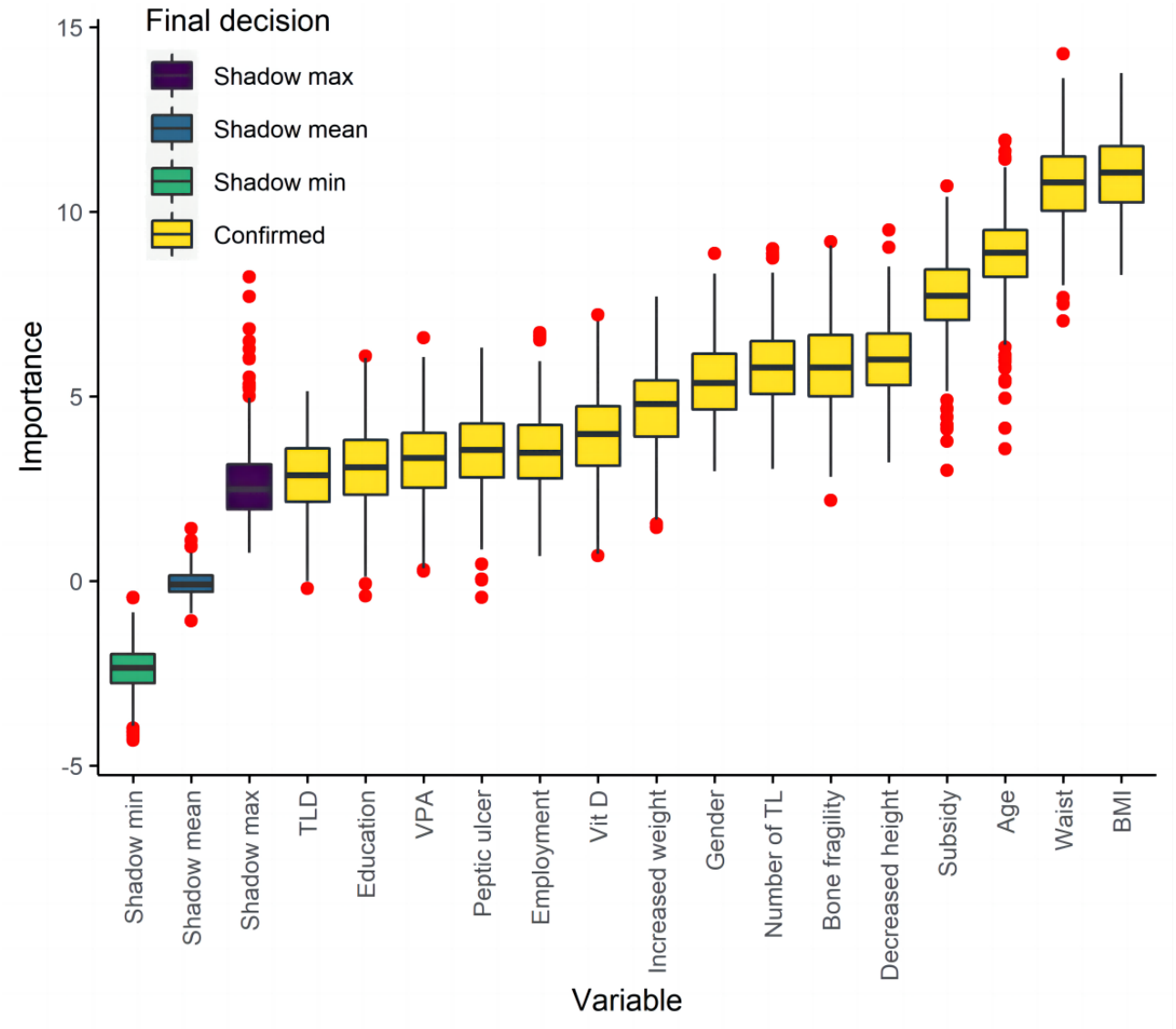
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Results

The characteristics of the potential predictors collected from the questionnaire are summarized in Table S1 in Multimedia Appendix 1. The mean age of the participants was 61.30 (SD 7.65) years, 73.3% (586/800) were women, 53.5% (428/800) had obtained a tertiary or higher degree, and 39.4% (315/800) were employed (Table S1 in Multimedia Appendix 1). The overall prevalence of osteoporosis was 10.6% (85/800); the prevalence was 0.9% (2/214) for men and 14.2% (83/586) for women.

In the feature selection process, univariate logistic regression identified 45 potential predictors (P<.10), which were subsequently used as input variables for the Boruta algorithm (Table S1 in Multimedia Appendix 1). The Boruta algorithm confirmed 15 variables as significantly important predictors, with BMI, waist circumference age, social subsidy, decreased body height, bone fragility, number of teeth lost, gender, increased body weight, the intake of vitamin D supplements, peptic ulcer, employment status, vigorous physical activity, education level, and tooth loss caused by disease being ranked in order of feature importance (Figure 1). Among these variables, age, gender, education level, decreased body height, BMI, number of teeth lost, and the intake of vitamin D supplements were further selected based on their accessibility and convenience for daily self-assessment and health care practice. Compared with participants without osteoporosis, participants with osteoporosis tended to be older, have decreased more in height, have lower BMI, and have lost more teeth, were more likely to be women and to take vitamin D supplements, and were less likely to have a tertiary or higher degree (Table S1 in Multimedia Appendix 1).

Figure 1. Importance of shadow variables and predictors selected by the Boruta algorithm. Shadow variables were obtained by shuffling the values of the original variables across participants and served as an external reference to decide whether the importance of any given original variable was significant; shadow max, shadow mean, and shadow min represent the maximum, mean, and minimum important values among shadow variables, respectively; variables confirmed as important were those with an importance significantly higher than the maximum shadow variable importance. TL: teeth lost; TLD: tooth loss caused by disease; Vit D: intake of vitamin D supplements; VPA: vigorous physical activity.



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The training set and testing set consisted of 560 (70%) and 240 (30%) participants, respectively. All the selected predictors and osteoporosis status were balanced between the training and testing set (Table 1). Figure 2 shows the discriminative performance of the predictive models based on ROC curves in the testing set. Among the full models, the NB model had the highest AUC at 0.859, while the LR model had the lowest AUC at 0.825 (Figure 2). A similar pattern was observed in the simplified models, where the NB model and SVM model achieved the highest AUC at 0.858 and the LR model had the lowest AUC at 0.845 (Figure 2). A comparison of the full models and simplified models with different algorithms in terms of other performance metrics is shown in Table 2. The NB model had the highest sensitivity at 0.87 for the full model and 0.83 for the simplified model (Table 2). The SVM model had the highest specificity at 0.86 for the full model, and the GBM model had the highest specificity at 0.87 for the simplified model (Table 2). Considering AUC, sensitivity, and specificity, the NB simplified model was identified as the best-performing model (hereby referred to as the POST).

Table . Characteristics of the predictors for full models and simplified models for the training and testing sets. *P* values were calculated with the chi-square test for categorical variables and a 2-tailed *t* test for continuous variables.

		Training set (n=560)	Testing set (n=240)	*P* value
Age[a] (years), mean (SD)		61.41 (7.61)	61.06 (7.75)	.56
Women, n (%)[a]		407 (72.7)	179 (74.6)	.64
Education level, n (%) [a]				.56
	Primary and above	69 (12.3)	31 (12.9)	
	Secondary	197 (35.2)	75 (31.2)	
	Tertiary or above	294 (52.5)	134 (55.8)	
Employment status, n (%)				.76
	Employed	216 (38.6)	99 (41.2)	
	Retired	223 (39.8)	90 (37.5)	
	Other (eg, housewife, unemployed)	121 (21.6)	51 (21.2)	
Receives social subsidy, n (%)		87 (15.5)	38 (15.8)	>.99
Decreased body height (cm)[a,b], mean (SD)		1.47 (1.83)	1.64 (2.26)	.26
Increased body weight (kg)[c], mean (SD)		8.17 (6.79)	8.05 (6.99)	.81
BMI (kg/m^2)[a], mean SD		23.15 (3.24)	22.85 (3.36)	.23
Waist circumference (cm), mean (SD)		78.36 (8.92)	77.21 (8.87)	.09
Number of teeth lost[a], mean (SD)		2.18 (4.97)	1.85 (4.43)	.38
Tooth loss from disease, n (%)		199 (35.5)	84 (35)	.95
Bone fragility, n (%)		24 (4.3)	11 (4.6)	>.99
Peptic ulcer, n (%)		43 (7.7)	17 (7.1)	.88
Vigorous physical activity, n (%)		160 (28.6)	60 (25)	.34
Intake of vitamin D supplements, n (%)[a]		158 (28.2)	60 (25)	.40
Osteoporosis, n (%)		55 (9.8)	30 (12.5)	.32

[a]Predictors used only in simplified models.

[b]Calculated by subtracting the current height from the past highest height.

[c]Calculated by subtracting the past lightest weight from the current weight.

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Figure 2. ROC curves and AUC values for osteoporosis for (A) full models and (B) simplified models. Higher AUC indicates better discrimination. Full models were constructed with the 15 predictors selected by the Boruta algorithm, including age, gender, education level, employment status, social subsidy status, decreased body height, increased body weight, BMI, waist circumference, number of teeth lost, bone fragility, peptic ulcer, vigorous physical activity, and intake of vitamin D supplements. Simplified models were constructed with the 7 predictors selected based on their accessibility and convenience for daily self-assessment and health care practice from the predictors selected by the Boruta algorithm, including age, gender, education level, decreased body height, BMI, number of teeth lost, and the intake of vitamin D supplements. AUC: area under the receiver operating characteristic curve; GBM: gradient boosting machine; LR: logistic regression; NB: naive Bayes; ROC: receiver operating characteristic; SVM: support vector machine.

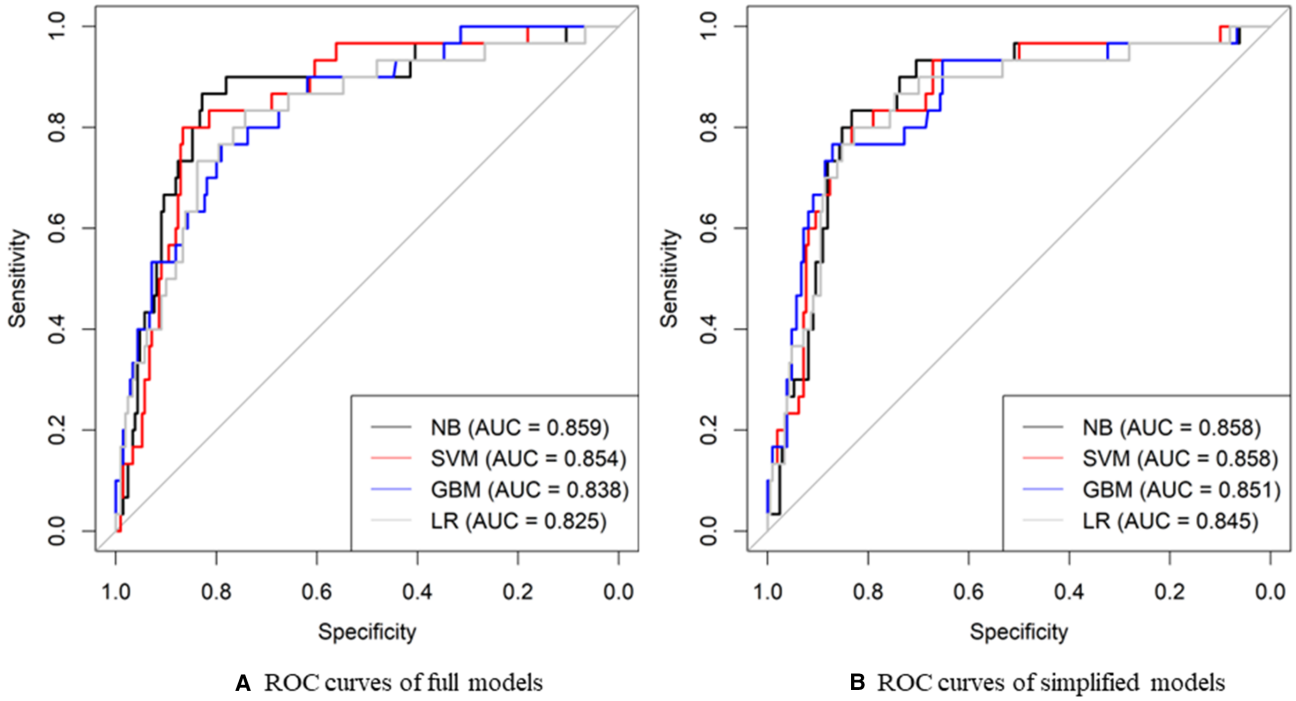


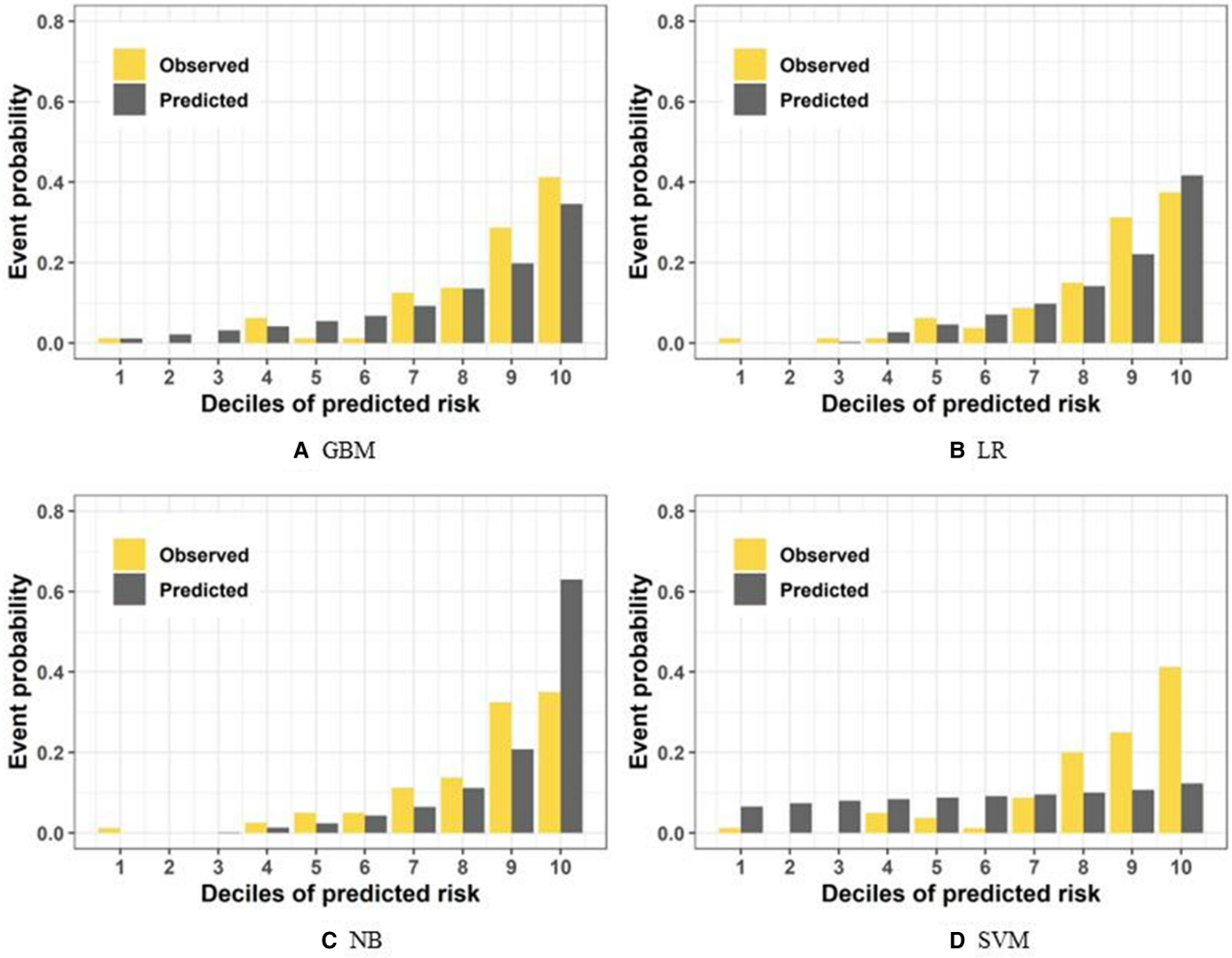
Table . Performance metrics of full models and simplified models trained by the 4 different algorithms. Full models were constructed with the 15 predictors selected by the Boruta algorithm, including age, gender, education level, employment status, social subsidy status, decreased body height, increased body weight, BMI, waist circumference, number of teeth lost, bone fragility, peptic ulcer, vigorous physical activity, and intake of vitamin D supplements. Simplified models were constructed with the 7 predictors selected based on their accessibility and convenience for daily self-assessment and health care practice from the predictors selected by the Boruta algorithm, including age, gender, education level, decreased body height, BMI, number of teeth lost, and intake of vitamin D supplements. The cutoff point was the optimal point on the receiver operating characteristic curve that could obtain maximal sensitivity and 1–specificity.

	Naive Bayes		Linear Regression		Gradient boosting machine		Support vector machine	
	Full models	Simplified models	Full models	Simplified models	Full models	Simplified models	Full models	Simplified models
Accuracy	0.83	0.83	0.75	0.83	0.79	0.85	0.85	0.83
Sensitivity	0.87	0.83	0.83	0.80	0.77	0.73	0.80	0.80
Specificity	0.82	0.83	0.74	0.83	0.79	0.87	0.86	0.83
Positive predictive value	0.41	0.42	0.32	0.40	0.34	0.45	0.45	0.41
Negative predictive value	0.98	0.97	0.97	0.97	0.96	0.96	0.97	0.97
F_1-score	0.56	0.56	0.46	0.53	0.47	0.56	0.58	0.54
Cutoff point	0.20	0.11	0.09	0.15	0.11	0.18	0.09	0.10

The calibration bar plots show the observed vs predicted decile risks of full models and simplified models (Figure S1 in Multimedia Appendix 1 and Figure 3). For the full models, the predicted risk and the observed risk fitted well in LR, while the GBM slightly underestimated the highest risk decile and NB and the SVM overestimated the highest risk decile (Figure S1 in Multimedia Appendix 1). The calibration bar plots of the simplified models showed a similar pattern to the full models, except that the SVM underestimated the highest risk decile (Figure 3).

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Figure 3. Risk of observed osteoporosis according to deciles of predicted risk of simplified models, including (A) GBM, (B), LR, (C), NB, and (D) SVM. Simplified models were constructed with the 7 predictors selected based on their accessibility and convenience for daily self-assessment and health care practice from the predictors selected by the Boruta algorithm; they included age, gender, education level, decreased body height, BMI, number of teeth lost, and the intake of vitamin D supplements. GBM: gradient boosting machine; LR: logistic regression; NB: naive Bayes; SVM: support vector machine.



Discussion

Principal Findings

In this study, we developed and validated a self-administrated questionnaire to assess potential risk factors for osteoporosis and collected data from 6 representative clinics across 3 main districts in Hong Kong. We used machine learning–based methods to confirm significantly important variables and further selected 7 predictors based on their accessibility and convenience for daily self-assessment and health care practice. A set of machine learning models was constructed to predict osteoporosis risk, and the best-performing model, the POST, was identified. The POST demonstrated accurate discriminatory abilities in predicting osteoporosis with simple inputs that make it a convenient tool for daily self-assessment and other health care practices.

Machine learning algorithms could capture high-dimensional, nonlinear relationships among predictors and provide a novel approach to the compelling requirement for accurate personalized prediction of osteoporosis. In our study, we constructed both typical machine learning models and the traditional LR model and found that machine learning models had higher AUC values compared with the LR model. Previously established osteoporosis screening scores, including Simple Calculated Osteoporosis Risk Estimation (SCORE) [10], the Osteoporosis Risk Assessment Instrument (ORAI) [12], the Osteoporotic Self-assessment Tool (OST/OSTA) [17], the Osteoporosis Index of Risk (OSIRIS) [8], Osteoporosis Prescreening Risk Assessment (OPERA) [11], the Male Osteoporosis Screening Tool (MOST), and the Male Osteoporosis Risk Estimation Score (MORES) [9], are all derived from traditional statistical models and achieve high sensitivity (78.5%-98%) with relatively low specificity (29%-64.2%). Low specificity indicates a high false positive rate, reflecting potential resource waste for subsequent DXA use. The machined learning–based POST in our study has balanced high sensitivity (83%) and specificity (83%), and therefore has the potential to be used as a cost-effective osteoporosis preclinical screening tool to determine people at high risk who require further testing using DXA.

The selection of predictors for target outcomes is a crucial step in prediction model construction research. Traditionally, a stepwise process of regression models or empirical determination has been commonly used to select predictors.

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However, our study sought to improve upon this practice by combining regression and machine learning methods with an empirical, knowledge-based method to select predictors. Our findings indicate that the performance of simplified models that used only 7 predictors selected consecutively by regression, the Boruta algorithm, and empirical knowledge was comparable to that of the full models, which used 15 predictors identified by the Boruta algorithm. However, the simplified models, with fewer predictors, demonstrated better applicability to health promotion practice. Our study's predictor selection process could provide an example for future studies.

BMI, waist circumference, and age were identified as the top 3 important variables by the Boruta algorithm. Consistently, these variables have also been commonly selected and set as the parameters in previously established osteoporosis screening scores [9-17]. We selected 7 predictors based on their accessibility and convenience for daily self-assessment and health care practice from the Boruta-identified predictors to compute simplified models, including age, gender, education level, decreased body height, BMI, number of teeth lost, and the intake of vitamin D supplements. These variables are commonly found in daily life and are highly objective, allowing individuals to provide accurate values without the need for additional clinical or lab examinations. People in the high-risk group are recommended to receive a DXA scan, and confirmed osteoporosis patients should receive appropriate treatment, while people in the low-risk group could postpone a DXA scan. The application of POST is not limited to specialized health care facilities and can be extended to community health care settings, as well as at-home use. This would enable the identification of at-risk individuals who may not have access to specialized health care services, thereby improving access to timely treatment of osteoporosis patients.

Strengths and Limitations

Our study has several strengths, including that we collected potential risk factors from the literature and constructed a self-administered questionnaire for risk factor measurement; collected the data from 6 representative clinics spanning 3 main districts in Hong Kong; used machine learning–based algorithms for both predictor selection and model construction so as to capture multidimensional, nonlinear relationships that were not limited by the statistical assumptions of traditional statistical models; and obtained data on osteoporosis outcomes with limited misclassification due to the objective and accurate measurement of BMD by DXA.

However, several important limitations should be noted. First, the machine learning algorithms are known as "black box" models because of their complexity and uninterpretability. The models cannot compute effect size to clarify relationships between predictors and outcomes. Instead, the machine learning algorithms produce variable importance values to indicate which variables are more important to the outcome. Second, the sample size of this study was relatively not large. Future studies should include more samples as model input to further improve accuracy. Third, there was an unbalanced gender distribution, with a higher proportion of women, which could have limited the representativeness of our findings in the male population and induced potential gender-related bias. Future studies should consider more balanced gender representation, potentially supplemented by gender-specific models. Fourth, this study lacked external validation, which is our next planned research project. Fifth, the POST was derived from the Chinese population in Hong Kong and may not generalize to other populations with different ethnic, economic, and cultural backgrounds.

Conclusions

In conclusion, we used machine learning methods to develop and internally validate the POST to predict osteoporosis among the Chinese population in Hong Kong. The POST showed accurate discrimination, with potentially important implications for the optimization of osteoporosis screening and clinical decision-making.

Acknowledgments

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Authors' Contributions

YJX conceived and designed the study and provided administrative, technical, and material support to the study. YJX collected the data; QY analyzed the data and drafted the manuscript; and QY, YJX, HC, JQ, AYL, FWN, KCC, DZ, YG, HHW, ZL, and CH made critical revisions to the manuscript. All authors read and approved the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary tables and other material.
[DOCX File, 750 KB - aging_v6i1e46791_app1.docx]

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Abbreviations

AUC: area under the receiver operating characteristic curve
BMD: bone mineral density
DXA: dual-energy x-ray absorptiometry
FPAHK: Family Planning Association of Hong Kong
GBM: gradient boosting machine
I-CVI: Content Validity Index for Items
LR: logistic regression
MORES: Male Osteoporosis Risk Estimation Score
MOST: Male Osteoporosis Screening Tool
NB: naive Bayes
OPERA: Osteoporosis Prescreening Risk Assessment
OSIRIS: Osteoporosis Index of Risk
OST/OSTA: Osteoporotic Self-assessment Tool
POST: Preclinical Osteoporosis Screening Tool
ROC: receiver operating characteristic
SCORE: Simple Calculated Osteoporosis Risk Estimation
SVM: support vector machine

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