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Original Paper

Technology-Mediated Enrichment in Aged Care: Survey and Interview Study

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Abstract

Background: Digital technologies such as virtual reality (VR), humanoid robots, and digital companion pets have the potential to provide social and emotional enrichment for people living in aged care. However, there is currently limited knowledge about how technologies are being used to provide enrichment, what benefits they provide, and what challenges arise when deploying these technologies in aged care settings.

Objective: This study aims to investigate how digital technologies are being used for social and emotional enrichment in the Australian aged care industry and identify the benefits and challenges of using technology for enrichment in aged care.

Methods: A web-based survey (N=20) was distributed among people working in the Australian aged care sector. The survey collected information about the types of technologies being deployed and their perceived value. The survey was followed by semistructured interviews (N=12) with aged care workers and technology developers to investigate their experiences of deploying technologies with older adults living in aged care. Survey data were analyzed using summary descriptive statistics and categorizing open-ended text responses. Interview data were analyzed using reflexive thematic analysis.

Results: The survey revealed that a range of commercial technologies, such as VR, tablet devices, and mobile phones, are being used in aged care to support social activities and provide entertainment. Respondents had differing views about the value of emerging technologies, such as VR, social robots, and robot pets, but were more united in their views about the value of videoconferencing. Interviews revealed 4 types of technology-mediated enrichment experiences: enhancing social engagement, virtually leaving the care home, reconnecting with personal interests, and providing entertainment and distraction. Our analysis identified 5 barriers: resource constraints, the need to select appropriate devices and apps, client challenges, limited staff and organizational support, and family resistance.

Conclusions: This study demonstrates that technologies can be used in aged care to create personally meaningful enrichment experiences for aged care clients. To maximize the effectiveness of technology-mediated enrichment, we argue that a person-centered care approach is crucial. Although enrichment experiences can be created using available technologies, they must be carefully selected and co-deployed with aged care clients. However, significant changes may be required within organizations to allow caregivers to facilitate individual technology-based activities for enrichment.

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KEYWORDS

aged care; older adults; technology; social enrichment; virtual reality; robots; videoconferencing; care providers

Introduction

Background

For many of the people now living into advanced old age, opportunities to engage in social, creative, or fun activities may diminish because of mobility constraints and decreasing social networks [1]. It can be especially challenging for those who move into institutional care homes to stay socially connected and engaged. Residential care homes provide 24-hour care and monitoring; however, they can be lonely places to live [2,3]. There may be few opportunities for aged care clients to leave the care home to socialize or engage in activities that provide them with joy and enrichment.

Psychosocial care, attending to people's needs for social connectedness and emotional enrichment, is an important component of aged care service provision [4]. In Australia, where this study was conducted, this is provided through both residential care, for people living in care homes, and community-based care, for people living independently. In both types of care settings, social enrichment is often provided through a program of structured activities, which might include group games such as bingo, exercise, and music [5,6]. Many organizations are now incorporating technology-based activities into their social programs. These initiatives are often led by the care organizations [7]. There is also a large body of research evaluating trials of technologies used for social well-being in aged care, including robot pets for companionship and comfort [8], social robots for entertainment [9,10], videoconferencing and social networking tools for communication [11], video games for playful interactions [12], and virtual reality (VR) for reminiscence [13]. Communication technologies can be valuable for expanding older adults' social lives, helping people who are otherwise alone feel a sense of connection with the world [14-17].

Researchers have noted, however, that not all older adults will gain benefit from technology-based social interventions [18]. There must be a good fit between the technologies being used (and the activities they are used for) and the needs of people being supported. Achieving this alignment requires care and attention from those responsible for introducing technology [19,20]. In residential aged care in Australia, this includes lifestyle coordinators who are responsible for running activity programs and technology vendors who are sometimes responsible for introducing technology into aged care.

Current research on the use of emerging technologies by older adults typically involves trials of specific technologies, focusing on the health and well-being benefits for clients [8,21]. These studies provide useful insights into the potential benefits of new technologies to enrich the lives of older adults; however, they do not provide a broader view of the issues faced during the process of deploying new technologies in aged care. However, past research has identified significant barriers to the successful implementation of emerging technologies (eg, social robots) in care settings [22-24], including technical problems [22], negative preconceptions about new technology [22], and a lack of acceptance from end users [24]. Care staff may need to invest additional time and effort to overcome these barriers, placing further burdens on their already busy schedules. This is particularly challenging in the Australian aged care system, where a Royal Commission recently revealed significant neglect partially because of underresourcing and insufficient staff training.

Given that residential aged care is a complex and sensitive setting, there is a risk that introducing new technologies may cause harm. Therefore, there is a need to understand and carefully manage the opportunities and challenges that occur when technologies are used to support people in aged care. Gaining an in-depth understanding of what works and does not work will help inform future good practice in this sensitive setting.

Objectives

This study aims to understand how technologies are being used to enrich the lives of older adults in aged care and identify lessons for good practice in this area. This study focused on understanding the experiences of people responsible for introducing and facilitating technologies in aged care settings. This includes those who work in aged care, such as personal care assistants, diversional therapists, and lifestyle coordinators, along with external technology vendors and providers who introduce and deploy technology in aged care.

The study focused on the following questions:

1. What technologies are being used to provide social and emotional enrichment in aged care?
2. How do staff value the different technologies used for enrichment in aged care?
3. What kinds of enrichment experiences are enabled when introducing technology-based activities in aged care?
4. What challenges or barriers need to be overcome when using technologies for social and emotional enrichment in aged care?

Methods

Ethics Approval

All procedures were approved by the University of Melbourne Human Research Ethics Committee (ID 1851239.1). Survey respondents read a plain language statement about the study, which included information about the length of time required, anonymity of responses, and data management. Respondents had to provide consent before proceeding with the survey. Interviewees were provided with a copy of the plain language statement and signed a consent form before proceeding with the interview.

Data Collection

Overview

This study involved a web-based survey targeting aged care staff and technology providers, comprising a combination of Likert scale and open text responses. The survey was designed to obtain information about the types of technologies being used for enrichment in the Australian aged care system. We also conducted semistructured interviews to gain an in-depth understanding of the experiences of aged care and technology providers using technology in aged care.

Web-Based Survey

The survey was designed using the SurveyMonkey tool and tested for length and clarity by the research team. It had 3 sets of questions (Multimedia Appendix 1). The first set of questions asked about background information, such as the respondents' role in aged care. The second set asked respondents about their own experiences of deploying technologies in aged care using the question, "What type of technology have you used in aged care for social or activity purposes?" The question specified *social or activity purposes* to guide respondents to nominate technologies used as part of the activity programs in aged care; that is, to provide social and emotional enrichment, in contrast to technologies used to support medical care. Participants were asked to describe the technologies and why they were using them in free text boxes.

In the third set of questions, respondents used Likert scales ranging from 1 (not at all valuable) to 5 (highly valuable) to rate the perceived value of the following 6 technologies: VR, robot pets, social robots, social networking tools or systems, videoconferencing tools, and digital storytelling apps. These technologies were chosen because of considerable interest in their use in aged care [21,25-28]. Respondents had the option to select *not applicable* if they did not know enough about the technology to make a judgment.

Interviews

A total of 12 interviews were conducted, 9 (75%) via phone or internet and 3 (25%) in person. Interviewees were asked to provide details about their experiences of deploying technologies in aged care and their views on the benefits and challenges involved in using different technologies to enrich the lives of aged care clients (Multimedia Appendices 2 and 3). The interviews focused on technologies used to support psychosocial caregiving rather than those used to support instrumental care, such as sensors for fall monitoring. All interviews were audio recorded and then transcribed verbatim for subsequent analysis.

Participants

Survey Respondents

The survey was openly distributed to aged care and technology providers throughout Australia in late 2018 and republicized in late 2019. It was distributed via the researchers' professional networks, notices in relevant email lists and industry publications, and social media platforms (Twitter and LinkedIn). The survey was open (not password protected). No incentives were offered for responding to the survey.

We received 20 complete responses to the web-based survey. Table 1 shows the different types of aged care provided by the respondents. Respondents worked in various roles, including as activity coordinators and project managers, and in design innovation, community engagement, and operational excellence. Other respondents included nurses and consultant geriatricians working in hospital care units as well as developers and managers working for technology vendors.

Table 1. Web-based survey respondents: type of aged care organization (N=20).

Organization	Values, n (%)
Residential aged care	9 (45)
Mixed residential and home-based aged care	4 (20)
Hospital care units	3 (15)
IT[a] providers	4 (20)

[a] IT: information technology.

Interviewees

We conducted a total of 12 interviews, and 6 (50%) interviewees completed the survey and agreed to participate in the follow-up interview. We contacted other potential interviewees directly and identified them through their professional networks. We used purposive sampling to ensure that we included people with expertise in using technology for enrichment in aged care. All the interviews were conducted between October 2018 and December 2019. Table 2 provides more details about the interviewees, among whom 67% (8/12) worked in aged care facilities as care staff, lifestyle team members, or managers. The remaining 33% (4/12) of the interviewees were technology developers and vendors responsible for introducing technology into aged care settings. All had the experience of introducing new technologies in aged care for providing social and emotional enrichment for aged care clients.

Table 2. Interview participants.

Pseudonym	Perspective	Survey completed
Alan	IT[a] company (founder)	No
Barry	Care provider (service or project manager)	No
Claire	Care provider (pastoral care)	No
Del	Care provider or IT (innovation manager)	Yes
Eric	Care provider or IT (project officer)	Yes
Frank	Care provider (volunteer)	Yes
Graham	IT company (founder)	No
Helen	Care provider (funding manager)	Yes
Ian	IT company (founder)	Yes
Jacquie	Care provider (lifestyle manager)	No
Ken	Care provider (CEO[b])	Yes
Larry	IT company (founder)	No

[a] IT: information technology.

[b] CEO: chief executive officer.

Data Analysis

Quantifiable survey responses were analyzed using summary counts and descriptive statistics. The open-ended survey responses and interview transcripts were analyzed using reflexive thematic analysis [29]. The data were coded by WZ and JW using an inductive approach. WZ identified initial themes, which included 8 themes under the *benefits* category and 15 under the *challenges* category. These were documented in a written report for discussion among the researchers. JW conducted the next stage of the analysis, refining and combining the themes to identify a final set of 9 themes, 4 that aligned with benefits, described below as technology-mediated enrichment experiences. The 15 challenges were recategorized into 5 overarching themes associated with key barriers to the effective implementation of technology-based enrichment experiences in aged care.

Results

Web-Based Survey

Types of Technologies Used

VR was the most common technology used by the survey respondents (13/20, 65% of respondents). Other popular technologies included computer or video games (10/20, 50% of respondents) and social networking systems (8/20, 40% of respondents). Commercial VR products such as Samsung Gear, Google Daydream, HTC Vive, and Oculus VR systems had been used for a variety of purposes, including virtual tours, reminiscence, entertainment, pain distraction, and staff training. Computer or video games ranged from digital card games to exergames. Social networking tools such as Facebook were used for social connectedness, whereas some respondents described bespoke apps that were designed for social connectedness.

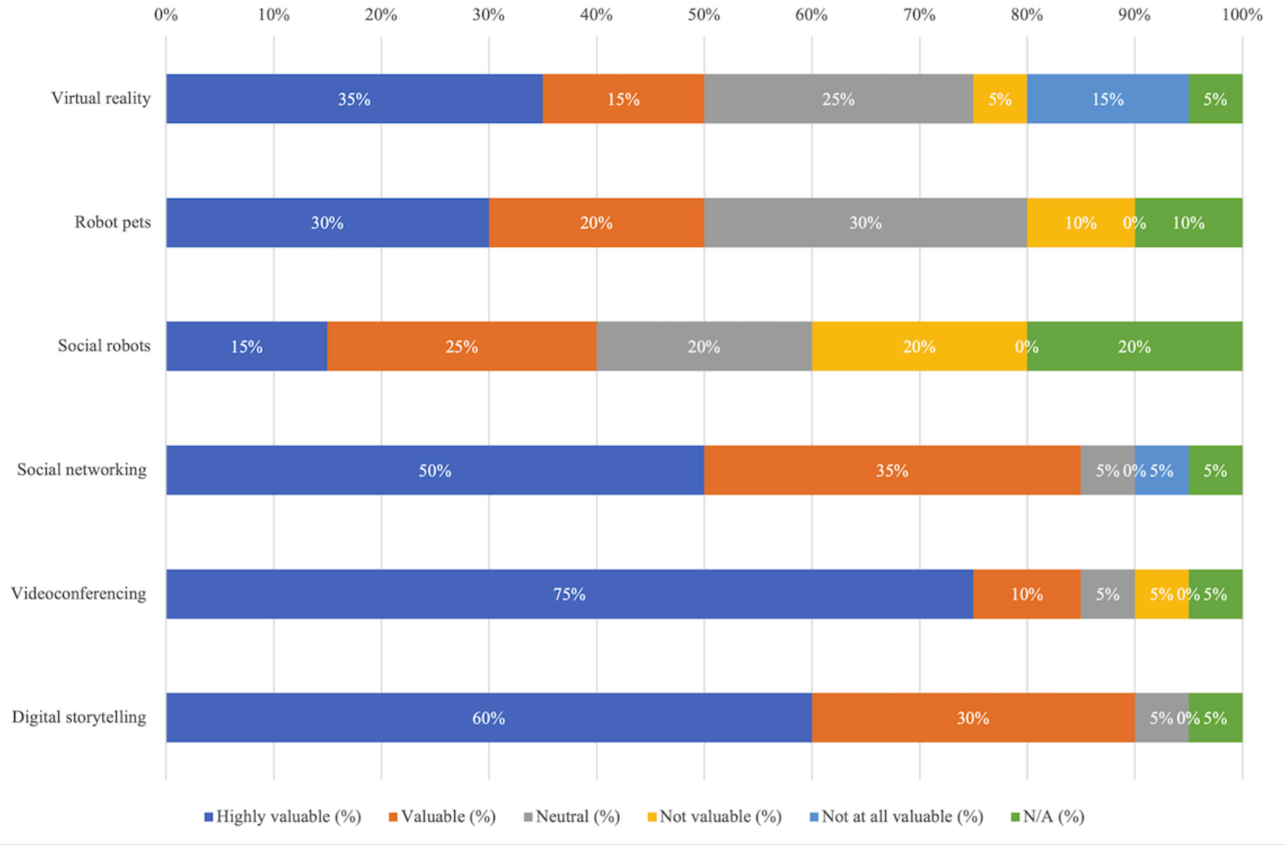
A total of 30% (6/20) of the respondents said they were using *tablets and mobile phones*, and 25% (5/20) were using *CDs, DVDs, radios, and televisions* for enrichment. Tablets and mobile phones were used for facilitating video calls through apps, such as Skype and Facetime, and for providing older people with personalized music, games, audiobooks, and video browsing experiences. CDs, DVDs, radios, and televisions provided similar functions. A survey respondent described using a customized television that displays only old-time music, programs, and commercials, aiming to connect people with their old memories.

A total of 25% (5/20) of the respondents used social or companion robots in aged care. These included robot pets, such as Paro, the seal and Hasbro toy animals, which were primarily used for comfort, diversion, and entertainment purposes.

Perceived Value of Different Technologies

Figure 1 shows the percentage of survey participants who perceived different technologies as highly valuable, valuable, neutral, not valuable, or not at all valuable. “Not applicable” denotes that they did not know enough about the technology to make a judgment. Notably, VR, robot pets, and social robots, which could be considered the most innovative of the technologies listed, had the highest variation in perceived value.

Figure 1. Distribution of respondents’ perceived value of different technologies. N/A: not applicable.



At the end of this block of Likert scale ratings, respondents were asked if they had any comments about why the technologies listed were or were not valuable for use in aged care. Earlier in the survey, they were asked to comment on the benefits and challenges they had faced when using technology in aged care. We examined these responses together to identify the perceptions about specific technologies. Where respondents' comments are included below, they are identified as S1 to S20 to indicate which survey respondent made this comment. Regarding the use of VR, although some respondents (6/20, 30%) found VR to be useful for virtual travel, there were also concerns about the high cost and frequent need for troubleshooting when using VR (3/20, 15%), the difficulty of using it for people with dementia (2/20, 10%), potential for discomfort such as headache and dizziness (3/20, 30%), the burden on staff time and need for staff training (3/20, 30%), and perceived resistance from clients (2/20, 10%). For example, a survey respondent said that a client had said, “I don’t want to put electricity to my head” (S18).

Some respondents (6/20, 30%) believed that robot pets could provide beneficial outcomes for people with dementia or those experiencing loneliness. Others expressed reservations about their value; for example, “Some that I’ve seen have been a bit spooky and border on child-like toys” (survey respondent [S] 8) and “[They] are just a novelty and gimmick long term as they do not foster real person-to-personal connection” (S13). Social robots that talk and provide entertainment [10] were valued for their potential to address social isolation but were also seen to lack *real person-to-person connection* (S13). A respondent noted that commercial smart speakers could provide similar benefits and were preferable over specialized robots:

> *At the moment, Google Home and Alexa can give some of the same benefits (company, feedback) that a social robot could. I think the social robot would have to offer something significantly enhanced in order to differentiate it.* [S8]

Videoconferencing tools received the most positive perceived value: out of 20, a total of 17 (85%) believed them to be valuable or highly valuable and 1 (5%) respondent expressed concern that it was difficult for clients with severe dementia to use videoconferencing tools, even with the help of staff. Similarly, we noticed a positive perception of values for social networking tools and digital storytelling apps. One respondent commented that social networking tools are useful for “allowing elders to connect with remote family members in dynamic and rich ways,” and other apps, for example, audio books and screen readers, are valuable “for those who cannot physically read words in a book, or even physically turn pages” (S13).

Interviews

Technology-Mediated Enrichment Experiences

A thematic analysis of interview data identified four kinds of technology-mediated enrichment experiences: (1) enhancing social engagement, (2) virtually leaving the care home, (3) reconnecting with personal interests, and (4) providing entertainment and distraction.

Enhancing Social Engagement

Many interviewees discussed the social benefits that technology could provide for aged care clients. In particular, videoconferencing tools connect people living in residential aged care with loved ones who may not be able to visit them regularly. Claire captured the power of this connection:

> *I remember one lady who's actually just turned 101 last week. She is in Sydney while her daughter is in Melbourne. We had the iPad and did the Skype calls with her daughter. It's so beautiful when they say goodbye to each other. She gets the iPad, and she kisses the iPad, and goes "love you [kiss]." It is so beautiful to see that interaction and for the daughter. She's just so happy.* [Claire]

In addition to one-on-one communication, videoconferencing tools enabled clients to participate in family events. Claire shared another compelling example: a client who was a family matriarch who had always previously been involved in family events was devastated to learn that she was not attending her grandson's wedding. In response, Claire suggested that they use Skype to "bring the wedding to you here." This example shows the care and creativity required to create a meaningful connection for a person living in aged care:

> *Over the following three months we prepared this whole gathering where we would Skype the wedding, bring it here, and she agreed that all of the residents would be invited to the wedding...So we set up the whole place as a high tea, and we skyped in and...it was really really beautiful and then after the wedding was finished we turned it off...We then reminisced. Everybody started talking about wedding experiences, their own weddings, other people's wedding, while we had this lovely high tea.* [Claire]

This story by Claire illustrates how technologies can be used to not only connect residents to the outside world but also facilitate conversation within the care home, suggesting that technology-mediated connections can provide multiple social benefits. Other interviewees described how some technology-mediated activities provided *talking points*; clients would share their personal experiences with caregivers, family members, or other residents after taking part in a new activity. This was particularly apparent for interviewees who used VR to enable clients to virtually *travel* to new places or revisit childhood hometowns:

> *VR has an ability to open up the mind in a way like nothing else I've seen. When [the headset] comes off, I then go back and have them share their memories of that place. It might be their brothers, their sisters, their parents, where they went to school, where they played, what it was like growing up, and they start to share the stories of their life. And they may go from a very dormant non-communicative state to actually having a full-on conversation for the first time in a long time. And that really helps the connection with families as well.* [Frank]

Interviewees emphasized that technologies should serve as a medium for promoting social interactions among people rather than as a stand-in for social interaction. Technologies such as social robots or smart speakers could potentially engage in conversations with users, thereby appearing to address people's experience of loneliness and isolation. However, interviewees were generally not supportive of this concept, preferring to use technology that connected people to each other rather than to a device. When asked to describe what the *ideal technology* for older adults would look like, Alan said the following:

> *It would involve interacting with people rather than with an artificial intelligence, but it might have an artificial intelligence in it. I think it would be an active thing that involves the older adult having to do something...doing something important as distinct from just being entertained...Something meaningful. And ideally with people.*

Similarly, Claire said the following:

> *When we talk about having robots in care [and] all these games and stuff, that's all very well but it will never ever be the same in terms of meaning making [and] connection...They don't want to be shoved in a corner somewhere and think it's all over. It's about staying connected. So whatever it takes to keep people connected, that's what we do. That's what the technology is good for.*

Leaving the Care Home

Using technology to connect residents to the outside world provided benefits beyond social engagement. Interviewees described instances in which using new technologies gave clients something to look forward to, helped them access places they had been to in the past or would like to visit, and opened their world to new experiences. Immersive VR was particularly useful in realizing this benefit:

> *We had a lady who was in the [VR] session. She didn't speak any English. And she was 99 years old. And she loved it. She was at a stage where probably everyone told her you're never going to go anywhere, see anywhere again. So the idea of them being immersed in places like the Aurora Borealis, Egypt or the Middle East, the States. The world that just opened for that had been closed off.* [Larry]

The interviewees shared examples of using other tools such as YouTube or Google Earth to help residents stay connected with the outside world. Claire shared 1 example in which she helped a resident to go home using technology. Through this process, she gained opportunities for conversation, which helped alleviate her client's distress:

> *I was asked to see her and she was crying and crying, just inconsolable, and...she kept on saying "I wanna go home, I wanna go home..."And I actually thought, "what am I going to do?" I do a lot of bereavement counselling and I thought, "oh, this is going to be really hard." And I said to her, "tell me, where do you live? What's your address?" And all I had was my phone. I put her on my phone on Google Earth, on satellite view. I said, "Let's have a look where you live" and suddenly the place came up and she stopped*

> *crying! And she sat up and said, "No, my place has changed. We painted the garage door, and we chopped that tree down." So obviously the photo was a little bit out of date, and it prompted this amazing conversation.* [Claire]

A key constraint for people living in residential aged care is that they may have few opportunities to experience life outside the care home. For Barry, being able to be transported to another place would be an ideal way for technologies to provide enrichment:

> *If we could have something that could "beam me up scotty" and take them to places that they have enjoyed in the past, that would be a technology that residents and people would certainly enjoy.*

Furthermore, within a care home, people's lives may be overly controlled and structured. Offering new experiences and the chance to virtually leave the care home could provide an antidote to the lack of control people have when living in residential care homes. For Del, the greatest benefit that technologies provide is "the ability to bring a different experience...it adds to a culture of greater flexibility rather than control or paternalism."

Reconnecting With Personal Interests

Interviewees spoke at length about the value of using technology to connect people in aged care with their personal interests and passions. They noted that this benefit was evident when deploying technology one on one compared with conducting group activities. Interviewees shared stories about using VR or YouTube videos to help aged care clients rediscover their personal interests:

> *I had the privilege of working with a guy who was turning 100. He was a car fanatic. When asked about his dream, he said, "I would love to have been in one of the leading car categories in the world," and he said "but today I would love to be able to sit in a Formula 1 race car." So I went onto VR, I found a Formula 1 race car, I put the goggles on him, and he did a lap at the track in Germany, hollering at the top of his voice, whooping and hollering, having such a ball. And it's something that he still talks about with his family, because he got to live a dream.* [Frank]

This story further emphasizes the unique capability of VR to provide a sense of being transported to a time or place outside of the care home. It also highlights how a joyful experience emerged, because the activity was designed to respond to the client's past interests. This opportunity to realize a long-held dream appeared to create a sense of elation, which may have been momentary but would nevertheless have been valuable for an aged care client who may normally have few opportunities to experience such joy in his day-to-day life.

Another interviewee who ran a technology company that introduced information technology (IT) solutions for aged care described how it was important to identify people's personal interests to find opportunities to use technology in meaningful ways. The interviewee described a client who was able to reconnect with past interests by watching YouTube videos:

> *There was a gentleman that'd been part of this Isle of Man race, a motorbike race in the 50s or 60s. We quickly went to YouTube, found the race, and the guy was able to re-live that race. And that's not complex, but it takes conversation and trying to understand what's possible. Some people are interested in games, some people are interested in learning. Some people are just interested in photos of the people they love, or Facetime or Zoom or whatever.* [Graham]

When asked about the ideal technology-based enrichment activity in aged care, Del pointed out the need to offer a range of experiences to cater to individual client needs:

> *It would be a smorgasbord. There would be a range of things for people to interact with...Choice and agency is really important, so your ability to choose a range of scenes, your ability to choose a range of experiences...*

Providing Entertainment and Distraction

In addition to providing joy by reconnecting residents to their personal interests, technology-based activities also provided general entertainment and distraction. This was considered particularly valuable for those living with dementia, with technology-based activities distracting clients from the psychological and behavioral symptoms of dementia, including agitation, distress, and wandering. This benefit was particularly apparent when using robot pets and VR. For example, an interviewee noted the utility of Paro, the seal, a therapeutic robot, for calming and entertaining residents:

> *I think the benefits of the PARO seal, it gives that response, and it keeps residents happy, and if they wander it actually settles them down and calms them down. They couldn't stop her [one resident] wandering, but you give her the Seal and it just calms her down, and you get that complete, I'll say peace of mind that you don't have to worry that she's off trying to get out of the building.* [Ken]

For Helen, technology had the potential to help manage some of the more challenging behaviors associated with dementia, including violence. She noted that music, in particular, could be calming and that aged care homes should provide pleasant activities to give people joy and comfort at the end of life:

> *Wouldn't you want something nice and bright and something around you when, you know, it's the end of your life? And probably music is - anything with music is so calming and soothing for anybody, whether you're young or old. So that sort of this could be helpful in the technology side.* [Helen]

Even simple activities, such as using an iPad to provide personal access to television programs, could give people an opportunity to escape discomfort. Eric shared an unusual example:

> *We've been using Snapchat with residents as an activity. They really enjoy playing with the Snapchat filters and seeing what they can do...They're just taking photos with the iPad with Snapchat on it and sharing it around the facility.* [Eric]

This example shows that there can be value in using technology for playfulness and entertainment in aged care. The interviews demonstrated that technology-based activities can provide numerous ways of enriching the lives of older adults in aged care. Using technology effectively in aged care, however, involves managing many challenges and overcoming barriers, as discussed next.

Barriers to Technology-Mediated Enrichment

Our analysis identified five key challenges and barriers encountered by interviewees when introducing technologies for enrichment in aged care settings: (1) resource constraints, (2) selecting appropriate devices and apps, (3) client challenges, (4) limited organizational and staff support, and (5) resistance from families.

Resource Constraints

Participants described a range of constraints that limited their deployment of technologies in aged care, including funding, staff numbers, and workload. Financial constraints associated with business decision-making specifically affect the procurement of technology products and upkeep costs. According to Alan, aged care organizations focus on the following:

> *By and large [they are] focused on their profit and loss statements regardless of whether they're for profit or non-profit organisations. You know there's this kind of concept that non-profits are...trying to do things for love which is sometimes true but mostly they have budgets too and people who work there want to get paid. So the technologies that I've seen getting introduced into aged care environments mostly only work if they're actually improving the bottom line of the organisation.*

An interviewee commented on the disparity among regions, noting that aged care organizations in regional areas struggled more with funding issues, which led to difficulties in providing the infrastructure to support technology use in aged care:

> *City facilities are going to have more than what country facilities have. The sad part about being in the country is you're a forgotten race really and...you're not big enough to receive all the funding for it, to be able to do this [provide WiFi] for your residents.* [Helen]

Larry who runs a technology-based activity program for aged care organizations noted the tight budgets of aged care activities programs, which meant it was difficult for them to afford the technology programs his company provides:

> *I'm not privy to their budgets but in the activity side of things, I think that the people in those teams work very hard to engage a lot of people on a tight budget, so that can be a constraint.*

Constraints on staff time were especially problematic in facilitating individual technology-based activities. In aged care homes, group activities are often prioritized over one-on-one activities [6]. Frank, who volunteered in aged care homes, noted that these group activities rarely catered to individual interests and needs:

> *The organisation has a calendar and it is activities everyday. For instance this morning there is a bus trip that some of them have gone on and there is also an activity where someone will come around and play old Italian songs to them. That's the limit of stimulation that they get in a day and it's always done in a group context. One-on-one interaction does not happen. They tend to be herded into groups to do activities. Someone sitting down and actually spending one on one time is very very rare.*

The focus on group activities meant that single-user technologies such as VR were sometimes difficult to implement. As noted above, interviewees found VR to be a valuable way of providing enrichment in aged care, as it enabled clients to *leave* the care home and reconnect with past interests. However, using VR in aged care requires careful facilitation and one-on-one support, which is time-consuming for staff who would normally run group activities:

> *In regard to VR it...does take a bit of one on one time with each customer for them to be able to use it. It's hard to run that as a group activity because it's really focused on one person at a time.* [Eric]

A further challenge is that staff needed time to not only facilitate activities but also learn how to use the technology. This meant that there was an opportunity for external organizations to provide services that aged care staff may not have the time or skills to deliver themselves:

> *In an aged care environment, it's a bit harder I think than in independent living space. In care we are finding that there's so many demands on their time, and the traditional roles they've had have been more clinical, a bit more care. They're great with the emotional side of things, but the skills, the tech skills, we're having to upskill in that a lot.* [Graham]
>
> *And the other thing is that I think there's great benefits in an external person delivering the service because we've got expertise in how to do that and use the technology, whereas the people in the lifestyle team may be squeezed for time, and I don't know what training they've had with this.* [Larry]

A Need to Select Appropriate Devices and Apps

Many participants used commercially available products, including VR headsets, Skype, and Google Earth. However, these technologies were not designed specifically for older people. Interviewees noted that their designs did not always accommodate the needs of older adults, sometimes creating negative user experiences. Alan noted that a lack of inclusion of older adults in the design and development process led to products of limited value for people in aged care:

> *Some products aren't useful because they don't work very well. There are two reasons, one is they're targeting a problem that no one has, or they might be targeting an important problem, but they're not well implemented. People are not following*

> *established development techniques and involving older adults into the development as much as they should be.* [Alan]

The content and apps used also needed to be carefully selected to meet the needs of individual clients. Selecting content that did not connect the client with their personal interests could potentially discourage clients or lead to a lack of interest in the activity. Barry noted that it was not possible to implement a *one-size-fits-all* approach when choosing technology-based activities to enrich the lives of individual residents:

> *Our residents have such a vast variety of likes, dislikes, and there’s so many different factors that come into play as far as that sort of thing is concerned. I'm not sure that there is just one thing that we could put in place that is going to be technology is going to make their day more enriched or anything like that.* [Barry]

Client Challenges

Interviewees spoke of the challenges faced by aged care clients when using new technologies. In some cases, these challenges were attributed to a lack of familiarity with using technology. In others, interviewees noted that technology deployment could be challenging because of frailty and cognitive decline, especially in residential care settings:

> *I don’t think the technology is the barrier, I think the barrier is the change in residential care. You know 20 years ago our average age of a resident was probably about 75. And that person was scooting about, helping cook meals, do some cleaning and assisting around the place. People are now starting to stay home a lot longer. And...once they come into residential aged care, they’re there simply because they’re at a point where they can't look after themselves...They come in [to aged care] because of issues with dementia or incontinence or things like that. They can't look after themselves or use their hands and their eye sight is going so therefore they can't cook for themselves or clean themselves so therefore using interactive technology becomes a little bit more difficult.* [Barry]

The interviewees also expressed concerns that the sensory experience of VR may not be appropriate for people with dementia. Barry commented that VR can *displace* people, noting that care is required when introducing such an immersive experience. In line with this observation, Jacquie said that the care home she worked in introduced a VR program in a staged approach:

> *We decided to first trial residents who still had quite good cognitive ability...But to not necessarily use it straight away on residents living with dementia because it might be a bit too much for them in the beginning. [Interviewer: Why do you think it is too much for people with dementia?]. I think the sensory experience.* [Jacquie]

For Claire, a further challenge is that clients could experience strong emotional responses when using technology for communication and reminiscence. Although this was often a positive aspect of using technology, there were concerns about the risk of *retraumatizing* clients by “going back to a place or something that might have [a bad] memory.” This concern was not limited to reminiscence activities but extended to situations in which technology was used to facilitate communication with loved ones, which could sometimes be upsetting for clients. Claire carefully monitored these activities:

> *One time I had an experience where this lady...she was in her late 80s and she had a daughter who was only 60, who developed early-onset dementia. So her daughter was in a nursing home and she was in a nursing home. Her daughter was really bad in comparison to this lady, she was quite advanced...So we used to Skype because she wanted to see her daughter because she couldn’t physically see her...My resident on my side, she got very upset seeing her daughter all the time and she kept saying “it’s not fair...” I actually said to her, “Look, wouldn’t you rather not do this?” and she said “look, despite it being so difficult I do want to do this because I just want to make sure she’s alright.*” [Claire]

For Claire, this example emphasized how important it was for staff members to be highly skilled in facilitating communication activities for clients. The skills required extended beyond being able to help clients use technology:

> *If you don’t really understand deep listening and good communication and be able to listen to that and be open to the emotional and spiritual work which the meaning making needs I think you could in some ways do harm.* [Claire]

Using technology for enrichment then required considerable practical and emotional support, usually provided by care staff and volunteers.

Limited Organizational and Staff Support

Interviewees noted that it was crucial to have organizational support, especially support from care staff. Frank, a volunteer who conducted individual VR sessions with aged care residents, said that a lack of staff support was a significant challenge for him:

> *The biggest challenge I get is pushback from staff. They have their day planned out for this resident. And quite frankly if they can get a resident into [a group] activity it makes their life easier. They are ignorant of the benefit of this sort of stuff.* [Frank]

In many cases, technologies were incorporated into the activities program offered in residential care homes, and staff running these programs needed to have the skills, capacity, and willingness to use technology. Eric, a technology service provider, said the following:

> *Probably the biggest challenge is getting a routine around an activities calendar...The VR headset especially, they are a bit fiddly to use at the moment so it takes someone with a bit of specialist knowledge to set it up and have it working in a way that the residents can use it, and because it can be a bit*

> *difficult it doesn’t always get incorporated into the activities schedule.* [Eric]

Ian, also an IT service provider, noted similar constraints that affected his program:

> *The demographics of people that generally work in aged care did struggle with technology too. Even iPads. We were pretty early on introducing iPads in the organisation and in terms of lifestyle and entertainment type activities. But staff, they struggled with them. Some of them were flat out scared with it, and even just the organisation and support from management were not necessarily there.* [Ian]

Ian went on to say that there was an “overall inability” within aged care organizations to “do what other people would take as everyday bread and butter IT.” Del suggested that there needed to be a “cultural shift” within organizations, including support from “middle management,” to ensure that technologies were included in the activities program and incorporated into routine care work. Similarly, Graham, a technology provider, noted that “on the ground” support was crucial. Participants claimed that the success of a technology program typically depended on the staff at each aged care home:

> *The on the ground part is so critical because it can either succeed or fail on that...Basically they [management] can make a decision across a group - so we’ve got one provider that we work closely with and they're rolling it out across six of their homes...From a head office [perspective], they’ve said “yes, we are rolling out,” but then based on each site it is so dependent on the make up of the staff there and turnover as well.* [Graham]

Resistance From Families

In addition to support from staff and management within aged care organizations, interviewees noted that family support was also crucial. Resistance from family members created a barrier that made it difficult for some technologies to be accepted within the aged care setting and limited the benefits the technologies could provide. In the case of robot pets and VR, interviewees noted that family members sometimes saw these as *toys* or *games* that were inappropriate for their loved ones:

> *We’ve looked at things like the furry seal and so on, but...haven't had the acceptance by residents and I don’t think it’s the residents so much, I think it’s been the family rejection of the things - family members saying, “oh you know my mum or my dad isn’t a child anymore why are you giving them these toys to play with?” Which is sad...but that's something that we have found.* [Barry]
>
> *Occasionally [a challenge] was family members didn't want their loved one to be involved in it. I think that was also that sort of fear thing. “Why would I want my mother playing with a seal?” Or “she doesn't need to look at virtual reality” I think they were scared of the technology.* [Ken]

In the case of using video calls to connect older people with their family and friends, the connection could only be established with the active participation of family members. In some cases, interviewees observed that although clients were eager to connect with their families, it was not always possible to establish this connection:

> *I think video calls are as good as anything in connecting people, but you've got to get both sides happy with it, which is why I'm getting frustrated with my client that I want to get connected to his daughter, but I just can't get her phone number...Whether there’s a family feud there, I don’t know.* [Ken]

A lack of family support was not a universal challenge. Other interviewees described positive experiences, with technology-based activities sometimes providing new opportunities for family members to connect with those living in aged care or learn new things about their loved ones’ lives. However, when family members were not engaged in the programs or when they actively disapproved of the decision to use certain technologies, this created tension that could prevent the ongoing use of technology for enrichment in aged care.

Discussion

Principal Findings

This study aimed to understand how technologies are used to enrich the lives of people living in aged care and identify lessons for good practice in this area in the future. The survey and interview findings provide insights into the types of technologies being used in the Australian aged care sector before the advent of the COVID-19 pandemic. These included VR, videoconferencing, and entertainment tools such as YouTube. In terms of perceived value, there were mixed responses for the emerging technologies of VR, robot pets, and social robots. Others such as videoconferencing were viewed more favorably.

Despite mixed views about its perceived value, VR was the most common technology used by our respondents. This finding aligns with the growing research interest in the use of VR in aged care [13,25,30-33]. Studies have demonstrated that VR can be valuable as a calming tool for people with dementia [21], as a tool to support reminiscence in aged care [13], and as a way for people with dementia to enjoy experiences such as attending a concert [34]. Conversely, recent studies have identified usability issues for residents [13,30] and highlighted challenges for staff in implementing VR in aged care [31]. This tension between benefits and challenges was evident in our interviews. On the one hand, we heard compelling stories about the use of VR for virtual travel and reminiscence. On the other hand, interviewees were cautious about the challenges of using VR with aged care clients who are often frail and may experience confusion when confronted with the immersive sensory experiences offered by VR.

Notably, our participants were mostly using off-the-shelf or commercially available technology rather than bespoke apps. For example, videoconferencing provided social connections, tablets and mobile phones provided entertainment, and YouTube and Google Earth provided an easy way to revisit places and connect with past interests. This contrasts with many previous studies evaluating the use of technologies in aged care settings, which have focused on systems designed specifically for use in a particular aged care context [35-37]. Numerous studies have reported evaluations of robot pets, such as Paro, the seal [28], and other social robots designed to provide companionship or lead social activities in aged care [10]. Given this extensive research, it is surprising that of the 20 survey respondents, only 5 (25%) said they had used social or companion robots, and there were limited discussions about robots in the interviews.

Our analysis of interviewees' stories identified 4 kinds of enrichment experiences or social and emotional benefits for clients. Participants described using a range of technologies that enhanced clients' social engagement, enabled clients to *leave* the care home, provided opportunities to reconnect with personal interests, and provided entertainment and distraction. All of these involved providing personally meaningful and individual experiences. One of the key constraints of residential aged care is that it can be difficult to provide residents with choice and agency over the activities they are involved in [3]. When used effectively, technology-based activities could help address this need, thereby enhancing agency and control for people living in aged care [33]. However, this may be difficult to achieve in practice. Our findings show that to use technology effectively, care and technology providers need to overcome many challenges, including resource constraints, selecting appropriate devices and apps, client challenges, limited organizational and staff support, and resistance from families.

Lessons for Deploying Technology for Enrichment in Aged Care

Our interview findings paint a picture of the sociotechnical context that needs to be considered when introducing new technologies into aged care settings, including personal, technological, and social or organizational issues [18]. In the next section, we discuss 3 lessons that can be distilled from our findings, each aligned with an element of this sociotechnical context.

Lesson 1: A Person-Centered Care Approach Is Crucial

To create meaningful enrichment experiences, a person-centered care approach is crucial. Aged care activities are often designed in a *one-size-fits-all* model. However, our findings suggest that technology-mediated enrichment activities work best when designed to cater to individual interests and needs. By tailoring activities to meet the needs of individual clients, our participants were able to elicit moments of joy, such as the "whooping and hollering," which Frank witnessed when he introduced a client to the Formula 1 VR experience.

Notably, our participants spent considerable time getting to know individual clients and understand their needs before introducing technology. For instance, the Formula 1 activity was only introduced after Frank asked the client what his dreams were. Another interviewee, Graham, said that providing personalized connection requires conversation with clients about what they need. Claire also observed that it was crucial for caregivers to listen to and talk with clients to choose technology-based activities that provided personal enrichment.

In addition to meeting individual needs, interviewees were careful to consider their clients' physical and cognitive health when making decisions about introducing technology to individual clients. For instance, interviewees were cautious about introducing technology to aged care residents who were frail or had advanced dementia, conditions that contribute to the complexity of residential aged care [38]. This caution highlights the gatekeeping role that care providers can have in choosing who will experience a technology-based activity [19]. Gatekeeping can be viewed as a paternalistic approach to care and therefore conflicts with the goal of providing aged care clients with agency and control. However, it may be required to ensure that the technologies provide benefits and do not cause harm. Indeed, understanding an individual's needs and preferences means knowing when a technology-based activity may not be the best solution [18]. Adopting a person-centered care approach then means accepting that a one-size-fits-all approach is not suitable when deploying technology for enrichment in aged care, despite the efficiency challenges this creates in an organizational setting.

Lesson 2: Enrichment Experiences Can Be Created Using Available Technologies, but They Need to Be Carefully Selected and Co-Deployed With Aged Care Clients

Building on the need for a person-centered approach, our findings suggest a need for *co-deployment* of technologies in the care settings in which they are used. We use the term *co-deployment* to refer to collaboration between providers and users when choosing to use, or deploy, particular technologies. This is similar to, but moves beyond, the notion of *co-design*. A study by Wherton et al [39] used the term *co-deployment* to refer to "the mutual shaping of technologies 'in-use'," arguing that "older people, their carers, service providers and technology designers must be able to work together to shape technologies and services over time."

Our findings suggest that in residential care settings, co-deployment starts with choosing to introduce technologies that align with people's needs, interests, and values. It may not be necessary to design bespoke technologies to meet these needs; instead, caregivers can use available technologies to design technology-mediated enrichment experiences. As noted earlier, many of the experiences our interviewees described were enabled by the use of commercially available technologies rather than bespoke tools or technologies specifically designed for use in aged care. Therefore, our findings suggest that there is a wide array of commercially available tools and apps that can be used to provide social and emotional enrichment in aged care settings. However, these tools need to be carefully selected and deployed as they are not usually designed with aged care clients in mind and may not always meet their needs.

Furthermore, our participants noted that some technologies, despite being designed for use in aged care, may not align with people's values or address people's needs for social connection. They were critical of the artificial intelligence devices being used as digital companions, refuting the notion that a conversational agent might provide companionship. This is in contrast to some of the recent research on the use of voice assistants and robot devices that suggests they can provide a sense of companionship [40]. However, recent research also notes that older adults find the concept of digital companionship to be a threat to their sense of dignity; the idea of having a robot pet in the future can be quite confronting [41]. This aligns with our survey responses. As with VR, respondents expressed mixed views about the perceived value of robot pets and social robots. The comments indicated that respondents believed these technologies did not align with human values. They were seen, for instance, to be *spooky* and *child-like* and were not seen to foster *real* personal connections. Despite these comments, however, other research has shown that robot pets, such as Paro, can bring joy and provide a sense of calm for people with dementia [8,42,43]. Indeed, one of our interviewees made a similar observation about Paro, noting its value in providing distraction and reducing agitation.

These divergent views and experiences again emphasize that a one-size-fits-all approach may not be appropriate. Some technology-based activities will work well with some clients because there is a careful match between the person's values, interests, and needs and the activity being introduced. However, the same technology or activity may not work effectively for others. For instance, the technology may be too difficult or uncomfortable to use for someone who is frail, it might support an activity that is not of interest to the person (eg, a robot that leads a game of bingo will not appeal to some people), or it may be experienced as demeaning. This points to the need both for a person-centered care approach (lesson 1) and a collaborative process of co-deploying technologies that are carefully selected from the array of tools available to meet the needs of individual clients.

Lesson 3: The Organizational Context Can Be a Barrier to Effectively Using Individual Technology-Based Activities in Psychosocial Care

Many of the challenges and barriers identified by our interviewees were related to the social or organizational context in which the technologies were being used. Aged care is a complex setting, particularly residential care, where clients are often frail and highly dependent on care [38]. In Australia, the context in which this study was conducted, aged care has been under scrutiny, with a Royal Commission recently highlighting significant neglect, underresourcing, and poor staff-client ratios [44].

This aligns with our interviewees' observations about the challenges of implementing new technology-based activities when care staff have limited time and resources. Technology-based activities require staff time to learn new skills and introduce activities with care and attention to the needs of individual residents. Resource constraints also affect the funding available to purchase and maintain new technologies, which require significant investment, especially when deployed at a scale for use with multiple clients in a residential facility. Technologies date quickly and may need to be updated or replaced regularly. They also require communication infrastructure, such as wireless networks. Previous research has shown that this can be a barrier; although Wi-Fi is taken for granted in many organizations today, it may still be unavailable in some aged care homes [20]. Similarly, one of our interviewees noted that IT skills taken for granted in other organizations may be absent in the aged care workforce.

Another important element of the organizational context is the norms and routines embedded in an aged care home, with many homes providing a full calendar of organized events on a daily basis [2,45]. These are often group activities. Previous research has shown that staff consider group activities to be a more efficient use of their time than one-on-one activities [5]. This creates a significant barrier for the use of technologies, such as VR and videoconferencing, which typically require one-on-one facilitation by a care provider. Other technologies, such as robot pets, have been used extensively in group settings [8]. However, our study showed divergent views on the value of robots in providing social and emotional enrichment in aged care.

One potential solution to these challenges is to establish a network of volunteers who can work on a one-on-one basis with aged care clients. Such volunteers, however, need to be well supported by staff and management within the care home. Another solution is to use external consultants and organizations that specialize in introducing technology into aged care homes. Some of the interviewees were IT providers from these organizations. Although external consultants may fill an IT skills gap in aged care, there is a need for caution to ensure that such external providers are fully aware of the needs and concerns of aged care clients. Our research showed that combining care and technology requires sensitivity and expertise across multiple domains.

Limitations and Future Work

First, our study had a small sample size. In particular, we received only 20 responses to our survey, which limits the generalizability of our findings. However, aged care workers are a hard-to-reach group, and those who use technology for client enrichment have specialized expertise. Given the focus on this expertise, a small sample size may be sufficient to provide *information power* [46], especially for in-depth qualitative research.

Second, we focused only on the Australian aged care sector. Care programs in other countries may make use of technology in ways not covered by this study or may have other kinds of constraints not mentioned by our sample. Future work with other samples should be conducted to confirm and extend our findings.

Third, this study did not include the perspectives of older adults themselves or their family members. Previous research has focused on the views and experiences of older adults and family members in evaluation studies of technologies in use in aged care [13,33,35]. In this study, however, we aimed to gain a better understanding of staff experience. In aged care settings, technology-based activities are often facilitated by staff members. Their perspectives and experiences can, therefore, be valuable for understanding what works and does not work well when introducing technology for enrichment in aged care. However, future research in this area should consider the perspectives of all stakeholders, including older adults, family members, and people working in aged care.

Finally, the data for this study were collected before the onset of the COVID-19 pandemic. The use of technology is likely to have expanded following the COVID-19 pandemic, given that aged care homes worldwide had to introduce videoconferencing for family visits and consultations by health specialists [47]. Restrictions brought in to curb the spread of the virus left many older people in aged care more isolated than before [48,49]. This is likely to have increased the need for technologies to maintain social connections. During the COVID-19 pandemic, it has become essential for aged care organizations to use videoconferencing to enable their clients to stay connected to family members and friends [50]. However, it is uncertain whether aged care organizations were prepared to rapidly introduce technology to meet their clients' social needs during the COVID-19 pandemic. Future work should study the experiences of technology providers during the pandemic to explore what has changed and whether new kinds of technology use have emerged in response to societal restrictions.

Conclusions

This study showed that a person-centered care approach is required to create personally meaningful and enriching technology-mediated activities in aged care. Although a range of technologies is available, they need to be co-deployed in response to individual needs and interests. However, this requires considerable one-on-one attention and care from staff and volunteers who facilitate the activities, which, given the resource constraints in the aged care sector, may become a barrier to ongoing use. To successfully deploy technologies for enrichment in aged care, significant changes may be required within the aged care sector and within organizations to allow caregivers to facilitate individual technology-based activities to create meaningful enrichment experiences for clients.

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Authors' Contributions

JW conceived and designed this study. JW and ER collected data. WZ and JW conducted data analysis. WZ, JW, and RMK drafted the manuscript. All authors provided input for the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey questions.
[PDF File (Adobe PDF File), 69 KB - aging_v5i2e31162_app1.pdf]

Multimedia Appendix 2
Interview questions for aged care staff.
[PDF File (Adobe PDF File), 124 KB - aging_v5i2e31162_app2.pdf]

Multimedia Appendix 3
Interview questions for information technology staff.
[PDF File (Adobe PDF File), 122 KB - aging_v5i2e31162_app3.pdf]

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Abbreviations

IT: information technology
VR: virtual reality

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Original Paper

Perceptions of In-home Monitoring Technology for Activities of Daily Living: Semistructured Interview Study With Community-Dwelling Older Adults

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Abstract

Background: Many older adults prefer to remain in their own homes for as long as possible. However, there are still questions surrounding how best to ensure that an individual can cope with autonomous living. Technological monitoring systems are an attractive solution; however, there is disagreement regarding activities of daily living (ADL) and the optimal technologies that should be used to monitor them.

Objective: This study aimed to understand older adults' perceptions of important ADL and the types of technologies they would be willing to use within their own homes.

Methods: Semistructured interviews were conducted on the web with 32 UK adults, divided equally into a *younger* group (aged 55-69 years) and an *older* group (≥70 years).

Results: Both groups agreed that ADL related to personal hygiene and feeding were the most important and highlighted the value of socializing. The *older* group considered several activities to be more important than their younger counterparts, including stair use and foot care. The older group had less existing knowledge of monitoring technology but was more willing to accept wearable sensors than the younger group. The younger group preferred sensors placed within the home but highlighted that they would not have them until they felt that daily life was becoming a struggle.

Conclusions: Overall, technological monitoring systems were perceived as an acceptable method for monitoring ADL. However, developers and carers must be aware that individuals may express differences in their willingness to engage with certain types of technology depending on their age and circumstances.

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KEYWORDS

aging; wearable sensors; environmental sensors; social robots; activities of daily living; aging; older adults; elderly; robots; wearables

Introduction

Background

The global population of people aged ≥60 years is projected to increase to >2 billion by 2050 [1]. In the United Kingdom alone, one-quarter of the population is expected to be aged ≥65 years by 2050 [2]. Although modern medical care has facilitated this rise in life expectancy, it has also increased the length of time that individuals are likely to require long-term care [3]. Often, the systems in place to provide this care are poorly equipped to do so in an effective manner [4]. A potential solution to this may be to create smart environments that support older adults' ability to live independently in their own homes, which would reduce the need for care home facilities and allow them to focus on those with the most severe difficulties [5]. Moreover, many older adults prefer to remain in their own homes for as long as possible [6]. To determine their suitability for home care, if needed, an individual is assessed on their activities of daily living (ADL) performance [7].

ADL are any of the activities that are fundamental for an individual to live independently [8]; for example, feeding, washing, and mobility. Several scales and methods can be used to assess ADL function, including a variety of activities ranging from the very basic to more complex activities (instrumental ADL [iADL]) [9]. One of the key scales that is often used because of its inclusion of both basic ADL and iADL is the Groningen Activity Restriction Scale (GARS) [10]. However, it has been proposed that these scales may lack accuracy and objectivity; therefore, technological solutions have been proposed as alternative methods for assessing ADL [9]. It has been suggested that encouraging the use of monitoring technology may help to maintain the levels of autonomy [11], allow older adults to acknowledge their own needs in terms of assistance [3], and help caregivers to provide interventions or assistance at the most appropriate time or at a suitable level for the individual [12].

Despite their potential, many older adults are unaware of the existence of monitoring technology; therefore, they are seldom used [11]. Monitoring technologies can typically be divided into 2 broad categories.

- Wearable sensors are sensors with some physical attachment to a person, such as a wrist-worn device [9].
- Environmental sensors are sensors placed around the home with which a person does not necessarily need to have any direct interaction but which will monitor activity within a room, such as a motion sensor [9].

Of those who are aware of the technology, there is often a reluctance to embrace it, which may be because of diminished openness to new experiences or feelings that the technology may be too advanced for their abilities [13]. However, few studies have focused on older adults' perceptions of the monitoring technology; therefore, the reasons for their limited use remain unclear. A comprehensive study of technology aimed at assisting older adults in their own homes, which included some monitoring technology [11], found that although technology may offer some solutions, it is not yet well-integrated into the daily care of older adults and is less accepted, especially among older adults (aged ≥65 years). These findings are echoed by Berridge and Fox [14], who found that adult children were more willing to use technology than their older parents, although older adults were able to comprehend their use. A review of fall-monitoring technology [13] noted that older adults approach technology differently than their younger counterparts but are showing increasing rates of adoption. Therefore, continually questioning the utility and acceptance of new technologies remains relevant [11].

In the studies by both Berridge and Wetle [14] and Verloo et al [11], the older adults were already in need of some form of home care, which implies that they were in a state of decline. The aim of many specific ADL monitoring systems is to identify individuals before they reach this stage [9]. Therefore, there is a need to understand the perceptions of both *younger* older adults—those who are less likely to require assistance at the time of installation—and *older* older adults who may already be experiencing some form of physical or cognitive decline. It is anticipated that by engaging with older adults and understanding their perspectives on the activities that they consider important to live, as well as their opinions on the types of technologies that can monitor them, future developments in this area will be better accepted by the older adults who they aim to help.

Objectives

This study aimed to understand the perceptions of both *younger* older adults (aged 55-69 years) and *older* older adults (≥70 years) related to ADL monitoring technology and the activities that they should monitor.

Theoretical Framework

This study was guided by the theoretical framework developed by Peek et al [15] and subsequently used by Verloo et al [11]. This framework provides us with some basic foundational components that have been shown to influence community-dwelling older adults' acceptance of technology, including perceived concerns, perceived benefits, and older adult characteristics.

Methods

Design

This study used a qualitative design to collect data on the perceptions of older adults using one-to-one and photo-elicitation interviews (PEIs). Reporting on the study was based on a checklist for explicit and comprehensive reporting of qualitative studies [16].

Population and Settings

This study included community-dwelling older adults aged ≥55 years. All participants lived in the United Kingdom without a medical prescription for home care. All interviews were conducted on the web using the video call software Microsoft Teams (1/33, 3%), Zoom videoconferencing (24/33, 73%), WhatsApp (6/33, 18%), and Facebook Messenger (2/33, 6%).

Participant Recruitment

Participants were recruited through social media and email contact from charity groups, including Age UK and the University of the Third Age. To be included, participants had to be aged ≥55 years, be able to live independently in the community without receiving specific home care, and have access to a form of video call software. Participants were divided into 2 groups: *younger* (aged 55-69 years) and *older* (aged ≥70 years).

Ethics Approval

This study was approved by the institutional human research ethics committee (18/19–75V2).

Data Collection Procedure

Data were collected between July 21, 2020, and February 2, 2021. Older adults who expressed interest in participating via social media platforms and through email contact with older adult charity groups, including Age UK and the University of the Third Age, were contacted and provided with written details of the study. Once they were given an opportunity to reflect on the study requirements, a date, time, and video call software were agreed upon. On the day of the interview, the interviewer verified that participants understood the information that had been provided to them and gained verbal consent that they were happy to continue with the interview. Data collection used 14 photographs of relevant technologies and a semistructured interview guide (Multimedia Appendix 1). Interview audio was recorded for subsequent transcription.

Data Collection Instruments

Overview

The research team developed and tested semistructured interview guides and PEIs (Multimedia Appendix 1). These guides used open-ended questions to encourage participants to discuss their thoughts on ADL and monitoring technologies (wearable and environmental-based systems). The interviewer had the freedom to reformulate, reorganize, or clarify questions during the interviews to gain a deeper understanding of the community-dwelling older adults' thoughts and opinions. The guidelines were divided into 2 broad categories: ADL and monitoring technologies.

ADL Instrument

Participants were asked, "What activities do you consider fundamental to your daily life?" and then showed the activities included in the GARS. They were asked to rank these activities on a scale of 1 (low importance) to 5 (high importance) and encouraged to explain their decisions. Following this, they were asked whether there were any activities they felt were important but not included in the GARS and asked to describe what they thought would make these ADL difficult to perform in the future.

Monitoring Technology Instrument

Information was collected primarily using PEIs, where participants were shown image examples of wearable and environmental sensors during their interviews (Multimedia Appendix 1). They were asked whether they had any awareness of each technology type, and then, the purpose of each was explained. Participants were asked the following: "What do you like/dislike about the technology shown here?"; "What do you think the benefits of using this technology to monitor activities of daily living might be?"; and "What concerns do you have with the use of these types of technology?"

Data Analysis

We recorded 18 hours and 32 minutes of interviews and PEIs (mean 42, SD 12 minutes). All interviews were transcribed verbatim from the audio recordings. The data were analyzed using a realist thematic analysis approach [17]. One of the key advantages of this approach is the appreciation of both quantitative and qualitative data, which can be gathered from interviews [18,19]. A total of 3 authors (NC, DM, and JJ) were involved in the analysis of the transcripts, with a collective discussion to finalize the included codes.

The first interview transcription was analyzed, and initial codes were identified, which were then grouped and refined into themes. Using a deductive approach, the second interview was analyzed, similar themes were identified, and additional themes were added. This process was continued for each interview transcript, each time adding or refining the existing themes. By adopting this data-driven approach, it was possible to continuously test the truth of emerging themes, allowing some quantitative aspects of this research to be obtained simply. The realist thematic approach allows quantitative-type information to be collected, such as the frequency of a theme (indicating strength) and the number of participants expressing similar thoughts or experiences (indicating prevalence) [17]. After all the interviews were analyzed, the list of themes was checked and compared with another investigator to identify any disparities between them. If any disputes arose, the original transcript was checked, and the dispute was settled through discussion between the researchers. The data were stored and analyzed using Microsoft Excel (Multimedia Appendix 2).

Results

Samples and Sociodemographic Data

This study included 33 community-dwelling older adults from the United Kingdom; 17 (52%) *younger* and 16 (48%) *older*. The younger group comprised 17 community-dwelling older adults (n=9, 53%, women and n=8, 47%, men) aged 55 to 67 (mean 61.9, SD 4.0) years. The older group comprised 16 community-dwelling older adults (n=9, 56%, women and n=7, 44%, men) aged 70 to 81 (mean 74.0, SD 4.5) years.

Findings

Overview

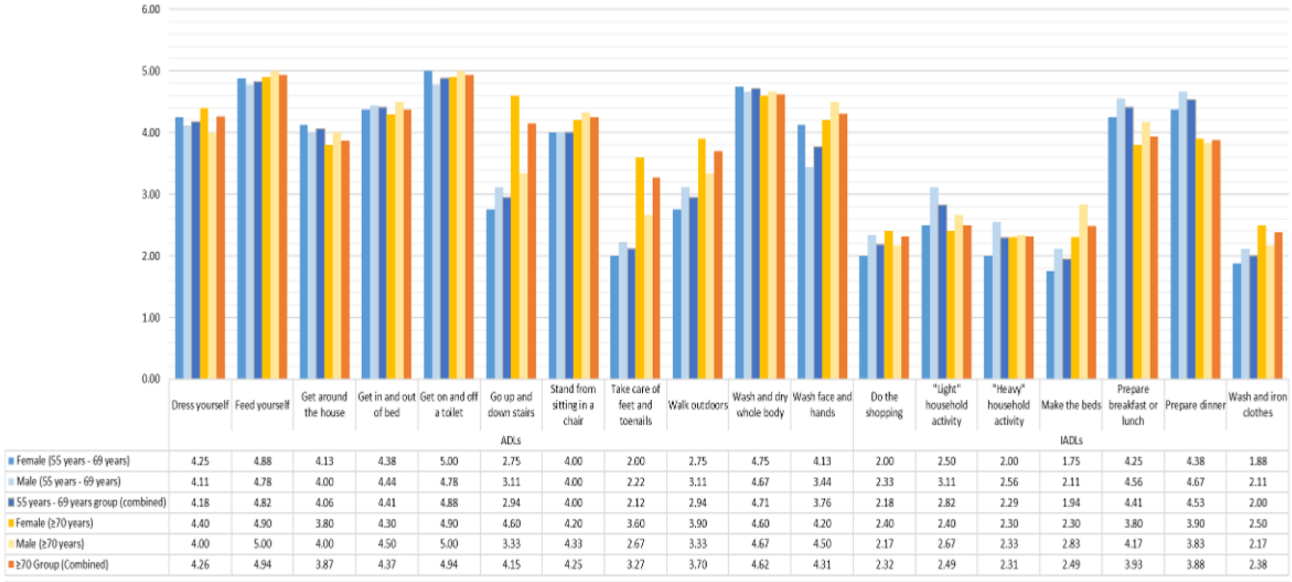
We have divided the description of our results into two main sections: *ADL Findings* and *Monitoring Technology Findings*. *ADL Findings* include (1) factors that influence the perceived importance of GARS activities, (2) additional activities, (3) factors that may influence ADL performance, and (4) factors that influence the acceptance or rejection of assistance in performing ADLs. *Monitoring Technology Findings* is divided into three subcategories: (1) general monitoring systems, (2) wearable sensors, and (3) environmental sensors. Within each of these, the results are further divided into factors influencing potential acceptance, potential advantages, and potential disadvantages. Participants did not highlight any general disadvantages but made some suggestions for future development, which are given at the end of this section. An example quote for each identified element is provided, along with an indication of how many participants shared the same sentiment. More examples can be found in the accompanying Microsoft Excel file (Multimedia Appendix 2). The sample size included in this study was not large enough to accurately provide statistical differences between groups. However, the realist approach to the adopted analysis allows quantitative data to indicate the strength and prevalence of participants expressing similar thoughts or opinions [17].

ADL Findings

Factors That Influence Perceived Importance of GARS Activities

The perceived importance of the GARS activities is summarized in Figure 1. In general, ADL received higher importance overall than iADL, except for iADL related to food. Both the younger and older groups ranked *get on and off toilet*, *feed yourself*, and *wash and dry whole body* as the most important ADL. The ≥70 years group placed more importance on *go up and down stairs*, *take care of feet and toenails*, and *walk outdoors* than the 55 to 69 years group, especially women. The 55 to 69 years group placed more importance on *light household activity*, *prepare breakfast or lunch*, and *prepare dinner* than the ≥70 years group. *Make the beds*, *do the shopping*, and *wash and iron clothes* were considered of the lowest importance, especially in the 55 to 69 years group. The statements provide some greater context relating to why activities were deemed *high importance* or *low importance*.

Figure 1. Relative importance of Groningen Activity Restriction Scale activities.



	Dress yourself	Feed yourself	Get around the house	Get in and out of bed	Get on and off a toilet	Go up and down stairs	Stand from sitting in a chair	Take care of feet and toenails	Walk outdoors	Wash and dry whole body	Wash face and hands	Do the shopping	"Light" household activity	"Heavy" household activity	Make the beds	Prepare breakfast or lunch	Prepare dinner	Wash and iron clothes
	ADLs											IADLs						
■ Female (55 years - 69 years)	4.25	4.88	4.13	4.38	5.00	2.75	4.00	2.00	2.75	4.75	4.13	2.00	2.50	2.00	1.75	4.25	4.38	1.88
■ Male (55 years - 69 years)	4.11	4.78	4.00	4.44	4.78	3.11	4.00	2.22	3.11	4.67	3.44	2.33	3.11	2.56	2.11	4.56	4.67	2.11
■ 55 years - 69 years group (combined)	4.18	4.82	4.06	4.41	4.88	2.94	4.00	2.12	2.94	4.71	3.76	2.18	2.82	2.29	1.94	4.41	4.53	2.00
■ Female (≥70 years)	4.40	4.90	3.80	4.30	4.90	4.60	4.20	3.60	3.90	4.60	4.20	2.40	2.40	2.30	2.30	3.80	3.90	2.50
■ Male (≥70 years)	4.00	5.00	4.00	4.50	5.00	3.33	4.33	2.67	3.33	4.67	4.50	2.17	2.67	2.33	2.83	4.17	3.83	2.17
■ ≥70 Group (Combined)	4.26	4.94	3.87	4.37	4.94	4.15	4.25	3.27	3.70	4.62	4.31	2.32	2.49	2.31	2.49	3.93	3.88	2.38

In general, of the 33 participants, the activities considered *high importance* related to maintaining physical function, as described by 10 (30%; younger woman, n=1, 10%; younger men, n=2, 20%; older women, n=5, 50%; and older men, n=2, 20%) participants:

> *If you can keep yourself active then, through things like getting in and out of bed and, you know...or on the toilet, or getting off the toilet, then it all comes, you know, under that one umbrella, so to speak, of keeping yourself active* [027BB]

Alternatively, the activities considered of *high importance* were because of existing conditions, explained by participant 010BC (younger man, 1/30, 3%) as follows:

> *I'm diabetic, I have to keep an eye on it [taking care of feet and toenails]—you know, your feet are quite important* [010BC]

Of the 33 participants, many participants viewed the relationships between activities as an important factor, such as getting in and out of bed for 5 (15%; younger man, n=1, 20%; older women, n=2, 40%; and older men, n=2, 40%) participants, getting in and out of a chair for 5 (15%; younger men, n=3, 60%; older women, n=1, 20%; and older man, n=1, 20%) participants, moving around the house for 1 (3%; older woman) participant, taking care of feet and toenails for 4 (12%; older women, n=3, 75%, and older man, n=1, 25%) participants, light household activity for 1 (3%; younger man) participant, and shopping for 2 (6%; younger woman, n=1, 50%, and older man, n=1, 50%) participants:

> *well getting out of bed is, you've got to do that to do everything else* [029MG]

> *I mean standing up from sitting in a chair, again, you're not going to be very independent if you can't do that* [021GD]

> *you have to do everything—you need to be able to [move around the house] to do everything else* [006BR]

> *if you've got problems with your feet you won't be able to [do] much of the other stuff* [013MB]

> *it's all about having clean crockery for use in the kitchen—you can't cook for yourself without clean crockery so that goes with preparing food and feeding yourself...I mean I could eat off a dirty plate if I couldn't wash up, it's just not healthy* [032TB]

> *it's still important [shopping] because I think you need to get out and socialise as well don't you, the older you're getting.* [012SH]

Of the 33 participants, the ability to perform the shown ADL was linked to the idea of maintaining pride and dignity, especially among the younger group, as mentioned by 12 (36%; younger women, n=4, 33%; younger men, n=4, 33%; and older men, n=4, 33%) participants:

> *it's anything that takes that confidence away, and your self-esteem, it just rips it apart...it's just demoralising, [performing ADLs] is vitally important because if you are dirty, or smelly, you just don't feel nice about yourself.* [024SK]

Of the 33 participants, walking outdoors was considered an important activity because of its relationship with mental health in both the younger and older groups, as described by 7 (21%; younger woman, n=1, 16%; younger men, n=4, 67%; older woman, n=1, 17%; and older man, n=1, 17%) participants:

> *"walk outdoors" I think is essential for mental health, but it's not absolutely necessary...I think it's essential for mental health but, er, not for existing* [019GW]

Of the 33 participants, regarding low-importance activities, the acceptance of assistance, either mechanical or human, was a key factor, as described by 12 (36%; younger women, n=5, 42%; younger men, n=4, 33%; older men, n=3, 33%) participants:

> *With things like the household activity and the ironing, if I got to the stage where I couldn't do that I would pay somebody to do it, so I don't regard that as a heavy priority because—the same as do[ing] the shopping, I mean we've been having food, um Tesco, deliveries so I don't regard them as a big thing because you can get somebody else to do it couldn't you. Same as make the beds* [007JR]

For some of the 33 participants, some activities were less important as they were considered autonomous, as described by 4 (12%; younger men, n=2, 50%, and older women, n=2, 50%) participants:

> *and of course, getting in and out of bed and making beds, well you just do these things automatically without even thinking about it* [018CW]

Of the 33 participants, some activities were considered less important as they had little impact on everyday function, as described by 8 (24%; younger woman, n=1, 13%; younger men, n=3, 37%; older women, n=3, 37%; older men, n=1, 13%) participants:

> *One can always live in a house that is not that tidy and not, um, it's not going to affect whether you are, sort of, capable of fending for yourself. If the house gets dirtier then it's not the end of the world* [021GD]

However, several of the 33 participants noted that the specificity of the activity being considered would have an impact on its difficulty and importance; for instance, making versus changing the beds for 4 (12%; younger women, n=2, 50%; older woman, n=1, 25%; and older man, n=1, 25%) participants, meal preparation for 6 (18%; younger woman, n=1, 17%; younger man, n=1, 17%; older women, n=3, 50%; and older man, n=1, 17%) participants, and household activity for 12 (36%; younger women, n=3, 25%; younger men, n=4, 33%; older women, n=3, 25%; and older men, n=2, 17%) participants:

> *"making the beds" I think depends on how much making the beds—if you are just pulling it straight it's fine but if you are going to re-cover a duvet after its been washed, that's probably a bit too heavy for a lot of people* [019GW]

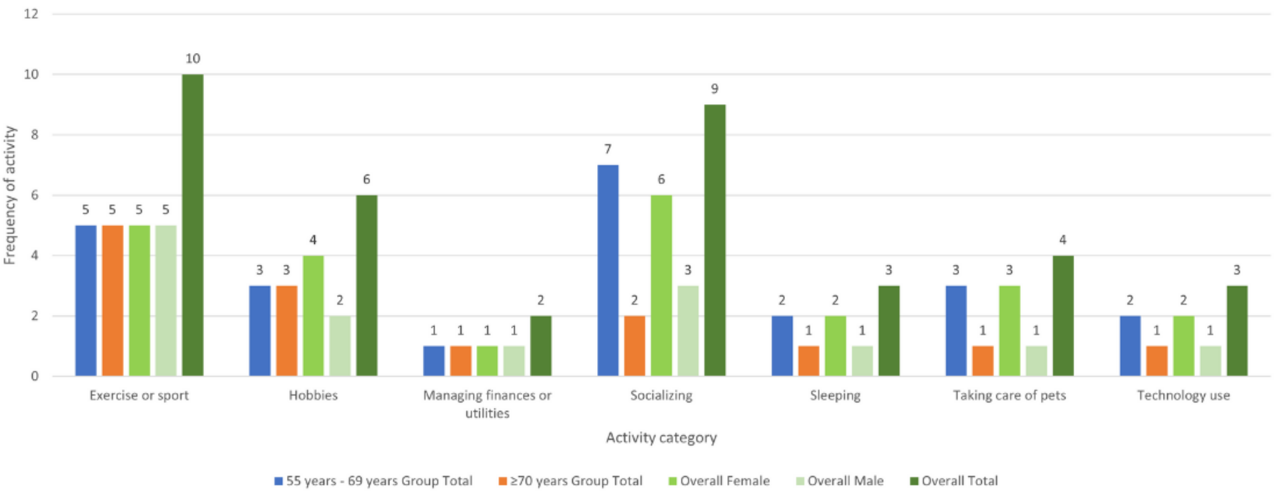
> *I mean there is slightly, but I would put them together for the purposes of this, yeah, well, because to my mind you need more motor skills to prepare dinner than you do for a breakfast or a lunch...but it needn't be [more complex] because you can always prick holes in something and stick it in the microwave* [020PP]

> *changing the bed, or turning a bed, hoovering which involves pushing, that's quite physical, um, and maybe getting the washing and hanging the washing out maybe. Or, you know, bending down to get it out of the washing machine, that's quite—I would call that heavy. But light stuff, like maybe putting the duster round or, um, like you said, a little bit of washing up, not too much of a problem* [024SK]

Additional Activities

During the interviews, the participants identified 7 extra activities that were not present on the GARS (Figure 2). Exercise or sports (10/33, 30%) and socializing (9/33, 27%) were the most frequent additional activities.

Figure 2. Frequency of additional activities. Exercise or sport refers to moderate to vigorous physical activity such as exercise classes but not walking outdoors, as this is specified in the Groningen Activity Restriction Scale. Hobbies refer to low-intensity activities, often with a social aspect, such as crafts, poetry groups, and choirs.



Exercise or sport was cited most frequently, explained by participant 008AE (older woman, 1/33, 33%) as follows:

> *I've always done yoga so I do believe that you have to use your body rather than sit in a chair and go arthritic. So I think I look at it and my attitude is a little bit different by doing yoga for a lot of years and knowing I got to keep my body mobile* [008AE]

Socializing was cited most frequently by those aged 55 to 69 years, with mental health being a commonly cited reason for its importance, explained by participant 022CB (younger woman, 1/33, 33%) as follows:

> *I think that is important because if you've got, see, people socially—*sigh*—there's nothing worse than being alone, because you get depressed...I think that ought to be mentioned, meeting people and socialising with people* [022CB]

Factors That May Influence ADL Performance

Of the 33 participants, one of the main factors that community-dwelling older adults consider to influence their ADL performance, either currently or they perceive will influence performance in the future, is their housing situation, as described by 13 (39%; younger women, n=4, 31%; younger men, n=3, 23%; older women, n=4, 31%; and older men, n=2, 15%) participants. Interestingly, for the women among the 33 participants, this was because of who they lived with and how they divided ADL between them, as described by 7 (21%; younger women, n=2, 29%; younger men, n=2, 29%; and older women, n=3, 43%) participants:

> *I'm sort of in charge in the kitchen I suppose...I cook, and he said he washes up but he means "loads the dishwasher" and he does generally do the hoover—he does generally get the hoover out, so yeah, I suppose we do things between us really, yeah.* [028PG]

In contrast, the men among the 33 participants tended to focus more on the practical environment, as described by 5 (15%; younger women, n=2, 40%; younger men, n=1, 20%; and older men, n=2, 40%) participants:

> *depending on where you live you've got to get up and down the stairs* [019GW]

Of the 33 participants, the most common influencing factor in ADL performance was physical ability, as described by 13 (39%; younger women, n=4, 31%; younger men, n=3, 23%; older women, n=4, 31%; and older men, n=2, 15%) participants:

> *it's just as your body gets weaker and your joints start to pack up, erm, I mean a lot of those—anything that requires real physical movement, they're the ones that can get difficult when you get so much older.* [025JD]

Mental health was cited as an important factor by one of the participants (younger women, 1/33, 3%):

> *because if you're depressed you don't feel like getting out of bed, but if you physically can't get out of bed, that's frustrating and, um, also it might make you feel depressed because you can't get out of bed* [024SK]

In relation to exercise, self-control was highlighted by one of the participants (younger man, 1/33, 3%):

> *I know I should be doing exercise and I know I shouldn't be eating fatty foods so, you know, it's down to me if I choose to do it or not and then it's down to me what the consequences are. I know the consequences, I know the rules so, you know, it's down to me and I should really just stick with it* [017SC]

Factors That Influence the Acceptance or Rejection of Assistance in Performing ADL

Of the 33 participants, maintenance of pride or dignity was a key factor in community-dwelling older adults resisting assistance with ADL, as well as the embarrassment of having to rely on someone else, as described by 4 (12%; younger woman, n=1, 25%; younger man, n=1, 25%; and older women, n=2, 50%) participants:

> *imagine having a complete stranger come in and have to work with you quite intimate—well, very*

> *intimate—I mean, it's just not natural, you know...You know, if you have a completely new carer come in to [do] these things for you, you haven't instantly got a rapport. I mean, you feel embarrassed...there's embarrassment because human beings do not naturally, you know, expose private actions to complete strangers* [024SK]

Cost was another factor, especially in relation to mechanical assistive technology such as stairlifts (younger woman, 1/33, 3%):

> *If you can pay for your own Stanna lift then fantastic and it wouldn't necessarily be a problem but if finance is a problem then going up and down stairs might be* [024SK]

In contrast, others stated that they would be willing to accept assistance if they physically needed it or if it would improve their ability to remain independent (older women, 2/33, 6%):

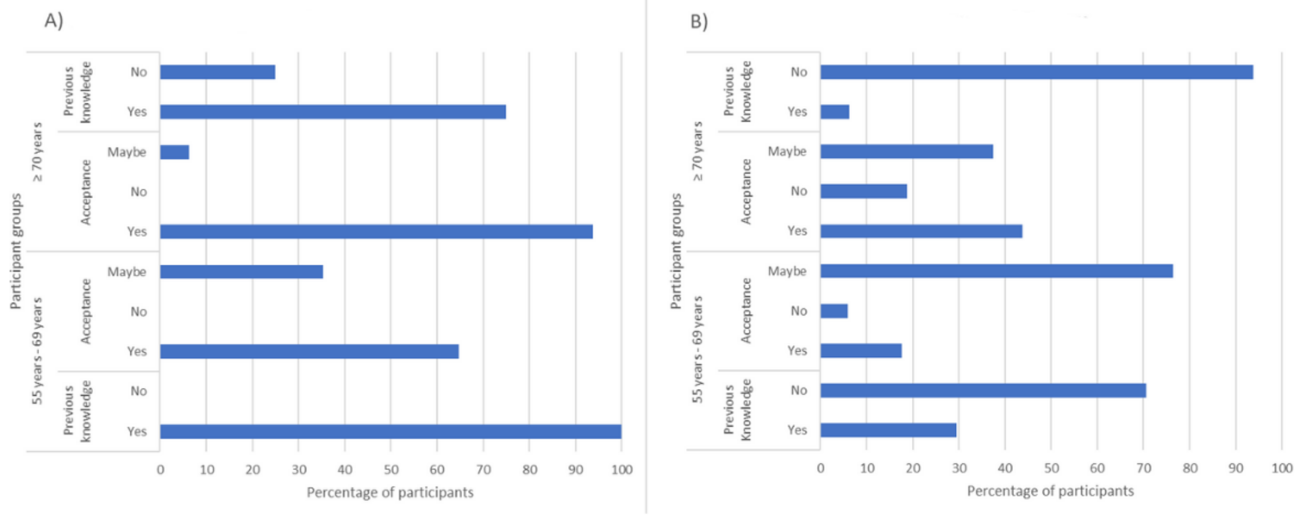
> *I've got a seat in my shower that I never use. I had that fitted—I did have that. I did say "can you fit me a seat, for when I need it," and I did—I think I used it after I had my hip done, because I thought "better be on the safe side—I'll sit on the seat."* [022CB]

Monitoring Technology Findings

Overview of Monitoring Systems in General

The existing knowledge and acceptance of wearable sensors and environmental sensors are summarized in Figure 3. Overall, the younger group had more existing knowledge of monitoring technology than their older counterparts did. When asked if they would use the technology, the older group was more likely to accept it without delay, whereas the younger group was more likely to say that they would consider using it in the future.

Figure 3. Summary of existing knowledge and overall acceptance of types of monitoring technology; (A) wearable sensors and (B) environmental sensors.



Factors Influencing Potential Acceptance of Monitoring Systems in General

Of the 33 participants, for both groups, health status and general technology acceptance were the key influencing factors for 10 (30%; younger women, n=2, 20%; younger men, n=2, 20%; older women, n=4, 20%; and older men, n=2, 20%) participants:

> *I do think that when you live alone, whatever your stage of mobility, you could fall over at any old time can't you, so...yes. A reserved yes [to having some kind of system]...because I don't like to think that I'm quite at the stage where I need it yet. But that the whole point, like, you should have them before you need them* [020PP]
>
> *I do try but I find it difficult and I think you do as you get older but I do try [using a] mobile phone and I'm trying to use the iPad. I don't say I find it easy but I have to keep trying because I think you have to learn to do these things because that's the way of the future isn't it? To have to use these gadgets* [008AE]

The younger age group mentioned experience with technology as an influencing factor when considering monitoring technology (younger women, 4/33, 12%):

> *I think a lot of it is confidence, and so many people I know who can't manage with like the portal, and the internet and all the different ways—it's because they don't have enough expertise in it. We were born in a generation where [there was] nothing like that* [016AA]

However, of the 33 participants, it was noted that this might become less of an issue in the future by 8 (24%; younger women, n=3, 23%; younger men, n=2, 15%; older women, n=2, 15%; and older men, n=1, 8%) participants:

> *I think it's the generations are getting older and they're not so worried about technology. It's just like a day-to-day thing for us but when you're sort of in your 80s now you've never been used to it."* [003MC]

In contrast to these positive influences, of the 33 participants, 4 (12%; younger women, n=1, 25%, and younger men, n=3, 75%) participants from the younger group suggested that monitoring technology is limited in its usefulness; therefore, they would be hesitant to use anything:

> *I have a bit of scepticism here because if somebody thinks they are being monitored, I mean theres the sort of "whats in it for them" and if they feel that people are just checking up on them, erm again thinking to my Mum, she would be quite canny so a device could easily be fooled.* [009JJ]

Of the 33 participants, the issue of data use was also highlighted by 2 (6%; younger woman, n=1, 50%, and older man, n=1, 50%) participants:

> *not specifically about the wearing of it, um, I think there are concerns about the whole data collection issue, and what happens with it, and how secure it is. Um, but I mean the actual, the technology I don't have a problem with. The problem lies with what people do with the information once they've got it* [013MB]

Perceived Advantages of Monitoring Systems in General

Of the 33 participants, the main advantage of monitoring systems was reassurance, especially for the younger group, who frequently considered using them from the perspective of a carer, as described by 5 (15%; younger woman, n=1, 20%; younger men, n=3, 60%; and older woman, n=1, 20%) participants:

> *Even if not necessarily for you, for your carer or family...they would be able to see if you're moving around and, I don't know if the timescale would be on it, but they would know what time you're moving about* [030DG]

Of the 33 participants, health monitoring was another advantage, especially the potential use for health care workers or as a means of supporting medical care, as described by 3 (9%; younger woman, n=1, 33%; younger man, n=1, 33%; and older man, n=1, 33%) participants:

> *I can see that it has got its place, and from a medical point of view, if it's being fed into a database and it could highlight problems, erm, then that could be good. If it would highlight problems and then a doctor or a medical person of some kind was alerted that you should go and talk to that person, I could see that would be useful.* [017SC]

Of the 33 participants, the ability to check whether someone was physically active rather than sedentary was highlighted as an advantage by the younger group, as described by 3 (9%; younger women, n=2, 67%, and younger man, n=1, 33%) participants:

> *as you get worse as you get older, you know, you might lose some sight or something like that, you know, so having a sensor for getting up and down and that sort of thing, they would know wouldn't they, what, how much they're moving. I don't know, yeah. I don't think it's a bad idea as you get older* [031SG]

In addition to monitoring activity, of the 33 participants, 3 (9%; younger women, n=2, 67%, and older women, n=1, 33%) participants suggested that monitoring technology could provide reminders to conduct certain activities:

> *Obviously as you get older and the old brain cells are going "oh did I go for my walk today," "oh no I haven't" so yeah. And maybe I am sitting around more one day than another, so yeah, yeah. Yeah I think they could probably be quite a good tool actually, yeah.* [012SH]

Overview of Wearable Sensors

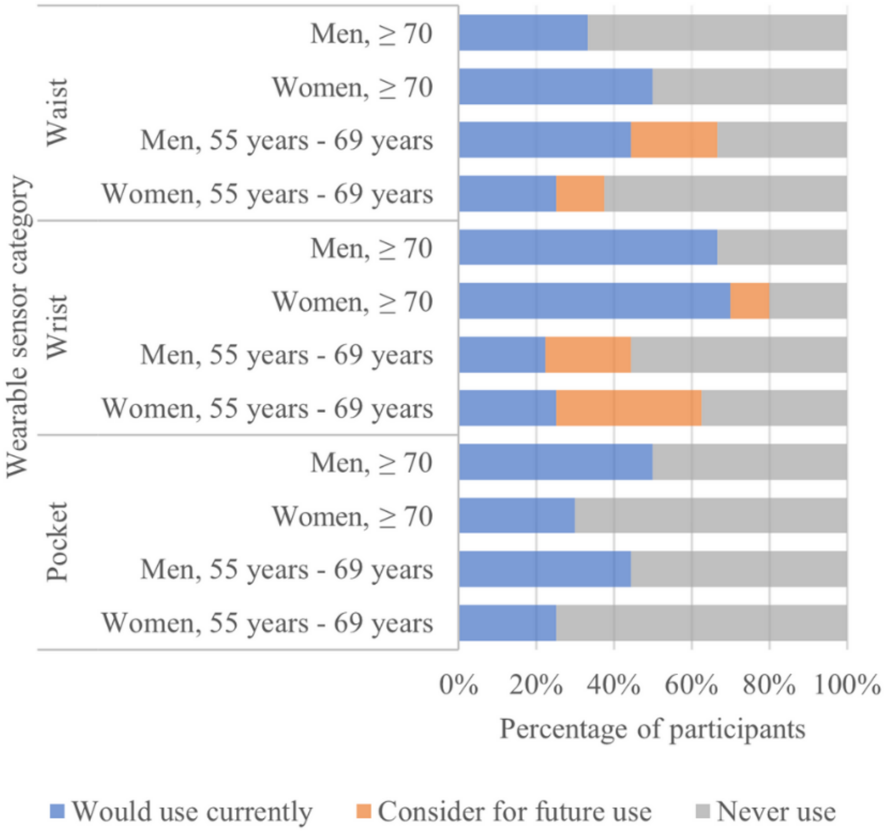
Participants from both groups stated that they had more knowledge of wearable sensors than other types of technology, with 100% (17/17) of the younger group and 75% (12/16) of the older group expressing existing knowledge (Figure 3). Overall, 100% (16/16) of the older group would accept at least one form of a wearable monitoring system, 94% (15/16) would consider using it immediately, and 6% (1/16) would consider using it in the future. Approximately 100% (17/17) of the younger group would also accept at least one form of wearable monitoring system; however, only 65% (11/17) would consider using it immediately, whereas 35% (6/17) would consider it for future use.

The acceptance of each specific wearable technology type is summarized in Figure 4. Of the 33 participants, wrist sensors were the most acceptable form of wearable technology in both groups, which may reflect the type of technology the participants were accustomed to, as described by 8 (39%; younger women, n=2, 15%; younger men, n=2, 15%; older women, n=3, 23%; and older man, n=1, 8%) participants:

> *yeah, got them. Got Fitbits. But I know there are all sorts of heart monitors and stuff like that you can wear nowadays* [023DK]

Although considered acceptable, many of the younger group participants stated that they would not use the wrist sensor currently but would consider it for future use (Figure 4). The same can be applied to a waist-worn sensor, which was the second most acceptable form of wearable technology; however, again, several younger participants would consider it for future use rather than use it immediately. The ring was the least acceptable technology type, although it was slightly more popular among the older group.

Figure 4. Acceptance of wearable sensors among community-dwelling older adults.



Factors Influencing Potential Acceptance of Wearable Monitoring Systems

Of the 33 participants, one of the main reasons for the high acceptability rate of wearable technology was how commonly the technology was currently used and how easily these sensors could be combined with other technologies such as a watches, as described by 4 (12%; younger man, n=1, 25%; older woman, n=1, 25%; and older men, n=2, 50%) participants:

> *well I think people are used to seeing things on people...and it's not remarkable anymore. I mean I think technology is so widely accepted now that people don't even comment. Fitbits, you know, people used to say "oh what's that" but now it's just a watch.* [015AA]

However, of the 33 participants, it was suggested by 3 (39%; younger man, n=1, 33%; older woman, n=1, 33%; and older man, n=1, 33%) participants that a wrist-worn sensor would need to be combined with a watch, as people are already accustomed to wearing a watch and do not want to wear multiple things:

> *I don't think I'd like things on my wrist—my wrist is my watch...it depends if that could all be one thing, that wouldn't be too bad, but I don't think I would have two things on my wrist, or one on each wrist. I don't think I'd have that.* [032TB]

Of the 33 participants, The design of the sensor was also a common influencing factor, especially among the older group, as described by 8 (24%; younger women, n=2, 25%; younger men, n=1, 13%; older woman, n=3, 37%; and older men, n=2, 25%) participants:

> *I'd go for the watch because not all trousers, or skirts, have pockets, erm, and a ring—I'm very fussy with the rings I wear. But I very much like the watch. I think that looks really nice actually* [025JD]

One of the participants stated that one of the main influencing factors for them was curiosity (older man, 1/33, 3%):

> *it would be interesting, I don't know if it would, you know, be useful. Or whether I would get, personally, anything out of it. But it would certainly allow me, if I wanted to take a scientific interest, to be able to analyse it. Just out of curiosity really.*

Among the women of the 33 participants, health status was the main factor that would make them consider using a wearable system in the future, as described by 3 (9%; younger women, n=2, 67%, and older woman, n=1, 33%) participants:

> *I suppose if you get to a point or stage where you require that then I would want it but we don't require it, and we hope we won't* [016IA]

Advantages of Wearable Monitoring Systems

Of the 33 participants, one of the main advantages of the community-dwelling older adults related to wearable systems is the ability to monitor health, either their own or that of someone else, as described by 3 (9%; younger woman, n=1, 33%; younger man, n=1, 33%; and older woman, n=1, 33%) participants:

> *Yeah, I think if its monitoring heart rate and stuff like that—the movement—that basically covers what these things will do. This firstly then these secondary. A combination of both, but predominantly the [wearable] one. That definitely gives you more details of your personal health* [023DK]

Of the 33 participants, motivation was another key advantage identified by both groups, especially in relation to exercise, as described by 10 (30%; younger women, n=1, 10%; younger men, n=4, 40%; older women, n=3, 30%; and older men, n=2, 20%) participants:

> *I've set myself a target of going on a little walk every day to build up my fitness again, so I'm just trying to—just out of curiosity, seeing how far I'm going every day* [007JR]

Of the 33 participants, the unintrusive nature of the sensors and the fact that they can be hidden was a major advantage for several groups, as described by 10 (30%; younger men, n=2, 20%; older women, n=5, 50%; and older men, n=3, 30%):

> *I mean, that could be hidden. You've got it on and it's hidden up a sleeve, you're not going to be able to see it...the strap around the waist could be hidden. It could be easily hidden underneath clothing and then, you know, if you're wearing a jacket or something as well it's not going to be seen, and people wouldn't ask* [023DK]

Disadvantages of Wearable Monitoring Systems

Older women noted that the potential need to charge the system could be a disadvantage of wearable monitoring systems (older women, 2/33, 6%):

> *oh yes, charging, that's the thing* [005PC]

Of the 33 participants, both groups suggested that comfort may be a barrier, as described by 2 (6%; younger man, n=1, 50%, and older woman, n=1, 50%) participants:

> *I don't think I would find it a problem unless it affected my sleep, you know, if it was uncomfortable and woke me up.* [027BB]

Younger men suggested that the cost of the system would discourage them from using wearable sensors (younger men, 2/33, 6%):

> *I mean I've always been quite, sort of, interested in the Fitbits and that sort of thing—the physical activity monitors and that but never...I've never wanted to spend that much money"* [010BC]

As these systems are wearable, of the 33 participants, the possibility of losing, forgetting, or damaging the sensor was the most stated disadvantage by 17 (52%; younger women, n=6, 35%; younger men, n=5, 29%; older women, n=2, 12%; and older men, n=4, 24%) participants:

> *I'd wear one on a belt but I know what I'm like for losing things, and if I had that one in my pocket I'd probably lose it...or put it in the washing machine* [007JR]

Of the 33 participants, the practicality of everyday use was another commonly stated disadvantage by 11 (33%; younger women, n=3, 27%; younger men, n=4, 36%; older women, n=3, 27%; and older man, n=1, 9%) participants, especially concerning ring and pocket sensors:

> *I think the ring can pose a problem, particularly of you are doing work, you can actually catch the ring in something and harm your finger. And erm, I mean, you know, I wear a wedding ring and another ring and I take those off if I am going to do some work for safety reasons. So I think you would be taking that off I would imagine, and perhaps forgetting to put it back on again* [019GW]

Younger men stated that the reaction of other people was a key disadvantage, especially in relation to appearing vulnerable (younger men, 2/33, 6%).

> *Because people will be saying "well what's that" you know what I mean? It'll be people saying "why you wearing this" and you'll have to start making excuses. You don't want to come across as being vulnerable* [001WB]

Overview of Environmental Sensors

There was little existing knowledge of environmental monitoring systems: 29% (5/17) of the younger group and 6% (1/16) of the older group were aware of at least one type (Figure 3). One of the participants explained that they had worked with the floor and chair sensors (younger man, 1/33, 3%):

> *at a home for people with dementia so we had the mats and the chair sensor to basically monitor when they were getting out of bed. Put a foot on the floor, the beeper would go off and we would go and see if they're okay. Y'know especially at night times. Some people who are at risk of falling, we had the chair exit pads but not all this other stuff* [001WB]

One of the participants recalled seeing something similar to a passive infrared monitoring system on a television program (younger man, 1/33, 3%):

> *I've seen some similar, somewhere I've seen similar to the PIR setup in a room for motion sensor, just to check when people are actually moving. I can't remember where—it might have been something like "Tomorrow's World" [British science and technology TV programme which ran until 2003] or something like that. I saw it years ago* [023DK]

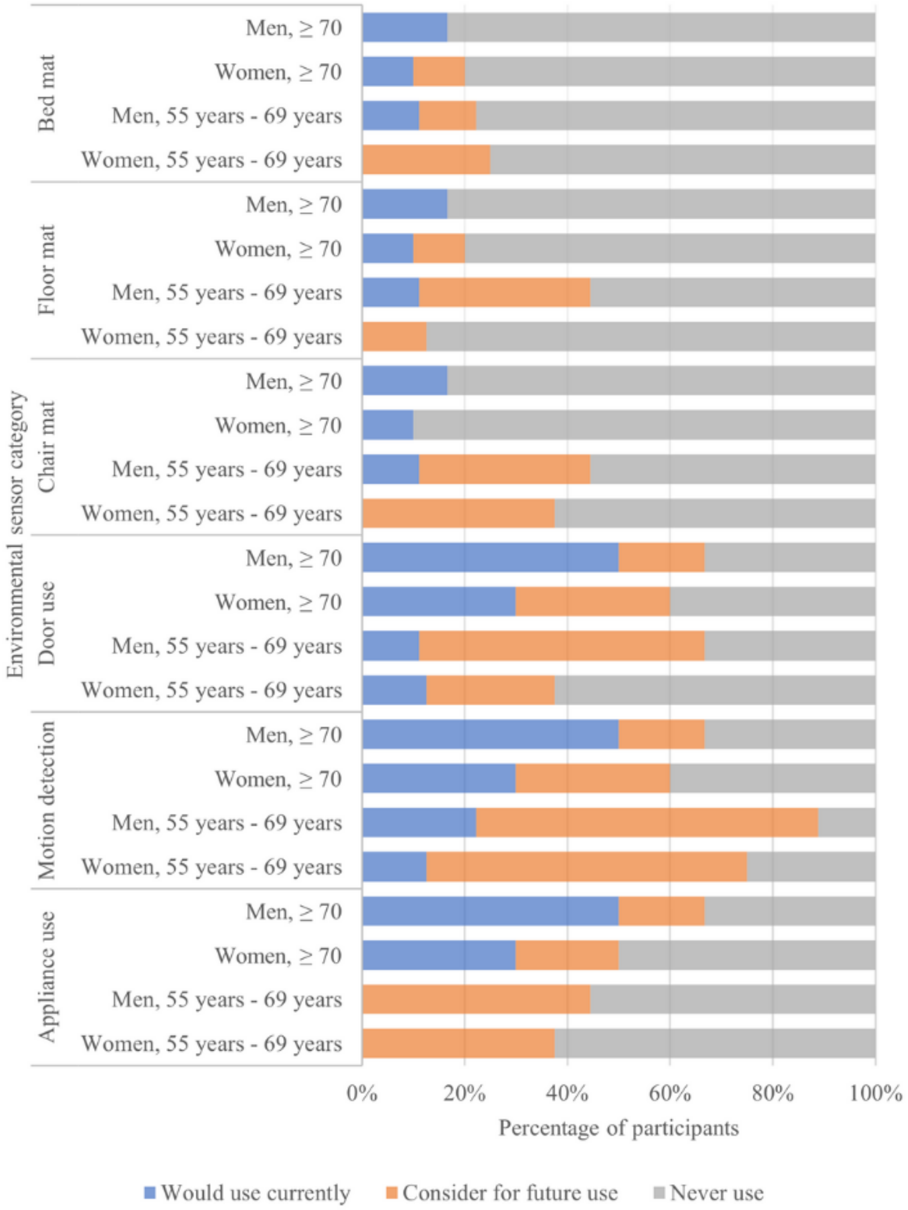
Of the 33 participants, experience with family or friends was mentioned by 2 (6%; younger woman, n=1, 50%, and older woman, n=1, 50%) participants:

> *I've heard about the anti-wandering ones because my friend's mother-in-law had one of those [laughs]—and the bed* [020PP]

The younger group was more accepting of environmental sensors overall, with just 6% (1/17) saying they would not consider their use compared with 19% (3/16) of the older group. However, the younger group was more likely to consider using environmental sensors in the future (13/17, 76%) than immediately (3/17, 18%) compared with the older group (6/16, 38%, would consider using it in the future, and 7/16, 44%, would use it immediately).

The acceptance of each specific environmental technology type is summarized in Figure 5. Motion sensors were the most accepted form of technology in the younger group, whereas motion and door sensors were most accepted equally by the older group. The pressure sensors were least accepted by both groups; however, several of the younger group participants would consider the chair mat in the future.

Figure 5. Acceptance of environmental sensors among community-dwelling older adults.



Factors Influencing Potential Acceptance of Environmental Monitoring Systems

Of the 33 participants, the main factor influencing community-dwelling older adults' acceptance of environmental monitoring systems in both groups was the perception of usefulness, with many stating that they did not see why they would be useful, as described by 12 (36%; younger women, n=3, 25%; younger men, n=3, 25%; older women, n=3, 25%; and older men, n=3, 25%) participants:

> *I think we would know what we are doing. I don't think we'd need data to tell us what we were doing...personally, I don't think it would help, I don't think it would make any difference to us to see it written down in the data round the house* [028PG]

Of the 33 participants, health status was identified by 9 (27%; younger woman, n=1, 11%; younger men, n=3, 33%; older women, n=4, 44%; and older man, n=1, 11%) participants:

> *if you're not particularly able then I would think the chair monitor—you know, you do not want people sitting day-in, day-out and not moving. If I was unfortunate enough to be struck down with something like dementia then the one on the door would be*

> *essential—on the front door would be essential* [025JD]

Of the 33 participants, media influence was both a positive and negative factor for 3 (9%; younger woman, n=1, 33%; older woman, n=1, 33%; and older man, n=1, 33%) participants:

> *yeah, I'd be like James Bond wouldn't I with sensors all over the place! Yeah that would be lovely. Yeah, excellent.* [014PC]
>
> *I don't fancy them, it's a bit "big brother is watching you"* [021GD]

Advantages of Environmental Monitoring Systems

Of the 33 participants, reassurance not only for the individual but also for those caring for an older relative was the most stated advantage of having an environmental monitoring system in both groups, especially for the younger group, as described by 11 (33%; younger women, n=5, 45%; younger men, n=3, 27%; and older women, n=3, 27%) participants:

> *You never know what's around the corner, then I would actually feel reassured with all this stuff at the top* [001WB]
>
> *I think it's—for people that have been through that or whatever sort of illnesses you've had with your elderly parents or whoever, this would probably be quite reassuring...I would have loved something like that for my mum. It would have been brilliant.* [012SH]

One of the participants stated that having an environmental sensor may allow certain conditions to be diagnosed earlier than otherwise (younger women, 1/33, 3%):

> *my mum had dementia and I was constantly getting called to her flat, something like this before she got to that stage where it got messy, these things could probably have diagnosed her earlier* [012SH]

Of the 33 participants, mostly the women in both the older and younger groups stated that a key advantage would be identifying sedentary behavior, either in themselves or others, as described by 7 (21%; younger women, n=2, 29%; younger man, n=1, 14%; and older women, n=4, 57%) participants:

> *if it got to the stage where I did need that, I mean, bearing in mind that there's always the threat of DVT if you spend too long sitting down. I mean, if you have somebody who's had a stroke or something and they aren't moving around much, I think that would be very informative.* [025JD]

Of the 33 participants, safety was also mentioned by 3 (9%; younger woman, n=1, 33%; younger man, n=1, 33%; and older woman, n=1, 33%) participants in both the older and younger groups, relating to personal safety for 2 (6%; younger woman, n=1, 50%, and older woman, n=1, 50%) participants and the potential for home security for 1 (3%; younger man) participant:

> *I suppose if you had someone with dementia, it would tell you if they'd been out, or gone out when they shouldn't.* [025JD]
>
> *if there's only 1 person in the house, and then all of a sudden there's three or four things moving about—there's somebody in a bedroom, someone in the living room, and then you think "this person lives on their own," but there's movement in two or three different places at one time—a quick phone call or something like that...Rather than find out later that they've been burgled* [023DK]

Of the 33 participants, the unintrusive nature of the sensors was a key advantage, especially within the older group when compared with wearable sensors, as described by 4 (12%; younger woman, n=1, 25%; older women, n=2, 50%; and older man, n=1, 25%) participants:

> *Obviously the ones that are installed on your ceiling or on your wall are not obtrusive at all, whereas you've got to remember to wear the other thing and of course you would realise that you have always got it with you* [019GW]

Disadvantages of Environmental Monitoring Systems

One of the participants identified the potential cost of the system as a disadvantage (younger woman, 1/33, 3%):

> *Expense wise, a little one would be cheaper than putting something in every room. That's—you know, finance is another issue* [024SK]

Of the 33 participants, the issue of coping with habitual behavior, such as closing doors, was identified by 4 (12%; younger woman, n=1, 25%; younger man, n=1, 25%; and older women, n=2, 50%) participants, especially in relation to door sensors:

> *door one, um, apart from the front doors, wouldn't work too much for me because I tend to not close doors anyway* [020PP]

Of the 33 participants, 2 (6%; younger man, n=1, 50%, and older woman, n=1, 50%) participants stated that the environmental sensors posed a risk of damage to the house:

> *it's worth noting, because one question would be if it does mark, then people would say "well then, I've got to redecorate"* [027BB]

Of the 33 participants, concerns over privacy issues were identified by most groups, as described by 5 (15%; younger women, n=3, 60%; older woman, n=1, 20%; and older men, n=1, 50%) participants:

> *Someone is always listening to you, someone is always looking at you, that the only thing. There isn't much privacy there, is it?* [018CW]

One of the participants stated that they considered the potential for reduced human contact within health care to be a disadvantage (older woman, 1/33, 3%):

> *the only slight misgiving I have on that is, um, that if—that they could end up, sort of, replacing the one-to-one...So these would keep you safe, say, these would alert somebody to a situation perhaps, or give them information but they couldn't replace the, sort of, the human contact element* [021GD]

Future Development Considerations of Monitoring Systems in General

Following the discussion of the various currently available monitoring technologies, some participants highlighted ways in which they could be developed in the future. Of the 33 participants, the main outcome from the younger group was that any future development should be based on a specific need, as described by 2 (6%; younger woman, n=1, 50%, and younger men, n=1, 50%) participants:

> *yep, if something's got a use and it makes life easier then I'm all for it, but if someone has invented some technology and then tries to find a use for it, I don't think that is a great improvement...If there is a need, get the technology to deal with it rather than develop technology and then find a use for it...We should get the machine to do whatever it wants to do properly and reliably rather than find out what else you can make it do—unless it is of some use.* [017SC]

One of the participants highlighted the need for more education relating to these types of technology (younger man, 1/33, 3%):

> *Yeah so I guess it's the educational side of it, yes. Teaching them about it—making sure the IT works for them rather than it's just there* [003MC]

One of the participants suggested that being able to combine many measures into a single sensor may be beneficial rather than having multiple sensors (older woman, 1/33, 3%):

> *it would be better to have one that would just do the lot rather than one that just picks one thing out, really...One that could combine the whole lot would be better.* [006BR]

Discussion

Principal Findings

Overview

Although there have been studies on older adults' perceptions of assistive technology [11] and fall monitors [13], little is known about their perceptions of ADL monitoring technology. A recent review of ADL monitoring technology found that there is a need for a clear consensus on which ADL are important to monitor and what types of technology older adults are most likely to use to enhance the effectiveness of current ADL monitoring systems [9]. The sample size used in this study, as well as the inclusion of both younger and older groups, makes this one of the most comprehensive studies of older adults' perceptions of ADL monitoring technology to date. PEIs made it possible to clarify the perceptions of specific types of technologies; however, the images used in PEIs were not exhaustive examples of the types of monitoring technology available. It should also be noted that all participants were from the United Kingdom and were already comfortable using technology, which means that the following conclusions cannot necessarily be applied globally. Differences in aspects such as education level and access to technology may also alter the results, although this was not a specific consideration of this study.

Relationship Between ADL Importance and Monitoring Technology

There is currently a strong link between the ADL considered the most important by the community-dwelling older adults and the ADL most frequently identified by current monitoring systems, and feeding and personal hygiene activities are both the most common activities supported by monitoring systems [9] and are considered the most important activities by community-dwelling older adults. In this study, these are also the activities that community-dwelling older adults suggested they would be the least likely to accept or ask for help with, particularly those relating to personal hygiene, such as washing and toileting, which were closely associated with feelings of pride and dignity.

One of the main challenges in developing ADL monitoring technology is identifying the activities that are important for monitoring [9]. Although hygiene-related activities are considered important, many older adults express concern about them being directly monitored [20], and they often require several sensors that focus only on these activities [9]. The activities considered important by community-dwelling older adults were different between the younger and older groups, with those aged ≥70 years placing more importance on stair use than their younger counterparts; however, this is not commonly detected by ADL monitoring systems. Instead, it often features in sensors specifically designed to monitor falls; however, the requirement for several different, highly specialized systems may be alienating some community-dwelling older adults. It was highlighted that most community-dwelling older adults were inclined toward fewer sensors, suggesting that a simple sensor capable of monitoring several activities would be preferable, which highlights the potential need for collaboration between those developing fall technology and ADL monitoring technology.

It was also noted that some activities have a large influence on others, namely, mobility and standing from sitting in a chair, which are both required to perform almost any other ADL. This suggests that it might be less important to directly monitor specific activities; instead, the focus should be on movements that are considered the most influential. For example, squatting plays a role in sitting, toilet use, and potentially other activities. Further investigation is required to identify the link between functional movement and specific ADL. Physical ability was a theme shared by both ADL performance and technology acceptance, highlighting that it is a very influential aspect in the acceptance of monitoring technology by the community-dwelling older adults.

Link Between Existing Knowledge of Technology and Acceptance of ADL Monitoring Technology

Our results demonstrated that there were different levels of existing knowledge related to monitoring technology, with most people being aware of wearable sensors and very few being aware of environmental sensors. One of the key reasons for this is the presence of similar technology in general use; for example, many noted that wearable sensors resemble smart watches such as Fitbit. It is evident that there is a link between existing knowledge and acceptance, as wearable sensors had the highest previous knowledge and acceptance, whereas environmental sensors had the lowest score in both categories (Figure 3). This contrasts with existing studies, which have suggested that wearable sensors are often the least accepted [21-23], whereas environmental motion sensors have been the most accepted [24]. It is notable that the younger group had more experience with environmental sensors than the older group, which many of them stated was because of having older relatives who had used the technology. The younger group was also more accepting of environmental sensors as they could relate their potential use to their relatives and wanted to have sensors that could help reassure their future carers or potentially help them diagnose health concerns earlier. On the basis of this, it may be that as monitoring technology becomes more commonly used, it will also become more accepted.

The high acceptance of monitoring technology in this study may be due, in part, to the sample group, who were all accepting of technology in general and comfortable using it, hence their willingness to use video calling software to participate in the interview. It should be noted that this may not be representative of the entire older adult community; for example, Verloo et al [11] suggest that older adults have limited interest in technology, and therefore, generalizations are difficult. However, this study was also conducted during the UK COVID-19 lockdown restrictions, during which technology became more prominent in many people's lives as a means of maintaining social connections with family and friends. Alongside this, some participants also noted that because of limited social interaction, people might be less aware of medical emergencies or emerging health concerns than they may have been previously and therefore were more appreciative of having technology in the home to monitor things such as sedentary behavior than they may have been in the past.

Common Themes

Some common themes emerged across both technology types, namely, relating to health status as an influencing factor and cost as a disadvantage. Health status highlights the potential of these sensors to be used to support health care, which is one of the main objectives for their development [9,12,25,26]; however, many of the participants highlighted that they would not use these sensors until they needed them, which goes against the idea of using them to detect when this point of need may be occurring. Owing to their ability to monitor continuously, which human health care workers cannot [20], it may be beneficial to focus future work on highlighting how this may be beneficial to older adults. Particular emphasis should be placed on older adults at most risk of becoming frail or developing certain health conditions such as dementia. However, the fact that cost was highlighted as the main disadvantage across all technology types shows the prominence of this issue. This sentiment is echoed by several other studies that have been conducted over several years, demonstrating that this is a key issue for developers to overcome in future development, finding a technology that is both beneficial and cost-effective [3,11].

A key disadvantage was the potential for reduced human contact, particularly among older women. This may be linked to a higher incidence of loneliness among this population because of the unequal distribution of risk factors such as the death of a partner among men and women [27] and the subsequent need to maintain social relationships. Although these technologies are often developed to assist health care and allow older adults to live at home for as long as possible [9], the development of future systems should be careful not to completely replace human care with technological assistance. Human interaction can provide emotional connections that even the smartest technology cannot replicate. These emotional connections cannot be underestimated in the care of older adults, as they are known to be closely linked with other factors such as depressive symptoms and subsequent reductions in physical activity and overall health. However, it is possible to use sensors to reduce the workload for human carers by automatizing some tasks; therefore, the carers can be more available to provide more human interaction to older users.

Socializing and communication were considered among the most important ADL by community-dwelling older adults and are commonly identified by monitoring technology [9], despite not appearing on many traditional ADL scales [28]. Social interaction is becoming an increasingly prevalent aspect of health care because of the growing adoption of a biopsychosocial approach [29]; therefore, this study indicates that its presence in monitoring technology should continue. Although not included in this study, socially assistive robots (SARs) may represent the best opportunity for developing this, as they have already been shown to have benefits for socialization [13,30]. In addition to monitoring socializing activities, SARs may play an active role in supporting the community-dwelling older adults through conversation or facilitating communication between people. It should be noted that this study was conducted during the national lockdowns in response to the COVID-19 pandemic, which several participants noted had made them more aware of potential isolation from friends and relatives. Future work should include SARs and explore their potential usefulness in the monitoring of ADL performance, as well as their role in supporting community-dwelling older adults to continue living independently in the community.

Conclusions

Overall, technological monitoring systems are perceived as acceptable methods of monitoring ADLs. However, developers and carers must be aware that individuals may express differences in their willingness to engage with certain types of technology depending on their age and circumstances. In addition to the increase in population aging, there will be an increase in older adults with interest in technology, which may reduce some of the existing barriers [11]; however, technical developers should continue to ensure that technology is created for a specific purpose that can be clearly conveyed to community-dwelling older adults who may not have much technological experience. Community-dwelling older adults highlighted the need for systems to be combined and simple; they do not want multiple sensors as these can create a technology overkill. In the future, technical developers should consider this and note that as technology becomes more widespread, it will become more accepted.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview guide used for web-based interviews.
[DOCX File , 1138 KB - aging_v5i2e33714_app1.docx]

Multimedia Appendix 2
Complete participant quotes from web-based interviews.
[XLSX File (Microsoft Excel File), 68 KB - aging_v5i2e33714_app2.xlsx]

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Abbreviations

ADL: activities of daily living
GARS: Groningen Activity Restriction Scale
iADL: instrumental activities of daily living
PEI: photo-elicitation interview
SAR: socially assistive robot

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Original Paper

Technology Acceptance and Usability of a Mobile App to Support the Workflow of Health Care Aides Who Provide Services to Older Adults: Pilot Mixed Methods Study

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Abstract

Background: Health care aides are unlicensed support personnel who provide direct care, personal assistance, and support to people with health conditions. The shortage of health care aides has been attributed to recruitment challenges, high turnover, an aging population, the COVID-19 pandemic, and low retention rates. Mobile apps are among the many information communication technologies that are paving the way for eHealth solutions to help address this workforce shortage by enhancing the workflow of health care aides. In collaboration with Clinisys EMR Inc, we developed a mobile app (Mobile Smart Care System [mSCS]) to support the workflow of health care aides who provide services to older adult residents of a long-term care facility.

Objective: The purpose of this study was to investigate the technology acceptance and usability of a mobile app in a real-world environment, while it is used by health care aides who provide services to older adults.

Methods: This pilot study used a mixed methods design: sequential mixed methods (QUANTITATIVE, qualitative). Our study included a pre– and post–paper-based questionnaire with no control group (*QUAN*). Toward the end of the study, 2 focus groups were conducted with a subsample of health care aides (*qual*, qualitative description design). Technology acceptance and usability questionnaires used a 5-point Likert scale ranging from *disagree* (1) to *agree* (5). The items included in the questionnaires were validated in earlier research as having high levels of internal consistency for the Unified Theory of Acceptance and Use of Technology constructs. A total of 60 health care aides who provided services to older adults as part of their routine caseloads used the mobile app for 1 month. Comparisons of the Unified Theory of Acceptance and Use of Technology constructs' summative scores at pretest and posttest were calculated using a paired *t* test (2-tailed). We used the partial least squares structural regression model to determine the factors influencing mobile app acceptance and usability for health care aides. The α level of significance for all tests was set at $P \leq .05$ (2-tailed).

Results: We found that acceptance of the mSCS was high among health care aides, performance expectancy construct was the strongest predictor of intention to use the mSCS, intention to use the mSCS predicted usage behavior. The qualitative data support the quantitative findings and showed health care aides' strong belief that the mSCS was useful, portable, and reliable, although there were still opportunities for improvement, especially with regard to the mSCS user interface.

Conclusions: Overall, these results support the assertion that mSCS technology acceptance and usability are high among health care aides. In other words, health care aides perceived that the mSCS assisted them in addressing their workflow issues.

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KEYWORDS

usability; technology acceptance; Unified Theory of Acceptance and Use of Technology; UTAUT; older adults; caregivers; health care aides; mobile phone

Introduction

Background

Health care aides are unlicensed support personnel who provide direct care, personal assistance, and support to people with health conditions that affect their daily function [1]. Currently, there is a shortage of health care aides due to challenges in recruitment, high turnover, an aging population, the COVID-19 pandemic, and low retention rates. For example, a recent study conducted in the United States found that the 3-year retention rates among health care aides were as low as 36% [2]. In Canada, there is a shortage of health care aides who provide care to older adults. As a result, Canada is seeking approximately 200,000 new health care aides over the next 10 years to meet the needs of the growing aging population [3].

Workflow issues have a negative impact on health care aides' job satisfaction and quality of care. The scope of practice and decision-making, service authorization and access to client information, relationships, safety, critical incidents, communications, documentation, travel, scheduling and navigation, and education are the most common workflow issues identified by health care aides [4]. The implementation of information communication technologies (ICTs) can improve workflow issues and job satisfaction [4]. There is a positive correlation between job satisfaction and employee retention [5]. Multifeatured mobile apps are among the many ICTs paving the way for eHealth solutions in workforce shortages [6,7]. With various modes of implementation, such as telemonitoring and electronic health records, the development of ICTs has the potential to benefit workflow and tasks within the health care sector [8,9].

Knowledge of the usability and acceptance ICTs in health care settings is imperative for the success of ICT deployment. Perez et al [10] recently identified the drawbacks and benefits of ICT adoption by health care aides. A major deterrent is the cumbersome and time-consuming nature of the adoption and implementation of ICTs. In contrast, the major benefits include improved workflow, inclusion of time management skills, protocol simplification, standardized procedures, and staff scheduling. Moreover, the lack of ICT solutions for care providers of persons living with dementia is highlighted by Grossman et al [11]. This study identified >200,000 mobile health (mHealth) apps, only 22 of which were intended for dementia care. To reduce the burden on caregivers, the literature identifies useful ICT features, including information and resources, family communication and coordination, memory aids for care activities and socialization, carer support resources, medication management, and personal health records [11].

The COVID-19 pandemic has been a major contributor to the recent uptake of technology [12]. A study analyzing older adults' experiences using technologies reported that more than half of the participants had adopted new technologies since the beginning of the pandemic [13]. In clinical settings, real-time health information has become a key feature of ICT solutions, owing to the infectious nature of the virus. The inherent need for modernized technology deployment in long-term care settings during COVID-19 outbreaks and in a postpandemic world is critical for support staff such as health care aides [12].

In light of the COVID-19 pandemic, an understanding of user-technology interactions is fundamental to ICT design and deployment in care settings. Health care aides, nurse managers, and other health care providers benefit from ICT use through improved communication, workflow support, and information accessibility [10,14]. Furthermore, there is an opportunity to enhance communication between clients and their family members [15]. The impact of this understanding can improve workflow issues, job satisfaction, and job retention in health care aides.

In collaboration with Clinisys EMR Inc, we developed a mobile app intended to support the workflow of health care aides who provide services to the older adult residents of a care facility. The mobile app was trialed in a long-term care setting by health care aides. Thus, the purpose of this study was to investigate the technology acceptance and usability of a mobile app in a real-world environment, while it is used by health care aides who provide services to older adult residents.

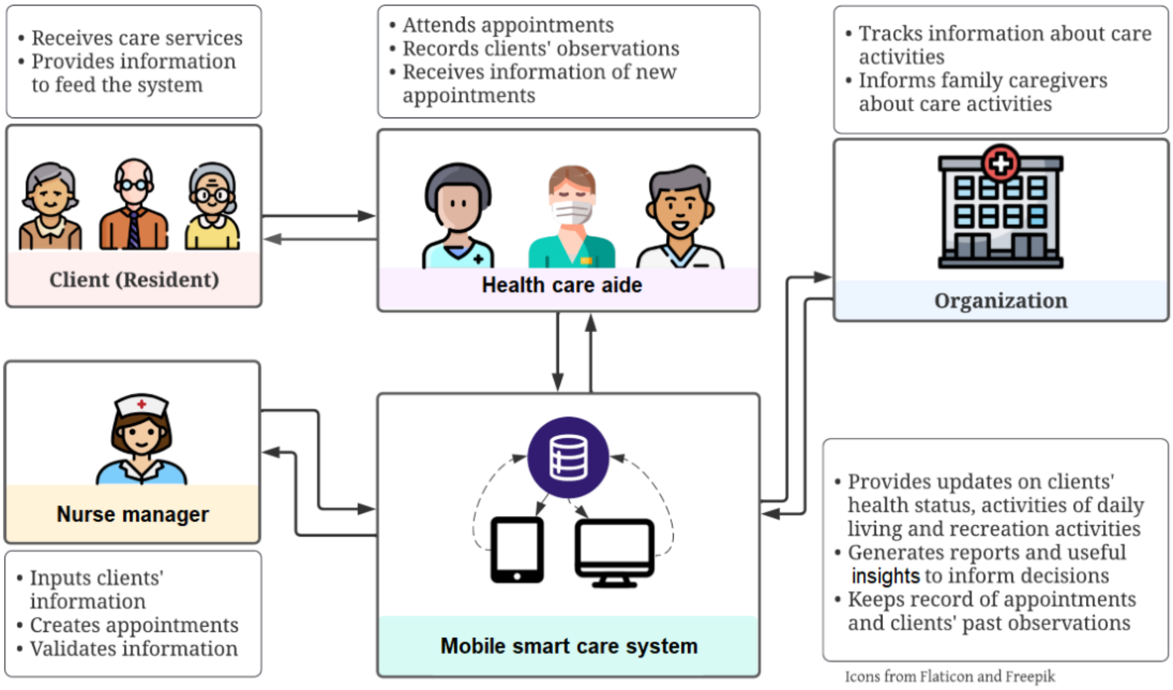
Theoretical Framework: Brief Description

Technology acceptance relates to user beliefs, whereas usability is a concept associated with the actual use of technology [16]. Theories that explain the acceptance and adoption of technologies are based on 2 foundational theories that posit why an individual chooses whether to use a technology. These theories are the Theory of Planned Behavior [17] and its predecessor, the Theory of Reasoned Action [18], which are based on the main premise: as much of human behavior is under volitional control, most behaviors can be accurately predicted from an *appropriate measure* of the individual's intention to perform the behavior in question [19]. The Unified Theory of Acceptance and Use of Technology (UTAUT), in its UTAUT [20] and UTAUT2 [21] versions, has emerged as the dominant model explaining the behavioral intention to use technologies and behavior connected to the use of technologies. The UTAUT posits that performance expectancy, effort expectancy, and social influence are the direct determinants of the behavioral intention to use the technology under study, whereas facilitating conditions and behavioral intention to use the technology are the 2 determinants of usage behavior. The UTAUT2, modified from the UTAUT, includes 3 new constructs: hedonic motivation, price value, and habit. In this study, we selected the UTAUT as our theoretical model, as it has been tested more frequently in health care settings [22-24], consequently having higher levels of validation compared with the UTAUT2.

The Technology: Mobile Smart Care System

Figure 1 shows the architecture of the Mobile Smart Care System (mSCS). The mSCS is a tablet-compatible web-based appl that allows access to an electronic medical record system. The mobile user interface of the mSCS enables health care aides to access their clients' care plans and observations (eg, bathing, feeding, grooming, dressing, bowel control, bladder control, toilet use, transfer in and out of bed, and mobility) previously uploaded to the electronic medical record by their supervisors (ie, nurse managers). The health care aides recorded their observations and reported their completed activities. The mSCS also enabled supervisors (nurse managers) to monitor health care aides' care plan activities and observations with an integrated module on the client's history (previous appointments). The mSCS was installed on tablets using the Android operating system.

Figure 1. The Mobile Smart Care System architecture at a glance.



Icons from Flaticon and Freepik

Methods

Study Design

This was a pilot study using a mixed methods design: sequential mixed methods (*QUANTITATIVE, qualitative*) [25]. Our study included a pre– and post–paper-based questionnaire with no control group (*QUAN*). Toward the end of the study, 2 focus groups were conducted with a subsample of health care aides (*qual*, qualitative description design).

Setting

This study recruited health care aides from a facility that is part of the Wing Kei Care Centre (Alberta, Canada) from August 17 to October 19, 2021. The Wing Kei Care Centre is home to 145 older adults and has 77 private rooms, 36 semiprivate rooms, and an 80-bed long-term care center. The Wing Kei Care Centre provides culturally specific programs and services for Chinese older adults.

Sample Size Calculation

The quantitative aspect of the study required a sample size of 60 health care aides to achieve a statistical power of 0.80 with a small effect size (ie, 0.25) and an α of .05 for a partial least squares (PLS) structural regression model [26]. The qualitative component of the study involved 10 health care aides. The target sample size was determined based on researchers' previous experience and existing literature [27].

Participants

The health care aides were employed at 1 of the 3 sites that are part of the Wing Kei Care Centre. They provided services to older adults as part of their routine caseloads and were recruited using convenience sampling. To be included in this study, the health care aides had to be familiar with using digital technologies such as smartphones or tablets.

Variables

Intention to use and actual usage behavior related to the mSCS were used as the outcome measures in the multivariate PLS structural regression model (from here on referred to as the PLS model) to determine the factors that had an effect on the acceptance and usage behavior of the mSCS. Performance expectancy, effort expectancy, and social influence were considered direct determinants of behavioral intention with regard to using the mSCS. Behavioral intention regarding the use and facilitation conditions for using the mSCS were treated as direct determinant factors for usage behavior of the mobile app. We included demographic data such as sex, age, level of comfort using digital technologies (eg, computers, smartphones, the internet, and tablets) and years of experience working as a health care aide as potential confounding variables. Dichotomous variables were coded *0* or *1* (eg, sex). Every item in section B-1 in the questionnaire was related to each dependent, and the independent variables were scored on a 5-point Likert scale, ranging from *disagree* (1) to *agree* (5). We calculated 3 summative scores by adding all the items from the UTAUT constructs (except for usage behavior, 10 items), all the items from each UTAUT construct (2 items for each of the 5 constructs), and all the items from the level of comfort using digital technology (4 items). The maximum possible value of the first summative score based on the 5-point Likert scale was 50 points (2 items for each of the 5 constructs). Therefore, a summative score higher than 30 points and closer to 50 points suggests that the technology acceptance of the mSCS was high. The maximum possible value of the second summative score based on a 5-point Likert scale was 10 (2 items per construct). Therefore, a summative score higher than 6 points and closer to 10 points would suggest that performance expectancy, effort expectancy, social influence, facilitating conditions, and behavioral intention to use the mSCS were high. For the third scale, a summative score higher than 12 points and closer to 20 points suggests that health care aides have high levels of comfort in using digital technologies.

Data Sources and Instruments

Table 1 summarizes the UTAUT constructs using measurement items. We designed and administered a paper-based initial questionnaire (10 items; 2 items per UTAUT construct) and an exit questionnaire (12 items; eg, the exit questionnaire had 2 additional questions about usage behavior with the mSCS) to understand the factors that affected the actual use of the mSCS. The purpose of the initial questionnaire was to obtain a baseline for mSCS acceptance, whereas the exit questionnaire was aimed at understanding usage behavior and whether the health care aides' expectations of the mSCS were met. The questionnaire for the health care aides had 3 sections. Section A-1 included demographic data such as sex, age, and years of experience working as a health care aide. Section A-2 in the questionnaire used a 5-point Likert scale to determine the health care aides' level of comfort in using digital technologies, ranging from *disagree* (1) to *agree* (5). Section B-1 included questionnaire items that used a 5-point Likert scale ranging from *disagree* (1) to *agree* (5). The items included in this section were previously validated as having high levels of internal consistency [20,28].

Focus groups were guided by 6 questions that examined the health care aides' experiences (ie, usefulness and ease of use) with the mSCS during their work day and their satisfaction with the system while carrying out routine tasks. We also asked about the potential influence of the mSCS on the quality of care provided, the challenges and barriers associated with using the system, and the possibility of using the system in a home care setting.

Table 1. Summary of the construct and corresponding measurement items.

Construct	Corresponding items (initial questionnaire)	Corresponding items (exit questionnaire)	Source
PE[a]			
	PE1: using the mSCS[b] will improve the management of care for my clients.	PE1: using the mSCS improved my ability to care for my clients.	[20]
	PE2: overall, the mSCS will be useful for doing my job as a health care aide.	PE2: overall, the mSCS was useful for my job.	[20]
EE[c]			
	EE1: learning to use the system will be easy for me.	EE1: learning to use the mSCS app was easy for me.	[20]
	EE2: overall, I will find the mSCS easy to use.	EE2: overall, the mSCS was easy to use.	[28]
SI[d]			
	SI1: my colleagues at work think that I should use the mSCS to manage my caregiving activities.	SI1: my colleagues think that I should use the mSCS to manage my caregiving activities.	[28]
	SI2: in general, my supervisor will support my use of the mSCS to manage my caregiving activities.	SI2: in general, my supervisor supported my use of the mSCS to manage my caregiving activities.	[28]
FC[e]			
	FC1: I will receive good technical support with the mSCS.	FC1: I received good technical support with the mSCS.	[28]
	FC2: the mSCS will be fast to get into.	FC2: the mSCS was fast to get into.	[28]
BI[f]			
	BI1: if possible, I will use the mSCS to manage my caregiving activities.	BI1: if it were up to me, I would continue to use the mSCS to manage my caregiving activities.	[28]
	BI2: if possible, I will continue to use the mSCS app to provide a better service to my clients.	BI2: if it were up to me, I would continue to use the mSCS as a way to care for my clients better.	[28]
UB[g]			
	N/A[h]	UB1: I used the mSCS to organize my caregiving activities.	[28]
	N/A	UB2: I used the mSCS to manage my caregiving activities.	[28]

[a] PE: performance expectancy.

[b] mSCS: Mobile Smart Care System.

[c] EE: effort expectancy.

[d] SI: social influence.

[e] FC: facilitating conditions.

[f] BI: behavioral intention.

[g] UB: usage behavior.

[h] N/A: not applicable.

Ethics Approval

This study was approved by the ethics committee of the University of Alberta (Pro00095093).

Procedures

A member of the research team at the care center sent a letter of invitation along with the information letter and consent form by email to potential participants who matched the inclusion criteria. Health care aides who were interested in participating signed the consent form and then emailed the form back to the project coordinator.

The project coordinator administered the initial questionnaire to each health care aide who agreed to participate in the study. Next, they provided a tablet with the mSCS installed on it to each health care aide and provided instructions on how to use the mSCS. The app also had a tutorial video that taught the health care aides how to use the tablets and access the system through the mSCS (ie, Clinisys portal). Each health care aide used the system for 1 month. After the trial period, the project coordinator emailed each health care aide the exit questionnaire for completion. Health care aides then emailed the completed questionnaires back to the project coordinator. Each health care aide received an honorarium of CAD $25.00 (US $19.99) for each of the research activities completed (ie, the initial usability questionnaire and exit usability questionnaire).

The focus groups were held with health care aides at the care center toward the end of the study. A total of 2 focus groups were conducted, with 6 health care aides in each focus group for 12 health care aides. Thus, the 12 health care aides completed both the quantitative and qualitative components of the study. Each health care aide who participated in a focus group received an honorarium of CAD $25.00 (US $19.99).

Data Analyses

Descriptive statistics were used to summarize the demographic data of the health care aides. SPSS (version V 28.0; IBM Corp) and SmartPLS (version 3.2.0) [29] statistics packages were used to generate descriptive, univariate, and bivariate statistics and a PLS structural regression model, respectively. The sample size was estimated using G*Power (version 3.1.9.4; Universität Kiel) [30]. Comparisons of the outcome and independent variable summative scores at pretest and posttest were calculated using a paired *t* test. We used a PLS structural regression model to determine the factors that influenced mSCS acceptance and usability for the health care aides. To determine whether to include mediator and moderator variables in the PLS structural model, bivariate correlations (ie, Spearman ρ or Pearson correlation) between performance expectancy, effort expectancy, social influence, behavioral intention to use, and current use of the mSCS that were independent of sex, age, level of comfort using mobile apps, and years of experience working as a health care aide were calculated. Finally, a PLS structural measurement model evaluation was conducted using the following: (1) a reliability measurement for each construct (internal composite reliability [ICR]), (2) a convergent validity measurement of each set of items with respect to their associated construct being assessed by examining the factor loadings of the items on the model's constructs, and (3) the discriminant validity that was analyzed using an average variance extracted (AVE) indicator. The PLS structural regression model was evaluated using path coefficients, explained variance (R^2), and effect size (f^2) for each path segment of the model. In addition, bootstrapping resampling was used to verify the statistical significance of the path coefficients of the PLS structural regression model. We used 5000 bootstrap subsamples [26]. The alpha level of significance for each test was set at $P \leq .05$ (2-tailed).

The focus groups were digitally recorded and transcribed verbatim, using thematic descriptive methods [31]. Thematic analysis guided data analysis. The analyst (ER) began the analysis by inductively generating codes that were refined as the coding progressed. After the coding hierarchy was developed, the key themes were generated. During the analysis, the analyst verified emergent codes and themes through discussion with research team members.

Results

Participants

A total of 75 health care aides were invited to participate. Of these, 15 (20%) did not respond to the invitation to schedule the training session and administration of the demographic data form and pretest. In all, 60 (80%) health care aides were enrolled and completed the pretest. A health care aide took part in 2 weeks of the study but dropped out before the exit interview. Thus, the final sample size, with complete initial and exit data, consisted of 59 health care aides. The final number of questionnaires analyzed at the exit phase was for 59 health care aides, representing 98% (59/60) of the cases.

Table 2 shows the demographics of health care aides. Their average age was 45.16 (SD 8.97) years. The health care aides had almost 8 years of work experience (mean 7.43, SD 4.74 years), and almost all were identified as female (59/60, 98%). The health care aides reported high levels of comfort using digital technologies (19.71, SD 1.18).

Table 2. Demographics of the health care aides (N=60).

	Values
Age and work experience, mean (SD)	
Age (years)	45.16 (8.97)
Number of years of experience working as a health care aide	7.43 (4.74)
Level of comfort using digital technologies, mean (SD)	
I am comfortable using a computer	4.95 (0.29)
I am comfortable using a tablet	4.97 (0.18)
I am comfortable using a smartphone	4.84 (0.62)
I am comfortable using the internet	4.95 (0.39)
Summative scale[a]	19.71 (1.18)
Gender, n (%)	
Female	59 (98)
Male	1 (2)
Nonbinary	0 (0)
Transgender	0 (0)

[a] *Disagree* (1) to *Agree* (5). Summative scale—minimum to maximum: 4 to 25.

Technology mSCS Acceptance and Usability: Quantitative results and Pre- and Posttest Comparisons

Table 3 shows the descriptive statistics and hypothesis tests (paired t tests) of the technology acceptance of the mSCS in terms of a summative scale (all the UTAUT construct items) and for each UTAUT construct, respectively. The results shown in Table 3 indicate that, overall, acceptance of the mSCS was high in the exit interviews, after the health care aides used the mSCS. Overall, the health care aides' expectations regarding their acceptance of the mSCS were met, as the means of the summative score were >30, and there were no differences between the initial and exit summative scores. These results suggest that the health care aides would continue to use the mSCS in the future if they were able to do so.

Table 3. Health care aides' level of technology acceptance using the Mobile Smart Care System summative scale per Unified Theory of Acceptance and Use of Technology (UTAUT) construct (initial and exit comparisons).

UTAUT constructs	Initial (n=60), mean (SD)	Exit (n=59), mean (SD)	Paired t test statistics (2-tailed; n=59)				
			P value	t test (df)	95% CI	Effect size	Power (%)
Performance expectancy	9.37[a] (1.56)	9.07 (1.92)	.32	1.003 (59)	−0.298 to 0.898	0.221	50
Effort expectancy	9.33[a] (1.45)	9.43 (1.57)	.72	−0.362 (59)	−0.652 to 0.452	0.090	20
Social influence	9.17[a] (1.59)	9.02 (1.82)	.61	0.517 (59)	−0.430 to 0.730	0.117	33
Facilitating conditions	9.32[a] (1.49)	9.42 (1.58)	.72	−0.356 (59)	−0.662 to 0.462	0.090	20
Behavioral intention	9.27[a] (1.45)	9.23 (1.78)	.90	0.123 (59)	−0.507 to 0.573	0.032	21
Usage behavior	N/A[b]	9.10 (1.96)	N/A	N/A	N/A	N/A	N/A
Summative scale[c]	46.5 (6.96)	46.9 (5.46)	.68	−0.414 (59)	−2.510 to 1.650	0.054	10.9

[a] *Disagree* (1) to *Agree* (5); 2 items per UTAUT construct; minimum summative scale: 2, maximum summative scale: 10.

[b] N/A: not applicable.

[c] Minimum summative scale: 10, maximum summative scale: 50 (all of the Unified Theory of Acceptance and Use of Technology construct items).

Regarding the results for each UTAUT construct, according to health care aides' responses, they believed the mSCS was useful (high performance expectancy), easy to use (low effort expectancy), fit with their needs (high facilitating conditions), and the influence of others on their use was high. Importantly, health care aides would be willing to use the mSCS in the future if they were able to do so (average intention to use the mSCS, behavioral intention construct 9.27, SD 1.45; maximum 10). At exit, the mSCS showed high levels of usability (average usage behavior with the mSCS, USE [actual use] 9.10, SD 1.96). We did not find any statistically significant differences between the initial and exit summative scores for any of the UTAUT constructs.

Technology mSCS Acceptance and Usability: Multivariate Analyses (PLS Model)

As we did not find any statistically significant differences between the initial and exit summative scores for any of the UTAUT constructs, we ran only one PLS model (the exit model). The bivariate analysis showed the health care aides' responses related to performance expectancy, effort expectancy, social influence, behavioral intention, and usage behavior with the mSCS. The constructs were independent of sex, age, level of comfort using digital technologies, and years of experience working as health care aides (Multimedia Appendix 1).

The PLS results for the structural model are shown in Table 4. During the exit interview, we found, as the UTAUT model predicted, a strong positive correlation between usefulness (performance expectancy; performance expectancy→behavioral intention, β=.856; P=.004) and behavioral intention to use the mSCS. However, contrary to what the UTAUT suggests, we found that effort expectancy (degree of ease of use; effort expectancy→behavioral intention, β=−0.083; P=.57) and social influence (social influence→behavioral intention, β=.044; P=.83) were not salient constructs for intention to use the mSCS. In addition, as the UTAUT model predicted, we found a strong positive and statistically significant correlation between behavioral intention to use the mSCS and usage behavior with the mSCS (behavioral intention→usage behavior, β=.789; P<.001). Finally, we also found that although the facilitating conditions and usage behavior were positively correlated, as predicted by the UTAUT model (ie, facilitating conditions→ usage behavior, β=.098; P=.47); this relationship was not statistically significant in this study.

Table 4. Determinants of behavioral intention and usage behavior regarding the Mobile Smart Care System (5000 bootstrap subsamples).

Path segment	Health care aides (n=59)							
	β[a]	*t* test statistics (df=59)	*P* value	95% CI	f^2[b]	R^2[c]	$R^{c}_{adjusted}$	Power %
PE[d] →BI[e]	0.856	2.906	.004	0.029 to 1.154	0.689	0.690	0.673	100
EE[f]→BI	−0.083	0.566	.57	−0.313 to 0.266	0.010	—[g]	—	—
SI[h]→BI	0.044	0.214	.83	−0.201 to 0.600	0.002	—	—	—
BI→UB[i]	0.789	7.672	<.001	0.559 to 0.976	1.474	0.748	0.739	100
FC[j]→UB	0.098	0.716	.47	−0.146 to 0.388	0.022	—	—	—

[a] Path coefficients.

[b] Effect size.

[c] Explained variance.

[d] PE: performance expectancy.

[e] BI: behavioral intention.

[f] EE: effort expectancy.

[g] R2 ($R^{c}_{adjusted}$) and power are calculated for constructs BI (PE, EE, and SI contributes to the explained variance of BI) and UB (BI and FC contribute to the explained variance of UB).

[h] SI: social influence.

[i] UB: usage behavior.

[j] FC: facilitating conditions.

PLS Model Validity and Reliability

Table 5 shows the results of the construct correlations and descriptive statistics, ICR, Cronbach α, and AVE of the constructs of the PLS. The square root of each AVE (shown on the diagonal in Table 5) was greater than the related interconstruct correlations in the construct correlation matrix, indicating adequate discriminant validity for all the constructs. All AVE values were >0.5, indicating good convergent validity at the construct level [26]. All ICR and Cronbach α values were >.70, indicating good internal consistency at the construct level [26]. The PLS models also showed that all item loadings were statistically significant at the 0.001 level, and 100% of the item loadings were >0.70, indicating excellent values of convergent validity at the indicator level [26] (see Table 6 for more details).

The explained variance (ie, R^2) of the constructs of the PLS model was 0.690 and 0.748 for behavioral intention to use the mSCS and actual usage behavior with the mSCS, respectively, which appears to be strong according to the published criteria [26].

Table 5. Construct correlations and construct reliability and validity of the partial least squares structural regression model (n=59).

Construct	Values, mean[a] (SD)	ICR[b]	Cronbach α	AVE[c]	BI[d]	EE[e]	FC[f]	PE[g]	SI[h]	UB[i]
BI	9.23 (1.78)	0.972	.943	0.946	0.973[j]	—[k]	—	—	—	—
EE	9.43 (1.5)	0.885	.741	0.794	0.569[l]	0.891[j]	—	—	—	—
FC	9.41 (1.57)	0.883	.756	0.791	0.646[l]	0.899[l]	0.890[j]	—	—	—
PE	9.06 (1.92)	0.965	.928	0.932	0.828[l]	0.731[l]	0.792[l]	0.966[j]	—	—
SI	9.01 (1.82)	0.916	.821	0.845	0.655[l]	0.605[l]	0.606[l]	0.774[l]	0.919[j]	—
UB	9.10 (1.96)	1.000	1.000	1.000	0.562[l]	0.562[l]	0.614[l]	0.806[l]	0.708[l]	1.00[j]

[a] *Disagree* (1) to *Agree* (5); 2 items per Unified Theory of Acceptance and Use of Technology construct; minimum summative scale: 2, maximum summative scale: 10.

[b] ICR: internal composite reliability.

[c] AVE: average variance extracted.

[d] BI: behavioral intention.

[e] EE: effort expectancy.

[f] FC: facilitating conditions.

[g] PE: performance expectancy.

[h] SI: social influence.

[i] UB: usage behavior.

[j] Square root of AVEs reported along diagonal (Fornell-Larcker criterion).

[k] —: not applicable.

[l] *P*<.01.

Table 6. Reliability and convergent validity of the partial least squares structural regression model—measurement model (n=59).

Construct and item	Item loading	*t* test (df=59)	95% CI	ICR[a]	AVE[b]	Cronbach α
PE[c]				0.965	0.932	.928
PE1	0.965	35.699[d]	0.884 to 0.987			
PE2	0.966	48.068[d]	0.909 to 0.988			
EE[e]				0.885	0.794	.741
EE1	0.884	6.300[d]	0.446 to 0.965			
EE2	0.899	13.774[d]	0.828 to 1.000			
SI[f]				0.916	0.845	.821
SI1	0.947	41.169[d]	0.891 to 0.984			
SI2	0.897	12.970[d]	0.693 to 0.954			
FC[g]				0.883	0.791	.756
FC1	0.950	24.337[d]	0.896 to 0.993			
FC2	0.824	6.810[d]	0.485 to 0.953			
BI[h]				0.972	0.946	.943
BI1	0.972	32.278[d]	0.900 to 0.993			
BI2	0.973	46.060[d]	0.909 to 0.993			
UB[i]				1.000	1.000	1.000
UB1	Deleted	N/A[j]	N/A			
UB2	1.000	N/A	N/A			

[a] ICR: internal composite reliability.

[b] AVE: average variance extracted.

[c] PE: performance expectancy.

[d] *P*<.01.

[e] EE: effort expectancy.

[f] SI: social influence.

[g] FC: facilitating conditions.

[h] BI: behavioral intention.

[i] UB: usage behavior.

[j] N/A: not applicable.

Technology MSCS Acceptance and Usability: Qualitative Results

Focus Groups

Of 59 health care aides who completed the exit questionnaire, 12 (20%) participated in the focus group. The health care aides' average age was 46.83 (SD 7.5) years, they had almost 9 years of work experience (mean 9.01, SD 4.08 years), and almost all identified as female (11/12, 92%). The following themes emerged from the qualitative data analysis: (1) the mSCS is useful, (2) the mSCS is portable and reliable, and (3) there are still opportunities for improvement.

The mSCS Is Useful

Most health care aides valued the usefulness and relative advantage of the mSCS in their daily lives, compared with not using an electronic system to access care plans and tasks. Health care aids identified that the mSCS saved time, "because we can document right away whatever we observed the resident, rather than paperwork and it takes time" (participant HCA1P2). They also stated that using the system is "faster than handwriting," and "prevents spelling errors" (participant HCA1P6). Using the mSCS on a tablet was convenient and allowed for multitasking, as described in the statement by participant HCA2P1 "[you] can just bring this along [the tablet] with the resident when we're waiting for them." The mSCS was informative when health care aides completed care tasks. For example, according to participant HCA1P2, "If residents, are new, I can check in the system [mSCS]. I can check the care plan and about their status. So I don't even ask my co-worker…" Having a resident's medical history that was easily accessible was useful for quick reference. This was especially true for new staff, such as participant HCA2P3, who stated, “If we have new clients, we have the reporting time [that] shares the information for the new client.”

The mSCS Is Portable and Reliable

Most health care aides valued having the mSCS on a tablet, as it made it portable and reliable. Regarding portability, participant HCA2P2 commented, “It’s very handy, you can carry it anywhere.” Some health care aides also believed that having the mSCS on a tablet allowed better accessibility to the “system” in comparison with having the information in a point-of-care system located on a computer at the nurse’s station. By reliability, the participants meant that they only needed to wait for a short time for connection to save their data. For example, participant HCA2P3 mentioned “And the system won’t hang up. You can just go straight forward. In between it won’t break down...”

There Are Still Opportunities for Improvement

Most health care aides mentioned that the mSCS user interface was easy to understand and enter information; however, many of its aspects needed to be improved. For example, participant HCA1P3 stated that they faced some “interface issues”:

> *…the little dots to input the selection [are a very small interface]. It probably should be a bigger block so you can easily click it because sometimes when you’re clicking it clicks [and you go] onto the different [places]… [and it causes] a wrong selection…*

Participant HCA2P3 stated that the font size needed to be enlarged “because we are aging.” The health care aides mentioned that visual indicators or aids, such as color, could help to quickly and easily confirm that information was entered correctly. The lack of these interface elements led to incorrect documentation and sometimes made the mSCS confusing to use. For example, HCA2P4 stated the following:

> *There’s lots of dates. And we’ve been confused with those dates because, oh, I haven’t started this thing, how come the date is here?*

Finally, although the health care aides appreciated the simplicity of the fields when they were entering information, an option to include more detailed information was strongly recommended.

Discussion

Principal Findings

In this study, we aimed to investigate the technology acceptance and usability of a mobile app in a real-world environment used by health care aides who provide services to older adults. We found that (1) the acceptance of the mSCS was high among health care aides, (2) the performance expectancy construct was the only predictor of intention to use the mSCS, and (3) the intention to use the mSCS predicted usage behavior with the mSCS. The qualitative data supported the quantitative findings, showing the health care aides’ strong belief that the mSCS was useful, portable, and reliable; although, they also suggested opportunities for improvement, especially in the mSCS user interface. Overall, these results support the assertion that mSCS technology acceptance and usability were high among health care aides.

We found that the performance expectancy construct was a predictor of intention to use the mSCS. In other words, the health care aides accepted the mSCS because it improved their ability to care for their clients. This finding is consistent with the results of previous studies on the application of UTAUT in mHealth, health, rehabilitation, and assistive technologies [28,32,33]. Lim et al [32] found that performance expectancy had a significant influence on primary care physicians’ acceptance of mHealth technology (ie, use of mHealth apps to support their clinical work). Liu et al [28] revealed that performance expectancy had a significant influence on the acceptance of GPS technology among people living with dementia and family caregivers. Finally, Liu et al [33] reported that performance expectancy was the most significant factor in new technologies for rehabilitation acceptance.

Health care aides had the perception that mSCS assisted their workflows. Qualitative and quantitative analyses showed that the perception of usefulness and relative advantage of the mSCS in health care aides daily work, and the workflow was superior compared with not using an electronic system. The usefulness and relative advantage of the mSCS are related to documentation and charting tasks. In other words, as the health care aides believed that the mSCS saved time with documentation and charting tasks, resulting in more time to provide care to older adults.

Effort expectancy was not a factor affecting intention to use the mSCS. In fact, although not statistically significant, we obtained a negative correlation between effort expectancy and intention to use the mSCS. This meant that the health care aides perceived some issues regarding mSCS use, although they would continue to use this technology if they are able to do so. This result is consistent with that of previous studies [33-36]. Liu et al [33] found that effort expectancy was not a significant factor in the acceptance of new technologies for rehabilitation. A meta-analysis conducted by Taiwo and Downe [34] reported that the effects of effort expectancy on intention to adopt were weak or had no significance. Braun [35] found support for the premise that users’ effort expectancy partially predicted their intention to use social networking websites [35]. As far as our study is concerned, the fact that effort expectancy was not a factor in the intention to use the mSCS may have different explanations. The most plausible reason for this is that the mSCS user interface still requires improvement. Comments from the health care aides during the focus groups revealed that they “experienced difficulties completing the report due to a lack of options [in the user interface],” and sometimes they encountered “interface issues.”

In this study, social influence was not a factor affecting intention to use the mSCS. In other words, the health care aides were not influenced by the degree of difficulty or social pressure from their colleagues or supervisors toward using the mSCS. As is evident in the literature, the role of social influence on behavioral intention to use technologies has mixed results. In some studies, social influence was a factor that affected the intention to use the technologies under study [28], whereas in other studies, this was not the case [23,33]. The meta-analysis conducted by Taiwo and Downe [34] revealed small effect sizes for social influence, showing conflicting evidence that social influence is salient for technology acceptance. Future research on technology acceptance should continue to explore whether social influence affects intention to use technologies.

The combined results of performance expectancy, effort expectancy, and social influence on intention to use the mSCS suggest the following: in a nonmandatory health care setting, no matter how difficult it is to use the mSCS, or whether there is external social pressure to use the mSCS, health care aides will only accept the mSCS if they perceive it will help them attain their goals at work.

We found that facilitating conditions did not affect usage behavior in the mSCS. This finding was surprising, as previous studies in the areas of eHealth, mHealth, and assistive and rehabilitation technologies have consistently found the opposite [23,28,33,37,38]. One possible reason we obtained this result is because the technology under study was used under *ideal* conditions, that is, we had a dedicated project coordinator who served as an *intermediary* between the health care aides and the technology provider (ie, Clinisys EMR Inc), which meant that issues with use were immediately resolved, and we had a dedicated nurse manager who inputted older adults' information into the mSCS. These 2 conditions may not have allowed the health care aides to experience the importance of having good technical support, as they did not have to interact with the service provider.

Finally, we found that intention to use predicted usage behavior with the mSCS. This result supports the core tenets of the UTAUT model, that is, if health care aides have the intention to use the technology (ie, mSCS), they will use it if they are able to do so. In more concrete terms, the mSCS was accepted, and as a result, it would be adopted by health care aides.

Limitations

This study has 5 limitations. First, as this study was conducted in only one long-term care facility, it represents a starting point for investigating the crucial factors that influence health care aides' intention to adopt a mobile app and usage behavior of a mobile app. Consequently, we caution against generalizing our results to other health service providers as well as other long-term care facilities. Second, all but one of our participants were identified as female (59/60, 98%). In the future, it would be ideal to have an equal number of men and women represented in the data analyses to examine gender differences. Third, the health care aides who returned the technology acceptance and usability questionnaire might have been inclined to prefer the mSCS and, thus, were willing to fill out the questionnaire. Fourth, the results of our pre- and posttest for our variables resulted in a statistical power that was lower than the conventional cutoff value of 0.80. Thus, future studies should pursue larger sample sizes when the effect size is low. Fifth, we did not record the cultural or language demographic characteristics of the health care aides; as a result, we are unable to assert whether cultural or language factors affect the technology acceptance and usability of the mSCS for this population. Finally, we experienced a ceiling effect (ie, most of the values obtained for our constructs approached the upper limit of the technology acceptance and usability questionnaire). Thus, in future studies, it would be reasonable to use a 7-point Likert scale in technology acceptance and usability studies, especially when the scale is new.

Conclusions

This study clearly showed that mSCS was accepted by the health care aides. The study also surpassed expectations regarding the technological acceptance of the mSCS, which were found to have been met for all the health care aides. In conclusion, the results suggest that health care aides would continue to use the mSCS if they were able to do so. The health care aides found the mSCS to be useful, portable, and reliable. They perceived that mSCS addressed the workflow issues.

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Authors' Contributions

AMC and LL led the overall design of the evaluation, and CD contributed to the design. ER conducted the data analysis, which was led and supervised by AMC. HPLP led the data collection and played the role of a project coordinator. AMC drafted the manuscript and HPLP, CD, ER, SK, and LL edited and reviewed the manuscript. LL was the principal investigator and the grant holder.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Correlational analyses of confounding variables.
[DOCX File , 37 KB - aging_v5i2e37521_app1.docx]

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Abbreviations

AVE: average variance extracted
ICR: internal composite reliability
ICT: information communication technologies
mHealth: mobile health
mSCS: Mobile Smart Care System
PLS: partial least squares
UTAUT: Unified Theory of Acceptance and Use of Technology

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Original Paper

Predicting Falls in Long-term Care Facilities: Machine Learning Study

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Abstract

Background: Short-term fall prediction models that use electronic health records (EHRs) may enable the implementation of dynamic care practices that specifically address changes in individualized fall risk within senior care facilities.

Objective: The aim of this study is to implement machine learning (ML) algorithms that use EHR data to predict a 3-month fall risk in residents from a variety of senior care facilities providing different levels of care.

Methods: This retrospective study obtained EHR data (2007-2021) from Juniper Communities' proprietary database of 2785 individuals primarily residing in skilled nursing facilities, independent living facilities, and assisted living facilities across the United States. We assessed the performance of 3 ML-based fall prediction models and the Juniper Communities' fall risk assessment. Additional analyses were conducted to examine how changes in the input features, training data sets, and prediction windows affected the performance of these models.

Results: The Extreme Gradient Boosting model exhibited the highest performance, with an area under the receiver operating characteristic curve of 0.846 (95% CI 0.794-0.894), specificity of 0.848, diagnostic odds ratio of 13.40, and sensitivity of 0.706, while achieving the best trade-off in balancing true positive and negative rates. The number of active medications was the most significant feature associated with fall risk, followed by a resident's number of active diseases and several variables associated with vital signs, including diastolic blood pressure and changes in weight and respiratory rates. The combination of vital signs with traditional risk factors as input features achieved higher prediction accuracy than using either group of features alone.

Conclusions: This study shows that the Extreme Gradient Boosting technique can use a large number of features from EHR data to make short-term fall predictions with a better performance than that of conventional fall risk assessments and other ML models. The integration of routinely collected EHR data, particularly vital signs, into fall prediction models may generate more accurate fall risk surveillance than models without vital signs. Our data support the use of ML models for dynamic, cost-effective, and automated fall predictions in different types of senior care facilities.

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KEYWORDS

vital signs; machine learning; blood pressure; skilled nursing facilities; independent living facilities; assisted living facilities; fall prediction; elderly care; elderly population; older adult; aging

Introduction

Background

Falls are a serious and complex safety concern, leading to mortality, morbidity, and increased health care costs associated with aging. Accidents are the fifth leading cause of death in older adults, and falls account for two-thirds of all accidental deaths [1]. Individuals who live in institutions fall more often (1.5 falls per bed per year) than community-living individuals, of whom the latter are generally healthy older people [1]. Between these 2 groups, it is estimated that 60% will experience a fall each year [2]. Most falls have a multifactorial origin. Previously reported fall risk factors include gait impairment, balance impairment, age, sex, cognitive decline, diminished vision, fall history, medications that affect the central nervous system, and several comorbidities [3-10]. Current fall risk profiles in nursing homes rely primarily on strength, gait, and balance measures [11]. Frequent administration and quantification of instruments that consider comprehensive risk factors create a challenge both in terms of impeding workflow and interpreting results. Evidence for the best choice for fall risk assessment in long-term facilities remains limited [2,12,13].

Electronic health records (EHRs) contain routinely collected real-time information that represents most fall risk factors and thus offer the potential for dynamic surveillance of senior residents in long-term facilities to identify short-term fall triggers. Although the wide range of fall risk factors embedded in EHR data poses methodological challenges to most traditional statistical approaches, machine learning algorithms (MLAs) can screen a multitude of interacting risk factors from big data. Machine learning (ML) is a subfield of artificial intelligence that can use sample data to build a model for predicting future outcomes or identifying hidden patterns of intrinsic structures within input data without explicit programming or data engineering. The two most commonly used ML methods are supervised and unsupervised learning. Supervised learning trains algorithms based on labeled training data, whereas the unsupervised learning approach does not require labeled training and can find structures within the data. Several EHR-based MLAs have been developed for fall risk predictions in hospitalized patients [14-18]. Few studies have explored the utility of ML approaches for senior residents in community-dwelling or long-term assisted living facilities [19-23]. Here, we developed an EHR-based supervised ML model using a gradient boosting (Extreme Gradient Boosting [XGBoosting]) algorithm to evaluate fall incidents within a 3-month window. By implementing advanced MLAs on EHR data from different types of long-term care facilities, we expected that our model would uncover the impact of a wide range of clinical and pathophysiological fall predictors across heterogeneous cohorts. We also hypothesize that these MLAs will outperform traditional fall risk assessments and standard ML techniques that are less compatible with EHR data in terms of dealing with missing data and class imbalances. Our previous studies with EHR data have shown that XGBoosting outperforms other ML models, such as logistic regression and simple forms of neural network-based models [24].

As most residents at long-term care facilities are at heightened risk of falls, more accurate short-term risk predictions would help identify individuals who may require more assistance with daily activities and enable care practices that are tailored to address short-term changes in fall risk and provide more dynamic fall risk profiles of residents for staff. Although previous research has primarily focused on identifying factors that increase the risk of falls, special emphasis must be placed on identifying factors that can reduce fall risk. In this context, it is critical to explore both the positive and negative associations between individual predictors and fall risk.

Objective

The primary objective of this study is to determine the utility of ML in predicting short-term falls in long-term senior care settings and determine whether performance accuracy remained consistent in different types of facilities that are characterized by different levels of residents' frailty and staff care (independent living, assisted living, and nursing homes). The inclusion of various measurements associated with vital signs, in addition to traditional risk factors that are incorporated into standard fall risk assessments, was one of the key designs of our ML models. Vital sign measures, such as blood pressure and respiratory rate, are dynamic parameters that reflect real-time changes in physiological function because of aging, frailty, different diseases, and treatments [25]. Although changes in vital signs are recognized as potential precursors to falls [26], the predictive value of these variables for fall risk in long-term senior care facilities has not been fully explored.

Methods

Data Source and Inclusion and Exclusion Criteria

This study used data collected from a proprietary database containing EHR data from senior living communities (Juniper Communities, LLC) in the United States. The Juniper facilities included in this study were skilled nursing facilities, independent living facilities, assisted living facilities, and other non-major facilities without specific designations. Data were extracted from 2007 to 2021. Data were deidentified in compliance with the Health Insurance Portability and Accountability Act. As this study constituted nonhuman participants research per 45 Code of Federal Regulations 46.102, institutional review board approval was not required. Initially, the Juniper EHR contained data from 2785 residents. The first step of the filtration process removed residents who did not have the first measurement time, the last measurement time, or any EHR data, including diagnostic codes. We then excluded all residents age <60 years. Finally, we removed all residents who did not have at least 1 month of data available before the MLA runtime, defined as the time at which our algorithm predicted a fall. Figure 1 shows the participant inclusion and exclusion diagram.

Participants and fall incidence (positive cases) were identified according to both the International Classification of Diseases (ICD), Ninth Revision, and the ICD, Tenth Revision, as the EHR included resident data from October 2015. These codes included W00-W119 and R29.6 [27]. For a portion of the study cohort that did not have fall ICD codes, fall incidences were identified from string searching progress notes with fall-related strings, such as “fall” and “on the floor.” To meet the gold standard definition of our study, the fall had to occur within a 3-month period before the last measurement, as shown in (Figure 2A). The last measurement time was defined as the time at which data were collected from the resident. We used the distribution of the time differences between the fall incidents and the last measurement time (Figure 2B) of our cohort as a guideline for selecting the prediction window. We determined that the selection of a 3-month prediction window offered a good trade-off between maximizing the number of positive cases; that is, participants who experienced a fall within the given time while remaining within a reasonably short prediction window. A shorter prediction window reduces the number of positive cases, leading to a more imbalanced data set.

Figure 1. Participant encounter inclusion and exclusion diagram. EHR: electronic health record.

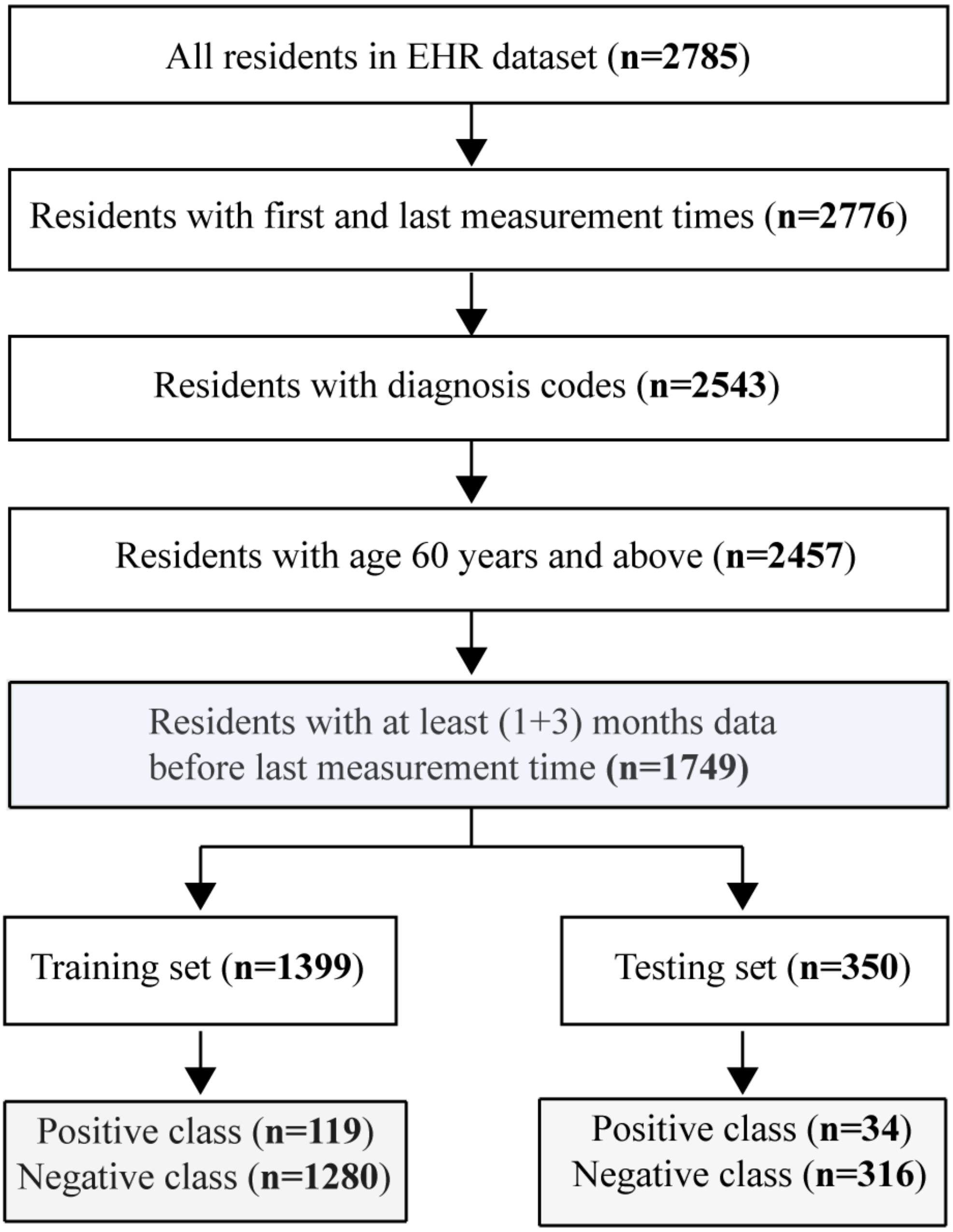
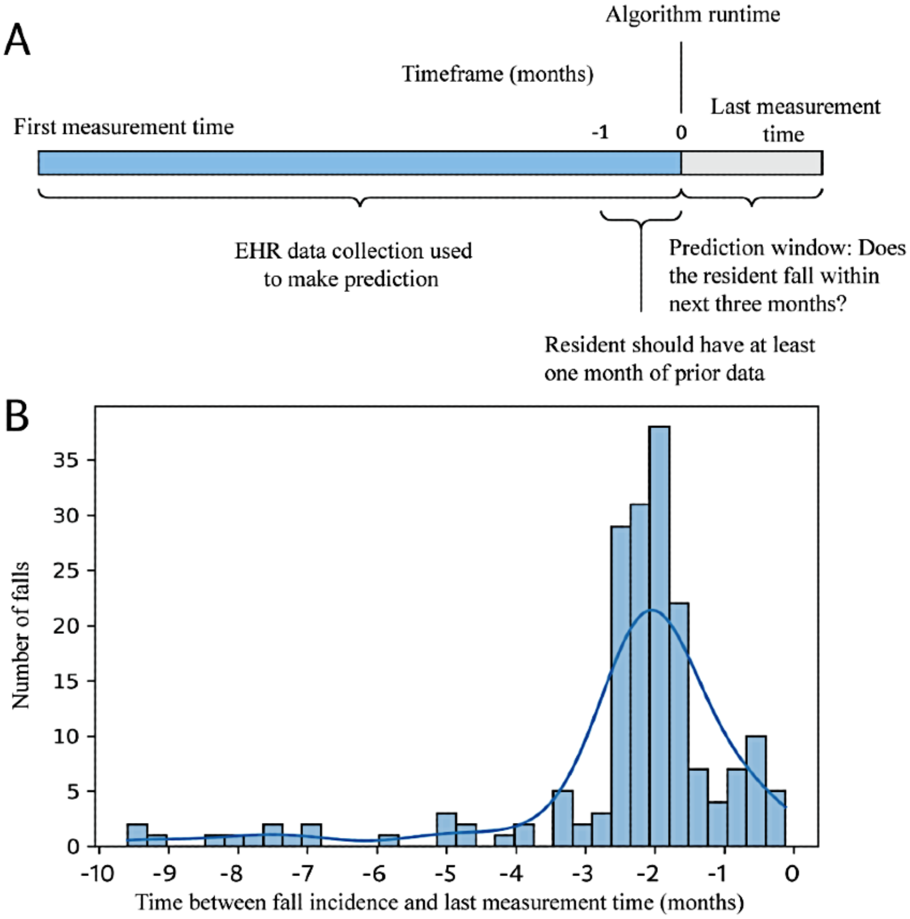


Figure 2. (A) Study design timeline. (B) Selection of the optimal prediction window based on the distribution of the fall incidence time. EHR: electronic health record.



ML Input Features for Fall Prediction

We conducted a literature search to gather previously reported fall risk factors and determine whether they could be identified within the EHR system based on relevant ICD codes, string searches, or keyword queries. We included several major risk factors such as age, sex, previous fall history, weakness, dizziness, cognitive impairment, dementia, depression, impaired mobility, and gait or balance abnormalities [3,28,29]. The fall history was included as the time difference between the MLA runtime and the most recent history of falls normalized to a year. In addition to dementia, depression, and mood disorders, we included other comorbidities [30] and medications implicated in fall risk [31-33] (Table S1 in Multimedia Appendix 1). Medications included benzodiazepines [9,34], antiepileptics [35], angiotensin-converting enzyme inhibitors [32], antidepressants [9], antipsychotics [36], narcotics [37], diuretics [36,38], β-blockers [39], antihistamines [33], neuromuscular blocking agents [40], calcium channel blockers [32], antiarrhythmics [41], sedatives, and hypnotics [9]. The participants' vital sign measures and laboratory results were queried using the key names in the EHRs. The complete list of features and associated ICD codes can be found in Tables S1 and S2 in Multimedia Appendix 1. The feature importance metric was used to preselect the best features for the ML models, reducing the number of features from 250 to 68. Bolded features in Table S1 in Multimedia Appendix 1 are those that were preselected on the feature importance metric. These features included age, sex, specific vital sign measurements (diastolic and systolic blood pressure, heart rate, respiratory rate, and temperature), specific physical and movement features (height, weight, history of falls, and lower extremity fracture or dislocation), specific comorbidities (hypertension, chronic heart failure, stroke and cerebrovascular, and number of active diseases), and medications (benzodiazepines, angiotensin-converting enzyme inhibitors, antiepileptic and anticonvulsants, and total number of active medications). In addition to feature importance, the Shapely Additive Explanations (SHAP) analysis enhances the interpretability of the model by showing positive and negative associations and their strengths between individual features and fall risk.

For vital sign measurements, 4 months of data were used before the algorithm runtime. We filtered out data (vital signs and laboratory measures) that were identified as extreme outliers using the physiological minimum and maximum values. After removing these outliers, summary statistics, including minimum (min), maximum (max), mean, standard deviation (SD), last measurement (last), and the number of measurements (number), were used as input features. We calculated the summary statistics of the patient data over the last 1 month. Features related to comorbidities or medications were added as either previous or current comorbidities and medications. Given that our data did not provide structured information about medication dosage, we were not able to include dosage as an input feature.

Comparison With Standard of Care

An internal fall risk assessment conducted by Juniper Communities staff served as a comparator. Participant scores (0-25) were tallied from several items, including the level of consciousness or mental status, history of fall, ambulation elimination, vision, gait, balance, medications, systolic blood pressure, and previous predisposition (eg, vertigo, obesity, osteoporosis, or Parkinson disease).

ML Model

Our primary model, XGBoosting, was a gradient boosting algorithm [42] implemented in Python [43]. XGBoosting combines the results from various decision trees to obtain the prediction scores. Within each decision tree, the resident population was split into successively smaller groups, as each tree branch divided the residents who entered it into 1 of 2 groups based on their covariate value and a predetermined threshold. Fall residents were represented at the end of the decision tree, which were a set of leaf nodes. After the XGBoosting model was trained, successive trees were developed to improve the accuracy of the model. Successive iterations of trees use gradient descent on the prior trees to minimize the error of the next tree that was formed. XGBoosting has been shown to exhibit excellent performance for a wide range of classification problems in acute and chronic conditions [44-48]. For comparison with the structurally complex XGBoosting model, logistic regression and multilayered perceptron models were also trained and tested. A multilayered perceptron is a common network architecture with feed-forward neural networks composed of several layers of nodes with unidirectional connections. Unlike the XGBoosting model, logistic regression and multilayered perceptron models are unable to incorporate missing data; therefore, the median of observation was used for imputation of the features. In addition, we standardized our data for both the logistic regression and multilayered perceptron models. All the 3 models were trained using the same 68 inputs. The development environment of our MLAs (software package, library, and version) is summarized in Table S3 in Multimedia Appendix 1.

We used a standard approach to train ML models. We partitioned the data set into a train:test ratio of 80:20 with stratified sampling because the positive class was relatively small with respect to the negative class. Both the training and test sets included a random mix of all four types (skilled nursing facilities, assisted living facilities, independent living facilities, and others) of long-term facilities within Juniper Communities. All the models underwent hyperparameter selection using a 5-fold cross-validation grid search. The optimization of hyperparameters was confirmed by evaluating the area under the receiver operating characteristic (AUROC) curve for different combinations of hyperparameters included in the grid search. For XGBoosting, the optimization parameters were the maximum tree depth, regularization term (lambda), scale positive weight, learning rate, and number of estimators. The scale positive rate can be readily optimized within the XGBoosting algorithm to handle class imbalance in the data set (a lower number of residents who experienced a fall). We used a parameter space of (4, 6, 8, 10) for tree depth, (0.5, 1.0, 2, 3) for lambda, (1, 3, 5, 7, 9, 11, 13) for scale positive weight, (0.0001, 0.001, 0.01, 0.1) for learning rate, and (50, 75, 100, 125, 150, 500) for the number of estimators. The XGBoosting model used 6, 1.0, 13, 0.001, and 75 as the optimized values for the aforementioned parameters. For logistic regression, the optimization parameters were the penalty term, class weight, optimization problem solver, and inverse of regularization strength. The optimization parameters of the multilayered perceptron model included the maximum iteration, hidden layer size, and learning rate. For the logistic regression and multilayered perceptron models, missing values were handled using various imputation approaches. Missing measures of vital signs were imputed using the forward and backward filling approaches. For all other features, the mean measurement of the features across all the training set data was used for the imputation. For the logistic regression model, the inputs were scaled using a standard scaler from scikit-learn. The optimization algorithms for the logistic regression model included the limited-memory Broyden-Fletcher-Goldfarb-Shanno algorithm and L2 regularization. The multilayered perceptron model incorporated a hidden layer of size 250. The convergence of the solver iteration was determined either by reaching a maximum number (100) of iterations or by reaching a value of 1e-9 for the tolerance optimization parameter. All other parameters were kept at default values from the scikit-learn multilayered perceptron classifier. The performance of each model was assessed against the test data set with respect to the receiver operating characteristic (ROC) curve, sensitivity, and specificity. The confidence intervals (CIs) for these metrics were constructed using 1000 bootstrapped samples. SHAP [49] analysis was performed to evaluate the feature importance.

Exploratory Analyses

Several exploratory analyses were conducted in this study. In the first experiment, we examined how the performance of the XGBoosting, logistic regression, multilayered perceptron, and comparator changed after reducing the prediction window to 2 months. We conducted a secondary experiment in which we separated the training and testing sets based on the type of facility (skilled nursing, independent living, and assisted living facilities). In the first case, data from the skilled nursing facility were used as the testing set, whereas data from all other facilities were used for model training. In the second case, assisted living facility data were used as the testing set, whereas data from all other facilities were used for model training. Owing to the small number of positive cases, independent living facilities were not tested separately. We conducted a third experiment in which we modified the input features of all 3 ML models to evaluate their impact on the model performance. First, we removed vital signs from the input features. Then, we included only the vital signs and demographic information (age and sex) and removed all other features, such as fall history, comorbidities, and medical conditions.

Results

Data Set Characteristics

In total, 2785 residents were included in this study, of whom 153 (153/2785, 5.49%) fell within the 3-month prediction window of our algorithm, as defined by our gold standard. The number of women was approximately twice that of men. Group differences were calculated using an exact binomial test for noncontinuous variables and 2-tailed Welch *t* test for continuous variables to handle the unequal variance associated with the 2 groups. The fall incidents varied among the types of facilities (Table S4 in Multimedia Appendix 1). Skilled nursing facilities had the highest (49/489, 10%) and independent living facilities had the lowest (5/69, 7%) fall incidents. Table S5 in Multimedia Appendix 1 summarizes the demographic and diagnostic information for nonfall residents (negative cases; age: mean 85.7, SD 9.5 years) and fall residents (positive cases; age: mean 86.6, SD 8.2 years).

Model Performance

The complete list of performance metrics for the MLAs and comparator is shown in Table 1. The ROC curves for the hold out test set are shown in Figures 3A and 3B. The XGBoosting model exhibited the highest performance with an AUROC of 0.846 for the prediction of falls within the next 3 months. The logistic regression model and the multilayered perceptron model demonstrated AUROCs of 0.711 and 0.697, respectively. The comparator (Juniper fall assessment) had an AUROC of 0.621. We selected an operating sensitivity of 0.70 for all 3 ML models and 0.35 for the comparator (based on the Juniper fall risk score threshold). The feature importance plot (Figure 4) shows the most important XGBoosting features, including the number of active medications, number of active diseases, SD of weight, mean diastolic blood pressure, and SD of respiratory rate. Younger age, lower weight fluctuations, and a larger number of active diseases were associated with a lower fall risk. A higher number of active medications was associated with a higher risk of falls. A higher mean value of diastolic arterial blood pressure (DiasAB) and higher fluctuations in respiratory rate were associated with lower fall risk.

Table 1. Performance metrics and 95% confidence intervals (CIs) of the gradient-boosted decision trees model (Extreme Gradient Boosting) with the top 68 features, the Juniper fall risk assessment score, and other machine learning models (logistic regression and multilayered perceptron) for the 3-month prediction of fall.

Variable	Extreme Gradient Boosting	Logistic regression	Multilayered perceptron	Juniper fall risk
Area under the receiver operating characteristic curve (95% CI)	0.846 (0.794-0.894)	0.711 (0.645-0.773)	0.697 (0.624-0.765)	0.621 (0.547-0.693)
Sensitivity (95% CI)	0.706 (0.577-0.833)	0.706 (0.553-0.859)	0.706 (0.571-0.833)	0.351 (0.217-0.485)
Specificity (95% CI)	0.848 (0.809-0.888)	0.614 (0.560-0.668)	0.612 (0.566-0.657)	0.883 (0.854-0.911)
Positive likelihood ratio	4.647	1.828	1.813	3.014
Negative likelihood ratio	0.346	0.479	0.481	0.733
Diagnostic odds ratio (95% CI)	13.400 (6.026-29.796)	3.816 (1.764-8.256)	3.766 (1.741-8.147)	4.113 (1.881-8.995)
True positive	24	24	24	12
True negative	268	194	193	279
False positive	48	122	123	37
False negative	10	10	10	22
F1[a]	0.393	0.262	0.248	0.289

[a] *F* score is defined as the harmonic mean between precision and recall.

Figure 3. Row 1: Receiver operating characteristic (ROC) curves of the Extreme Gradient Boosting (XGBoost) model for three-month prediction compared with (A) the Juniper fall risk assessment and (B) other machine learning ML models. Row 2: ROC curves of the XGBoost model for a two-month prediction window compared with (C) the Juniper fall risk assessment and (D) other ML models. Row 3: ROC curves across different facilities. (E) Skilled nursing facility separated as a testing set and (F) Assisted living facility separated as a testing set. AUROC: area under the receiver operating characteristic; ML: machine learning; MLP: multilayered perceptron; LR: logistic regression.

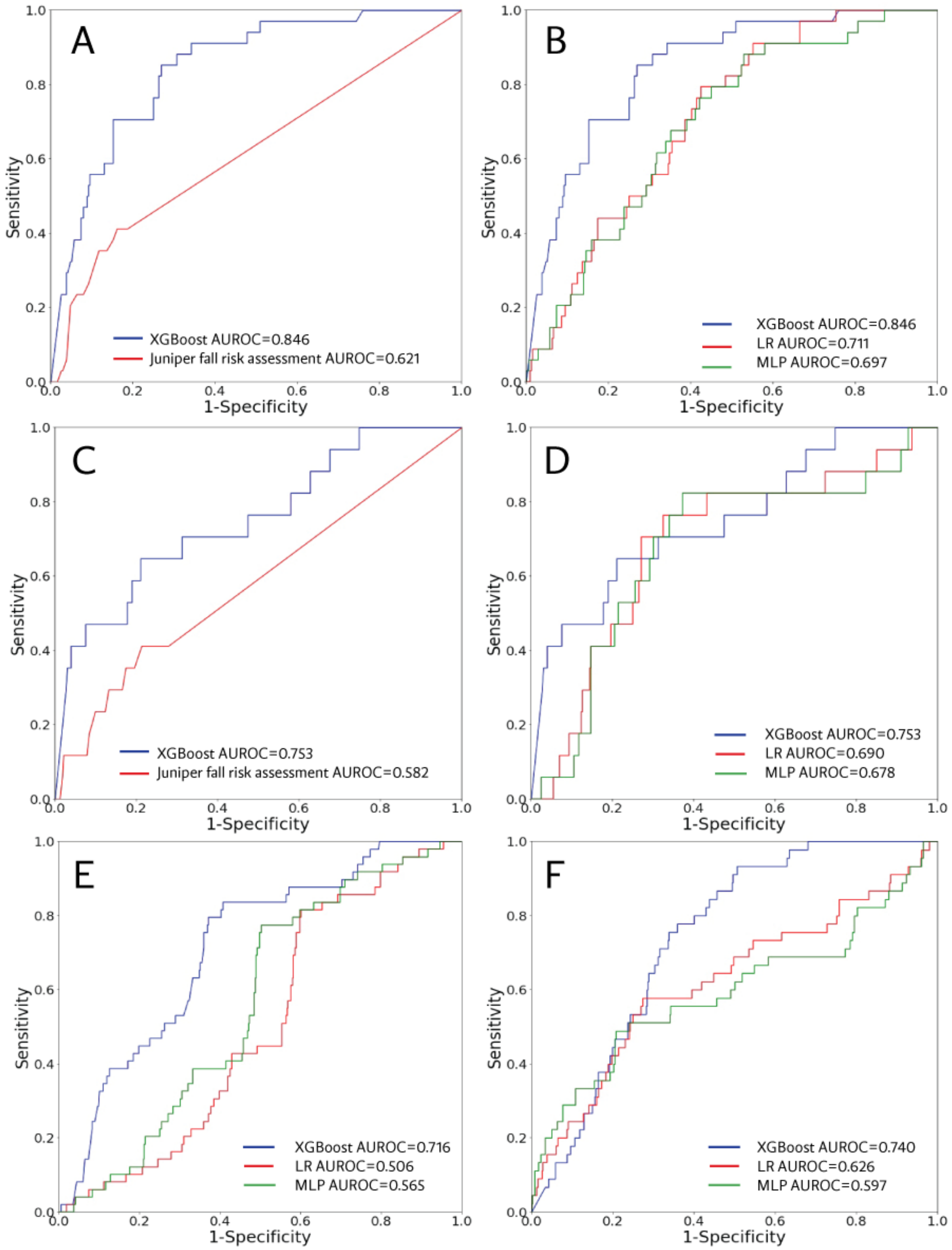
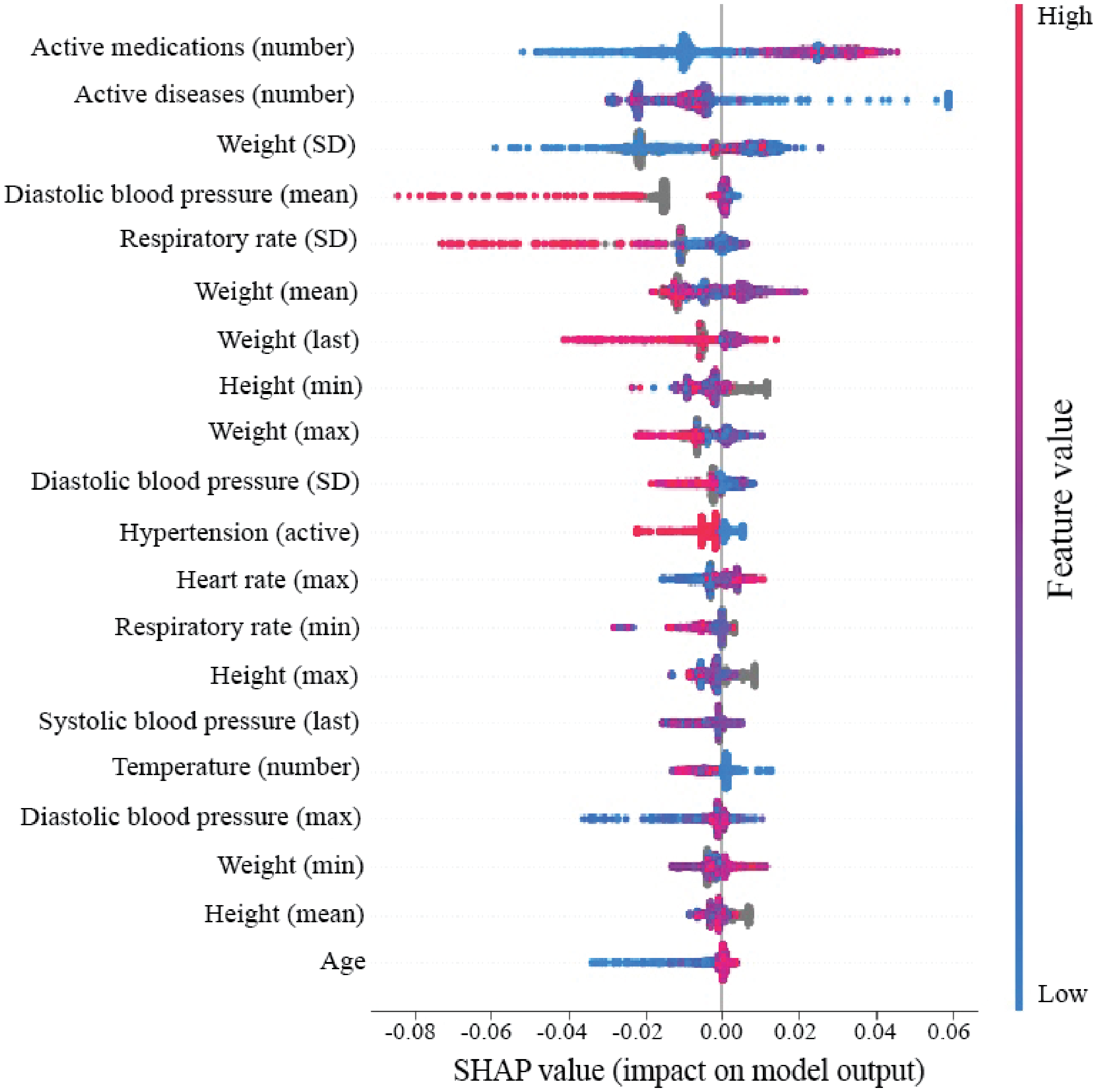


Figure 4. Feature correlations and distribution of feature importance for the Extreme Gradient Boosting (XGBoost) model at the three-month prediction window. The y-axis on the SHAP plot presents the features in order of importance from top to bottom. The SHAP values on the x-axis quantify the magnitude and direction in which each feature impacts the model prediction. SHAP: Shapely Additive Explanations.



Reduction of Prediction Window

The ROC curves for the 2-month prediction window on the hold out test set are presented in Figures 3C and 3D. The XGBoosting model exhibited the highest performance with an AUROC of 0.753. The logistic regression and multilayered perceptron models demonstrated AUROC of 0.690 and 0.678, respectively. The AUROC associated with the Juniper fall risk assessment score was 0.582. Table S6 in Multimedia Appendix 1 presents additional performance metrics. Figure S1 in Multimedia Appendix 1 shows the XGBoosting SHAP plot for the 2-month prediction window.

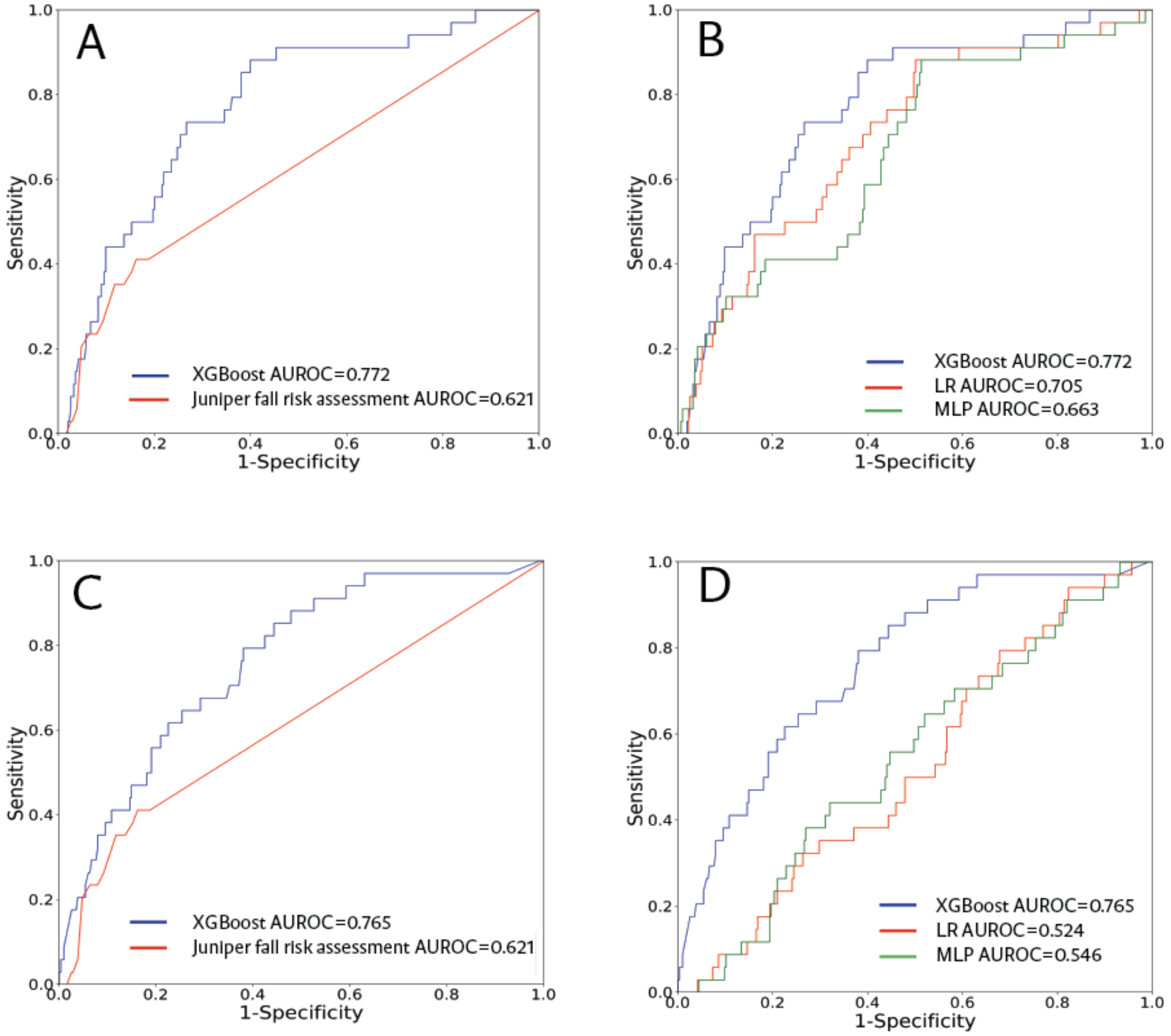
Separating Training and Testing Data Set by Facility Type

The EHR data set used in this study contained data from various care facilities. As part of the post hoc analyses and external validation, we separated the training and test sets based on facility type. The ROC curves for the models are shown in Figures 3E and 3F, showing that the XGBoosting AUROCs were higher than all other predictors for both the skilled nursing facility (0.716) and assisted living facility (0.740) test sets.

Modifying Input Features

The ROC curves associated with the modified input features (3-month prediction window) are shown in Figure 5. When all variables related to vital signs were removed, the XGBoosting model maintained the highest performance with an AUROC of 0.772. Similarly, when using only demographic information (age and sex) and vital signs as input features, the XGBoosting model achieved the best performance, with an AUROC of 0.765. The SHAP plots of the models with the modified features are shown in Figures S2 and S3 in Multimedia Appendix 1.

Figure 5. (A) Comparison between receiver operating characteristic (ROC) curves of Extreme Gradient Boosting (XGBoost) without vital signs and Juniper the fall risk model. (B) Comparison between ROC curves of XGBoost and other machine learning ML models without vital signs. (C) Comparison between ROC curves of XGBoost using only demographic information (age and sex) and vital signs and the Juniper fall risk model. (D) ROC curve of three ML models using demographic information and vital signs. AUROC: area under the receiver operating characteristic; ML: machine learning; MLP: multilayered perceptron; Logistic: Logistic Regression.



Discussion

Summary of the Study

We developed an EHR-based ML model for short-term fall prediction in different long-term care facilities. Initially, 250 features were extracted from the EHR data, although only 68 features passed the initial selection process based on the feature importance metric. These features were used to train the final XGBoosting, logistic regression, and multilayered perceptron models. Using individual data collected from the residents' EHR system, XGBoosting outperformed the Juniper fall risk assessment tool, which yielded only an AUROC of 0.621 versus 0.846 for XGBoosting. XGBoosting achieved a good trade-off in balancing the true positive and true negative rates (Table 1), outperforming the 2 other baseline ML models in both metrics.

Best EHR-Based Features for Fall Prediction

Unlike standard fall risk assessment tools, MLA models can flag the importance of individual variables in predicting fall risk. The number of active medications was identified as the most significant feature associated with a higher fall incidence, followed by a resident's number of active diseases and weight changes. The impact of the number of medications on fall incidents has been reported by previous observations in nursing homes, demonstrating that fall risk is associated with polypharmacy regimens that include at least one fall-increasing drug [41]. The 68 selected (out of 250) best features included several well-established fall risk factors, such as age, sex, history of falls, benzodiazepine, and antiepileptic medications. Except for the number of active medications, active diseases, hypertension, weight, and age, all other features with the highest ranking were measurements of vital signs, which were not used in the Juniper fall assessment. The most significant vital sign measure was mean diastolic blood pressure, with higher values inversely correlated with fall risk. Given that most of our study participants were women, this finding is also in line with a previous study on the relationship between blood pressure and falls in community-dwelling adults aged ≥60 years [50], where an increase in diastolic and systolic blood pressure reduced the risk of falls in women. The negative correlation between the number of active diseases and fall risk was likely because of the expected mobility restrictions of residents with multiple concurrent comorbidities. Separating weakness, dizziness, and unsteadiness due to other comorbidities did not affect the performance. Including the difference between consecutive vital sign measurements as individual features also did not improve the performance; therefore, we removed these features from the feature matrix to simplify our model.

Reduction of Prediction Window

Although the performance of all 3 MLAs and the comparator risk stratification tool used by Juniper relapsed after reducing the prediction window to 2 months, the XGBoosting model continued to exhibit the highest performance. The observed performance decline associated with the 2-month prediction window was likely because of the lack of data, as illustrated in Figure 2B (loss of positive cases from 153 to 80). The optimal prediction window (3 months) was selected based on the frequency of the data present in the EHR. Owing to the importance of vital signs in predicting short-term fall risks, more frequent and consistent collection of these variables may allow shorter prediction windows without losing accuracy.

External Validation

In addition to our primary model, which used EHR data from various facilities for training and testing, we explored other models in which one of the facilities was excluded from the training set but used for external validation. In both test cases, the XGBoosting-based model outperformed other ML algorithms. The XGBoosting AUROC in the assisted living facility test case was slightly higher (0.740) than that in the skilled nursing facility test case (0.716). This difference may be explained by the presence of a wider range of medication and comorbidities and more frequently measured vital signs in skilled nursing facility residents, making this cohort potentially a better training set for other facilities with fewer disabilities and medical conditions in their residents. In general, individuals living in skilled nursing facilities demand a higher level of nursing care and assistance with their daily activities than residents in assisted living communities or independent living facilities. In this study, the skilled nursing facility fall incidents were approximately 1.4 times higher than those of independent living facility fall incidents, which is consistent with previous epidemiological reports [28].

Impact of Vital Signs

Several previous studies have identified history of falls as one of the most prominent risk factors for falls [51,52]. In our cohort, the history of falls was among the 68 preselected features, although it did not always rank among the top 20. When removing vital signs from the input features, fall history, lower extremity fractures, dizziness, and vertigo appeared among the top-ranking features. Moreover, our findings suggest that the combination of vital signs with traditional risk factors can achieve higher prediction accuracy than using either group of features alone.

Implications of Findings

The Centers for Medicare and Medicaid Services facilities are required to complete a fall risk assessment upon residents' admission, using the minimum data set (MDS) tool. Given that reassessments are not conducted frequently [53-55], changes in a resident's fall risk status may not be detected in a timely manner. The United States Centers for Disease Control has established the Stopping Elderly Accidents, Deaths & Injuries program [56] to evaluate clinical fall risk prevention programs and provide best practice recommendations. The existence of the Stopping Elderly Accidents, Deaths & Injuries program highlights the gap in existing risk prediction and risk stratification tools that are generalizable and have high accuracy. Commonly used fall risk stratification tools, such as the Morse Fall Scale, St Thomas's risk assessment tool in falling inpatients, and the Berg Balance Scale [31,57], rely on a clinician's assessment of gait, mental status, and mobility. As Juniper facilities have their own internal fall risk assessment, this was an appropriate comparator for our study, as opposed to comparing our MLA with any of the aforementioned tools. Traditional models overlook other significant fall risk factors that we identified in our ML models, such as diastolic blood pressure and respiratory rate, which are measurements easily obtained from EHR data without interrupting the clinical workflow. The sensitivity of these tools is inconsistent across the literature, ranging from 33.33% to 95% [58]. Using the MDS data set, the study by Marier et al [53] examined the use of MDS in tandem with EHR data, as the latter incorporates more frequent clinical measurements that may indicate changes in an individual's health status, thus potentially providing improved risk assessment [51]. The study determined that the use of EHR data improved fall risk identification by 13% compared with using only MDS data, which may be attributed to the fact that EHR is updated more frequently. Long-term care facilities have a lower rate of EHR implementation and use than other clinical settings (18%-48%). Using an XGBoosting-ML approach with EHR data without vital signs, the study by Ye et al [27] predicted fall incidents in hospitalized patients >65 years of age. At the 1- and 2-month prediction windows, they were able to predict only 55% to 58% of falls, which may be attributed to the lack of vital signs in their model. The EHR-based ML models for fall prediction are also cost-effective. Early identification of high-risk individuals can enable prompt intervention, such as the removal of environmental hazards or providing additional assistance with specific daily activities (bathroom visits), behavioral therapy, and exercise for muscle strengthening.

Study Limitations and Future Directions

Our study has several limitations. First, this study was restricted to retrospective data with highly imbalanced classes, missing data, and a higher prevalence of women in the data set. Although the ML algorithms implemented several optimization parameters to overcome these shortcomings (see Table S6 in Multimedia

Appendix 1 for model performance evaluation in women and men), the impact of EHR data quality and class balance on model performance could not be evaluated in this study. Regarding medication use, previous research has identified a dose-response relationship between medications, particularly benzodiazepines [59], and fall risk. Given that our data did not provide structured information about medication dosage, we were not able to include dosage as an input feature. The lack of standardized data collection methods for residents of different types of communities poses another methodological challenge. In particular, the collection of vital sign measures was highly variable across facilities and individuals. Given the importance of vital signs for fall risk, a more frequent and consistent collection of vital signs could leverage the extraction of fine-grained features (change in diastolic pressure between measurements). Although the study findings were validated across different types of Juniper care facilities, the generalizability of the findings outside Juniper Communities warrants further investigation. More than half of the individuals' fall incidences were not recorded using ICD codes (gold standard), and a manual search of their progress notes was required to identify these falls. Other study limitations include the lack of information regarding the severity of medical conditions and the potential that some fall events were missing from the EHRs. Further research and the use of our MLAs for fall risk prediction before implementation are warranted. Future directions for this research will focus on developing and implementing more interpretable ML models, such as the explainable boosting machine or deep learning techniques (eg, recurrent neural networks). This will allow for the incorporation of additional forms of digitized physiological and behavioral data that may be relevant to fall risks. Recurrent neural networks can process sequences of input data with variable lengths, making them applicable for recognizing patterns in electrocardiogram signals, motion, and speech notes [60-63].

Conclusions

This study shows that the XGBoosting technique can use a large number of features from EHR data to make short-term fall predictions with a better performance than conventional fall risk assessments and other ML models. The integration of routinely collected EHR data, particularly vital signs, into fall prediction models may generate a more accurate fall risk surveillance than models without vital signs. Our data support the use of ML models for dynamic, cost-effective, and automated fall prediction in different types of senior care facilities.

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Conflicts of Interest

RT, AG, SS, MH, GB, JH, JC, QM, and RD are employees or contractors of Dascena (Houston, Texas, United States). Dascena seeks to promote objectivity in research by establishing standards that provide a reasonable expectation that the design, conduct, and reporting of research will be free from bias resulting from Investigator financial conflicts of interest. As such, Dascena maintains an active and enforced Financial Conflict of Interest Policy, developed to be in conformance with Federal regulation 42 CFR Part 50 Subpart F and 45 CFR Part 94.

Multimedia Appendix 1
Supplementary materials.
[DOCX File , 676 KB - aging_v5i2e35373_app1.docx]

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Abbreviations

AUROC: area under the receiver operating characteristic
EHR: electronic health record
ICD: International Classification of Diseases
MDS: minimum data set
ML: machine learning
MLA: machine learning algorithm
ROC: receiver operating characteristic
SHAP: Shapely Additive Explanations
XGBoosting: Extreme Gradient Boosting

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Original Paper

A Model for Estimating Biological Age From Physiological Biomarkers of Healthy Aging: Cross-sectional Study

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Abstract

Background: Individual differences in the rate of aging and susceptibility to disease are not accounted for by chronological age alone. These individual differences are better explained by biological age, which may be estimated by biomarker prediction models. In the light of the aging demographics of the global population and the increase in lifestyle-related morbidities, it is interesting to invent a new biological age model to be used for health promotion.

Objective: This study aims to develop a model that estimates biological age based on physiological biomarkers of healthy aging.

Methods: Carefully selected physiological variables from a healthy study population of 100 women and men were used as biomarkers to establish an estimate of biological age. Principal component analysis was applied to the biomarkers and the first principal component was used to define the algorithm estimating biological age.

Results: The first principal component accounted for 31% in women and 25% in men of the total variance in the biological age model combining mean arterial pressure, glycated hemoglobin, waist circumference, forced expiratory volume in 1 second, maximal oxygen consumption, adiponectin, high-density lipoprotein, total cholesterol, and soluble urokinase-type plasminogen activator receptor. The correlation between the corrected biological age and chronological age was r=0.86 (P<.001) and r=0.81 (P<.001) for women and men, respectively, and the agreement was high and unbiased. No difference was found between mean chronological age and mean biological age, and the slope of the regression line was near 1 for both sexes.

Conclusions: Estimating biological age from these 9 biomarkers of aging can be used to assess general health compared with the healthy aging trajectory. This may be useful to evaluate health interventions and as an aid to enhance awareness of individual health risks and behavior when deviating from this trajectory.

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KEYWORDS

biological age; model development; principal component analysis; healthy aging; biomarkers; aging

Introduction

Biological age (BA) is a measure that quantifies where an individual is on the aging trajectory, assessed by the physiological profile, in comparison with the average person of that given chronological age (CA) within the population from which the equation was generated [1,2]. The predictive abilities of BA have been investigated in relation to age-related diseases such as cardiovascular disease (CVD) and type 2 diabetes (T2D) and some BA models have been found to predict mortality better than CA [3-5]. Parallels can be drawn between the changes that occur with aging and the changes that occur with an unhealthy lifestyle (especially related to physical inactivity and obesity) and the risk of developing CVD and T2D [6,7]. Therefore, the objective assessment of BA is an appealing approach for risk stratification and health literacy within public health promotion. However, truly measuring the current state of aging, and thereby objectively determining BA, would entail studies that follow people until they die and biomarkers representing all bodily functions. This is practically impossible and objectively unfeasible for use in a clinical setting. To circumvent this, BA models conceptualizing some mechanisms of aging are proposed as surrogate measures of BA. Despite a substantial research effort [8-10], there is still no agreement upon which panel of biomarkers to use when defining BA [11]. Targeting health promotion and management of lifestyle-related diseases, studies have developed several BA models that evaluate the degree of severity of the metabolic syndrome [12], the relation to waist circumference [13], the relation to physical fitness level [14,15], and the organ-specific health status [16], just to mention a few.

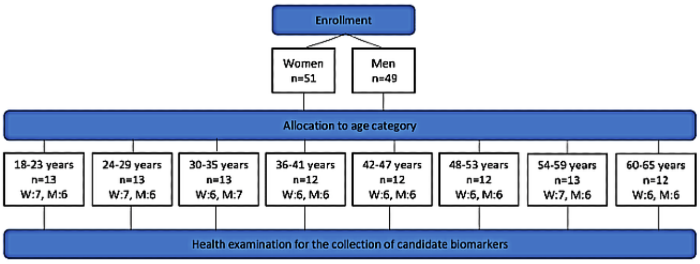
Increasing life expectancy and low fertility rates will have a profound impact on future resources and health care needs [17,18]. Forecasts anticipate that by 2050, people aged 65 years or above will constitute more than 20% of the population worldwide [19,20]. This is the decade in life where chronic diseases (eg, CVD, cancer, and T2D) frequently manifest [21], making healthy aging a key objective for research [22-24]. Healthy aging is defined as an extension of health span [25] also characterized by the "healthy aging phenotype" avoiding major chronic diseases as well as cognitive and physical impairments [22]. The important work from Lara and colleagues [26] has resulted in a panel of biomarkers of healthy aging. The purpose of our study was to apply a novel approach in order to incorporate biomarkers of healthy aging into a BA model. For this purpose, we used the first principal component (1PC) obtained from principal component analysis (PCA) as the method to assess individual BA. The goal was to create a BA model based on the healthy aging phenotype. In this way, the model can be used to identify those deviating from the healthy aging trajectory. Thus, no difference between average CA and estimated BA was expected in the study population of healthy individuals.

Methods

Participants

We included 100 healthy Danish individuals, 51 women and 49 men, between 18 and 65 years of age, to participate in an extensive health examination and the data collection of candidate biomarkers for the BA model. We recruited an equal number of women and men in each 5-year age category (Figure 1).

Figure 1. Flow chart of the allocation of enrolled participants in age categories. W: women; M: men.



Ethics Approval

The study was approved by the Regional Ethics Committee, Denmark (H-18031350), recorded as a Clinical Trial (Clinical Trial number: NCT03680768), and performed in accordance with the Helsinki declaration. Participants were informed orally and in writing about the study protocol and the potential risks before obtaining written consent.

Candidate Biomarkers

On the day of the health examination, participants came to the laboratory following an overnight fast and having avoided exercise activities and alcohol consumption for 24 hours and restrained from smoking for at least 4 hours. Information on the participants' previous and current health status included weekly alcohol consumption, smoking habits, present medications, past medical history, and self-administered questionnaires on physical activity level (Physical Activity Scale 2.1) [27] and quality of life (12-item Short Form version 2

[SF-12v2]). We gathered data on the candidate biomarkers listed in Table 1. These 32 variables are all physiological components of healthy aging that are associated with aging, age-related diseases, and are affected by changes in lifestyle. In addition, this panel of biomarkers covers multiple areas of human function, and they are suitable to study in humans in vivo. For a more comprehensive description of the rationale for including these 32 variables as candidate biomarkers, we refer to our protocol paper (Clinical Trial number: NCT03680768) [28].

Table 1. Candidate biomarkers measured in the study participants (n=100) showing means with SDs and outcome units per year increase (regression slope with 95% CI).

Biomarkers[a]	Mean (SD)	Slope (CI)
Body composition		
Weight (kg)	75.7 (13.1)	0.03 (–0.2 to 0.2)
Waist circumference (cm)	83.4 (9.8)	0.2 (0.05 to 0.3)
Hip circumference (cm)	101.4 (7.1)	–0.001 (–0.1 to 0.1)
Waist/hip ratio	0.8 (0.07)	0.002 (0.001 to 0.003)
Fat mass (%)	26.8 (8.3)	0.09 (–0.03 to 0.2)
Muscle mass (kg)	52.8 (10.9)	–0.05 (–0.2 to 0.1)
Metabolic health		
Fasting blood glucose (mmol/l)	5.1 (0.4)	0.01 (0.004 to 0.015)
HbA_{1c}[b] (mmol/mol)	32.8 (3.2)	0.12 (0.08 to 0.16)
AGEs[c] (AU)	1.8 (0.5)	0.027 (0.022 to 0.031)
Insulin (pmol/l)	44.4 (25.3)	0.05 (–0.32 to 0.42)
Triglycerides (mmol/l)	0.9 (0.4)	0.002 (–0.004 to 0.008)
Free fatty acids (µmol/l)	440 (212)	2.36 (–0.72 to 5.46)
Leptin (pg/ml)	8411 (9472)	–60.0 (–199.8 to 79.9)
Adiponectin (mg/ml)	11515 (6490)	106.6 (13.4 to 199.8)
HDL[d] (mmol/l)	1.5 (0.4)	0.01 (0.006 to 0.017)
LDL[e] (mmol/l)	2.8 (0.8)	0.02 (0.01 to 0.03)
TC[f] (mmol/l)	4.5 (0.9)	0.03 (0.02 to 0.04)
TC/HDL ratio	3.1 (0.9)	0.003 (–0.01 to 0.02)
Immune function		
CRP[g] (mg/l)	1.6 (3.4)	–0.04 (–0.09 to 0.01)
suPAR[h] (ng/ml)	2.09 (0.5)	0.01 (0.003 to 0.017)
Cell blood count		
Hemoglobin (mmol/l)	8.7 (0.8)	0.004 (–0.01 to 0.02)
Hematocrit (%)	41.6 (3.8)	0.03 (–0.03 to 0.09)
Cardiorespiratory function		
Diastolic BP[i] (mmHg)	78.0 (10.1)	0.4 (0.3 to 0.5)
Systolic BP (mmHg)	124.2 (16.7)	0.6 (0.3 to 0.8)
FEV_1[j] (L)	3.9 (0.9)	–0.02 (–0.04 to –0.01)
FVC[k] (L)	4.9 (1.0)	–0.02 (–0.04 to –0.01)
FEV_1/FVC ratio (%)	77.8 (11.6)	–0.13 (–0.20 to –0.05)
Physical capacity		
VO_{2max}[l] (ml/minute/kg)	39.3 (8.11)	–0.18 (–0.28 to –0.06)
STS[m] (stands)	23.4 (5.2)	–0.07 (–0.14 to 0.01)
Handgrip strength (kg)	36.0 (9.4)	–0.8 (–0.2 to 0.1)
Biceps strength (kg)	35.0 (11.5)	–0.1 (–0.3 to 0.03)
Quadriceps strength (Nm)	152.4 (51.3)	–0.7 (–1.4 to 0.1)

[a] Missing values were present in leptin (n=99), CRP (n=87), hematocrit (n=97), hemoglobin (n=99) and bicep's strength (n=98).

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

[c] AGE: advanced glycation end product.

[d] HDL: high-density lipoprotein.

[e] LDL: low-density lipoprotein.

[f] TC: total cholesterol.

[g] CRP: C-reactive protein.

[h] suPAR: soluble urokinase plasminogen activator receptor.

[i] BP: blood pressure.

[j] FEV_1: forced expiratory volume in 1 second.

[k] FVC: forced vital capacity.

[l] VO_{2max}: maximal oxygen consumption.

[m] STS: 30-second sit-to-stand chair rise.

Procedures

Variables of *body composition* were measured by dual-energy X-ray absorptiometry scanning (Lunar Prodigy Advance; Lunar). Waist and hip circumference were measured twice using a standard measuring tape. Variables of *metabolic health* and *immune function* were measured from venous blood samples. We extracted plasma and stored it at –80°C before analysis. Plasma concentrations of C-reactive protein, total cholesterol (TC), low-density lipoprotein (LDL), high-density lipoprotein (HDL), triglycerides, free fatty acids, and glycerol were measured separately by spectrophotometry (Cobas 6000 c501; Roche). Plasma fasting blood glucose (FBG) concentration was measured on an automated analyzer (Hitachi 912; Roche). Plasma insulin, adiponectin, and leptin concentrations were measured by RIA kits (HADP-61HK; Millipore). Plasma concentrations of soluble urokinase plasminogen activator receptor (suPAR) were measured using the commercially available suPARnostic ELISA kit, according to the manufacturer's instructions (ViroGates). Advanced glycation end products (AGEs) were measured noninvasively using an AGE reader (Diagnoptics Technologies). We measured glycated hemoglobin type A_{1c} (HbA_{1c}) on whole blood using DCA Vantage Analyser (Siemens Healthcare) for the analysis. Resting arterial blood pressure (BP) was measured in triplicate (with 1-minute intervals) using an automatic monitor (Boso-medicus control). Forced vital capacity (FVC) and forced expiratory volume in 1 second (FEV_1) were assessed by spirometer measurements (Vyntus SPIRO spirometer) with participants sitting on a chair and wearing a nose clip and mouthpiece. Initially, participants breathed normally before conducting a rapid maximal inspiration immediately followed by an expiration with a maximal effort that continued until no more air could be expelled while maintaining an upright posture. The procedure was repeated a minimum of 3 times and a maximum of 7. The trial with the highest reading was used and the Vyntus SPIRO software (SentrySuite) automatically assessed the repeatability, acceptability, and usability criteria defined by the American Thoracic Society and the European Respiratory Society [29]. The handgrip, biceps, and quadriceps strength were measured by a handheld dynamometer (Takei, A5401; Physical Company), a digital back strength dynamometer (Takei TKK 5402; Takei Scientific Instruments Co. Ltd.), and a handheld dynamometer (microFET2; Hoggan Health Industries, Inc.), respectively. At least three attempts were made until no rise in strength occurred. Each test was interspersed with 1-minute rest. Maximal oxygen consumption (VO_{2max}) was measured by a graded exercise test, performed on a bicycle ergometer (Lode Corival) using breath-by-breath (Quark PFT Ergo; Cosmed) oxygen consumption measurements. After 5 minutes of warm-up at 50 and 100 W for women and men, respectively, the load increased by 25 W every minute until voluntary exhaustion. VO_{2max} was determined as the highest 30-second rolling average of VO_2.

Exclusion and Inclusion of Candidate Biomarkers

To observe the trajectory of normal healthy aging, we excluded participants diagnosed with or having a previous history of T2D, CVD, cancer, and thyroid dysfunction and who were free of the use of medication to lower cholesterol levels, glucose concentration, and BP [16,30-32]. In addition, a 99% reference interval (mean ±2.96×SD) was applied to examine any potential outliers [30]. To acknowledge age-related decrements within the healthy aging spectrum, however, extreme values below or above the reference interval were individually assessed [33]. We excluded the candidate biomarker AGE from the study due to technical problems affecting the reliability of the measurements.

The actual selection between the remaining 31 candidate biomarkers followed a systematic stepwise method in alignment with previous studies [3,30,34]. To begin with, all candidate biomarkers were submitted to Pearson correlation analysis to assess the strength and direction of association between CA and the candidate biomarkers. All biomarkers that were significantly correlated with CA ($|r|>0.15$; $P\leq.05$) were included. To minimize redundancy arising in the analysis, we assessed intercorrelation between the included biomarkers. If the correlation between biomarkers was high ($|r|\geq0.7$) and they have a similar clinical function, they are likely to be dependent on the same biological factor and one is excluded depending on the strength of the relationship with CA and the clinical relevance.

Principal Component Analysis

PCA is a factor analysis that reduces dimensions but preserves most of the information in the original data set. PCA is a linear transformation that applies orthogonal rotation to find factors/principal components that capture the largest amount of information in the data [35]. As the PCA produces uncorrelated principal components disclosing which variables are most valuable for clustering the data, it can be used to elucidate the minimum numbers of candidate biomarkers necessary for estimating BA [36]. Traditionally, all principal components with an eigenvalue above 1 are included, or alternatively the number of principal components that together contain 80% of the variation in the data set. However, we will follow the approach first applied by Nakamura et al in 1988 [37] and applied by others since [12,30,31,38], and use the 1PC from the PCA to estimate individual BA.

To do so, included biomarkers were normalized to a mean of 0 and unit SD, which gives them equal weight in the PCA. The subsequent estimation of BA was performed in 3 steps. First, based on the PCA loading scores, a standardized individual BA score (BAS) was modeled:

$$\mathrm{BAS} = w_0 + (w_1x_1) + (w_2x_2) +\cdots+ (w_Nx_N) \quad (1)$$

where x represents the original value of each of the N biomarkers (without units). The coefficient w_n is defined as

$$w_n = \text{loading score}_n/\sigma_n \quad (2)$$

and the constant w_0 as

where w_n represents each of the N biomarkers and and σ represent the original mean and SD for each biomarker, respectively. The loading scores represent the contribution of each biomarker to 1 unit vector of the principal component.

Second, we transform the BA score into BA in units of years by application of the T-scale method [37]:

where σ_{CA} and are the SD and mean of CA, respectively, of the sample size. However, this introduces a regression toward the mean effect (overestimation of younger individuals' BA and underestimation of older individuals' BA) [39], which is why the correction model proposed by Dubina et al [40] is applied:

where BAc is the corrected biological age, y_i represents individual CA, is the mean CA of the study sample, and represents the slope in the linear regression assessing the relationship between BA and CA.

Statistics

We present candidate biomarkers as means with SDs and by linear regression to describe the direction and change of the candidate biomarkers per year. We assessed normal distribution using q-q plots and histograms, and checked variance of homogeneity and assessment of linearity by plotting residuals versus predicted values. Paired *t* test was used to assess differences within sex and the difference between BAc and CA (age difference) was calculated as CA – BAc. The statistical analyses were performed in SAS Enterprise Guide 7.1 and MATLAB R2018b. Statistical significance was considered at $P \leq .05$ in all statistical tests.

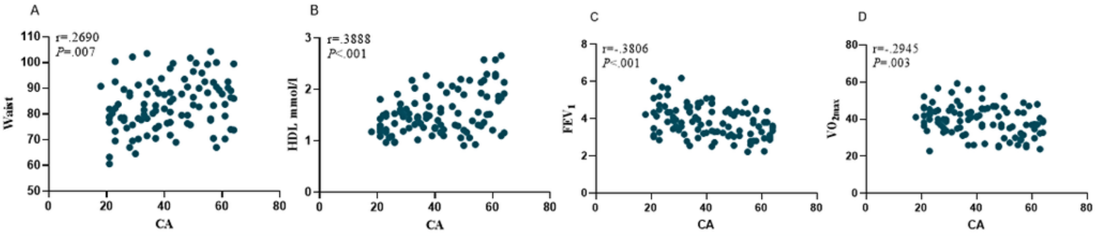
Results

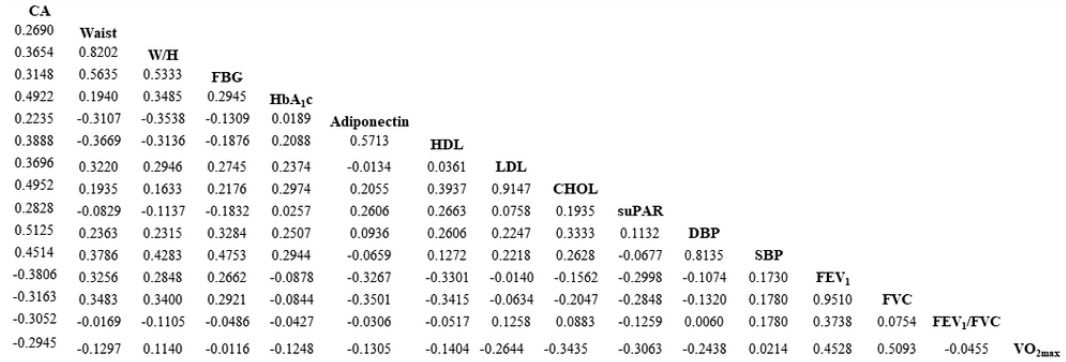
Systematic Stepwise Selection of Biomarkers

Correlation Analysis

Pearson correlation coefficient was calculated for each of the 31 candidate biomarkers as a function of CA (Multimedia Appendix 1). Overall, 15 biomarkers substantially correlated with CA covering 5 domains. *Body composition* (waist circumference and waist/hip ratio), *metabolic health* (FBG, HbA_{1c}, adiponectin, HDL, LDL, and TC), *immune function* (suPAR), *cardiorespiratory function* (diastolic and systolic BP, FEV_1, FVC, FEV_1/FVC ratio), and *physical capacity* (VO_{2max}). We observed positive correlations in waist circumference, waist/hip ratio, FBG, adiponectin, HbA_{1c}, HDL, LDL, TC, suPAR, diastolic BP (DBP), and systolic BP (SBP) and negative correlations for FEV_1, FVC, FEV_1/FVC ratio, and VO_{2max} (Figure 2).

Figure 2. Top: Scatterplots and Pearson's correlations of: waist circumference (A), high density lipoprotein (B), forced expiratory volume in 1. sec (C), maximal oxygen uptake (D). Bottom: Pearson's correlation coefficients of the 15 biomarkers significantly correlated with age and their inter-correlations. CA: chronological age; W/H: waist to hip ratio; FBG: fasting blood glucose; HbA_{1c}: glycated hemoglobin type A_{1c}; HDL: High density lipoprotein; LDL: Low density lipoprotein; CHOL: total cholesterol; suPAR: soluble urokinase plasminogen activator receptor; DBP: Diastolic blood pressure; SBP: Systolic blood pressure; FEV_1: Forced expiratory volume in 1. sec; VO_{2max}: maximal oxygen uptake.





	CA	Waist	W/H	FBG	HbA_1c	Adiponectin	HDL	LDL	CHOL	suPAR	DBP	SBP	FEV_1	FVC	FEV_1/FVC
Waist	0.2690														
W/H	0.3654	0.8202													
FBG	0.3148	0.5635	0.5333												
HbA_1c	0.4922	0.1940	0.3485	0.2945											
Adiponectin	0.2235	-0.3107	-0.3538	-0.1309	0.0189										
HDL	0.3888	-0.3669	-0.3136	-0.1876	0.2088	0.5713									
LDL	0.3696	0.3220	0.2946	0.2745	0.2374	-0.0134	0.0361								
CHOL	0.4952	0.1935	0.1633	0.2176	0.2974	0.2055	0.3937	0.9147							
suPAR	0.2828	-0.0829	-0.1137	-0.1832	0.0257	0.2606	0.2663	0.0758	0.1935						
DBP	0.5125	0.2363	0.2315	0.3284	0.2507	0.0936	0.2606	0.2247	0.3333	0.1132					
SBP	0.4514	0.3786	0.4283	0.4753	0.2944	-0.0659	0.1272	0.2218	0.2628	-0.0677	0.8135				
FEV_1	-0.3806	0.3256	0.2848	0.2662	-0.0878	-0.3267	-0.3301	-0.0140	-0.1562	-0.2998	-0.1074	0.1730			
FVC	-0.3163	0.3483	0.3400	0.2921	-0.0844	-0.3501	-0.3415	-0.0634	-0.2047	-0.2848	-0.1320	0.1780	0.9510		
FEV_1/FVC	-0.3052	-0.0169	-0.1105	-0.0486	-0.0427	-0.0306	-0.0517	0.1258	0.0883	-0.1259	0.0060	0.1780	0.3738	0.0754	
VO_{2max}	-0.2945	-0.1297	0.1140	-0.0116	-0.1248	-0.1305	-0.1404	-0.2644	-0.3435	-0.3063	-0.2438	0.0214	0.4528	0.5093	-0.0455

Assessment of Redundancy

We observed high intercorrelations for some of the variables (Figure 2, bottom) and selected those with the strongest correlation with age or with the highest clinical significance within each cluster. Therefore, as FEV_1, FVC, and FEV_1/FVC ratio all represent pulmonary function and FEV_1 has the highest correlation with age (r=–0.3806; P<.001) compared with FVC (r=–0.3163; P=.001) and FEV_1/FVC (r=–0.3052; P=.002), FEV_1 was selected. In the same manner we selected TC (r=0.4952; P<.001) over LDL (r=0.3696; P<.001). HbA_{1c} and FBG concentration are both markers of glycemic control, and a high correlation between HbA_1c and FBG has been shown in people with and without T2D [41,42]. We suggest that the moderate intercorrelation (r=0.2945; P=.003) found in this study is due to the sample size. HbA_{1c}, which shows a higher correlation with age, has previously been used in the literature in BA models [31] and is generally preferred over FBG due to its higher applicability in a clinical setting. Thus, to reduce redundancy, we only include HbA_{1c} as a marker of glycemic control despite an intercorrelation less than 0.7.

We observed a high intercorrelation between waist circumference and waist/hip ratio, the latter having the highest correlation with CA. Despite this, waist circumference was selected due to its strong association with visceral adipose tissue [43], its clinical importance as the best single anthropometric measure able to identify individuals at high risk of CVD and T2D, and its simplicity [44-46]. In addition, the inherent problem of the equation that an individual who is morbidly obese could have the same waist/height ratio as a normal-weight individual made us select waist circumference. Finally, DBP and SBP had an intercorrelation of r=0.8135 (P<.001), and a very similar correlation with age (r=0.5125; P<.001 and r=0.4514; P<.001, respectively). Instead, we calculated mean arterial pressure (MAP = 1/3SBP + 2/3DBP) to capture both parameters. MAP had a correlation with age of r=0.510 (P<.001) and an intercorrelation with SBP and DBP of r=0.943 (P<.001) and r=0.961 (P<.001), respectively. Thus, a total of 9 biomarkers were submitted to the PCA: waist circumference, FEV_1, HbA_{1c}, adiponectin, HDL, TC, suPAR, MAP, and VO_{2max} (scatterplots and Pearson correlation with age for all 9 biomarkers are available in Multimedia Appendix 2).

Applying PCA

Following the normalization of the data set comprising the 9 biomarkers, we applied PCA for women and men separately, with and without the inclusion of CA. By including and excluding CA, we could assess if the direction of the 1PC was similar in both cases, thus assuming that the 1PC can be seen as a general aging factor. The analysis showed high loading scores for CA on the 1PC for both women and men (0.473 and 0.515, respectively), confirming the close relationship between age and 1PC (Table 2). In the second PCA, we excluded CA and found that the relationship between the 9 biomarkers and the 1PC persisted. The 1PC had eigenvalues above 1.0 and accounts for 30.96% (females) and 25.04% (males) of the total variance in the battery of 9 biomarkers (Table 3). These results indicate that the 9 biomarkers reflect underlying measures of a healthy aging trajectory.

To clarify how the variables contribute to the estimation of the BA model, we calculated the percentage contribution of each variable using the following equation:

where a^2_n is the given loading score and N is the number of variables (Table 3). In women, TC concentration contributed the most (21.8%) followed by MAP (18.9%) and HbA_{1c} (16.7%). For men, waist circumference contributed the most (24.1%) closely followed by VO_{2max} (22.6%) and TC concentration (14.5%).

Table 2. The linear combination of normalized variables for the 1PC by gender (chronological age included).

Principal component analysis variables	Loading scores for 1PC[a]	
	Women	Men
Chronological age	0.473	0.515
Mean arterial blood pressure[b]	0.392	0.294
Glycated hemoglobin	0.348	0.352
Waist circumference	0.144	0.378
Forced expiratory volume in 1 second	–0.164	–0.340
Maximal oxygen consumption	–0.287	–0.321
Adiponectin	0.199	0.078
High-density lipoprotein	0.346	0.127
Total cholesterol	0.405	0.337
suPAR[c]	0.220	0.167
Eigenvalue[d]	3.50	2.90
Explained variance %[e]	35.04	28.96

[a] 1PC: first principal component comprising the best fit line with the largest sum of squares distances.

[b] Mean arterial blood pressure = (1/3SBP + 2/3DBP), where SBP is systolic blood pressure and DBP is diastolic blood pressure.

[c] suPAR: soluble urokinase plasminogen activator receptor.

[d] Eigenvalue: the sum of squared distances for 1PC.

[e] Explained variance %: how many percent does the 1PC explain of the total variance in the data set.

Table 3. The linear combination of normalized variables for the 1PC[a] by gender (chronological age excluded) and the relative contribution of each physiological variable to BA[b] estimation.

	Women		Men	
	Loading scores	Contribution (%)	Loading scores	Contribution (%)
Mean arterial blood pressure[c]	0.435	18.9	0.349	12.2
Glycated hemoglobin	0.408	16.7	0.324	10.5
Waist circumference	0.173	3.0	0.491	24.1
Forced expiratory volume in 1 second	–0.138	1.9	–0.309	9.5
Maximal oxygen consumption	–0.341	11.6	–0.475	22.6
Adiponectin	0.228	5.2	–0.046	0.2
High-density lipoprotein	0.390	15.2	–0.020	0.04
Total cholesterol	0.467	21.8	0.3804	14.5
suPAR[d]	0.238	5.7	0.254	6.4
Eigenvalue[e]	2.79	N/A[f]	2.25	N/A
Explained variance %[g]	30.96	N/A	25.04	N/A

[a] 1PC: first principal component comprising the best fit line with the largest sum of squares distances.

[b] BA: biological age.

[c] Mean arterial blood pressure = (1/3SBP + 2/3DBP), where SBP is systolic blood pressure and DBP is diastolic blood pressure.

[d] suPAR: soluble urokinase plasminogen activator receptor.

[e] Eigenvalue: the sum of squared distances for 1PC.

[f] N/A: Not applicable.

[g] Explained variance %: how many percent does the 1PC explain of the total variance in the data set.

Biological Age Model

By applying Equation 1, the loading scores from the PCA were used to construct individual standardized BAS as a function of the 9 biomarkers as shown in the following equations:

$$BAS_{female} = –11.04 + (0.03MAP) + (0.126HbA_{1c}) + (0.018Waist) – (0.018FEV_1) – (0.053VO_{2max}) + (3.205·10^{–5}·Adiponectin) + (0.909HDL) + (0.500TC) + (0.400suPAR)$$

$$BAS_{male} = –11.23 + (0.037MAP) + (0.103HbA_{1c}) + (0.066Waist) – (0.431FEV_1) – (0.067VO_{2max}) – (1.058·10^{–5}·Adiponectin) – (0.062HDL) + (0.442TC) + (0.828suPAR)$$

Subsequently, the BAS was scaled by applying Equation 4.

$$BA_{female} = (BAS × 13.6) + 41.3$$

$$BA_{male} = (BAS × 13.8) + 41.1$$

Scaling the score into units of years makes it more feasible to use when applying it to health promotion in the general population. Introducing this relationship between CA and BA has been shown to create some bias at the regression ends. Thus, following the previously mentioned correction model of Dubina et al [40] (Equation 5), the final BA models are expressed as

$$BAc_{female} = –56.67 + (0.27MAP) + (1.02HbA_{1c}) + (0.1453Waist) – (2.03FEV_1) – (0.43VO_{2max}) + (0.0003·Adiponectin) + (7.39HDL) + (4.06TC) + (3.24suPAR) + (0.20CA)$$

$$BAc_{male} = –70.37 + (0.34MAP) + (0.95HbA_{1c}) + (0.60Waist) – (3.96FEV_1) – (0.62VO_{2max}) – (9.73·10^{–5}·Adiponectin) – (0.57HDL) + (4.06TC) + (7.61suPAR) + (0.32CA)$$

The corrections are visualized in Figure 3, showing how the overestimation of BA in younger adults and underestimation of older adults are attenuated. In addition, Figure 4 visualizes the regression of BAc on CA (R^2=0.73; P<.001 and R^2=0.65; P<.001). BAc is scattered relatively close and symmetrically above and below the regression line with a standard error of the estimate of 8.2 years (women) and 10.2 years (men). We found no statistical difference between mean CA and mean BAc in women (P=.99) or men (P=.99). To assess the agreement between CA and BAc, we made a Bland-Altman plot and found a mean difference of 0.002 in women and – 0.006 in men, respectively (Figure 5).

Figure 3. Regression lines before (BA) and after (BAc) correction for women and men, respectively.

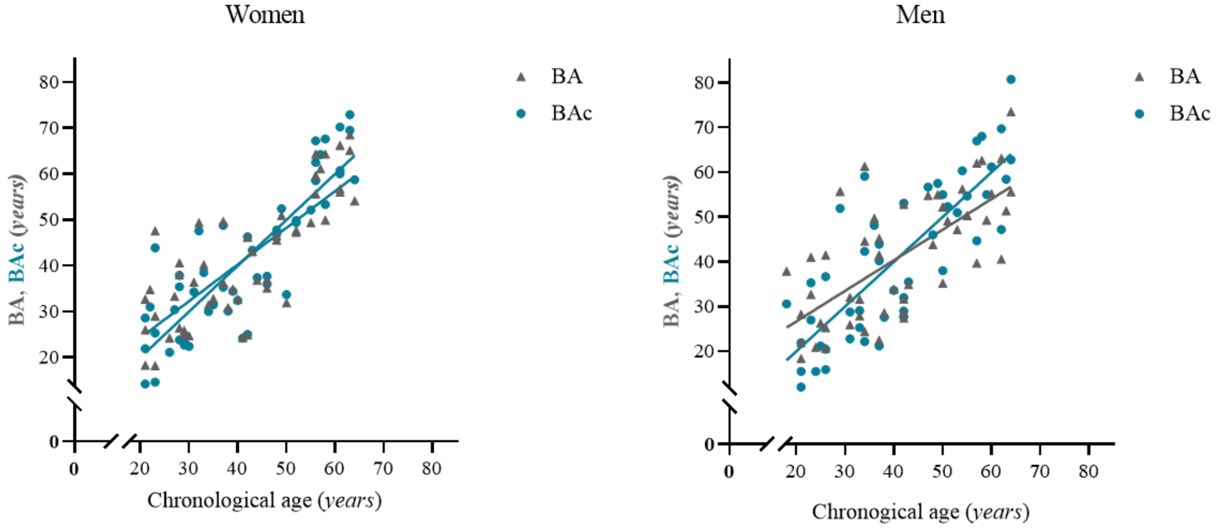


Figure 4. The BAc regression lines for women and men, respectively with 95% Confidence interval (shaded area), 95% Prediction intervals (black dotted lines) and line of identity (red dotted line). Slope (b), correlation coefficient (r) and coefficient of determination (R2).

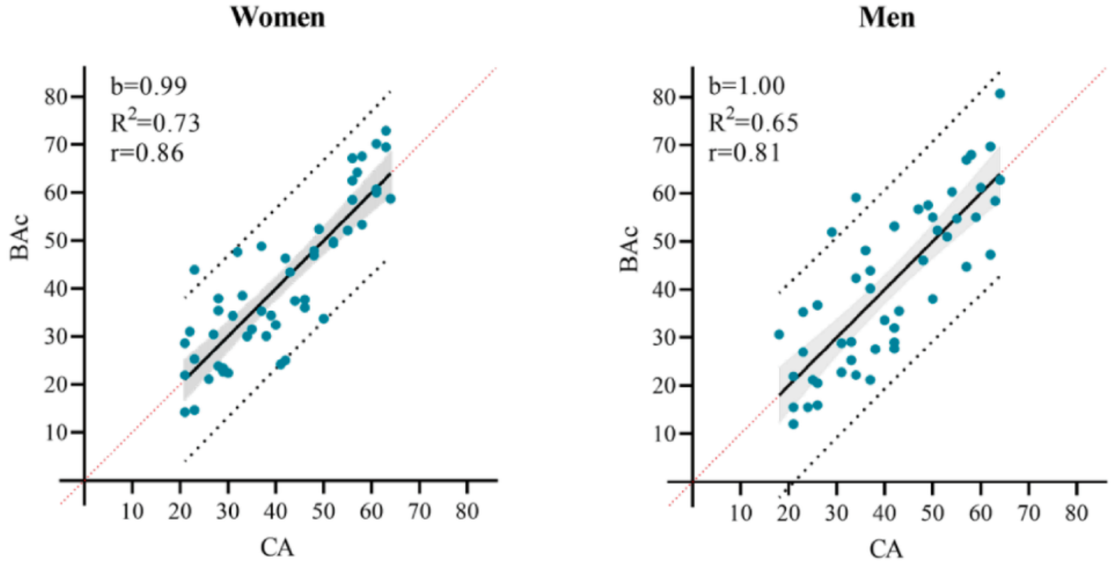
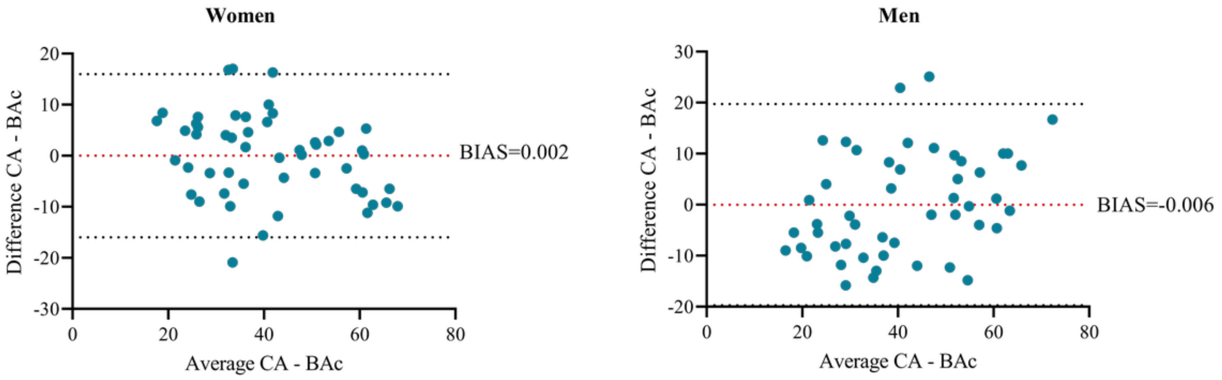


Figure 5. Bland Altman plot for women and men, respectively with BIAS (red dotted line), upper and lower limits of agreement (black dotted lines).



Discussion

Principal Findings

In this study, we aimed to develop a BA model, able to measure healthy aging trajectory, using simple, clinically relevant biomarkers that would respond to changes in health behavior. We selected 9 biomarkers listed in Table 3 and applied PCA to estimate individual BA. The 9 biomarkers represent metabolic health (HDL, TC, and adiponectin) and bodily functions (FEV_1, MAP, and suPAR), and include very important clinical age–related variables (VO_{2max}, HbA_{1c}, and waist circumference)

[28]. We found no difference between BAc and CA in the healthy reference group of women and men, and the BA model for both women and men showed a high linear relationship with CA. The disagreement between CA and BAc was low and unbiased. A higher variation in the BA model for men resulted in a lower coefficient of determination (R^2=0.65; P<.001) compared with the BA model for women (R^2=0.73; P<.001).

Sex differences were also observed in the relative contribution of each biomarker to the BA estimate. This indicates that some biomarkers of aging are influenced by sexual dimorphism [47]. HDL, for example, contributes 15.2% ($[0.39^2/0.999] \times 100$) in women and a negligible 0.04% in men ($[–0.02^2/1.001] \times 100$). HDL levels are higher in women than in men of the same age [48]. However, during menopause HDL levels decrease (and LDL increase), thereby increasing the cumulative risk of CVD [49]. In general, the multifaceted effects of menopause on metabolism may imply that further development of the model should evaluate if separate models for pre- and postmenopausal women are required. Waist circumference contributed the most (24.1%) in the estimation of BA for men but only 3.0% in the estimation of BA for women. This agrees well with the sex difference in fat distribution—men have a relatively more central distribution of fat with aging even in the absence of weight gain [50]. By contrast, a similar deterioration of VO_{2max} and FEV_1 between sexes is expected [47]. This was not the case in our study, as VO_{2max} and FEV_1 contributed more to the BA model for men. This difference may be balanced by normalizing VO_{2max} and FEV_1 to lean mass and height, respectively. In addition, the small sample size should be mentioned as a limitation in these observations.

The BA model is based on a healthy reference adult subsample of the population. However, in 8% (4/51) of the women and 16% (n=8/49) of the men, the age difference (CA – BAc) was more than +10 years (Figure 5). One of these women and 7 of these men stand out by having a BMI between 25 and 36 kg/m^2. Because BMI is causally related to morbidity and mortality [51], it could be argued that individuals with a BMI over 24.9 kg/m^2 are not suitable to be included in this study representing a healthy aging reference group. However, cardiorespiratory fitness (VO_{2max}) may be an even better predictor for CVD and premature all-cause mortality [52]. Further, a better VO_{2max} was found to attenuate the risks related to overweight and obesity [53,54]. The majority (41/51, 80%, and 46/49, 94%, of women and men, respectively) of the study participants adhered to the recommendations of a minimum of 150 minutes/week of moderate to vigorous physical activity and had a moderate to high cardiorespiratory fitness level [28]. Therefore, we did not use high BMI as exclusion criteria. Within this consideration, there also lies an effort to recruit a subsample of the population representing normal healthy aging instead of an extremely healthy and active subsample often more prone to participate.

Comparison With Previous Work

In our data set, the highest correlated biomarker with CA was MAP (r=0.51; P<.001). MAP reflects vascular resistance and BP measurements are the commonly used biomarkers in BA studies [1,4,32,37,55]. However, in contrast to our study, pulmonary function (FEV_1 and FVC) consistently appears as the most significant parameter related to CA in these former studies [1,4,32,37,55]. In our study, FEV_1 only appears as the third most correlated biomarker (r=–0.38; P<.001). A possible explanation is that the biomarkers used for BA estimations rely on register-based data collected in the mid- and late 20th century, primarily representing individuals from Asia and the United States. Thus, it reflects a certain time era and population behavior, for example, regarding smoking prevalence, which has decreased since then [56]. Finally, it is important also to take into account the difference in health behavior seen between ethnic groups.

To estimate BA, we used the 1PC as a general aging factor. In the field of BA prediction models, PCA is considered an improvement compared with multiple linear regression [31]. Even so, PCA is still a linear model, thereby assuming that biomarkers change linearly throughout the age span [57]. While many biomarkers are assumed to decline with a slope of 1% per year [58], some biomarkers may deviate from this linearity, especially toward the higher end of the age span. The proportions of total variance explained by the PCA in our study (31% and 25% women and men, respectively) were similar to those found in other studies using the 1PC, varying from 23% to 42% [3,12,30,32] in women and from 20% to 37% in men [3,12,30,31,37,55]. These studies found that using PCA was valid and clinically useful. However, recent studies [5,34,36] comparing different models found that the Klemera and Doubal model (KDM) [59] was superior at predicting mortality outcomes [60]. Keeping in mind that these results also depend on the specific set of biomarkers included, the algorithm from the KDM should be included in future research on the present BA estimation.

Future Research

This is a first-generation model which is why this work should be used to initiate further research to understand the interpretation of the model fully. Larger sample size is necessary to do a proper sensitivity analysis on how changes in each biomarker affect the BA estimate. In addition, a larger sample size would improve the validity of the selected biomarkers. In this study, the biomarkers were selected based on their significant correlation with CA in a cross-sectional analysis. Using cross-sectional data provides information on the age difference in the biomarkers at a specific point in time. To improve the statistical validity of the measures selected as biomarkers, a significant longitudinal correlation with CA should be investigated. This way the age difference in the biomarkers can be assessed over time [9].

Applying the BA model to longitudinal data is an important future investigation, to see if a relatively high BA is a predictor of poor health outcomes such as T2D, CVD, and mortality. Furthermore, investigating the BA model in health-related interventions will provide evidence as to whether the model can be used as a valid clinical tool for measuring disease risks. Our study has strength in its reproducibility—a key element for BA applicability. The majority of the 9 biomarkers are common measurements in the clinic and in science, where standard quantitative techniques are used. Thus, quantifying BA by the combination of these 9 biomarkers has the advantage of being less susceptible to artifactual variations related to the method of measurement and being accessible from stored plasma samples and databases in national health registers. That being said, the feasibility of measuring suPAR and adiponectin in regular clinical routine is low. Thus, future studies should investigate how the exclusion of suPAR and adiponectin affects the ability of the BA model to identify high-risk individuals and to assess the effect of health-enhancing interventions.

Conclusions

The 9 physiological variables identified in this study as aging biomarkers are highly relevant to assess age-related changes affecting the risk of disease and physical capacity. The BA model has potential for clinical use, due to low technical difficulty and minimally invasive techniques. Estimation of BA has potential as an outcome measure in health-promoting interventions and as a pedagogical aid. Future research is required to investigate how the model will work in populations deviating from the healthy aging spectrum (eg, in individuals with T2D, CVD, or low cardiorespiratory fitness). We expect that the indicator of being biologically old is easy to understand, as a risk of disease and premature mortality, which explains why this indicator might drive individual motivation toward a healthier lifestyle. However, work remains to be performed to improve the model's validity as a clinical tool and its predictive abilities including, but not restricted to, its reanalysis in a much larger sample size, test-retest reliability, and assessment of the longitudinal stability of the biomarkers.

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Authors' Contributions

KLSH and JWH conceptualized the study and in collaboration with AB-K, K-ÅH, HBDS, and JCBJ designed the study. KLSH, MF, PH, and AB performed the data collection. K-ÅH and AB-K did the formal analysis. KH wrote the first draft, and AB-K, K-ÅH, JCBJ, HBDS, FD, and JWH revised and edited the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Correlation coefficient with chronological age for the nine measurements included as biomarkers in the BA model. (A) Waist circumference (cm), (B) High Density Lipoprotein (HDL) (mmol/L), (C) Forced Expiratory Volume in the first second (FEV_1) (L), (D) Maximal oxygen consumption (VO_{2max}) (ml/min/kg), (E) Total cholesterol concentration (mmol/L), (F) Mean Arterial Pressure (MAP) (mmHg), (G) Glycated hemoglobin (HbA_{1c}) (mmol/mol), (H) Adiponectin (mg/ml), (I) soluble urokinase plasminogen activator receptor (suPAR) (ng/ml).

[PNG File , 492 KB - aging_v5i2e35696_app1.png]

Multimedia Appendix 2

Candidate biomarkers measured in the study participants (n=100) and their correlation with age.

[DOCX File , 19 KB - aging_v5i2e35696_app2.docx]

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Abbreviations

1PC: first principal component
BA: biological age
BAc: corrected biological age
BAS: biological age score
BP: blood pressure
CA: chronological age
DBP: diastolic blood pressure
FBG: fasting blood glucose
FEV_1: forced expiratory volume in 1 second
FVC: forced vital capacity
HbA_{1c}: glycated hemoglobin
HDL: high-density lipoprotein
KDM: Klemera and Doubal model
LDL: low-density lipoprotein.
MAP: mean arterial pressure
PCA: principal component analysis
SBP: systolic blood pressure
SF-12: 12-item Short Form
suPAR: soluble urokinase plasminogen activator receptor
T2D: type 2 diabetes mellitus
TC: total cholesterol
VO_{2max}: maximal oxygen consumption

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Original Paper

Using Smart Speaker Technology for Health and Well-being in an Older Adult Population: Pre-Post Feasibility Study

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Abstract

Background: Although smart speaker technology is poised to help improve the health and well-being of older adults by offering services such as music, medication reminders, and connection to others, more research is needed to determine how older adults from lower socioeconomic position (SEP) accept and use this technology.

Objective: This study aimed to investigate the feasibility of using smart speakers to improve the health and well-being of low-SEP older adults.

Methods: A total of 39 adults aged between 65 and 85 years who lived in a subsidized housing community were recruited to participate in a 3-month study. The participants had a smart speaker at their home and were given a brief orientation on its use. Over the course of the study, participants were given weekly check-in calls to help assist with any problems and newsletters with tips on how to use the speaker. Participants received a pretest and posttest to gauge comfort with technology, well-being, and perceptions and use of the speaker. The study staff also maintained detailed process notes of interactions with the participants over the course of the study, including a log of all issues reported.

Results: At the end of the study period, 38% (15/39) of the participants indicated using the speaker daily, and 38% (15/39) of the participants reported using it several times per week. In addition, 72% (28/39) of the participants indicated that they wanted to continue using the speaker after the end of the study. Most participants (24/39, 62%) indicated that the speaker was useful, and approximately half of the participants felt that the speaker gave them another voice to talk to (19/39, 49%) and connected them with the outside world (18/39, 46%). Although common uses were using the speaker for weather, music, and news, fewer participants reported using it for health-related questions. Despite the initial challenges participants experienced with framing questions to the speaker, additional explanations by the study staff addressed these issues in the early weeks of the study.

Conclusions: The results of this study indicate that there is promise for smart speaker technology for low-SEP older adults, particularly to connect them to music, news, and reminders. Future studies will need to provide more upfront training on query formation as well as develop and promote more specific options for older adults, particularly in the area of health and well-being.

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KEYWORDS

technology; older adults; communication inequalities; digital health; elderly population; smart technology; smart speaker; well-being; health technology; mobile phone

Introduction

Background

As the global population ages, new solutions that address multiple dimensions of health and well-being are needed to ensure healthy aging. In addition to promoting physical health, a range of factors may contribute to emotional and social well-being, which are key pillars for healthy aging and the ability of older adults to lead rich, independent lives [1]. Those from lower socioeconomic position (SEP) often face heightened challenges grappling with the environmental demands of maintaining autonomy because of poor health and mobility and are often at greater risk for isolation and lower psychological well-being than their higher SEP counterparts [2]. However, the ways in which protective factors may be leveraged to contribute to healthy aging are often underemphasized.

Factors that may help low-SEP older adults compensate for limitations or lack of resources or may help them leverage their positive capabilities and interests may be vital to promoting and maintaining well-being [2]. Information and communication technologies are low-cost, innovative resources that allow older adults to facilitate and maintain a connection with the outside world and improve psychological, social, and physical well-being [3].

Previous research has indicated that there is an association between technology use and well-being among older adults, with internet use reducing loneliness, predicting better mental health, increasing life satisfaction, and improving communication [4,5].

Technology offers the opportunity to increase connections with friends and family and connect to the necessary resources and knowledge (such as providing links to news sources or services) to remain engaged with the society at large without in-person interactions with others [3]. In addition to the connection to others, the ability of technology to link older adults to interests such as music can also foster greater emotional well-being. In light of the COVID-19 pandemic, the potential of technology to help alleviate loneliness has become even more salient [6].

However, several challenges have historically impacted the ability of older adults to fully engage with technology [7]. For example, vision issues may make it difficult for older adults to see screens, and dexterity challenges may impact the ability to use a keyboard or mouse. Even during the COVID-19 pandemic, when in-person activities were limited, older adults were less likely to say that the internet was an essential part of life compared with younger adults [8]. Literacy issues may inhibit the ability to read what is presented on the screen. These issues may be further exacerbated in low-SEP older adults, particularly those who are unable to afford adequate care to address vision or dexterity issues [7]. Further challenges for low-SEP individuals include decreased access to internet services, cutting them off from a crucial channel of health information and well-being resources [9]. This may help fuel communication inequalities or the differences in access to, understanding of, and acting upon health information [10], which may impact which older adults are able to benefit from technology. Such differences could create disparities, as some groups are more readily able to engage with technology to access health information and resources compared with others. Voice interface technology, such as the Amazon Echo or Google Home, shows great promise in reducing social isolation and assisting in healthy aging. The voice technology uses a zero-user interface design in which users engage with a smart speaker through voice commands. This technology works without screens and keyboards to create a system that is more accessible to older adults, as it removes barriers related to vision, dexterity, or literacy [11] and may thus reduce barriers to technology use that disproportionately impact low-SEP older adults. These interfaces also allow for the use of natural communication (speaking) instead of navigating and scrolling through webpages or learning how to operate new technology.

A key component of this interface is the feature of voice-activated personal assistants, which use artificial intelligence to create tailored, personal interactions through adaptive learning systems that may converse directly with the user in a back-and-forth discussion [11]. In addition to providing a simple way to engage with the speaker, it is proposed that the voice-activated personal assistants feature may also provide companionship and entertainment to older adults, providing the ability to alleviate loneliness and increase psychological well-being [11]. Reminders offered through the system may also help improve health behaviors such as medication adherence [12]. Voice interfaces provide a rich set of services through their *skills*, which are voice-based apps (similar to voice-based versions of apps that appear on smartphones). Commonly used skills include the ability to play music, find recipes, check the news, and ask health-related questions.

Although there is promise in enhancing well-being through these devices, research involving smart speakers and older adults is still in its early stages. Often, research involving smart speakers is conducted using one-time quantitative or qualitative surveys that gauge potential interest or initial reactions. A feasibility study conducted in a California retirement community deployed smart speaker devices in residents' homes, conducting focus groups and training workshops [13]. Feedback from participants indicated high satisfaction with technology, with 75% of participants reporting daily use. Participants felt that the speaker helped them stay connected with the community, family, and the digital world [13,14].

However, it is vital to replicate and expand these studies with more groups of older adults to truly gauge their acceptance and relevance for this age group. Although the features of voice technology are poised to remove barriers to traditional technology use, more research is needed on the exact features of the technology that are perceived as most beneficial for older adults and the areas in which they require additional learning to use the speaker successfully. Furthermore, research should focus on low-SEP individuals, particularly given the previous findings of challenges with other forms of technology, to ensure that using these smart speakers does not further propagate communication inequalities. Measuring the potential barriers and facilitators of speaker use can determine whether these speakers will resonate with older adults in ways that can foster health and well-being.

Objectives

This study aimed to investigate the feasibility of using voice interface technology in group of low-SEP older adults living in a subsidized residence for older adults. Our specific aims included (1) documenting the frequency of use of technology and the ways in which the technology was used; (2) assessing the acceptability and usability of the technology, as measured through process data and survey assessment; and (3) measuring the interest in and the use of the speaker for health information seeking.

Methods

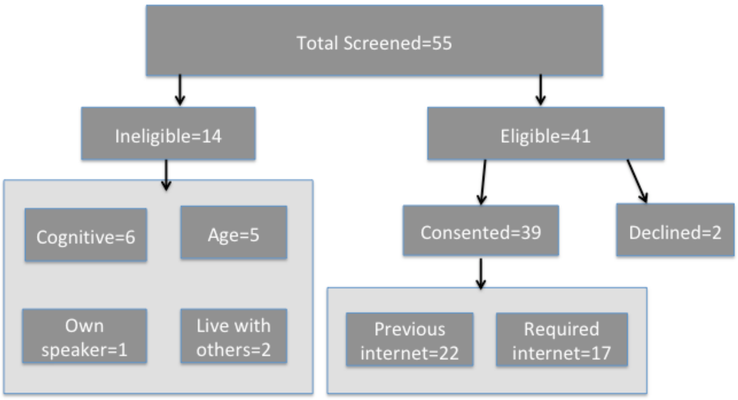
Ethics Approval

Older adults were recruited from a residence facility for older adults subsidized by the United States Department of Housing and Urban Development (HUD) in South Georgia to participate in a 3-month feasibility study. This study was reviewed and approved by the Harvard T.H. Chan Institutional Review Board (19-0304).

Recruitment

The eligibility criteria for the study included being in the age range of 62-85 years, living alone, and not having a smart speaker currently at their residence. The upper bound of 85 years was determined because of the increased risk of cognitive concerns such as memory loss or dementia past this age. The site principal investigator made an initial presentation to a group of 52 residents. In the presentation, she presented the features of the smart speaker and the details of the study through a Microsoft PowerPoint presentation. At the end of the presentation, interested residents were invited to fill out a screening form for consideration for joining the project. The names of those who appeared eligible were discussed with the center staff to determine if they were cognitively able to participate. There were 24 individuals who filled out the screening form after the presentation; however, only 15 individuals were eligible. There were 11 individuals who filled out the screening form but were ineligible: 3 individuals were excluded because of cognitive concerns, 5 individuals were excluded because of age >85 years, 2 individuals were excluded because of living with others, and 1 individual was excluded because of already owning a smart speaker (Figure 1).

Figure 1. Participant flowchart.



Although many participants expressed hesitance to adopting a new technology, there were several factors that helped to overcome this hesitance. The first was the partnership with and advocacy of the management staff at the residence in helping to recruit and reassure residents. Throughout the study, they served as champions for the project and helped to encourage residents to participate. They also kept a speaker unit in their office to learn about the speaker and to demonstrate its use to the residents. Second, as the first participants were connected to their speakers, other residents became interested after seeing the participants demonstrate the speaker's capabilities. Once the first residents provided positive reports on their speaker use, more residents agreed to participate. Therefore, we created a rolling enrollment process that spanned 2.5 weeks to recruit and enroll the remaining participants, reaching a final number of 39 participants (Figure 1). During this time, 3 additional residents were deemed ineligible because of cognitive concerns, and 2 eligible participants declined to participate.

Screened, eligible participants were then walked through the consent process by the study team. Before signing the consent form, each participant reviewed the terms of use of the smart speaker with the site principal investigator and then discussed a set of comprehension questions to ensure that participants understood the basics of the smart speaker (such as data tracking and privacy) before signing. After signing the terms of use of the speaker, the site principal investigator reviewed all study details with the participant and then had them sign the study consent form.

Before installing the smart speaker, the research team verified that each resident had internet access in their apartment. Overall, 56% (22/39) of the participants had internet access in their apartment before the study. Those without internet connection were provided connection through either a 3-month account setup and paid for by the study staff or assistance to obtain a low-cost internet connection offered for HUD housing–based residents in their own name. Most participants (14/17, 82%) elected to set up their own internet accounts.

Once internet connectivity was established or verified, the study staff visited the participant's residence to install the smart speaker in the home. Each participant's speaker was connected using their unique study account ID and study-generated email address. After the speaker was connected and activated, the staff provided the participant with a brief orientation to the speaker, including how to ask questions to the unit, adjust the volume, play music, and set reminders and alarms. In addition to the brief introduction, each participant received an introductory sheet on the smart speaker that provided instructions on how to make simple queries or give commands.

The participants were then involved in the study for a 3-month period. During the study, participants received weekly check-ins with study staff in the form of phone calls and help desk hours.

All issues were documented by the study staff and addressed as needed. The site principal investigator held 3 workshops throughout the study period in which participants' questions were answered and additional tips were shared on how to use the speaker. Periodic newsletters introduced other ways to use the device, providing wording to request that the speaker perform actions such as reading Bible verses, tracking calories, and playing games. Emphasis was placed on activities that increased health (connecting to services such as WebMD or calorie trackers) or mental well-being (learning to have conversations with the speaker and connecting to podcasts or games).

At the end of the study, if the participant desired to continue with the speaker, the study staff assisted them in connecting the speaker to their personal accounts. If the participant did not want to continue using the speaker, the study staff assisted them with deregistering the speaker and canceling internet accounts, if needed.

Data Collection

Once participants consented to participate in the study, they received a paper-based pretest survey that asked them about their mental well-being, loneliness, social well-being, demographics, prior technology use, comfort with technology, and social networks.

During the 3-month study period, participants' speaker use data were recorded through their study account; each query made to the speaker was documented in the speaker's records. As a user operates the smart speaker, each interaction with the speaker is recorded in the user's personal account. One key component of the study was the use of back-end data to record the interactions with the device. To do so, the study staff created study-related email accounts and study-related accounts with the speaker's parent company. These accounts were created so as not to use participants' real names in any recording; the study accounts only contained links to the participant's ID number. Process data were also tracked through a spreadsheet in which the study staff recorded each weekly check-in call with the participants, including any specific comments that were made.

At the end of each participant's 3-month study period, the participant was given a paper-based posttest that asked for repeated measures on health and well-being as well as asked questions on usability and perceptions of the speaker.

Measures

Pre- and Posttest Measures

Responses from the paper-based pre- and posttest survey, along with the process data gathered throughout the survey, were included in this study.

Sociodemographics

The participants were asked about their age, sex, income, and highest level of education. Food security was measured by providing the statement, "in the past 12 months, the food we bought ran out and we did not have money to get more," with response options being never, sometimes, or often true. Income security was measured by asking participants to select a phrase that described their household income, with options being living comfortably, getting by, finding it difficult, or finding it very difficult on present income.

Current Use of Technology

We asked participants if they had ever used the internet, how often they used it, and if they had internet access at their residence. Participants were asked to select the devices they currently owned and used, with response options including smartphone, tablet, computer, and smart television. Participants were also asked to indicate their level of comfort with technology, with response options including not comfortable at all, somewhat comfortable, comfortable, and very comfortable using technology.

Perceived Usability of the Speaker

In the posttest, participants were first asked how often they used the speaker during the 3-month study period. They were then asked to rate whether the speaker was easy to use, if it seemed easier to use over time, and if they understood how to ask the speaker a question, with response options ranging from totally disagree to totally agree. Participants then rated how often the speaker correctly understood their questions, with response options ranging from all the time to never.

Reactions to the Speaker

On the basis of the feedback gathered throughout the study, we created an index of reactions to the speaker content, including how connected the speaker made them feel to the world, if it helped them keep track of appointments, if the speaker helped them keep track of the day or time and appointments, and if it made them feel less lonely.

Process Data Notes

A spreadsheet was created that tracked each interaction with the participants, including phone calls and in-person interactions. For each interaction, the study staff listed the topic of the call, including any issues or positive statements about the speaker. Resolutions for these issues were also noted.

Analysis

Responses to the pretest and posttest were analyzed. Frequencies and percentages were gathered from all pretest and posttest variables. Process notes were analyzed for counts of certain types of issues or interests expressed by the participants.

Results

Overview

The final sample comprised 39 participants (Table 1). Most (36/39, 92%) of the participants were female and White (38/39, 97%). The demographics of the study participants closely matched the demographics of the community. All the participants had an income of ≤US $35,000, with the majority having an income of <US $15,000 per year. Approximately half (20/39, 53%) of the participants felt that they were getting by on their current income, although 34% (13/39) of the participants indicated that they sometimes or often experienced food insecurity.

Before the study, 56% (22/39) of the participants were using the internet (on a computer or smartphone) at least once per day, and 33% (13/39) of the participants rarely or never used the internet, with those who had in-unit internet access significantly more likely to use the internet frequently (Table 2; χ^2=11.6; *P*=.02). The most frequently owned device was a smartphone (21/39, 54%).

Table 1. Participant demographic characteristics (n=39).

Demographic	Values
Sex, n (%)	
Female	36 (92)
Male	3 (7)
Age (years), mean (SD; range)	72.62 (5; 64-82)
Race, n (%)	
White	38 (97)
Black	1 (2)
Income (US $), n (%)	
0-9999	11 (29)
10,000-14,999	15 (40)
15,000-19,999	8 (21)
20,000-34,999	3 (8)
Education, n (%)	
<8 years	1 (2)
8-11 years	5 (12)
12 years or completed high school	5 (12)
Post high school training other than college (vocational or technical)	9 (23)
Some college	10 (25)
College graduate	5 (12)
Postgraduate	2 (5)
Income security, n (%)	
Living comfortably on present income	6 (15)
Getting by on present income	21 (53)
Finding it difficult on present income	10 (25)
Finding it very difficult on present income	2 (5)
Food ran out and did not have money to buy more, n (%)	
Never true	26 (66)
Sometimes true	12 (30)
Often true	1 (2)

Table 2. Technology use before the study (n=39).

	Values, n (%)
Frequency of internet use	
Never	9 (23)
Rarely	4 (10)
Once or twice a month	0 (0)
Once a week	0 (0)
A few times per week	2 (5)
Once a day	3 (7)
Many times per day	19 (48)
Had internet access at their residence before the study	22 (56)
Devices owned	
Smartphone	21 (55)
Tablet	17 (44)
Computer	11 (28)
Smart television	6 (15)
None of the above devices owned	8 (21)
Comfort with using the internet	
Not comfortable at all	5 (12)
Somewhat comfortable	13 (33)
Comfortable	10 (25)
Very comfortable	11 (28)

End of Study Device Uptake

By the end of the study period, 38% (15/39) of the participants said that they had used their speaker once per day, and 38% (15/39) of the participants had used it several times per week. There were no significant differences between having internet access before the study and use or usability ratings of the smart speaker.

After the study, 72% (28/39) of the participants kept the speaker, with 53% (9/17) of the participants who did not have prior access keeping the speaker and retaining their internet access to continue use. Of the 11 participants who did not keep their speaker (Textbox 1), 3 had to do so because of their inability to maintain their internet connection. One cited increased concerns about privacy. Another stated that the speaker had given her the confidence to get the internet and try new things but that she felt that she got more value from a newly purchased tablet.

Textbox 1. Reasons given for terminating speaker.

Reason given by participants

1. Relied on a study-based internet connection and were not able to maintain internet connection. (3 participants)
2. Had increased privacy concerns and did not want to use the speaker (1 participant)
3. Felt that other newly purchased devices (tablet) provided more value (1 participant)
4. Had trouble hearing the speaker and lost interest (1 participant)
5. Had difficulty with the internet provider and lost interest (1 participant)
6. Did not have any other devices; did not want to maintain the internet connection (1 participant)
7. Liked the device but did not want to continue using it (1 participant)
8. Did not use the device often and did not want to maintain the internet connection (1 participant)
9. No reason given (1 participant)

Self-reported Uses of the Speaker

Common uses of the speaker that were quantified in the posttest are reported in Table 3, with all participants (39/39, 100%) citing that they used the speaker for the weather and 89% (34/39) of the participants saying that they used the speaker to listen to music. On reviewing the process data, we found that participants cited additional uses in their conversations with study staff, including using the speaker to read Bible verses, relying on the unit for reminders (such as for medication or physician appointments), meditation, and asking about the date and time. Another finding noted in the process data notes was that participants enjoyed saying *good morning* and *good night* to the unit.

Table 3. Percentage of participants using the speaker for various activities (n=38).

Activity	Values, n (%)
Weather	38 (100)
Music	34 (89)
Health	21 (55)
News	17 (44)
Conversation	17 (44)

Reactions to the Speaker

More than half of the participants agreed or strongly agreed that the speaker was useful (24/39, 63%), helped them obtain the required information (24/39, 62%), and helped them keep track of the day and time (24/39, 62%; Table 4). Approximately half of the participants said that the speaker provided another voice to talk to (19/39, 49%) and felt that the speaker made them feel more connected to the world (18/39, 46%). Although almost half of the participants (17/39, 44%) felt that the speaker reconnected them to interests such as music or history, fewer participants (9/39, 23%) reported that the speaker helped them with their health.

Table 4. Reactions to the speaker (n=39).

Speaker reaction	Strongly disagree or disagree, n (%)	Neutral, n (%)	Agree or strongly agree, n (%)
Having a speaker made me feel more connected with the world.	4 (10)	16 (41)	18 (46)
Having a speaker makes me feel more confident about using technology.	5 (12)	15 (38)	19 (48)
Having a speaker gave me an opportunity to strengthen my relationships at the Towers.	8 (20)	22 (56)	8 (20)
Having a speaker made me feel closer to my family (children, grandchildren).	10 (25)	19 (48)	7 (17)
The speaker made me feel like I had another voice to talk to.	8 (20)	10 (25)	19 (48)
The speaker helped me keep track of what day or time it was.	4 (10)	10 (25)	24 (61)
The speaker made it easier to get the information I need.	2 (5)	11 (28)	24 (61)
The speaker helped me keep track of my commitments and appointments.	2 (5)	20 (51)	15 (38)
The speaker made me feel less lonely.	8 (20)	19 (48)	9 (23)
The speaker provided me with a sense of comfort.	9 (23)	19 (48)	9 (23)
By the end of the study period, the speaker interactions were important to me.	5 (12)	16 (41)	18 (6)
The speaker reconnected me to my interests (such as music, art, or history).	6 (15)	15 (38)	17 (43)
The speaker helped me with my health or nutrition.	11 (28)	17 (43)	9 (23)
I felt like there was something lacking in my interactions with the speaker.	13 (32)	18 (48)	7 (19)
The speaker met my expectations.	5 (13)	15 (40)	17 (45)
The speaker was useful to me.	2 (5)	12 (31)	24 (63)

Process Data Findings and Responses

During the early weeks of the study, 31% (12/39) of the participants commented in their check-in calls about the difficulties with asking questions to the unit. Owing to frequent comments about this issue, a workshop was held to provide assistance. Within this workshop, it was revealed that there were the following concerns: (1) participants felt that the device was giving inconsistent answers to the same question, (2) participants felt that the device was not acknowledging them, and (3) participants were often asking questions that were too long or complex (such as multipart questions). Many participants were asking multipart questions that the speaker could not process, were pausing too long between the wake word and their request, or were spending time trying to frame their request in a polite manner (during which time the speaker determined that the request was not relevant). Within this trial session and workshop, it was also determined that there were some options that required skills (particular apps that are saved within the speaker preferences only once the user activates them) to provide reliable answers to particular questions. For example, if the participant wanted the speaker to read Bible verses, a particular skill could be enabled that would provide the desired results of requesting a particular verse. However, without requesting to open this skill, the speaker may pull from various other sources (or interpret their request as asking the speaker to recite the whole Bible from the beginning), thus the answer discrepancy. Owing to these issues, the research team offered suggestions and created a newsletter that addressed common ways of wording (such as focusing on brief, direct commands) and simple directions to enable commonly desired skills.

Another issue discovered through process notes was that 5 participants had volume issues. Volume issues were often exacerbated by loud air conditioner units that were in the same room as the speaker, as most participants preferred that the speaker be placed in their living room. Each participant who noted a volume issue was provided with an additional Bluetooth speaker that could increase volume.

Within the process notes, several direct quotations noted also speak of the positive reaction to the speaker (Textbox 2).

Textbox 2. Reactions to the speaker.

Quotes from participants about their speaker interactions

- “it is nice to have someone to talk to.”
- “it’s like [the speaker] is a little friend.”
- “I enjoy the company.”
- “The speaker has ‘become part of the family’.”
- “at least I have somebody to talk to.”

Discussion

Principal Findings

This feasibility study indicates promise for the use of smart speaker technology in a group of low-SEP older adults. By providing the speaker and related support to older adults, the research team was able to observe the barriers and facilitators of initial speaker use in this population. Overall, the speaker was well received by most of the sample, with 38% (15/39) reporting daily speaker use and 38% (15/39) reporting using it several times per week. Participants perceived the speaker as useful and assisting them in finding the information they needed. Although there were initial barriers to uptake in using the speaker, frequent monitoring and check-ins with study staff alerted the study staff to these issues; once addressed, the perceived ease of use of the speakers appeared to increase.

Notably, most of the participants (28/39, 72%) opted to continue using the speaker after the study period ended. This illustrates the journey of many participants from being technology hesitant to routinizing technology use in their day-to-day lives. Although there was a learning curve for understanding how to frame questions to the speaker, it was embraced by many respondents. At the end of the study, 53% (9/17) of the participants who did not have internet access before the study elected to maintain internet access and continue using the speaker. This echoes the patterns observed by the Pew Research Center that once older adults are on the web, the technology becomes a daily fixture; among internet users aged ≥65 years, 75% use the internet on a typical day at least daily, with 51% saying they go on the web several times per day and 8% say they use the internet almost constantly [15]. This percentage has increased among smartphone users, with 76% of those owning a smartphone using the internet several times per day or more.

Participants found many sources of value of the speaker, including connecting to the world, accessing information, and using the device for reminders. Process data notes taken during check-ins reflect the interest in using the speaker for reminders of doctors’ appointments and social engagements, particularly to remember events happening within the residence. Participants indicated the value of the speaker to help them keep track of the day and time, a feature that was deemed useful for keeping track not only of appointments but also to anchor them to the present. The frequency and enthusiasm with which participants used the speaker for this purpose and for connecting to music and other interests suggests the potential for this technology to be an asset to this population, particularly in overcoming some of the additional challenges to mobility, dexterity, and resource access by low-SEP older adults [2]. For example, the connection participants felt to music and other interests through the speaker was an integral part of facilitating interest and continued use and may also connect to emotional well-being. Future analyses will explore the back-end data of the device to determine in detail the frequency and variety of use of the speaker.

This study identifies some potential strengths and weaknesses of smart speakers in this population. Despite the initial hesitance with the speaker, most participants found value in the speaker, using it several times per week, with many even reaching daily use. Future analyses of our back-end data will further explore how this has been integrated into their lives.

This study also points to potential issues that should be addressed when designing a smart speaker study within this population. First, initial hesitance to technology use may be noted, particularly because of privacy concerns. Within this project, the buy-in and assistance of the staff at the residence were critical to project success, as they provided space for residents to convene for speaker-related activities and served as champions for our process. Second, this study points to the need for targeted training on using the device once it is installed, with emphasis placed on how to properly craft questions and how to activate certain skills of interest. Of note is the lower percentage of participants (9/39, 23%) who felt that the speaker helped them with their health or nutrition. Within the study, the newsletters that were provided to participants emphasized different health-related activities for participants to try, such as asking for calorie information in certain foods but process findings suggest that these queries did not always yield useful information. These frustrations with correctly framing questions have also been cited in a previous qualitative study, in which groups of older adults were invited to test out the speaker [16]. Studies that intend to use a smart speaker for health-related purposes should be prepared to provide direct training on how to ask questions about health-related topics or should train residents to use a selected health-related skill (such as a specific nutrition app). Further benefit may be gained by orienting the user to skills that are specifically created to address the needs of older users [16]. Furthermore, in this study, we noted that several participants had difficulty in hearing the speaker. We tested a smaller version of the speaker; the full-size unit with a larger speaker may be required as well as the option to receive a Bluetooth speaker that can reach a higher volume.

This study had some limitations. As we created study accounts, we were not able to sign participants up for some of the specific older adults–focused skills that required passwords and personal details; therefore, we were unable to study the use of these targeted apps. Our recruitment also occurred within one senior housing unit in which participants would often share tips and experiences with other participants in the study. It is unknown whether we would have had the same success if we had conducted this study with home-dwelling older adults.

Despite these challenges, smart speakers are still poised to alleviate some of the main barriers to technology use in this population once these factors are addressed. Many functions that were of value to the participants were integrated quickly into routines upon brief demonstration (playing music, setting reminders, and the asking for time) and showed immediate value at a low cost. Several participants reported gaining confidence in technology because of the ease of the speaker for basic functions, and they were eager to learn how to explore more uses. Speaker manufacturers may consider building in features that can aid in understanding additional speech patterns and have easier-to-navigate menus of information options built into basic features. Although some of these features may appear in certain skills geared toward older adults, these functions would assist a larger section of the population that has low literacy and low health literacy use the unit to find the required information. Future research may explore in greater detail the value of other aspects of the speaker, such as the aforementioned specific skills designed for older adults as well as other smart devices that can be linked to the speaker to assist further with daily life, such as smart switches and thermostats, that may assist low-SEP adults in living independently.

Conclusions

Smart speakers show great promise for providing low-SEP older adults with an opportunity to increase their connection with music, news, and the weather as well as providing a way to anchor them to the date and time. As research using this speaker in this population progresses, special attention should be paid to the design of health-related skills and services to determine the best way to engage older adults with relevant, useful health content.

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Conflicts of Interest

None declared.

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Abbreviations

SEP: socioeconomic position

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Original Paper

Detecting Anomalies in Daily Activity Routines of Older Persons in Single Resident Smart Homes: Proof-of-Concept Study

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Abstract

Background: One of the main challenges of health monitoring systems is the support of older persons in living independently in their homes and with relatives. Smart homes equipped with internet of things devices can allow older persons to live longer in their homes. Previous surveys used to identify sensor-based data sets in human activity recognition systems have been limited by the use of public data set characteristics, data collected in a controlled environment, and a limited number of older participants.

Objective: The objective of our study is to build a model that can learn the daily routines of older persons, detect deviations in daily living behavior, and notify these anomalies in near real-time to relatives.

Methods: We extracted features from large-scale sensor data by calculating the time duration and frequency of visits. Anomalies were detected using a parametric statistical approach, unusually short or long durations being detected by estimating the mean (μ) and standard deviation (σ) over hourly time windows (80 to 355 days) for different apartments. The confidence level is at least 75% of the tested values within two (σ) from the mean. An anomaly was triggered where the actual duration was outside the limits of 2 standard deviations ($\mu-2\sigma$, $\mu+2\sigma$), activity nonoccurrence, or absence of activity.

Results: The patterns detected from sensor data matched the routines self-reported by users. Our system observed approximately 1000 meals and bathroom activities and notifications sent to 9 apartments between July and August 2020. A service evaluation of received notifications showed a positive user experience, an average score of 4 being received on a 1 to 5 Likert-like scale. One was poor, two fair, three good, four very good, and five excellent. Our approach considered more than 75% of the observed meal activities were normal. This figure, in reality, was 93%, normal observed meal activities of all participants falling within 2 standard deviations of the mean.

Conclusions: In this research, we developed, implemented, and evaluated a real-time monitoring system of older participants in an uncontrolled environment, with off-the-shelf sensors and internet of things devices being used in the homes of older persons. We also developed an SMS-based notification service and conducted user evaluations. This service acts as an extension of the health/social care services operated by the municipality of Skellefteå provided to older persons and relatives.

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KEYWORDS

Activities of daily living; smart homes; elderly care; anomaly detection; IoT devices; smart device; elderly; sensors; digital sensors; Internet of things

Introduction

Emerging technologies have, in recent years, given rise to the internet of things (IoT). IoT is a combination of smart devices, sensors, and actuators used to connect and interact through the internet and to collect, share and analyze data. Kevin Ashton first coined the term IoT in 1999 to promote radio frequency identification technology [1]. IoT usability and its real-time monitoring capabilities have paved the way for a new range of applications. IoT applications in environments such as smart homes [2], for example, have the potential to support and assist older persons and help them live independently in their homes [3]. These systems can also help indicate the ability of older adults to perform basic daily routines such as cooking and bathing [4].

The need for assistive technologies is driven by the older population, with Sweden's older population, for example, expected to increase by 45% and 87% by 2050 for the age groups of 65-79 years and ≥80 years, respectively [5]. Smart homes fitted with IoT devices can allow older persons to live independently in their homes and allow the “elderly to age in place for twice as long” [6]. Affordable and low-maintenance IoT-based monitoring systems can also provide significant benefits in challenging times, such as the recent global COVID pandemic, particularly for older persons who were the most vulnerable group in the COVID-19 pandemic. A significant proportion of COVID-19 related deaths (48.9%) were among care home residents (the Swedish Public Health Agency [7]). Activities of daily living (ADL) in ambient assisted living applications can therefore play an even greater role in a pandemic through protecting older persons and reducing the pressure on health care providers.

Human activity recognition (HAR) is one of the most important research topics within ADL applications for smart homes. This is at least partially due to the level of support it can provide to older persons and to health care providers. HAR is a challenging and well-researched topic. Advanced IoT devices and low-cost sensors can, however, make activity data collection less expensive [8]. HAR activities can be classified by their granularity and atomic events [9] (eg, open a door). HAR can also help infer high-level activities such as kitchen or breakfast activities through considering contextual environment information [10-15], which only requires a limited number of sensors. The detection of abnormal behaviors by ADL applications is very relevant in health care monitoring systems, particularly in health care systems of older persons where abnormal behavior detection can be of crucial importance [16].

Our research objectives are focused on building a model to identify and learn behavioral patterns and, through this, allow the detection of anomalies in the behavior of older persons using ADL applications and IoT data. This also allows family members to be notified in near real-time. The contributions of our paper are as follows:

- We propose, develop, and evaluate an iVO data analytics architecture for anomaly detection to detect normal and abnormal patterns in the daily activities of older persons.
- We build a statistical real-time anomaly detection method that includes online data processing.
- We ran our trial in a real-life environment for approximately 64 days for nine different participants, median age 89 years, living in single-resident apartments. We collected data for analysis for approximately 2 years for each household to model the behavior.
- We developed an SMS-based notification service to interact with the relatives of older participants, and we conducted user evaluations. Notifications of normal daily activities and anomalies were sent via SMS to relatives as positive and negative notifications via our developed real-time online system.

The “Internet of Things (IoT) within health and care” (iVO) project [17] started in 2018 and was founded with a focus on older persons living independently in smart home environments. Participant apartments were at three locations in Sweden, in the municipalities of Skellefteå, Kiruna, and Uppsala. Pilot study participants were from Skellefteå municipality, 12 apartments being included, and around 1000 activities being observed over 2 months in the summer of 2020. In the following sections, we present the implementation of this study, the results, discussion, and conclusions.

Methods

This section describes our research method. This includes the experimental setup, iVO architecture for anomaly detection service, the identification of participant routines and needs (based on interviews), and types of installed sensors.

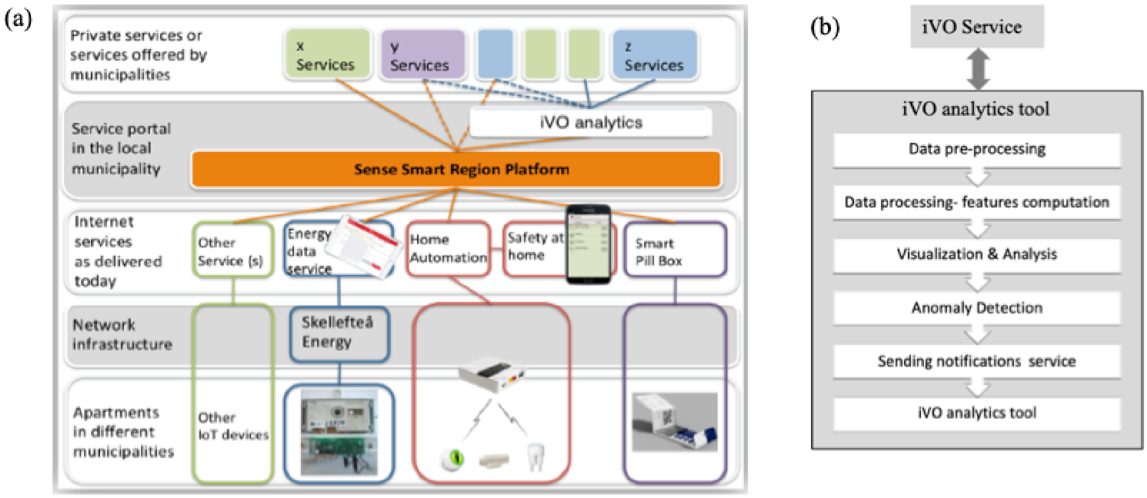
Experimental Setup

The experimental study reported in this paper, however, includes 12 participants with a median age of 89 years. Three participants were later excluded due to unexpected life events. We used a statistical method to classify participant behavior into normal and abnormal (anomalies). This was based on whether the amount of time spent on an activity in each room was low or high in duration. The experimental setup worked according to routines collected during the interviews. The main focus was the meal activities.

iVO Architecture for Anomaly Detection Service

The iVO architecture is a layered architecture with horizontal connectivity of different sensors and service providers. iVO architecture is built using FIWARE [18], connecting off-the-shelf sensors and IoT devices via an IoT platform. The platform is called societal development through secure IoT and open data (SSiO) [19]. The SSiO platform was designed and implemented for different IoT applications and services within a smart city, a detailed description of the iVO architecture being given in Saguna et al [20]. The installed sensors are connected via gateways to a service provider (an iVO project partner) to push the sensor data into the SSiO platform, as shown in Figure 1a. The iVO analytics component is shown in Figure 1b.

Figure 1. (a) iVO architecture with SSiO platform, (b) iVO analytics. iVO: internet of things within health and care; SSiO: societal development through secure IoT and open data.



Participant' Routines and Needs Identification Based on Interviews

The project's first pilot study for the selected age group has been described by Saguna et al [20]. We identified targeted activities through the interview process. The interviews also provided information on the needs of participants and their relatives and activities of interest. The interviews were conducted with the participants along with their relatives who answered questions on the activities they would like the model to recognize, their general opinion of home monitoring, their expectations of implementation, and details about their daily routines. All interviews were documented and recorded by researchers. All participants gave their written consent to use their data.

Most of the participants and their relatives expressed their interest in monitoring meal activities in the kitchen. A matrix of the activities of each participant was constructed based on the environmental setups in each household, on the number of sensors, available kitchen appliances, and the interview responses. The interviewees expressed an interest in receiving both negative and positive notifications. Negative notifications notify that anomalies have been detected in behavioral patterns and positive notifications notify that the activity behavior is normal. This is shown in Table 1.

Table 1. End- users' preference for activity recognition.

Apartment ID and Age[a]	Activities[b]	Number of sensors[c]	Notifications
1; 96	• Breakfast: 6:00-9:00 • Lunch: 11:00-13:00 • Bathroom: 22:00-5:00 • Bathroom: 00:00-23:59	• Total: 9 • Water boiler, kitchen & bathroom motion sensor	N/P[d]
2; 91	• Breakfast: 7:00-9:00	• Total: 11 • Kitchen motion sensor, micro	N[e]
3; 94	• Breakfast: 7:00-10:00	• Total: 8 • Coffee machine, kitchen motion sensor	N
4; 99	• Breakfast: 6:00-7:00 • Lunch: 11:00-13:00 • Dinner: 16:00-18:00	• Total: 9 • Coffee machine, micro, kitchen motion sensor	N
5; 89	• Breakfast: 5:00-8:00	• Total: 9 • Coffee machine, kitchen motion sensor	N
6; 83	• Breakfast: 7:00-10:00	• Total: 10 • Water boiler, kitchen motion sensor	N/P
7; 94	• Bathroom: 4:00-6:00	• Total: 11 • Bathroom motion sensor, water meter	N/P

[a] Apartment ID and age are defined for each participant in this study; each apartment has a single resident.

[b] Meals activities in the kitchen and visitation to the bathroom: from the interview data, we identified the most common routines among all participants, including a start time and end time of each activity.

[c] Number of sensors: the total number of installed sensors at each apartment and the type of sensors used to monitor each corresponded activity in this study implementation.

[d] N/P: negative and positive notifications. The type of notifications that the relatives are interested in receiving on each individual’s activities. Negative and positive notifications represent abnormal and normal behavior in performing the activity, respectively.

[e] N: negative notifications.

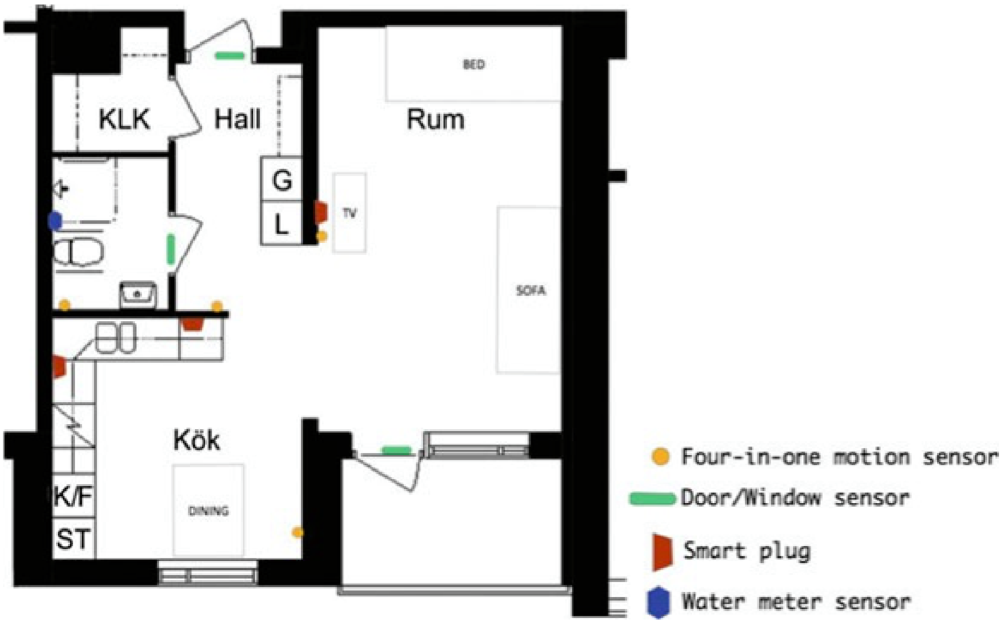
Ethics Approval

The ethical principles raised by and applied to the project were considered in collaboration with the department of homecare at Skellefteå municipality and were approved by the regional ethical committee. The participants gave their consent for the use of their data and the installation of in-home sensors. The project was, overall, in compliance with the European Union’s General Data Protection Regulation guidelines [21]. The data collection and processing included in this study were approved by the Regional Ethical Board in Umea, Sweden (diary no. 2018-189/31).

Sensors, Data Sets, and Data Preprocessing Module

iVO smart homes use a wide range of off-the-shelf IoT devices and sensors, these systems also being referred to as dense-sensing network technologies [22]. This study, however, only looked at motion sensors, wall plugs, and smart water meters. The sensor installation and floor plan of an older person’s home are shown in Figure 2. All nine apartments have a similar floor plan. Data cleaning is an essential part of the first phase of the study implementation. It is unavoidable that sensors will fail, sensor readings will be lost, and sensor data sets are duplicated, leading to vagueness and imprecision, false positives, and false alarms [23]. This is of even greater importance in older person care health monitoring systems [24]. A reliable monitoring system, therefore, needs to be built before the feature engineering phase is begun. Data cleaning applies, in particular, to motion sensors, redundant data being removed, and missing reading values being identified. Outliers due to visitors or home care visits were excluded.

Figure 2. The generic layout of a participant apartment and sensor placements [20].



Data Processing Module

In this module, we calculated daily duration and visit frequencies for all rooms to extract patterns from and analyze user behaviors. Daily durations are further processed into hourly-based durations. Our analysis used historical data sets from the 2-year data sets. Scalability and re-usability are, however, notable challenges to building individualized activity models [25]. Features engineering is the first step in this module, the time duration feature being the length of time the person spent moving or not moving in the room until transiting to another room/location. The frequency of visits is the number of times the person transits to another room and returns. We used a fixed time window, which is specified by the start and end times of the routines described in the interviews. These time windows, described in Table 1, are used to classify data into normal and abnormal activities.

Proposed Anomaly Detection Module

Hawkins has defined an outlier as “an observation that deviates so much from other observations as to arouse suspicions that it was generated by a different mechanism” [26]. Detecting anomalies in data has been studied in the statistics community since the 19th century [27]. There are different approaches to detecting anomalies, including the mining-based approach, the logic-based (rule-based) approach, the ontology-based approach [28], and the statistical-based approach [16]. A statistical parametric model can be a simple approach to anomaly detection problems, assuming that the data is normally distributed, fits certain distributions, and that the value of these parameters is unknown. These must be estimated from the given data. Selecting the correct statistical tool for anomaly detection, however, requires the validation of a normality assumption [29].

Normally distributed data can often be tested using histograms. A histogram may not, however, reveal the shape of the distribution. The selection of the normality test tool was based on a comparative study of different normality tests. This study showed that the Shapiro-Wilk test was the most suitable tool for data sets of sample sizes of between 50 and 2000 [30], the null hypothesis in this test being that the sample is a normal distribution. This hypothesis is rejected if P values are less than .05 (95% CI). Results of the tests can be found in Table 2.

Table 2. Shapiro-Wilk normality test.

Apartment and activities[a]		Shapiro-Wilk normality test (test statistics *W* and P values)[b]
1		
	Breakfast: 6:00-9:00	*W*=.981, *P*<.001 (reject H0)
	Lunch:11:00-13:00	*W*=.972, *P*<.001 (reject H0)
2	Breakfast: 7:00-9:00	*W*=.954, *P*<.001 (reject H0)
3	Breakfast: 7:00-10	*W*=0.926, *P*<.001 (reject H0)
4		
	Breakfast: 6:00-7:00	*W*=.979, P=.047 (reject H0)
	Lunch:11:00-13:00	*W*=.949, *P*<.001 (reject H0)
	Dinner:16:00-18:00	*W*=.962, P=.001 (reject H0)
5	Breakfast: 5:00-8:00	*W*=.967, P=.003 (reject H0)
6	Breakfast: 7:00-10:00	*W*=.958, P=.009 (reject H0)
8		
	Breakfast: 7:00-10:00	*W* =.943, *P*<.001 (reject H0)
	Lunch: 10:00-13:00	*W*=.967, P=.005 (reject H0)
	Dinner: 17:00-20:00	*W*=.729, *P*<.001 (reject H0)
9	Breakfast: 08:00-10:00	*W*=.982, P=.05 (fail to reject H0)

[a] Meals activities in the kitchen and visitation to the bathroom: from the interview data, we identified the most common routines among all participants, including a start time and end time of each activity.

[b] If the P value of the Shapiro test is smaller than .05 (the threshold), then the data significantly deviates from a normal distribution.

The normality test results show that 12 out of 13 (92%) tested meal activities in our study do not show a normal distribution. We, therefore, selected Chebyshev's inequality theorem, a nonparametric statistical method, to detect anomalies [31] in user daily activities based on time duration. Chebyshev's inequality constructs the upper and lower interval for the percentage of the data that falls outside of k standard deviations from the mean. It holds no assumptions about the distribution of the data and can be used in situations where at least 75% of the data is within 2 standard deviations of the mean. This can be more than 75% in some cases.

The inequality in Equation (1) calculates an upper bound ¼ for the probability of random values exceeding (k) 2 standard deviations from the mean. We, therefore, define an outlier as a data point of a time duration in minutes or hours that exceeds the expected duration by 2 standard deviations [13].

$$P(|X-\mu| \geq k\sigma) \leq 1/k^2 \textbf{(1)}$$

X is the random variable, μ is the mean, and σ is the standard deviation.

A value for p, the significance level of the intervals, is 0.25. This determines which data are potential outliers. To find k using Equation (2):

$$k = 1/\sqrt{p} \textbf{ (2)}$$

The significance level is 0.25 with a confidence level of 75% and a k value of 2. Equation (3) can be used to determine the probability that a randomly selected value is in the interval, around 75% of observations falling within 2 standard deviations of the mean.

$$\mu \pm k\sigma \textbf{ (3)}$$

Durations that lie between the lower and upper thresholds are considered to be normal. Data from wall plug sensors was also processed and added to the notifications as additional context. We, however, restricted the model to the duration feature, wall plug sensors, and visit frequencies not being used in the anomaly detection classification process. Our observations showed duration to be the most important feature, duration showing how long a participant remained in a room to perform an activity.

Types of anomalies with example situations:

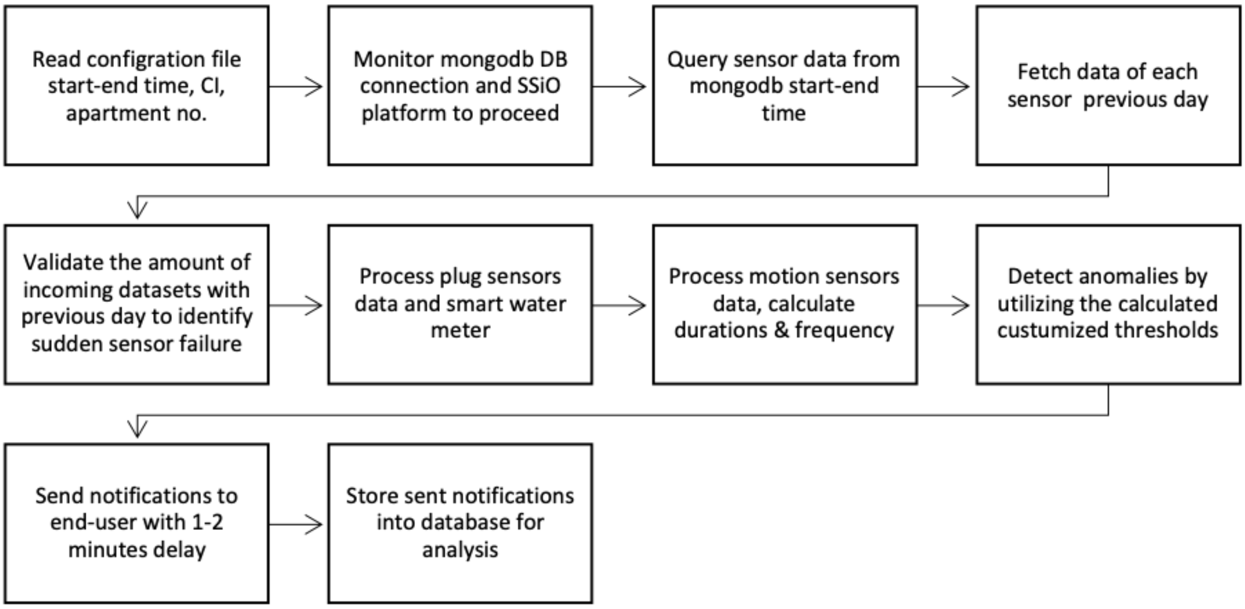
- Unusually long/short activity: duration in a room in a specific timeframe is unusually long/short, indicating a fall/unconsciousness or health issues [11,15,16].
- Not present: when a user is expected to be in a room in a specific timeframe but is not [13].

Notification Service Module

Our implementation delivers positive or negative notifications to relatives and caregivers. Positive notifications represent normal days, and negative notifications represent anomalous days. The notifications were sent via SMS [15]. Negative notifications are sent when activities deviate from the observed normal behavior, which is based on analyzed historical data. Positive notifications are sent when the user's behavior is normal and when the relative expresses an interest in receiving such notifications. The design of the notification service process in Figure 3 starts by reading a configuration file, which automates a schedule and starts the service process.

We contacted the relatives before running the system to inform them of the activities they would be notified about. They were shown a notification format and the information that would be included. They were optimistic about the possibilities that the system could provide, the system providing comfort through being able to remotely check in on their parents daily. A consensus was reached with participant relatives on the content of the notification and the type of communication to be used (ie, SMS).

Figure 3. The process for notification service implementation. DB: database; No: Apartment number; SSiO: societal development through secure IoT and open data.



The notification structure included the number of minutes spent on the meal activity, across how many visits, whether they used any appliances, and the normal duration of the activity for that participant based on their identified patterns. An example of the structure and information for one positive notification sent for apartment 1 is shown below:

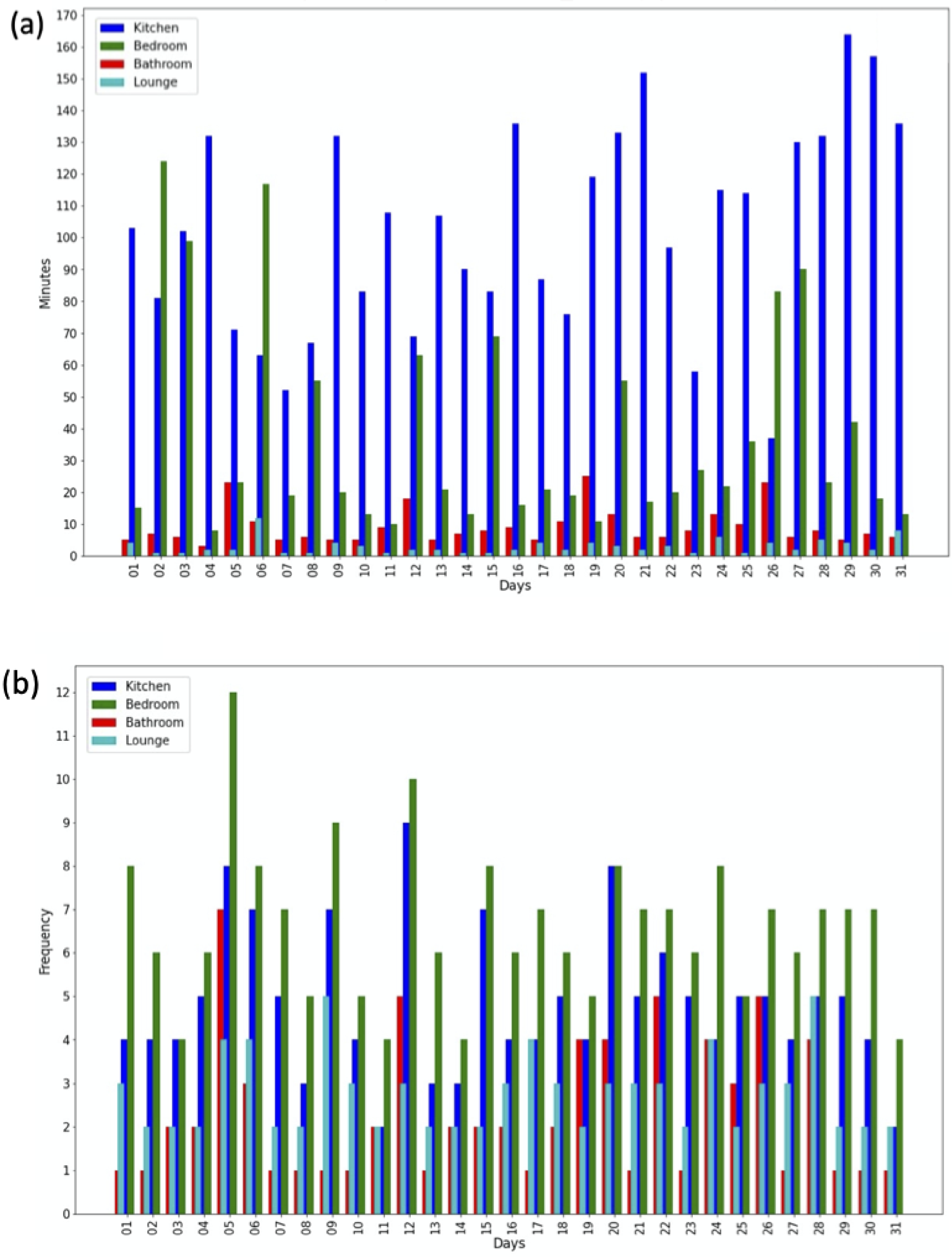
> *50.4 minutes of activity in the kitchen between 07.00 and 10:04, during 8 visits. The kettle has been used. Our analysis shows that 9-70 minutes is the normal time duration in the kitchen. If that message is not correct and deviates from the actual event, we are grateful for feedback with a description of the deviation.* [LTU iVO Message ID: 1, 2020-07-21]

The relatives were given the option to reply to every notification. This response included feedback when there was anomalous behavior.

Results

Duration and visit frequency are essential in the analysis of user daily behavior. Figure 4a shows time durations in minutes in different rooms of the apartment, frequencies of visits being shown in Figure 4b. The participant in apartment 1 spent more time in the kitchen than in the other rooms, except for 2 days in the trial month. This indicates that the participant is active during the morning due to eating breakfast. The number of transitions from and to the bedroom in Figure 4b shows that the participant is active, the participant remaining in the bedroom for only short periods of time. Such behavior conforms with a typical morning.

Figure 4. (a) Data for the duration in all rooms between 06.00 and 10.00 in apartment 1 (August 2020), (b) Data for the number of visits to all rooms between 06.00 and 10.00 in apartment 1 (August 2020).

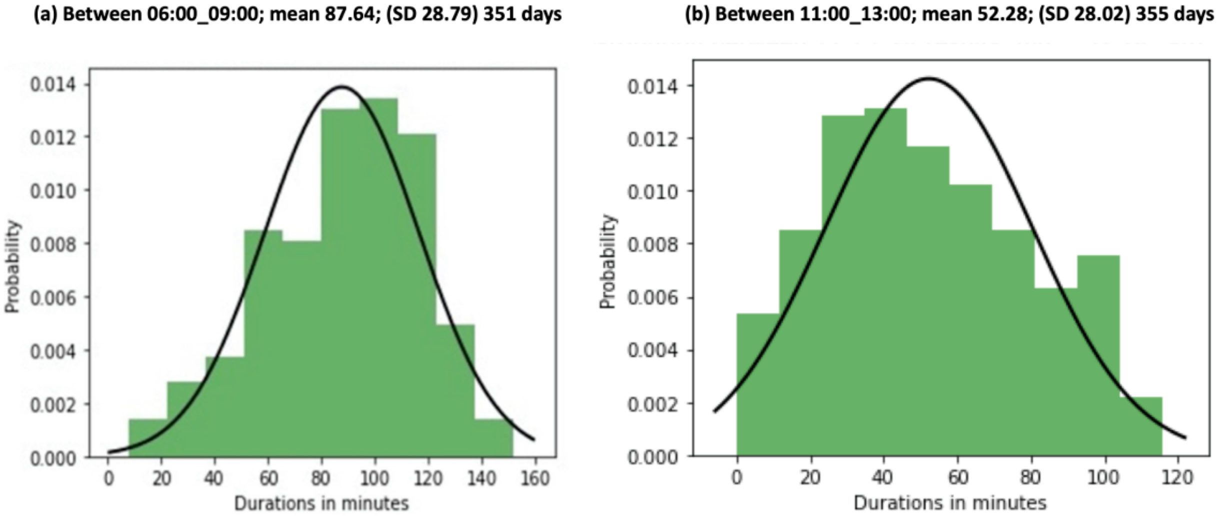


Visits to the bathroom also show consistency, multiple visits for short periods of less than 10 minutes. The duration in the bathroom for four days on the 5th, 12th, 19th, and 26th of August 2020 was, however, 20-25 minutes. These days were cross-checked with this participant's profile and showed that home care visited the participant to help them with bathing. The participant spent less time in the bedroom and more time in the kitchen on most weekend days (1, 2, 8, 9, 15, 16, 22, 23, 29, 30) in August. The kitchen was the most used room in the apartment, especially in the morning, as opposed to in the lounge and bedroom. User behavior can easily be interpreted from durations and transitions between the rooms.

The value of the inequality is used when we only know probability distribution estimates, mean and standard deviation. These approximations are derived from the historical data sets of extracted features of time duration in the kitchen, as the example in Figure 4a shows.

Figures 5a and 5b show the distribution of time durations of two-meal activities for 351 days in 2019 and 2020. It can be seen that the participant spent between 1-2 hours in the kitchen in the morning on 250 of the 351days (Figure 5a). There are only a few days in the year when the participant spent less than half an hour and more than two hours in the kitchen during a year, these being on the extreme right and left sides of the distribution.

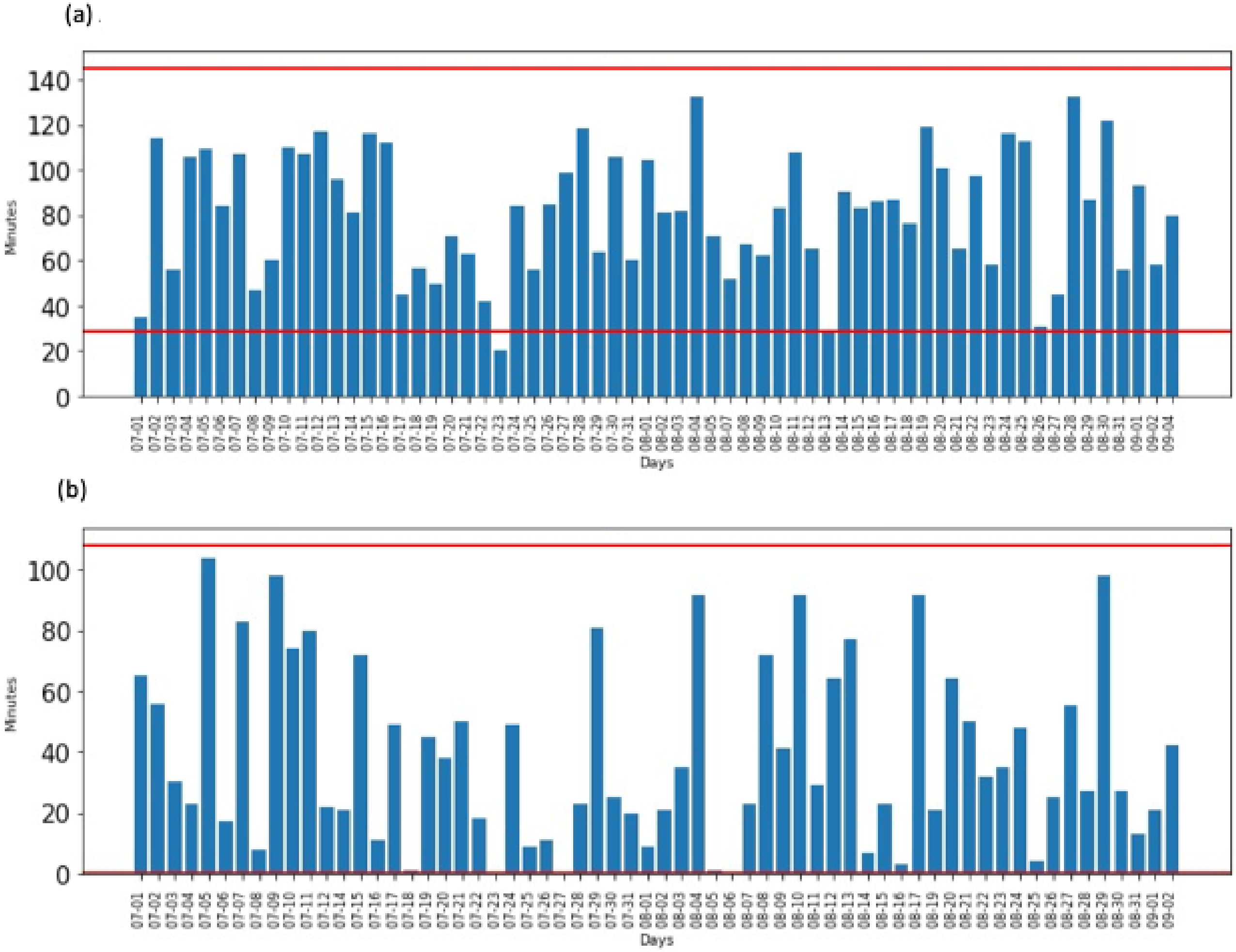
Figure 5. Probability distribution with mean (SD) for 351 days in the kitchen between (a) 6:00 and 9:00 and (b) 11:00 and 13:00 in apartment 1.


(a) Between 06:00_09:00; mean 87.64; (SD 28.79) 351 days

(b) Between 11:00_13:00; mean 52.28; (SD 28.02) 355 days

Figures 6a, Figures 6b, and Multimedia Appendices 1, 2, and 3 show the activity of a participant in the kitchen in the morning and mid-day. Figure 6a shows the time spent in minutes in the kitchen between 6:00 and 9:00 in July and August 2020. The red lines represent the calculated minimum and maximum thresholds and are based on the mean and standard deviation information given in Figure 5, which was calculated from the 2019 and half of 2020 data (355 days). This provides valuable information on probability.

Figure 6. (a) Data of durations in kitchen between 06:00 and 09:00 in apartment 1, (b) Data of duration in kitchen between 11:00 and 13:00 in apartment 1, (red lines represent lower/upper bounds) for July and August 2020.



About 80% of the duration lies within the range of 29 to 145 minutes. The kitchen was not used by the participant in the breakfast activity time range on August 6 and September 3, this being anomalous. The time duration for lunch activity between 11 and 13 (Figure 6b) shows either very short or long stays. It is noticeable that the level of activity is low in the kitchen, which could be due to lunch only being prepared in the kitchen but eaten in another room.

Table 3 summarizes the estimates of each average mealtime duration as calculated from the historical data (80 to 355 days) for eight apartments. The values are depicted in Figure 5 and Multimedia Appendix 4. The number of trial days of each observed mealtime and the average duration in the notification trial between July and August 2020 is also depicted.

Table 3. Average duration in the kitchen as observed from total historical days is consistent with average duration in the kitchen as observed from total trial days.

Household and mealtime from interviews[a]		Total historical days[b]	Average Duration for historical days[c]	Number of trial days[d]	Average Duration for trial days[e]
Apartment 1					
	6:00-9:00	351	87	69	82
	11:00-13:00	355	52	66	39
Apartment 2	7:00-9:00	364	34	51	32
Apartment 3	7:00-10:00	144	40	60	42
Apartment 4					
	6:00-7:00	126	24	56	23
	11:00-13:00	140	47	42	63
	16:00-18:00	137	44	46	38
Apartment 5	5:00-8:00	128	29	46	30
Apartment 6	7:00-10:00	81	41	52	41
Apartment 8					
	7:00-10:00	115	40	62	41
	10:00-13:00	119	41	64	44
	17:00-20:00	115	17	57	23
Apartment 9	8:00-10:00	145	55	45	73

[a] Meals routines in the kitchen collected from the interview data, including a start time and end time for each.

[b] Number of past days defines regular activity patterns defined from the records in 2019 and the first half of 2020 data.

[c] Average duration associated with each meal during 2019 and the first half of 2020 data.

[d] Number of observed days during the trial July-August 2020 for each meal activity.

[e] Observations of average duration associated with each meal during the trial July-August 2020.

For example, participant 1 follows a pattern of performing the breakfast activity between 6:00 and 9:00. This shows that she was consistent in her habits. The regular pattern derived from the historical data showed a duration of 87 minutes, while observations from the notification gave a duration of 82 minutes. Most of the participants are consistent in their habits, following a pattern in daily meal activities. The activities also occurred within the self-reported timings.

We observed approximately 1000 meals in nine apartments between July and August 2020. We also observed bathroom activity. Table 4 shows the number of positive and negative notifications for normal and anomalous behavior sent to each household’s relative. The notifications are based on the end-users wishes defined in Table 1.

Table 4. Types of notifications sent for eight apartments for each mealtime during July-August 2020.

Apartment ID, type of notification[a], and total number of observed mealtime activities[b]	Mealtime from interviews[c]	Number of observed activities for each mealtime[d]	No. of normal activity/positive notifications[e]	No. of anomalies/negative notifications[f]
1: N/P[g] (n=135)				
	6:00-9:00	69	56	13
	11:00-13:00	66	63	3
2: N[h]	7:00-9:00	51	49	2
3: N	7:00-10:00	60	58	2
4: N (n=144)				
	6:00-7:00	56	56	0
	11:00-13:00	42	40	2
	16:00-18:00	46	46	0
5: N	5:00-8:00	46	46	0
6: N/P	7:00-10:00	52	51	1
8: N/P (n=183)				
	7:00-10:00	62	51	11
	10:00-13:00	64	60	4
	17:00-20:00	57	52	5
9: N	8:00-10:00	45	40	5
Total		716	668	48

[a] The type of meals notifications, negative and/or positive, for each apartment received based upon their requests

[b] The total number of observations of each apartment's meals activities.

[c] Meal routine activities in the kitchen collected from the interview data, including a start time and end time for each.

[d] Number of observed activities per apartment per meal activity, breakfast/lunch/dinner during the trial July-August 2020.

[e] The number of normal activity of users during the trial (July-August 2020) and that match the regular activity patterns defined from the 2019 and first half of 2020 data.

[f] The number of anomalous activity of users during the trial (July-August 2020) and that deviated from regular activity patterns defined from the 2019 and first half of 2020 data.

[g] N/P: negative and positive notifications.

[h] N: negative notifications.

For example, about 80% (56) of our observations of breakfast activity for participant 1 fall between –2 and +2 standard deviations of the mean. Fifty-six (80%) days were normal, and 13 of the 69 observed days (19%) were abnormal. Normal activity falls between the 29 and 145 minutes minimum and maximum threshold, respectively. The majority of meal notifications (119/135, 88%) were sent to participant 1 in the notification trial to confirm her expected morning and lunch meal behavior.

The regular patterns derived from the historical records and the observations in the trial show that the participant's behavior closely matches the routines they self-reported in the interviews. The participant regularly follows their breakfast and lunch activity routines, including timing. These routines are therefore reliable enough to be used for alerts.

A total of 716 meal activities were observed for the 8 apartments, 668 (93%) being normal and 48 (7%) being abnormal. The participants are within the same age group. It can therefore be noted that approximately 93% of the total 716 meal activity observations for all apartments corresponded to the expected behavior.

Our system sent out 421 notifications to 8 apartments. Some of the apartments expressed an interest in receiving positive and negative notifications. Three hundred seventy-three (88%) positive notifications were sent, corresponding to normal behavior during breakfast, lunch, and dinner; 48 (7%) negative notifications were sent, corresponding to anomalous behavior. More than 75% (537/715) of observed meal activities for all apartments fell within 2 standard deviations of the mean and so correspond to normal behavior. The results closely match the participant routines reported in the interviews.

Feedback on the effectiveness of and user satisfaction with the system was collected. This can provide information on the actual well-being of older persons and can also help relatives to understand that monitoring systems can improve current interventions but cannot substitute the existing health care system. The feedback results from 5 apartments out of 9 are shown in Table 5. The table summarizes the non-mandatory weekly questions sent to end-users on their satisfaction with the notifications received, end-users scaling our service on a scale of 1-5. The results show a positive user experience. We received an average of 4 on a 1-5 Likert-like scale, one being poor, two fair, three good, four very good, and five excellent. The relative of the apartment 6 participant, for example, responded to the notification: “No activity in the kitchen between 05:00 and 07:59.” The feedback was: “I was in contact with my mother at 08.03, and she was in the kitchen..” Another example of feedback was from a relative of the apartment 4 participant, who responded to a change in dinner pattern. Notification: “No activity in the kitchen between 16:00 and 17:59.” Feedback: “Late dinner!” This informed our system of the pattern change and validated our anomaly recognition method. Relatives were also asked to provide weekly feedback via SMS on our system’s overall performance. Weekly notification: “Hello, How have you experienced our iVO. LTU notifications in the last week on a scale of 1-5 (5 is best)? Thank you for taking part!” The participant in apartment 6, for example, in the second week of feedback expressed his satisfaction with the accuracy of notifications. “At the same time, every day, we get a positive notification, which I think is good.” The overall experience was positive, the relatives finding it helpful to know when to contact the participants, based on their normal/abnormal activity routines. The notifications also allowed them to be informed that “all is well” with older participants, which is the overall focus of the iVO project.

Table 5. Summary of weekly feedback from relatives of each apartment (ID) on a scale of 1-5 where 1 is poor, and 5 is excellent.

Date	H2	H4	H5	H6	H9
2020-07-08	5	5	3	No-reply	No-reply
2020-07-17	5	5	No-reply	No-reply	No-reply
2020-07-27	5	5	3-4	4	No-reply
2020-08-04	4	5	No-reply	4	No-reply
2020-08-12	4	5	3-4	4	4
2020-08-18	5	5	3-4	No-reply	No-reply

Discussion

Principal Findings

Our study demonstrates, through nine cases, how a data-driven approach and longitudinal data from interviews can convert large amounts of sensor data into knowledge. Our approach can detect anomalies in ADLs and utilize notifications to alert relatives of these anomalies. An important aspect of this approach is that it can facilitate the interpretation of data from real-world smart homes and use this in real-time monitoring systems to identify activities that deviate from the normal patterns of older persons. This enhances our understanding of personalized setups and different individual daily routine preferences. The results support the use of data from off-the-shelf sensors and IoT devices (installed in real homes) and the improvement of health care services by feedback to caregivers in near real time. This further enables older persons to live independently in their homes for longer.

Comparison With Prior Work

We used, in our research, statistical methods to detect anomalies, an approach that has been used in other studies [13,16,32]. The statistical methods we used to detect anomalous behavior in ADLs are in line with previous studies. We, however, in the interests of accurate interpretation, tested the assumptions of data normality. Konios et al [32] recruited 30 volunteers aged 30 to 45 years to conduct a study of the recognition of low-level activities such as steps in preparing and drinking tea/coffee. They used the mean ±1.5 standard deviations as the threshold for classifying normal and anomalous events. Another similar study [16] used low-level activities from the annotated CASAS public data set [33]. The mean and ±1 standard deviation were used to classify activities as normal and abnormal behavior. The mean ±2 standard deviations were, however, used in [13] to detect anomalous behavior at the 95% CI, thresholds being calculated using 2 months of history data of students’ working activity. Our method uses Chebyshev’s inequality, thresholds being based on intervals in which only 75% of the data is within 2 standard deviations, 95% being within 2 standard deviations in a normally distributed data set.

Our results are distinct in that they were collected in an uncontrolled environment and used real-world data of older participants in their homes. Konios et al [32], in contrast, used a lab setting; Jakkula et al [13] used synthetic data and one day of real data from a lab environment to validate their approach. The work in Paudel et al[16] was implemented using annotated public data sets.

Our overall approach builds on earlier work [12,14,34], all being real-world implementations. The data collection process, sensor setup, the method used for pattern identification, and the behavior of older persons, however, differ. Beunk et al [12] aimed to visualize sensor information, duration, and start time from log data, notifications being sent to caregivers, participants, and relatives using real-world monitored activities of 5 participants aged ≥ 65 years. Kasteren et al [14] used 180 days of real-world data obtained from power usage, motion sensors, and interviews to carry out a behavioral analysis of the 3 participants. The distribution of daily activities aggregated over multiple days was visualized using radar plots. Interviews and motion sensors were used to identify residents' sleep and daily movements. Another longitudinal study [34] evaluated the usage of unobtrusive technologies in detecting a change in activities and cognitive decline by statistically analyzing 200 days of data on the daytime and nighttime activities of 233 senior participants with a mean age of 83 years.

Our study proposes a solution that detects anomalies in different types of activities in real-time. Our approach is validated by comparing longitudinal data collected from interviews with observed patterns collected from historical data (80-355 days of sensor data). This was processed to classify activities into normal and anomalous behavior and so allow notifications to be generated.

The Strengths of the Used Approach

Routines are defined as being designed behavioral patterns that are used to orchestrate activities. The clock, time duration, contexts, and order are also used in this [35]. Data collected from participants on routines helps validate the analysis of sensor data and so contributes to the minimization of false positives [14]. This also helps more reliable and personalized notifications to be delivered, which helps ensure that the needs of older persons are addressed. Adherence to regular daily routines by older persons contributes to a reduction of stress, increases feelings of safety [36], and improves sleep quality [37]. Our proposed approach to ADL analysis used routine data (data collected from the interviews) of older participants to identify anomalies in ADLs. This approach is similar to that used by other studies [12,14,34]. Our approach, however, differs from [13,16,32], which used annotated activity data. Our study relies on sensor labels and routines defined in the interviews.

HAR activities are, as in Saguna et al [10], classified as low-level activities such as walking and high-level activities such as making coffee. It is important, as mentioned in Hussain et al [38], to use historical sensor data to analyze individual high-level activity behavior patterns (ie, ADLs). Obtaining the required historical data from real-world environments is, however, challenging, especially for older adults. Activity recognition with a focus on health care could also be defined as behavior recognition, this relying on historical data captured from sensors to infer ADLs as high-level activities. This type of high-level activity recognition could reduce human resource costs, allowing the detection of anomalies from the normal behavior of older persons and caregivers to be informed of this.

Some studies [15] collected data from a controlled environment and for nonolder participants [13]. The findings from these are, however, difficult to generalize to the ADL applications of older persons. Most of the research work within HAR [39] also relies on annotated public data sets generated in controlled environments or lab settings [40]. Solutions based on controlled environments may not be suitable for real-world deployments. We, however, collected historical data from motion and wall plug sensors for time periods ranging from 3 months to one year and for nine real homes.

Activity data can be tracked and collected from multiple sensor technologies, wearable devices often being used in activity monitoring systems to capture the data of older persons [22] and to infer low-level activities such as walking or falling [8]. Wearable devices, however, lack practicality, especially for older users [38]. Hernandez et al [40] also investigated previous HAR work between 2014 and 2019 and showed that data is primarily collected from mobile and wearable devices rather than dense-sensing networks.

The deployment of dense-sensing networks in anomaly detection systems is highly recommended in the health care systems of older persons. This is due to their practicality and to their robustness to changes in the environment [22]. These networks can also gather more general information, which can be used to recognize ADLs (ie, high-level activities such as leaving home or sleeping) [8]. In this trial, we used the data from four motion sensors in each apartment to analyze the behavior of users, this being a similar approach to that used in Beunk et al and Kasteren et al [12,14].

The strength of our approach lies in the handling of noise arising from off-the-shelf sensors, which are prone to malfunctioning [41]. This noise is handled by building mechanisms that eliminate erroneous readings or noise from the preprocessing of sensor data. This ensures better accuracy than previous approaches [42] and reduces false alerts [24].

Detecting anomalies in activity patterns using time series sensor data without annotations is challenging. We, however, analyzed the behavior of older persons by developing algorithms that can build temporal features such as duration in and the number of visits to each room. Determining changes in these activities using duration time is, therefore, an important development in the analysis of behavioral patterns [35]. Anomalies can therefore be detected using these temporal features. There is a need for near real-time technology in support of older persons in their activities. Examples of this include reminders to take medicine and interaction to provide immediate support in ongoing activities such as preparing a meal [8,43]. The data processing in real-time ADL analysis is challenging [39]. Our approach, however, uses near real-time analysis in the collection, monitoring, preprocessing, and processing of sensor data for each apartment.

Effectiveness of the Developed iVO System

The estimated probability distribution of each activity and for each apartment is given in Figure 5 and Multimedia Appendix 4. The activity patterns are reflected in the mean time duration for each activity, which is drawn from historical data and is given in Table 3. There is a close correspondence between the historical patterns and the test data set patterns for morning activities (notification trial July-August 2020) for all eight participants. The historical data set shows that they use on average 44 to 47 minutes on breakfast/lunch, the trial data showing that they use 45 to 50 minutes. There are, however, some variations, such as the dinner activity of 2 apartments (4 and 8) and the lunch activity of 3 apartments (1, 4, and 9). The average duration for each participant based on the historical data and the notification trial shows routine consistency. The strength of our approach is the ability to identify the regularity in the timing and duration of the different ADLs and to from this identify deviations from this. The importance of the timing, duration, and regularity of activity routines is highlighted in Chung et al [44], and changes in routines, furthermore, potentially signaling cognitive decline or a health issue. Our approach showed that most participants followed a routine in their activities in the trial period.

The most suitable method for constructing thresholds must be selected, the correct handling of changes or irregularities in routines and a reduction in false alerts being dependent on correct selection [14]. These methods need to be reliable if our anomaly notifications are to be effective. We, therefore, set up notification alerts for three types of anomalies: (1) not present, (2) maximum time spent exceeded, and (3) minimum time spent not reached. Our approach used the historical data used to determine statistical thresholds for anomalies (2) and (3), assumptions including data normality, homogeneity of variances, and linearity. These assumptions are important in the selection of a suitable method, their violation leading to result misinterpretation [29]. Previous work has used statistical methods [13,16,32]. We, however, perform the normality test (Table 2), which allows us to determine an appropriate statistical method—Chebyshev's theorem for classifying normal and anomalous behavior. Identifying changes using this method allowed us to consider confidence levels of 75% to be normal. This was, however, 93% for all participants and all activities.

The number of activities monitored, identified, and notifications generated in the trial period also reflect the effectiveness of our system. Our system observed 716 meal activities in the trial period in 8 apartments, 668 (93%) being normal and 48 (7%) being anomalies. Our system generated 421 notifications, 373 (88%) positive notifications that correspond to normal behavior during breakfast, lunch, and dinner, and 48 (7%) negative corresponding to anomalies.

Implications

Our findings show that our system can benefit relatives and can be used by formal health care providers in Skellefteå municipality. Relatives and caregivers received timely notifications of older participants' activities. The system was also able to distinguish between normal and anomalous behavior, which can be used to detect long-term changes in routines and which can signal the early stages of cognitive decline. We believe that this type of system can have a direct impact on the enabling of older persons to live independently for longer. Feedback collected on our system (Table 5) was mainly positive and reflects a high level of user satisfaction with the iVO service. Some participants showed an interest in continuing the service after the trial period ended.

Limitations

Our approach is limited to the use of duration to identify anomalies. The root cause of the anomalies can, however, only be known via feedback from relatives. A direct method for establishing the root causes of anomalies would help us to understand anomalies better. This approach would, however, make our system too intrusive, interrupt the day-to-day lives of participants, and have an impact on their normal routines. Our preference is that relatives communicate with participants about anomalous behavior and that feedback to our system is then provided by relatives. The use of Chebyshev's inequality is another limitation. Thresholds are based on loose intervals with only 75% within 2 standard deviations. This can be compared with a normally distributed data set where 95% is within 2 standard deviations. These loose intervals mean the thresholds are wider apart and can therefore lead to fewer anomalies.

Conclusions

We developed an SMS-based notification service based on information provided in interviews on the needs of participants and their relatives, on the activities they were interested in, and on data from the off-the-shelf sensors and IoT devices installed in homes. We also conducted user evaluations. This service acts as an extension of the municipality health/social care services and helps older persons to live in their homes independently. We proposed, developed, and implemented an anomaly detection framework for the recognition of anomalous daily activities of older persons living in single resident smart homes, using the real-life uncontrolled setting of 9 older participants. This paper proposed a probabilistic approach to the temporal analysis of ADL of nine older participants in a real-world environment. The method introduces a way of indicating whether the probability of a performed activity is considered to be normal or anomalous behavior using duration.

Our system observed approximately 1000 meals and bathroom activities. Notifications were also sent to 9 apartments between July and August 2020. Four hundred twenty-one notifications (59%) out of the observed meals activities (716) were sent to 8 apartments on each meal activity, with our approach considering more than 75% (537) of observed meal activities to be normal. This figure was, however, in reality, 93% of meal activities, these falling within 2 standard deviations of the mean and so corresponding to their normal behavior. The behavior patterns derived from the historical processed sensor data closely match the routines participants reported in the interviews. We received positive user experience feedback on the service from 5 out of 9 participants' relatives (55%) and an average of 4 points on a 1-5 satisfaction scale. The results ultimately support the use of IoT devices in homes as an extension of health/social care services, which can, in turn, increase the opportunity to age in the home independently.

Future Work

We will, in the next phase of this project, use advanced data analytics methods to further investigate the data. We would include other types of anomaly classes in this, such as transitions or visits of unusually short durations, which can indicate unrest and the detection of an unusual presence. Other types of context sensors and features also need to be considered in the analysis. Contextual information such as weather conditions and holidays could, for example, improve results and reduce false positives in detected routines [45]. Future research can furthermore test algorithms that monitor real-time ADLs using data for that specific week, which will allow for weekly variations in routines. Data based on a monthly moving window would also allow for seasonal variations in routines. We are working towards using reinforcement learning as a multi-armed bandit problem (MAB). We plan to conduct follow-up interviews for the study as part of a workshop to communicate our results and understand further needs. Direct feedback from older persons is another important aspect. This would, however, increase the cognitive load upon them. There was no appropriate communication channel for feedback on the alerts or activity updates sent to relatives by older persons, which was not implemented due to the increased burden of daily feedback on older persons. This type of feedback was mainly gathered via the relatives, who communicated with their older relatives about an anomalous notification. This will be addressed further in our future research.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Observations of participants in apartments 2-9 for different meal activities in the kitchen during the trial, July and August 2020. The redlines represent the lower and upper bounds.

[PNG File , 2528 KB - aging_v5i2e28260_app1.png]

Multimedia Appendix 2

Observations of participant's visits frequency and water boiler usage during breakfast in the kitchen in apartment 1 during the trial, July and August 2020.

[PNG File , 231 KB - aging_v5i2e28260_app2.png]

Multimedia Appendix 3

Observations of participant's visits frequency and water boiler usage during lunch in the kitchen in apartment 1 during the trial, July and August 2020.

[PNG File , 245 KB - aging_v5i2e28260_app3.png]

Multimedia Appendix 4

Probability distribution (PDFs) of the duration of each meal activity of each participant, apartment 2-9, during 2019 and the first half of 2020. The total number of days varies from 80 to 355 days of different apartments, including the mean (mu) and standard deviation (std) duration values of mealtimes.

[PNG File , 410 KB - aging_v5i2e28260_app4.png]

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Abbreviations

ADL: activity daily living
HAR: human activity recognition
IoT: internet of things
iVO: internet of things within health and care
SSiO: societal development through secure IoT and open data

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Original Paper

Benefits of, Barriers to, and Needs for an Artificial Intelligence–Powered Medication Information Voice Chatbot for Older Adults: Interview Study With Geriatrics Experts

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Abstract

Background: One of the most complicated medical needs of older adults is managing their complex medication regimens. However, the use of technology to aid older adults in this endeavor is impeded by the fact that their technological capabilities are lower than those of much of the rest of the population. What is needed to help manage medications is a technology that seamlessly integrates within their comfort levels, such as artificial intelligence agents.

Objective: This study aimed to assess the benefits, barriers, and information needs that can be provided by an artificial intelligence–powered medication information voice chatbot for older adults.

Methods: A total of 8 semistructured interviews were conducted with geriatrics experts. All interviews were audio-recorded and transcribed. Each interview was coded by 2 investigators (2 among ML, PR, METR, and KR) using a semiopen coding method for qualitative analysis, and reconciliation was performed by a third investigator. All codes were organized into the benefit/nonbenefit, barrier/nonbarrier, and need categories. Iterative recoding and member checking were performed until convergence was reached for all interviews.

Results: The greatest benefits of a medication information voice-based chatbot would be helping to overcome the vision and dexterity hurdles experienced by most older adults, as it uses voice-based technology. It also helps to increase older adults' medication knowledge and adherence and supports their overall health. The main barriers were technology familiarity and cost, especially in lower socioeconomic older adults, as well as security and privacy concerns. It was noted however that technology familiarity was not an insurmountable barrier for older adults aged 65 to 75 years, who mostly owned smartphones, whereas older adults aged >75 years may have never been major users of technology in the first place. The most important needs were to be usable, to help patients with reminders, and to provide information on medication side effects and use instructions.

Conclusions: Our needs analysis results derived from expert interviews clarify that a voice-based chatbot could be beneficial in improving adherence and overall health if it is built to serve the many medication information needs of older adults, such as reminders and instructions. However, the chatbot must be usable and affordable for its widespread use.

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KEYWORDS

medication information; chatbot; older adults; technology capabilities; mobile phone

Introduction

Older adults (defined here as those aged ≥65 years) have multiple chronic diseases [1] and consequently take far more medications than the average individual [2]. One study estimated that 39% of older adults had ≥5 concurrent prescriptions, and this number had tripled from that 20 years ago [3]. Complicating this situation further is the reduced mental capacity of older adults [4]. This means that the cognitive burden of keeping track of medications is well beyond the capabilities of many older adults, resulting in poor adherence [5] and consequently affecting health. Older adults often rely on caregivers and low-tech solutions such as pillboxes, but technology is often seen as a barrier for older adults. However, as Olsen et al [6] described, although the range and frequency of technology use among older adults may be less than that of younger adults, the capability still exists for certain types of technologies. A technology that relies on their existing knowledge and experience has the capacity for widespread adoption. The primary significance of this study is that it gauges the potential incorporation of a tool capable of improving medication understanding and adherence among older adults using a technology that mimics everyday human behavior of voice conversations: a chatbot. Indeed, voice-based chatbots have already been seen as a potential aid for older adults [7] and early-stage implementations of such systems for medication information exist [8], although these are clearly not in common use and many barriers remain to their successful adoption. To understand the capabilities of a medication information chatbot for older adults, we conducted a qualitative needs analysis using interviews with a wide range of geriatrics experts. The interviews were limited to geriatrics experts, as this was felt to be the best way to engage experts, whereas actual older adults would be better engaged through separate simulation-based studies. We then analyzed the experts’ beliefs about the capabilities of older adults with such a chatbot with regard to managing their medications and what their medication information needs were.

The subject of older adults and chatbots has been explored previously in several studies. Martin-Hammond et al [9] assessed the general attitudes of older adults toward intelligent assistants (IAs; a class of agents that includes the voice-based chatbots studied here), finding them very positive. The study participants viewed IAs as great opportunities that could facilitate collaboration between themselves and their caregivers. They also considered IAs to be very useful in providing recommendations and alerts for serious illness. However, they preferred the assistants to be more flexible so that all sections of older adults could use them, including those with low technical resources and skills. Moreover, having an interactive IA that could mimic natural interactions regarding health information was viewed as more desirable. Chatbots have also been proposed to improve Wikipedia use and editing to circumvent the steep learning curve for older adults [10]. A study on the use of chatbots for psychological support purposes showed that they could be useful for resolving problems and lowering distress [11]. The chatbots were designed to mimic therapists, and the agent’s usability was associated with their helpfulness. Overall, these studies suggest that well-designed intelligent agents would be well-received by older adults despite the technology not currently being used.

With regard to medication information, older adults find pharmacists most useful, both for managing their medication lists and educating them with instructions [12]. A study was conducted to understand older adults’ expectations and requirements for a personal health application that could meet their information needs [13]. The interviewed patients and caregivers reported the following as top requirements: (1) having the capability to disclose medication side effects and interactions in a clear and easy manner, (2) being able to connect their providers and pharmacies, and (3) being able to share their medication information with other providers. Another study noted an interesting aspect of interviewing patients upon discharge from the hospital. Although having information about their medications, alternative treatment options, and side effects were the most important needs, some patients did not actually want to fully understand the medications and their side effects, as they were afraid that knowing them might change their attitude toward the medications [14]. This suggests that although a chatbot could be beneficial, it should be designed to not overwhelm patients with details beyond their grasp. For instance, even common medications have a long list of side effects that patients are unaware of, so providing information on a long list of rare side effects for a new medication may give the patient the false impression that the medication is dangerous relative to the medications they already regularly take.

The role of caregivers, such as home care nurses, was explored in a study [15], wherein the challenges of the transition of care between various settings were studied. Whenever older adults were moved from hospitals to home or nursing care, changes to their medications and administration instructions would change. In such cases, home care nurses played a big role in helping the older adults adapt and follow the new medication changes and manage medication compliance. This highlights the importance of caregivers and their roles in managing the overall health of older adults. This suggests that voice-based chatbots cannot fully replace existing human interactions for medical information, and should thus focus on supplementing existing relationships and information sources. One of the aspects of medication management for older adults was their trust in resources. A survey conducted to identify the resources that were trusted more [16] for health information needs showed that older adults placed living resources higher than nonliving resources. The top priorities for seeking information were health care providers and pharmacists.

Overall, the use of health applications and computer assistants in older adults to assist with their medication management and self-care has been an area of interest [17-21]. We continue to explore this area in this study to make medication management easier and safer in older adults. Specifically, this paper’s contribution is to summarize the beliefs of geriatrics experts on the benefits, barriers, and needs of such a voice-based medication information chatbot. Using structured interviews and a rigorous qualitative coding process, we identified key themes from this group.

Methods

Overview

The needs analysis collected data on high-level needs to assess the feasibility and system requirements for an artificial intelligence (AI)-powered medication information voice chatbot for older adults. For the purposes of this study, we define an *AI-powered medication information chatbot* as an automated dialogue agent that integrates human language understanding to provide evidence-based information about prescription medications. Data were collected through semistructured interviews with geriatrics experts, including physicians, nurses, researchers, and pharmacists. A total of 8 interviews were conducted, each with at least 1 of the investigator coauthors, of whom all were nursing faculty members (ML, PR, and METR). All interviews were recorded, transcribed, and deidentified. Manual coding was performed using the 3 nursing experts as well as an expert in AI and natural language processing (KR), with each interview being coded by 2 investigators (2 of ML, PR, METR, and KR). Intercoder agreement was noted to evaluate the reliability of the analyzed feedback.

Study Funding

This research was funded by the UTHealth School of Nursing through an Aging in Place seed grant.

Ethics Approval

The study was approved by the UTHealth Center for the Protection of Human Subjects (approval number: HSC-SBMI-20-0526).

Data Collection

We collected data using semistructured interviews with 8 participants selected to ensure a diversity of geriatrics expertise, including physicians, nurses, pharmacists, and researchers. Most of the interview participants were from Houston, Texas. Interviews were conducted via WebEx by 1 or 2 of the coauthors (ML, PR, and METR). They consisted of open-ended questions regarding older adults, their view on technology, use, limitations, barriers, what would older adults need most with regard to medication information, and what could be provided using technology (Textbox 1 describes the open-ended questions). The focus was on both the current generation of older adults aged 65 to 75 years (at the time of the study, this represents those born roughly between 1945 and 1955) as well as adults relatively soon to join this group, individuals aged 55 to 65 years (born between 1955 and 1965). It was assumed that adults aged ≥75 years (born before 1945) may have different needs, both from an aging perspective and a technology familiarity perspective (eg, almost all adults ≤75 years have owned smartphones). For the purpose of the interview, it was assumed that the term medication applies to prescription medications that have been prescribed within the past 6 months, as opposed to medication, and one may expect to have been using long-term. Each interview lasted 30 to 40 minutes. All interviewees were informed that their participation in the interview would not be revealed to anyone beyond the investigators, and that their responses would be kept in strictest confidence. If the interviewee was specialized in any specific disease condition and wanted to limit their responses to that area, they were encouraged to do so. However, if the interviewees had a generalized idea, they were welcomed to share those views as well. The interviews were audio-recorded, and later, a research assistant transcribed the content verbatim to analyze the responses in text format.

Textbox 1. Common framework of open-ended questions used for the semistructured interviews.

Open-ended questions

- Question 1: What are older adults' comfort level and capabilities with the use of technology in general?
- Question 2: What are older adults' comfort level and capabilities regarding the use of voice-based technology like Alexa, Siri, etc?
- Question 3: What are their barriers to using technology for health information?
- Question 4: Would technology be uniquely suited to address any specific information needs of older adults, and if so, what would those needs be?
- Question 5: What are the major medication information needs for older adults?
- Question 6: What kind of questions would an older adult ask to meet this information need?
- Question 7: What would be the overall pros and cons, hopes and concerns for this kind of project?

Data Analysis

The transcribed interviews were analyzed using predetermined codes (Textbox 2). When important information was mentioned in an interview that did not correspond to an existing code, an ad hoc code was created to be reconciled later (eg, the code Need: Reminders was added by using this ad hoc process, representing the need for the system to give users medication reminders). For each interview, two of the four investigators (KR, ML, PR, and METR) coded according to the semiopen set of themes (Textbox 2). Of note, the coding scheme includes both a *benefit* and *nonbenefit*, as well as a *barrier* and *nonbarrier*. The negated codes were added because the interview participants frequently asserted that a particular benefit/barrier did not exist (eg, technology familiarity was not seen as a major hurdle for adults aged 55 to 75 years, so this was coded as Nonbarrier: Technology Familiarity/Assistance).

Textbox 2. Codes representing a set of themes.

Benefits/nonbenefits

- Usability
- Support overall health
- Increased understanding
- Increased adherence
- Reduced adverse events

Barriers/nonbarriers

- Usability
- Technology familiarity/assistance
- Cost/affordability
- Trust in technology
- Difficulty hearing
- Cognitive ability/mental status
- Privacy and security

Needs

- Usability
- Reminders
- Indication
- Contraindication
- Instruction/dosage
- Adverse reaction
- Drug interaction
- Information

The codes were reconciled with the help of a third investigator (MG or SM). During this step, the ad hoc codes were considered, reconciled, and either included (if in use in at least 3 interviews) or dropped. Most of the ad hoc codes were used only once or twice, whereas other ad hoc codes were merged (eg, under the Usability need). This process was iterative and involved member checking with the interview participants. All interview participants were shown and agreed to the final interview descriptions.

The final codes for each interview were then counted for each category of benefit/nonbenefit, barrier/nonbarrier, and need. This count represents the number of times each interviewee's response was directly mentioned or indirectly aligned with our themes. The initial subcategories did not include all the final lists, as shown in Textbox 2. The new codes include benefit: usability, support for overall health; barrier: usability, security; and need: usability, reminders, instruction, and information. The final counts for each interviewee in each category are presented in Table 1.

Table 1. Number of times each interviewee mentioned the preset themes in their responses.

Preset theme	Mention of preset theme, n							
	Expert 1	Expert 2	Expert 3	Expert 4	Expert 5	Expert 6	Expert 7	Expert 8
Benefits								
Usability	1	2	0	0	1	4	2	4
Support overall health	0	1	1	1	1	2	1	3
Increased understanding	2	3	3	0	1	0	0	3
Increased adherence	1	1	1	2	0	2	0	3
Reduced adverse events	0	1	0	1	1	0	0	1
Other benefit	0	0	0	4	2	0	0	1
Barriers								
Usability	5	2	3	0	0	0	0	0
Technology familiarity/assistance	2	2	1	5	5	2	1	4
Cost/affordability	1	1	3	4	2	2	1	3
Trust in technology	1	0	0	0	1	0	1	0
Difficulty hearing	1	0	1	0	0	0	0	1
Cognitive ability/mental status	0	0	3	0	1	0	0	0
Privacy and security	2	5	1	0	0	0	0	3
Other barrier	0	0	3	1	2	0	3	0
Needs								
Usability	10	2	5	3	12	2	7	1
Reminders	2	4	1	12	2	5	4	1
Indication	2	2	2	1	2	2	2	0
Contraindication	0	0	0	0	0	0	2	0
Instruction/dosage	3	2	2	2	2	4	0	1
Adverse reaction	2	1	3	4	3	1	1	1
Drug interaction	1	0	1	3	2	0	1	0
Information	3	1	2	4	0	0	0	2
Other need	0	2	2	3	1	0	5	0
Nonbenefits								
Overreliance on technology	0	0	0	0	1	0	0	0
Other	0	0	0	0	0	1	0	0
Nonbarriers								
Technology familiarity/assistance	3	3	2	3	4	1	2	2
Technology familiarity/use	1	0	0	0	0	0	0	0
Cost/affordability	2	0	0	0	0	0	0	0
Trust in technology	1	0	1	0	0	0	0	0
Cognitive ability	1	0	0	0	0	0	0	0
Other	0	0	1	0	1	0	0	0

Results

We have only focused on the aggregate results of the qualitative analysis in this section for brevity. We have provided a separate supplement that has detailed summaries of each of the 8 interviews and key quotes that illustrate each of the experts' unique perspectives as well as their individual qualifications.

Overall Common Themes

After aggregating the feedback from all interviews (Table 1), we have described the top 3 subcategories under each category, which were deemed important for designing or implementing the use of the medication information voice chatbot.

Benefits

With regard to benefits, the most significant benefit would be related to usability. Being voice-based and having met most of the needs, a chatbot would be deemed very useful. Its ease of use; access to information; not having to type or see small print; and being connected to the pharmacy, health care providers, and their caregivers are some of the benefits categorized under usability. The next benefit would be that older adults would have increased knowledge and understanding of their medications by using a chatbot. Other equally beneficial aspects include increased adherence to medications and support for overall health.

Barriers

Some of the most important barriers were related to technology familiarity and assistance. Overall, older adults from lower socioeconomic backgrounds and those who are very old (≥75 years) might have difficulty with technology. Next, the cost and affordability of such technology could be problematic, which would be mitigated if it were covered by insurance (eg, Medicare). The final concern was regarding privacy and security. Many older adults were not comfortable with devices listening to their conversations and may have been confused as to where their information could be sent or used.

Needs

Among all the needs, having a voice-based chatbot that is usable (easy to use and useful) was deemed the most important (Textbox 3). Having the chatbot remind patients regarding medications, appointments, or refills was the next important need. Finally, information about adverse reactions and instructions to take medications were noted as equally important by our interviewees.

Textbox 3. Usability: components for each category.

Benefits

- Voice adaptation
- Easy to use than other apps which require typing or seeing
- Easy access to information

Barriers

- Difficult to use
- Complex language
- Learning curve with different format of apps
- Failure to troubleshoot errors
- Voice recognition accuracy
- Usable only for a spectrum of population
- Inaccurate interoperability of chart among providers

Needs

- Ease of use
- Simple language and native language support
- Audible
- Technical support and troubleshooting errors
- Connect to personalized information
- Integration with existing devices
- Connect with pharmacy, physician and caregiver
- Disease-specific medication information, pronounce medication, track list of medications

Nonbenefits

Only 2 interviewees mentioned the nonbenefits of the chatbot (ie, specific assertions that a potential benefit would not be realized). One expert was concerned about overreliance on technology, whereas another suggested that many older adults would not use it after the setup was completed by family.

Nonbarriers

In contrast to what many may think that older adults are not familiar with technology, the experts largely agreed that for the age range we are focused on, this is actually not a problem. Technology familiarity and assistance emerged as one of the most important nonbarriers among older adults when using voice-based technology. This is especially noted in higher socioeconomic groups with access to and experience with using technology. They were also more likely to be in their 60s and have well-connected families and younger generations who helped them catch up on technologies.

Discussion

Principal Findings and Comparison With Prior Work

Our study explored the benefits, barriers, and needs of using a voice-based chatbot to address the medication information requirements of older adults. To gain insights, we conducted semistructured interviews with experts in geriatrics. Our experts' feedback regarding chatbots and older adults aligns with previous study results: they could be useful overall, help older adults take care of themselves, and should be flexible to meet all older adults' technical skills [9,11]. Our analysis of their feedback identifies many pointers that clear certain misconceptions regarding technology use in older adults and provides insight into the prominent aspects of implementing medication information chatbots. The most important aspect was that chatbots could be used by many older adults, and that technology familiarity is not a barrier that would have been expected.

The use of a medication information chatbot would benefit many older adults. The first and foremost benefit would be that voice-based chatbots help overcome many aging issues, such as diminished vision, tactile and dexterity issues, and patients with arthritis who cannot type. This in itself will give chatbots a benefit over a non–voice-based smartphone app that requires typing or looking up for information. In fact, age-related changes, such as fine motor skills, vision, hearing loss [22], and osteoarthritis [23], were found to be barriers to technology use in older adults. By being voice-based, these barriers can be addressed by making it easier to access medication information. However, the chatbot would have to be audible and come with a range of volume controls for older adults with hearing loss issues.

Next, if the chatbot could be connected with the pharmacy, providers, and caregivers, it would be very beneficial for older adults, as it would lower the burden of independently keeping track of medication lists. With the help of frequent reminders, older adults can have better medication adherence. Having access to knowledge would in turn lead to increased patient knowledge regarding health in general. It would also make them more independent in taking care of themselves, requiring fewer nursing homes or assisted living arrangements.

Having an interactive voice-based technology would mean more socializing for older adults who live alone, resulting in more use in some cases. Older adults use technology to socialize in terms of using it for calling or emailing [22]. In particular, with voice-based interactive technology, older adults reported feeling that they had a connection with it or felt less lonely, and some even quoted as it had become a friend [24]. Other benefits include increased peace of mind for caregivers, reduced chances of errors and a safety net, and sometimes helping with reminders for activities of daily living and prescription refills. The use of conversational agents in older adults after hospital discharge has been previously studied [25]. Their findings align with our experts' feedback and suggest that having a bot integrated with telemedicine in such a patient population would benefit in supporting their health, as they could help them understand medical information and read out discharge instructions. Overall, older adults would find them easier to use compared with other mobile health apps, as they are age-friendly.

Technology familiarity may not be a significant barrier, according to our experts. In fact, many older adults aged ≤75 years were found to use some sort of technology for daily living, such as smartphones or computers. Similar findings were reported in a study performed in older adults. They participated in a focus group and voiced more positive attitudes toward technology than negative attitudes [26]. Another study mentioned that more than 50% of their older adult respondents reported using technologies such as smartphones and computers, whereas a lesser percentage used tablets [22]. These results contradict the stereotype that older adults might not favor the use of technology. Our study builds on this prior work by focusing on a high-value AI—a voice-based chatbot for medication information.

Our interviewees highlighted that older adults who are relatively younger (in their 60s) and have relatively high socioeconomic status have had experience with technology. Those who used or were exposed to technology while they worked and who were close to family members (especially younger generations) were likely to be comfortable using technology in general, or voice-based technology in particular. Many adults already use apps such as Alexa and Siri in their day-to-day activities. For such older adults, technology familiarity/assistance/use would not be a major barrier. However, for adults aged ≥70 years, those from lower socioeconomic status, and those who live alone or have weak family connections, technology familiarity could act as a barrier. Some of these factors can be overcome by making the chatbot affordable, making it easy to use, and helping with the setup process. Similarly, results from a more general study of older adults and barriers to technology use for daily living activities showed similar themes for barriers, such as educational limitations and limited access to technology [23].

Some of the other barriers put forth by the experts include concerns regarding cost and affordability. It might help integrate the chatbot into an app or already existing device to make it more affordable, as well as the fact that a stand-alone app may not be as highly used. Another option was to cover the cost of the chatbots through health insurance. The cost barrier for purchasing technology and device maintenance has been highlighted previously [23,27]. Security and privacy concerns were the next set of barriers. Many interviewees stated that older adults were skeptical about technologies that overheard their conversations and used that information to reach out for advertising. They were also confused about how and where their information would be shared. These concerns were more prominent among adults with paranoia, dementia, and mild cognitive impairment. Security and privacy concerns, along with data management confusions, were identified as key barriers in other studies as well [28,29]. Concerns related to how easy the chatbot would be for older adults to set up and use by themselves were also raised. For the chatbot to reach a wide variety of adults, experts believed that the technology must be extremely user-friendly and easy to use. This aligns with the results from a focus group conducted on older adults who were asked to provide feedback after using a tablet. They mentioned some of the barriers that were directly or indirectly related to the usability of such technologies, such as lack of instruction and guidance to use, lack of knowledge, and too much or too complicated technology [27]. Overall, even though certain barriers exist for the use of technology, our experts believe that a voice-based chatbot could be considered by many older adults, which aligns with the generally positive outlook noted in other studies [27,28].

To design and create a medication information chatbot, our experts suggested many pointers that could be essential needs expected of a chatbot. The most important being a usable chatbot. Many features were combined under usability (Textbox 3), such as the following specific suggestions: *ease of use of technology, easy setup, technical support and troubleshooting, simple language, native language support, has to be audible, personalized, useful for caregivers, can repeat back question, multiplatform, connected to personalized information, integrated with other existing devices, disease-specific medication information, integration with pharmacy, collaborate with provider, pronounce medication, ability to intake and store patient's information, adverse reaction information, adverse reactions only mentioned when asked, track list of medications, and prompts family about refills due.*

The importance of having a usable technology to ease adaptability was reported earlier [28] in a focus group conducted on older adults. They mentioned that they would be frustrated with navigating through the technology or setting it up and felt that sometimes technologies made their life more difficult if they were not made simple to use. Some of their suggestions included simple instructions along with fewer buttons. Interestingly, they felt that speech-activated tools would be simpler for their age group. Training older adults was considered an option to overcome the usability barrier. Some of the older adults who were trained to use Alexa [24] reported that the training process made their adaptation to technology easier. Some of the components discussed under usability (Textbox 3), such as integration with pharmacies and collaboration with providers, were also considered important by older adults [13]. Moreover, the idea that the chatbot should mention adverse reactions only when asked to mimic the concerns expressed by some older adults who did not want to fully understand the side effects for the fear of change in their attitude toward taking the medications [14]. As caregivers were found to be very crucial in managing older adults' overall health after discharge from the hospital [15], having a chatbot with the ability to connect to caregivers and prompt them regarding older adults' medication refill needs would be useful.

Apart from a usable chatbot, it would require assisting adults with reminders, such as medication refill reminders, clinician appointments, and reminders about general health, such as checking blood pressure or blood sugar levels. Information about adverse reactions and instructions, as well as the dosage and timing of medication administration, were also important requirements for a chatbot functionality. This aligns with older adults' expectations of a personal health app [13] and their medication information needs upon discharge from the hospital [14]. Similar needs were expressed by adults in a study on the use of chatbots for hypertension medication management [30]. This study included 33% of the adults aged >65 years. Their needs included having the ability to have medication lists, ability to set reminders, medication information and side effects, refill reminders, and integration with pharmacy and autorefill capacity. They also believed that having the chatbot integrated with a patient portal and being able to connect with the care team via a chatbot could help them update health data, such as blood pressure and weight. Most of them also wanted their chatbot to be personalized and being available on their phones.

To help with reminders, a chatbot would need patient-specific information that could be entered by the patient or caregiver, or received electronically. The latter would be favored because, from our analysis, having an easy-to-use chatbot would also reduce the manual tasks of entering information. For medication-specific information, it would require accessing data such as side effect resources to answer questions about adverse reactions [31] or extracting information from the Food and Drug Administration–mandated drug labels using natural language processing [32,33]. Such functionality can be used to answer questions about adverse reactions, drug interactions, and general information about the drug.

Many studies assert that the chatbot would be broadly accepted if it integrated with already existing technology and had multiple functionalities other than helping with medication administration or providing medication information. Some of them also suggested piloting this voice-based technology as an app on a smartphone. These features were viewed as highly important by older adults as well [30]. Our experts also suggested that they could be integrated into either home smart speakers (easy for older adults already using Alexa, Google Home, or Siri) or smart pill dispensers. Older adults felt that home smart speakers [34] were much simpler to use and were very impressed with its range of functionalities. Integrating medication information voice assistants into such systems might increase its adoption rates. According to an infographics report by eMarketer [35] in 2018, 7.3% of the population aged ≥65 years would have used a smart speaker device and its use would see a huge increment from use in 2017 (36.3%). This suggests that integration with smart speakers would benefit a large patient population.

Apart from discussing the benefits and barriers, our experts also emphasized some nonbenefits (potential benefits unlikely to be realized) and nonbarriers (ie, potential barriers they did not think would be problematic). Nonbenefits were few but included overdependence on technology and ignoring the chatbot. Older adults expressed fear of excessive reliance on technology in a pilot study [34] on their interaction with Google Home (voice assistant). Their specific concerns were the possible loss of creativity and less physical and mental exercise with the use of such agents. The other nonbenefit was that some older adults ignored the chatbot. This was expected to occur if the chatbot was not set up out of their own interest (eg, their family had set it up for them without consultation). Some older adults mentioned similar attitudes [28] wherein they were given smartphones by their family members (thinking older adults would find it a useful tool), but they never knew how to use it or what to do with it, and therefore never used it.

The significant nonbarrier derived from our analysis was technology familiarity and use, as discussed above. Other nonbarriers include trust in technology and age. Our experts mentioned that many older adults already use technologies, such as smartphones or computers, and some even use voice-based technologies such as Alexa or Siri in their daily lives. This translates to the idea that many older adults trust technology and have no inhibitions to share their information while using it. Another nonbenefit is age, as one of our experts mentioned that some of the older adults are more tech-savvy regardless of their age. However, as per the Pew Research Center [36], even though technology use has been on the rise among older adults in general, adoption and use declines above the age of 70 years when compared with ages 65 to 69 years. The adoption and use of certain technologies, such as smartphones, was seen to be higher among affluent, well-educated, and younger populations. Perhaps when other factors are considered along with age, someone who is affluent and older (above 70 years) might use technology more than someone who does not match the affluence scale but is younger. Another survey [37] was that apart from overall lesser adoption among older adults aged >75 compared with younger older adults, there was also a difference in the type of technology that older adults aged >75 used more than their younger counterparts, such as desktops and e-readers. These findings suggest that there might be differences in the adoption rates of voice-based medication information chatbots based on the older adults' age and other factors, such as education and income levels.

Limitations

Our needs analysis had several limitations. First, as our interviewee group was a small (8 experts) convenience sample, this may have led to a chance of bias. For instance, each of the interviewees was based in urban areas and a large part of a university-based hospital system. We originally planned to combine these interviews with a simulation study with older adults, but the COVID-19 pandemic prevented any use of a realistic simulation environment. Therefore, the identification of important needs from the adults' perspective was missed, limiting our analysis to only geriatrics experts. We plan to conduct such a simulation-based study to supplement the findings of this study once the pandemic allows such a study to be conducted safely, specifically incorporating a diversity of patients across racial, ethnic, and socioeconomic groups. Second, as described above on the issue of usability, it is highly possible for 2 systems with highly similar sets of features to diverge greatly in their usability based on a small number of traits, which means that the overall perception of a system (as with any interactive system) is highly system-specific. Thus, it would be appropriate to repeat this study with a more specific focus on a specific medication information chatbot. Third, our interview participants were asked to focus on medication information needs for relatively recently prescribed medications (within 6 months). However, the medications that the patient has been taking for a long time are still associated with information needs, and these likely diverge from those of recently prescribed medications.

Conclusions

A medication information chatbot would have an advantage in helping older adults with their medications, especially with reminders, instructions, increasing knowledge, and medication adherence. Even though technological capabilities would seem to be a barrier, most older adults are sufficiently familiar with technology, especially those from higher socioeconomic populations and adults who are close to younger generations. For the chatbot to be useful across a broad spectrum of older adults, designing an affordable chatbot that is easy and usable with troubleshooting capabilities, as well as connected with providers and pharmacies, would be of high priority. Usability has emerged as a significant factor, both under the need to construct a chatbot and the benefits of a chatbot. These findings suggest a framework for a voice-based, AI-powered medication information chatbot, although many of the findings require further investigation. Future work should dive deeper into identifying technological solutions to the particular needs and barriers that older adults face regarding medication information.

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Authors' Contributions

KR conceived the study and secured funding along with METR and ML. KR, METR, ML, and PR designed this study. METR, ML, and PR conducted interviews. SM transcribed the interviews. KR, METR, ML, and PR performed the initial coding. MG and SM contributed to the reconciliation and finalization of themes. MG analyzed the final coded data and drafted the manuscript with contributions from KR. All authors reviewed and approved the final version of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

AI: artificial intelligence
IA: intelligent assistant

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Original Paper

Stakeholder Perspectives on In-home Passive Remote Monitoring to Support Aging in Place in the Province of New Brunswick, Canada: Rapid Qualitative Investigation

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Abstract

Background: The province of New Brunswick (NB) has one of the oldest populations in Canada, providing an opportunity to develop and test innovative strategies to address the unique health challenges faced by older adults. Passive remote monitoring technology has the potential to support independent living among older adults. Limited research has examined the benefits of and barriers to the adoption of this technology among community-dwelling older adults.

Objective: This study aimed to explore perceptions of in-home passive remote monitoring technology designed to support aging in place from the perspective of older adults, their family or friend caregivers, social workers, and government decision-makers in the province of NB, Canada.

Methods: Between October 2018 and March 2020, a rapid qualitative investigation of 28 one-on-one interviews was conducted in person or via telephone. Participants included 2 home support services clients and 11 family or friend caregivers who had used passive remote monitoring technology in their homes; 8 social workers who had worked as case managers for home support services clients; and 7 individuals who were key government decision-makers in the adoption, policy development, and use of the technology in the province of NB. The interviews focused on the following topics: decision to adopt the passive remote monitoring system, barriers to adopting the passive remote monitoring system, benefits of the passive remote monitoring system, impact on client health outcomes, and privacy concerns. The interviews were audio recorded, transcribed, and analyzed by a team of 6 researchers. Data analysis was conducted using a rapid assessment process approach that included matrix analysis.

Results: Participants reported that the use of the remote monitoring system allowed older adults to live at home longer and provided caregiver relief. Stakeholders were invested in meeting the home support (home care) needs of older adults. However, when it came to the use of remote monitoring, there was a lack of consensus about which clients it was well-suited for and the role that social workers should play in informing clients and caregivers about the service (role ambiguity, gatekeeping, and perceived conflicts of interest).

Conclusions: Our findings highlight many benefits and challenges of the adoption of passive remote monitoring for clients, their family or friend caregivers, and public provincial health and social services systems. Passive remote monitoring is a valuable tool that can provide support to older adults and their family or friend caregivers when it is a good fit with client needs. Further work is needed in NB to increase public and social workers' awareness of the service and its benefits.

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KEYWORDS

aging in place; home care; older adults; passive remote monitoring

Introduction

Background

Population aging is a significant demographic trend affecting countries worldwide. A recent 2020 United Nations report estimated that worldwide, the population of adults aged >65 years will double from 703 million in 2019 to 1.5 billion by 2050 [1]. The growth in the number of people living past the age of 80 years has been even more rapid and is expected to triple within the same time frame. In Canada, it is estimated that 5.5 million people will be aged ≥80 years by 2068, up from 1.6 million in 2018 [2]. Moreover, the number of centenarians grew by over 10% from 2019 to 2020, and the gap between the number of older adults and the number of children continues to widen.

This increase in human longevity is largely because of advances in medicine and public health and high population fertility rates between 1946 and 1964 (the birth of the *Baby Boomer* generation), which increased the size of this aging cohort. However, a longer life span does not necessarily mean living longer in good health [3,4]. It is well-established that at a population level, the prevalence of chronic diseases and disabilities increases with age [4]. As a result, attention has shifted from a focus on increasing life spans to healthy aging, an approach that emphasizes the quality of life and functional ability, not just living longer [4].

As older adults experience a decline in their health and functional abilities, they often require additional resources and support to safely live in their homes. In Canada, this is often achieved through a combination of publicly and privately funded home care or home support services and unpaid caregiving by friends and family. In Canada, family caregivers are estimated to support 96% of individuals receiving long-term home care [5] and are estimated to provide three-quarters of care services to older adults living at home [6], saving the Canadian health and continuing care systems an estimated US $66.5 billion annually [7].

Recently, there has been increased interest and investment in technological solutions designed to provide options for older adults to choose how and where they wish to live in their later years [8]. These technologies may also be cost-effective ways of supplementing in-person services and supporting family or friend caregivers and may ultimately prevent or delay hospitalization or institutionalization [9]. Given the current workforce shortage in long-term care across Canada [10] and the increasing number of older adults wishing to stay in their own homes, innovative technological solutions have the potential to play an important role in the lives of community-dwelling older adults and their families.

The trend toward increased use of technology in older adult care aligns with the model for geriatric care proposed by Alwan [11] >10 years ago. He envisioned a model of care enabled by technology that highlighted the potential benefits for older adults, their paid and unpaid caregivers, social and health care service providers, and health care and social systems. He imagined seamless systems that would foster client-centered care and immediate, tailored interventions based on real-time data [12]. Passive remote monitoring technologies that describe technologies embedded in the home to collect behavioral and physiological data and communicate between all stakeholders without requiring input from end users were central features of this new approach to home care, which held the promise of supporting older adults to maintain their independence for longer, delay institutionalization, and reduce costs [11,12].

Since then, much novel health monitoring and in-home technologies and systems have become available to the public, ranging from wearable smartwatches to in-home smart appliances and technology integrations that allow one to manage their home’s functionalities at the touch of their phone. Thus, there is generally more awareness and openness by the public to in-home technologies that can assist people with activities of daily living and entertainment [13]. However, passive remote monitoring systems tailored to the needs of older adults with increasing home care or home support needs and their caregivers seem to be less widely used, in part because of concerns about personal privacy by multiple stakeholders, costs, and uncertainty about their effectiveness [14].

Home Support Services for Older Adults in New Brunswick

In New Brunswick (NB), Canada, many older adults are eligible to receive publicly funded home care and home support services [15]. In this provincial context, *home support services* refer to nonmedical services such as assistance with activities of daily living, respite care, and help with shopping or errands. The province’s Department of Social Development is responsible for funding and managing home support services for older adults who are eligible to receive them, whereas a variety of third-party companies or individuals deliver these services. In contrast, *home care* refers to services provided by regulated health care professionals (eg, registered nurses and occupational therapists). Home care is funded by the province’s Department of Health [16]. In terms of funding, individuals can pay out of pocket for either type of service if they are not eligible to receive publicly funded services or if they wish to supplement the services they receive. In this study, we focus on an in-home passive remote monitoring system that is available as part of the suite of publicly funded home support services offered by the NB Department of Social Development.

The Passive Remote Monitoring Service

CareLink Advantage is a private company that operates in several Canadian provinces. Their service was initially developed by adapting home security system technology to address the specific needs of community-dwelling older adults requiring increasing levels of support to maintain their independence. The system was designed so that it can be tailored to client needs, offering a client-centered solution to home support needs. In terms of the physical system, clients can choose a combination of passive monitoring devices for their home system, including motion detectors, bed and chair sensors, medication adherence monitors, and motion-activated video cameras. Once installed, the system allows for ongoing passive remote monitoring to occur. First, behavioral norms are established for clients. Then parameters are set to alert a family or friend caregiver by phone or SMS text message when unusual behavior such as wandering or mismanagement of medication has been detected [17]. These real-time notifications allow the caregiver to check on the client and intervene if necessary. In addition, family or friend caregivers can log into a secure portal where they can see client data such as sensor activity and 15-second video clips of the outside entrance of the home, allowing them to see changes over time [17].

Since 2008, CareLink Advantage has been included in the suite of services funded by the NB Department of Social Development for older adults in the province who are eligible to receive publicly funded home support services [18]. However, despite older adults making up >20% of the province's population, adoption has been extremely low, with <100 clients having used the service over the past 12 years (McDonald, personal communication, 2020). It is unclear why adoption has been so low. Therefore, the purpose of this study was to understand the experiences and perspectives of key stakeholders in NB regarding the adoption of CareLink Advantage.

Methods

Overview

We conducted a qualitative study using semistructured interviews that were analyzed using a rapid assessment process [19] to generate a preliminary understanding of the experiences and opinions of key stakeholders in the province regarding the remote monitoring system. This rapid assessment process is an intensive, team-based ethnographic approach to qualitative data analysis that uses triangulation, iterative data collection, and iterative data analysis to quickly gain *the insider's perspective*, which informs future data collection and analysis [19]. Project timelines can be as short as 4 to 5 days, with at least two researchers involved; however, the study becomes more robust with more researchers and time spent on data collection and analysis [20]. This process is also noted to benefit from a diverse team of researchers performing research, where the combination of experience and knowledge acts as a substitute for the time spent in the field.

This rapid assessment process was an ideal choice of methodology for this study as it suited the need to efficiently analyze a large and complex data set containing 28 qualitative interviews with >35 hours of transcripts, spanning >4 different data subsets representing clients, their family or friend caregivers, social workers, and decision-makers. This approach facilitated the process of comparing data subsets and gaining a better understanding of how the remote monitoring system is perceived across the 4 key stakeholder groups. The quick turnaround of this analysis generated the timely findings needed to inform 2 other related and concurrent projects evaluating the use of the remote monitoring system in 2 other Canadian provinces. Using this method also leveraged the wide range of expertise and experience represented by a core team of 6 researchers and 3 additional participants throughout the lifetime of the project.

Participants

To obtain a rich data set that captured a range of perspectives on passive remote monitoring technology, we sought participants from 4 key stakeholder groups using a combination of purposive, snowball, and convenience sampling. The target stakeholders included (1) older adults aged ≥55 years who used the remote monitoring system in the province with or without subsidy from the Department of Social Development, (2) family or friend caregivers with experience using the passive remote monitoring system in the past or present, (3) social workers with experience working as case managers for older adults receiving home support services from the Department of Social Development, and (4) individuals who were engaged in the initial adoption and ongoing administration of the passive remote monitoring system as part of the range of home support services covered by the Department of Social Development (ie, government decision-makers). Social workers were eligible to participate regardless of whether any of their clients had used the technology. Clients and family or friend caregivers who did not have experience using the system were not eligible to participate in the study.

Participants were recruited using several approaches. Eligible clients and family or friend caregivers were identified and contacted by the Department of Social Development and CareLink Advantage to inform them about the study and invite them to contact the research team if they were interested in participating. This indirect approach was used to protect client privacy. The Department of Social Development also sent out a recruitment email internally to the staff, including social workers who worked as case managers for older adults. In addition, the research team used snowball sampling [21] by asking interview participants at the end of their interviews to inform people in their social circles about the study if they were eligible. Finally, key stakeholders who had been involved in the initial adoption of the passive remote monitoring system in this province but were now retired were personally invited directly by the research team to participate in interviews. All participants received a letter of information about the study and provided written informed consent before partaking in the interviews.

Data Collection

A series of in-person or telephonic semistructured qualitative interviews were conducted using an interview guide. The questions were designed to explore participants' experience using (clients or caregivers), recommending, or implementing (social workers or government decision-makers) the remote monitoring system. Some questions specifically focused on the implementation process at the public and individual levels. Other questions were included to shed light on the issues of client information sharing, storage, and privacy, as this was a common barrier anecdotally reported to be hindering the adoption of the passive remote monitoring system in the province. The questions led each participant to discuss their experience with how the remote monitoring system supported the client’s ability to delay or eliminate the option of leaving their home for long-term care.

Data Analysis

Following the steps outlined by Hamilton and Finley [22], a team of 6 researchers collaboratively developed a data extraction template based on semistructured interview guides used for data collection. The data analysis process was tested and refined by independently applying it to 2 interview transcripts, reviewing the results, and collaboratively refining the process. Next, the researchers were split into 2 teams of 3 researchers to analyze the interviews. One team analyzed client and caregiver (n=13) interviews, and the second team analyzed social worker and government decision-maker (n=15) interviews. Each researcher independently reviewed the assigned transcripts and met with their team (3/6, 50%) to compare and discuss their findings. Then the 2 teams (6/6, 100%) met to compare, discuss, and summarize the findings into a matrix. Team members had varying levels of personal engagement with digital technologies to support the caregiving of older adults, and these personal experiences were used at times to delve deeper into a particular quote or theme that was emerging. Through dialog between team members, we discussed the differences in our analysis and arrived at a shared understanding of the data. To ensure trustworthiness, the following strategies were used throughout the data analysis process: peer debriefing, investigator triangulation, iterative analysis, and maintenance of an audit trail [21,23].

Ethics Approval

This study was approved by the Research Ethics Board at the University of New Brunswick (REB#: 2017-057).

Results

Participants

Participants included 2 home support services clients and 11 family or friend caregivers who had used passive remote monitoring technology in their homes; 8 social workers who had worked as case managers for home support services clients; and 7 individuals who were key government decision-makers in the adoption, policies, and use of the technology in the province of NB. Caregiver participants were not necessarily associated with the 2 client participants.

On the basis of the information shared during the interviews, participants had the following characteristics: the 2 client participants lived in close proximity to their caregivers and had a comprehensive setup that included cameras; medication dispensers; and passive sensors on the bed, refrigerator, and exits of the home (Table 1). Of the 11 caregiver participants, 9 (82%) were adult children caring for parents, 1 (9%) was caring for a relative or sibling, and 1 (9%) was caring for both a parent and a sibling. Of the 11 caregivers, 1 (9%) lived with the client, 2 (18%) lived outside of the province, and 8 (73%) lived in close proximity to the client. Approximately 55% (6/11) of caregivers reported their loved ones having a camera in their home. Of the 8 social worker participants, 6 (75%) had received a 1-hour training session from either the passive remote monitoring company or the local contractor hired to service the passive remote monitoring company’s clients. None of the participants confirmed that they had participated in the pilot study. In the decision-maker group, of the 7 participants, 3 (43%) were former social workers who had clients using the remote monitoring system, and 2 (29%) were hired by a community organization funded by the province to pilot the remote monitoring system in the province.

Table 1. Remote monitoring component use and paid in-person care across client and family or friend caregiver data subsets.

Interviewer code	Participant type	Remote monitoring system components				
		Bed sensor	Door or room sensor	Medication adherence	Cameras	Paid in-person care
1006_01	Patient	✓	✓	✓	✓	
1009_01	Patient	✓	✓		✓	
1008_01	Caregiver	✓			✓	
1010_01	Caregiver	✓	✓	✓	✓	
1014_01	Caregiver	✓	✓		✓	✓
1015_01	Caregiver	✓	✓		✓	
1016_01	Caregiver	✓	✓			
1018_01	Caregiver	✓	✓			
1020_01	Caregiver	✓	✓		✓	
1022_01	Caregiver		✓		✓	
1024_01	Caregiver	✓		✓		
1025_01	Caregiver	✓	✓			✓
1027_01	Caregiver	✓	✓			✓

Key Messages

The summary matrix (Multimedia Appendix 1) provides the key messages by each participant group for the categories included in the data analysis template. The categories were (1) the decision to adopt the passive remote monitoring system, (2) barriers to adopting the passive remote monitoring system, (3) benefits of the passive remote monitoring system, (4) impact on client health outcomes, and (5) privacy concerns.

The Decision to Adopt the Passive Remote Monitoring System

Decision-Maker Adoption

Approximately 29% (2/7) of the decision-maker participants in our study were directly involved in bringing the remote monitoring system to the province. In their interviews, they recounted how they had first learned about the technology at a conference in Ontario and then worked with the Department of Social Development to spearhead a pilot that led to CareLink Advantage being included in the basket of services available to older home support clients:

> *...as we were touring exhibits, we saw CareLink and we had never heard of it and so the guy showed us how on his Blackberry he could see how his mother who had dementia was managing with her meds and her mobility in her apartment. She was miles away and it kind of blew us away, we never thought of that and so he explained how the technology works with basic home security apparatus and cameras and with camera positions specifically over the medications so he could tell whether she had taken her pills today or not and her whole system of alarms on doors, alarms on the bathroom and elsewhere and we looked at that. We thought my goodness, that has great applications for New Brunswick and so we came back and brought the publicity material to the Department of Social Development who agreed to a pilot project. I think there were several nursing homes involved and we had clients scattered around and so on the success of the pilot project, the department agreed to make it a benefit for persons dealing with parents at home. We could see right away that it had enormous potential* [Participant 1029, lines 7-27]

Both decision-maker participants indicated that there were few barriers to government adoption. However, they noted a lack of awareness of the service. For example, participant 1029 stated the following:

> *Every family that I've asked, my first question is did anybody explain this technology to you and they say no...I ask them, social workers or people in the field, what do you know about CareLink and they just draw a blank because they don't know.* [Participant 1029, lines 136-141]

Client Adoption

It seemed to be well understood across all participant groups that the technology had to be considered a good fit for the needs of the client and their family or friend caregiver by all parties involved in deciding whether to install remote monitoring devices (social worker, client, and family or friend caregiver).

Social workers played a key role in determining who was a good fit for the service based on their assessment and circumstances and shared information about the system only when they thought it would be appropriate. The importance of a good match between client needs and CareLink Advantage was highlighted by several social worker participants. As one of the participants explained, introducing CareLink Advantage to a client involved using "...their own kind of understanding of what the technology is to share with the client when they feel it's something that might meet the need of a client so they wouldn't be exploring it in every situation, just when they think that there's an appropriate use for it" [Participant 1017, lines 314-319]. Another stated the following:

> *...not everyone receives the information because it wouldn't be appropriate for everyone to receive it either and that's part of the social worker's role when they're developing their case plan and talking to families.* [Participant 0206, lines 132-135]

Although the fit was identified as being very important, social workers were divided on their perceptions of which clients they should recommend passive remote monitoring to. For example, the geographical distance between clients and their family or friend caregivers was interpreted differently. One social worker stated the following:

> *...they need some form of supervision...typically, those are the people who are living independently who have family nearby who CareLink have an option for.* [Participant 1004, lines 40-51]

In contrast, a decision-maker who used to be a social worker shared stories of how the service had been extremely helpful to a caregiver who lived in another country:

> *...after we installed that [monitoring devices], she came twice or three times a year and it was less stressful for her. She felt like she knew what was going on. She felt like she was able to make sure that her mom was treated well. Like she felt like she was there, so huge impact.* [Participant 1019, lines 699-704]

Cognitive status and wandering behaviors were also considered by the social workers when making their recommendations. Some viewed the technology as an excellent service for clients who needed high levels of supervision and felt the technology could delay or avoid residential care. As one of the social workers explained, CareLink Advantage can be a helpful service for clients experiencing memory loss and their families:

> *Family members are concerned because they forget and most of the time too it could be like security issues like they're forgetting like the stove on. They might go for a walk and don't remember where they live. They could lose themselves like they're wandering.* [Participant 1023, lines 276-280]

This participant stated that in these situations, "...[CareLink Advantage] helps certainly because it reassures everybody. It shows either the need for a placement or it shows either that the person is still able to stay in her house" [Participant 1023, lines 415-417]. Another social worker emphasized the following:

> *...supervision is a big thing when a client has Alzheimer's or dementia and...families often want to keep their loved one home [as] long as possible. So, the more supervision we have in the home, the more possible it is to do that. And that's what I think CareLink can do, is kind of provide more of that supervision piece without giving up too much privacy.* [Participant 1003, lines 233-236]

In contrast, some social workers felt that clients with substantial cognitive impairments and a high propensity to wander were too risky for passive remote monitoring as they always needed a person with them or at least the caregiver to continually monitor their electronic devices for any notifications. For example, one of the social workers stated that CareLink is "Not for somebody that is at risk of wandering, but it's good when they are kind of in their early stages and then they are kind of in that gray area" (Participant 1007, lines 36-38). Another emphasized the importance of having family or friend caregiver support for the service to be useful:

> *Certainly if people are able to stay in their home like longer, but it has its limits too. Like one time I had one client she had Lifeline, CareLink, but the family/friend caregiver was not checking his phone or his computer so he'd get nothing.* [Participant 1023, lines 508-514]

Family or friend caregivers were also identified by almost all participants as playing a key role in deciding to adopt the remote monitoring system. This was in part because of the requirement of having a designated person to receive system notifications if anything unusual should happen. It was also reported that caregivers played a stronger decision-making role in selecting home support service options when older adults had cognitive impairment and were less able or unable to make their own decisions. Whenever possible, clients were directly involved in the decision about adopting the passive remote monitoring system. The 2 clients who participated in our study reported that they were selected to have CareLink Advantage and agreed to have it. One client shared the following:

> *...they didn't ask us if we was interested, they come in and said we were selected. And wanted to know if we'd like to have it, and I thought, Oh, this is a Godsend. This is wonderful. So they spent over a half day here, and put things together, putting things up and I was so happy.* [Participant 1009-01, lines 60-63]

Barriers to Adopting CareLink Advantage

Perceived barriers to the adoption of CareLink Advantage included a lack of awareness and knowledge of the service, preference for traditional or familiar home support services, additional caregiving responsibility required, hesitancy to promote a service offered by a private company, costs, privacy, and language.

Lack of awareness and knowledge of the service was identified as the primary barrier to adoption. In particular, social workers felt that the passive remote monitoring system was not promoted or visible enough in the province, making it difficult for clients and caregivers to understand what it was and how it worked:

> *I mean they gave us pamphlets as well to pass out to clients...but it's still a newer service to introduce to clients. So you kind of have to keep reminding yourself that it exists.* [Participant 1012, lines 35-37]

Some social workers expressed an interest in learning more about the technology so that they would feel more comfortable explaining the service, whereas others wanted informational pamphlets to hand out to clients. There was also sentiment by some social workers that it was not their job to promote the passive remote monitoring system or explain it to people:

> *...it's my decision to offer it and put their decision...forward it if they want it, but making the decision to have it has to come from the client.* [Participant 1012, lines 182-184]

Decision-makers felt that the biggest barrier to adoption was communication between social workers and caregivers or clients about the service. They identified several structural factors that influenced social workers' knowledge about the passive remote monitoring system and their ability to discuss it with their clients and caregivers. Social workers' gaps in knowledge about available services were thought to be the result of a combination of high turnover and insufficient orientation to the services. For example, one of the decision-makers shared the following:

> *The staff in the regions don't get a formal prescribed orientation or training program, they just kind of pluck [them] in the job and they learn, they pickup stuff from the person that was previously in that job. Whatever they pickup they pickup pretty informally and so if the person that occupied that particular social work position before knew nothing about CareLink Advantage, guess what, the new person coming in is gonna know nothing about CareLink Advantage either.* [Participant 1029-01, lines l178-1183]

In addition, decision-makers felt that because of the social workers' demanding workloads, they had little time to learn more about the passive remote monitoring system or take on the responsibility of teaching or guiding caregivers about the technology:

> *...there is pressure there to put in plans that you know will be successful because for you to go back in and see them every 3 months because things are unfolding, can be a challenge when you have a number of clients that you're managing...so it's finding that balance of...what do I know is successful and how do I get that setup so that people aren't knocking on my door every minute.* [Participant 1017, lines 716-721]

There was a sense that social workers, clients, and caregivers were apprehensive about the technology and preferred more traditional services with which they were familiar, especially when they were in crisis and feeling overwhelmed. For example, one of the decision-makers shared the following:

> *...some people's misunderstanding as to the benefits of the technology is also a challenge. People still*

> *really push for needing the hands-on care then they feel they're not doing anything if there isn't someone physically there doing the care.* [Participant 1017, lines 227-231]

This was supported by statements from social workers such as the following:

> *But I think that a lot of the reason why I don't use it as much, for one, I don't offer it to every family because sometimes a person is needed and CareLink would not be enough to meet the need or address the concern.* [Participant 1004, lines 122-126]

Another social worker noted that when in crisis, caregivers often feel overwhelmed and unable to take on a new challenge or responsibility and see how the passive remote monitoring system can help them. They said the following:

> *The caregiver is saying like I'm stressed, I'm burnt out, I just don't have the capacity...she's getting up at night and I know it's happening five times a night, I need someone to be there to manage that, not me, that kind of thing. So, I think there's probably some ways you could you know, if we were creative about the problem-solving we probably could make it work, but by that time the caregivers are like turned off.* [Participant 1017, lines 390-393]

Decision-makers from the NB Department of Social Development felt that some social workers seemed to view discussing CareLink Advantage with clients as a conflict of interest as the service is run by a private business. One of the participants explained the following:

> *...it was unclear to them what their role was:...they're looking to the social worker to help explain that and kind of promote that when that's not really their role, right...Because...the expectation of the social workers...give the client the options of what's available to them.* [Participant 0206, lines 97-98 and 102-103]

Caregivers perceived the cost of the internet as a barrier to using the system, although it was only required if video cameras were desired in the home. Social workers also raised concerns about cost, internet access, and potential power outages, particularly in rural areas of the province. Caregivers also reported pushbacks from home support services agencies related to personal care workers who had privacy concerns if they were monitored when they came into the home. Installation services not offered in the client's preferred language were also identified as a potential barrier. Finally, client pride was also identified as a potential barrier, with one of the participants noting the following:

> *...it's hard for a lot of people to admit that they may need that level of monitoring, right?* [Participant 0206, line 151]

Benefits of CareLink Advantage

Benefits for caregivers and clients were identified by all participant groups. Interestingly, decision-makers felt that the main benefit of the passive remote monitoring system was to caregivers who require support, with one explaining the following:

> *...you see it more as a support for the caregiver to kind of give them that relief and that sense of security of what's going on in the home.* [Participant 1017, lines 1202-1204]

For clients, the main benefits identified were increased peace of mind and increased access to services when needed. One client noted the following:

> *...with this in your home, it's more-or-less lifesaving... If something happens, it goes directly to their home, or television or cellphone, whatever it's on.* [Participant 1009, lines 103-107]

Caregivers also reported that clients felt safer and that they themselves experienced a sense of relief and reassurance that their friend or family member was safe. One caregiver stated that with the system in place,

> *...it was safe...for us to go to work knowing that if she opened the door somebody will notice...and we would react, we would go or call first and then if she didn't answer well, we got in the car and go see where she was.* [Participant 1027, lines 218-220]

In addition, caregivers reported feeling less stress, greater peace of mind, and better sleep, and some were able to take vacations, knowing that they would be alerted if anything was wrong. One of the caregivers stated that the remote monitoring system provided a strong sense of relief to her and her siblings:

> *It took away so much stress for me, it was unbelievable, I was at my wit's end worrying all the time. It was such a big, big relief for me and my sister...because she's so far away and she's so guilty that she's not here to help. She knew the burden was on me, but...she could see how, you know, what my mother was doing through the sensors.* [Participant 1016, lines 252-258]

Another highlighted the sense of peace and relief from worry that the system provided:

> *...it gives you a good peace of mind that everything is under control and you don't need to worry...* [Participant 1025, line 547]

A third caregiver provided an example of how they were able to remain connected and reassured when apart, even on vacation:

> *...So, we're on vacation you can just click in, and you can see him there and if we wanted to talk to him on the phone you clicked, he was in his chair in the kitchen close to the phone well then, we would call, and you'd know he could reach the phone.* [Participant 1020, lines 365-370]

In addition to providing benefits to clients and caregivers separately, social workers mentioned that the passive remote monitoring system contributed to better relationships between caregivers and clients. For instance, one of the participants shared that having CareLink Advantage allowed caregivers to focus less on the older adult's health. They stated the following:

> *Mostly what you hear are the caregivers, right, that they feel much more at ease and more comfortable, they can start to have different conversations with their, you know, often it's their parents you know instead of you know, did you take your medications or whatever they know, right, so it can help with that.* [Participant 0206-01, lines 347-350]

Another benefit perceived by caregivers was the ability to monitor the care provided by home support workers. For example, one of the caregivers shared that having the passive remote monitoring technology in the home provided confirmation that care was being provided as expected:

> *The expected time for them usually to arrive is usually between 9:30 and 10:00 in the morning and I could see you know, the door was open and I would get a ding on my thing to indicate the door was open or had been opened. Through the motion I could see, through the motion sensors so graph bars that there was activity, oh, now they're in the bathroom. She's getting a shower so I knew that she was getting the services from the personal care worker, they were doing what they were supposed to be doing as regards to showers...* [Participant 1016, lines 158-165]

Another caregiver shared that they did not trust home support workers because of negative experiences that they had in the past:

> *She was supposed to give him a shower she never did. She went out seven times outside to smoke, seven times in three hours. That's not normal.* [Participant 1024, line 854]

This participant stated that the system provided reassurance and suggested that it should be used more widely to prevent abuse:

> *It was reassuring for me. That's why I want it out there more. I want the social worker to push it because I want to see it more and you see where the abuse is being made.* [Participant 1024, lines 852-853]

Decision-makers and social workers also identified cost savings to provincial health and long-term care systems, as well as to families, as a key benefit, as the passive remote monitoring system is less expensive than in-person care. One of the social workers added that it might help address the current workforce shortage.

Impact of CareLink Advantage on Client Health Outcomes

Caregivers reported no changes in health care use, whereas social workers and decision-makers stated that there was no formal process to evaluate the impact of the passive remote monitoring system on client health outcomes. However, all 4 groups reported that clients using the passive remote monitoring system were able to stay in their homes longer or completely avoid going to a nursing home:

> *...it kept her in her home until she passed away...So it was just the best thing that could ever happen, it was very very good, positive and the people were so, they were just so wonderful to work with.* [Participant 1015, lines 61-64]

A social worker commented on the health outcomes related to staying at home longer:

> *...I see often-times a lot of clients need to go to special care homes or nursing homes that do have 24-hour supervisions, but those transitions can be really, really tough. And sometimes clients' health deteriorate with those transitions leaving home and being in a new environment and it's hard to adapt to that...in terms of possibly keeping them home longer and what is affecting you know their emotional health, maybe in that regard [it is beneficial].* [Participant 1012, lines 257-265]

Decision-makers highlighted that it supported client choice:

> *...it's giving them other options and it's offering them the ability to stay home longer...We want to be able to keep seniors in their home as long as it's possible so I think with CareLink that's what it gave us. It gave us more options to be able to do that.* [Participant 1019, lines 375-379]

Clients also reported increased accessibility to emergency services when required and increased peace of mind and sense of security. For example, one of the clients shared their experience using the system to access emergency services when they fell:

> *...I came to on the floor, between the bathroom and the bedroom, and I pushed the button then and I guess it must, I can't remember whether [name removed] was up here at the time or they called him and told him. But they had an ambulance come and they [paramedics] took me to the hospital, because they call the ambulance for you.* [Participant 1009, lines 108-112]

Caregivers stated that the passive remote monitoring system allowed them to keep track of evolving care needs such as increased supervision, maintaining client routines, ensuring adequate nutrition, and assisting with adherence, adjustments to treatment, and medication protocols through observation of changes in behaviors such as increased sleep in older adults. One of the participants shared that having CareLink Advantage in her mother's home allowed her to monitor her pain:

> *She was bed, not to say bedridden, but she was always laying in bed for the longest times whether through boredom or through just, she told me a lot of times she's just tired, arthritic pain. We were able to monitor and watch that. It then became a concern, it actually became a concern to us because we noticed that she was in bed a lot, more so than we would ever have thought so that became an issue for us. It raised to the point that when I told the doctor about how long she was staying in bed, well take a look at her meds and stuff and we started actually adjusting her meds.* [Participant 1016, lines 88-95]

Similarly, social workers identified CareLink Advantage as facilitating the tracking of evolving client care needs. They emphasized that although the passive remote monitoring system helped keep clients home longer, at some point, institutional placement was often unavoidable when care needs were beyond what home support services could offer.

Privacy Concerns

Interestingly, clients themselves had few personal privacy concerns about the monitoring, although they acknowledged that caregivers and visitors coming into their homes might feel it was an intrusion. One acknowledged that the passive remote monitoring system might provide more privacy than having personal support workers coming into the home:

> *Well, I guess, it does make me feel safer...There was a time when I didn't, when we had certain caretakers in here with the key to everybody's door...* [Participant 1006, line 276]

This view was also expressed by a decision-maker who indicated technology was less invasive and disruptive than having multiple home support workers entering the home:

> *...in a way it may be invading their privacy in a way, but it's less invasive than if you have a person in your home like everyday.* [Participant 1021, lines 352-353]

On the other hand, family or friend caregivers were concerned about the privacy of the client but felt that this was outweighed by the additional sense of security and honoring their wish to stay in their own home. A family or friend caregiver discussed choosing monitoring devices that would have less effect on her family member's privacy:

> *...let's start off with the door and the mattress pad and let's just start slowly... She's only alone like half an hour in the morning and two in the afternoon, but when we leave for lunch we know she goes to bed from one to three.* [Participant 1023, lines 314-318]

Consistent with the views of the clients in our study, some caregivers reported that clients did not mind the cameras and sensors and did not have objections related to privacy. They also identified the privacy of paid caregivers coming into the home as a concern.

Social workers' concerns about privacy were centered on the use of technology, which conflicts with provincial privacy legislation. These concerns focused mainly on the video components of the system:

> *I think the idea of cameras is really scary to a lot of people...most seniors they want to be as independent as they can be and the idea of someone checking in on them, or being notified, you know, is taking away their independence...I think the idea of cameras can be really off putting and viewed as really invasive...I mean as soon as cameras are mentioned, their eyes go wide. You know they are shaking their head and they just have no interest at all.* [Participant 1012, lines 290-296]

They also questioned the privacy of care providers or visitors who were not aware of the presence of cameras and what information should be available to alert them:

> *...the cameras, in the spare room or something just in case they open the client's cameras and...went in to change from their one set of change to their work clothes or whatever the case may be, or just for the person general knowledge that there are cameras and that there is someone looking in.* [Participant 1012, lines 400-407]

The perceived impact of monitoring devices on privacy was viewed as a barrier to the adoption of passive remote monitoring systems in the province. The option of having cameras in the home was perceived by the decision-makers as being particularly concerning to the social workers, a view that was supported by the interviews with social workers. Decision-makers perceived social workers as focusing too much on their own concerns and not enough on the benefits of the system. Finally, the decision-makers also reported that more stringent data collection, storage, and management policies had been applied at the Department of Social Development since the pilot and the need to keep up with evolving provincial and federal policies on health data security.

The decision-maker group perceived that social workers had a strong ethical lens and were committed to protecting the privacy of their clients. However, they felt that privacy issues needed to be weighed against safety, and if the home support services client were to be admitted to a long-term care facility, their privacy would be compromised even more:

> *There have been some well positioned persons of influence who are really, who expressed very strong feelings on the privacy thing...our response to that has always been look, the elder is living at home with dementia and cognition may be seriously compromised anyway and their son who is the power of attorney and responsible for mama's care signs off on this thing, stop worrying about the privacy issues because at the end of the day what we have to be more concerned about is the safety of your old mom...I think the response for that is, you know, you got to apply common sense, good reason and you got to make sure that the care of mom is top priority.* [Participant 1029, lines 224-236]

Another decision-maker highlighted the heightened concern over privacy when cameras were in the home and felt that it was unwarranted, given that regardless of the presence of a camera, older adults have more privacy at home than they would when living in a nursing home:

> *So staff perception of the cameras was heightened and I believe that was the biggest barrier to implementing it...I said to them you know, if you believe that somebody who leaves their home early and goes to a nursing home is going to have more privacy than you would have in your own home with cameras that are only being viewed by family members, then you need to think again.* [Participant 1030, lines 63-71]

Discussion

Principal Findings

Overall, it was clear that all stakeholders shared a common goal of helping meet the individual needs of older adults who require support services to live safely in their own homes using a client-centered approach. However, when it came to the use of the CareLink Advantage remote monitoring service as a tool to help meet these needs, there was a lack of consensus about which clients it was well-suited for and the role social workers should play in informing clients and caregivers about the service. Our findings highlighted many benefits of the passive remote monitoring service for clients, their family or friend caregivers, and public provincial health and social services systems, as well as the challenges associated with adopting novel technology that people are unfamiliar with or uncertain about. To our knowledge, this is one of the first studies to examine an in-home remote monitoring system for older adults by triangulating data from 4 diverse stakeholder groups. Thus, our research contributions are 2-fold. First, our findings provide insights that advance the understanding of the implementation and use of in-home remote monitoring systems in older adults' homes. Second, this study provides a useful example of a rapid methodological approach that can be replicated by others.

Staying Home Longer

A key finding was that all participant groups reported that the remote monitoring system allowed clients to live at home longer than they would have been able to without the technology. To date, limited research has examined the impact of in-home remote monitoring systems on older adults' ability to live at home longer. A recent scoping review [24] identified only 14 studies published before February 2019 that examined outcomes related to having this type of technology in the homes of community-dwelling older adults. Although a wide range of outcomes was assessed in these studies, none of them tested the impact of passive remote monitoring on the length of time older adults were able to live at home or time until institutionalization was required. One qualitative study did find that older adults reported a strong desire to age in place and saw passive remote monitoring technology as a tool to make that happen [25]. Although our study provides preliminary evidence that suggests that in-home passive remote monitoring technology may enable older adults to live at home longer, further research with robust quantitative designs is needed to test this relationship.

More recently, Pais et al [26] conducted a 12-month observational study in Switzerland to evaluate the useability, functionality, and effects of an in-home monitoring system comprising a combination of wearable and passive monitors on older adults, their family caregivers, and home care nurses. Consistent with our findings, the study by Pais et al [26] found that most older adults, family caregivers, and nurses perceived that the monitoring system helped older adults stay at home longer. Similarly, a recent systematic review of stakeholder perspectives on technology use among community-dwelling older adults with dementia found that the perceived potential for technologies to allow them to stay in their own homes and avoid or delay institutionalization was an important facilitator of technology adoption among older adults with dementia [27]. They also found that family or friend caregivers had positive perceptions of technologies with the potential to enhance the independence and quality of life of people with dementia [27].

Our findings contribute to the growing evidence that suggests that providing older adults with the option to live at home is important and that in-home technologies are perceived as a means through which to achieve this desired outcome. Moreover, our qualitative findings, along with those of others, support the need for stronger empirical evidence linking in-home technology interventions to staying at home longer and delaying or avoiding institutionalization.

Caregiver Relief

Another key finding was that the remote monitoring service provided valuable benefits for family or friend caregivers of older adults. In discussing the benefits of remote monitoring technology to support aging in place, many social workers and policy makers mentioned the family or friend caregiver's need for support. The role of a family or friend caregiver is to fulfill an increasing demand for home-based care, precipitated by an aging population and governments promoting policies to alleviate the pressures on the health and continuing care systems [28]. This role can be unsustainable for unpaid family or friend caregivers who juggle paid work in addition to maintaining the care recipient's needs; it is reported that family or friend caregivers often have no choice to reduce or leave paid work to maintain the needs of the person they care for [20]. Unpaid caregiving can also have negative consequences on relationships between the caregiver and the care recipient, other family members, and across wider social circles [29]. Physical injuries and burnout are also common outcomes of unpaid caregiving [12]. These are some of the negative social, financial, and health repercussions associated with the unpaid family or friend caregiver role [28].

In our study, all groups recognized the impact of the passive remote monitoring system on improving the family or friend caregiver's *peace of mind*. Moreover, many caregivers recognized the outcomes of this peace of mind, such as better sleep and the ability to take vacations. These observations point to a decrease in caregiver burden, which refers to the often-negative impacts of caregiving on the caregiver's physical and mental health and overall quality of life [29]. Thus, our findings suggest that the use of CareLink Advantage can provide caregiver relief, which may prevent caregiver burnout and burden and promote less stressful relationships between family or friend caregivers and the older adults they care for.

These findings align with those of Leslie et al [30], who concluded from a series of interviews and surveys with unpaid family caregivers that technology can improve their capacity to provide care to older adults and safeguard their own well-being. Although the evaluation of the impact of passive remote monitoring systems on caregiver burden specifically is yet to be produced, related studies testing assistive technologies to help clients with daily tasks and remote monitoring of vital signs [31] have concluded that their use contributes to reducing caregiver burden.

Social Workers' Role

Gatekeeping

There seemed to be inconsistency and a lack of standardization regarding social workers' decisions to recommend the passive remote monitoring system for clients. Although all social workers emphasized the importance of conducting a holistic and comprehensive needs assessment to inform their care plan, the criteria used to determine whether the passive remote monitoring system was a good fit for clients (ie, that the service does a good job meeting the needs of the client) was subjective and varied. Most social workers felt that the passive remote monitoring system would be a good fit for clients in the early stages of dementia who required additional supervision to live safely at home. Others felt that it was not appropriate for older adults prone to wandering or those who did not have a family or friend caregiver who lived close by. This finding is consistent with that of a recent study on home care nurses in Finland [32]. Nurses in this study identified older adults with memory problems as the target group who could benefit most from in-home monitoring. Similar to some of the social workers in our study, these nurses were also worried about wandering behaviors and feared that their clients would wander outside in the middle of the night and get lost, especially because of the long daylight hours in Finland. The similarity of our findings suggests that protecting older adults and ensuring their safety are critical factors influencing care planning decisions when considering the inclusion of in-home passive remote monitoring technologies. Our results also suggest that social workers in the province could benefit from having clear criteria from their needs assessment that would inform their decision of whether to recommend the passive remote monitoring system to their clients and ensuring that all social workers receive training or information about the system as part of their orientation. Finally, it is possible that firsthand experience (or lack thereof) working with clients who had CareLink Advantage may have influenced social workers' perspectives, resulting in inconsistencies.

Role Ambiguity

Role clarity [33,34] ensures that employees know what is expected of them [34]. Role ambiguity occurs when employees do not have a clear understanding of their work roles [35]. Research has shown that professionals' uncertainness about their roles promotes and aggravates role ambiguity, which can be harmful to everyone [35] and may lead to job burnout and role overload [36]. Our study indicated that social workers were not always sure of their role when it came to informing clients about CareLink Advantage. Decision-makers shared that frontline social workers have very demanding caseloads, resulting in high job demands and a high rate of job turnover. They also felt that these circumstances made it difficult to ensure that all social workers were knowledgeable about all the home support services available to clients. Thus, it makes sense that social workers would default to the services that they were more familiar and comfortable with when discussing home support service options with clients.

Perceived Conflicts of Interest

Both social workers and decision-makers identified a perceived conflict of interest for social workers regarding the promotion of the passive remote monitoring system as it was a private business. Interestingly, they did not perceive the same conflict of interest about traditional in-person home support services such as having a personal support worker in the home, although these services are also provided by private businesses. This finding points to a broader discussion about the ethics of the privatization of home support and home care services. As Bjornsdottir [37] explains, there has been a substantial political and policy shift over the past few decades, focused on cost containment (often through strategies such as outsourcing services and rationing care) and increased individual and family responsibilities for home care. Thus, it is interesting that this was only identified as an ethical concern for CareLink Advantage and not for all outsourced services, which also include other technology-based services such as Lifeline. Some strategies that could help alleviate this perceived conflict of interest include having standardized criteria and guidelines for determining which services to recommend to clients based on their needs assessment and using an interprofessional team (eg, occupational therapists and registered nurses) to make the assessment and recommendations for each client.

Privacy

Our research revealed diverse perspectives regarding the privacy of having the passive remote monitoring system in the home. It was interesting that of all the participant groups, social workers seemed to be the most concerned about the potential for the passive remote monitoring system to invade their clients' privacy. Clients themselves did not have the same concerns, whereas both caregivers and decision-makers remarked that having numerous personal support workers coming into client homes on a regular basis was more invasive than the remote monitoring technology. Another important finding was that most conversations about privacy were explicitly focused on having a video camera in the home, although this is an optional component.

Limitations

The findings of this study must be seen considering some limitations. These include: (1) the sample size of clients interviewed—that is, only 2 client participants—which was limited solely to one province, and hence, results may not be applicable to other jurisdictions; (2) the interviews were exclusively conducted in English, which limits the access to other respondents; (3) limited experience of some social workers with the passive remote monitoring system because of low client uptake; and (4) the use of convenience sampling also limits the transferability of our findings to other settings, and hence, the results cannot be treated as representative of the generalized population. A recent study by Young and Casey [38] has shown that samples as small as 6 to 9 participants can provide robust identification of themes and codes in qualitative interview studies. Although our overall sample size was sufficient and the inclusion of multiple perspectives allowed for triangulation, we were unable to reach the minimum sample size for the client group. Therefore, further research is needed on this group to corroborate our initial findings and explore additional perspectives that may not have been included in our study.

Despite these limitations, we believe that the findings emphasize the need for further research on in-home passive remote monitoring technology, which is designed to support aging in place in provinces.

Recommendations

On the basis of the findings generated from this study, we propose recommendations for practice and research. First, the adoption of in-home monitoring technologies to support aging in place in NB would be better supported by having standardized education and training for frontline social workers about the service and by establishing standardized eligibility criteria for clients. Second, stronger empirical evidence linking in-home technology interventions to staying at home longer and delaying or avoiding institutionalization is needed. We recommend examining these relationships using strong longitudinal research designs, such as randomized controlled trials.

Conclusions

Our findings show that CareLink Advantage passive remote monitoring is a valuable tool that can provide older adults and their family or friend caregivers in NB with support when it is a good fit for client needs. Key benefits included empowering older adults to stay in their own homes longer and providing caregivers with peace of mind and relief, which improved their quality of life. Our findings also highlight the need to increase public and social workers’ awareness of the service and its benefits. Social workers would also benefit from improved role clarity and more explicit eligibility criteria or guidelines for clients who could benefit from CareLink Advantage.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Summary matrix.
[DOCX File , 22 KB - aging_v5i2e31486_app1.docx]

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Abbreviations

NB: New Brunswick

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Original Paper

Decision-making Factors Toward the Adoption of Smart Home Sensors by Older Adults in Singapore: Mixed Methods Study

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Abstract

Background: An increasing aging population has become a pressing problem in many countries. Smart systems and intelligent technologies support aging in place, thereby alleviating the strain on health care systems.

Objective: This study aims to identify decision-making factors involved in the adoption of smart home sensors (SHS) by older adults in Singapore.

Methods: The study involved 3 phases: as an intervention, SHS were installed in older adults' homes (N=42) for 4 to 5 weeks; in-depth semistructured interviews were conducted with 18 older adults, 2 center managers, 1 family caregiver, and 1 volunteer to understand the factors involved in the decision-making process toward adoption of SHS; and follow-up feedback was collected from 42 older adult participants to understand the reasons for adopting or not adopting SHS.

Results: Of the 42 participants, 31 (74%) adopted SHS after the intervention, whereas 11 (26%) did not adopt SHS. The reasons for not adopting SHS ranged from privacy concerns to a lack of family support. Some participants did not fully understand SHS functionality and did not perceive the benefits of using SHS. From the interviews, we found that the decision-making process toward the adoption of SHS technology involved intrinsic factors, such as understanding the technology and perceiving its usefulness and benefits, and more extrinsic factors, such as considering affordability and care support from the community.

Conclusions: We found that training and a strong support ecosystem could empower older adults in their decision to adopt technology. We advise the consideration of human values and involvement of older adults in the design process to build user-centric assistive technology.

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KEYWORDS

aging in place; health care systems and management; telehealth; assistive technology; assisted living facilities

Introduction

In Singapore, an aging population is on a rapid increase, and approximately 25% of Singaporeans will be aged ≥65 years by 2030 [1], posing a strain on hospitals and nursing homes. To ease this growing demand, the Singapore government has continuously enhanced community-based homecare and day care services, allowing older adults to *age in place*.

Background

Smart home devices have been shown to reduce anxiety surrounding an emergency and have helped improve the confidence of older adults living alone [2]. Acknowledging this, the Singapore Housing and Development Board (HDB) started the Smart Enabled Homes initiative by encouraging the installation of smart home devices and apps in senior-friendly HDB studios [3]. The Singapore Ministry of Health also supports older adults in living independently by facilitating a wide range of social and community support services, including senior activity centers (SACs) [1]. SACs are drop-in centers often located in HDB rental blocks, where residents living in the same block or surrounding blocks are supported by affordable or free activities held by SACs. SACs also provide support services for frail or homebound older adults.

Many countries have demonstrated the demand and trend in adopting smart home devices for older adults [4-6]; however, adoption of smart home technologies among older adults remains low because of many factors [7]. In a recent scoping review, Astell et al [8] confirmed that assistive technologies were often viewed as a blatant indicator of aging so that older adults resisted the use of these technologies. This perspective strongly impacted the adoption of assistive technologies by older adults, whereby older adults using these technologies were tagged as being *old*, *lonely*, or *frail* [9]. This scoping review also highlighted older adults' desire to depict their identity as consistent with independence, self-reliance, and competence.

Studies have found that perceived benefits or usefulness are the most critical motivational factors for accepting technology (eg, internet) by older adults [10]. The Technology Acceptance Model (TAM) [11] has been widely recognized and adopted as a tool to measure the acceptance of technology. The TAM proposes 2 key variables—*perceived usefulness* and *perceived ease of use*—to determine the use and acceptance of technology. To extend this to the older population, Chen and Chan [9] proposed a senior TAM that captures aspects such as computer self-efficacy and age-related cognitive and physical changes. To understand older adults' behaviors in using the internet in China, Pan and Jordan-Marsh [12] expanded the TAM model to include 2 additional variables—*subjective norm* and *facilitating conditions*—which highlighted the importance of policy making in alleviating social and cultural obstacles facing older adults.

Technology acceptance and intention to use and adopt technology by older adults have been measured in many studies [12-15]. However, decision-making factors leading to the adoption of technology by older adults have not yet been exhaustively researched by any studies, not only by Astell et al [8]. Davenport et al [16] proposed a decision tree model comprising potential barriers to and facilitators of smart technology that requires decision processes by older adults. However, neither a perceived need for, acceptance of, nor intention to use technology by older adults necessarily leads to a decision to adopt technology or an actual adoption of technology. Thus, a gap remains in thoroughly understanding the decision-making process of older adults beyond their perceived acceptance of technology up to the point of their use and adoption of technology.

Objectives

This study aimed to bridge this gap by exploring the in-depth decision-making factors leading to the adoption of technology by older adults. In particular, we introduced and installed smart home sensors (SHS) for older adults in Singapore and investigated their decision-making process until full adoption (postintervention installation and use) of SHS in their homes.

Methods

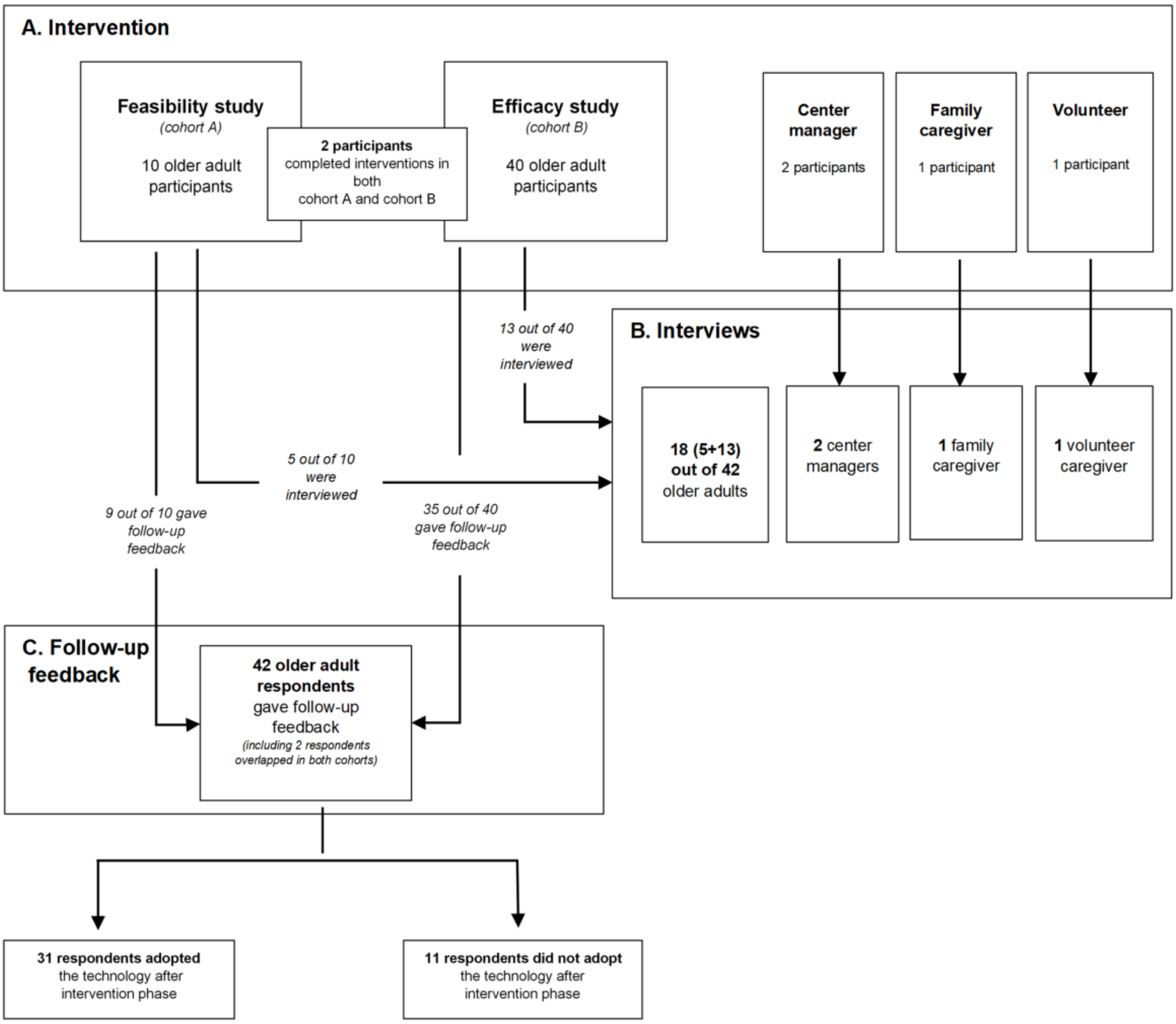
Ethics Approval

This study was approved by the institutional review board of Nanyang Technological University (NTU; IRB-2017-12-003, IRB-2018-01-002, and IRB-2019-04-030), Singapore. We collaborated with a commercial service provider partnered with HDB to provide SHS for this study. We recruited older adults from an SAC in Singapore, Adventist Home for the Elders (AHE).

Study Design

To gain a deeper understanding of the decision-making process of older adults toward the adoption of SHS, this study comprised 3 phases (Figure 1).

Figure 1. Overview of the study design and study participants. The study comprised 3 phases. Phase A is the intervention phase consisting of the feasibility study and the efficacy study (A). Participants involved in both studies are shown with overlapping participants depicted. Phase B is the interview phase, and the participants involved from the preceding phase A are depicted (B). Phase C is the follow-up feedback, and participants come from the feasibility study and from the efficacy study in phase A (C).



Intervention

The intervention comprised 2 parts: a feasibility study (cohort A) conducted between April and May 2018 and an efficacy study (cohort B) conducted between October 2018 and March 2019. The feasibility study aimed to assess the study design, tools, and technology systems with a small group of participants in preparation for the subsequent larger efficacy study. As an intervention, SHS were installed in the HDB flats of older adults for 4 to 5 weeks. The SHS technology comprised a bedroom assistant, 3 motion sensors, a smart plug, a door contact, a key tag, and a mobile app. Motion sensor, strategically placed in selected rooms (kitchen, bathroom, and living room), are considered to have higher chances of detecting emergency or fall cases. These sensors detect movement activities without capturing images. The smart plug shows appliance use (eg, which appliances are currently in use based on the amount of electricity consumed). Door contact can sense the opening and closing of the main entrance door. The key tag monitors the in-home and out-of-home statuses. The bedroom assistant comprises motion and sound sensors that detect irregular noise or inactivity in the bedroom. The sensors were linked to a mobile app to provide notifications to designated caregivers or next of kin in case of an emergency. The mobile app can also be used to monitor care recipients' daily activities, receive intelligent notifications if something unusual occurs, and make calls for 24/7 personal assistance. On pressing an emergency button in the bedroom, an alarm is sent via the mobile app and as an SMS text message. After the intervention period, the AHE offered to waive subscription fees for SHS for a period of 2 years for all older adult residents of their HDB blocks, including the participants of this study.

Interviews

With maximum variation sampling [17], interviews were conducted with multiple stakeholders (n=22, including 18 older adults [users of SHS], 2 SAC center managers, 1 family caregiver [predefined SHS contact person], and 1 older adult volunteer). In addition to family caregivers, center managers and an older adult volunteer played the role of caregivers in the study. This extended caregiver role was designed based on a typical SAC setting in Singapore, where older adults living in the same HDB building are good neighbors who take care of each other. In addition, center managers are well trusted and provide support to the older adults daily.

Follow-up Feedback

Feedback from older adults (N=42) was collected after the intervention to understand the reasons for the adoption of or not adopting SHS (ie, subscribing or not subscribing to SHS after the intervention). Questions also included their decision to continue subscription beyond 2 years and the subscription fees they would be able to afford.

Sampling and Recruitment

With the assistance of center managers at the AHE, we did purposeful sampling to recruit older adults for the study. In particular, inclusion criteria for the recruitment of older adults for the intervention were that they (1) were aged ≥55 years; (2) had voluntarily consented to take part in the study; (3) were able to communicate and express themselves clearly; and (4) were living alone or had the necessity of using SHS; furthermore, for interviews and follow-up feedback, that they (5) had taken part in the SHS intervention for at least 4 weeks.

We found that 10 older adults from cohort A and 40 from cohort B were eligible for recruitment for interviews and follow-up feedback (with 2 belonging to both cohorts). In total, 42 older adults consented to participate in the follow-up feedback. Overall, 2 participants did not provide consent, 3 were hospitalized, and 1 no longer resided in the AHE (Figure 1). Using purposeful sampling, we selected 43% (18/42) of participants for in-depth interviews (5 from cohort A and 13 from cohort B). We strived to represent different ethnicities in the community to reflect the Singapore context using maximum variation sampling [17]. We conducted interviews in Chinese (n=9), Malay (n=3), and English (n=6). In addition to conducting interviews with 18 older adults, 2 center managers, 1 family caregiver, and 1 volunteer were interviewed in English, with the aim of gaining a holistic perspective in the decision-making process. To understand the reasons for adoption or not adopting SHS after the intervention, follow-up feedback was collected from older adult participants who had completed at least 4 weeks of intervention.

Data Collection and Analysis

Semistructured interviews were administered to participants directly after the intervention in May 2018 for cohort A and in April 2019 for cohort B. Interviews were based on a retrospective perspective on the timing of the intervention proposed by Sekhon et al [18]. Before the interviews, interview guidelines were developed for different study participant types (ie, older adults, family caregivers, and volunteers) based on 7 constructs of the theoretical framework of acceptability, including affective attitude, burden, intervention, coherence, ethicality, opportunity costs, perceived effectiveness, and self-efficacy [18]. Interview questions (Multimedia Appendix 1) were designed to elicit perceptions of general feelings, usefulness, satisfaction, effectiveness, convenience, intentions of subscription, and other concerns of older adults toward the service. *Service* mentioned in interviews referred to SHS. For example, 1 open-ended question was, “How did this service benefit you? Would you please share some details with us?”

Trained and experienced interviewers conducted semistructured interviews with participants at their preferred locations, mostly at their homes, to make them feel comfortable with the interview. On the basis of their experience, the interviewers would rephrase questions when they felt that the participants did not understand them initially. They would also probe deeper when they felt that participants had more to share about their experiences. We anonymized the identities of all participants, giving each a code from E001 to E042. The interview guidelines were transcribed into Chinese and Malay by 3 interviewers before the interviews. All interviews were transcribed and translated (9 from Chinese to English and 3 from Malay to English) and classified based on the type of study participant. A data-driven inductive approach was chosen to conduct a thematic analysis of the 22 transcripts [19,20]. At the start of coding, 3 researchers (YC, SQL, and NBN) individually conducted preliminary scanning of all transcripts and separately came up with a first draft of the coding scheme. Each transcript was carefully read and relevant words, sentences, and sections were identified as meaningful units of text and labeled with codes using the open code approach. Through an iterative process of comparing coded transcripts, we discussed our thoughts on code and subcode designations. We agreed to delete redundant themes, combined themes with similar meanings, and added new themes that might have been missed in others’ coding schemes. Thereafter, a common coding scheme is refined based on the definition of each code. We then separately coded transcript 1 using a refined coding scheme to strike the required credibility and reliability [21,22]. Next, we reviewed coding accuracy and consistency and discussed discrepancies. Following this, we achieved a final consensus on the coding scheme and felt intercoder reliability was reached. The remaining transcripts, 2-22, were equally shared and coded following the agreed coding scheme. Thereafter, codes were categorized to form themes and subthemes after discussions among the 3 coders (Multimedia Appendix 2).

As we wanted to collect feedback postintervention from all 42 participants regarding adopting or not adopting SHS, we decided to create a simple self-report questionnaire using a 5-point Likert scale. On the basis of preliminary data analysis of transcripts, we developed questions regarding reasons for adopting or not adopting SHS, depending on whether participants continued with SHS subscription. Open-ended questions were included to gather further details (Multimedia Appendix 3). Follow-up feedback was collected from all the 42 participants in May 2019.

Results

Overview

The demographics of the 42 study participants are presented in Table 1. Most participants were female (28/42, 67%) and of Chinese ethnicity (35/42, 83%), and 60% (25/42) had a primary education level or no formal education. Overall, 52% (22/42) of the participants had family support, although the majority lived alone (33/42, 79%). A total of 60% (25/42) of participants had above-average to excellent health status. The detailed demographic information is presented in Table 1.

Table 1. Demographics of older adult participants (N=42).

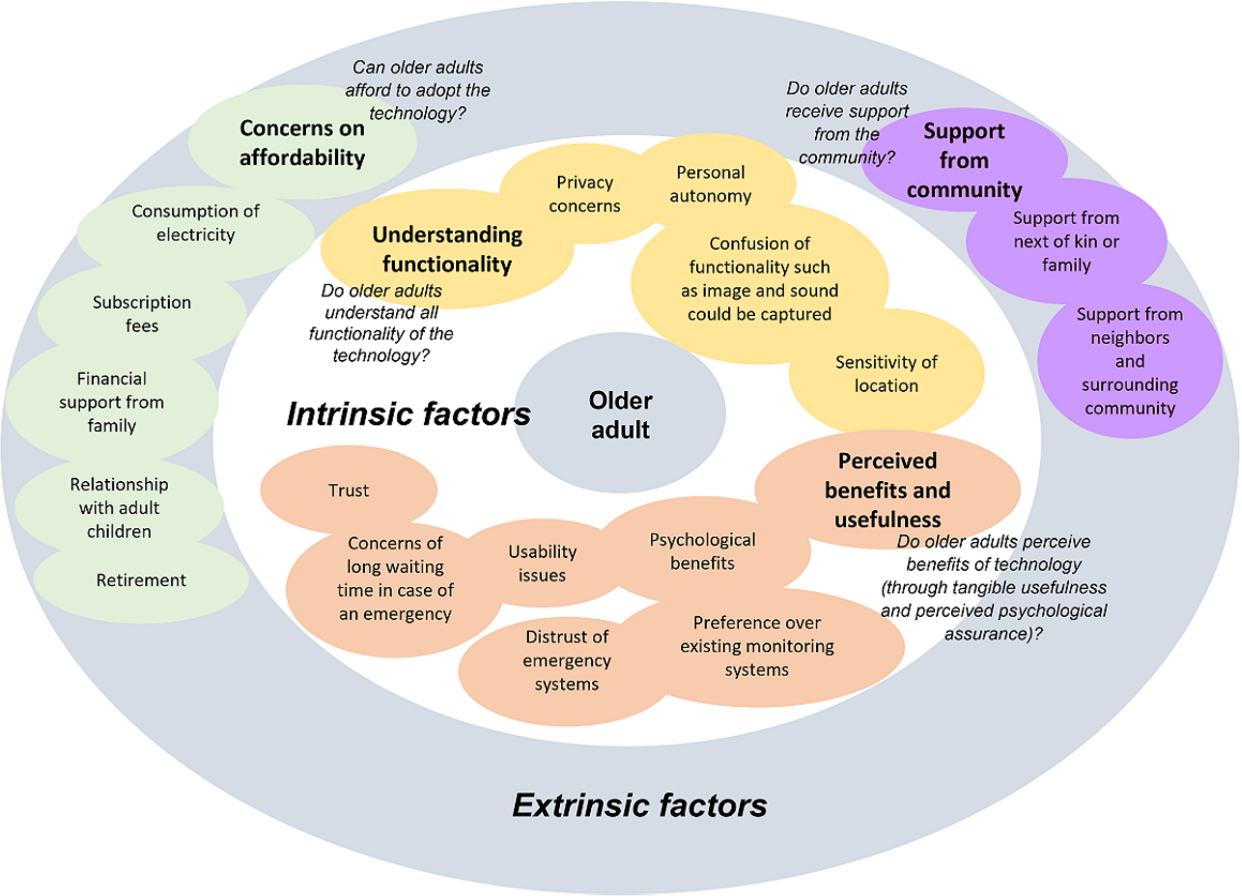
Measurements	Value
Age (years), mean (SD)	71.07 (6.46)
Gender, n (%)	
Male	14 (33)
Female	28 (67)
Ethnicity, n (%)	
Chinese	35 (83)
Malay	6 (14)
Indian	1 (2)
Education level, n (%)	
No formal education	6 (14)
Primary	19 (45)
Secondary	14 (33)
Preuniversity	2 (5)
University	1 (2)
Living arrangement, n (%)	
Alone	33 (79)
With family	8 (19)
Family support, n (%)	
Without support	20 (48)
With support	22 (52)
From children	15 (68)
From spouse	4 (18)
From siblings	2 (9)
From other relatives (eg, niece)	1 (5)
Health status, n (%)	
Very poor	2 (5)
Below average	5 (12)
Average	10 (24)
Above average	19 (45)
Excellent	6 (14)

Figure 1 shows an overview of the study design and study participants. From the follow-up feedback, we found that 74% (31/42) of participants adopted SHS after the intervention, whereas 26% (11/42) of participants did not. Among those who subscribed to SHS after the intervention, from responses to open-ended questions, approximately 29% (9/31) were not sure about the duration of subscription they would continue with. For those who did not subscribe to SHS after the intervention, most (9/11, 82%) were not sure about the reasons, and only a few explicitly expressed reasons *not interested* or *afraid of being monitored*. Multimedia Appendix 3 provides details on the price, reasons, and duration of SHS subscription.

The interview participants comprised 18 older adults of different ethnicities (15 Chinese and 3 Malay). Overall, of the 18 participants, 13 (72%) were female and 5 (28%) were male; 2 (11%) center managers, 1 (6%) family caregiver, and 1 (6%) older adult volunteer were female of Chinese ethnicity.

A total of 4 themes emerged from the interview results. Further analysis of the themes led to the decision-making factors shown in Figure 2. We elaborate on each theme and the resulting decision-making factors in the following sections.

Figure 2. Decision-making factors toward smart home sensor adoption by older adults.



Theme 1: Understanding SHS Functionality

Understanding technology is an important prerequisite for its adoption. However, this is a challenge, particularly for older adults. Misunderstanding functionality can cause many concerns, especially in the initial stages when users get to know and use the technology for the first time. From interviews, we see that, initially, participants resisted using SHS as they did not understand the technology. In general, older participants took approximately 2 weeks to familiarize themselves with SHS and gradually felt comfortable with it. This demonstrated that understanding technology requires time. However, without a clear explanation of the technology, misunderstandings could still arise, even when given sufficient time.

Misunderstanding SHS has resulted in concerns about the intrusion of privacy. In our study, although it was explained that neither video cameras nor images were captured, older adults still felt stressed about having SHS installed in their homes. Older adults understood that motion sensors could detect their movements; however, they were unsure if they captured their images as well. In the first week, some participants expressed that they felt:

> *It is watching and capturing my every action.* [E014, female, aged 67 years]
>
> *I thought it captured my action and speech.* [E023, female, aged 73 years]

Another concern stemmed from the misunderstanding of the emergency alert functionality. Some older adults showed pessimism about receiving a response during an emergency. They found that if they and their next of kin did not understand the SHS emergency alert functionality, they could rely on receiving help in case of an emergency. Some asked:

> *How I can be responded [to] if anything happens to me.* [E024, female, aged 64 years]

On the one hand, this misunderstanding of the SHS functionality led some participants to avoid passing by or touching the sensors, as they were concerned that this would mistakenly alert their next of kin. On the other hand, 1 participant felt a false sense of security as she thought she could trigger an alert at any time by touching the sensors everywhere in her house, so she expressed:

> *It is really very convenient for me in a way.* [E008, female, aged 70 years]

Owing to uncertainty and confusion regarding SHS, 1 older adult pressed the emergency button to test whether it was really working. He was excited when he received a call from his family member, who was designated a contact person.

This shows that an explicit explanation is needed on how SHS detects movement and how the contact person is notified. This was also demonstrated when a few older adults who initially did not understand the SHS and felt it was intrusive changed their minds after the SHS service provider showed them how data were captured on the laptop. The participants then started to understand the functionality better. One older adult said that he felt safer after seeing the dashboard on a laptop:

> *Because it's all by written or like captured like... they view they show me all the graph lah.* [E028, male, aged 75 years]

Appreciation for SHS rose when older adults understood the functionality. They expressed:

> *Some people don't understand. They thought it was an infringement of their privacy, but actually it is not. I told them it is not, so I feel that this sensor is very good.* [E008, female, aged 70 years]

Some participants showed a great interest in learning innovative things and expressed the need for more knowledge about SHS. They were not fully satisfied with brief explanations, such as *sensors are for your safety*. They were eager to learn about SHS in greater detail. They shared:

> *Like [explaining to us], what is the purpose of installing one in the bedroom, why one in the kitchen and one in the washroom etc. Ah... like they can have a presentation at the center downstairs, project the sensor onto the screen and tell us "ah the reason to have one sensor installed in the kitchen is so that it can detect leaked gas" or something along those lines.* [E036, male, aged 66 years]

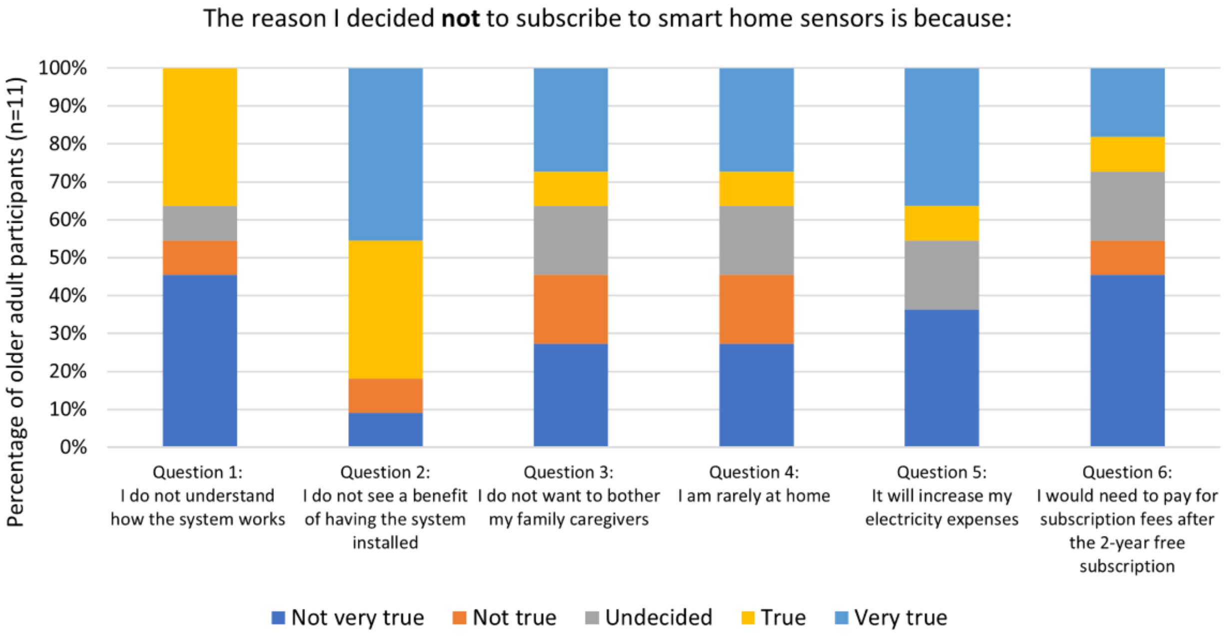
From the follow-up feedback, 36% (4/11) of those who did not adopt the SHS after the intervention did not understand how the system worked, which was not the reason why they decided not to subscribe. This means that there must be other factors that influenced their decision to not adopt SHS. An adequate understanding may not lead to the adoption of technology directly; nevertheless, it may lead to other factors in decision-making, such as the perceived benefits or usefulness of the technology.

Theme 2: Perceived Benefits and Usefulness of SHS

Overview

The perceived benefits and usefulness of SHS include psychological benefits and advantages of using SHS over other monitoring systems that older adults had experienced in the past. Figure 3 shows the reasons why the participants decided not to adopt the SHS. The most salient reason was not seeing a benefit in having SHS installed in their homes (Question 2: 9/11, 82% indicated *true* or *very true*).

Figure 3. Reasons for not subscribing to SHS after the intervention (n=11). SHS: smart home sensors.



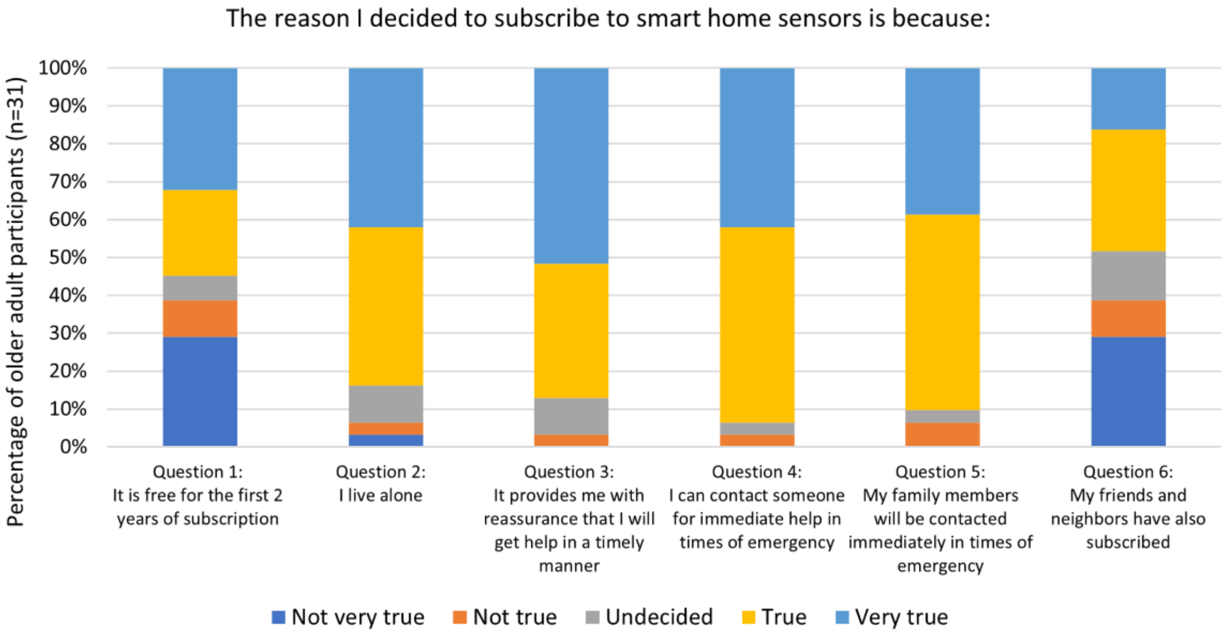
Subtheme 2.1: Psychological Benefits

Assurance and a sense of security were the 2 main psychological benefits perceived from using SHS. Rather than mentioning specific tangible benefits, older adults said that the SHS made them feel at ease. Their feelings of security were mainly based on their trust in technology, that it will help them in case of an emergency. Some summarized psychological benefits as *easier* and *convenient* for them to remain safe. For example, with the emergency button, older adults said that they felt they would receive a response in case of an emergency and would be attended to immediately. One older adult said:

> *If something occurs, let's say something occurs while sleeping, all I need to do is just pressing.* [E039, male, aged 74 years]

From the follow-up feedback, of the 42 participants, we found 31 (87%) older adults subscribed to SHS after the intervention (see Figure 4 for the reasons). The most salient reason was because someone would be contacted for help in case of an emergency (Question 4: 29/31, 94% indicated *true* or *very true*). In turn, family members would be notified when there is an emergency (Question 5: 28/31, 90% indicated *true* or *very true*), and as such, these reasons provided participants with a sense of reassurance that they would get help in a timely manner (Question 3: 27/31, 87% indicated *true* or *very true*), especially so if they live alone (Question 2: 26/31, 84% indicated *true* or *very true*).

Figure 4. Reasons for subscribing to SHS after the intervention (n=31). SHS: smart home sensors.



Some older adults' perceived usefulness of SHS lies in receiving a quick response in case of emergency. For example, 1 older adult pressed the emergency button as a test. He felt that the system was very useful when his nephew called to check on him.

One older adult shared that she felt that SHS was helpful as her goddaughter had told her that she could see her movements via the mobile app. Another older adult, whose spouse used SHS, shared that it was useful because she could monitor her spouse's movements. These comments demonstrate that positive feedback from caregivers regarding the usefulness of SHS can provide confidence to older adults. One older adult shared that his nephew:

> *Can see where I am, my activity in a particular hour, whether it is in the living room or bedroom or anywhere in the house... It's useful. If I am not at home, he will know too.* [E031, male, aged 73 years]

Older adults were also motivated by neighbors' experiences of using SHS:

> *I know because my neighbor the other time like in early 2018 [possibly Feasibility study], I think she already get I think like oh okay this is good actually [...] She already have it so I know what is actually happening [Laughter] [...] I'm aware of it long time ago.* [E028, male, aged 85 years]

On the one hand, older adults find SHS nonintrusive, as it is integrated into their daily lives and is only noticed in an emergency. On the other hand, this can lead to a feeling of indifference toward SHS or that *it is useless*, which could downplay its real value. Some shared that it did not bring much difference to their lives:

> *Nothing to disturb me, to attract our attention or whatever.* [E024, female, aged 64 years]

Subtheme 2.2: Preference of SHS Over Existing Monitoring Systems

Older adults expressed their preference for SHS compared with pull alarms already installed in their apartments. The reason is, in an emergency, older adults need to pull their cords to alarm their neighbors. Compared with this, older adults preferred SHS as being more convenient to use, as they preferred having to press a button rather than pulling a cord.

In addition, older adults found SHS less intrusive compared with video surveillance systems. A family caregiver shared:

> *It's better than those pinhole surveillance cameras, as it does not...it protects our privacy.* [FC001, female, aged 45 years]

However, the older adult volunteer shared an opposite viewpoint that the pull alarm worked better, as it could notify neighbors. In addition, hearing the alarm ring made her feel *it is useful*. She also specified its usefulness for different age groups. For older adults aged 60 to 70 years, she found the pull alarm to be more convenient. However, for those aged >70 years, she thought it was good for them to have SHS, as they might not be mobile enough to pull the cord.

One older adult had a previous bad experience with the pull alarm system. She accidentally pulled the cord and sounded the alarm, but no one had attended her for half an hour. This made her feel that even if she had installed SHS, it would not make much of a difference and no one would hear or attend her in case of an emergency. Although SHS is a completely different technology, the older adult still projected her bad experiences and distrust of the emergency systems onto it. Thus, she refused to continue using SHS.

The older adults also provided constructive suggestions to the researchers. They spoke about concerns regarding sensor locations where they felt uncomfortable, such as in the bathroom. In terms of more locations for emergency buttons, one older adult commented:

> *Because the pull alarm is installed in three rooms, you can pull it if you are near to any of them, for this emergency button [of SHS], you can only press the emergency button only when you are close to it. If the distance is too far, then you can't reach it, most of the elderly feel dizzy, symptoms of stroke or heart attack, you can't even walk.* [E021, male, aged 85 years]

Older adults who chose to adopt SHS prioritized its usefulness and necessity over its costs. An older adult shared:

> *If your product is good, even if it costs money, people will still install it, right? And if it's bad, no one will install even if it's free, right?* [E030, male, aged 70 years]

Therefore, affordability is not only linked to cost but also to perceived benefits, such as an increased sense of security, assurance, and safety. We found that understanding technology and perceived benefits and usefulness seem to be among the first factors older adults consider when deciding to adopt SHS technology, and these are intrinsic motivational factors.

Theme 3: Concerns on Affordability

Most Singaporean older adults retire at 60 years of age and rely mainly on the Central Provident Fund for retirement, housing, and health care. We find that affordability concerns can be categorized into 2 categories: concerns about the consumption of electricity and subscription fees.

Subtheme 3.1: Consumption of Electricity

Concerns regarding the adoption of SHS include an increase in electricity consumption due to multiple sensors and electricity plugs. Eleven participants did not subscribe to SHS after the intervention, and one of the reasons was the perception that installing the system would increase their electricity expenses. Overall, 45% (5/11) of the participants indicated that an increase in electricity bills discouraged them from subscribing, 18% (2/11) were undecided, and 36% (4/11) indicated that an increase in electricity bills was not the reason why they did not subscribe. Participants presumed that the SHS would increase their consumption of electricity by 30%. In reality, the consumption of electricity has been measured by the SHS service provider to be much lower. However, for some older adults, extra electricity charges made them think twice about adopting SHS.

Subtheme 3.2: Concerns on Subscription Fees

The SHS monthly fee in Singapore dollars (SG) would be approximately SG $25 (US $18.2) based on its market price. This might not be much for a working person; however, there are a large number of retired older adults in Singapore. However, if older adults felt that SHS was beneficial and useful, they would be willing to save money to pay for it. An older adult shared:

> *It's currently 25 [Singapore] dollars (US $18.2) a month, actually it's ok, just consider it a dollar a day only mah, just eat a dollar less worth of food everyday lor [laughs]. It's the same, isn't it? Drink less coffee, spend less of everything. Still ok la. Because it is beneficial to us, especially us the elderly who live alone. It is considered a form of guarantee, a form of security for us, so it's not bad lah.* [E008, female, aged 70 years]

Some older adults considered this amount reasonable; however, they were not sure whether others would find it affordable. Some felt that they could afford it if they could save some money elsewhere. One shared:

> *That is very reasonable for... the children give us and we can keep aside the money.* [E040, female, aged 78 years]

Some older adults (especially those who were healthier) did not think that the subscription fee was too large to pay. In the follow-up feedback, we asked participants who continued with the SHS subscription (n=31) to provide their estimate of an appropriate monthly subscription fee (in SG). Overall, 35% (11/31) of respondents indicated either between SG $10 (US $7.3) and SG $15 (US $11), 35% (11/31) of respondents indicated between SG $20 (US $14.5) and SG $25 (US $18.2), 19% (6/31) were undecided, and 10% (3/31) preferred to pay <SG $10 (US $7.3) or no fee at all (Multimedia Appendix 3).

As SHS were installed for a month, they became part of the older adults' lives. Hence, some wanted to keep the SHS for themselves or for their spouses. They felt a need to continue with SHS either because of living alone (33/42, 79% lived alone) or medical issues (17/42, 40% had an average or less than average health status).

As most older adults aged ≥65 years are retired and have no income in Singapore, they rely heavily on their children for financial support, especially if they do not have sufficient savings. Thus, the relationship between older adults and their family caregivers (15/22, 68% of those with family support had adult children as caregivers) could adversely affect the affordability and subsequent adoption of SHS. If parents and children are in a good relationship, they can support their parents in paying for SHS. However, some older adults had issues with their children. One older adult complained:

> *My children should be the one paying, but they don't want to help me. I told them—I have 4 daughters—it only requires each of you to fork out a few dollars every month. It's just the cost of a bowl of noodles, am I right?... But if I'll have to pay, there's nothing I can do. I am not working, I have no money.* [E014, female, aged 70 years]

In addition, if older adults receive government subsidies, they might feel that they can afford SHS. However, financial support is only one form of support. Other forms of support from multiple stakeholders in the community are also required for technology adoption.

Theme 4: Care Support From the Community

In this study, the importance of community support was highlighted. We noticed that older adults who could not rely on their family turned to the community for support. Some shared that they did not think it was necessary to install SHS, as they had no next of kin who would come to help:

> *I have nobody to rely on. I have a lot [of] nephews a lot of nieces but they have their own family to run.* [E024, female, aged 64 years]

Some believed that neighbors were more reliable than next of kin, who stayed far away. They expressed that in the case of an emergency, if they had to wait for help from their next of kin, they might die due to a delayed response. Thus, they would rather trust their neighbors.

One older adult shared that neighbors are often the best assistance in an emergency. Neighbors were suggested to be volunteer caregivers who could take care of each other:

> *The best [emergency response] is the nearby people come. [...] You get me? They nearest. Whoever. That's why I tell [center manager], why don't we have a committee that a group of people who want, volunteer, whoever want. [help to keep a lookout for each other during emergency] This comes from the heart. [...]* [E024, female, aged 64 years]

This close relationship among neighbors is not uncommon when all residents are aged ≥55 years, staying in the same HDB block. Some older adults felt very reassured with their neighbors who always *look for* him or her. Older adults believed that help from neighbors was necessary, especially during the weekends and nighttime. They found they must maintain the Kampung spirit (*Kampung*—village spirit refers to a sense of community and solidarity [23]). One older adult shared:

> *My neighbor will come look for me lah. They will say "how come I didn't see you? [...] actually my floor the neighbor they are quite nice, When we don't ... we don't see...because ah I always sit outside the flat."* [E018, female, aged 61 years]

During the intervention, we observed that some older adults preferred to have a volunteer, such as the center manager or a neighbor, as their emergency contact. We found 1 older adult who was willing to volunteer as a caregiver for several older adult participants during the intervention. This older adult volunteer felt that she takes care of her neighbors anyway every day and would want to help them in case of an emergency. She shared her thoughts that although family members can be predefined as contact persons in case of an emergency, she did not think they could come immediately if they stayed far from their parents. She shared:

> *Neighbors are more important, you know? My door is always open when I'm in, when close means nobody in. So, the neighbor always you know, they they... ah. They will know of my existence.* [E018, female, aged 61 years]

Support from center managers is also important for encouraging older adults to adopt SHS. We found that when SHS were recommended by the center manager, older adults were more likely to accept them, especially if they had a good relationship with the center manager.

In addition, some older adults found the SHS service provider to be very friendly and helpful and felt reassured that the SHS could be well maintained by the service provider. Some shared that the service provider had said:

> *This one [increase of electricity price] compared to your life—your life it's more important.* [E024, female, aged 64 years]

The older adults shared the same viewpoint and thus felt encouraged by the SHS service provider to continue using the SHS.

On the basis of these findings, we developed an older adult–centric decision-making model involving 5 layered factors (Figure 2), ranging from intrinsic *motivated factors* such as understanding the technology and perceiving its benefits and usefulness to more *extrinsic motivated factors* such as affordability and support from multiple stakeholders in the community, which could encourage older adults toward a decision to adopt SHS technology.

Discussion

Principal Findings

Our findings show that multiple factors are involved in the decision-making process toward the adoption of SHS by older adults, and we acknowledge that not all factors could be exhaustively captured in a single study. However, we find that the insights gained from this study and the proposed layered factors involved in the decision-making process could be used to guide more informed awareness when considering the adoption of technology by older adults.

Although adult children and family members feel empowered by SHS to monitor their parents and be alerted when an emergency occurs, older adults are often left misinformed about the technology. Adult children often feel confident in their ability to persuade their parents to adopt the given technology [24]. However, we found from our study that older adults need not only persuasion or reassurance from their family but also empowerment to understand the technology, thereby enabling them to make informed decisions through adequate knowledge and appreciation of the benefits of the technology [25,26].

Moreover, in contrast to the prevalent misconceptions, older adults show more positive than negative attitudes toward technology. Older adults' desire to learn, ability to understand, and willingness to use new technology have often been underestimated [27]. From our study, we find that there exists a gap between the expected and the actual understanding of technology. Older adults lacked an introduction to, as well as sufficient, information about SHS. Training materials, with the aim of teaching older adults the functionality of the technology, should be provided in an accessible form, such as simple and concise user manuals, verbal introduction by the SHS service provider, short testimonial videos, or visuals in posters. Older adults' questions and concerns could be addressed as frequently asked questions posed by older adults. These training materials and educational concepts focused on older adults as the main users of the technology could help improve vendor outreach and ultimately drive new government policy.

From our findings, we identified human needs for trust, privacy, and personal autonomy when older adults considered adopting SHS. Human values are the guiding principles of what is considered important in people's lives and often go beyond financial considerations [28]. People's choices or engagement with technology depend on how technology can support them in maintaining their values [29]. These human values are important to be identified for a better design and development of assistive technology.

In Singapore, there is a general sense of public trust in the government as it places increasing emphasis on citizen well-being and public services. Citizens can benefit from outcomes translated from policy implementation [30]. Our study was facilitated by pre-existing trust and long-standing relationships between older adults and the research team, SAC center managers, and SHS service providers. There had been a long-standing research collaboration between the research team at NTU and SAC, including several research projects and community engagement events; for example, the Singapore Intergenerational National Games [31]. In addition, the pre-existing relationship with SAC center managers was critical in the recruitment of participants for the study. We found that older adults valued the center manager's opinions and trusted their recommendations to use the SHS. Furthermore, there had been a program launched at the SAC together with the SHS service provider to install SHS at the SAC; thus, the older adults were somewhat familiar with the SHS service provider and SHS technology [32]. We observed that older adults' positive attitudes toward the SHS service providers could lead to greater user satisfaction and continued adoption of SHS.

Furthermore, we found that the older adults in our study trusted the SHS service provider and SAC center manager in handling their private data. One study suggests that users trusted the company providing SHS and felt that they were not worthwhile targets for privacy breaches [33]. As trust in entities that collect data is related to the need for users to have control over their own data [29], this was a critical factor in the use and adoption of SHS in our study.

Although older adults might trust the SHS service provider with their private data, they might not want to be constantly monitored and have all their movement data shared with emergency contacts. Privacy concerns have been recognized as barriers to adopting sensor-based technologies that use video surveillance systems [34]. One study found that older adults and their adult children perceived privacy as the most-cited concern [24]. In our study, the SHS system provided movement data of older adults to their adult children or caregivers, which could become a potential issue of privacy and personal autonomy. For some, sharing personal information with people with whom they are close to may make them feel safer; however, there does not seem to be a universal consensus regarding this [33]. Older adults' relationships with their adult children could be very different from case to case, and for various reasons, the amount of personal information they may be willing to share could differ. To address this potential issue, we suggest that older adults be empowered to predefine the person, duration, and range of personal data they wish to share to maintain their autonomy.

Technology is becoming increasingly ubiquitous, and older adults may find it difficult to identify perceived benefits, especially when the user does not directly interact with the technology, as in the case of SHS, unless there is an emergency. Many older adults would be unfamiliar with this rather new technology, as SHS was only introduced to Singapore less than 10 years ago when HDB piloted the Smart Elderly Monitoring and Alert System in HDB flats where older adult residents resided in 2014 [35]. A novelty of SHS is its discreet monitoring of movement, unlike well-known camera surveillance systems that capture images and voices. On the one hand, this rather passive use of SHS makes its acceptance easier for older adults, as it is considered very nonintrusive and can be well integrated into daily lives. On the other hand, we find that this novelty makes it challenging for older adults to fully grasp the benefits of SHS. It could lead to the feeling of "it makes no difference for me" or "it is useless." However, this could indicate a deeper human need for personal autonomy.

In this study, we observed that older adults shared common personal autonomy values. On the one hand, older adults would rather trouble their friends or neighbors when they needed help, which, in the Asian context, is considered an integral part of friendship. In being able to lend a helping hand to others, older adults felt validated that they were still useful and capable. This helps to maintain the friendship network. On the other hand, older adults tend to be more optimistic about their own future than someone else's at a very old age [36]. Horton [37] found that older adults had the impression that other people would benefit from assistive technology but not themselves. In our study, particularly those who did not adopt the SHS after the intervention expressed that they were capable of handling most situations and downplayed the severity of situations they might encounter. They held on to their personal autonomy by showing little or no interest in SHS. Many studies have accounted for this attitude of older adults resisting assistive technology because it associates them with the negative context of becoming old [8].

We found that a user-centric design involving older adults is essential for the successful adoption of technology [38,39]. System designers should strive to understand the requirements of older adults, incorporate their feedback, and adapt technology to meet age-related needs, such as changes in abilities, health status, living arrangements, and family structures [40]. During our study, older adults provided feedback on the design of the SHS system, thereby demonstrating their active wish to participate in the improvement and design of SHS. Thus, we found that older adults should be more involved in the user-centric design of SHS technology based on human values.

For example, during the study, we identified the need to rely on neighbors and fellow older adults in the community rather than on their children who live far away. Thus, we made a simple change to the intervention design by including an older adult volunteer as emergency contact for some older adult participants in the study. This shows how the needs of older adults can be incorporated into the implementation of SHS, which could eventually lead to a higher adoption rate of the technology. We also found that older adults expressed the need to hear an emergency alarm when it was triggered using the pull lever in the old system. The sounding of an alarm not only gave the older adults feedback and reassurance that the call for help was successfully made but also that the loud noise would alert neighbors who they trusted would quickly come to help them. In contrast, the older adults were unsure how they would know if the SHS alarm was successfully triggered in the case of an emergency, as no alarm was sounded. This example shows, on the one hand, how technology could potentially disrupt existing relationships and support structures and be detrimental to the community spirit of helping one another. On the other hand, these findings also present an opportunity for technology to be adapted to the needs of older adults. The sensors need not only trigger a silently sent alarm to the emergency contact but they can also be redesigned to additionally sound an alarm. This would preserve the existing emergency response structures in the community and among neighbors and still have all the advantages of the new system.

Furthermore, we identified the need to develop custom technology solutions for different aging societies [41]. In our study, the uniqueness of the Singapore setting [42] highlights the importance of a support ecosystem involving multiple stakeholders in the community, ranging from family to neighbors, center managers, and SHS service providers, in older adults' decision-making processes to adopt technology. Although the engineering teams focused on prototype and algorithm development, the medical science teams concentrated on outcome research. The convergence of medicine and informatics could lead to the development of new interdisciplinary research models and new assistive products for the care of older adults.

Limitations

Although we identified the need for financial support when older adults consider the adoption of SHS, in this study, we could not further investigate the impact of cost on the decision to adopt technology, as study participants were offered a 2-year free subscription if they wished to continue using the SHS. Thus, we would need to investigate whether the introduction of a subscription fee has an effect on the number of older adults who continue or who subsequently drop the SHS subscription.

The inclusion criteria were subjectively assessed, and this could be improved by using a more objective method, such as a questionnaire, or performing a set of tasks to assess this. In addition, cognitive ability was not assessed, which could play a role in the willingness and ability to adopt technology.

We acknowledge that our findings are specific to the context and unique structures surrounding living and caring for older adults in Singapore. Older adults who choose to live in an SAC are generally more open to trust center managers and their neighbors and are more willing to be helped by others. They also sought to share information with others and integrate it into the community. For example, some older adults share home-cooked meals and often participate in activities organized by the SAC. As such, our findings may not be generalizable to other countries with different circumstances. Nevertheless, our insights could serve as inspiration for potential solutions.

Conclusions

This study combined quantitative and qualitative methods to explore the factors and influences of the decision-making process toward the adoption of SHS technology by older adults in Singapore. SHS were installed in the homes of 42 older adults for a period of 4 to 5 weeks. Our findings show that both intrinsic and extrinsic factors are involved in the acceptance and adoption of SHS technology. We found that training and a strong support ecosystem could empower older adults in their decisions to adopt technology.

We also identified human values, such as trust, privacy, and personal autonomy, as important factors in influencing older adults' choices of engagement with SHS. Our study was facilitated by long-built trust between older adults and multiple stakeholders, which was established over the years through various activities held by SACs, programs organized by NTU, and interactions between older adults and the research team.

In the future, besides providing adequate training for older adults to understand the technology they are to use, we advise their involvement of older adults in the design process to build user-centric assistive technology. We find it important to consider the integration of human values in technological solutions and their adaptation to the needs of older adults. In addition, these systems should be evaluated using qualitative methods to explore lived experiences with the technology.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Interview questions.
[DOCX File , 22 KB - aging_v5i2e34239_app1.docx]

Multimedia Appendix 2
Coding scheme, sample quotes, and mappings to themes and subthemes.
[DOCX File , 29 KB - aging_v5i2e34239_app2.docx]

Multimedia Appendix 3
Follow-up feedback questionnaire with responses.
[DOCX File , 26 KB - aging_v5i2e34239_app3.docx]

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Abbreviations

AHE: Adventist Home for the Elders

NTU: Nanyang Technological University
SAC: senior activity center
SG: Singapore dollars
SHS: smart home sensors
TAM: Technology Acceptance Model

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Original Paper

A Text Messaging Intervention to Support Latinx Family Caregivers of Individuals With Dementia (CuidaTEXT): Development and Usability Study

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Abstract

Background: Latinx family caregivers of individuals with dementia face many barriers to caregiver support access. Interventions to alleviate these barriers are urgently needed.

Objective: This study aimed to describe the development of *CuidaTEXT*, a tailored SMS text messaging intervention to support Latinx family caregivers of individuals with dementia.

Methods: *CuidaTEXT* is informed by the stress process framework and social cognitive theory. We developed and refined *CuidaTEXT* using a mixed methods approach that included thematic analysis and descriptive statistics. We followed 6 user-centered design stages, namely, the selection of design principles, software vendor collaboration, evidence-based foundation, caregiver and research and clinical advisory board guidance, sketching and prototyping, and usability testing of the prototype of *CuidaTEXT* among 5 Latinx caregivers.

Results: *CuidaTEXT* is a bilingual 6-month-long SMS text messaging–based intervention tailored to caregiver needs that includes 1-3 daily automatic messages (n=244) about logistics, dementia education, self-care, social support, end of life, care of the person with dementia, behavioral symptoms, and problem-solving strategies; 783 keyword-driven text messages for further help with the aforementioned topics; live chat interaction with a coach for further help; and a 19-page reference booklet summarizing the purpose and functions of the intervention. The 5 Latinx caregivers who used the prototype of *CuidaTEXT* scored an average of 97 out of 100 on the System Usability Scale.

Conclusions: *CuidaTEXT*’s prototype demonstrated high usability among Latinx caregivers. *CuidaTEXT*’s feasibility is ready to be tested.

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KEYWORDS

Latinx individuals; mHealth; dementia; caregiving

Introduction

Background

Family caregiving for individuals with dementia has a serious emotional, physical, and financial toll [1-8]. Most individuals with dementia live at home and are cared for by their relatives [9]. As the US health care system focuses mainly on acute care, relatives provide >80% of the long-term care for individuals with dementia [4,5]. For these reasons, caregiver support is a key component of the National Alzheimer's Project Act [10].

Most family caregiver interventions have been designed for non-Latinx White individuals, and the results might not generalize to other groups because of linguistic, cultural, and contextual reasons [11-13]. The number of Latinx individuals with dementia is projected to increase from 379,000 in 2012 to 3.5 million by 2060, more than any other group [14]. Latinx individuals are more likely to become family caregivers than non-Latinx White individuals [15]. Latinx individuals also provide more intense and longer caregiving and experience higher levels of caregiver depression and burden [8,15-21]. However, despite their high interest in participating in caregiver support interventions [22], Latinx caregivers of individuals with dementia are less likely to use caregiver support services [23,24]. This disparity is partly due to Latinx caregivers' more frequently experienced barriers related to transportation, financial, language, and cultural aspects compared with non-Latinx White caregivers [23,24]. Therefore, the need for targeted caregiver support interventions among Latinx individuals is crucial. This need is in line with the National Institute on Aging's call to address health disparities in aging research [25].

SMS text messaging offers distinct advantages over websites and apps for delivering interventions [26-28]. Although nearly all Latinx individuals engage in SMS text messaging, Latinx individuals' low use of websites and apps could perpetuate disparities in access to caregiving support [29]. Caregiver interventions for Latinx individuals need to capitalize on SMS text messaging, as SMS text messaging interventions (1) are effective in treating or preventing other health conditions such as tobacco addiction or diabetes; (2) can be used anywhere at any time; (3) are more cost-effective than other delivery systems; (4) can be personalized to caregivers' preferences and characteristics including language, culture, and needs; (5) are highly scalable among Latinx individuals, as most own a cell phone with SMS texting capabilities, more than other groups; and (6) have been specifically shown to engage Latinx individuals [30-35].

Objectives

To address Latinx individuals' disparities in access to caregiving support, we developed *CuidaTEXT* (a Spanish play on words for self-care and texting). To our knowledge, this is the first SMS text messaging intervention for caregiver support of individuals with dementia among Latinx individuals or any other ethnic group. Only one other SMS text messaging intervention exists in the context of dementia [36]. However, that intervention was designed to increase dementia literacy among non-Latinx Black users and is not geared toward Latinx individuals or caregivers specifically. The aim of this study was to describe the development of *CuidaTEXT*, a tailored SMS text messaging intervention to support Latinx family caregivers of individuals with dementia. This development corresponds to Stage 1a of the National Institutes of Health Stage Model for Behavioral Intervention Development (intervention generation) [37]. This intervention will later be feasibility-tested (Stage 1b) among Latinx family caregivers of 20 individuals with dementia (ClinicalTrials.gov NCT04316104).

Methods

Overview

This was a mixed methods project guided by user-centered design principles [38]. The basis for user-centered design is that gathering and incorporating feedback from users into product design will lead to a more usable and acceptable product. Mixed methods are required, given the lack of literature on SMS text messaging interventions for Latinx family caregivers of individuals with dementia and the strengths of a combined qualitative and quantitative approach [39]. We followed 6 user-centered design stages informed by previous research used to develop successful behavioral intervention software [40]. The user-centered design stages are described in the next sections.

Ethics Approval

All study procedures were approved by the institutional review board of the University of Kansas Medical Center (STUDY00144478). All participants provided written informed consent.

Stage 1: Selection of Design Principles

A total of 2 design principles were specified. First, we selected the social cognitive theory as the main behavior change principle [41]. This principle has been successfully used in previous SMS text messaging interventions [30]. The social cognitive theory informs the identification of barriers to desired behaviors, setting of realistic goals, encouragement of gradual practice to achieve performance accomplishments of healthy behaviors (eg, relaxation techniques or exercising), integration of testimonials and videos to promote vicarious learning, integration of praise to elicit social persuasion, and education to increase dementia knowledge. Second, we chose the stress process framework [42] to guide the development of messages to encourage coping and social support behaviors (mediators), which are aimed at improving role strains (eg, perceived income adequacy and family interaction), intrapsychic strains (eg, mastery, self-esteem, and loss of self), and, ultimately, outcomes (eg, caregiver depression, affect, and self-perceived health).

Stage 2: Vendor Collaboration for Text Messaging Design and Delivery

This stage aimed to materialize the vision and design specifications of *CuidaTEXT*. We developed a checklist of necessary features to identify potential vendors, including message personalization, 2-way SMS text messaging, scheduling, conditional branching logic for SMS text message responses, information tracking, technical support, and cost. We identified 3 vendors based on our previous experiences and a basic internet search. The 3 identified vendors met all the features, and we selected the one with the most affordable cost. Their services also included configuration, account setup, initial onboarding, training guides and videos, access to the vendor system, mobile number support, and bug fixes during the intervention. We contracted with them early in the project to avoid delays (eg, developing the scope of work, registering as a vendor, contracts, and software programming).

Stage 3: Evidence-Based Foundation

This stage aimed to identify core content categories based on previous successful behavioral interventions. We searched specifically for general caregiver support interventions considered evidence-based informed by the Administration for Community Living [43], PubMed literature results using the Medical Subject Headings terms *Caregivers*, *Dementia*, and *Hispanic Americans*, and recommendations on behavioral interventions from the research team. Content categories included dementia education, problem-solving skills training, social network support, care management, and referral to community resources [1,26,27,44-58].

Stage 4: Advisory Board Guidance

Advisory board guidance provided expert opinion to inform the SMS text messaging intervention based on Latinx caregiver needs [22,40,59,60]. We conducted 5 parallel advisory board meetings with up to 6 Latinx caregivers and 16 clinicians and researchers (health professionals), each lasting 60 minutes. We used purposive sampling for the Latinx caregivers and quota sampling for the health professionals (including at least one person with expertise in psychiatry, social work, neurology, dementia care interventions, Latinx research, SMS text messaging intervention development, or behavioral health). We conducted the caregiver advisory board sessions in Spanish and the health professional group sessions in English. We held all sessions via videoconference from December 2020 to May 2021 and recorded each to facilitate notetaking and analysis. The process for each meeting was similar: the research team showed the groups a step-by-step explanation of the components of the study, asked specific questions pertinent to the phase of the study, and then facilitated open discussion about the project. The research team took detailed notes of all sessions, which were used for further analysis. We organized the notes for qualitative review using a pragmatic approach, a qualitative description methodology, and thematic analysis methods [61-63]. We coded the content of the notes using Microsoft Word by identifying codes and themes within the text [64]. In addition, 2 researchers (JPP and MAR) independently reviewed the codes and resolved coding disagreements through discussion and consensus.

Stage 5: Sketching and Prototyping

On the basis of the previous stages, 3 researchers (JPP, MAR, and PEK) brainstormed a pool of potential SMS text messages in English on a shared spreadsheet and later sorted the messages by topic (initial draft keywords). We edited messages following the *Seven Principles of Communication*: completeness, concreteness, courtesy, correctness, clarity, consideration, and conciseness [65]. This theory is popular in business communications and has been used in patient reporting [66,67]. Bilingual, bicultural members of the research team translated the messages into the primary Spanish dialects represented in the United States (Mexican and Caribbean).

In addition to the SMS text message libraries, we developed a reference booklet for participants that summarized the purpose of the intervention and its functions. The booklet is not necessary to use *CuidaTEXT*. However, the research team considered it to be useful for those who want to learn about the intervention faster or increase personal sense of agency. On the basis of our previous development experience with the Latinx community [22,30], we made the booklet available in both English and Spanish and used lay language and a pictorial format. A total of 7 research team members tested the SMS text messaging prototype powered by the vendor on their own cell phones from early June to August 2021 and provided feedback that was used for message refinement iteratively, as suggested by the literature [68,69]. We recorded the feedback via SMS text message responses within the vendor platform and emails from the research team to the vendor's programmer. We organized the data (SMS text messages and emails) for qualitative review using a process identical to that described in Stage 4.

Stage 6: Usability Testing

Usability testing aimed to test a short prototype of the SMS text messaging intervention and assessments among actual Latinx caregivers. We used the vendor's platform to preview the behavior and opinions of diverse Latinx caregivers in a variety of key scenarios (ie, reading specific messages, using keywords, sending SMS text messages, opening links to websites and videos, and downloading PDF files). The testing sessions were conducted via videoconference in June 2021, lasted approximately 90 minutes per person, and were conducted in English and Spanish based on participant preferences. We took detailed notes of the observations during the usability testing sessions and participants' comments at the end.

Sample and Assessment

We recruited 5 individuals, as suggested by software development cost-benefit analyses [70]. In this framework, the first participant discovers most flaws, and after the fifth user, findings tend to repeat without learning much new. Participants were recruited from 3 previous projects at the research center using purposive sampling. Eligibility criteria included Spanish- or English-speaking individuals who were aged 18 years or older, identified as Latinx, reported providing care for a relative with a clinical or research dementia diagnosis, and with an Ascertain Dementia 8cognitive screening score ≥2, indicating cognitive impairment [71,72]. Participants also had to report owning a cell phone and being able to use it to read and send

SMS text messages. Participants received US $20 prepaid gift cards for completing assessments. We used 3 usability evaluation modalities. First, direct observation of task completion (eg, texting keywords) with the intervention prototype via monitoring of participants' SMS text message responses was conducted. Second, open-ended interviews of user experience with the different tasks and suggested changes to improve the intervention (see Multimedia Appendix 1 for a sample) were conducted. Third, the caregiver participants completed the System Usability Scale about their experience with the prototype [73]. The System Usability Scale is a valid and reliable 10-item, 5-point Likert scale. According to the developers of the scale, scores >68 out of 100 indicate higher levels of usability. We modified the design features iteratively after each participant and provided the new version to the following participant, as suggested by the literature [74]. After 2 consecutive participants reviewed and approved an SMS text message, the following participant received an SMS text message with different features. In addition to the usability evaluation, we administered a survey to gather baseline characteristics.

Data Analysis

We analyzed the qualitative data (detailed notes) from the open-ended interviews using a process identical to that described in Stage 4. We analyzed quantitative baseline characteristics using central tendency estimates, frequencies, and percentages on SPSS software (IBM Corp) [75].

Results

Overview

This section focuses on Stages 4 to 6 of the user-centered design proposed in this project. First, we summarize the findings from each stage. Second, we explain how these findings informed the intervention development within each stage. Third, we describe the final version of the intervention.

Findings From Advisory Board Guidance (Stage 4)

Table 1 shows the themes, subthemes, and descriptions of the aspects to be considered in the development of *CuidaTEXT*, according to the advisory boards. Both Latinx caregivers and health professionals contributed to all the themes. Building on the evidence-based foundation established in Stage 3, feedback from this stage informed the sketching and prototyping of *CuidaTEXT*. First, the advisory board emphasized that messages should include specific content on logistics (eg, guidance on *CuidaTEXT*'s functions and motivation messages), social support, caregiver needs, care recipient needs, preparation for the care recipient's death, and reminders for physician visits or medicines. This feedback informed the addition of the suggested SMS text message content. Second, advisory board members highlighted the importance of allowing the inclusion of >1 relative within the family to reduce burden and increase social support. This feedback informed the decision to enroll >1 caregiver per individual with dementia in future studies. Third, the advisory board suggested that the domains of SMS text messages sent to caregivers should alternate often and be tailored to the needs of caregivers. This feedback informed the inclusion of high-priority message content at the beginning of the intervention (eg, who to contact in case of elder abuse or suicidal thoughts and removing weapons in the home) and the frequent alternation of domains. This feedback also reinforced the need to use 2-way SMS text messaging, as originally planned. Fourth, the preferences of caregiver advisory board members varied widely with respect to the number of messages per day *CuidaTEXT* should send participants. A participant emphasized that they would abandon the intervention if they received >1 message per day except at the beginning, which required more messaging. Others wanted to receive 5 or more messages per day. Eventually, a consensus was reached that *CuidaTEXT* should tailor the number of messages to the preferences of caregivers. This feedback informed the decision to send few daily automatic messages per day to participants (generally 1). Fifth, the advisory board emphasized the need to make keyword names as simple and recognizable as possible and suggested several edits in line with this idea. This feedback informed the refinement of some keyword names. Sixth, the advisory board suggested adding diverse information regarding COVID-19. However, after some discussion, a consensus was met not to develop automatic SMS text messages for *CuidaTEXT*, given the rapid evolution of COVID-19 information. This feedback informed the exclusion of COVID-19 automated information into *CuidaTEXT*. Seventh, an advisory board member, guided by her experience, highlighted the scarce existing resources for caregivers with hearing issues and suggested that *CuidaTEXT* was made as *hearing impairment friendly* as possible. This feedback reinforced the idea of delivering the intervention via SMS text messaging. This feedback also informed the use of hearing impairment–inclusive messaging, including SMS text messaging–based contact information of all shared resources (eg, text telephone contact numbers) and video links with closed caption subtitles. Eighth, the advisory board suggested several *CuidaTEXT* reference booklet edits for simplification. This feedback informed the refinement of the *CuidaTEXT* reference booklet.

Table 1. Themes, subthemes, and descriptions of topics elicited during the advisory board sessions with Latinx caregivers and health professionals.

Themes and subthemes	Description
Messages should include specific content	
Logistics	Motivate participants to be in the program
Dementia education	Address the whole family to be all on the same page; dementia stages and variation between individuals; signs and symptoms; address stigma by normalizing dementia
Social support	Communication with the individual with dementia; include concrete examples (eg, allowing individuals with dementia enough time to answer) and resources (eg, Alzheimer's Association, health professionals, services in Spanish, support groups, and legal assistance); communication with the health provider (eg, expectations, what to report, encouraging clinical diagnosis, and requesting interpreters); improve family communication (eg, understanding family roles and find strengths, knowing importance of family support, and disclosing the diagnosis to the family); and develop active listening skills (eg, reflecting and nonverbal language)
Caregiver needs	Cope with depression, anxiety, and stress (eg, relaxation); choose one's battles; use sense of humor; find positive aspects of caregiving; address loneliness; cope with loneliness; capitalize on spirituality; and maintain a healthy lifestyle
Care recipient needs	Address behavioral symptoms as specifically as possible; address aggressive behavior (eg, understanding the disease causing it, distraction techniques, and communication when the person is aggressive); address anxious behavior (distraction techniques and prevention); help the individual with dementia; address daily care of the individual with dementia, including healthy eating, dressing, hygiene, and doing fulfilling activities
Preparation for the care recipients' death	Information about what to expect at the end of the life of the individual with dementia; grieving strategies and tips
Appointments for the physician or medicine	Set notifications to remind caregivers of medications or physician visits
Need to integrate other family members	More than 1 family member should be allowed to participate, to share responsibilities, avoid burdening a caregiver by having to educate the rest, promote collective understanding about what the individual with dementia is experiencing, and reduce the isolation of the caregiving process
Messages should follow a certain order	Alternate content often (eg, educational, caregiver tips, and resources) and tailor content to caregivers' needs
Messages should have a certain dose	Limit mandatory message frequency to 1 per day (in general) and tailor frequency and timing to caregivers' preferences
How to integrate COVID-19 into *Cuida-TEXT*	Reliable education about caring during COVID-19, including what to do if infected, risks, vaccines, and vaccine locations and resources for those experiencing technological divide. As changes in COVID-19 evolve quickly, it was decided not to automate messages and send only ad hoc information as needed
Some keyword names need editing	Use simple and recognizable keyword names if possible; allow platform recognition of alternative spellings and typos; and edit specific keywords: *STRESS* vs *RELAX*, *GRIEF* vs *ENDOFLIFE* or *LOSS*, *BANO* vs *ORINAR*, *DUELO* vs *FINDEVIDA*, *PACIENTE* vs *SERQUERIDO*
CuidaTEXT could benefit people with hearing impairment	Given that SMS text messages are visual, this intervention can be optimized for people with hearing impairment
Reference booklet needs editing	Shorten booklet and include fewer and more realistic examples by including a matrix of the different keyword messages

Findings From Sketching and Prototyping (Stage 5)

Table 2 shows the themes, subthemes, and descriptions of aspects considered in the development of *CuidaTEXT* based on the feedback from SMS text messages from the team during the testing of the prototype and suggestions provided by the vendor's programmer. These aspects led to several solutions. First, we allowed the platform to recognize common misspelling or alternative spellings for keywords (eg, for the keyword *Behavior*, the platform should also accept *Behaviour*, *Behaviors*, *Behaviours*, and *Behavour*). Second, we edited words to eliminate misspellings or replace words that required high literacy levels or specialized knowledge (eg, glutes vs rear). Third, we used a vendor-owned link shortener to save SMS text message characters, as using a third-party link shortener could lead to phone carriers identifying messages as spam and subsequently blocking them. Fourth, we added code to embed the participant's first name in SMS text messages to personalize them. Fifth, we adjusted the time of delivery of each daily automatic SMS text message to account for participants' time zone. Sixth, we requested that the vendor allow keyword libraries to loop back to the first SMS text message after reaching the last one on the list.

Table 2. Themes, subthemes, and descriptions of topics elicited during the sketching and prototyping stage, gathered via SMS text message responses from the team and correspondence with the SMS text messaging vendor.

Themes and subthemes	Description
Testing actions	
Testing keyword responses	Ensuring the platform responded with an automatic SMS text message instantly upon sending a specific keyword
Testing live chat	Ensuring the platform received SMS text messages other than keywords, intended for the coach, such as "thank you!"
Testing alternative spellings of keywords	Ensuring alternative spellings and misspellings of keywords are recognized by the platform as such
Testing links and PDF downloads	Ensuring links to websites directed to the right place and downloaded PDF files
Testing SMS text message reminders	Ensuring reminders for medications or physician appointments were sent at the specified date and time
Testing other logistics	Ensuring no cross-project contamination and other features (eg, nonbusiness hours response and *START* keyword to enroll)
Concerns	
Messages need editing	Alerting the presence of misspellings in the SMS text message sent by the platform or suggesting editing the wording
Need to use a different link shortener	The link shortener the team had used would be identified as spam by the cell phone carrier and blocked
Need to embed first names in messages	The team wanted a function that automatically embedded the first name at the beginning of some SMS text messages
Need to tailor timing to time zone	The team wondered how messages could be sent at specific times depending on participants' time zone
Need keyword libraries to loop	Keywords stopped sending after they reached the bottom of the library
Need to edit *out of business hours* timing	The response on sending a message out of business hours was not set correctly
Preference to embed links within words	The team wondered if links could be embedded within words that would open upon clicking on them

Findings From Usability Testing (Stage 6)

Of the 5 participating caregivers in the usability testing, 4 (80%) were women. The mean age was 44.6 (SD 6.8; range 33-50) years. All participants were insured, and their mean level of education was 15.6 (SD 2.2; range 12-18) years. All 5 participants identified as Latinx, 40% (2/5) as Native American, 20% (1/5) as White, and 40% (2/5) as >1 race. All participants were born outside of the United States, including Mexico (1/5, 20%), Central America (2/5, 40%), and South America (2/5, 40%). All but one participant completed the intervention and assessments in Spanish, and their self-perceived level of spoken English was medium (2/5, 40%), high (1/5, 20%), and very high (2/5, 40%). Participants were daughters (3/5, 60%), a son (1/5, 20%), and a granddaughter (1/5, 20%) of an individual with dementia. Their average care recipient's age was 77.0 (SD 5.1; range 72-83) years.

In general, participants completed the surveys and texting tasks without any major issues (eg, reading specific messages, using keywords, sending SMS text messages, opening links to websites and videos, and downloading PDF files). Observations of participants' reactions during the usability testing and comments at the end of the testing revealed some minor concerns and generally positive feedback (Table 3). We addressed the concerns in various ways. First, we replaced expressions that were hard to understand (eg, 24/7 for Spanish speakers with *at any time*). Second, we added context to several SMS text messages to improve understanding. For example, we explained that a *caregiver forum* is a web platform to share experiences with other caregivers, that the content of a PDF file of a Latin American healthy recipe book alternated pages in English and Spanish, the function of specific keywords, the keyword options using simple graphics, that keywords can be sent more than once for additional messages, and that websites and other resources had a Spanish-language option. Third, we tailored the response to the keyword *STOP* (discontinuing the intervention). We also tailored the notification *CuidaTEXT* automatically sends out when a participant texts outside of business hours by including both languages within the same message because the platform did not allow separate messages in English and Spanish.

Participants shared mostly positive feedback at the end of the interview, including the following. First, satisfaction with the intervention in terms of general content, logistics, and simplicity was high. Comments included the following: "I think the program is great," "I love the information and the testimonials," "The messages made me feel like I'm not alone and put things into perspective," and "The messages are simple, and the gratitude-theme messages helped." Second, participants expressed their gratitude to the *CuidaTEXT* team for developing the intervention. Comments included the following: "Thank you for creating this type of program!" Third, they expressed their need and that of the community to use this intervention. Comments included the following: "I hope we can use it soon because we need it" and "I think it's going to be very helpful for caregivers emotionally and personally." The mean System Usability Scale score was 97 and ranged from 90 to 100, which is above the standard cutoff of 68. These scores indicate that the intervention's usability holds promise.

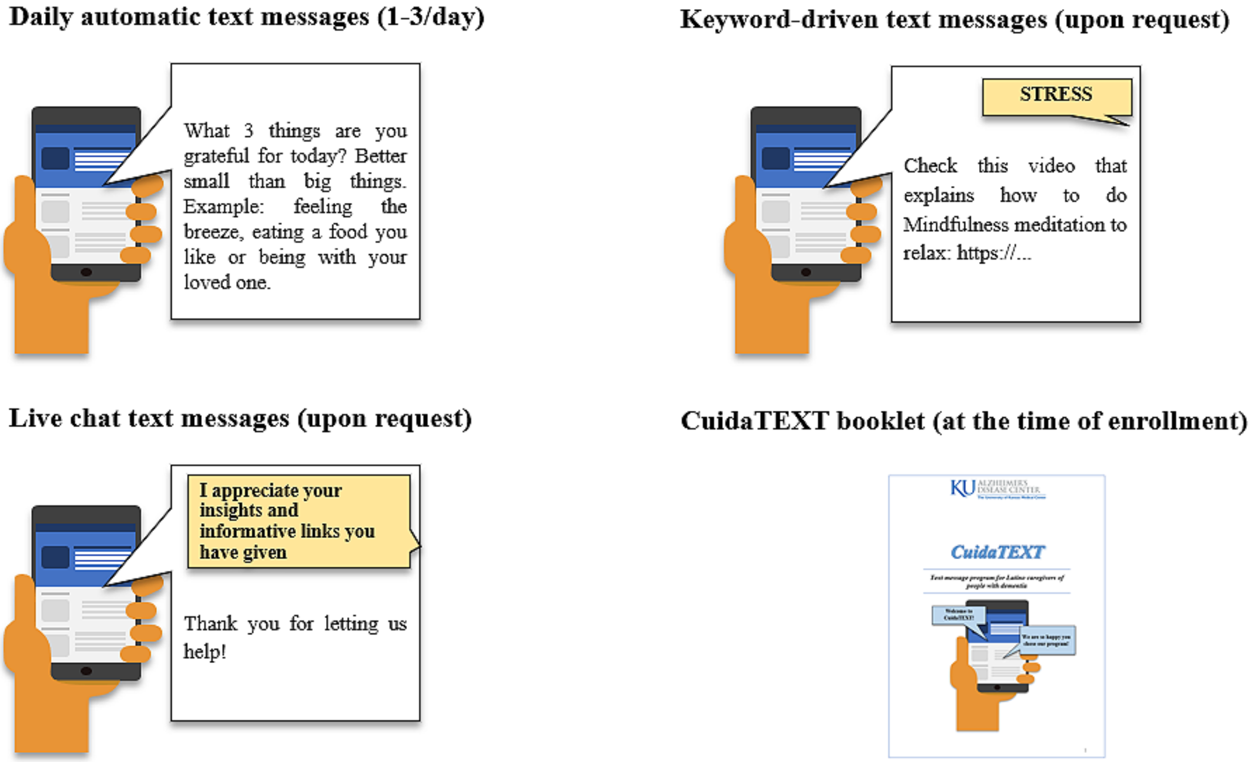
Table 3. Themes, subthemes, and descriptions of topics elicited during the pilot test with 5 Latinx caregiver participants via observation or comments.

Themes and subthemes	Description
Participants' concerns	
Expressions are hard to understand	Expressions such as 24/7 or the + sign for *more* were hard to understand, especially for Spanish-speaking Latinx individuals
CuidaTXT is hard to read in Spanish	Spanish-speaking participants had issues pronouncing the original name *CuidaTXT* and suggested *CuidaTEXT*
Context is needed for understanding	Some SMS text messages required additional context or an explanation to be understood, for example, for the word *forum*
Branching did not work	In one instance, responding *YES* or *NO* to a specific question was not followed by a preconfigured response
Need to edit language of functions	The response on discontinuing the program or sending a message out of business hours was only in English
Need for caregiver lifestyle messages	A participant suggested adding nutrition as a healthy lifestyle action for caregivers
Other comments from participants	
Satisfaction with the intervention	Satisfaction with the intervention in general, content, logistics, and simplicity
Gratitude for the intervention	Expressions of gratitude for developing the intervention
Highlighting need for this intervention	Highlighting the need for this intervention among Latinx individuals and themselves

Final Product

Figure 1 summarizes the final *CuidaTEXT* product, including an example of the 3 types of SMS text messaging interaction modalities (daily automatic, keyword-driven, and live chat messages) and the reference booklet. The final version of *CuidaTEXT* includes 244 English- and 244 Spanish-language messages within the daily automatic SMS text message library. These messages will be automatically sent to all participants, starting with approximately 3 messages per day for the first 2 weeks, 2 per day for the following 2 weeks, and 1 per day for the remainder of the intervention. This daily automatic SMS text message library includes logistics messages that greet the participant on starting and completing the intervention, explain the intervention functions (eg, reminding participants of the keywords they can use for help with specific topics), and reinforce participants for being in the intervention after 2 weeks initially and monthly. The remainder of the daily automatic library includes the messages that the research team and advisory board considered the core from each domain. These domains include messages for (1) dementia education, (2) caregiver self-care messages, (3) support to and from others, (4) education about the dying and grief processes, (5) generic problem-solving strategies for behavioral symptoms, (6) specific strategies to help with the daily care of individuals with dementia, and (7) specific strategies to help address or cope with the behavioral symptoms of individuals with dementia.

Figure 1. Final *CuidaTEXT* product: SMS text messaging interaction modalities and booklet.



Daily automatic text messages (1-3/day)

What 3 things are you grateful for today? Better small than big things. Example: feeling the breeze, eating a food you like or being with your loved one.

Keyword-driven text messages (upon request)

STRESS

Check this video that explains how to do Mindfulness meditation to relax: https://...

Live chat text messages (upon request)

I appreciate your insights and informative links you have given

Thank you for letting us help!

CuidaTEXT booklet (at the time of enrollment)

CuidaTEXT also contains messages for 2 types of keyword-driven messages, the content keywords and menu keywords. Content keywords automatically send tips, resources, or other types of content in response to SMS text messages that include a specific keyword (eg, *STRESS* and *RESOURCES*). These keywords reflect the same domains as the daily automatic SMS text message library, except that their content is not considered core but rather an in-depth expansion for those who need further support with those domains. Menu keywords simply remind the participant which content keywords are in that category. For example, texting the menu keyword *CAREGIVER* will drive an automatic response reminding participants that content keywords within that domain include *STRESS*, *WELLBEING*, and *LIFESYLE*. Table 4 shows the function and an example of each content keyword, the menu keyword they belong to, and the number of messages in each content keyword library.

Any SMS text message other than keywords sent by participants will be received as a live chat by a bilingual and culturally proficient coach trained in dementia care. The coach will be available during business hours and will assist participants in whatever their need is (eg, additional information about a caregiver grant and programming 3-way calls with a clinic). The coach will have a bachelor's degree or higher in a behavioral health-related area, will be trained in dementia care, and will be given a list of general contacts to find local resources (eg, Alzheimer's Association hotline and Eldercare Locator). The final version of the *CuidaTEXT* reference booklet includes 19 pages with nine chapters: (1) What Is Dementia, (2) Signs and Symptoms of Dementia, (3) Why Focus on Latino Caregivers, (4) *CuidaTEXT* (Automatic Messages), (5) Assistant, (6) Notifications, (7) Keywords, (8) Materials, and (9) Contact Information.

Table 4. Keywords and their function and size of each keyword library in number of messages (n).

Content keyword (English and Spanish)	Menu keyword (English and Spanish)	Function of content keyword	Messages, n
EDUCATION and EDUCACION	None	Basic dementia information: types, stages, and impact	54
STRESS and CALMA	CAREGIVER and CUIDADOR	Strategies to cope with stress, such as relaxation	33
WELLBEING and BIENESTAR	CAREGIVER and CUIDADOR	Strategies and tips to improve well-being, such as gratitude and cognitive restructuring	30
LIFESTYLE and SALUDABLE	CAREGIVER and CUIDADOR	Tips to maintain a healthy lifestyle, such as exercising	21
FAMILY and FAMILIA	SUPPORT and APOYO	Tips to improve family communication	19
DOCTOR and MEDICO	SUPPORT and APOYO	Tips to improve communication with health providers	15
PATIENT and PACIENTE	SUPPORT and APOYO	Tips to improve communication with the individual with dementia	37
CHILDREN and NINOS	SUPPORT and APOYO	Tips to communicate with children about dementia	17
LISTENING and ESCUCHA	SUPPORT and APOYO	Strategies to improve listening skills	33
RESOURCES and RECURSOS	SUPPORT and APOYO	Contact information of resources such as support groups, legal and financial assistance, or food delivery	26
SOLVE and SOLUCION	None	General strategies to solve challenging behaviors	19
GRIEF and DUELO	None	Education on end-of-life care and tips for grieving	30
ACTIVITITES and ACTIVIDADES	CARE and CUIDADO	Tips to think of fun activities and adjust them to the abilities of individual with dementia	52
EATING and COMER	CARE and CUIDADO	Tips to make eating easier and healthier for the individual with dementia	36
DRESSING and VESTIR	CARE and CUIDADO	Tips to help the individual with dementia get dressed and groomed	18
BATHING and DUCHA	CARE and CUIDADO	Tips to help the individual with dementia take a bath or shower	24
TOILET and BANO	CARE and CUIDADO	Tips to manage the incontinence or constipation of the individual with dementia	24
MEDICATIONS and MEDICAMENTO	CARE and CUIDADO	Tips to improve medication adherence	27
HOME and CASA	CARE and CUIDADO	Tips to keep the home safe	50
DRIVE and CONDUCIR	CARE and CUIDADO	Tips to detect when it is no longer safe for the individual with dementia to drive and how to manage it	22
ANGER and ENFADO	BEHAVIOR and CONDUCTA	Tips to cope with manage the aggressive behavior of the individual with dementia	31
NERVOUS and NERVIOS	BEHAVIOR and CONDUCTA	Tips to cope with manage the anxious behavior of the individuals with dementia	33
DEPRESSION and TRISTE	BEHAVIOR and CONDUCTA	Tips to cope with manage the depressed mood of the individual with dementia	19
DELUSIONS and DELIRIOS	BEHAVIOR and CONDUCTA	Tips to cope with manage the psychotic symptoms of the individual with dementia	22
REPEAT and REPETIR	BEHAVIOR and CONDUCTA	Tips to cope with manage the repetitive behaviors of the individual with dementia	20
SLEEP and DORMIR	BEHAVIOR and CONDUCTA	Tips to improve the sleep quality of the individual with dementia	18
WANDER and DEAMBULAR	BEHAVIOR and CONDUCTA	Tips to cope with manage the wandering behavior of the individual with dementia	23
INAPPROPRIATE and INAPROPIADO	BEHAVIOR and CONDUCTA	Tips to cope with manage the inappropriate sexual behaviors of the individual with dementia	18
HOARDING and ACUMULAR	BEHAVIOR and CONDUCTA	Tips to cope with manage the hoarding behavior of the individual with dementia	12

Discussion

Principal Findings

This study aimed to describe the development of *CuidaTEXT*, an SMS text messaging intervention, to support Latinx family caregivers of individuals with dementia. We followed user-centered design principles to ensure the intervention's tailoring and usability among Latinx caregivers of individuals with dementia. After a series of user-centered design stages, *CuidaTEXT*'s prototype showed a very high usability score, indicating great promise for the intervention's feasibility and acceptability.

Comparison With Previous Work

To our knowledge, this is the first SMS text messaging intervention for caregiver support of individuals with dementia among Latinx individuals and any other ethnic group. Very few evidence-based and culturally tailored caregiver support interventions have been developed for Latinx individuals. These interventions include fotonovelas, webnovelas, support groups, care management, and psychoeducational programs [28,45,56,57,76]. The modality of all these interventions has been individual or group face-to-face, computer-based, telephone-based, or mail-based. *CuidaTEXT* has the potential to address implementation gaps in these interventions by (1) increased accessibility compared with face-to-face or web-based interventions; (2) improved acceptability compared with phone-based interventions; (3) tailoring the content to the needs of caregivers rather than using rigid curricula; (4) addressing stigma by privately sending SMS text messages to the caregivers' cell phone; and (5) reduced demand on the health care workforce to deliver the intervention, therefore improving fidelity and facilitating future scale-up of the intervention. Although *CuidaTEXT* was developed for Latinx individuals, similar interventions may be beneficial for other ethnic groups, especially those in rural areas, given the nearly universal cell phone ownership of most populations in the United States [31].

The advisory board suggested SMS text message content related to dementia education, social support, care, caregiver needs, community resources, and appointment reminders. These domains are most frequently included in multidomain caregiver support interventions, which have been shown to be more efficacious than single-domain interventions [1,26]. As mentioned in a recent federally commissioned report, of all interventions to improve caregiver well-being, multicomponent interventions use the most targeted components, and they possibly address at least one critical need across a wide range of individual caregiver needs, thus improving outcomes for caregiver and individuals with dementia [77].

The advisory board encouraged the inclusion of >1 family member per individual with dementia. This idea is in line with the fact that caregiving tasks and decision-making among Latinx individuals are more likely to be shared by multiple relatives of the individuals with dementia [78,79]. In fact, interventions rarely include other family members, which is likely a reflection of centering interventions on non-Latinx White caregivers [77,80]. According to our advisory board, the potential benefits of including more >1 family member may include improving caregiving quality and reducing caregiver burden.

Limitations

This study has several limitations. First, most participants in the usability testing stage identified as the adult children of individuals with dementia, were women, were relatively highly educated, were medically insured, and had at least a medium level of English proficiency. This sample may have placed a higher focus of the refinement of the intervention on these groups than on men, spousal caregivers, and those with lower educational attainment, who lack of medical insurance, with limited English proficiency, or who may have uniquely different needs. However, most caregivers are women, and individuals from many of these other groups were represented in other stages of the development of *CuidaTEXT* (eg, advisory board). Second, the eligibility to participate in the caregiver advisory board sessions and the usability testing was based on self-report of the care recipient's dementia status. In addition, we excluded individuals who could not read and send SMS text messages. Although the size of this group is minimal [31], future efforts could include this group by developing training to those without texting experience. Third, *CuidaTEXT* does not consider caregivers' baseline characteristics to tailor the automated content of SMS text messages and does not tailor the timing at which SMS text messages are sent, as suggested by some advisory board participants. We consider that including keyword-driven messages addresses many of the same concerns and reduces the reliance on a baseline assessment. Any need beyond those addressed by the keyword-driven messages can also be addressed via live chat with a coach. Fourth, this study assessed the usability of the *CuidaTEXT* prototype. Although this prototype included the most relevant aspects of *CuidaTEXT*, future studies need to assess the usability of the entire intervention.

Implications and Future Directions

This study has implications for public health, clinical practice, and research. Regarding the public health implications, *CuidaTEXT* or similar interventions have high potential for implementation, given their ubiquitous accessibility and reliance on technology rather than on human labor. Experts in dementia caregiver interventions highlight the importance of designing interventions with implementation in mind from the beginning of the intervention for its future success [81]. The user-centered design used to develop this intervention will increase the chances of this intervention being usable, acceptable, feasible, and effective in the future. Regarding clinical practice, usability testing participants described the prototype as something that was needed by them and the Latinx community. If *CuidaTEXT* proves to be effective in future studies, this intervention could be easily implemented in clinics and community organizations, by having the caregivers send an SMS text message to enroll or by having staff enter their phone numbers and names on a website. The SMS text messaging modality may be combined with other modalities to enhance its effectiveness. For example, coaches or social workers could, in addition to interacting via live chat SMS text messages, conduct ad hoc visits or calls with the caregiver. Other findings from this study might also be useful to clinicians, including the need to consider shared caregiver roles within Latinx families and other preferences. The findings reported in this manuscript may also inform future research. Future SMS text messaging studies (whether they are dementia-related or not) might decide to address the content or logistics of their interventions based on the feedback we received from the advisory board sessions or usability testing feedback. Caregiver studies might want to test the efficacy of the same caregiver support intervention to only the primary caregiver versus multiple caregivers within the same family. Future studies will test the feasibility and acceptability of *CuidaTEXT* among a diverse sample of Latinx caregivers, including variations in regional, linguistic, age, socioeconomic status, relationship to the individual with dementia, hearing functioning, and other important characteristics. This diverse representation will allow further intervention refinement, informed by qualitative analysis of SMS text messaging interactions and open-ended questions about their experiences using *CuidaTEXT*. If the future feasibility study is successful, we will conduct a fully powered randomized controlled trial to assess its efficacy.

Conclusions

This study describes the development of *CuidaTEXT*, the first tailored SMS text messaging intervention specifically designed to support family caregivers of individuals with dementia in the Latinx community. The prototype of *CuidaTEXT* has shown very high usability, addresses Latinx caregiver needs, and has the potential for widespread implementation. The findings from several stages of the user-centered design provide useful information to guide the development and refinement of caregiver support interventions for Latinx individuals and other groups. This information contributes to efforts to address dementia disparities among Latinx individuals and gaps in the implementation of caregiver support interventions for this sizable population. We will soon test the feasibility and acceptability of this promising intervention (*CuidaTEXT*) in a 1-arm trial among Latinx family caregivers of 20 individuals with dementia (ClinicalTrials.gov NCT04316104).

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Sample usability testing interview.
[DOCX File , 17 KB - aging_v5i2e35625_app1.docx]

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Original Paper

Improving a Mobile Telepresence Robot for People With Alzheimer Disease and Related Dementias: Semistructured Interviews With Stakeholders

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Abstract

Background: By 2050, nearly 13 million Americans will have Alzheimer disease and related dementias (ADRD), with most of those with ADRD or mild cognitive impairment (MCI) receiving home care. Mobile telepresence robots may allow persons with MCI or ADRD to remain living independently at home and ease the burden of caregiving. The goal of this study was to identify how an existing mobile telepresence robot can be enhanced to support at-home care of people with MCI or ADRD through key stakeholder input.

Objective: The specific aims were to assess what applications should be integrated into the robot to further support the independence of individuals with MCI or ADRD and understand stakeholders' overall opinions about the robot.

Methods: We conducted in-person interviews with 21 stakeholders, including 6 people aged >50 years with MCI or ADRD living in the community, 9 family caregivers of people with MCI or ADRD, and 6 clinicians who work with the ADRD population. Interview questions about the robot focused on technology use, design and functionality, future applications to incorporate, and overall opinions. We conducted a thematic analysis of the data obtained and assessed the patterns within and across stakeholder groups using a matrix analysis technique.

Results: Overall, most stakeholders across groups felt positively about the robot's ability to support individuals with MCI or ADRD and decrease caregiver burden. Most ADRD stakeholders felt that the greatest benefits would be receiving help in emergency cases and having fewer in-person visits to the doctor's office. Caregivers and clinicians also noted that remote video communication with their family members using the robot was valuable. Adding voice commands and 1-touch lifesaving or help buttons to the robot were the top suggestions offered by the stakeholders. The 4 types of applications that were suggested included health-related alerts; reminders; smart-home–related applications; and social, entertainment, or well-being applications. Stakeholders across groups liked the robot's mobility, size, interactive connection, and communication abilities. However, stakeholders raised concerns about their physical stability and size for individuals living in smaller, cluttered spaces; screen quality for those with visual impairments; and privacy or data security.

Conclusions: Although stakeholders generally expressed positive opinions about the robot, additional adaptations were suggested to strengthen functionality. Adding applications and making improvements to the design may help mitigate concerns and better support individuals with ADRD to live independently in the community. As the number of individuals living with ADRD in the United States increases, mobile telepresence robots are a promising way to support them and their caregivers. Engaging all 3 stakeholder groups in the development of these robots is a critical first step in ensuring that the technology matches their needs. Integrating the feedback obtained from our stakeholders and evaluating their effectiveness will be important next steps in adapting telepresence robots.

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KEYWORDS

mild cognitive impairment; socially assistive robot; robot technology; caregiver support; gerontology; aging in place; qualitative research; mobile phone

Introduction

Background

More than 6 million Americans aged ≥65 years are currently live with Alzheimer disease and related dementias (ADRD), and it is projected that this number will increase to nearly 13 million Americans aged ≥65 by 2050 [1]. Approximately 80% of people with ADRD and most people with mild cognitive impairment (MCI) receive care in their homes [2]. In the United States, 83% of care provided to older adults is from family members, friends, or other unpaid caregivers; 48% of these caregivers provide help to older adults with ADRD [1]. Caregivers of people with ADRD can often be burdened emotionally and financially; they experience emotional, financial, and physical challenges due to care responsibilities at twice the rate of caregivers of older adults without dementia [1]. The primary reason family members or friends act as caregivers for people with MCI or ADRD is to allow them to remain living in the community rather than in a long-term care facility, but this may become challenging, especially for caregivers supporting people with ADRD who live alone. ADRD caregivers report worsening of their own health due to care responsibilities and are required to take a leave of absence from work or quit work [3].

Various types of robots can help people with MCI or ADRD. Mobile telepresence robots, which are the focus of this study, can be used to mediate communication and social exchange between family members, friends, and others who may not be colocated. Such contact can alleviate loneliness, support medication compliance and other important daily activities, and alert caregivers and clinicians in a timely way to address changing patient needs. Studies have established the feasibility of mobile telepresence robots for supporting social interactions between caregivers and people with MCI or ADRD [4]. If telepresence is complemented by autonomous robotics, the potential range of benefits expands even further through innovative approaches to care that can allow people with MCI or ADRD to remain living independently in the community, which may help to alleviate loneliness and enhance the quality of life of people with ADRD, as well as ease the burden of caregiving [5-11].

Although several types of robots have been developed to assist people with MCI or ADRD, and the feasibility of telepresence for supporting social interactions between caregivers and people with dementia has been established [4], research on dementia-specific adaptations and acceptance of these robots that incorporate perspectives across 3 key end-user stakeholder groups (ie, individuals with MCI or ADRD, caregivers, and clinicians) has been limited in scope [4,5,11-14]. For example, there is limited research on how autonomous robotics features can assist a mobile telepresence robot in supporting at-home care of people with MCI or mild to moderate ADRD. Robots have often been developed in an ad hoc manner by technology companies with limited understanding of the needs, preferences, and feedback from key stakeholders [15-17]. The ways in which robots can assist people with MCI or ADRD, their caregivers, and clinicians need to be explored further.

Objectives

In this study, we engaged these 3 key stakeholder groups in the design of dementia-specific adaptations to an existing, commercially available mobile telepresence robot that is already being used in several other settings, such as in schools for homebound students and for home health care by remote clinicians. The overall purpose of this qualitative study was to obtain stakeholder feedback and identify how an existing, commercially available mobile telepresence robot can be enhanced to support at-home care of people with MCI or mild to moderate ADRD, with the ultimate goal of developing an autonomous mobile telepresence robot. The specific aims of the study were to (1) assess what applications should be integrated into the robot to support the independence of individuals with MCI or ADRD and (2) understand stakeholders' overall opinions about the robot.

Methods

Overview

The study consisted of qualitative interviews with 3 key stakeholder groups (people with MCI or ADRD, caregivers, and clinicians) to obtain feedback on how to adapt an available mobile telepresence robot and further understand stakeholders' opinions about the potential utility of the robot.

Ethics Approval

The study protocol was approved by the Institutional Review Board at the Veterans Affairs (VA) Bedford Healthcare System (approval number 110818). Participation in the study was voluntary, and informed consent was obtained from each participant.

Study Population

Study inclusion criteria consisted of the following for each of the three stakeholder groups, respectively: (1) male or female Veteran aged ≥50 years with MCI or early ADRD living in the community (ie, not a nursing home or assisted living facility): people with MCI or ADRD were categorized as having MCI versus early ADRD based on the most recent clinic visit note at the time of recruitment and had to be alone at home for at least 4 hours, and there had to be no indication of incompetence in the Veteran's medical record; (2) male or female family caregivers aged ≥18 years who had a family member with an established diagnosis of memory loss, MCI, or any cause of dementia: the caregiver needed to have a family member with MCI or early ADRD who frequently spent at least 4-hour stretches alone at home apart from any caregiver in the last 12 months; and (3) male or female clinician with experience in managing patients with MCI or ADRD: clinician participants must have provided care to patients with cognitive impairment and/or supported families of such patients for at least one year.

Recruitment

Our goal was to recruit at least six participants from each of the 3 key stakeholder groups: people with MCI or ADRD, caregivers, and clinicians. To recruit people with dementia, we identified patients with MCI or early ADRD from the current VA Bedford outpatient primary care and dementia clinics using electronic medical records. Once identified, the VA Bedford study coordinator (JM) reviewed the electronic medical records of the patients to determine whether they met the inclusion criteria. Those who met the inclusion criteria were mailed an invitation letter for participation in the study; the letter included a phone number to call should they wish to opt out of the study. The study coordinator made a recruitment phone call to patients who did not call back to opt out.

Family caregivers were recruited through family relationships with people with dementia who were recruited for this study or through inputs from VA clinical providers. Caregivers also received a letter of invitation, and the study coordinator followed up with telephone calls or email.

VA Bedford providers with expertise and experience in managing patients with MCI or ADRD were recruited by the VA study principal investigator (LM) and/or study coordinator via email. Using an opt-in approach, the recruitment email instructed the invited clinician to contact the study coordinator if they were willing to participate. Up to 3 emails were sent to each clinician.

Interview Guide

The interview guide contained semistructured questions to elicit open responses from participants, as well as structured questions that asked participants to rate their responses on a Likert scale as well as to categorize options (eg, from most useful to least useful) and then provide a rationale for their response. Questions related to perceived usefulness and perceived ease of use were used to assist in understanding stakeholders' preferences regarding technology and identify adaptations that can be made to the robot (ie, the mobile robot, as both concepts may affect stakeholders' attitude toward using the mobile robot, which can then influence their behavioral intention to use the mobile robot and thereafter, affect actual use). We conducted a literature review to understand the types of questions and qualitative themes found in previous research studies relating to mobile telepresence robots as well as other types of robots that have been developed to assist people with ADRD [18-23]. On the basis of this literature review, we developed interview questions that focused on domains that we established a priori to help guide our understanding of how stakeholders perceive the mobile robot's usefulness and ease of use: (1) technology use, (2) design and functionality of the robot, (3) future applications to be incorporated into the robot, and (4) overall opinions about the robot. We established these as key domains because they would allow us to elicit information from stakeholders to accomplish this study's overall purpose and specific aims. We asked participants similar questions across all stakeholder groups. Table 1 provides relevant questions for these domains. Of note, for the question "Please let me know how you would rank these applications that could be used or built into the robot (from most useful to least useful)," the 6 categories of applications were chosen by subject-matter expert team members with extensive clinical knowledge (LM) and technical knowledge (AR)—based on their professional experience in working with people with MCI or ADRD, conducting research on robots, and/or developing robots. The subject-matter experts met to brainstorm and discuss what types of applications would enhance the mobile telepresence robot for this population and chose the 6 applications that would be the most feasible to add to the robot.

Table 1. Domains and relevant interview questions.

Domain	Interview question
Technology use	• How often do you use the internet? • How often do you use the internet for health-related reasons or to get answers to health-related questions? • What kinds of technology do you regularly use at home? • Thinking about the technology you just mentioned you regularly use: choose one of the following that best describes your comfort level. a. I am very comfortable using this technology. b. I am somewhat comfortable using this technology. c. I am somewhat uncomfortable using this technology. d. I am very uncomfortable using this technology. e. Not sure. • Do you use any applications for health purposes?
Design and functionality of the robot	• What do you like about the design and functionality of the robot? • What do you not like about the design and functionality of the robot? • Do you have any suggestions for changes to be made to the design and functionality of the robot?
Future applications to be incorporated into the robot	• What kinds of new applications would be useful to build into the robot? • Please let me know how you would rank these applications that could be used/built into the robot (from most useful to least useful). a. Medication reminders or dispensing b. Communication with family/caregivers c. Reminders about the day’s schedule d. Communication with medical staff/providers e. Emergency help access f. Social stimulation activities such as games or reading the news
Overall opinions about the robot	• On the basis of the video/materials we showed you and what you now know about the current version of the robot, what is your overall opinion about the robot (1=useless to 10=excellent)? Why did you give that rating? • What is the greatest value you think it would provide? • Do you foresee any challenges in using the robot?

Data Collection

From July to August 2019, a total of 3 health service researchers (MS, JM, and JS) who are experienced in qualitative methods, conducted the semistructured interviews. Each stakeholder participated in 1 in-person individual or group interview, which lasted approximately 60 minutes. Interviews were conducted either at the VA Bedford main facility or at the participant’s home. People with MCI or ADRD and family caregiver participants received a US $50 gift card for their participation in the interview and an additional US $30 gift card to compensate for travel time if they participated in person at VA Bedford. To thank them for their time and insight, the VA clinician participants received a modest meal, which did not exceed a value of US $20 per person. Before the interviews, all participants provided informed consent and agreed to be audio-recorded for transcription purposes.

After obtaining consent, the interviews began by asking participants to complete a stakeholder group–specific demographics questionnaire. As part of the interview process, we also provided participants with information about the existing, commercially available mobile telepresence robot, which included a photo (Figure 1) and a brief explanation.

This robot is a wheeled, upright (approximately 122 cm tall), self-propelled device that weighs 8.6 kilograms with a 14.5-cm screen; it moves about under remote control and provides 2-way video communication between a remote user who pilots the robot through an app accessed via a computer, tablet, or smartphone and a person who is physically present with the robot. In addition, we presented a video (television news segment) to visually display the robot’s current capabilities. The video featured a student who was immunocompromised and could not attend school in person. However, the student was able to attend school and remain in the classroom virtually through the mobile telepresence robot. Through this video, the participants were able to see how the robot displayed the student’s face on the screen and enabled her to talk to and socialize with her classmates and teacher in the classroom and how she could control the robot, allowing it to move through the classroom and down the hallways. We then asked the participants questions from the interview guide.

Figure 1. Mobile telepresence robot used in the study.

Data Analysis

Interview transcripts were the primary data source for the directed content analysis. Coding and data analysis focused on four a priori domains: (1) technology use, (2) design and functionality of the robot, (3) future applications to be incorporated into the robot, and (4) overall opinions about the robot. Using a code book that contained domains with definitions, the core analytic team (MS and JS) jointly coded 1 interview transcript and examined the transcript for evidence of the established domains. The 2 researchers discussed the coding process, resolved any discrepancies, and reached a consensus on definitions and coding classification. Thereafter, the transcripts were divided and coded separately by the 2 researchers using NVivo (version 12; QSR International) qualitative software.

Upon completion of coding, we generated coding reports for each domain and stakeholder group. The data in the coding reports were reviewed and then synthesized into a matrix, which allowed us to organize the data to facilitate the final interpretation. Next, we used a matrix analysis technique to assess patterns within and across stakeholder groups [24,25]. Thereafter, for each of the 4 domains, we identified salient themes while noting similarities and variations across stakeholder groups. In addition, we compared patterns in the Likert ratings and responses across stakeholder groups. To ensure wider perspectives, we included study team members (JM, LM, and AR) beyond the core analytic team to review and comment on the study findings.

Results

Participant Characteristics

Overall, a majority of participants (20/21, 95%) were White across all 3 stakeholder groups. The 6 people with MCI or ADRD in our study sample were men (mean age 73 years, range 69-80 years), with 4 (67%) of these participants living with a family caregiver and 2 (33%) were living alone. All 9 caregiver participants in this study were women (mean age 60 years, range 42-80 years). Of the 9 participants, caregivers' relationships with family members with MCI or ADRD included 6 (67%) participants who were the adult child or child-in-law of the family member with MCI or ADRD and 3 (33%) participants who were the spouse or partner. Of the 6 clinician participants, 4 (67%) were women and 2 (33%) were men. All had advanced degrees ranging from master's to doctoral, with an average of 20 years of experience in their respective fields. They estimated that, on average, 89% of their patients were aged ≥60 years, and 76% of their patients had cognitive impairment.

Person With Dementia and Family Caregiver Technology Use

Although most individuals with MCI or ADRD reported that they were able to use their mobile phones for basic functions (eg, phone calls or SMS text messages), overall, they reported lower use of technology and the internet than caregivers, who reported higher use:

> *I don't really use [the internet] that much. I'm not interested and it's confusing.* [Person A with MCI or ADRD]

> *If I walk out the door without my phone, no I go back in the house to get it. It's not one of these, oh yeah I forgot it I'll get it when I get home.* [Family caregiver A]

Most individuals with MCI or ADRD had never used the internet or applications for health-related reasons or to get answers to health-related questions; similarly, caregivers also reported lower use for health-related reasons or questions. However, most caregivers reported using at least one app for health purposes.

Design and Functionality of the Robot

Overall, stakeholders across all 3 groups expressed that they liked the mobility and size of the robot (approximately 122 cm tall), as well as the ability to connect and communicate in an interactive way. However, they expressed concerns related to the size of the robot for individuals living in smaller apartments and trailers, as well as the stability of the robot, questioning whether it could tip over easily. In addition, stakeholders queried whether the screen size and quality (14.5 cm and 320×240-pixel display) would provide enough support for those with visual impairments who would need a screen with higher-quality contrast and that could display larger text or image. Across all stakeholder groups, voice commands and 1-touch lifesaving or help buttons were the 2 top suggestions offered:

> *I would [add voice activation] especially if someone has physical trouble, like if they're [a person with disability]. That would be a big help.* [Person B with MCI or ADRD]

> *I don't know whether my dad would find it as easy to use unless it is voice activated. Now [that] he has a voice control for the television [he] loves it.* [Family caregiver B]

> *[I]f there's a trigger, [a person] just falls, and somebody is on the floor and there's some device that [the robot] has that alerts you whether it be the bracelet or something. [A person] can activate an emergency system and then as opposed to having a false alarm, the person, the communicator or the emergency system would be able to say, oh, Mr. Smith, you're on the floor. It would help with that. And that would actually be extremely important.* [Clinician A]

As presented in Table 2, stakeholders offered several suggestions on what features could be added to the robot and provided input on how those features could help improve the design, functionality, and use of the robot in the context of people with MCI or ADRD. The features listed in Table 2 are presented from most often suggested to least often suggested across all stakeholder groups. Adding a voice command feature to the robot was suggested most often, whereas adding lights to the robot was the least often suggested feature.

Table 2. Feature to add to the robot, number of stakeholders who requested each feature, and stakeholders' feedback.

Feature to add to the robot	Stakeholders who requested each feature (N=21),[a] n (%)	Stakeholders' feedback on how this can help to improve the robot's design and functionality or help stakeholders
Voice command; option to change the voice (eg, male vs female voice)	• Person with MCI[b] or ADRD[c]: 5 (83) • Caregiver: 4 (44) • Clinician: 6 (100)	• Helps with safety (eg, more easily able to call for emergency help as well as call family members and providers) • Helps with feeling comfortable with robot (choice of male voice vs female voice)
Screen adjustment capacity (eg, photograph and touch screen zoom capability)	• Person with MCI or ADRD: 0 (0) • Caregiver: 5 (56) • Clinician: 5 (83)	• Helps in emergency situations, during telehealth appointments • Helps those who have visual impairments or when visual adjustments are needed
Size, collapsible, or foldable options	• Person with MCI or ADRD: 3 (50) • Caregiver: 3 (33) • Clinician: 3 (50)	• Helps those who live in smaller dwellings • Helps with ease of moving the robot, if carrying it from room to room or to another floor of the house
Buttons (eg, lifesaving or help call, or on or off)	• Person with MCI or ADRD: 2 (33) • Caregiver: 2 (22) • Clinician: 4 (67)	• Helps with safety
Volume adjustments	• Person with MCI or ADRD: 0 (0) • Caregiver: 2 (22) • Clinician: 5 (83)	• Helps those with hearing impairments
Alarm, bell, or beeping sound	• Person with MCI or ADRD: 0 (0) • Caregiver: 3 (33) • Clinician: 3 (50)	• Helps to alert when someone is calling/dialing in • Helps to alert a person that robot is near them so the person is not startled
Customizable color, print, or pattern options	• Person with MCI or ADRD: 2 (0) • Caregiver: 3 (33) • Clinician: 1 (17)	• Helps with connection and comfort with the robot (eg, select a color or pattern/print that the patients like)
Attachments (eg, arms, handles, or cupholders)	• Person with MCI or ADRD: 0 (0) • Caregiver: 3 (33) • Clinician: 3 (50)	• Helps patients, particularly with mobility challenges, around the house • Helps caregivers to have more control in the home virtually (eg, use the robot to pick up and look at medication bottles, start the microwave, or pick up clutter) • Helps the robot go upstairs in a lift
Entertainment options (eg, music, television, or movies)	• Person with MCI or ADRD: 0 (0) • Caregiver: 2 (22) • Clinician: 3 (50)	• Helps people feel more engaged and comforted by something familiar and enjoyable to them • Helps to increase participation
Lights	• Person with MCI or ADRD: 0 (0) • Caregiver: 1 (11) • Clinician: 1 (17)	• Helps those who have visual impairments • Helps with nighttime vision for the robot to be able to gather visual information in a dimly lit house • Helps with lights around the robot to see the robot easily if the lights are off or the house is dimly lit

[a] Person with mild cognitive impairment or Alzheimer disease and related dementias: n=6; caregiver: n=9; clinician: n=6.

[b] MCI: mild cognitive impairment.

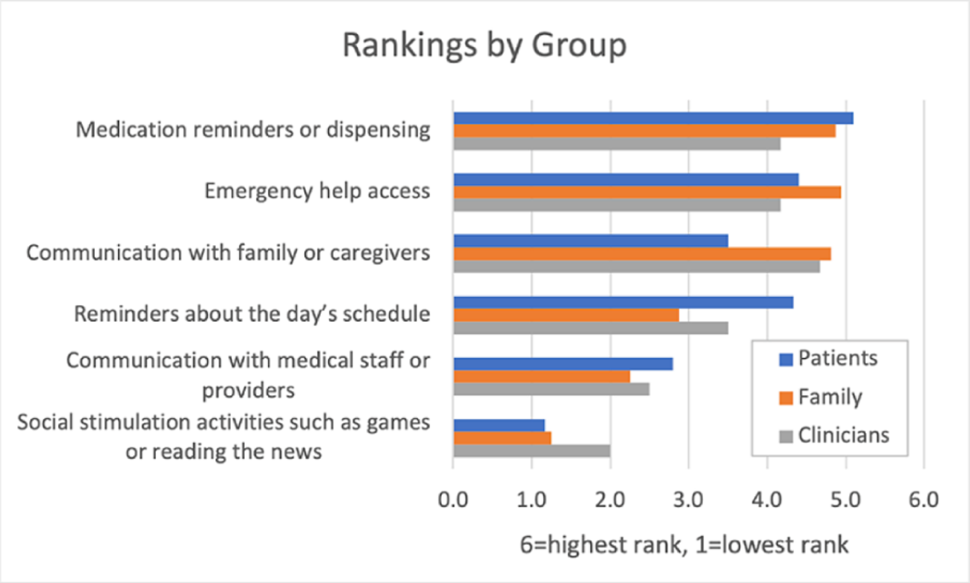
[c] ADRD: Alzheimer disease and related dementias.

Future Applications to Incorporate Into the Robot

Overview

When stakeholders in each of the groups were asked by the study team to rank 6 possible robot applications (ie, medication reminders or dispensing, communication with family or caregivers, reminders about the day's schedule, communication with medical staff or providers, emergency help access, and social stimulation activities such as games or reading the news) from most useful to least useful, overall across stakeholder groups, participants rated *medication reminders or dispensing* and *emergency help access* as the 2 most useful applications. For people with MCI or ADRD, the top 3 applications were *medication reminders or dispensing*, *emergency help access*, and *reminders about the day's schedule*. Similarly, caregivers and clinicians included *emergency help access* and *medication* *reminders or dispensing* in their top 3 rankings. However, although *communication with family/caregivers* ranked the highest and second highest choice among clinicians and caregivers, respectively, among people with MCI or ADRD, this application ranked fourth overall. Across all 3 stakeholder groups, *social stimulation activities such as games or reading news* ranked the lowest. Figure 2 presents the mean scores of the 6 applications ranked across each stakeholder group with 1 being the lowest and 6 being the highest.

Figure 2. Mean score of the 6 applications ranked across stakeholder groups.



In addition to ranking the options of possible applications provided by the study team, stakeholders across the 3 groups offered their own specific suggestions on the types of applications they perceived as useful to include in the mobile robot to enhance the opportunity for individuals with MCI or ADRD to live at home independently. We categorized these suggestions across the 3 stakeholder groups into 4 types of applications: health-related alerts, reminder prompts, smart-home–related applications, and social, entertainment, or well-being applications.

Health-Related Alerts

Suggested applications include health-related alerts such as those that could inform providers of a change in patients' blood sugar or blood pressure levels, as well as those that could be triggered if a person falls. Similar to a bracelet or necklace alert, activation and connection to a previously imputed emergency response system such as family members, ambulance, police, emergency medical technicians, and/or health care providers, could occur.

Reminders

Suggested applications include those offering real-time, step-by-step prompts on how to complete multistep activities such as getting dressed, making a microwave meal, or turning the oven on/off; those about medication, doctors' appointments, other scheduled activities, and wake-up or bedtime prompts, especially for those who have sleep problems; and those that can prompt a person with MCI or ADRD to perform and help with activities of daily living or instrumental activities of daily living (eg, prompt for eating, bathing, or bathroom use).

Smart-Home–Related Applications

Suggested applications include smart-home technology integration, in which the robot can detect motion, connect to a home security alert, and recognize home hazards (eg, smoke and carbon monoxide detection, or tripping hazards). In addition, the robot can work similarly to or in conjunction with a voice-activated smart-home device (eg, the robot turns on or off appliances in the home).

Social, Entertainment, or Well-being Applications

Suggested applications that could enhance the well-being and comfort of a person with MCI or ADRD include community or social connection applications, such as ride share applications that could assist transportation arrangement and allow individuals with MCI or ADRD to go out into the community independently (eg, attending religious groups for social connection); those that stream music, movies, and television shows either directly on the robot's screen or projected onto a wall, which could also be turned on virtually by a caregiver; and games to help with cognitive engagement and exercises to help with balance and mobility. In addition, an app related to identifying family members or friends to assist with recall could enhance social connection and well-being, such as integrating contact numbers of specific family members or friends into the robot, uploading photos and voice recordings of their family members or friends, and inputting specific memories with family members or friends and important dates (eg, birthdays and anniversaries) into the robot.

Overall Opinions About the Robot

Of the 3 stakeholder groups, caregivers reported the highest overall rating for the robot (mean 8.1; rated on a scale of 1 to

10). All caregivers (9/9, 100%) positively perceived the robot and liked that they could virtually check in and communicate with their family members, especially if their family members were to be left alone for an extended period. A caregiver described how her family member may trust the robot more than humans to help around the house:

> *If I can control [the robot] from afar that's helpful. If it can do some things on its own like little reminders and things, that's helpful. It just serves as a bridge and the fact -- like I said for my dad where he doesn't trust humans to come into the house maybe he would let a machine.* [Family caregiver C]

However, of the 9 caregiver stakeholders, 7 (78%) noted that additional features and applications would have to be added to the robot for it to be more useful; thus, the reason for not rating the robot a 10.

Overall, ratings from the clinician and people with MCI or ADRD stakeholder groups (mean 7.4 and 6.4, respectively) were slightly lower than the caregiver group, noting that additional features and applications had to be added to the robot for it to be more useful. Similar to the caregiver group, all clinicians (6/6, 100%) expressed positive perceptions about the robot and its potential to increase a person's independence and ability to stay home alone:

> *What we worry about with people at that stage is that they can continue to do as much as they can, but they need support. And we do know more and more people are living alone. And often the only option is bringing in a home health aide who again might not be the person they want to see there. Or they end up needing to move often. I just think that this will provide them the support that they need, if they welcome it, to be able to keep doing what they're doing as long as possible. It seems like it's enough support. But it's not too much. Especially if it's like a menu of things. If it's like they don't have to accept all of these things at once. You could titrate [support].* [Clinician B]

However, one of the main reasons clinicians rated the robot lower on the scale was that they perceived that the robot in its current state did not offer much beyond what could be done with other virtual connection platforms such as Skype, Facetime, or other modalities used in video telehealth sessions:

> *I think that a lot of the things that it's used for can already be done through Facetime or Skype or what not. I think that there's a little bit extra better quality to this.* [Clinician C]

Although the robot was perceived to be beneficial in terms of living independently if additional features and applications were added, 50% (3/6) of the people with MCI or ADRD rated the robot lower on the scale for two main reasons: (1) they perceived that they did not need the robot as they had family members who cared for them and (2) they did not know if they could use the robot in their homes because of challenges with size and mobility:

> *We don't have [the robot] now. We do fine without [the robot]. I got my wife. I call her my guidance counselor...I wouldn't use it...trying to figure out how to use [the robot would be a challenge].* [Person C with MCI or ADRD]

> *If [my children] lived really far away, I could see where that might be nice to see them once in a while and be able to talk to them instead of just on the phone. It would be good that way, but [my] children don't live far away so me personally it's not exciting to have.* [Person D with MCI or ADRD]

> *[F]rom what you say [the robot] can do I'd be happy with it but it's going to get in the way. It's going to have to use the other bedroom all the time...[The robot is] too tall and too wide.* [Person E with MCI or ADRD]

In addition, 1 person with MCI or ADRD, who noted that he did not really have any family or friends, reported that the robot could provide companionship to someone who lives alone:

> *I think [the robot] would offer companionship because like I said I don't have any family really. I don't have any friends at all so I'm kind of alone all the time. It doesn't really bother me. I get used to it after a while. But yeah, I think for somebody like me, [the robot] would offer companionship.* [Person F with MCI or ADRD]

Greatest Value

All (6/6, 100%) stakeholders with MCI or ADRD reported that the greatest value provided by the robot would be help in case of emergency and/or fewer in-person visits to the doctor's office (ie, ability to conduct tele-visits):

> *[O]n an average I'll be honest with you I avoid the doctor as much as possible. I avoid them like the plague because it's something I don't like—the smell of hospitals. They make me sad and they're a depressing place. That's another reason I don't like going...[I]f I can avoid going to the doctor and I can just sit at home and say [to the doctor] see this, [the robot would help].* [Person F with MCI or ADRD]

> *[I]f there was a button that [people] could just push on the [robot] itself. [The robot] would have programmed in your address and how to get into the house for the emergency responders. And if it could automatically open a door, if the doors are locked.* [Person B with MCI or ADRD]

Similar to people with MCI or ADRD, all the clinician stakeholders (6/6, 100%) agreed that the greatest value of the robot would be its ability to provide help in case of an emergency, as well as help their patients with safety at home and increase a person's independence, particularly if additional design features and applications were incorporated:

> *[T]he security feature. So often we hear someone falls or something very minor escalates, like they leave a potholder on the stove and turn and walk away and the potholder burns and there's a kitchen fire. And it's not even necessarily the gravity of the act. I think that it's the fear of what could happen ends up*

> *curtailing the person's independence...[T]he daughter or son being able to say [using the robot], what's that box doing in the middle of the floor? Move that to the right. [This] could prevent a fall.* [Clinician B]

Clinicians also highlighted that the robot offers an alternative for in-person doctor visits and can provide clinicians with access to the patient during an emergency. Although caregivers noted similar opinions regarding emergency help, some discussed that in-person doctor's appointments helped their family members get out of the house and increased social interactions.

All caregivers (9/9, 100%) reported that remote video communication with their family members with MCI or ADRD was one of the greatest values of the robot; this technology allows caregivers to perform quick check-ins or longer calls with their family members, as well as observe what is happening when caregivers are unable to make an in-person visit:

> *Being able to look at the house to see by chance maybe there's something on the floor that they might trip over that you could say [to the robot] go such and such a place, there's something on the floor, pick it up. Being able to [see that] without actually physically being there. I live close to my parents, but some people [live] hours away. Having something like this would probably help with a lot of people [with ADRD] being able to stay in their own homes.* [Family Caregiver A]

> *Really to be able to see her all the time [is the greatest value]. To see what she's doing because I've gone to the house and the stove is on. I'm like why is the stove on? I don't know. I'm like okay we need to be able to see her all the time.* [Family Caregiver D]

Concerns

Although there were many positive responses to the mobile telepresence robot, all 3 stakeholder groups expressed concerns about using the robot, including technology usability, privacy, and security. In all, 50% (3/6) of people with MCI or ADRD were concerned about the technology needed to operate the robot because they did not own a computer/smartphone and lacked knowledge of how to use this technology:

> *I think if [the robot] was voice commanded so you could speak to it to do things that would be the biggest help. But otherwise, whoever needs it has to make sure they either have a phone that they know how to use, [or] can use it [like] a laptop...I think people who might be in need of that are probably going to be older and not as likely to be tech savvy and be able to use computers and phones.* [Person D with MCI or ADRD]

In all, 44% (4/9) of the caregivers and 67% (4/6) of the clinicians also expressed similar concerns about the ability to use the robot by people with MCI or ADRD (eg, ability to fix the robot if presented with technological challenges, lack of Wi-Fi, or equipment needed to operate the robot):

> *I think my mother would be good with [the robot]. I think my father, it might be challenging for him only because I don't feel that he has the attention span. I think that maybe if this machine was in front of him and he saw what it could do, I think it might spark a little interest.* [Family Caregiver E]

> *I think [there are a lot of] unknowns. We only got to see the interface if somebody was talking on the other end. I think there are a lot of other things that are sort of unclear including how it would work, how it would sync with other devices, that sort of thing. Ease of use.* [Clinician D]

To address these concerns, people with MCI or ADRD and caregivers suggested the development of a step-by-step tutorial (video and written instructions) that could teach users how to operate the robot. In contrast, a clinician perceived that people with MCI or ADRD would not experience technological challenges in operating the robot:

> *You'd be surprised that patients are starting to become more tech savvy. Believe it—even cognitively impaired people. I've got a couple on my video conferencing, they're doing okay, and the family members are also [okay] because everybody [uses] Skype so they're starting to be more at ease with it.* [Clinician A]

Of the 6 people, although 1 (17%) with MCI or ADRD was concerned about privacy or security, the other 5 (83%) were not. However, caregivers and clinicians expressed more concerns about privacy and security. They discussed the tension between caregivers wanting to check in with their family members but feeling as though they may be infringing on their family members' privacy when controlling the robot. Concerns regarding privacy and patient dignity (eg, when a patient is changing or going to the bathroom), especially when there are multiple permissible remote users, were also noted:

> *[F]or the most part, he would appreciate it although there are probably moments where it may feel intrusive...[need to make the robot] so it's not intrusive into any person's private moments...I think that's the only thing I would think about if someone's like, Hi, daughter, didn't realize you were right here.* [Family Caregiver F]

> *I'm trying to picture a sort of dual control of the on/off [which would help with] the privacy concern. I mean the problem is that it helps him with the privacy concern but it doesn't help me with the check on him. Cause he is liable to turn it off and forget that he turned it off and then if I can turn it on anytime I need to or want to—how does that give him the privacy that he is looking for. So there's that tension there.* [Family Caregiver B]

> *[T]here could be privacy issues. All of that needs to be [thought about] to avoid abandonment, meaning the [robot] gets driven into a corner, thrown down the stairs...I could see, especially if someone's losing their cognition. How do we make sure that we embed this in a way that's the person's needs are respected and that it's done on their terms? As much as the family and the clinician's terms. How do we remind*

> *them, for example, if they have a [tele-] appointment with their doctor how do we make sure that we give them plenty of reminders so that a face just doesn't show up in the middle of them watching [TV] in their underwear? And all of the sudden they're embarrassed and they say I never want to do this again. How do we build in enough fail safe features for privacy?* [Clinician B]

To help alleviate concerns, caregiver and clinician stakeholders noted that privacy and security terms would need to be spelled out clearly, such as those related to who would have main control over the robot, if any data are recorded and the security associated with it, and whether someone could easily access the robot and obtain private information.

Discussion

Principal Findings

We conducted this qualitative study to obtain feedback from the 3 groups of key stakeholders (people with MCI or ADRD, family caregivers, and clinicians) on how to adapt an existing, commercially available mobile telepresence robot to specifically support individuals with MCI or early ADRD so that they can continue to live at home independently. Through these interviews, we received consistent feedback across groups, which could enhance the robot's usability. Suggestions that differed by stakeholder group provided us with a complete understanding of the adaptations that need to be made to strengthen the utility of the robot for all stakeholder groups.

People with MCI or ADRD, family caregivers, and clinicians all described multiple possible updates to the design and functionality as well as the applications of the remotely navigable telepresence robot. Family caregivers and clinicians clearly perceived the need for additional support for people with MCI or early stage ADRD to allow them to live alone or be left alone for long periods. Both stakeholder groups felt that the augmented version of the mobile telepresence robot in our study could play an important role. Compared with clinicians and family caregivers who were the most enthusiastic of the 3 stakeholder groups, people with MCI or ADRD reported lower ratings for the robot. Despite these lower ratings from people with MCI or ADRD, many stakeholders across all groups perceived that the robot had the potential to increase a person's independence and ability to stay at home. For example, stakeholders perceived the videoconferencing function (already available in the robot) to be useful in facilitating communication with friends or family members and for video telehealth visits with providers, which helps strengthen relationships by bridging the distance between individuals [26]. However, similar to previous research that highlights the importance of developing robots based on stakeholder feedback [18,19,27], incorporating several adaptations regarding the robot's design, functionality, and applications would be critical to enhance use for their needs, such as additional development of voice command and help button functions as well as applications related to medication reminders or dispensers and emergency response access [20]. These were perceived as critical features or applications to help people with MCI or ADRD maintain independent living at home; stakeholders raised concerns that these may be barriers to adoption if not incorporated. Among the 3 stakeholder groups, medication reminders and emergency help access ranked the highest, with reminders regarding daily schedules, rounding out the top 3 for those with MCI or ADRD. Although all 3 functions were beyond what the robot could do at the time, the fact that 2 of the 3 related specifically to help with memory decline highlights the importance of engaging disease-specific stakeholders in such studies. Similarly, concerns about the ease of use of the technology with strong recommendations from all 3 groups regarding the integration of voice commands also underline the benefits of including people with MCI or ADRD in the development of products or interventions for which they are the primary target as well as family caregivers and clinicians. Our findings echo previous studies that highlight the importance of aligning and customizing technology functions and applications to end-product users [12,18,19,28-31].

Our results underscore the importance of engaging and obtaining end-user input from different groups of stakeholders in technology development—the individual with MCI or ADRD, the caregiver, and the clinician—which provides for the opportunity to tailor according to the needs and interests of all who are involved in the care of people with MCI or ADRD. Although this is an important component of technology development, to the best of our knowledge, only a few previous studies have interviewed all 3 groups [12,18]. In addition, engaging community-dwelling people with MCI or ADRD is a critical and feasible component of technology development; however, studies have usually lacked the involvement of people with MCI or ADRD in technology development [16]. This lack of involvement may lead to the implementation of technology that is not tailored or suitable to the individuals who the technology intends to serve [16]. Family caregivers are also important stakeholders and are quite likely one of the most critical given how this type of technology (mobile telepresence robots) may help alleviate caregiver burden. Caregivers of people with MCI or ADRD are their primary advocates; the primary people with whom they communicate with; and may usually be the primary decision-makers in the household. By involving caregivers as a stakeholder group in our study, we were able to obtain input on what types of features and applications of the mobile telepresence robot can help reduce caregiver burden.

The feedback provided on the adaptations to the mobile telepresence robot and possible applications for the inclusion of all 3 stakeholder groups aligned with concepts such as perceived ease of use and usefulness as well as trust [32]. These concepts are critical to the adaptation of mobile telepresence robots in health care communication settings and can lead to barriers in adoption if not resolved. Previous studies have noted that barriers to the acceptance of mobile telepresence robots included challenges in using technology and concerns about the ability of older adults to operate the robots [18,33,34]. In our study, compared with caregivers, people with MCI or ADRD reported overall lower use of technology and the internet, which may have affected their perceptions about the usefulness and ease of use of mobile telepresence robots. People with MCI or ADRD and caregivers expressed concerns regarding the technology use required by people with MCI or ADRD to operate the robot. One of the most often suggested design features that stakeholders across the 3 groups wanted (particularly people with MCI or ADRD) to have incorporated into the robot was voice command technology. This simple design improvement has the potential to increase the perceived ease of use and usefulness of robots. In addition, stakeholder feedback can assist in understanding preferences that may potentially enhance trust, thereby leading to a higher adoption of technology. Similar to previous research [19], people with MCI or ADRD in our study did not seem to be concerned with privacy and security. However, in contrast to previous research on caregivers who were more likely to perceive no ethical dilemma when balancing this with the safety of people with dementia [35], privacy and security were the main concerns expressed by both caregivers and clinicians. Caregivers and clinicians were unable to offer solutions that they felt would alleviate their concerns but noted that these challenges would need to be resolved for end users, such as themselves, to trust the robot. Given the dearth of studies focusing on privacy and security with robots for people with MCI or ADRD, additional exploration is warranted and should be incorporated into future research [13].

Although applications related to social stimulation activities (eg, *games or reading the news*) ranked lowest across all 3 stakeholder groups, stakeholders offered suggestions in terms of what types of social, entertainment, or well-being applications they would want to see in the robot; for example, ride share applications that could assist transportation arrangements and allow individuals with MCI or ADRD to go out into the community independently and applications that could assist with recall to help identify family members or friends as well as specific memories and important dates (eg, birthdays and anniversaries). These suggested applications to enhance the robot are important because they may enable people with MCI or ADRD to be even more socially engaged and connected to their family and friends—a key component of what a telepresence robot is supposed to be doing. In particular, as highlighted during the COVID-19 pandemic, social interactions and connections are critical. The pandemic heightened feelings of loneliness as the number of older adults who were socially isolated grew and they were unable to participate in social activities, thus significantly affecting their mental health [36]. Before the COVID-19 pandemic, about one-fourth of the older adults living in the community in the United States were thought to be socially isolated, with approximately 40% of these older adults reporting feeling lonely [37]. Compared with well-established risk factors such as smoking, high blood pressure, and obesity [37-39], social isolation and loneliness can increase the risk of depression, poorer cognitive function, and dementia leading to an increased risk of mortality and morbidity [39]. In the United States, deaths caused by Alzheimer disease and dementia have increased by 16% during the COVID-19 pandemic [1]. The pandemic has shown the importance of developing innovative technology that can improve social connections and support for older adults [36,40]. Our study results echo findings from another study of community-dwelling older adults, highlighting that one of the roles of a mobile robot was to provide friendship or companionship or to provide help [27]. In addition, our study also underscores stakeholders' perceptions that one of the greatest values of a mobile telepresence robot is the connection that it can offer to people with MCI or ADRD through remote video communication with family members and friends. Although the robot, as is, provides access and social connections, integrating stakeholders' suggestions on applications into the robot would only further enhance engagement and social connections.

Through this qualitative study, we were able to obtain feedback from key stakeholders and identify the types of features and adaptations they prefer on an existing, commercially available mobile telepresence robot to enhance the support of at-home care for people with MCI or mild to moderate ADRD. As discussed earlier, stakeholders offer several suggestions regarding their desires. Some of these features and adaptations may be more feasible than others. For example, participants noted voice command as a highly desired feature, which is becoming more common in robots (eg, Alexa and Siri). A technology company that focuses on designing and engineering robots may find this feature more feasible to include in a mobile telepresence robot because of the advancements in this technology compared with other desired features such as attachments (eg, arms, handles, or cupholders), which may be challenging because of the robot's center of gravity, or a robot that cleans the house, which is a function that is beyond current capabilities. Moving forward, an important next step for companies that design and engineer robots is to assess the feasibility of the desires from an engineering perspective and balance the challenges in fulfilling the desired features and functions of the stakeholders while also ensuring the robot's usability for the target population.

Limitations

There are a few limitations to our study that should be acknowledged. Similar to the challenges faced by most qualitative studies, participants volunteered to be a part of the study, and interviews elicited those particular perspectives; thus, interviews may have been subject to selection bias. In addition, stakeholders only viewed the robot through a video and did not see the robot in person; this may have limited their ability to visualize and understand the robot's full capacity of what it could offer. Our study participants were all from the Greater Boston area; thus, we only had a sample of participants from 1 geographic area. In addition, because of the small sample size, particularly within each stakeholder group, we were unable to compare similarities and differences in feedback within each stakeholder group, such as whether caregivers of varying education levels made similar or different suggestions on features and applications to incorporate into a mobile telepresence robot. Because this was a qualitative research study, we did not collect large quantitative data sets that would allow comparisons with the general or larger Veteran patient population. These comparisons are interesting areas for future research. However, a major strength of our work is that, to our knowledge, this is one of the few studies to elicit stakeholder feedback about adaptations that can be made to a telepresence robot from all 3 user groups: people with MCI or ADRD, family caregivers, and clinicians. In addition, our findings are generalizable to other assisted technologies for individuals with MCI or ADRD, caregivers, and clinicians.

Conclusions

Recognizing the central role of each of these 3 end-user groups (people with MCI or ADRD, caregivers, and clinicians) is crucial for the development and adoption of technology for people with MCI or ADRD to help them remain living in the community. We learned from these 3 stakeholder groups what a mobile telepresence robot can and cannot do for people with MCI or ADRD; a robot may help to increase social connection and reduce feelings of loneliness, increase medication compliance and adherence to health routines, increase the independence of people with MCI or ADRD, and increase caregiver well-being [41]. Our results provide insights into the ways in which a mobile telepresence robot can be adapted to enhance utility from the perspective of all 3 stakeholder groups, which can ultimately be used to develop autonomous robotics features. Future research should continue to incorporate the perspectives of all 3 stakeholder groups in studies to further investigate what adaptations are needed for different types of robots to ensure optimal use by all end users.

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Authors' Contributions

AR and LM contributed substantially to the conception and design of the study. MHS, JM, and JLS contributed substantially to the collection and analysis of qualitative interview data. All authors contributed to the interpretation of the data and preparation of the manuscript. All the authors have read and approved the final version of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

ADRD: Alzheimer disease and related dementias
MCI: mild cognitive impairment
VA: Veterans Affairs

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Original Paper

Delivering Personalized Recommendations to Support Caregivers of People Living With Dementia: Mixed Methods Study

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Abstract

Background: Estimates suggest that 6.2 million Americans aged ≥65 years are living with Alzheimer dementia in 2021, and by 2060, this number could more than double to 13.8 million. As a result, public health officials anticipate a greater need for caregivers of persons with Alzheimer disease or related dementia and support resources for both people living with dementia and their caregivers. Despite the growing need for dementia caregiver support services, there is a lack of consensus regarding how to tailor these services to best meet the heterogeneous needs of individual caregivers. To fill this gap, *Care to Plan* (CtP), a web-based tool for caregivers of people living with dementia, was developed to provide tailored support recommendations to dementia caregivers.

Objective: The aim of this study is to formally explore the feasibility, acceptability, and utility of CtP for 20 family members of people living with dementia within a health system over a 1-month time period using a mixed methods parallel convergent design.

Methods: A moderately sized health system in the mid-Atlantic region was selected as the site for CtP implementation, where 20 caregivers who were family members of people living with dementia were enrolled. The web-based CtP tool was used by caregivers and facilitated by a health care professional (ie, a *senior care navigator* [SCN]). Caregivers were given a 21-item review checklist to assess barriers and facilitators associated with reviewing CtP with an SCN. Following the 21-item review checklist, semistructured telephone interviews, which included 18 open-ended questions, focused on the facilitators of and barriers to CtP implementation and recommendations for future implementation.

Results: Quantitative results suggested that 85% (17/20) of caregivers indicated that CtP was helpful and 90% (18/20) would recommend CtP to someone in a similar situation. The qualitative analysis identified 4 themes regarding facilitators of and barriers to implementation: caregiver factors, SCN factors, CtP tool system factors, and recommendations and resources factors.

Conclusions: CtP was found to be not only feasible but also a valuable tool for caregivers seeking resources for themselves and their people living with dementia. Long-term evaluation findings aim to generate results on how CtP can be integrated into care plans for caregivers and how SCNs can provide additional support for caregivers of people living with dementia over an extended period.

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KEYWORDS

caregivers; caregiving; Alzheimer; dementia; intervention; COVID-19

Introduction

Background

In 2019, more than 16 million family members and other unpaid caregivers provided care for people living with dementia [1]. Current estimates suggest that 6.2 million Americans aged ≥65 years are living with Alzheimer dementia in 2021, and by 2060, this number could more than double to 13.8 million [1]. Consequently, public health officials anticipate a greater need for caregivers of persons with Alzheimer disease or related dementia (ADRD) and resources to support these caregivers and their care recipients. Caregivers of people living with dementia often experience physical, emotional, physiological, and financial challenges [2-4]. Caregivers who experience excessive burden are at an increased risk of mood disorders, cognitive decline, cardiovascular diseases, and other ailments that decrease their health [3]. Compounding their burden, caregivers may lack quality information about support strategies that can alleviate the potential challenges of dementia care [5].

Among interventions designed to assist caregivers, strategies where caregivers are actively involved with the intervention and that feature tailored and flexible support systems appear most effective [6]. A systematic review by Hodgson and Gitlin [7] identified more than 200 randomized controlled trials to support caregivers of people living with dementia. Among these interventions, the use of innovative technologies to educate and support caregivers is an emerging area of interest [8,9]. In addition, individualized care counseling, as opposed to group interventions, has demonstrated better outcomes in managing caregivers' distress [10]. However, few interventions developed for caregivers of people living with dementia have been implemented in practice [11]. A recent review found that only 6 out of 200 efficacious studies for caregivers of people living with dementia have been translated into practice [6]. Moreover, there is a lack of consensus on how to tailor and deliver these services to caregivers of people living with dementia to meet their diverse needs. For example, dementia care needs often vary because of kin relationship with the care recipient, dementia stage, and perceived stress related to dementia care provision [6].

To fill this gap, *Care to Plan* (CtP), a web-based tool for caregivers of people living with dementia, provides tailored support recommendations along with additional guidance from a care navigator (ie, health professional) who can assist caregivers in completing the web-based tool and discussing the CtP's individualized recommendations [12]. In developing the prototype of the CtP, 21 caregivers of people living with dementia were recruited to test the feasibility and utility of the CtP tool. Following the prototype testing, stakeholders, including professionals, community advocates, and family caregivers of people living with dementia, were recruited to form a community advisory board. This board reviewed the tool's language and improved its user-friendliness [5]. The function, usability, and clarity of the CtP prototype were positively appraised in a multiphase pilot testing process that included 30 dementia caregivers [12].

Objectives

The objective of this study was to formally explore the feasibility, acceptability, and utility of CtP for 20 family members of people with ADRD within a health system over a 1-month period using a mixed methods approach. This approach contributes to the evidence base of CtP by determining the implementation potential of this web-based tool in an actual health care system that offers support and services for caregivers of people living with dementia within their system. The quantitative and qualitative evaluation of CtP will provide insights into subsequent refinement of CtP, a more extensive evaluation of efficacy, and efforts to effectively disseminate and implement CtP within health care systems or similar real-world contexts.

Methods

Site Description

A moderately sized health system in the mid-Atlantic region was selected as the site for the CtP implementation. The health system represents more than 600 physicians and advanced practice providers offering services and programs in prevention, primary care, diagnostics, neurosciences, oncology, orthopedics, aging-related services, rehabilitation, medical education, home care, and hospice. The system's network serves approximately 2 million individuals annually, from primary care clinics to residential long-term care facilities.

The health care system uses a senior care navigator (SCN) program, where 3 SCNs provide phone support for older adults and their family caregivers. All the 3 SCNs are certified dementia practitioners and certified senior advisors. One SCN is a licensed practical nurse who has served as an SCN for more than 20 years. The other 2 SCNs have completed graduate work in gerontology. Moreover, all SCNs have experience in supporting residents in long-term care communities, with a focus on serving those who reside at home. Through the SCN program, SCNs connect with callers to provide a variety of support services, including medication management, transportation, meals, and behavioral health help. The CtP tool was incorporated into the health care system's SCN program to integrate itself into SCN consultation routines with caregivers. The prior professional relationship established between the principal investigator of the CtP and a center director within this health care system increased the feasibility of rapid and efficient CtP implementation at this site. Before the launch of the CtP, all 3 SCNs were selected to test the use of the CtP tool, participate in project meetings, and contribute to the promotion of CtP.

Recruitment

A total of 20 caregivers who were family members of people living with dementia were enrolled. Sources of recruitment included an SCN case management program, a geriatric assessment clinic, a memory care clinic, a memory café program, an evidence-based caregiver intervention program, community webinars or educational events, the health care system's Intranet, approved flyers, advertisements, emails, and social media. Caregivers who were interested and agreed to be contacted about the study were referred to the research team for enrollment.

Ethics Approval

The study reported in this paper was approved by the University of Minnesota Institutional Review Board (approval number: STUDY00005971).

Inclusion and Exclusion Criteria

The following inclusion criteria were applied to potential participants: (1) the care recipient had a provider diagnosis of ADRD; (2) the caregiver was aged >21 years; (3) the participant was English-speaking; (4) the participant self-identified as someone who provides help to people living with dementia because of their cognitive impairments; (5) the participant indicated a willingness to use CtP; and (6) the participant resided in 1 of the 4 regions serviced by the health care system (based on zip code). Those who did not meet these criteria were not eligible. In addition, those who endorsed a history of a serious mental health disorder whose (1) symptoms were exacerbated in the last 6 months and (2) were not receiving steady, ongoing pharmacological or other treatment for these symptoms were excluded from the project.

Design

This study examined the use of CtP, a free web-based care planning tool that generates individualized service recommendations for caregivers of people living with dementia. A convergent parallel mixed methods design (quantitative + qualitative) was implemented to examine the feasibility, acceptability, and utility of CtP over a 1-month period [13]. Baseline and follow-up data were collected via telephone, with the exception of 1 participant who requested a hard copy through mail.

Following enrollment and an initial survey, an SCN contacted the caregiver to guide them through the CtP via telephone. SCNs placed particular emphasis on helping caregivers understand the recommended resources provided. A 21-item multiple-choice assessment (the CtP Review Checklist; Table S1 of Multimedia Appendix 1) was collected at 1 month after enrollment by the UMN research staff. Following the CtP Review Checklist administration, caregivers were asked to complete a semistructured telephone interview about their experience with the CtP tool, which lasted approximately 30 to 45 minutes. The 3 SCNs also participated in semistructured interviews to obtain their perceptions when administering CtP.

Intervention

A team of SCNs from the health care system collaborated with the UMN research team to identify resources and contacts in the 4 geographic regions served by their health care system. The web-based CtP tool is located on a secure platform and can be used directly by caregivers or facilitated by an SCN [14]. In this study, all caregivers used the CtP tool together with an SCN because feedback from the original CtP development study suggested that caregivers preferred this human guidance when using the web-based tool [15]. CtP was also designed to be user-friendly and featured visual cues and videos for navigating the tool (see Multimedia Appendix 1 for figures of CtP). CtP includes a 20-item assessment, administered over the phone with an SCN, specifically designed to determine caregivers' needs and match them with resources that might help. Items on the assessment were based on 6 dimensions of the validated Risk Appraisal Measure linked to caregiver risk and amenable to intervention: depression, burden, self-care and health behaviors, social support, safety, and patient problem behaviors [12]. Risk for caregiver distress and their care recipient's risk for nursing home admission were also assessed based on several contextual characteristics [15]. Following the completion of the brief assessment, CtP generated an individualized support recommendation based on their responses (for details on how individualized responses were matched to support service recommendations, see the studies by Gaugler et al [15,16]). Caregivers received region-specific resources based on their zip codes and tailored recommendations based on assessment responses in seven categories: (1) skills building (ie, educational programs), (2) problem solving (ie, care consultation), (3) changing your thinking (ie, therapy), (4) taking a break (ie, respite), (5) brain health (ie, exercise and meditation), (6) support groups, and (7) high-powered combinations (ie, evidence-based multicomponent programming; see Multimedia Appendix 1 for figures of CtP). More than 30 resources were incorporated into the tool, with an average of 12 per each of the 4 regions. Example resources include the local Area Agencies on Aging, the Alzheimer's Association, and other local agencies or programs. Recommendations were developed based on clinical expert recommendations from 422 clinical professionals and scientific experts from across the United States [15]. Information on the resources provided to caregivers over the telephone by the SCNs was also later mailed by the research staff.

Data Collection

Measures: Context of Care

Demographics and context of care variables were collected at baseline for caregivers of people living with dementia and included gender, age, race, ethnicity, marital status, number of living children, income, employment, relationship to care recipient, and education. Caregiver's residence and Medicaid coverage status were also collected at baseline. To remain consistent with the caregiving literature and other CtP publications, income cutoffs were different between caregivers of people living with dementia and people living with dementia [14,15,17].

Measures: Objective Stressors

Primary caregiver objective stressors (eg, dementia severity among care recipients) were also collected for caregivers of people living with dementia. These stressors included dependence of people living with dementia on their caregiver to complete 6 activities of daily living (ADL) [18] and 6 instrumental ADL [19]. An 8-item memory impairment scale assessed the intensity of memory loss, communication deficits, and recognition of impairment at each time point of people living with dementia [20]. The frequency and level of ADRD-related behavioral problems were measured using the Revised Memory and Behavior Problem Checklist [21].

Measures: Caregiver Outcomes

Caregiver self-efficacy was measured using 8 items examining participants' certainty that they could carry out specific behaviors related to dementia care [22]. Caregiver distress was measured using the 20-item Center for Epidemiological Studies-Depression (CES-D) scale [23]. Three additional measures of caregiver distress were included: a 5-item measure of role overload, a 5-item measure of role captivity, and a 5-item measure of loss of intimate exchange [20].

CtP Review Checklist

Approximately 1 month after using CtP with an SCN, caregivers were administered a 21-item review checklist to assess barriers and facilitators associated with using CtP with an SCN. The 21-item review checklist was specifically designed to test the feasibility and utility of CtP. Its design and creation have been described previously [15]. Items on the 21-item checklist were administered as a 5-point Likert scale ranging from strongly disagree to strongly agree and a *not applicable* option. An example item in the checklist was "I would recommend CtP to others in a similar situation." A full list of the items is presented in Table 1 (Cronbach α=.90). Following the 21-item review checklist, caregivers participated in 30-minute semistructured telephone interviews. Open-ended questions focused on facilitators and barriers to CtP implementation and use and recommendations for future implementation. Example items include "What were some of the factors that made CtP easy to use?" "What were some of the factors that made CtP difficult to use?" (see Multimedia Appendix 1 for all base questions). The interviews were digitally recorded and transcribed later.

Table 1. One-month Care to Plan (CtP) Review Checklist scores (Likert-type scale: 1=strongly disagree, 2=disagree, 3=feel neutral, 4=agree, and 5=strongly agree).

	Value, mean (SD)	Agree and strongly agree, n (%)
It was easy to review the CtP tool with (health system).	4.70 (0.80)	16 (80)
The information provided by the Senior Care Navigator was clear to me.	4.55 (0.76)	17 (85)
The questions I answered during the CtP assessment were easy to understand.	4.35 (0.75)	19 (95)
I was able to understand the services recommendations provided by CtP.	4.50 (0.61)	19 (95)
The person guiding me through CtP was helpful.	4.55 (0.60)	19 (95)
I valued having a Senior Care Navigator available to discuss the recommendations from CtP.	4.35 (0.59)	19 (95)
After using CtP, I was able to find a service that looks as though it will meet my needs.	4.35 (1.35)	13 (65)
After using CtP, I was able to find a service that looks as though it will meet my relative's needs.	4.95 (1.36)	11 (55)
There are financial constraints to me being able to use the services recommended by CtP[a].	4.05 (1.67)	8 (40)
There are time constraints to me being able to use the services recommended by CtP[a].	3.50 (1.79)	9 (45)
I am planning on using a service recommended by CtP.	4.15 (1.42)	13 (65)
The care navigator helped me contact a service recommended by CtP.	4.30 (1.75)	9 (45)
CtP was helpful.	4.35 (0.75)	17 (85)
CtP could be improved[a].	3.25 (1.48)	6 (30)
I wish I would have completed CtP sooner.	3.95 (1.28)	10 (50)
Transportation issues make it unlikely that I will be able to use the recommendations provided by CtP[a].	4.65 (1.09)	17 (85)
CtP provided me with a sufficient number of options to support me.	4.05 (1.23)	14 (70)
CtP provided me with a sufficient number of options to support my relative.	4.50 (1.36)	15 (75)
The resources recommended by CtP were new to me.	3.00 (1.21)	9 (45)
I would recommend CtP to others in a similar situation.	4.45 (0.69)	18 (90)
I would use CtP again in the future.	4.15 (0.93)	15 (75)
Summary score	4.22 (0.69)	N/A[b]

[a] Item reverse coded.

[b] N/A: not applicable.

Data Analysis

Quantitative Analysis

Authors JC and CMP conducted a quantitative descriptive analysis of the baseline descriptive characteristics of caregivers and people living with dementia. These authors also completed Kendall Tau-B and Spearman bivariate correlations. Bivariate correlations were conducted for the following measurements to identify subcategories of caregivers that benefited more or less: CtP Review Checklist scores, baseline context of care, primary objective stressors (ADL, instrumental ADL, Memory Impairment, and Revised Memory and Behavior Problems Checklist-Frequency), resources (caregiver self-efficacy) and caregiver distress (CES-D, role overload, and role captivity loss of intimate exchange). In addition, the percentage of agree and strongly agree responses was calculated for individual items from the CtP Review Checklist scores to measure the agreeableness of that item. An additional variable that summed up and averaged all 21 items in the CtP Review Checklist for each participant was created as a summary measure of the feasibility, usability, and perceptions of CtP. All quantitative data were analyzed with SPSS (version 24; IBM Corp) [24].

Qualitative Analysis

Authors JC, CMP, ANM, KL, ZGB, and CJJ open coded all qualitative data from the semistructured telephone interview about caregivers' experience with the CtP tool. We followed thematic analysis best practices as described by Braun and Clarke [15] to code themes collected for qualitative analysis. All coders read a different subset of transcripts at random and generated preliminary coding categories based on common ideas they identified in the data. Thereafter, coders met regularly to discuss their preliminary codes to refine and adjust their codes to best portray the data as a whole. Disagreements in codes were resolved by consensus. Authors JC and CMP reviewed the codes to discern overarching themes, which were then reviewed and agreed upon by all the authors [25]. Regular debriefings discussed the interpretation and overarching themes and led to saturation, as described by Dey and Saunders et al [26,27]. All quantitative data were analyzed using NVivo (version 12) [28].

Results

Sample Characteristics

Sample characteristics of caregivers are presented in Table 2. Caregivers were primarily White (15/20, 75%), married (17/20, 85%), and female (18/20, 90%) with a mean age of 66.7 (SD 11.43) years (Table 2). Most caregivers also had less than a bachelor's degree (13/20, 65%) and a total household income of at least US $80,000 (10/20, 50%; Table 2). Slightly over half of the caregivers in our study who used CtP were the spouse or partner of the people living with dementia (11/20, 55%), followed by adult children (7/20, 35%). Caregivers reported varying levels of caregiver distress (based on their Revised Memory and Behavior Problems Checklist-Reaction, loss of intimate exchange, role captivity, role overload, and CES-D) and resources (self-efficacy). Notably, the average caregiver score exceeded the CES-D cutoff of 16, indicating depression (mean 16.95, SD 10.69) [17].

The characteristics of the people living with dementia are presented in Table 3. People living with dementia were primarily White (15/20, 75%), married (13/20, 65%), and male (12/20, 60%) with a mean age of 80.16 (SD 7.91) years. Most people living with dementia had less than a bachelor's degree (3/10, 15%, with a bachelor's degree or higher) and had a total household income of at least than US $30,000 (16/20, 80%).

Table 2. Caregiver baseline descriptive characteristics (N=20).

Caregiver demographics	Values	Spearman rho correlation with Care to Plan summary score (*P* value)
Female, n (%)	18 (90)	.50
Age (years), mean (SD)	66.68 (11.43)	.82
White population, n (%)	15 (75)	.90
Married, n (%)	17 (85)	.84
Number of living children, mean (SD)	2.25 (1.55)	.98
Annual income of ≥US $80,000, n (%)	10 (50)	.46
Employed, n (%)	7 (35)	.64
Spouse of people living with dementia, n (%)	11 (55)	.19
Adult child of people living with dementia, n (%)	7 (35)	.46
Bachelor’s degree (4-year college) and higher, n (%)	7 (35)	.10
Primary objective stressors, m ean (SD)		
ADL[a] dependencies	2.40 (2.77)	.50
IADL[b] dependencies	9.00 (3.11)	.53
Memory impairment	21.10 (5.06)	.40
RMBPC-F[c]	9.85 (4.41)	.88
Resources, mean (SD)		
Caregiver self-efficacy	28.10 (6.29)	.09
Caregiver distress, mean (SD)		
CES-D[d]	16.95 (10.69)	.25
RMBPC-R[e]	15.85 (12.03)	.46
Loss of intimate exchange	5.50 (2.21)	.96
Role captivity	6.70 (3.36)	.16

[a] ADL: activities of daily living.

[b] IADL: instrumental activities of daily living.

[c] RMBPC-F: Revised Memory and Behavior Problems Checklist-Frequency.

[d] CES-D: Center for Epidemiological Studies-Depression.

[e] RMBPC-R: Revised Memory and Behavior Problems Checklist-Reaction.

Table 3. Baseline descriptive characteristics of people living with dementia (N=20).

Demographics of people living with dementia	Value
Female, n (%)	8 (40)
Age (years), mean (SD)	80.16 (7.91)
White population, n (%)	15 (75)
Married, n (%)	13 (65)
Number of living children, mean (SD)	2.85 (1.66)
Bachelor’s degree or higher, n (%)	3 (15)
Annual income of ≥US $30,000, n (%)	16 (80)
Lives with a caregiver, n (%)	14 (70)
On Medicaid, n (%)	3 (15)

Empirical Associations Between 1-Month CtP Checklist and Other Domains

There were no statistically significant (*P*<.05) correlations between the CtP Review Checklist summary score and caregiver context of care, objective stressors, or distress achieved statistical significance.

Mixed Qualitative and Quantitative Results

Qualitative analyses identified 4 themes regarding facilitators of and barriers to the implementation and use of CtP within four overarching categories: (1) caregiver factors, (2) SCN factors, (3) CtP tool system factors, and (4) recommendations and resources factors. Facilitators in each category are discussed later, followed by the barriers. A summary of all the themes, facilitators or barriers, their descriptions, and supporting quotes can be found in Table S2 in Multimedia Appendix 1. Relevant item-level quantitative results from the CtP Review Checklist complemented our quantitative results to offer a more robust description of our themes (Table 1).

Facilitators to CtP Implementation and Use: Caregiver Factors

Caregivers found that the tool appropriately tailored recommendations to their needs and context of care. This was consistent with the analysis of the 1-month CtP Review Checklist, in which 65% (13/20) of caregivers agreed or strongly agreed that, after using the tool, they were able to find a service that would meet their needs and 55% (11/20) of their people living with dementia needs (Table 1). Giving names to categories of need helped some caregivers better conceptualize their caregiving for both themselves and their people living with dementia. One caregiver noted, “It made me think of different things that I hadn’t previously thought of” (Wife, aged 71 years). Another caregiver explained:

> *It broke things down to different types of situations and needs. And in some ways even though I’ve been living with this, it helped me better understand my situation and my husband’s situation...It seemed very thorough, and a logical progression and dealt with not just my husband and his needs, but with me and my needs.* [Wife, aged 76 years]

The helpfulness of the CtP was a recurring theme in the qualitative results. Caregivers said that they enrolled in the study because they were overwhelmed and needed help. The aforementioned caregiver pointed out, “I didn’t know what I didn’t know” and “(I) can use all the help I can get” (Wife, aged 76 years). The helpfulness of CtP was also reflected in the CtP Review Checklist, in which 85% (17/20) of the caregivers agreed or strongly agreed that CtP was helpful (Table 1). CtP was also a source of help that caregivers of people living with dementia could turn to with the help of an SCN. SCNs spoke with caregivers during a time of potentially overwhelming need, and predefined but nuanced categories could simplify how to route caregivers to the help they needed. For example, CtP could:

> *Help to better define the challenges that caregivers are faced with, that family members are faced with. I think it helps to really provide the proper channeling of resources in the right categories.* [SCN]

Overall, 90% (18/20) of the caregivers reported that they would recommend CtP for others in a situation similar to them and 75% (15/20) would use CtP again (Table 1).

Facilitators to CtP Implementation and Use: SCN Factors

Many caregivers appreciated having an SCN available to guide them through the CtP tool. Qualitative analyses highlighted that caregivers appreciated their SCN’s familiarity with caregiving support and the ability to explain the available resources. For those who were new to caregiving for people living with dementia, connecting with someone who was knowledgeable in these areas was especially useful. One caregiver explained how having:

> *Someone who can speak to it personally even though it might not have been exactly the situation in our household, just somebody who totally gets it and how life-changing it is, not just for the person but for the whole family...I really appreciated that part.* [Daughter, aged 58 years]

Even those who did not find an absolute need for the SCN liked knowing there was someone they could go to should the need arise: “I like the idea that there’s someone there. I haven’t really found it necessary to use a navigator, per se. Again, I think it’s because I was so early in the situation” (Wife, aged 71 years).

Caregivers also noted that scheduling CtP with an SCN held them accountable for using the tool, even if it was just via a telephone conversation. Although caregivers could have used the CtP website themselves, some admitted that, with competing demands on their attention, they might not have actually used the tool. One caregiver noted, “I think it was just the time it was going to take to do it, and I think that was my problem” (Wife, aged 74 years). In addition, caregivers acknowledged that the SCN could discuss barriers to enacting CtP recommendations and hold them accountable for their own self-care without judgment. Another study recognized how SCNs helped prioritize self-care while also guiding them through resources:

> *I actually appreciated the Care Navigator...Just that sometimes when you’re so overwhelmed by everything that’s going on, even though you’re a big person, you still need somebody to kind of take you by the hand and say “Let’s get through this. Let’s walk through this and kind of just help you focus.”* [Daughter, aged 56 years]

Finally, having SCNs go through the CtP tool added a personal touch for caregivers. Because of their background, SCNs could empathize with caregivers’ situations and make themselves available as emotional pillars of support. One caregiver said that the SCN “could share experiences of her own that would make this helpful. So, it was great talking with her” (Daughter, aged 57 years). Another study explained in detail how SCNs’ experiences made them allies:

> *It’s that connection of somebody who kind of understands personally what you’re going through,*

> *kind of no judgement, someone I felt comfortable enough to share some very candid things with, just the overall frustration and grief and loss you feel. Yeah. So, I thought that was really helpful to have another person who really totally has walked through these steps and several steps ahead. That's always very helpful.* [Daughter, aged 52 years]

The rapport and personal connection were amplified by the fact that SCNs often had personal caregiving experiences of their own. They could recommend the same resources that helped them:

> *I think all the content that's in there is quite pertinent, and I think it's information that individuals are really going to need, and I base my answer or comments on the fact that personally I've had to go through this experience of caregiving with my mom, dad and my aunt, and I've actually used the resources, so now as a professional when I'm suggesting the resources and I'm hearing familiar stories of people that are going through struggles with caregiving I can share with them that they're at the right place getting this information.* [SCN]

The CtP Review Checklist also reflected how useful caregivers found their SCNs: 85% (17/20) of the caregivers either agreed or strongly agreed that the information provided by the SCN was clear to them, and 95% (19/20) valued having an SCN available to discuss the recommendations from CtP (Table 1).

Facilitators to CtP Implementation and Use: CtP System Factors

Among the caregivers who described themselves as *tech savvy*, most caregivers found the website interface user-friendly and navigated CtP with ease. Some caregivers even alerted the staff to glitches while moving through the recommended resource pages, which were fixed early on in the project. Although some found that having an SCN helped set time aside in their busy schedules to go through the tool, others found that being able to use the tool on their own worked better for their hectic schedules. Participants could complete CtP when it was most convenient for them:

> *I applaud you and do thank you for putting it on the computer instead of doing it all orally. I could do it at my time where I was in a good frame of mind and things were calm here at home. I could do it privately, and I thought it was easy to maneuver. I thought it was really very easily-- yeah, so it was well-done.* [Wife, aged 77 years]

The CtP tool was easy for SCNs to learn as well:

> *As far as the mechanics go, the mechanics of Care to Plan I think are easy to learn and navigate. I kind of took a lead role to spend a little bit more time to understand it and then kind of shared it with my colleagues, but I think that the tool itself is built to be easy to learn and to be replicated, so I think that that's a good feature of the tool.* [SCN]

Facilitators to CtP Implementation and Use: Recommendations and Resources Factors

According to the CtP Review Checklist, most caregivers agreed or strongly agreed that CtP provided them with sufficient options for both their needs and that of their people living with dementia; 70% (14/20) of caregivers agreed or strongly agreed that CtP offered them a sufficient number of options to support themselves, and 75% (15/20) of caregivers either agreed or strongly agreed that CtP offered them a sufficient number of options to support their people living with dementia (Table 1). The qualitative interviews complemented these results by adding that caregivers appreciated having a variety of vetted, localized support and resources all in one place. "There's something for everyone, and not everyone needs everything, but it's a broad range for everyone" (Wife, aged 74 years). Another noted, "I have not asked for something that they did not have an answer for" (Wife, aged 80 years). The CtP resources empowered caregivers to get help:

> *For me, getting information really reduced my fear level. It felt like I could guide my family better and then also, to remind me that I needed to take care of myself first before I could take care of my mom and dad. That can't fade out.* [Daughter, aged 52 years]

When working with CtP, caregivers were able to explore and connect to supportive resources in their area. One explained how they went from having no resources to having multiple avenues for assistance available in all facets of their caregiving and their sisters' needs:

> *I didn't know nothing about it till I found out about Care to Plan...when I took and called the [local] Area on Agency and everything and they told me if I run into any problems with her and might [be] needing help with a light meal and stuff, and that if she...needed a cell phone, they could get her a cell phone. And the Meals and Wheels was real good, and now I find they could do recreation with her.* [Sister, aged 66 years]

Overall, caregivers' reception to CtP implementation was positive: 30% (6/20) of the caregivers noted that the tool could be improved, and 50% (10/20) wished they would have had the opportunity to use the tool sooner in their caregiving role (Table 1).

Barriers to CtP Implementation and Use: Caregiver Factors

Caregivers generally appreciated the wealth of resources and options suggested by CtP tailoring; however, time constraints made it difficult to take the next steps. Caregivers expressed difficulties in dedicating time to using their resources, feeling overburdened with busy schedules and with their caregiving responsibilities. For instance, one caregiver said:

> *It's a matter of sitting down and-- because I'm constantly having to be actively around Dad, and alert of what's going on. So a lot of times, I sit down and start getting started on something, and then I end up getting sidetracked because I have to get up and intercept him. <laughs> And so...and so a lot of times,*

> *I get sidetracked. But yes, I definitely plan on using some of the tools I have learned, most definitely.* [Daughter, aged 58 years]

With limited time available for themselves, exhausted caregivers do not have the energy for looking through the recommended resources as they would otherwise want to: A wife of one of the people living with dementia explained:

> *It's like I'm too tired of thinking to get on the computer and try to research stuff like that. It's like when I'm not having to do something, I don't want to do anything else.* [Wife, aged 74 years]

Caregivers stated that their lack of time to review or access support systems or other resources was exacerbated by the pandemic.

Several caregivers in the early stages of dementia caregiving reported that the resources and recommendations were not currently relevant. However, caregivers recognized their probable utility in the future. One caregiver referred to the resources noting that, "Well, I think that's going to come in later, the use of these actual features-- the support groups and the respite care" (Wife, aged 74 years).

An unintended consequence of working through the CtP tool with early stage caregivers of people living with dementia was that it provided them with the idea of caregiving needs that may become necessary for their care recipient in the future. On the basis of the suggested resources, one caregiver noted how "...[CtP] just opened my eyes to things that I'll be facing as time goes on, and how to better understand and cope with it" (Daughter, aged 58 years). Another explained how CtP heightened but also provided solace for their anxiety about their future as a caregiver:

> *I found it very, very helpful, just the reading itself, the information that was given to me. That's very helpful. It really is. But as I also said, I guess it kind of frightens me a little bit knowing what might be or probably will be happening in the future...But it's nice to know that there are people there. Care to Plan is there.* [Wife, aged 71 years]

Quantitative analysis also identified financial and time constraints as barriers to using services recommended by CtP: 40% (8/20) reported financial constraints, and 45% (9/20) reported time constraints (Table 1). Of the total respondents, 85% (17/20) also reported transportation issues, making it unlikely that they would be able to use the recommendations provided (Table 1). However, 65% (13/20) of the caregivers reported planning to use a service recommended by the CtP (Table 1).

Barriers to CtP Implementation and Use: SCN Factors

Rapport was also affected by SCN interactions and approach, where some SCNs were naturally engaging and talkative, whereas others were perceived to have approached the use of CtP more rigidly, describing:

> *I think most of us in this position find it difficult to give a yes/no, black/white [answer]...and I found myself wanting to explain my answers...and the person that did it was very much on--and I understand. I've been very much on task and, in a nice way, [the SCN] basically said, "Just answer"...and I had to restrain myself at times to try to explain my answer and not--he wasn't having any of that, basically, and I understand. I mean, I've done research myself, so I understand how that is. It was a little frustrating.* [Wife, aged 78 years]

According to the CtP Review Checklist, only 45% (9/20) of the respondents reported that their SCN helped them contact a service recommended by CtP (Table 1). Some of these caregivers felt confident enough to walk through the tool themselves but appreciated the guidance of an SCN, just in case they needed them:

> *Maybe I missed it but I'm a visual person and it would have been really nice to...in hindsight...[hear] "here's the link why don't you log on, take a look and then we will set up a call and I'll go over it with you so that you know what is available here and answer any questions that come up."* [Daughter, aged 48 years]

Barriers to CtP Implementation and Use: CtP System Factors

Caregivers attributed their own technical literacy levels to successfully using the web-based tool on their own but could see how it may be difficult for those not as technically literate. One caregiver said, "I'm very computer-savvy, so I think somebody who isn't might...have found that difficult" (Wife, aged 78 years). However, for some, internet access was a barrier to completing the tool on their own. As one caregiver noted, "I don't have Internet service where I live" (Wife, aged 71 years).

Barriers to CtP Implementation and Use: Recommendations and Resources Factors

Although most caregivers found their CtP recommendations helpful, some were disappointed with their results. According to the CtP Review Checklist, most caregivers were able to find services that met their needs, as well as their relatives, through CtP; 65% (13/20) of the caregivers reported finding a service that met their needs (Table 1). However, 55% (11/20) of the caregivers found a service that met the needs of the people living with dementia (Table 1). Both SCNs and caregivers were frustrated by the lack of a variety of options and tailoring capacity of the CtP tool. Some simply wanted more options to present. For example, 1 caregiver said, "I only got two recommendations and I knew about both of those. I was hoping to get more, more choices of, like, respite care and things that were available" (Wife, aged 75 years). This was reflected in the CtP Review Checklist, in which only 45% (9/20) of the caregivers reported that the resources recommended by CtP were new to them (Table 1). Moreover, 25% (5/20) of the caregivers did not agree that CtP offered them a sufficient number of options to support their people living with dementia (Table 1).

In addition, SCNs and caregivers alike would have preferred further initial questions that helped narrow down the recommendations specific to the current context of care, such as assessing the eligibility of caregivers or people living with dementia for some of the resources beforehand. For example, 1 SCN explained: “I as a navigator don’t ask them on their veteran status and it seems like the VA keeps popping up as a resource and it’s not always appropriate’ (SCN).

Similarly, a caregiver lamented that resources were not available for their particular context saying, “I guess because [name of the person living with dementia] didn’t have issues that they had solutions for, I wasn’t given any solutions for taking care of [name of the person living with dementia]” (Wife, aged 76 years).

Resources were also recommended by caregiver zip codes, which led to some issues in terms of geography and distance to resources. This caregiver explained how the location of the resources recommended was troublesome:

> *It was more the Southside [city] instead of on this side of the water...[city] is on what’s called the Southside, and it’s across the bay. You have to go across the Chesapeake Bay...and it just didn’t appeal to me.* [Wife, aged 77 years]

Finally, using CtP during the COVID-19 pandemic shutdowns meant that some resources were unavailable or unusable for caregivers to act on. One caregiver explained “that with the restrictions for group meetings, we couldn’t have any support groups” (Wife, aged 74 years). The pandemic restrictions “kind of put a damper on implementing some of the pieces I wanted to” (Daughter, aged 52 years). Others talked about being more comfortable using the resources once the COVID-19 pandemic is over:

> *I’ve used some of them, but I’m planning on using more as soon as some of this COVID flack thing. She’s kind of scared to go out right now.* [Sister, aged 66 years]

Discussion

Principal Findings

The objective of this study was to formally explore the feasibility, acceptability, and utility of CtP, an individualized tool for caregivers of people living with dementia that connects them to a diverse array of services that can alleviate caregiver burden and improve other dementia caregiver outcomes. Given that family caregivers receive little support and assistance themselves during their time caregiving [17], CtP is one of the few resources developed for caregivers of people living with dementia that have been implemented in practice [15]. Being one of the few resources for caregivers of people living with dementia, we found that CtP was well-accepted and used by our participants. Caregivers of people living with dementia overwhelmingly agreed that CtP was helpful. The tailored approach used by CtP and the social support provided by SCNs reduced barriers for caregivers of people living with dementia, which is a hallmark characteristic of effective caregiver interventions [9]. Similarly, CtP was further tailored to the needs of caregivers of people living with dementia through linkage with an SCN who provided guidance when using the tool.

Our findings indicated that caregivers of people living with dementia generally appreciated the *single point of entry* for vetted resources and recommendations tailored to them. Quantitative data suggested that the vast majority of caregivers found the tool easy to use. Qualitative data reinforced the helpfulness and convenience of the CtP tool by highlighting its ease of use and its connection to vetted, local resources. Caregivers recognized the value of CtP and wished that they had used it earlier in their caregiving roles.

Alongside the tool, caregivers appreciated having SCNs to discuss barriers to enacting CtP recommendations. Caregivers were able to use their SCNs to navigate community resources, including points of contact, eligibility requirements, and the most effective ways to access services. SCNs also helped caregivers remain accountable for their self-care and well-being. For instance, as SCNs built rapport with caregivers, they were able to make personal connections with caregivers and became their emotional pillars of support, especially during times of overwhelming need. The CtP tool served as a new means by which SCNs can engage family caregivers and help them consider their options both in their current caregiving role and in what that role may require in the future. Thus, CtP serves as another important tool in the *toolbox* of approaches and supports at the disposal of a health care system for families caring for relatives with ADRD.

Although quantitative data suggested that the overwhelming majority of caregivers of people living with dementia found SCNs to be helpful and valued having an SCN available to discuss the recommendations from CtP, qualitative research revealed more nuances in their interactions. Building rapport between SCNs and caregivers of people living with dementia was valuable, as SCNs walked through the CtP tool. The more options CtP presented to caregivers, the more likely they were to feel overwhelmed and in need of SCN support. Less than half of the caregivers reported using their SCN to contact the service recommended by CtP. Having an SCN on standby, available to answer questions, and guide them through the CtP tool (especially during crises or transitions, such as the COVID-19 pandemic) was valuable for caregivers. These results reflect similar studies in which the support of professionals and the simultaneous use of caregiving technologies alleviated challenges during care provision [29,30].

Although quantitative results revealed that most caregivers who used CtP received a sufficient number of options to support themselves or their people living with dementia, caregivers also felt frustrated by the lack of tailored options, as highlighted in the qualitative findings. For example, although caregivers may have received a diverse array of options from the CtP tool, in some cases, they already knew about those options or were unable to accept CtP recommendations because of extraneous constraints such as available time and distance. Some obstacles could be alleviated through more support provided by SCNs and care organizations as well as additional recommended resources on CtP itself. Additional barriers to CtP implementation suggested that the successful use of the CtP tool was dependent on the existing resources of caregivers and highlighted the systematic inequity of today’s digital divide for high-speed internet access [31].

Our study had several limitations. First, the sample was homogenous in terms of race, gender, household income, and marital status; caregivers of people living with dementia were predominantly affluent, White women. With a more educated cohort, our study may have attracted more *tech-savvy* caregivers who are not only more comfortable and receptive to newer technologies but also have more resources to apply such technologies to their lives. Therefore, our results may not be generalizable to a more diverse, less-educated population. As a pilot study, our small sample size inhibited our ability to conduct a more rigorous quantitative analysis of our results. Future research could examine the associations between primary objective stressors, resources, and distress among caregivers of people living with dementia and CtP implementation. Social desirability bias (ie, where a participant may underreport undesirable answers to interview questions) may have also influenced our results. However, our study encouraged participants to report barriers to using the CtP tool. For these reasons, we believe that social desirability bias was curbed. As building rapport between SCNs and caregivers was integral to this pilot study, future research could also explore the personalities of SCNs or their caregivers and how the implementation of CtP (or other innovative technologies) is affected by them.

Within the broader literature of caregiving for people living with dementia, CtP addresses important gaps within the literature. The use of technologies such as CtP offers an innovative, practical, and personalized approach to support caregivers of people living with dementia in health care systems. The application of technology has considerable potential to improve the well-being of caregivers [6,29]. However, SCNs were clearly an integral component of CtP; caregivers appreciated having an expert SCN on standby who understood their own situation. Having a personal connection with caregivers to provide active support over time is another key characteristic of effective interventions to support caregivers of people living with dementia [9]. This study ultimately highlights the importance of complementing both technology and interpersonal connection to support dementia caregivers. Given these conclusions and the 1 month duration, this study encompassed, longer term results that may yield more insight as to how CtP was integrated into routine care and how SCNs provided additional support for caregivers of people living with dementia during their caregiving journey.

The CtP web-based assessment tool with SCNs serving as guides was valuable for caregivers seeking resources to support themselves and their care recipients living with dementia. By sharing the challenges and perspectives of caregivers in their own words, we obtained a richer understanding of their lived experiences. This study highlighted the need for interventions, such as CtP, and the need for financial, time, and transportation constraints to be addressed to improve the utility of caregiver support programs. Although technology-based resources, such as CtP, may overcome certain barriers to care, including knowledge or social support, policy-level changes are necessary to achieve greater equity in caregiving interventions. The lack of high-speed internet, inaccessible transportation, and a strong health care system are all policy-level characteristics unique to a geographic area, and technological resources alone cannot overcome. Further implementation research that is necessary to identify how to best translate and link tailored support assessment tools such as CtP to community programming so that caregivers of people living with dementia are better supported.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary information about Care to Plan.
[DOCX File , 144 KB - aging_v5i2e35847_app1.docx]

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Abbreviations

ADL: activities of daily living
ADRD: Alzheimer disease or related dementia
CES-D: Center for Epidemiological Studies-Depression
CtP: Care to Plan
SCN: senior care navigator

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Original Paper

Emotional Word Use in Informal Carers of People Living With Dementia: Linguistic Analysis of Online Discussion Forums

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Abstract

Background: Informal dementia care is uniquely stressful and necessitates effective methods of identifying and understanding the needs of potentially at-risk carers so that they can be supported and sustained in their roles. One such method is examining carers' engagement in online support platforms. Research has explored emotional word use on online discussion forums as a proxy for underlying emotional functioning. We are not aware of any research that has analyzed the content of posts on discussion forums specific to carers of people living with dementia in order to examine their emotional states.

Objective: We addressed the following research questions: (1) To what extent does emotional language use differ between carers of people living with dementia and noncarers? (2) To what extent does emotional language use differ between spousal and parental carers? (3) To what extent does emotional language use differ between current and former carers?

Methods: We used the Linguistic Inquiry and Word Count (LIWC) program to examine emotional word use on a UK-based online forum for informal carers of people living with dementia and a discussion forum control group. Carers were separated into different subgroups for the analysis: current and former, and spousal and parental.

Results: We found that carers of people living with dementia used significantly more negative, but not positive, emotion words than noncarers. Spousal carers used more emotion words overall than parental carers, specifically more negative emotion words. Former carers used more emotional words overall than current carers, specifically more positive words.

Conclusions: The findings suggest that informal carers of people living with dementia may be at increased risk of negative emotional states relative to noncarers. Greater negativity in spousal carers may be explained by increased caregiver burden, whereas greater positivity in former carers may be explained by functional relief of caregiving responsibilities. The theoretical/applied relevance of these findings is discussed.

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KEYWORDS

dementia care; online forum; emotional language; emotional states; dementia; aging; elderly population; digital health; online health

Introduction

Informal dementia care has been described as uniquely stressful [1]. Potgieter et al [2] describe a number of characteristics that may contribute to this, including the continuous, intense, and unpredictable nature of symptoms and the extended course of dementia. Research shows that carers of people living with dementia are significantly more stressed than nondementia carers [3], and this stress is associated with poorer physical [4-6] and psychological [7,8] health. Carers are also likely to suffer declines in the availability of people to provide informal support over time [9], making them an at-risk group on physical, psychological, and social levels.

Carers are not a homogeneous group; the pattern of individual differences seen between different groups of carers is not always clear. For example, caring for an ill spouse presents different challenges than caring for an ill parent [10]. Research shows that 58% of all primary carers care for a parent, whereas 26% care for a spouse [11], and that spousal carers are more burdened by caregiving than parental carers [12]. *Dementia caregiver burden* has been associated with depression, poor physical health, and reduced quality of life [13]. Pinquart and Sorensen [12] explain that parental carers may be able to moderate care demands through alternative "distractor" roles and social activities outside the home. According to Etters et al [14], spousal carers have closer relationship ties to the care recipient, which are likely to be compromised by their growing dependency and diminished quality of communication [14-16], leading to a loss of companionship and reciprocity within the marital relationship [17]. Furthermore, spousal carers may have their own chronic health conditions [12] and may share reciprocal, fluctuating caring roles with their spouse [18], which can also lead to increased burden.

Additionally, there is a growing body of research looking at the postcaring period, most commonly former carers whose loved ones have died or been admitted to a care setting [19,20]. Longitudinal research shows that, unlike current carers, who become more depressed, former carers experience improved burden [21], quality of life, mental health, perceived health status, and social participation over time [20,22,23]. In a qualitative longitudinal study of spousal carers of people living with dementia, masked for review [24] found that most carers remain or become resilient over time, despite deteriorating health of the care recipient and care status transitions, including insitutionalization and widowhood. Bond et al [22] suggest that this could reflect the alleviation of time constraints and functional relief of caregiving responsibilities seen in former carers.

The research discussed so far suggests that carers of people living with dementia experience poorer outcomes than nondementia carers and that spousal and current carers in particular may be more at risk of negative emotional states than parental and former carers of people living with dementia. This necessitates effective methods of identifying and understanding the needs of potentially at-risk carers so that they can be supported and sustained in their roles [25]. One such method is examining carers' engagement in online support platforms. Growing numbers of carers of people living with dementia are turning to internet-based platforms for support [26]. This may be driven in part by declines in the availability of people to provide informal support to carers over time [27]. Online platforms allow carers to access support without the need for face-to-face interaction [28], which is particularly useful for those carers who are socially isolated or physically less mobile [29]. Research shows that online support can improve the well-being of carers of people living with dementia, through reducing anxiety, depression, and increasing confidence and self-efficacy [26,30]. In a qualitative evaluation of online peer support for informal carers, masked for review [31] found that the online environment creates a unique forum within which carers exchange practical information about caring and developed friendships and a sense of belonging to their caregiving community. Online discussion forums in particular have been found to improve the quality of the relationship between the carer and the care recipient, potentially through carers learning how to better interact with the care recipient, thus reducing conflict and criticism [28].

One of the main ways in which carers interact online is through written communication. There is evidence to suggest that the content of carers' communications may provide a window through which we can examine their underlying functioning. For example, research has shown that emotional language use is a reliable predictor of underlying social and psychological states [32]. A recent study by Vine et al [33] examined emotion vocabularies in participant-generated written speech and examined their relationships to individual differences in mood, personality, and well-being. The authors found that emotion vocabulary is associated with underlying functioning; specifically, larger negative emotion vocabulary is associated with more psychological distress and poorer physical health, while larger positive emotion vocabulary is associated with higher well-being and better physical health. Online discussion forums in particular allow us to examine emotional language use as a proxy for underlying emotional states [34,35]; for example, increased use of positive emotional words on posts may be associated with greater positivity, and increased use of negative words has been associated with greater negativity [36-38]. Online discussion forums have been used as secondary data sources in several dementia studies [26,39]. They have also been used to examine language use a proxy for mental distress [35]. However, no research has systematically analyzed the content of posts on discussion forums specific to carers of people living with dementia in order to examine their emotional states. Posts on online discussion forums are advantageous over other more traditionally used data sources as they provide a naturalistic, real-time insight into carers' experiences that are not a potential artifact of a quantitative survey or qualitative interview schedule.

This study aims to add to the existing literature by innovatively examining emotional word use as a proxy for underlying emotional states, across spousal and parental carers of people living with dementia, current and former carers of people living with dementia, and noncarers using posts from online discussion forums using the Linguistic Inquiry and Word Count (LIWC) program [40]. Although the LIWC program has been commonly used to explore emotion analysis, to the best of our knowledge, this is the first time it has been applied to the dementia care context. By using the LIWC program to examine the proportion of emotional word use as a window onto underlying emotional states, for example, increased use of positive words indicating greater positivity [33,36-38], we may be able to facilitate better identification and understanding of the needs of potentially at-risk carers so that they can be supported and sustained in their roles [25]. We address the following research questions: (1) To what extent does emotional language use differ between carers of people living with dementia and noncarers? (2) To what extent does emotional language use differ between spousal and parental carers? (3) To what extent does emotional language use differ between current and former carers? Given that carers of people living with dementia experience poorer outcomes than nondementia carers [3-8,27] and that spousal and current carers in particular may be more at risk of negative emotional states than parental [12,14-18] and former [20-24] carers of people living with dementia, we propose the following 3 hypotheses: (1) Carers of people living with dementia will use more negative words than noncarers, (2) spousal carers will use more negative words than parental carers, and (3) former carers will use more positive words than current carers.

Methods

Setting

Our data were drawn from Dementia Talking Point, a UK-based online discussion forum, hosted by Alzheimer's Society, for informal carers and people living with dementia to share experience and provide peer support [11,38]. Dementia Talking Point is well used, with 122,447 threads, 1,793,837 posts, and 73,428 users as of January 27, 2022. The forum contains a number of subforums, all of which are actively used and publicly viewable without registration.

Procedure

We selected 3 subforums for this study on August 21, 2018: "I have a partner with dementia," "I care for a person with dementia," and "Younger people with dementia and their carers." We chose these subforums as they were most relevant to the study aims and population (ie, they were most likely to contain spousal and parental, and current and former informal carers of people living with dementia). The second author manually selected the 100 most recent posts from each subforum (N=300) and collated them into a Microsoft Excel spreadsheet. In line with Lyons et al [17], a maximum of 500 words per post were read to ensure that they met the inclusion criteria. Only 18 (6%) of 300 posts were over 500 words, so they were shortened to 500 words prior to analysis.

We included original posts rather than comments on posts, and 1 post per user. For those users with repeated or multiple posts, we used their earliest entry, as subsequent posts were likely to be comments on or duplications of the first post. Posts were only included if the user disclosed that they currently or previously cared for a spouse or parent living with dementia. As this information was not readily available, we determined it from the content of the posts. For example, to determine carer type, the second author looked for references such as "my wife" and "my dad" to identify spousal and parental carers, respectively. To determine care status, the second author looked for entries such as "We're stuck at home" (current carer) and "I miss him/her so much since they were admitted" (former carer). Both authors independently coded the data to identify carer type and care status and reached an agreement with a κ of 0.93. Where there was conflict between coding, both authors discussed cases until a consensus was reached. We originally intended to include both bereaved former carers and carers who had admitted the care recipient into a care setting, but only the latter group was present; the final sample did not include any bereaved former carers. We excluded carers of grandparents, neighbors, and friends as they were not relevant to the study aims. No further information specific to the caregiving context was available from the data set.

To identify significant effects of group, carer type, and care status on emotional word use (η_p^2=0.5), a power calculation using G*Power [41] indicated that the required sample size for 95% power with α=.05 was N=105 per condition. Using this method, we identified 270 carers. Finally, 100 control group posts were selected from an online personal finance discussion forum [35]. The finance discussion forum we used had been used as a control group in a previous linguistic analysis [35] and was appropriate here due to the relatively low likelihood of containing carers or extremes of emotion. To improve the robustness of the control group further, control entries were excluded if the user disclosed that they currently or previously cared for a person living with dementia (Table 1).

Table 1. Frequencies of participant demographic characteristics.

Participants	Frequency, n (%)
Noncarers (control)	100 (27)
Carers	270 (73)
Spousal	119 (43)
Current	84 (71)
Former	31 (26)
Missing	4 (3)
Parental	151 (55)
Current	59 (39)
Former	84 (56)
Missing	8 (5)
Total	
Current	143 (55)
Former	115 (45)

Data Analysis

We used the LIWC program [40] to analyze the discussion forum posts. The LIWC program is designed to capture people's underlying social and psychological states by assessing the emotional, cognitive, and structural components of text based on a psychometrically validated dictionary of over 6400 words [42].

We examined percentage emotional word use (dependent variable; affective processes, positive, negative, anxiety, anger, sadness) across group (independent variable 1; carers and noncarers), carer type (independent variable 2; spousal and parental), and care status (independent variable 3; current and former). Affective process words encapsulated all emotion words of different valences (eg, happy, ugly, bitter). These were included as an overarching measure of linguistic emotionality. Positive words included words such as happy, pretty, and good. Negative words included words such as hate, worthless, and enemy. Anxiety words included words such as nervous, afraid, and tense. Anger words included words such as hate, kill, and annoyed. Finally, sadness words included words such as grief, cry, and sad [40]. We used negative, but not positive, emotion subdimensions (ie, anxiety, anger, sadness) for 2 reasons: First, positive emotion subdimensions were not available on the LIWC database, and second, to reflect the fact that dementia care has been shown to be uniquely stressful [1], including a wide variety of negative emotion subdimensions allowed us to capture the negative impact of dementia care more comprehensively. Although it is apparent from Table 1 that the distribution of current and former carers is different in spousal and parental carers, which may warrant further investigation, we did not conduct additional subgroup analyses as the subgroup sizes were small and uneven (eg, n=84, 71%, spousal carers were currently providing care as opposed to only n=31, 26%, formerly providing care), compromising statistical power. Furthermore, we did not control for the influence of carers' individual characteristics on emotional word use as relevant carer demographic information was not available from the naturalistic data set.

In Table 2, we include some adapted example quotes to illustrate how emotion words typically appeared in selected carers' posts. In line with our ethics approach (see later), these quotes have been adapted from the original posts to maintain the anonymity and confidentiality of the users. All statistical analyses were conducted using SPSS Statistics V25 (IBM Corporation) using multivariate analyses of variance (MANOVA) and Welch *F* tests.

Table 2. Example adapted quotes to illustrate how emotion words appeared in carers' posts.

Emotion words	Adapted example quotes from carer posts
Affective processes[a]	"My Dad was the *kindest* man I have ever met. Now he can be *nasty* and sometimes I get *frightened*."
Positive	"…we've been the *lucky* ones really."
Negative	"My husband has vascular dementia. The past year has been *hellish*."
Anxiety	"Lately I'm feeling *scared* and bewildered…"
Anger	"Now he is verbally *abusive*…"
Sadness	"…I get *teary* when I'm on my own."

[a] "Affective processes" is an overarching category including positive, negative, anxiety, anger, and sadness words.

Ethical Considerations and Governance

This study was approved for partnership within the Alzheimer's Society Research Partnerships program. Ethical approval was not sought for the following reasons: Posts on Dementia Talking Point are publicly viewable without registration; under clause 5.4 of the "Terms and Conditions of Use" of Dementia Talking Point, users of Dementia Talking Point consent to their posts being accessed by researchers; under clause 5.3, users have the opportunity for their posts not be included in research; we do not present direct quotations from users; we only include the percentage emotional word use, and no identifying information can be ascertained from these percentages, so the data remain fully anonymous and confidential. As this is a secondary data study, we will not be interacting with the forum users in any way. Finally, according to the Economic and Social Research Council (ESRC) Framework for Research Ethics, online forums "that are intentionally" public may be considered "in the public domain" [38].

Results

Descriptive Statistics

This study aims to analyze emotional word use of spousal and parental, and current and former carers of people living with dementia and noncarers using posts from an online discussion forum.

Data were analyzed using 2 MANOVA: 1 for the effect of group (carer and noncarer) on emotional word use and 1 for the effect of carer type (spousal and parental) and care status (current and former) on emotional word use. Levene and Box tests indicated that the assumption of homogeneity of variance and equality of covariance ($P<.001$) had been violated. Therefore, *F* values were calculated using Welch *F* tests. As data were skewed, a log transformation was conducted on all variables following an analysis of descriptive statistics (see Table 3).

Table 3. Descriptive statistics[a] for effect of group, carer type, and care status on emotional word use (values are mean and SD).

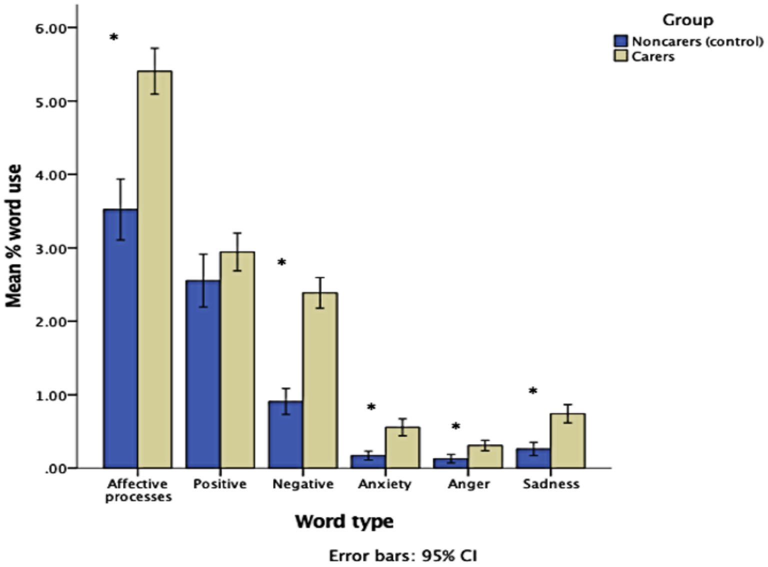
Participants	Emotional word types, mean (SD)					
	Affective processes	Positive	Negative	Anxiety	Anger	Sadness
Group						
Carers	5.41 (2.63)	2.94 (2.17)	2.39 (1.76)	0.56 (0.97)	0.31 (0.59)	0.74 (1.04)
Noncarers	3.52 (2.09)	2.55 (1.81)	0.91 (0.89)	0.17 (0.31)	0.13 (0.29)	0.26 (0.46)
Carer type						
Spousal	5.56 (2.94)	2.69 (2.17)	2.82 (2.00)	0.69 (1.27)	0.39 (0.73)	0.77 (1.12)
Parental	5.20 (2.32)	3.07 (2.10)	2.04 (1.46)	0.43 (0.63)	0.24 (0.44)	0.73 (.98)
Care status						
Current	4.72 (2.11)	2.28 (1.65)	2.37 (1.56)	0.58 (0.76)	0.38 (0.70)	0.48 (.82)
Former	6.10 (2.49)	3.66 (2.25)	2.38 (1.81)	0.43 (0.59)	0.23 (0.42)	1.10 (1.20)

[a] Non-log-transformed descriptive statistics are presented for illustrative purposes.

Effect of Group on Emotional Word Use

There was a significant large effect of group on emotional word use: Pillai trace=0.22, $F_{(7, 366)}$=14.49, *P*<.001, η_p^2=0.22. Welch *F* tests revealed that carers used significantly more affective process ($F_{(1,153.46)}$=48.16, *P*<.001), negative ($F_{(1, 205.97)}$=101.32, *P*<.001), anxiety ($F_{(1, 316.58)}$=40.97, *P*<.001), anger ($F_{(1, 277.69)}$=14.23, *P*<.001), and sadness ($F_{(1, 287.35)}$= 34.96, *P*<.001) emotion words than noncarers. There was no difference between carers and noncarers in the use of positive emotion words ($F_{(1, 180.13)}$=2.24, *P*=.14). See Figure 1.

Figure 1. Clustered bar chart showing the effect of group on emotional word use (**P*<.05). Error bars represent 95% CIs. Non-log-transformed data used for illustrative purposes.



Effect of Carer Type and Care Status on Emotional Word Use

There was a significant medium effect of carer type on emotional word use: Pillai trace=0.07, $F_{(7, 248)}$=2.75, *P*=.01, η_p^2=0.07. Welch *F* tests revealed that spousal carers used significantly more negative ($F_{(1, 242.53)}$=11.23, *P*=.001) and anxiety ($F_{(1, 215.88)}$=4.33, *P*=.04) emotion words than parental carers. Parental carers used significantly more positive emotion words than spousal carers ($F_{(1, 221.67)}$=5.12, *P*=.03). There was no difference between spousal and parental carers in the use of affective process ($F_{(1, 232.60)}$=.51, *P*=.48), anger ($F_{(1, 207.35)}$=2.56, *P*=.11), or sadness ($F_{(1, 240.15)}$=.01, *P*=.92) emotion words. See Figure 2.

There was a significant large effect of care status on emotional word use: Pillai trace=0.25, $F_{(7, 248)}$=11.72, *P*<.001, η_p^2=0.25. Welch *F* tests revealed that former carers used significantly more affective process ($F_{(1, 246.79)}$=20.70, *P*<.001), positive ($F_{(1, 256.72)}$=39.52, *P*<.001), and sadness ($F_{(1, 204.09)}$=25.54, *P*<.001) emotion words than current carers. There was no difference between current and former carers in the use of negative ($F_{(1, 212.56)}$=0.61, *P*=.44), anxiety ($F_{(1, 256.81)}$=2.73, *P*=.10), or anger ($F_{(1, 255.59)}$=2.98, *P*=.09) emotion words (Figure 3). Finally, there was no significant interaction between carer type and care status on emotional word use: Pillai trace=0.04, $F_{(7, 248)}$=1.39, P=.21, η_p^2=0.04.

Figure 2. Clustered bar chart showing the effect of carer type on emotional word use (*P<.05). Error bars represent 95% CIs. Non-log-transformed data used for illustrative purposes.

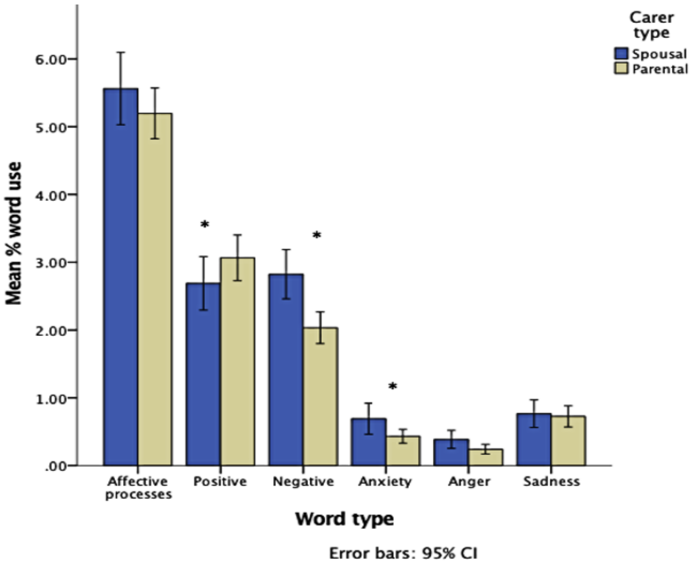
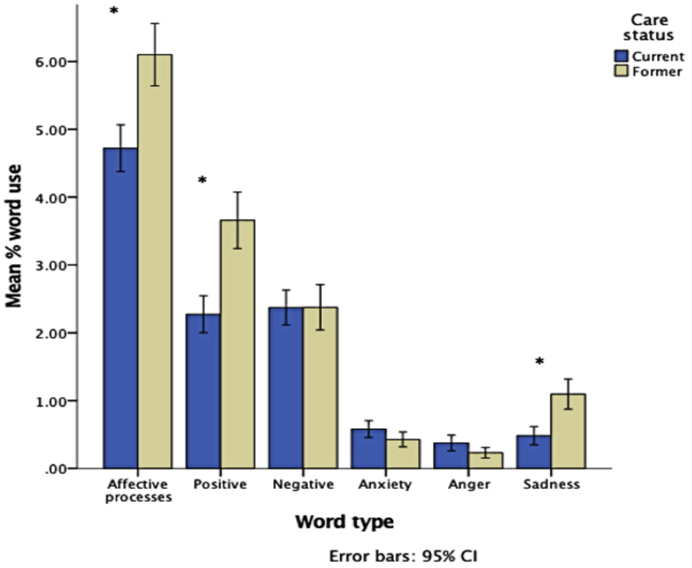


Figure 3. Clustered bar chart showing the effect of care status on emotional word use (*P<.05). Error bars represent 95% CIs. Non-log-transformed data used for illustrative purposes.



Discussion

Principal Findings

This study is the first of its kind to innovatively identify the extent to which online emotional language use differs between different groups of carers of people living with dementia, including noncarers. By examining posts on Dementia Talking Point, we were able to access naturalistic, carer-initiated, and real-time data from potentially unrepresented carers who may not take part in traditional research [43]. This provides an unbiased insight into the carers' emotional states, which may enable better identification and understanding of the needs of potentially at-risk carers so that they can be better supported in their roles [25].

In line with the first hypothesis, we found that carers of people living with dementia used more affective process, negative, anxiety, anger, and sadness words, but not more positive words, than noncarers. Given that increased use of negative words indicates greater negativity [36-38], our findings suggest that informal carers of people living with dementia may be at increased risk of negative emotional states relative to noncarers. This is perhaps unsurprising and may reflect the fact that dementia carers experience unique stressors [1,2], which may negatively impinge on their psychological health [3,7,8].

We know that carers are not a homogeneous group and that there are individual differences in response to caregiving stressors. However, the direction of these individual differences has not always been clear in the literature. We demonstrate clear differences in emotional word use across both carer type and carer status, suggesting that some groups of carers are more at risk of negative emotional states than others. For example, we found that spousal carers of people living with dementia used more negative and anxiety words than parental carers, whereas parental carers used more positive words. The carers did not differ in their use of affective process, anger, or sadness words. This suggests that spousal carers are, at least in part, more negative than parental carers, which offers partial support to the second hypothesis. Our spousal carers may be relatively more negative and anxious due to the increased burden experienced by this group compared to parental carers [12,13]. This may reflect a loss of companionship and reciprocity within the marital relationship [17], which is compounded by the fact that spousal carers typically have closer relationship ties to the care recipient than parental carers [14]. Conversely, parental carers may be more positive because they are more likely than spousal carers to have alternative roles and social activities to moderate the impact of caregiving stress on their emotional states [12]. These findings have novel implications for supportive services for spousal carers of people living with dementia. The findings suggest that spousal carers are potentially more at risk of negative emotional states than parental carers and therefore may need to be prioritized, identified, and supported to sustain them in their role [25]. Specifically, spousal carers' increased use of negative emotional language could be used by online discussion forums as a form of risk filter to provide targeted, tailored, and timely support to carers who otherwise may not have presented for support themselves [30]. Indeed, online peer support settings may be a suitable forum within which these at-risk spousal carers can be supported, not just by the service itself, but also through conversations with fellow spousal carers who may be best placed to share lived experience, advice, and guidance [31]. Research shows that this online support could potentially improve the well-being of these spousal carers by reducing anxiety and depression, increasing confidence and self-efficacy [26], and enhancing the quality of the relationship between carer and care recipient [28].

Finally, we found that former carers of people living with dementia used more affective process, positive, and sadness words than current carers. Carers did not differ in their use of negative, anxiety, or anger words. This suggests that former carers are more positive than current carers, which supports the third hypothesis. Former carers may be more positive than current carers because the people living with dementia have been admitted into a care setting, resulting in functional relief of caregiving responsibilities [22]. This may enable the carer to pursue things that were previously difficult, such as hobbies, interests, and social activities [24]. We do not suggest that former carers are entirely positive; indeed, our findings show that former carers were more emotional overall, particularly sadder, than current carers. This may reflect the sense of loss or "void" left by the care recipient after they have moved into a care setting [20]. Again, these findings are of importance to supportive service providers of current and former carers of people living with dementia. If we assume that increased positive language use in former carers indicates increased positivity, then our findings suggest that the postcaring period is not exclusively a time of negativity. Carer services, which are typically problem focused [44], should move away from a deficit approach and instead aim to routinely assess and promote the more rewarding aspects of caregiving. For example, if humor and peer support are shown to facilitate positivity in former carers, then support providers may wish to adopt an assets-based approach that celebrates the resources that carers possess rather than risk factors, challenges, and barriers alone. Indeed, recent research has shown that promoting humor and uplifts amongst an online caregiving community promotes a sense of hope and optimism [45]. Taken together, the differential patterns of emotional language and emotional states found between spousal, parental, current, and former carers reinforce the diverse heterogeneity of the caregiving population and the fact that there is no one-size-fits-all solution for support services [45]. Instead, services need to be tailored to the specific needs and circumstances of different carer types and care statuses.

Limitations

Although this study is strengthened by its innovative methodological approach, there are a number of limitations to using such methods that need to be addressed. First, by using just 1 online discussion forum, our sample comprised only carers with internet access and those who were aware of the Dementia Talking Point website [46]. Furthermore, we could only ascertain limited care demographic data; data such as care duration, gender, and time since the care recipient was admitted into a care setting would have allowed us to better understand our findings. It was apparent that the distribution of current and former carers was different in spousal and parental carers, which may have warranted further investigation. However, the relatively small and uneven subgroup sizes precluded us from conducting additional subgroup analyses and may actually reflect real-world demographic characteristics [11]. Finally, due to ethical reasons, we had limited sociodemographic information available for users of the online personal finance discussion forum we used as our control group. Variation in their sociodemographic characteristics may have unknowingly influenced our findings relating to the first hypothesis. Furthermore, if the finance forum was being used to discuss financial systems, there may have been limited opportunities for emotional word use. If being used to seek support for financial difficulties, the use of negative emotion words may have been inflated relative to a general population. Although secondary data are useful, they pose methodological constraints [47], and this somewhat limits the generalizability of our findings to the carer population.

Although the LIWC program is useful in that it allows us to analyze percentage word use, it does not consider applied meaning or contextual information. It may also make errors in identifying and counting individual words [42]. This may have resulted in the emotional valence of some words being misinterpreted, which could have affected our findings. Fortunately, this is not likely, as the LIWC program uses probabilistic models of language use [42], but future work could adopt qualitative analysis to complement the quantitative LIWC analysis; this mixed method approach would allow more in-depth analysis, which could be triangulated to ensure the rigor of the findings.

Second, we originally intended to include a variety of former carers in our sample, including bereaved former carers.

However, the 100 most recent posts that we selected did not include bereaved former carers. The emotional state of bereaved former carers is likely to be different from those who have admitted the care recipient into a care setting [24], so our findings cannot be generalized to all former carers.

Finally, this was a cross-sectional study based on discussion board posts at a given point in time. We were therefore unable to capture any changes in carers' emotional states over time. This is problematic, given that carers of people living with dementia experience changes in well-being over time [20-24]. The cross-sectional design also precluded us from examining whether the users' posts were met with support from other users. Future research should adopt longitudinal methods to examine changes in language use over time, with specific reference to how language use elicits certain patterns of online support.

Conclusion

An analysis of emotional language use on online discussion forums indicates that carers of people living with dementia may be at increased risk of negative emotional states relative to noncarers. Spousal carers may be more negative than parental carers, and former carers may be more positive than current carers. Although further mixed method research using more representative samples of carers with more sociodemographic information is required, our findings are novel and have important implications that could be of interest to supportive services in general and internet-based support platforms in particular.

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Conflicts of Interest

None declared.

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Abbreviations

LIWC: Linguistic Inquiry and Word Count

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Original Paper

The Acceptability of Digital Technology and Tele-Exercise in the Age of COVID-19: Cross-sectional Study

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Abstract

Background: With the COVID-19 pandemic, telehealth has been increasingly used to offset the negative outcomes of social isolation and functional decline in older adults. Crucial to the success of telehealth is end user adoption.

Objective: This study aims to investigate perception and acceptability of digital technology among Asian older adults.

Methods: The Healthy Ageing Promotion Program for You (HAPPY) dual-task exercise was conducted virtually to participants aged ≥60 years. Questionnaires were administered digitally and collected data on demographics, perceptions of digital technology and evaluation of HAPPY, the 6-item Lubben Social Network Scale, intrinsic capacity using the Integrated Care for Older People tool, and a functional screening with the FRAIL scale and five chair rises. Descriptive analysis was used.

Results: A total of 42 participants were digitally interviewed. The mean age was 69.1 (4.7) years. Hearing, vision, and 3-item recall difficulty were present in 14% (n=6), 12% (n=5), and 24% (n=10) of participants, respectively. Of the participants, 29% (n=12) had possible sarcopenia and 14% (n=6) were prefrail. Around 24% (n=10) were at risk of social isolation. Most of the participants (n=38, 91%) agreed that technology is good, and 79% (n=33) agreed that technology would allow them to be independent for longer. Over three-quarters of participants (n=33, 79%) agreed that they have the necessary knowledge, and 91% (n=38) had technological assistance available. However, 57% (n=24) were still apprehensive about using technology. Despite 71% (n=30) of older adults owning their devices, 36% (n=15) felt finances were limiting. Through digital HAPPY, 45% (n=19) of participants reported feeling stronger, 48% (n=20) had improved spirits, and 40% (n=17) and 38% (n=16) had improved mood and memory, respectively.

Conclusions: The majority of older adults in this study believed in digital technology and had the necessary knowledge and help, but almost half still felt apprehensive and had financial barriers to adopting technology. A digitally administered exercise program especially in a group setting is a feasible option to enhance intrinsic capacity in older adults. However, more work is needed in elucidating sources of apprehension and financial barriers to adopting technology.

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KEYWORDS

senior; telehealth; digital exercise; acceptability; telemedicine; elderly; older adults; outcome; isolation; decline; function; adoption; perception; exercise; physical activity; questionnaire; COVID-19

Introduction

State-mandated lockdowns during the COVID-19 pandemic, while necessary to curb spread, has led to social isolation, reduced physical activity, and functional decline [1]. To mitigate the effects of the pandemic, telehealth has been used in many countries to offset the negative outcomes, especially among vulnerable older adults who are often advised to stay at home [2]. There are many uses of telehealth, such as screening for geriatric syndromes, monitoring, management, and psychosocial support. Telehealth has also been used to deliver physical exercise and social activities to encourage physical activity and reduce loneliness [3,4].

The success of telehealth depends on end user adoption. Age is often quoted as a barrier to accepting new technology. Several themes and predictors have been identified in the perception and readiness of using digital technology including self-efficacy, digital literacy, obstacles to using technology, prior experience, frequency of use, sources of support, performance expectancy, perceived usefulness, social influence, computer anxiety, perceived security, and physician's opinion [5,6]. Several suggestions have been made to target these factors, such as reimbursement change, provision of telecommunication devices as a medical necessity, and improving accessibility [7].

Our paper describes technology acceptability in older adults who were undergoing an on-site frailty intervention that subsequently transited into digital form. The Healthy Ageing Promotion Program for You (HAPPY) dual-task exercise program was first rolled out in 2017. The program was adapted from Cognicise and is a group multicomponent exercise focusing on cognition and physical function, originating from the National Center for Geriatrics and Gerontology in Nagoya, Japan. Prior to the COVID-19 pandemic, this program was ongoing in more than 50 different sites with at least 700 participants across Singapore and has shown to reverse frailty and improve cognition [8] (Figure 1).

On-site HAPPY was conducted by health coaches and peer leaders who were trained to perform dual-task exercise by Japanese physiotherapists. The training program consisted of 3 sessions of theoretical training and cocreation of dual-task exercise and 8 hours of on-site training as assistant instructor and assessment (Figure 2). Digital HAPPY in early stages was led only by health coaches.

During the COVID-19 lockdown, the program was delivered virtually through the Zoom platform. More than 100 participants including their peers continued to participate. In the early phase of the national lockdown in April 2020, about 40% of participants agreed to participate in digital HAPPY, but only 14% eventually participated. As the nation remained in a semilockdown state, efforts to encourage more older adults to join the virtual platform persisted. Since March 2021, more than 700 participants now participate in digital HAPPY (Figure 3).

Initial recruitment and evaluation were focused on those who were prefrail or had underlying cognitive impairment, but anyone in the community could join in the program [8]. An invitation to participate in digital HAPPY was sent through a WhatsApp message when activities were discontinued overnight and all older adults were advised to stay at home. Participation in digital HAPPY was open to anybody who was interested, was comfortable in using the Zoom platform, and owned a personal device.

Little is known on the perception and acceptability of digital technology among Asian older adults, which is critical in increasing the uptake of telehealth. In addition, due to decline in sensory input and mobility with aging, it is less clear if tele-exercise has a perceived positive impact on older adults. Hence, as our frailty intervention underwent transition from on-site to digital, it was timely for us to study the acceptability of technology and perceived self-reported benefit of tele-exercise in our community-dwelling older adults during the pandemic lockdown.

Figure 1. The Healthy Ageing Promotion Program for You (HAPPY) conducted on-site at community centers pre–COVID-19 (left) and in outdoor spaces with social distancing post–COVID-19 (right).

Figure 2. Training program. HAPPY: Healthy Ageing Promotion Program for You.

Volunteer Training Session

Day 1
Sharing / practical training

- Overview of Dementia prevention
- Overview of HAPPY exercise class
- Practical training of HAPPY exercise

Day 2
Visit HAPPY exercise

- Observe existing HAPPY classes
- Review

Day 3
Group activities

- Invent your own HAPPY exercise
- Group presentation
- Review

Minimal 8 session
On site training

- Work as an assistant instructor
- Work as a main instructor
- Assessment session

TRAINING PROGRESS CHECKLIST

Name

HAPPY Site

PART 1
Lecture and Site Visit

☑ **Session 1**
Hands on with HAPPY exercise
Try out 6 HAPPY exercises and 10 warm-ups

☑ **Session 2**
Site visit
Observe HAPPY session conducted by HAPPY volunteers

☑ **Session 3**
Practicum
Teach HAPPY exercise to each other in groups

PART 2
Centre Attachment (4 Sessions)

☑ **Vital signs taking** Date Sign
☑ **Help warm-ups** Date Sign
☑ **Conduct warm-ups 1** Date Sign
☑ **Conduct warm-ups 2** Date Sign
☑ **Scissors, paper, stone** Date Sign
☑ **Walking in Pairs** Date Sign
☑ **Body Numbers** Date Sign
☑ **HAPPY Ladder** Date Sign
☑ **Group with Themes** Date Sign
☑ **Circuit training** Date Sign

PART 3
Assessment (2 Sessions)

☑ **Assessment 1**
Plan and conduct an entire session
Date Sign

☑ **Assessment 2**
Plan and conduct an entire session
Date Sign

HAPPY
Healthy Ageing Promotion Programme for You

For Seniors, By Seniors
Strengthen your physical and mental wellbeing

Friday 5 October 2018
5.00pm to 8.30pm
Bedok Public Library, Level 3,
Programme zone

Figure 3. Digital Healthy Ageing Promotion Program for You (HAPPY) administered over the Zoom platform. Initial roll out had several issues with the inability to turn on the camera and not knowing how to angle the camera toward themselves (left). Over the year, participants acquired skills on using Zoom (right).

Methods

This is a cross-sectional descriptive study on technology acceptability in older adults, nested as part of a larger study—the HAPPY program previously described.

Recruitment

All existing participants of digital HAPPY aged ≥60 years were invited via WhatsApp to participate in the digital survey regarding technology acceptability between September and December 2020. Positive responders were sent the weblink. Consent was taken online. Participants needed to have access to technology, defined as older adults who had devices (eg, mobile, tablet, or computer), internet connection, and ability to use WhatsApp and Zoom.

The questionnaire can be found online [9], including questions on demographics, health conditions, lifestyle habits, acceptability of digital technology, and perceived self-reported benefits of HAPPY, and were administered by a trained research assistant. Social isolation was measured using the 6-item Lubben Social Network Scale [10]. A score below 12 (maximum 30) suggests a risk of social isolation. Intrinsic capacity was measured using the Integrated Care for Older People tool administered digitally, which included questions on cognition, psychology, and vitality, and a hearing and vision screening [11]. Participants were also asked to complete five chair rises. The cutoff for possible sarcopenia was based on the Asian Workgroup for Sarcopenia 2019 recommendations of ≥12 seconds [12]. The FRAIL scale was used to screen for frailty where scores of 3 to 5 represent frail and 1 to 2 represent prefrail [13].

Statistical Analysis

As this was an exploratory descriptive study, no sample size calculation was performed. Due to the small sample size, descriptive analysis was conducted.

Ethics Approval

Ethics approval was obtained from the National Healthcare Group Domain Specific Review Board (reference number: 2020/00668). Reporting is in accordance with the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) checklist.

Results

Only 42 (14%) of the participants who participated in the first 3 months agreed to be interviewed digitally, as many were apprehensive about digital consenting. The mean age was 69.1 (SD 4.7) years; 93% (n=39) of participants were female and 29% (n=12) of participants had up to 6 years of education, with 91% (n=38) being from the Chinese ethnic group. Only 7% (n=3) were employed, 62% (n=26) were retired, and 55% (n=23) had two or more chronic illness. Hearing, vision, and the 3-item recall difficulty was present in 15% (n=6), 12% (n=5), and 24% (n=10), respectively. Functionally, 29% (n=12) had possible sarcopenia, 15% (n=6) were prefrail, and 19% (n=8) had 1 or more falls in the past year. Slightly more than 1 in 5 were at risk of social isolation. Of the social media platforms, 93% (n=39) used WhatsApp, 79% (n=33) used YouTube, 21% (n=9) used WeChat, 19% (n=8) used Telegram, and 12% (n=5) used Instagram. Only 71% (n=30) owned their own device.

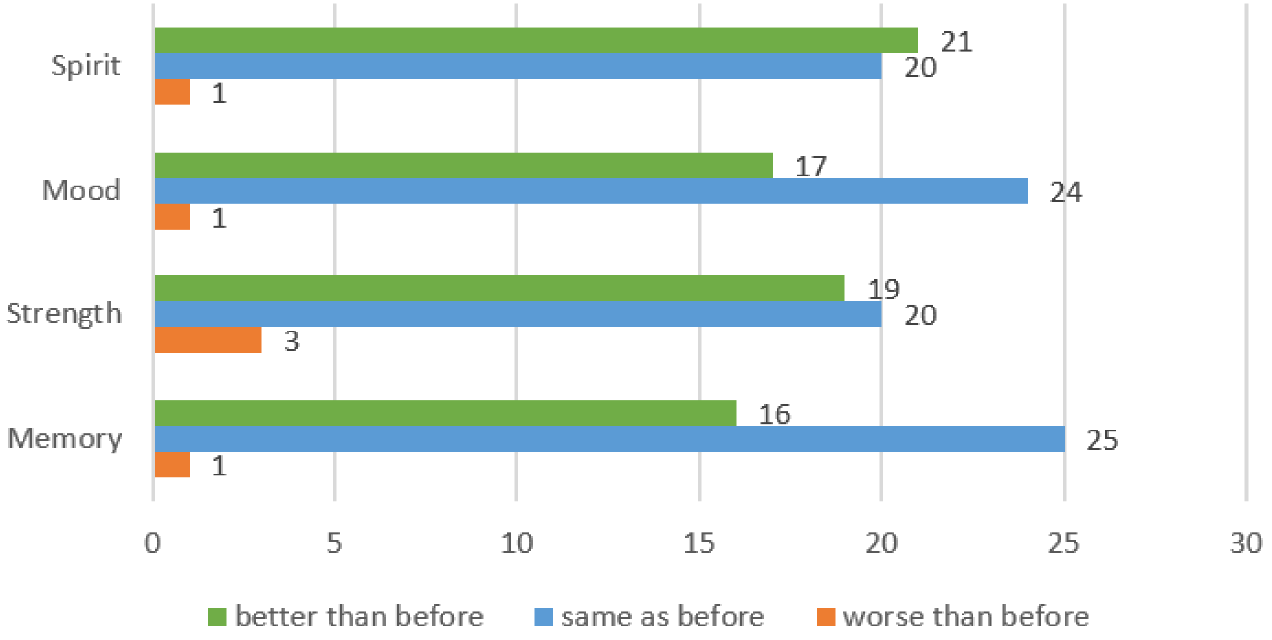
On the acceptability of technology (Table 1), 91% (n=38) agreed that technology is a good idea and 79% (n=33) agreed that technology would allow them to be independent for longer. Someone was available for technological assistance for 91% (n=38) of participants. The majority (n=36, 86%) had access to technology. Financial status did not limit their activities in using technology in 45% (n=19) of participants. Despite that 79% (n=33) agreed that they have the necessary knowledge to use the system and 86% (n=36) agreed that they could complete the task if someone showed them or through an instruction manual, 57% (n=24) were apprehensive about using technology. In addition, 41% (n=17) disagreed or were neutral that technology is easy to use and that technology is easy to learn.

Of the participants, 93% (n=39) had attended on-site HAPPY exercises before. With digital HAPPY, 45% (n=19) reported feeling stronger than before, 48% (n=20) reported improvement in spirits, 40% (n=17) improvement in mood, and 38% (n=16) reported improvement in memory (Figure 4).

Table 1. Acceptability of technology in older adults (N=42).

	Strongly disagree, n (%)	Disagree, n (%)	Slightly disagree, n (%)	Neutral, n (%)	Slightly agree, n (%)	Agree, n (%)	Strongly agree, n (%)
You have the knowledge necessary to use the system	0 (0)	6 (14)	0 (0)	3 (7)	10 (24)	20 (48)	3 (7)
A specific person (or group) is available for assistance with technology difficulties	0 (0)	2 (5)	0 (0)	2 (5)	1 (2)	36 (86)	1 (2)
Your financial status does not limit your activities in using technology	0 (0)	15 (36)	0 (0)	8 (19)	1 (2)	17 (41)	1 (2)
When you want or need to use technologies, they are accessible for you	0 (0)	4 (10)	1 (2)	1 (2)	1 (2)	34 (81)	1 (2)
Your family and friends think/support that you should use technology	0 (0)	1 (2)	0 (0)	7 (17)	1 (2)	32 (76)	1 (2)
Using technology is a good idea	0 (0)	2 (5)	0 (0)	2 (5)	3 (7)	24 (57)	11 (26)
Using technology would allow you to be independent for longer	1 (2)	4 (10)	0 (0)	4 (10)	3 (7)	24 (57)	6 (14)
Technology is easy to use	0 (0)	5 (12)	5 (12)	7 (17)	7 (17)	17 (41)	1 (2)
Technology is easy to learn	0 (0)	6 (14)	4 (10)	7 (17)	10 (24)	15 (36)	0 (0)
You could complete a task using technology if there is someone to demonstrate how	1 (2)	3 (7)	1 (2)	1 (2)	10 (24)	21 (50)	5 (12)
You could complete a task using technology if you have just the instruction manual for assistance	1 (2)	1 (2)	2 (5)	2 (5)	12 (29)	22 (52)	2 (5)
You feel apprehensive about using the technology	0 (0)	13 (31)	1 (2)	4 (10)	10 (24)	12 (29)	2 (5)

Figure 4. Bar Chart of Characteristics Before and After Online HAPPY Intervention. HAPPY: Healthy Ageing Promotion Program for You.



Discussion

Principal Findings

Our study is particularly relevant during the current COVID-19 pandemic, with the reinforcement of social distancing especially among older adults. More than three-quarters of the seniors had the necessary knowledge to use the system. COVID-19 has accelerated technology adoption among older adults not only in the health care sector but also on social platforms, education, grocery and food delivery, socialization, and tele-exercise. Almost all the older adults used WhatsApp and more than three-quarters used YouTube.

Odeh and colleagues [14] found that older adults were generally satisfied with equipment use and not concerned about confidentiality or absence of direct contact with health care, and telehealth increased their self-efficacy in managing their own health. Results of our survey indicate that more than three-quarters of older adults acknowledged the potential of technology in keeping them independent for longer. Help from family and friends was also available when needed, which may reflect the benefits of living in multigenerational homes typical of an Asian society.

While the majority had access to technology, finance was an issue for more than half. The digital divide can be affected at four different levels including motivational access, material access, skills access, and use access [15]. Nearly half of our participants were neutral or disagreed that technology is easy to use and learn, with more than half of participants feeling apprehensive about technology. Hearing, vision, or cognitive impairment could have contributed to the difficulties. Further studies are needed to identify sources of these apprehension to address them. Navigating the complexity of technology, such as purchasing and learning to use the equipment or app and connecting to the internet, requires upskilling of the older adults, as well as providing them with financial resources. Singapore launched the Seniors Go Digital initiative in May 2020 and has made the phone plans and equipment more affordable for older adults to reduce the digital divide [16]. There has been workflows instituted since the advent of COVID-19 to facilitate this [17], but policies continue to evolve to make health care and services more accessible.

There has been emerging research on digitally administered social activities and exercise for improving strength and reducing falls and loneliness, and studies have shown that uptake was influenced by perceived usefulness, enjoyment, social influence, gender, experience, and ease of use among other factors [18]. One in two older adults are at risk of social isolation locally but only one in four of our participants were at risk [19]. Many of them were already participating in HAPPY exercises before going digital and were socially connected prior to the lockdown. Older adults reported feeling stronger, better spirit, and improved mood and memory after participating in digital HAPPY. Improvement in mental and physical health have been shown with physical exercise, but the benefits seen and attained with tele-exercise during the pandemic lockdown is even more crucial to reduce functional decline and loneliness. We have previously found that these activities provide windows of opportunities used to digitally assess sarcopenia risk, suggesting that both screening and intervention can be performed on the same platform [20]. Hence, tele-exercise helped improve access and ensure they remained connected with the wide community even during social distancing.

To summarize, our study indicates that older adults are more than happy to adopt digital technology, and tele-exercise can feasibly be used to prevent and delay functional decline and loneliness. More work needs to be done on improving electronic interfaces that can be user friendly to older adults who have multiple sensory impairments and joint disability. While these efforts in reducing the digital divide and improving access to telehealth and digital technology are still underway, in certain population groups such as those with sensory or cognitive impairment, in-person clinic or home visits would still be the mainstay.

The majority of older adults believe in digital technology and have the necessary knowledge and help, but almost half still feel apprehensive and have financial barriers to adopting technology. A digitally administered exercise program especially in a group setting is a feasible option to improve function.

Limitations

Our participants are not representative of a community sample, as they were preselected themselves to participate in digital HAPPY, and those who agreed for the digital interview already had the necessary knowledge. Despite that, more than half of the participants were apprehensive and cited financial barriers to access technology. While our study population is small, it did show that tele-exercise is beneficial in improving physical and cognitive function. Further population studies are needed to identify the areas of apprehension to and benefits of initiatives and taking up Seniors Go Digital.

Conclusions

Digital technology including telehealth is increasingly important in this COVID-19 era. Older adults are generally accepting of technology, with top barriers being technology specific, and they are willing to adopt and adapt. However, more studies are needed to elucidate the source of their apprehension and to guide interventions to boost telemedicine infrastructure. Tele-exercise has the potential to be a useful modality to reduce functional decline and social isolation in older adults.

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Conflicts of Interest

None declared.

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Abbreviations

HAPPY: Healthy Ageing Promotion Program for You
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

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Original Paper

Barriers to Telemedicine Video Visits for Older Adults in Independent Living Facilities: Mixed Methods Cross-sectional Needs Assessment

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Abstract

Background: Despite the increasing availability of telemedicine video visits during the COVID-19 pandemic, older adults have greater challenges in getting care through telemedicine.

Objective: We aim to better understand the barriers to telemedicine in community-dwelling older adults to improve the access to and experience of virtual visits.

Methods: We conducted a mixed methods needs assessment of older adults at two independent living facilities (sites A and B) in Northern California between September 2020 and March 2021. Voluntary surveys were distributed. Semistructured interviews were then conducted with participants who provided contact information. Surveys ascertained participants' preferred devices as well as comfort level, support, and top barriers regarding telephonic and video visits. Qualitative analysis of transcribed interviews identified key themes.

Results: Survey respondents' (N=249) average age was 84.6 (SD 6.6) years, and 76.7% (n=191) of the participants were female. At site A, 88.9% (111/125) had a bachelor's degree or beyond, and 99.2% (124/125) listed English as their preferred language. At site B, 42.9% (51/119) had a bachelor's degree or beyond, and 13.4% (16/119) preferred English, while 73.1% (87/119) preferred Mandarin. Regarding video visits, 36.5% (91/249) of all participants felt comfortable connecting with their health care team through video visits. Regarding top barriers, participants at site A reported not knowing how to connect to the platform (30/125, 24%), not being familiar with the technology (28/125, 22.4%), and having difficulty hearing (19/125, 15.2%), whereas for site B, the top barriers were not being able to speak English well (65/119, 54.6%), lack of familiarity with technology and the internet (44/119, 36.9%), and lack of interest in seeing providers outside of the clinic (42/119, 35.3%). Three key themes emerged from the follow-up interviews (n=15): (1) the perceived limitations of video visits, (2) the overwhelming process of learning the technology for telemedicine, and (3) the desire for in-person or on-demand help with telemedicine.

Conclusions: Substantial barriers exist for older adults in connecting with their health care team through telemedicine, particularly through video visits. The largest barriers include difficulty with technology or using the video visit platform, hearing difficulty, language barriers, and lack of desire to see providers virtually. Efforts to improve telemedicine access for older adults should take into account patient perspectives.

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KEYWORDS

telemedicine; barriers to access to care; older adults; eHealth; e-visit; access; accessibility; barrier; elder; gerontology; geriatric; need assessment; mixed method; cross-sectional; telehealth; community care; independent living

Introduction

Telemedicine, the practice of medicine using technology to deliver care at a distance, is an innovation with increasing uptake across the United States [1,2]. During the COVID-19 pandemic, the availability of telemedicine has skyrocketed due to waivers from the Centers for Medicare & Medicaid Services and other insurance providers, which have decreased restrictions on telemedicine use and increased payment parity compared with in-person visits [3,4]. Telemedicine visits enable patients to receive care remotely; they decrease the risk of infectious exposure for patients who are more vulnerable and increase the ease of access to care by decreasing cost, transportation challenges, and time spent going to see outpatient providers [5,6]. Among Medicare Advantage enrollees from January to June 2020, the weekly number of telemedicine visits increased 20-fold compared with prepandemic periods [7]. Many are hopeful for continued widespread use even beyond the pandemic [8].

Despite the increasing availability of telemedicine and its many advantages, older adults experience high barriers to access compared to younger adults [9,10]. A Pew Research report published in 2017 demonstrates that, while there is increasing internet and home broadband use among older adults, increasing age is still associated with a lack of confidence in using electronic devices [11]. It is estimated that 38% of US adults older than 65 years are not ready for video visits and that 72% of adults older than 85 years are not ready for video visits due to difficulties with hearing, vision, speaking, cognition, or difficulty with access or familiarity with internet-enabled devices [9]. One study of homebound older adults found that 82% of patients in one home-based primary care program required assistance from a caregiver to participate in virtual visits [12]. Providers were aware that barriers for these patients included cognitive or sensory impairment, but they were not knowledgeable about key access-related issues, such as their patients' internet connectivity, ability to pay for cellular plans, or video-capable device access.

While much has been published on the feasibility of telemedicine in older adults domestically and abroad [13-18], there is limited information regarding the challenges of telemedicine from the perspective of patients. Existing work in the United States tends to focus on homogeneous English-speaking older adults [19-22]. To address this gap, we investigated the top barriers to telemedicine visits from the perspectives of older adults with differing socioeconomic backgrounds and primary spoken languages in two independent living facilities in Northern California. Our goal is to better inform proposed solutions to improve telemedicine access for diverse community-dwelling older adults.

Methods

Overview

We conducted a mixed methods needs assessment of two independent living facilities in Northern California as part of a quality improvement project to increase telemedicine access. Voluntary surveys (Multimedia Appendix 1) in English, Chinese, and Russian were distributed to older adults residing in the independent living facilities at both sites. Surveys were distributed by staff at each site as paper or electronic surveys to ensure accessibility. Site A houses residents who are mostly middle and upper-middle class native English speakers. Site B provides subsidized senior housing and serves a large group of non–English-speaking residents. These two sites were chosen to better understand the needs of older adults with differing socioeconomic and language backgrounds.

Surveys queried demographic information including gender, education level, preferred language, and residents' previous experiences and preferences with technology or devices. While five-point Likert scales assessed comfort level, support, desire for, and barriers regarding telephone and video visits (Multimedia Appendix 1), responses were categorized as "agree" if participants selected "agree" or "strongly agree," and "disagree" if they selected "disagree" or "strongly disagree." Caregivers served as proxies for residents who could not physically respond. Surveys were translated from English to Russian and Chinese by independent researchers (authors LT and AX) to better serve residents in site B.

Follow-up semistructured phone interviews were conducted with surveyed participants who provided their contact information and were willing to speak to investigators to elaborate on perceived barriers (n=15; 8 participants from site A and 7 from site B). The questions asked during these interviews are reproduced in Multimedia Appendix 2. These interviews were deidentified and then translated and transcribed. Interview analysis followed the tenets of thematic analysis as described by Clarke and Braun [23], in which an inductive approach was taken and emerging concepts from the interviews were tagged as codes and then grouped into categories and ultimately themes. All interviews were independently read and coded with descriptive labels by three investigators (authors AM, AX, and M Mesias). Investigators met to discuss the coded transcripts halfway through reading all the interviews to resolve any coding discrepancy and, through consensus, finalize a set of codes used to code the rest of the transcripts as well as to recode prior transcripts. Final descriptive codes and representative quotes were then coalesced into broad categories and reviewed to identify emerging themes through an iterative process of discussion and collective consensus.

Ethical Considerations

Given that this is a quality improvement project and not human participant research, this study received institutional review board (IRB) exemption from the Stanford University (IRB Protocol 58211).

Results

Demographics

Of the 700 surveys distributed, 249 surveys were completed (245 by patients, 4 by caregiver proxies). There were 125 participants from site A, 69.3% (n=87) of whom were female. Site B had 119 participants, with 84.9% (101/119) being female participants. There were 5 participants that did not designate a site on their survey and were excluded from site-specific analyses. At site A, the average age of participants was 85.5 (SD 6.6) years, while at site B, the average age was 83 (SD 6.6) years. When combined, the average age of all participants was 84.3 (SD 6.7) years. At site A, 88.9% (111/125) of participants had a bachelor’s degree or beyond, and 99.2% (124/125) listed English as their preferred language. At Site B, 42.9% (51/119) had a bachelor’s degree or beyond, and 13.4% (16/119) preferred English, while 73.1% (87/119) preferred Mandarin. Demographic information of survey participants is recapitulated in Table 1.

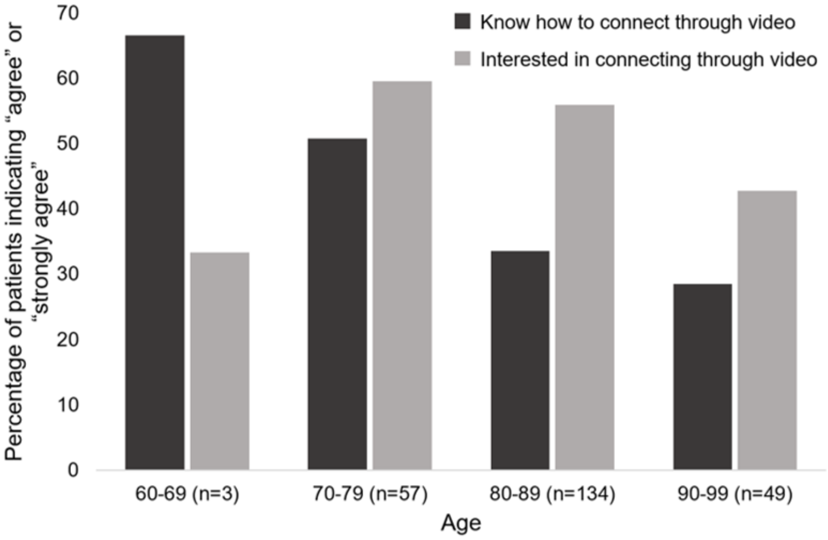
Table 1. Demographic information of survey participants. Participants from two independent living facilities were selected to ascertain the barriers that older adults experience in accessing telemedicine and to conduct a quality improvement project.

	Site A (n=125)	Site B (n=119)	Combined (N=249)
Age (years), mean (SD)	85.5 (6.6)	83.0 (6.6)	84.3 (6.7)
Age groups (years), n (%)			
60-69	0 (0.0)	3 (2.5)	3 (1.2)
70-79	23 (18.4)	31 (26.1)	57 (22.9)
80-89	70 (56.0)	63 (52.9)	134 (53.8)
90-99	29 (23.2)	20 (16.8)	49 (19.7)
≥100	0 (0.0)	3 (2.5)	3 (1.2)
Gender, n (%)			
Male	38 (30.4)	14 (11.8)	53 (21.3)
Female	87 (69.3)	101 (84.9)	191 (76.7)
Unspecified	0 (0.0)	4 (3.4)	5 (2.0)
Race/ethnicity, n (%)			
White	116 (92.8)	22 (18.5)	138 (55.4)
Non-White	9 (7.2)	97 (81.5)	111 (44.6)
Preferred language, n (%)			
English	124 (99.2)	16 (13.4)	143 (57.4)
Other	1 (0.8)	103 (86.6)	106 (42.6)
Level of education, n (%)			
No bachelor’s degree	14 (11.2)	65 (54.6)	79 (31.7)
Bachelor’s degree and beyond	111 (88.8)	51 (42.9)	166 (66.7)

Survey Responses Regarding Use and Interest in Telemedicine

Regarding telemedicine visits, of the 249 participants 53% (n=132) of all participants were interested in connecting with their health care team through video visits, and 65.5% (n=163) preferred connecting through telephone. Regarding telemedicine comfort, 69.9% (174/249) of participants knew how to connect with their health care team through telephone. However, only 36.5% (n=91) knew how to connect with their health care team through video visits. Of those 91 participants, 68% (n=61) were from site A. For the 91 participants that were comfortable using video platforms, computers were the most preferred device (n=20, 23%), followed by smartphones (n=17, 19%) and iPads/tablets (n=10, 11%). We found that, while comfort with video visits decreased with increasing age (coefficient of determination, R^2=0.96), it appears that increased age was not associated with decreased interest in telemedicine video visits (R^2=0.07; Figure 1).

Figure 1. Age is associated with decreases in comfort with technology but not interest in telemedicine. While participants' comfort with video visits decreased with increasing age (R2=0.96), interest in video visits was not associated with age (R^2=0.07) in participants aged 60-99 years.



Barriers Surrounding Telemedicine

The largest reported barriers to telemedicine visits for the 249 participants were hearing difficulties (n=89, 35.7%), not being familiar with how to use technology or the internet (n=75, 30.1%), not knowing how to get connected to the telemedicine platform (n=74, 29.7%), and language barriers (n=66, 26.5%; Figure 2). Of note, 65 of the 66 responses that indicated "cannot speak English very well" as a top barrier came from participants at site B. Other barriers from both sites included lack of interest in seeing providers outside of a clinic (n=61, 24.5%); poor internet connectivity (n=39, 15.7%) or lack of smart device (n=32, 12.9%); or difficulties with attention and memory (n=33, 13.3%), expressing oneself (n=31, 12.4%), or seeing (n=21, 8.4%).

Top barriers differed depending on the site (Figure 3). The top three barriers reported for the 125 participants at site A included not knowing how to connect to the platform (n=30, 24%), not being familiar with the technology (n=28, 22.4%), and difficulty hearing (n=19, 15.2%). At site A, 30% (n=37) of participants did not perceive any barriers to accessing telemedicine via video visits. The top barriers reported by 119 participants at site B included not being able to speak English well (n=65, 54.6%), not being familiar with the technology or internet (n=44, 37%), and lack of interest in seeing a provider outside of the clinic (n=42, 35.3%).

Figure 2. Perceived barriers to accessing telemedicine from both sites. Participants from both sites were asked to choose the biggest barriers (up to three) to connect with health care providers through video visits. Top perceived barriers reported include hearing difficulties, unfamiliarity with technology/internet or how to connect to the telemedicine platform, and language barriers.

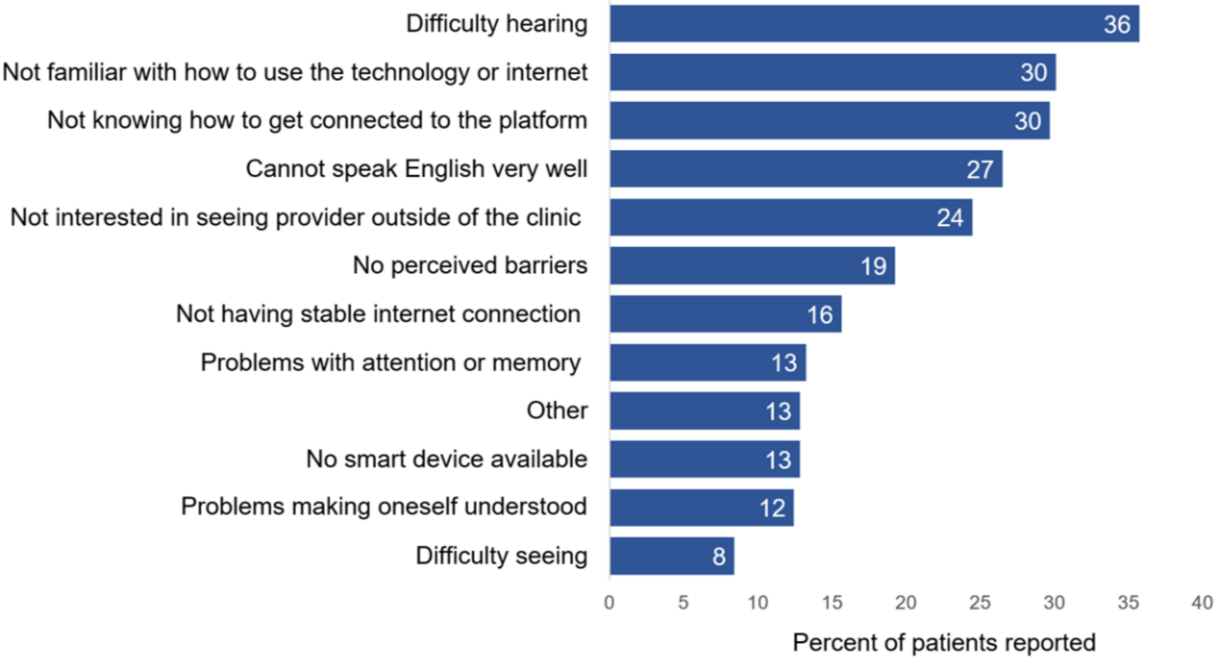
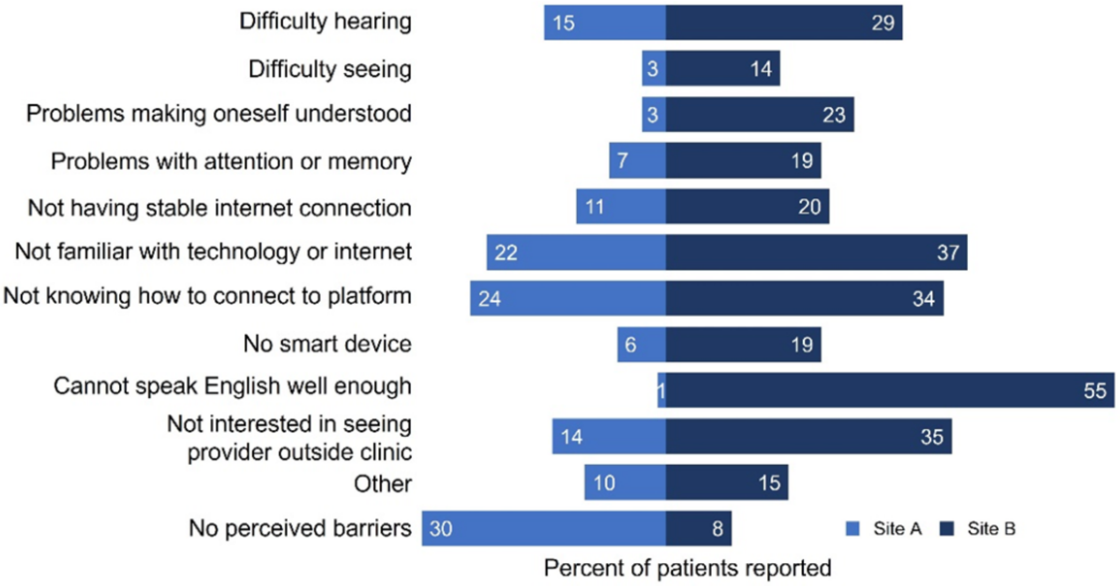


Figure 3. Site-specific perceived barriers to telemedicine access. When broken down by sites, top barriers differed. Site A participants cited unfamiliarity with technology/internet and connecting to the telemedicine platform, and hearing difficulties. Similarly, site B participants reported unfamiliarity with technology/internet and connecting to the telemedicine platform, though other major barriers included difficulty with English and lack of interest in seeing providers outside of the clinic.



Qualitative Themes

Several themes emerged from interviews exploring participants' reported barriers regarding telemedicine perceived limitations of video visits, the overwhelming process of learning the technology for telemedicine, and desire for in-person or on-demand help with telemedicine.

Perceived Limitations of Video Visits

While most survey respondents expressed interest in connecting with their health care provider through telemedicine, many participants highlighted the limitations of telemedicine in comparison to in-person visits. One participant expressed the limitations of video visits in assuring a comprehensive workup:

> *Through video, there is no way to measure blood pressure...I can only tell you I don't feel comfortable. If I were the doctor, hearing what I said, I would not know what to do because the symptoms are too broad.*

Another participant noted that "video chats only solve part of the problem," and that for regular checkups, she would still need to call and present herself to a health care facility. These perspectives highlight a perception of the lack of completeness of care when done through video visits.

Participants also described hesitancy to replace the much valued in-person experience with their health care provider. For instance, one participant stated:

> *I would rather that the doctor can actually touch me, examine me with a stethoscope, or see if a part is tender...I also think in-person communication is sometimes better...*

Other participants describe preferring to speak to a human rather than technology and the experience of desiring personal contact and seeing expressions.

The Overwhelming Process of Learning the Technology for Telemedicine

One significant barrier surrounding telemedicine was the lack of familiarity with technology and the telemedicine platform. Some participants noted that they were intimidated by technology due to their age. One participant explained:

> *So I got an iPhone, it's daunting as a 90-year-old. It's got a billion buttons. I went out and purchased the manual, which is not produced by Apple--it's produced by other people because Apple just presumes that people know how to use it [iPhone]*

Some participants expressed familiarity with using technological devices for socialization and record keeping; the process of using unfamiliar with video platforms for telemedicine was more daunting. One participant highlighted this dichotomy well:

> *I have a really old device and I use it to keep in contact with relatives & keep updated with the news...There are many steps to book the [telemedicine] app, I have received a lot of information (eg. email) on how to connect. I feel like I am not smart enough to persist through the whole [set of instructions]*

Others corroborated that they are reluctant to do video visits because "I just don't enjoy setting it up." They noted the process is cumbersome, and they need to experiment and get outside help before knowing how to navigate the platforms. Even for those who have successfully set up video visits in the past, the challenges of remembering how to log back on and remembering one's password make the process difficult. One participant explained:

> *I can't tell you how many times I've had to change my password...If my fingers hit the wrong button [the platform] notifies me the password is not*

> *working…We've had to reset the password 2-3 times and it took at least 2-3 hours to get a new password.*

Some noted that they are familiar with platforms they already use such as Zoom or WeChat and would prefer if their care providers switched to simpler platforms for telemedicine video visits:

> *[The telemedicine platform is] very complicated -- much more so than Zoom. I have very poor vision and I'm old and it's no good for me... I think just having help at the time I have to get on is the best or you should switch to a simpler system.*

Furthermore, for the participants who did not speak English as their primary language, setting up telemedicine visits involved an added layer of difficulty as most of the instructions are in English. One participant elaborated:

> *If I use English, it will be very hard. I am comfortable with computers, and am willing to give it a try...I hope there is someone who speaks Chinese to help with technology.*

Some participants reported relying on a spouse, an adult child caregiver, or a social worker to aid with these language barriers.

Desire for In-Person or On-Demand Help With Telemedicine

Given the complexity of the setup process and the different telemedicine platforms used by different health care providers, participants noted the importance of having in-person help to establish video visits. For example:

> *I need a person to sit down with me next to my computer to help me set up my account: here's the icon you click on, the name of your account, where you keep your password, how you enter and use it...I need personal help.*

Many recognized that in-person assistance was not always feasible or safe during times of quarantine during the COVID-19 pandemic and hoped for easier access to on-demand assistance with troubleshooting. One participant recalled a story in which she followed all the instructions for downloading the video visit platform and did not understand the step about clearing cookies on her computer and went online to find the information technology desk number for help. She relayed:

> *until you give thorough instructions, it's not going to work. A lot of people give up. A live body [to help] would be the best thing.*

Another participant emphasized the specialized help needed for older adults:

> *[My healthcare system] is investing a lot in telemedicine. It would be good to have a team of helpers who could help a patient, mostly older people, and get in touch in advance to help them set up appointments.*

Others voiced frustrations with being placed on hold for a long time when trying to call their clinic for assistance.

Discussion

Of the 249 older adults who completed our survey, most (53%, 132/249) were interested in using telemedicine to connect with care providers through video visits. While older age was associated with decreasing familiarity with technology, it did not diminish interest in telemedicine. Participants identified several barriers regarding telemedicine use, especially in conducting video visits. The top barriers included not knowing how to connect to the platform (including language barriers that make instructions difficult to understand), not being familiar with the technology, difficulty hearing, and lack of interest in seeing providers outside of the clinic.

The digital divide for older adults, who experience challenges with using telemedicine, is well documented [9-12,14,15]. While some have hypothesized as to why these challenges exist from secondary proxies such as insurance data and provider surveys, our study elucidates some of the unique barriers from the perspective of community-dwelling older adults themselves.

We found that older adults are more familiar with telephone than online video platforms, though the majority of participants were interested in learning to use both as a means of connecting with their providers. Similar to a study on older adults' experiences with technology for socialization [24], we found that, while some older adults are familiar with more widespread technological platforms for social connection, it becomes much more challenging to set up telemedicine platforms for video visits. The challenges of adopting telemedicine for older adults is partly due to a lack of familiarity with video and internet technology and partly due to the challenges of adopting new technological skills in the face of increasing functional deficits such as hearing, vision, memory, and cognition [9]. Given a multitude of institution-specific platforms used for telemedicine, it is important to make sure platforms are streamlined and easy to use or consider adopting platforms that already have widespread social adoption. On demand telephone or in-person support for troubleshooting and caregiver training will also help, as many older adults rely on caregivers and adult children for technology assistance.

Our participants also highlighted the challenges of navigating telemedicine platforms when English is not their first language. Socioeconomic disparities in digital access are well documented [25], and it has been shown that non-White patients, patients who needed interpreter services, and patients who received Medicaid were less likely to have video visits [26]. Actionable steps toward ameliorating these disparities include creating simple instructions in multiple languages for how to use telemedicine platforms and offering language and culturally concordant telemedicine training.

We found that in addition to technology barriers, there are nuanced reasons for reluctance in older adults to conduct video visits. Reluctance to adopt telemedicine may stem from the perception that video visits are inferior to in-person care due to the lack of human touch possible through the physical exam. This is congruent with a national survey of older adults whose chief concern about telemedicine focused on limitations in physical exam and worries about decreased quality of care and connection to providers [27]. However, once older adults have successfully completed a telemedicine visit, they are more willing to continue using telemedicine as part of their care, especially to see providers with whom they have prior established in-person relationships [16]. As telemedicine becomes a greater staple in modern care delivery even beyond the pandemic [28,29], it is important to have clear messaging about the role of telemedicine in augmenting, not replacing, in-person care. When used properly, telemedicine services have the potential to improve health outcomes, access and timeliness of care, and at-home management of chronic disease [30-32]. Improving understanding of telemedicine, specifically increasing education about its role and limitations to the older adult population, may clarify misconceptions and further encourage adoption.

This is a community-based study and has some limitations. Sites A and B are not representative of all older adult residents; we chose these sites to better understand the barriers regarding telemedicine access within our community independent living facilities, as there was a wide range of ages, socioeconomic backgrounds, and primary languages spoken. Furthermore, there may be selection bias given the voluntary nature of the surveys completed; data represent only those who were willing and available to participate.

The COVID-19 pandemic necessitated the rapid scale-up of both provider use and patient adoption of telemedicine. There was little time available to elicit patient perspectives in the process of designing technological platforms for care delivery. Older adults make up many patients in our health care system, though their perspectives are rarely formally elicited. Decreased use of telemedicine exposes this already vulnerable population to further health care inequities. In our study, we surveyed the perspectives of older adults to ascertain their perceived barriers to telemedicine access and highlight themes that further our understanding of the challenges that lead to decreased access to care. Due to site-specific differences in reported telemedicine barriers, any intervention to improve access should be tailored to the specific needs of that site. Our study will not only inform our own quality improvement initiatives in our community but also, we hope, open the door to larger scale studies in understanding the patient experience as telemedicine becomes a larger cornerstone of care delivery.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
The survey distributed to older adults residing in the independent living facilities at both sites.
[DOCX File , 17 KB - aging_v5i2e34326_app1.docx]

Multimedia Appendix 2
Questions that were asked of older adults that opted for a follow-up interview by phone.
[DOCX File , 14 KB - aging_v5i2e34326_app2.docx]

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Abbreviations

IRB: institutional review board

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Original Paper

The Factors Associated With Nonuse of Social Media or Video Communications to Connect With Friends and Family During the COVID-19 Pandemic in Older Adults: Web-Based Survey Study

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Abstract

Background: Digital technologies have enabled social connection during prolonged periods of physical distancing and travel restrictions throughout the COVID-19 pandemic. These solutions may exclude older adults, who are at higher risk for social isolation, loneliness, and severe outcomes if infected with SARS-CoV-2.

Objective: This study investigated factors associated with nonuse of social media or video communications to connect with friends and family among older adults during the pandemic’s first wave.

Methods: A web-based, cross-sectional survey was administered to members of a national retired educators’ organization based in Ontario, Canada, between May 6 and 19, 2020. Respondents (N=4879) were asked about their use of social networking websites or apps to communicate with friends and family, their internet connection and smartphone access, loneliness, and sociodemographic characteristics. Factors associated with nonuse were evaluated using multivariable logistic regression. A thematic analysis was performed on open-ended survey responses that described experiences with technology and virtual connection.

Results: Overall, 15.4% (751/4868) of respondents did not use social networking websites or apps. After adjustment, male gender (odds ratio [OR] 1.60, 95% CI 1.33-1.92), advanced age (OR 1.88, 95% CI 1.38-2.55), living alone (OR 1.68, 95% CI 1.39-2.02), poorer health (OR 1.33, 95% CI 1.04-1.71), and lower social support (OR 1.44, 95% CI 1.20-1.71) increased the odds of nonuse. The reliability of internet connection and access to a smartphone also predicted nonuse. Many respondents viewed these technologies as beneficial, especially for maintaining pre–COVID-19 social contacts and routines, despite preferences for in-person connection.

Conclusions: Several factors including advanced age, living alone, and low social support increased the odds of nonuse of social media in older adults to communicate with friends and family during COVID-19’s first wave. Our findings identified socially vulnerable subgroups who may benefit from intervention (eg, improved access, digital literacy, and telephone outreach) to improve social connection.

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KEYWORDS

digital technology; loneliness; older adults; COVID-19; elderly; lonely; mental health; factor; usage; social media; video; communication; connection; connect; family; friend; age; support

Introduction

Digital technologies have brought people together while maintaining physical distance during the novel COVID-19 pandemic [1], with more older adults reporting use of technology to connect virtually with family and friends than ever before. The 2020 Canadian Internet Use Survey found that almost one-third (29%) of older adults aged ≥65 years reported using these services more often since the pandemic, whereas 18% indicated that the pandemic was the first time they communicated with family or friends using video platforms [2]. Although these technologies remain a lifeline to many, there are concerns that technology-based solutions may exclude many older adults, who are at higher risk for social isolation and loneliness and less likely to have the knowledge or capacity to use these technologies [3,4]. Moreover, vaccine rollouts in many regions of North America have relied on complicated websites to book appointments, require internet access and email addresses or mobile phone numbers capable of receiving text messages for registration, and use social media platforms to advertise immunization clinics. This all leads to important access barriers for older adults who are also at greater risk of severe outcomes if infected with SARS-CoV-2 [5].

Prior to the pandemic, research has shown that older adults of advanced age, men, those with lower household income and education, those living alone, those who are Black or Hispanic, or those with a disability are less likely to use the internet and health information technology [6-9]. Digital access (eg, internet access and device affordability), capacity (eg, vision or hearing issues), and an understanding of how to use these technologies are also important [3]. With the dramatically shifting landscape, what is less clear is who is being left behind in this upswell of new users. Since technology has played a vital role during this pandemic and will continue to do so postpandemic, timely data on nonusers are important to appropriately target interventions and supports. We conducted a survey among community-dwelling older Canadians to assess their use of social media or video communications to connect with friends and family and examined factors associated with their nonuse of this technology early in the COVID-19 pandemic.

Methods

Web-Based Survey

We conducted a closed, web-based, and cross-sectional survey with members of a national retired educators' organization (RTOERO) between May 6 and 19, 2020. More than three-quarters of the members (76.5%, 62,000/81,000) had registered an email address with the organization and were eligible to participate. Members were invited by email from RTOERO's chief executive officer and sent reminders at 7 and 10 days. Study materials were provided in English and French. The questionnaire was co-designed and pretested with RTOERO leadership and included 32 questions that examined the impact of COVID-19 on daily life, loneliness, and the use of digital technologies for social connectivity [10].

Social media and video communication use was measured by asking "Do you use any social networking websites (eg, Facebook) or apps (eg, Zoom or FaceTime) to communicate with friends and family?" (yes/no). Respondents were also asked about their internet connection, smartphone access, loneliness, and sociodemographic characteristics including age, gender, ethnicity, language, living arrangement, self-perceived health status and location of residence (rural/urban). The questionnaire was pretested in English with 18 RTOERO board members and staff and French with 1 staff member for usability, technical functionality, clarity, flow, sensitive questions, and timing. The pretest results were not included in the final analysis. In the pretest, it took respondents on average 13 minutes to complete the survey (median: 14 minutes).

Surveys were only analyzed if the respondent clicked "Submit" and responded to more than 1 question. Nonusers of social media were compared to users through Pearson chi-square tests in univariable analyses on sociodemographic factors (age, gender, rurality, health status, and ethnicity), access factors (internet connection and smartphone access), and relational factors (living arrangement, loneliness, communication frequency, and social support). Corresponding adjusted associations were made using multivariable logistic regression including all covariates in the model. Survey questions on gender and ethnicity included "Prefer to self-identify" or "Prefer not to say" response options, which were collapsed into an "Other" category and retained in the regression analysis. Otherwise, respondents with missing (ie, don't know or blank) covariate values were excluded from the model.

We conducted an inductive thematic analysis of free-text responses to 4 survey questions that included an open-ended response option; these questions asked respondents to describe feelings of loneliness, strategies they use to avoid feeling lonely, how RTOERO could support members, and if they had any other comments or suggestions. Responses were reviewed for descriptions of experiences with virtual connection and a set of 14 initial codes were generated by the analyst (SDN) and discussed with the study team. Themes were identified by examining patterns across the codes and were presented, along with illustrative quotations, to both the study team and RTOERO members for input and reflection.

Ethics Approval

Participation was voluntary, and informed consent was obtained electronically. The study was approved by the Research Ethics Board at Women's College Hospital (#2020-0051-E) and reporting followed the Checklist for Reporting Results of Internet E-Surveys [11].

Results

The survey completion rate among those who consented to participate was 88.8% (4891/5509). There were 12 respondents excluded who answered ≤1 question, leaving 4879 respondents in the final analysis. Most respondents were women (71%, 3421/4818), aged 65-79 years (67.4%, 3279/4863), White (91.6%, 4454/4861), and in good self-reported health (89.7%, 4370/4873; Table 1); this age and sex distribution mirrored the broader RTOERO membership (67% women and 14.5% aged <65 years, 64% aged 65-79 years, and 21.5% aged ≥80 years; personal communication by JG). Overall, 15.4% (751/4868) of respondents did not use social networking websites or apps to communicate with friends and family. Nonuse was higher in men (21.6%, 301/1394) than women (12.7%, 434/3418; *P*<.001).

A higher proportion of nonusers were men, aged ≥80 years, who lived alone and reported fair or poor health (Table 2 and Multimedia Appendix 1 by gender). These sociodemographic factors remained independently associated with nonuse of social media after adjustment. A moderate or poor internet connection and lack of smartphone access also increased the odds of nonuse, as did lower levels of social support.

Within the open-ended response data, we identified 3 relevant themes: (1) the benefits of technology, (2) maintaining pre–COVID-19 social contacts and routines, and (3) virtual connection not being a substitute for in-person connection (Table 3). References to the use of technology during the pandemic were overwhelmingly positive. Many commented that technology kept them socially connected during lockdown: “*I find I'm doing more emails and video-chats, especially with friends and relatives who live alone. Those communications benefit them and me, I feel*” (woman, age group 55-59 years). Video chat apps like Zoom and WhatsApp were valued by those living alone to alleviate loneliness: “*I am widowed so do have feelings of loneliness at times. If anything, I have had more contact on social media with others now*” (man, age group 75-79 years).

Table 1. Characteristics of older women and men who were survey respondents, May 2020.

Characteristic	All respondents (N=4879), n (%)	Women[a] (n=3421), n (%)	Men[a] (n=1397), n (%)
Age group (years; all respondents: n=4863; women: n=3416: men: n=1395)			
<65	1027 (21.1)	846 (24.8)	174 (12.5)
65-79	3279 (67.4)	2295 (67.2)	945 (67.7)
≥80	557 (11.5)	275 (8.1)	276 (19.8)
Living arrangement (all respondents: n=4762; women: n=3356; men: n=1351)			
Lives alone	1415 (29.7)	1138 (33.9)	266 (19.7)
Does not live alone	3347 (70.3)	2218 (66.1)	1085 (80.3)
Location of residence (all respondents: n=4752; women: n=3348; men: n=1354)			
Urban	3962 (83.4)	2791 (83.4)	1132 (83.6)
Rural	751 (15.8)	531 (15.9)	209 (15.4)
Outside Canada	39 (0.8)	26 (0.8)	13 (1)
Self-reported health status (all respondents: n=4873; women: n=3417; men: n=1397)			
Excellent or very good or good	4370 (89.7)	3082 (90.2)	1238 (88.6)
Fair or poor	492 (10.1)	330 (9.7)	154 (11)
Don’t Know	11 (0.2)	5 (0.2)	5 (0.4)
Ethnicity (all respondents: n=4861; women: n=3410; men: n=1397)			
White	4454 (91.6)	3153 (92.5)	1264 (90.5)
Non-White	269 (5.5)	189 (5.5)	76 (5.4)
Other[b]	138 (2.8)	68 (2)	57 (4.1)
Social media use (all respondents: n=4868; women: n=3418; men: n=1394)			
Yes	4113 (84.5)	2983 (87.3)	1090 (78.2)
No	751 (15.4)	434 (12.7)	301 (21.6)
Don’t Know	4 (0.1)	1 (0)	3 (0.2)

[a] 61 respondents did not identify their gender.

[b] Includes respondents who selected either “Prefer to self-identify” or “Prefer not to say.”

Table 2. Odds ratios for nonuse of social media or video communications in a sample of older Canadians, May 2020 (N=4526).

Characteristic	Social media use		Odds ratio	
	Nonuser, n (%)	User, n (%)	Crude OR[a] (95% CI)	Adjusted OR (95% CI)
Gender (nonuser: n=735; user: n=4073)				
Men	301 (41)	1090 (26.8)	1.90 (1.61-2.23)	1.60 (1.33-1.92)
Women	434 (59)	2983 (73.2)	ref[b]	ref
Age group (years; nonuser: n=749; user: n=4102)				
<65	103 (13.8)	924 (22.5)	ref	ref
65-79	488 (65.2)	2782 (67.8)	1.57 (1.26-1.97)	1.24 (0.98-1.57)
≥80	158 (21.1)	396 (9.7)	3.58 (2.72-4.71)	1.88 (1.38-2.55)
Living alone (nonuser: n=729; user: n=4020)				
Yes	286 (39.2)	1124 (28)	1.55 (0.96-2.49)	1.68 (1.39-2.02)
No	443 (60.8)	2896 (72)	ref	ref
Rural residence (nonuser: n=723; user: n=3976)				
Yes	105 (14.5)	646 (16.2)	0.88 (0.70-1.10)	0.90 (0.71-1.14)
No	618 (85.5)	3330 (83.8)	ref	ref
Self-reported fair or poor health (nonuser: n=748; user: n=4100)				
Excellent or very good or good	633 (84.6)	3725 (90.9)	ref	ref
Fair or poor	115 (15.4)	375 (9.1)	1.81 (1.44-2.26)	1.33 (1.04-1.71)
Ethnicity (nonuser: n=730; user: n=3981)				
White	41 (5.6)	227 (5.7)	ref	ref
Non-White	689 (94.4)	3754 (94.3)	0.98 (0.70-1.39)	0.85 (0.59-1.22)
Internet connection (nonuser: n=737; user: n=4078)				
Very good or good	647 (87.8)	3709 (91)	ref	ref
Moderate or poor	90 (12.2)	369 (9)	1.40 (1.09-1.79)	1.39 (1.06-1.82)
Access to a smartphone (nonuser: n=745; user: n=4098)				
Yes	436 (58.5)	3460 (84.4)	ref	ref
No	309 (41.5)	638 (15.6)	3.84 (3.25-4.55)	3.08 (2.58-3.69)
Loneliness (nonuser: n=727; user: n=4022)				
Always or often	82 (11.3)	321 (8)	1.37 (1.05-1.78)	1.05 (0.78-1.41)
Some of the time	226 (31.1)	1455 (36.2)	0.83 (0.70-0.99)	0.81 (0.67-0.98)
No	419 (57.6)	2246 (55.8)	ref	ref
Communication frequency (nonuser: n=749; user: n=4102)				
High (≥3 times in past week)	645 (86.1)	3866 (94.2)	ref	ref
Low (0-2 times in past week)	104 (13.9)	236 (5.8)	2.64 (2.07-3.38)	2.01 (1.54-2.62)
Received offers of assistance (nonuser: n=742; user: n=4092)				
Yes	248 (33.4)	1660 (40.6)	ref	ref
No	494 (66.6)	2432 (59.4)	1.36 (1.15-1.60)	1.44 (1.20-1.71)

[b] OR: odds ratio.

[a] Ref: reference category.

Table 3. Themes and illustrative quotes based on free-text responses to the web-based survey, May 2020.

Theme	Description	Illustrative quotes
Technology and virtual connection is beneficial for some older adults to stay connected	Considering the COVID-19 pandemic, some older adults have found using technology to stay connected virtually to be beneficial as they are unable to see people in person. They may be using technology for various activities, including, but not limited to, video calling, emailing, and messaging their friends and family.	• "Zoom, What's App etc have been excellent platforms for keeping families connected across the globe and for maintaining local social activities such as card games, yoga, book clubs etc." • "I find I'm doing more emails and video-chats, especially with friends and relatives who live alone. Those communications benefit them and me, I feel." • "Zoom app has been very helpful, able to see my mom, family members and girlfriends."
Technology and virtual connection has allowed for some older adults to maintain connections and help to enable their routine	The internet has allowed for older adults to shift their regular activities to the web to facilitate social interactions. Some of those who were previously engaged in various activities with others were able to continue this engagement virtually during the pandemic. In this sense, the move to web-based activities is assisting in maintaining existing relationships and social connections. The theme of routine and regularity was also discussed as older adults indicated activities occurring a certain number of times a week or having scheduled calls with friends and family.	• "My book club, my walking group, my outdoor club and my monthly lunch friends now meet on Zoom." • "Virtual Storytelling on-line events 3 times per week; Church groups three time per week; Book club once a week; weekly family gatherings online; daily work with political social justice groups; long walks in nature; great friends; lots of exercise scheduled at the same time daily" • "I participate in a virtual exercise class twice a week, virtual bridge club twice a week and Facetime chats twice a week. Family zoom calls periodically. I text a friend that I am coming by and walk past her house and wave and talk through an open window."
Technology and virtual connection is not a replacement for social interaction	Although technology and virtual connection has been positive for some, there is still critiques that it is not the same as or a replacement for in-person interactions. Respondents indicated that although they are using virtual connection or technology to stay connected now, they still long for that in-person interaction and connection.	• "Although I've connected with family and friends by telephone, it isn't the same as face to face" • "Virtual book club however human closeness and touching (i.e. hugs) is imperative for high quality living" • "I try to reach out via social media to my best friend daily. I phone family members who are not on social media. However, regardless of the advances of social media, nothing will ever replace face-to-face contact or the human touch."

Women described how technology allowed them to shift their regular activities to the web to maintain pre—COVID-19 routines: "*My book club, my walking group, my outdoor club and my monthly lunch friends now meet on Zoom*" (woman, age group 70-74 years). For others, social networking technology was used to establish new social routines.

Despite this, some respondents acknowledged the limitations of these technologies, still longing for in-person interaction: "*texting and phone calls are great, but the one-on-one contact is missing*" (man, age group 75-79 years) and "*regardless of the advances of social media, nothing will ever replace face-to-face contact or the human touch*" (woman, age group 65-69 years).

Discussion

Principal Findings and Comparison With Prior Work

In a survey of 4879 older retirees of the education sector, we found that 1 in 7 were not using social networking websites or apps to communicate with friends and family early in the COVID-19 pandemic. We identified several characteristics associated with an increased likelihood of nonuse including male gender, advanced age, living alone, poorer health, poor internet connection, a lack of smartphone access, and lower social support. Our findings are consistent with studies of technology use in older adults, which similarly show that advanced age, male gender, being unmarried, and poorer self-reported health are important predictors of nonuse and telemedicine unreadiness [3,12].

We found that sentiments toward technology use during the early weeks of the pandemic were mostly positive, with respondents describing how technology facilitated social connections, allowed them to maintain routines, or helped them adjust to a new way of life. Qualitative studies on the experiences of older adults during the pandemic's first wave report similar findings, with technology being described as having a facilitative role in allowing older adults to engage in the things that matter most to them despite ongoing restrictions [13-15].

Implications

Loneliness and social isolation are top concerns of older adults during the COVID-19 pandemic [10,16], so developing effective strategies to maintain social connection while adhering to public health recommendations is essential. For many older adults, digital communication has been a source of joy and comfort during the often uncertain times of the pandemic [16]. Efforts are needed to enable access and build digital literacy to support those who wish to use these technologies but are currently unable to. This includes rigorous research on what strategies are effective and for whom and addressing structural barriers to technology use, including universal internet access [4]. Such improvements could have far-reaching impacts beyond enhanced social connection. Now more than ever, digital technologies are being used to deliver lifesaving health care and health promotion services, including access to COVID-19 testing and vaccines and other essential services including education, groceries, banking, shopping, and government resources and support. Improving the adoption and use of these technologies in older adults and removing structural barriers to access will ensure the benefits of technology are equitably realized. This is especially important as telehealth expands and is incorporated into routine clinical practice [12].

Despite its benefits, technology-based solutions are not a panacea for social connection. In our study and others [17], older adults have acknowledged that even with virtual connection, gaps in social connection and support remain. A recent comparative study using nationally representative longitudinal survey data in the United States and United Kingdom found that virtual contact during the pandemic did not compensate for the lack of in-person contact in terms of supporting older adults' mental well-being in either country [18]. In fact, the authors found that in the United States, older adults with more frequent virtual contact were more likely to feel lonely during the pandemic and have become lonelier in both countries [18]. Although we did not find an association between loneliness and social media use/nonuse, future research is needed to better understand temporal associations and the potential unintended consequences of virtual connection, particularly for subgroups like older women, who have been reported to be more likely to rely on virtual-only contact during the pandemic [18].

These findings underscore that the value of in-person and offline connections cannot be forgotten. Weekly telephone call interventions with volunteers have shown benefit to both older adults living in long-term care [19] and those in the community [20] during the COVID-19 pandemic. Supporting older adults to remain socially connected through more traditional means is an important and more accessible complement to technological solutions; both are needed to ensure solutions to the issue of loneliness do not further exclude older adults who are not on the internt [4,21,22]. Outdoor environments and spaces are a safe option for connecting in-person at a distance, and the use of these spaces have been shown to be an important predictor of social connectedness pre–COVID-19 [23]. Improving equitable access to safe, accessible open spaces within neighborhoods and enhancing existing ones to better facilitate social interaction would again pay dividends now and in the future.

Limitations

Our study has several limitations. Our study is based on a convenience sample of community-dwelling, retired educators who had internet access. Due to this sample, the prevalence of social media use was likely overestimated in our study. Estimates of social media use by older adults during the pandemic for social connection are wide-ranging (eg, 37% to 80% based on surveys using similar methodologies conducted during the first wave in the United States and Canada) [24,25]. The rates of use are expected to be lower in the general population of older adults, who may face access barriers due to lower levels of education, lower income, health challenges, and ethnicity or race. In a racially diverse study of US older adults, 76% reported minimal video-based socializing; access to and discomfort with technology were described as a key barrier to coping, maintaining social connection, and accessing health care during the pandemic [26]. There are other factors that are associated with nonuse of digital technologies that we did not evaluate, including cognitive impairment, frailty, vision or hearing impairments, and non-English/French speaking ability [27,28]. The unique needs and barriers of these population subgroups warrant thorough investigation and consideration when designing interventions, programs, and services.

Conclusion

Among a sample of retired educators with internet access, we found that male gender, advanced age, living alone, poorer health, and lower social support increased the odds of nonuse of social media to communicate with friends and family during the first wave of the COVID-19 pandemic. The reliability of internet connection and smartphone access also predicted nonuse. Strategies to improve the uptake of digital technologies for social connection must address structural barriers to accessing technology and build digital literacy among older adults. Complementary approaches, such as telephone outreach, are also needed to improve social connection without further excluding older adults who remain offline.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Characteristics of social media users and nonusers, stratified by gender, May 2020.
[DOCX File , 18 KB - aging_v5i2e34793_app1.docx]

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Abbreviations

OR: odds ratio

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Original Paper

Examining the Impact of COVID-19 on People With Dementia From the Perspective of Family and Friends: Thematic Analysis of Tweets

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Abstract

Background: The COVID-19 pandemic is taking a serious toll on people with dementia. Given the rapidly evolving COVID-19 context, policymakers and practitioners require timely, evidence-informed research to address the changing needs and challenges of people with dementia and their family care partners.

Objective: Using Twitter data, the objective of this study was to examine the COVID-19 impact on people with dementia from the perspective of their family members and friends.

Methods: Using the Twint application in Python, we collected 6243 relevant tweets over a 15-month time frame. The tweets were divided among 11 coders and analyzed using a 6-step thematic analysis process.

Results: Based on our analysis, 3 main themes were identified: (1) frustration and structural inequities (eg, denied dignity and inadequate supports), (2) despair due to loss (eg, isolation, decline, and death), and (3) resiliency, survival, and hope for the future.

Conclusions: As the COVID-19 pandemic persists and new variants emerge, people with dementia and their family care partners are facing complex challenges that require timely interventions. More specifically, tackling COVID-19 challenges requires revisiting pandemic policies and protocols to ensure equitable access to health and support services, recognizing the essential role of family care partners, and providing financial assistance and resources to help support people with dementia in the pandemic. Revaluating COVID-19 policies is critical to mitigating the pandemic's impact on people with dementia and their family care partners.

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KEYWORDS

coronavirus 2019; COVID-19; Twitter; social media; dementia; Alzheimer disease; thematic analysis; aging; older adult; elderly population; caregiver; support service; peer support; online health community

Introduction

The COVID-19 pandemic is taking a serious toll on people living with dementia. Beyond having 1 of the highest COVID-19 mortality rates [1], people with dementia have experienced challenges to their mental, physical, and cognitive health [2]. In attempts to mitigate the spread of the COVID-19 virus, governments have implemented various infection control measures, such as public curfews, social distancing protocols, regional lockdowns, required masking, quarantines, visitation bans, and travel restrictions [3].

Studies show that people with dementia and their family care partners (eg, a spouse, common-law partner, or other family member who provides care to a person with dementia) [4] have experienced major barriers to accessing health services and community-based supports during the first wave of the pandemic. More specifically, challenges to service use included reduced or terminated adult day programs, respite services, cognitive rehabilitation therapy, friendly visitor services, senior center programs, and limited knowledge of or access to technology [5-7]. In addition, people with dementia and their family care partners experienced a range of unintended consequences from COVID-19 lockdowns and infection control measures, such as social isolation, loss of informal supports, and care partner fatigue and burnout [8-11].

As the pandemic continues to unfold, new coronavirus variants, such as Omicron, continue to create challenges for health and support services [12], and future variants are expected [13]. With this rapidly changing situation, policymakers and practitioners require timely and comprehensive data to address the changing needs of at-risk population groups, including people living with dementia. More specifically, research-based evidence is needed to inform COVID-19 policies to help mitigate the impact of the pandemic on people with dementia and their family care partners. However, new publications on dementia continue to report findings primarily based on the early stages of the pandemic with little knowledge of the COVID-19 barriers over time [5,9,14,15].

Given the rapidly evolving COVID-19 context, conducting in-person research remains a critical challenge with frequent changes to public health orders ranging from regional lockdowns to travel bans [16]. With a daily average of 500 million tweets, Twitter provides a novel and timely means for people to share their COVID-19 experiences [17]. Specifically, health care providers, policymakers, family members, and friends of people with dementia have been using Twitter to share their opinions, experiences, and concerns about the pandemic [18,19]. Accordingly, the purpose of this study was to use Twitter to examine the COVID-19 impact on people with dementia from the perspective of their family members and friends.

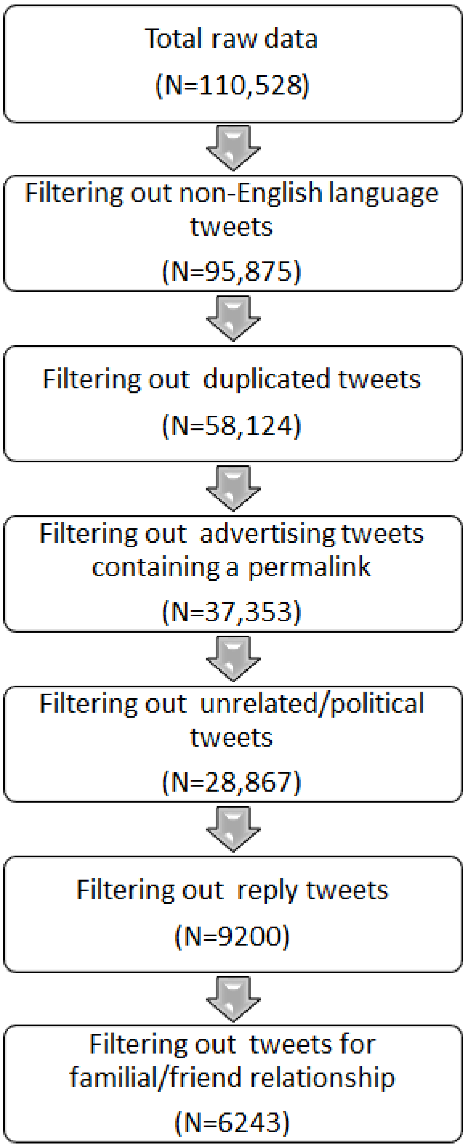
Methods

Tweet Extraction

Tweets were collected using Twint, an advanced scraping tool that enables users to scrape tweets without the use of Twitter's application programming interface. This feature enables Twint scrapers to avoid certain restrictions, such as the number of tweets scraped, the frequency and period of scrapes, and the requirement of a Twitter account [20]. Thus, Twint was used to asynchronously scrape tweets for the period of September 8, 2020, to December 8, 2021.

Given that existing Twitter studies already explore the early stages of the pandemic (ie, February 15-September 7, 2020, and March 17-24, 2020) on people with dementia [19,21], our study's time frame focused further into the pandemic (ie, September 8, 2020, to December 8, 2021). Our full set of search terms included "dementia" OR "Alzheimer" used in combination with "COVID-19" OR "COVID" OR "Corona," resulting in 110,528 tweets. We searched for tweets worldwide rather than focusing on tweets only from a certain country. Filters were applied to exclude non-English language tweets, reply tweets, advertising or spam tweets, and unrelated tweets, such as political tweets about "Trump" or "Biden" (refer to Figure 1). Only original tweets were cited, and replies to tweets were removed as they often were missing information and only contained half of the conversation. These filters are consistent with previous research analyzing Twitter data [18,22]. To improve the likelihood of scraping tweets that described personal COVID-19 experiences of dementia, we excluded tweets that did not include synonyms for familial relationships (eg, "mother," "father," "grandparent") or friends or acquaintances (eg, "neighbor" and "pal"). The remaining 6243 tweets were put into a Microsoft Excel spreadsheet for data analysis.

Figure 1. Twitter filters.



Data Analysis

Tweets were analyzed using a 6-step thematic analysis process [23]. First, 2 researchers (authors JB and MEO) read and reread 200 tweets to support familiarization with the data. Memos were used to document any new codes or ideas about the data to help supplement and revise an a priori code book [19]. This coding scheme comes from our previous Twitter research on the COVID-19 impact on dementia that was conducted at the early stages of the pandemic (ie, February 15-September 7, 2020) [19]. Second, the 2 researchers refined an existing coding scheme by deleting 2 codes (eg, questioning the cause of death and positive stories of survival) that were not identified within the current data. The final version of the revised codebook consisted of 9 codes: (1) death, (2) fear for the person with dementia’s health/well-being, (3) challenges and unmet needs, (4) separated/restricted visiting, (5) formal care provider/workforce issues, (6) supports described, (7) the informal care partner’s health/well-being, (8) stigma against dementia, and (9) irrelevant tweets (eg, no intersection of COVID-19 and dementia). A tweet code was included for irrelevant tweets that were not excluded by our filters and still required hand-coding to identify the tweets as irrelevant (eg, no intersection of COVID-19 and dementia). Approximately, 1200 tweets were coded as irrelevant. Third, the codebook was pilot-tested by having the full research team (ie, 11 coders) independently code the same set of 100 tweets, and then a meeting was held to discuss any coding questions or concerns. Fourth, a group coding exercise was organized, with the team collaboratively coding an additional set of the same 25 tweets to address issues of uncertainty. A final coding exercise was held by having each team member independently code another matching set of 25 tweets and then comparing codes to further support intercoder reliability. Fifth, after the practice coding exercises were completed, the 6243 tweets were divided among the 11 coders, with each coder receiving a different set of 567 (9.1%) tweets to code. The lead author oversaw and managed intercoder reliability by randomly reviewing 25% of all the coding, resulting in an intercoder reliability average of 83.4%. Any coding uncertainties or discrepancies were resolved through team meetings using group consensus. Sixth, once the coding was completed, 2 team meetings were held to discuss the patterns and relationships (eg, similarities, differences, overlap) among the codes, and theme piles were used to identify the overarching themes. The theme titles were reviewed and refined through group discussion to ensure clarity of the theme titles and properties.

Rigor

We used 4 measures to support rigor in our study. First, a comprehensive audit trail was kept to document notes about the context of the research, methodological decisions (eg, code book revisions), and the 6-step thematic analysis process [24]. Second, each researcher used reflexive memoing to document interesting findings, similarities, differences, emerging patterns, and relationships throughout the coding process [23]. Third, our research team consisted of multidisciplinary researchers (eg, psychology, community health and epidemiology, computer science) with diverse skills and theoretical perspectives that provided a more insightful and nuanced approach to interpreting our study's findings. Fourth, the first author managed intercoder reliability by randomly reviewing 25% of the codes to cross-check the data analysis, resulting in an intercoder reliability average of 83.4%.

Ethical Considerations

Our research used publicly available tweets posted on Twitter. No interaction was made with the users who posted the tweets. We removed the Twitter handles and usernames to help protect the anonymity of the tweeters. Consequently, our Twitter research did not require review by an institutional ethics review board.

Results

Drawing on our thematic analysis, 3 main themes were identified: (1) frustration and structural inequities (eg, denied dignity and inadequate supports), (2) despair due to loss (eg, isolation, decline, and death), and (3) resiliency, survival, and hope for the future.

Frustration and Structural Inequities: Denied Dignity and Inadequate Supports

A predominant theme focused on frustration and structural inequities experienced by people with dementia and their care partners amidst the infection control policies to mitigate COVID-19. Family care partners reported that due to structural inequities, people with dementia were often revoked of their fundamental dignities and denied their basic rights. Family members spoke of restraint use, overmedication, dehydration, weight loss, neglect, elder abuse, ageism, isolation, no physician visits, vaccination challenges (delays or no access to COVID-19 vaccines), and understaffing in care facilities. The following tweets illustrate some of these issues:

> *…My Dad died Alone in Hospital with Alzheimers and they wouldnt let me see or talk to him. He was Overmedicated and Restrained. Thats Elder Abuse!*
>
> *Is that in protocol of a hospital for an alzheimer patient to keep them tied as animals?? proper hygiene of a COVID patint was also neglected his dead body was in same t-shirt after 10 days of his admission to hospital…*
>
> *The remote GP is also a fact in care homes, with at least one care home reporting that the local GP will not visit the dementia floor "because of Covid" unless it is an end of life situation…*
>
> *Her father had dementia. She says he was tied up in his bed because there weren't enough staff even before covid.*

Tweets described that COVID-19 policies failed to address the needs and showed a lack of regard for people with dementia. Family care partners discussed circumstances where restrictive policies went beyond necessary health precautions and compromised the health of people with dementia. For example, visitation bans and restriction of family presence within care facilities created barriers for people with dementia, especially for people who were unable to advocate for their personal health needs. Family members expressed frustration with instances where they were not allowed to accompany their loved one with dementia within ambulance transport, the hospital, or during treatment within acute care settings. This frustration with COVID-19 restrictions is demonstrated in the following tweets:

> *My Grandma had a fall this morning (she's okay just shaken up), she has dementia and had to be taken in the ambulance ON HER OWN because of covid. My aunty couldn't go with her. Yet we are allowed to go out and exercise with a group of 10 people. This is a load of crap.*
>
> *So. the fella with dementia can't have his wife who has been isolating at home and double vaxxed accompany him for emerg appt on wound care but COVID partner can be there for birth. Is that not ageism at it's finest…*

Many tweets identified financial challenges and inadequate supports during the pandemic. For example, some family care partners were unable to be employed while providing care, and others described financial issues, such as debt, unemployment, and costly medical insurance. Limited housing options for people with dementia were discussed within the community, and long-term care homes were described as being overwhelmed by COVID-19. These challenges are captured in the following tweets:

> *Being unemployed really sucks. I left my kids and jobs behind to come back to the UK to look after my father as his dementia has made life hard. Now it looks like we have more COVID restrictions coming in this week as well. Stay positive people and follow the damn rules!!!!*
>
> *…I am the sole caregiver for my mom who has dementia. She has gotten pretty bad. It has been really difficult. I have no help and there are not a lot of services right now with Covid.*
>
> *My step Mom died of covid in the nursing home yesterday. She had Alzheimer's. The nursing home is*

> *overwhelmed with covid 19. Sending in national guard because staff ill too. Not seeing this on the news…*

Despair Due to Loss: Isolation, Decline, and Death

Psychological loss was at the core of many tweets. Many people lamented the impacts of social distancing on the lives of people with dementia. Isolation, a consequence of pandemic mitigation strategies, was blamed for accelerating cognitive, psychological, and physical decline.

> *Just FaceTimed my gma for the first time in a while. Been in covid lockdown at ret. home for 8mos. Her Alzheimers has accelerated. Cant see neighbors. No visitors. Just TV in her room. They allowed her to finally leave cus she wouldnt stop crying. Doesnt know anybody anymore.*

Isolation from pandemic mitigation strategies were also blamed for hastening death.

> *COVID killed my mother Not inthe hospital gasping for air, this 90 year old nursing home resident with mild dementia was moved out of her unit and placed on a wing where she knew no one then shut shut off visitors for safety 6 months later she gave up, mom died from loneliness*

Some simply described the experiences of losing a loved one with dementia due to COVID-19.

> *Today is a sad day for cabbit, my father is no longer with us. Alzheimer's took his mind, but covid took his body. I'll miss you daddy.*

Many tweets, however, conveyed complicated reactions to their loss of a loved one who was living with dementia to COVID-19. These reactions, which span anger, helplessness, and a sense of futility, seem to be factors that could interrupt the process of making meaning from loss and thereby disrupt the grieving process and create psychological vulnerability to future mental health challenges (eg, from a depressed mood).

> *Hes had dementia, a few strokes, and heart surgery, but what finally did him in was a combo of COVID and the selfishness of some I used to call family. This week felt like a long panic attack but with anger. We knew wed lose him, but him being taken feels so much worse.*

Some lamented the challenges of concomitant dementia and active COVID-19 infection requiring hospitalization or medical interventions that made the loss even more challenging to process, accept, and make meaning from.

> *My father died this morning. He had a lot of medical issues, but COVID sent him to the hospital, which meant we werent able to see him during his last weeks. Considering he had Alzheimers, I cant imagine how terrifying that mustve been. Wear the damn masks and stay inside.*

> *My grandma had dementia, which is always terminal. Covid-19 took her last good years away and she died in a coma on a ventilator and no one could touch her. No one dies a good, peaceful death if they have covid-19.*

Many expressed anger when describing their experiences with losing a loved one with dementia due to COVID-19. Although anger was reported earlier in the pandemic related to mask usage and lack of social distancing [19], as the medical science has evolved to illuminate ways to prevent or mitigate COVID-19 infection, the nature of the tweeters' anger has similarly evolved. For some, the anger was directed at those who were unvaccinated, those who interacted without wearing masks, and government-led mitigation strategies. These tweets convey a sense of helplessness and struggles to find meaning from deaths that these tweeters felt could have been avoided.

> *This covid shit is no joke at all. My mom mom passed this morning. After a total of 20+ years living with a heart AND kidney transplant + recently being diagnosed w/ dementia, my gmom fought long and hard just to be taken out by something that could have been prevented…*

The experiences of losing someone with dementia who resided in long-term care were described. Many of these conveyed the sense of helplessness and sense of tragedy at the numerous cases of COVID-19 in long-term care, further compounding the sense of loss and likely to interfere with the process of grieving.

> *My paternal grandfather passed away in October, 1 month after being admitted to a nursing home rampant with COVID b/c Drs decided my 88 year old grandmother could not longer care for him and his worsening dementia at home. It was the only facility their insurance would cover...*

> *I left mum 13/3 in her dementia care home - she died 1/4 one of many who died after hospital discharged covid positive patients into homes. The voice of the voiceless #neverforgotten*

Disrupted grieving rituals were also commonly described. Adherence to grieving rituals helps with reminiscence through a shared experience with others [25]. Sharing the loss with others creates a sense of universality in the experience and is also psychologically healing [26]. The pandemic has disrupted the shared grieving process of gathering at funerals, potentially making the grieving process unduly prolonged and creating psychological vulnerability to future mental health concerns.

> *I literally just had to attend my Grandfathers funeral via zoom. Hes been in stable condition over the last few years (Alzheimers and Dementia) but his nursing home had an outbreak of COVID and he passed a few days later. How is this fair? Were never prepared for death.*

> *Today, the final goodbye to Grandad . 96 years old. Alzheimers robbed him of 10 years ,COVID ravaged him in 3 days. 30 in church only 15 at the crematorium…not allowed to see him in chapel of rest, no sharing our grief with family, no remembering him at a wake. Sad and angry*

> *1 year ago my mom died of Alzheimers. Because of Covid she never had a funeral. I feel like Ive failed her*

Resiliency, Survival, and Hope for the Future

Another predominant theme was resiliency, survival, and hope for the future. Resiliency was often discussed in terms of one's ability to fight, survive, and recover from the COVID-19 virus. Some tweets of people with dementia and their family members described psychological resilience, mental toughness, and determination to fight against COVID-19. More specifically, these tweets discussed the pandemic in terms of going to a battle or being in a fight. Many tweets also described resiliency in terms of surviving COVID-19 against multiple odds. For example, these tweets highlighted that despite facing numerous challenges, they still fought the virus and won. Resiliency against the virus is highlighted in tweets such as:

> *My nana had the vaccine yesterday shes 86, has dementia, had both her hips replaced, had a stroke and a cornea transplant AND fought covid in an english hospital when she only speaks portuguese and came out stronger on the other side, i am so thankful for her.*
>
> *…My mom has suffered so many indignities with Alzheimers. Shes fought through them all. 17 cases of Covid in her unit and she didnt get it. My mom is determined to leave this earth on her terms. Not Covids.*

People also shared tweets on factors that they perceived as being linked to COVID-19 resiliency and recovery against the virus. Specifically, these factors included different aspects, such as self-care (eg, eating well and staying positive), formal supports (eg, health care), lifestyle factors (eg, physical activity and sleep/rest), and getting the COVID-19 vaccine. The following tweets illustrate factors that people credited with recovery from the virus:

> *My mother 77 with Alzheimer because of her veganist diet survived corona. Me too. By just eating and drinking more. To be optimist. Fruits are the secret. Normal sleep. A bit sleep during the day 2 hours during corona. 5 days cure. Keep walking. Lots of sunshine please. Open windows.*
>
> *My mother who is 88 and lives with severe dementia caught COVID in August came through some days when we were told the end was nigh and is back home getting stronger and stronger. This is down to the vaccine and great care at Queens Hospital Romford @NHSuk*

Many tweets discussed a strong sense of relief and hope for the future. These tweets were often strongly linked to the COVID-19 vaccine. For example, people expressed relief and elation after receiving their COVID-19 vaccination. Many conveyed that the vaccines helped them overcome anxiety and fear that they or their loved ones with dementia would not be protected against the virus. Family members and care partners described breathing a sigh of relief after their family members with dementia were vaccinated, especially in care facilities. Relief is captured in the following tweets:

> *We just received word that the Alzheimers memory care facility my dad lives in is getting vaccines. I cannot express what a relief this is for my mom. They were Covid free until just before Thanksgiving. Weve been holding our breath for 3 weeks, now we can exhale.*
>
> *My grandmother gets her vaccine on the 28th. She has severe dementia and lives in a memory care facility thats had several COVID diagnoses, so Im beyond relieved…Im glad to know shell be protected.*
>
> *My mom (end stage cancer) gets her Pfizer vaccine today. My dad (Alzheimers) got his a few weeks ago. I want to celebrate…Ive had a year of low level panic for them. My heart is with all those who lost their loved ones to Covid. #vaccine*
>
> *Dad - who turns 75 in a week-and-a-half, has advanced Parkinsons (and dementia) and lives in aged care - just got his first #COVID19Vaccine today. Relief is pretty much the only thing Im feeling about it. #Covid*

People described hope by sharing and envisioning their future plans related to the easing of COVID-19 restrictions. For example, many looked forward to reconnecting in person with people with dementia in care facilities. These tweets often described long-awaited anticipation to engage in face-to-face visits, partake in activities, and provide hugs and a human touch. This sense of hope and anticipation to reconnect is highlighted in tweets such as:

> *The news that I can go see my Gran next week makes me so so happy. So much lost time over the past year with COVID and over that time her dementia has worsened and now wont remember me but to be able to give her a huge hug means more than anything. Family first always*
>
> *Covid restrictions lifted at girlfriends moms alzheimer dementia care facility. Busting her out today for a pre mother's day ride on Verde Valley Railroad…*
>
> *I talk to my mom almost daily and before my dads Alzheimers got bad, the same. As soon as Covid restrictions lift, Ill be back visiting him weekly again.*

Discussion

Principal Findings

Our study aimed to examine the COVID-19 impact on people with dementia from the perspective of their family members and friends. Understanding COVID-19 challenges is critical to informing targeted policies, programs, and resources to support people living with dementia. Drawing on thematic analysis, our study identified 3 main themes: (1) frustration and structural inequities (eg, denied dignity and inadequate supports), (2) despair due to loss (eg, isolation, decline, and death), and (3) resiliency, survival, and hope for the future. Our findings have important COVID-19 policy and research implications.

Based on our findings, we believe that policymakers must eliminate structural inequities and barriers to health care for people with dementia due to the pandemic. More specifically, governments must revisit COVID-19 policies and infection control measures (eg, visitation bans, restricting family presence, confinement, quarantine, and lockdowns) to ensure that people with dementia and their care partners have equitable access to health care and support services. Too often, tweets highlighted issues of restraint use, overmedication, dehydration, weight loss, neglect, ageism, isolation, psychological deterioration, cognitive decline, no physician visits, vaccination challenges (delays or no access to COVID-19 vaccines), and understaffing in care facilities, especially in long-term care homes. Banerjee and Estabrooks [27] assert that long-term care residents, including people with dementia and staff, were often last in line for COVID-19 testing, last to receive personal protective equipment, and directed not to send their residents to hospitals in order to keep the hospital beds open for others. Similarly, the existing literature shows that compared to prepandemic years, people with dementia in long-term care homes have experienced increased use of antipsychotic medications [28], increased confinement and social isolation [29-31], reduced physician visits, decreased access to specialist services, and reduced hospital transfers for illness [32]. Consequently, improving COVID-19 outcomes for people with dementia requires addressing structural inequities in health and support services.

Policymakers need to recognize the essential role of family care partners for people with dementia during the pandemic. Many tweets highlighted care partner challenges related to health care navigation, barriers in health care communication, and COVID-19 visitation restrictions that inhibited their support for people with dementia in care facilities (eg, hospitals, emergency departments, medical clinics, and long-term care homes). Moreover, visitation restrictions were often blamed for psychological loss and accelerating cognitive, psychological, and physical decline in people with dementia. Consequently, COVID-19 policies must be loosened to allow family care partners to accompany, access, and provide necessary support to people with dementia in care facilities. In the United States alone, over 16 million people provide unpaid care to people with dementia at an economic value of US $244 billion [33]. Furthermore, numerous tweets identified financial challenges, issues of economic uncertainty, and inadequate resources among people with dementia and their family care partners. These issues of financial hardship among people with dementia and their care partners are reflected in the existing COVID-19 literature [34,35]. Accordingly, policies and programs are needed to provide financial assistance and resources to help support and sustain people with dementia and their family care partners.

Although many tweets highlighted COVID-19 challenges, some tweets also discussed resiliency and hope for the future. Numerous tweets described people with dementia beating the virus and surviving against multiple odds. People also shared a strong sense of optimism and hope related to COVID-19 vaccines and the easing of restrictions. Many of these tweets discussed future plans to engage in face-to-face visits, partake in activities, and provide hugs and a human touch. These findings suggest that resiliency and hope may play an important role for people with dementia and their care partners during times of adversity, such as a pandemic. However, further research is needed to examine this area.

Limitations

Although a rigorous process was undertaken to perform this study, our research includes limitations. For example, our study did not collect any sociodemographic information about the tweeters. Accordingly, it is difficult to make specific inferences or generalizations about our findings in relation to age, ethnicity/culture, and gender or sex. Moreover, our study did not collect data based on the tweeter's country or geographic location. Twitter research with sociodemographic and geographical components would provide more insight into COVID-19's impact in relation to sociodemographic and geographical characteristics. However, statistics show that Twitter users are from different countries across the world, with a leading number of users (in the millions) in the United States (76.9), Japan (58.95), India (23.6), Brazil (19.05), Indonesia (18.45), and the United Kingdom (18.4) [36]. Consequently, it is interesting to note that our themes were consistent across our data.

Another limitation of our Twitter study is that it is based on cross-sectional research rather than longitudinal data. For example, longitudinal data over different years would provide greater insight into COVID-19 policy responses, changes, and implications over time. Accordingly, further research with longitudinal data would provide useful information on the temporal aspects of different policies and their related outcomes (eg, social, emotional, cognitive, and physical health).

In addition, our research is limited by our scraping strategy that focused on tweets with familial relationships, friends, and acquaintances. Although we aimed to have an inclusive scraping strategy, it is possible that we may have missed relevant data on the COVID-19 impact on people with dementia. For example, future research could use a broader search filter to ensure no relevant findings were overlooked. Moreover, further Twitter research is needed to focus on the lived experiences of people with dementia during the pandemic.

Lastly, each tweet is limited to Twitter's 280-character limit. Consequently, it is possible that we might be missing important background details or contextual factors needed to fully understand the tweet's meaning. To help mitigate this issue, we held research team meetings to discuss and clarify any coding uncertainties by using group consensus.

Conclusion

Given the rapidly evolving COVID-19 context, policymakers and practitioners require timely, evidence-informed research to address the changing needs of marginalized population groups, including people with dementia. Using Twitter data, the objective of our study was to examine the COVID-19 impact on people with dementia from the perspective of their family members and friends. Our study identified 3 main themes: frustration and structural inequities (eg, denied dignity and inadequate supports), despair due to loss (eg, isolation, decline, and death), and resiliency, survival, and hope for the future.

As the pandemic persists and new variants emerge, people with dementia and their family care partners are facing complex challenges that require timely interventions. However, addressing these challenges is neither a straightforward nor a simple task. Rather, tackling these challenges requires interventions informed by lived experiences and evidence-based research. More specifically, tackling COVID-19 challenges requires revisiting infection control policies to ensure equitable access to health and support services, recognizing the essential role of family care partners, and providing financial assistance and resources to help support people with dementia throughout the pandemic. Re-evaluating COVID-19 policies is critical to mitigating the pandemic's impact on people with dementia and their family care partners.

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Authors' Contributions

JDRB conceived the idea with MEOC. MEOC, JDRB, SA, MA, and RJS devised the Twitter scraping approach. SA created the Twint script for scraping tweets. SA and MA scraped for tweets. JDRB, MEOC, AC, MA, SA, CB, KSG, SK, SG, RGS, and RJS coded the tweets. JDRB oversaw the coding process and intercoder reliability. All authors contributed example tweets and participated in the thematic analysis. JDRB wrote the first draft of the manuscript, with analytic sections written by AC, MEOC, JDRB, AS, and CB, and all authors revised the manuscript.

Conflicts of Interest

None declared.

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Original Paper

An Electronic Patient-Reported Outcomes Tool for Older Adults With Complex Chronic Conditions: Cost-Utility Analysis

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Abstract

Background: eHealth technologies for self-management can improve quality of life, but little is known about whether the benefits gained outweigh their costs. The electronic patient-reported outcome (ePRO) mobile app and portal system supports patients with multiple chronic conditions to collaborate with primary health care providers to set and monitor health-related goals.

Objective: This study aims to estimate the cost of ePRO and the cost utility of the ePRO intervention compared with usual care provided to patients with multiple chronic conditions and complex needs living in the community, from the perspective of the publicly funded health care payer in Ontario, Canada.

Methods: We developed a decision tree model to estimate the incremental cost per quality-adjusted life year (QALY) gained for the ePRO tool versus usual care over a time horizon of 15 months. Resource utilization and effectiveness of the ePRO tool were drawn from a randomized clinical trial with 6 family health teams involving 45 participants. Unit costs associated with health care utilization (adjusted to 2020 Canadian dollars) were drawn from literature and publicly available sources. A series of sensitivity analyses were conducted to assess the robustness of the findings.

Results: The total cost of the ePRO tool was CAD $79,467 (~US $ 63,581; CAD $1733 [~US $1386] per person). Compared with standard care, the ePRO intervention was associated with higher costs (CAD $1710 [~US $1368]) and fewer QALYs (–0.03). The findings were consistent with the clinical evidence, suggesting no statistical difference in health-related quality of life between ePRO and usual care groups. However, the tool would be considered a cost-effective option if it could improve by at least 0.03 QALYs. The probability that the ePRO is cost-effective was 17.3% at a willingness-to-pay (WTP) threshold of CAD $50,000 (~US $40,000)/QALY.

Conclusions: The ePRO tool is not a cost-effective technology at the commonly used WTP value of CAD $50,000 (~US $40,000)/QALY, but long-term and the societal impacts of ePRO were not included in this analysis. Further research is needed to better understand its impact on long-term outcomes and in real-world settings. The present findings add to the growing evidence about eHealth interventions' capacity to respond to complex aging populations within finite-resourced health systems.

Trial Registration: ClinicalTrials.gov NCT02917954; https://clinicaltrials.gov/ct2/show/NCT02917954

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KEYWORDS

eHealth; multimorbidity; primary care; cost-effectiveness; older adult; elder; cost; patient reported outcome; community; complex care; aging; Canada; North America; chronic disease; chronic condition; decision tree; model; sensitivity analysis

Introduction

Community-dwelling older adults (≥ 65 years old) with multiple chronic conditions and complex care consume a substantial amount of health care resources [1,2]. Existing evidence has shown that patients with multimorbidity have more frequent hospital admissions, longer hospital stays, and that health care costs exponentially increase with the greater number of health conditions, placing a high economic burden on health systems [3,4]. Provision of care is particularly challenging for this population due to the lack of specific assessment tools for multimorbidity, and the more complex management and coordination of care, which involves different professionals and clinical settings. The difficult management of multimorbidity—with guidelines that focus on single conditions, multiple therapies, and medications—can reduce treatment adherence and patients' health-related quality of life (HRQoL) [2,4,5]. Moreover, older adults are at a higher risk of poor health outcomes given the complexity of social, environmental, and other contextual issues that they face within and outside the health system, such as social frailty and access to home and community care that meet their needs [6,7].

To address these challenges, there is growing interest in person-centered, integrated, and holistic care approaches that may help coordinate personalized and comprehensive care involving older adults, their caregivers, and health care providers [4,8]. Additionally, self-management programs have created efficiency gains, yielding improvements in health status and reductions in unnecessary health care utilizations [8]. However, there are few existing digital tools to enable these person-centered approaches for older adults in primary care settings [9]. The electronic patient-reported outcome tool (henceforth, called the ePRO tool) is one of such digital tools, which can facilitate collaborative care based on individualized goals created by older adults and providers, also known as goal-oriented care. The tool is delivered through the internet and mobile devices, and can be useful for complex care given their ability to improve access, continuity and efficiency of care, patient self-management, and communication [10].

A randomized trial had shown that ePRO plus usual care did not significantly improve the HRQoL in older adults with complex needs, partly due to recruitment challenges [10]. However, ethnographic data collected as part of the trial highlighted the importance of the coherence or meaningfulness of the intervention to the end users (ie, patients and providers) and uncovered the challenge to align coherence across diverse groups. When coherence was well aligned, users were more likely to see the value of the technology and use it more over time. In addition to assessing perceived value, there is a need to examine whether the challenges to improve clinical outcomes balance the additional investment in provider and technology costs associated with administering the ePRO tool within a clinical setting. While previous studies have shown eHealth interventions to be cost-effective [11], the cost-effectiveness of the ePRO tool, which was implemented in the community setting, has not been formally evaluated. This study was therefore conducted to estimate the cost of ePRO tool and examine whether the benefits gained from the tool outweighed its costs from the perspective of Canada's publicly funded health care system.

Methods

Study Design and Population

We performed a cost-utility analysis of the ePRO compared with standard care. The analysis was based on data from a pragmatic, stepped-wedge, cluster randomized trial with patients from 6 comprehensive primary care practices—called family health teams (FHTs)—across Ontario, Canada. FHTs provide integrated primary care, led by a physician or a nurse practitioner, and assisted by other professionals such as registered nurses, social workers, and dietitians [12]. A usual care pathway for older adults with multiple chronic conditions may include routine visits to their health care providers with or without their caregivers.

All FHT sites started in the control period, during which all recruited patients received usual care, and were randomly assigned to either the early or late intervention groups, with an initial control period of 3 and 6 months, respectively. The FHTs were then switched to the intervention period, during which patients and providers used ePRO as part of the primary care, for 12 months in the early intervention group and 9 months in the late intervention group. Enrollment occurred from January to August 2018, and the trial from April 2018 to June 2019.

Consistent with the trial, the study population for this cost-utility study was community-dwelling individuals aged 60 years or older with complex chronic conditions, defined as diagnosed with 2 or more chronic conditions and 10 or more visits to their primary health care provider within the past year. This number of visits has been identified as an indicator of complexity [10]. Chronic conditions were identified through the FHTs electronic medical records. Additional eligibility criteria included the perceived willingness to engage in goal-oriented care conversations, ability to use a smartphone or tablet, capable of providing consent to participate, and willing to complete surveys until completion of the trial. Detailed information on the trial can be found elsewhere [10].

Ethics Approval

Research ethics approval was granted by the University of Toronto's Health Sciences Research Ethics Board (approval number 33944) and the ethics committees of all participating practices.

Intervention and Comparator

The development and usability of the ePRO tool were grounded in user-centered co-design, with a 4-phased approach [13-16]. The ePRO tool has 2 key features: (1) My Goals, which allows patients, caregivers, and providers to create goal-oriented patient care plans using a mobile device during a 15-30-minute care planning appointment. Specified-measurable-attainable-realistic-time–specific goal principles were used to guide goal setup and include free-form text to write down general feelings on progress; and (2) Outcome Measures, which helps patients, caregivers, and providers to monitor patient measures and outcomes (daily, weekly, or monthly) through validated and reliable health status scales such as Patient-Reported Outcomes Measurement Information System (PROMIS), Global Health Scale (GHS), Health Assessment Questionnaire (HAQ), 9-item Patient Health Questionnaire (PHQ-9) and Generalized Anxiety Disorder 7-Item (GAD-7) scale [9,17-19].

Given that eHealth tools to support self-management are an emerging class of technology, there are no comparable interventions identified for the analysis. Therefore, the standard care comparator in this analysis is multidisciplinary primary care provided by FHTs.

Time Horizon

The cost-utility analysis compared the costs and outcomes over 15 months of follow-up, which is consistent with the length of the stepped-wedge follow-up period. Costs and health outcomes were not discounted.

Measurement of Effectiveness

The ePRO effectiveness is measured as the effect of the intervention on HRQoL compared with usual care after adjusting for the family practice sites and multiple measurements at baseline, 3, 6, 9, 12, and 15 months. The trial measured QoL using the Assessment of Quality of Life 4-Dimension (AQoL-4D), a generic instrument that uses multiattribute utility theory, which makes it suitable for cost-utility evaluations [20]. It has also demonstrated validity in chronically ill community-dwelling populations [20]. At each time point, the individual responses of the AQoL-4D questionnaire were converted to weighted multiattributable utility values (ranging from 1.00 [full health] to 0.00 [death equivalent health states]). We used an area under the curve method to estimate quality-adjusted life years (QALYs) and a mixed effect linear regression to estimate the effect of ePRO on QALYs compared with usual care, while controlling for baseline utility values [21], the age of participants, sex, and number of comorbidities and baseline utilities. The baseline QALYs were informed by the observed data during the initial period of the stepped-wedge trial, when all patients received multidisciplinary primary care by Ontario FHTs for 3 or 6 months.

Resources and Costs

Overview

We estimated costs from the perspective of a publicly funded health care system in the province of Ontario, Canada, and considered costs associated with ePRO and health care utilization.

Cost of the ePRO Tool

The cost of ePRO tool consisted of technology costs and training costs. Technology-related costs of the intervention were based on real-world costs incurred during the clinical trial. We excluded costs related to trial co-ordination and included any recurrent program costs borne to the government in future adoption. Cost sheets provided by the technology and research partners were stratified by different activities, the quantity used, and the price of each unit. The technology program costs comprised technology support, technology training, licensing, communication, onboarding management, app modification, new feature development, and professional services support costs (Table 1).

Table 1. Input parameters of the model.

Parameter	Base estimate (2020 CAD $[a])	Probability distribution (SD)	Data source
Professional services support	10,284	N/A[b]	ePRO[c] clinical trial
Technical support (before onboarding)	2971	N/A[b]	ePRO clinical trial
Technical support (after onboarding)	2971	N/A[b]	ePRO clinical trial
License	9182	N/A[b]	ePRO clinical trial
Communication with health care teams	5942	N/A[b]	ePRO clinical trial
Management (before onboarding)	8912	N/A[b]	ePRO clinical trial
Management (after onboarding)	3714	N/A[b]	ePRO clinical trial
Modifications	12,855	N/A[b]	ePRO clinical trial
New features	15,405	N/A[b]	ePRO clinical trial
Total technology costs	72,234	Gamma (11,131)	ePRO clinical trial
Health services utilization per person/year	5500	Gamma (541)	[22]
Total training costs	7233	Gamma (852)	Ministry of Health and Long-Term Care Report [23,24]
Reduction of health services utilization in the standard care group	0.03	Normal (0.003)	[25]
Reduction of health services utilization in the ePRO group	0.04	Normal (0.004)	[25]
Number of patients in the trial	45	N/A	ePRO clinical trial

[a] CAD $1=US $0.80.

[b] N/A: not applicable (used based estimates only).

[c] ePRO: electronic patient reported outcome.

The training costs were included in the analysis as they were considered an opportunity cost. Although they did not represent an additional cost to the public payer, for the time of the training, the clinicians were not in their usual care routine. The training was offered to 5 FHT professionals involved in the delivery of the intervention: family physicians, registered nurses, nurse practitioners, registered social workers, and diabetes educators [26]. The training was administered in 2-hour sessions and was calculated using the hourly wages of the health care providers obtained from published provincial resources. Training costs, together with their sources, for the ePRO intervention are provided in Multimedia Appendix 1.

Cost Associated With Health Care Utilization

We obtained the cost associated with health care utilization among patients with complex needs from a retrospective population-based study reporting the health system costs associated with multimorbidity in Ontario [3]. Based on this study, we calculated the total health system costs for older adults living in community with 2-5 comorbidities; these costs were inflated to 2020 values using the health care–specific Consumer Price Index reported by Statistics Canada (Multimedia Appendix 2).

We derived the impact of ePRO on health care system costs based on the 13-item Patient Activation Measure (PAM), a validated tool that provides a weighted score on a scale of 0-100, with 4 associated activation levels, and is used to compare self-management capabilities [27]. In level 1, patients are aware of the importance of their role; in level 2, they have the confidence and knowledge necessary to take action regarding their treatment; in level 3, they actually take action and gain independence; and in level 4, they are able to maintain the behavior even under stress [27]. A score of less than 47.0 places a patient in level 1, 47.1-55.1 level 2, 55.2-72.4 level 3, and more than 72.5 in level 4. Self-management capacity levels, measured using PAM, are associated with reduced utilization across primary and secondary care [25,28,29]. In the absence of administrative and reliable self-reported utilization data, PAM level changes between pre- and postintervention were used to quantify changes in resource use cost from the baseline [25]. Research has demonstrated an inverse correlation between increasing PAM scores and reduction in cost, even after controlling for confounding demographic and comorbidity factors; therefore, it can be used as a credible proxy for future cost savings [25]. We based the percentage of reduction in health services utilization on literature findings of an 8% cost reduction per 1 increase in PAM level change [25]. The PAM questionnaire was administered to patient participants of the study at baseline, 3, 6, 9, 12, and 15 months. To calculate the cost reduction in each group, we multiplied the 8% reduction per level by the percentage of participants in each group that had their PAM levels increased while in that state. For example, if in one of the groups 10% of patients achieved a 1-level increase and 20% achieved a 2-level increase over the course of the trial, the total health system costs for that group were reduced by 24% (0.08 × 0.1 + 0.16 × 0.2).

Analysis

We used a decision tree to estimate the expected total costs and outcomes associated with ePRO and usual care after consultation with clinical partners. The tree splits into 2 branches, ePRO tool intervention and usual care. The incremental cost-effectiveness ratio of ePRO versus usual care was calculated by dividing the differences in total costs by the difference in QALYs. We conducted sensitivity analyses to address the uncertainties of our model and to better understand the impact of model assumptions on cost-effectiveness results, including a tornado diagram for the incremental net monetary benefit at a CAD $50,000 (~US $40,000)/QALY willingness-to-pay (WTP) threshold, and a probabilistic sensitivity analysis with 10,000 Monte Carlo simulations, sampled using the related distribution of the parameters (Table 1).

Results

Base Case Analysis

The total cost of the ePRO tool was CAD $79,467 (~US $63,581; CAD $1733 [~US $1386] per person); of these, the technology component accounted for 90.89% (CAD $72,234 [~US $57,794]) of the total costs. The trial reported that ePRO combined with usual multidisciplinary care did not significantly impact patient HRQoL (*P*=.24) or patient activation (*P*=.17) [10]. Our base case analysis showed that, compared with the standard care, the addition of the ePRO intervention was associated with higher costs (CAD $7133 [US $5707] vs. CAD $5423 [US $4338] per patient) and slightly fewer QALYs (0.42 vs. 0.45) than usual care (Table 2). The technology cost was a key driver of an incremental cost. Although the ePRO intervention could reduce health system costs compared with standard care (CAD $5258 [US $4206] vs. CAD $5324 [US $4259], respectively), this saving was insufficient to offset the added technology cost.

Table 2. Base case results.

Strategy	Mean costs (CAD $[a])	Incremental costs (CAD $)	Mean QALYs[b]	Incremental QALYs	ICER[c] (CAD $/QALY)
Usual care	5423	—	0.45	—	—
ePRO[d]	7133	1710	0.42	–0.03	Dominated[e]

[a] CAD $1=US $0.80.

[b] QALY: quality-adjusted life year.

[c] ICER: incremental cost-effectiveness ratio.

[d] ePRO: electronic patient-reported outcome.

[e] ePRO was more costly and produced fewer QALYs than usual care.

Sensitivity Analyses

Results of the deterministic sensitivity analysis showed that the effectiveness of ePRO is the most influential driver of the cost-effectiveness findings. ePRO would be considered a cost-effective option, that is, having a positive incremental net monetary benefit, if it could improve by at least 0.03 QALYs. Other key determinants included the technology and the training costs for the implementation of the tool. However, individual variation in none of these costs could change the cost-effectiveness results (Figure 1). The probabilistic sensitivity analysis results showed that ePRO has a 17.3% probability of being cost-effective at the WTP threshold of CAD $50,000 (~US $40,000)/QALY (Figures 2 and 3); this probability increased to 25.1% if the WTP threshold increased to CAD $100,000 (~US $80,000)/QALY.

Figure 1. One-way sensitivity analysis (tornado diagram). ePRO: electronic patient-reported outcome; EV: expected value; IT: information technology; NMB: net monetary benefit; QALY: quality-adjusted life year;.

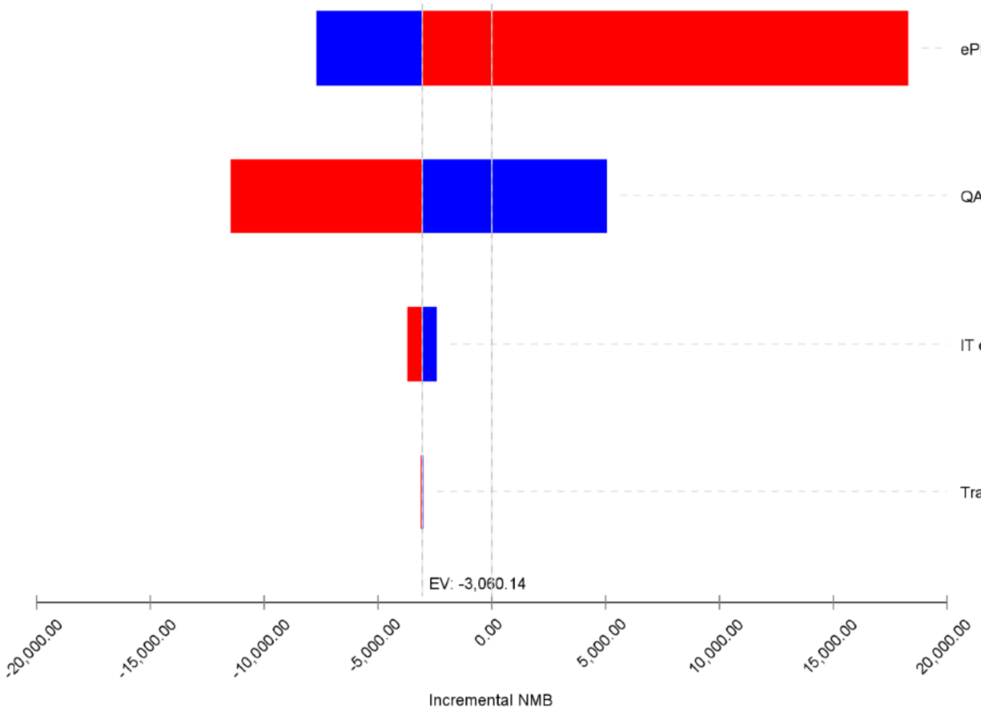


Figure 2. Probabilistic sensitivity analysis. WTP: willingness-to-pay threshold.

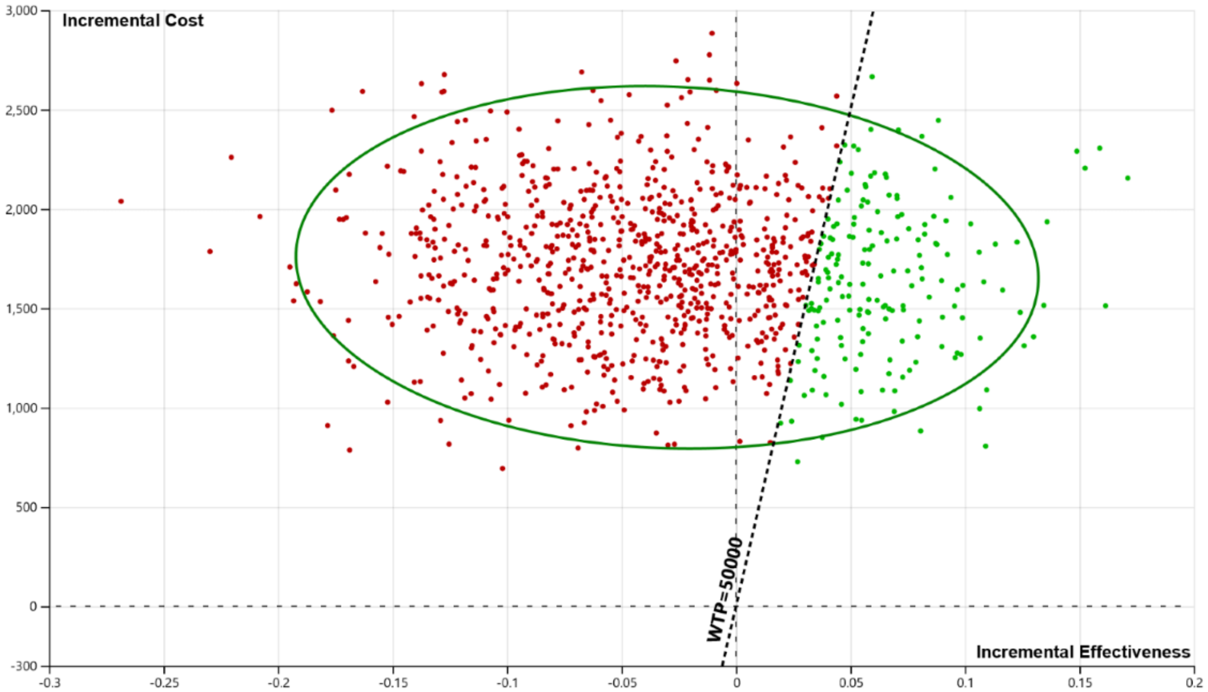
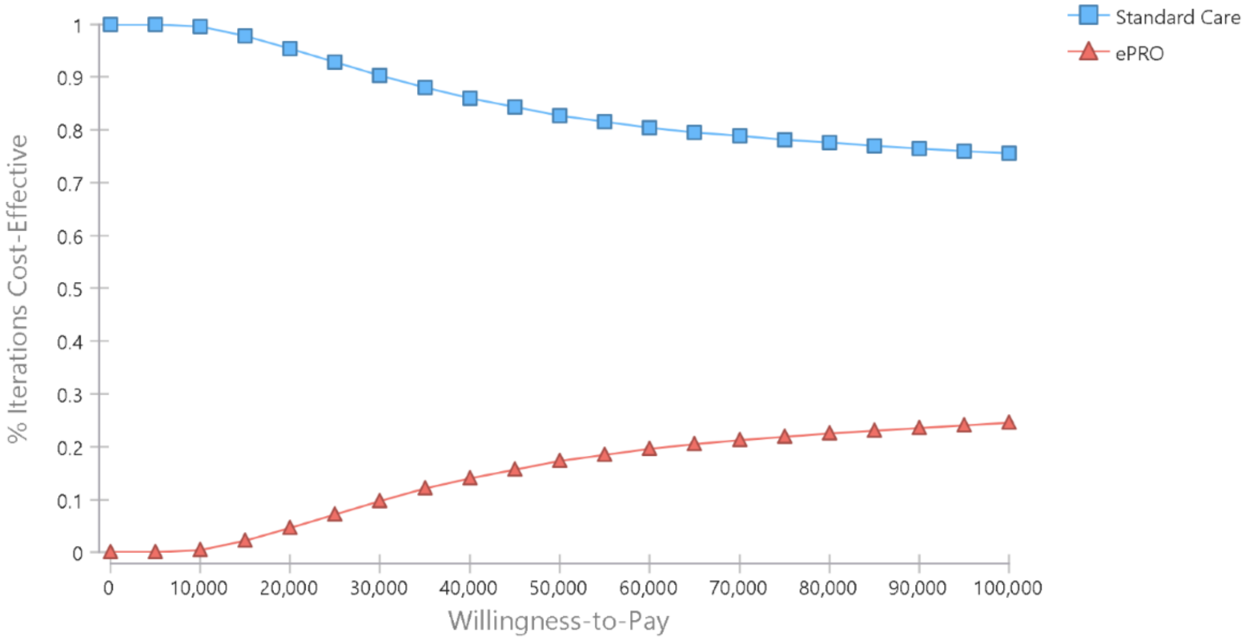


Figure 3. Cost-effectiveness acceptability curve. ePRO: electronic patient-reported outcome.



Discussion

Principal Findings

Our study showed the ePRO tool was not cost-effective at a commonly used WTP threshold of CAD $50,000 (~US $40,000)/QALY. The main driver of our cost-effectiveness results is the effectiveness of the ePRO tool on QALYs. Our results were robust to changes in input parameters and model assumptions with the probability of being cost-effective of 17.3% at the WTP values of CAD $50,000 (~US $40,000)/QALY.

Previous studies assessing the cost-effectiveness of eHealth interventions reported mixed findings, where some interventions were considered cost-effective or cost-saving, whereas other studies reported that eHealth interventions were not cost-effective [11,30]. Some economic evaluations of these technologies also reported comparable HRQoL among patients receiving eHealth and those receiving usual care [31-33]. Consistent with these results, our study showed that the addition of ePRO to usual care was not cost-effective because the tool generated fewer QALYs than usual care. Lower QALYs observed in this cost-utility analysis mirrored insignificant changes in HRQoL that might be due to the lack of statistical power resulting from recruitment challenges and low response rates to the surveys [31-33].

Some aspects of the ePRO tool must be considered when interpreting this economic evaluation. The ePRO tool is not targeted to patients with a specific disease, but rather to a heterogeneous population with a different number and variety of conditions. Hence, effectiveness of the ePRO tool may be different for patients with different conditions, given their complex needs and individual preferences [11]. Accessibility and digital literacy also have a direct impact on the effectiveness of eHealth interventions, as they can increase access and be convenient for some patients, but may also be inappropriate or inaccessible to others [7].

Furthermore, being a tool that is mainly focused on improving the patient’s engagement in the treatment and changing health behaviors, a trial-based cost-effectiveness analysis may not be the ideal design as it may take more than 10 years for health interventions to change patients’ behaviors and respective health outcomes [9,11,34]. With prolonged use of the tool, more significant effects may be detected, especially in chronic conditions that are mostly affected by changes in the behavior of the patients. Additional outcomes, such as patient and provider satisfaction, disease management, and self-care activities, with a longer time horizon could be useful in identifying whether ePRO had any other relevant benefits. Previous economic evaluations of eHealth technologies with no impact in clinical outcomes concluded that they were cost-effective due to their low cost and effectiveness when considering outcomes beyond HRQoL [32,35]. eHealth interventions can also have gains in efficiency with the increase in the number of users and sharing of data systems and infrastructure [31].

Another relevant consideration is that with prolonged use of the app and in less controlled conditions, patient adherence may decrease [36]. Data collected during the stepped-wedge trial indicated that adherence to the tool was moderate; however, this does not necessarily translate into fidelity to the model of care—a shift from the more classic, passive behavior of the patient toward their health to a model with higher engagement of both providers and patients in goal-setting conversations and oriented care [37,38]. It is possible that even with patients continually using the tool, the expected effects on health outcomes may not fully materialize if this shift in the model of care does not occur.

Study Limitations

This analysis had some important limitations. First, our economic evaluation was based on a single stepped-wedge trial, which limits the generalizability of our study for the real-world setting and a more heterogeneous population. Despite being a pragmatic trial that intended to approximate as much as possible the usual care conditions, the trial faced recruitment challenges and low response rates to outcome measures. Moreover, the trial was conducted within the context of FHTs, but ePRO could also be applicable to other models of primary care. The use of health care payer perspective in this analysis excludes some benefits that can add value to the ePRO tool. A societal perspective would allow the inclusion of indirect costs such as informal and unpaid time in caregiving, increased poverty, and loss of income due to time away from work [6]. For an intervention focused on primary care, out-of-pockets costs may be relevant, especially in health systems similar to Canada, where hospital-level costs are publicly funded, but many outpatient and nonphysician services are not funded. Some eHealth interventions were found to be cost-effective due to the inclusion of costs pertinent to a societal perspective [39,40].

Lastly, we used the PAM scores as a proxy to calculate the reduction in health care service utilization costs of the patients in the trial. Although an increase in patient activation levels has been associated with a reduction in these costs, these values can vary, and this was not tested in the Canadian setting [25,29]. However, our sensitivity analysis showed that our results were robust to a change in the effect of the ePRO tool on health care utilization.

Conclusion

Our cost-utility analysis highlighted that the ePRO tool is not a cost-effective technological solution for community-dwelling older adults with multiple chronic conditions when compared with usual care. However, the tool would become a cost-effectiveness option if it could improve QALYs by at least 0.03 unit. This study highlights the minimal effectiveness of eHealth solutions required to make the solutions cost-effective in response to the rising trends of complex, aging populations within finite-resourced health systems. Fidelity and adherence to the eHealth tools could improve their effectiveness, and this relationship should be investigated in future studies. Pragmatic trials with larger number of participants, fewer missing data, and longer follow-up time could help inform the implementation of the eHealth intervention, such as ePRO tool, in a finite-resourced setting.

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Conflicts of Interest

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Multimedia Appendix 1
Family health team provider training costs.
[DOCX File , 15 KB - aging_v5i2e35075_app1.docx]

Multimedia Appendix 2
Health care utilization costs (person-level costing using administrative databases in Ontario).
[DOCX File , 15 KB - aging_v5i2e35075_app2.docx]

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Abbreviations

AQoL-4D: The Assessment of Quality of Life 4-Dimension
ePRO: electronic patient-reported outcome
FHT: family health team
GAD-7: Generalized Anxiety Disorder 7-Item scale
GHS: Global Health Scale
HAQ: Health Assessment Questionnaire
HRQoL: health-related quality of life
ICER: incremental cost-effectiveness ratio
PAM: Patient Activation Measure

PHQ-9: 9-item Patient Health Questionnaire
PROMIS: Patient-Reported Outcomes Measurement Information System
QALY: quality-adjusted life year
WTP: willingness to pay

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Original Paper

Associations Between Implementation of the Caregiver Advise Record Enable (CARE) Act and Health Service Utilization for Older Adults with Diabetes: Retrospective Observational Study

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Abstract

Background: The Caregiver Advise Record Enable (CARE) Act is a state level law that requires hospitals to identify and educate caregivers (“family members or friends”) upon discharge.

Objective: This study examined the association between the implementation of the CARE Act in a Pennsylvania health system and health service utilization (ie, reducing hospital readmission, emergency department [ED] visits, and mortality) for older adults with diabetes.

Methods: The key elements of the CARE Act were implemented and applied to the patients discharged to home. The data between May and October 2017 were pulled from inpatient electronic health records. Likelihood-ratio chi-square tests and multivariate logistic regression models were used for statistical analysis.

Results: The sample consisted of 2591 older inpatients with diabetes with a mean age of 74.6 (SD 7.1) years. Of the 2591 patients, 46.1% (n=1194) were female, 86.9% (n=2251) were White, 97.4% (n=2523) had type 2 diabetes, and 69.5% (n=1801) identified a caregiver. Of the 1801 caregivers identified, 399 (22.2%) received discharge education and training. We compared the differences in health service utilization between pre- and postimplementation of the CARE Act; however, no significance was found. No significant differences were detected from the bivariate analyses in any outcomes between individuals who identified a caregiver and those who declined to identify a caregiver. After adjusting for risk factors (multivariate analysis), those who identified a caregiver (12.2%, 219/1801) was associated with higher rates of 30-day hospital readmission than those who declined to identify a caregiver (9.9%, 78/790; odds ratio [OR] 1.38, 95% CI 1.04-1.87; *P*=.02). Significantly lower rates were detected in 7-day readmission (*P*=.02), as well as 7-day (*P*=.03) and 30-day (*P*=.01) ED visits, among patients with diabetes whose identified caregiver received education and training than those whose identified caregiver did not receive education and training in the bivariate analyses. However, after adjusting for risk factors, no significance was found in 7-day readmission (OR 0.53, 95% CI 0.27-1.05; *P*=.07), 7-day ED visit (OR 0.63, 95% CI 0.38-1.03; *P*=.07), and 30-day ED visit (OR 0.73, 95% CI

0.52-1.02; *P*=.07). No significant associations were found for other outcomes (ie, 30-day readmission and 7-day and 30-day mortality) in both the bivariate and multivariate analyses.

Conclusions: Our study found that the implementation of the CARE Act was associated with certain health service utilization. The identification of caregivers was associated with higher rates of 30-day hospital readmission in the multivariate analysis, whereas having identified caregivers who received discharge education was associated with lower rates of readmission and ED visit in the bivariate analysis.

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KEYWORDS

electronic health record; caregiver; diabetes; hospital readmission; emergency department utilization; CARE Act; EHRs; older adults; utilization

Introduction

Recent data from the Centers for Disease Control and Prevention have shown that 29.2% of older Americans (aged ≥65 years) have diabetes [1]. Older adults with diabetes endure many daily health management challenges surrounding their diet, blood glucose levels, medication and insulin injections, and skin and foot care [2-6]. Due to these challenges, older adults are more likely to experience acute and chronic complications related to their diabetes, which can subsequently lead to increased health care service utilization including hospitalization, emergency department (ED) visit, and mortality [7,8]. The total direct and indirect costs attributed to diabetes in the United States substantially increased from US $261 billion in 2012 to US $327 billion in 2017 [9].

Among older adults with diabetes, caregivers can play a critical role in helping older adults with diabetes maintain or improve their health [10]. A family caregiver need not be related to the patient by blood or marriage; a friend, neighbor, partner, or paid caregiver could be identified by the patient as serving in this role [11]. A caregiver can assist with tasks at home such as medication management, dietary adherence, and skin and foot care [12,13]. They can also help organize complex medication regimens, operate specialized medical equipment, and communicate with and coordinate care by multiple providers [13]. A cross-sectional study indicated that patients with diabetes who have a caregiver were more likely to report moderate or high medication adherence than those with no caregivers [14]. Another study showed that inpatient diabetes education for patients or caregivers is associated with reduced hospital readmission among patients with poor glycemic control [15]. Furthermore, a recent systematic review and meta-analysis of 11 randomized controlled trials found that the integration of caregivers into the discharge planning process significantly reduced the risk of hospital readmission compared to noninclusion of caregivers for older adult patients discharged to home [16]. However, 50% of family caregivers looking after spouses or partners do not receive sufficient assistance or training from health care professionals to complete skilled medical or nursing tasks [17]. This is problematic because a position statement from the Association of Diabetes Care & Education Specialists addressed the importance of preparing the patient and caregiver to perform self-management survival skills by the time of discharge [18]. Collectively, the evidence demonstrates the importance of including and educating caregivers to help alter the unfavorable trajectories of the outcomes for older adults with diabetes.

The Caregiver Advise Record Enable (CARE) Act [19,20] supports the inclusion and education of caregivers in hospital discharge planning. Since the law's introduction in 2014, it has already been mandated in 40 states and territories [21] and requires hospitals to implement procedures to identify and educate caregivers [11]. Given the recent introduction of the CARE Act, we aimed to understand the impact of the implementation of the CARE Act on health service utilization outcomes (ie, hospital readmission, ED visits, and mortality) of older patients with diabetes. The following research questions were asked: (1) Were there differences in health service utilization between pre- and postimplementation of the CARE Act? (2) Was there an association between the identification of caregivers for older adult patients with diabetes and health service utilization outcomes? and (3) Was having identified caregivers who received education and training on how to care for an older patient with diabetes associated with more positive health service utilization outcomes than patients whose identified caregivers did not receive education and training?

Methods

Study Design and Setting

This was a retrospective, observational study. The CARE Act was implemented for inpatients at the University of Pittsburgh Medical Center (UPMC). As an integrated finance and delivery system, the UPMC presented a unique opportunity to study the implementation of the CARE Act.

Sample

Data were retrieved from patients who were admitted as inpatients, were aged ≥65 years at time of admission (the reason for admission did not need to be a diabetes diagnosis), had an associated International Classification of Diseases 10th Revision diagnosis of diabetes (E10-E14) [22], and were discharged between May and October 2017. This time period was selected because the CARE Act was implemented at UPMC in April 2017. The data before the implementation of the CARE Act were retrieved from September 2016 to mid-March 2017. Data were excluded from the analysis for patients who received care from skilled nursing, rehabilitation, or home health care services; those who transferred to another hospital; or patients who were considered same day observations or same day surgery patients.

Implementation of the CARE Act

The Pennsylvania CARE Act was implemented in UPMC, a large integrated academic health center. The CARE Act includes 3 main requirements [20,23-25]: (1) ask each patient if they would like to identify a caregiver at admission to hospital, (2) notify the caregivers prior to discharge about the discharge occurring, and (3) educate and train the caregiver. UPMC has specific sections in the electronic health record (EHR) system dedicated to complying with the CARE Act. First, the admission screen was designed to instruct providers to ask the patient if they wanted to identify and record the contact information (eg, relationship with the patient such as spouse, children, or partner) of caregivers. The admitted hospital inpatients are given the option to identify a caregiver to participate in their discharge education and training. Patients can choose to decline identifying a caregiver. For example, a patient with a clinical background may not feel a need to identify a caregiver, or a patient may not have anyone available for support once they are home. Second, if a caregiver is identified and recorded, the intention is for providers to coordinate the discharge planning so that the caregivers can be present. The discharge notification screen is used to notify patients that their caregivers can schedule a visit time for discharge education and training. Third, a patient or caregiver education and training screen was applied where providers could document the different types of educational content and delivery modes (eg, tube feedings, dressing changes, medication management, foot care, teach-back method). The education and training can occur over multiple sessions. Staff were encouraged to perform a “teach-back” process to verify that the caregiver understood what was taught.

Measurement

All data were retrieved from the EHR. The independent variables included caregiver identification (yes vs no) and caregiver education (yes vs no). The dependent variables included 7-day and 30-day hospital readmissions, 7-day and 30-day ED visits, and 7-day and 30-day mortality. Outcome intervals were from the date of index discharge date. The risk factors included age, race, sex, marital status, income, the number of comorbid conditions (Elixhauser comorbidity index) [26], admission to the intensive care unit (ICU), ICU length of stay (LOS), and surgery. Other variables included insurance type, caregiver relationship to patient, and the reasons of hospitalization.

Statistical Analysis

SPSS statistics software (version 25; IBM Corp) was used for analysis. Descriptive statistics for continuous variables, such as age, ICU LOS, and the number of comorbidities, were reported as mean (SD). Categorical variables, such as gender and marital status, were described using frequency counts and percentages. Likelihood-ratio chi-square tests (bivariate tests) were used to test whether (1) there were differences in health service utilization between pre- and postimplementation of the CARE Ac; (2) caregiver identification status (yes vs no) was individually associated with each outcome (7- or 30-day hospital readmissions, 7- or 30-day ED visits, and mortality); and (3) providing education to identified caregivers (yes vs no) was individually associated with each outcome. Subsequently, multivariate logistic regression models were applied to examine each analysis after adjusting for risk factors. A P value <.05 was considered statistically significant.

Ethics Approval

The study received Quality Improvement approval (ID 634) from UPMC. It has been vetted for ethics and approved for dissemination outside the organization.

Results

A total of 2591 patients (Table 1) with diabetes were included in our analyses. The mean age of participants was 74.6 (SD 7.1) years. Of the 2591 patients, 46.1% (n=1194) were female; 86.9% (n=2251) were White and 9.4% (n=243) were Black; 97.4% (n=2523) had type 2 diabetes; 56.7% (n=1475) were married; and the mean income was US $47,853 (SD 15,223). Clinical characteristics showed that patients had a mean Elixhauser comorbidity index of 5.0 (SD 2.0). Of these 2591 patients, 10.3% (n=286) had a stay in the ICU and the mean hospital LOS was 3.7 (SD 3.1) days. The most common reasons for hospitalization included acute kidney failure (6.5%, n=168), hypertensive heart disease with heart failure (5.8%, n=150), non-ST elevation myocardial infarction (5.1%, n=132), sepsis (2.4%, n=62), atrial fibrillation (2.1%, n=54), chronic obstructive pulmonary disease with (acute) exacerbation (2%, n=52), pneumonia (1.9%, n=49), chronic obstructive pulmonary disease with acute lower respiratory infection (1.8%, n=47), urinary tract infection (1.4%, n=36), and transient cerebral ischemic attack (1.2%, n=31). The most common payers were Medicare Part A (39.9%, n=1034), UPMC for Life Medicare Health Maintenance Organization (19.8%, n=514), Security Blue Referred (8.4%, n=218), Advantra-Medicare Health Maintenance Organization (5%, n=130), and Freedom Blue (4.2%, n=108).

Table 1. Differences in characteristics between caregiver identified and caregiver declined.

Characteristic	Overall (N=2591)	Caregiver identified (n=1801)	Caregiver declined (n=790)	*P* value[a]
Age (years), mean (SD)	74.6 (7.1)	74.7 (7.0)	74.3 (7.1)	.16
Elixhauser comorbidity index, mean (SD)	5.0 (2.0)	5.0 (2.0)	5.1 (2.1)	.25
LOS[b] (days), mean (SD)	3.7 (3.1)	3.7 (3.0)	3.7 (2.9)	.99
Income (US $), mean (SD)	47,853 (15,223)	48,097 (15,150)	47,296 (15,383)	.22
ICU[c], yes, n (%)	286 (11)	195 (10.8)	73 (9.2)	.22
Gender, female, n (%)	1194 (46.1)	812 (45.1)	382 (48.4)	.12
Marital status, married, n (%)	1475 (56.9)	1114 (61.9)	361 (45.7)	<.001
Race, White, n (%)	2251 (86.9)	1569 (87.1)	682 (86.3)	.66
Surgery, n (%)	618 (23.9)	460 (25.5)	158 (20)	.002
Diabetes, type 2, n (%)	2523 (97.4)	1748 (97.1)	775 (98.1)	.22
Comorbidities, n (%)				
Hypertension	1329 (51.3)	927 (51.5)	402 (50.9)	.78
Heart failure	841 (32.5)	575 (31.9)	266 (33.7)	.38
Kidney failure	729 (28.1)	524 (29.1)	205 (25.9)	.10
Myocardial infarction	232 (9)	150 (8.3)	82 (10.4)	.10
Stroke	73 (2.8)	49 (2.7)	24 (3)	.66
Hyperlipidemia	31 (1.2)	25 (1.4)	6 (0.8)	.16

[a] Compares differences between caregiver identified and caregiver declined.

[b] LOS: length of stay.

[c] ICU: intensive care unit.

We compared the differences in health service utilization between pre- and postimplementation of the CARE Act; however, no significance was found. We then compared the differences in health service utilization between those who identified a caregiver and those who declined to identify a caregiver after implementation of the CARE Act. Of the 2591 patients, 1801 (69.5%) identified a caregiver, whereas 790 (30.5%) declined to identify a caregiver. The caregiver relationship to patient (note: there missing values for this variable for 7 participants) included spouse (55%, 986/1794), child (28.7%, 516/1794), parent (0.1%, 2/1794), and other (16.2%, 290/1794). Patients who identified a caregiver were more likely to be married (*P*<.001) and hospitalized for surgery (*P*=.002) than those who declined to identify a caregiver (Table 1). No significant differences were found in any patient outcomes between individuals who identified a caregiver and those who declined to identify a caregiver in the bivariate analyses (Table 2). However, after adjusting for risk factors (including Elixhauser comorbidity index, ICU [no/yes], ICU LOS, age, medical/surgical patient type, race, sex, marital status, and median zip code income) to perform the multivariate analyses, the 30-day readmission rate among the patients who identified a caregiver (12.2%, 219/1801) was significantly higher than the rate for patients who declined to identify a caregiver (9.9%, 78/790; odds ratio [OR] 1.38, 95% CI 1.04-1.87; *P*=.02). No significant differences were found in 7-day hospital readmission,7-day and 30-day ED visits, or 7-day and 30-day mortality between the 2 groups after adjusting for the risk factors (Table 2).

Table 2. Differences in patient outcomes between caregiver identified and caregiver declined.

Patient outcome	Caregiver identified (n=1801), n (%)	Caregiver declined (n=790), n (%)	Unadjusted *P* value	Risk-adjusted *P* value[a]	Odds ratio (95% CI)
Readmission					
7-Day	82 (4.6)	30 (3.8)	.38	.16	1.37 (0.88-2.13)
30-Day	219 (12.2)	78 (9.9)	.09	.02	1.38 (1.04-1.83)
Emergency department visit					
7-Day	135 (7.5)	53 (6.7)	.47	.28	1.21 (0.86-1.69)
30-Day	302 (16.8)	128 (16.2)	.72	.24	1.15 (0.91-1.45)
Mortality					
7-Day	11 (0.6)	3 (0.4)	.44	.36	1.91 (0.48-7.58)
30-Day	27 (1.5)	12 (1.5)	.97	.68	1.17 (0.56, 2.42)

[a] Risk-adjusted variables included the number of comorbid conditions, intensive care unit (no/yes), intensive care unit length of stay, age, medical/surgical patient type, race, sex, marital status, and income.

Among the 1801 patients who identified caregivers, 399 (22.2%) caregivers received education, whereas 1402 (77.8%) did not receive education. Patients with diabetes whose identified caregiver received education were more likely to be surgical patients (*P*=.01), male (*P*<.001), and married (*P*<.001) than those whose identified caregiver did not receive education (Table 3). In the bivariate analyses, significantly lower rates of 7-day readmission (*P*=.02) as well as 7-day (*P*=.03) and 30-day (*P*=.01) ED visits were detected among patients with diabetes whose identified caregiver received education than those whose identified caregiver did not receive education. After risk adjustment (multivariate analyses), there was no significant decrease in 7-day readmission (OR 0.53, 95% CI 0.27-1.05; *P*=.07) and 7-day (OR 0.63, 95% CI 0.38-1.03; *P*=.07) and 30-day (OR 0.73, 95% CI 0.52-1.02; *P*=.07) ED visits. No significant associations were found for the other outcomes before or after adjusting for risk factors (Table 4).

Table 3. Differences in characteristics between identified caregivers who received education and training and those who did not receive education and training.

Characteristic	No education and training, (n=1402)	Received education and training, (n=399)	*P* value
Age (years), mean (SD)	74.7 (7.0)	74.8 (7.0)	.70
Elixhauser comorbidity index, mean (SD)	5.0 (2.0)	4.99 (2.0)	.77
LOS[a] (days), mean (SD)	3.7 (3.0)	3.7 (3.1)	.94
Income (US $), mean (SD)	47,687 (14,689)	49,542 (16,612)	.03
ICU[b], yes, n (%)	147 (10.5)	48 (12)	.39
Gender, female, n (%)	672 (47.9)	140 (35.1)	<.001
Marital status, married, n (%)	810 (57.8)	304 (76.2)	<.001
Race, White, n (%)	1213 (86.5)	356 (89.2)	.005
Surgery, n (%)	338 (24.1)	122 (30.6)	.01
Diabetes, type 2, n (%)	1359 (96.9)	389 (97.5)	.43
Comorbidities, n (%)			
Hypertension	722(51.5)	205 (51.4)	.97
Heart failure	457 (32.6)	118 (29.6)	.25
Kidney failure	410 (29.2)	114 (28.6)	.79
Myocardial infarction	113 (8.1)	37 (9.3)	.44
Stroke	37 (2.6)	12 (3)	.69
Hyperlipidemia	16 (1.1)	9 (2.3)	.11

[a] LOS: length of stay.

[b] ICU: intensive care unit.

Table 4. Differences in patient outcomes between identified caregivers who received education and training and those who did not receive education and training.

Patient outcome	Received education and training (n=399), n (%)	No education and training, (n=1402), n (%)	Unadjusted *P* value	Risk-adjusted *P* value[a]	Odds ratio (95% CI)
Readmission					
7-Day	10 (2.5)	72 (5.1)	.02	.07	0.53 (0.27-1.05)
30-Day	39 (9.8)	180 (12.8)	.09	.14	0.76 (0.52-1.10)
Emergency department visit					
7-Day	20 (5.0)	115 (8.2)	.03	.07	0.63 (0.38-1.03)
30-Day	51 (12.8)	251 (17.9)	.01	.07	0.73 (0.52-1.02)
Mortality					
7-Day	1 (0.3)	10 (0.7)	.25	.26	0.30 (0.04-2.42)
30-Day	4 (1.0)	23 (1.6)	.33	.32	0.57 (0.19-1.71)

[a] Risk-adjusted variables included the number of comorbid conditions, intensive care unit (no/yes), intensive care unit length of stay, age, medical/surgical patient type, race, sex, marital status, and income.

Discussion

Our primary focus was to examine the relationships among the CARE Act identification and education tenets and the various health service utilization outcomes of older adults with diabetes. We found that the identification of a caregiver for older patients with diabetes being discharged to home was significantly associated with higher 30-day readmission rates after adjusting for risk factors. We also found that having a caregiver who received education was associated with lower rates of 7-day readmission and 7-day and 30-day ED visits, but these associations were not significant after adjusting for risk factors.

Our findings suggest that patients with diabetes who identified a caregiver were at an increased risk for 30-day hospital readmission. One possibility is that the identification of a caregiver is simply a proxy for more serious illnesses or higher care needs following surgery. This finding aligns with a descriptive qualitative study that showed that patients with diabetes who require a caregiver are at higher risk for hospital readmission [27]. In addition, a retrospective, case-control study using deidentified EHR data found that 10% of patients with diabetes were readmitted within 30 days of discharge [28], which is similar with the 30-day readmission rate in patients who declined a caregiver (9.9%) but lower than that in those who identified a caregiver in our study (12.2%). Although our study did not explore factors that may have contributed to the increased 30-day hospital readmission rate in patients who identified a caregiver, several potential reasons may exist (eg, patients having more complex medical conditions [29], a severe issue that needs further care after hospitalization [29,30], or an escalation of diabetic treatments such as insulin injections [28,30]). It also might be attributed to caregivers paying more attention to the patients' abnormal signs or symptoms. We believe further investigation and study of these factors is warranted.

We also found that having a caregiver who received education was associated with lower rates of 7-day readmission and 7-day and 30-day ED visits than those whose identified caregiver did not receive education, but these association did not remain significant after adjusting for risk factors. This finding might indicate that educating caregivers to properly care for older patients with diabetes is important for reducing health service utilization, as these patients are at a high risk of acute and chronic complications related to their illness [31]. In addition, caregivers might reduce the burden of the many daily tasks associated with relevant diabetes management [2,3,32].

Our study did not find associations between identifying a caregiver or caregiver education with the mortality rate for older patients with diabetes. This might be attributed to the low incidence of mortality, small sample size, comorbidities, or the time frame selected for data analyses. To our knowledge, no published articles have evaluated the impact of CARE Act implementation on mortality rate. Therefore, future work could investigate this effect using a longer duration since only 6 months of data were retrieved.

The study has several limitations. The sample consisted of mostly White patients with a high mean income, limiting any conclusions related to racially and ethnically diverse samples. Additionally, the study was not designed to assess causality or identify a mechanism by which improvement occurs. Other potential confounding factors not included in the analysis (eg, severity of disease and clinical documentation issues) may have influenced the patients' outcomes. Moreover, the design does not truly account for the policy implementation, and as a result it is not clear if other hospital policies or practices in place at the time that could have influenced these results. Another limitation of the study is the short time range of the EHR data. It would be beneficial to determine if these findings could be replicated using a larger sample size over a longer period of time. Furthermore, although all the patients had diabetes, they were not necessarily in the hospital for a reason related to diabetes. The patient's utilization of health services outside of UPMC was also not captured. However, this would be present for both groups—those who identified a caregiver and those who did not.

In conclusion, our study found that the implementation of the CARE Act was associated with certain health service utilization changes. The identification of caregivers was associated with higher rates of 30-day hospital readmission in the multivariate analysis, whereas the identification of caregivers who received education was associated with lower rates of readmission and ED visit in the bivariate analysis. Future research directions are aimed at determining whether patient outcomes are influenced by the education delivered (who, what, when, and how) to hospitalized patients with diabetes and their caregivers [32].

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Authors' Contributions

YZ conceived and designed study aim 2, conducted the literature search, performed the statistical analyses, interpreted the data, and drafted and revised the manuscript. BA contributed to study design, interpreted the data, revised and edited the manuscript, and supervised all of YZ’s research activities. JR conceived the study design and aim 1, identified subgroup relevance for aim 2, interpreted the data, revised and edited the manuscript, and oversaw the study progress, as well as facilitated collaboration among study team members. SCAD and JCH contributed to data extraction from electronic health records, analysis design, and accuracy check for data analysis; interpreted the data; and revised the manuscript. BF was involved in discussions around literature support and the conceptual design of study aim 1, interpreted the data, and revised the manuscript. HD was involved in discussions of study design, interpreted the preliminary data, and revised the manuscript. CF contributed to study design, implemented caregiver education and training, interpreted the data, and revised the manuscript. GM contributed to study design and manuscript revisions. AB is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. SCM and DL contributed to manuscript revisions. AEJ is the principal investigator of the funded study, who conceived and designed the study and revised the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

CARE Act: Caregiver Advise Record Enable Act
ED: emergency department
EHR: electronic health record
ICU: intensive care unit
LOS: length of stay
OR: odds ratio
UPMC: University of Pittsburgh Medical Center

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Original Paper

A Computerized Cognitive Test Battery for Detection of Dementia and Mild Cognitive Impairment: Instrument Validation Study

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Abstract

Background: Early detection of dementia is critical for intervention and care planning but remains difficult. Computerized cognitive testing provides an accessible and promising solution to address these current challenges.

Objective: The aim of this study was to evaluate a computerized cognitive testing battery (BrainCheck) for its diagnostic accuracy and ability to distinguish the severity of cognitive impairment.

Methods: A total of 99 participants diagnosed with dementia, mild cognitive impairment (MCI), or normal cognition (NC) completed the BrainCheck battery. Statistical analyses compared participant performances on BrainCheck based on their diagnostic group.

Results: BrainCheck battery performance showed significant differences between the NC, MCI, and dementia groups, achieving 88% or higher sensitivity and specificity (ie, true positive and true negative rates) for separating dementia from NC, and 77% or higher sensitivity and specificity in separating the MCI group from the NC and dementia groups. Three-group classification found true positive rates of 80% or higher for the NC and dementia groups and true positive rates of 64% or higher for the MCI group.

Conclusions: BrainCheck was able to distinguish between diagnoses of dementia, MCI, and NC, providing a potentially reliable tool for early detection of cognitive impairment.

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KEYWORDS

cognitive test; mild cognitive impairment; dementia; cognitive decline; repeatable battery; discriminant analysis

Introduction

In proportion with the growth of the aging population, the incidence of dementia is on the rise and is projected to affect nearly 14 million people in the United States and upwards of 152 million people globally in the coming decades [1-3]. Current rates of undetected dementia are reported to be as high as 61.7% [4], and available treatments are limited to promoting quality of life rather than reversal or cure of the disease process. The ability to properly identify and treat dementia at this scale requires an active approach focused on early identification. Early detection of dementia provides access to timely interventions and knowledge to promote patient health and quality of life before symptoms become severe [5-8]. Early and accurate diagnosis also allows for proper preparation for patients, caregivers, and their families, resulting in improved caregiver well-being and delayed nursing home placements [9-12]. Further, it helps to characterize patients with early-stage dementia for clinical trials, exploring the latest therapeutics and validating biomarkers indicative of specific pathologies. Despite the benefits, early detection is a challenge with current clinical protocols, leaving many patients undiagnosed until symptoms become noticeable in later stages of the illness [13].

Considered an early symptomatic stage of dementia, mild cognitive impairment (MCI) signifies a level of cognitive impairment between normal cognition (NC) and dementia [14]. While not all MCI cases progress, the conversion rate of MCI to dementia has been observed to be approximately 5% to 10% [15]. This stresses the importance of identifying MCI in early detection and clinical intervention for dementia, which is included in recommendations from the National Institute on Aging and the Alzheimer's Association [16]. Detection of MCI has been successful when using brief cognitive screening assessments. The widely used Montreal Cognitive Assessment (MoCA) has demonstrated 83% sensitivity and 88% specificity in distinguishing MCI from NC, and 90% sensitivity and 63% specificity in distinguishing dementia from MCI [17-19]. Similar performance has also been observed for the Mini-Mental State Examination (MMSE) and the Saint Louis University Mental Status (SLUMS) exam [20-22]. While these screening tests do well in their ability to detect MCI, they have many limitations. First, these tests are time- and labor-intensive (ie, verbal administration by a physician or test administrator and hours for training, recording responses, scoring, and interpreting results). Second, these paper-based tests cannot allow for tracking of timing, which is an important indicator of an individual's cognitive health [23]. Also, there is a lack of detailed insight into different cognitive domains because their individual subtests are, by design, simple and suffer from ceiling effects [19,24,25].

Neuropsychological tests (NPTs) represent a more extensive and comprehensive class of cognitive evaluation [26]. They allow for research into certain cognitive domains (eg, attention, working memory, language, visuospatial skills, executive functioning, and memory), research that is used to support clinical diagnoses and further delineate specific neurocognitive disorders. NPTs can determine patterns of cognitive functioning that relate to normal aging, MCI, and dementia progression with a specificity of 67% to 99% [27]. A major strength of NPTs is their ability to characterize cognitive impairment, providing clues to underlying pathology, and thereby improving diagnostic accuracy to guide appropriate treatment. However, NPTs come with downsides, including financial cost, long appointment times, and high levels of training and expertise required to conduct and interpret tests. Prior studies have also shown that some NPTs demonstrate high accuracy in differentiating dementia patients from healthy participants, but do not have adequate psychometrics to distinguish MCI from dementia [28-31].

Computerized cognitive assessment tools have been developed to address the issues of accessibility and efficiency [31-34]. They are more comprehensive than screening tests but less expensive and quicker than clinical NPTs, and they aim to maximize accessibility to both patients and providers. They also yield multiple benefits, including maintaining testing standardization, alleviating the time pressures of modern clinical practice, and providing a comprehensive assessment of cognitive function to strengthen a clinical diagnosis. Importantly, in the new era of practicing amid the COVID-19 pandemic [35-37], increasing the accessibility of remote cognitive testing for vulnerable and high-risk patients is essential.

This study evaluated BrainCheck, a computerized cognitive test battery available on mobile devices, such as smartphones, tablets, and computers, making it portable and allowing it to be administered remotely. In addition to offering automated scoring and instant interpretation, BrainCheck requires short administration and testing times, comparable to traditional screening instruments, but provides detailed insight into multiple aspects of cognitive functioning that only comprehensive NPTs can. BrainCheck has previously been validated for its diagnostic accuracy in detecting concussion [38] and dementia-related cognitive decline [39]. Furthering its validation for dementia-related cognitive decline, we sought to assess BrainCheck's utility as a diagnostic aid to accurately assess the severity of cognitive impairment. We measured BrainCheck's ability to distinguish individuals with different levels of cognitive impairment (ie, NC, MCI, and dementia) based on their comprehensive clinical diagnoses. Our goal was to further demonstrate the utility of BrainCheck for cognitive assessment, specifically as a diagnostic aid in cases where NPT may be unavailable or when a comprehensive evaluation is not indicated.

Methods

Ethics Approval

This study was approved by the University of Washington (UW) Institutional Review Board (IRB) for human subject participation (review number STUDY00000790).

Recruitment

Participants were recruited from a research registry maintained by the Alzheimer's Disease Research Center associated with the UW Medicine Memory and Brain Wellness Center clinic [40]. This registry is a continually updated database of individuals who have expressed interest and signed an IRB-approved consent form to be contacted about participation in Alzheimer disease (AD) and related dementias research studies, many of whom have been recently evaluated at the clinic and, hence, have a clinical diagnosis or evaluation. Those with listed addresses within a 70-mile radius of Seattle, Washington, were contacted by phone or email, based on information provided within the registry. If the person was unable to physically use an iPad, if the person was too cognitively impaired to understand or follow instructions, or if the primary contact (eg, spouse) indicated that the person was unable to participate, they were not recruited for the study. When study procedures were modified from in-person to remote administration due to the COVID-19 pandemic (approximately March 2020), participants outside the initial geographical range were contacted to explore remote testing capabilities. We required that these participants have access to either an iPad with iOS 10 or later or a touchscreen computer and Wi-Fi connectivity to participate in the study.

Using the provided primary cognitive diagnosis within the registry, participants were divided into one of three groups: (1) NC, indicated by subjective cognitive complaint or no diagnosis of cognitive impairment, some of which were self-reported; (2) MCI, representing both amnestic and nonamnestic subtypes; or (3) dementia, which included dementia due to AD, frontotemporal dementia, vascular dementia, Lewy body dementia, mixed dementia, or atypical AD.

A total of 5 participants were not recruited from the registry but via snowball sampling from other participants. The recruitment of these participants was simply due to convenience, typically a family member or friend that was also available at the time of testing. Out of these 5 participants, 4 of them were placed into the NC group after their self-reports denied symptoms or a history of cognitive impairment; these 4 were not patients of the memory clinic. The remaining participant was a patient from the memory clinic, just not a part of the registry, and was placed in the AD group based on their most recent diagnosis retrieved from their medical records. Testing for these 5 participants was administered on-site.

Study Design and Procedures

On-site Administration

Data for on-site administration was collected from October 2019 to February 2020. A session was held either in the participant's home or in a well-lit, quiet, and distraction-free public setting. Consent forms were reviewed and signed by the participant or their legally authorized representative and an examiner, with both parties obtaining a copy. The study was designed for participants to complete one session with a moderator using a provided iPad (model MR7G3LL/A; Apple Inc) connected to Wi-Fi to complete the BrainCheck battery. Prior to testing, participants were briefed on BrainCheck, and moderator guidance was limited to questions and assistance requested by the participant during the practice portions. Participants received a gift card (US $20) for participation at the conclusion of the study session.

Remote Administration

Due to the COVID-19 pandemic and interest in preliminary data on remote cognitive testing, study procedures were modified to accommodate stay-at-home orders in Washington state. Data collection resumed from April to May 2020, with modified procedures using remote administration. These participants provided written and verbal consent and were administered the BrainCheck battery remotely over a video call with the moderator. Participants used their personal iPads or touchscreen computer browsers to complete the BrainCheck battery. The same method for on-site administration, as described above, was used for remote administration.

Measurements

A short description for each of the five assessments comprising the BrainCheck battery (V4.0.0) is listed in Table S1 in Multimedia Appendix 1. More detailed descriptions may be found in a previous validation study [38]. After completion of the BrainCheck battery, the score for each assessment was calculated using assessment-specific measurements by the BrainCheck software (Table S1 in Multimedia Appendix 1). The BrainCheck Overall Score is a single, cumulative score for the BrainCheck battery that represents general cognitive functioning. This score was calculated by taking the average of all completed assessment scores. If an assessment was timed out, a penalty was applied by setting this assessment score to zero. The normalized assessment scores and BrainCheck Overall Scores were corrected for participant age and device used (ie, iPad vs computer) using the mean and SD of the corresponding score from a normative database previously collected by BrainCheck [38,39]. The score generated followed a standard normal distribution, where a lower score indicates lower assessment performance and cognitive functioning.

Statistical Analysis

Statistical analyses were performed using Python (version 3.8.5; Python Software Foundation) and R (version 3.6.2; The R Foundation) programming languages. All tests were 2-sided, and significance was accepted at the 5% level (α=.05). Comparison of means of groups was made by an analysis of variance test for normally distributed data. The chi-square test was used to analyze differences in categorical variables.

To evaluate BrainCheck performance among participants in different diagnostic groups while adjusting for age, sex, and administration type, linear regression was used in which the outcome variables were duration to complete BrainCheck battery, individual BrainCheck assessment scores, and BrainCheck Overall Scores. *P* values were corrected using the Tukey method for multiple comparisons. To assess the accuracy of the BrainCheck Overall Score in the binary classification of participants in the different diagnostic groups (ie, dementia vs NC, MCI vs NC, and dementia vs MCI), receiver operating characteristic (ROC) curves with area under the curve (AUC) calculations were generated to determine diagnostic sensitivity and specificity. In these binary classifications, sensitivity (ie, true positive rate) and specificity (ie, true negative rate) are measured, with the more severe group as cases and the less severe group as controls. For example, the MCI group represents cases in the MCI versus NC classification, but it represents controls in the dementia versus MCI classification. In assessing BrainCheck for three-group classification, we used volume under the three-class ROC surface method from Luo and Xiong [41] to define optimal cutoffs for the BrainCheck Overall Score and find the maximum diagnostic accuracy.

Results

Participant Characteristics and Demographics

A total of 241 individuals were contacted to participate, and 99 participants completed the study. Demographic details of the participants are provided in Table 1. The three groups did not differ to a significant degree in terms of education, administration type, or recruitment type, but there were differences in age and sex.

Table 1. Participant demographics.

Demographics	Normal cognition (n=35)	Mild cognitive impairment (n=22)	Dementia (n=42)	*P* value
Participants (N=99), n (%)[a]	35 (35)	22 (22)	42 (42)	—[b]
Age (years), mean (SD)	67.8 (9.6)	73.5 (5.9)	71.5 (9.0)	.04[c]
Sex, n (%)				.005[d]
Female	25 (71)	8 (36)	16 (38)	
Male	10 (29)	14 (64)	26 (62)	
Education level, n (%)				.70[d]
Some college or less	2 (6)	2 (9)	8 (19)	
Bachelor of Arts or Bachelor of Science college graduate	10 (29)	6 (27)	11 (26)	
Post–bachelor's degree	14 (40)	9 (41)	16 (38)	
N/A[e]	9 (26)	5 (23)	7 (17)	
Administration type, n (%)				.37[d]
On-site	29 (83)	16 (73)	29 (69)	
Remote	6 (17)	6 (27)	13 (31)	
Recruitment type, n (%)				.09[d]
Registry	31 (89)	22 (100)	41 (98)	
Snowball	4 (11)	0 (0)	1 (2)	

[a] Percentages in this row were calculated based on the total sample number.

[b] No statistical test was run.

[c] This *P* value was calculated using the analysis of variance test.

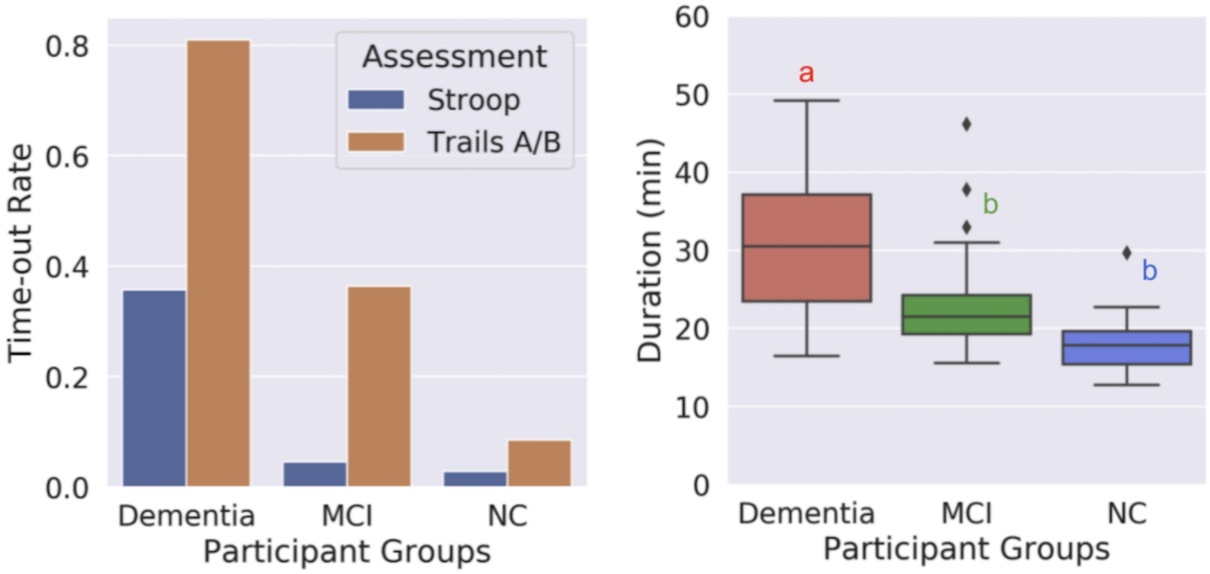
[d] This *P* value was calculated using the chi-square test.

[e] N/A: not applicable; a response was not given.

Completion of Assessments

We found that most participants in the NC group were able to complete the assessments, whereas the dementia group had a higher time-out rate, with the MCI group falling in between the two (Figure 1). The time-out function occurs when a participant cannot complete a trial of the assessment in 30 seconds; it is embedded in the assessments of the Stroop test and the Trail Making Test, Parts A and B (Trails A/B). Time-outs were mainly due to response delays, where participants were attempting the test but could not answer quickly enough. Overall, the dementia group took significantly more time to complete the BrainCheck battery (median 30.5, IQR 23.4-37.1 min) compared to the MCI group (median 21.5, IQR 19.3-24.2 min) and the NC group (median 17.8, IQR 15.4-19.6 min).

Figure 1. Completion of assessments and durations to complete BrainCheck battery. A. Time-out rates of the Stroop test and Trails A/B assessments for each diagnostic group. The BrainCheck Stroop and Trails A/B assessments time out if participants cannot complete a trial of the assessment in 30 seconds. B. Duration (min) to complete the BrainCheck battery for each diagnostic group. Letters (a, b) indicate significant differences between groups (*P*<.05) in the linear regression model, with age, sex, and administration type as regressors; any two groups sharing a letter are not significantly different. MCI: mild cognitive impairment; NC: normal cognition; Trails A/B: Trail Making Test, Parts A and B.



BrainCheck Performance

BrainCheck assessments were compared across the three groups using a linear regression model with age, sex, and administration type as regressors (Figure 2 and Table 2). Individual scores, such as the BrainCheck Overall Score, were normalized for age and device. Overall, participants with greater cognitive impairment showed lower BrainCheck assessment scores. All individual assessments except Trails B showed significant differences in performance between the NC and dementia groups, whereas two of the seven assessments (ie, Immediate Recognition and Digit Symbol Substitution) showed significant differences in performance between all three groups (Figure 2 and Table 2). Digit Symbol Substitution, Flanker, and Trails A/B assessments showed long tails in the scores of the dementia group because some participants in the dementia group only completed parts of the assessments or exhibited low accuracy (Figure S1 in Multimedia Appendix 1).

The BrainCheck Overall Score is a composite of all individual assessments within the BrainCheck battery, representing overall performance (see details in the Measurements section). Using an existing normative population database, partly compiled from controls in previous studies [38,39], the BrainCheck Overall Score was adjusted for age and the device used to generate the normalized BrainCheck Overall Scores. The normalized BrainCheck Overall Scores differed significantly among these three groups (*P*<.001). Pairwise comparisons with Tukey adjustments for multiple comparisons show that the NC group scored significantly higher than the MCI group (*P*=.002) and the dementia group (*P*<.001), and the MCI group scored significantly higher than the dementia group (*P*<.001; Figure 3).

Figure 2. Pairwise comparison of participant groups based on normalized scores of BrainCheck assessments. For each assessment, any two groups sharing a letter are not significantly different. Otherwise, they are significantly different (*P*<.05) in linear regression models, with age, sex, and administration type as regressors. The outliers identified by the IQR method in each assessment were removed before the comparison. MCI: mild cognitive impairment; NC: normal cognition; Trails A: Trail Making Test, Part A; Trails B: Trail Making Test, Part B.

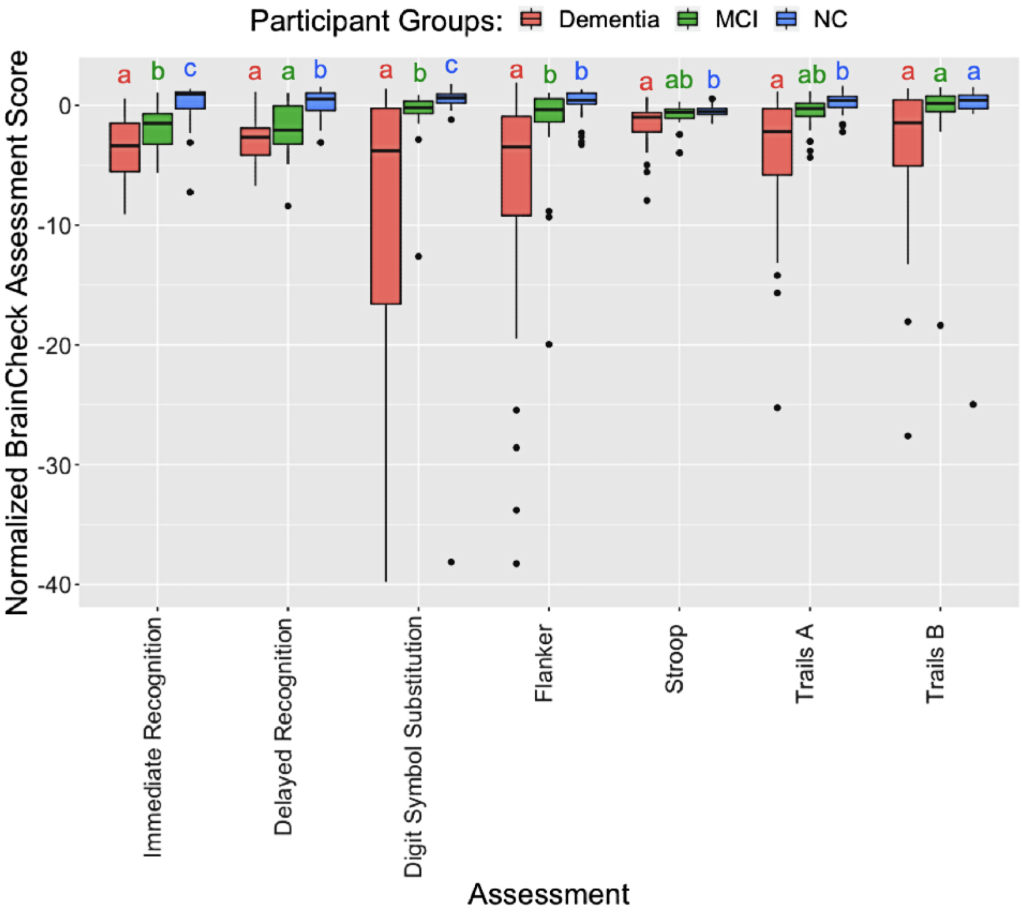


Table 2. Linear regression model analyses using each BrainCheck assessment score and the BrainCheck Overall Score as the outcome variable in separate models, with age, sex, and administration type as regressors.

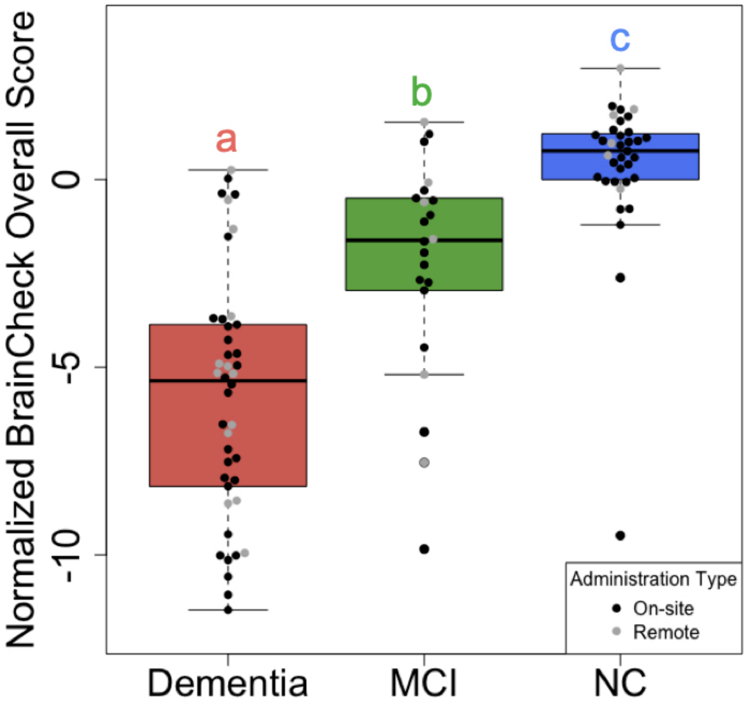
Assessment	Estimated marginal mean (SE)			Contrast estimate (*P* value)		
	NC[a]	MCI[b]	Dementia	Dementia vs NC	Dementia vs MCI	MCI vs NC
Immediate Recognition[c]	0.17 (0.44)	–1.93 (0.50)	–3.36 (0.36)	–3.54 (<.001)	–1.43 (.04)	–2.10 (.005)
Delayed Recognition	0.06 (0.34)	–2.16 (0.39)	–2.92 (0.28)	–2.98 (<.001)	–0.76 (.23)	–2.23 (<.001)
Digit Symbol Substitution[c]	0.80 (0.27)	–0.21 (0.29)	–1.23 (0.29)	–2.02 (<.001)	–1.01 (.04)	–1.01 (.03)
Flanker	0.76 (0.45)	–0.74 (0.51)	–2.64 (0.41)	–3.4 (<.001)	–1.89 (.009)	–1.5 (.06)
Stroop test	–0.43 (0.12)	–0.63 (0.13)	–0.91 (0.12)	–0.49 (.01)	–0.28 (.23)	–0.21 (.46)
Trail Making Test, Part A	–0.01 (0.33)	–0.75 (0.36)	–1.69 (0.30)	–1.67 (<.001)	–0.94 (.11)	–0.74 (.29)
Trail Making Test, Part B	0.51 (0.21)	0.21 (0.23)	–0.16 (0.24)	–0.67 (.08)	–0.37 (.47)	–0.30 (.57)
Normalized BrainCheck Overall Score[c]	0.71 (0.55)	–2.15 (0.62)	–5.63 (0.45)	–6.34 (<.001)	–3.48 (<.001)	–2.86 (.002)

[a] NC: normal cognition.

[b] MCI: mild cognitive impairment.

[c] These assessments indicate significant differences across all three diagnostic groups.

Figure 3. Comparison of normalized BrainCheck Overall Scores among groups. The normalized BrainCheck Overall Score follows a standard normal distribution. Letters (a, b, c) indicate significant differences (*P*<.05) on the linear regression model, with age, sex, and administration type as regressors. MCI: mild cognitive impairment; NC: normal cognition.



BrainCheck Diagnostic Accuracy

Using ROC analysis, BrainCheck Overall Scores achieved a sensitivity of 88% and a specificity of 94% for classifying between dementia and NC participants (AUC=0.95), a sensitivity of 86% and a specificity of 83% for classifying between MCI and NC participants (AUC=0.84), and a sensitivity of 83% and a specificity of 77% for classifying between dementia and MCI participants (AUC=0.79; Figure 4).

Using methods described by Luo and Xiong for three-group classification [41], the optimal lower and upper cutoffs of the normalized BrainCheck Overall Score in maximizing diagnostic accuracy were –3.64 and –0.06, respectively. This achieved true positive rates of 80% for the NC group, 64% for the MCI group, and 81% for the dementia group (Figure 5).

Figure 4. ROC curves for the BrainCheck Overall Score in classifying participants of different groups. ROC curves with AUCs for the BrainCheck Overall Score in the binary classification of (A) dementia vs NC, (B) MCI vs NC, and (C) dementia vs MCI. In these binary classifications, sensitivity (ie, true positive rate) and specificity (ie, true negative rate) are measured with the more severe group as cases and the less severe group as controls. AUC: area under the curve; MCI: mild cognitive impairment; NC: normal cognition; ROC: receiver operating characteristic.

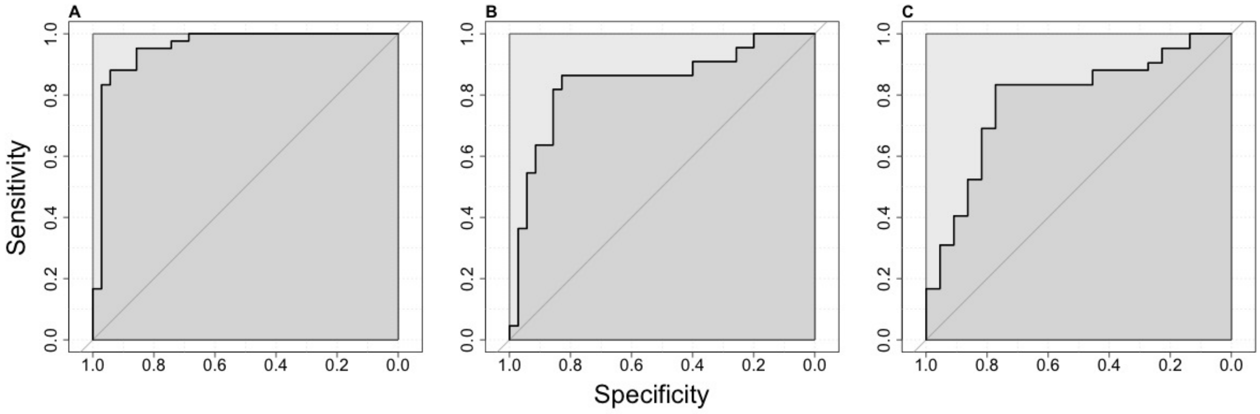
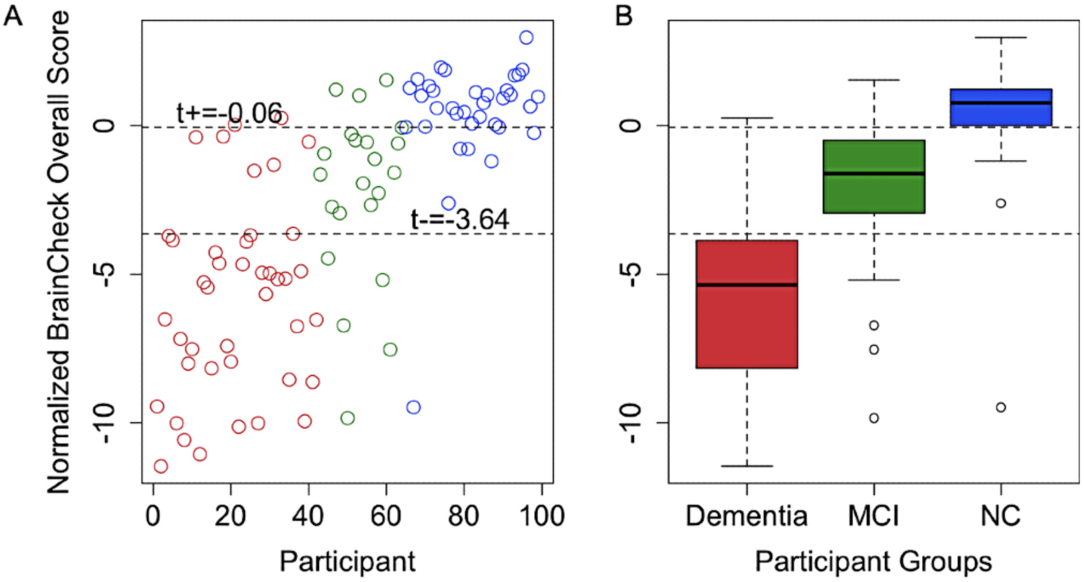


Figure 5. Optimal BrainCheck cutoff scores for distinguishing NC, MCI, and dementia groups. A. Individual participant normalized BrainCheck Overall Scores, where the x-axis is the index of the participant, sorted by primary diagnosis (dementia: red, MCI: green, and NC: blue). The values t+ and t-, respectively, represent the optimal upper and lower cutoffs of the normalized BrainCheck Overall Score in maximizing diagnostic accuracy. B. Box plots of normalized BrainCheck Overall Scores for each diagnostic group. The normalized BrainCheck Overall Score follows a standard normal distribution. The dashed lines label the optimal cutoff scores for distinguishing the diagnostic groups. MCI: mild cognitive impairment; NC: normal cognition.



Discussion

Principal Findings

Consistent with prior findings in concussion [38] and in dementia and cognitive decline [39] samples, this study demonstrated that BrainCheck is consistent in its capability to detect cognitive impairment and can reliably detect severity and differentiate between cognitive impairment groups (ie, NC, MCI, and dementia). As expected, participants with more severe cognitive impairment performed worse across the individual assessments and on BrainCheck Overall Scores. The BrainCheck Overall Scores separated participants of different diagnostic groups successfully with high sensitivity and specificity.

BrainCheck Overall Scores were more robust in distinguishing between these groups where participants in the dementia group had significantly lower scores than those in the NC group. The BrainCheck battery was able to distinguish between NC and dementia participants, with 94% sensitivity and 88% specificity. These findings show that the BrainCheck Overall Score demonstrates better accuracy for differentiating NC from dementia, compared to the MMSE, SLUMS, and MoCA screening measures [22,41,42]. People with MCI usually experience fewer cognitive deficits and preserved functioning in activities of daily living compared to those with dementia [43], and our findings of sensitivity and specificity with separating MCI from other groups were slightly lower than the NC versus the dementia differentiations (Figure 5). Nonetheless, the BrainCheck Overall Score showed sensitivities and specificities greater than 80% in distinguishing MCI from NC and dementia groups, which is comparable to the MoCA, SLUMS, and MMSE [18-22,42]. Furthermore, a review of validated computerized cognitive tests indicated AUCs ranging from 0.803 to 0.970 for detecting MCI, and AUCs of 0.98 and 0.99 in detecting dementia due to AD [44], which were comparable with the results found in this study.

Although not all individual assessments in the BrainCheck battery differentiated between NC, MCI, and dementia, we observed a general trend for each assessment showing that dementia participants had the lowest scores, whereas the NC participants had the highest scores. Individual assessments that did show significant differences in the scores between NC and MCI groups and between dementia and MCI groups included Immediate Recognition and Digit Symbol Substitution. Notably, Digit Symbol Substitution showed significant differences in performance between all three diagnostic groups, whereas a previous study found that Digit Symbol Substitution did not show significant differences between cognitively healthy and cognitively impaired groups (n=18, *P*=.29) [39], likely due to this study having a larger sample size. Individual assessments with no significant differences between the MCI group and the NC and dementia groups were the Stroop and Trails A/B tests (Figure 2 and Table 2). All of these tests include time-out mechanisms if participants are unable to complete the test, and time-out rates were higher in the more cognitively impaired groups (Figure 2). Therefore, when calculating the BrainCheck Overall Score, we have introduced a penalty mechanism for timed-out assessments.

In comparison to comprehensive NPTs, which can typically last a few hours and sometimes require multiple visits [43], BrainCheck demonstrated shorter test duration, with median completion times of 17.8 (IQR 15.4-19.6) minutes for NC participants and 30.5 (IQR 23.4-37.1) minutes for dementia participants (Figure 1). Shorter test durations observed in individuals with no or less cognitive impairment suggest that computerized cognitive tests could be useful for rapid early detection in this population, prompting further evaluation, whereas those with dementia have likely already undergone a comprehensive evaluation. The wide variance in completion time for the dementia group may have uncovered the difficulty that participants with more severe cognitive impairment may have faced in completing the BrainCheck battery, compared to the lower variance observed in the NC group.

A limitation of this study was that participants were not diagnosed by a physician at the time point of BrainCheck testing. Thus, participants were placed into the diagnostic groups based on their most recent clinical diagnosis available in their electronic health record, or for the few NC participants without medical evaluations, based on their report of no cognitive symptoms or diagnosis of cognitive impairment. The period from the most recent clinical diagnosis to the date of BrainCheck testing varied among the diagnostic groups; the dementia group had the fewest days from their latest clinical evaluation (median 82.5, IQR 44.5-141.25 days), followed by the MCI group (median 244, IQR 105-346.5 days) and the NC group (median 645, IQR 225.5-1112.5 days). These large time intervals in a degenerative population leave room for cognition to worsen over time, potentially blurring the lines in the severity of cognitive impairment, where participants may have progressed to MCI from NC and to dementia from MCI during that period. This would make distinguishing NC from cognitive impairment more difficult, yet diagnostic accuracy among the groups remains high. Furthermore, the median number of days since the last clinical evaluation for NC participants was as high as 645 days. This could suggest that the NC participants did not feel an inclination to seek out further cognitive evaluation during the extended time period, and may not have experienced noticeable cognitive decline. Future validity studies should ensure that a physician evaluation and diagnosis occur closer to the time of BrainCheck testing to address these limitations.

Another limitation was that although not all individual assessment scores could differentiate the three groups, the pattern of differences across these scores may contain useful diagnostic information. The use of the BrainCheck Overall Score as an average of all individual assessment scores appears to work effectively, but does not take into account the other relationships seen across individual scores. Furthermore, some individual scores may be more informative for detecting cases, whereas others may be informative for gauging severeness. Future studies recruiting a larger sample size in each group will allow for an investigation into whether machine learning methods can extrapolate these relationships and improve the diagnostic accuracy of BrainCheck.

When administration type was considered in linear regression model analyses, scores only showed significant differences among the three diagnostic groups instead of administration types. While remote administration was not designed into the original study, stay-at-home orders due to COVID-19 required modifications, and efforts were made to provide preliminary data for remote use. With preliminary outcomes indicating feasibility for remote administration, a more robust study and increased sample size will be needed to fully validate BrainCheck's cognitive assessment via its remote feature.

Conclusions

The use of computerized cognitive tests provides the opportunity to increase test accessibility for an aging population with an increased risk of cognitive impairment. The findings in this study demonstrate that BrainCheck could distinguish between three levels of cognitive impairment: NC, MCI, and dementia. BrainCheck is automated and quick to administer, both in person and remotely, which could help increase accessibility to testing and early detection of cognitive decline in an ever-aging population. This study paves the way for a comprehensive longitudinal study, exploring BrainCheck in early detection of dementia and monitoring of cognitive symptoms over time, including further comparison to gold-standard neuropsychological assessments.

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Authors' Contributions

BH and RHG were responsible for the conceptualization of the study and provided study supervision. SY, KS, and BH were responsible for the formal analysis. RHG was responsible for funding acquisition. KS, HQP, and BK were responsible for study investigation. SY, BH, and RHG were responsible for the study methodology. KS and RHG were responsible for securing study resources. SY, KS, HQP, BK, and BH wrote the original draft of the manuscript. All authors reviewed and edited the manuscript.

Conflicts of Interest

The principal investigator, RHG, serves as Chief Medical Officer of BrainCheck. All authors report personal fees from BrainCheck, outside of the submitted work, and KS, DH, BH, and RHG report receiving stock options from BrainCheck. The study was funded by BrainCheck.

Multimedia Appendix 1
Supplementary information.

[DOCX File , 156 KB - aging_v5i2e36825_app1.docx]

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Abbreviations

AD: Alzheimer disease
AUC: area under the curve
IRB: Institutional Review Board
MCI: mild cognitive impairment
MMSE: Mini-Mental State Examination
MoCA: Montreal Cognitive Assessment
NC: normal cognition
NPT: neuropsychological test
ROC: receiver operating characteristic
SLUMS: Saint Louis University Mental Status
Trails A/B: Trail Making Test, Parts A and B
UW: University of Washington

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Original Paper

Using GPS Tracking to Investigate Outdoor Navigation Patterns in Patients With Alzheimer Disease: Cross-sectional Study

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Abstract

Background: Spatial disorientation is one of the earliest and most distressing symptoms seen in patients with Alzheimer disease (AD) and can lead to them getting lost in the community. Although it is a prevalent problem worldwide and is associated with various negative consequences, very little is known about the extent to which outdoor navigation patterns of patients with AD explain why spatial disorientation occurs for them even in familiar surroundings.

Objective: This study aims to understand the outdoor navigation patterns of patients with AD in different conditions (alone vs accompanied; disoriented vs not disoriented during the study) and investigate whether patients with AD experienced spatial disorientation when navigating through environments with a high outdoor landmark density and complex road network structure (road intersection density, intersection complexity, and orientation entropy).

Methods: We investigated the outdoor navigation patterns of community-dwelling patients with AD (n=15) and age-matched healthy controls (n=18) over a 2-week period using GPS tracking and trajectory mining analytical techniques. Here, for the patients, the occurrence of any spatial disorientation behavior during this tracking period was recorded. We also used a spatial buffer methodology to capture the outdoor landmark density and features of the road network in the environments that the participants visited during the tracking period.

Results: The patients with AD had outdoor navigation patterns similar to those of the controls when they were accompanied; however, when they were alone, they had significantly fewer outings per day (total outings: $P<.001$; day outings: $P=.003$; night outings: $P<.001$), lower time spent moving per outing ($P=.001$), lower total distance covered per outing ($P=.009$), lower walking distance per outing ($P=.02$), and lower mean distance from home per outing ($P=.004$). Our results did not identify any mobility risk factors for spatial disorientation. We also found that the environments visited by patients who experienced disorientation versus those who maintained their orientation during the tracking period did not significantly differ in outdoor landmark density ($P=.60$) or road network structure (road intersection density: $P=.43$; intersection complexity: $P=.45$; orientation entropy: $P=.89$).

Conclusions: Our findings suggest that when alone, patients with AD restrict the spatial and temporal extent of their outdoor navigation in the community to successfully reduce their perceived risk of spatial disorientation. Implications of this work highlight the importance for future research to identify which of these individuals may be at an actual high risk for spatial disorientation as well as to explore the implementation of health care measures to help maintain a balance between patients' right to safety and autonomy when making outings alone in the community.

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KEYWORDS

Alzheimer disease; dementia; spatial disorientation; getting lost; outdoor navigation; risk factors; environmental; GPS tracking; community; mobile phone

Introduction

Background

Spatial disorientation is one of the earliest and most distressing symptoms seen in patients with Alzheimer disease (AD) [1,2]. It is defined as moments where patients are unsure about their whereabouts and are unable to navigate to an intended location [3]. This symptom manifests behaviorally as patients making navigation errors when in the community, which in turn can lead to a risk of them getting lost in both unfamiliar and familiar environments [4]. Being a prevalent problem worldwide, up to 70% of patients with dementia experience at least 1 getting lost episode over their disease course, while others experience multiple episodes [5-8]. Indeed, up to 40,000 people with dementia in the United Kingdom get lost in the community for the first time every year, and these incidence rates are likely to increase with the projected global rise in the patient population of dementia [5,9].

Although unpredictable in its onset, common real-world situations where patients with AD are likely to experience a getting lost episode include (1) when they perform routine activities in the community (ie, daily neighborhood walks and going to the corner shop), (2) when they are purposefully left unsupervised by their carer (ie, waiting for carer outside the shop), and (3) during night time while the carer is asleep [10,11]. Getting lost episodes can cause various negative consequences for the patients, such as increasing their chances of a care home admission by 7 times, decreasing their sense of autonomy, and increasing their risk of sustaining injuries and even potential death [7,12]. Extending beyond the patients themselves, other consequences of these episodes include increasing carer burden and distress as well as the involvement of law enforcement groups (ie, the police) and community search resources [11,13-15].

Despite getting lost episodes leading to significant negative consequences for the patients, their carers, and beyond, very little is still known about exactly why these episodes, and spatial disorientation in general, occur in patients with AD. From a neural standpoint, it has been suggested that spatial disorientation is seen more in AD as opposed to in other dementias [16,17]. Indeed, this is due to the pattern in which the AD neuropathology spreads, appearing early in regions of the brain that underlie spatial navigation. For example, neuropathology induced alterations to the medial temporal and parietal lobe structures result in impairments to egocentric (body-based) and allocentric (map-based) navigation strategies, respectively, as well as the interaction between the two [1]. Such navigation impairments can play a fundamental role in causing patients to make navigation errors when out in the community that they are ultimately unable to recover from, and hence leading to them getting lost.

In addition to the spatial navigation impairments, previous studies from our group have suggested that certain environmental factors, such as increased outdoor landmark density and complex road network structure, may act as risk factors for spatial disorientation by potentially triggering patients to make navigation errors [18,19]. However, these factors were identified using retrospective police case reports of missing people with dementia, and owing to the unavailability of trajectory data for the missing individuals, the true extent to which these factors contribute to spatial disorientation is unclear.

To date, very few studies have investigated the outdoor navigation patterns of patients with AD in the community, exploring these patterns in a general sense and, more specifically, relating them to factors such as caregiver burden and the individual's own well-being [20-23]. However, none of these studies have related the measured navigation patterns of these individuals to the occurrence of spatial disorientation or environmental risk factors. Exploring this relationship can potentially offer insight into variables that are associated with spatial disorientation. Specifically, we are interested in mobility risk factors, which if identified can potentially be used to establish which individuals may be at a high risk for getting lost in the community.

Aims

We thus conducted an outdoor navigation study on a sample of community-dwelling patients with AD and age-matched healthy controls, using GPS tracking over a 2-week period. Our first aim is to understand the outdoor navigation patterns of the patients over an extended period and in naturalistic, free-living conditions. Here, we wanted to investigate whether there are potential differences between healthy older adults and (1) patients overall, (2) patients when they are alone versus accompanied, and (3) patients who experienced and did not experience spatial disorientation in the tracking period. Our second aim is to test whether we could validate our previous study findings of environmental risk factors for getting lost episodes [18,19], by retrospectively investigating whether patients with AD experienced spatial disorientation when navigating through environments with a high outdoor landmark density and complex road network structure.

For our first aim, we present the following hypotheses (H):

First, Patients with AD would exhibit reduced outdoor navigation in the community when compared with healthy older adults based on findings from previous studies [20,22] and, more specifically, owing to the widely reported impairments in spatial navigation seen in patients with AD [1] (H1).

Second, we expect the potential reductions in outdoor navigation for the patients with AD to be relatively more apparent when they are alone than when they are accompanied on outings (H2).

Third, we also hypothesize that we will identify mobility patterns that support previously reported risk factors, which were identified through interviews and case reports, for spatial disorientation in patients. Specifically, patients who experience disorientation in the tracking period will have higher distances traveled from home (ie, venturing into unfamiliar environments) and have made increased nighttime outings into the community, thereby supporting commonly reported situations where spatial disorientation occurs for patients with AD using ecological outdoor navigation data [10] (H3).

For our second aim, we present the following hypothesis:

Patients who navigated through environments with both a high outdoor landmark density and complex road network structure will be the ones who experience spatial disorientation during the tracking period, as these 2 built features have been suggested as environmental risk factors for spatial disorientation in patients with AD by our previous studies [18,19] (H4).

Methods

Recruitment

A total of 16 community-dwelling patients with AD and 18 age-matched healthy controls were recruited to participate in this study (see Multimedia Appendix 1 for details). Before study participation, all participants underwent an initial telephone screening procedure to assess their eligibility for the study. The inclusion criteria were as follows: being aged between 50 and 80 years, living at home, and, if in the patient group, must have been given a clinical diagnosis for AD and have a carer (relative or spouse) that knows them well and who is willing to assist in the study. The exclusion criteria were having a previous history of alcohol or substance abuse, the presence of a psychiatric condition, the presence of any other significant medical condition that may be likely to affect participation in the study (head injury, loss of vision, and mobility issues), and for the patients, the presence of a comorbid neurological condition not related to AD.

Signed informed consent was obtained from all participants before undergoing the experimental protocol.

Ethics Approval

Ethical approval for the study was provided by the Faculty of Medicine and Health Sciences Research Ethics Committee at the University of East Anglia (FMH2017/18-123) as well as the National Health Service Health Research Authority (project ID205788; 16/LO/1366).

Experimental Protocol

All participants underwent an experimental protocol consisting of a cognitive testing session and 2-week GPS tracking (detailed in the next subsections).

Background Demographics and Cognitive Testing

The cognitive testing session for healthy controls was conducted in a quiet testing room at the university campus, and that for the patients, in a quiet room in their own home. Here, the background demographics of the participants including their age, sex, level of education, and whether they had any previous history of getting lost episodes were collected from their carers. In addition, the participants completed a range of cognitive tests and spatial navigation questionnaires. Of relevance to this study, the participants completed the Mini-Addenbrooke's Cognitive Examination (Mini-ACE) and the Santa Barbara Sense of Direction (SBSOD) scale. The Mini-ACE is a sensitive, validated cognitive screening test for dementia, with lower scores indicating higher cognitive impairment; the SBSOD is a self-report scale that measures real-world environmental spatial abilities, with higher scores indicating higher spatial ability [24,25]. As the patients with AD may lack insight into their own navigational abilities because of the disease [26], we also asked their carers to complete the Spatial Orientation Screening (SOS) questionnaire. This is a newly developed screening tool that assesses the carer's reports of the patient's navigational impairments in the community, with higher scores indicating higher impairments [27].

GPS Tracking

After the cognitive testing session, all participants underwent GPS tracking of their outdoor navigation patterns in the community for a 2-week period, under naturalistic conditions. Here, outdoor navigation in the community is defined as any movement that occurs outside of the participant's home and includes movement inside indoor locations in the community (eg, shopping malls and supermarkets). An exploratory time frame of 2 weeks was chosen for the tracking period to capture the participants' outdoor navigation patterns over repeated weekdays and weekends as well as to account for potential day-to-day fluctuations in these patterns. Participants were tracked in parallel in groups of 3, with the entire data collection period spanning from November 2018 to November 2019 (ie, 12 months and 14 days).

All participants were visited at home and provided with a GPS tracker (Trackershop Pro Pod 5 [28]). They were instructed to wear the tracker (ie, by placing it in their coat or trouser pockets) whenever they left the house during the tracking period. All participants were asked to wear the tracker regardless of whether they were alone or accompanied and regardless of the mode of transport used when outside. For each outing, participants were asked to record the date and time of the outing, mode of transport used, and whether they were alone or accompanied during the outing in a navigation diary, which was provided to them as a template form. To account for the cognitive impairments seen in the patients, their carers were asked to ensure that they (ie, the patients) did not forget to wear the tracker whenever they left the house during the tracking period.

The GPS devices for the first batch of 22 participants (13 controls and 9 patients) recorded data of 1 sample every 3 seconds (ie, 0.33 Hz), whereas for the remaining 12 participants (5 controls and 7 patients), data were recorded of 1 sample every 5 seconds (ie, 0.20 Hz). The differences in sampling frequencies were due to the GPS company changing the lowest sampling frequency (from 0.33 to 0.20 Hz) of the devices on the web, midway through data collection. The devices recorded the following variables for each data point—date and time, address (street name), speed (kilometers per hour), battery level (percentage), distance traveled (kilometers), signal accuracy (percentage), and latitude and longitude coordinates.

Spatial Disorientation Behavior in the Tracking Period

Following the GPS data collection, we retrospectively obtained information about the spatial disorientation behavior of the patients during the tracking period from their carers. The carers were asked if there were any instances (that they knew of) in this period where their loved one experienced (1) a getting lost episode and (2) a subtler instance of spatial disorientation behavior, where the carers had to intervene and correct the navigation of the patient. On the basis of their carer's responses, a simple yes or no for each disorientation behavior during the tracking period was recorded for all the patients.

Data Analysis

GPS Trajectory Data Preprocessing

Preprocessing of the collected GPS trajectory data was carried out in MATLAB (version R2017b; MathWorks) and consisted of data cleaning, smoothing, and transportation mode classification.

For each participant, the data cleaning procedure involved identifying and removing days with no outdoor navigation from their data. Here, we identified 1 patient with almost no recorded data, owing to a faulty GPS tracker. This patient was removed for the analysis, leaving a total of 15 participants in the patient group. Following data cleaning, the data smoothing procedure was run on the remaining data of all participants, which involved identifying and removing spikes (ie, large high-frequency displacements in the data that reflect sensor noise or artifacts) in the data. Following recommendations in the literature, data points representing spikes were identified and removed using distance thresholds set between every consecutive pair of recorded data points (ie, the hypothetical distance that an individual could cover, assuming a set maximum speed, in the time difference between the data points) [29,30].

We next classified each participant's trajectory data points into three transportation modes—stationary, by foot, and in vehicle. As a first step, we grouped all trajectory data points into time windows. For participants with data recorded at 0.33 Hz, each time window had a duration of 9 seconds, and for participants with data recorded at 0.20 Hz, each time window had a duration of 10 seconds. For both sets of participants, we set a duration for the time windows that was not only similar but also as small as possible, to ensure consistency between data recordings and to increase the accuracy of our transportation mode classification. Each time window was then classified into transportation modes (ie, *stationary*, *by foot*, and *in vehicle*) based on set mean and maximum speed values of the data points in that time window [31].

For further details of preprocessing (including distance thresholds for data smoothing and speed thresholds for transport mode classification), see Multimedia Appendix 1.

Outdoor Navigation Variables Analysis of GPS Trajectories

Overview

To explore the outdoor navigation patterns of the participants, total outings made, distance traveled (total and by foot), time spent moving outside, and distance traveled from home were all measured. These variables were selected as they have been suggested to represent important aspects of outdoor navigation in previous GPS tracking studies of people with dementia [20-22]. In addition, a study showed that the outings of people with dementia are dependent on time of day [20]. Thus, we also chose to look at total daytime and nighttime outings made to explore this pattern further. Finally, because qualitative findings from a previous study suggested that people with dementia stick to familiar routes when navigating in their neighborhood [32], the similarity of trajectories was our final variable of interest to investigate this pattern quantitatively.

Outings Made (Total, Daytime, and Nighttime)

From each participant's trajectories, we identified the total number of outings they made. Here, an outing is defined as a journey that starts when the participant leaves their home and ends when they return home. Outings were identified by first calculating the distance of all recorded data points to the centroid of the participant's home address. In line with previous research, all data points within 30 m (ie, 3 times the SD of the GPS device's measurement error, allowing 97% confidence for determining true position) of the home address centroid (ie, GPS coordinates denoting the center of the private residence) were considered to reflect the participant being at home [33]. An outing was then identified whenever the participant's trajectory left home and covered a minimum distance of 100 m, which has been shown to be a reasonable threshold to identify outings [34]. The total number of outings made by each participant over the tracking period was computed and normalized by dividing this value by the total number of recorded days.

Because of the influence of time of day on outdoor navigation in people with dementia [20], we were particularly interested in the total number of daytime (6 AM to 6 PM) and nighttime (6:01 PM to 5:59 AM) outings made. Although we recognize that the outdoor environments will have differing characteristics during these time bands according to the season (eg, amount of daylight), for consistency purposes, we used the same time bands for all participants, despite groups of participants being tracked at different times of the year. Keeping consistent time bands also has the advantage of accounting for variables apart from daylight alone that could influence participants leaving the house at different times of the day (eg, carer availability if typically working from 9 AM to 5 PM and rush hour pedestrian and vehicle traffic). The values of these variables were normalized for the total number of days that the GPS data was recorded.

Time Spent Moving Outside

For time spent moving outside home, the GPS devices used in this study automatically stopped recording data when no movement was detected for 2 minutes. Hence, for this variable, we calculated the sum of the total duration of each of the participant's outings, excluding the periods where the participant was not moving. This variable was then normalized for the total number of outings made by the participant.

Distance Traveled (Total, by Foot, and From Home)

To compute total distance traveled, the distance between each pair of consecutive data points was summed across all the participant's outings and normalized for the total outings made. The same method was used to calculate the distance traveled by foot, this time by using only the portions of each participant's trajectories where they were walking (ie, walking trajectories). Again, this value was normalized for total outings made. To compute the distance traveled from home, we calculated the mean distance of the data points in each outing to the participant's home and averaged this value across all outings.

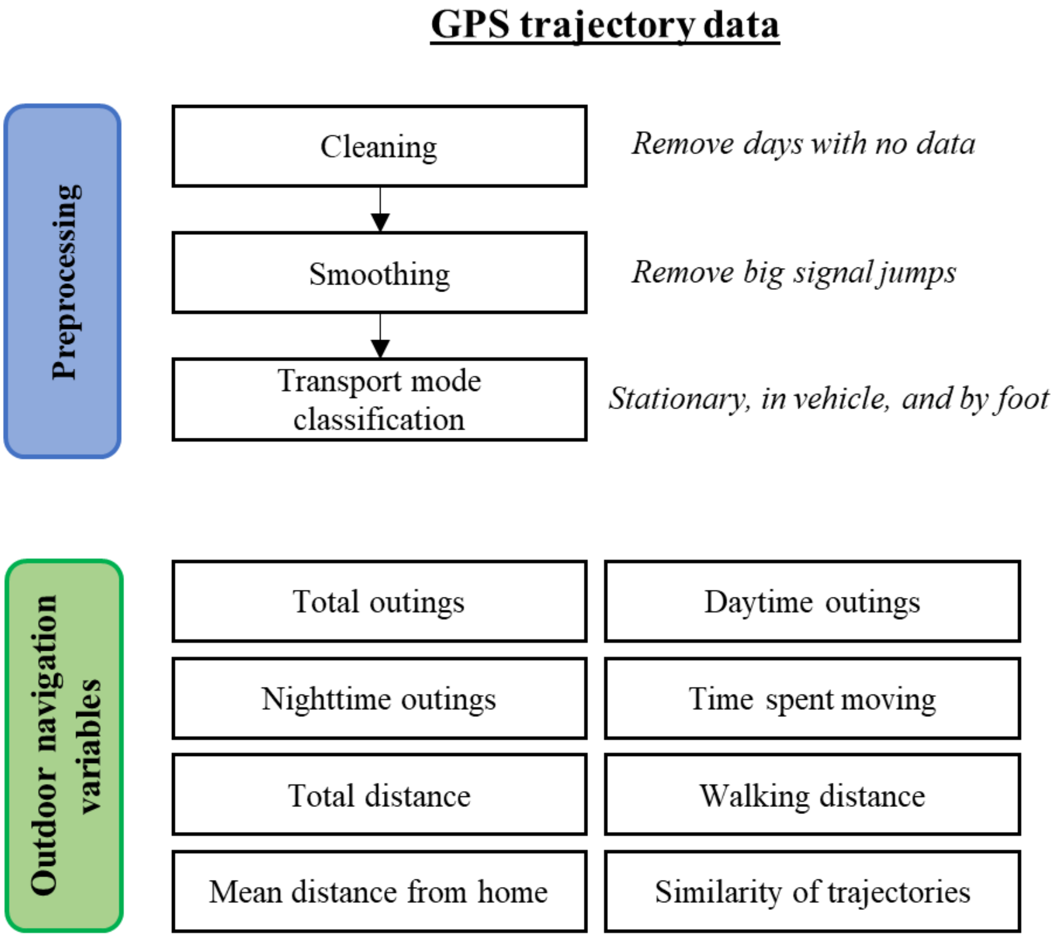
Similarity of Trajectories

To compute our final variable of interest, similarity of trajectories, we used a metric known as the discrete Fréchet distance, which is derived from the continuous Fréchet distance metric [35]. The continuous Fréchet distance is used to assess the similarity of trajectories by measuring how similar 2 continuous curves are in their shape, considering the location and ordering of the data points that make up the curve [36]. A common example used to explain the concept of continuous Fréchet distances is that of a man walking his dog on a leash, where the man will be on one continuous trajectory (A) and the dog on another continuous trajectory (B). The continuous Fréchet distance refers to the minimum length of a line that is required to connect the man on trajectory A to the dog that is on trajectory B, with both walking forward simultaneously. The discrete Fréchet distance is a variation of this measure, whereby only the discrete data points that make up the trajectory (ie, the trajectory fixes) are considered, and all possible pairwise distances between the trajectories' data points are assessed, with the maximum over all pairwise distances being the final computed value (see the study by Tao et al [37] for details). Here, the more similar the 2 trajectories are to each other, the lower the discrete Fréchet distance. We chose to use this metric as it works well for how our trajectory data set is structured, with the GPS data points for each participant being sampled at regular, discrete intervals. Furthermore, this metric gives a good approximation of the more comprehensive continuous Fréchet distance, is relatively inexpensive computationally, and has been used in previous studies for calculating trajectory similarity from naturalistic GPS data [37,38]. The discrete Fréchet distance DFD between 2 separate trajectories, *A* and *B*, is calculated using the formula as follows [35,37]:

where a_1 and b_1 represent the first set of points in trajectories *A* of length *n* and *B* of length *m*. For each participant, we calculated the discrete Fréchet distances for all combinations of their outing trajectories using a MATLAB function [39], and computed the mean of these values.

An overview of the GPS trajectory data preprocessing procedure and summary of all the outdoor navigation variables are illustrated in Figure 1.

Figure 1. Overview of GPS trajectory data preprocessing procedure and summary of outdoor navigation variables used in this study. The collected GPS trajectory data from all participants undergo a data cleaning and smoothing procedure, followed by transport mode classification. In total, 8 outdoor navigation variables are then generated from the preprocessed data.



Analysis Steps

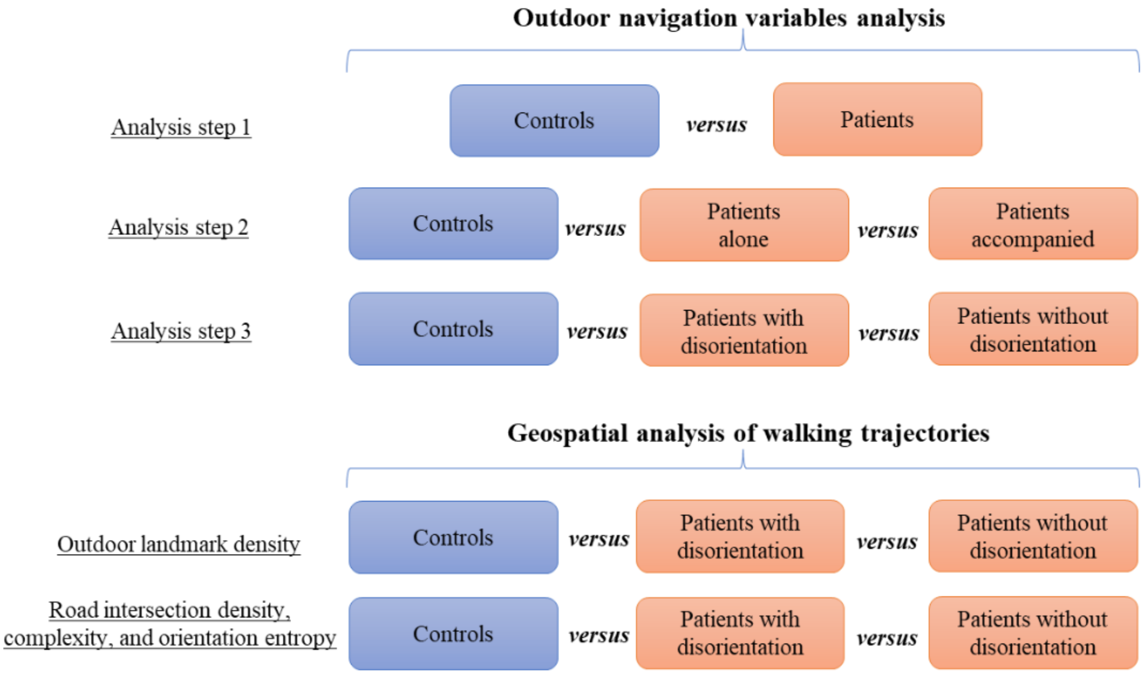
We conducted our analysis in 3 different steps using RStudio software package (version 3.4.2) [40]. In the first step, we compared differences of all variables between the controls and patients using 2-tailed *t* tests. In the case of a nonnormal distribution, Wilcoxon rank-sum tests were used [41].

Then, in the second step, using information from the navigation diaries, we split the outings of each person with AD into outings made alone and outings made accompanied. The rationale for this is based on our prediction that the outdoor navigation patterns of the patients with AD would be influenced by whether they are alone or accompanied. When accompanied, they can rely on other individuals (ie, the carer) to navigate, whereas this is not possible when they are alone; hence, the latter situation is more likely to highlight patterns that are more reflective of their navigation impairments. For controls, we do not expect their outdoor navigation patterns to be influenced by whether they are alone or accompanied, owing to not having AD induced neuropathology that impairs navigational behavior, and hence did not split the data of this group. We then compared differences in all of the outdoor navigation variables across three groups—controls (all outings), patients (outings alone), and patients (outings accompanied). Linear mixed models were used to assess these differences using the *nlme* package in R [42], with group chosen as the fixed-effect, between-subjects factor and participant as the random-effect, within-subjects factor in the model. This statistical model was chosen as it accounts for participants in two of the groups (ie, patients when alone and patients when accompanied) being the same individuals, and the resulting interdependence that arises in the collected data of these individuals under both conditions. After running a separate mixed model for each variable, ANOVAs that were built in the R package were run to assess overall group significance, followed by post hoc pairwise tests (also built in the R package) that were corrected for multiple comparisons using the false discovery rate method [43].

For the final step, using the information on spatial disorientation during the tracking period that we obtained retrospectively from the carers of the patients, we divided these individuals into two groups (disoriented vs not disoriented during tracking period). We then investigated group differences in all the outdoor navigation variables across controls, patients with disorientation, and patients without disorientation using 1-way ANOVAs. In the case of a nonnormal distribution, Kruskal-Wallis tests were used [44].

An illustration summarizing the different analysis steps for the outdoor navigation variables are provided in Figure 2.

Figure 2. Overview of different analysis steps for the outdoor navigation variables analysis and geospatial analysis of walking trajectories. For the outdoor navigation variables analysis, a total of 3 between-group comparisons are made. For the geospatial analysis, between-group comparisons are made for the composition of the 2 different environmental variables (ie, outdoor landmark density and road network structure) in the buffer zones of the walking trajectories.



Geospatial Analysis of GPS Trajectories

We conducted a geospatial analysis of our participants' trajectories to test our findings that increased outdoor landmark density and complex road network structure may contribute to spatial disorientation in patients. For this, we imported and plotted each participant's walking trajectories (ie, data points classified as by foot) into ArcGIS software (Esri) [45], using the World Geodetic System 1984 geographic coordinate system [46]. We chose to focus on only the participants' walking trajectories as we assume that spatial disorientation is unlikely to occur for the patients when they are not walking (ie, passively sitting in vehicle). We recognize that disorientation can still occur for patients if they were actively driving a vehicle; however, we assume that none of the patients in our sample are active drivers given that they have cognitive impairments.

We first tested whether the patients who experienced disorientation during the tracking period showed walking trajectories that passed through areas with an increased outdoor landmark density. Here, we used the same outdoor landmark data set and spatial buffer methodology as in our previous study to measure the outdoor landmark density in the areas that all participants visited. In brief, the data set contained all outdoor landmarks that are visually accessible from open street view, and the methodology involved generating a spatial buffer zone around the trajectories to capture all landmarks surrounding the visited locations (see the study by Puthusseryppady et al [18] and Multimedia Appendix 1 for details). Here, we selected a radius of 50 m for the buffer zones generated around the participants' walking trajectories, as previous studies have suggested this distance as being appropriate to capture all environmental features, such as outdoor landmarks, which are directly accessible along a traveled route [47,48]. To account for the measurement error in the GPS device (10 m), we added another 30 m to the buffer zones (ie, 3 times the SD of the measurement error to ensure 97% confidence for determining position) in addition to the initial 50 m, following guidelines in the literature [33]. Hence, for each participant, geodesic buffer zones of 80 m were generated around their walking trajectories, and the number of outdoor landmarks falling within these buffer zones (normalized for total walking distance) was then computed. Group comparisons on this variable were then made across the controls, patients with disorientation, and patients without disorientation using a Kruskal-Wallis test.

We next tested whether the patients who had experienced disorientation during the tracking period had walking trajectories that passed through areas with a high road intersection density and complexity. For this, we used the same road network data set and spatial buffer methodology as in a previous study (see the study by Puthusseryppady et al [19] and Multimedia Appendix 1 for details). In brief, the data set contained all roads and intersections in the United Kingdom, and the methodology involved generating a spatial buffer zone around the trajectories to capture all roads and intersections that were used by the participants on their outings. Here, to account for measurement error in the GPS device, a buffer zone radius of 30 m was chosen and generated around the participants' walking trajectories. The number and average complexity of the road intersections (normalizing the former for total walking distance) falling within the buffer zones of all participants were computed, and group comparisons were made using Kruskal-Wallis and 1-way ANOVA tests, respectively.

Finally, we tested the impact of road orientation entropy in contributing to the patients experiencing spatial disorientation during the tracking period. Road orientation entropy measures the orientation of roads within a given area and is an indicator of how ordered the layout of the road network is within this area. Here, higher road orientation entropy indicates lower order, and lower road orientation entropy indicates higher order. As we found a buffer radius of 2 km to be sensitive to identify changes in road orientation entropy between different locations in our previous study [19], we chose to use this distance (plus a 30 m error buffer) for our buffer zones here. Subsequently, buffer zones of 2.03 km were generated around the participants' trajectories, and the orientation entropy of the roads falling within these buffer zones were computed using the Shannon entropy (see the study by Puthusseryppady et al [19] and Multimedia Appendix 1 for details). Group comparisons were then made using a 1-way ANOVA.

An illustration summarizing the different analysis steps for the geospatial analysis of the GPS trajectories are provided in Figure 2.

Results

Participant Demographics

The controls and patients in this study did not differ statistically in their age or sex; however, a statistical difference was seen for number of years of education, with controls having higher number of years of education than the patients. The patients performed significantly worse than controls on the Mini-ACE; the scores of all these individuals met the upper cut-off of ≤25/30 for mild dementia and fall within ranges previously reported for patients with mild AD [25,49]. Most patients were reported by their carers to have a past history of at least 1 getting lost episode in the community (Table 1).

Table 1. Participant demographics.

	Controls (n=18)	Patients (n=15)	Significance, *P* value
Age (years), mean (SD)	68.33 (7.53)	70.33 (6.86)	.40
Education (years), mean (SD)	15.44 (3.11)	12.80 (1.78)	*.01* [a]
Gender, n (%)			.84
Men	9 (50)	8 (53)	
Women	9 (50)	7 (47)	
Mini-ACE[b] score, mean (SD)	28.52 (1.50)	18.13 (5.64)	*<.001*
Had getting lost history, n (%)	N/A[c]	12 (80)	N/A

[a] Values in italics indicate a statistically significant group difference.

[b] Mini-ACE: Mini-Addenbrooke's Cognitive Examination.

[c] N/A: not applicable.

Outdoor Navigation Variables Analysis

The results of our first analysis of the outdoor navigation variables (controls vs patients) showed that overall, there were no significant group differences for any variable. However, when compared with those for the controls, trends were seen for patients making fewer nighttime outings (controls: mean 0.39, SD 0.32 outings; patients: mean 0.22, SD 0.24 outings; *P*=.09) and having a lower-distance traveled by foot (controls mean 1.95, SD 1.30 kilometers; patients mean 1.44, SD 1.10 kilometers; *P*=.07), but these results were not statistically significant.

The results of our second analysis (ie, after splitting the data of the patients into outings made alone and accompanied) showed significant group effects for 88% (7/8) of the variables (Table 2).

Post hoc pairwise comparisons between the groups showed that compared with controls, patients when alone had significantly fewer outings per day (total outings—controls: mean 2.28, SD 0.79; patients alone: mean 1.04, SD 0.78; *P*<.001; day outings—controls: mean 1.89, SD 0.62; patients alone: mean 1.02, SD 0.76; *P*=.003; night outings—controls: mean 0.38, SD 0.31; patients alone: mean 0.01, SD 0.04; *P*<.001), lower time spent moving per outing (controls: mean 1.17, SD 0.58 hours; patients alone: mean 0.41, SD 0.55 hours; *P*=.001), lower total distance covered per outing (controls: mean 23.37, SD 22.64 kilometers; patients alone: mean 4.60, SD 10.40 kilometers; *P*=.009), lower walking distance per outing (controls: mean 1.94, SD 1.02 kilometers; patients alone: mean 0.94, SD 1.14 kilometers; *P*=.02), and lower mean distance from home per outing (controls: mean 4.69, SD 4.10 kilometers; patients alone: mean 0.80, SD 1.86 kilometers; *P*=.004; Figure 3). For the last variable (ie, similarity of trajectories across all outings), no significant differences were seen between these 2 groups. Meanwhile, when comparing the controls with patients when accompanied, no significant differences were seen in any of the variables except for total and night outings made per day. Here, compared with controls, patients when accompanied made significantly fewer total outings (controls: mean 2.28, SD 0.79; patients accompanied: mean 1.57, SD 0.85; *P*=.02) and night outings per day (controls: mean 0.38, SD 0.31; patients accompanied: mean 0.21, SD 0.24; *P*=.04; Figure 3). A trend was also seen for patients when accompanied making fewer day outings per day than the controls (controls: mean 1.89, SD 0.62; patients accompanied: mean 1.36, SD 0.77; *P*=.06); however, this result was not statistically significant. The above results are summarized in Figure 3.

When comparing patients when they were alone with when they were accompanied, significant differences were seen with patients when alone making fewer night outings per day and having less time spent moving per outing compared with when they were accompanied (night outings—patients accompanied: mean 0.21, SD 0.24; patients alone: mean 0.01, SD 0.04; *P*=.04; time spent moving per outing—patients accompanied: mean 0.92, SD 0.57 hours; patients alone: mean 0.41, SD 0.55 hours; *P*=.04; Figure 3). No significant differences were seen in any of the remaining variables, although compared with those for patients when they were accompanied, trends were seen for patients when alone having fewer total outings per day (patients accompanied: mean 1.57, SD 0.85; patients alone: mean 1.04, SD 0.78; *P*=.09), lower total distance per outing (patients accompanied: mean 17.63, SD 14.90 kilometers; patients alone: mean 4.60, SD 10.40 kilometers; *P*=.08), and lower mean distance from home per outing (patients accompanied: mean 3.28, SD 3.15 kilometers; patients alone: mean 0.80, SD 1.86 kilometers; *P*=.07), however these results were not statistically significant.

To explore whether interindividual differences in the outdoor navigation variables for the patients when alone were related to their subjective perception of spatial ability, we correlated their output on all variables (on outings alone) with their respective scores on the SBSOD scale, as a post hoc analysis. We also explored whether their output on the outdoor navigation variables on outings alone were related to their navigation impairments as reported by their carers, by correlating these variables with their scores on the SOS as well. Pearson correlations and Spearman correlations (for nonnormally distributed variables) were run for this. The results showed no significant correlations between patient scores on either the SBSOD or the SOS with any of the outdoor navigation variables.

For our third analysis, we found that none of the patients were reported by their carers to have gotten lost during the tracking period. However, 6 individuals were reported to have experienced more subtle moments of spatial disorientation, where they did not get lost but their carer had to intervene and correct their navigation. The results did not show any significant group differences for any of the outdoor navigation variables (Table 3).

Table 2. Comparison of outdoor navigation variables (controls vs patients accompanied vs patients alone).

Outdoor navigation variable	Controls, mean (SD)	Patients accompanied, mean (SD)	Patients alone, mean (SD)	Group significance, *P* value	Post hoc (controls—patients accompanied), *P* value	Post hoc (controls—patients alone), *P* value
Outings per day	2.28 (0.79)	1.57 (0.85)	1.04 (0.78)	*<.001* [a]	*.02*	*<.001*
Day outings per day	1.89 (0.62)	1.36 (0.77)	1.02 (0.76)	*.004*	.058	*.003*
Night outings per day	0.38 (0.31)	0.21 (0.24)	0.01 (0.04)	*<.001*	*.04*	*<.001*
Time spent moving per outing (hours)	1.17 (0.58)	0.92 (0.57)	0.41 (0.55)	*.001*	.22	*.001*
Total distance per outing (kilometers)	23.37 (22.64)	17.63 (14.90)	4.60 (10.40)	*.011*	.34	*.009*
Walking distance per outing (kilometers)	1.94 (1.02)	1.33 (0.91)	0.94 (1.14)	*.04*	.14	*.02*
Mean distance from home per outing (kilometers)	4.69 (4.10)	3.28 (3.15)	0.80 (1.86)	*.005*	.21	*.004*
Similarity of trajectories across outings (mean discrete Fréchet distances)	0.14 (0.13)	0.09 (0.08)	0.04 (0.09)	.10	.30	.12

[a] Values in italics indicate a statistically significant group difference.

Figure 3. Violin plots of post hoc pairwise comparisons of the outdoor navigation variables. Single brackets show pairwise comparison, the waves represent a mirrored kernel density estimation of the probability distribution of the variables, the black dots indicate group means, and the lines intersecting the black dots indicate the group SDs: (A) outings per day, (B) day outings per day, (C) night outings per day, (D) time spent moving per outing, (E) total distance per outing, (F) walking distance per outing, and (G) mean distance from home per outing. Note that ranges of violin plots extend slightly above and below the actual range of data, as plots show smoothed-out distribution. **P*<.05, ***P*<.01, ****P*<.001.

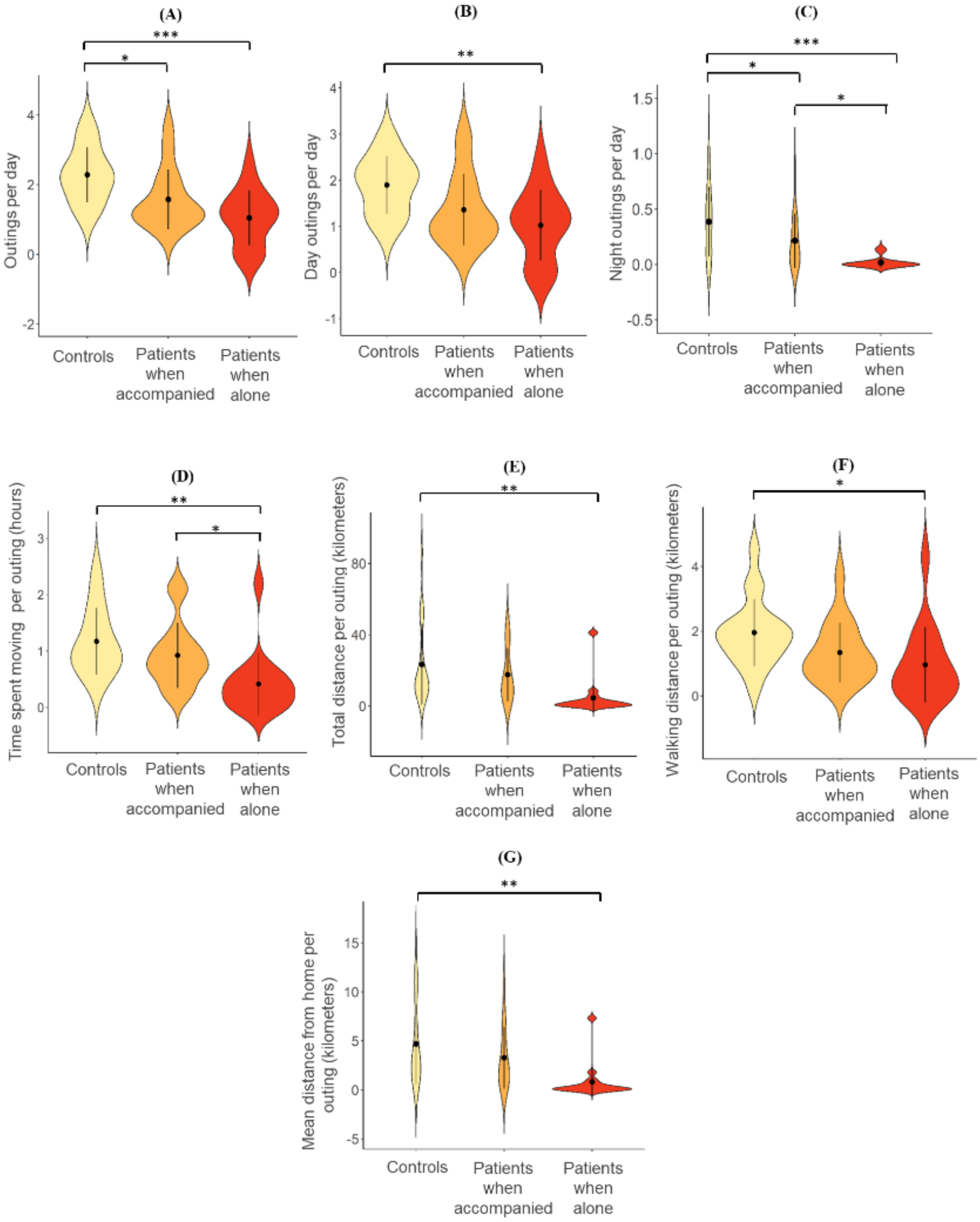


Table 3. Comparison of outdoor navigation variables (controls vs patients with disorientation vs patients without disorientation).

Outdoor navigation variable	Controls, mean (SD)	Patients with disorientation, mean (SD)	Patients without disorientation, mean (SD)	Group significance, *P* value
Outings per day	2.28 (0.79)	1.70 (0.71)	2.11 (0.92)	.25
Day outings per day	1.89 (0.62)	1.49 (0.62)	1.87 (0.80)	.79
Night outings per day	0.38 (0.31)	0.20 (0.19)	0.23 (0.27)	.24
Time spent moving per outing (hours)	1.17 (0.58)	1.13 (0.75)	0.82 (0.44)	.17
Total distance per outing (kilometers)	23.37 (22.65)	21.62 (16.41)	15.47 (13.85)	.60
Walking distance per outing (kilometers)	1.94 (1.02)	1.94 (1.49)	1.09 (0.61)	.06
Mean distance from home per outing (kilometers)	4.69 (4.10)	4.13 (3.13)	2.81 (2.89)	.34
Similarity of trajectories across outings (mean discrete Fréchet distances)	0.14 (0.13)	0.11 (0.09)	0.09 (0.08)	.59

Geospatial Analysis of GPS Trajectories

Our first set of results for the geospatial analysis showed that there was a significant group difference in the outdoor landmark density surrounding the walking trajectories (*P*<.001). Post hoc pairwise Wilcoxon rank-sum tests showed that the walking trajectory buffer zones of the controls had a significantly higher outdoor landmark density than that of the patients with and without disorientation (*P*=.002 and *P*<.001, respectively). However, there were no significant differences when comparing the outdoor landmark density falling within the walking trajectory buffer zones of the patients with disorientation with those without (*P*=.60).

Our second set of results showed that there were no significant group differences in the density or complexity of the road intersections that were encountered by the participants' walking trajectories (*P*=.43 and *P*=.45, respectively). Our final set of results showed that there was a significant group difference in the road orientation entropy surrounding the participants' walking trajectories (*P*=.01). Post hoc pairwise *t* tests showed that the road orientation entropy surrounding the walking trajectories of controls was significantly higher than that of the patients with and without disorientation, respectively (*P*=.03 for both). However, there were no significant differences seen in the road orientation entropy surrounding the walking trajectories of the patients with disorientation and those without (*P*=.89).

Discussion

Principal Findings

We found that patients with AD overall did not exhibit any significant differences in their outdoor navigation in the community when compared with the controls, which was not in support of our hypothesis H1. However, after dividing the patients' data into outings made alone and accompanied, we found that when alone, patients exhibited lesser and more restricted outdoor navigation in the community compared with the controls, which supports our hypothesis H2. When they were accompanied, most of their outdoor navigation patterns were similar to those of the controls; they only differed from controls in terms of their number of daytime and nighttime outings. Furthermore, our results did not highlight any significant mobility risk factors for spatial disorientation in the patients with AD, which was not in support of hypothesis H3, and finally, we did not find an association between increased outdoor landmark density and complex road network structure with spatial disorientation in these individuals, which was not in support of hypothesis H4.

In more detail, our results showed that on outings alone, patients cover lower distances (total and walking), spend less time moving outside, and stay closer to home, with the latter 2 findings being in line with previous studies [20,22]. Expanding on the finding from one of these studies that the timing of outings made by patients with AD are less varied than that by controls [20], we show here that patients make less daytime and nighttime outings when alone. Furthermore, it has previously been reported qualitatively that patients with AD stick to using familiar routes in their neighborhood [32]. Our findings did not corroborate these previous findings, as we found no significant differences in the similarity of routes taken by controls and patients, regardless of whether the latter were on outings alone or accompanied. However, it is worth mentioning here that measures of route similarity are likely to be influenced by differences in environmental constraints seen across the locations that the participants have navigated (ie, having few vs various route options), which we did not consider here. Further, the discrete Fréchet distance metric used here is one of many that can be used to compute trajectory similarity. Whether our results still hold true when considering other trajectory similarity measures, such as dynamic time warping and longest common subsequence [37], remains to be investigated by future studies. Overall, this is the first study, to the best of our knowledge, that has systematically investigated differences in the outdoor navigation patterns of patients with AD in the community when they were alone versus accompanied.

It is apparent that the restricted outdoor navigation patterns seen in patients with AD on outings made alone is associated with spatial disorientation, with the carers of most of these individuals (n=11) indicating on the SOS questionnaire that the patients refrain from traveling and participating in activities alone owing to them (ie, the patient) being worried about finding their way.

With most of the patients in our sample having had a previous history of getting lost in the community, our findings reflect a method adopted by these individuals (likely in response to these episodes) to reduce the risk of them experiencing spatial disorientation. Indeed, this risk reduction strategy agrees with a previous study that reported that restricting outdoor navigation to very familiar locations acts as a protector against getting lost for patients with AD [50]. However, further to a fear of spatial disorientation, other factors may also explain the restricted navigation patterns of patients when alone, including physical mobility and visual acuity impairments, as well as fear of accidents and falling and so on, which were not measured here. In addition to the patients themselves, we also consider the potential influence that their carers may have on the adoption of this risk reduction strategy, particularly regarding them being hesitant toward the patient making outings alone. Therefore, it is likely that the combination of external intervening behavior from the carers and the internal curtailing of navigation behavior by the patients themselves underlie their restricted outdoor navigation patterns when alone. To the best of our knowledge, this is the first study to relate the outdoor navigation patterns of patients with AD in the community to spatial disorientation, with previous studies having only related these patterns to caregiving burden and the individual's own well-being [21,23].

We were unable to identify significant mobility risk factors for spatial disorientation in the patients with AD, suggesting that spatial disorientation cannot be explained by looking solely at how these individuals move in the community. However, considering that patients restrict their outdoor navigation to reduce their risk of spatial disorientation, it could very well be that the variables that they are restricting actually reflect risk factors for spatial disorientation. Along these lines, increased daytime and nighttime outings, time spent moving outdoors, distance traveled (total and walking), and traveling further away from home may all represent factors that increase the likelihood of patients experiencing spatial disorientation. Further research is required to determine whether any of these variables truly represent mobility risk factors for spatial disorientation in the community. Another point worth mentioning is that although we analyzed the spatial and temporal extent of the participants' outings, we did not record information on the purposes of the outings made. It may be that contextualizing the patients' outings offer further insight into potential mobility risk factors for spatial disorientation (ie, patients may experience disorientation when making a certain kind of outing), which is indeed a factor worth exploring in future studies. Our geospatial analysis of the GPS trajectories showed that the areas visited by patients who did and did not experience disorientation had a similar outdoor landmark density and complexity of road network structure. This null result suggests that we are not able to validate our findings from our previous studies at this stage [18,19]. This discrepancy in results could likely be due to differences in sample size, with this study having only 6 patients with spatial disorientation compared with the much larger sample of 210 individuals in our previous studies. Moreover, there was a lack of clarity on the specific locations where the patients felt disoriented in this study because disorientation was measured retrospectively by carer responses after the outings happened, whereas the previous studies used a spatial buffer analysis on locations from where patients with dementia were reported to have experienced spatial disorientation and went missing from. It is also possible that, owing to the carer having a personal relationship with the patient, their noting of patient disorientation may have been influenced by their previous navigational experiences with the patient (ie, falsely identifying disorientation in moments where patients may not actually be disoriented). To overcome these limitations, future studies should attempt to replicate our investigation using a relatively larger sample size of disoriented patients with AD, as well as a finer grained buffer analysis on the specific locations where this behavior occurred. Future studies may also look to use sensor-based measurements of navigation activity, which may be more accurately able to infer participant disorientation in specific environments using machine learning approaches that can identify whether participants exhibit deviations from performance benchmarks.

Although the risk reduction strategy of restricting outdoor navigation suggests that patients are aware of their navigation impairments when in the community, our post hoc analysis results showed no correlations between patient scores on the SBSOD scale and their outdoor navigation behavior when alone. Although the exact reason for this is unclear at present, with SBSOD scale scores having shown to correlate with scores on specific navigation tasks (learning new spatial layouts, making directional judgments in familiar environments, etc) [24], the lack of explicit measures of navigation ability in our outdoor navigation variables could explain this null result. We also did not find any relationship between patient scores on the SOS questionnaires and their outdoor navigation behavior when alone. This null result could be due to the SOS questionnaire being a new and yet to be validated instrument [27]; hence, the extent to which it relates to ecological measures of outdoor navigation in the community is unclear. More importantly, it can be argued that the carers' responses on the second half of the SOS questionnaire (ie, using a Likert scale to rate the patient's current navigation abilities compared with how it was in the past) can potentially be influenced by their own anxiety levels about the condition of the patient. As these responses can potentially factor into the overall questionnaire score, it may very well be that these scores may not be reflecting the true extent of patients' navigation impairments. Finally, the relatively low variability between patients in their outdoor navigation variables when alone could also be a factor underlying the null correlations seen with their scores on the SBSOD scale and SOS questionnaire.

The finding of patients exhibiting significantly less outings, distance traveled, and time spent moving outside when they were alone has significant implications in how health care professionals can help manage well-being and independence in these individuals. Given the importance of outings for cognitive and physical health [51], as well as quality of life and psychosocial well-being [52], health care practitioners should advise that, at least in instances where there is a previous history of getting lost, patients with AD are accompanied regularly for outings. Indeed, this activity can potentially help maintain the ability to perform daily functions for the patients, thereby reducing their risk of institutionalization and alleviating caregiver burden in the long term [53]. However, considering that this may place an increased burden on the carer, the implementation of future technologies that can enable patients with AD to feel more at ease and assist their navigation when making independent outings should be explored. This can potentially include investigating the effect of wearing GPS trackers in evoking feelings of safety when going on outings alone, as well as the use of augmented reality, which may be able to use street maps to assist patients with AD with provided directions to their home when on outings alone.

Limitations

Despite our novel findings, there are some limitations to our study that need to be addressed. We did not consider the extent to which premorbid lifestyle patterns may explain the restricted outdoor navigation patterns seen in the patients on outings alone. Because of our limited sample size, we also did not investigate further the effect of gender and different age groups, both of which have been suggested as factors influencing outdoor navigation patterns [20,54]. Future studies should focus on patients who have not yet gotten lost before and investigate longitudinally the effect that the incidence of a getting lost episode has on changes in their outdoor navigation patterns, including how this varies by gender and age. This approach would not only help gain a more holistic view of how outdoor navigation patterns are affected in patients owing to spatial disorientation but also potentially help identify mobility risk factors for spatial disorientation and getting lost episodes in these individuals as well. In addition, we also did not consider interindividual differences in use of technology during navigation, which could have influenced the results as it is possible that patients who are more competent with navigation aid devices such as smartphones may be less likely to experience spatial disorientation during their outdoor navigation. Future studies investigating spatial disorientation over an extended period could control for this potential confound by recruiting patients with minimal everyday use of navigation aid devices, to ensure accurate capturing and reporting of spatial disorientation episodes.

Conclusions

In conclusion, our results showed that patients with AD when alone restrict the spatial and temporal extent of their outdoor navigation in the community to reduce their risk for experiencing spatial disorientation. From a research perspective, our findings highlight the potential for exploring navigation patterns before getting lost episodes occur to identify mobility risk factors that may contribute to spatial disorientation. Furthermore, our results underscore the utility of using GPS tracking to elucidate the causal impact of environmental variables on spatial disorientation. Our findings also have ethical implications. Restricting outdoor navigation in the community can have a negative impact on the patients' autonomy and overall quality of life [55]. Hence, this may not be the most appropriate solution to the problem as not all these individuals may actually be at a high risk for experiencing spatial disorientation in the community. To strike a balance between their right to autonomy and safety, an important step for future studies is to identify which patients are indeed at a high risk for spatial disorientation by assessing their navigation performance in naturalistic community settings. Identifying such a group would in turn have clinical implications, as more measures can be implemented into the safeguarding plan of these individuals to prevent them from getting lost in the community in the future.

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Authors' Contributions

VP, MHA, MP, and MH came up with the concept and design of the work. VP, SM, GC, MP, and MH analyzed the data and interpreted the results. VP, SM, MHA, GC, MP, and MH drafted the paper.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Methods of participant recruitment, data preprocessing, and geospatial analysis over and above what is already included in the main text.
[DOCX File , 22 KB - aging_v5i2e28222_app1.docx]

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Abbreviations

AD: Alzheimer disease
Mini-ACE: Mini-Addenbrooke’s Cognitive Examination
SBSOD: Santa Barbara Sense of Direction
SOS: Spatial Orientation Screening

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Original Paper

Assessment of Social Behavior Using a Passive Monitoring App in Cognitively Normal and Cognitively Impaired Older Adults: Observational Study

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Abstract

Background: In people with cognitive impairment, loss of social interactions has a major impact on well-being. Therefore, patients would benefit from early detection of symptoms of social withdrawal. Current measurement techniques such as questionnaires are subjective and rely on recall, in contradiction to smartphone apps, which measure social behavior passively and objectively.

Objective: This study uses the remote monitoring smartphone app Behapp to assess social behavior, and aims to investigate (1) the association between social behavior, demographic characteristics, and neuropsychiatric symptoms in cognitively normal (CN) older adults, and (2) if social behavior is altered in cognitively impaired (CI) participants. In addition, we explored in a subset of individuals the association between Behapp outcomes and neuropsychiatric symptoms.

Methods: CN, subjective cognitive decline (SCD), and CI older adults installed the Behapp app on their own Android smartphone for 7 to 42 days. CI participants had a clinical diagnosis of mild cognitive impairment (MCI) or Alzheimer-type dementia. The app continuously measured communication events, app use and location. Neuropsychiatric Inventory (NPI) total scores were available for 20 SCD and 22 CI participants. Linear models were used to assess group differences on Behapp outcomes and to assess the association of Behapp outcomes with the NPI.

Results: We included CN (n=209), SCD (n=55) and CI (n=22) participants. Older cognitively normal participants called less frequently and made less use of apps ($P<.05$). No sex effects were found. Compared to the CN and SCD groups, CI individuals called less unique contacts ($\beta=-0.7$ [SE 0.29], $P=.049$) and contacted the same contacts relatively more often ($\beta=0.8$ [SE 0.25], $P=.004$). They also made less use of apps ($\beta=-0.83$ [SE 0.25], $P=.004$). Higher total NPI scores were associated with further traveling ($\beta=0.042$ [SE 0.015], $P=.03$).

Conclusions: CI individuals show reduced social activity, especially those activities that are related to repeated and unique behavior, as measured by the smartphone app Behapp. Neuropsychiatric symptoms seemed only marginally associated with social behavior as measured with Behapp. This research shows that the Behapp app is able to objectively and passively measure altered social behavior in a cognitively impaired population.

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KEYWORDS

passive monitoring; smartphone app; cognitive impairment; social behavior; dementia; mHealth; mobile app; cognitive; mental health; social withdrawal; well-being

Introduction

Alzheimer disease is a neurodegenerative disease that is pathologically characterized by abnormal amyloid and tau deposition [1]. The disease starts with a preclinical phase without any symptoms, and cognition and functional abilities decline over time toward the symptomatic stages of prodromal Alzheimer and Alzheimer-type dementia [1]. Social withdrawal, characterized by reduced social interaction and subjective feelings of loneliness [2], has been identified as one of the earliest symptoms of Alzheimer disease [3]. Alzheimer disease patients would benefit from early detection of symptoms of social withdrawal, since loss of social interactions is associated with accelerated symptom progression [3] and an increased risk of conversion to dementia [3-6].

Common methodology for assessment of social behavior is the use of clinical questionnaires such as the World Health Organization Disability Assessment Schedule [7] or Social Functioning Scale [8]. However, reliability of self-report questionnaires may be influenced by diminished social awareness in Alzheimer disease patients, depending on disease severity [9,10], while caregiver-reported questionnaires rely on recall and are burdensome and subjective. Consequently, self- or caregiver-reported clinical questionnaires on social behavior may not be a reliable tool for this particular patient group. Therefore, to detect symptoms of social withdrawal in Alzheimer disease, objective measures of social withdrawal are needed.

Smartphone apps are a potential tool for objective and passive assessment of social withdrawal. Advantages of smartphone apps include the possibility to collect large amounts of data in the natural environment of a participant, without the need for active involvement. The smartphone app Behapp [11] is designed to assess various aspects of behavior and includes measures such as call history, app use, and location that could be used as a proxy for social behavior [12]. In this study, we will therefore use the smartphone app Behapp to passively assess social behavior. Little information on social activities in older adults, both cognitively normal (CN) and cognitively impaired (CI), is available, and we will therefore also test the effect of factors that are known to influence social behavior, such as age, sex, education [13-15], and neuropsychiatric symptoms. Since Alzheimer disease patients often suffer from neuropsychiatric symptoms such as depression and apathy [16] and these symptoms might increase the risk of progressing to Alzheimer-type dementia [17-19], neuropsychiatric symptoms could consequently lead to increased social withdrawal.

The first aim of this research is to investigate the association between demographic characteristics and Behapp outcome variables in a CN control group. Second, this study aims to test if social behavior as measured using the passive smartphone app Behapp is altered in CI patients compared to 2 groups: CN older adults and people with subjective cognitive decline (SCD) [20], who are at risk of developing cognitive impairment [21]. Third, we will explore the association between the Behapp outcomes and neuropsychiatric symptoms as measured through the Neuropsychiatric Inventory (NPI).

Methods

Participants

We included 288 participants from 3 cohorts (Table 1): Hersenonderzoek.nl [22], the Amsterdam Dementia Cohort [23], and the Psychiatric Ratings Using Intermediate Stratified Markers (PRISM) study [24] (Multimedia Appendix 1, Table S1). For all participants, a minimum age of 45 years and minimum participation duration of 7 days were required. All participants owned an Android phone except for one participant, who received an Android phone for the duration of the study. Participants were included from 2017 to the beginning of 2020, before the start of the COVID-19 pandemic. Participants were assigned to group CN, SCD, or CI. All participants provided informed consent before participation in the study.

Table 1. Demographic characteristics of the 3 diagnostic groups.

	Total (n=288)	CN[a] (n=209)	SCD[b] (n=55)	CI[c] (n=24)	Group comparisons[d] (*P* value, difference)
Age (years), mean (SD)	63 (8)	63(8)	61 (7)	68 (8)	.002, CI>CN, CI>SCD
Female, n (%)	164 (56.9)	122 (58.4)	34 (61.8)	8 (33.3)	.046, CI<CN, CI<SCD
Education (years), mean (SD)	11 (3)	11 (2)	10 (2)	13 (5)	.003, CI>CN, CI>SCD
Cohort, n (%)					
Hersenonderzoek.nl	232 (80.6)	195 (93.3)	36 (65.5)	1 (4.2)	—[e]
ADC[f]	21 (7.3)	0 (0)	18 (32.7)	3 (12.5)	—
PRISM[g]	28 (9.7)	14 (6.7)	0 (0)	14 (58.3)	—
ADC + PRISM	7 (2.4)	0 (0)	1 (1.8)	6 (25.0)	—
App running time (days), mean (SD)	38 (9)	38 (9)	38 (9)	36 (11)	.78
NPI[h] available, n (%)	41 (14)	0 (0)	19 (35)	22 (92)	—
NPI total score, mean (SD)	6.3 (8.5)	—	7.7 (11)	5 (5.6)	.97

[a] CN: cognitively normal.

[b] SCD: subjective cognitive decline.

[c] CI: cognitively impaired.

[d] Significant differences between the groups are shown in the last column: *P* values are given, and if *P*<.05, the group differences are given (eg, CI>CN meaning CI had higher mean than CN group).

[e] NA: not available.

[f] ADC: Amsterdam Dementia Cohort.

[g] PRISM: Psychiatric Ratings Using Intermediate Stratified Markers.

[h] NPI: Neuropsychiatric Inventory.

Ethical Approval

Ethical approval was obtained before start of the study in both the Netherlands and Spain. All research centers in the Netherlands obtained ethical approval from the Ethical Review Board University Medical Centre of Utrecht (17-021/D) for the PRISM cohorts and from the Ethical Review Board VU University Medical Centre (2017.254) for the hersenonderzoek.nl and Amsterdam Dementia Cohort cohorts. In Spain, the PRISM study was approved by Comité Ético de Investigación Clínica Hospital General Universitario Gregorio Marañón (59359).

Behapp App

Behapp is a smartphone app for Android phones, developed to objectively and passively measure sociability and social exploration [2,11]. Upon installation on the personal smartphone, each participant received an unique code to activate the app. Data collection via the app was set to stop automatically after 42 days.

After installation, Behapp continuously monitored measures of communication events (eg, incoming and outgoing phone calls), app activity (eg, social media or entertainment apps), and location via GPS. Data were encrypted before saving on the participants' device and deleted immediately after uploading to the secured data server. Content of calls, SMS messages, and apps were not registered, collected, or saved by Behapp [25].

Behapp Outcome Definitions

All Behapp outcomes are demonstrated in Table 2. For the calls category, the following definitions are used: unique contacts are the number of unique phone numbers from incoming or outgoing calls. Single use contacts are number of contacts called exactly once during the duration of the study. Mean repeated contacts are total number of calls divided by the number of unique contacts. The number of calls and duration of calls variables were divided by the number of days a participant participated in the research.

For the app use category, the following definitions are used: an app is open if it is running in the foreground. An app is opened if a participant brings the app to the foreground. Mean duration of opened apps is calculated as the total duration of the apps in the foreground during the duration of the study divided by the total number of times apps are opened during the duration of the study. Similar to the calls category, the number of times app opened variables were divided by the number of days a person participated in the research.

Table 2. Descriptive characteristics of each Behapp outcome for the cognitively normal group.

Category, subcategory, and variable	Median (25%-75%)	Age	Edu[a]	Missing data, n (%)[b]
Calls				
Incoming[c]				
Number	0.3 (0.1-0.7)	–[d]		3 (1)
Number of nonzero duration calls	0.6 (0.2-1.1)	–		3 (1)
Duration (s)	81.3 (17.7-177.4)	–		3 (1)
Number of unique contacts	0.2 (0.1-0.3)	–		3 (1)
Number of single use contacts	0.1 (0.1-0.2)	–		3 (1)
Outgoing[c]				
Number	0.7 (0.3-1.4)			3 (1)
Duration (s)	79.5 (27.6-207.5)	–		3 (1)
Number of nonresponse calls	0.1 (0-0.3)			3 (1)
Number of unique contacts	0.3 (0.2-0.6)			3 (1)
Number of single use contacts	0.2 (0.1-0.3)			3 (1)
Missed[c]				
Number	0.2 (0.1-0.3)	–		3 (1)
Number of unique contacts	0.1 (0-0.2)	–		3 (1)
All				
Mean repeated contacts	2.6 (2-3.5)			3 (1)
App use				
All[c]				
Number of times opened	86.1 (44.1-151.5)	–		10 (5)
Duration opened (s)	3743.1 (1821.6-7482)			10 (5)
Number of times opened at night	1.4 (0.2-4.8)			10 (5)
Communication				
Number of times opened[c]	13.7 (6.5-26.3)	–	+[e]	10 (5)
Mean duration opened (s)	67.8 (50.7-86.4)	+		11 (5)
Social media				
Number of times opened[c]	1 (0-4.4)	–		10 (5)
Mean duration opened (s)	104 (50.6-143.5)			71 (34)
Entertainment				
Number of times opened[c]	0 (0-0.1)	–		10 (5)
Mean duration opened (s)	69.2 (27-138.4)			136 (65)
News magazines				
Number of times opened[c]	0.5 (0-3.7)			10 (5)
Mean duration opened (s)	62.2 (31.9-118.9)			67 (32)
Location				
Stay points				
Total number of stay points[c]	1.5 (1.1-2.3)			40 (19)
Total number of unique stay points[c]	0.4 (0.3-0.6)			40 (19)
Total number of nightly stay points excluding home[c]	0.1 (0-0.3)			40 (19)

Category, subcategory, and variable	Median (25%-75%)	Age	Edu[a]	Missing data, n (%)[b]
Total number of unique nightly stay points[c]	0.1 (0-0.1)			40 (19)
Total number of outside office hours stay points[c]	0.3 (0.2-0.4)			40 (19)
Total number of unique outside office hours stay points[c]	0.2 (0.1-0.3)			40 (19)
Total number of single visits[c]	0.3 (0.2-0.4)		+	40 (19)
Percentage of stay points visited once	70 (60-77.8)			40 (19)
Mean time spent stationary (min)	838.8 (550.8-1208.2)			40 (19)
Travel				
Mean distance traveled (km)	27.5 (17.7-44.3)			40 (19)
Standard deviation distance traveled (km)	34.9 (16-57)			40 (19)
Mean time traveled (min)	68.7 (51.7-96.8)			40 (19)
Standard deviation time traveled (min)	54.7 (40.8-90.6)			40 (19)
Total number of trajectories[c]	0.6 (0.1-1.2)			40 (19)
Maximum distance from home (km)	124.8 (64.3-301.6)			42 (20)
Average distance from home (km)	37.3 (19.4-90.9)			42 (20)
Home				
Percentage of time spent at home	77.9 (64.4-88)			40 (19)

[a] Edu: education.

[b] N and percentage of participants of whom the data for that specific variable is missing.

[c] Variables with values per day (total value divided by the number of days of participation).

[d] Indicates a significant negative association.

[e] Indicates a significant positive association.

For the location category, the following definitions are used: a stay point is a location based on GPS where a participant stayed for at least 60 minutes within a circle with radius 350 meters and center defined by the first measured location. Nightly stay points are stay points between midnight and 6 AM. Home is defined as the stay point where most time is spent between midnight and 6 AM during the duration of the study. Outside office hours stay points are any stay points except home, measured after 7 PM on weekdays and all day during the weekend. Mean time spent stationary is defined as the mean duration spent at stay points calculated from all stay points during the duration of the study. Again, the total number of stay points or trajectories variables were divided by the number of days a person participated in the research.

CN Control Group

Participants in the CN group (n=209) did not report any memory complaints. They either self-registered online that they did not have any neurological or psychiatric diseases (n=195) or visited a memory clinic and scored approximately average on the Mini-Mental State Examination (MMSE) according to their age and years of education as compared with normative data (n=14). To find normal social behavior in cognitively normal older adults and to address our first aim to find possible associations between demographic characteristics and Behapp outcome variables in a cognitively healthy control group, this group was larger than the SCD and CI groups.

Diagnostic Groups

Participants in the SCD group (n=55) self-reported memory complaints. The majority of this group (n=36) self-registered online and therefore were not neuropsychologically tested. The rest of this group (n=19) visited a memory clinic because of memory complaints but did not show objective cognitive deficits during neuropsychological testing [23].

Participants in the CI group (n=24) had a clinical syndrome diagnosis of either mild cognitive impairment (MCI; n=5) or Alzheimer disease dementia (n=19) [1]. Amyloid status was available from 5 participants, from which 4 participants were amyloid positive and 1 MCI participant was amyloid negative.

The outcomes of the Behapp app from the SCD and CI groups were compared with the CN group to address our second aim.

Neuropsychiatric Symptoms

The NPI [26] is a caregiver-based instrument that measures the severity and frequency of neuropsychiatric symptoms, including delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, sleep dysfunction, and appetitive disturbances. The NPI was administered before the installation of the Behapp app. Outcomes were available for 20 SCD and 22 Alzheimer disease participants in the Amsterdam Dementia Cohort and PRISM cohort. Scores for each neuropsychiatric domain were derived by multiplying the severity score and frequency score from each domain. The total NPI score is the sum of all domain scores ranging from 0 to 144, with a higher score indicating more neuropsychiatric symptoms.

Statistical Analyses

Statistical analyses were performed using R (version 4.0.2, R Foundation for Statistical Computing). Mann-Whitney *U* tests and Spearman rho were used to assess the association between the Behapp outcomes and demographic characteristics (ie, age, sex, and years of education) in the CN control group. Normality was tested using the Saphiro-Wilk test. Since the Behapp data were skewed, medians and quartile values are used to describe the data. Baseline characteristics of the CN, SCD, and CI groups were compared using analysis of variance, *t* test, Kruskal-Wallis test, or chi-square test, when appropriate.

Each Behapp outcome was logarithmically transformed to meet the normality assumptions and standardized to the control group by subtracting the mean of the control group and dividing by the standard deviation of the control group from each corresponding variable. There were no outliers that needed to be removed. Linear models were used with the standardized Behapp outcomes as dependent variable and group as independent variable, corrected for age, sex, and years of education. Regression models were used to examine associations between standardized Behapp outcome measures and the total NPI score, corrected for age, sex, and years of education. A $P<.05$ was considered significant. Assuming 3 clusters of Behapp outcomes (calls, app use, and location) in which the variables are highly correlated (Multimedia Appendix 1, Figure S1), all *P* values were corrected for 3 multiple comparisons using Bonferroni correction (*P* value/3). Since we were mainly interested in association patterns rather than individual relations, we decided not to reduce the number of variables.

Results

CN Control Group

The control group that did not experience any memory complaints consisted of 122 women and 87 men with a mean age of 62.7 years and a mean education of 10.6 years (Table 1). Descriptive characteristics for all Behapp outcomes can be found in Table 2. Older participants called less frequently and opened apps less frequently (Table 2). Individuals with a higher education opened communication apps more often and had a higher total number of single visits (Table 2). No differences were found between females and males.

Diagnostic Groups

In total, 209 CN, 55 SCD, and 24 CI participants were included with an age range of 46 to 83 years. Demographic characteristics of the 3 groups can be found in Table 1. CI participants had the highest age ($P=.002$), highest years of education ($P=.003$), and fewest females ($P=.046$) compared to the CN and SCD groups. The number of measuring days did not differ between the groups.

Compared with the CN and SCD participants, CI individuals had fewer unique outgoing contacts and contacted these same contacts more often. CI and SCD individuals both had higher scores in mean repeated contacts relative to CN (Figure 1, Table 3).

CI individuals made less use of apps compared with the CN participants. Compared with the CN and SCD groups, the CI group made less use of communication and news magazines apps (Figure 1, Table 3).

For the location variables, after correction for multiple comparisons, no differences were found between CI individuals and CN and SCD groups. Compared with CN individuals, SCD individuals visited fewer places at night excluding home (Figure 1, Table 3).

Figure 1. Differences in Behapp outcomes between the 3 diagnostic groups (cognitively impaired [CI], subjective cognitive decline [SCD], and cognitively normal [CN]) participants. Green squares indicate that the first mentioned group shows on average higher values on that Behapp outcomes than the second mentioned group. Red squares indicate that the first mentioned group shows on average lower values on that Behapp outcome than the second mentioned group. All analyses are corrected for age, sex, and education (ie, Behapp outcome ~ diagnostic group + age + sex + education). ** indicates *P*<.01; * indicates *P*<.05; . indicates *P*<.10, after correction for multiple comparisons. SCD: subjective cognitive decline; CN: cognitively normal; CI: cognitively impaired.

Table 3. Differences between diagnostic groups for each Behapp outcome.

Variable	SCD[a] vs CN[b], β (SE)	*P* value	CI[c] vs CN, β (SE)	*P* value	CI vs SCD, β (SE)	*P* value
Calls						
Incoming: number	0.23 (0.14)	.30	0.16 (0.21)	>.99	–0.06 (0.24)	>.99
Incoming: number of nonzero duration calls	–0.12 (0.18)	>.99	–0.35 (0.27)	.61	–0.23 (0.31)	>.99
Incoming: duration (s)	0.24 (0.14)	.29	–0.14 (0.22)	>.99	–0.38 (0.25)	.39
Incoming: number of unique contacts	0.20 (0.14)	.46	0.10 (0.21)	>.99	–0.10 (0.24)	>.99
Incoming: number of single use contacts	0.02 (0.16)	>.99	–0.30 (0.24)	.68	–0.31 (0.28)	.80
Outgoing: number	0.13 (0.17)	>.99	–0.54 (0.25)	.10	–0.67 (0.29)	.06
Outgoing: duration (s)	–0.13 (0.18)	>.99	–0.37 (0.27)	.51	–0.24 (0.31)	>.99
Outgoing: number of nonresponse calls	0.18 (0.16)	.72	–0.11 (0.24)	>.99	–0.29 (0.27)	.83
Outgoing: number of unique contacts	0.10 (0.17)	>.99	–0.60 (0.25)	.06	–0.70 (0.29)	.049
Outgoing: number of single use contacts	0.14 (0.16)	>.99	–0.58 (0.24)	.05	–0.72 (0.28)	.03
Missed: number	0 (0.16)	>.99	–0.14 (0.24)	>.99	–0.14 (0.27)	>.99
Missed: number of unique contacts	–0.02 (0.16)	>.99	–0.17 (0.24)	>.99	–0.15 (0.27)	>.99
All: mean repeated contacts	0.41 (0.16)	.04	0.80 (0.25)	.004	0.39 (0.28)	.49
App use						
All: number of times opened	–0.40 (0.17)	.06	–0.83 (0.25)	.004	–0.43 (0.29)	.41
All: duration opened (s)	–0.35 (0.18)	.16	–0.50 (0.27)	.19	–0.15 (0.31)	>.99
All: number of times opened at night	–0.02 (0.16)	>.99	0.02 (0.23)	>.99	0.04 (0.27)	>.99
Communication: number of times opened	–0.04 (0.18)	>.99	–0.89 (0.27)	.004	–0.84 (0.31)	.02
Communication: mean duration opened (s)	–0.12 (0.17)	>.99	0.14 (0.27)	>.99	0.26 (0.30)	>.99
Social media: number of times opened	–0.17 (0.15)	.75	–0.38 (0.23)	.28	–0.21 (0.26)	>.99
Social media: mean duration opened (s)	–0.05 (0.19)	>.99	–0.06 (0.37)	>.99	–0.01 (0.40)	>.99
Entertainment: number of times opened	–0.18 (0.15)	.73	–0.29 (0.23)	.60	–0.11 (0.26)	>.99
Entertainment: mean duration opened (s)	0.06 (0.34)	>.99	0.49 (0.63)	>.99	0.43 (0.68)	>.99
News magazines: number of times opened	0.10 (0.16)	>.99	–0.60 (0.23)	.03	–0.70 (0.26)	.03
News magazines: mean duration opened (min)	0.15 (0.18)	>.99	0.11 (0.33)	>.99	–0.03 (0.36)	>.99
Location						
Total number of stay points	0.05 (0.19)	>.99	0.02 (0.25)	>.99	–0.03 (0.30)	>.99
Total number of unique stay points	–0.06 (0.18)	>.99	–0.52 (0.25)	.11	–0.46 (0.29)	.35
Total number of nightly stay points excluding home	–0.55 (0.20)	.02	–0.28 (0.27)	.89	0.27 (0.31)	>.99
Total number of unique nightly stay points	–0.41 (0.18)	.08	–0.18 (0.25)	>.99	0.23 (0.29)	>.99
Total number of outside office hours stay points	0.18 (0.18)	.89	–0.19 (0.24)	>.99	–0.38 (0.28)	.54
Total number of unique outside office hours stay points	0.19 (0.18)	.86	–0.22 (0.24)	>.99	–0.41 (0.28)	.43
Total number of single visits	0.11 (0.19)	>.99	–0.39 (0.25)	.38	–0.50 (0.30)	.28
Percentage of stay points visited once	0.13 (0.19)	>.99	–0.34 (0.25)	.56	–0.47 (0.30)	.36
Mean time spent stationary (min)	–0.31 (0.18)	.27	–0.08 (0.25)	>.99	0.23 (0.29)	>.99
Mean distance traveled (km)	–0.07 (0.17)	>.99	–0.12 (0.23)	>.99	–0.05 (0.28)	>.99
Standard deviation distance traveled (km)	–0.09 (0.18)	>.99	0.03 (0.24)	>.99	0.11 (0.29)	>.99
Mean time traveled (min)	–0.18 (0.17)	.93	0.07 (0.23)	>.99	0.24 (0.28)	>.99
Standard deviation time traveled (min)	–0.25 (0.18)	.49	0.14 (0.24)	>.99	0.39 (0.29)	.52
Total number of trajectories	0.13 (0.18)	>.99	0.38 (0.24)	.36	0.25 (0.29)	>.99

Variable	SCD[a] vs CN[b], β (SE)	*P* value	CI[c] vs CN, β (SE)	*P* value	CI vs SCD, β (SE)	*P* value
Maximum distance from home (km)	–0.32 (0.20)	.32	–0.61 (0.27)	.08	–0.29 (0.32)	>.99
Average distance from home (km)	–0.36 (0.19)	.20	–0.55 (0.27)	.12	–0.20 (0.31)	>.99
Percentage of time spent at home	0.10 (0.19)	>.99	0.32 (0.25)	.62	0.23 (0.30)	>.99

[a] SCD: subjective cognitive decline.

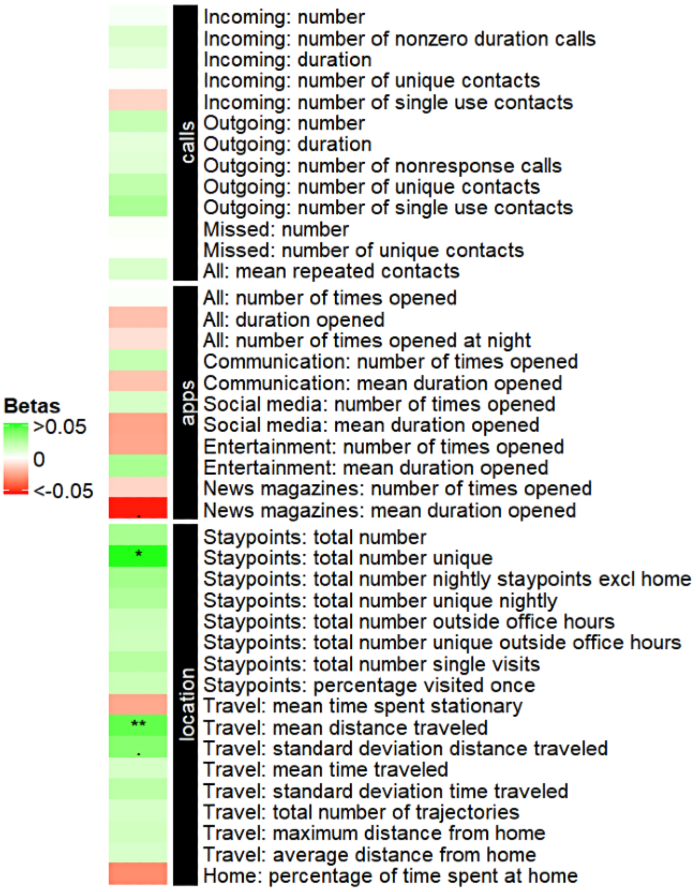
[b] CN: cognitively normal.

[c] CI: cognitively impaired.

Neuropsychiatric Symptoms

Total NPI scores were available for 19 SCD participants and 22 CI participants. Scores did not differ between the groups (Table 1). In the combined sample, higher NPI total scores were associated with a higher mean distance traveled (Figure 2). Irritability, apathy, appetite, and depression were the most present neuropsychiatric symptoms in both the CI and SCD groups. When stratifying for these subscores, higher irritability scores were associated with longer use of news magazine apps and longer distance traveled (Multimedia Appendix 1, Table S2). We observed no other associations between Behapp outcomes and NPI subscores. Similar results were found when also correcting for diagnostic group.

Figure 2. Association between Behapp outcomes and the neuropsychiatric inventory (NPI) total score. Green squares indicate that the Behapp outcome is positively related to the NPI, while red squares indicate that the Behapp outcome is negatively related to the NPI. All analyses are corrected for age, sex, and education (ie, Behapp outcome ~ NPI total score + age + sex + education). * indicates *P*<.05; . indicates *P*<.10, after correction for multiple comparisons.



Discussion

Principal Findings

The most important finding of this study to assess social behavior in CN and CI participants is that CI participants differ from CN and SCD individuals according to the signal generated by the passive monitoring app Behapp. Differences were especially found in variables showing repetitive and unique behavior.

In the CN control group, we found that older individuals called less frequently and made less use of apps. A possible explanation for this age effect is that older participants are overall less inclined to use their smartphone and make more use of traditional ways to communicate—for example, calling with their landline, reading a printed newspaper, or simply forgetting to take their phone when going out. Since this behavior cannot be registered with the Behapp app, our findings do not necessarily mean that older adults experience diminished social behavior. No clear pattern of associations with education was found. No sex effects were found, which was unexpected as women usually have larger social networks [14].

The most important Behapp outcomes to distinguish CI participants from CN and SCD participants were related to repetitive or unique social behavior: CI patients called more often with the same contacts. Although the CI group is significantly older, it is unlikely that the found effects can be explained by older age alone, since the total amount of calls, traveling, and visited places for each group is similar, and the analyses were corrected for age. This reduced exploratory behavior for CI patients is in line with previous studies that showed that individuals with CI had smaller social networks [27]. Furthermore, CI participants made less use of communication and news magazine apps, which suggests they are less socially engaged. However, since CI participants made less use of apps in general, these results should be interpreted with caution. Additionally, a trend was seen that CI patients travel less far from home compared to cognitively healthy participants. This is in accordance with previous findings with GPS trackers in multiple studies showing that the mobility range of Alzheimer disease patients is diminished [28,29]. SCD participants showed similar behavior patterns as the CN group, except for the number of nightly stay points. SCD is a heterogeneous condition [20], in which some may develop Alzheimer disease later on, but the presence of amyloid biomarkers was small in our sample and we therefore cannot compare preclinical Alzheimer disease to controls.

To our knowledge, no previous research is available about the association between social behavior as measured with a smartphone app and neuropsychiatric symptoms in an Alzheimer disease population. Since neuropsychiatric symptoms are frequently prevalent in Alzheimer disease patients [30] and multiple neuropsychiatric symptoms, such as depression, are related to social withdrawal [3], we expected to find associations between NPI scores and Behapp outcomes. However, we found that neuropsychiatric symptoms were associated with further distance traveled only in the combined SCD/CI group. A possible explanation for these findings is that overall scores were low, and consequently, the range of NPI scores was small. We observed some associations on subscores but these are difficult to interpret given the large number of tests.

Comparison With Prior Work

One can argue whether Behapp is a proxy for social behavior, since the app does not capture offline communication. Especially in this older generation, interaction with other people is often face to face or calling with a landline. However, prior work shows a proof of principle that Behapp can capture changes in human behavior caused by an external factor, which in our case is the disease [12]. Other work shows an association of the Behapp outcomes with 2 questionnaires assessing social functioning and loneliness (in preparation). It is therefore assumed that the Behapp outcomes are a proxy for social behavior, albeit not the full range of social behavior, and are helpful to capture changes in social behavior.

Strengths and Limitations

Despite our unique data set, large control group, and sufficient follow-up time, this study has some limitations. First, the Behapp app was not available on smartphones with an iOS operating system, which could lead to a selection bias. One participant received an Android phone for the duration of the study, but removal of this participant did not influence the results. Second, the Behapp app measures only one aspect of social functioning: on one hand, other forms of social contact are possible that cannot be measured with a smartphone such as meeting someone in person, and on the other, altered social behavior in Alzheimer disease patients does not automatically lead to subjective feelings of loneliness in these patients. The Behapp app only assesses communication via calls, while an increasing amount of communication is via social media apps. Because of privacy regulations, it is impossible to track the number of text messages sent with social media apps. We could therefore have missed important communication information. Further research should include questionnaires to identify methods of communication used and to assess loneliness. Third, mobility patterns of an individual are often influenced by their partner, especially when they are CI. The Behapp app only measured mobility patterns of the participant and did not take into account mobility patterns of possible partners or caregivers, which could explain why we did not find stronger associations. Fourth, another limitation is that the CI group consisted of individuals with both MCI and Alzheimer-type dementia. Since patients living with dementia experience by definition more difficulties with instrumental activities of daily living [31], effects could have been larger when stratifying analyses for these clinical groups. Besides this, the CI group was small, and therefore important associations could have been missed. Finally, the majority of participants in the CN and SCD groups did not receive an extensive neuropsychological assessment; their normal cognition is not objectified.

Future Directions

Further research should focus on confirming our results with larger groups, with extensive neuropsychological assessment to confirm cognition status, and in longitudinal cohorts. We recommend using objective and passive smartphone apps in intervention studies aiming to diminish social withdrawal, using outcome variables measuring unique and repetitive behavior in particular.

Conclusion

This research shows that the Behapp smartphone app is able to objectively and passively find differences between CI and CN participants. These findings provide support for the use of passive monitoring tools for characterizing altered social behavior in Alzheimer disease, although more research needs to be done.

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Authors' Contributions

MM wrote the text and performed the main analyses. LMR and CdB advised on the analyses and text. MM and LMR recruited participants and collected data. SCW prepared the data and literature search. RRJ, JASV, and MJHK provided the BEHAPP app and algorithms to extract outcomes. PJV supervised the process. All authors agree with the presented findings.

Conflicts of Interest

JASV serves as a consultant for NoBias Therapeutics Inc. MJHK received (unrelated) research funding from Novartis during the conduct of the study. The other authors do not report any declarations of interests.

Multimedia Appendix 1
Supplementary material.
[DOCX File , 66 KB - aging_v5i2e33856_app1.docx]

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Abbreviations

CI: cognitively impaired
CN: cognitively normal

EFPIA: European Federation of Pharmaceutical Industries and Associations
IMI JU: Innovative Medicines Initiative 2 Joint Undertaking
MCI: mild cognitive impairment
NPI: Neuropsychiatric Inventory
PRISM: Psychiatric Ratings Using Intermediate Stratified Markers
SCD: subjective cognitive decline

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Review

The Effectiveness of Assistive Technologies for Older Adults and the Influence of Frailty: Systematic Literature Review of Randomized Controlled Trials

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Abstract

Background: The use of assistive technologies (ATs) to support older people has been fueled by the demographic change and technological progress in many countries. These devices are designed to assist seniors, enable independent living at home or in residential facilities, and improve quality of life by addressing age-related difficulties.

Objective: We aimed to evaluate the effectiveness of ATs on relevant outcomes with a focus on frail older adults.

Methods: A systematic literature review of randomized controlled trials evaluating ATs was performed according to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines. The Ovid Medline, PsycINFO, SocIndex, CINAHL (Cumulative Index to Nursing and Allied Health Literature), CENTRAL (Cochrane Central Register of Controlled Trials), and IEEEXplore databases were searched from January 1, 2009, to March 15, 2019. ATs were included when aiming to support the domains autonomy, communication, or safety of older people with a mean age ≥65 years. Trials performed within a laboratory setting were excluded. Studies were retrospectively categorized according to the physical frailty status of participants.

Results: A total of 19 trials with a high level of heterogeneity were included in the analysis. Six device categories were identified: mobility, personal disease management, medication, mental support, hearing, and vision. Eight trials showed significant effectiveness in all or some of the primary outcome measures. Personal disease management devices seem to be the most effective, with four out of five studies showing significant improvement of disease-related outcomes. Frailty could only be assessed for seven trials. Studies including participants with significant or severe impairment showed no effectiveness.

Conclusions: Different ATs show some promising results in well-functioning but not in frail older adults, suggesting that the evaluated ATs might not (yet) be suitable for this subgroup. The uncertainty of the effectiveness of ATs and the lack of high-quality research for many promising supportive devices were confirmed in this systematic review. Large studies, also including frail older adults, and clear standards are needed in the future to guide professionals, older users, and their relatives.

Trial Registration: PROSPERO CRD42019130249; https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=130249

(JMIR Aging 2022;5(2):e31916) doi:10.2196/31916

KEYWORDS

assistive technology; older adults; systematic review; frailty

Introduction

Advancements in medicine and public health have led to a rise in life expectancy and are among the main reasons for the changing demographic structure in many countries. In the European Union, the share of people aged 65 years and over is projected to rise by almost 31 million (or 7%) until 2040, while the overall population is estimated to decrease by approximately 1 million [1]. The growing number of older citizens, often with multiple morbidities, leads to an increased demand for health care services and professionals [2]. Coupled with rising costs for diagnosis and treatment, politicians and stakeholders anticipate difficulties in providing adequate care in the near future. One essential approach is to empower older adults to manage their own health and remain independent as long and extensive as possible [3].

The use of assistive technologies (ATs) in older persons' care has been fueled by these developments, helping to maintain seniors' autonomy, safety, or communication at home or in residential facilities [4-8]. Thus, ATs may not only increase older adults' quality of life (QoL) but also contribute to a relief of health care systems and, in particular, formal and informal caregivers [2]. In recent years, a variety of devices addressing problems associated with, for example, dementia [9-11], hypertension [12,13], Parkinson disease [14,15], and loneliness [16] have entered the market. In the literature, the term AT is used to include, among others, telemedical applications [17,18], robotics [4,19], virtual reality [20,21], and sensors [22], but can also cover more conventional technologies such as hearing or vision aids [23,24]. The lack of a uniform definition and the resulting heterogeneity preclude harmonized recommendations, guidance, and structured research [4,25-27]. Despite a large amount of existing literature on the use of ATs for older people, the effectiveness of these devices remains unclear [3,18,28-30]. Users, as well as their formal and informal caregivers, are often overwhelmed by the different options, and up-to-date guidance from insurance companies or other institutions is lacking [31-33].

Previous research has shown that, so far, AT is not likely to replace personal care but rather to supplement it [34]. Ideally, older adults should be able to use ATs with no or little help or supervision to avoid adding workload to the caregiver [35]. In particular, frail older adults with increased dependency could benefit from AT. However, this population often expresses a mixed attitude toward ATs and needs special support when using these devices [36]. The process of becoming a regular user of AT as an older adult is complex [3,36-38]. Usability, the ease of integration into daily life, access and affordability, and individual aspirations and characteristics are some factors influencing the use of AT among older adults [29,38,39].

In this study, we systematically reviewed randomized controlled trials (RCTs) to provide a synthesis of high-quality evidence on the effectiveness of ATs for nonfrail and frail older adults. In this context frailty is defined as "a state of increased vulnerability to poor resolution of homeostasis following a stress, which increases the risk of adverse outcomes including falls, delirium and disability" [40]. It has been previously suggested that frailty also firmly relates to functional status [41]. We defined the effectiveness of ATs as the capability to positively impact issues related to autonomy, communication, and/or safety. These three areas of impact were chosen by an expert committee within the project Future City Ulm 2030, which aims to design a holistic and sustainable urban environment with the inclusion of digital solutions such as ATs. RCTs are widely considered to be the gold standard for effectiveness research, providing the highest level of evidence for causality [42]. The analysis in this review was based on this concept. Three research questions were defined:

RQ1: What are the primary measures used to evaluate ATs?

RQ2: What types of ATs have effectively influenced autonomy, communication, and/or safety in adults aged 65 years and older?

RQ3: What influence does frailty have on the effectiveness of an AT?

Methods

Design

A systematic literature review was performed using the guidelines from the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement [43] (see the PRISMA Checklist in Multimedia Appendix 1). The analysis was based on a protocol published in the PROSPERO register under registration number CRD42019130249.

Search Strategy

The following databases were searched: Ovid Medline, PsycINFO, SocIndex, CINAHL (Cumulative Index to Nursing and Allied Health Literature), CENTRAL (Cochrane Central Register of Controlled Trials), and IEEEXplore. The search string was composed of three parts, focusing on age, methodology, and technology, respectively, combined by the operator AND. The three parts were (1) a previously published search filter for geriatric medicine [44], adapted slightly for the purpose of this study; (2) a sensitivity- and precision-maximizing version of the Cochrane RCT filter in the Ovid format [45]; and (3) a string for technology developed with experts and terms used for AT identified through other related systematic reviews [28,37,46]. The complete search string in the Ovid syntax is provided in Multimedia Appendix 2; the string was adapted to fit the requirements of other databases. Searches were performed on March 15, 2019, and all records were imported to the web-based software Covidence for screening. Reference lists of the selected studies and other systematic reviews on the topic were screened for additional records.

Inclusion and Exclusion Criteria

Eligible for inclusion were peer-reviewed studies published in English or German between January 1, 2009, and March 15, 2019, reflecting the momentum that research on the effectiveness of AT has gained in the last decade. The date restriction was the only filter used in the database search. We included technologies that can assist with issues regarding autonomy, communication, or safety. Other inclusion criteria were (1) a study population with a mean age of 65 years or higher; (2) the study design being an RCT, including a control group with no intervention, an alternative intervention, or a placebo device; (3) the home of the senior, a residential facility, a nursing home, or similar as the study setting; and (4) any sort of technical, socioeconomic, ethical, or medical outcome measuring the impact of the technology on stakeholders (eg, patients, relatives, nurses, physicians).

Exclusion criteria were (1) studies performed in a laboratory setting; (2) studies analyzing robotics, virtual reality, telemedicine, or lifestyle interventions or technologies for rehabilitative or therapeutic purposes; (3) technologies demanding regular involvement of formal or informal caregivers; and (4) applications that have to be used in periodic training units. These exclusion criteria were selected to focus the analysis on technologies that are affordable and usable for the target population in their daily life without external support from relatives, caregivers, or medical staff.

Data Extraction and Analysis

Two authors (MLF and VM) independently screened all records and the studies selected for full-text analysis. Discrepancies were discussed and a third person was consulted, if necessary, until consensus was reached. Data extraction was carried out independently by both authors. The effectiveness of devices was recorded by extracting outcome data and statistical significance for primary outcome measures ($P<.05$). RCTs with a crossover design were individually analyzed for potential carryover effects by three authors (MLF, VM, and MD) (see Multimedia Appendix 3). If a serious impact was expected, only the first part of the study until the crossover was considered to ensure comparability with noncrossover trials. In semicrossover or delayed-start trials, where the control group switches to the intervention after a predefined period, only the first study phase was analyzed, making such studies identical to RCTs with a parallel-group design.

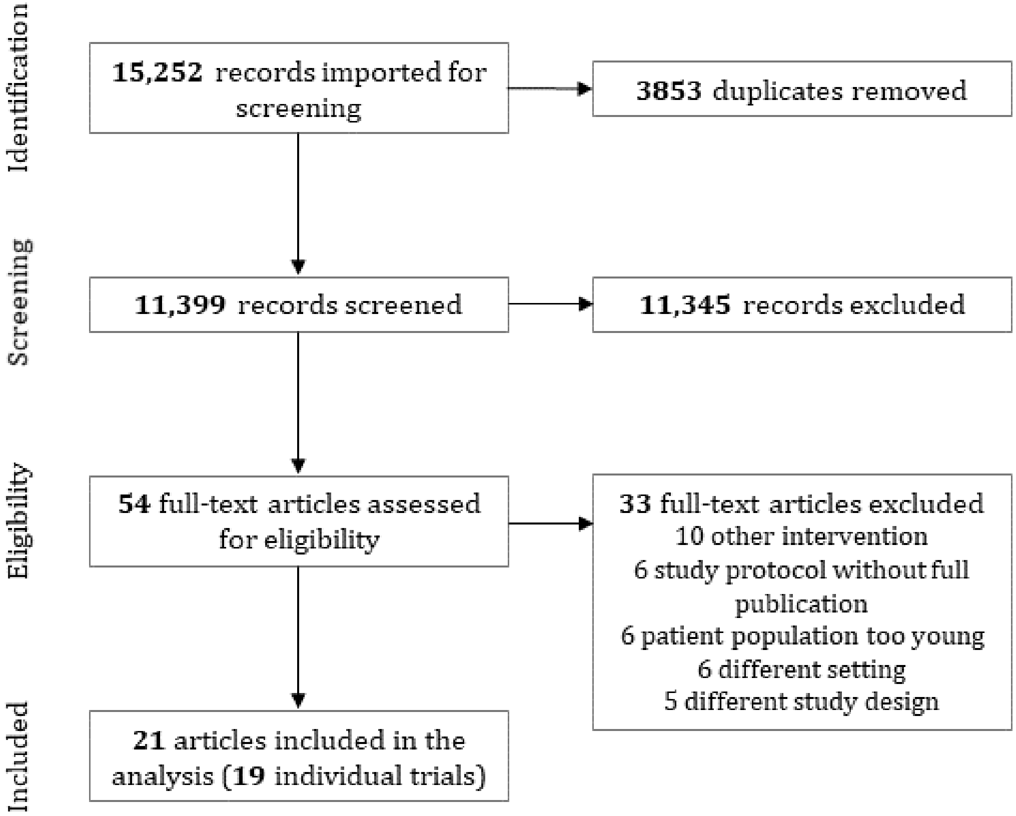
In cases of missing data, authors were contacted via email up to twice. The study population's frailty status was categorized retrospectively according to their functional level into one of the four following categories: not impaired/independent (nonfrail), slightly impaired (prefrail), significantly impaired, and severely impaired/disabled (frail) [41]. A risk of bias (RoB) analysis was performed according to the Cochrane RoB tool to judge the quality of the selected studies [47]. Funding and the recruitment process were also assessed. Due to the heterogeneity of interventions and outcomes, it was not possible to perform a meta-analysis. A qualitative synthesis and a narrative review were performed to interpret study results and draw conclusions. To identify additional insights, subgroups according to frailty status and device category were considered. Figures were created using Microsoft PowerPoint and Excel for Mac Version 16.35.

Results

Included Studies

After removal of duplicates, the search yielded 11,399 records. No articles were identified through other sources as described above. A total of 54 full texts were assessed for eligibility, 21 of which were included in the review (Figure 1). Reasons for exclusion of full texts were (1) the kind of intervention (such as the evaluation of training sessions or the use of therapeutic devices; n=10), (2) a study protocol without full publication (n=6), (3) the patient population being too young (n=6), (4) a different setting (mostly laboratory, n=6), and (5) a different study design (n=6) (also see Multimedia Appendix 4). The 21 records covered 19 individual trials with a total study population of 1768 participants.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram for the study selection process.



Description of Studies

Table 1 summarizes data on the design and participants of the 19 studies included in the analysis. The articles were published between 2010 and 2018. The trend shows an increase in research output across 2017 and 2018, the years with the highest number of publications respectively (n=4). Overall, most studies were conducted in Europe (n=10), followed by five studies from the United States. Among the 19 studies, 10 were confirmatory RCTs and the rest were pilot or feasibility RCTs. Most studies employed a regular parallel-group design. Two studies were conducted using a delayed-start/semicrossover approach [23,48] and five studies employed a crossover design [8,11,14,24,27]. Of those five, two trials were judged to have a low risk of carryover, one studying an electronic vision enhancement system [24] and the other evaluating the benefit of video calls versus regular phone calls for patients with dementia [8].

Having a mean age ≥65 years as an inclusion criterion for our search, there were still large differences in the inclusion criteria at the study level: ≥18 years in three studies [13,14,24], 45-90 years in one study [17], 55-79 years in one study [49], ≥60 years in one study [11], and ≥65 years in six studies [7,23,50-53]. The other seven trials did not have age as an inclusion criterion but targeted conditions present specifically in older adults, such as cardiovascular conditions, dementia, or being a senior housing resident [6,8,12,22,27,48,54]. Table 1 provides the mean (SD) age for each study stratified by intervention and control group.

Most studies had participants' homes as their study site (n=14). The investigation period varied from 1 month [8,11,14,17] to 12 months [7,22,23]. The largest trial included 203 study participants [52]. The mean ages of study populations ranged from 68.9 years to 87.8 years. Only one study assessed frailty at baseline based on the Fried Frailty Score [53]. Frailty could be estimated retrospectively for six other studies [7,14,22,23,50,54]. On average, the frailty levels were found to be slightly impaired/prefrail (n=4), significantly impaired/frail (n=1), and severely impaired/frail (n=1) (Table 2).

Table 1. Overview of included studies, describing the study design and participants.

Study	Year	Country	Study design			Study participants		
			Study type	Group design	Setting	Participants randomized, n	Age (years), mean (SD)	
							IG[a]	CG[b]
Scheffer et al [52]	2012	Netherlands	Full	Parallel group	Home	203	80.8 (9.0)	81.2 (9.3)
Mira et al [50]	2014	Spain	Full	Parallel group	Home	102	70.9 (8.0)	72.9 (6.0)
Hägglund et al [54]	2015	Sweden	Full	Parallel group	Home	82	75.0 (8.0)	76.0 (7.0)
Humes et al [49]	2017	United States	Full	Parallel group	Home	163	68.9 (5.9)	69.5 (6.7)
Rantz et al [22]	2017	United States	Full	Parallel group	Nursing home	171	83.6 (9.4)	86 (8.0)
Ong et al [51]	2018	Singapore	Full	Parallel group	Home	197	77.0	77.0
Levine et al [48]	2016	United States	Full	Delayed-start	Home	54	71.5 (12.2)	70.5 (10.5)
Adrait et al [23]; Nguyen et al [55]	2017	France	Full	Delayed-start	Home	51	83.0 (6.2)	82.3 (7.2)
Elston et al [14]	2010	United Kingdom	Full	Crossover[c]	Home	42	71.5 (11.3)	70.4 (8.7)
Bray et al [24]; Taylor et al [56]	2017	United Kingdom	Full	Crossover[d]	Home	100	69.79 (19.97)	72.94 (16.63)
Tchalla et al [7]	2013	France	Pilot	Parallel group	Home	96	87.8 (6.5)	85.3 (6.3)
Goldstein et al [17]	2014	United States	Pilot	Parallel group	Home	60	69.0 (10.6)	69.6 (11.3)
Lam et al [12]	2016	United States	Pilot	Parallel group	Home	134	68.9 (13.2)	71.1 (13.0)
Or and Tao [13]	2016	Hong Kong	Pilot	Parallel group	Home	63	69.3 (9.7)	69.7 (10.2)
Lauriks et al [6]	2018	Netherlands	Pilot	Parallel group	Nursing home	54	84.3 (5.6)	83.1 (7.1)
Schoon et al [53]	2018	Netherlands	Pilot	Parallel group	Home and nursing home	86	79.9 (5.5)	80.9 (7.0)
Brath et al [27]	2013	Austria	Pilot	Crossover[c]	Home	77	69.4 (4.8)	69.4 (4.8)
Davison et al [11]	2015	Australia	Pilot	Crossover[c]	Nursing home	16	86.0 (5.2)	86.0 (5.2)
Van der Ploeg et al [8]	2016	Australia	Pilot	Crossover[d]	Nursing home	17	86.7 (range 83.0-93.0)	86.7 (range 83.0- 93.0)

[a] IG: intervention group.

[b] CG: control group.

[c] Crossover study with expected carryover effect.

[d] Crossover study without expected carryover effect.

Table 2. Frailty assessment.

Study	Frailty Scale	Frailty status[a]
Mira et al [50]	Barthel ADL[b]	Slightly impaired (prefrail)
Hägglund et al [54]	Short-Form 36 Physical	Slightly impaired (prefrail)
Rantz et al [22]	Gait speed[c]	Severely impaired (frail)
Adrait et al [23]; Nguyen et al [55]	Lawton-IADL[d]	Significantly impaired (frail)
Elston et al [14]	Gait speed	Slightly impaired (prefrail)
Tchalla et al [7]	Lawton-IADL[e]	Slightly impaired (prefrail)
Schoon et al [53]	Fried Frailty Score	18.6% of participants frail at baseline

[a] Categorized according to a method proposed by Brefka et al [41], except for Schoon et al [53].

[b] ADL: activities of daily living.

[c] Collection of ADL and IADL also mentioned with no data reported but provided by the authors upon request.

[d] IADL: instrumental activities of daily living.

[e] Timed-Up-and-Go test also performed with inconclusive results.

Types of ATs and Effectiveness

Overview

The 19 selected trials evaluated devices representing the following six domains: (1) mobility (n=5 [6,7,14,52,53]), (2) personal disease management (n=5 [13,22,48,51,54]), (3) medication (n=4 [12,17,27,50]), (4) mental support (n=2 [8,11]), (5) hearing (n=2 [23,49]), and (6) vision (n=1 [24]). All devices addressed at least one of the areas of autonomy, safety, or communication. An overlap was noticeable in the categories mobility and medication with devices targeting both autonomy and safety issues (Table 2). Interventions, controls, and primary outcomes studied in the included trials are presented in Table 2.

Mobility

Significant effectiveness was only reported in a pilot study for a nightlight path, which reduced falls among older people classified as slightly impaired/prefrail who had mild and moderate Alzheimer disease (odds ratio 0.73, 95% CI 0.15-0.88) [7]. Home automatization for people with dementia living in group homes [6], a mobile safety alarm with a drop sensor for community-dwelling older persons [52], and a gait-speed monitoring and feedback device for older people at risk for falling [53] were not effective. In a crossover study on the use of a metronome to improve QoL in individuals classified as slightly impaired/prefrail who were suffering from Parkinson disease, no evidence of effectiveness could be shown. The authors reported the possible impact of a carryover effect, which we agree with. Unfortunately, separate data were not reported for the first part of the study and could not be obtained from the authors [14].

Personal Disease Management

A system consisting of a tablet computer connected to a patient scale was effective for participants classified as slightly impaired/prefrail who had heart failure. Both primary endpoints, the effect on self-care behavior and health-related QoL, improved in the intervention group after a 90-day trial. System adherence was high with a median of 88% (IQR 78%-96%) [54]. In a semicrossover trial of a device reminding participants suffering from type 2 diabetes to perform self-monitoring of blood glucose, between-group comparison did not show improved levels of glycated hemoglobin. However, participants in the intervention group experienced a statistically significant decrease. Furthermore, the intervention group missed 6% of their measures and the control group missed 22% of measures, representing a statistically significant difference [48]. In another study, a medical alert protection system for older persons living alone was found to be effective in reducing the length of stay for hospital admissions. However, the number of emergency department visits and hospitalizations could not be significantly reduced [51]. In a pilot RCT evaluating the effect of a tablet computer–based self-monitoring system for older people suffering from type 2 diabetes and/or hypertension, systolic blood pressure was significantly more reduced in the intervention group compared with the control group. No significant differences were observed for diastolic blood pressure, blood glucose, glycated hemoglobin, chronic disease knowledge, and monitoring frequency. The within-group comparison showed a significant improvement of diastolic blood pressure in the intervention group ($\Delta=-5.7$, 95% CI –9.3 to –2.2). Approximately 30% (9/33) of participants in the intervention group reported technical problems [13]. An environmentally embedded sensor system for early illness alerts was not effective for a severely impaired/frail population [22].

Medication

A study of a tablet-based app for medication self-management reported a significant improvement in adherence as well as the number of missed doses (27.3% reduction in the intervention group) in a slightly impaired/prefrail population. A reduction of medication errors was only found for patients with a higher error rate prior to the study. Although the mean satisfaction score with the AT in the intervention group was high (8.5 out of 10), 59% (30/51) of intervention group participants required assistance using the AT and almost 12% (6/51) stated that the device did not help at all [50]. In a trial evaluating a “talking pill bottle,” informing hypertensive adults with low health literacy about the correct administration and dosage of their medication, no between-group effect but a significant reduction in blood pressure within the intervention group was reported. Additionally, a vast majority of participants found the device easy to use (63/68, 93%) and many agreed that it helped them to understand (77%) and correctly take their medication (74%) [12]. Two telemedical medication reminders (smartphone and pillbox) did not improve medication adherence [17]. A crossover trial of electronic blisters with an expected carryover did not report significant results [27].

Mental Support

A multimedia device with personalized music, videos, messages, and pictures installed by family members was tested in a pilot sample of 11 nursing home residents. Almost half of the participants needed assistance operating the device due to limited sensory or cognitive abilities. Nevertheless, staff and family members agreed they would recommend the AT for residents with dementia. During the 2-month crossover period, depression and anxiety were significantly reduced in the intervention group. However, a carryover effect seems likely, and no data are available for the precrossover phase of the study [11]. In the second study, video calls with family members were not effective in reducing agitation in nursing home residents with dementia [8]. A retrospective analysis of frailty was not possible for the studies evaluating ATs for mental support.

Hearing

Humes et al [49] compared the best-practice service for hearing aids to an over-the-counter and a placebo device, and found that both the best-practice and the over-the-counter device did effectively benefit participants. Only participants testing the best-practice device showed greater satisfaction than the placebo group. No differences in usage (hours/day) were detected among the groups [49]. In another RCT, hearing aids did not significantly improve dementia-related symptoms or QoL in older adults classified as significantly impaired/frail or benefit their caregivers [23,55].

Vision

A portable electronic vision enhancement system was compared to conventional optical magnifiers in a crossover trial that was published in two articles [24,56]. The authors did not report separate data for the first study phase before the crossover. However, a carryover effect was not expected in this study. Near-vision visual function was significantly improved (Δ=0.57, 95% CI 0.33-0.81) [24]. Although reading speed did not significantly increase when using the portable device, the researchers significantly associated the accessibility of smaller print sizes and the ease of carrying out other tasks with the portable device. When considering frequency of use, the study participants seemed to prefer optical low-vision aids to the electronic system (unstandardized effect size estimate –0.93, 95% CI –1.29 to –0.57) [56]. An economic evaluation was also performed, and the authors concluded that the AT was a cost-effective way to improve near-vision visual function with an incremental cost-effectiveness ratio of US $997.12 (95% CI US $651.89-2066.92) per unit. Improvements in QoL did not prove cost-effective [24]. A retrospective analysis of frailty was not possible for these studies evaluating ATs supporting vision.

Evaluation of Risk of Bias of the Included Studies

Figure 2 and Figure 3 show the results of the RoB analysis. In four categories, we considered more than 30% of the studies to have a high RoB due to issues in blinding of participants and personnel, blinding of outcome assessment, incomplete outcome data, and recruitment bias. The crossover studies had a lower RoB. In three studies, analyzing a medication self-management app [50], electronic vision enhancement system [24,56], and multimedia device for people with dementia [11], no category was judged to have a high RoB (Figure 3). All studies had incomplete reporting for at least one category. A full RoB assessment was therefore not possible.

Figure 2. Judgment of risk of bias categories for each included study presented as percentages across all included studies.

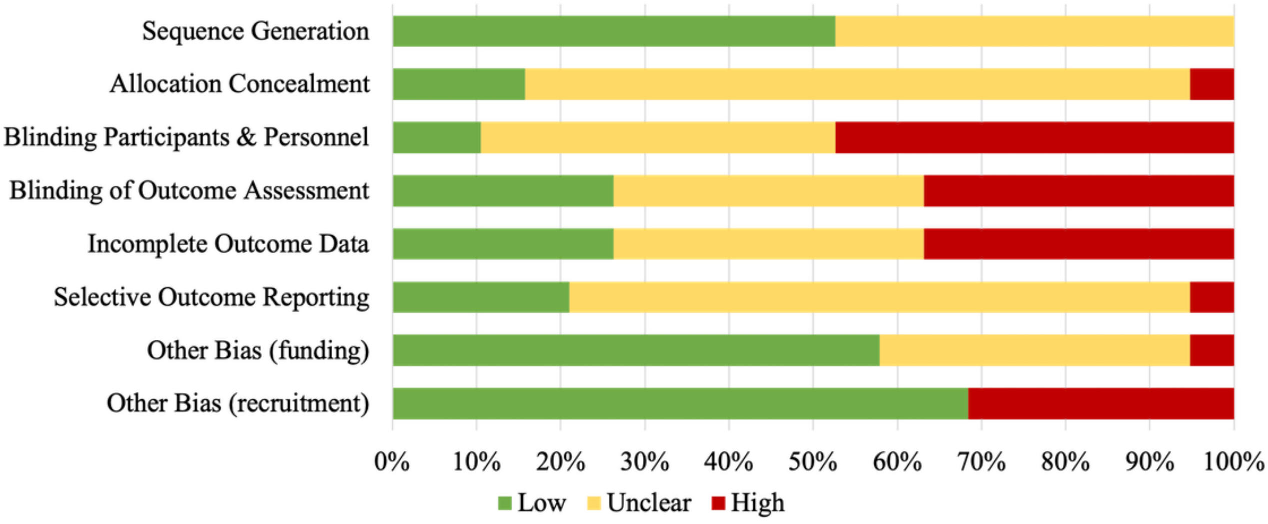
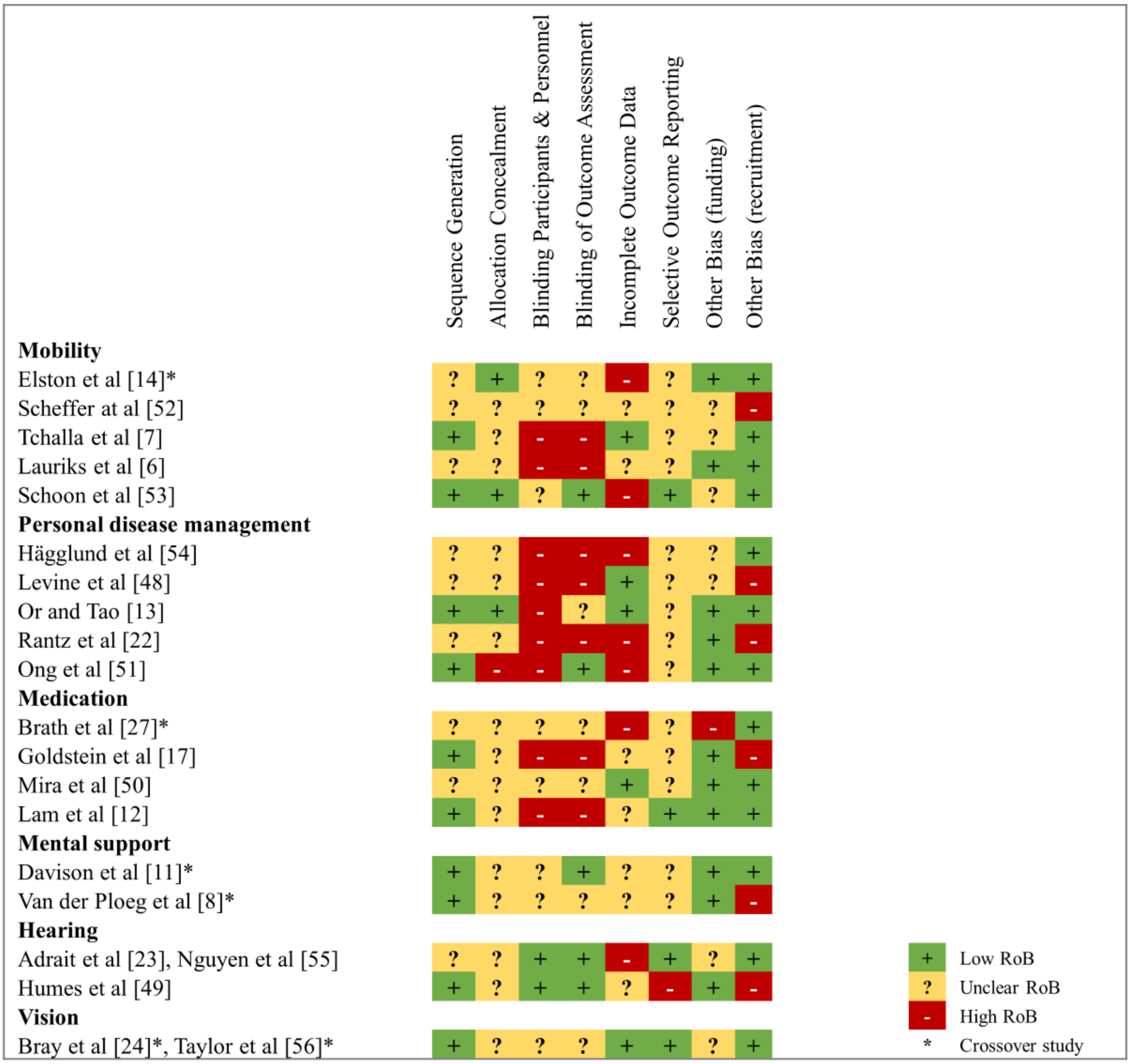


Figure 3. Judgment of risk of bias categories for each included study, ordered by assistive technology category and publication year.



	Sequence Generation	Allocation Concealment	Blinding Participants & Personnel	Blinding of Outcome Assessment	Incomplete Outcome Data	Selective Outcome Reporting	Other Bias (funding)	Other Bias (recruitment)
Mobility								
Elston et al [14]*	?	+	?	?	-	?	+	+
Scheffer at al [52]	?	?	?	?	?	?	?	-
Tchalla et al [7]	+	?	-	-	+	?	?	+
Lauriks et al [6]	?	?	-	-	?	?	+	+
Schoon et al [53]	+	+	?	+	-	+	?	+
Personal disease management								
Hägglund et al [54]	?	?	-	-	-	?	?	+
Levine et al [48]	?	?	-	-	+	?	?	-
Or and Tao [13]	+	+	-	?	+	?	+	+
Rantz et al [22]	?	?	-	-	-	?	+	-
Ong et al [51]	+	-	-	+	-	?	+	+
Medication								
Brath et al [27]*	?	?	?	?	-	?	-	+
Goldstein et al [17]	+	?	-	-	?	?	+	-
Mira et al [50]	?	?	?	?	+	?	+	+
Lam et al [12]	+	?	-	-	?	+	+	+
Mental support								
Davison et al [11]*	+	?	?	+	?	?	+	+
Van der Ploeg et al [8]*	+	?	?	?	?	?	+	-
Hearing								
Adrait et al [23], Nguyen et al [55]	?	?	+	+	-	+	?	+
Humes et al [49]	+	?	+	+	?	-	+	-
Vision								
Bray et al [24]*, Taylor et al [56]*	+	?	?	?	+	+	?	+

+ Low RoB
? Unclear RoB
- High RoB
* Crossover study

From the available information, it appears that testing an AT often purports difficulties with blinding participants and personnel. Nevertheless, unblinded studies are considered to have a higher RoB. In six studies, outcome assessors were not blinded, although it would have been possible [6,7,12,17,22,48,54]. These studies were thus judged to have a high RoB. Several studies had missing data or skewed dropout rates, and were thus considered to be at high RoB for incomplete outcome reporting [14,22,23,27,51,53,54]. The recruitment process was deemed to be sufficient in most studies. For six studies, it was judged that there was a high risk for the study population not being representative of the target population [8,17,22,48,49,52]. Only one study was judged to have a high RoB due to funding. The rationale for this decision was that the manufacturing company of the devices tested was the study sponsor and had a major influence on the study design [27].

Outcome Assessment

A total of 70 primary outcome measures were extracted from the 19 trials (Table 3 and Multimedia Appendix 5). ATs were evaluated using measures focusing on efficacy (n=30), functionality (n=8), mental status (n=8), QoL (n=7), health-related impact (eg, knowledge, behavior; n=5), usability (n=5), effect on caregivers (n=5), and economic aspects (n=2). The two trials with two publications each reported the largest diversity of measures with five (QoL, functionality, mental status, health impact, caregivers) [23,55] and four (QoL, efficacy, usability, economic) [24,56] outcome categories covered, respectively. The highest overall number of primary outcomes was collected by two studies with eight measures, respectively [6,22].

Table 3. Overview of interventions, domain(s) of interest, and outcomes studied in the included trials.

Study	Intervention	Control	Domain(s) of interest			(Primary) outcome(s)[a]
			A[b]	S[c]	C[d]	
Mobility						
Elston et al [14]	Metronome for the improvement of QoL[e] in people with Parkinson disease	Usual medication	✓	✓		Parkinson disease mobility, QoL
Scheffer et al [52]	Mobile safety alarm with a drop sensor for community-dwelling older persons	No mobile safety alarm	✓	✓		Frequency of going outside
Tchalla et al [7]	Nightlight path for patients with Alzheimer disease	No nightlight path		✓		Fall incidence
Lauriks et al [6]	Assistive home technology for people with dementia living in group homes	No assistive home technology		✓		QoL (self-rated, observed by caregiver); assessment of need for older persons; number and location of fall incidents; use of restraints; caregiver job satisfaction, workload, and general health
Schoon et al [53]	Gait speed monitoring and feedback device for older people at risk for falling	No gait speed monitoring	✓	✓		Subjective general health and mental well-being; number of weekly measurements (compliance); fall incidence; incidence of injurious falls; fear of falling
Personal disease management						
Hägglund et al [54]	Home intervention system for patients with heart failure	Standard heart failure information		✓		Heart failure self-care behavior; health-related QoL
Levine et al [48]	Automated self-management monitor for blood glucose for low-income seniors	No automated self-management monitor for blood glucose	✓	✓		Glycated hemoglobin level; frequency of self-monitoring of blood glucose
Or and Tao [13]	Tablet computer–based self-monitoring system for type 2 diabetes mellitus and/or hypertension	Conventional self-monitoring method	✓	✓		Glycated hemoglobin level; fasting blood glucose level; blood pressure; diabetes/ hypertension knowledge; self-monitoring frequency
Rantz et al [22]	Nonwearable sensor system to monitor the status of older persons	Usual care		✓		Walking speed; GAITRite[f]; QoL; depression; mental state; ADL[g] and IADL[h]; hand grip
Ong et al [51]	Medical alert protection system for older people living at home alone	Telephone follow-up		✓		Emergency department visits; number of hospitalizations; total length of stay for admitted patients
Medication						
Brath et al [27]	Mobile health–based electronic medication blisters for patients with diabetes	Standard medication blisters, routine care, handwritten medication intake diaries		✓		Medication adherence
Goldstein et al [17]	Telemedicine medication reminder systems: electronic pillbox, smartphone app for older adults with heart failure	Silent pillbox or silent smartphone	✓	✓		Medication adherence
Mira et al [50]	Medication self-management app for older adults taking multiple medications	Oral and written information on safe medication use	✓	✓		Self-perceived health status; medication adherence; medication errors; missed doses
Lam et al [12]	Talking pill bottle for patients with hypertension	Usual care	✓	✓		Self-efficacy for appropriate medication use; medication adherence; refill adherence; medication knowledge; blood pressure

Study	Intervention	Control	Domain(s) of interest			(Primary) outcome(s)[a]
			A[b]	S[c]	C[d]	
Mental support						
Davison et al [11]	Personalized multimedia device for people with dementia	Social control: weekly 30-min visits from researchers (reading, discussing things)			✓	Agitation; depression in dementia; anxiety in dementia
Van der Ploeg et al [8]	Internet video chat (Skype) for nursing home residents with dementia	Landline telephone			✓	Agitation; call duration
Hearing						
Adrait et al [23]; Nguyen et al [55]	Active hearing aid for patients with Alzheimer disease	Inactive hearing aid			✓	Neuropsychiatric symptoms; IADL Alzheimer disease– related QoL; caregiver QoL; patient and caregiver health profile; Alzheimer disease cognition
Humes et al [49]	Best-practice hearing aid and over-the-counter models	Placebo device			✓	Hearing aid performance and benefit
Vision						
Bray et al [24]; Taylor et al [56]	Portable electronic vision enhancement system for people with visual impairments	Optical magnifiers	✓			Near-vision visual function; vision-related QoL; cost-effectiveness and cost-utility; maximum reading speed; frequency of use

[a] If no distinction between primary and secondary outcomes was made, all outcomes are listed.

[b] A: autonomy.

[c] S: safety.

[d] C: communication.

[e] QoL: quality of life.

[f] Automatic measurement of certain variables (eg, velocity, step length) while participants walk across the GAITRite Mat.

[g] ADL: activities of daily living.

[h] IADL: instrumental activities of daily living.

Unfortunately, six outcome measures from crossover studies with expected carryover could not be analyzed due to a lack of data for the first phase of the study. Of the remaining 64 outcomes, 13 (20%) showed a significantly positive effect of the AT in the categories efficacy, usability, and QoL. However, considering the RoB, seven of those outcomes, covering all three categories, might be impacted [7,13,48,49,51,54] (Table 4). More detailed data on individual quantitative outcomes (test statistics, effect sizes, significance levels) can be found in Multimedia Appendix 5.

Table 4. Statistically significant outcome measures including a judgment of high risk of bias (RoB).

Outcome measure	Outcome category	Reason for high RoB
Bray et al [24]; Taylor et al [56]		Not applicable (no high RoB)
Near-vision visual function	Efficacy	
Vision-related QoL[a]	QoL	
Frequency of use	Usability	
Cost-effectiveness (near-vision visual function vs carer and intervention costs)	Economic	
Hägglund et al [54]		No blinding; all dropouts in IG[b]
Heart failure self-care behavior	Efficacy	
Health-related QoL	QoL[b]	
Hearing aid performance/benefit (Humes et al [49])	Efficacy	Per-protocol analysis; recruitment through newspaper ads
Usage frequency (Levine et al [48])	Usability	No blinding; risk of recruitment bias (people who refused to participate were older, had lower glycated hemoglobin levels, and were less likely to be African American)
Mira et al [50]		Not applicable (no high RoB)
Medication adherence	Efficacy	
Medication errors	Efficacy	
Total length of stay for admitted patients (Ong et al [51])	Efficacy	No blinding (allocation was discussed with the participants); very high dropout rates in IG (32% vs 1% in the CG[c]), resulting in a change in the IG:CG ratio from 1:1 to 1:3
Decrease of diastolic blood pressure (Or and Tao [13])	Efficacy	No blinding
Fall incidence (Tchalla et al [7])	Efficacy	No blinding

[a] QoL: quality of life.

[b] IG: intervention group.

[c] CG: Control group.

Discussion

Principal Findings

To our knowledge, this systematic review is the first to collect and synthesize evidence exclusively from RCTs evaluating the effectiveness of ATs for older adults in a realistic living environment (ie, no laboratory setting), taking into account participants' frailty status. More than 11,000 records were identified from a broad range of databases with different focuses. Only 19 RCTs fulfilled the inclusion criteria. The selected trials were very heterogeneous with respect to the ATs applied as well as the outcomes, which made it difficult to summarize the evidence [57]. Our analysis did not provide strong confirmation for the overall effectiveness of AT in older adults. Only personal disease management apps seem to be promising for this population.

Many older citizens wish to remain independent and continue living at home for as long as possible [58]. The hope is that AT can support this goal, positively impacting QoL, reducing health care utilization, and relieving caregivers [2]. The results of this review suggest some effectiveness of personal disease management apps. Four of the five personal disease management trials showed a significant improvement in self-care and monitoring of health- or disease-related indicators [13,48,51,54], effectively influencing safety and, in some cases, autonomy (related to RQ2). A recent review investigated the effectiveness of mobile health apps for blood pressure management in populations with digital barriers, among other older adults. The authors confirmed the promise of ATs for chronic disease management but also emphasized the need for more studies including vulnerable populations [57]. The willingness for and success of AT-supported self-management can also be dependent on the disease [59]. This could not be confirmed, as our analysis did not provide any additional insights for the effectiveness of personal disease management when stratifying by disease.

Considering other existing research, hearing aids seem to be an effective way to improve the domain of communication in adults aged 65 years and older [49,60,61]. With respect to other devices, the study evaluating a portable vision enhancement system reported an effective improvement due to the AT, but the authors stated that no other comparable evidence supported these results [24]. Further research is needed in all categories for a more reliable assessment.

Regarding frailty of older adults (RQ3), only one study included this population characterization in their evaluation of a gait speed feedback device [53]. Although no significant effectiveness could be shown, similar compliance and success rates for frail participants were found, suggesting that this mobility-supporting device can also be appropriate for this subgroup. We were able to retrospectively estimate the frailty status for a total of 6 out of the 19 studies (Table 2). However, some instruments used might not be ideal for the estimation of frailty, as they are influenced by the underlying disease of the study population [14,23]. In studies where, on average, participants were categorized to have significant or severe impairment (frailty), the AT did not show any effectiveness. As an example, out of the five personal disease management trials, only the one including participants categorized as severely impaired/frail did not show significant results in terms of improvement [22]. Additionally, ATs were also not effective in the four studies that were conducted in nursing homes. Overall, nursing home residents are known to be more dependent, with a high prevalence of frailty [40,53].

Altogether, our results indicate that ATs might not yet suitably address the needs of frail older adults. A possible explanation is the fact that ATs are not usually developed with the specific needs of this population in mind. A recent systematic review on the use of communication technologies to improve social well-being in older adults found that more off-the-shelf products exist than devices designed specifically for older adults [62]. A qualitative study on the use of AT by frail older people showed specific needs of this subgroup when becoming users of AT, such as prescription support, training, and follow-ups [36]. This highlights that frail older adults might face specific challenges when using AT that could affect the performance of such technologies. Further research should focus more on this vulnerable group, including measures of frailty for the study populations.

We also showed that the evaluation of an AT is usually unidimensional (RQ1). Many factors, especially social, economic, or ethical aspects, are hardly investigated [29]. For example, only two studies analyzed in this review evaluated the impact of the AT for formal caregivers, showing no improvement for their working conditions or health [6,23]. Two trials considered economic aspects of ATs [22,24]. Ethical challenges have not been taken into account at all, despite their importance for data management issues and in the setting of smart housing technology [29,63].

The unclear findings on the effectiveness of ATs for older adults align with those of other systematic literature reviews on the topic [18,28-30,62]. Our strict inclusion and exclusion criteria, especially the requirements for the type of technology, mean age, and setting, resulted in the inclusion of 19 RCTs in the final analysis. Almost half of the studies included were pilot or feasibility trials. This shows that there is still a lack of research addressing the use of ATs for older adults at home or in similar settings [57,62,64]. A crossover design, where the control group changes to the intervention after a predefined period, was found to be commonly used when evaluating ATs. Possible reasons for this could be the easier recruitment as every participant can test the device, which might also lead to a reduction of dropout numbers due to an increased motivation to remain in the study. However, the average dropout rates were similar among the two RCT types (parallel design: 13.8%; crossover design: 12.6%). In this context, three studies with a regular parallel-group design reported noticeably higher dropout rates in the intervention group and were judged to have a high RoB for incomplete outcome data [51,53,54]. The retraction of consent and complexity of ATs were mentioned as possible reasons for this. Several records were excluded because they evaluated ATs in a laboratory setting. To gain insightful and reliable evidence on the actual effectiveness of AT, it is necessary to evaluate the devices being used by older persons within a realistic setting [57]. The challenges that arise in terms of ethical, economic, and logistic issues when performing studies with older adults in their own homes are part of the reason for the current lack of research [35,65].

Limitations

There is a lack of a uniform definition concerning ATs for older people. This makes searching for and selecting suitable studies difficult, and increases the risk of missing relevant research. The search string resulted in almost 11,400 records. Only 19 were selected for the review, indicating an insufficient precision caused on the one hand by the lack of standardized terminology and on the other hand by the vast amount of existing literature evaluating AT in clinical settings rather than in the home environment. Additionally, the technologies considered in this analysis are heterogenous, thus limiting the possibilities for analysis, in particular the performance of a GRADE (Grading of Recommendations, Assessment, Development and Evaluations) assessment to rate the certainty of evidence as suggested by the Cochrane Collaboration. The number of trials per device type is not sufficient to form a definite conclusion of the effectiveness of AT. When the analysis for this review was performed, the new RoB 2 tool from the Cochrane Collaboration [66] was still undergoing pilot testing, and therefore we used the original RoB tool, first published in 2008 [47], for our analysis. Although the mean age of participants across all trials was 76.3 years, six identified trials included participants below the age of 65 years. Unfortunately, the authors did not present a stratified analysis by age, thus limiting the generalizability of the results to the older population.

Conclusion

Researchers, politicians, and health care professionals across the globe have high hopes for AT to support older adults. Many devices are freely available on the market and are often used even though the effectiveness is not supported by current research, as shown in this review. The number of available RCTs evaluating ATs in older populations is limited and many only include a small number of study participants. Further studies with larger, well-characterized samples of older adults are necessary to allow for further stratification (eg, for frailty). Additionally, it is important to expand the focus and include economic, social, ethical, and technological aspects besides the medical outcomes. Formal and informal caregivers may, in some cases, benefit from AT even more than the older adults themselves and should therefore be included in future studies. The new Medical Devices Regulation of the European Union includes stricter controls and requires an evaluation of all medical devices before certification. In this context, our review intends to add value by identifying the current gaps in the literature, emphasizing the importance of addressing several health-related dimensions while taking into account the heterogeneity of older adults by providing a good characterization of the participants with respect to frailty.

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Authors' Contributions

MLF, MD, and DD developed the study design and determined the inclusion and exclusion criteria. MLF and VM developed and tested the search strategy, independently screened the records, and selected the final trials to be included in the analysis. MLF and VM extracted the data and performed the RoB analysis. MD and DD were consulted in case of discrepancies. SB assisted with the frailty assessment. MLF prepared the manuscript and all authors read and commented on the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA Checklist.
[PDF File (Adobe PDF File), 97 KB - aging_v5i2e31916_app1.pdf]

Multimedia Appendix 2
Search string.
[PDF File (Adobe PDF File), 40 KB - aging_v5i2e31916_app2.pdf]

Multimedia Appendix 3
Crossover vote.
[PDF File (Adobe PDF File), 43 KB - aging_v5i2e31916_app3.pdf]

Multimedia Appendix 4
Excluded articles based on full-text review.
[XLSX File (Microsoft Excel File), 14 KB - aging_v5i2e31916_app4.xlsx]

Multimedia Appendix 5
Quantitative outcome data.
[PDF File (Adobe PDF File), 296 KB - aging_v5i2e31916_app5.pdf]

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Abbreviations

AT: assistive technology
CENTRAL: Cochrane Central Register of Controlled Trials
CINAHL: Cumulative Index to Nursing and Allied Health Literature
GRADE: Grading of Recommendations, Assessment, Development and Evaluations
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QoL: quality of life
RCT: randomized controlled trial
RoB: risk of bias

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Review

Naturally Occurring Retirement Communities: Scoping Review

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Abstract

Background: As Canada’s population ages, there is a need to explore community-based solutions to support older adults. Naturally occurring retirement communities (NORCs), defined in 1986 as buildings or areas not specifically designed for, but which attract, older adults and associated NORC supportive service programs (NORC-SSPs) have been described as potential resources to support aging in place. Though the body of literature on NORCs has been growing since the 1980s, no synthesis of this work has been conducted to date.

Objective: The goal of this scoping review is to highlight the current state of NORC literature to inform future research and offer a summarized description of NORCs and how they have supported, and can support, older adults to age in place.

Methods: Using a published framework, a scoping review was conducted by searching 13 databases from earliest date of coverage to January 2022. We included English peer- and non–peer-reviewed scholarly journal publications that described, critiqued, reflected on, or researched NORCs. Aging-in-place literature with little to no mention of NORCs was excluded, as were studies that recruited participants from NORCs but did not connect findings to the setting. A qualitative content analysis of the literature was conducted, guided by a conceptual framework, to examine the promise of NORC programs to promote aging in place.

Results: From 787 publications, we included 64 (8.1%) articles. All publications were North American, and nearly half used a descriptive research approach (31/64, 48%). A little more than half provided a specific definition of a NORC (33/64, 52%); of these, 13 (39%) used the 1986 definition; yet, there were discrepancies in the defined proportions of older adults that constitute a NORC (eg, 40% or 50%). Of the 64 articles, 6 (9%) described processes for identifying NORCs and 39 (61%) specifically described NORC-SSPs and included both external partnerships with organizations for service delivery (33/39, 85%) and internal resources such as staff, volunteers, or neighbors. Identified key components of a NORC-SSP included activities fostering social relationships (25/64, 39%) and access to resources and services (26/64, 41%). Sustainability and funding of NORC-SSPs were described (27/64, 42%), particularly as challenges to success. Initial outcomes, including self-efficacy (6/64, 9%) and increased access to social and health supports (14/64, 22%) were cited; however, long-term outcomes were lacking.

Conclusions: This review synthesizes the NORC literature to date and demonstrates that NORC-SSPs have potential as an alternative model of supporting aging in place. Longitudinal research exploring the impacts of both NORCs and NORC-SSPs on older adult health and well-being is recommended. Future research should also explore ways to improve the sustainability of NORC-SSPs.

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KEYWORDS

naturally occurring retirement communities; NORC; NORC supportive service programs; aging in place; older adults; scoping review

Introduction

Background

Supporting older adults to age in their communities has been a focus of Canadian aging strategies and policies [1,2]; however, Canada continues to fall short in developing community-based solutions that are designed for, and by, older adults. The COVID-19 pandemic has highlighted not only the challenges and risks of long-term care, but also the critical need to examine alternative community housing models. Hunt and Gunter-Hunt [3] first coined the term naturally occurring retirement communities (NORCs) in 1986, defining them as “a housing development that is not planned or designed for older people, but which over time comes to house largely older people.” With time, the body of research on NORCs has grown to include NORC supportive service programs (NORC-SSPs): initiatives that bring older adults living in NORCs and health and community supports together to offer programs and activities to foster aging in place.

Benefits of Reviewing NORC Literature

NORCs have been described by Kloseck et al [4] as “untapped resources to enable optimal aging at home” because they offer social-relational connections and build on the strengths of communities. Since the initial paper by Hunt and Gunter-Hunt [3] defining NORCs >30 years ago, there has been a growing body of literature on NORCs and NORC-SSPs; specifically in the last year, 3 review papers have conducted broad explorations of aging-in-place models, including NORC programs, from different perspectives [5-7]. Mahmood et al [5] described key barriers and challenges of NORC-SSPs as well as cohousing and village models within the domains of the age-friendly communities framework. Hou and Cao [6] conducted a systematic review of NORCs, cohousing, and university-based retirement community literature to explore the push-and-pull factors of migration. Chum et al [7] conducted a scoping review to explore models that included NORCs, congregate housing and cohousing, sheltered housing, and continuing care retirement communities for the purpose of identifying themes across models that support aging in place. These well-designed reviews offer further insight into NORCs and NORC programs; however, no in-depth synthesis of NORC literature has been conducted to date. A review of this literature would offer several benefits. First, a review would highlight the current state of the research and identify gaps that could guide researchers in advancing the evidence related to NORCs and NORC-SSPs. Second, a review would document and describe the different variations of NORCs and NORC-SSPs along with the methods used to identify NORCs. Third, a review would identify how and in what ways NORCs can be, and have been, used to support older adults in their community and document the benefits of NORCs to the health and well-being of individuals and to communities as a collective. Finally, a review can offer critical data that could be used to advocate for further support of NORCs. The objective of this paper is to describe the state of the literature on NORCs.

Methods

Approach

A scoping review was considered the appropriate approach, given the fact that no previous review of the literature had been conducted. Furthermore, our aim is to capture the full breadth of the literature, bringing all scholarly work on NORCs together, as opposed to analyzing the methodological quality of the existing evidence [8].

A scoping review as outlined by Arksey and O’Malley [9] and updated by Levac et al [10] was conducted. The scoping review followed the 5-step process proposed by Arksey and O’Malley [9]: (1) identifying the initial research question; (2) identifying relevant studies; (3) selecting the studies; (4) charting the data; and (5) collating, summarizing, and reporting the findings [9]. A sixth step, consulting with stakeholders, is considered optional and was not included in this review.

Identifying the Research Question

As per the recommendations of Levac et al [10], we kept the research question broad but with “a clearly articulated scope of inquiry.” The research question included clearly defining key concepts (NORCs), the population of focus (older adults), and the outcomes (support). Thus, the following research question was developed to guide the search: How and in what ways do NORCs support older adults to remain living at home in their communities?

We articulated three subquestions to help guide the data extraction:

1. What methods are used in the literature to identify NORCs?
2. What mechanisms or resources are in place in NORCs and how are these provided (delivered)?
3. What outcomes are used to determine the benefits of NORCs?

Identifying Relevant Studies

A professional health sciences librarian (Paola Durando) performed the scoping review search in July 2020. A subsequent search was conducted by the authors in January 2022. To conduct a comprehensive search within NORC literature, the only search term used was *naturally occurring retirement communit**. Expanders to include equivalent subjects and related words were used in some databases. Databases were searched from their earliest data of coverage through January 2022. The following databases were searched: CINAHL, Ovid MEDLINE, HealthSTAR, Embase, APA PsycINFO, Allied and Complementary Medicine Database, JBI Evidence-Based Practice Resources, REHABDATA, Sociofile, Education Source, Education Resources Information Center, Urban Planning, and the Cochrane Library. In addition, the 3 aforementioned review papers [5-7] were examined and cross-referenced to handpick additional references that were not identified in our search.

Study Selection

Using the key search term *naturally occurring retirement communit**, 787 articles were identified from across the selected databases. These articles were imported and screened for study selection using Covidence screening software (Veritas Health Innovation Ltd). Many of these articles (343/787, 43.8%) were duplicates from 92% (12/13) of the databases and removed before screening. A search of REHABDATA yielded zero results. Only duplicates were found in Google and Google Scholar searches. An initial title and abstract screening was conducted, and the inclusion and exclusion criteria were applied to guide final study selection. All titles and abstracts were screened by 2 members of the research team (SD and CF). The inclusion and exclusion criteria are specified in Textbox 1. Any discrepancies were reviewed by a third member (SP) and discussed with the initial reviewer until consensus was reached.

Articles identified in the abstract and title screening as relevant for a full-text review (130/784, 16.6%) were reviewed by 2 members of the research team (SD and CF) by applying the inclusion and exclusion criteria. Any discrepancies were reviewed by a third member of the research team (SP) and discussions were held until consensus was reached. Article selection followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement, and the study process is described in Figure 1 [11]. During the full-text screening, a subset of articles (10/130, 7.7%) was excluded because of the lack of direct focus on NORCs. These articles primarily consisted of studies that sampled from different populations of older adults, some of whom lived in NORCs. The primary objectives of these studies were not to understand or demonstrate the impact of living in NORCs, and there was no specific reference to NORCs in the results or discussion. Other articles that fell into this category were those that mentioned NORCs in passing within larger discussions of aging in place (13/130, 10%). We chose to exclude both these categories of studies from the final extraction because they did not directly contribute to answering the research question. In addition, any article that was not from a scholarly source was excluded (22/130, 16.9%). After full-text review, of the 130 studies, 64 (49.2%) were selected for extraction.

Textbox 1. Inclusion and exclusion criteria.

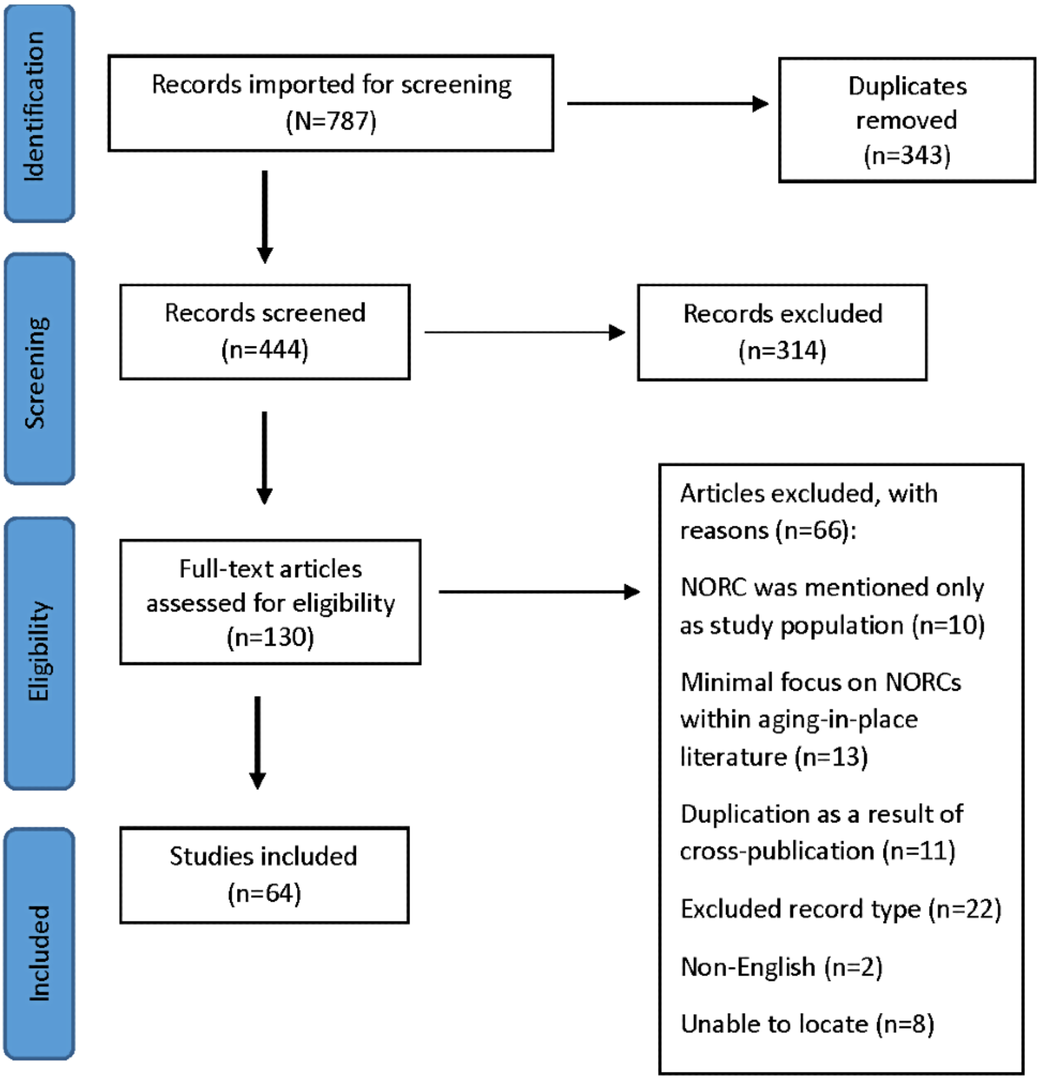
Inclusion criteria

- English language
- Scholarly sources, including peer- and non–peer-reviewed journals
- Subject matter
  - Descriptions
  - Critiques
  - Reflections on naturally occurring retirement communities
  - Research in naturally occurring retirement communities

Exclusion criteria

- Non-English
- Article types
  - Book chapters
  - Dissertations
  - Conference abstracts
  - Reports
  - Magazine or newspaper editorials
- Subject matter
  - Aging-in-place literature with little or no mention of naturally occurring retirement communities
  - Research that sampled from naturally occurring retirement communities but did not connect results to setting

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow chart. NORC: naturally occurring retirement community.



Charting the Data

During the study selection phase, the authors developed a data charting table. Variables included author, date, location, study design, and NORC definition used. Data extraction was informed by the conceptual framework developed by Greenfield et al [12], which examines the potential of NORC programs to promote aging in place. This framework identifies the different elements of NORCs as well as the outcomes of NORCs at the individual, community, and organization levels. The conceptual framework is aligned with the studies' research questions and structures the presentation of the results.

As per the recommendations of Levac et al [10], 2 authors (SD and CF) independently extracted data from 8% (5/64) of the articles before convening to determine the consistency of their approach. Once consensus was reached, the authors proceeded with the full data extraction. Once data were extracted, the authors conducted a qualitative content analysis of the final articles (n=64), guided by the framework developed by Greenfield et al [12].

Ethics Approval

As this is a scoping review, ethics approval was not required.

Results

Overview

Of the 64 articles included in this scoping review, 60 (94%) were written in a US context, with the remaining 4 (6%) written from Canadian perspectives [4,13,14,15]. The articles were published between 1985 and 2021; Table 1 shows the breakdown of the published articles by decade. Of the 64 articles, 25 (39%) presented information about NORCs, whereas the remaining 39 (61%) specifically looked at NORC-based programs. Authors of nearly half (31/64, 48%) of the articles used a descriptive research approach; of these, most were cross-sectional (25/31, 81%). Of the 64 articles, 8 (13%) [3,14,16-21] presented general descriptions or overviews of NORC or NORC-SSP concepts. Articles presented findings from, or described, a single NORC or NORC program (25/64, 39%) or ≥2 NORCs (24/64, 38%). Other articles presented descriptions of approaches to identifying NORCs [22,23] or descriptions of frameworks and tools to characterize NORCs or NORC programs [12,24,25]. In 11% (7/64) of the articles, authors compared examples of NORCs or NORC programs to other aging-in-place concepts, including the village model [26-29], campus-affiliated retirement communities [29], or new urbanism [30], and in 3% (2/64) of the articles, authors compared the concepts of horizontal and vertical NORCs [31,32]. Authors conducted studies comparing two groups within NORCs in which one receives an intervention and the other does not in 5% (3/64) of the included articles [33-35]. Methods used to conduct research in NORCs typically included surveys, interviews, focus group discussions, and observational methods.

Table 1. Decade of publication.

Years	Number of articles
1980-1989	1
1990-1999	1
2000-2009	20
2010-2019	42

How Are NORCs Identified?

Definition of NORCs

Of the 64 articles, 33 (52%) provided a specific definition of NORCs. Authors of 20% (13/64) of the articles cited the 1986 definition proposed by Hunt and Gunter-Hunt [3]. Some authors (12/64, 19%) went further to define NORCs by including the percentage or proportion of the community and the age of its residents [17,21,24,29,31-33,36-40]. The range of inclusion criteria cited in the literature is demonstrated in Table 2.

Table 2. Summary of naturally occurring retirement community inclusion criteria.

Percentage and age	Citation	Studies in which the citations were found
50% are older adults	Hunt and Gunter-Hunt [3]	[17,21,29]
40%-50% of the population is aged >60 years	New York State definition [41]	[37]
50% of the residents aged >65 years	Hunt [42]	[24,33]
50% of the residents should be aged >60 years	Hunt and Ross [43]	[31,37,40]
50% of the residents are aged ≥60 years	Lanspery [44]	[38]
≥50% of the population is aged at least 50 years	Hunt [30]	[39]

A subset of articles focused specifically on NORC-SSPs: authors cited definitions from the study by Vladeck [45] that focus on bringing partnerships together to deliver services to concentrated areas of older adults [21,26,31,46]. Although most of the articles written about NORCs were indeed describing a geographical area inhabited by a large proportion of older adults, some authors referred to NORCs as communities with purposeful programs, services, and activities to assist the older adult residents but did not differentiate these as NORC-SSPs or NORC programs. For the purpose of this review, we consider these articles as part of the body of both NORC and NORC-SSP literature.

All articles presented NORCs or NORC programs within North America. When locations were specified, NORCs and NORC-SSPs were described in Wisconsin (5/64, 8%), New York State (18/64, 28%), Florida (3/64, 5%), Georgia (4/64, 6%), Missouri (4/64, 6%), Maryland (3/64, 5%), California (1/64, 2%), New Jersey (2/64, 3%), and Oregon (1/64, 2%) in the United States, and Ontario in Canada (4/64, 6%).

Aurand et al [47] explored neighborhood NORCs in Tallahassee, Florida, and described differences in rural, rural development, suburban, single-family, multifamily residential, urban commercial, and urban mixed residential neighborhoods, finding that even the most urban neighborhoods in a midsized city may lack convenient access to amenities that support aging in place. Hunt and Gunter-Hunt [3] explained in their pivotal 1986 article that NORCs vary greatly and may range in size from a single apartment building to an entire neighborhood. As NORCs are *naturally* occurring, the literature represented a range of NORCs: some authors described vertical NORCs or those in apartment buildings with or without programs (16/64, 25%), whereas others described horizontal or neighborhood NORCs with or without programs (24/64, 38%). In addition, authors compared vertical and horizontal NORCs and NORC programs (5/64, 8%) [31,32,46,48,49].

Methods Used to Identify NORCs

Among the 64 included publications, the authors of 6 (9%) articles about NORCs described identification processes. The purpose of 33% (2/6) of these articles was to present the process of identifying NORCs [22,23]; in both, authors used US Census data to identify areas with large proportions of older adult residents. Of the remaining 4 articles, 3 (75%) presented similar processes to identifying NORCs as part of descriptive case studies [25,47,50]. The exploration of older adult migrants in rural areas by Hunt et al [51] used a different method of identification, choosing to compile a list of rural Wisconsin NORCs by surveying key informants of local aging initiatives or through the University of Wisconsin. Key informants were asked to identify “rural areas or towns with a population of less than 10,000 residents in your country that have attracted numerous older people (aged 65+) as either permanent or seasonal residents” [51].

Among the 39 NORC-SSP articles, in 9 (23%), authors described some methods for identifying the NORCs they described: an article presented a 1991 analysis of housing occupancy in New York State to identify potential NORCs [45]. The remaining articles presented relationships as the way of identifying NORCs and NORC programs. Anetzberger [52] described a Cleveland, Ohio, NORC collectively mobilizing to secure a federal grant, whereas in the article by Altman [37] about a New York, New York, NORC-SSP, the author describes the NORC's connection to the UJA Federation of New York, a local agency network that has played a critical role in the development of NORC programs in New York State [36]. Similar connections to local organizations were presented for other NORCs in Georgia [37,53], New York State [21,39,54,55,56], and California [31].

What Are the Mechanisms and Resources in Place in NORCs?

Overview

This section of the results builds on the conceptual framework developed by Greenfield et al [12] to examine the promise of NORC programs and the village model to promote aging in place. A summary of all results related to this framework can be found in Table 3.

In 72% (46/64) of the articles, authors described resources within NORCs, which are categorized as internal and external resources. Most of the findings presented in this section refer to articles written about NORC-SSPs, rather than geographic NORCs, because NORC-SSPs include programs of some kind.

Table 3. Summary of key findings from the included articles (N=64)[a].

Domain and categories	Articles, n (%)	Examples
Resources		
External resources: partnerships with external service delivery and planning organizations [12]	33 (52)	[4,12-17,19-21,24,27-29,31,32,36-40,45,46,48,50,52,53-61]
Internal resources: staff, volunteers, and organizational mission of program	21 (33)	[4,12,15,16,21,26-28,31,36-40,45-50,52-57,59-63]
Activities and services		
Civic engagement and empowerment activities	16 (25)	[4,15-17,21,31,36,37,39,46,50,52,55,56,59,62,63]
Social relationship–building activities	25 (39)	[12,15-17,21,27-29,31,32,37-40,46,50,52,56,58,59,62-66]
Services to enhance access to resources	26 (41)	[16,17,21,27-29,31,32,36,38-40,46-50,52,53-56,58,61-63,65,66]
Initial outcomes		
Participants' greater self-efficacy, collective efficacy, and sense of community	11 (17)	[15-17,21,32,50,52,53,62,67,68]
Participants' greater social support and reduced isolation	10 (16)	[15,19,33,48-50,52,53,61,62]
Participants' greater ability to access support and reduced unmet needs	14 (22)	[15-17,21,29,40,50,52,53,57,59,61,69]
Intermediate outcomes		
Individual-level, community-level, and organization-level benefits	6 (9)	[26,31,33,35,50,57]
Long-term goal		
Aging in place	1 (2)	[50]
Other domains: funding and sustainability		
Philanthropic and organizational grants	11 (17)	[21,26,29,31,33,36,39,53,55,57,63]
Government funding	17 (27)	[4,17,21,27,29,31-33,37,45,50,55,56,60,61,63,65]
Co-op board funding	1 (2)	[37]
Membership fees	6 (9)	[21,27,31,33,39,63]
Small donations and annual funding	4 (6)	[31,39,60,63]

[a] From the conceptual framework developed by Greenfield et al [12].

External Resources

Greenfield et al [12] define external resources as "partnerships with external service delivery and planning entities." In 52% (33/64) of the articles, authors described external resources, demonstrating their importance to the success of the NORC programs. Of the 64 articles, 19 (33%) presented external partnerships with health-related service organizations; Vladeck and Segel [45] describe New York, New York, NORC programs as having a health partner that is typically a home care agency, local hospital, nursing home, or combination of agencies that connect into the NORC to provide services. Authors reported health partners from service areas that included nonspecified health services [17,19,24,27,45], home care services [17], primary care physicians [57,58], nursing [4,21,36,46,53-57], occupational therapy [50,53], social work and counseling [21,24,36,46,50,53-57], pharmacy [57], and hospital-specified services [29,57].

An important external partner described in the literature was the landlord or property manager [15,32,36,52,55,56]. In some cases, the relationship was described as a financial partnership [37,52]. Altman [36] states that the landlords' "financial participation is crucial, not only because the funds are needed to support the program's operation but also because they become invested in a critical way in helping make the program a success. We found that having paid for a seat at the table, the housing company becomes engaged in both the planning and implementation of programs and feels more comfortable turning to the supportive service program for help when it identifies a resident in trouble." In other contexts, the role of the landlord had less focus on financial contributions and more on in-kind contributions, including the use and maintenance of space for programs and activities [15,32].

Other external partners described in the literature included transportation agencies [17,24], churches [36], university partners (for research and student training) [21,50,59], and community agencies providing social activities [24,36,50]. In some cases, community agencies hosted outreach programs at their own facilities [48,46].

Internal Resources

Greenfield et al [12] describe internal resources as staff, volunteers, and organizational mission of the NORC program. Of the 64 articles, 21 (33%) presented the role of hired staff in running and supporting the NORC programs. Anetzberger [52] reports that the Community Options NORC-SSP employs resource coordinators who "help older residents on site to identify needs and then access or develop services or activities to address these needs." A St Louis, Missouri, NORC-SSP had an entire team dedicated to supporting the program, including an activities coordinator, an outreach coordinator, a support services coordinator, a research and leadership development liaison, and a manager to oversee operations and administration [50]. This team worked to strengthen and develop the external community partnerships supporting the neighborhood.

Authors referred to the role of volunteers in running NORC programs in 22% (14/64) of the articles [4,12,15,21,28,31,36,45,48,49,56,59,60,62]. Opinions regarding the value of volunteers were sometimes mixed. Greenfield and Frantz [60] found in interviews with NORC program leaders that some felt that volunteer programs require significant staff oversight and volunteers were perceived as less accountable than staff, whereas others felt that without volunteers they would not be able to provide a sufficient number of programs to their membership. Authors described volunteers as both community members outside of the NORC and NORC-SSP participants themselves. Enguidanos et al [31] described a NORC program in metropolitan Los Angeles, California, that has a robust volunteer program, consisting primarily of older adults who were members of the NORC. Although there were struggles in recruiting and retaining volunteers (largely in part because of scheduling and long-term commitment issues), the volunteers provided 3141 hours of support to the NORC-SSP in a little more than 3 years, consisting primarily of individual supportive services such as peer counseling and friendly visits. Interestingly, the examination by Greenfield et al [28] of volunteering in age-friendly supportive service initiatives, including NORC-SSPs, found that programs with larger numbers of paid staff were associated with lower levels of older adult volunteer participation, but this had no impact on community volunteer participation.

Other internal resources mentioned in the literature included the role of neighbors and other NORC residents in supporting each other [4,21,26,49,55,56,62], whether through participation in formal advisory groups of the NORC programs or in providing peer-to-peer support to other members. The examination by Greenfield [49] of the role of neighbors' support in NORCs revealed that NORC-SSP members felt that neighbors were valuable for information sharing and for informal network expansion but that participants sometimes valued more the services and support provided by staff and external community partnerships.

Activities and Services

NORC-SSPs typically consist of activities and services to support older adults to age well in their communities. Greenfield et al [12] categorize activities and services into three broad categories: civic engagement and empowerment activities, social relationship–building activities, and services to enhance access to resources.

Civic Engagement and Empowerment Activities

NORC-program members were described as actively engaged in 25% (16/64) of the articles. In some articles, empowerment and engagement was described as members taking on volunteer roles within the program [31,36,39]. Elbert and Neufeld [50] described a method of community building in which groups of neighbors developed "Resident Councils." These councils met monthly to learn about available resources from each other and identify opportunities to work together toward common goals. Enguidanos et al [31] reported that although older adult engagement is important in the NORC-program model, it was difficult at early stages of development in 2 Los Angeles, California, NORCs to get older adult members to take on major roles and responsibilities.

Social Relationship–Building Activities

Authors described activities to build social relationships in 39% (25/64) of the articles. Examples included coffee hours [31, 62, 64], craft and hobby groups [15, 31, 56, 59], book clubs [40, 46], friendly visits [27, 28, 37, 58], day trips and outings [21, 31, 32,46, 50, 52, 62], congregate meals [15, 16, 21, 27, 31, 39, 52, 62, 65, 66], nutrition programming [17, 29, 40, 65], exercise classes [15, 17, 21, 29, 31, 37, 38, 56, 59, 62, 65], and guest speakers and education classes [17, 21, 29, 31, 38-40, 46, 50, 62, 63, 65, 66].

Services to Enhance Access to Resources

Of the 64 articles, 26 (41%) presented NORC-SSP offerings, including services that enhanced access to resources. In 16% (10/64) of the articles, authors described the offering of educational classes and guest speakers to the NORC-program memberships, whereas 16% (10/64) presented case management [17,29,32,36,38,48-50,63,65], 13% (8/64) presented increased access to health assessments and screenings [38-40,53,56,58,61,65], and 17% (11/64) presented the provision of services referral [16,21,27,28,36,50,52,53,56,58,63].

Funding and Sustainability

Authors discussed funding and sustainability in 42% (27/64) of the included articles. Among these 27 articles, in 3 (11%), authors broadly discussed the importance of funding NORC programs [14,20,38], whereas the remaining articles described examples of various sources of funding used to support NORCs and NORC programs. Funding came from philanthropic and organizational grants (11/64, 17%), government funding (17/64, 27%), co-op board funding (1/64, 2%), membership fees (6/64, 9%), and small donations and annual fundraising (4/64, 6%).

Although many funding sources were acknowledged, authors described challenges in maintaining the sustainability of NORC programs in some contexts. In the exploration by Greenfield and Frantz [60] of sustainability processes among NORC-SSPs, the authors found that respondents identified the diversification of funding sources as a key sustainability strategy. Although many authors referred to government funding, a respondent in the study by Greenfield and Frantz [60] explained as follows: "So much of our budget relies on the generosity of the state, and we consider them a partner. But every year it is a struggle to convince legislators that this is a worthy program to put resources toward." Other articles reported that NORC-SSPs diversified funding by linking sustainability success with private-public partnerships [31,45,50].

What Are the Outcomes of NORCs?

Overview

The articles included in this review presented a range of quantitative outcomes as well as anecdotal descriptions of the influence of NORCS on aging in place. Although the scoping review did not grade the level of the evidence presented in the studies, it is clear that robust outcome studies have not been completed; as a result, this section reports on outcomes that *show promise* for the NORC-program concept. Greenfield et al [12] organize outcomes into three categories: initial outcomes, intermediate outcomes, and long-term goals.

Initial Outcomes

Initial outcomes of participating in NORC programs can be grouped into three subcategories: (1) self-reported self-efficacy, collective efficacy, and greater sense of community; (2) self-reported increased social support and reduced isolation; and (3) self-reported access to support and reduced unmet needs.

NORC-program participants reported increased self-efficacy (6/64, 9%) [15,16,21,52,53,67], collective efficacy (2/64, 3%) [16,67], and greater sense of community (7/64, 11%) [17,32,50,52,53,62,68] in association with participation in the development of the NORC program or participation within the program itself.

NORC-SSP members reported increased social support and reduced isolation (10/64, 16%) through their participation in NORC programs. Increased social supports came from interactions with NORC-program staff, participation in service programs, and their increased interactions with neighbors and friends as a result of membership in the program.

NORC-program participants reported access to support and reduced unmet needs (14/64, 22%), primarily through the program's function of providing increased access to services and information, including providing referrals, screenings, and educational workshops.

Intermediate Outcomes

Greenfield et al [12] posit that the initial outcomes associated with participation in NORC programs lead to other individual-level benefits, including better physical health and psychosocial well-being.

Although the literature connects initial outcomes, including increased social connections and self-efficacy, to participation in NORCs and NORC programs, only a few studies were longitudinal in design (6/64, 9%), making it difficult to identify intermediate outcomes. Those that were longitudinal in nature had mixed results: a longitudinal 5-year program evaluation of a single NORC by Elbert and Neufeld [50] found that participants self-reported improvements or maintenance of their health over time, whereas in their 2.6-year evaluation, Cohen-Mansfield et al [33] found that there were no changes in physical health when comparing members with nonmembers, although members felt that participation had improved their social life and a little more than half reported feeling less isolated since becoming a member.

Greenfield et al [12] include community-level and organization-level benefits within intermediate outcomes. Indeed, the literature supports that participation in NORC programs leads to increased linkages between partners and community [4,21,36,39,40,53,57]. Benefits at the organizational level (eg, program sustainability) are less clear; explorations of sustainability in NORC-SSPs [60,63] highlighted the complexity of maintaining a program, most notably securing ongoing funding.

Long-term Goal: Aging in Place

The framework developed by Greenfield et al [12] presents the notion that all initial and intermediate outcomes work to support a long-term goal of the NORC program in facilitating aging in place. There is a consensus in this body of research that (1) North American older adults prefer to age at home and (2) additional supports are required for older adults to age in place successfully. By its nature, a NORC is a naturally existing high-density area of older adults, which makes it a natural fit for older adult–focused programs and services, otherwise known as the creation of a NORC-SSP. However, insufficient data are presented in the literature to provide evidence that participation in NORCs and NORC-SSPs leads to an increase in the ability to age in place. An article by Elbert and Neufeld [50] found that NORC members moved to long-term care homes 45% less than nonmembers; indeed, in the 10% of the population who had died in their homes, the average individual was aged 90 years, suggesting that participation in a NORC was linked to increased ability to age in place. This was the only article in the review demonstrating a link between an increased stay at home and the existence of a NORC.

Discussion

Principal Findings

This is the first synthesis of the literature on NORCs and provides an important examination of how NORCS are described and the potential benefit of NORCs to older adults and communities. Since the 1980s, the body of literature around NORCs and NORC-SSPs has grown, as has the spread of the programs themselves. This scoping review yielded articles (n=64) that described NORCs and NORC programs across North America. Of the included articles, 94% (60/64) were written focusing on a US context. There is a notable absence of international perspectives in this body of research. However, we know that there is significant work looking at aging in the community that is being conducted in other countries; for example, cohousing work in the Netherlands [70,71] and aging-in-place research out of Japan [72]. This suggests that perhaps NORC is not a globally standardized term for describing neighborhoods or communities with high proportions of older adults living in them, and it will be important to examine whether concepts such as NORCs are described and understood in international contexts.

It is clear that, even in the similar North America context, there is a lack of consensus as to what specifically constitutes a NORC. Although the definition proposed by Hunt and Gunter-Hunt [3] was used by most authors, there were still significant discrepancies in terms of the age of NORC members and their proportions. It is also noteworthy that only a few (6/64, 9%) of the articles described methods for identifying NORCs. This lack of standardized method for the purpose of NORC identification makes it difficult to compare among and across NORCs and may also explain why most of the literature focuses on North America. NORCs very well could exist worldwide but have not been identified because of a lack of existing methods and terminology.

The literature highlighted the importance of both external resources such as partnerships and internal resources such as staff and volunteers as being key to the success of a NORC-SSP. Multiple partners are important to the successful functioning of a program; notably, Blumberg et al [53] describe >30 partnerships involved in an Atlanta, Georgia, affordable public housing NORC program, including connections to farmers' markets, the university's occupational therapy program, Medicare, and access to food stamps. Further research could explore partners' roles and experiences engaging in NORC programs to provide better understanding of how partnerships and networks develop over time and contribute to the sustainability of a NORC program.

Authors also described activities and services of NORC programs in detail and looked at both social programs and service delivery. These 2 categories of activities are cited in the conceptual framework developed by Greenfield et al [12] as critical to reducing social isolation and enhancing access to supports and in turn addressing gaps in unmet needs within community-dwelling older adult populations. The study by Greenfield et al [12] has also cited the critical importance of civic engagement and empowerment activities to enhance older adults' perceptions of both self- and collective efficacy, leading to both individual- and community-level benefits. However, only a few (16/64, 25%) articles presented older adult participants in leadership roles in the operation of NORC programs, characterized through volunteer roles, sitting on decision-making councils, and other such roles to drive development of their NORC program.

The literature included in this review also highlights the complexities around the funding and sustainability of NORC programs. A variety of means were used to fund NORC programs, including philanthropic and organizational grants, government funding, co-op board funding, membership fees, and annual fundraising. No single method seemed to be more sustainable than others, and as Greenfield and Frantz [60] reported, it seems that the key to success is to diversify funding sources. Authors who described funding tended to cite philanthropic and organizational grants (11/64, 17%; and 10/61, 16%, respectively) and government funds (17/64, 27%) as ways in which NORC programs were funded. The authors of this review would be interested to learn more about the potential for NORC programs to explore less traditional funding models that were described, including what sustainability might look like for a NORC program that adopts a social enterprise model, continually self-generating funds for operations rather than relying on more traditional grants, which can be less predictable.

Regarding the impacts of NORCS, interestingly, health and well-being outcomes were reported primarily for NORC programs, aligning well with the conceptual framework developed by Greenfield et al [12]; however, the authors of this review would be interested to gain more understanding as to whether simply living in a geographic region described as a NORC has positive impacts on older adult health and well-being or it is the leveraging of resources and supports to develop a NORC program that has the positive impact on participants.

Implications for Research and Practice

On the basis of the findings from the literature, NORCs show great promise in initial outcomes that benefit the health and well-being of older adult participants. Although older adults in NORC programs demonstrated increased self- and collective efficacy and greater sense of community, increased social supports and reduced isolation, and self-reported access to support and reduced unmet needs, the research is largely descriptive. Although the purpose of this review was not to weigh the levels of evidence, it is clear that more robust study designs are needed. There are also significant gaps in the literature when looking at intermediate and long-term outcomes. Indeed, only a few articles (6/64, 9%) were longitudinal in nature, spanning a maximum of 5 years in study duration. Further research into NORC programs should look longitudinally at health and well-being outcomes to determine the long-term impacts of participating in a NORC program, including whether participation leads to an increased ability for an older adult to age in place. Longitudinal work should also explore organization-level benefits, including the journey of a NORC program to operational sustainability.

There are clear challenges in conducting community-based research, and traditional randomized controlled trials may not be feasible to examine NORC outcomes. Other community models to support aging, including the village model in the United States [73,74] and cohousing models in Europe [70,71], also face similar gaps in high-level, longitudinal research evidence and determining feasibility, and methodologies consistent with older adult–driven programs is needed to gather high-quality evidence and offer evidence-based options for both older adults and decision-makers.

Recent work by the Ontario COVID-19 Science Advisory Table demonstrates ways in which NORCs can be better used to support community-dwelling older adults; the Science Table's members identified NORCs in Toronto, Ontario, Canada, a city of high COVID-19 incidence, for the purpose of rapidly facilitating community-based COVID-19 vaccination clinics [75]; yet, documented examples of using NORCs in such ways are few and far between, likely because of a lack of definition and identification methods. These gaps need to be addressed to better understand both the concept of a NORC and the potential way in which NORCS can be leveraged to support aging adults in the community. To begin with, further work could explore the refinement of the definitions of both NORCs and NORC programs. The literature demonstrated a lack of consensus, especially regarding what constitutes a NORC in terms of size, proportion, age, and other parameters. The literature also lacked methodologies for identifying NORCs. Clarifying both the definition and methodologies would help key stakeholders, including scholars, policy makers, municipalities, and communities, to further identify and describe existing NORCs, adding not only to a growing body of research but also to the growing concept of leveraging NORCs through supportive programs to aid older adults to age in the community.

Some authors of articles included in this review (16/64, 25%) described different engagement activities that sought to empower older adults living in NORCs. Research exploring the village model found that older adults are highly involved in the development of their programs, including policy development, governance, and actual service delivery [76]. Research into connections between engagement and well-being found that older adults who participate in volunteering activities report more positive well-being outcomes [77,78]. Further research should specifically explore the engagement of the older adult participant in NORC programs to examine both the impact of this engagement on older adult well-being and the impact on the success and growth of the program.

Challenges with sustainability, particularly related to funding, have also been reported in research conducted on the village model [79]. Ultimately, this highlights the overall challenge of older adult–driven and community-focused programs to obtain sustainable government-level funding needed to create a stable long-term program. The COVID-19 pandemic has highlighted that most of the government funding for older adults in North America is directed toward institutional care, with much less to home care and even less to community, older adult–driven programs. As a society, we have learned that we need to consider how to better support older adults living in the community to ensure that they can remain safe and connected for as long as possible. This review highlights funding as one of the core requirements for long-term viability.

There was also a surprising lack of information surrounding the question of how much a NORC program costs to run annually. Although variation within different contexts would be expected, this information is critical to present to municipalities or other stakeholders who would be interested in the economic impacts of such a program to determine the budget allocation required to support such programs. In addition, details related to annual costs would help with planning new NORC communities. Further research should explore the cost breakdown of a NORC program and the cost-benefit of the model in comparison with other current means of supporting older adults, including home care and long-term care facilities.

Conclusions

With our rapidly aging population, there is a clear need to consider how to support older adults living in communities. NORCs hold great promise and are a highly undeveloped approach to developing older adult communities. The body of research around NORCs and NORC programs has been growing for >30 years in North America, and this review provides a critical launching point to begin a focused program of research related to NORCS. NORC programs have the potential to leverage existing resources and partnerships for the purpose of supporting older adults to live well in the community. On the basis of this review, it is clear that further research needs to be conducted to more clearly define what constitutes NORCs and NORC programs, how to identify them in different contexts, and how to create an impact on older adults' health and well-being over time.

Authors' Contributions

CD and VGD conceptualized the study. CD developed the search strategy. SD and CF conducted the screening, data extraction, and data analysis. SP was the third rater during the screening. SP interpreted the data. SP wrote the first manuscript draft. CD, VGD, SD, and CF revised the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

NORC: naturally occurring retirement community
NORC-SSP: naturally occurring retirement community supportive service program
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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Review

Voice-Enabled Intelligent Virtual Agents for People With Amnesia: Systematic Review

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Abstract

Background: Older adults often have increasing memory problems (amnesia), and approximately 50 million people worldwide have dementia. This syndrome gradually affects a patient over a period of 10-20 years. Intelligent virtual agents may support people with amnesia.

Objective: This study aims to identify state-of-the-art experimental studies with virtual agents on a screen capable of verbal dialogues with a target group of older adults with amnesia.

Methods: We conducted a systematic search of PubMed, SCOPUS, Microsoft Academic, Google Scholar, Web of Science, and CrossRef on virtual agent and amnesia on papers that describe such experiments. Search criteria were (*Virtual Agent* OR *Virtual Assistant* OR *Virtual Human* OR *Conversational Agent* OR *Virtual Coach* OR *Chatbot*) AND (*Amnesia* OR *Dementia* OR *Alzheimer* OR *Mild Cognitive Impairment*). Risk of bias was evaluated using the QualSyst tool (University of Alberta), which scores 14 study quality items. Eligible studies are reported in a table including country, study design type, target sample size, controls, study aims, experiment population, intervention details, results, and an image of the agent.

Results: A total of 8 studies was included in this meta-analysis. The average number of participants in the studies was 20 (SD 12). The verbal interactions were generally short. The usability was generally reported to be positive. The human utterance was seen in 7 (88%) out of 8 studies based on short words or phrases that were predefined in the agent's speech recognition algorithm. The average study quality score was 0.69 (SD 0.08) on a scale of 0 to 1.

Conclusions: The number of experimental studies on talking about virtual agents that support people with memory problems is still small. The details on the verbal interaction are limited, which makes it difficult to assess the quality of the interaction and the possible effects of confounding parameters. In addition, the derivation of the aggregated data was difficult. Further research with extended and prolonged dialogues is required.

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KEYWORDS

intelligent virtual agent; amnesia; dementia; Alzheimer; systematic review; mobile phone

Introduction

Background

Older adults often complain about amnesia or increasing memory problems, although these cognitive changes affect some individuals more than others [1]. Although some degree of cognitive slowing is typical of normal aging, when the acquired cognitive impairment has become severe enough to compromise social or occupational functioning, the diagnosis of dementia is typically established [2]. Alzheimer disease (AD) is the most commonly diagnosed form of dementia. If the functional abilities of patients are still essentially preserved while their cognitive abilities are in between those associated with normal aging and dementia, people are typically diagnosed with mild cognitive impairment [2].

This gradation in cognitive abilities does not suggest a necessary sequence of normal cognitive slowing to mild cognitive impairment to dementia; most people will only experience normal cognitive slowing upon aging, some will develop mild cognitive impairment and some will develop dementia. For the latter category, the period between first serious cognitive complaints and the diagnosis of dementia can be 10 years and depends on many factors such as age, sex, and general physical premorbid condition [3]. The duration of survival after AD diagnosis is 10.2 years for men aged 65 years and 13.2- years for women of the same age [4]. In this period after diagnosis of AD, the period for need for home care typically lasts 3.7-4.7 years and for institutional care, 2.2-3.2 years [4].

During the period of normal cognitive decline without the need for additional care, people may benefit from personalized support. In follow-up phases, where people need extended home care or institutional care, the need for personalized support increases. In the early phases, such support is often provided by partners, children, friends, or other relatives. When these are not available, but the patient is still living independently at home, professional help by, for example, case managers, district nurses, and meal delivery services may be needed upon the indication of a patient’s general practitioner. If the need for institutional care arrives, people may move to a nursing home and be cared for by nurses and other health care professionals. However, in each of these phases, informal caregivers or health care professionals are often not sufficiently available for the needs of the patient. For example, Buchan et al [5] have identified a global shortage of 17 million health care workers in 2019. This shortage will only increase owing to the growing percentage of older adults in the total population (9% in 2019 and 12% in 2030) [6]. Hence, society is looking for alternative solutions such as technological systems that could support health care professionals in their work by taking over automatable tasks. One such potential solution can be offered by intelligent virtual agents (IVAs).

IVAs can be defined as interactive digital characters that exhibit human-like qualities and can communicate with humans using natural human modalities such as facial expressions, speech, and gestures [7]. This broad definition includes intelligent virtual characters that manifest themselves as text-based chatbots on smartphone or tablet and virtual characters in the form of a human head or a complete person on a tablet or computer screen. Several other terms are used for this type of agent, such as virtual assistant, (embodied) conversational agent, cognitive assistant, chatbot, intelligent assistive technology, and virtual human. IVAs have also been the subject for a series of conferences on this theme organized by the Association for Computing Machinery since 1998 [7]. As it has been a topic of research for more than 3 decades now for many applications, a large volume of research papers have been published on this subject.

For the purpose of this study, the main interest is in IVAs implemented as onscreen virtual characters that support older adults through autonomous verbal interaction. This specification is based on 3 reasons. First, from the perspective of the patient, verbal interaction is considered the easiest and most natural way to communicate and build rapport with an agent [8]. Second, a virtual character is more inviting to have a verbal communication with than a text-based chatbot. Third, once a person is used to this type of communication, a many-year support period during various forms of slowly progressing cognitive decline could be possible: talking is something people can do for a long period, whereas pushing buttons on a touchscreen still assumes some digital literacy, and this may disappear with cognitive decline [9].

IVAs have potential advantages for organizations that deliver home or institutional care. These organizations could decrease the need for a 24×7 human support team if a large part of the frequently asked support questions can be handled through an intelligent dialogue with an IVA. Furthermore, IVAs are immediately available and there is no need to wait in line for the availability of a health care organization employee. Interaction data can be stored and analyzed both on a personal and on an aggregated level, where the latter is of interest to the health care organization as well as to governmental health care control institutions. Obviously, ethical and privacy concerns need careful consideration and as a start can be addressed by a compliance check with the ethics guidelines for trustworthy artificial intelligence (AI), as published by the European Commission [10,11]. At the same time, IVAs have not yet been widely introduced in the consumer market and can thus far be found primarily in laboratory environments. Thus, the question arises as to whether IVAs have actually been developed and evaluated as verbal coaches or companions for cognitively impaired older adults. Therefore, this research first considered related systematic reviews and then identified the current state of the art through a systematic literature review.

Other Reviews

Other systematic reviews on virtual agents in health care revealed that the number of experiments with voice-enabled agents was rather limited. Xie et al [12] conducted a review on AI specifically for caregivers of persons with dementia, but did not report on any virtual agents for which an actual experiment had been conducted. Schachner et al [13] reviewed papers on AI-based conversational agents for chronic conditions. Although they found 2052 articles, only 10 met their inclusion criteria for research on chronic diseases involving an AI-based conversational agent. Of these 10, 2 papers dealt with dementia, but did not include a virtual agent.

Ienca et al [14] performed a systematic review on intelligent assistive technology for several forms of dementia including AD and included 571 studies. They examined the technological type of the interventions among others, but did not make a clear distinction on whether the intervention involved a virtual agent capable of 2-way verbal communication.

Bevilacqua et al [15] conducted a systematic review of the effectiveness of coaching through technology among older adults. From their original set of 2186 articles, 8 met their inclusion criteria, among which the criterion of the study was a randomized controlled trial. This criterion was more stringent than the ones used in this study, meaning that studies that could be included in this study might be excluded in their search strategy. In contrast, none of the studies they found aimed at people with cognitive problems.

Car et al [16] conducted a scoping review on conversational agents in health care. They did not report on any virtual agents such as those depicted in Figure 1, as their results were restricted to smartphone apps. Laranjo et al [17] also conducted a systematic review on conversational agents in health care. From the initial 1513 search results, they included 17 studies that evaluated 14 different conversational agents with unconstrained natural language input capabilities. From their results, 2 studies focused on an embodied conversational agent similar to that in Figure 1, but one of these studies was aimed at military personnel with posttraumatic stress syndrome (PTSS) and the other one, on training for people with autism spectrum disorders.

Figure 1. A virtual agent under development at the Behavioural Science Institute.

King and Dwan [18] created an inventory of electronic memory aids for people with dementia who experience memory loss increasing with age. They found 16 studies that met their inclusion criteria, one of which also met the criteria drawn up for this study: a study by Tokunaga et al [19] on a memory-aid service agent.

Provoost et al [20] reviewed embodied conversation agents in clinical psychology. They included 54 publications after an initial search result of 1117 references, but the disorders studied were autism, depression, anxiety, PTSS, schizophrenia, and substance abuse. Depression and anxiety are often associated with dementia. However, the studies related to these subgroups did not meet the criterion of a virtual agent.

Loveys et al [21] specifically examined the design features of embodied conversational agents and the extent to which these have an effect on the relationship quality between human and agent. Their systematic review resulted in 43 studies that examined design features such as language use, behavior, emotional expression, embodiment, appearance, personality, environment, and a combination of these. However, none of these studies were aimed at people with dementia.

Milne-Ives et al [22] performed a recent systematic review on the effectiveness of AI conversational agents in health care. They found 31 studies including a variety of conversational agents, among which were 14 chatbots and 6 embodied conversational agents; however, none specifically targeted people with cognitive problems such as dementia.

It is possible that some of the papers that were excluded from the aforementioned reviews met the inclusion criteria for this study. In any case, there is a gap when it comes to IVAs for people with amnesia, dementia, or AD, and with whom 2-way verbal interaction experiments have been conducted. This gap calls for a specific systematic review on that topic.

Objectives

This study aimed to evaluate IVAs and their interaction functionality, which have demonstrated a verbal communication for people with amnesia. Our hypothesis is that IVAs designed to assist older adults with memory problems have a positive usability. This review reports on studies with various voice-based IVA applications that have been developed to support these patients and the studies, which included (pilot) evaluations with this target group.

Methods

Eligibility Criteria

For the purpose of this review, an IVA was defined as an agent with a virtual embodiment (full body or face only) that was capable of *speaking* to a human (ie, playing a generated audio file). The agent shall be capable of having a 2-way verbal dialogue, that is, the human could speak to the agent, the agent could process the human input, and as a result, the agent would speak to the human. Therefore, the agent should also be capable of speech recognition, that is, converting the human audio signal (human utterance) into a text string. This text string should then be made available for response determination or natural language understanding, that is, intent, belief, or desire determination and action selection. Verbal response actions should be input for a text-to-speech function. The agent should be displayed on a permanently available screen and should not require the mounting of a virtual reality headset that is difficult to wear in a 24×7 setting and may also cause motion sickness and disorientation [23].

Studies eligible for review were further required to (1) include an experiment, pilot study, or randomized controlled trial with experimental results, thus not describing only requirements or designs; (2) target participants from an older adult population with potentially memory-related problems; and (3) be published in a peer-reviewed journal or in peer-reviewed conference proceedings.

Studies were excluded if (1) the agent was a physical robot, a purely text-based chatbot, or a virtual reality or augmented reality character; (2) the study concerned a Wizard of Oz study in which the researcher mimicked the agent and circumvented automated speech recognition and natural language processing (NLP) challenges; (3) the paper language was other than English; (4) the search result concerned a thesis or dissertation (as far as these were not peer reviewed and therefore did not meet publishable standards); (5) the search result was an abstract only, a PowerPoint, or a website; and (6) the full text was not available for the authors.

Search Strategy

A systematic search was conducted for keywords on papers included in electronic databases from health and computer sciences including PubMed, SCOPUS, Microsoft Academic, Google Scholar, Web of Science, and CrossRef. The search term was (*Virtual Agent* OR *Virtual Assistant* OR *Virtual Human* OR *Conversational Agent* OR *Virtual Coach* OR *Chatbot*) AND (*Amnesia* OR *Dementia* OR *Alzheimer* OR *Mild Cognitive Impairment*) and the search period was 2010 to present. This period has been defined for several reasons. First, the statement by Wargnier et al [24] that they did not find a publication on a usability interaction of a talking virtual agent with older adults with cognitive impairment. Second, 2010 was named as the start of the era of deep learning in speech recognition, which caused an explosion in the success of speech recognition applications [25,26]. Third, the limited number of relevant papers originating before 2010 and found in other systematic reviews [12-16,18,20-22]. The Publish or Perish tool was used to conduct the search, collect the results, and export them via csv-files to an Excel spreadsheet for study selection [27].

Study Selection

Two reviewers (RB and YvdS) independently conducted the search and compared and agreed on the results. Titles were screened upon clearly including the words of the search or being strongly related, based on the assumption that the title of the research paper should be clear on its contents. In case of doubt, the abstract was consulted. From this selection, the abstracts were reviewed for a second selection. The abstracts should include a reference to a verbal interaction experiment of a virtual agent with older adults and should be published in a peer-reviewed journal paper or conference proceedings. Abstracts that met these criteria were subsequently discussed and selected for full-paper text analysis. Studies deemed eligible for review were included in data synthesis.

Data Collection

The data of the selected papers are provided in a table format. The top row includes the authors, title of the paper, journal or conference proceedings where it was published, and the year of publication. Row 2, column 1 describes the data on the study: country, study design type, target sample size, controls, and study aims. In row 2, column 2, the actual experimental population is reported, whereas row 2 and column 3 details the intervention. Row 3, column 1 specifies the typical interaction between the IVA and the human, with specific attention to the verbal interaction options for the human and the NLP techniques that were applied. Row 3, column 2 provides a summary of the reported results, and row 3, column 3 presents an image of the IVA.

Quality of Study Evaluation

The standard quality assessment criteria for evaluating primary research papers developed for qualitative research by Kmet et al [28] were used by reviewers TB and ST to evaluate the quality of the studies found and the risk for bias. This method uses the checklist presented in Textbox 1.

The eligible papers were scored for the aforementioned items as yes (2 points), partial (1 point), no (0 points), or not applicable. Agreement was reached on whether an item could be scored or defined as *not applicable* and ignorable. The score of the reviewers TB and ST per item was averaged. The overall score per paper was calculated by dividing the summed score by the total number of scored items, multiplied by 2. This resulted in a score between 0 and 1.

Textbox 1. Standard quality assessment criteria.

Checklist used

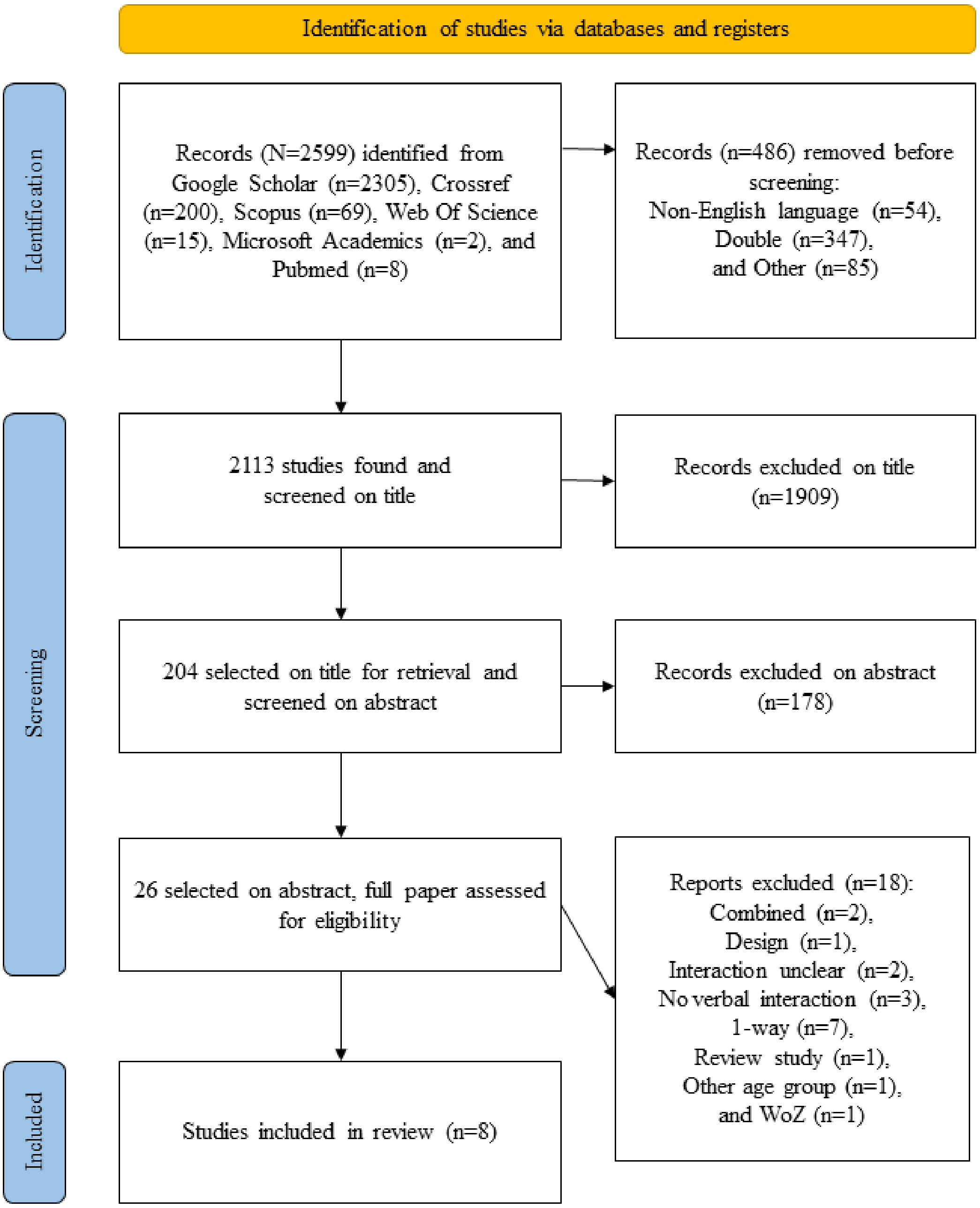
- Question or objective sufficiently described?
- Study design evident and appropriate?
- Method of participant or comparison group selection or source of information or input variables described and appropriate
- Participant and comparison group, if applicable, characteristics sufficiently described?
- If interventional and random allocation was possible, was it described?
- If interventional and blinding of investigators was possible, was it reported?
- If interventional and blinding of participants was possible, was it reported?
- Outcome and (if applicable) exposure measures well defined and robust to measurement or misclassification bias? Means of assessment reported?
- Sample size appropriate?
- Analytic methods described or justified and appropriate?
- Some estimate of variance is reported for the main results?
- Controlled for confounding?
- Results reported in sufficient detail?
- Conclusions supported by the results?

Results

Study Selection

The search was conducted in the first week of March, 2021. In total, 2599 papers were found, and the study flow in accordance with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) methodology can be found in Figure 2 [29]. Most of the papers (2305/2599, 88.69%) found by the reviewers YvdS and RB were obtained from Google Scholar search. A total of 486 records were removed before screening, because they were published in a different language (n=54, 11.1%), they appeared more than once in the list (sometimes under a slightly different title; n=347, 71.4%), or for other reasons (n=85, 17.5%) such as not showing an author or having an illegible title. The resulting 2113 papers were screened on the text of the title and papers that did not clearly mention one of the search terms or a synonym in the title were excluded. In case of doubt, the abstract was consulted. This resulted in 204 papers that were subsequently screened by the reviewers for their abstracts. After screening abstracts, 26 papers were selected for full-text analysis. After full-text analysis, 8 papers that satisfied all the criteria were included in this review. Multimedia Appendix 1 [29] and Multimedia Appendix 2 [29] present the PRISMA checklists.

Figure 2. Study flow.



Selected Studies

This review resulted in 8 selected studies. The study data are summarized in Table 1 and sorted by avatar. The average number of participants in the studies was 20 (SD 12).

Table 1. Selected studies.

Authors and title	Study design	Experiment population	Intervention	Human-agent interaction	Results	Agent image
Ali R et al [30]. Aging and engaging: A pilot randomized controlled trial of an online conversational skills coach for older adults.	Country: United States; study design: pilot randomized controlled trial; N=18; intervention and control group; study aim: to assess feasibility and acceptability of the VA[a]	N=18, 1 lost to follow-up; aged >60 years; having self-reported mild communication difficulties with social skills that could be attributable to memory problems	In the intervention group, the VA had weekly sessions with each participant, including three 2- to 3-minute open dialogues with the participant on a selection of general topics (eg, weather, pets, retirement, life goals, growing older, and spirituality). The control group was provided with videos.	The VA was a web-based application using computer system including camera and microphone from the participant's home to record participant utterances and expressions. Open dialogue included ASR[b] and TTS[c]. The ASR used a hierarchical tree to classify participant utterances and determine responses.	The system usability score was 69.5 on a 0-100 scale, where 68 was considered as "good" usability. Participants randomized to the VA demonstrated significantly fewer impairments in nonverbal communication at follow-up compared with the control group, whereas the results were nonsignificant for participants with verbal impairment.	Figure 3
Razavi et al [31]. Dialogue design and management for multisession casual conversation with older adults. Precursor study to Ali R et al [30].	Country: United States; N=8. Evaluative study aimed at older adults where each participant had a 10- to 20-minute conversation with the VA. The system was designed for geriatric patients and with input from gerontologists. Study aim: examination of conversation quality.	N=8; older adults. No details given.	Have a short conversation on several topics, categorized as easy, medium, and hard. They covered 30 themes among which were hobbies, weather, cooking, life goals, and spirituality. Average duration was a few minutes with 3-5 turns; no details given.	A 2-way interaction; VA asks question or reacts on participant response [1].	Participants were asked to score 4 variables on a 5-point scale from strongly disagree (1) to strongly agree (5). Ease of use was scored as 4.3, learnability as 3.9, confidence in using as 4.3, and user-friendliness as 4.6.	Figure 4
Wargnier et al [24]. Usability assessment of interaction management support in LOUISE[d], an ECA[e]-based user interface for elders with cognitive impairment.	Country: France; feasibility study; N=14; no control group. Study aim was usability assessment of the LOUISE system.	N=14; aged >65 years; diagnosed with cognitive impairment	VA asked participant to perform 4 tasks: drink water, take a pill, measure blood pressure, and select meal. Participants could choose between 2 VA embodiments: "Louise" (left image) and "Charlotte" (right image).	The VA questions were provided verbally. Participants could verbally answer with "yes" or "no." Microsoft Speech ASR was used.	All but one participant could interact with LOUISE. Of the 14 participants, 11 completed the 4 scenarios, but from these 11 situations, only 1 was conducted "in WoZ mode," and 1 showed sensor failures. Thus, ultimately data from 9 participants were available. Participants often forgot they could only say "yes" or "no." ASR error rate was 20%.	Figure 5
Tokunaga et al [32]. Virtual caregiver: Personalized smart elderly care.	Country: Japan; feasibility study; N=11; no controls.	N=11; 9 women; older inhabitants of the daycare center	VA conducted greeting, confirmation of basic personal information, quiz, and playing music. Measurement was done using a 10-question usability score between 1 and 4. Design of the avatar was similar to Tokunaga et al [19].	The VA makes statements and asks questions. The paper does not provide details on the user input types. No description of NLP[f] function was given.	Average usability score was 3.58. Participants found playing music as especially useful.	Figure 6

Authors and title	Study design	Experiment population	Intervention	Human-agent interaction	Results	Agent image
Tokunaga et al [19]. Implementation and evaluation of interactive memory-aid agent service for people with dementia. Related to Tokunaga et al [32].	Country: Japan; exploratory study; N=17. Study aim was to confirm that the patients could interact with the agent service using some interactions (eg, voice or touch).	N=17; older adult patients, aged 46-84 years, 12 women. Mean MMSE[g] 22.9, meaning some cognitive impairment.	A nondetailed scenario in which participant had to perform certain tasks upon verbal instruction of the VA. The participant could respond by voice or by touch button.	VA asks questions, and the participant reacts. No details were provided. NLP characteristics were unclear.	Participants did not always hear the agent because of hearing impairments or microphone quality. Touch button operation was difficult for the older adults not accustomed to smartphones or tablets. VA did hear the patient only after a second utterance. Patients were sometimes surprised and did not know what to do if the system did not react as expected.	Figure 7
Tsiourti et al [33]. A virtual assistive companion for older adults: design implications for a real-world application.	Countries: Switzerland, Portugal, and the Netherlands; N=20; design: longitudinal evaluation study; goals: to examine empirically interaction with ECA at home and explore ECA acceptance, perceived usability, and usefulness.	A total of 24 older adults living at home with average age of 77.9 years in 2 countries: the Netherlands (N=11) and Switzerland (N=13). In Netherlands, the number of dropouts was 4.	In the Netherlands, researchers visited participants for joint sessions with the VA 2-3 times a week. System user options were tried in no specific order or method but included reminders and memory programs. Detailed use scenarios on Switzerland were unclear, participants seemed to use the system autonomously.	The users interacted with the companion using a multimodal interface including automatic speech recognition and a graphical touch-based user interface menu (messages and agenda). ASR used Kinect for Windows SDK[h] to perform speech recognition for predefined speech commands that the users had to remember.	Empirical findings were problems with speech recognitions, remembering of user interaction options by participants, and the nonintuitiveness of the user interface. Acceptance was "well received." Usability was 62.2 for participants from Switzerland and 52 for those from the Netherlands on an unspecified scale. Usefulness in participants from the Netherlands was not reported and in participants from Switzerland as 2.3-2.5 on a scale of 0 to 5.	Figure 8
Jegundo et al [34]. Perceived usefulness, satisfaction, ease of use, and potential of a virtual companion to support the care provision for older adults.	Country: Portugal; observational study; N=46.	Target group was older adults needing formal care. Convenience sample of older adults in day-care centers; 34 women, 12 men; mean age 63.6 (SD 20.5) years.	All interactions were by touch; only interaction on "News" was by voice. Sessions were all witnessed by researchers.	VA responded verbally by "News" commands ("Open news" or "Read news"). All other interactions were through touch buttons (play game or show agenda).	CaMeLi[i] presents a good degree of usefulness, satisfaction, and ease of use. CaMeLi was a barrier to 11 participants and a facilitator for 35 participants.	Figure 9

Authors and title	Study design	Experiment population	Intervention	Human-agent interaction	Results	Agent image
Oliveira et al [35]. A multiplayer voice-enabled game platform for the elderly.	Country: Portugal; design: quiz game with VA as host; n=21; no control group; study aim: feasibility	A total of 2 groups: "Young" (aged 24-28 years; n=4) and "Elder" (aged 59-88 years; n=17); divided into 2 subgroups: "tested at home" (n=9) and "tested at the senior university" (n=8). Target group comprised people with dementia, but cognitive status of participating older adults was not described.	Participants had to answer quiz questions by a web-based quiz host. Answers could be open answers.	ASR and TTS were developed at the university laboratory. A 2-way spoken question and answer was used. VA used was a passive cartoon.	Participants enjoyed the game and were stimulated to interact with each other.	Figure 10

[a]VA: virtual agent.

[b]ASR: automated speech recognition.

[c]TTS: text-to-speech.

[d]LOUISE: Lovely User Interface for Servicing Elders.

[e]ECA: embodied conversational agent.

[f]NLP: natural language processing.

[g]MMSE: Mini Mental State Examination.

[h]SDK: software development kit.

[i]CaMeLi: Care Me for Life.

Figure 3. Agent by Ali et al [30].

Figure 4. Agent LISSA (Live Interactive Social Skills Assistance) by Razavi et al [31].

Figure 5. Agent Louise (left) and Charlotte (right) by Wargnier et al [24].

Figure 6. Virtual caregiver by Tokunaga et al [32].

Figure 7. Agent by Tokunaga et al [32].

Figure 8. Agent Mary by Tsiourti et al [33].

Figure 9. Agent by Jegundo et al [34].

Figure 10. Agent by Oliveira et al [35].

A total of 3 studies might have been included but on detailed consideration have been excluded. Parsons et al [36] reported on a human avatar that is portrayed as a physician and conducts a neuropsychological assessment. However, this was not explicitly aimed at older adults with memory problems, and the verbal interaction description lacked details to judge the dialogue form. In all, 2 studies reported the recording of human utterances in response to an avatar interview question, which were subsequently analyzed offline on the prevalence of cognitive impairment [37,38]. Therefore, they were not considered real dialogue.

Study Quality Evaluation

The results of the quality assessment are presented in Table 2. The average quality score was 0.69 (SD 0.08).

Table 2. Scores of methodological quality assessment of the included studies.

	Ali et al [30]	Razavi et al [31]	Wargnier et al [24]	Tokunaga et al [32]	Tokunaga et al [19]	Tsiourti et al [33]	Jegundo et al [34]	Oliveira et al [35]
Objectives	2	1.5	1	1	1	1	1.5	1.5
Study design	1.5	1	1.5	1.5	1.5	2	2	1.5
Method	2	1.5	1	0.5	0.5	1	1.5	1.5
Participants	2	0.5	1.5	1	1.5	1	1.5	1.5
Random allocation	1	N/A[a]	N/A	N/A	N/A	N/A	N/A	N/A
Blinding investigators	2	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Blinding participants	0	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Outcomes	1.5	2	0.5	2	1	1.5	1.5	0.5
Sample size	1	1.5	1.5	1	1.5	1.5	1.5	1.5
Analytic methods	1	N/A	N/A	N/A	1.5	N/A	1.5	2
Variance estimates	2	2	1	1	N/A	N/A	2	1
Confounding controls	1.5	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Results reporting	1.5	2	1.5	2	2	1	1.5	1
Conclusions	1.5	1.5	1	1	1	1.5	2	1.5
Total	20.5	13.5	10.5	11	11.5	10.5	16.5	13.5
Maximum score	28	18	18	18	18	16	20	20
Summary score	0.73	0.75	0.58	0.61	0.64	0.66	0.83	0.68

[a] N/A: not applicable.

Discussion

Principal Findings

Despite the fact that IVAs have been a topic of study since 1998, the number of studies that actually show a 2-way verbal interaction with older adults with amnesia is relatively low, and only 8 studies were found. One of the main bottlenecks is the quality of the speech-to-text function. For example, Sidner et al [39] described this function as *a technical challenge*, and therefore chose touch buttons on a screen as human input means to the virtual agent. Several other studies followed the same approach and were not included in this review.

In the studies found, it was particularly difficult to assess participants' perception of verbal interaction. In 4 studies, the user could only give yes or no or a few other short commands [24,33,34,40]. The user verbal command options in the studies by Tokunaga et al [19,32] were unclear. Only the studies by Ali et al [30] and Razavi et al [31] report a short (3-5 turns) open dialogue on a range of topics such as *weather, pets, retirement, life goals, growing older, and spirituality.* A total of 9 studies also provided little information on their NLP pipeline. Ali et al [30] and Razavi et al [31] designed a pattern-matching solution based on *gist-clauses*, which are a combination of the IVA question and the answer received. Wargnier et al [24] and Tsiourti et al [33] used Microsoft speech recognition components for speech recognition, and the utterance text strings were matched with predefined commands. Oliveira et al [35] used an in-house developed speech recognition subsystem. In addition to this information, a few other details are provided that allow us to compare the advantages and disadvantages. The other 3 studies did not provide any information regarding the NLP pipeline. However, all 8 studies reported a generally positive attitude of the participants toward the agent. Video recordings would have been helpful in assessing the details of human-agent interaction.

The main qualitative outcome reported in these studies was the usability of the system. This usability was measured differently between the studies, and the methods and data are provided in Table 3. Ali et al [30] and Jegundo et al [34] used the well-known System Usability Scale [40]. Wargnier et al [24] and Tsiourti et al [33] did not use existing usability questionnaires from the literature, such as the System Usability Scale, but created new usability questionnaires. The studies by Tokunaga et al [19,32] were more oriented toward the functional performance of the agent, whereas Oliveira et al [35] did not report clear usability measurement methods and results. A comparison between the usabilities is difficult to make because of the difference in the methods and scales used. The difference in scales also does not allow us to calculate an aggregated mean value of the usability for the studies combined. Furthermore, the reason for the relatively low number of participants (μ=20) is probably the explorative or feasibility assessment character of the studies found. A system usability study should preferably include between 20 and 30 participants [40]. Our hypothesis that IVAs designed to assist older adults with memory problems have a positive usability, given the data from the table, indicates that there is reason to believe that it is true.

Table 3. Comparison between usability scores.

Reference	Usability
Ali et al [30]	Mean 4.17 (SD 0.68) on a scale of 1 to 6, where 1=awful, 2=poor, 3=okay, 4=good, 5=excellent, and 6=best imaginable
Razavi et al [31]	Mean 4.33 (SD 0.67) on a scale of 1 to 5 ("strongly agree" to "strongly disagree")
Wargnier et al [24]	Pleasantness: mean 3.38 (SD 0.43); ease of following instructions: mean 3.38 (SD 0.47) on a scale of 1 to 4
Tokunaga et al [32]	Experimental questionnaire: 1=lowest, 4=highest; mean 3.58 (SD not given)
Tokunaga et al [19]	No quantitative usability data
Tsiourti et al [33]	Usability: mean 62.2 for Switzerland and mean 52 for the Netherlands on an unspecified scale (SD not provided)
Jegundo et al [34]	USE[a] questionnaire from Lund [41]; 7-point Likert scale; total score 5.06 (SD 1.10) on a scale of 1 to 7
Oliveira et al [35]	No quantitative usability data

[a] USE: Usefulness, Satisfaction, and Ease of Use.

Other outcome data reported were *efficacy of nonverbal improvement* (1/8, 13%), *efficacy of verbal improvement* (1/8, 13%), *conversation quality* (1/8, 13%), *feasibility of interaction* (2/8, 25%), *observer usability assessment* (1/8, 13%), *critical incident registration* (1/8, 13%), and *speech recognition quality* (2/8, 25%). The reported values were difficult to combine at an aggregated level and to make them result in a general recommendation.

All agents found in this review were female characters, except for one. Studies from Western countries show *white-skinned* agents with varying hair colors and ages and a realistic look, whereas studies from Japan feature an anime-influenced character with a Japanese female look. These papers provide little information on facial muscle motions and lip synchronization when talking. Of the 8 studies, 5 (63%) showed mainly the head and shoulders of the agent, whereas the remaining 3 (37%) studies showed almost the complete agent body.

The duration of the interactions between the participant and the agent was relatively short, with a few turns per topic. These studies provide little information on the exact duration and how and when the interaction was stopped. These studies were concentrated in the United States (2/8, 25%), Europe (4/8, 50%), and Japan (2/8, 25%). No studies from China or Korea were found; however, this may be because of the selection of papers in the English language.

Reports on the cognitive status of the participants vary in the 8 studies. For 5 (63%) of the 8 studies, no related details were given, 1 (13%) study included participants with self-reported mild difficulties, 1 (13%) study included participants diagnosed with mild cognitive impairment, and 1 (13%) study conducted a Mini Mental State Examination among the participants. The latter study reported an average Mini Mental State Examination score of 22.9, consistent with mild dementia and a relevant target group for an intervention with a virtual agent.

According to our assessment, the quality of the studies varied between 0.58 and 0.83. Kmet et al [28] did not specify an absolute value for these outcomes, for example, in the sense that papers could be classified as having a good or bad methodological quality based on that value. Nevertheless, the overview in the study quality evaluation section of this paper enables comparison between the included studies. Although the study objectives and design were generally clear, only 1 (13%) of the 8 studies included a random allocation of participants to separate conditions [30]. The average number of participants in the studies (n=18) was rather low, and most articles seemed to focus more on the technical development of the system than on a thorough user evaluation. Moreover, verbal interactions were generally short. Most studies also lacked control of confounding parameters.

The results of this study, in terms of the number and scope of the studies found, were compared with the findings of relevant reviews mentioned in the *Introduction* section of this paper. The observation from Car et al [16] that there is a predominance of text-based conversational agents, with only a few apps using speech as the main mode of communication, remains valid. Although speech is considered a comfortable interaction modality for older adults, the difficulty of realizing free speech-based interaction with an agent is still present.

Xie et al [12] called for more systematic designs and evaluations of AI systems, and this is supported by the results herein showing a limited number of experimental studies targeting older adults with memory problems. Schachner et al [13] also found that the number of studies is scarce and mostly quasiexperimental, and Bevilacqua et al [15] concluded that the number of studies should increase.

For further research, it would be useful to evaluate IVAs, as shown in Figure 1, targeting people with other health conditions. For example, Laranjo et al [17] found 2 studies, one for military personnel with PTSS and one on training for people with autism spectrum disorders. Provoost et al [20] reviewed embodied conversation agents in clinical psychology, targeting individuals with autism, depression, anxiety, PTSS, schizophrenia, and substance abuse. Milne-Ives [22] discovered virtual agents for alcohol counseling, depression, and suicide prevention.

Regarding the design features of the virtual agent, Loveys et al [21] provided input for the design process by evaluating requirements for language use, behavior, emotional expression, embodiment, appearance, and personality. These findings may be considered when developing future virtual agents for people with amnesia.

Limitations

This study has some limitations. Although the authors made an effort to screen the titles, abstracts, and papers carefully and applied a snowball method to identify additional studies by checking the references in selected papers, we do not exclude the possibility that some studies were overlooked. Second, in many studies, the actual implementation of the dialogue and the information exchange was difficult to assess. Third, many studies describe only the requirements or designs of virtual agents but provide no or very little information on the experiments conducted. Such studies were excluded, but we cannot rule out that, by doing so, relevant studies were missed. Fourth, *memory problems* is used in this paper as an umbrella term for the more formal terms dementia, Alzheimer, amnesia, or mild cognitive impairment, but was not used as an explicit search term, and this may have caused that a study was overlooked.

Conclusions

Few studies have described actual experiments with IVAs in dialogue with older adults with memory problems. The dialogue contents are quite simple and superficial, especially on part of the participants, and often limited to only *yes* or *no*. More research is needed to develop real, useful, and prolonged dialogue between virtual agents and older adults. Another conclusion is that more research into the effectiveness of IVAs is needed, for example, through randomized controlled trials.

The reporting on the human-agent interaction characteristics often lacks many details, such as the exact contents of the dialogues, the starting and ending of the dialogue, and the graphical features of the avatar (static and dynamic). This makes it difficult to compare the experiments and to assess the status of the applied technology. A more standardized approach toward reporting human-agent interaction characteristics would be helpful for future research. Audio and video recordings of such interactions would provide even more information that will benefit the research community.

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Authors' Contributions

RB conceptualized the study and methodology, performed the formal analysis (review of papers) and investigation, and was involved in writing the original draft. YvdS performed the formal analysis (review of papers) and investigation and was involved in the review and writing of the manuscript. ST performed the formal analysis (quality assessment) and investigation and was involved in the review and writing of the manuscript. TB received the funding and was involved in the methodology, formal analysis (quality assessment), investigation, and review and writing of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA (Preferred Reporting Item for Systematic Reviews and Meta-Analyses) checklist.
[PDF File (Adobe PDF File), 139 KB - aging_v5i2e32473_app1.pdf]

Multimedia Appendix 2
PRISMA (Preferred Reporting Item for Systematic Reviews and Meta-Analyses) abstract checklist.
[PDF File (Adobe PDF File), 45 KB - aging_v5i2e32473_app2.pdf]

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Abbreviations

AD: Alzheimer disease
AI: artificial intelligence
IVA: intelligent virtual agent
NLP: natural language processing
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PTSS: posttraumatic stress syndrome

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Review

Inclusion of Older Adults in Digital Health Technologies to Support Hospital-to-Home Transitions: Secondary Analysis of a Rapid Review and Equity-Informed Recommendations

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Abstract

Background: Digital health technologies have been proposed to support hospital-to-home transition for older adults. The COVID-19 pandemic and the associated physical distancing guidelines have propelled a shift toward digital health technologies. However, the characteristics of older adults who participated in digital health research interventions to support hospital-to-home transitions remain unclear. This information is needed to assess whether current digital health interventions are generalizable to the needs of the broader older adult population.

Objective: This rapid review of the existing literature aimed to identify the characteristics of the populations targeted by studies testing the implementation of digital health interventions designed to support hospital-to-home transitions, identify the characteristics of the samples included in studies testing digital health interventions used to support hospital-to-home transitions, and create recommendations for enhancing the diversity of samples within future hospital-to-home digital health interventions.

Methods: A rapid review methodology based on scoping review guidelines by Arksey and O'Malley was developed. A search for peer-reviewed literature published between 2010 and 2021 on digital health solutions that support hospital-to-home transitions for older adults was conducted using MEDLINE, Embase, and CINAHL databases. The data were analyzed using descriptive statistics and qualitative content analysis. The Sex- and Gender-Based Analysis Plus lens theoretically guided the study design, analysis, and interpretation.

Results: A total of 34 studies met the inclusion criteria. Our findings indicate that many groups of older adults were excluded from these interventions and remain understudied. Specifically, the *oldest old* and those living with cognitive impairments were excluded from the studies included in this review. In addition, very few studies have described the characteristics related to gender diversity, education, race, ethnicity, and culture. None of the studies commented on the sexual orientation of the participants.

Conclusions: This is the first review, to our knowledge, that has mapped the literature focusing on the inclusion of older adults in digital hospital-to-home interventions. The findings suggest that the literature on digital health interventions tends to operationalize older adults as a homogenous group, ignoring the heterogeneity in older age definitions. Inconsistency in the literature surrounding the characteristics of the included participants suggests a need for further study to better understand how digital technologies to support hospital-to-home transitions can be inclusive.

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KEYWORDS

older adults; digital technology; transitions; older adult population; digital health; Digital Hospital; health intervention; aging; gender diversity; home transition; epidemiology

Introduction

Background

Transitioning across health care settings is a complex experience for older adults and their caregivers [1,2]. Older adults [3] and family caregivers (ie, family members, friends, or neighbors) who provide unpaid assistance or care to someone living with an injury, disability, or illness [4] frequently experience unmet care needs as the patients leave the hospital and transition to home [5-10]. Transitions in care are often more difficult for older adults who experience frequent hospitalizations and are often discharged with ongoing and complex care needs exceeding those that existed at the initial hospitalization [11,12]. Thus, researchers have urged integrated care strategies to better meet their care needs after hospitalization [12]. Here, we define integrated care as “the promotion of the comprehensive delivery of quality services across the life-course, designed according to the multidimensional needs of the population and the individual and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care” [13].

Unsupported hospital-to-home transitions can result in adverse events, such as medication-related problems (eg, harmful drug effects) [14], readmissions to hospitals [15], lack of continuity of care [16], and even mortality [17,18]. To help overcome challenges during this transition period, older adults and their family caregivers attempt to develop, integrate, and use knowledge and skills to manage transitions in care settings and related changes in illness trajectories [19]. Improving transitions in care can help improve the quality and cost of care and promote more equitable care for vulnerable older adults [20]. An emerging area of research is the use of technology to help support hospital-to-home transitions for patients and their family caregivers [2,20-22].

Technological advances may help integrate health and social care in at-risk populations [23]. Technologies aimed at improving health outcomes for older adult populations as they transition across care settings have demonstrated success and promise [20,24-28]. Technologies to support care transitions can increase access to support for older adults as they transition from hospital-to-home by reducing architectural and physical barriers to accessing care in the community [20,29,30]. Other benefits of technology in supporting care during transitions include eliminating barriers to attending in-person support programs, such as restricted mobility, time constraints, transportation costs, and a lack of respite care for individuals caring for others [31].

Spurred by the COVID-19 pandemic, as face-to-face care options became less available initially, health systems and providers turned to digital tools as an alternate means of supporting older adults and families [32-34]. During this *digital revolution* [35], there has been increasing attention to whether or how health technologies support equitable access and use for all older adults who may benefit [36,37]. The rapid virtualization of health and social care to support hospital-to-home transitions poses a risk to access and equity and may create structural inequalities [38].

Older adults may be most vulnerable to inequitable access to and use of digital health technologies, given their overall lack of use of existing technologies [39]. Barriers to using technology for older adults include lower levels of digital literacy, lack of perceived usefulness, and physical and cognitive deficits that may make using digital tools challenging [40]. Similarly, previous studies have shown that older adults are overlooked in technological health research [41,42]. Barriers to technology use are even more prevalent in older adults from racial or ethnic minorities and socioeconomically disadvantaged groups [43]. Therefore, an equity-informed review of existing programs is required to create equity-informed guidelines to guide future development, delivery, and implementation of technologies to support hospital-to-home transitions for older adults. In the context of human experiences, including experiences with transitions in case, experiences are shaped by multiple social positions [44,45]. Moreover, a *one-size-fits-all* approach to transitional interventions may not work well for all people, of all social identities, given the high adverse events during transitional periods among persons from minority groups (eg, racial minority groups [46] and nonheterosexual individuals living in poverty [47]). Researchers have a growing interest in examining intersectionality in qualitative and quantitative research [44]. By including both qualitative and quantitative research in our review and noting how well the characteristics of particular groups have been reported, we hope to provide direction for future studies to better examine the multiple social positions left out of digital transitional care intervention research. Despite growing awareness of digital inequity, there are current knowledge gaps related to intersectionality and transitions, particularly within digital health interventions [48]. Addressing these knowledge gaps is a priority for the digital bridge intervention currently being developed by our research team [2,49]. Moreover, our results will provide recommendations that will inform the design and structure of other future digital health interventions that support hospital-to-home transitions for older adults.

Objectives

To help inform recommendations for future technologies to assist with hospital-to-home transitions for older adults, we conducted a secondary analysis of a rapid review of existing technologies. The protocol for this broader review has been published elsewhere [21]. The initial review mapped the published literature on studies that tested digital health interventions to support hospital-to-home transitions. This review included all relevant interventions with samples of at least one older adult for comprehensiveness. Preliminary findings from the review indicated that less than one-fifth of the included studies were conducted exclusively with older adults and highlighted the need to explicitly examine interventions with older adults [21]. The broader review did not consider sex nor gender in its analysis, nor any other intersectional factors that influence participation in digital technology interventions. A secondary analysis focusing on sex, gender, and other intersectional factors was not part of the planned protocol [21]. Thus, the purpose of this secondary analysis was to (1) identify the characteristics of older adults targeted by studies testing the implementation of digital health interventions to support hospital-to-home transitions; (2) identify the characteristics of the samples included within studies testing digital health interventions to support hospital-to-home transitions; and (3) create recommendations for enhancing equity, diversity, and inclusion in future digital health intervention research. The specific research questions for this secondary analysis were as follows: “What are the targeted populations within existing digital health interventions supporting hospital-to-home transitions?” “What are the actual participants within existing digital health interventions supporting hospital-to-home transitions?”

Methods

Design

A rapid review was deemed appropriate, given the need to generate timely recommendations for future digital health interventions, as the COVID-19 pandemic has prompted an immediate need for novel technological supports [21,50,51]. Consistent with prior studies that conducted a secondary analysis of reviews [52-54], a secondary analysis entailed reexamining relevant data to answer different research questions and addressing knowledge gaps identified in the initial review [55]. We used modified and hybrid guidelines for rapid reviews [56] and the systematic guidelines of Arksey and O’Malley for scoping reviews [57,58]. This approach was deemed appropriate because scoping reviews allow for an iterative approach to data collection and analysis, whereas rapid reviews allow a timely synthesis of the existing literature. For example, we limited the search to select databases and conducted this review in a short period [59]. Our 5-stage rapid scoping review model included (1) identifying the research question, (2) identifying relevant studies, (3) selecting studies, (4) charting data, and (5) summarizing and reporting the results [58]. In the remainder of this section, we outline the specific steps undertaken to complete the review. As this secondary analysis aimed to answer different research questions than intended within the published protocol, the methods used in this study necessitated some deviations from the original protocol, as described in the following sections [21].

As there are no reporting guidelines for rapid reviews, we relied on elements of the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) Protocols checklist as a guide for reporting this review [60].

Theoretical Framework

This study was theoretically informed by a Sex- and Gender-Based Analysis Plus (SGBA+) lens [61]. The SGBA+ lens has been applied in the context of other reviews in health research [62,63]. As a theoretical framework, SGBA+ draws on intersectionality frameworks. Other intersectional frameworks include the Theoretical Domains Framework [64] and intersectionality-based policy analysis framework [65]. However, SGBA+ was specifically chosen, as it allowed researchers to examine sample characteristics within research processes and data, including biological sex and the multiple social positions that older adults hold (eg, ethnicity, income, age, race, education, and gender) to determine whether intervention findings are relevant to the needs of all older adults [61,66]. For this review, sex is defined here as a biological construct. In contrast, gender is defined as a social construct that refers to the socially prescribed dimensions of being a *female* or *male* [67].

This review explores how existing digital health interventions supporting hospital-to-home transitions represent sex, gender, and identity perspectives within their target and actual samples. These insights can be used to create equity-informed recommendations for future digital health interventions.

Identifying the Research Question

The widespread shift to digital health during the COVID-19 pandemic has revealed digital equity to be a critical issue [38]. During the analysis phase of the larger rapid review [21], we identified the need to re-examine the data for identification.

Identifying Relevant Studies

Relevant literature on digital health solutions currently applied to facilitate the transition from hospital-to-home for older adults was searched for as part of a larger review. A comprehensive, peer-reviewed search was created by an experienced information specialist in consultation with the research team and translated by the information specialist to MEDLINE (Ovid), CINAHL, and Embase (Ovid). The search was run on these databases by HC on November 26, 2020, for the larger review. In addition, the reference lists of 20 included articles were examined, and 6 content experts were consulted to identify additional studies for the larger review.

For this analysis, KMK and HS reran this search on September 20, 2021, using established guidelines [68] to ensure articles are up-to-date. KMK and HS used the same search strategy reported in the published protocol, including concepts related to *digital health*, *navigation*, and *transition of care from hospital to home* [21]. New (unique) articles retrieved from the updated search were reviewed as described in the following sections.

Selecting Studies

Studies were included in the larger review [21] if they (1) empirically tested a digital health intervention and (2) supported a hospital-to-home transition (ie, continued from the hospital-to-home or community settings). The intervention had to be (3) tested with older adults (aged ≥65 years) who were recruited before their hospital discharge, (4) conducted in high-income countries [69], and (5) published in English in or after the year 2010 [21]. No limitations were imposed on the study design. The larger review was limited to interventions conducted in high-income countries for two reasons: digital and health infrastructure and resources can differ between high- and low-income countries, and the intent of the primary review was to provide recommendations for the digital bridge (a digital health intervention currently under development) [21,70]. As per the protocol, studies were excluded if the hospital setting was ambulatory (eg, emergency department visits) or if the discharge destination was an institution (eg, long-term care) [21]. We deviated from the protocol by limiting this review to technological interventions that are not strictly telephone based, given the extensive investigations and syntheses of telephone-based health interventions [71-75]. We also reduced the age of older adults to ≥55 years to be comprehensive to ensure *young old* adults are included [76].

As per the published protocol [21], study selection within the larger review used a single screener strategy after minimum interrater reliability was achieved (κ=0.80) during the title and abstract screening phases (ie, reviewed titles and abstracts together). Owing to the complexity of the inclusion criteria and limited information in titles and abstracts, we only screened for inclusion criteria 1, 4, and 5 during the title and abstract screening, whereas the remaining were screened for full-text review [21]. Interrater reliability was not reexamined during the full-text review stage, as we decided that 2 reviewers (KMK and HS) would independently screen articles at this stage because the papers had already undergone rigorous screening and interrater calculations. This secondary analysis did not need to be screened, as the purpose was to conduct an additional analysis to explore a question not addressed in the original study.

The study selection for this secondary analysis was modified from the published protocol to enhance comprehensiveness. The first author (KMK) independently reviewed the titles and abstracts of articles excluded from the larger review on August 31, 2021, to ensure that no potential article was missed with the single screener approach. However, no additional relevant articles were identified. After the search was updated for this review, 4 authors (KMK, DP, CMJ, and HS) reviewed the titles and abstracts (ie, 2 reviewers independently screened each article) over a 3-week period. After screening all titles and abstracts, 2 individuals (KMK and HS) reviewed articles from the initial full-text review and the updated search over an additional 3-week period. Team discussions, led by the senior author (HS), were used to resolve conflicts for both searches (ie, discrepancies in inclusion and exclusion and reasons for exclusion) until 100% agreement was obtained. Covidence software was used to facilitate the screening process [77].

Charting the Data

The first author extracted data from the included articles using a modified form from the larger study. Extracted data included the study characteristics (ie, author, year, country, and design), details of the study inclusion criteria (ie, target sample), and details of the participants (ie, actual sample). Next, a spreadsheet was used to categorize the studies into three categories informed by SGBA+: sex, gender, and other identity constructs. All extracted data were reviewed and verified by a second reviewer (HS) to enhance the data quality and accuracy. Data were collected over approximately 2 months.

Summarizing and Reporting the Data

Data were organized numerically using descriptive statistics and summarized using a narrative descriptive synthesis [78]. The narrative descriptive synthesis entailed the first and senior author mapping the findings into deductive themes informed by the SGBA+ framework, including sex, gender, geography, culture, age, and disability [61,66]. After coding all studies, the data were classified into 9 broad identity constructs. The constructs represented in this review included age, patient population, race and ethnicity, sex and gender, sexual orientation, education, disability, language, and technology access and comfort.

Results

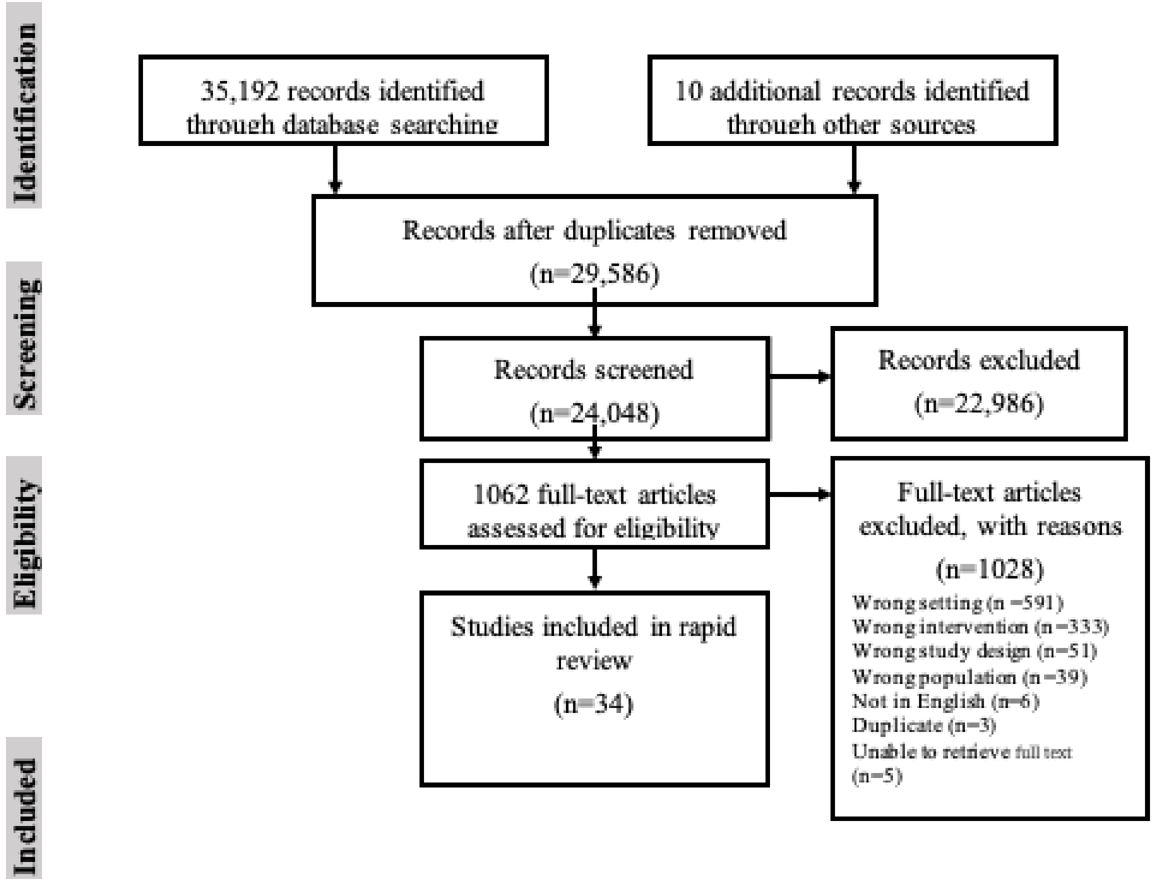
Overview

In total, 34 articles met the inclusion and exclusion criteria. The search process is outlined in Figure 1. A total of 16 studies were conducted in Europe [79-94], 12 were conducted in North America [3,73,95-105], 3 in Asia [106-108], and 2 in Australia [109,110]. Multimedia Appendix 1 shows the distribution of studies based on location. In addition, of 34 studies, 1 (n=1, 3%) study used qualitative methodology [111], 1 (n=1, 3%) study was a report [98], and another used a case study design (n=1, 3%) [81]. A total of 9% (n=3) of studies used a mixed methods methodology [3,87,96], whereas the remaining studies (28/34, 82%) used a quantitative methodological approach. Of the 28 quantitative studies, 8 (n=8, 28%) used a randomized controlled trial design [89,90,97,101,106,107,109,110]. Other quantitative studies have used observational or nonrandomized trial designs.

Across all studies, 9809 participants were included (mean 297 participants per study, range 1 [65] to 3661 [70], SD 383). Across the 8 randomized controlled trials, 4434 participants were included (sample size mean 986 per study).

A total of 7 studies reported smaller sample sizes because of particular inclusion and exclusion criteria and limitations of the interventions (eg, dropouts) [3,87,90,91,100,102,105]. However, a small sample size was a deliberate choice for scholars in 2 studies [3,100].

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram adapted from Moher et al [60].



Digital Health Interventions

Overview

Multimedia Appendix 2 [3,83-94,100-103,105-108,110,111] summarizes the breadth of the methodological characteristics, aims of the studies, and a brief description of the digital interventions in detail. Briefly, web-based, tablet, and mobile app tools are the most common means of delivering digital interventions [3,83-94,100-103,105-108,110,111]. Electronic health records and databases [79,81,95,97,98,102,104] have been widely used for digital innovation. The use of wearable body sensors or devices [80,99,107], web-based chatting platforms [82], and automated emails [109] were less common.

The focus of digital health interventions varied. For example, some were related to medication reconciliation [79,81,97,104], whereas others aimed at providing education (eg, about rehabilitative exercises), internet-based care, and resources [83,86,89,92,94,96,100,104-106,111] and improved communication and care coordination with older adults' care providers [3,82,91,104,108]. A total of 2 interventions aimed to improve communication processes among health care providers regarding discharge processes and care plans [93,109]. Many interventions aimed at monitoring bodily function and health status (including mental health) [80,84,85,88,90,94,99,101-103,107,110], often to alert members of the older adult's care team of the need to schedule follow-up appointments or calls to help prevent adverse effects [97,98]. One study used digital technology to support home-delivered meals [87].

Regarding the targeted samples in the studies, the minimum age for inclusion in 3 studies was 55 years [3,99,105]. Other studies required participants to have a minimum age of 60 to 65 years, except for one that used 70 [94] and 75 years [79]. Conversely, 2 studies had a maximum age of 75 [79,106] and 80 years [89]. Justifications for maximum ages were not provided. A total of 7 studies did not report on their targeted age but instead referred to geriatric patients [81,83,101,102,109,110] or "elders" [98]. Multimedia Appendix 3 [3,83-94,100-103,105-108,110,111] outlines the targeted populations of the included studies. It is worth noting that none of these studies specifically set out to include an analysis of heterogeneous groups of patients.

There was heterogeneity in the mean age of the participants included in the studies. The mean of age included older adult participants ranged from 65 to 69 years [83,99,105,111], 70 to 74 years [3,80,84,85,89,94,101,106,108], and 75 to 79 years [82,87,92,97,101] to 80 to 84 [86,88,90-93,96,104,107,109,110]. Only 2 studies had a mean age of ≥85 years [79,109]. A few studies did not specify the mean patient age [88,95,98,100,102,112].

The patient populations in all the studies included mainly frail geriatric patients or older adults. Only one study purposely examined older adults with cognitive impairment (ie, patients with mild cognitive impairment) and vascular cognitive impairment (eg, vascular dementia) [89]. In terms of their targeted population, many studies (n=14, 41%) excluded older adults with cognitive impairments [82, 84-86, 88-90, 92, 94, 101, 102, 105, 110, 111]. These studies excluded older adults who could not communicate because of cognitive challenges [107], postoperative delirium [112], and dementia [82,86,88,89,107].

Owing to the nature of our inclusion criteria, all patients were hospitalized, although the reasons for hospitalization varied. Hospitalizations included patients identified with nutritional risk (n=1, 3%) [87], chronic obstructive pulmonary disease (n=1) [88], heart failure (n=4) [88,90,94,101], diabetes (n=2) [81,105], and stroke (n=2) [3,83]. Two studies required participants to live with multimorbidity, defined as living with ≥2 chronic conditions [3,107]. One study included patients hospitalized for any nonelective reason [104]. A total of 14 studies included patients who underwent or had been scheduled for a surgical procedure [102], such as elective surgery [80], hip surgeries [82,86,92,96,108,111], total knee arthroplasty [106], oncological surgeries [84,85,100] (eg, lung or gastrointestinal cancers) [91], or cardiac or major vascular surgery [112]. The family caregivers of patients participated in 5 studies [96,100,102,107,110].

Racial, Ethnic, and Cultural Diversity in Digital Health Transition Interventions

Racial, ethnic, cultural, and religious diversity were rarely considered in the inclusion criteria or target sample.

A total of 23% (8/34) of studies described their actual sample's ethnicity, race, and culture [85,96,100,101,104,105,111,112]. The samples within all these studies were primarily White, except one, which included participants who were primarily Black (75% of the sample) [105]. This study also included 1 Asian participant (5%) [105]. In contrast, one of the studies dichotomized participants' race and ethnicity as *White* or *others* [100]. Participants were racially diverse in a study conducted by Choi et al [111], whereby participants were White (60%), African American (20%), Asian or Pacific Islander (7%), and Hispanic (13%). Similarly, in a study by Madigan et al [101], most of the sample was White, and the minority was African American (26%) [101]. Another study included participants who were White (68%), Hispanic (13%), Black (13%), and Asian (7%) [104]. Similarly, another study included African (15%) and Asian (4%) participants [112]. Multimedia Appendix 4 [3,83-94,100-103,105-108,110,111] describes the details of the participants (ie, actual sample). It is worth noting that none of these studies specifically set out to include an analysis of heterogeneous groups of patients.

Sex and Gender Diversity of Digital Health Transition Interventions

None of the articles aimed to recruit a specific sex or gender in their inclusion criteria or had sampled for both sex *and* gender diversity.

In their actual samples, the percentage of females (sex) in the studies ranged from 0% [81] to 100% [106]. All but 3 studies (n=31, 91%) [93,98,102] reported the sex of the included participants. One study had only females in the study [106]. One case study included only 1 male participant [81]. Most studies had almost equal proportions of males and females, with approximately 50% in each category [3,88,95,97,100] or proportions of sexes ranging between approximately 40% and 59% [79,80,91,99,105,107,111]. Most of the other studies had much higher (ie, ≥60%) proportion of females than males within the sample (n=15, 44%) [82, 86, 87, 90, 92, 96, 99, 101, 103, 104, 107-111]. A total of 18% (6/34) of studies had a higher proportion (≥60%) of males compared with females within the sample [80,81,84,85,89,94]. None of the studies reported on participants' gender identities or representations of gender-diverse older adults.

Sexual Orientation

Sexual orientation was not reported in the inclusion criteria or the sample of any of the included studies.

Education

Education level or literacy was a requirement for participation in 3 studies. One had limited inclusion to "those with junior high school-level education or higher" [108], and the others had limited inclusion to "school attendance >3 years" [89] and "low-literate older adults" [111].

A total of 8 studies reported the educational level of the sample [85,87,89,96,100,105,111,112]. Of these studies, 2 reported the length of education (between an average of 8-10 years [87,89]), but they did not report the educational details (eg, level and type of education). Of the remaining studies, 5 primarily included participants with an educational level of high school or less [85,96,105,111,112]. Participants with predominantly higher-level education, such as college, university, or graduate training, have been reported in a few studies [96,100,105,111,112].

Disability

A few studies excluded older adults with sensory or communication impairments (eg, severe aphasia or hearing loss) to ensure their ability to use the technology [83-88, 102, 106-108, 111] and vision [84-86,88,89,102,106,111]. Studies have also excluded older adults with arthritis [106] and neurological disorders [106]. A total of 21% (7/34) of studies excluded older adults with life-threatening illnesses [86-88,92,99,104,107]. Having a good health status or efficient disease control was a requirement in some studies [101,106]. Older adults with psychological conditions (eg, depression) were excluded from some studies [82,83,88,89]. Older adults with stroke were excluded from 6% (2/34) of studies [86,89]. Finally, studies excluded older adults using a wheelchair [99], severe ambulatory impairment [84,85], or inability to walk independently with a gait aid [86].

Language

The participants' language proficiency was not discussed in the actual sample. However, some studies identified language as an inclusion criterion, but the reasons were not specified. Specifically, English-speaking proficiency was required in 20% (7/34) of the studies [3,96,100,103,105,110,111]. Other language requirements included Dutch [84,85], Italian [89], Danish [86], and Swedish [83,88]. It is worth noting that these were the primary languages of the countries in which these studies were conducted.

Technology Access and Comfort

Although some studies required participants or a caregiver to have internet access in their home [84,85,92] or working telephone line [101,102,108,110], access to the internet or device was not a requirement in all studies [86]. For example, Backman et al [96] provided participants with a loaner device if they did not have access to a mobile phone or computer. Similarly, because of low recruitment, the inclusion criteria were broadened in 2 studies to include those who did not have a phone [84,85].

Some studies included those with low technical literacy, providing training on device use and assistance with device setup [80,86,96,103,107,111]. However, others require participants to have technical literacy, including the capability to use [84,85,87,107] or familiarity with the tested device [82,106].

Discussion

Principal Findings

To our knowledge, this is the first rapid review to synthesize the characteristics of older adults (aged ≥55 years) within digital health interventions supporting hospital-to-home transition using an equity lens. Specifically, we described the target and actual sample characteristics of the 34 studies. Our findings indicate that many older adults were not recruited within these interventions and remain understudied (eg, older adults with cognitive impairment and oldest older adults). This study relied on an intersectionality framework to understand how different social identities influence participation in digital health interventions to improve hospital-to-home transitions and, in turn, the digital divide. On the basis of the study findings, we created a list of research implications to enhance the consideration of equity variables to ensure meaningful participation for diverse groups of older adults within the target and actual samples of digital health interventions (Multimedia Appendix 5).

We noted variability across studies in the age groups of older adults who were targeted and, in turn, who were included in the studies. It is well known that the hospitalization experiences and subsequent health and social service needs of older adults differ significantly depending on age [113-116]. Some studies did not specify a target age group of older adults [81,83,98,101,102,109,110] and recruited participants based on setting or program (eg, aged acute ward [109] and geriatric ward [102]). However, others were limited to a maximum age of 80 years [89]. However, justification within studies limiting the maximum age was poor.

The theorization of *fourth age* typically starts around age 80 years (when studies cut older adults off) and is seen as a time of dependence in which additional care needs may be needed [115], which inevitably translates into differing needs among older adults and requires important consideration for future intervention development. Thus, we used an equity-informed lens to identify older adults aged >80 years as an understudied group. Others have also noted this gap in the literature; thus, older adults aged >80 years should be considered in future digital health interventions [117].

In addition to age, 2 studies required older adults to have a *good health* status because of the perceived ability of the researcher to use technology [83,102]. Many studies have excluded older adults with cognitive and functional impairments or a poor health status. Older adults with poor health status have worse outcomes during transitions in care than the general older adult population [118]. Thus, excluding older adults with a poor health status may result in greater health inequities [48]. Furthermore, this limits the transferability of evidence to practice, given the high number of older adults with dementia and other comorbidities requiring hospitalization and returning home [119]. An equity perspective taken by our review elucidates the need for future research to consider how interventions can be designed for or adapted to understudied groups of non–English-speaking older adults with poor health from racial and ethnic minority groups [120], as these groups may be most vulnerable to adverse events during hospital-to-home transitions [120-123].

In addition, many studies have limited their interventions to older adults with access to and comfort with technology. This criterion runs the risk that novel technologies to support hospital-to-home transitions are exclusionary rather than inclusive of the older adults they aim to help. Older adults often face numerous barriers to the effective use of technological interventions because of a lack of access to and experience and skills with digital tools [124,125]. In addition, older adults with lower socioeconomic status have reduced access to digital resources and may be unable to afford the technology or internet required to use digital tools [126]. Socioeconomic status affects digital access and health status [127]. Such interventions may cause or worsen access disparities, as specific groups of patients are known to fall behind the average population in terms of their use of virtual services (this is often referred to as the *digital divide*) [128]. Some of the included studies posited suggestions for recruiting individuals from lower socioeconomic status, including the provision of a loaner device that had data (providing internet access) to mitigate the reliance on a personal device or internet access and financial barriers [84,85,96]. Other studies included those with low technology comfort by providing training on device use and assistance with device setup [80,86,96,103,107,111]. However, some studies have excluded older adults with impaired sensory, cognitive, or communication functions. As these impairments are common in the oldest older adults [129], commonly referred to as the *oldest old* or *old old* (ie, ≥85 years) [130], this restriction may explain why studies tended to include those younger within the older adult category. Although these impairments could reduce participants' ability to use digital intervention, their participation can be supported by adapting technologies that are compatible for people with disabilities to use [131]. Thus, hospital-to-home interventions seeking to incorporate digital technologies should consider the intersection between disability and age and offer training and practice for the implemented technology [132]. Future research should explore ways to meet the needs of older adults with various impairments by designing technology that is as inclusive as possible [133]. In efforts to reduce inequities related to age and disability, strategies such as including individuals with disabilities (eg, dementia [134]) in technological development have been used [135].

The digital divide (ie, the disadvantage of those who are either unable or do not choose to use technologies) is the largest among older adults with low education, older adults with limited English proficiency, and certain racial or ethnic groups (eg, Hispanic or Black) [136,137]. Simultaneously, there are also cohorts of older adults that commonly face health inequities in low-income countries [138,139]. Many of the studies included in this review did not report the minority languages or race and ethnicity of the sample. Systematic reviews have noted inequalities and disparities in access to various health services among racial, ethnic, and language minorities [140,141]. To help overcome barriers to care for minority populations, reliable reporting of such characteristics is necessary to target improvement efforts to ensure equitable access to care [142]. Future studies should report on racial, ethnic, and cultural backgrounds and experiences to ensure that the needs and experiences of these groups are considered [143]. Moreover, future studies should include strategies for recruiting diverse groups of participants by offering technologies in different languages [144]; using racially, ethnically, and culturally diverse research staff [145,146]; and providing compensation for participation [146]. Carefully worded recruitment advertisements can also support gender diversity within these groups [147]. Highlighting the various genders incorporated into current interventions can help make research recommendations for including more diversity in future interventions and studying sex- and gender-based differences.

Limitations

In this secondary review of 34 articles describing the inclusion of older adult participants in hospital-to-home interventions, we experienced some limitations. First, our findings are limited to the data reported in the studies, and not all studies have reported particular characteristics (eg, education, race). Another limitation of our review is that we only included a synthesis of data that pertained to the SGBA+ framework and may have inadvertently excluded commentary on other meaningful measures of diversity (eg, immigration status). Second, we only included a synthesis of data that pertained to the SGBA+ framework and may have inadvertently excluded commentary on other meaningful measures of diversity (eg, immigration status). Third, our review was also limited by its rapid review methodology, whereby only one person screened the titles and abstracts in the larger review. In addition, we may have missed potentially relevant articles because of our use of a rapid methodology and searching for a limited number of databases. Fourth, there is a risk that articles may have been missed because of our search strategy, as digital health interventions are not described consistently [21]. However, it is worth noting that the intent of that study was not to capture all articles but to provide an overview of the literature [21]. Fifth, the results should be interpreted with caution, as we could not confidently determine which studies reported unique interventions versus the reported results of one intervention within multiple studies. Finally, we recommend that future studies examine digital health interventions in low- and middle-income countries, as our review is limited to digital health interventions in high-income countries.

Conclusions

To the best of our knowledge, this is the first review that has mapped the literature focusing on the characteristics of older adults included in studies of digital interventions supporting hospital-to-home transition. These findings suggest that the literature on digital health interventions tends to operationalize older adults as a homogenous group, ignoring the heterogeneity in older age definitions. In addition, few studies have reported on racial, ethnic, cultural, or gender diversity, which can facilitate a further digital divide among older adults. Inconsistency in the literature surrounding the characteristics of the included participants suggests a need for further study to better understand how digital technologies to support hospital-to-home transitions can be inclusive. Specifically, the SBGA+ framework can inform future research and interventions to support older adults during hospital-to-home transitions.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Geographical spread of studies.
[PNG File , 22 KB - aging_v5i2e35925_app1.png]

Multimedia Appendix 2
Supplementary table of study characteristics.
[DOCX File , 44 KB - aging_v5i2e35925_app2.docx]

Multimedia Appendix 3
Targeted populations of the included studies.
[DOCX File , 46 KB - aging_v5i2e35925_app3.docx]

Multimedia Appendix 4
Details of the participants (ie, actual sample).
[DOCX File , 50 KB - aging_v5i2e35925_app4.docx]

Multimedia Appendix 5
List of research implications.
[DOCX File , 16 KB - aging_v5i2e35925_app5.docx]

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Abbreviations

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SGBA+: Sex- and Gender-Based Analysis Plus

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Review

Virtual Reality Intervention for Managing Apathy in People With Cognitive Impairment: Systematic Review

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Abstract

Background: Apathy is common in people with cognitive impairment. It leads to different consequences, such as more severe cognitive deficits, rapid functional decline, and decreased quality of life. Virtual reality (VR) interventions are increasingly being used to manage apathy in individuals with cognitive impairment. However, reports of VR interventions are scattered across studies, which has hindered the development and use of the interventions.

Objective: This study aimed to systematically review existing evidence on the use of VR interventions for managing apathy in people with cognitive impairment with regard to the effectiveness, contents, and implementation of the interventions.

Methods: The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines were followed. The PubMed, Embase, CINAHL, and PsycINFO databases were systematically searched for experimental studies published up to March 13, 2022, that reported the effects of VR interventions on apathy in older adults with cognitive impairment. Hand searching and citation chasing were conducted. The results of the included studies were synthesized by using a narrative synthesis. Their quality was appraised by using the Effective Public Health Practice Project quality assessment tool. However, because the VR interventions varied in duration, content, and implementation across studies, a meta-analysis was not conducted.

Results: A total of 22 studies were identified from the databases, of which 6 (27%) met the inclusion criteria. Of these 6 studies, 2 (33%) were randomized controlled trials, 1 (17%) was a controlled clinical trial, and 3 (50%) were quasi-experimental studies. Individual studies showed significant improvement in apathy and yielded within-group medium to large effect sizes. The level of immersion ranged from low to high. Minor adverse effects were reported. The VR content mostly included natural scenes, followed by city views and game-based activities. A background soundtrack was often used with natural scenes. Most (5/6, 83%) of the studies were conducted in a residential care setting and were implemented by health care professionals or researchers. Safety precautions were taken in most (5/6, 83%) of the studies.

Conclusions: Although preliminary evidence shows that VR interventions may be effective and feasible for alleviating apathy in people with cognitive impairment, the methodological limitations in the included studies make it difficult to reach a firm conclusion on these points. The implementation of the interventions was highlighted and discussed. More rigorous studies are encouraged.

Trial Registration: PROSPERO International Prospective Register of Systematic Reviews CRD42021268289; https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021268289

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KEYWORDS

virtual reality; apathy; cognitive impairment; dementia; systematic review

Introduction

Background

Apathy is defined as an observable behavioral syndrome that is reflected in a reduction in goal-directed behaviors (as indicated by a lack of effort, initiative, perseverance, and productivity) [1]. Apathy is found in 2% to 75.2% of patients with cognitive impairments [2,3]. It is associated with suspected lesions in the prefrontal cortex and basal ganglia, which reduces a patient's ability to initiate, sequence, and complete tasks, thereby affecting their everyday activities and autonomy [4-7]. As a result, patients who have developed apathy have exhibited more severe cognitive deficits, rapid functional decline, and decreased quality of life than the general population [3,8,9].

Virtual reality (VR) interventions are increasingly being used in caring for people with cognitive impairment. VR can be defined as a computer technology that reproduces a real or imaginary environment and simulates the user's presence in that physical environment; therefore, the user would have a feeling of *being there* and be able to interact with the virtual environment through the engagement of their senses [10,11]. The level of immersion can be classified as low, moderate, or high [12]. Using a head-mounted display (HMD) or surround projection can be classified as being of a high level of immersion, defined as including more than 2 sensory modalities (eg, visual, auditory, and proprioceptive or motor) and stimuli that are oriented spatially. A moderate VR immersion level accommodates 1 to 2 sensory modalities with large-screen projection and stimuli, which may or may not be oriented spatially. A low VR immersion level only accommodates 1 sensory modality. A higher level of immersion is suggested because the patient may feel a higher level of presence, thus substantially increasing the behavioral responses [13,14].

How VR interventions alleviate apathy can be explained by a biomedical model and a psychosocial model. The biomedical model suggests that VR allows users to interact with a virtual, enriched environment, which triggers the reorganization and reconstruction of new cellular synapses to repair the brain lesions causing apathy, which refers to the neuroplasticity of the brain and nervous system [15]. When users receive multisensory feedback, they experience the illusion of place and then respond to the virtual environment as they would to the real world, resulting in better performance with more intensive, repetitive, and engaging experiences [15,16]. The psychosocial model suggests that users perceive themselves as being present in the virtual world [17,18] and that this immersion is envisaged as a mental sensation of engagement that would promote motivation [17]. VR achieves immersion by removing real-world sensations that individuals might not be able to process because of cognitive impairment and replacing them with virtual experiences. This gives a specific kind of stimulation, making it easier for users to focus and forget about their actual surroundings, thereby facilitating involvement.

VR may be an effective, customizable, and affordable solution for managing apathy in patients with cognitive impairment. For example, VR increases a sense of reality through digital media over tangible prompts in reminiscence therapy, thus increasing therapy effectiveness and treatment compliance [19,20]. As an accessible, low-cost, and customizable solution, VR also provides an alternative to *live music therapy*, which has been proven to be an effective solution for managing apathy but is too expensive and complicated to organize when a social distancing policy is in place [21-23]. Hence, in recent years, there have been an increasing number of studies investigating the benefits of VR interventions for patients with cognitive impairment. However, the reports on the apathy outcomes of VR interventions are scattered across studies. There is inconsistent evidence regarding the effectiveness of VR interventions [24-29], making the evaluation of effects difficult. Their study designs, VR contents, and implementation procedures have also differed; in addition, they have not been systematically reviewed in terms of quality. This has hindered the development of VR interventions and their adoption in practice.

Objectives

This systematic review aimed to address this knowledge gap by reviewing the existing evidence on the use of VR interventions for managing apathy in people with cognitive impairment. The objectives of this review are to (1) evaluate the effects of VR interventions for managing apathy in people with cognitive impairment, (2) identify the content of the VR interventions for managing apathy in people with cognitive impairment, and (3) understand the implementation of VR interventions for managing apathy in people with cognitive impairment.

Methods

Design

This study was conducted with reference to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement [30,31]. The review protocol has been registered with PROSPERO (CRD 42021268289).

Eligibility Criteria

The eligibility criteria are listed herein. The inclusion criteria were set according to the Population, Intervention, Comparison, Outcome, and Study design framework [32]. Studies that met the following criteria were included: (1) population: older adults with cognitive impairment, including those with subjective cognitive decline, mild cognitive impairment, and dementia; (2) intervention: a VR intervention using either immersive-type or on-screen approaches; (3) comparison: an active, a passive, or no control group for comparison; (4) outcome: apathy measured quantitatively with validated instruments; (5) study design: a randomized controlled trial or quasi-experimental study; and (6) published in English.

The exclusion criteria were as follows: (1) conference abstracts and reviews or (2) any article involving a multi-domain intervention with other modalities, such as augmented reality, because in such a situation, it would not be possible to attribute the reported intervention effect solely to the VR intervention.

Sources of Information

In total, 4 databases (PubMed, Embase, CINAHL, and PsycINFO) were searched from inception to March 13, 2022. These databases are relevant to the research questions because PubMed focuses on biomedicine and health, Embase contributes to the biomedical research community by providing information and showing biomedical evidence to support essential life sciences functions, CINAHL contains articles on a wide range of topics such as nursing and biomedicine, and PsycINFO mainly covers journal articles in psychology and related disciplines.

To minimize the possibility that relevant articles not published in these 4 databases might be overlooked, the reference lists of the included studies were screened against the same set of eligibility criteria and included if relevant. Hand searching of articles in Google Scholar was also performed.

Search Strategies

The following search strategy was developed with reference to the research questions and refined with the support of a university librarian (Pao Yue-Kong Library, Hong Kong Polytechnic University). The search keywords are listed herein (Multimedia Appendix 1 provides details of the search conducted in each database):

1. [Dementia]
   OR
   [Cognitive impairment]
   OR
   [Alzheimer disease]
   OR
   [Mild cognitive impairment]
   AND
2. [Virtual Reality]
   OR
   [Head mounted]
   OR
   [Simulation]
   OR
   [Virtual]
   AND
3. [Apathy]
   OR
   [Apathetic]
   OR
   [Lack of initiati*]
   OR
   [Lack of interest]

Selection Process

Articles retrieved from the databases were managed using EndNote (version 20.0; Clarivate). Duplicate articles were first removed. Next, the screening of titles and abstracts against the eligibility criteria was conducted independently by the first and second authors (KYH and PMC, respectively). Subsequently, full-text screening was carried out independently by the third and fourth authors (TWC and WYS, respectively). Any disagreements over the reviews were resolved by consensus and by discussion with the fifth author (HYH).

Data Extraction Process and Data Items

Each study was evaluated independently and duplicated using a pretested standardized data extraction form. For each study, the following information was extracted: (1) publication data (ie, year, author, and title), (2) study design, (3) setting, (4) sample, (5) VR intervention components, (6) outcomes, and (7) adverse events.

Risk of Bias and Quality Assessment

The Effective Public Health Practice Project quality assessment tool was used to assess the risk of bias in the included studies [33]. In total, 6 domains of bias were scored with three rating categories: (1) strong, (2) moderate, and (3) weak. The 6 domains of bias are selection bias, study design, confounders, blinding, data collection method, and withdrawals and dropouts. The global rating of the study is strong if there is no weak rating in all components, whereas the study quality is rated as moderate or weak if there is 1 weak rating or ≥2 weak ratings, respectively. All the selected articles were scored by 2 authors in duplicate and independently. Disagreements were resolved through discussion.

Effect Measures

Apathy is the outcome of interest that can be assessed quantitatively using validated instruments; for example, the Neuropsychiatric Inventory (Apathy subscale), the Apathy Evaluation Scale, the Structured Clinical Interview for Apathy, and the Dementia Apathy Interview and Rating Scale [34]. Continuous outcomes of apathy were reported by means and SDs. The corresponding within-group effect size of the intervention on apathy reported in the individual studies was calculated.

Synthesis

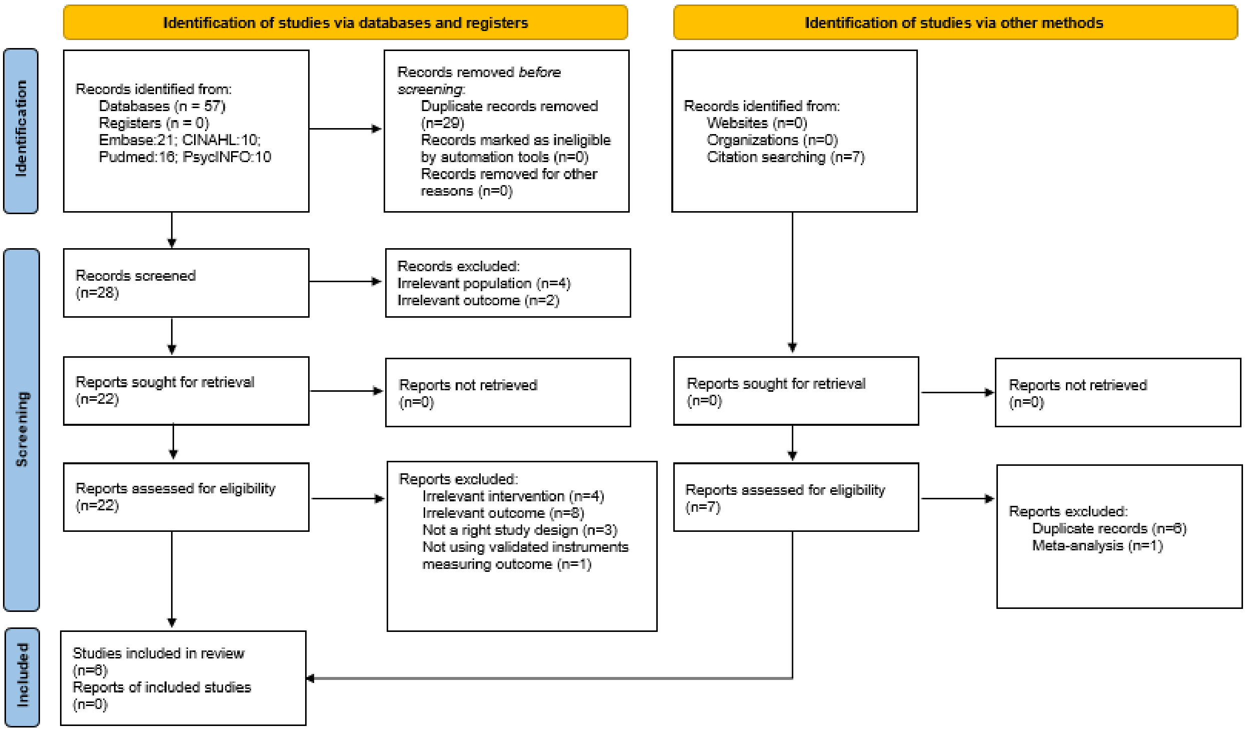
The data extracted from the individual studies were narratively synthesized. These descriptions facilitated the examination of patterns across studies in a systematic manner. A meta-analysis was not conducted because of the heterogeneity of the included studies [23].

Results

Study Selection

As shown in Figure 1 [35], a total of 57 articles were identified from the databases; after removing duplicates, the titles and abstracts of 28 (49%) were screened. Of these 28 articles, 6 (21%) were excluded (n=4, 67%, because of incorrect study population and n=2, 33%, because of irrelevant study outcome), leaving the full text of 22 (79%) to be screened against the eligibility criteria. Of these 22 articles, 16 (73%) were excluded because they involved an irrelevant intervention (n=4, 25%), had an irrelevant outcome (n=8; 50%), did not use validated instruments measuring the outcome (n=1, 6%), or did not have the right study design (n=3, 19%). After searching the citations in the included articles, no further eligible articles were identified. In the end, of the 57 articles identified from the databases, 6 (11%) were included in this review.

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



Study Characteristics

The characteristics of the included studies are presented in Table 1. Among the 6 included studies, 2 (33%) were randomized controlled trials (parallel-group and crossover design each) [26,27], 1 (17%) was a nonequivalent group controlled trial [29], and the remaining 3 (50%) were quasi-experimental studies with a single-group pre- and posttest design [24,25,28]. Most (5/6, 83%) of the studies were conducted in Australia [24-26,28,29], and 1 (17%) was conducted in South Korea [27]. Of the 6 studies, almost all (n=5, 83%) were conducted in a residential care setting [24-26,28,29], except for 1 (17%) that was conducted at a memory clinic [27]. The number of participants ranged from 10 to 46. All participants had various degrees of cognitive impairment, ranging from subjective cognitive decline to severe dementia. Only 17% (1/6) of the studies clearly defined apathy as “a lack of interest and diminished motivation” [29]. Of the 6 studies, 4 (67%) used the Person-Environment Apathy Rating Scale [24-26,28] to measure the apathy level before and during the VR intervention and 2 (33%) adopted the Apathy Evaluation Scale to measure apathy before and after the VR intervention [27,29].

Table 1. Characteristics of the included studies (N=6).

Study, country	Study design	Setting; sample	VR[a] content; facilitator background	Device or devices; immersion level	Dosage	Outcome measurement and main findings	Adverse events
Brimelow et al, 2020 [24], Australia	QERMSG[b]	RACF[c]; mild to severe cognitive impairment (n=13)	360^{o} video relaxing scenes, leisure and lifestyle coordinator	Samsung Galaxy S7 and Samsung Gear VR headset; high	One 4-5 minutes	PEAR[d]; mean total score: before: 15.54 (SD 6.11), during: 11.38 (SD 3.93); *P*=.005; within group effect size *r*=0.78	Blurring vision; headset-related discomfort
Brimelow et al, 2021 [25], Australia	QERMSG	RACF Mild to severe cognitive impairment (n=25)	Participant preferred natural scenery and household; OT[e] and RN[f]	Samsung Galaxy S7 and Samsung Gear VR headset; high	Six 10-minutes over 3 weeks	PEAR; mean Apathy Subscale score: before and during: no information given; *P*<.001; within group effect size *r*=0.56	Mild headache; giddiness sensation; headset-related discomfort
D'Cunha et al, 2020 [26], Australia	Mixed methods crossover RCT[g]	RACF; mild to severe cognitive impairment (n=11)	Virtual cycling to simulate paddling in a lake or biking in a mountain; OT	Projector screen and pedal exercisers (Body Charger GB3030 UBE); moderate	One 25-mins	PEAR; mean Apathy Subscale score: control: 13.4 (SD 2.72), during VR: 12.6 (SD 2.37); *P*=.49; between-group effect size *g*=0.31	Lower body discomfort during cycling
Kang et al, 2021 [27], South Korea	RCT	Memory clinic; SCD[h] and MCI[i] (n=45)	Multiple cognitive games; clinical neuropsychologist	Head-mounted Oculus Rift CV1 display; high	Eight 20-30 minutes	AES[j]; mean score: VR group, before: 47.43 (SD 10.20), after: 54.35 (SD 9.41), within group comparison *P*=.006; within group effect size *g*=0.68; control group, before: 52.83 (SD 9.38), after: 51.22 (SD 8.72), group×time effect size n^2=0.17; group×time interaction *P*=.01	Nausea, oculomotor discomfort, and disorientation
Moyle et al, 2018 [28], Australia	QERMSG	RACF; dementia (n=10)	VR forest; trained care worker	Large interaction-enabled screen display and kinectmotion sensors; moderate	One 15 minutes	PEAR; mean Apathy Subscale score: before: 18.30 (SD 5.10); during: 12.10 (SD 2.69); after: 18.70 (SD 4.24); before-during: *P*=.01, effect size *g*=1.39; before-after: *P*>.05, effect size *g*=0.08	Not reported

Study, country	Study design	Setting; sample	VR[a] content; facilitator background	Device or devices; immersion level	Dosage	Outcome measurement and main findings	Adverse events
Saredakis et al, 2021 [29], Australia	Nonequivalent group controlled trial	RACF; Minimal to moderate cognitive impairment (n=46)	Wander (Parkline Interactive), YouTube VR (Google LLC); researcher	VR group: Oculus Go HMD[k] and laptop group: laptop computer; low	Three 20-minutes	AES mean score: VR group, before: 35.3 (SD 8.7), after: 36.0 (SD 6.1); within group effect size g=−0.09; laptop group: before: 41.8 (SD 7.1), after: 40.2 (SD 8.1), within group effect size g=0.20; control group, before: 44.3 (SD 9.5), after: 43.6 (SD 9.4); within group effect size g=0.1; time×(VR and laptop groups vs control group); P=.88; effect size n^2=.00; time×(VR vs laptop group); P=.24; effect size n^2=.03	Headache, heavy head feeling

[a] VR: virtual reality.

[b] QERMSG: quasi-experimental repeated measures single-group.

[c] RACF: residential aged care facilities.

[d] PEAR: Person-Environment Apathy Rating Scale.

[e] OT: occupational therapist.

[f] RN: registered nurse.

[g] RCT: randomized controlled trial.

[h] SCD: subjective cognitive decline.

[i] MCI: mild cognitive impairment.

[j] AES: Apathy Evaluation Scale.

[k] HMD: head-mounted display.

Effects of the VR Interventions

Of the 6 included studies, 4 (67%) reported a significant positive within-group improvement in apathy during [24,25,28] or after [27] the VR intervention and yielded a medium to large effect size (0.56 to 1.39), whereas 2 (33%) reported no significant improvement [26,29].

Whereas 67% (4/6) of the studies used HMDs to implement a high VR immersion level [24,25,27,29], 33% (2/6) used a large-screen display to implement a moderate VR immersion level [26,28] and 17% (1/6) used a laptop computer to implement a low VR immersion level [29]. Large-screen displays along with pedal exercisers were included in 17% (1/6) of the studies [26].

Of the 6 included studies, only 1 (17%) compared the effects of a VR intervention delivered with a high-immersion HMD with those of a VR intervention delivered with a low-immersion laptop computer, but it did not show a significant difference between the 2 groups. Instead, the 2 VR groups still showed a significantly better improvement than the passive control group [29].

Mild adverse reactions were reported in 67% (4/6) of the studies, including eyestrain, blurred vision, and discomfort induced by a weighty headset [24,25,27,29].

Content of the VR Interventions

In 67% (4/6) of the studies, there were natural scenes in the VR content, including underwater themes, beaches, farmyard animals, travel destinations, snowscapes, lakes, and mountain views [24-26,28], whereas 33% (2/6) of the studies included games and customized images related to personal experience (eg, home and school) [27,29]. Animals and natural scenes dominated the participants' choices. Some participants reported that they found the realistic, colorful scenery visually appealing and had developed a sense of being outdoors [24-26,28]; a few participants preferred content that allowed interaction with the system (eg, challenges or tasks), whereas others did not [28]. Most of the participants preferred having customized content and a list of scene choices so that they could select content based on their own interests [24,25,28,29]. Apart from the natural scenes, 50% (3/6) of the studies combined the VR scenes with some background soundtrack or narration; for example, a forest scene with bird calls and travel destinations with music that participants had memories of [24,28,29]. Of the 6 included studies, 1 (17%) combined VR with a cycling experience, which allowed participants to paddle around a familiar lake and travel on a downhill path on a mountain biking track [26], and 1 (17%) consisted of multiple games involving 8 multi-domain cognitive tasks that allowed participants to exercise their visuospatial skills through learning and transference outcomes [27].

Of the included studies, 50% (3/6) delivered the VR intervention once, with the duration ranging from 4 to 25 minutes [24,26,28], whereas 50% (3/6) reported that there were 3 to 8 sessions and that the duration of each session ranged from 10 to 30 minutes [25,27,29].

Implementation of the VR Intervention

In 67% (4/6) of the studies, the VR intervention was delivered by health care professionals such as registered nurses, occupational therapists, clinical neuropsychologist, and researchers [24,26,27,29], whereas in 33% (2/6), the VR intervention was implemented by frontline care workers working at residential aged care facilities [25,28].

In the studies (4/6, 67%) using high-immersion VR, the following hardware equipment was used: a Samsung Gear VR headset, an Oculus Quest HMD, and an Oculus Rift CV1 HMD with Oculus Touch controllers held by the participants with both hands [24,25,27,29]. Videos were presented on projector screens in 33% (2/6) [26,28] of the studies and on a laptop computer in 17% (1/6) [29] of the studies, which were of moderate and low immersion levels, respectively.

Safety was the top priority in the implementation of the VR interventions. Researchers included different safety measures in their studies. For instance, older adults with vision impairment and incomplete range of motion in their hips, knees, and ankles were excluded at recruitment [25,26,28]. A safety protocol was developed for use by the care staff and an on-site physiotherapist [26]. Furthermore, the videos used in the VR intervention did not contain sudden scene changes to reduce the risk of cybersickness [24,25,27,29]. In 50% (3/6) of the studies, the participants were instructed to remain seated throughout the whole experience to reduce the risk of falls [24,27,29].

Study Quality

The quality ratings of the included studies are presented in Table 2. Of the 6 included studies, 5 (83%) were rated as *weak* and 1 (17%) was rated as *moderate* according to the Effective Public Health Practice Project quality assessment tool. The quality was generally low, mainly because of the unrepresentativeness of the target population, uncontrolled confounders, or a lack of blinding.

In all the included studies, participants were recruited from 1 to 3 residential aged care facilities or clinics by convenience sampling. A formal power analysis to estimate the sample size was not performed in any of the included studies. Of the 6 studies, 2 (33%) included >40 participants [27,29], whereas the other 4 (67%) had small samples [24-26,28]. Of the 6 studies, only 2 (33%) identified their confounders [26,27]; none reported adjusting for confounders such as gender, age, education level, and health status, which potentially threatened the validity of the results. Concerning blinding, there was no mention in any of the studies of whether the outcome assessors or participants were blinded to the group allocation and the research question. This is likely because blinding the participants is impossible because of the nature of VR interventions. Nevertheless, the included studies measured apathy with validated instruments. Therefore, we were convinced of the appropriateness of the data collection methods.

Some common risks of bias across different studies have been identified. Some items might not have been included in the research findings because of selective reporting. For instance, missing or insufficient data and some negative research findings might have been excluded by the authors. Publication bias is also possible.

Table 2. Assessment of the quality of the included studies using the Effective Public Health Practice Project quality assessment tool.

Study, year	Selection bias	Study design	Confounders	Blinding	Data collection method	Withdrawal and dropouts	Global rating
Brimelow et al, 2020 [24]	Weak	Weak	Weak	Moderate	Strong	Weak	Weak
D'Cunha et al, 2020 [26]	Weak	Strong	Weak	Moderate	Strong	Strong	Weak
Kang et al, 2021 [27]	Weak	Strong	Weak	Moderate	Strong	Strong	Weak
Moyle et al, 2018 [28]	Weak	Weak	Weak	Moderate	Strong	Weak	Weak
Brimelow et al, 2021 [25]	Weak	Weak	Weak	Moderate	Strong	Moderate	Weak
Saredakis et al, 2021 [29]	Strong	Moderate	Weak	Strong	Strong	Strong	Moderate

Discussion

Principal Findings

To the best of our knowledge, this is the first systematic review to evaluate the effectiveness, contents, and implementation of VR interventions for managing apathy in people living with cognitive impairment. A wide range of strengths and weaknesses were highlighted in the included studies (n=6). Our findings showed preliminary evidence that VR interventions can have a positive impact on apathy. However, the methodological limitations of the individual studies make it difficult to come to a firm conclusion. Even so, the findings showed that implementing a VR intervention may have a positive effect on apathy, regardless of the immersion level.

Among the 6 included studies, the largest effect size was found in 1 (17%) study using a large-screen display, which was categorized as a moderate level of immersion [28], followed by 2 (33%) studies using HMDs, which was categorized as a high level of immersion [24,27], whereas 2 (33%) studies used moderate-immersion VR. In the study by D'Cunha et al [26], a large projector screen was used instead of an HMD: the authors explained that using an HMD may isolate the user from the social environment, hindering the improvement in apathy. In the study by Moyle et al [28] too, a large-screen display was used for the VR intervention. Yet, the results are not consistent between the 2 studies, with one showing insignificant results [26] and another demonstrating significant improvement with a large effect size [28]. Therefore, we argue that content, rather than level of immersion, affects the intervention effects on apathy, supported by the evidence of the study by Saredakis et al [29], who compared the effects of the high-immersion VR group with the low-immersion laptop computer group that shared the same content and found that there was no significant difference between the groups. Our assumption may contradict the theories of García-Betances et al [13] and Witmer et al [14], who advocated that the higher the immersion level used, the greater the observed effect. More research in this area may be needed.

Natural scenes were widely used and preferred in the VR interventions. However, the studies (n=3) that solely used natural scenes showed conflicting results [24,26,28]. The studies (n=2) that showed significant improvement in apathy had played relaxing music during the VR session to enhance the participants' pleasure [24,28], whereas the study that showed negative results required participants to engage in activities that involved physical strain without background music [26]. Therefore, we suspect that music combined with natural scenes may produce a better improvement in apathy. This is because pleasure derived from being immersed in a VR environment may increase participants' engagement [36], whereas music has been proven to be a useful medium to improve the mood of people with cognitive impairment. In addition, the Attention Restoration Theory suggests that natural environments can restore mental fatigue by triggering spontaneous forms of attention; thus, being immersed in a natural environment can provide positive psychological effects, leading to a reduction in apathy among participants [37,38]. Even the authors of the study that reported insignificant results after exposing participants to natural scenes in VR have suggested integrating music into the design of the content of a future VR intervention [26]. Hence, it is assumed that including background music with a VR intervention may assist in reducing apathy by removing distractions from the real world during the VR session [28].

The included studies reported that participants appreciated and enjoyed the *realistic surroundings*, which were understood to be of high graphical fidelity and a colorful VR environment. Surprisingly, instead of providing a VR environment that was *as real as possible*, the study by Brimelow et al [24] adopted an approach that involved making intentional adjustments to the visual presentations, such as a high-contrast design (eg, a scene of penguins in the snow), to accommodate age-related visual decline [24]. By contrast, participants from another study complained that they had visuoperceptual difficulties recognizing the objects displayed on the screen and that the sound was too soft to be heard clearly [28]. Therefore, customized adjustments to legibility and auditory features in VR interventions created for people with cognitive impairment is advocated.

Of the 6 included studies, 2 (33%) investigated the effects of a game-based VR intervention on apathy. The study by D'Cunha et al [26] included a paddling task, and the study by Kang et al [27] used tasks involving multiple cognitive domains. Despite the high level of interaction, the study with the paddling task had relatively high dropout and incompletion rates [26]; 1 out of 10 participants withdrew before the intervention started, and 3 out of 10 participants from the intervention group stopped cycling shortly after commencing the VR intervention because of discomfort in the lower part of their body. It was presumed that the combination of VR and intensive motor training consumed more energy, making it difficult for the participants to continue, and could have resulted in a higher incompletion rate. By contrast, the intervention that used tasks involving multiple cognitive domains required minimal physical energy [27]; the increased interest and motivation of the participants was noted and might have contributed to higher engagement and a lower dropout rate. In future studies, interventions should be designed and implemented carefully whenever physical effort is required.

The facilitators of the VR interventions in the included studies were those who had prior knowledge of the participants, except for the study by Saredakis et al [29] in which the intervention was delivered by the researchers. The interventionist plays an important role in ensuring a good intervention outcome because inadequate trust in the interventionist would inhibit participants from engaging in the program [39]. Of note, a few adverse events were reported in the studies. This finding was similar to that reported in another systematic review of the use of VR for individuals with neurocognitive disorders [40]. This also implies that VR interventions are likely to be safe for people with cognitive impairment. Nevertheless, it is still important to note that some common forms of cybersickness such as eyestrain and blurred vision were reported, especially during a dynamic water scene [24]. Therefore, closely monitoring the side effects of VR on participants with cognitive impairment is needed because they may have limited ability to communicate their discomfort. Some measures such as avoiding sudden scene changes, replacing a dynamic scene with a static scene (eg, a farmyard), and asking participants to open their eyes slowly could be used to help them to adjust to a change in lighting and minimize symptoms of cybersickness [24,25,27,29].

It is worth noting that all included studies had a relatively small sample size, which pointed to the potential for selection bias and low statistical power. To provide solid evidence on the effectiveness of VR interventions, it is suggested that larger sample sizes should be adopted in further research. Moreover, of the 6 studies in this review, 5 (83%) were conducted in residential aged care facilities in Australia. Generalizing the results to more diverse settings or other nations could be the direction of future investigations. As 50% (3/6) of the studies merely conducted a single, short episode of the intervention, limited evidence was found to support the sustained effect of VR interventions. It is suggested that future studies should be designed to last longer and include multiple sessions. In addition, the participants had different levels of cognitive impairment, ranging from mild to severe. It is suggested that future studies should focus on a specific level of cognitive impairment to investigate the effect of VR interventions. Last but not the least, the ethnicity of the sample was not reported in all the studies; whether race would have an impact on the response is yet to be confirmed. As the studies were not of high quality, the findings on the significant impact of VR interventions should be interpreted with caution.

Limitations

Although different databases and keywords were included in the search process, it is possible that articles written in languages other than English were excluded. In total, 4 relevant databases were searched; yet, some relevant articles might not have been identified. Although advice from a librarian was sought, in future research the search can be expanded to databases that include publications in other languages.

Another potential limitation was that only published studies were considered in this review. Existing VR applications have reached the stage of commercialization, which means that technology companies might not have published the trial results of VR applications for different target populations in the market [41]. It is possible that some relevant data may not have been captured because of their unpublished status.

Conclusions

A total of 6 studies were included in the final analyses. This systematic review indicated that VR interventions are likely to be effective in reducing apathy and are unlikely to cause harm for people with cognitive impairment. Several recommendations on VR practices have been mentioned in terms of levels of immersion, social interactions, themes and the adjustment of content, physical effort, and the interventionist-resident relationship. As VR technology offers benefits for delivering safe, flexible, cost-effective, and repeatable interventions for patient care, it is believed that the scope of VR will be expanded with further technological innovations. However, the quality of the existing evidence is limited. To generate stronger scientific evidence on VR interventions, full power, large-scale, and high-quality studies need to be conducted.

Authors' Contributions

KYH and PMC conceived and designed the analysis and formulated the overarching research goals and aims; performed the initial screening of titles; conducted the analysis; and carried out the critical review, commentary, or revision of the manuscript. TWC, WYS, and HYH performed full-text screening, conducted data analysis, generated tables, and wrote the initial draft of the manuscript. DSKC developed the methodology and performed the final review of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Details of the search conducted in each database.
[PDF File (Adobe PDF File), 10 KB - aging_v5i2e35224_app1.pdf]

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Abbreviations

HMD: head-mounted display
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
VR: virtual reality

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Review

Recommendations for the Design and Delivery of Transitions-Focused Digital Health Interventions: Rapid Review

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Abstract

Background: Older adults experience a high risk of adverse events during hospital-to-home transitions. Implementation barriers have prevented widespread clinical uptake of the various digital health technologies that aim to support hospital-to-home transitions.

Objective: To guide the development of a digital health intervention to support transitions from hospital to home (the Digital Bridge intervention), the specific objectives of this review were to describe the various roles and functions of health care providers supporting hospital-to-home transitions for older adults, allowing future technologies to be more targeted to support their work; describe the types of digital health interventions used to facilitate the transition from hospital to home for older adults and elucidate how these interventions support the roles and functions of providers; describe the lessons learned from the design and implementation of these interventions; and identify opportunities to improve the fit between technology and provider functions within the Digital Bridge intervention and other transition-focused digital health interventions.

Methods: This 2-phase rapid review involved a selective review of providers’ roles and their functions during hospital-to-home transitions (phase 1) and a structured literature review on digital health interventions used to support older adults’ hospital-to-home transitions (phase 2). During the analysis, the technology functions identified in phase 2 were linked to the provider roles and functions identified in phase 1.

Results: In phase 1, various provider roles were identified that facilitated hospital-to-home transitions, including navigation-specific roles and the roles of nurses and physicians. The key transition functions performed by providers were related to the 3 categories of continuity of care (ie, informational, management, and relational continuity). Phase 2, included articles (n=142) that reported digital health interventions targeting various medical conditions or groups. Most digital health interventions supported management continuity (eg, follow-up, assessment, and monitoring of patients' status after hospital discharge), whereas informational and relational continuity were the least supported. The lessons learned from the interventions were categorized into technology- and research-related challenges and opportunities and informed several recommendations to guide the design of transition-focused digital health interventions.

Conclusions: This review highlights the need for Digital Bridge and other digital health interventions to align the design and delivery of digital health interventions with provider functions, design and test interventions with older adults, and examine multilevel outcomes.

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KEYWORDS

transitions; health; medical informatics; aged; mobile phone

Introduction

Background

Hospital-to-home transitions can be a challenging time for older adults [1-10] owing to the high risk of adverse events, including medical errors, hospital readmission, and death [4,7,11,12]. It has been noted that almost half of the adverse events experienced during these transitions could be prevented or minimized [4,7,11,12]. Furthermore, pressures facing health care systems have resulted in decreased lengths of hospital stay, leading to patients being discharged *quicker and sicker* and an increased risk of hospital readmissions and poor health outcomes [13-16]. The costly and negative impacts of poor transitions have made transitions a high priority for the health care system and prompted significant efforts to improve hospital-to-home transitions [17].

Multidisciplinary teamwork is one of the critical aspects of high-quality continuity of care [18]. Facilitating successful hospital-to-home transitions involves team effort because multiple tasks must be completed by various health care providers across inpatient and community settings [16]. Information-sharing and communication issues combined with a lack of role clarity can cause poor continuity of care and service fragmentation during transitions [16,19-22].

Improving hospital-to-home transitions entails improving communication and coordination among multiple providers and across multiple health care settings [23,24]. Rennke and Ranji [17] have suggested that successful hospital-initiated transitional care programs include a "bridging" strategy with pre- and postdischarge interventions. Although numerous transitional care models and strategies have been proposed [17,25-31], they require considerable resources, such as a dedicated transition provider, because of the additional work required [16,17,32,33]. However, this may not be a feasible or affordable solution for health care organizations because organizations tend to seek solutions that are "high-value, low-cost" [17].

The use of digital health technologies is an approach used to facilitate safe hospital-to-home transitions because they can augment provider roles and functions during transitions while attempting to minimize costs [34-36]. Many digital health technologies have been proposed to mitigate transition issues experienced by older adults and their caregivers and facilitate efficiency and coordination in the discharge process. For example, digital health interventions can be used to monitor older adults' symptoms [37], provide educational material and discharge instructions [38,39], and facilitate timely information sharing among providers across settings [40]. However, digital health technologies, in general, have not been well integrated into clinical practice settings because of persistent barriers, including poor fit with providers' roles and functions because digital health interventions add additional functions to the existing workloads of providers [41,42]. An improved understanding of which providers are involved in care transitions and how the technologies can support their existing provider functions may address some of these implementation barriers [43,44].

Objectives

Despite the vast landscape of digital health technologies, there have been limited syntheses of digital health interventions used to support hospital-to-home transitions and the lessons learned from their implementation. This information is critical to avoid duplication of problematic factors that can limit the uptake of digital health technologies within the development and implementation of new transition-focused digital health interventions. To guide the development of an information communication technology to support transitions from hospital to home (the Digital Bridge intervention [45]), the specific objectives of this review were as follows:

- Understand the various roles and functions of health care providers supporting hospital-to-home transitions for older adults, allowing future technologies to be more targeted to support their work.
- Describe the types of digital health interventions used to facilitate the transition from hospital to home for older adults and elucidate how these interventions support the roles and functions of providers.
- Describe the lessons learned from the design and implementation of these interventions.

- Identify opportunities to improve the fit between technology and provider functions within the Digital Bridge intervention and other transition-focused digital health interventions.

Methods

A rapid review methodology [46] was suitable for this review because we intended to generate a timely overview of the existing landscape of digital health technologies. This rapid review was based on our previously published protocol [43].

Phase 1: A Selective Literature Review to Understand Roles and Functions of Health Care Providers Supporting Hospital-to-Home Transitions

A selective review [47,48] was undertaken using MEDLINE (Ovid) and Google Scholar on September 19, 2020, to provide greater insights and clarity regarding health care providers' roles and their essential functions [44] in supporting hospital-to-home transitions. These 2 databases were selected for the following reasons: (1) they are multidisciplinary, (2) MEDLINE (Ovid) is a widely used database to identify peer-reviewed health-related literature [49], and (3) Google Scholar is a "powerful addition to other traditional search methods" to help identify known studies [50]. A selective literature review limited the search to "key studies that significantly contribute to our understanding" [47,48]. The search terms included concepts related to *navigation*, *hospital-to-home transition*, and *older adults* [43]. Any study design published in English that identified a role and function related to a hospital-to-home transition was included. The following data were extracted from relevant articles:

1. What provider role (ie, job title) is identified?
2. What is the provider's function (ie, responsibilities related to supporting a hospital-to-home transition)?

Key roles were identified, and their functions were thematically analyzed on NVivo 11 (QSR International) using inductive thematic analysis [51]. Subsequently, the coded functions were organized according to the 3 categories of continuity of care: informational, management, and relational [52]. These categories were used because they could create a shared understanding and language for continuity of care across disciplinary and organizational boundaries [52].

Phase 2: Identifying Digital Health Technologies Supporting Transitions

Literature Search

In phase 2, MEDLINE (Ovid), CINAHL (EBSCO), and Embase (Ovid) were searched on November 26, 2020, to identify literature on digital health interventions supporting the transition from hospital to home for older adults (Multimedia Appendix 1). These databases were selected because they (1) could identify health-related literature and (2) were determined by our research team (including a medical librarian HVC) to be appropriate for the scope of our search [43]. The review adhered to the PRISMA-S (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Literature Search) checklist [53]. The reference lists of some included articles (n=20) were hand searched, and content experts (n=6) were consulted to identify additional studies.

Study Selection

The search results were uploaded to the Covidence website. On the basis of the inclusion and exclusion criteria (Multimedia Appendix 2 [54,55]), each article's title and abstract were screened by a single reviewer from the screening team (HS, TT, KK, RT, DP, MH, CMJ, AA, or JXN), followed by a full-text review conducted independently by 2 reviewers from the screening team. Any conflicts were resolved through team discussions. Studies were included if they tested a digital health intervention that supported a hospital-to-home transition for older adults and were published in or after 2010. For this review, an intervention that *supported a hospital-to-home transition* had to have recruited participants before their hospital discharge and continued in the home or community setting. The studies had to include ≥1 older adult but did not need to focus on older adults exclusively. No limits were imposed on study design to ensure that we included relevant studies, but articles had to report findings from empirical studies. Given that we intended to inform recommendations for the Digital Bridge intervention [45], a high-technology intervention for use in a "high-income country," strictly telephone-based interventions, and interventions tested in a "low-income country" were excluded [54].

Data Extraction

The following data were extracted from the articles using a customized form informed by the Template for Intervention Description and Replication framework [56]: author details; country and year of publication; sampling strategy; inclusion and exclusion criteria; the medium of technology, function of technology, and who provided the intervention; study findings; and limitations and future directions. Data regarding intervention effectiveness were not extracted, reported, or synthesized in this review because this was outside its purpose, scope, and intent [57].

Data Analysis

We descriptively reported study characteristics and qualitatively analyzed data using a thematic analysis [51]. We first analyzed each study's discussion using data-driven codes to identify *lessons learned*. We then coded data deductively by grouping the technology functions according to the 3 categories of continuity of care described by Haggerty et al [52]. The technology functions and providers involved in intervention delivery were compared with the provider roles and functions identified in phase 1.

Results

Phase 1

The literature review revealed several provider roles that commonly support hospital-to-home transitions (Textbox 1). In addition to the professional roles of allied health clinicians, pharmacists, nurses, and physicians, several navigation-specific roles were noted. Key provider functions during transitions are presented in Textbox 2. Of note, roles and functions supporting transitions differed by type of institution and many roles performed overlapping functions.

Textbox 1. Provider roles identified as engaged in facilitating hospital-to-home transitions.

Navigation-specific roles: providers with known navigation-related role titles [58]

- Advanced practice navigator, care manager (could be a nurse, social worker or clerical staff [59]), care or program coordinator, care transition nurse, case manager, discharge coordinator, discharge liaison nurse or liaison nurse, discharge planner or facilitator or discharge planning nurse (typically a social worker or nurse [60]), case manager, discharge coordinator, geriatric care manager, guided care nurse, intensive geriatric service worker, nurse navigator, post–acute care coordinator (typically allied health or nurse [61]), patient navigator, surgical coordinated transitional care program nurse, transition coach

Allied health

- Occupational therapist, physiotherapist, social worker

Pharmacist

- Hospital or community pharmacist

Nursing

- Trained nurse (trained in device use), research nurse, cancer nurse specialist, telemedicine nurse, rehabilitation nurse, nurse tutor, nurse practitioner, registered nurse, chronic obstructive pulmonary disease nurse, clinical nurse specialist, community nurse, telemedicine nurse

Physician

- Community physician (eg, primary care physician, ambulatory physician, or community physician), hospital physician (eg, hospitalist, resident, or most responsible physician), specialist

Textbox 2. Key functions performed by providers during the hospital-to-home transitions.

Informational continuity: "The use of information on past events and personal circumstances to make current care appropriate for each individual" [52]

- Communicate or liaise: communication or liaising with patients, caregivers, and other providers
  - Ensure the flow of information across multidisciplinary teams in the same or different sectors [62,63]. Advise and share relevant information about the patient with other providers (eg, primary care provider) [64-67]. Coordinate with other providers to ensure that services, resources, and equipment are set up for the patient. Make connections with community-based services and resources [68,69]. Communicate with patients and caregivers promptly [63]. Inform patients and caregivers and family when and how they will be contacted and whom to follow-up with if they do not receive follow-up [60,68,70,71]
- Educate: providing education to patients and caregivers
  - Educate patients about condition, disease management, symptoms, adverse events or red flags, symptom management, dietary recommendations, medication instructions, general condition or health, explain care protocols [25,68,72-81], reinforce education (eg, teach-back strategies) [82], and provide verbal or written instructions and demonstrations [63,83]
- Knowledge: providers having relevant knowledge
  - Have solid knowledge about disease and treatment, community services, where patients can seek support, and the best practices [79]. Be familiar with available community services and their eligibility
- Support or resource: providing relevant information to patients and caregivers
  - Provide informational or social support and personalized hospital-to-home support [83,84]
- Counsel (fell within 2 different categories): providing advice and recommendations to motivate behavior change
  - Provide medication, rehabilitation, dietary, or emotional counseling to patients and caregivers to motivate behavior change [79-81,85]
- Document: documenting relevant information accurately
  - Document all actions and entire plan to ensure timely information exchange between providers and ownership of the accuracy and completeness of the information [65,86]

Management continuity: "A consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs" [52]

- Confirm and verify: confirming and verifying that appropriate processes and procedures were carried out to ensure continuity of care
  - Confirm that discharge summaries have complete information about a patient [87] and are sent to the team [75]. Ensure that follow-up appointments and services have been scheduled [65,75,78,88]. Confirm that patients and caregivers and families understand discharge instructions and that logistics are in place in preparation for discharge [75]. Verify that the appropriate practitioners are involved [75]
- Plan: creating a personalized care plan for patients
  - Create or contribute to a patient's care plan based on knowledge of the patient's individual needs and goals [89]
- Refer: referring patients and caregivers to appropriate services and resources
  - Refer patients to appropriate community services and resources to maintain continuity of care after discharge (eg, transportation) [62,72,90-93]
- Assist in navigation: helping patients and caregivers to navigate the health system
  - Assist patients in navigating through complex health systems and discharge pathways [62,72,90-93]
- Advocate: advocating patients' access to appropriate resources and services
  - Advocate for access and entry to appropriate health and social services across settings and providers to ensure that patients' needs are met, and break down health system and communication barriers [58,63,94]
- Follow-up: following up with patients and caregivers after discharge
  - Postdischarge follow-up and outreach with patients to identify unmet needs [95]
- Arrange or set up: facilitating access to different providers, services, and resources
  - Coordinate with different providers and services to arrange and organize timely access to postdischarge appointments and services, including primary care, medication delivery, medical devices, and transportation. Assist patients and caregivers and families in meeting their health care needs (eg, assistance completing forms) [25,58,61,62,90,91,96-98]

- Assess patients’ needs: assessing patients’ various needs to support safe transitions
    - Have a comprehensive knowledge of the patients’ care needs (eg, “patient’s medical, functional, cognitive, affective, psychosocial, nutritional, and environmental status” [76,99]) and goals to inform care and discharge plan through assessment findings [58,63,100]. Assess patients’ needs for home care and community support and resources, and identify and address potential medication adherence issues to prevent readmission [63,67,76,78,83,95,101,102]
- Direct care provision: clinical intervention
    - Provide in-person and hands-on clinical care (eg, medical, nursing, or rehabilitation intervention) [58]
- Manage: manage health and social care and needs during transitions
    - Be a manager of the patient’s care and discharge pathways [72,89]
- Monitoring: activities conducted to monitor patients’ status after discharge
    - Monitor patients for medical, health, physical, or functional status declines or the inability to self-manage their condition [86,87]. Monitor the results of medical tests and treatment adherence [89]. Conduct ongoing evaluations of the discharge plan and patient and caregiver and family needs (eg, through home visits) and create a new action plan or refer to other providers if necessary [63,89]
- Improve: improving care based on organizational quality improvement initiatives
    - Participate in quality improvement plans [59]
- Prepare: preparing providers, patients, and caregivers for patients’ discharge
    - Prepare personalized discharge plans with the patient, caregiver and family, and providers and complete discharge preparation, including determining discharge location [62,89-91]. Prepare discharge hand-over sheets [75]. Prepare a community care plan [96]

Relational continuity: “An ongoing therapeutic relationship between a patient and one or more providers” [52]

- Collaborate: work with patients, caregivers, and other providers to manage care
    - Collaborate with patients, caregivers and family, and other providers (eg, hospital physician-primary care physician) to create care plans [60,103]
- Empower: facilitate patient and caregivers’ involvement in the case
    - Facilitate active participation of patients and caregivers and family in care and integrate them as full partners in decisions about treatment [60,85,89,104]
- Counsel (2 categories): providing counseling to patients and caregivers in an understandable way
    - Provide individual medication counseling and ensure that patients can comprehend medication instructions and potential side effects of medication [80]. Provide emotional or dietary counseling and counseling regarding the patients’ rehabilitation needs to motivate behavior change [69,79,85]
- Coaching: providing coaching and guidance to patients and caregivers
    - Provide clinical advice, troubleshoot problems, and provide coaching about self-management skills [72,85,104-106]. Answer questions regarding concerns or issues from patients or caregivers and family [107]. Inform patients about what to expect during the transition and provide tips on communication with providers [82]
- Rapport: building relationships with patients and caregivers
    - Develop rapport and trusting relationships with patients and caregivers or family [25,98,108-110]

Phase 2

Overview

The phase 2 database search identified 29,359 articles. Additional articles (n=10) were identified from hand-searching reference lists of the included articles. After removing duplicates, 81.88% (24,048/29,369) remained for the title and abstract screening and 4.02% (967/24,048) met the criteria for full-text review. Of these 967 articles, 142 (14.7%) met the study inclusion criteria (see Figure 1 [111] for the PRISMA [Preferred Reporting Items for Systematic Reviews and Meta-Analyses] flow diagram). Table 1 provides details of the study characteristics.

The studies were conducted in multiple countries, most of them in the United States (Table 1). They were published between 2010 and 2020, with a growing rate of publications over the years (Figure 2).

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram. Adapted from Moher et al [111].

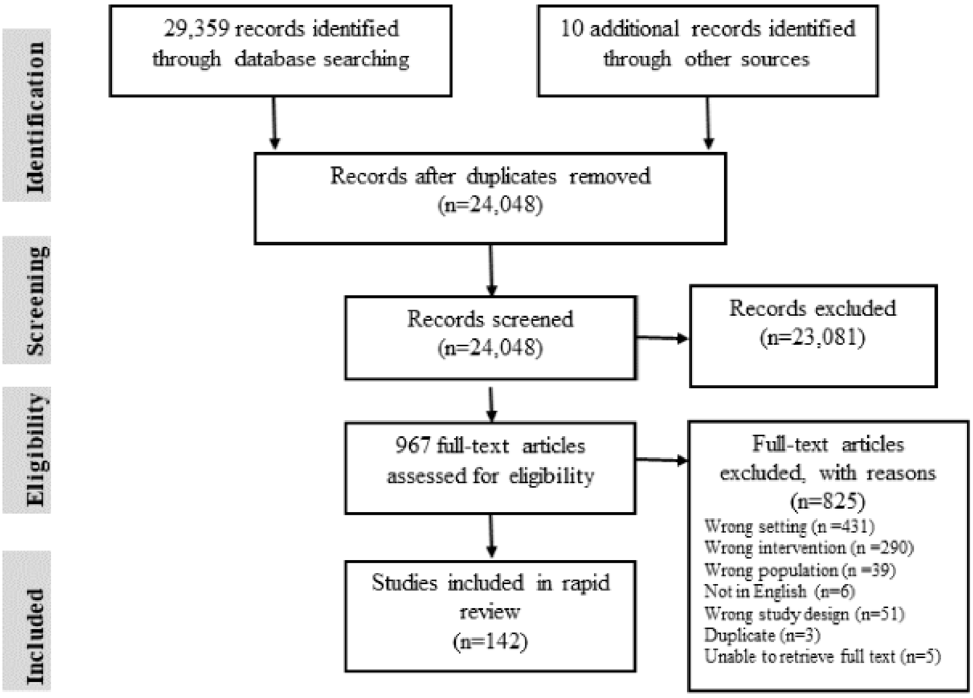


Table 1. Study characteristics.

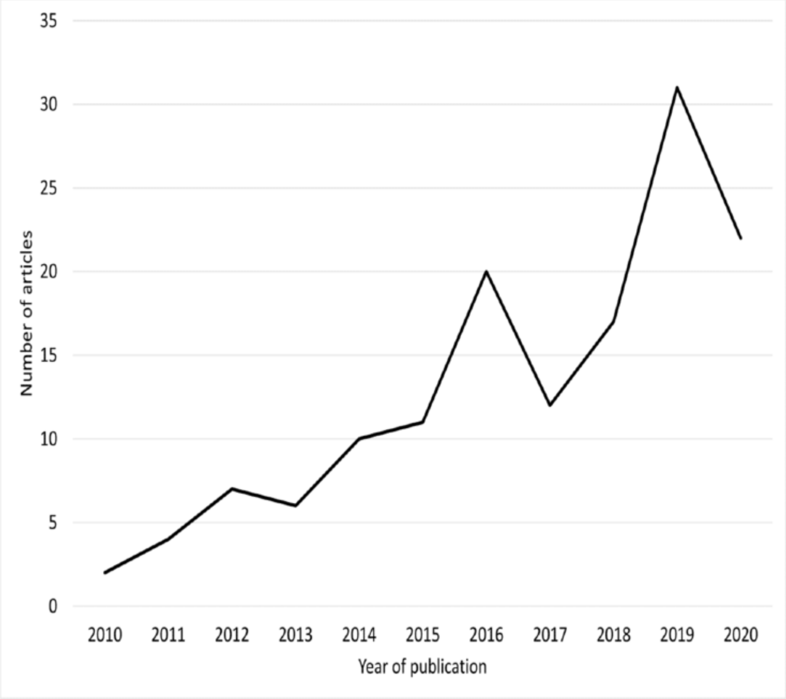
Study	Country	Medical condition and intervention details
Amir et al, 2017 [112]	Israel	Cardiac (heart failure)
Ammenwerth et al, 2015 [113]	Austria	Cardiac (coronary heart disease)
Amroze et al, 2019 [114]	United States	Non–condition-specific criteria
Andikyan et al, 2012 [115]	United States	Cancer (gynecologic cancer)
Arcilla et al, 2019 [116]	United States	Multiple chronic conditions (eg, congestive heart failure, chronic obstructive pulmonary disease, and diabetes mellitus)
Austin et al, 2012 [34]	United States	Cardiac (congestive heart failure)
Avery et al, 2019 [117]	United Kingdom	Cancer (major abdominal surgery, including surgery for esophageal, gastric, or hepato-pancreato-biliary cancer)
Aziz et al, 2011 [118]	United Kingdom	Surgery (abdominal surgery)
Backman et al, 2020 [119]	Canada	Orthopedic (after hip fracture)
Barken et al, 2018 [120]	Norway	Respiratory (chronic obstructive pulmonary disease)
Barnason et al, 2019 [121]	United States	Cardiac (coronary artery bypass surgery or percutaneous coronary intervention)
Bednarski et al, 2019 [122]	United States	Cancer (colorectal cancer surgery)
Belarmino et al, 2019 [123]	United States	Cancer (radical prostatectomy)
Bernocchi et al, 2016 [124]	Italy	Neurological (stroke)
Bernocchi et al, 2012 [125]	Italy	Multiple conditions (chronic obstructive pulmonary disease, cardiac, dermatologic, diabetes, pulmonological, traumatic brain injury, and stroke)
Boeni et al, 2015 [126]	Switzerland	Diabetes
Book et al, 2013 [127]	Germany	Cancer (prostate, bladder, kidney, breast, or other types of cancer)
Bouwsma et al, 2018 [128]	Netherlands	Surgery (gynecological surgery)
Bouwsma et al, 2018 [35]	Netherlands	Surgery (gynecological surgery)
Campbell et al, 2019 [129]	United States	Orthopedic (total knee or hip arthroplasty)
Carrier et al, 2016 [130]	France	Cancer (colorectal surgery)
Chang et al, 2020 [131]	China	Cancer (esophagectomy)
Chen et al, 2010 [132]	Australia	Patients admitted to the aged care hospital ward
Chen et al, 2019 [133]	China	Cardiac (chronic heart failure)
Chiang et al, 2012 [134]	China	Cardiac (chronic heart failure)
Cox et al, 2018 [135]	United States	Medical and surgical intensive care unit patients (receipt of mechanical ventilation for >48 consecutive hours and successful extubation before discharge)
Cox et al, 2019 [136]	United States	Cardiac (cardiorespiratory failure)
Davis et al, 2015 [137]	United States	Multiple conditions (acute chronic disease)
Day et al, 2018 [138]	United States	Orthopedic (total joint arthroplasty)
Dendale et al, 2012 [139]	United States	Cardiac (severe heart failure)
DeVito Dabbs et al, 2016 [140]	United States	Surgery (lung transplantation)
DeVon et al, 2010 [141]	United States	Cardiac (coronary heart disease)
Dexter et al, 2013 [142]	United States	Orthopedic (total hip replacement)
Dorothy et al, 2016 [143]	United States	Cardiac (cardiovascular surgery)
Duncan et al, 2018 [144]	United States	Neurological (stroke and transient ischemic attack)
Dunn et al, 2015 [145]	United States	Patients on medical or surgical units on warfarin
El-Kareh et al, 2012 [44]	United States	Patients with positive and untreated or undertreated blood, urine, sputum, or cerebral spinal fluid cultures
Evangelista et al, 2015 [146]	United States	Cardiac (chronic heart failure)
Finn et al, 2011 [13]	United States	Patients on medical service

Study	Country	Medical condition and intervention details
Fitzsimmons et al, 2016 [147]	United Kingdom	Respiratory (chronic obstructive pulmonary disease)
Frail et al, 2016 [148]	United States	Patients taking ≥1 long-term medication
Gesell et al, 2019 [149]	United States	Neurological (stroke)
Gunter et al, 2018 [150]	United States	Surgery (vascular surgery)
Gurwitz et al, 2014 [40]	United States	Patients being discharged from an inpatient unit
Gustavell et al, 2019 [151]	Sweden	Cancer (pancreaticoduodenectomy)
Gustavell et al, 2019 [152]	Sweden	Cancer (pancreaticoduodenectomy)
Haynes et al, 2020 [153]	United States	Cardiac (decompensated heart failure)
Heaton et al, 2019 [154]	United States	Multiple conditions (acute myocardial infarction, pneumonia, congestive heart failure, chronic obstructive pulmonary disease, or diabetes)
Heiney et al, 2020 [155]	United States	Cardiac (heart failure)
Hewner et al, 2014 [156]	United States	Multiple conditions
Ho et al, 2016 [157]	China	Respiratory (chronic obstructive pulmonary disease)
Holleck et al, 2017 [158]	United States	Patients admitted to medical service
Holt et al, 2011 [159]	United States	Surgery (plastic surgery)
Hu et al, 2014 [160]	China	Cardiac (percutaneous coronary intervention)
Jayaram et al, 2017 [161]	United States	Cardiac (heart failure)
Jeungok et al, 2017 [162]	United States	Orthopedic
Jonker et al, 2020 [163]	Netherlands	Cancer (elective oncologic resection of a solid tumor)
Kamoen et al, 2020 [164]	Belgium	Neurological (ischemic stroke)
Kang et al, 2019 [165]	China	Neurological (stroke)
Karapinar-Çarkit et al, 2014 [166]	Netherlands	Patients discharged from the cardiology and respiratory wards
Katz et al, 2016 [167]	United States	Cancer (pancreatectomy)
Keeping-Burke et al, 2013 [168]	Canada	Cardiac (coronary artery bypass graft surgery)
Khan et al, 2018 [169]	Denmark	Cardiac (on- or off-pump coronary artery bypass graft or heart valve surgery)
Klement et al, 2019 [170]	United States	Orthopedic (total joint arthroplasty)
Kogut et al, 2014 [171]	United States	Chronic medical conditions
Lacson et al, 2018 [172]	United States	Respiratory (pulmonary nodules)
Lafaro et al, 2020 [37]	United States	Cancer (colorectal, gastric, pancreatic, and liver cancer surgery)
Lavu et al, 2019 [36]	United States	Surgery (pancreaticoduodenectomy)
Layton et al, 2014 [173]	United States	Cardiac (coronary artery disease or congestive heart failure)
Lehnbom et al, 2014 [174]	Australia	Patients discharged from a hospital unit
Lin et al, 2020 [175]	China	Cardiac (coronary artery disease)
Lindhardt et al, 2017 [176]	Denmark	Patients admitted to internal medicine units and at nutritional risk
Lowres et al, 2016 [177]	Australia	Cardiac (cardiac surgery)
Luo et al, 2019 [178]	China	Orthopedic (total hip arthroplasty)
Lyu et al, 2016 [179]	China	Cancer (head and neck tumor)
Madigan et al, 2013 [180]	United States	Cardiac (heart failure)
Markle-Reid et al, 2020 [181]	Canada	Neurological (stroke and multimorbidity)
Martirosov et al, 2020 [182]	United States	Patients admitted to hospital
Mathar et al, 2015 [183]	Denmark	Respiratory (chronic obstructive pulmonary disease)
McCloskey et al, 2015 [184]	Canada	Patients discharged from geriatric rehabilitation

Study	Country	Medical condition and intervention details
McGillion et al, 2020 [185]	Canada and United Kingdom	Cardiac and major vascular surgery
Melholt et al, 2018 [186]	Denmark	Cardiac (ischemic heart disease or heart failure, including patients who had undergone coronary artery bypass or valve surgery)
Meng-Yao et al, 2020 [187]	China	Neurological (stroke)
Metcalf et al, 2019 [188]	United States	Cancer (radical cystectomy)
Moffet et al, 2015 [189]	Canada	Orthopedic (total knee arthroplasty)
Moro Agud et al, 2016 [190]	Spain	Patients admitted to a hospital unit
Mousa et al, 2019 [191]	United States	Surgery (arterial revascularization with groin incision)
Moy et al, 2014 [192]	United States	Patients admitted to medical service
Nazar et al, 2016 [193]	United Kingdom	Patients on ≥4 medicines or had changes in medicines during the hospital stay
Newnham et al, 2015 [194]	Australia	Patients discharged from the acute general medical ward
Nielsen et al, 2020 [195]	Denmark	Surgery (kidney transplantation)
Nilsson et al, 2020 [196]	Sweden	Cancer (prostate cancer surgery)
Nundy et al, 2013 [197]	United States	Cardiac (heart failure)
Ong et al, 2016 [198]	United States	Cardiac (heart failure)
Ostrovsky et al, 2016 [199]	United States	Non–condition-specific criteria (medical fee-for-service patients)
Park et al, 2017 [200]	South Korea	Orthopedic (total knee replacement)
Pastora-Bernal et al, 2018 [201]	Spain	Orthopedic (arthroscopic subacromial decompression)
Pavic et al, 2020 [202]	Switzerland	Cancer (palliative cancer care)
Pavic et al, 2020 [203]	Switzerland	Cancer (palliative cancer care)
Pedone et al, 2015 [204]	Italy	Cardiac (heart failure)
Piau et al, 2019 [205]	United States	Cancer
Piette et al, 2020 [206]	United States	Patients admitted with an illness that is associated with increased rehospitalization risk
Ponce et al, 2016 [207]	United States	Surgery (neurosurgical or orthopedic)
Prince et al, 2019 [208]	United States	Cancer (hematologic malignancies)
Ramkumar et al, 2019 [209]	United States	Orthopedic (total knee arthroplasty)
Reed et al, 2020 [210]	United States	Diabetes
Reider-Demer et al, 2018 [211]	United States	Neurological (elective neurosurgery)
Requena et al, 2019 [212]	Spain	Neurological (stroke)
Ritchie et al, 2016 [213]	United States	Multiple conditions (heart failure and chronic obstructive pulmonary disease)
Sabir et al, 2019 [214]	United Kingdom	Non–condition-specific criteria
Saleh et al, 2014 [215]	Norway	Respiratory (chronic obstructive pulmonary disease)
Santana et al, 2017 [216]	Canada	Patients admitted to medical teaching units with multiple comorbidities and complicated medication profiles
Scheper et al, 2019 [217]	Netherlands	Orthopedic (joint arthroplasty)
Schneider et al, 2017 [218]	United States	Neurological (stroke)
Sinha et al, 2019 [219]	United States	Patients admitted to general medicine service
Smith et al, 2016 [220]	United States	Patients admitted to general medicine, geriatrics, or cardiology inpatient services; medically complex (≥2 comorbid conditions)
Sorknaes et al, 2011 [221]	Denmark	Respiratory (chronic obstructive pulmonary disease)
Sorknaes et al, 2013 [222]	Denmark	Respiratory (chronic obstructive pulmonary disease)
Sui et al, 2020 [223]	China	Cancer (surgical resection for non–small cell lung cancer)
Sun et al, 2017 [224]	United States	Cancer (major abdominal cancer surgery)

Study	Country	Medical condition and intervention details
Sun et al, 2017 [225]	United States	Cancer (lung cancer surgery)
Tamblyn et al, 2019 [226]	Canada	Patients admitted to medical and surgical hospital units
Tamblyn et al, 2018 [227]	Canada	Patients admitted to medical and surgical hospital units
Timmers et al, 2019 [228]	Netherlands	Orthopedic (total knee replacement)
Treskes et al, 2020 [229]	Netherlands	Cardiac (myocardial infarction)
van den Berg et al, 2016 [230]	Australia	Neurological (stroke)
Van der Meij et al, 2018 [231]	Netherlands	Surgery (intermediate-grade abdominal surgery)
Vest et al, 2015 [232]	United States	Non–condition-specific criteria
Vesterby et al, 2017 [233]	Denmark	Orthopedic (fast-track hip replacement)
Vianello et al, 2016 [234]	Italy	Respiratory (chronic obstructive pulmonary disease)
Villani et al, 2014 [235]	Italy	Cardiac (heart failure)
Wade et al, 2012 [236]	Australia	Frail older adults with multiple chronic conditions
Wang et al, 2017 [237]	China	Respiratory (chronic obstructive pulmonary disease)
Wang et al, 2018 [238]	China	Cancer (colorectal cancer or other digestive and urinary tumors and permanent stoma after surgery)
Wang et al, 2018 [239]	China	Orthopedic (hip replacement surgery)
Wan et al, 2018 [240]	China	Neurological (hypertensive ischemic stroke)
Whitehouse et al, 2020 [241]	United States	Diabetes
Wilcock et al, 2019 [242]	United Kingdom	Patients admitted to a hospital
Wolf et al, 2016 [38]	Sweden	Cardiac (acute coronary syndrome)
Zheng et al, 2019 [243]	China	Orthopedic (total joint arthroplasty)
Zhou et al, 2019 [244]	China	Cancer (breast cancer surgery)
Zhou et al, 2020 [245]	China	Cancer (breast cancer surgery)

Figure 2. Year of article publication.



Participants Targeted

Medical Conditions and Interventions Targeted

Digital health interventions were most frequently used to facilitate transitions for cardiac conditions (eg, cardiac surgery and chronic heart failure; 28/142, 19.7%) and cancer (eg, cancer surgery and cancer management; 26/142, 18.3%). Fewer digital health interventions targeted patients admitted to specific hospital units (eg, geriatric, medical, or intensive care unit; 19/142, 13.4%) and patients with multiple conditions (12/142, 8.5%), orthopedic conditions (16/142, 11.3%), neurological conditions (eg, stroke and brain tumor; 12/142, 8.5%), other surgical interventions (eg, after kidney transplantation; 11/142, 7.7%), and respiratory conditions (eg, chronic obstructive pulmonary disease management; 10/142, 7%). In addition, a small number of digital health interventions supported transitions for patients who had diabetes (3/142, 2.1%) or non–condition-specific criteria (eg, age group and medical health plan; 5/142, 3.5%).

Age Groups Targeted

In total, 15.5% (22/142) of the included interventions were conducted with samples of strictly older adults. Other interventions did not specify a targeted age range within their inclusion criteria (54/142, 38%) or had included participants aged 18 to 21 years or older (49/142, 34.5%).

Details of Digital Health Technologies

Intervention Type

Of the 142 interventions, 47 (33%) were classified into multiple categories of intervention types (N=193 intervention classifications). Of the 6 intervention-type characterizations, smartphone, tablet, or web-based interventions (91/193, 47.2%) were the most common than telemonitoring and wearables, clinical documentation system (45/193, 23.2%), clinical documentation systems (29/193, 15%), automated telephone calls or automated SMS text messaging (14/193, 7.3%), email interventions (10/193, 5.2%) or other interventions (eg, television video; 4/193, 2.1%).

Provider Roles and Functions Involved in the Intervention

As shown in Table 2, a total of 35.9% (51/142) of the interventions used multiple provider roles (n=202 provider roles identified) in the implementation of the digital health intervention, with nurses (64/202, 31.7%) and physicians (61/202, 30.2%) being the most common providers of digital health interventions. Discharge-specific personnel such as a transition coach, nurse care transition coordinator, discharge facilitator, advanced practice nurse, and systems navigator were less common (18/202, 8.9%).

Some interventions had designated a study-specific health care provider to carry out the digital health intervention activities, whereas others added the responsibility onto a provider's existing workload. The responsibilities of providers also differed based on the type and purpose of technology and whether communication between patients and providers was initiated by patient or provider. Among some interventions with patient-initiated communication, providers had to always be available for consultation during the intervention period.

The digital health interventions were most commonly used up to 7 days after discharge (29/142, 20.4%) or between 31 and 90 days after discharge (39/142, 27.5%). It was less common for the interventions to continue for 91 days to <6 months after discharge (18/142, 12.7%) or beyond 6 months after discharge (7/142, 4.9%).

Table 2. Provider roles and examples of involvement in technology intervention used to facilitate hospital-to-home transitions (N=202).

Provider role; providers, n (%)	Specific examples	Examples of provider role–technology interactions
Physician; 61 (30.2)	Community physician (eg, primary care physician, ambulatory physician, and community physician), hospital physician (eg, hospitalist, resident, and most responsible physician), and specialist (eg, cardiologist, surgeon, occupational physician, geriatrician, and pulmonologist)	Family physicians were alerted when patient data (eg, biometric or symptoms) fell outside predefined parameters and asked to visit or contact the patient [139]
Nurse; 64 (31.7)	Specially trained nurse (trained in device use), research nurse, cancer nurse specialist, telemedicine nurse, rehabilitation nurse, nurse tutor, nurse practitioner, registered nurse, chronic obstructive pulmonary disease nurse, clinical nurse specialist, and community nurse	They reviewed all transmitted biometric and symptom data, flagged patients whose data fell outside the predefined parameters, and communicated with or assessed patients using communication technology [153,168]
Clinician; 19 (9.4)	Discipline not specified	Clinicians were alerted when patient responses were outside predefined parameters, and they reviewed flagged responses [161]
Allied health; 19 (9.4)	Occupational therapist, physiotherapist, social worker, and psychologist	Conducted telehealth consultations or sessions [37,183]
Pharmacist; 18 (8.9)	Hospital or community pharmacist	Access information from other providers in the same facility or across facilities, settings or receive information from them and send information to them [214]
Navigation-specific roles; 18 (8.9)	Advanced practice nurse or provider, care manager, care or program coordinator, care transition nurse, case manager, discharge planner or facilitator or discharge planning nurse, nurse navigator, post–acute care coordinator, system navigator, and transition coach	Provided 24-hour consultation, which was accessible to patients through technology [175]
Other; 3 (1.5)	Physician's assistant, unit supervisor, surgical team's physician's assistant	Used to communicate with other providers and send and receive information [208]

Technology Functions

In terms of the technology functions that supported hospital-to-home transitions, most (116/142, 81.7%) of the technologies fell into multiple categories (ie, 57/142, 40.1%, fell into 2 categories and 59/142, 41.5%, fell into 3 categories).

Of the 317 total technology functions within the included interventions, 142 (44.8%) were related to *management continuity*, including following up, assessing, and monitoring patients' status after hospital discharge, as well as facilitating referrals. Some technologies could identify values outside a predefined range during follow-up, assessment, and monitoring of patients' status. However, others required human resources to review all data to identify abnormal values. In both cases, if values fell outside the range, a human resource (eg, provider or study personnel) had to follow-up and provide appropriate guidance and immediate treatment or the technology instructed a patient to initiate contact with a provider. *Informational continuity* was supported among 32.2% (102/317) of the identified technology functions, including facilitating communication (eg, between inpatient and outpatient providers or between patient and provider) and educating patients and caregivers. *Relational continuity* (eg, counseling and rapport building) was least supported by the technologies (73/317, 23%).

Outcomes of Interest

Of the total outcomes of interest (n=315) examined in the articles, more than half of the outcomes evaluated the effect of the intervention on patient-level factors (eg, disease knowledge, quality of life, and changes in physical or psychological functioning) and technology-user interactions (eg, use of technology, patient satisfaction with technology, and the perceived value of technology) at 28.6% (90/315) and 28.3% (89/315), respectively. Of all outcomes, 17.5% (55/315) related to health care use, examined through health care–related costs and hospital readmission rates or emergency department visits at various time points (eg, 30, 60, 90, and 180 days after discharge). The intervention effect on provider-related outcomes (eg, changes in provider workflows, provider burden, and clinical documentation accuracy), implementation-related outcomes (eg, compliance; 9/315, 2.9%), and caregiver- and family-related outcomes (eg, caregiver stress; 3/315, 1%) were less commonly examined (23/315, 7.3%). *Other* outcomes (eg, documentation time, economic evaluations; 46/315, 14.6%) were measured.

Lessons Learned From Digital Health Interventions

The lessons learned from the interventions pertained to challenges (eg, researcher-identified limitations or challenges of interventions) and opportunities (eg, researcher-identified strengths of interventions and recommendations); these were categorized into two broad categories: (1) technology-related and (2) research process–related (Table 3).

Table 3. Summary of the lessons learned from implementation of digital health interventions.

Challenge and description	Examples
Technology-related challenges	
Usability issues	
Participants' physical, functional, and sensory function	• Low vision • Hand tremor
Patients' and providers' lack of technical skills and experience	• Forgetting log-in information or not remembering to charge the device • Accidentally disabling device features • Low technology comfort
Device-related technical issues	• Internet connectivity issues • Software updates affecting function • Immaturity of the prototype
Fit and compatibility issues	• Poor fit with patients' or providers' routine • Device incompatible with older devices • Not integrated into organization's electronic documentation system • Identifying provider functions rather than their roles may enable the technology to accommodate differences among jurisdictions and changing scopes of practice
Technology content and function	
Patient-facing content	• Hypertext links were distracting and confusing • Language too technical • Offensive tone and complexity of the wording • Symptom-reporting questions too specific or broad caused misunderstanding
Expectations of patient-initiated provider contact	• Not all participants were confident about the appropriate circumstances in which to contact the provider
Device notifications	• Excessive alerts caused "alert fatigue" and resulted in less attention being paid to the alert or ignoring it altogether
Technology-related opportunities	
Technology function and features	
Enhancing functionality	• Address and improve multiple components of the transition process
Accessibility, adaptations, and customization	• Low-vision adaptations • Adapt for participants with low technological literacy and no social support • Self-directed apps • Use of personal devices when possible and compatibility across multiple data and operating systems • Provision of the device when participants do not have access to a personal device
Training	• Technical setup • Training on technology use • Engage caregivers in the intervention when possible
Fit with workflows, workloads, and buy-in	• Participants, family, caregivers, and providers should inform the technology design and how technology could be integrated into the day-to-day practices of all stakeholders • Accounting for providers' ethical, legal, and professional responsibilities
Research process–related challenges	
Data collection	
Recruitment and retention challenges	• Lack of interest • High attrition
Small sample size	• Unable to explore the relationship between participants' profiles, participants' adherence and compliance to intervention or conduct subgroup analyses
Sampling bias	• Homogenous samples • Inclusion limited to those with technology comfort or access

Challenge and description	Examples
Missing data	• Impacting reliability of intervention results
Outcome measures	• Outcome measures such as rehospitalization and survival may not be sufficiently sensitive to determine intervention impact • Single-blinded evaluator could introduce measurement error
Interventions across settings or institutions	• Cross-setting coordination challenges
Research process–related opportunities	
Data collection	
Recruitment considerations	• Video of 10-to-15–minute duration describing the intervention (potential benefits and utility) during recruitment to reduce apprehension • Consideration of low compliance rates within sample size calculations • Comparing the characteristics of participants with those of individuals who declined can indicate selection bias and affect the intervention's generalizability and acceptability
Outcomes	• Careful consideration of outcome measures (eg, objective or subjective) and end points
Missing data	• Begin intervention during hospitalization • Schedule follow-ups during routine patient visits to minimize data lost during follow-up

Technology-Related Challenges and Opportunities

Technology-related challenges and opportunities pertained to the use of the devices.

Technology-Related Challenges

Among digital health interventions, researchers reported usability issues with the technology because of patients' physical condition [177], patients' or providers' lack of technical skills and experience [159,176,177,202], and the technology not fitting into patients' or providers' routine and workflow [119,173]. Regarding fit with workflows, researchers emphasized that health care providers operate within regulated environments; ethical, legal, and professional considerations related to providers' roles and care settings had to be accounted for in the design of digital health technology interventions [148,159,227]. Technical issues such as internet connectivity issues, software updates, or immaturity of the prototype [148,152,177] also decreased usability and interfered with the technology's function (eg, restricted data transfer and alert failure) [152,202]. In addition, some researchers encountered compatibility issues with older devices and other organizations' electronic documentation systems, which created usability issues [44,145,148,150,192,210,212].

In terms of the technical content, researchers found that some participants perceived the patient-facing content as problematic because of the technical language, tone, or complexity [152,162], as well as hypertext links that caused confusion [39,152]. Patient-initiated technology functions also presented a challenge because not all participants could use the functions or follow the instructions as intended [196]. Researchers also found it challenging to set alerts that would be appropriate for all patients because excessive alerts caused "alert fatigue" and resulted in less attention being paid to the alert or ignoring it altogether [40,44,152,157].

Technology-Related Opportunities

A few researchers emphasized that designing digital health interventions to address and improve multiple components of the transition process may enhance functionality [119,145]. In addition, they indicated that technology accessibility, adaptations, or customization could accommodate individual preferences and increase applicability to different populations [39,140,205,227]. Researchers indicated that increasing accessibility could start with providing the technology to participants without a personal device to reduce disparities of access based on technology ownership [150]. Researchers suggested using participants' devices to enhance usability when possible, which may require compatibility across multiple data and operating systems [122,167,212]. In addition, technical setup and training on using the technology and engaging caregivers in the intervention could support the usability and intervention quality, safety, and adherence [112,135,157]. Moreover, building self-directed functions might help overcome logistical barriers associated with scheduled interventions [136]. This finding extends to timely feedback because researchers found that participants wanted to be notified when providers had reviewed their responses [150].

To address the technology's fit with workflows, workloads, and buy-in, some researchers believed that participants, family, caregivers, and providers should be engaged in helping to design the intervention [136,148,228]. Researchers found that interventions that placed high accountability and responsibility on health care providers and added additional work to their workload resulted in provider-related usability issues because providers "struggled to find time in their day" to carry out intervention activities [40,150,195]. Researchers noted that identifying functions rather than provider roles may enable the technology to accommodate differences among jurisdictions (eg, country and institution) and changing scopes of practice over time [227]. Alternatively, if human resources are limited, interventions using automated telephone calls or central monitoring centers for multiple institutions could be considered to reduce the number of personnel and time required for monitoring [188]. Thus, understanding how technology could be integrated into the day-to-day practices of all stakeholders was an essential task for technology developers, along with helping providers envision ways to implement the technology in practice [119,181].

Research Process–Related Challenges and Opportunities

Challenges and opportunities within the reported research processes pertained to the recruitment process, data collection, and study and intervention designs.

Research Process–Related Challenges

Recruitment challenges and high attrition were commonly reported within the studies [135,246]. As several interventions had a small sample size, researchers acknowledged limitations, including being unable to explore the relationship between participants' profiles and adherence and compliance information or conduct subgroup analyses [112,135,157,205]. Researchers reported that sampling bias could have had an impact on the generalizability of their results because the samples were small [115,141,165] and homogenous (ie, primarily White) [150] and could have been exacerbated because inclusion was limited to participants with internet-enabled devices [201]. Missing data was another concern reported by researchers that may have affected the reliability of the intervention results [158].

Beyond data collection, researchers reported that interventions conducted at a single site may have reduced generalizability to other settings [160,181,218,226,241]. The study by DeVito Dabbs et al [140] indicated that outcome measures such as rehospitalization and survival may not be sufficiently sensitive to identify the impact of a technology intervention.

Researchers found that effectively integrating the technology in clinical environments would likely require early engagement with patients and providers, support from senior leadership, integration within existing electronic systems [119,144,148,166], and testing of technologies in real-world settings to identify implementation barriers [140]. Finally, researchers of a digital health technology intervention that operated across settings or institutions reported challenges with coordination among providers in hospital, primary care, and community settings [148].

Research Process–Related Opportunities

Several researchers recommended more extensive and diverse participant samples in future digital health interventions [150,171,173,247] and consideration of low compliance rates within sample size calculations [173]. They believed that providing participants with an explanation of the potential benefits and utility of the technology may also enhance study participation [173]. In addition, comparing the characteristics of participants with those of individuals who declined participation gave researchers insight into selection bias and the intervention's generalizability and acceptability [151,169,231,237].

Regarding outcomes of interest, researchers advised carefully considering which outcome measures (eg, objective or subjective) [173,224] and end points to use [186,193]; multicenter studies with longer follow-up time (ie, >30 days after discharge) might be required to observe the intervention's effect on patient-clinician relationships [160,181]. Opportunities identified by researchers to improve data include analyzing technology log data for objective data on patients' and providers' use of technology [186,193], beginning the intervention within the hospital setting, and incorporating the follow-ups into routine patient visits to potentially minimize data lost during follow-up [141,148].

Discussion

Recommendations

This rapid review provides an overview of digital health interventions supporting hospital-to-home transitions and describes how the technologies have been used to support the roles and functions of health care providers in supporting these transitions. Consistent with the aim of a rapid review approach, we have compiled a set of recommendations (Table 4) to guide the design of new and existing digital health interventions such as Digital Bridge that support hospital-to-home transitions based upon the reviewed literature. Our review extends and complements the existing literature [41,42,248] by highlighting transition-specific considerations within the design and implementation of future digital health interventions that better support provider roles and functions during transitions.

Table 4. Recommendations to guide the design and implementation of digital health interventions to facilitate hospital-to-home transitions.

Recommendation	Description
Recommendation 1: align the design and delivery of digital health interventions to provider functions	• As roles and functions can differ based on several factors (eg, the organizations, jurisdiction, and care settings), technology functions should consider the roles and functions relevant to their target setting; alternatively, to increase generalizability, technology may need to support specific provider functions (ie, provider responsibilities) rather than outlining specific roles (ie, provider titles) • Address multiple functions within transitional care, including functions supporting informational, management, and relational continuity of care • Integration of technology with multiple organizations and across care settings • Added provider functions with technology use should be minimal (eg, automated and self-directed functions could be integrated into interventions to reduce provider functions) • Share functions related to technology use with patients and caregivers when possible • Begin before or immediately after hospital admission and extend care into the community
Recommendation 2: design for, and test with, older adults	• To ensure that technology functions effectively meet the transitional care needs of older adults, digital health interventions should be designed for, and tested with, older adults • Consider strategies to recruit and retain older adults with poor health • Consider how technology functions may affect inequities • Include caregivers, when possible, in digital health interventions because they play valuable roles in hospital-to-home transitions
Recommendation 3: examine multilevel outcomes	• Examine reasons for declining and dropping out of interventions • Examine multilevel outcomes • Provider-level outcomes may give insight into whether technology functions are perceived to support provider functions effectively • Evaluate specific technology functions

Recommendation 1: Align the Design and Delivery of Digital Health Interventions With Provider Functions

This review demonstrates that many existing technologies that support hospital-to-home transitions encounter implementation-related barriers. The health care system is complex, and the discharge process is often “busy, rushed and emotional” [249]. During hospital-to-home transitions, patients move from one setting to another and provider functions and responsibilities become unclear because communication often fails to cross boundaries [250]. Thus, a critical lesson from this review is that digital health interventions should emphasize the provider functions that the technology supports rather than focusing on how professional groups can use solutions because roles and functions can differ by organization and care setting.

We have highlighted that many providers involved in transitions tend to have overlapping functions. We have outlined specific provider functions that could be built into the design of digital health interventions to support transitional care workflows and potentially reduce provider burden. These functions may address the factors presently limiting uptake of digital health interventions, including poor fit with providers’ functions and provider perceptions of low degree of usefulness [41,42,248]. To meaningfully support hospital-to-home transitions, digital health interventions may need to address multiple functions involved in patient care beyond primarily supporting functions related to management continuity (eg, monitoring) and informational continuity. On the basis of the findings from this review, technology functions related to relational continuity warrant further exploration. These are the components that are appropriate for technology to address and support and the ones that rely on the interface between people and technology.

Moreover, technologies should be designed to minimize the burden on providers and be designed in such a way that they can support provider functions. Although technologies demonstrate their ability to support specific provider functions such as remote monitoring and patient education, they add functions and place high levels of accountability on single providers. For instance, remote monitoring technologies could yield large quantities of data that providers then become responsible for sorting through and acting on, adding another function to their workload [120,153]. Integration of such technologies in clinical practice could be unfeasible because the added provider functions are among the prominent barriers to the uptake of technologies [41].

Perceived usefulness may be improved by highlighting how the purpose and function of the technology fit with the functions of providers during hospital-to-home transitions and whether it could result in time savings and the workload reduction of providers and by outlining the responsibilities of providers in the delivery of digital health interventions [140]. Furthermore, as technologies integrate more advanced and automated functions, the burden on providers may be reduced. For instance, automated reminders may reduce demands on providers [34]. However, advanced technologies may not be suitable for all patients and these individuals may require training to recognize red flags and when to re-engage with providers [152]. Sharing responsibility with, and facilitating more active involvement of, patients and caregivers (when appropriate) or adding trained volunteers may be another way to reduce the added responsibility faced by health care providers [251].

Recommendation 2: Design for, and Test Digital Health Interventions Specifically With, Older Adults

Older adults have unique transitional care needs that the providers strive to meet through their functions. Provider functions to achieve relational and informational continuity of care have been deemed necessary to achieve high-quality hospital-to-home transitions for older adults [22,252]. However, we identified these functions to be a gap in the existing digital health interventions supporting hospital-to-home transitions because these functions were least supported by technology. We believe that these should be integrated within technology functions of future digital health interventions.

Of note, this review revealed that digital health interventions were rarely designed to meet the unique needs of older adults or exclusively tested with older adults. Thus, we contend that future technology functions should be designed to meet these specific transitional care needs while also accounting for design considerations related to older adults' complex needs, including physical, cognitive, and sensory needs [253-255]. Moreover, new strategies may be needed to recruit and retain older adults with poor health status. Using human-centered design principles, including co-designing and testing with clinicians and older adults with complex care needs, may enhance the use and effectiveness of interventions [41,248] and could reveal how better to integrate relational management into the technology functions. Furthermore, critical investigations of how the functions of existing digital health interventions may have contributed to the exacerbation of inequities are necessary to highlight new insights and guidance for functions of future interventions to eliminate such disparities [255,256].

Recommendation 3: Examine Multilevel Outcomes

We recommend that those leading digital health interventions examine outcomes of interest at multiple levels, including the patient, provider, organization, and system levels. Most transitional interventions examined the impact of digital health interventions on patient-level outcomes. However, not all studies had examined why participants declined or dropped out of digital health interventions, which would have provided valuable insights for future work. Provider-, organization-, and system-level outcomes were less common but are essential to consider. Although patient-level outcomes are helpful, costs and benefits need to be assessed for health care organizations and health systems, including economic feasibility and quality measures [257]. In particular, exploring patient-level outcomes can provide insight into whether the technology functions effectively support the provider functions.

Moreover, evaluating specific technology functions may provide insights into which ones may need to be refined. Researchers may also further explore the feasibility and benefits of transition-specific roles to support digitally enabled transitions because these studies were limited. In addition, reporting research-level outcomes, including insights and reflections from the research teams, may contribute valuable knowledge that could guide future interventions.

Limitations

Several factors limit this review. First, the rapid review methodology (eg, single-reviewer title and abstract screening and limited number of databases searched) may have led to missing relevant articles. Title and abstract screening were initiated after a minimum interrater reliability among screeners of κ=0.80 (ie, sufficient interrater reliability) was achieved to reduce the risk of missing relevant articles [258]. Second, there is a lack of standardized terminology and definitions for hospital-to-home transitions, provider roles and functions, transitional interventions, and digital health technologies. Thus, our inclusion criteria were difficult to apply and we had to create additional parameters to judge whether the studies related to these areas. For example, to be considered a *hospital-to-home transition intervention*, the intervention had to begin (ie, recruitment) at the hospital and extend to the community. It is also possible that some articles that failed to provide a detailed methodology could have been mistakenly excluded. However, this review was not intended to map the relevant literature entirely but rather to provide an overview of the landscape. Third, although we planned to conduct a quality appraisal using the Mixed Methods Appraisal Tool [259,260], we decided against a formal quality appraisal for two reasons: (1) the studies did not report sufficient details of their intervention design and methods for the team to appraise their quality confidently and accurately (eg, *Is randomization appropriately performed?* and *Are outcome assessors blinded to the intervention provided?*) and (2) this review intended to focus on critical lessons learned from the processes involved in designing, delivering, and evaluating the interventions rather than the interventions' effectiveness (eg, outcomes); thus, an appraisal was not critical to meet these objectives. We recommend that future digital health interventions report comprehensive details of their methods to enable future reviews to critically appraise them. Fourth, the inclusion criteria were modified to capture the most relevant literature and data during the review process. However, this led to deviations from the protocol (eg, excluding telephone-based interventions). Fifth, the purpose of phase 1 was to characterize typical roles and critical functions involved in transitions to create a general understanding of the context rather than to create an exhaustive list of all roles. However, we acknowledge that several roles, including the roles and functions of specialized health professionals, may not have been reflected in the results. In addition, roles and functions may also differ by factors such as the institution, country or region, and clinical setting. Thus, technology designers should consult with their intended users to ensure that the technology aligns with their roles and functions. Sixth, each article was reported as a single intervention because we could not link articles that reported a single intervention's outcomes within multiple articles. Finally, the findings are not limited to older adults because we included any study that included at least one older adult. Nonetheless, this review provides valuable information to guide the design and implementation of existing and new digital health interventions such as the Digital Bridge.

Conclusions

In conclusion, this review provides an overview of the landscape of digital health interventions that support hospital-to-home transitions and identifies recommendations for future studies based on the lessons learned. The findings from this review will serve as a valuable guide for the design and implementation of Digital Bridge and other digital health interventions to support hospital-to-home transitions.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategies.
[DOCX File , 31 KB - aging_v5i2e35929_app1.docx]

Multimedia Appendix 2
Phase 2 inclusion criteria.
[DOCX File , 19 KB - aging_v5i2e35929_app2.docx]

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Abbreviations

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRISMA-S: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Literature Search

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Review

The Effect of Cognitive Function Health Care Using Artificial Intelligence Robots for Older Adults: Systematic Review and Meta-analysis

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Abstract

Background: With rapidly aging populations in most parts of the world, it is only natural that the need for caregivers for older adults is going to increase in the near future. Therefore, most technologically proficient countries are in the process of using artificial intelligence (AI) to build socially assistive robots (SAR) to play the role of caregivers in enhancing interaction and social participation among older adults.

Objective: This study aimed to examine the effect of intervention through AI SAR on the cognitive function of older adults through a systematic literature review.

Methods: We conducted a meta-analysis of the various existing studies on the effect of AI SAR on the cognitive function of older adults to standardize the results and clarify the effect of each method and indicator. Cochrane collaboration and the systematic literature review flow of PRISMA (Preferred Reporting Item Systematic Reviews and Meta-Analyses) were used on original, peer-reviewed studies published from January 2010 to March 2022. The search words were derived by combining keywords including Population, Intervention, and Outcome—according to the Population, Intervention, Comparison, Outcome, Time, Setting, and Study Design principle—for the question “What is the effect of AI SAR on the cognitive function of older adults in comparison with a control group?” (Population: adults aged ≥65 years; Intervention: AI SAR; Comparison: comparison group; Outcome: popular function; and Study Design: prospective study). For any study, if one condition among subjects, intervention, comparison, or study design was different from those indicated, the study was excluded from the literature review.

Results: In total, 9 studies were selected (6 randomized controlled trials and 3 quasi-experimental design studies) for the meta-analysis. Publication bias was examined using the contour-enhanced funnel plot method to confirm the reliability and validity of the 9 studies. The meta-analysis revealed that the average effect size of AI SAR was shown to be Hedges g=0.43 (95% CI –0.04 to 0.90), indicating that AI SAR are effective in reducing the Mini Mental State Examination scale, which reflects cognitive function.

Conclusions: The 9 studies that were analyzed used SAR in the form of animals, robots, and humans. Among them, AI SAR in anthropomorphic form were able to improve cognitive function more effectively. The development and expansion of AI SAR programs to various functions including health notification, play therapy, counseling service, conversation, and dementia prevention programs are expected to improve the quality of care for older adults and prevent the overload of caregivers. AI SAR can be considered a representative, digital, and social prescription program and a nonpharmacological intervention program that communicates with older adults 24 hours a day. Despite its effectiveness, ethical issues, the digital literacy needs of older adults, social awareness and reliability, and technological advancement pose challenges in implementing AI SAR. Future research should include bigger sample sizes, pre-post studies, as well as studies using an older adult control group.

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KEYWORDS

older adult population; older adults; cognition; cognitive function; artificial intelligence; socially assistive robots; AI SAR; social prescription; dementia; social support; aging; caregiver; caregiving; meta-analysis; review; Cochrane collaboration; assistive robot; assistive technology

Introduction

Population aging is progressing worldwide due to the development of medical technology, and it is predicted that the number of older adults aged ≥65 years will increase from 730 million in 2019 to 1.5 billion in 2050 [1]. The World Health Organization has marked dementia and the mental health of older adults as public health problems due to an increase in the older adult population [2]. Dementia is a disease that occurs mainly in older adults aged ≥65 years and causes cognitive dysfunction, hyperactivity, sleep disturbance, violence, and depression, weakening daily life activities and making social activities difficult [3,4]. Currently, most patients with dementia are receiving treatment through drug therapy, but the medication rate is low since the symptoms of dementia impair the patients' ability to recognize the need to take medication [5]. To overcome these problems, treatment methods that combine nonpharmacological treatment with drug treatment are increasing. Psychosocial therapy is being used as a representative nonpharmacological treatment for the improvement of cognitive function of older adults around the world. The United Kingdom's National Health Service is implementing social prescribing, a nonpharmacological intervention program that connects patients with mental health conditions including dementia with nonmedical support sources in the community. Representative social prescribing programs include line dance, gardening, art therapy, music therapy, counseling therapy, and caring therapy [6]. According to previous studies, treatment methods based on interaction and conversation, rather than medication, for older adults with weakening cognitive function provide a sense of relief and stability, which in turn increases emotional support and social communication and thereby helps them recover their cognitive function [7]. As the older adult population increases, so does the population of older adults with cognitive impairment, and as a result, human resources and various nonpharmacological treatment programs are required. However, due to the rapidly aging global population, there is a shortage of caregivers; caregivers are particularly reluctant to take care of older adults with dementia due to mental stress, and the number of caregivers for patients with dementia is decreasing. As an alternative solution to this problem, technologically proficient countries such as the United States, Korea, Japan, and Australia are prioritizing the development of artificial intelligence (AI) socially assistive robots (SAR) as a part of digital health care [8]. According to previous studies, AI SAR have been found to be effective in preventing the overwork of caregivers for older adults, increasing work efficiency, and performing 24-hour monitoring [9,10].

AI SAR are robots designed to interact with humans (eg, older adults) using AI. As a method of promoting interaction and social participation among older adults, the development and research of AI SAR are actively being conducted [11,12]. AI SAR started in the form of an animal-type pet robot in early development and have been developed into various forms such as human- and doll-like robots. Regardless of the form, AI SAR were found to effectively increase the frequency of independent communication by making older adults initiate conversations [13]. Due to the development of various technologies, AI SAR have developed to the extent in which they can interpret and express not only verbal expressions, gestures, eye contact, and emotional expressions but also nonverbal communication methods, and their ability to communicate with older adults is also developing at an increasing rate. The role of AI becomes more important particularly when an infectious disease such as COVID-19 becomes prevalent, which limits the visiting service of nursing personnel.

AI SAR have been proven to be effective in enhancing interaction [14,15], improving the quality of life [16], improving depression and anxiety [17], and improving the quality of life of patients with dementia [18] for older adults aged ≥65 years. In addition, there has been a meta-analysis study published on the effect of the use of robots on older adults aged ≥65 years [19]. However, in an effectiveness study through a meta-analysis of AI SAR, it was confirmed that the study results including agitation, depression, and quality of life [19-21], etc, were inconsistent depending on the intervention method, SAR method, and characteristics of the older adults. A meta-analysis is necessary to standardize these various results, methods, and indicators. In other words, although the intervention using AI SAR has various effects on older adults, which has been proven through various studies, a meta-analysis based on the results of existing studies is necessary to clarify what kind of effect each indicator has. Currently, there is a lack of meta-analysis studies that analyze the effect of robots on cognitive function by setting a control group.

Therefore, the purpose of this study was to understand the effect of intervention using AI SAR on the cognitive function of older adults through a systematic literature review. To this end, the detailed goals were as follows: (1) to search and review the existing literature on the effect of AI personal care on cognitive function; (2) to objectively identify the feasibility of the effect of nursing care service through AI SAR and the effect of AI SAR on cognitive function based on the results of the collected theses; and (3) to provide the basis for supporting policies and research on providing AI SAR to older adults aged ≥65 years.

Methods

Study Design

This systematic literature review and meta-analysis study identified the intervention effect of AI SAR to understand its effect on the cognitive function of older adults aged ≥65 years.

Search Strategy

This study was conducted according to the systematic literature review method by the Cochrane collaboration and the systematic literature review flow of PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) [22,23]. The target data included original, peer-reviewed studies published from January 2010 to March 2022. The databases used for the search included PubMed and Google Scholar.

The search words were derived by combining keywords including Population, Intervention, and Outcome according to the Population, Intervention, Comparison, Outcome, Time, Setting, and Study Design (PICOTS-SD) principle (Multimedia Appendix 1).

- Population: “Elderly” OR “Elderly People” OR “older adults” OR “older people” OR “senior” OR “Dementia” OR “Alzheimer” OR “Cognitive impairment”
- Intervention: “Robot” OR “AI robot” OR “social assistive robot” OR “social interactive robot” OR “assistive robot” OR “companion robot” OR “robot interaction” OR “health care robot”
- Outcome: “MMSE” OR “Mini-Mental State Examination” OR “cognitive function” OR “cognitive” OR “cognitive impairment” OR “cognitive disorder” OR “mental health”

Eligibility

This study used the PICOTS-SD selection and constituted the question “If older adults aged ≥65 years are provided with AI SAR, what would be the effect on cognitive function in comparison with a control group?” The PICOTS-SD criteria for this question includes older adults aged ≥65 years (Population), AI SAR (Intervention), comparison group (Comparison), popular function (Outcome), and prospective study (Study Design). Subsequently, a systematic literature review was conducted, focusing on the core research.

From the above PICOTS-SD criteria, studies in which even one condition among subjects, intervention, comparison, and study design was different than those indicated were excluded from the literature review.

Quality Assessment

To minimize the deviation that occurs in literature search, 2 researchers searched and collected the data and then confirmed whether the same results were obtained. In addition, only peer-reviewed studies were included to increase the validity of the literature selection.

A risk of bias (ROB) assessment was performed to evaluate the quality of the literature selected in this study. Both subjective and objective evaluations were performed in the ROB assessment. For subjective evaluation, Cochrane ROB assessment was used [22]. Cochrane ROB assessment consisted of (1) Random Sequence Generation, (2) Allocation Concealment, (3) Blinding of Outcome Assessment, (4) Incomplete Outcome Data, (5) Selective Reporting, and (6) Other Bias, and the researchers confirmed that the studies were selected according to the guidelines. Subjective evaluation was conducted using a funnel plot.

All studies were reviewed by 3 researchers and selected based on a consensus of opinions to confirm the validity and consistency of the study.

Data Extraction and Data Synthesis

In this study, data were extracted and processed for the analysis of the selected studies. Data were synthesized by entering into Excel the (1) characteristics of the literature (year, journal, author, country, and study design), (2) research method (intervention, number of experimental groups, and number of control groups), and (3) research results (mean and SD of the experimental group and control group).

Data Analysis

This study calculated the effect size from 9 studies to analyze the effect of AI SAR on the cognitive function of older adults. To calculate the effect size, a normal distribution of the mean of each study was applied using a random effects model. For assigning weights in the random effects model, the DerSimonian and Laird method was used, including between-study variance [24]. For the effect size, the Standardized Mean Difference was used as an analysis value, and 95% CI and inverse of variance were used for weights [25].

To analyze the heterogeneity of the 9 studies investigated in this study, a visual review was conducted using a Forest plot and a Galbraith plot. The effect size, direction, and CI of each study were analyzed using the Forest plot, and they were listed by year, effect size, and sample size. In the Galbraith plot, the effect size divided by the SE was plotted on the y-axis, and the reciprocal of the SE was plotted on the x-axis. If a data point was plotted within 2 SEs on the regression line, then it was interpreted as having no heterogeneity.

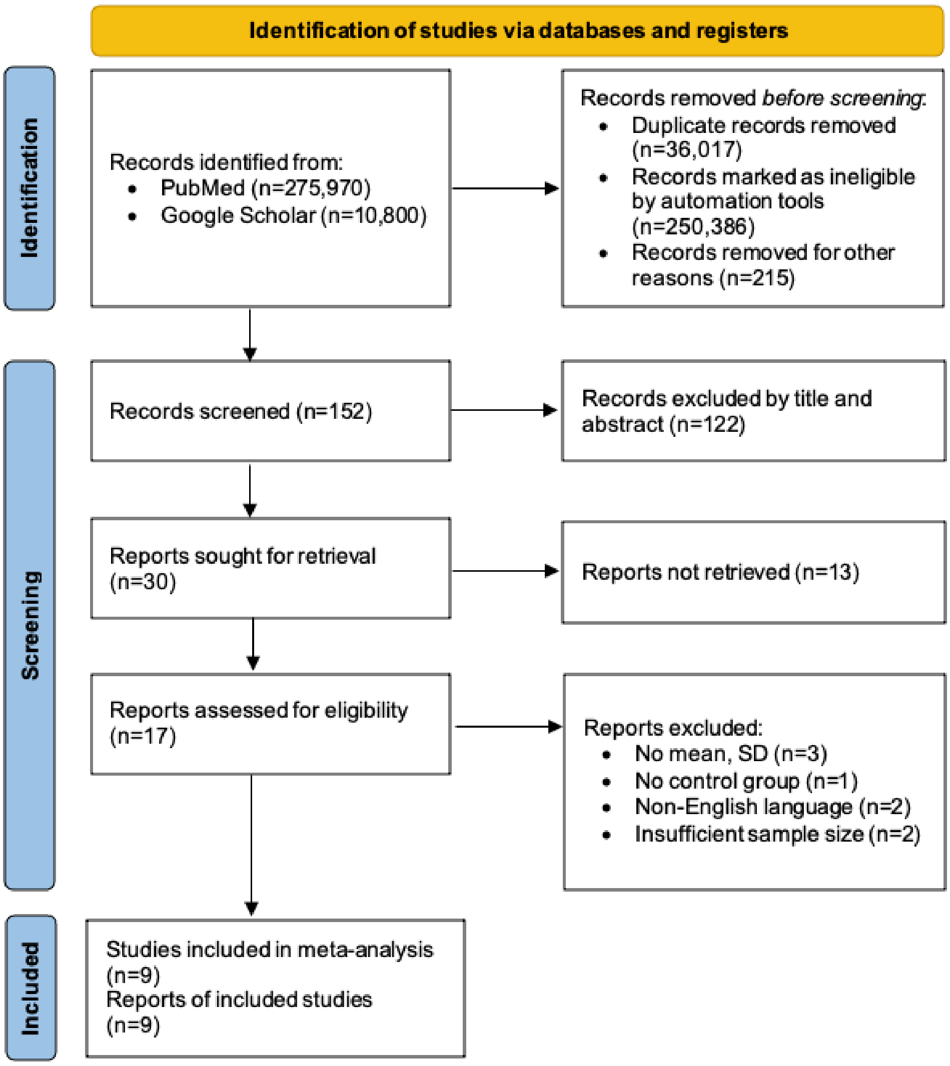
To identify the reporting bias of this meta-analysis study, publication bias was classified by analyzing the contour-enhanced funnel plot and determining whether it was symmetrical.

Results

Search Result

In total, 275,970 studies from PubMed and 10,800 studies from Google Scholar were searched using keywords to select the suitable literature for this study. Titles and abstracts were reviewed for 152 studies, excluding duplicate studies (36,017 cases), those marked ineligible by automation tools (250,386 cases), and those removed for other reasons (215 cases). A total of 30 studies were selected as a result, and among them, 9 studies were included in the meta-analysis, excluding those that were not retrieved (13 cases), lacked statistics (3 cases), lacked a control group (1 case), were in a non-English language (2 cases), and had an insufficient sample size (2 cases; Figure 1).

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow chart.



Characteristics of Studies Included in the Meta-analysis

The characteristics of the 9 studies selected through the PRISMA procedure are shown in Table 1. The selected studies were conducted between January 2010 and March 2022, and they evaluated the effectiveness of AI SAR on cognitive function improvement in older adults aged ≥65 years, using Mini Mental State Examination (MMSE) evaluation and comparison with a control group. A total of 575 individuals aged ≥65 years participated in the selected studies, including 273 in the experimental group and 302 in the control group. Among the selected studies, there were 6 randomized controlled trials and 3 quasi-experimental design studies.

All selected studies used MMSE to measure cognitive function, and other indices were used, including the Global Deterioration Scale (GDS), Neuropsychiatric Inventory (NPI), Apathy Scale for Institutionalized Patients with Dementia Nursing Home version (APADEM-NH), Quality of Life in Late-stage Dementia (QUALID) scale, Apparent Emotion Rating (AER) Instrument, Korean version of the Cohen-Mansfield Agitation Inventory (K-CMAI), Subjective Memory Complaint Questionnaire (SMCQ), Korean version of the Consortium to Establish a Registry for Alzheimer's Disease (CERAD-K), Geriatric Depression Scale Short Form: Korean Version (GDSSF-K), Japanese version of the Montreal Cognitive Assessment (MOCA-J), Tokyo Metropolitan Institute of Gerontology-Index of Competence (TMIG-IC), Functional Independence Measure (FIM), Duke Older Americans Resources and Services (OARS) Procedures, Mobility subsection of Dysfunction section of

Sickness Impact Profile (SIP), and Craig Handicap Assessment and Reporting Technique (CHART).

Table 1. Characteristics of the studies included in the meta-analysis.

Author, year	Study design	Sample size (intervention group; control group)	Intervention	Outcome indicator
Tanaka et al, 2012 [26]	Randomized controlled trial	18; 16	Community robot resembling a 3-year-old boy	MMSE[a] and BMI
Yoshii et al, 2021 [27]	Quasi-experimental design	47; 47	Humanoid robot	MMSE
Valentí Soler et al, 2015 [28]	Randomized controlled trial	33; 38	PARO robot	MMSE, GDS[b], NPI[c], APADEM-NH[d], and QUALID[e]
Valentí Soler et al, 2015 [28]	Randomized controlled trial	30; 38	NAO robot	MMSE, GDS, NPI, APADEM-NH, and QUALID
Koh and Kang, 2018 [29]	Quasi-experimental design	17; 16	PARO robot	MMSE, AER[f], and K-CMAI[g]
Park et al, 2021 [30]	Randomized controlled trial	45; 45	Humanoid robot (Sil-bot)	MMSE, SMCQ[h], CERAD-K[i], and GDSSF-K[j]
Otake-Matsuura et al, 2021 [31]	Randomized controlled trial	32; 33	Photo-integrated conversation moderated by robots	MMSE-J[k], MOCA-J[l], GDS-15-J[m], and TMIG-IC[n]
Oh et al, 2015 [32]	Quasi-experimental design	17; 25	Silver-care robot	MMSE and GDS
Tomita et al, 2007 [33]	Randomized controlled trial	34; 44	X10 ActiveHome kit	MMSE, FIM[o], OARS[p], SIP[q], and CHART[r]

[a] MMSE: Mini Mental State Examination.

[b] GDS: Global Deterioration Scale.

[c] NPI: Neuropsychiatric Inventory.

[d] APADEM-NH: Apathy Scale for Institutionalized Patients with Dementia Nursing Home version.

[e] QUALID: Quality of Life in Late-stage Dementia.

[f] AER: Apparent Emotion Rating.

[g] K-CMAI: Korean version of the Cohen-Mansfield Agitation Inventory.

[h] SMCQ: Subjective Memory Complaint Questionnaire.

[i] CERAD-K: Korean version of the Consortium to Establish a Registry for Alzheimer's Disease.

[j] GDSSF-K: Geriatric Depression Scale Short Form: Korean Version.

[k] MMSE-J: Japanese version of the Mini Mental State Examination.

[l] MOCA-J: Japanese version of the Montreal Cognitive Assessment.

[m] GDS-15-J: Japanese version of the 15-item Geriatric Depression Scale.

[n] TMIG-IC: Tokyo Metropolitan Institute of Gerontology-Index of Competence.

[o] FIM: Functional Independence Measure.

[p] OARS: Duke Older Americans Resources and Services Procedures.

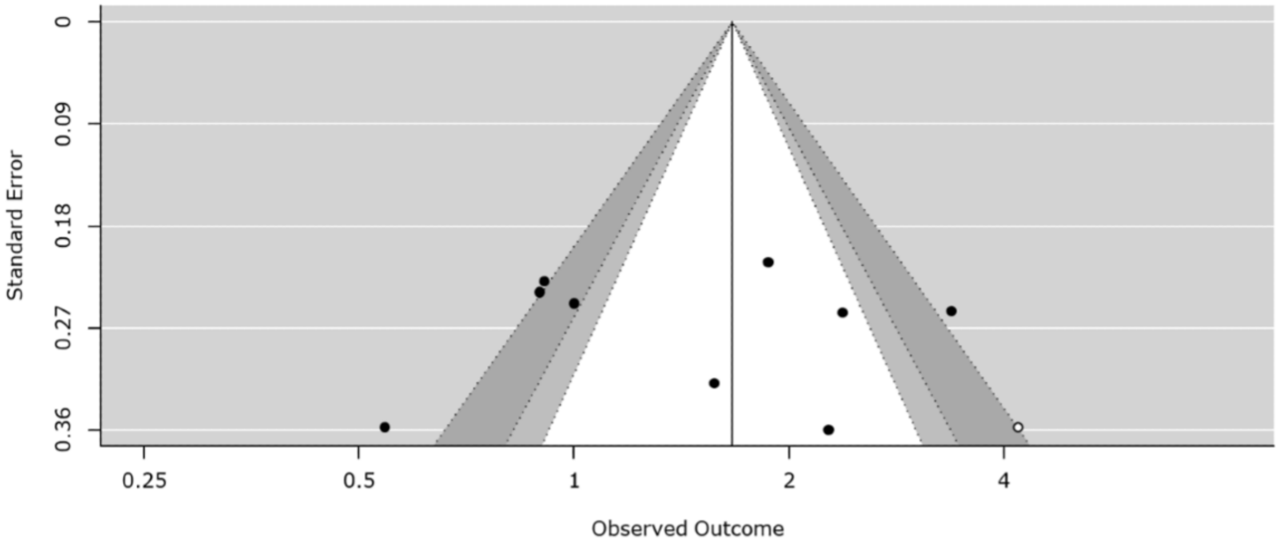
[q] SIP: Mobility subsection of Dysfunction section of Sickness Impact Profile.

[r] CHART: Craig Handicap Assessment and Reporting Technique.

Assessment of Publication Bias

To secure the reliability and validity of the 9 studies that were selected, publication bias was examined using the contour-enhanced funnel plot method. As a result, it was confirmed that the selected literature in this study represents a well-behaved data set, showing general symmetry (Figure 2).

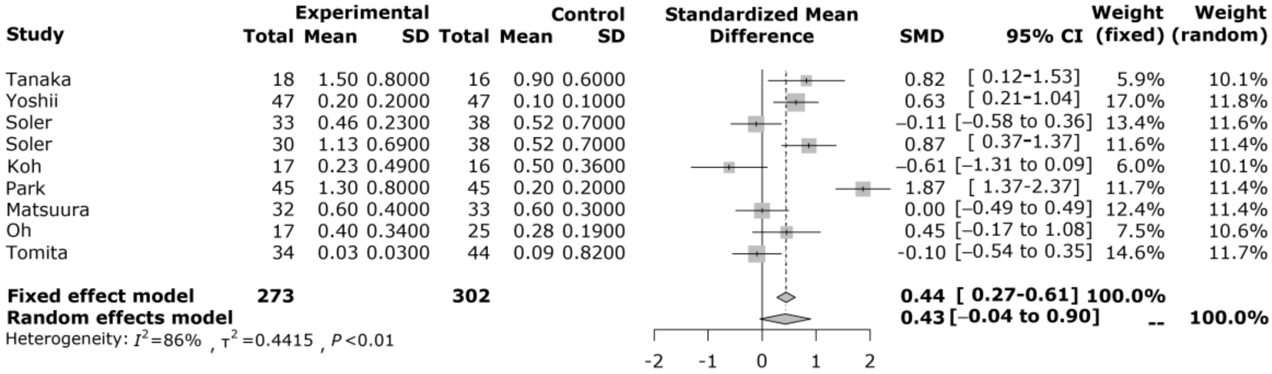
Figure 2. Adjusted funnel plot to examine publication bias.



Effect Size of AI SAR

For the 9 studies included in the systemic literature review, the standardized mean differences were calculated by the Hedges *g* formula using the mean, SD, and sample size of the pre-post change of the MMSE indices of the experimental and control groups. This was visualized as a Forest plot (Figure 3). As a result of the meta-analysis, the average effect size of AI SAR was shown to be Hedges *g*=0.43 (95% CI –0.04 to 0.90), indicating that AI SAR are effective in reducing the MMSE scale, which reflects cognitive function. The overall size heterogeneity was confirmed according to the ratio of the interstudy variance to the total variance (I^2=86%; *P*<.001). Furthermore, as a result of confirming the heterogeneity between studies using the Galbraith plot, it was confirmed that all studies had no heterogeneity within the 95% CI as the SEs were within 2 (Figure 4).

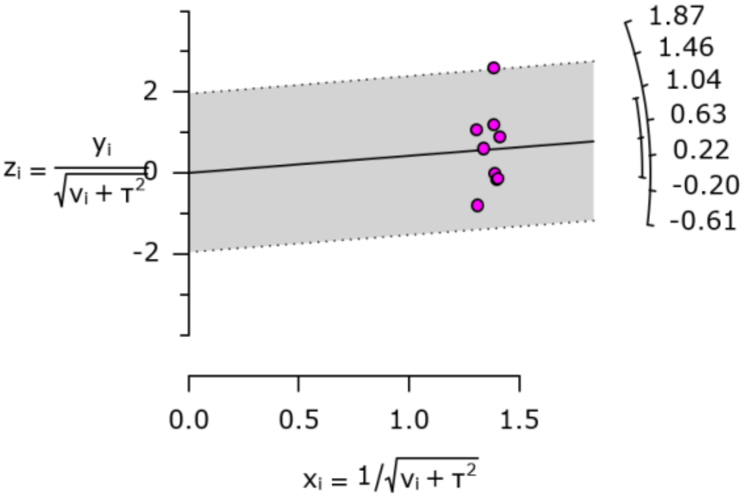
Figure 3. Forest plot results. SMD: standardized mean difference.



Study	Experimental			Control			SMD	95% CI	Weight (fixed)	Weight (random)
	Total	Mean	SD	Total	Mean	SD				
Tanaka	18	1.50	0.8000	16	0.90	0.6000	0.82	[0.12-1.53]	5.9%	10.1%
Yoshii	47	0.20	0.2000	47	0.10	0.1000	0.63	[0.21-1.04]	17.0%	11.8%
Soler	33	0.46	0.2300	38	0.52	0.7000	–0.11	[–0.58 to 0.36]	13.4%	11.6%
Soler	30	1.13	0.6900	38	0.52	0.7000	0.87	[0.37-1.37]	11.6%	11.4%
Koh	17	0.23	0.4900	16	0.50	0.3600	–0.61	[–1.31 to 0.09]	6.0%	10.1%
Park	45	1.30	0.8000	45	0.20	0.2000	1.87	[1.37-2.37]	11.7%	11.4%
Matsuura	32	0.60	0.4000	33	0.60	0.3000	0.00	[–0.49 to 0.49]	12.4%	11.4%
Oh	17	0.40	0.3400	25	0.28	0.1900	0.45	[–0.17 to 1.08]	7.5%	10.6%
Tomita	34	0.03	0.0300	44	0.09	0.8200	-0.10	[–0.54 to 0.35]	14.6%	11.7%
Fixed effect model	**273**			**302**			**0.44**	**[0.27-0.61]**	**100.0%**	
Random effects model							**0.43**	**[–0.04 to 0.90]**	**--**	**100.0%**

Heterogeneity: I^2=86% , τ^2=0.4415 , *P*<0.01

Figure 4. Galbraith plot to identify heterogeneity.



Discussion

Principal Findings

Due to the aging global population and technological developments, AI SAR for the care of older adults are continuously being developed. The purpose of this study, therefore, was to objectively identify the effect of AI SAR on the cognitive function of older adults through a systematic literature review and prepare and provide recommendations regarding AI SAR policy. The effectiveness of care services using robots in aging populations is socially recognized through continuous research and publications, but many experts agree that more objective evidence is needed. To this end, this study conducted a systematic review and meta-analysis on 9 studies that analyzed the effect of AI SAR on cognitive function improvement in older adults aged ≥65 years since 2010. As a result, it was found that AI SAR showed a significant effect in improving the cognitive function of older adults aged ≥65 years (Hedges *g*=0.43, 95% CI: –0.04 to 0.90). This is consistent with the results of a systematic review article, which states that robots are effective in improving cognitive function in older adults [34]. The difference between previous studies and this study is that the effects of various indicators were confirmed (GDS, NPI, APADEM-NH, QUALID, K-CMAI, SMCQ, CERAD-K, GDSSF-K, TMIG-IC, MOCA-J, FIM, OARS, SIP, and CHART).

In all 9 studies, a control group was designed to analyze the effects. With these results, we will mainly discuss (1) interactive robots, (2) the prospect of resolving the shortage of caregivers, (3) the possibility of expanding the digital social prescription program, and (4) what needs to be overcome for the application of AI SAR.

First, it is essential for AI SAR to be an interactive robot. The 9 studies that have been analyzed have in common that AI SAR could interact with older adults through dialogue. According to previous studies, the cognitive function of older adults aged ≥65 years was shown to be more effective in two-way communication than one-way communication [35]. In this case, the form of the robot greatly affects the formation of rapport. The 9 studies that have been analyzed made use of SAR in the form of animals, robots, and humans. Among them, AI SAR in anthropomorphic form were able to improve cognitive function more effectively. According to a literature review on AI SAR marketing, it is necessary to develop a robot that resembles a human being as much as possible, and it emphasizes the need to develop customized robots for customers by customer segmentation [36]. In this study, it was also found that human-shaped dolls and humanoid forms increased cognitive function more effectively than nonhuman, doll-shaped robots.

Second, as AI SAR have recently been developed to the extent that they can communicate with each other, they have been loaded with various functions including health notification, play therapy, counseling service, conversation, and dementia prevention programs. The development and expansion of AI SAR programs are expected to improve the quality of care for older adults and prevent an overload of caregivers. By conducting a meta-analysis of 9 studies, this study was able to objectively confirm that AI SAR are effective in improving cognitive function. This is evidence that AI SAR can relieve some of the work of caregivers looking after older adult patients with cognitive impairment, including patients with dementia. Older adults living alone with cognitive function impairment particularly require continuous monitoring due to the risk of various incidents when they are alone at home, which demands that caregivers be on-call 24 hours a day. However, since technological advancements have allowed AI SAR to continuously monitor older adults for 24 hours a day and contact facilities in the case of an emergency, it is expected to partially replace the work of caregivers in the future.

Third, AI SAR can be expanded to digital social prescription programs as a nonpharmacological intervention that improves the cognitive function of older adults aged ≥65 years. Social prescription began based on an idea conceived in the 1990s, in which patients were encouraged to exercise as part of their treatment. In the United Kingdom, the National Health Service defines social prescribing as a general practitioner prescribing a nonpharmacological intervention community program to a patient using community resources [37]. Recently, due to the shortage of mental health counselors and caregivers, digital social prescriptions, which convert existing social prescription programs to programs using digital technology, are expanding [38]. Social prescription has conflicted with existing prescription methods for the past 10 years, and there has been a lot of controversy. The main argument is that it is difficult to prove the effectiveness of social prescription, which is a nonpharmacological treatment, unlike existing pharmacological treatments. However, AI SAR are a representative digital social prescription program and a nonpharmacological intervention program in the form of a care service that communicates with the older adults aged ≥65 years 24 hours a day. The data collected through this 24-hour monitoring will be an important stepping-stone in proving that AI SAR are effective as a digital social prescription program. However, more objective research and development is necessary to support this.

Fourth, despite the effectiveness of AI SAR, there are currently problems to be overcome, including (1) ethical issues, (2) the digital literacy needs of older adults, (3) social awareness and reliability, and (4) technological advancements, etc.

The ethical and social issues of AI SAR should be addressed first. The development of AI SAR has replaced some of the existing caregivers, and AI SAR have been developed to a level that can provide care for older adults. However, as they enter the daily life of older adults, personal information is highly likely to be exposed. This is because AI SAR generate and transmit various real-time data using a camera, microphone, and voice tool.

AI SAR are a digital device, and basic digital literacy is required, particularly for charging and the user manual of the device. However, older adults have low digital literacy and limited access to devices, especially in low-income countries, rural areas, and in higher age groups [39]. The low digital literacy of older adults will cause problems in the use of AI SAR. In other words, the digital literacy of older adults is a basic requirement for the application of AI SAR. Therefore, to improve the digital literacy of older adults at a social level, it is necessary to provide a pre-education service to expand the AI SAR service.

Socially, there is a negative view on robots managing various tasks in daily life. Robots took on many tasks as they became gradually more developed and interactive. In the case of AI SAR, they live together with older adults and carry out 24-hour monitoring. Due to this, if a systemic defect causes AI SAR to make a mistake when concerning the older adults, who are a vulnerable group, it is possible that a negative view on the introduction of AI SAR in society might spread. To prevent this, systematic and continuous algorithm development and cognitive training of AI SAR is suggested, including the need to develop an internal algorithm that makes AI SAR apologize for their mistakes [40].

AI SAR still require further technological advancement and have challenges that need to be addressed. Currently, they perform limited word selection and dialogue based on algorithms, and functions such as dementia prevention programs are provided with limited technology. It is clear that the role of AI SAR should gradually expand at a time when the global population is aging, the number of caregivers is decreasing, and technological advancement is becoming essential for solving these issues. To improve the cognitive function of older adults, more development is needed to provide physical care, and technological advancement is necessary to indirectly help them engage in social activities through various communications.

This study possesses some limitations. First, the number of sampled studies that investigated the improvement of cognitive function through SAR was insufficient. It is necessary to conduct future research by including single pre-post studies as well as studies conducted by selecting an older adult control group. Second, only studies using MMSE to measure cognitive function improvement were selected, but various indices such as GDS and NPI also exist. A meta-analysis including all the different indices is recommended for obtaining more objective results in the future. Third, the types of AI SAR used in the 9 selected studies were all different. This is a limitation as it is difficult to measure the nonsampling error that occurs due to the different types of AI SAR. Lastly, we searched using the PubMed and Google Scholar databases. Therefore, we may be missing articles from another database such as IEEE, Embase, and Cochrane Library. In future, we will consider searching using the IEEE, Embase, and Cochrane Library databases.

Conclusion

In this study, a meta-analysis was performed on 9 studies to examine the effect of AI SAR on improving cognitive function in older adults. As a result, AI SAR were found to be effective in improving cognitive function, suggesting that it is possible to (1) socially expand interactive robots, (2) solve the shortage of caregivers, and (3) expand AI SAR use into a digital social prescription program. Furthermore, the challenges of ethical issues, the digital literacy needs of older adults, social cognition and reliability, and technological development must be solved for the commercialization and expansion of AI SAR. Nonetheless, in times of pandemics such as COVID-19, the need for AI-assisted care is likely to further increase due to its safety.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Search keywords.
[DOCX File , 12 KB - aging_v5i2e38896_app1.docx]

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Abbreviations

AER: Apparent Emotion Rating
AI: artificial intelligence
APADEM: Apathy Scale for Institutionalized Patients with Dementia Nursing Home version
CERAD-K: Korean version of the Consortium to Establish a Registry for Alzheimer’s Disease
CHART: Craig Handicap Assessment and Reporting Technique
FIM: Functional Independence Measure

GDS: Global Deterioration Scale
GDSSF-K: Geriatric Depression Scale Short Form: Korean Version
K-CMAI: Korean version of the Cohen-Mansfield Agitation Inventory
MMSE: Mini Mental State Examination
MOCA-J: Japanese version of the Montreal Cognitive Assessment
NPI: Neuropsychiatric Inventory
OARS: Older Americans Resources and Services
PICOTS-SD: Population, Intervention, Comparison, Outcome, Time, Setting, and Study Design
PRISMA: Preferred Reporting Items for Systemic Reviews and Meta-Analyses
QUALID: Quality of Life in Late-stage Dementia
ROB: risk of bias
SAR: socially assistive robots
SIP: Sickness Impact Profile
SMCQ: Subjective Memory Complaint Questionnaire
TMIG-IC: Tokyo Metropolitan Institute of Gerontology-Index of Competence

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Viewpoint

Bridging Connectivity Issues in Digital Access and Literacy: Reflections on Empowering Vulnerable Older Adults in Singapore

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Abstract

This article describes a ground-up initiative for a volunteer-run digital literacy program in Singapore targeting vulnerable older adults, focusing on the barriers faced in running this program and training these beneficiaries. It further offers possible solutions to overcome these hurdles, providing insight for individuals or organizations seeking to start similar ground-up initiatives.

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KEYWORDS

COVID-19; digital literacy; digital literacy training; digital disparities; digital divide; social construction of health technologies; health technology; COVID-19 pandemic; pandemic; COVID; social isolation; elder; older adult; Asia; access; barrier; empower; volunteer; vulnerable; digital skill; low income

Introduction

Digitalization is a phenomenon that has become increasingly prominent over the years, as countries seek to adapt to the changing world and improve the standards of living of their citizens [1]. Singapore, an island state in southeast Asia, has not been spared from this digital wave, and it has developed plans to facilitate digitalization from as early as the 1980s [2]. Although digitalization is often quoted as a boon to many, there remain those who have not been recipients of its bounty [3]; sociodigital divides are surfacing between generations [4], with vulnerable older adults increasingly being unable to keep up with such rapid digital progress [5].

On January 23, 2020, the first case of COVID-19—a coronavirus that sparked a global pandemic in 2019—touched the shores of Singapore [6]. As with other international societies, swift lockdown measures were put in place to limit the spread of the virus [7]. Such measures limited the physical interaction of day-to-day activities, leading to companies and organizations shifting their businesses to internet-based platforms. Digital literacy thus became essential to run even the most basic of errands, further exacerbating and exposing the pre-existing inequalities of the digital divide [8]; technologically illiterate older persons [9], already a vulnerable subset of the population [10], not only lost their access to essential services and the community [11] but also their quality of life and a sense of well-being [12].

Different groups of volunteers in Singapore then collaborated during the global COVID-19 pandemic and sought to improve the digital access and literacy levels of these now socially isolated older adults. However, the efforts to reach vulnerable older adults (those older than 60 years) in Singapore were fraught with difficulties and challenges, and these were made possible only through various interventions at the societal, grassroots, and individual levels. In this article, a ground-up initiative for a volunteer-run digital literacy program in Singapore targeting vulnerable older adults (Project Wire Up) is briefly described; reflections from the planning and execution of this initiative are then divided into (1) barriers faced and the individual, grassroots, and societal interventions that helped facilitate digital literacy in this vulnerable population; and (2) possible solutions to overcoming these hurdles, providing insight for individuals or organizations seeking to start similar ground-up initiatives. Considering the pandemic, this initiative was only started when in-person visits by hospital volunteers were allowed, in accordance with existing government regulations during the lockdown period.

Project Wire Up

Description

Project Wire Up is an ongoing ground-up initiative by volunteers from TriGen Ltd, a nonprofit organization based in Singapore, in collaboration with the Singapore General Hospital [13]. Project Wire Up started in 2020 and aims to address social isolation and a lack of access to essential services among older adults by improving digital access and literacy levels. In particular, this program targets vulnerable and socially isolated older adults of a lower socioeconomic status (ie, those living in rental public housing apartments or those receiving financial assistance). As of the end of 2021, more than 300 of these vulnerable older adults have benefited from the program, with new participants being enrolled and trained every day.

The program adopts a 3-pronged approach where older adults are (1) equipped with smartphones, (2) trained by volunteers for 6 sessions over 3 months, and (3) reconnected to their social networks. To equip these older adult participants with the tools to facilitate digital literacy, special arrangements were made with local telecommunication companies and the Infocomm Media Development Authority of Singapore (IMDA), a statutory board in Singapore that develops and regulates the information communications and media sectors of Singapore [14], to offer subsidized smartphones as well as mobile network and data plans to these participants. Prior to the availability of these schemes, the program relied on goodwill donations of smartphones from the public together with promotional “limited-time-only” mobile plan schemes from local telecommunication companies.

Digital skill training is facilitated by trained volunteers, mainly in health care–related fields, matched with these participants based on language and location. Volunteers guide participants through a tiered curriculum of increasing difficulty that is personalized according to the needs, wants, and abilities of the participants. The curriculum often starts with empowering these participants to carry out basic hardware operations, including essential functions such as making phone calls and establishing contact lists. Following this, participants are then taken through a tiered curriculum that involves educating the participants on (1) communication platforms (eg, WhatsApp, Telegram), (2) government services and lifestyle apps, and (3) electronic payment and digital banking. Table 1 presents the details of the curriculum [15,16]. Participants are then further educated regarding the importance of cybersecurity and identification of scams (including phishing) to ensure their digital safety.

Table 1. Summary of the tiered curriculum [16].

Tier number	Tier name	Examples of topics taught
0	Basic operation of hardware	Turning the phone on and off, charging the phone, adding to and searching through contact list, sending text messages, and making calls
0	Cybersecurity and scams	How to spot a scam, staying safe when on the internet, protecting personal data, and securing accounts on media platforms
1	Communication skills and platforms	Email, Google, WhatsApp, Telegram, Zoom, Microsoft Teams, Facebook, Instagram, and Tiktok
2	Government services and lifestyle apps	YouTube, local entertainment apps, local government service apps, getting around (eg, Grab, local taxi services), and local health apps
3	Electronic payments and digital banking	Local bank, local supermarket, and food delivery apps

Ethics Approval

As this paper only describes a volunteer-based initiative in Singapore, no ethics approval was required.

Barriers to Improving Digital Access and Literacy in Vulnerable Older Adults

Commencing a ground-up volunteer-based initiative lends itself to various difficulties, and Project Wire Up is no exception. The barriers faced when facilitating digital literacy and access among vulnerable older adults are described below, ranging from more macrolevel issues, such as acquiring funding for the program, to more microlevel issues, such as being able to engage the elderly. These barriers are grouped into the following categories: financial and logistical barriers, establishing initial contact and engaging the elderly, and cognitive impediments.

Financial and Logistical Barriers

To effectively execute a program aimed at empowering older adults with smartphones and the knowledge to use them requires the availability of the following basic resources: smartphones and the mobile or data plans. One of the concerns brought up most commonly by participants as a barrier to them having previously accessed this resource is the cost involved in purchasing new or used mobile devices and subscribing for the appropriate mobile phone plans. This proved to be a significant concern given that participants were already from a lower socioeconomic stratum, which would preclude them from accessing financial resources to make such purchases. Although the physical devices themselves could be obtained through donation drives or through a 1-time purchase using donations in cash, it was challenging to identify a reliable, realistic, and sustainable way to support these participants in financing their own mobile phone plans.

Mobile phone plans in Singapore are either prepaid, in which a sum of money is paid to the mobile phone plan service provider and deductions are made from this predetermined amount in the account based on the usage, or postpaid, in which the individual pays at the end of the month based on the usage and costs incurred during the preceding month. As such, regardless of the type of payment plan, using a smartphone or mobile device would inadvertently incur a recurring cost over a long period. Special requests to local telecommunication companies to indefinitely extend advertised “promotional limited-time-only” deals to Project Wire Up beneficiaries were for naught, understandably, given (1) hesitancies regarding the risk of defaulting payments from the program beneficiaries and (2) logistic requirements at repeatedly issuing these deals only for these specific individuals and tracking them over time. Therefore, the sustainability of any improvements made for improving digital access among this population was under threat.

Initial alternative solutions considered for financing these plans were also problematic. Under the Singapore law, individuals are not allowed to purchase telephone connections for others, given the responsibility to be undertaken for any activities, illegal or otherwise, done via telephone; therefore, the program and telecommunication companies were unable to make such a compromise. Although the participants themselves might be able to afford the initial set-up and purchase, it was logistically unfeasible for charitable monetary donations to be channeled for making monthly depositions or payments either into the beneficiaries’ mobile phone accounts or even to the beneficiaries, owing to concerns regarding whether that money would truly be used for this purpose.

Difficulties in Engagement

Singapore is a multiethnic country with the lingua franca generally being Malay (Bahasa Melayu Singapura) among the older adults (although now only spoken by an ethnic minority of younger persons in Singapore), and Singapore Standard English among the younger adults and youth [17]. A significant number of these older adults were not English educated and hence were most comfortable in speaking their dialects (as opposed to Singapore Standard Mandarin or Bahasa Melayu Singapura) [18]. As with all heterogenous societies, language proved to be a significant barrier for volunteers that had to be overcome; however, before even such language barriers could be overcome, commencing sessions with these older participants involved establishing initial contact, and this proved to be a significant barrier to facilitating digital literacy and access.

Initial contact was made primarily through telecommunication; however, with the rising number of scams in Singapore [19], these older participants were wary of volunteers. As such, building trust and rapport via telecommunication or in person understandably took a while. This was further confounded by individual characteristics; some participants, despite their desire to learn, were by personality reticent or slow to warm up, and allowing strangers into their personal space took a significant amount of time, trust, and rapport. In some cases, after a few visits for a multitude of reasons, participants declined volunteer visits and were lost to follow-up.

Furthermore, as the program continued, it was noted that these older adults differed considerably in their abilities to pick up new digital skills, partly due to their different educational backgrounds and physical conditions. As expected with any training program, participants had varying levels of interest as well as different needs and wants that had be addressed. As such, despite the tiered “formal” curriculum, this program ended up serving primarily as a guide, using which each volunteer needed to review and identify aspects that were relevant and personalized to their beneficiaries.

Physical and Cognitive Impediments

As part of eventual government-directed funding for this program, it was compulsory for participants to attend digital learning programs at learning hubs distributed at various locations in the country and pick up at least 1 basic digital skill before they could qualify for this program. Although the requirement that older adults had to pick up at least 1 basic digital skill at specific locations was well intended, this disadvantaged many older adults who often have physical impediments.

Thus, these participants with physical impairments were also less likely to engage in the acute uptake of technology, as documented clearly in earlier studies [20]. For example, some older adults had visual impediments that prevented them from clearly viewing the icons or buttons on the mobile device. Others had underlying dexterity issues, possibly secondary to neuropathy, resulting in challenges when navigating the newer mobile devices that are typically operated using touch screens instead of mechanical buttons.

Furthermore, given the target population, a significant number of the beneficiaries of this program had suffered from various forms of subtle and sometimes explicit cognitive impairment, either formal or subclinical. Such impairments have been known to impede the uptake and usage of digital technology [20]. Participants often could not recall volunteers' multiple visits, much less the complex steps to achieve an outcome on the smartphone. Repeated visits for the same lesson plan were often required before older adults were deemed to have mastered that particular skill set (sometimes involving rudimentary skill sets such as identifying the application of a phone to even make outgoing calls).

Ageist Attitudes

Of particular note is also the concept of self-ageist attitudes, which might exacerbate all the preceding barriers, with the elderly themselves sometimes imbibing and reinforcing such stereotypes [21]. Volunteers highlighted that self-deprecating stereotypes about their age from these older adults themselves significantly contributed to participants giving up easily in view of the multiple intermediate steps often needed to access certain services. Many participants also expressed a fear of technology related to their anxiety with digital devices, consistent with local findings suggestive of this phenomenon [22].

Overcoming Barriers to Improving Digital Access and Literacy in Vulnerable Older Adults

There are several barriers to achieving digital access and literacy; although a majority of these are often within the locus of control of individuals, many of these barriers require interventions at the societal and grassroots level. The following section details the micro- and macrolevel interventions and assistance that helped overcome these barriers to digital access and literacy among a vulnerable group of older adults.

Government and Societal Level

Government Support in Lowering Operational Barriers to Digitalization

The initial phases of the program relied entirely on mobile phones donated by the public and time-limited goodwill extensions of promotional deals for mobile phone plans from telecommunication companies. Thankfully, a few months into the pandemic, the Singapore government launched a subsidized mobile device scheme for underprivileged older adults as part of the larger "Seniors Go Digital" initiative [15]. This scheme provided subsidized smartphone and mobile plans to financially deserving older adults (aged 60 and above) who were keen on embracing digital technology but could not afford it. This ensured that the financial and logistic barriers to the sustainability of this program were largely removed.

Grassroots and Community Level

Reaching Vulnerable Older Adults Through Grassroots Organizations

Grassroots organizations played a significant part in ensuring the success of this digital access and literacy program. First, these organizations facilitated the identification of at-risk vulnerable adults who might be open to embracing digitalism, capitalizing on their knowledge of these vulnerable older adults residing in their vicinity. Second, as these older adults themselves were also familiar with the staff of these grassroots organizations, the support of these organizations allayed suspicions toward Project Wire Up volunteers, which have been heightened considering the recent local prevalence of scams [19]. As such, to facilitate participation and enrollment, staff from the grassroots organizations would aid the team in making the first visit to potential participants to inform them of the program prior to first contact from program volunteers.

Facilitating the Last Mile Delivery

Although governmental efforts may reduce operational barriers to obtaining and paying for a mobile phone and plan, they often come with a caveat and requirement. In case of the "Seniors Go Digital" initiative, participants who had expressed interest in the program found themselves hampered by the last mile delivery of phones and setting up of digital plans. In particular, potential participants had difficulties in going to learning hubs to learn digital skills or going to distribution hubs to collect their phones due to physical limitations and the general inconvenience in doing so, especially with concerns related to the ongoing pandemic. Project Wire Up closed this gap by engaging with digital telecommunication companies, with the support of the IMDA [14], to bring the equipping and training process to the participants themselves via door-to-door outreach efforts.

Prior to a scheduled outreach program, a list of interested older adults would be prepared with assistance from grassroot organizations via door-to-door visits in the neighborhood and they would be invited to attend the event. Thereafter, on the day of the outreach program, telecommunication companies would bring their staff and the digital devices to a location in the neighborhood to aid in the registration process. Volunteers would bring these potential participants to the venue of the outreach program and thereafter accompany them back to their respective homes to commence the training sessions.

Linking Older Adults to a Digital Community

It has been well demonstrated that older adults who are more socially connected are more likely to use digital technology [23]. It naturally follows that the sustainability of this continued use of digital devices was also partly dependent on whether these vulnerable older adults were eventually linked, or connected, to a digital community. Based on the experience of this program, this connection often occurred in the form of WhatsApp or Telegram groups with neighbors and volunteers or periodic "activities over Zoom" organized by volunteers and grassroots organizations. For example, a grassroots organization facilitated the implementation of the "Radin Mas Silver Click!" program, a recurrent monthly program involving health talks, exercise classes, cooking classes, and support groups over Zoom in which any elderly adults in their catchment area or community could participate once they were equipped with the appropriate digital devices. Although not all individuals may be keen on joining digital communities and virtual event platforms, with various factors potentially influencing their willingness to join digital communities [24], providing the option for those who are keen is the first step toward facilitating sustained and perhaps even improved digital literacy and access.

Individual or Volunteer Level

Motivating Older Adults

Communicating with participants in their preferred spoken language or mother tongue (dialect) proved helpful; however, despite language barriers, sessions were more fruitful when they were not too result-oriented and when volunteers themselves focused on genuinely helping the participants develop their digital literacy skills. On doing so, participants were more willing to proceed at a pace they were comfortable with, which further motivated them to continue learning (as opposed to finding the endeavor highly insurmountable).

Targeting and personalizing the training, especially at the beginning, to the participants' lifestyles and perceived needs were helpful in ensuring participants' investment in the initial phase of the learning journey. This finding corroborates existing ones suggesting that a key enabler in digital literacy programs is helping older adults see the relevance of and need for digital technology [25]. For example, those who were avid television or music connoisseurs were shown the capabilities of video and music streaming apps; identifying particular interests (cooking, news, art, jazz, etc) also further engaged participants and motivated them to continually learn about the app functions. In tandem with this, engaging caregivers or family members of these older adults and focusing on social connectivity with friends further encouraged participants to be proficient in apps such as video calling.

Volunteers in this program also noted that as they gradually got to know their participants and developed an amicable relationship with them over time with their repeated visits, these older adult participants were gradually more receptive to their suggestions, and they were also more willing to try learning new skills [26]. This goes in tandem with recent geragogy studies in this region, where ageist stereotypes could often be countered by relatable, empathetic, and engaging instructors [27].

Teaching Simply and Using a Tiered Curriculum

Pacing the teaching and repeating sessions, although often onerous for the volunteers and participants, showed greater results. Older adults found themselves able to absorb new knowledge when complex steps were simplified into algorithms that were easier to understand. Repeated sessions facilitated rapport building, which in turn allowed participants to progress at their own pace. By prioritizing functions, participants who were not proficient at the get-go were found to have progressed better if simple functions including turning the phone on and off, unlocking the phone, charging the phone, and even accepting or rejecting calls or entering contacts and clicking photographs were introduced first. In doing so, with repeated reassurance, coaxing, and encouragement, more difficult features such as electronic payments and internet banking, video streaming, and even ride-hailing apps could be introduced and taught.

The usage of a tiered curriculum (given in Table 1) [16] facilitated this process; volunteers had an idea of what skills were "easier" or "harder," and these provided a roadmap for volunteers regarding which groups of digital skills they could teach their beneficiaries. This allowed for a more progressive pacing of the training. This efficacy of using a flexible curriculum and having personalized curriculums tailored to the learner's capabilities is also consistent with recent geragogy studies in the region [27].

Using Aide-mémoire

Given the complex nature of learning, volunteers found that older adults who were more successful were diligent with taking notes or writing and recording the steps. Volunteers further facilitated this process by writing things down, typing them on a phone pad, or capturing a photograph of the written instructions. For those who were illiterate, voice and audio recordings with instructions from volunteers were also helpful. Furthermore, within reason, volunteers were available for assistance if participants contacted them outside of these sessions. Certain smartphone models also allowed for the activation of accessibility options like readback for visually impaired participants, which significantly improved their usage of the smart devices.

Giving participants homework also facilitated learning, allowing volunteers track the participants' progress; this also involved random "tests" during which participants were contacted by volunteers and asked to assist in certain tasks. Unfortunately, for participants who were more passive learners, such a learning style was unsuccessful; therefore, volunteers spent a significant amount of time finding out what worked best for each participant.

Using Accessibility Functions on Mobile Devices

Given that many older adults have physical impediments, volunteers found various solutions for the different physical impediments that the older adults may have. For example, for older adults with visual impairments, volunteers increased the font size, contrast, and brightness of the device. Alternately, some volunteers used devices with larger screens. In addition, volunteers taught older adults how to use the voice-enabled functions in the phones (eg, Siri for Apple iPhones or voice-recorded messages in the WhatsApp messaging app). Despite this, volunteers found that given the linguistic issues or preferred language of communication, many of these voice-assisted devices do not recognize dialects [28], which are often the predominantly spoken languages among older Chinese adults of lower socioeconomic status in Singapore aged 55 and older [29].

For older adults with dexterity issues, the touch screens were made less sensitive. However, some older adults still found it challenging to navigate a touch screen and ended up being "demoted" to use an older device employing mechanical buttons.

It became clear that though volunteers attempted to help older adults overcome these physical impediments, there still exist systemic gaps in the mobile device industry to meet the needs of older adults, especially those who are illiterate and suffer from various physical impediments. More efforts are required from the private and public sectors to provide high-quality mobile devices that can help older adults, especially those with low socioeconomic statuses, overcome their physical impediments.

Conclusions

This pandemic era has shown us the importance of embracing digitalization and how the elderly population has struggled to keep up with this changing tide. Although volunteer-based ground-up initiatives are important in helping this population, they face several difficulties. This article highlights some barriers that similar programs might face in facilitating digital access and literacy among their participants, and we hope that the lessons we have shared may be of value in the development of other similar volunteer-based ground-up initiatives in other parts of the world.

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Authors' Contributions

LLL and KWAT are joint senior authors of this paper.

Conflicts of Interest

None declared.

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Abbreviations

IMDA: Infocomm Media Development Authority of Singapore

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Viewpoint

Shared Access to Patient Portals for Older Adults: Implications for Privacy and Digital Health Equity

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Abstract

Growing reliance on the patient portal as a mainstream modality in health system interactions necessitates prioritizing digital health equity through systems-level strategies that acknowledge and support all persons. Older adults with physical, cognitive, sensory, and socioeconomic vulnerabilities often rely on the involvement of family and friends in managing their health, but the role of these care partners in health information technology is largely undefined and poorly understood. This viewpoint article discusses challenges and opportunities of systematic engagement of care partners through shared access to the patient portal that have been amplified in the context of the COVID-19 outbreak and recent implementation of federal information blocking rules to promote information transparency alongside broader shifts toward care delivery innovation and population aging. We describe implementation considerations and the promise of granular, role-based privacy controls in addressing the nuanced and dynamic nature of individual information sharing preferences and fostering person- and family-centered care delivery.

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KEYWORDS

patient portal; electronic health record; care partners; proxy; health equity; health informatics; health services; elderly; older adults; aging; cognition; health system; care delivery; elderly care

Introduction

Shifts toward virtual care delivery in response to the COVID-19 pandemic have demonstrated both the promise and difficulty of electronic modalities in reaching patients who are more vulnerable. The patient portal has had a prominent role throughout the pandemic due to its use in telehealth, the scheduling and provision of COVID-19 test results, and more recently the coordination of hospital-based vaccination efforts. Older adults are more commonly affected by physical, cognitive, sensory, and socioeconomic vulnerabilities that amplify the importance of transparent information exchange. Older adults are also highly diverse with respect to technology access and digital health literacy, which affect ease of portal use [1,2]. As the patient portal becomes a mainstream modality in health system interactions, efforts to achieve digital health equity and respect for older adults' wide-ranging circumstances, preferences, and capabilities must be prioritized.

Organizational efforts to promote use of the patient portal have primarily focused on increasing patient engagement through public awareness campaigns, clinician and staff training, work process redesign, and information technology support [3]. However, millions of older Americans manage their health with the involvement of family, friends, caregivers, and other care partners who are not part of the formal care delivery system [4]. Care partner engagement has a profound effect on patient quality of life, quality of care, and resource use, but is not well supported in care delivery [4,5]. At a basic level, care partners are often unable to access information about patient health and treatments—information that is necessary and appropriate when coordinating or enacting the patient's care plan. Attaining the full promise of consumer health information technologies will require meeting the needs and preferences of *all* patients, including those who delegate or comanage their care. This viewpoint seeks to raise awareness of the challenges and opportunities of systematic engagement of care partners through shared access to the patient portal, and to highlight policy and practice considerations that affect efforts to expand shared access.

Shared Portal Access: The Current Landscape

Health systems commonly allow patients to authorize a care partner to "share access" to their portal account in a registration process through which the care partner is granted their own identity credentials (login and password) [6]. Shared (proxy) portal access is thus an existing functionality that respects patient preferences for involving other individuals in their care. Whether care partners access the portal through *shared* access, using their own identity credentials, or *patient* access, using patient identity credentials, has important ramifications for patients, care partners, and clinicians (Table 1). Care partners' informal use of patient identity credentials obscures whether and when they are involved in electronic interactions. In contrast, shared portal access affords patients greater control over both granting and revoking access to their portal account, and clinicians the ability to identify with whom they are communicating via electronic interactions. The growing capacity of electronic health records to accept patient-generated health information such as patient-reported questionnaires and patient-uploaded legal documents amplifies the importance of using proper identity credentials to the integrity of electronic health information. Shared portal access also confers advantages to care partners, including greater legitimacy in their interactions with health systems, access to timely and comprehensive information about patient health, and a mechanism to interact with clinicians and manage care tasks electronically.

Table 1. Care partners and patient portals: implications of using shared (proxy) versus patient access.

Effects	Benefits of care partners' use of their own identity credentials through shared (proxy) access	Drawbacks of care partners' use of patients' identity credentials through patient access
Patient autonomy and control	Patients clarify which care partners they would like to share access to their portal account and retain the ability to revoke access.	Patients share their own identity credentials with care partners, who are not distinguishable from one another or the patient.
Care partner legitimacy	Clinicians are able to discern which care partner they are communicating with electronically when someone other than the patient contacts them.	Clinicians are not able to distinguish between the patient and care partners in electronic interactions and direct messaging.
Transparency and efficiency of triadic interactions with patients and care partners	Clinicians asynchronously interact with the patient and their care partners, facilitating consistent, transparent, and timely information exchange.	Clinicians may not be as direct and honest in their visit notes and direct messages if they are unsure of who is accessing and acting on the information. Inefficiencies may result from coordinating clinician–care partner interactions by telephone.
Integrity of patient-generated information in their health record	Care delivery systems can identify who is responding to portal surveys or uploading legal documents if someone other than the patient.	Care delivery systems cannot discern when care partners respond to patient assessments or upload legal documents, such as advance directives.
Care partner assessment	Clinicians and care delivery systems may field electronic screening assessments of care partners to identify and monitor their capacity and needs.	Clinicians and care delivery systems may not know whether a care partner is involved or which care partner to screen or monitor. Screening assessments must be completed by phone or paper survey.
Tailored support of the care partner	Gathering care partner–reported information enables tailored delivery of education and support to care partners.	Clinicians and care delivery systems may not know when care partners are at risk of burnout or lacking knowledge of patient health and treatments.

A small but growing body of evidence finds that care partners' registration and use of the patient portal may yield benefit across dimensions of patient and care partner engagement, satisfaction with communication, and confidence managing care [7,8]. Although shared portal access is reportedly desired by patients and valued by families [2,9-11], uptake has been limited [12-14]. Studies involving convenience samples from care delivery organizations indicate that when care partners do access the portal, it is most often informally, using patient identity credentials [13-17]. In a recent study involving a text analysis of 3000 adult portal messages, care partners who direct messaged clinicians with patient credentials identified themselves about half of the time [17].

The reasons for this low uptake are complex and likely multifactorial. Health care organizations may be reluctant to encourage shared access due to misplaced concerns about the privacy requirements of the Health Insurance Portability and Accountability Act [18,19]. Portal design is often not simple or user-friendly [20]. Finally, while federal programs offering incentive payments for electronic health record adoption did require organizations to offer a patient portal, they set a low threshold for the proportion of patients using them, providing little incentive for robust implementation efforts [21].

Little attention has been directed toward identifying organizational best practices for the implementation of shared portal access functionality; where offered, awareness is low and the registration process is cumbersome and not well understood

[11,15,22]. Safeguarding the privacy of electronic personal health information is a critical concern to health care systems. However, concern for data privacy may inhibit appropriate and beneficial access to information needed by care partners who are involved in oversight of or delivering hands-on care [23-26]. Provider policies and procedures were cited as a barrier to technology use by nearly half (48.6%) of out-of-home family caregivers in one study [22]. Although decisions about the types of information made available to care partners through the patient portal are made at the organizational level, the heterogeneity and fluidity of older adults' circumstances and information sharing preferences preclude a uniform, "one size fits all" approach. Access policies must be flexible to support privacy preferences that may shift over time in the context of age-related changes in function [27]. Further, developing strategies that recognize and address older adults' highly varied circumstances and preferences, such as the involvement of direct care workers when appropriate and desired, will be especially critical if digital health equity is to be achieved [27].

Importantly, decisions about the types of information and functionalities available to care partners made at the organizational level rather than by individual patients can inhibit patient autonomy and care partner access to information, limit clinician insight regarding patient privacy preferences, and reduce the relative advantage of differentiated patient and care partner identity credentials. A historical health record can contain years of data, some of which may be sensitive, such as mental health treatment and diagnoses and information about stigmatized conditions. A patient may have current health issues that they are not ready to share with a care partner. However, that same patient may want their care partner to be able to communicate with a physician or request appointments or prescription refills, but not see their clinical notes. Alternatively, other patients, such as those with memory issues or vision loss, for example, may want a care partner to have access to clinical notes so that they may know what happened during a clinical visit and understand the care plan. No blanket policy for shared access can adequately address these different scenarios.

A Look Forward

Achieving widespread patient engagement through the patient portal will require that organizations address the diverse needs and preferences of all patients, including those with greater socioeconomic and physical vulnerability [2,28,29]. The current landscape of shared access indicates that multifaceted efforts will be needed to increase awareness, clarify the value and importance of differentiating patient and care partner identity credentials, and simplify registration processes. Online electronic identity proofing, already available at some health systems [30], holds promise for overcoming cumbersome in-person registration processes and paper-based documentation but disproportionately benefits subpopulations with digital health literacy skills and technology access [31]. A recent review of best practices to engage patients in electronic health records recommended that organizational awareness and marketing efforts target high-cost, high-need subpopulations with greater vulnerability [28]. Such efforts should encompass both patients and their care partners, in recognition of the broader social context in which many older adults comanage or delegate care [29,32], and the arbitrary distinction between patient and care partner roles, which may co-occur simultaneously [32]. Organizational efforts to engage care partners must also resonate with the needs and concerns of clinicians and staff by enhancing knowledge about the importance of proper identity credentials and addressing concerns regarding potential impacts on workflows, time demands, or both [2,3,33,34].

Recognizing that registration and use of the patient portal are separate and significant dimensions of patient engagement [2], additional changes will be needed to enhance the usability of the portal among older adults and care partners with less technology "readiness" and experience. Strong evidence finds that simplifying the user interface, reducing technical language, and enhancing the visual layout of content increases the perceived value of the portal by both patients and care partners [29,35]. The development and implementation of electronic health record certification criteria that require vendors to develop granular, role-based privacy controls would be transformative in acknowledging the nuanced, complex, dynamic nature of individuals' preferences for sharing their health information [27] and affording patients greater control over who has privileges to undertake health management tasks on their behalf [36]. Putting these privacy controls into the hands of patients may provide peace of mind to clinicians concerned about the privacy of their patients' protected health information.

Benefits of the patient portal have been generally conceptualized as accruing to patients [37]. However, portal benefits including convenience, continuity, activation, and understanding are equally relevant to care partners, who may additionally benefit from greater legitimacy in their interactions with clinicians and staff due to having their own unique identity credentials. Routine assessment and support of family caregivers are elements of high-quality clinical care and robust systems of long-term services and supports but systems-level approaches are lacking and most interventions have been trialed outside care delivery [4,38]. As an existing mechanism to facilitate bidirectional communication and outreach, shared portal access is a relevant tool in efforts to promote a more optimal person- and family-oriented care delivery system [4,39] and address an identified challenge to disseminate novel technologies to support care partners in real-world practice settings [34,40].

Conclusion

The development and spread of strategies to engage care partners through the patient portal is especially timely. As of April 5, 2021, federal information blocking rules require that health care providers give patients electronic access without charge or delay to all the health information in their electronic medical records through patient portals or third-party smartphone apps, dramatically expanding the comprehensiveness and timeliness of health care information that is available through the patient portal [41]. The importance of transparent processes to systematically normalize the engagement of care partners in electronic interactions will undoubtedly grow in the coming years given increasing reliance on telehealth and electronic information exchange, the growth of patient-generated health data, and the combination of population aging alongside growth in community-based care settings. Most importantly, through clarifying and respecting differentiated identity credentials, shared portal access sets the stage for protecting the privacy and security of personal health information, while supporting a culture of trust, individual rights, and appreciation for the reality of the broader social context in which individuals commonly comanage their care.

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Authors' Contributions

JLW and CMD contributed to conception or design of the work. All authors contributed to data collection, analysis, and interpretation, as well as drafting and providing critical revision of the article. All authors gave final approval of the version to be published.

Conflicts of Interest

None declared.

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Corrigenda and Addenda

Correction: A Model for Estimating Biological Age From Physiological Biomarkers of Healthy Aging: Cross-sectional Study

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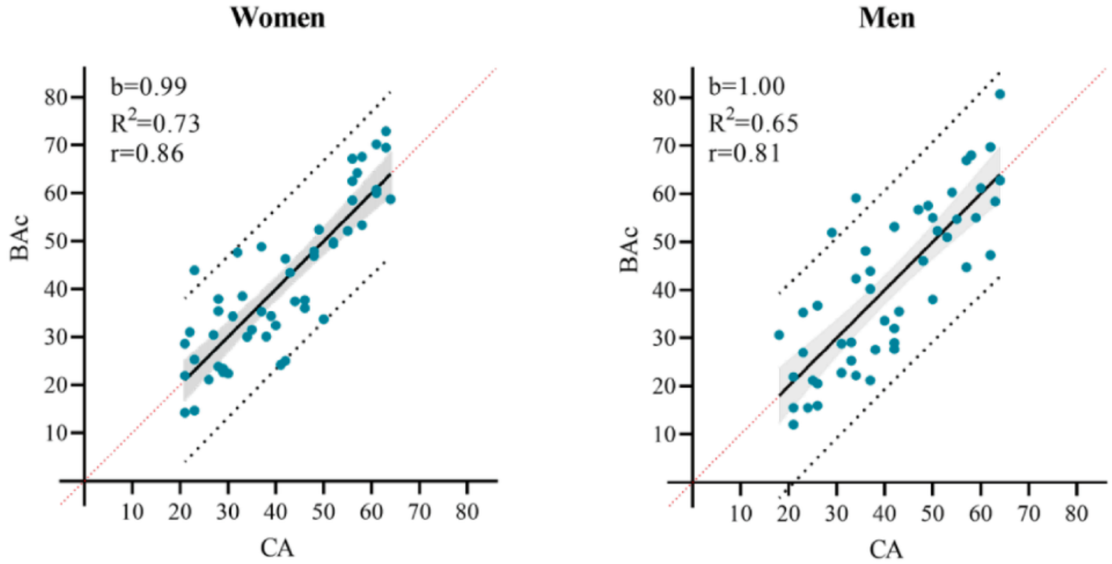
In “A Model for Estimating Biological Age From Physiological Biomarkers of Healthy Aging: Cross-sectional Study” (JMIR Aging 2022;5(2):e35696) the authors noted one error.

In the originally published article, Figure 4 inadvertently appeared with the same image as that of Figure 3. In the corrected version of the article, Figure 4 was updated with the following image:

Figure 4. The BAc regression lines for women and men, respectively with 95% Confidence interval (shaded area), 95% Prediction intervals (black dotted lines) and line of identity (red dotted line). Slope (b), correlation coefficient (r) and coefficient of determination (R2).



The correction will appear in the online version of the paper on the JMIR Publications website on June 28, 2022, 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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