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Contents

Original Paper

Older Adults' Experiences With Using Technology for Socialization During the COVID-19 Pandemic: Cross-sectional Survey Study

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Abstract

Background: Technology use has become the most critical approach to maintaining social connectedness during the COVID-19 pandemic. Older adults (aged >65 years) are perceived as the most physiologically susceptible population to developing COVID-19 and are at risk of secondary mental health challenges related to the social isolation that has been imposed by virus containment strategies. To mitigate concerns regarding sampling bias, we analyzed a random sample of older adults to understand the uptake and acceptance of technologies that support socialization during the pandemic.

Objective: We aimed to conduct a population-based assessment of the barriers and facilitators to engaging in the use of technology for web-based socialization among older adults in the Canadian province of British Columbia during the COVID-19 pandemic.

Methods: We conducted a cross-sectional, population-based, regionally representative survey by using the random-digit dialing method to reach participants aged >65 years who live in British Columbia. Data were analyzed using SPSS (IBM Corporation), and open-text responses were analyzed via thematic analysis.

Results: Respondents included 400 older adults aged an average of 72 years, and 63.7% (n=255) of respondents were female. Most respondents (n=358, 89.5%) were aware of how to use technology to connect with others, and slightly more than half of the respondents (n=224, 56%) reported that, since the beginning of the pandemic, they used technology differently to connect with others during the pandemic. Additionally, 55.9% (n=223) of respondents reported that they adopted new technology since the beginning of the pandemic. Older adults reported the following key barriers to using technology: (1) a lack of access (including finance-, knowledge-, and age-related issues); (2) a lack of interest (including a preference for telephones and a general lack of interest in computers); and (3) physical barriers (resultant of cognitive impairments, stroke, and arthritis). Older adults also reported the following facilitators: (1) a knowledge of technologies (from self-teaching or external courses); (2) reliance on others (family, friends, and general internet searches); (3) technology accessibility (including appropriate environments, user-friendly technology, and clear instructions); and (4) social motivation (everyone else is doing it).

Conclusions: Much data on older adults' use of technology are limited by sampling biases, but this study, which used a random sampling method, demonstrated that older adults used technology to mitigate social isolation during the pandemic. Web-based socialization is the most promising method for mitigating potential mental health effects that are related to virus containment strategies. Providing telephone training; creating task lists; and implementing the facilitators described by participants, such as facilitated socialization activities, are important strategies for addressing barriers, and these strategies can be implemented during and beyond the pandemic to bolster the mental health needs of older adults.

Introduction

The potential impact of the global COVID-19 pandemic has been thought to have devastating implications for older adults, who have a high risk of developing COVID-19. Older adults have been experiencing social isolation as a result of physical distancing, which may lead to long-term mental health problems [1,2]. Early reports from China [3] have suggested that mental health support should be integrated into pandemic planning. However, nearly 1 year into the pandemic, such support has yet to be realized. Early in the pandemic, global calls were issued to address the risks of social isolation for older adults, which can be mitigated by using technologies that help reduce social isolation in times of physical distancing and address vital socialization functions [4,5]. Rapid funding calls were issued by health research agencies to determine how to best address and support the mental health needs of older adults [6].

Many technologies are available for mitigating the mental health consequences of social disconnection that has resulted from the COVID-19 pandemic [5]. A growing number of older adults have been adopting technology [7], and technology-facilitated social connection interventions have a strong evidence base for improving the mental and physical health of older adults [8-12]. However, to date, much of this evidence has come from self-selecting samples of older adults who are recruited via convenience sampling and participant members of community groups [13]. These groups may not provide accurate cross-sectional data on older adults' use and uptake of technology at the population level. This is particularly true for nonrandomized studies of technology and older adults. It is likely that self-selecting participants disproportionately represent people from higher socioeconomic strata and younger age groups, those with higher educational levels and greater digital literacy, and those who prefer in-person communication over web-based platforms [14].

In our previous study [O'Connell ME, unpublished data, 2021], which was related to the pandemic, we hypothesized that pandemic-created conditions have resulted in technology

becoming essential tools for meeting the socialization needs of older adults. We found that older adults value one-on-one remote telephone mentoring and the use of structured task-lists for guiding their engagement with web-based socialization activities. However, to understand whether web-based socialization is acceptable to a population-based sample of older adults, more research is needed.

The purpose of this study is to conduct a province-wide survey in the Canadian province of British Columbia and to understand the barriers and facilitators to engaging in web-based socialization activities among older adults. This will complement our existing British Columbia–based study, which involves an environmental scan of web-based socialization programs and in-depth interviews with older adults who engage with and disengage from web-based socialization activities during the pandemic.

Methods

Recruitment

In January 2021, we conducted a population-based, cross-sectional survey with adults aged >65 years. The survey was conducted by the Canadian Hub for Applied and Social Research (CHASR). We used a random-digit dialing approach to call landlines and mobile phones within the province of British Columbia. Upon providing consent to participate, individuals were asked to confirm that they were aged >65 years and resided within the province before they proceeded to answer the substantive and sociodemographic questions. Sociodemographic questions involved the following topics: gender, the highest level of education, and household income. The survey questions were intended to obtain a snapshot of technology use during the pandemic, which included aspects such as any changes to technology use, barriers and facilitators, and how technology was used to mitigate social isolation during the COVID-19 pandemic. The survey was piloted by CHASR staff among a random sample of five older adults to ensure that questions were acceptable and understandable to participants. The specific survey questions are shown in Textbox 1.

Textbox 1. Survey questions.

1. Are you aware of how you can use technology to connect with others?

2. Since the beginning of the pandemic, are you using technology differently to connect with others?

3. Was this new technology or had you used it before?

4. Are you still using technology or did you stop?

5. What stops you from using technology to connect with others?

6. What would help or has helped you use technology to connect with others?

7. Are finances a barrier to your use of technology?

Data Analysis

Data analyses were performed using SPSS, version 27.0 (IBM Corporation). Descriptive statistics, including means and frequencies, were used to describe the study sample.

Thematic Analysis

Of the 7 questions, 2 were used to obtain open-text data, and we sought to thematically analyze these data to understand the main barriers and facilitators to using technology. We used a qualitative approach to open-text survey analysis, as per Braun et al [15]. For both questions 5 and 6 (Textbox 1), three authors (KH, LK, IR) conducted a thematic analysis. Responses were read, reread, coded with a descriptive label, and organized into broad themes. Themes and exemplar quotes were reviewed by the team to ensure consensus on the content and nature of the themes.

Results

Characterization of the Sample

Participants were aged an average of 72.2 years (range 65-107 years; SD 7.38 years), and 63.7% (255/400) of the sample were female. The majority of participants (264/400, 66%) completed some level of postsecondary education; 21.5% (85/400) of participants completed or took some technical or college courses, 28.8% (115/400) took some or completed university courses, and 15.8% (63/400) completed postgraduate training (eg, Master's, professional, or doctoral degree). The remaining participants completed some (44/400, 11%) or all of high school (91/400, 22.8%). Of the 248 participants who reported their total household income from all sources, including pensions, 25 (10%) reported an income of less than Can $25,000/year (US $19,858/year), 74 (29.8%) reported an income that ranged from Can $25,000/year to Can $75,000/year (US $19,858/year to US $59,574/year), and 55 (22.1%) reported an income of over Can $75,000/year (US $39,574/year).

Using Technology to Connect With Others

The majority of respondents (358/400, 89.5%) stated that they were aware of how to use technology to connect with others. Since the beginning of the pandemic, slightly more than half of the participants (224/400, 56%) reported that they used technology differently to connect with others. Furthermore, 55.9% (223/400) of respondents reported that they adopted new technology since the beginning of the pandemic. Age was not associated with using technology differently during the pandemic (point-biserial correlation coefficient [r_{pb}]=−0.09; P=.089), but increasing age was associated with fewer people reporting that they knew how to use technology to connect with others (r_{pb}=−0.21; P<.001). Compared to those with lower education, participants with higher education were more aware of how to use technology to engage with others (Spearman rank correlation coefficient [r_s]=−0.16; P=.002) and were more likely to report that the pandemic changed the way that they used technology (r_s=−0.17; P=.001).

Barriers to Web-Based Socialization

In total, 91% (364/400) of participants reported that they continued to use the technologies that they started using during the pandemic. The remaining 9% (36/400) reported that they stopped using technology. The reasons for stopping the use of technology or not using technology varied. In total, 53 respondents stated that they did not use or stopped using technology during the pandemic. The three main reasons for not using technology included the following: (1) a lack of interest; (2) a lack of access; and (3) physical limitations. These barriers are described below.

Participants' lack of interest was reported to by a result of their disinterest in computers in general, preferences for and comfort with the use of telephones, and feelings of simply being "too old." One respondent's lack of interest in computers was described as follows:

> I like to do other things and I've never been that way inclined. It came out when I was too old to be bothered with it.

Another respondent said, "I'm old school and I don't need it." Others explained that when they retired, they did not want to deal with computers anymore. For instance, one participant stated:

> When I retired, I said, "I don't want to look at another one for years. I have other things to do."

Participants also stated that their affinity for using the telephone arose because telephones were their main means of connection. One participant simply stated, "I would rather talk to people on the phone." Others described their desire to hear a human voice and felt that this was impossible to achieve with other forms of technology. A participant said:

> I watch a lot of young people who do not socialize the way I like to socialize. I would rather communicate with people over the phone over text messages. I do not choose to do anything online; I am computer illiterate.

A final quote from one woman indicated how personal disinterest can drive one's aversion to technology. She stated:

> I do not like technology at all, and people should use their minds and not technology. Old ladies do not like it. I don't do gadgets.

A lack of access to technology for socialization included barriers such as financial costs, a lack of trust, and a lack of knowledge. Several older adults stated that they simply "don't have a computer" and that this prevented them from using computers for socialization. Others felt the costs of either technology or the internet was "too expensive." For example, one respondent simply said their main barrier was "not having the internet because it's too expensive; [I] can't afford it." Others described a lack of knowledge as an insurmountable challenge. For instance, a respondent said, "I have no idea about anything." Another respondent expressed a newfound desire to learn about using technology since the start of the pandemic but felt that they did not have the skills to do so. This respondent stated:

I don't feel good at it and never had the need until last year and I wish I had done it.

Several participants felt that although their lack of knowledge was a problem, they would use technology if training was more accessible. A respondent stated that they would use technology "if there had been an affordable course for education." They went on to say:

I started using computers in 1969, but I didn't keep up. If there was a course for other idiots like me, I would be more aware. But I have looked, and it is too expensive to pay for a weekend course.

The final barrier was related to those who were physically unable to use technology for web-based socialization, which included five individuals. One of the physical challenges described included eyesight ("I have bad eyesight and it is worse to see things; it is difficult"). Furthermore, two individuals believed that their experiences of having a stroke impacted their ability to engage with technology. One stated:

I have had a stroke and only have my left hand with which to type, so I haven't done any typing since that stroke. It is intimidating.

Two respondents experienced cognitive challenges resulting from a head injury, and one person reported "cognitive impairment" as a primary barrier that impeded their use of technology.

Facilitators to Web-Based Socialization

We also asked participants to describe what helped them or would help them use technology for socialization during the pandemic. In total, 91.5% (366/400) of respondents provided at least 1 facilitator to technology use. The themes that described key facilitators were related to the following: (1) prior knowledge of technology; (2) the act of asking others for help; (3) technological accessibility; and (4) social motivation.

Respondents believed that prior knowledge of and familiarity with technology was fundamental to their ability to use technology to socially connect with others during the pandemic. Many participants indicated that learning how to use specific technologies helped them to stay connected with others during the pandemic. One respondent stated:

I guess learning how to use it and people guiding us along, do this do that here's how to mute, hints that people have given through the months.

Many older adults had prior knowledge of technology use. One respondent said:

I go to work and use a lot of technology in my work.

Other respondents obtained technology knowledge by seeking answers and instructions from web-based platforms. One person stated that they were familiar with technology and adopted new tools to connect with others since the pandemic began. This person said:

I've been using the internet for years. Zoom was new to me. My husband has used it before. It wasn't new, but I hadn't used it personally. We use it now to connect without any problems.

Several participants also described how they used their limited technology skills to learn more by simply searching the internet. One participant said that they "just [found] information on the internet on how to do it."

Many older adults felt they were not capable of independently using technology and heavily relied on access to help, which typically came from family members or friends when the need to use technology arose. A respondent said:

If I have a question, I can ask [my kids]. They're my tech support.

Another respondent stated:

My son, who was a computer expert, helps me Skype so I can see my friends in a different province.

Participants also depended on their friends—fellow older adults—to adopt new technologies during the pandemic. One participant said:

A friend of mine introduced me to using my iPad, and if I have a problem, I phone her.

Participants emphasized the importance of having access to the support they needed to use technology, especially during a pandemic, as technology was their only connection to people. One participant stated:

When I have problems with my computer or iPad, my son is the one who would come and troubleshoot it for me. Email has helped me and Zoom as well. I am retired, so I just email or telephone them to have a one-on-one conversation. I find it really important right now to have a one on one in this time of virus with our technology, such as phone or email.

Several older adults also indicated that they put little time and effort into maintaining or using technology and preferred having someone facilitate their technology experiences. For instance, a participant stated:

When I do go online with Zoom, I rest in the comfort of somebody else facilitating it.

Older adults' perceptions of the accessibility and user-friendliness of technological devices, services, and platforms considerably determined their willingness to use technology to socially connect with others. Older adults repeatedly voiced a desire for clearer instructions (than those that are typically available) on how to use technologies and technology applications. They also described the need for or use of supportive technology services that facilitate their technology use. One respondent stated:

I'm not very comfortable using Zoom. It is difficult to connect. I can use other things, but experiences with Zoom or group meetings is very confusing and has been cutting out. it could be clearer and easier to connect. I am older but not isolated from tech.

Access to up-to-date technologies and devices, such as smartphones, and the availability of reliable internet connectivity were additional facilitators of older adults' engagement with technology. One participant said:

Well, more education on different modern stuff. Things like newer cellphone, cameras, and etc. We don't use latest technology. When you look at my date of birth, you'll see that I'm no youngster.

Several respondents believed that their use of technology was enabled or obstructed by their environment as a result of both social and material factors. Older adults who lived in rural or isolated communities experienced heightened barriers to technology use. Additionally, older adults who remained in the workforce reported a heightened use of and increased access to technology for work-related activities. A respondent stated that a main facilitator was "the fact that I am still working."

Older adults also believed that their engagement with technology for connecting with others was largely driven by social motivation. A participant stated:

I am doing it too because everyone is doing it: social interest.

This motivation has arisen not only due to a desire to maintain social connections that were established prior to the pandemic, but also due to social pressures to use technology, as older adults' friends, family members, and wider social circles and communities have increasingly used web-based platforms as a result of pandemic-related restrictions. One participant described this social pressure and its related implications for learning how to use technology for web-based socialization. This participant stated that "this technology was used by my peers and I had to learn it."

Discussion

Principal Results

The 400 older adults we surveyed were aware of how to use technology to connect with others and reported that, since the beginning of the pandemic, they used technology differently to connect with others during the pandemic. More than half of the respondents (223/400, 55.9%) reported that they adopted new technology since the beginning of the pandemic. Nevertheless, older adults reported several key barriers to using technology, such as a lack of access, a lack of interest, and physical barriers. However, participants described more facilitators than barriers. Such facilitators included personal knowledge, support from family and friends, and the social pressures imposed by the pandemic. These findings are promising as we enter the second year of the pandemic. Although there have been optimistic plans for vaccinating the majority of Canadians within the year, it is unclear whether such plans will be realized. A clearer understanding of the use of web-based socialization technology among older adults will provide important opportunities for identifying future interventions and support services during and beyond the pandemic.

Limitations

The sample in this cross-sectional study was predominantly female and more well educated than the general population. Therefore, our sample may not be representative of the general population. Furthermore, in an effort to keep the survey brief (as it was conducted via telephone), we only included a minimal number of demographic-related questions. In ongoing research, we intend to closely examine the individual situations of older adults in greater depth. Although we used a random sampling approach and were able to gather the perspectives of individuals who did and did not use technology (which is a challenge in the majority of technology-related research), our results are influenced by an element of response bias. We were unable to report a true response rate due to the limits of random-digit dialing, as the overall number of refusals could not be tracked with certainty. For example, it was unclear whether phone hang-ups were actually from households with eligible participants (adults aged >65 years).

Comparison With Prior Work

The implications of social isolation and the reduced number of social networks were well documented prior to the pandemic [16]. However, our findings show that many older adults are doing their best to obtain family and community support to access technologies and demonstrating many strengths during the pandemic. These findings are in line with prior qualitative work by the first author, wherein older adult cancer survivors described their previous life and illness experiences of coping with the pandemic [17,18]. Drawing further information from older adults' interests, motivations, and willingness with regard to their engagement with technology has promising implications for mitigating the devastating effects of the isolation that has been imposed by the pandemic.

In prior and ongoing work that was conducted during the pandemic, we studied the landscape of web-based socialization and the potential of remote technology training and mental health support. This survey study mirrors our prior study of a small sample of older adults, in which structured task lists were seen as integral in supporting older adults' use of technology to meet their web-based socialization needs [O'Connell ME, unpublished data, 2021]. Furthermore, our population-based survey study demonstrated that clear instructions for using technologies, such as Zoom, for socialization purposes are needed for older adults to feel confident in their use of such technology. Our findings also support the potential of partnering with community groups that provide technological support (eg, task lists) and implementing remote training for using technology to encourage technology use among older adults.

In this study, the fact that several respondents did not feel confident in their technology use is an important implication. A lack of exposure to technology (ie, the digital divide) can result in additional psychological barriers to technology use (ie, the double digital divide). For example, participants from rural areas are unlikely to have access to the physical infrastructures that are needed for facilitating exposures to technology. This adds a psychological, technology adoption–related barrier to the existing technology adoption barriers that are described in the rural technology acceptance model [19]. The psychological barriers to technology adoption include those that are revealed in our study, such as the low perceived ease of use of new technologies, which was noted in the technology accessibility theme. A more fundamentally important psychological barrier to technology adoption may be the perception that technology is not going to be useful [19]. Data from O'Connell et al [19] are in line with those of other studies; the COVID-19 pandemic

has changed how older adults perceive technology's usefulness. They now see technology use as a method for maintaining social and community ties while complying with physical distancing measures and have therefore increased their adoption of technology. In a previous study, we described how remote training and support can help facilitate technology adoption, which would help people maintain social and community connections during the pandemic [O'Connell ME, unpublished data, 2021]. We also reported how the process of the pandemic's impact on older adults' perceptions of technology is described in the COVID-19–technology acceptance model [O'Connell ME, unpublished data, 2021].

In terms of addressing the challenges of the digital divide, incorporating the perspectives of older adults is an integral aspect of the increased use and uptake of digital technologies [20]. The first step in achieving positive, technology-driven outcomes in mental health (and other fields) is the articulation of barriers and facilitators. By conducting studies that examine older adults' perspectives via exploratory qualitative analyses, we were able to better understand older adults' perceived needs, challenges, and benefits in the context of evolving technologies. The cocreation of technologies with older adults has been suggested as an effective means of increasing technology engagement among older adults with mental health conditions [21].

We found that older adults' engagement with technology may be impeded or facilitated by a range of factors, and this finding is in line with those of related, prepandemic research. Our results were similar to the findings of previous studies that examined older adults' views on using technology to maintain social connectedness before the pandemic. Széman [22] has noted that older adults prefer to use simple software and websites. This implies that the difficulty and complexity of new technologies have always prevented older adults from using such technology to connect with others. On the other hand, our findings indicate that older adults can learn how to effectively use technologies to build or maintain social connections, especially when they experience the social pressure to do so [23]. Prior research has found that feelings of fear and resentment toward using technology can be overcome by training and increasing the frequency of use, as people gain confidence as they continue to use technological devices and navigate through websites and social media platforms [24].

Familial support and the drive to maintain family relationships have previously been identified as key facilitators of technological engagement among older adults. In our study, older adult participants used technology as a means of maintaining contact with close family members, and this finding is similar to those of previous studies [22,25]. These studies have indicated that engagement and communication with family members, especially with grandchildren, are driving factors for participants' willingness to learn about new technologies. Notably, many previous studies that implemented technological interventions also provided either in-person or remote support to older adult participants to provide assistance or ensure that applications were operating in the correct manner [26,27]. In such studies, interventions that were not supported by research staff relied on support from family members [28]. This calls attention to the importance of older adults' access to support while they learn how to use new technologies, regardless of whether this support comes from family or external sources. This was made evident by the frequency with which our respondents described how they relied on friends, family members, or supportive services to facilitate or provide instructions on the use of technology for social engagement.

Studies similar to ours have found that physiological barriers, such as hearing and vision loss [29] or issues with dexterity and poor coordination [25,30-32], may impede older adults' willingness to engage with technology. This sentiment was also reported by our respondents, who stated that physical or cognitive limitations related to injuries or age-related decline inhibited their use of technological applications.

Conclusions

Older adults are facing an unprecedented challenge during the COVID-19 pandemic. This study provides information on the facilitators of accessing technology that supports socialization and the barriers that are the most important to older adults. Our findings regarding these barriers and the mounting evidence in existing literature demonstrate that partnerships with community groups can potentially bolster socialization support for older adults. These study findings have immediate implications for supporting older adults. However, our findings' sustained importance will be determined by how we can facilitate the use of technologies for socialization now and in the future.

Conflicts of Interest

None declared.

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Abbreviations

CHASR: Canadian Hub for Applied and Social Research
r_{pb}**:** point-biserial correlation coefficient
r_s**:** Spearman rank correlation coefficient

Original Paper

Evaluation of the Usability and Acceptability of the InnoWell Platform as Rated by Older Adults: Survey Study

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Abstract

Background: As the global population ages, there is increased interest in developing strategies to promote health and well-being in later life, thus enabling continued productivity, social engagement, and independence. As older adults use technologies with greater frequency, proficiency, and confidence, health information technologies (HITs) now hold considerable potential as a means to enable broader access to tools and services for the purposes of screening, treatment, monitoring, and ongoing maintenance of health for this group. The InnoWell Platform is a digital tool co-designed with lived experience to facilitate better outcomes by enabling access to a comprehensive multidimensional assessment, the results of which are provided in real time to enable consumers to make informed decisions about clinical and nonclinical care options independently or in collaboration with a health professional.

Objective: This study aims to evaluate the usability and acceptability of a prototype of the InnoWell Platform, co-designed and configured with and for older adults, using self-report surveys.

Methods: Participants were adults 50 years and older who were invited to engage with the InnoWell Platform naturalistically (ie, at their own discretion) for a period of 90 days. In addition, they completed short web-based surveys at baseline regarding their background, health, and mental well-being. After 90 days, participants were asked to complete the System Usability Scale to evaluate the usability and acceptability of the prototyped InnoWell Platform, with the aim of informing the iterative redesign and development of this digital tool before implementation within a health service setting.

Results: A total of 19 participants consented to participate in the study; however, only the data from the 16 participants (mean age 62.8 years, SD 7.5; range 50-72) who completed at least part of the survey at 90 days were included in the analyses. Participants generally reported low levels of psychological distress and good mental well-being. In relation to the InnoWell Platform, the usability scores were suboptimal. Although the InnoWell Platform was noted to be easy to use, participants had difficulty identifying the relevance of the tool for their personal circumstances. Ease of use, the comprehensive nature of the assessment tools, and the ability to track progress over time were favored features of the InnoWell Platform, whereas the need for greater personalization and improved mobile functionality were cited as areas for improvement.

Conclusions: HITs such as the InnoWell Platform have tremendous potential to improve access to cost-effective and low-intensity interventions at scale to improve and maintain mental health and well-being in later life. However, to promote adoption of and continued engagement with such tools, it is essential that these HITs are personalized and relevant for older adult end users, accounting for differences in background, clinical profiles, and levels of need.

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Introduction

Capitalizing on Technology to Support Health and Well-being

As the global population rapidly ages, there has been an increased focus on the development of strategies to support and maintain health and well-being in later life. As described in detail in our previous work [1], the international literature indicates that approximately two-thirds of adults aged ≥65 years report internet use [2,3], and these older adults also represent the fastest growing group of internet users [4]. Globally, government initiatives have been launched to improve the digital literacy and web-based safety of older adults [5,6]. Thus, using health information technologies (HITs) for mental health screening, intervention delivery, and routine outcome monitoring will be increasingly practical options for older adults.

The Usability and Acceptability of HITs

Although there are more than 400,000 health care apps available on the market, app use data indicate that most health-related apps have fewer than 10,000 downloads [7]. Recognizing that HITs, such as apps, have enormous potential for empowering self-management [8], the health, medical, and research sectors internationally are prioritizing strategies to enhance community and consumer acceptability, usability, and engagement with such digital tools. Participatory design methodologies facilitate the active participation of key stakeholders in the design of HITs, with the aim of ensuring that the end product meets the needs of the end user, improves usability, and increases engagement of all individuals [9-11]. Despite this evidence, with the exception of a diet diary app for older adults with macular degeneration, few HITs have been designed specifically for older adults.

Importantly, as reported by LaMonica et al [12], the majority of a sample of older adults (198/209, 95%) presenting to a specialized memory clinic reported that they were interested in a web-based tool designed to support healthy aging, including physical health and cognition, self-management of existing conditions, and routine tracking of changes in health outcomes over time. Similarly, most respondents (172/206, 82%) also reported interest in a tool to assess and track mood-related concerns and changes [12]. Given older adults' interest in and motivation to use HITs to improve health and well-being [12,13], it is critical that HITs are tailored to the older adult community, taking into consideration their unique needs as users.

The InnoWell Platform

In 2017, the Australian Government Department of Health and InnoWell Pty Ltd (a joint venture between the University of Sydney and PwC [Australia]) entered into a 3-year funding agreement to deliver Project Synergy (2017-2020). The objective of Project Synergy is to conduct a series of collaborative research trials with the specific purpose of co-designing and implementing innovative HITs, including the InnoWell Platform, to enable improved mental health service delivery in Australia, facilitating better outcomes for people with lived experience and their supportive others as well as health professionals and service providers [14]. As detailed in papers by Davenport et al [15] and Iorfino et al [16], the InnoWell Platform comprises a multidimensional assessment targeting a range of biopsychosocial domains to capture a holistic view of the consumer. These data can be complemented by objective behavioral data collected via third-party integrations (eg, Fitbit) and informant-based information, including information provided by supportive others and health professionals. The assessment results are delivered in real time to the consumer at which point they can choose from a range of nonclinical care options (eg, apps and e-tools) that they can engage with immediately. If the consumer is engaged in care through a mental health service, the results are designed to be reviewed collaboratively with a health professional to promote shared decision making in relation to both clinical and nonclinical care options, accounting for consumer preferences. Additional information about the functionality and objectives of the InnoWell Platform is available on the InnoWell website [17].

Through participatory design, we configured a prototype of the InnoWell Platform specifically for older adults, including modification of health domains, informational material, and care options, to ensure relevance and appropriateness for this end user group [1]. This study, a supplement to the original co-design research, aims to evaluate the usability and acceptability of the prototyped older adult configuration of the InnoWell Platform. It is important to note that the InnoWell Platform is indicated for the support of assessment, monitoring, and management of mental ill health and maintenance of well-being; however, as the digital tool is still being validated through a clinical trial [15], recommendations regarding adherence or frequency of use have not been defined [18]. Rather, consumers are free to engage with the InnoWell Platform as it suits their needs.

Methods

Participants

Participants were required to be aged ≥50 years, be proficient in English, and complete the required informed consent process. As the study design was naturalistic, there was no predetermined sample size in relation to the number of participants who were able to engage with the prototype. To align with our previous work, we defined *older adults* as aged ≥50 years [1,12], as age 50 years relates to the onset of disorders in later life [19] as well as the identified age range during which it is recommended to address risk factors (ie, cardiovascular disease, obesity, diabetes, etc) known to interfere with healthy aging [20].

This study was advertised through the University of Sydney's Brain and Mind Centre (BMC) research clinics and private organizations (ie, InnoWell) associated with the BMC. Interested participants were directed to a study-specific webpage on REDCap (Research Electronic Data Capture), a research data collection tool, where they were able to read detailed information about the study before providing consent electronically. Recruitment ran for 5 months (May to September 2020).

90-Day Naturalistic Engagement With the InnoWell Platform

Participants were invited to engage with the InnoWell Platform naturalistically (ie, in a manner of their choice) for a period of 90 days; there were no specifications set in terms of frequency or patterns of use. On providing informed consent to participate in the study, the participants received an email invitation to the InnoWell Platform. They were then required to create an account, at which point they were asked to set up their profile by answering a series of demographic questions (ie, year of birth, level of education, and gender at birth). Having established a profile in the InnoWell Platform, participants were asked to complete a comprehensive multidimensional assessment comprising self-report questionnaires assessing a range of biopsychosocial domains specifically tailored to the older adult community (ie, cognition, sleep, and instrumental activities of daily living). The assessment results are then available in real time. In addition, participants were able to access psychoeducational material about all biopsychosocial domains, including clinical care options should that be warranted. In addition, a range of nonclinical care options are available to facilitate the self-management of mental health and well-being. The assessment tools embedded within the InnoWell Platform enable participants to reassess themselves across any or all of the biopsychosocial domains, thus allowing them to track progress over time. Importantly, all steps outlined earlier are voluntary, enabling the participant to discontinue at any time, with the option to return to the InnoWell Platform should they choose to do so. As the InnoWell Platform is designed to be intuitive, enabling independent use by consumers, this approach was believed to best mirror *real-world* engagement with the digital tool, thus facilitating evaluation of the acceptability and usability in this context.

In conjunction with their engagement with the InnoWell Platform, participants were asked to complete short web-based surveys via REDCap at baseline regarding their demographics, health, and well-being, including the Kessler Psychological Distress Scale, an internationally recognized, 10-item scale [21], and the World Health Organization-5 (WHO-5) Well-Being Index, a well-validated, 5-item measure of well-being in older adults [22]. On day 90, participants completed web-based questionnaires about their use of and feedback on the InnoWell Platform as well as the System Usability Scale [23], a 10-item, 5-point Likert-scale evaluating the usability and acceptability of the digital tool. Importantly, no data were collected directly using the InnoWell Platform.

Data Analysis

Descriptive statistics were used to analyze all aspects of the assessment data. Given that the overall sample size was small (N=16), response options were collapsed for some analyses, combining *strongly agree* and *agree* as well as *strongly disagree* and *disagree*. The Statistical Software Package for Social Sciences version 25 (IBM Corp) was used for all analyses.

Ethics

The research study was approved by the Human Research Ethics Committee of the University of Sydney (project 2019/172).

Results

Demographics

A total of 19 participants consented to participate in the study; however, only the data from the 16 participants (mean age 62.8 years, SD 7.5; range 50-72) who completed at least part of the survey at 90 days were included in the analyses. The demographic information is presented in Table 1. Overall, participants had a minimum of 12 years of education, were married or living with a partner, and were functioning independently without the need for care or support services.

Table 1. Participant demographic information.

Demographic and response	Participant, n (%)
Language	
English	16 (100)
Other	0 (0)
Aboriginal or Torres Strait Islander	
No	16 (100)
Yes	0 (0)
Gender at birth	
Female	9 (56)
Male	7 (44)
Gender identification	
Female	9 (56)
Male	7 (44)
Sexual orientation	
Bisexual	1 (6)
Gay or lesbian	0 (0)
Prefer not to answer	1 (6)
Straight	14 (88)
Highest level of education	
Postgraduate diploma, masters, or PhD	6 (37)
Undergraduate degree	5 (31)
Certificate or diploma (includes TAFE[a] and trade qualification)	3 (19)
Year 12 or equivalent	2 (13)
Relationship status	
Divorced	4 (25)
Married or living with partner	10 (63)
Separated (but still legally married)	1 (6)
Single (and have never been married)	1 (6)
Living circumstances[b]	
Living with family (including partners and dependents), friends, or flat mates	12 (75)
Living on my own	3 (19)
Living in a retirement village or self-care unit	1 (6)
Do you have children?	
Yes	12 (75)
No	4 (25)
Do you have a disability?	
Yes	1 (6)
No	15 (94)
Do you receive a government-based benefit?	
Yes	6 (38)
Age pension	3 (49)
Carer allowance	1 (17)

Demographic and response	Participant, n (%)
Financial assistance for carers (eg, care payment, carer allowance, and carer supplement)	1 (17)
Other	1 (17)
No	10 (62)

[a]TAFE: Technical and Further Education.

[b]All participants lived independently.

Self-Reported Mental Health and Well-being

In relation to mental health and well-being, participants generally reported low levels of psychological distress (median 16.2, range 10-32 with a score of 50 representing the most severe level of psychological distress), although 2 participants indicated high (26) or very high (32) distress levels. Similarly, most participants endorsed good mental well-being (median 64.0, range 12.0-96.0 out of a possible 100 points); however, one participant had a percentage score of 12 on the WHO-5, reflecting the worst possible well-being according to established scoring procedures [24].

Use of the InnoWell Platform

Table 2 reflects the frequency and regularity with which participants engaged with the InnoWell Platform, with most participants having used the digital tool only once, at the point of the initial invitation. Participants were unsure (indicating *maybe*) if the InnoWell Platform would be useful for individuals with mental health concerns, and, as shown in Figure 1, they gave it an average rating of 3 stars.

Table 2. Patterns of use of the InnoWell Platform.

Question	Participant, n (%)[a]
When did you first use the InnoWell Platform?	
Today	2 (12)
Less than a week ago	0 (0)
Less than a month ago	0 (0)
More than a month ago	4 (25)
Approximately 2 months ago	2 (12)
Approximately 3 months ago	8 (50)
How often did you use the InnoWell Platform?	
Every day or almost every day	0 (0)
Once or twice a week	0 (0)
Once or twice a month	3 (19)
Less than once a month	13 (81)
How many times (in total) have you logged into the InnoWell Platform?	
1 time	8 (53)
2-5 times	6 (40)
6-10 times	1 (7)
11-20 times	0 (0)
>20 times	0 (0)
When using the InnoWell Platform how long did you normally stay logged on?	
1-5 min	7 (47)
6-10 min	5 (33)
11-20 min	3 (20)
21-30 min	0 (0)
When would you most commonly use the InnoWell Platform?	
Early morning (5 AM to 9 AM)	2 (14)
Midmorning (9 AM to noon)	3 (21)
Early afternoon (noon to 3 PM)	0 (0)
Midafternoon (3 PM to 6 PM)	5 (36)
Evening (6 PM to 11 PM)	4 (29)
Night time (11 PM to 5 AM)	0 (0)
What device did you most commonly use to access the InnoWell Platform?	
Personal laptop	6 (38)
Smartphone	4 (25)
Tablet	3 (19)
Personal desktop computer	2 (12)
Shared desktop computer	1 (6)
Do you think the InnoWell Platform is useful or helpful for people with mental health concerns?	
No	0 (0)
Maybe	11 (69)
Yes	5 (31)
Do you like the InnoWell Platform?	
No	1 (6)

Question	Participant, n (%)[a]
Maybe	9 (56)
Yes	6 (38)
If it was still available, how many times do you think you might use the InnoWell Platform in the next 12 months?	
None	4 (25)
1-2 times	3 (19)
3-10 times	8 (50)
10-50 times	1 (6)
>50 times	0 (0)

[a]In some instances, percentages do not sum to 100 due to rounding errors.

Figure 1. Participant star ratings of the InnoWell Platform (N=16).

Usability and Acceptability of the InnoWell Platform

The usability ratings of the InnoWell Platform are summarized in Table 3. Overall, participants reported a suboptimal user experience (median 65, range 45-100 out of a possible 100 points). Although they did not indicate that the InnoWell Platform was difficult to use or overly complex, most respondents noted that they were unsure if they would use the digital tool.

As shown in Textbox 1, participants' qualitative feedback on their initial impressions of the InnoWell Platform also varied, with one participant describing it as "impressive", whereas another stated, "I wasn't sure how to use it."

Textbox 2 highlights the participants' favorite features of the InnoWell Platform, including ease of use, the comprehensive nature of the multidimensional assessment, and the ability to track health status over time, all of which are core elements of its conceptualization and design [7,8].

Importantly, participants also provided valuable suggestions as to how best to improve the InnoWell Platform to enhance the user experience and promote engagement, including the need for greater personalization as well as improved technical functionality to enable use on different devices (Figure 2).

Table 3. System Usability Scale ratings of the InnoWell Platform (n=15).

Statement	Participant, n (%)		
	"Strongly disagree" or "disagree"	"Neutral"	"Strongly agree" or "agree"
I think that I would like to use this system frequently.	4 (27)	8 (53)	3 (20)
I found the system unnecessarily complex.	11 (73)	4 (27)	0 (0)
I thought the system was easy to use.	0 (0)	5 (33)	10 (67)
I think that I would need the support of a technical person to be able to use this system.	8 (53)	7 (47)	0 (0)
I found the various functions in this system were well integrated.	0 (0)	10 (67)	5 (33)
I thought there was too much inconsistency in this system.	10 (67)	5 (33)	0 (0)
I would imagine that most people would learn to use this system very quickly.	0 (0)	5 (33)	10 (66)
I found the system very cumbersome to use.	11 (73)	4 (27)	0 (0)
I felt very confident using the system.	0 (0)	7 (47)	8 (53)
I needed to learn a lot of things before I could get going with this system.	8 (53)	6 (40)	1 (7)

Textbox 1. Initial impressions of the InnoWell Platform.

What were your first impressions of the InnoWell Platform?

- Positive

  - "Impressive and if used with your GP (general practitioner) & Psychologist it offers a much better set of tools for managing depression and anxiety than doing the simple DAS (Depression, Anxiety, Stress) scales."

  - "Easy to use, relevant, accessible. Favourable impression overall"

  - "Quite good"

  - "The ease of use, it was simple and easy to navigate on a mobile phone."

  - "I thought it was very useful in directing your attention to those aspects of your lifestyle which were likely to affect physical and mental health outcomes"

  - "Clean, easy to use interface"

- Neutral

  - "InnoWell is a program for assessing the mental health of members of the community"

  - "Given that I don't appear to have any real issues it is hard to comment on the need for reassurance or help"

  - "Program might be of use"

  - "I have to admit I only used it once and now I cannot find it. Maybe I don't need it right now..."

- Negative

  - "Never even looked at it, until you asked me to evaluate it..."

  - "I wasn't sure how to use it"

  - "The system assumes user curiosity about negative aspects. Not enough reward built in. Not sure what it was or what value it would be"

  - "It could be that the number of times I felt certain ways could be inaccurate. Also it relies on the honesty of the participant."

Textbox 2. Preferred features of the InnoWell Platform.

What do you like best about the InnoWell Platform?

- "The ability to chart states of health/well-being over period of time."

- "Self help resources"

- "That it alerted the user to health considerations."

- "Quick & easy"

- "It provides a quick assessment of my mental state"

- "It focuses the mind about mental health"

- "Comprehensive range of health areas covered; Opportunity to question/challenge oneself about issues, health in general"

- "It covers a comprehensive range of scales that are integrated and presented simply through the dashboard which can flag issues to discuss with mental health support"

- "Easy to use"

- "It seeks to help and direct if required"

- "I found it beneficial to check in regularly on my mental health"

Figure 2. Suggested improvements to the InnoWell Platform.

| Suggested improvements: | "Maybe including an option for email alerts to be sent to participants to remind them to use Innowell and update it." | "I found that the questions I have been asked over the three months don't really relate to my situation. At no point was I asked about my living situation. I found the questions to be geared towards mental health issues with no option to note what could be you're particular issue. As a full time carer for a relative with cognitive impairment I felt that what I needed to say or add to the conversation was unable to be included." |
| | "The answer options don't present well on iPhone, the words are truncated due to column width limitations. Also the sense of the question does not match answer options and needs to be interpreted which could lead to inconsistency of input. Eg, the how often due you feel questions should have never, hardly ever, sometimes type of responses." | "A prompt to use it would have been good for me! Insufficient return on 'investment.'" |

Discussion

Principal Findings

Although older adults are interested in and willing to engage with HITs to support health and well-being [1,12], because of age-related changes in cognition, vision, hearing, and perception as well as health-related needs and risk factors, it is critical that HITs are tailored to the older adult community, accounting for their unique requirements as users. Having engaged with the prototype of the InnoWell Platform for older adults, participants did not report difficulty in using the digital tool, with several describing it as *easy to use;* however, overall usability scores were subpar, potentially because of a lack of relevance to the individuals' current circumstances and health-related needs (or lack thereof in the case of this generally healthy sample). In other words, a clear purpose for using the InnoWell Platform may have been needed to promote engagement (eg, "Not sure what it was or what value it would be"), a finding that aligns with a previous review of factors that impact acceptance of HITs by older adults [25]. As the participants generally characterized themselves as healthy and independent, experiencing low levels of psychological distress and good mental well-being, they may not have been intrinsically motivated to engage with the

InnoWell Platform at this time. It is also plausible that older adults were satisfied with the outcomes of their initial self-assessment and, therefore, did not have a reason to engage further with the InnoWell Platform. The authors of a recent systematic review of HITs for the promotion of well-being of older adults came to a similar conclusion on the limited effects of digital interventions on the mental well-being of older individuals without notable health or social support requirements [26].

Older adults may also be less inclined to use HITs in isolation but rather have a firm desire for such tools to be integrated with standard care practices to enable the therapeutic relationship with health professionals [1]. This may be a particularly important consideration for this consumer group, as they tend to experience greater degrees of social isolation and loneliness [27]. Therefore, the likelihood of adoption of HITs, such as the InnoWell Platform, may be improved if they are recommended by a health professional, a finding that is supported by previous research [28,29]. In light of these results, we aim to develop functionality to better personalize the InnoWell Platform at the individual level to enhance the user experience and to implement and rigorously evaluate the impact of the enhanced digital tool when embedded within health services providing care to older adults as a means to improve outcomes, thus filling an identified gap in the literature [26].

Whether used independently or as part of standard care, HITs are becoming increasingly sophisticated to support healthy aging and prevent disease and disability, thus enabling independent living. Although our participants did not experience difficulty using the InnoWell Platform, a lack of familiarity with or confidence in using technologies has been identified in other studies as a potential barrier to uptake and adoption by older adults [30-32], specifically in relation to web-based health care information seeking [33]. As such, it is important to consider demonstrations and training opportunities for older adults who might otherwise not have the opportunity to learn to use available technologies [34]. This might include videos and instruction guides embedded within the digital tool itself or access to a digital navigator through a clinical service for assistance with technology set up and troubleshooting as needed [35].

Limitations

This study has some limitations that are important to note. The small sample size may limit the applicability and generalizability of the findings to the general population. In addition, it will be important to further test the perceived usability and acceptability of the digital tool with help-seeking older adults, for whom content and functionality may be more relevant. This study would also have been enhanced by tracking patterns of use and the application of system analytics to better understand how the older adults had engaged with the InnoWell Platform. The use of embedded analytics tools such as Google Analytics should be considered for future evaluation studies to investigate the relationship between participant characteristics and use data. Finally, we did not include a measure of digital literacy, which may have impacted the participants' feedback on the usability and acceptability of the InnoWell Platform, although little difficulty in using the digital tool was reported by participants.

Conclusions

It has been demonstrated that older adults will only adopt new technologies when their apparent usefulness and usability outweigh concerns related to technological complexity and decreased social connections [36]. However, reflecting the need to embrace technology as a result of COVID-19 restrictions, a recent survey by the Global Centre for Modern Ageing highlighted that 23% of Australians aged ≥60 years used technology that was previously unfamiliar to them (eg, tablets, apps, and videoconferencing), with 56% of that group indicating that they felt confident in using this new technology [37]. These findings highlight the tremendous opportunity to engage older adults with HITs to support their mental health and well-being, either through direct-to-consumer approaches or as part of standard care. However, this study helps to establish and confirm that it is critical that the design and purpose of any HITs are relevant, appropriate, and personalized for older adult end users, accounting for differing demographic factors, interests, clinical profiles, and levels of need. As demonstrated in this study, the evaluation of HITs helps capture practical feedback on the design of HITs, allowing for iterative refinement before broader implementation, thus facilitating engagement and adoption.

Authors' Contributions

The authors IBH and TAD were integral in securing funding to support this study. The study was designed by TAD and HML, with subsequent contributions by AER. IBH served as the scientific advisor for this study, contributing to methodology and study implementation. All data analyses were conducted by HML and AER. All authors have contributed to and approved the final manuscript.

Conflicts of Interest

IBH was an inaugural Commissioner on Australia's National Mental Health Commission (2012-18). He is the Co-Director, Health and Policy at the Brain and Mind Centre (BMC) University of Sydney. The BMC operates an early-intervention youth service at Camperdown under contract to headspace. He is the Chief Scientific Advisor to, and a 5% equity shareholder in, InnoWell Pty Ltd. InnoWell was formed by the University of Sydney (45% equity) and PwC (Australia; 45% equity) to deliver the $30 M Australian Government-funded Project Synergy (2017-20; a three-year program for the transformation of mental health services) and to lead transformation of mental health services internationally through the use of innovative technologies. TAD is the Director (Research and Evaluation), Design and Strategy Division, Australian Digital Health Agency. The source of funding does not entail any potential conflicts of interest for the other members of the Project Synergy research and development team. The other authors have nothing to disclose.

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Abbreviations

BMC: Brain and Mind Centre
HIT: health information technology
REDCap: Research Electronic Data Capture
WHO-5: World Health Organization-5

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Original Paper

Requirements for Unobtrusive Monitoring to Support Home-Based Dementia Care: Qualitative Study Among Formal and Informal Caregivers

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Abstract

Background: Due to a growing shortage in residential care, people with dementia will increasingly be encouraged to live at home for longer. Although people with dementia prefer extended independent living, this also puts more pressure on both their informal and formal care networks. To support (in)formal caregivers of people with dementia, there is growing interest in unobtrusive contactless in-home monitoring technologies that allow caregivers to remotely monitor the lifestyle, health, and safety of their care recipients. Despite their potential, these solutions will only be viable if they meet the expectations and needs of formal and informal caregivers of people with dementia.

Objective: The objective of this study was to explore the expected benefits, barriers, needs, and requirements toward unobtrusive in-home monitoring from the perspective of formal and informal caregivers of community-dwelling people with dementia.

Methods: A combination of semistructured interviews and focus groups was used to collect data among informal (n=19) and formal (n=16) caregivers of people with dementia. Both sets of participants were presented with examples of unobtrusive in-home monitoring followed by questions addressing expected benefits, barriers, and needs. Relevant in-home monitoring goals were identified using a previously developed topic list. Interviews and focus groups were transcribed and inductively analyzed. Requirements for unobtrusive in-home monitoring were elicited based on the procedure of van Velsen and Bergvall-Kåreborn.

Results: Formal and informal caregivers saw unobtrusive in-home monitoring as a support tool that should particularly be used to monitor (the risk of) falls, day and night rhythm, personal hygiene, nocturnal restlessness, and eating and drinking behavior. Generally, (in)formal caregivers reported cross-checking self-care information, extended independent living, objective communication, prevention and proactive measures, emotional reassurance, and personalized and optimized care as the key benefits of unobtrusive in-home monitoring. Main concerns centered around privacy, information overload, and ethical concerns related to dehumanizing care. Furthermore, 16 requirements for unobtrusive in-home monitoring were generated that specified desired functions, how the technology should communicate with the user, which services surrounding the technology were seen as needed, and how the technology should be integrated into the existing work context.

Conclusions: Despite the presence of barriers, formal and informal caregivers of people with dementia generally saw value in unobtrusive in-home monitoring, and felt that these systems could contribute to a shift from reactive to more proactive and less obtrusive care. However, the full potential of unobtrusive in-home monitoring can only unfold if relevant concerns are considered. Our requirements can inform the development of more acceptable and goal-directed in-home monitoring technologies to support home-based dementia care.

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Introduction

Background

Dementia is recognized as a major global health challenge, creating an immense rise in demand for care [1]. In 2019, the number of people with dementia worldwide was estimated at 50 million, a figure set to increase to 152 million by 2050 [2]. However, the quantity of available professional caregivers is not expected to increase along with the growing demand from an aging society [3]. Consequently, people with dementia will increasingly be encouraged, when possible, to live at home for longer [1]. Although extended independent living is preferred by people with dementia [4], this places more pressure on their informal and formal support network [5]. Most care for people with dementia is provided by unpaid informal caregivers such as spouses or relatives [6] who can feel heavily burdened by their care responsibilities, often resulting in stress-related illnesses [5,7], putting them at risk of becoming the so-called "invisible second patient." On the other side, formal caregivers involved in the home care of people with dementia often face an increased workload due to a rising shortage of staff [8,9] and the growing complexity of care [10], which require them to use their resources more effectively [11].

To support caregivers of people with dementia in home-based settings, there has been growing interest in assistive technologies for in-home monitoring. These surveillance systems provide 24/7 information about the daily functioning, lifestyle, and safety of people with dementia, possibly leading to a greater sense of control, which could help to delay the institutionalization of this population [10,12,13]. The development of in-home monitoring systems is progressing and is increasingly driven by the aim to minimize their obtrusiveness; that is, to reduce ''characteristics or effects associated with the technology that are perceived as undesirable and physically and/or psychologically prominent'' [14]. In practice, this is visible by moving away from in-home monitoring systems based on cameras, which pose major challenges concerning privacy [15,16]. Although more recent systems based on wearable sensors are less obtrusive when it comes to privacy, they are often more obtrusive in terms of the inconvenience associated with having to wear the system on the body [15,16]. To overcome these barriers, more unobtrusive, contactless in-home monitoring systems have been developed. These range from event-based, mostly motion-activated, sensors distributed in the home [10,17,18] to the most novel form of unobtrusive in-home monitoring systems based on analyzing the human body's reflection of radio waves using deep-learning algorithms and artificial intelligence (AI) [15,16,19,20]. The continuous monitoring of in-home activity through these AI-driven systems could help caregivers to detect small but meaningful changes over time, monitor disease progression [21], and not only detect but also predict and subsequently prevent falls [22].

Despite the promise of the possibilities of unobtrusive in-home monitoring, the added value and downside for informal and formal caregivers of people with dementia are still insufficiently mapped out. Research on unobtrusive monitoring systems that could be applied to support home-based dementia care has largely focused on its technical possibilities [21-24] instead of investigating what is needed from the technology to support caregivers of people with dementia in an unobtrusive and goal-directed manner. A recent review by Vermeer et al [13] highlights the importance of reporting concrete requirements for monitoring systems in dementia care so that they can be used by technology developers and based on the perspective of those who might use them. However, previous research on unobtrusive in-home monitoring involving (potential) end users [25-28] often failed to take these aspects into account, and mainly included the views of healthy older adults and their family members, with less attention devoted to the perspective of formal and informal caregivers of people with dementia who can be considered important target users. Furthermore, as unobtrusive in-home monitoring systems develop rapidly, previous studies involving end users are likely to become quickly out of date [13]. Advances in affective computing and AI are likely to add new possibilities such as monitoring emotion [29] or vital signs [30] remotely. At the same time, the shift to unobtrusive remote monitoring, which continuously creates and automatically models in-home data about people with dementia, might also present a new extent of threats related to privacy and ethics [18,31].

When developing meaningful, novel, and unobtrusive in-home monitoring technology with the goal of supporting home-based dementia care, an adequate comprehension of users' needs is essential to reach a fit among technology, context, and the user [32]. Unobtrusive in-home monitoring of people with dementia should not be developed simply because it can be, but with its possible benefits and barriers in mind as well as with consideration of the relevant needs and requirements to increase future acceptance.

Aim of the Study

Based on this background, the aim of this study was to comprehensively explore the views of formal and informal caregivers of community-dwelling people with dementia toward unobtrusive in-home monitoring. In particular, the study aims were to identify (1) relevant and nonrelevant monitoring goals of unobtrusive in-home monitoring, (2) expected benefits and barriers toward unobtrusive in-home monitoring, and (3) specific requirements for unobtrusive in-home monitoring technology that can serve as guidelines for developers.

Methods

Study Design

A qualitative research design was applied, including semistructured interviews and focus groups. Moreover, a topic list task was part of the interview and focus group sessions. The Ethics Committee of the University of Twente (Behavioral, Management, and Social Sciences) provided ethical approval for this study according to European regulations (request number 18939).

Participants and Sampling Procedure

Informal Caregivers

Inclusion criteria for participation of informal caregivers were as follows: (1) providing unpaid care to a community-dwelling person diagnosed with dementia or mild cognitive impairment (MCI) at the time of data collection, and (2) providing care from a distance or living together with the care recipient. Recruitment took place during public information meetings at Alzheimer and informal care cafes organized by different Dutch elderly and informal care institutions. Those who met the inclusion criteria and were interested in participating were asked to provide their contact details and were given a detailed information leaflet introducing the study. After 3 days, participants were called and if they still wished to participate, an appointment for a home visit was made. In total, 19 informal caregivers were interviewed.

Formal Caregivers

Inclusion criteria for participation of formal caregivers required participants to be home care professionals that, at the time of data collection, provided and/or managed the care for community-dwelling people diagnosed with dementia or MCI. Recruitment took place from a variety of Dutch home care institutions and public Alzheimer cafes where formal caregivers were informed about the purpose and procedure of the study. In total, 16 formal caregivers from 7 different home care institutions agreed to participate and were included in the study. Five caregivers were interviewed individually, followed by two focus groups (n=6 and n=5, respectively), which were held at two different local elderly care institutions.

Topic List Task

During the interviews and focus groups, all participants performed a topic list task to identify relevant and nonrelevant monitoring goals for unobtrusive in-home monitoring. Each participant received 16 topics representing different possible goals of monitoring, covering key aspects of daily functioning, safety, degeneration, and well-being of people with dementia. These topics were previously developed in cocreation with our expert panel consisting of experienced geriatricians and gerontologists, and based on commonly used scales to assess activities of daily living [33,34] and stages of dementia [35], as well as research into (the course of) behavioral and psychological symptoms of dementia [36,37]. We also considered the type of input unobtrusive in-home sensors would require. The final list of goals was clustered into four broad areas of attention commonly used by formal caregivers across the continuum of care for individuals [38]. Participants were asked to rate each goal with either a plus sign (+), indicating that this would be a relevant monitoring goal, a minus sign (–), indicating a nonrelevant monitoring goal, or a question mark (?) indicating uncertainty about the usefulness of a monitoring goal. We instructed participants to envisage that all goals could technically be monitored to any useful level of precision. During the task, participants were encouraged to support their choices and add goals when possible.

Interview and Focus Group Guide

We developed an interview and focus group guide containing open-ended questions based on our research questions, previous research in the field by Wild et al [25], and the value proposition design proposed by Osterwalder et al [39]. For both groups of participants, questions and procedures were essentially identical, except that the questions were adapted to fit the different roles and care duties of the groups. At the beginning of each interview and focus group, participants viewed two slides demonstrating the general concept and idea of unobtrusive in-home monitoring and examples to illustrate possible forms of outgoing monitoring information. All slides were explained in a standardized manner (see Multimedia Appendix 1) and clarification was given when needed. Subsequently, participants were asked about their perceived expected benefits of unobtrusive in-home monitoring. Questions targeting benefits mainly centered around why, if at all, participants would be willing to use such a system for their care recipient(s); how, if at all, it would influence the care and quality of care; and why or why not it would be able to support extended independent living of people with dementia.

Thereafter, participants performed the topic list task, followed by the last section that focused on concerns. Questions about concerns mainly centered around reasons not to use unobtrusive in-home monitoring, when such a system would become undesirable, and concerns related to their own and their care recipients' privacy and data sharing. The interviews were performed by a trained interviewer (CW), and focus groups were led by a moderator (CW) and comoderator (AB). After 24 interviews and 2 focus groups, saturation was reached. All sessions were audio-recorded, with prior permission of participants (see Multimedia Appendix 2 for the full interview and focus group guide). Interviews lasted about 1 hour and focus groups lasted about 1.5 hours each.

Data Analysis

The audiotapes of the interviews and focus groups were transcribed verbatim and content analysis was performed using the software package Atlas.ti 8 separately for each participant group. First, relevant fragments were selected and categorized into one of two main areas: (1) expected benefits and (2) expected barriers toward unobtrusive in-home monitoring. Subsequently, selected fragments were further categorized inductively into overarching themes and subthemes. To minimize single-researcher bias, a second analyst (AB) independently coded 10% of the data and verified whether the codes described were proper interpretations of the data. The final coding scheme was defined on the basis of consensus between the two analysts (CW and AB).

Data from the topic list of monitoring goals were used to generate frequency distributions across all response categories (relevant, nonrelevant, or questionable monitoring goals) per participant group.

As a last step, requirements toward unobtrusive in-home monitoring were created based on the procedures of van Velsen et al [40] and Bergvall-Kåreborn and Ståhlbröst [41].

First, user expressions that captured aspects the system should fulfill were identified and clustered into overarching *attributes*

(ie, needs that aim to guide the development). These were checked for distinctiveness by the second analyst (AB) and adjusted if needed.

Second, the *attributes* were translated into one or more *requirements* and categorized into four different domains: (1) functional requirements specifying desired technical features of the technology, (2) user experience requirements specifying how the technology should interact/communicate with the user, (3) service requirements specifying desired services surrounding the technology, and (4) work context requirements specifying how the technology should be integrated into the existing work context and routines. All requirements were checked by the second analyst (AB) and adjustments were made accordingly.

Lastly, all requirements were sorted by the corresponding overarching theme.

Results

Participant Characteristics

The characteristics of study participants are listed in Tables 1 and 2. Informal caregivers were children, partners, sisters- or brothers-in-law, or neighbors who provided care, from a distance or not, to a community-dwelling person with dementia or MCI. Most informal caregivers were daughters and sons providing care from a distance to their parent with Alzheimer disease. Notably, most informal caregivers reported being active as a caregiver for the patient several years before an official diagnosis was made. Formal caregivers were experienced home care professionals, including district nurses, case managers, care assistants, and occupational therapists providing on average of 20.3 hours (SD 6.3) of care per week to community-dwelling clients with dementia.

Table 1. Characteristics of informal caregivers (N=19).

Characteristic	Value
Age of caregiver (years), mean (SD)	60.5 (13.1)
Age of care recipient (years), mean (SD)	82.6 (5.5)
Active as caregiver (years), mean (SD)	10.5 (10.1)
Time since diagnosis[a] (years), mean (SD)	4.6 (3.5)
Gender, n (%)	
Female	16 (84)
Male	3 (16)
Care hours per week, n (%)[b]	
<8	6 (32)
8-24	7 (37)
24-40	6 (32)
Relation with care recipient, n (%)	
Daughter/son	11 (58)
Spouse/partner	5 (26)
Sister-/brother-in-law	2 (11)
Neighbor	1 (5)
Living situation, n (%)	
Living together with care recipient	7 (37)
Living elsewhere	12 (63)
Type of cognitive impairment of care recipient, n (%)	
Alzheimer disease	14 (74)
Lewy body dementia	1 (5)
Vascular dementia	1 (5)
Mild cognitive impairment	3 (16)

[a]Time since diagnosis was self-reported by the informal caregiver.

[b]Percentages may not total 100 due to rounding.

Table 2. Characteristics of formal caregivers (N=16).

Characteristic	Value
Age (years), mean (SD)	39.3 (11.3)
Care contact hours per week provided to community-dwelling people with dementia, mean (SD)	20.3 (6.3)
Work experience in current home care profession (years), mean (SD)	15.4 (9.1)
Gender, n (%)	
Female	15 (94)
Male	1 (6)
Function[a], n (%)[b]	
District nurse	8 (50)
Case manager for dementia	4 (25)
Personal care assistant	2 (13)
Occupational therapist	2 (13)

[a]Secondary vocational education (European Qualifications Framework [EQF] level 1-4): personal care assistant, district nurse; higher professional education (bachelor/associate degree; EQF level 5/6): district nurse, case manager for dementia, occupational therapist.

[b]Percentages may not total 100 due to rounding.

Goals of Unobtrusive In-Home Monitoring According to (In)formal Caregivers

Table 3 summarizes the responses from formal and informal caregivers toward possible monitoring goals of unobtrusive in-home monitoring systems that were defined during the topic list task. The top 5 monitoring goals seen as most useful by both groups included fall detection and prevention, and monitoring day and night rhythm, personal hygiene (eg, dressing, grooming, bathing, and toileting), nocturnal restlessness, and eating and drinking behavior. Monitoring goals rated as nonrelevant by both formal and informal caregivers included leaving the house (the action of doing so), social interaction (indoors), and telephone use (frequency of use). In general, both groups showed comparable results, although informal caregivers appeared to be less interested in monitoring eating and drinking behavior, nocturnal restlessness, and walking distance/speed compared with formal caregivers.

Table 3. Judgments of informal and formal caregivers of community-dwelling people with dementia for specific unobtrusive in-home monitoring goals.

Monitoring goals	Informal caregivers (N=19), n			Formal caregivers (N=16), n		
	+[a]	−[b]	?[c]	+	−	?
Environmental (safety): fall detection and prevention	19	0	0	16	0	0
Health-related						
Day and night rhythm/sleeping pattern	18	1	0	15	1	0
Nocturnal restlessness	12	5	2	16	0	0
Personal hygiene (dressing, grooming, bathing, toileting)	15	2	2	15	1	0
Eating/drinking and cooking activity	12	7	0	16	0	0
Physiological						
Cognitive deterioration	13	5	1	15	1	0
Physical deterioration	10	7	2	12	2	2
Walking distance/speed (indoors)	10	6	3	14	1	1
Radius of movement (indoors)	14	5	0	8	4	4
Psychosocial						
Agitation (agitated behavior)	13	4	1	12	4	0
Apathy (lethargy/loss of motivation and interest)	12	5	2	9	4	3
Negative emotional state (eg, anxiety, irritability, depression)	12	6	1	11	4	1
Positive emotional state (eg, joy, pleasure, relaxation)	10	7	2	9	5	2
Leaving the house (the action of leaving)	5	7	7	6	6	4
Telephone use (frequency of use)	4	5	10	5	7	4
Social interaction (indoors)	4	11	4	7	6	3
Total	183	83	37	186	46	24

[a]Personally relevant.

[b]Not relevant.

[c]Questions the usefulness.

Expected Benefits and Barriers Toward Unobtrusive In-Home Monitoring

Expected Benefits

Overview

Textbox 1 shows the recurrent themes on benefits of unobtrusive in-home monitoring that emerged for the informal and formal caregiver groups. The themes of both groups were generally in line with each other, with variations within these themes reflecting the different roles and care responsibilities of the groups.

Textbox 1. Expected benefits toward unobtrusive in-home monitoring stated by informal and formal caregivers of people with dementia.

Themes brought forward by both informal and formal caregivers

Cross-checking self-care information

- Better self-care surveillance
- In-person control visits

Extended independent living

- Safety at home
- Detecting and removing factors that hinder independence
- Helpful for initiating extra care needed
- Decision support for transition to residential care

Objective communication and substantiation

- Supporting objective communication around patient's situation
- Substantiating diagnostics and indications

Prevention and proactive measures

- Responding more quickly to care needs to prevent health risks
- Improved insight into inhibiting and activating factors of patient's behavior/ mood

Theme brought forward by only informal caregivers

Emotional reassurance

- Reassurance about safety of patient
- Regain of freedom and mobility for informal caregiver

Theme brought forward by only formal caregivers

Personalized and optimized care

- Providing care at the right times
- Time gain through remote surveillance of self-care behaviors

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Cross-Checking Self-Care Information

Informal and formal caregivers reported facing difficulties in obtaining complete information about the patient's living pattern as the patient might not always be able to accurately self-report on the past few days. Participants indicated that, particularly in the prediagnostic phase or in cases of little or no home care provision, there is a lot of doubt about how adequately self-care practices such as eating/drinking and personal hygiene are performed. The monitoring system could then help in cross-checking what the patient self-reports:

> *I would find it very helpful if you could find out if they had eaten because they often told us they had when they hadn't. [...] I saw with my parents that I didn't notice anything when I came by, and if we could have followed this we could have intervened more quickly.* [caregiving daughter, age 56]

Therefore, according to participants, unobtrusive in-home monitoring can be a substitute for constantly having to (physically) check self-care behaviors. By eliminating unnecessary control visits, such systems might reduce the burden of care while supporting the patient's physical privacy:

> *I think that you would have to visit someone less often, we regularly visit people just for controlling.* [district nurse]

Extended Independent Living

Informal and formal caregivers mainly expected more reassurance and safety with the use of unobtrusive in-home monitoring, which could indirectly contribute to patients being able to live at home for longer. Both groups saw potential in using such a system for detecting and removing factors or negative stimuli in the environment causing a patient, for example, to wander at night, which can ultimately hinder independent living:

> *People with dementia often have misunderstood behavior [...] Suppose there is a stimulus that causes someone to have nighttime unrest or to wander. Normally, wandering is a criterion that prevents someone from living at home. Suppose you can remove this stimulus because you know where it comes from, then you ensure that someone can stay home longer. And in that sense, I think the system is an added value.* [case manager]

Furthermore, both groups expected an unobtrusive in-home monitoring system to be helpful in initiating extra care, when needed, to prevent the collapse of day structure and routines. Moreover, participants noted that such a system could assist in determining to what extent living at home would still be reasonable:

> *I think it will help a lot to be able to say okay living at home is no longer responsible [...] When you have data for it, you can also look at a situation objectively, without adding emotion, because there are facts, and that might make the decision later that it is no longer possible at home easier.* [caregiving daughter, age 42]

Some participants noted that patients sometimes reside at home longer than is appropriate. Early detection of health risks by an in-home monitoring system could then enable a faster indication for admission to residential care. Formal caregivers emphasized that such a system could also bridge the time a patient is on the waiting list for admission.

Objective Communication and Substantiation

Informal caregivers, in particular, expected unobtrusive in-home monitoring to be helpful in providing others with an objective insight into how their loved one functions. Such a system might help the caregivers to be taken seriously when making their assessments, especially considering that people with dementia can often present themselves well in the company of others or during care times. Informal caregivers noted having difficulties in objectively explaining the daily challenges at home to others; therefore, the outgoing monitoring information/graphs would speak for themselves:

> *The caregiver is not believed [...] And if you then have very good friends who also say "Well, everything is not too bad, look, he gives such good answers." [...] And then I say "Yes, but you have to experience it once for 24 hours." Something like this [the system] would be fantastic, that you could show that.* [caregiving wife, age 72]

Formal caregivers mainly saw an added value in the objective, continuous manner of measuring when using an unobtrusive in-home monitoring system. Several formal caregivers reported that during care moments they often see snapshots of socially desirable behavior and that information from informal caregivers is not always reliable. Furthermore, they expressed that such a system could be an aid to substantiate diagnostics and indications:

> *Cognitive decline, well, that is super of course if you can monitor that instead of just taking the MMSE [Mini Mental State Examination].* [district nurse]

Prevention and Proactive Measures

From the interviews and focus groups, it became clear that informal and formal caregivers expected unobtrusive in-home monitoring systems to enable them to respond more quickly and accurately to care needs to prevent health risks such as malnutrition, under/overstimulation, sleep problems, and loneliness.

> *I think such as system is a good plan. Before you realize that something is wrong, you are 4 months further. If you understand something like this with sensors, you can intervene much sooner.* [caregiving daughter, age 56]

Similarly, in response to the question "What are further preventive measures that could be supported by the system?", district nurses and occupational therapists indicated "stimulating for instance eating and drinking," "meaningful daytime activities," and "medication, and indeed, keeping people busy." Another added, "it is also a bit of well-being that you can nicely link to this, care is very important but so is well-being, and preventing loneliness."

Both groups also felt that an unobtrusive in-home monitoring system would improve their ability to recognize influencing factors on the patient's behavior and mood, and enable responding in a proactive manner. Generally, participants felt that such a system could help to monitor what relaxes or irritates a patient to be able to proactively take action sooner, as well as to fall back on this knowledge at a later stage of dementia.

> *Well, you could measure, when the home care has washed her, is she sad afterward? [...] And can you do something with it? Yes, then you can start to question: Is it because of the way it was done?* [caregiving brother-in-law, age 45]

Emotional Reassurance

Informal caregivers reported seeing added value in unobtrusive in-home monitoring in terms of emotional support and reassurance. In particular, wearable alarm systems have been criticized for providing little reassurance because patients often forget to wear them or because alarm buttons are not always pressed when they should be. Furthermore, informal caregivers highlighted that the insight into daily activities obtained through unobtrusive in-home monitoring can result in a sense of involvement at a distance, which can enable them to regain freedom and mobility to some degree:

> *[...] So if the system can indicate like everything is all right, and it is reliable, it also gives you a reassuring feeling. Just as I knew my brother was a caregiver a few years ago. Then I was reassured on a distance, you can also compare it to that.* [caregiving daughter, age 50]

> *For informal caregivers, it would be a great relief because they can leave for a while and the system takes it over.* [caregiving wife, age 72]

Personalized and Optimized Care

Formal caregivers expected that unobtrusive in-home monitoring would help them to work in a more person-centered way by tailoring care moments to the individual rhythm of the patient. For example, if a client gets out of bed at a deviating time, then a care moment can be scheduled accordingly:

> *With something like this [the system], it would be possible to provide care differently. If you see someone sleeps longer you could consider putting on*

those compression stockings a little later than originally planned. [district nurse]

Specifically, in the prediagnostic phase, there can be doubt about self-care behaviors, causing formal caregivers to sometimes lose a substantial amount of time to physically control activities (eg, eating, drinking, and sleeping behaviors). In some cases, formal caregivers arrive and find that the patient is already asleep. Formal caregivers generally agreed that an unobtrusive in-home monitoring system that enables them to better supervise these factors can save them time:

[...] Sometimes we come for a check-up moment and then the client is asleep and at another moment he might be out of bed, wandering around. So you could take more targeted action instead of those check-ups, and see if you can go there at that moment. [district nurse]

Expected Barriers

Overview

Textbox 2 summarizes the themes and subthemes brought forward on the expected barriers, which were consistent between the informal and formal caregivers.

Textbox 2. Expected barriers toward unobtrusive in-home monitoring brought forward by informal and formal caregivers of people with dementia.

Information overload

- Risk of feeling monopolized by the system
- (Un)certainty of whether to respond to monitoring information
- Risk of disturbing daily work routines

Privacy concerns

- Risk for misuse of monitoring data
- Risk of losing control about data sharing
- Tradeoff privacy infringement versus extended independence

Ethical concerns: dehumanizing care

- Risk of replacing human contact by technology
- Risk of undermining the formal caregiver's professional view

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Information Overload

A topic of concern among informal and formal caregivers was the danger of information overload and feeling monopolized by an unobtrusive in-home monitoring system. Uncertainty about whether to respond to information would cause stress rather than reassurance. Both groups noted they do not feel the need to continuously check for new information but instead would like to be able to obtain a global picture of the patient's situation.

For example, in response to the question "What would prevent you from using such a system with your loved one?", one participant indicated:

If we would go completely nuts. If we have the feeling that we always have to go there. Sometimes it is nice that you don't know everything, too. We are not always at home and when someone has to get into the car first... [caregiving daughter, age 58]

Formal caregivers generally found it less of a problem to obtain more information than usual as they are experienced at setting priorities when responding to care needs. Some formal caregivers were rather concerned that receiving information from an unobtrusive in-home monitoring system could add an extra burden as their work might become less plannable, thereby disturbing work routines:

It might even become a burden, unplannable care. [district nurse]

Privacy Concerns

Both formal and informal caregivers saw misuse of monitoring data as a risk for the patient, and pleaded for strict protection mechanisms during collection, processing, and sharing of data. Several formal caregivers considered the degree of privacy invasion by an in-home monitoring system to be comparable to the current professional electronic patient records, which informal caregivers can also read in real time:

But what is the difference if you write in the report "I see madam has been sad almost all morning" or if you read in the [monitoring] system "Madam has been sad all morning"? [personal care assistant]

The extent to which privacy concerns about unobtrusive in-home monitoring were perceived as a problem by caregivers was dependent on what they expected to receive in return. Several caregivers weighted their concerns against the benefit of unobtrusive monitoring. In general, caregivers were willing to accept some privacy violation of their loved one/client in exchange for more safety and reassurance, independence, and quality of life:

I think that when you can keep the quality of life at a higher level by giving your privacy a little less protection, quality of life comes first. [caregiving brother-in-law, age 45]

Both groups generally were less critical about being monitored themselves as well during visits or care moments but would like the option to turn off the system at any time. Most informal caregivers were willing to share monitoring information to update formal caregivers. In turn, the formal caregivers would like to share information that is relevant for the electronic patient record within their team.

However, both groups saw a risk of losing control about data sharing and highlighted the need to maintain maximum control together with the patient as data owner:

> *I would like to attach very specific conditions to whom you are sharing it with.* [caregiving wife, age 75]

Ethical Concerns: Dehumanizing Care

Informal and formal caregivers expressed that an unobtrusive in-home monitoring system should not be at the expense of human contact. Both groups considered it a risk that such a system might make it easier to create distance from the patient. A caregiving brother-in-law (age 45) commented:

> *It is because a home care organization can very easily say "We are very busy, we see in the overview that today everything is fine with Ms. X, so we will visit her tomorrow and skip her today." I also see a risk factor because it might become easier to create distance.*

Although face-to-face contact was seen as important, several formal caregivers also noted that some patients prefer as few home visits as possible. If these patients could be monitored remotely in an unobtrusive way, it could prevent disturbance and unrest:

> *I sometimes have night shifts where I control if someone lays in bed, but then you also disturb someone because you enter their house and that gives a certain unrest.* [case manager dementia]

Formal caregivers, in particular, believed that unobtrusive in-home monitoring should be an additional resource and not a substitute for their professional view. They saw a risk that such AI-driven systems might undermine their professional identity:

> *I think the monitoring should always provide support and it shouldn't be the main resource. It still has to remain human work.* [personal care assistant]

> *It [the system] should not replace the professional view. It should be purely supportive and not determining, […] of course codetermining what you do, but simply be used to improve care.* [occupational therapist]

Requirements Toward Unobtrusive In-Home Monitoring

Overview

Table 4 presents the identified requirements for the development of unobtrusive in-home monitoring systems that aim to support home-based dementia care. The requirements mainly center around what is needed from in-home monitoring technology to realize preventive and proactive measures, and to reduce identified barriers. Separate full descriptions for each requirement, including example quotes to illustrate the data behind them, are provided in Multimedia Appendix 3.

Table 4. Requirements toward unobtrusive in-home monitoring based on informal caregiver (IC) and formal caregiver (FC) statements.

Themes and attributes	Requirement type[a]	Requirement	Indicated by IC	Indicated by FC
Supporting prevention and proactive measures				
Active support in daily living	Functional	Voice-based coaching function	Yes	Yes
Safety support	Functional	Autonomously detecting emergency situations and sending alarms	Yes	Yes
System as analysis tool	Functional	Recognizing patterns and deviations	No	Yes
Preventing information overload				
Tailored information	User experience	Information choice option	Yes	Yes
Tailored information	Work context	Outgoing information tailored to professional care context	No	Yes
One system	Work context	Integration into existing electronic client records	No	Yes
Creating overview of patient's situation	User experience	Information summaries at specific time intervals	Yes	No
Reducing privacy concerns				
Transparency/safety	Functional	Preventing unauthorized access	Yes	Yes
Minimized obtrusion	User experience	Unobtrusive design	Yes	Yes
Safe interconnected system	Functional	Secure data sharing with formal caregivers	Yes	No
Safe interconnected system	Functional	Secure data sharing among formal caregivers	No	Yes
Remain in control of data	Functional	Fine-grained data sharing options	Yes	No
Reducing ethical concerns (dehumanizing care)				
Room for professional's view	Work context	System must be supportive, not determining	No	Yes
Awareness for individual context	Functional	Context-aware system	Yes	Yes
Support ethical use	Service	Preuse instruction for caregivers	Yes	Yes
Support ethical use	Service	Shared decision-making tools	Yes	Yes

[a]Classification based on van Velsen et al [40]. Functional: requirements specifying desired technical features of the technology; User experience: requirements specifying how the technology should interact/communicate with the user; Service: requirements specifying desired services surrounding the technology; Work context: requirements specifying how the technology should be integrated into the existing work context and routines (concerning use within a formal care setting).

Functionality

Participants provided concrete examples of how unobtrusive in-home monitoring should go beyond monitoring by providing the patient with active support in daily living via a voice-based interface. Such a coaching function could aid in tasks that typically require learning and decision making. As described by participants, assistance should focus on maintaining day structure (eg, reminders about certain times for eating, sleeping, or medication intake) or, based on the level of inactivity, providing suggestions for exercising or taking a walk.

Furthermore, as formal caregivers are interested in deviations over time, with a special interest in detecting periods deviating from the expected disease progression, the system should enable recognizing patterns and deviations, and provide the possibility to analyze on a weekly or monthly basis, thereby functioning as an analysis tool.

Moreover, the system should be capable of autonomously detecting emergency situations and sending alarms to the most suitable caregiver(s) in charge, thereby resolving the problem of current (mostly wearable) safety technology that the patient might forget to wear or might be out of reach in emergency situations. To prevent false alarms, the system should open a communication channel to the patient first to check the need to intervene. However, the system should generally be context-aware instead of applying generic threshold values in determining alarming deviations.

Furthermore, as indicated by participants, the system must offer fine-grained data-sharing options for sharing care-relevant information with formal caregivers, thereby requiring a secure connection to existing electronic client records used in professional home care. Provided that consent of the patient and informal caregiver(s) is given, the system should offer possibilities for data sharing among the professional care team as well. Communication within such a system between home

care professionals and therapists or the general practitioner is seen as a desirable function to simplify multidisciplinary collaboration, but requires interoperability.

Lastly, the system must prevent unauthorized access during collection, storage, and sharing of data, thereby highlighting the importance of carefully making choices such as local vs cloud-based data processing.

User Experience

In line with participants' answers, the system must provide choice options for (types of) outgoing monitoring information and its frequency of delivery to avoid information overload. For nonacute aspects, the system should provide information summaries created at specific time intervals determined by the caregiver (eg, once/twice per week, biweekly). The information needs to be summarized in a way that allows caregivers to intuitively understand the situation and make judgments on how to respond. In most cases, summarizing all information to be able to review the week is seen as sufficient, as creating a sense of overview is key.

Furthermore, the level of unobtrusiveness of the system should be maximized. Key attributes of unobtrusiveness as expressed by participants include: (1) contactlessness, being passively guarded by the system in a low-effort manner and without having to wear devices or demanding active engagement; (2) simplicity, making the system easy to use to minimize dependence on help from others; (3) privacy-friendliness by solely monitoring motion and sound; and (4) reduced visibility through a pervasive design (built into the environment), thereby minimizing the chance of stigmatization and feeling constantly reminded of the system.

Services Surrounding the Technology

Participants' statements clearly showed that certain knowledge is required to prepare (in)formal caregivers for using unobtrusive in-home monitoring. We found that not only instructions on technical aspects of use are needed but, above all, instructions surrounding the ways of interacting with the patient while using the system are necessary. This is due to the fact that such systems were seen as likely to affect the caregiver-patient relationship and the amount of human contact with the patient. As indicated by the participants, one danger represents the development of a confrontational attitude when addressing monitoring information to the patient, which creates resistance. Instead, a respectful attitude directed at stimulating the positive is preferred.

Furthermore, participants indicated that the system must be introduced in a way that enables patients and (in)formal caregivers to make informed decisions based on realistic benefits and risks, thereby highlighting the need for shared decision-making tools. To prevent undermining the patient's autonomy in case they can no longer express their will reliably, a patient declaration from the previous, competent period should be used.

Integration to an Existing Work Context

Formal caregivers expressed that the system must be integrated into existing electronic client records to avoid having to collect care-relevant information from different information sources/systems, which will require interoperability. Outgoing monitoring information should be tailored to the professional care context, which means that it is presented in a way that matches the content structure of the existing client record (eg, the client care plan and care goals). Mail notifications should be sent in case new monitoring summaries have been added to the client record.

Moreover, formal caregivers highlighted that to reach a fit with existing work routines and prevent undermining their professional identity, an AI-driven system must be supportive and not determining. It must therefore unlock the monitoring data in a way that care professionals can draw adequate conclusions themselves. The system can help to make the picture more complete; however, it must leave room for the care professional's interpretation, thereby functioning as an extra aid to improve the professional view and quality of care.

Discussion

Principal Findings

The aim of this study was to explore the expected benefits, barriers, and relevant monitoring goals toward unobtrusive in-home monitoring from the viewpoint of formal and informal caregivers of community-dwelling people with dementia. Specific requirements that can guide the development of unobtrusive in-home monitoring technology were extracted. Extending previous work of others in the field that mainly included the views of healthy older adults [25-28,42], our study contributes to a better understanding of formal and informal caregivers' expectations referring to the newest generation of AI-driven in-home monitoring systems, and what is needed from such systems to support home-based dementia care in an unobtrusive way. In that regard, our study provides a response to previous research that highlights the need for concrete requirements of monitoring systems in home-based dementia care [13], and argues that the purpose of such technologies needs to be regularly reviewed to keep up with their rapid development and the changing needs of users [43].

In general, we found that both formal and informal caregivers of people with dementia saw unobtrusive in-home monitoring as a support tool that could contribute to a shift from reactive to more preventive and proactive care. Both groups expected such systems to inform about, above all, (the risk of) falls, day and night rhythm, personal hygiene, nocturnal restlessness, and eating and drinking behavior, suggesting that these systems could best be used for people with dementia at risk for self-neglect. Although both groups showed comparable monitoring preferences, informal caregivers appeared to be less interested in monitoring eating and drinking behavior, nocturnal restlessness, and walking distance/speed compared to formal caregivers. These monitoring goals might have been less relevant to informal caregivers living together with their care recipient (36.8%), who might already have adequate supervision for these daily activities. Our findings contribute practically to gaining a better understanding of the information needs of (in)formal caregivers of people with dementia toward AI-driven in-home monitoring systems. However, in line with Elers et al [42], we

generally recommend that people with dementia should always be in control of what information is collected.

Our results revealed that formal and informal caregivers of people with dementia generally expected cross-checking self-care information, extended independent living, objective communication, prevention and proactive measures, reassurance, and personalized and optimized care as the key benefits of unobtrusive in-home monitoring. At the same time, main concerns centered around information overload, privacy, and ethics.

With our focus on AI-driven in-home monitoring systems, our findings update those of Zwierenberg et al [10], who studied expectations of using rather simple monitoring systems tracking the location and movement of people with dementia. Interestingly, our study found that some benefits and barriers were two-sided, meaning that in some situations a barrier could even become a benefit and vice versa. This provided insight into novel opportunities and challenges for unobtrusive monitoring in home-based dementia care that yield implications for using such systems in a more targeted manner.

In line with previous research [31,44-46], we found that both formal and informal caregivers were concerned about consequences related to replacing human contact by technology. However, in contrast to earlier research [31,44-46], some of our participants indicated that less face-to-face contact does not always need to be a concern but might even become a benefit in certain situations. We found that in-person visits are frequently performed only as a means to control self-care behaviors of people with dementia, such as eating, drinking, and sleeping. At the same time, formal caregivers mentioned patients that prefer as few home visits as possible to prevent disturbance and unrest. Our findings show that using unobtrusive in-home monitoring from a distance might help to replace obtrusive and undesired control visits, thereby saving the caregiver's time while supporting the patient's sense of (physical) privacy. In that way, unobtrusive in-home monitoring may contribute to the better utilization of resources in home care, now and even more in the future.

Previous research among healthy older adults and their informal caregivers [25,47] showed that in-home monitoring systems are expected to enable extended independent living. This expectation was not fully shared by all of our participants. It became clear that formal and informal caregivers generally expected unobtrusive in-home monitoring to help prevent health risks. However, whether this proactive care would lead to extended independent living of people with dementia was not always clear to our participants. Most (in)formal caregivers expected the system to help delay institutionalization, whereas others hoped it would help to more quickly recognize when living at home would no longer be a reasonable option. The development of unobtrusive in-home monitoring technologies should therefore not be purely justified based on their potential to prolong independent living but rather based on their potential to deliver home-based care in a more beneficial way for both the patient and caregiver.

Our findings showed that unobtrusive in-home monitoring is not only seen as a technical innovation but also as a care process innovation. The last two-sided theme that emerged centered around personalized and optimized care. Formal caregivers expected that unobtrusive in-home monitoring would help them to work in a more person-centered way by tailoring care moments to the individual rhythm of the patient. However, in contrast to earlier research among formal caregivers of people with dementia [10], some of our participants expressed a tension between the need to deliver just-in-time/spontaneous care moments based on the monitoring data and work becoming less plannable as a consequence. Our findings indicate that the use of unobtrusive in-home monitoring asks for a shift in the way in which formal caregivers work from a structured to more flexible practice. We recommend considering this as an essential determinant when it comes to implementation.

In connection to the ongoing debate about privacy, our findings showed that participants were concerned about informational privacy (eg, misuse of monitoring data) and, to a lesser extent, physical privacy (eg, ''being monitored''). However, the extent to which these privacy concerns were perceived as problematic by (in)formal caregivers depended on the degree of safety, reassurance, and quality of life they expected to receive by the system in return. This "trade-off" phenomenon has been recognized in earlier research [10,25]. Although privacy intrusions were principally seen as justifiable by our participants, this does not resolve possible moral considerations involved in the use of remote monitoring systems for people with dementia [10]. For instance, future developers of AI-driven in-home monitoring systems should address the need for fairness, accountability, and transparency of algorithms [48].

The requirements identified in this study recommend several ways in which unobtrusive in-home monitoring of people with dementia should be designed in terms of functionality, user experience, accompanying services, and integration into the existing work context to enhance future acceptability. Part of our requirements are in agreement with previous research related to the broader category of technology to assist aging in place [42], which highlighted the need for detection of deviations, asking minimal action from the user, and secure information storage and transfer. Furthermore, our study generated several novel requirements that centered around proactive measures, and ways to reduce barriers relating to information overload, privacy, and ethics. In the following, we address three requirements that should be given more attention.

First, our participants provided concrete examples of how unobtrusive in-home monitoring technology should be enriched with functions providing patients with active support in daily living and maintenance of day structure via a voice-based interface. Participants spontaneously came up with these ideas, which was unexpected in some ways, as the interview and focus group guide did not address these topics. This highlights that there is a true need for in-home monitoring technology to go beyond safeguarding people with dementia, and further assist in reaching personalized goals and executing tasks independently.

Second, we found that to prevent undermining the formal caregiver's professional identity, unobtrusive in-home monitoring must be supportive and not determining. These

technologies should therefore be carefully introduced and any misconceptions relating to being controlled by the technology should be corrected. Our formal caregivers expressed that the system must unlock the monitoring data so that they can draw adequate conclusions themselves. This raises questions about an optimal ratio between human and algorithmic interpretation of the data. Based on our results, we recommend more processed and simplified data for the informal caregiver and less processed data for the formal caregiver.

Lastly, an important requirement for unobtrusive in-home monitoring systems is the integration into existing electronic client records to avoid formal caregivers having to collect care-relevant information from different sources/systems. Possibilities for secure data sharing between members of the formal care team (eg, home care professionals, therapists, general practitioners) were seen as a desirable function to support integrated dementia care. Although integrated care can improve the quality of care [49], it requires interoperable information systems. This becomes even more true when care providers from different agencies, informal caregivers, and patients are involved. Interoperability issues therefore first need to be solved to enable the optimal integration of in-home monitoring systems for people with dementia into the health care system.

Strengths and Limitations

Through in-depth conversations with various types of informal caregivers across a broad range of living situations and formal caregivers from 7 different care institutions, we were able to obtain rich information until the point of saturation was reached, which can be considered a strength of our study. Previous research noted that participants of pilot studies in particular might be more likely to have a positive orientation toward the technology, leading to bias [10,50]. Our study on expectations and needs with nonusers of unobtrusive in-home monitoring might have overcome this issue by increasing the chance of including participants that might have felt too critical or unmotivated to take part in a pilot study. In this way, our study might have been successful in including a broader range of views. However, the fact that actual use was not studied comes with a downside. As indicated by previous research [28,51,52], actual use of in-home monitoring may affect how users think about these technologies and may cause the attitudes of users to change, even after a short period of use. Most research on expectations and needs toward passive remote monitoring of people with dementia, including our own work, has not yet been tested against using these technologies in daily life. However, we have tried to overcome possible difficulties to imagine the technology in question by presenting participants with examples of unobtrusive in-home monitoring. These scenarios helped them to conceptualize the idea while at the same time being able to think beyond it.

Furthermore, our study only indirectly produced information about the perspective of people with dementia via their informal and formal caregivers, whereas it would have been preferable to include people with dementia more directly. We did so during the first interview but recognized that informal caregivers felt inhibited to freely speak about their needs in the presence of the patient. Furthermore, we generally aim to involve participants in a way that prevents participant burden and at a point in technology development that suits best their capacity. A recent review by Suijkerbuijk et al [53] on the development of assistive technologies for people with dementia showed that the more concrete the research materials are, the easier it potentially becomes for people with dementia to articulate their views. We therefore believe that collecting the views of people with dementia on more tangible prototypes/concepts in subsequent steps of development might be more adequate than asking them to envision hypothetical scenarios.

Lastly, although the primary goal of this study was to gain in-depth qualitative insights, questions remain as to whether the identified benefits, barriers, monitoring goals, and requirements can be generalized to a larger sample of caregivers and other relevant stakeholders. Adding large-scale quantitative data using an integrated mixed methods approach could help to answer this question.

Future Research

An essential component to developing acceptable in-home monitoring technologies that support home-based dementia care will be to incorporate these requirements into the design that will provide the greatest benefit for users. We plan to share our findings with involved participants to provide room for critical feedback. In addition, future research among (in)formal caregivers on actual use is needed to determine how their expectations translate into actual experiences evolving over time and personal outcomes such as delaying institutionalization or reducing caregiver strain.

Although informal caregivers of people with dementia providing care from a distance are most likely to benefit from unobtrusive in-home monitoring, this does not mean that caregivers living with their loved one cannot also benefit from this technology. Inclusion criteria for our study were intentionally inclusive for informal caregivers from different living situations. The benefit of regaining mobility and freedom that emerged in our study was mainly brought forward by informal caregivers who lived with their care recipient, indicating that there might be more possible differences in expectations related to the use of unobtrusive in-home monitoring between informal caregivers. Future research should investigate differences in needs for different informal care scenarios to create more personalized requirements for unobtrusive in-home monitoring.

Lastly, as grounded in our results, future research should investigate ways to combine unobtrusive monitoring with ways to support people with dementia in daily living and maintaining daily structure and health. Our participants provided the idea of a voice-based interface that may give reminders on certain times for eating, sleeping, or medication intake, or, based on the level of inactivity, provides suggestions for taking a walk. As commercially available, low-cost voice interfaces such as Google Home and Siri—all of which are already integrated into the lives of many—rapidly improve the ability to understand, and even anticipate, the needs of users, unobtrusive patient assistance could become more effective [18].

Conclusions

Unobtrusive monitoring technologies that aim to provide support in home-based dementia care are developing rapidly. Our results showed that formal and informal caregivers of people with dementia shared similar perspectives and needs. Both groups generally saw value in unobtrusive in-home monitoring, and felt that these systems could contribute to a shift from reactive to more proactive and less obtrusive care. Various concerns related to privacy, ethics, and information overload have to be considered as they are likely to hinder acceptance. This study also highlights the importance of developing and introducing AI-driven monitoring systems in a way that prevents caregivers from feeling undervalued. Our requirements can inform the development of more acceptable and goal-directed in-home monitoring technologies to support home-based dementia care.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Explanation of unobtrusive in-home monitoring used in interviews and focus groups.
[DOCX File , 330 KB - aging_v4i2e26875_app1.docx]

Multimedia Appendix 2
Interview and focus group guide.
[PDF File (Adobe PDF File), 182 KB - aging_v4i2e26875_app2.pdf]

Multimedia Appendix 3
Requirements for unobtrusive in-home monitoring: full descriptions and illustrative quotes.
[PDF File (Adobe PDF File), 225 KB - aging_v4i2e26875_app3.pdf]

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Abbreviations

AI: artificial intelligence
MCI: mild cognitive impairment

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Mobile Apps to Support Family Caregivers of People With Alzheimer Disease and Related Dementias in Managing Disruptive Behaviors: Qualitative Study With Users Embedded in a Scoping Review

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Abstract

Background: People with Alzheimer disease and related dementias often display disruptive behaviors (eg, aggression, wandering, and restlessness), which increase family caregivers' burden of care. However, there are few tools currently available to help these caregivers manage disruptive behaviors. Mobile apps could meet this need, but to date little is known about them.

Objective: The aims of our study were to identify existing mobile apps designed to support family caregivers of people with Alzheimer disease and related dementias in managing disruptive behaviors; explore whether family caregivers view these mobile apps as relevant to meeting their needs and as useful in managing disruptive behaviors; and document the types of mobile apps that are of interest and appeal to most family caregivers (with regard to format, ergonomics, and clarity).

Methods: A review of mobile apps initially conducted in February 2018 was updated in March 2019 with 2 platforms (App Store [Apple Inc.] and Google Play [Google]). The selected apps were first analyzed independently by 3 raters (2 students and 1 researcher) for each of the platforms. A focus group discussion was then held with 4 family caregivers to explore their perceptions of the apps according to their needs and interests. The content of the discussion was analyzed.

Results: Initially, 7 of 118 apps identified met the inclusion criteria. An eighth app, recommended by one of the knowledge users, was added later. Four family caregivers (women aged between 58 and 78 years) participated in the discussion. Participants expressed a preference for easy-to-understand apps that provide concrete intervention strategies. They reported being most inclined to use two apps, Dementia Advisor and DTA Behaviours.

Conclusions: Few mobile apps on the market meet the needs of family caregivers in terms of content and usability. Our results could help to address this gap by identifying what family caregivers deem relevant in a mobile app to help them manage disruptive behaviors.

Introduction

Background

Due to the aging population, an increased prevalence of dementia is expected in many countries over the coming years [1]. In Canada, it is estimated that dementia will affect around 674,000 people by 2031, which is almost twice as much as the number in 2011 [2]. People with Alzheimer disease and related dementias (ADRD) often display disruptive behaviors, such as aggression (behavioral or verbal), wandering, and agitation (excessive or inappropriate verbal or motor behaviors) [3,4]. About 50%-70% of the people with ADRD live at home and require increasing care as the disease progresses [5,6]. Managing disruptive behaviors can thus present real challenges for family caregivers. Although taking care of people with ADRD may often have a positive effect on caregivers (eg, sense of personal accomplishment and growth) [7], they remain at greater risk of suffering from negative psychological (eg, anxiety, depression), emotional, and physical (eg, intense fatigue, other health problems) consequences, as well as from financial issues and job loss [8]. Informal caregiving represents up to almost half of the care provided to people with dementia [9]; therefore, helping family caregivers to lower the frequency of disruptive behaviors, promoting their self-efficacy to manage these behaviors, and minimizing their stress when they occur is crucial.

Many technological tools are available to improve the quality of life of people with ADRD and to reduce the mental and emotional burden felt by family caregivers by helping them with the care, treatment, and management of the disease [10]. For example, GPS technologies, including tracking devices (eg, wandering path tracking and fall detection) [11] and intelligent interface devices (eg, Stay in Touch) [12] can help to locate the person with ADRD and to communicate with the family caregiver in case of emergency. Additionally, platforms offering informal support to family caregivers through sensors located in the home that can monitor the behaviors of the person with ADRD (eg, iCarer [13], passive remote patient monitoring [14], QuietCare [15]) may represent possible solutions for family caregivers to improve the care provided [13]. Finally, online communities have been created for family caregivers, which may reduce isolation [16] and support the sharing of experiential knowledge and skills [16,17].

These technologies are often reported to be complicated to use by caregivers or to require intensive and sustained training [18]; nonetheless, the increasing use of smartphones has generated considerable growth in the development of mobile apps in the health sector, including for people with ADRD. These apps mainly aim at improving the cognitive functions of the person with ADRD while maintaining social interactions [19]. Some of these apps can help reduce the anxiety of family caregivers by monitoring the person in and around the home in real time,

estimating the probability of wandering using geolocation, as well as facilitating care management and services by health care professionals [20]. Based on data collected by the mobile device, some apps also offer security options, such as calling emergency services, guiding the person to a safe place (using Google navigation) or informing family caregivers of the geographic location of the person with ADRD.

Although several mobile apps have been designed for people with ADRD, very few are specifically designed to be used by their family caregivers [19] with these primarily being conceived to monitor the location or activities of daily living [21] of the person with ADRD. However, family caregivers have also expressed other important needs, namely the management of their loved one's mood and disruptive behaviors [22]. It would thus be relevant to explore whether there are simple, credible, and accessible mobile apps that meet these needs [23]. Mobile apps have the potential to reach many family caregivers, as the majority use smartphones more than computers [23]. Being easy and quick to update, they allow family caregivers to access the most recent data [19]. Mobile apps are reported to be a more effective tool than conventional methods, such as classroom training, to inform caregivers about ADRD [23]. They could therefore be relevant and handy tools to promote learning and knowledge among family caregivers of people with ADRD. Supporting them in managing disruptive behaviors is essential if they are to increase their sense of competence or self-efficacy, which may in turn reduce their burden of care and improve their psychological well-being.

Context of the Study and Objectives

In fall 2017, the researchers (VP and MDM) were approached by a nonprofit organization (the Quebec chapter of the international Planetree network) with expertise in implementing best practices based on a person-centered approach. This organization wanted to adapt a Dutch mobile app to the Quebec context in order to reduce caregivers' burden by helping them manage disruptive behaviors of people with ADRD. However, a review of similar available mobile apps was deemed to be considered necessary prior to adapting the Dutch mobile app. The aim of this study was to provide family caregivers with a mobile app that could help them manage disruptive behaviors and thus reduce their burden of care. The following specific objectives were jointly defined by the local director of public health (MG), the director general of the Quebec chapter of the international Planetree network, and VP and MDM: identify existing mobile apps designed to support family caregivers of people with ADRD in managing disruptive behaviors; explore the family caregivers' view of these mobile apps regarding their relevance to meet their needs and their usefulness in managing disruptive behaviors; and document the types (eg, format, ergonomics, clarity) of mobile apps that are of interest and appeal to the most family caregivers.

Methods

Design

An increasing number of studies have been published in recent years aimed at identifying and analyzing mobile apps available on the market in various health disciplines [23-26]. To use a structured and systematic framework consistent with our objectives, a scoping review [27] was conducted. Although scoping reviews traditionally involve research studies, the method seemed appropriate for identifying apps available on the market and for targeting those which may support family caregivers of people with ADRD in managing disruptive behaviors. Scoping reviews may indeed provide an overview of the available documentation to examine the extent of the current knowledge on a particular subject [27]. The selected approach was based on the following 6 steps described by Arksey and O'Malley [27] and revised by Levac et al [28]: (1) formulation of research questions, (2) identification of relevant sources, (3) selection of relevant mobile apps, (4) data extraction and organization, (5) data analysis and results synthesis, and (6) consultation.

Formulation of Research Questions

This scoping review aimed to answer the following research questions: (objective 1) What mobile apps are available to support family caregivers of people with ADRD in managing disruptive behaviors and what are their characteristics? (objectives 2 and 3) Do these mobile apps meet the needs of family caregivers (ie, perceived relevance and usefulness) and arouse their interest in using them?

Identification of Relevant Sources

The search strategy was established by 5 occupational therapy students (PG, DL, CMM, MPP, MR, and MV) and validated by 2 researchers (VP and MDM). The search was conducted from February 21 to February 28, 2018, on the most popular commercial app stores, Google Play Canada (Google) and App Store Canada (Apple Inc), using the following keywords: "Démence," "démence proche aidant," and "Alzheimer proche aidant" in French; and "Dementia," "dementia caregiver," "Alzheimer," and "Alzheimer caregiver" in English. Two models of smartphones were used, a Samsung Galaxy A5 and an iPhone SE (Apple Inc), with Android (Google) and iOS (Apple Inc) operating systems respectively.

Selection of Relevant Mobile Apps

App inclusion criteria for apps included the following: French or English language; the targeting of disruptive behaviors associated with ADRD; a main function of informing, educating, or equipping family caregivers of people with ADRD; and free use. Meanwhile, the exclusion criteria for apps were those with an exclusive focus on psychological support for family caregivers or the screening for early signs and symptoms of ADRD, and those that required payment.

Two occupational therapy students (DL and CMM) first identified the mobile apps based on the titles. A minimum of 50 applications per store was first selected to ensure a good diversity in the results. After reaching this threshold, searches were continued until 10 consecutive applications no longer met the criteria (eg, memory game app for entertainment and not in conjunction with some cognitive stimulation to prevent the onset of ADRD) in order to ensure that as many relevant apps as possible were identified. DL, CMM, VP, and MDM then screened the relevance of the first identified apps to determine if they met all the inclusion criteria and did not meet any of the exclusion criteria based on their description. Apps common to both stores were identified and counted only once. When the search was updated (March 10-15, 2019), the apps that no longer satisfied the eligibility criteria were removed.

Data Extraction and Organization

The mobile apps selected in the previous step were then downloaded and organized in a Microsoft Excel data chart developed by the research team according to the following information: app name and download size description of the interface, internet connection required to access content (once the app has been downloaded); and content of the app (categories of information and how information is presented). The data were organized following two parallel processes, one for mobile apps identified in Google Play (coordinated by DL) and the other for App Store (coordinated by CMM). Apps that no longer satisfied the inclusion criteria following this in-depth analysis were excluded. In case of uncertainty, VP was consulted to validate the decision. The suggested Dutch app (Dementiegame) by Planetree network was subsequently included in the process.

Data Analysis and Results Synthesis

Data analysis was based on a qualitative and iterative process. The information collected was extracted to a grid based on the following predetermined themes: quality (credibility and accuracy of the information), accessibility and comprehensibility, and usability (speed and complexity). They were inspired by the themes central to the concepts of translational validity, which includes both face validity and content validity [29] and evolved throughout the process.

All the selected apps were analyzed independently by 3 raters (2 students and a researcher), for each of the app stores, Google Play (DL, MV, and MDM), and App Store (CMM, PG, and MDM). The apps were assessed by each rater according to their relevance, and disparities were resolved by consensus.

Consultation With Knowledge Users

A focus group meeting was conducted with family caregivers of people with ADRD (knowledge users) to explore their perceptions of the selected apps according to their needs and interest in using them. This method is more suitable for exploring the positive and negative components in usability and usefulness of new technology, crossing perspectives, and gaining more detailed feedback (generated by sharing information between the different participants) than are one-on-one single interviews [30].

Recruitment and Selection of Participants

Participants were recruited using a purposive nonprobability sampling technique (29). We presented the study (objectives and main stages of achievement) to caregivers (N=30) who

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attended meetings held by 2 community support organizations. A brief description of the study and the contact details of the person to reach were given to family caregivers interested in participating in the research project. To be included in the study, participants had to be a family caregiver (eg, husband, wife, daughter, son) of a person with disruptive behaviors associated with ADRD, speak French and have a good understanding of written French and English, and have concerns about disruptive behaviors exhibited by a family member with ADRD.

Data Collection (Focus Group)

Data were collected during a face-to-face focus group meeting at the Research Center of Aging. The meeting began with a presentation of the selected apps to the participants, who had received them a week prior to the focus group in order to allow for some familiarization. This presentation was made by MPP and PG to help caregivers understand the aim of the apps. The focus group, led by a researcher trained in the qualitative approach (MDM), allowed the participants to comment on the perceived relevance of the apps' content (useful information, meets users' needs) and their interest in future use. Participants were also encouraged to comment on issues or questions that had not been addressed. Evidence from previous studies [31,32] inspired the development of the focus group guide (Multimedia Appendix 1). The meeting lasted 94 minutes. The discussion was digitally audio-recorded and then fully transcribed by CMM and MR. Participants were also asked to complete a sociodemographic questionnaire documenting their age and gender, their relationship with and level of involvement in the care of the person with ADRD, and the type of mobile phone they used.

Data Analysis (Focus Group)

Transcription of the focus group meeting was content analyzed [33]. MV, DL, and MDM manually and independently coded the data using a grid with the predetermined themes of relevance to participants' needs and perceived usefulness. Participants' comments were first associated with these themes and then inductively subdivided into categories and subcategories as the analysis progressed. The coding and categorization were carried out independently and then corroborated by all members; if a discrepancy arose, the issue was discussed to reach a consensus.

The local director of public health (MG) and the director general of the Quebec chapter of the Planetree network were consulted during the process to ensure the relevance of the results and the selection of the most efficient knowledge transfer strategies. Meetings with members of the research team were held on a quarterly basis (2018) and then annually (2019, 2020).

Ethical Considerations

The study was approved by the ethics committee of Centre intégré universitaire de santé et de services sociaux de l'Estrie, Centre Hospitalier Universitaire de Sherbrooke. Participants completed a consent form before participating in the focus group.

Results

Selection of the Relevant Mobile Apps

Figure 1 shows the flowchart of the app selection process. The searches in Google Play and App Store identified 118 apps (22 available on both platforms, 50 available only in Google Play, and 46 available only in App Store) based on title screening. Their descriptions were then screened based on the inclusion and exclusion criteria. Apps were mainly excluded due to their aim not being in line with the research objectives, and several involved only disease screening, games, therapy, or even fundraising. Others were designed to help the person with ADRD to function and were based on functionalities that were not relevant to the present study (geolocation, management of schedules, alarm, etc). Finally, several apps did not target disruptive behaviors or did not provide tools to support the care provided by family caregivers (detailed descriptions of dementia types, causes, and symptoms). The population targeted by the apps was another reason for exclusion. An app could target several populations. Ultimately, 18 of the initially identified 118 apps (15.3%) remained after applying the inclusion and exclusion criteria.

Figure 1. Flowchart of the app selection process.
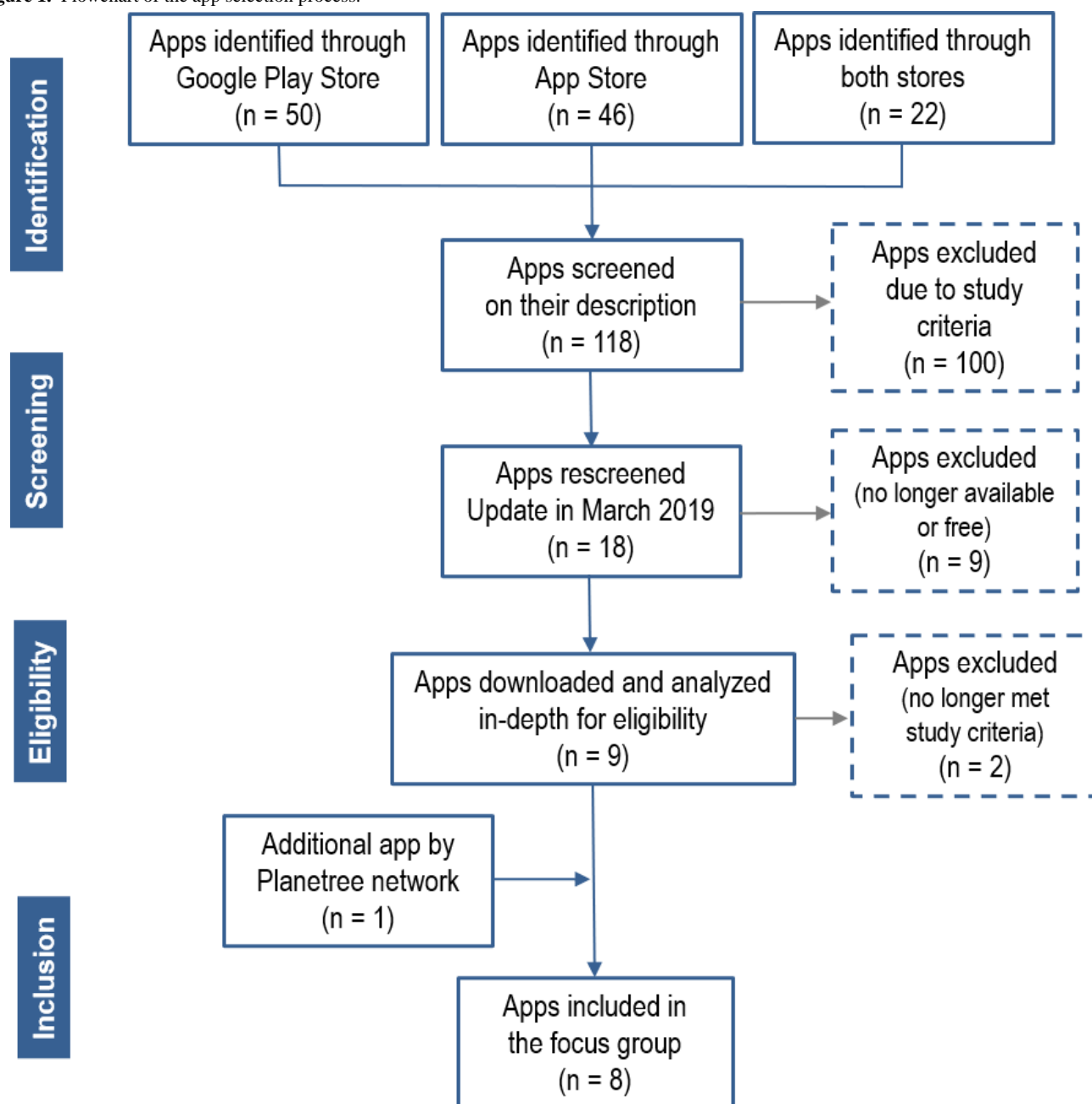
Following the update in March 2019, half of these 18 apps (n=9) were excluded because they were no longer free or no longer available. In addition, 1 app no longer targeted disruptive behaviors, and another only referred users to a website. In the end, 7 apps were eligible for the focus group. By adding the app suggested by the director general of the Quebec chapter of the Planetree network, 8 apps were ultimately included in the analysis: 1 was only available on Google Play, 1 on App Store, and 6 were available on both platforms.

Description of the Relevant Mobile Apps

Of the 8 apps selected, 7 were in English, and only 2 of these, Dementia Advisor (English and French) and Dementia Support (English, German, Dutch, and Portuguese) were available in more than one language. The Dutch app, Dementiegame, was only available in Dutch and was the only app in the form of an interactive game. Multimedia Appendix 2 provides a description

of the 8 apps that were presented to the family caregivers during the focus group meeting.

Consultation With Knowledge Users: Description of Participants

Four family caregivers of people with ADRD showed interest in the study and took part in the focus group meeting. Table 1 presents the characteristics of the sample. Participants were all French-speaking White women aged from 58 to 78 years. Two daughters and two spouses acted as the main family caregivers with an active and daily involvement with the person with ADRD. Participants were at different levels of caregiving, with relatives at the beginning, the middle, and the advanced stage of the disease. Only 1 participant had a deceased relative; however, she had an extensive caregiving experience with her husband and remained active in her caregiver role by supporting other loved ones. The participants were evenly distributed

between the 2 types of devices (Android or Apple) and their familiarity with the device was varied (quite to very familiar).

Table 1. Characteristics of focus group participants (n=4).

Participant	Age (years)	Relationship with the person with ADRD[a]	Intensity/frequency of interactions with the person with ADRD	ADRD stage	Mobile device/familiarity with it
1	58	Daughter	Active, daily	Advanced	Android/familiar
2	67	Daughter	Active, daily	Deceased	iPhone/very familiar
3	70	Spouse	Active, daily	Beginning	Android/quite familiar
4	78	Spouse	Active, daily	Middle	iPad/quite familiar

[a]ADRD: Alzheimer disease and related dementias.

Consultation With Knowledge Users: Relevance and Perceived Usefulness of the Mobile Apps

Participants were asked if the selected mobile apps met their needs and aroused their interest. Their feedback was divided into 2 themes: (1) relevance of the mobile apps and (2) perceived usefulness of the mobile apps. A total of 13 categories and 13 subcategories were identified in relation to these 2 themes. Multimedia Appendix 3 (relevance) and Multimedia Appendix 4 (perceived usefulness) summarize the results.

Relevance of Mobile Apps

Participants spontaneously rated the relevance of the mobile apps regarding the fit (or not) between content and perceived needs. Participants identified 3 mobile apps (DTA Behaviours, Dementia Advisor, and Dementia Emergency) that they thought contained the information that family caregivers may need to manage disruptive behaviors at a given point in the course of the disease. Referring to the DTA Behaviours app, one participant said, "Well, all the subjects that are named, I mean in any case, I went through ALL of them with my mother, ALL […] at different stages". Participants also noted that certain apps (Dementia Games and Dementia Emergency) did not seem relevant to supporting a caregiver in managing disruptive behaviors, as their content was more about actual changes in behaviors with ADRD than advice on how to deal with them. They also thought that some apps might be more helpful to other family members less involved in care than the main caregiver; for example, one participant said, "But on the other hand, the last one you presented to us [Dementiegame], I see [it] [as being for] children or brothers and sisters." Indeed, these apps relate more to the impact of the disease on daily living, a reality that other family members are less aware of as compared to the main caregiver.

Perceived Usefulness of Mobile Apps

First, participants were asked about the likelihood of their using the mobile app and about the context in which they might be more likely to use them. Not surprisingly, compatibility of the apps with their mobile device was the main factor influencing use. Furthermore, participants expressed little interest in certain apps (Care4Dementia and Alzheimer's Daily Companion) because they did not see any added value:

It's […] like a book. No need for a mobile application [to present such content], it's like […] I press here and it brings me [to a text], and [if I press there, it brings me back to another text]. Why not get a book and leave it at that?

Participants recommended using certain apps (DTA Behaviours, Dementia Support, and Dementia Advisor) before disruptive behaviors occurred. One participant expressed this idea in reference to the Dementia Advisor app: "The first thing I would do is look at all the daily situations presented, with a cool head." In addition, the apps may be used afterwards (for example, Dementia Advisor and DTA Behaviours) to get feedback on their interventions. As one participant said, "After the situation gets better also, but here I would go to see what I did, what I could have done better." Other apps seemed interesting in terms of using them on the spot when needed: "If my mom has a terrible attack, [I can open] my app […], then I'll see what I can do […], ok well. […] It's like here and now." Also, not surprisingly, participants said they were more attracted to easier-to-understand apps, especially those available in their mother tongue (ie, in French vs only in English). Family caregivers reported being inclined to use mobile apps when the information was clear, even if not in French (ie, DTA Behaviours, Dementia Advisor, and Dementia Emergency). The format of the mobile apps and, more precisely, the way in which the information was presented and organized, also influenced their opinion:

But […] the first one I had earlier, on [Android, Dementia Emergency], well I understood it very quickly […] I was not lost at all [because the information is well organized and easy to find]

Conversely, participants were less likely to use mobile apps that required more steps to find needed information; for instance, one participant did not like Care4Dementia because there was "too much research."

Overall Rating

Participants concluded that the ideal mobile app would include concrete intervention strategies to apply when disruptive behaviors occur. In this regard and based on the apps themselves (regardless of the platform/mobile device), participants reported that they could potentially use 2 of the apps, Dementia Advisor and DTA Behaviours. As one said, "These are tools that I need, really concrete: there is a behavior [which arises and the application tells you] and what you can do [to cope with it]". Figure 2 and Figure 3 show sample screenshots of Dementia Advisor and DTA Behaviours, respectively.

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Figure 2. Screenshots from the Dementia Advisor app.
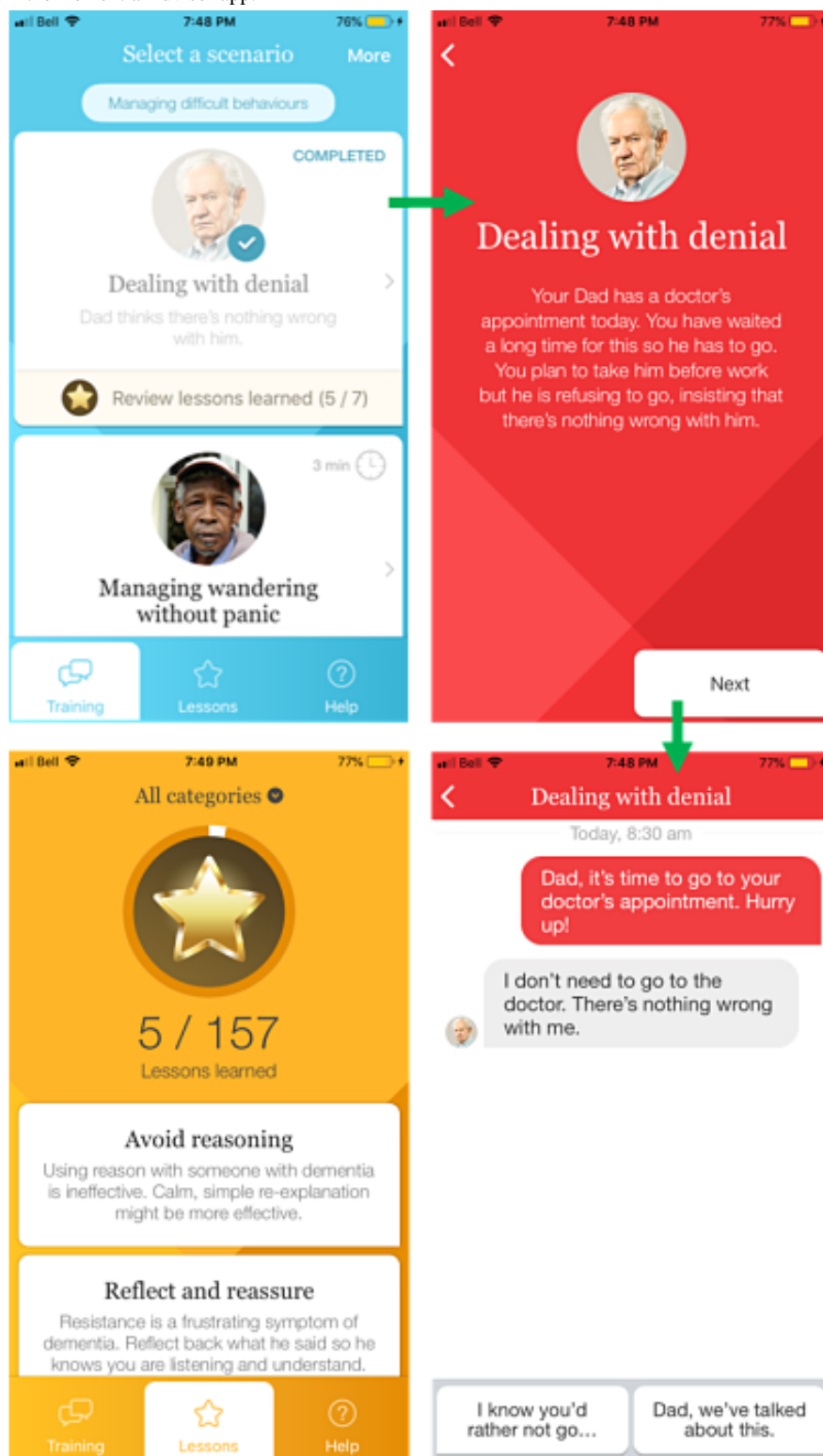
Figure 3. Screenshots from the DTA Behaviours app.

Discussion

Main Findings

This study aimed to identify currently available mobile apps in Canada developed to support family caregivers in managing disruptive behaviors of people with ADRD, explore the relevance and usefulness of these apps as perceived by caregivers, and document the types of apps that appeal to the most family caregivers. Of the 118 apps inventoried, 8 were selected to be reviewed by caregivers, and only 2 of these were perceived as relevant and useful by caregivers.

Our review suggested that there are currently a limited number of mobile apps on the market targeting family caregivers to help them deal with disruptive behaviors of people with ADRD. Because health apps only started expanding in 2013 [34], customized apps to assist caregivers in dealing with disruptive behaviors of people with ADRD are still scarce. Moreover, for the apps reviewed, it was challenging to determine if the

information provided was evidence-based and to what extent it met family caregivers' needs.

According to our results, few mobile apps sufficiently met the caregivers' needs in managing disruptive behaviors. More specifically, only Dementia Advisor and DTA Behaviors appealed to most of the participants by offering concrete strategies to manage disruptive behaviors of people with ADRD. Participants mentioned that these apps also have a well-organized design interface, providing customized and clear information for quick searches. As most users, including caregivers, now use smartphones [34], it is important to prevent apps from being difficult to use [35]. Past studies reported that the small size of smartphone screens and texts in the apps were common usability issues, especially for older caregivers [36,37]. Hence, app usability is a key factor that needs to be addressed to improve caregivers' experience [38]. Overall, our findings are in line with previous results as they highlighted the importance of adapting health apps to the needs of users, including caregivers [34].

Regarding the Dementiegame app, most participants said that it did not meet their current needs, due to difficulty navigating through the app and accessing information. Our results underline the importance for future studies to involve family caregivers in designing useful, relevant, and easy-to-use apps, especially by providing concrete strategies to help them deal with disruptive behaviors on a daily basis. In this regard, the 'living lab" approach might be adopted since it aims to develop innovative, sustainable solutions to the growing challenge of managing disruptive behaviors of people with ADRD [39].

Finally, our review of mobile apps was updated in May 2020, using the same 2 platforms (App Store and Google Play). One new relevant app called CogniCare was found. This app was updated recently in April 2020. It provides a rich source of useful tips and short videos to help family caregivers manage disruptive behaviors of their loved ones with ADRD. As our study and content analysis of the focus group discussion was completed before we found this new app, our results only apply to the apps previously reviewed in this paper.

Strengths and Limitations

This study has several strengths. First, for the scoping review, we followed a rigorous, reliable approach based on Levac [28]. Many scoping reviews do not include the last step (consultation), but we performed it using a rigorous method to validate the results with family caregivers. The diverse profiles of the family caregivers who participated in the focus group discussion was a strength of this study (children and spouses of various ages). Second, the analysis of the selected mobile apps, exploration of the app once downloaded, and data validation by 4 team members (2 per type of mobile app store) contributed to the study's reliability and reduced subjectivity bias. Finally, the study included only free apps. Although this decision may limit the number of apps, this methodological choice was deemed essential by the local director of public health to increase access to the general public, especially to caregivers with financial issues.

The study also has some limitations. First, as apps were searched for on the App Store Canada and Google Play Canada databases, the results only reflect the app market in this country. It was also not possible to cover all existing apps. Thus, an arbitrary limit was placed on our search. As a result, some apps could have been omitted, even though the cutoff used suggests that few relevant apps would have met the inclusion criteria. Third, some apps used external websites. As the information provided outside of the apps was not reviewed as thoroughly as was the in-app content, we do not know the quality of the content provided to family caregivers through these external links. Further studies should ensure that the applications developed to support caregivers of people with ADRD are based on evidence-based data (eg, theories of managing behavioral symptoms). Furthermore, the number of family caregivers in our focus groups was small, and no male caregivers could participate in the study within the timeframe of recruitment. Despite the group being all women, the 4 participants were varied in terms of age (58 to 78 years), relationship with the person with ADRD (2 spouses and 2 daughters), and literacy level. It is not surprising to have recruited only women, as around two-thirds of caregivers of people with dementia are women [40]. Moreover, the majority of persons who attended the meetings held by key community support organizations (where we recruited) were women. It is also well known that elderly women are more likely to participate in research studies than their male counterparts. Several studies carried out with caregivers of patients with dementia have mainly women as participants [41,42]. Although few in number, the participants had different levels of familiarity with the technology (from quite to very familiar) and had a rich experience of caregiving. Finally, the themes emerging during the focus group discussion triggered an emotional reaction in some participants, who were not comfortable discussing the app. Therefore, providing time at the outset to address emotional issues might have allowed participants to vent their emotions and then focus on the study's objectives. Recruiting former caregivers may provide access to rich experience while reducing the likelihood of being emotionally overloaded during the study.

Recommendations and Future Directions

The focus group discussion helped to identify what family caregivers find relevant and useful in a mobile app, even if future studies should involve more participants. Inclusion of concrete intervention strategies appears to be an important feature. These findings may guide the development of future apps for these caregivers. In addition, using mobile apps is an effective way to improve knowledge because they are ready at hand and can be consulted quickly. Apps are therefore likely to reduce difficulties, such as being afraid of leaving the family member alone at home, encountered by many current training courses. On the other hand, technological difficulties can impede their use, which underlines the importance of involving family caregivers with different degrees of digital literacy when designing apps [43]. In addition, as the medical terminology used in apps should be easy for target users to understand [44], future studies should determine to what extent the apps are comprehensible to caregivers with differing degrees of health literacy, a factor which was not fully examined in our study.

One important public health priority is to promote access to knowledge tools for every individual, especially the most vulnerable. In this regard, some of the apps reviewed require an internet connection, which may reduce caregivers' access to them, as not everyone can afford internet services. Moreover, most of the apps reviewed did not have password protection or require login. One common concern of mobile health apps is privacy, as users often enter their loved ones' health information [45,46]. Future attention should be paid to ways to protect users' private information, without this being a barrier to using the app.

Finally, with the constantly evolving market, a certain "volatility" of the available apps has been noted. In fact, some of the apps identified might have been discontinued, while new ones may have appeared. There are also variations between the 2 stores regarding available apps. It is therefore suggested that an app search be carefully planned to ensure exhaustivity and reproducibility with respect to the review of the apps. Indeed,

2 people may not find the same list of apps in Google Play due to the algorithms used to partially personalize the results [47]. In addition, we must remain critical about the list generated, as sponsored apps top the list despite not necessarily being the most relevant.

Conclusions

Considering the proliferation of mobile apps and their increased use by family caregivers, available mobile apps designed to help manage disruptive behaviors should meet their needs in terms of both content and usability. However, when this study was conducted, few apps met these criteria. Therefore, this study aims to reduce this deficiency by highlighting what caregivers consider relevant and useful in existing mobile apps, while identifying those tailored to family caregivers' needs. These findings may help caregivers to manage disruptive behaviors more effectively and satisfactorily, reduce their burden of care and, ultimately, delay the institutionalization of people with ADRD.

Multimedia Appendix 1
Guide for focus group discussion.
[DOCX File , 14 KB - aging_v4i2e21808_app1.docx]

Multimedia Appendix 2
Description of the eight selected apps presented to participants.
[PDF File (Adobe PDF File), 117 KB - aging_v4i2e21808_app2.pdf]

Multimedia Appendix 3
Emerging results for the relevance theme.
[PNG File , 208 KB - aging_v4i2e21808_app3.png]

Multimedia Appendix 4
Emerging results for the perceived usefulness theme.
[PNG File , 277 KB - aging_v4i2e21808_app4.png]

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Abbreviations

ADRD: Alzheimer disease and related dementias

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Review

The Value of Routinely Collected Data in Evaluating Home Assessment and Modification Interventions to Prevent Falls in Older People: Systematic Literature Review

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Abstract

Background: Falls in older people commonly occur at home. Home assessment and modification (HAM) interventions can be effective in reducing falls; however, there are some concerns over the validity of evaluation findings. Routinely collected data could improve the quality of HAM evaluations and strengthen their evidence base.

Objective: The aim of this study is to conduct a systematic review of the evidence of the use of routinely collected data in the evaluations of HAM interventions.

Methods: We searched the following databases from inception until January 31, 2020: PubMed, Ovid, CINAHL, OpenGrey, CENTRAL, LILACS, and Web of Knowledge. Eligible studies were those evaluating HAMs designed to reduce falls involving participants aged 60 years or more. We included study protocols and full reports. Bias was assessed using the Risk Of Bias In Non-Randomized Studies of Interventions (ROBINS-I) tool.

Results: A total of 7 eligible studies were identified in 8 papers. Government organizations provided the majority of data across studies, with health care providers and third-sector organizations also providing data. Studies used a range of demographic, clinical and health, and administrative data. The purpose of using routinely collected data spanned recruiting and creating a sample, stratification, generating independent variables or covariates, and measuring key study-related outcomes. Nonhome-based modification interventions (eg, in nursing homes) using routinely collected data were not included in this study. We included two protocols, which meant that the results of those studies were not available. MeSH headings were excluded from the PubMed search because of a reduction in specificity. This means that some studies that met the inclusion criteria may not have been identified.

Conclusions: Routine data can be used successfully in many aspects of HAM evaluations and can reduce biases and improve other important design considerations. However, the use of these data in these studies is currently not widespread. There are a number of governance barriers to be overcome to allow these types of linkage and to ensure that the use of routinely collected data in evaluations of HAM interventions is exploited to its full potential.

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Introduction

Background

Falls in older people are a major public health concern. In the United Kingdom, approximately 1 in 3 adults aged 65 years or more experience at least one fall a year, which can lead to serious injury, even death. Falls are the most common cause of death in this age group [1]. This situation is similar worldwide, where around 28%-35% of people in this age group fall every year; this increases to 32%-42% in those aged 70 years or more [2]. The effects of falls on a person can be devastating, not only physically but can result in a fear of falling in the future and a loss of confidence and independence and can have a significant impact on family, friends, and caregivers [3,4]. Annual National Health Service (NHS) expenditure on injurious falls is in excess of UK £2 billion (US $2.5 billion) [5]; in the United States, this figure amounted to US $50 billion in 2015 [6]. Health care costs per fall for older people in Finland and Australia are US $3611 and US $1049, respectively [2]. Furthermore, the costs of hospital, community, and social care continue to significantly accrue 12 months after a fall [1]. One of the main risk factors for falls is increasing age; the incidence of falls begins to rise beyond the age of 65 years [7]. Given that there is an additional 8.2 million people aged 65 years and more projected for the United Kingdom in 2050 [8], preventative measures for falls in this age group will be key to reducing costs [5].

International evidence suggests that falls in older people commonly occur at home (around 35% of people more than 65 years of age) [2,7,8], and these are associated with higher morbidity, earlier mortality, and health inequalities [5-9]. Hazards in the home are associated with injury, and by using risk assessments, home assessment and modification (HAM) interventions identify potential environmental hazards present in the home [10]. Measures are then agreed to reduce these, such as the removal of bath mats or inclusion of handrails on stairs [4]. A Cochrane review by Gillespie et al [11] found that HAM interventions were effective in reducing both the rate of falls and the risk of falling in older people. After gathering evidence on effectiveness, the National Institute for Health and Care Excellence [5] have recommended that all older people living in the community at an increased risk of falls should be considered for these interventions.

Issues surrounding the evaluation of these HAM interventions could call into question the validity of their findings. Past criticism of these trials has been over a lack of an adequate control group and rigorous design, that they are underpowered, and that follow-up times have been found to be lacking [12,13]. Most HAM trials included in the review by Gillespie et al [11] had follow-up times of 1 year or less; therefore, it is unclear whether the effects of these interventions could be sustained beyond this [11-13]. Trials often exclude participants with comorbid conditions, particularly cognitive impairment [14,15]; however, cognitive impairment is a risk factor for falls in older people [16]. This can threaten the generalizability of a trial's

findings. The research burden of extensive study assessments is a particular concern for this participant group and can cause study attrition [17]. Conversely, minimizing the amount of data collection to reduce this burden could limit the usefulness of a trial. Furthermore, different variables are needed to stratify participant groups and to control for confounders (eg, past falls, polypharmacy, and socioeconomic status) to determine for whom the intervention works best and why [18,19]. Finally, recall bias could cause errors in self-report data and skew evaluation results [20].

It has been suggested that the use of routinely collected data in aging-related research has the potential to improve research quality and efficiency. These large-scale data sources allow for larger sample sizes and, therefore, the possibility for stratifying the sample with respect to key covariates and allow for longer follow-up times and reduced study attrition, especially given the age profile of the target population. In addition, these data help build an understanding of fall patterns and of individual treatment pathways [21]. Data collected routinely from health and social care interactions are increasingly being used in research; electronic health records (EHRs) are a prime example of this. Such data can be highly useful in health research; its nonuse may even cause harm [22]. The use of routine data in HAM intervention evaluations may be particularly useful, as it could help address the many challenges identified above regarding participant characteristics and trial conduct. To date, we conducted a systematic review to investigate the use of routinely collected data in HAM intervention evaluations.

Objectives

Our objective is to conduct a systematic review to identify research studies using routinely collected administrative and EHR data to evaluate HAM interventions whose primary purpose is to reduce falls in older people. Given the aforementioned problems with prospectively collected data, namely, (1) lack of adequate control group, (2) short follow-up times, (3) lack of diversity in participants leading to a lack of generalizability of results, (4) research burden on participants because of extensive data collection, (5) study attrition (especially because of point 4), (6) lack of rich data (especially at baseline that would allow stratification of participant groups), and (7) recall bias, our rationale for undertaking this study was to understand the extent of routine data use in this field as an alternative. We aim to summarize the types of routinely collected data and their sources and to identify the questions that these data can answer. We also investigated the different methods and approaches of using these data. Finally, we sought to highlight the benefits and limitations of using these data, compared with other data types, in the evaluation of HAM interventions.

Methods

Search Strategy

Review methods followed the University of York Centre for Reviews and Dissemination [23] guidance, and reporting followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) [24] guidelines where relevant (PRISMA checklist, Multimedia Appendix 1 [24]. To identify relevant studies, we searched the following databases from inception until January 31, 2020: PubMed, Ovid, CINAHL, OpenGrey, CENTRAL, LILACS, and Web of Knowledge. We used the keywords developed for a previous study designed to capture all types of routine data [25] and keywords to represent falls, older people, and the home. Figure 1 shows the search strategy used for PubMed, which was adapted for use with each database. Limits were abstract only. In addition, we searched the reference lists of potentially relevant papers and systematic reviews.

Figure 1. Search strategy for PubMed.

1. "Administration record*" OR Anonymised OR Anonymized OR Anonymization OR Anonymisation OR "Big data" OR "Clinical data" OR "Clinical record*" OR "Data linkage" OR "Data mining" OR "Data science" OR "E-health" OR EHR OR "Electronic data" OR "Health record" OR Encrypt* OR Informatics OR "Linked data" OR "Publically available" OR "Publicly available" OR "Routine data" OR "Routinely collected" OR "Safe haven" OR "Medical record*" OR "Prison record*" OR "Housing record*" OR "Education record*" OR "Patient record*" OR Register* OR Registries OR Insurance)
2. (Fall OR Falls OR Falling OR Faller OR Fallers OR Slip OR Trip)
3. "Age 60+" OR "Aged 60+" OR "Ageing population" OR Elderly OR Elders OR Frail OR Frailty OR Geriatric* OR Gerontolog* OR "Old adult*" OR "Older adult*" OR "Old individual*" OR "Older individual*" OR "Old person" OR "Older person" OR "Old people" OR "Older people" OR Pensioner OR Retire OR Retired OR "Senior adult*" OR "Senior individual*" OR "Senior people" OR "Senior person" OR Seniors)
4. 4. (Home OR House OR Housing)
5. #1 AND #2 and #3 and #4

Inclusion and Exclusion Criteria

We included primary research reporting HAM intervention evaluations that used routinely collected data, defined as data collected as a matter of course and not specifically for research [26]. We defined HAM as an assessment by a professional to identify environmental hazards and their removal or reduction by modifications to the home. The aim of these interventions must have been to reduce falls among older people living at home in the community. Studies including participants aged less than 60 years were excluded to ensure that these interventions were specifically targeted to the older population. Any control group was eligible because the effects of the intervention were not reviewed here. Potentially eligible studies included clinical effectiveness, cost-effectiveness, or process evaluations and could be of any study design. We included original research and study protocols (if a description of the full study was not yet published) from peer-reviewed journals, conference proceedings, clinical guidelines, and policy documents. Papers not written in the English language were included if an English translation of the abstract was available.

Screening and Data Extraction

One reviewer screened the titles and abstracts of the papers identified by the search using the aforementioned criteria. Full-text papers were retrieved if deemed potentially eligible and assessed by two independent reviewers. A third reviewer was able to resolve any disagreements. We used a piloted and standardized data extraction form and contacted the study authors for additional information where needed.

Risk of Bias

We assessed the risk of bias using the Risk Of Bias In Non-Randomized Studies of Interventions (ROBINS-I) tool [27]. The Cochrane Methods Bias Group [28] recommends this tool for use in systematic reviews that include nonrandomized controlled studies, and this tool allowed us to assess bias consistently across all our included studies, regardless of their study design. The tool covers seven domains that correspond to the risk of bias that can arise from different aspects of a study. For each domain, there are a number of questions to answer that will indicate whether this risk is low, moderate, serious, or critical or that there is not enough information to make a judgment. From these, following the tool's guidance, an overall judgment about the risk of bias can then be reached. We identified studies' main sources of bias in these domains, while focusing on the number or rate of falls as the main outcome of interest. We also looked for any other potential sources of bias or study design issues, paying particular attention to bias arising from the types of data used.

Data Synthesis and Organization

Given the heterogeneity between studies' interventions, participants, and other factors, a meta-analysis was not appropriate. Instead, we summarized the findings using narrative synthesis organized into 3 broad areas:

1. The source of routine data, aligned with the 3 main sources of routinely collected data used in health research (health care providers, government agencies, and nongovernmental and third-sector organizations)
2. The type of routine data, including demographic data relating to the characteristics of a person and where they live, clinical and health data generated by a clinical encounter or relating to a person's health or health care, and administrative data gathered during the running of organizations (eg, registering people, for record-keeping, or when delivering a service)
3. The purpose of routine data, with 4 main categories: recruitment of participants and creation of study sample; stratification of the sample, a technique used to ensure that there is equal representation of a particular characteristic (eg, sex) or to enable subgroup analyses; generation of predictor variables and other covariates to measure effect

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on evaluation outcomes; and generation of outcome measures used to evaluate the effectiveness of the HAM interventions [29].

Results

Overview

After removing duplicates, we identified 867 papers in total—866 abstracts using electronic databases and 1 additional paper from the reference lists of the included studies. A total of 128 papers were identified as potentially eligible, and full-text papers were retrieved. Eight papers reporting 7 different studies met the inclusion criteria and were included in this study. All the studies were written in English. Two were protocol papers [18,30], and the remainder were reports of evaluations. Figure 2 summarizes the flow of studies in a PRISMA diagram [31].

Figure 2. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) flow diagram.
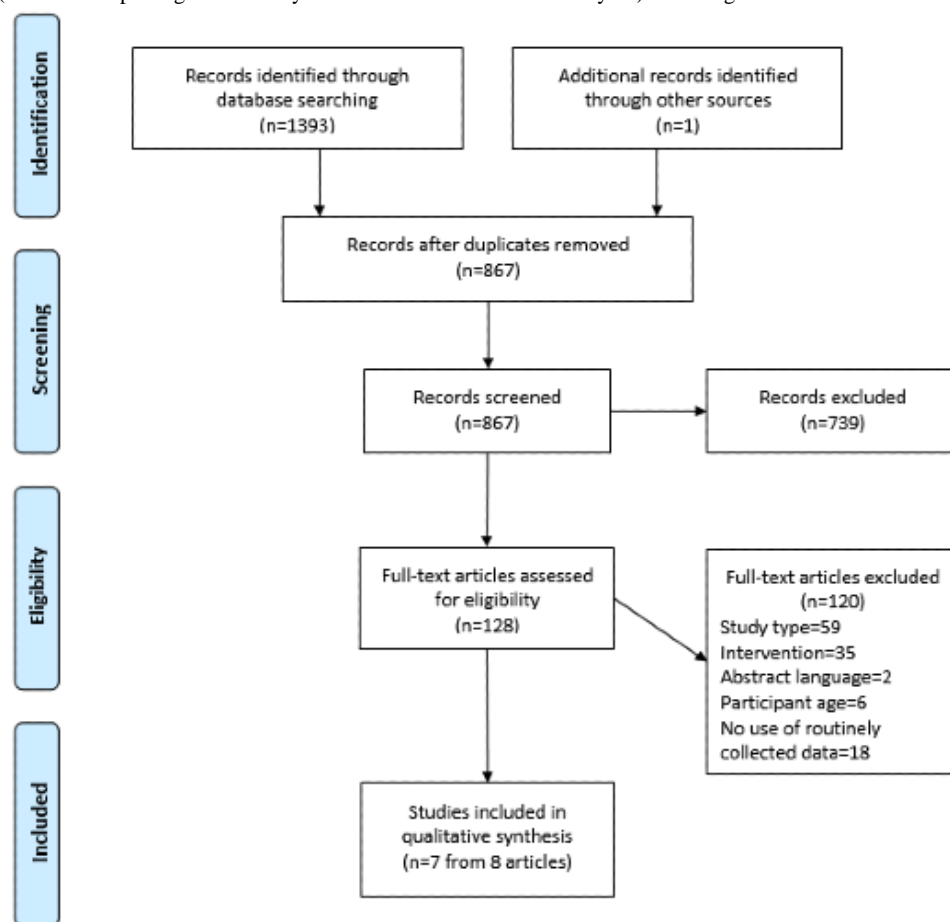
Multimedia Appendix 2 [14,18,30,32-36] summarizes the details of the studies included in this review. Each of these studies evaluated HAM interventions, either for effectiveness or for cost-effectiveness, and consisted of home assessment by an occupational therapist or other trained personnel in addition to the removal or adaption of potential hazards. Of the 7 papers, 5 used randomized controlled trial designs, whereas the studies by Hollinghurst et al [18], de Almeida Mello et al [32], and Maggi et al [33] used a longitudinal quasi-experimental design. The research was located in the following countries: Australia [14,34], Belgium [32,33], the United Kingdom [18]), New Zealand [35,36], and the United States [30].

Sources of Routine Data

The sources of routine data across all studies are summarized in Multimedia Appendix 2 For data sources hosting multiple databases, this table notes the original sources of each of these databases.

Health Care Providers

Two studies in this study used data from health care providers: in New Zealand—the University of Auckland optometry clinic, a private ophthalmology practice, and Dunedin and Auckland hospital [35], and in Australia—the Royal Prince Alfred Teaching and Research Hospital, Sydney [34]. The use of these data was approved by the Otago and Auckland ethics committees [35] and the Ethics Review Committee of the Central Sydney Area Health Service [34,37].

Government Agencies

Pega et al [36] used routine data obtained from the New Zealand Government's Integrated Data Infrastructure (IDI) database [38]. This is a large database containing data on people and households in New Zealand, including data on education, income, benefits, migration, justice, and health. Many data sets within the IDI can be electronically linked using identifiable data—first and last name, date of birth, age, sex, and country of birth, which are then removed or encrypted before their use

in research. The IDI follows strict governance procedures to ensure privacy and confidentially, including the use of a virtual platform to provide researchers access to data. Before accessing data, researchers must undertake a two-stage application process that costs US $500 plus tax (there is no charge for government organizations) [36,38].

The study reported by Maggi et al [33] and de Almeida Mello et al [32] sourced their routinely collected data from the Belgian Government's InterMutualist Agency (IMA). This organization collects data on patients from Belgium's 7 mutualities (health insurance associations) and prepares them for analysis [39]. Health insurance is mandatory in Belgium; therefore, it includes data on all legal residents (11 million citizens) [40]. The three main IMA databases include a population database of sociodemographic data, a health care database about health care utilization and cost data of ambulatory and hospital care, and a pharmaceutical database of medication prescription and cost data. These can be linked using multiple encrypted social security numbers [40]. Research use of person-level, pseudonomized health data requires an internal application and approval by the Information Security Committee and the supervision of a doctor, and access is provided via a virtual environment. This comes at a flat rate of €4660 or more if an analyst or medical expert is needed [39].

Day et al [14] used two official sources of data collected by the Australian Government. The electoral roll is managed by the Australian Electoral Commission [41] and under the *Commonwealth Electoral Act 1918,* which can be provided to approved medical researchers. The Australian Bureau of Statistics [42], a governmental organization that provides microdata to researchers and academics, curates the Australian national census and health survey. Recently, this organization has established DataLab, which is a web environment that gives users their own virtual workspace to access data where outputs can be vetted for disclosure risk. Access is given to accredited researchers only (the application process is outlined in detail [43]).

The St. Louis Area Agency on Aging (SLAAA) is a government organization that provides services and support for older people, including the HAM interventions evaluated by the Stark et al [30] study included in this paper [44]. The SLAAA collects data via the National Aging Program Information System database on the general health, nutritional, financial, functional, and environmental status of older adults in the area, and Stark et al [30] used these data as part of their study.

Nongovernmental or Third-Sector Organizations

Hollinghurst et al [18] used routinely collected data from the Secure Anonymized Information Linkage (SAIL) Databank [45]. SAIL is a data safe haven that houses many deidentified data sources predominantly about the Welsh population, including data from the NHS and the Welsh Government. Data sources in SAIL can be linked using twice-encrypted Anonymous Linking Fields based on a person's NHS number or Residential Anonymous Linking Field for a place of residence derived from Unique Property Reference Numbers [46,47]. Technical and procedural controls such as an external Information Governance Review Panel (IGRP) and scrutiny of

results by a SAIL Data Guardian mitigate the risk of disclosure. There is no charge for the data, except for support and infrastructure costs, such as data preparation and the use of computing [45,48]. Hollinghurst et al [18] accessed each of their data sources via the SAIL Databank.

Care and Repair Cymru [49] is a registered charity in the United Kingdom that provides HAM interventions to older people. They supplied Hollinghurst et al [18] study with data from their national registry, outlining information on their interventions and clients. Campbell et al [35] used data from the charity register of the Royal New Zealand Foundation for the Blind—a register of people who are living with vision loss in New Zealand.

Types of Routine Data

Demographic Data

The most commonly used demographic data used by studies were age, date of birth, sex, and address or area of residence. Examples of the latter are lower layer super output areas (LSOAs), used in the study by Hollinghurst et al [18], which are small geographical areas consisting of 1000 to 1500 people in the United Kingdom. These data formed part of the Welsh Demographic Service Data Set, an NHS data source available in SAIL Databank [45] that gives the demographic characteristics of people registered with General Practitioner practices in Wales [18,50].

In addition to the main demographic data given earlier, Pega et al [36] obtained information on participants' ethnicity and residential status from a database held by the New Zealand IDI database—the 2013 New Zealand Census of Population and Dwellings [38]. From the Australian national census and health survey, Day et al [14] extracted data on marital status, ethnicity, and type of residence (eg, own home or residential care). De Almeida Mello et al [32] and Maggi et al [33] used data on their participants' financial situation and their cohabitants from the IMA's database on reimbursed health care in Belgium.

Clinical and Health Data

Hollinghurst et al [18] used primary care data on patients' symptoms, signs, diseases, disabilities, and abnormal laboratory values from the Welsh Longitudinal General Practice data in the SAIL Databank [45]. Most of these variables were in Read code format (Read version 2)—standardized clinical codes used by health professionals in the NHS to record patient data electronically [51]. Maggi et al [33] and de Almeida Mello et al [32] used primary care data from the Belgian IMA [39] database on medication use and information on the presence of a caregiver and the level of nursing care received by their participants.

Pega et al [36] accessed two other New Zealand IDI data sources to retrieve secondary care data from hospital events: the Ministry of Health's New Zealand Health Tracker [52], which links data from primary and secondary care pertaining to publicly funded health events, and the Accident Compensation Corporation claims register, which contains information on all people to whom they have provided compensation for a nonfault accident. These data included the date of hospital admission, discharge,

and type of admission, as indicated by the International Classification of Disease, version 10 (ICD-10) coding. ICD-10 is an international classification system for diseases, causes of injury, signs and symptoms, and social circumstances [53]. Campbell et al [35], Hollinghurst et al [18], and Salkeld et al [34] used similar data. ICD-10 codes were also used by studies to ascertain the cause of a participant's death (if relevant) along with the date the death occurred; these data were extracted from the Belgian IMA database (de Almeida Mello et al [32] and Maggi et al [33]), and from the Welsh Annual District Death Extract, a government-curated register of all deaths relating to residents of Wales [18,53].

Administrative Data

Day et al [14] used self-report administrative data regarding the health status of the Australian population and their consumption of antidepressant and hypnotic medication collected as part of the Australian census and health survey. From the US St. Louis Area Agency on Aging NAPIS database, Stark et al [30] used self-report data about participants' previous falls and fear of falling. This government organization keeps a record of this information to help tailor their services to older people [44]. From data generated as part of their service provision in Wales, Care and Repair Cymru provided Hollinghurst et al [18] with information on HAM intervention types (eg, advice visit and stair rail) and their installation date.

Salkeld et al [34] included costs of hospital events in their study, recorded using Australian diagnosis-related groups. This Australian classification system is related to the number and types of patients treated in a hospital. Currently known as Australian refined diagnosis-related groups, each group has a cost attached and is used for hospital economic analyses [54]. Health Resource Group codes are the UK equivalent of these and were used by Hollinghurst et al [18] from a secondary care data set called the Patient Episode Database for Wales. Maggi et al [33] and de Almeida Mello et al [32] also used resource utilization costs from the Belgian IMA database [39].

Every 4 to 5 years, the Welsh Government [55] calculates the Welsh Index of Multiple Deprivation from routine data, including income, employment, health, and education. Welsh Index of Multiple Deprivation ranks small areas in Wales (LSOAs) according to their level of deprivation (1-1909). Hollinghurst et al [18] used deprivation quintiles, which allocated deprivation rankings to each LSOA ranging from quintile 1 to quintile 5, where quintile 1 indicates the areas of highest deprivation. The Care Inspectorate Wales Care Home registry provided the addresses of all care settings in Wales who provide care services to the public [56]. Both these data sources were accessed via the SAIL Databank but are also publicly available online.

Purpose of Routine Data

Recruitment of Participants or Creation of Study Sample

All but one of the studies included in this review used routine data to create study samples. Instead, Salkeld et al [34] recruited participants who were attending outpatient clinics and day centers for older people or were inpatients at a hospital.

Demographic and clinical information in routinely collected data allowed researchers to target their recruitment drive at participants according to their inclusion and exclusion criteria. Day et al [14] sent letters and made phone calls to 11,120 people aged over 70 years registered on the Australian electoral roll to recruit individuals who owned their own homes. Subsequently, researchers in this study used the Australian census and health survey to compare how their sample differed from the general population in terms of age, ethnicity, marital status, and health status [14]. Stark et al [30] formed their sample using SLAAA's NAPIS database to identify individuals at high risk of falling (aged more than 65 years and having a fall in the preceding 12 months or worried about falling). Campbell et al [35] used data from the Royal New Zealand Foundation of the Blind register and clinic and hospital records to identify participants aged over 75 years with poor vision and living in the community. Eligible participants were then invited to participate. In the study reported by de Almeida Mello et al [32] and Maggi et al [33], the Belgian National Institute for Health and Disability Insurance that provided HAM interventions in the real world, gave records of those who had received HAM interventions so that researchers could recruit to their study.

Three of the studies reviewed created electronic cohorts from routine data. As these were formed from anonymized data sources, it was not necessary to seek participants' consent to participate. Pega et al [36] used census data to identify the study population of people more than 65 years of age living in private accommodation. Hollinghurst et al [18] used data from their intervention provider, Care and Repair Cymru, to define a deidentified, electronic cohort of people living in Wales aged 60 years or more who received an intervention between 2009 and 2017. They also created a comparator group of people with similar demographic characteristics from the Welsh Longitudinal General Practice data who had not received an intervention from Care and Repair. Dates of death from the Annual District Death Extract from the Office of National Statistics [56] mortality data were used to censor participants who died during the course of the study. Maggi et al [33] and de Almeida Mello et al [32] also created an electronic cohort, this time for their comparator group only, from the Belgian IMA database. Using variables in the National Health Insurance data held in this database, researchers ensured that their intervention and comparator groups were matched in terms of age, risk of institutionalization, and health care utilization.

Stratification of the Sample

Pega et al [36] used census data to stratify their sample into 20 discrete cohorts by sex, age (65-69, 70-74, 75-79, 80-84, and 85 years or more), ethnicity (Indigenous New Zealanders: Maori and non-Maori), and whether participants were at high or low risk. The latter was determined according to the occurrence of any injurious falls in the previous five years identified using CD10. Maggi et al [33] de Almeida Mello et al [32] used routine data from the Belgian IMA [39] database to stratify their comparator group according to a participant's health impairment (mild or moderate to severe). This variable was derived from information on age, the cost of nursing, physiotherapy, and speech therapy at home, type of nursing care, and use of drugs for dementia.

Hollinghurst et al [18] stratified their sample according to participants' electronic Frailty Index (eFI) score. This index is used to predict outcomes including mortality, unplanned hospitalization, and nursing home admission and was calculated from 36 health deficit variables routinely collected and recorded in the Wales Longitudinal General Practice data set [57,58]. Depending on their eFI score, participants were categorized as either fit, mildly frail, moderately frail, or severely frail.

Generation of Predictor Variables or Covariates

Through electronic linkage between data sources within the SAIL Databank [45], Hollinghurst et al [18] assigned a deprivation index to the LSOA of participants' residences to explore whether deprivation levels, together with age and sex, modify the effectiveness of HAM interventions. Pega et al [36] used census data to create a variable indicating the proportion of people moving house at or after 65 years of age to estimate transitions into and out of modified and unmodified accommodation and to calculate the probability of participants moving into residential care.

Generation of Outcome Measures

To investigate whether their HAM intervention was cost-effective, Pega et al [36] compared the cost of hospitalization and the cost of attending a nonhospital health care setting after a fall between groups. As a secondary outcome measure, this study calculated the probability of hospitalization after a fall. To assess the cost-effectiveness of their HAM intervention, Salkeld et al [34] calculated the cost of participants' hospital utilization from the number of bed days and associated Australian diagnosis-related groups for each stay. Missing codes were imputed using the daily cost averaged across all codes. Campbell et al [35] measured the effectiveness of their HAM intervention according to the incidence of falls occurring postintervention using self-report calendars. Any falls reported as needing medical attention were confirmed using routine clinical data from hospitals and general practice records.

Maggi et al [33] and de Almeida Mello et al [32] linked their study participants individually to the IMA (2020) database, and this provided the main outcomes for their study; permanent institutionalization is defined as 90+ days at a nursing home or death. Individual-to-household data linkage allowed Hollinghurst et al [18] to measure intervention effectiveness from the number of hospital admissions for falls at home (identified with an ICD10 code) and the length of stay derived from admission and discharge dates. This study also measured the time it took for an individual to move to a care home after a fall using an anonymized list of care home addresses (from

the Care Inspectorate Wales registry) to address changes in the Welsh Demographic Service data.

Risk of Bias Findings

Table 1 shows the decisions regarding the risk of bias in each domain of the ROBINS-I tool and the decision made regarding the risk of bias in each study overall. After assessing the risk of bias, we judged that the studies included in this study were at an overall risk of low [14-36] to moderate bias [18,30,32,33]. The differences in bias were mainly because of design—all studies with overall low bias were randomized controlled trials (RCTs). The studies by Hollinghurst et al [18], de Almeida Mello et al [32], and Maggi et al [33] were longitudinal studies and, as such, were unable to reduce biases in the way that RCTs are inherently designed to do. Hollinghurst et al [18] did not adjust for previous falls, which is a predictor of subsequent falls; therefore, it was deemed at a serious risk of bias for confounding. The study by Stark et al [30] was a protocol only; therefore, there was not enough information available to determine whether this RCT was an overall low risk of bias.

It is worth mentioning that in the context of this study, using routinely collected data to measure outcomes can reduce the likelihood of bias in this domain. Blinding of participants is not possible in HAM evaluations; studies relying on self-report data to measure the number of falls are therefore subject to at least moderate bias (also known as response bias [29,30,32-34]. Both Hollinghurst et al [18] and Campbell et al [35] retrieved the number of falls from EHRs and were thus judged to be at a low risk of bias. Pega et al [36] also used routinely collected data to measure outcomes (New Zealand Tracker and Accident Compensation Corporation claims register). However, these two sources of data were not individually linked, and duplicated counts of falls may have occurred in some cases. This study was deemed to have a moderate risk of bias.

Recall bias occurs when participants misremember previous events or experiences and can lead to inaccuracies in the information recorded in studies [59]. As mentioned earlier, several studies used self-report data to account for previous falls, an important confounding factor, and inaccurate recall could result in an imbalance between groups, particularly in nonrandomized studies. For the studies that collected information on previous falls, only Pega et al [36] used routinely collected data to identify participants who had previously fallen, thus avoiding recall bias in this instance. Self-reported outcomes are particularly subject to this type of bias, where preexisting beliefs and memory can affect recall and sway study results in either direction [59]. In this study, four studies measured falls using self-report data and were, therefore, at risk of recall bias.

Table 1. Results of risk of bias assessment using the Risk Of Bias In Non-Randomized Studies of Interventions tool.

Reference	Domain							Overall risk
	Confounding	Selection bias	Classification bias	Deviation bias	Missing data	Outcome bias	Selective re-porting	
Campbell et al [35]	Low	Low	Low	Moderate	Low	Moderate	Low	Low
Day et al [14]	Low	Low	Low	Moderate	Low	Moderate	Low	Low
de Almeida Mello et al [32] and Maggi et al [33]	Moderate	Low	Low	Low	Moderate	Moderate	Moderate	Moderate
Hollinghurst et al [18]	Serious	Low	Low	Moderate	Low	Low	No information	Moderate
Pega et al [36]	Low	Low	No information	Low	Low	Moderate	Moderate	Low
Salkeld et al [34]	Low	Low	Low	Low	Low	Moderate	Low	Low
Stark et al [30]	Low	Low	Low	No information	No information	Moderate	No information	Moderate

Sampling bias, also known as volunteer bias, occurs when participants consist of individuals who have volunteered to participate in a study and may not be representative of the general population [59]. Only the study by Hollinghurst et al [18] was able to avoid this bias completely by using an anonymized electronic cohort, which precluded the need to seek participants' consent to participate.

Small sample sizes in intervention evaluations are problematic as they are often unable to detect significant or clinically relevant differences, and findings cannot be extrapolated to the general population [60]. After conducting a power calculation to determine their target sample size, Salkeld et al [34] reported that their study of 530 participants was underpowered and the difference in the number of falls between groups was not significant. This may have been a type II error rather than a true reflection of the effectiveness of HAM interventions [37]. Failing to hit sample size targets was likely related to their recruitment strategy (as mentioned earlier) and budget constraints [34]. All other studies in this study used routine data to recruit participants and reported no issues regarding sample size. Studies that featured electronic cohorts were over 8 times larger than those using recruitment models requiring consent [18,32,33,36].

Limited follow-up times can also be an issue in trials, as any long-term hazards or benefits can be missed and are usually only able to provide evidence of effectiveness in the short term [61]. Using self-report outcomes for falls, Maggi et al [33] conducted a 6-month follow-up—the shortest follow-up time for studies in this paper. The longest was in the study by Pega et al [36] that used routinely collected data to follow up outcomes until a participant's death or until age 110 years, although this was simulated data used in Markov modeling.

Discussion

Principal Findings

We identified 7 studies reported in 8 papers that used routine data to support the evaluation of HAM interventions. All studies were conducted in economically developed countries [62]. Government organizations provided the majority of data across studies, with health care providers and third-sector organizations providing data. Studies used a range of demographic, clinical or health, and administrative data. The purpose of using routinely collected data spanned recruiting or creating a sample, stratification, generating independent variables or covariates, and measuring key study-related outcomes.

The use of clinical data in research, particularly from EHRs, has risen considerably over recent years, and these are likely the most widely used source of routine data in health research today [63]. This coincides with a global increase (46% during 2011-2016) in EHR adoption across all health care service providers [64]. In this study, we have seen the versatile use of EHRs in HAM evaluations, from recruitment to outcome measurement. Although the provision of data by governments for health research is not as widespread, it is increasingly being advocated given the richness of the data they collect [65-67]. This is evident from the varied use of governmental data by the studies of this paper. In addition, many charities are now recognizing the value of their data, not only to improve their own services but also to enhance health research more generally [68,69].

Although the use of routinely collected data in health research is increasing, we only identified 7 studies that matched our inclusion criteria. This could be due to governance and system barriers surrounding the use of routinely collected data and data linkage in particular [22], although data safe havens used in studies from Wales [18] and New Zealand [36] improve accessibility. Linkage of household-level data is currently not commonplace, and there is a need for this type of data and

linkage of data for evaluation purposes more generally [21,70]. The absence of any studies from low-to-middle income countries may be a result of having fewer housing adaption provision in conjunction with less well-established routine data collection infrastructure and procedures [71,72].

This study shows that there is a clear value in the use of routinely collected data in HAM evaluation. It allows for objective data collection on key outcomes, including hospitalization, length of stay, care home admission, and mortality. Its use can reduce the risk of bias in trials where assessors may become unblinded to allocation and in participant recall and response. Longitudinal data sets such as EHRs are continuously updated and preclude the need for taking repeated measures from participants; this can reduce research costs and the burden on participants. In addition, target populations meeting specific inclusion criteria can be easily accessed. Forming electronic cohorts from routine data has particular benefits in that they can minimize recruitment bias and attrition, plus extended follow up and the creation of suitable control groups are far simpler to achieve. These larger samples also allow for greater validity, generalizability, and yield adequate statistical power. Moreover, hard-to-reach or minority

populations that are typically underrepresented in research can be easily included, such as those of advanced old age and other underrepresented groups including minority ethnic groups and people with multimorbidities [36,73,74]. However, too large a sample can detect significant differences that are not clinically relevant, and care needs to be taken to ensure appropriate sample size calculation with predefined clinically important differences in outcomes where possible [60].

Routine data are often used in mixed methods studies. The variables collected in these data sets are predetermined and rigid, generally restricted to codes, and rarely contain any contextual or in-depth qualitative information. These studies still need qualitative data and process evaluation to understand how service users experience these interventions and to get to the core of what actually matters to older people—all of which can influence an intervention's effectiveness [75]. Specific data collection via surveys and interviews is necessary to collect granular data or to answer specific questions that are not supported by routine data. If the use of routine data can reduce the burden of quantitative data collection, then more resources can be made available to enhance these data using alternative methods (Textbox 1) [76].

Textbox 1. Potential benefits and limitations of the use of routinely collected data in home assessment modification evaluations.

Benefits

- Rich data

- No or minimal participant burden

- Reusable for replication studies

- High external validity

- Diverse populations

- Fewer requirements for ethical approval

- Large control groups available for adequate statistical power

- Avoids recall bias

- Reduces study attrition

- No interference with routine care

- Lower cost and less resources needed for data collection

- Long observation periods

Limitations

- Data quality, for example, missingness

- Outcomes may need to be derived

- Randomization studies not possible with use of these data only

- Unavailability of confounding variables

- Data access issues, for example, governance

- Overpowered studies leading to spurious, significant findings

- Participant contact often not possible with anonymized routine data as consent not sought at study inception

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Benefits and Limitations of This Study

Despite the use of rigorous methods, this study has several limitations. Some studies may not have fully reported the use

of routine data in their publications; therefore, this study may be missing key information in this regard. We focused only on fall interventions based in participants' homes; nonhome-based fall intervention evaluations using routinely collected data were

excluded. Two protocols were included; therefore, results were not available for either of these studies. We did not attempt to identify unpublished studies, which means that this study could be subject to publication bias. We did not use MeSH headings in the PubMed search as, after piloting, this greatly reduced the search specificity. This means that some studies that met the inclusion criteria may not have been identified. However, we used a comprehensive search strategy, including the use of the LILACS database, of which most of its indexed journals are not indexed in other databases [77]. Our robust bias assessment using a standardized tool allowed objective evidence of bias in the studies of this paper and the comparison of bias between routine and nonroutine data use.

Conclusions

Despite the limited number of studies, we have seen that routine data can be used successfully in many aspects of evaluations of HAMs and can enhance methodological quality by reducing different types of bias while also improving other important design considerations. These advantages could be used further, for example, in the evaluation of HAM interventions to support people with disabilities. However, this study shows the under use of routine data in this important area of work. There are a number of governance barriers to be overcome to allow these types of linkage, and more work should be done to take advantage of the value that routinely collected data can offer.

Conflicts of Interest

JH is the lead author of one of the studies included in this review. The other authors have no conflicts to declare.

Multimedia Appendix 1
PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) checklist.
[DOC File , 64 KB - aging_v4i2e24728_app1.doc]

Multimedia Appendix 2
Summary of findings.
[DOCX File , 22 KB - aging_v4i2e24728_app2.docx]

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Abbreviations

ADR: Administrative Data Research
eFI: electronic Frailty Index
EHR: electronic health record
HAM: home assessment and modification
ICD10: International Classification of Disease, version 10
IDI: integrated data infrastructure
IGRP: Information Governance Review Panel
IMA: InterMutualist Agency
LSOA: lower layer super output area
NHS: National Health Service
NIHR: National Institute for Health Research Applied Research
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-analyses
RCT: randomized controlled trial
ROBINS-I: Risk Of Bias In Non-Randomized Studies of Interventions
SAIL: Secure Anonymized Information Linkage
SLAAA: St. Louis Area Agency on Aging

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Original Paper

Benefiting From Digital Use: Prospective Association of Internet Use With Knowledge and Preventive Behaviors Related to Alzheimer Disease in the Israeli Survey of Aging

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Abstract

Background: Previous work documented the beneficial association between internet use and improved cognition, functional capacity, and less cognitive decline among people in late adulthood. This work focused on potential mechanisms of such an association: knowledge on Alzheimer disease (AD) and preventive behaviors related to AD.

Objective: The aim of this study was to examine prospective associations of internet use and perceived computer skills with knowledge on AD and preventive behaviors related to AD.

Methods: The sample included 1232 older adults (mean age 71.12 [SD 9.07]) drawn from the Israeli branch of the Survey of Health, Aging, and Retirement in Europe (SHARE-Israel). The sample is representative of Israeli households of adults aged 50 or older and their spouses. Data analyzed were collected in person during 2015 (Wave 6), and in a drop-off questionnaire following the in-person 2017 data collection (Wave 7).

Results: Although both internet use and perceived computer skills were prospectively associated with knowledge and behaviors related to AD in bivariate analyses, after controlling for sociodemographics, only internet use was associated with more such knowledge (β=.13, P<.001) and behaviors (β=.22, P<.001).

Conclusions: Internet use emerged as a prospective predictor of protective factors against AD. Policymakers should advance digital engagement so as to enhance knowledge on AD and preventive behaviors among older adults.

Introduction

Background

Alzheimer disease (AD) is the most commonly occurring form of dementia, appearing predominantly in late adult life [1,2]. The disease causes a progressive cognitive, behavioral, and functional impairment, taking a heavy personal and financial toll on the patient, his/her family, and social services [3].

Although the neuropathological features resulting in neurodegeneration are well-recognized, the primary pathogenic factors and processes remain unclear. Hence, no effective treatments that can prevent the onset and progression of the disease exist hitherto, and much attention is directed at primary

prevention [4-6]. The sporadic forms of AD (as opposed to familial), which comprise the majority of cases, have multifactorial etiology comprising both genetic and potentially modifiable risk factors. The identified risk factors include depression, diabetes, physical inactivity, (midlife) hypertension, (midlife) obesity, smoking, high cholesterol, coronary heart disease, renal dysfunction, and low unsaturated fat intake, whereas the protective factors include high cognitive activity, low/moderate alcohol consumption, and Mediterranean diet [7].

Some evidence—both reviews [5,8,9] and randomized controlled trials [10,11]—indicates that cognitive stimulation in various forms can delay cognitive decline. Digital engagement—engaging in computers and the internet—could be surmised to be a form of cognitive stimulation, carried out both at leisure and at work. Indeed, recent studies found that internet use was associated with a reduction in dementia, even after controlling for health status, marital status, and numeracy skills [12], and that internet use was associated with improved cognition, functional capacity, and quality of life [13-15]. However, the mechanisms through which internet use was associated with improved cognition were not explicated. In her review of internet use as a prevention tool against cognitive decline, spanning online cognitive training programs, internet conversation, and use of internet/email, Klimova [9] postulated 2 mechanisms through which this effect might take place: (1) simply acquiring health knowledge and (2) transforming knowledge into norms and behaviors [16-18]. Knowledge about a health condition is a critical first step in facilitating appropriate and timely use of preventive health services [19] and behaviors, which are documented as risk/protective factors to AD [7].

The benefits accrued through internet use resonate the discourse on digital divide, specifically the "third digital divide" [20-24]. The concept of "digital divide" evolved in the last 2 decades. The initial focus was on people's physical/material access to computers, internet, and broadband internet, which was retrospectively labeled the "first digital divide." As more people gained access to digital media in developed countries [25,26], the interest in digital inequality has shifted from physical availability to how people use the technology [22,27], labeled the "second digital divide" or "usage gap" [28]. As the skill level of many people increased, the interest in the digital divide shifted to gains/outcomes/impacts or benefits that ensue from internet usage, labeled the "third digital divide." This third digital divide is postulated to correspond to offline economic, cultural, social, and personal resources/domains [29]. In the health domain, benefits from internet use span, to name a few, from comparing and switching health insurance, using high-reputed internet sources, arriving well-prepared to a medical visit to adopting positive health behaviors [29].

This study focused on potential pathways between internet use and improved cognition—knowledge and behavior—interpreting them as benefits of internet use. It examined the first phase of the link: the association between internet use and perceived computer skills, on the one hand, and knowledge on AD and AD-related preventive behaviors, on the other hand. Specifically, do people who are more engaged digitally know more about AD, and are they more engaged in modifiable behavioral risk/protective factors? The analysis was carried out on data

from the Israeli branch of the Survey of Health, Aging, and Retirement in Europe (SHARE-Israel), allowing for a prospective examination between the focal variables and controlling for covariates, both demographic and medical risk factors for AD. The demographic variables controlled for were gender, age, income adequacy, and education, often controlled for in internet use studies [15,30]. The medical risk factors controlled for were chronic conditions, as they may be associated with AD-preventive behaviors or knowledge on AD. Protective behaviors related to AD were not controlled for, as they were one of the focal dependent variables.

The Study Hypotheses

Based on the literature reviewed above, the study examines 2 hypotheses:

Hypothesis 1a: Internet use is prospectively associated with knowledge on AD and AD-related preventive behaviors.

Hypothesis 1b: Perceived computer skills are prospectively associated with knowledge on AD and AD-related preventive behaviors.

Hypothesis 2a: The above prospective associations between internet use and knowledge on AD and AD-related preventive behaviors hold also after controlling for background variables of gender, age, education, income adequacy, and reported medical risk factors.

Hypothesis 2b: The above prospective associations between perceived computer skills and knowledge on AD and AD-related preventive behaviors hold also after controlling for the aforementioned background variables.

Methods

Participants and Procedure

Data were drawn from 2 waves of the SHARE-Israel. The SHARE is a cross-national (27 European countries and Israel) panel database of microdata on health, socioeconomic status, and social and family networks [31], whose purpose is to provide a broad picture of life after the age of 50 for researchers and policy makers. Waves of data collection started in 2004, and thus far 7 waves were collected, the latest in 2017. The Israeli sample is representative of Israeli households of adults aged 50 or older and their spouses (the latter regardless of age) [32]. The design was based on a probability sample of households within 150 representative statistical areas delineated by geographical and sociodemographic criteria. More details on SHARE-Israel can be found on its official website [33].

In this study, respondents were interviewed during 2015 (Wave 6), when they were asked about internet use and perceived computer skills. They also responded to a supplementary paper drop-off questionnaire focusing on AD during 2017 (Wave 7). The data were collected by a comprehensive face-to-face interview using a computer-assisted personal interview, which lasted about 90 minutes, and a supplementary paper drop-off questionnaire, which was returned later. Informed consent had been obtained from all respondents prior to the interview. SHARE-Israel received ethical approval from the Institutional Review Board of the Hebrew University of Jerusalem and the

general survey had a countries-wide institutional review board [34].

As the survey questions regarding AD were included in the drop-off questionnaire administered at Wave 7, the sample of this study was limited to the 1232 respondents who completed this questionnaire and also participated in Wave 6 where they were asked on internet use and perceived computer skills. Response to the surveys was either in Hebrew, Arabic, or Russian, the 3 major languages spoken in Israel among adults aged 50 and over (Table 1).

Table 1. Descriptive characteristics of the study sample.

Variable	Value
Age (years), mean (SD); range	71.12 (9.07); 42-101
Gender (n=1232), n (%)	
0=men	516 (41.88)
1=women	716 (58.12)
Cohabitation (n=1232), n (%)	
0=Living without a partner	330 (26.79)
1=Living with a partner	902 (73.21)
Education (n=1222), n (%)	
0=Never attended an education program	56 (4.58)
1=Primary education	243 (19.89)
2=Lower secondary education	126 (10.31)
3=Upper secondary education	307 (25.12)
4=Postsecondary nontertiary education	73 (5.97)
5=Bachelor's or equivalent level	412 (33.72)
6=Master's or Doctoral equivalent level	5 (0.41)
Perceived income adequacy (n=1214), n (%)	
1=With great difficulty	126 (10.38)
2=With some difficulty	307 (25.29)
3=Fairly easily	345 (28.42)
4=Easily	436 (35.91)
Medical risk factors (n=1217), mean (SD); range	1.46 (1.40); 0-7
Internet use (during past 7 days) (n=1232), n (%)	
0=No	590 (47.89)
1=Yes	642 (52.11)
Perceived computer skills (n=1229), n (%)	
0=I never used a computer	350 (28.48)
1=Poor	97 (7.89)
2=Fair	229 (18.63)
3=Good	262 (21.32)
4=Very good	188 (15.30)
5=Excellent	95 (7.73)
Knowledge on Alzheimer disease	
Total score (n=1232), mean (SD); range	4.68 (2.31); 0-10
Alzheimer disease–related preventive behaviors	
Total score (n=1232), mean (SD); range	3.75 (2.09); 0-9

Measures

Internet Use

Participants were asked whether they had used the internet in the past week for either email, information search, shopping, or any other purpose at least once. Responses were on a dichotomous yes/no scale (coded as "1" [Yes] or "0" [No]). This measure has been used in previous research to indicate general and regular internet usage behavior [15,35].

Perceived Computer Skills

Participants were asked, "How would you rate your computer skill? Would you say they are ..." A 5-point scale was used, ranging from *poor* to *excellent*. An additional category was *I never used a computer*. Responses were coded so that *I never used a computer* was the lowest end (0) of the scale and *excellent* was the highest (5). This measure has been used in previous research to indicate subjective skills [36,37].

Knowledge on Alzheimer Disease

Questions tapping general knowledge on AD were adapted [19,38]. All 10 items were pretested in 2 prior Israeli samples. Responses were provided on a 3-point response scale, including *correct/incorrect/I don't know*. Sample items were "Alzheimer's disease could be contagious" (false, [19]), "Alzheimer's disease can be diagnosed with a blood test" (false, [19]), and "Symptoms of severe depression can be mistaken for symptoms of AD" (true, [38]) [see Multimedia Appendix 1]. Correct responses were summed up so that the knowledge on AD score ranged from 0 to 10. Cronbach α coefficient of the scale was fair, α=.63, considering it was based on dichotomous items [39].

Alzheimer Disease–Related Preventive Behaviors

Participants were asked to check whether they had engaged in the following behaviors on a regular basis in the past month. Nine behaviors were included: physical exercise; consumption of foods with high saturated fat and cholesterol; consumption of green vegetables, nuts, cereals, fish, or olive oil; limitation of total daily caloric intake; reduction of stress level, done in order to reduce, prevent, and cope with stress; communication with family or friends; participation in social activities; doing number games such as crossword puzzles or sudoku; and taking nutritional supplements, such as vitamin B_{12}, vitamin E, and omega 3 fatty acids. The items were identified as AD-protective factors [7]. All items were pretested in 2 small prior samples. The items were summed up so that the score could potentially range from 0 to 9. Cronbach α coefficient of the scale was fair, α=0.62, considering it was based on dichotomous items [39].

Sociodemographic characteristics included gender (1=female; 0=male), age in years, education level, and perceived household income adequacy. Perceived income adequacy was assessed by asking, "Thinking of your household's total monthly income, would you say that your household is able to make ends meet?." The answer scale was composed of 4 categories ranging from 1=*with great difficulty* to 4=*easily* [40]. Education level was coded by 1 of 7 categories classified by the International Standard Classification of Education (ISCED), ranging from 0 (preprimary) to 6 (second-stage tertiary education) [41]. Medical risk factors, as based on the Wave 6 report, included coronary

heart disease, hypertension, high cholesterol, diabetes, renal dysfunction, affective disorder, and BMI of 30 kg/m^2 or above. These were summed up to form a *medical risk factors* score [42] ranging from 0 to 7.

Data Analysis

We first performed univariate descriptive analyses, characterizing the study's participants. Then, Pearson correlations and unpaired *t* tests were conducted in order to examine Hypothesis 1 on bivariate associations between the main variables (for continuous and categorical variables, respectively). We then tested Hypothesis 2 in a series of hierarchical multiple regression analyses examining internet use and perceived computer skills' prediction of each of the dependent variables: knowledge on AD and AD-related preventive behaviors. As the predictors internet use and perceived computer skills were highly associated, they were not entered simultaneously, and thus separate regression analyses examined the prediction of each of these predictors. Step 1 in the regression included gender, age, education, and income adequacy, demographic variables traditionally controlled for in studying internet use [15]. We also included reported medical risk factors in this step to control for the possibility that reported conditions could be associated with increased knowledge and preventive behaviors. Step 2 additionally included either internet use or perceived computer skills. Data were analyzed using SPSS statistical software, PC version 25.0 (IBM).

Results

Descriptive Characteristics of the Sample

Wave 7 included 2131 individuals; 1638 of them returned the AD drop-off questionnaire, and 1232 of them also had data from the Wave 6 data collection. A comparison of the larger group of all Wave 7 respondents with those included in this analysis yielded no significant differences (*P*=.30, .70, and .15 for age, gender, and education, respectively) except in income adequacy (*P*=.008), which was slightly higher (mean difference of 0.1) in our analysis sample. Characteristics of the participants are presented in Table 1. The mean age in the current sample at Wave 7 (n=1232) was 71.12 (SD 9.07). Most participants were women (716/1232, 58.12%) or living with a partner (902/1232, 73.21%). About one-third of the sample had lower secondary education or less (425/1222, 34.78%), a quarter (307/1232, 24.9%) had an upper secondary education, and 40.10% (490/1222) a postsecondary or tertiary education. As for the perceived income adequacy, most of the sample reported being able to make ends meet easily or fairly easily (781/1214, 64.33%). The medical risk factor mean was 1.46 (SD 1.40).

Regarding digital engagement, about one-half of the sample (642/1232, 52.11%) had used the internet during the 7 days prior to the interview. Almost one-half of the sample (545/1229, 44.34%) rated their computer skills as good to excellent. Knowledge on AD and AD-related preventive behaviors are also displayed in Table 1. The mean knowledge on AD was at midrange (mean 4.68, range 0-10), whereas the mean reported

AD-related preventive behaviors was relatively low (mean 3.75, range 0-9).

Bivariate Analyses

As displayed in Table 2, significant differences were found between respondents who had used the internet during the past week and those who had not in both knowledge on AD (t_{1230}=7.33, P<.001, Cohen d=0.43) and AD-related preventive behaviors (t_{1230}=9.08, P<.001, Cohen d=0.52), such that internet users reported higher knowledge on AD and AD-related preventive behaviors.

As presented in Table 3, the prospective correlations between perceived computer skills and both knowledge on AD and AD-related preventive behaviors were significant and positive, though weak (r=0.08, P<.001 and r=0.13, P<.001, respectively). The findings therefore provided support for Hypothesis 1. In addition, the correlations of education with internet use and perceived computer skills were significant and positive (r=0.46, P<.001 and r=0.43, P<.001, respectively), whereas the associations of age with internet use and perceived computer skills were significant and negative (r=–0.22, P<.001 and r=–0.32, P<.001, respectively).

Table 2. Knowledge on Alzheimer disease and Alzheimer disease–related preventive behaviors by internet use.

Pathway	Internet users (n=642), mean (SD)	Noninternet users (n=590), mean (SD)	t value (df)	P-value
Knowledge on Alzheimer disease	5.13 (2.33)	4.18 (2.20)	7.33 (1230)	<.001
Alzheimer disease–related preventive behaviors	4.25 (2.07)	3.20 (1.97)	9.08 (1230)	<.001

Table 3. Correlations between the study variables.[a]

Study variables	KAD[b]	ADPB[c]	Internet use	Perceived computer skills	Education	Age
KAD	1					
ADPB	0.42[d]	1				
Internet use	0.21[d]	0.25[d]	1			
Perceived computer skills	0.08[e]	0.13[d]	0.68[d]	1		
Education	0.23[d]	0.29[d]	0.46[d]	0.43[d]	1	
Age	–0.01	–0.01	–0.22[d]	–0.32[d]	–0.12[d]	1

[a]N varies from 1205 to 1232.

[b]KAD: Knowledge on Alzheimer disease.

[c]ADPB: Alzheimer disease–related preventive behaviors.

[d]P<.001.

[e]P=.008.

Multivariate Analyses Predicting Knowledge on Alzheimer Disease

Table 4 presents the linear hierarchical regression models predicting knowledge on AD. Model 1 includes the demographic and medical risk factor variables. It shows a positive association of education and knowledge with AD: the higher the level of education, the better the knowledge on AD. A similar positive association of income adequacy (P=.006) and medical risk factors (P=.005) with knowledge on AD was found. No significant associations of gender (P=.87) and age (P=.84) with knowledge on AD were found.

To examine Hypothesis 2 regarding the positive association between internet use and knowledge on AD, we added internet use to our model (see Model 2a). There were 2 main findings. First, the prospective association of internet use with knowledge on AD was significant and positive (P<.001). Respondents who used internet revealed higher knowledge on AD compared with those who did not report this use. Therefore, this finding provided support for Hypothesis 2 regarding internet use. In addition, the adjusted R^2 (final step) in the sample was 6.9%.

To examine Hypothesis 2 regarding the positive association between perceived computer skills and knowledge on AD, we added perceived computer skills to our model (see Model 2b). The association between perceived computer skills and knowledge on AD was not significant (P=.09). Thus, this finding did not provide support for Hypothesis 2b regarding perceived computer skills. Note that when controlling for perceived computer skills, medical risk factors emerged as a significant predictor of knowledge on AD (P=.002), such that the more medical risk factors, the higher the knowledge on AD.

Table 4. Hierarchical linear regression predicting knowledge on Alzheimer disease.

Predictors	Model 1 (n=1190)			Model 2a (n=1190)			Model 2b (n=1187)		
	B[a]	SE B[b]	β [c]	B	SE B	β	B	SE B	β
Constant	3.11	0.58	—[d]	2.79	0.58	—	3.38	0.63	—
Gender (women=1)	0.02	0.13	.04	0.05	0.13	.01	0.00	0.13	.00
Age	0.00	0.01	.01	0.00	0.00	.01	–0.00	0.01	–.02
Education	0.30	0.04	.21[e]	0.23	0.04	.16[e]	0.31	0.04	.22[e]
Income adequacy	0.19	0.07	.08[f]	0.12	0.07	.05	0.21	0.07	.09[g]
Medical risk factors	0.14	0.05	.08	0.15	0.05	.09	0.13	0.05	.08[h]
Internet use	—	—	—	0.60	0.15	.13[d]	—	—	—
Perceived computer skills	—	—	—	—	—	—	–0.06	0.05	–0.04
Adjusted R^2	0.057	—	—	0.069	—	—	0.058	—	—
R^2 change	—	—	—	0.012	—	—	0.001	—	—

[a]Unstandardized beta coefficient.

[b]Standard error for the unstandardized beta (B).

[c]Standardized beta coefficient.

[d]—: Not available

[e]$P<.001$.

[f]$P=.006$

[g]$P=.003$.

[h]$P=.002$.

Multivariate Analyses Predicting Alzheimer Disease–Related Preventive Behaviors

Table 5 presents the hierarchical linear regression model predicting AD-related preventive behaviors. Similar to our findings regarding knowledge on AD, a positive significant association between education and income with AD-related preventive behaviors was recorded (<.001 and .036, respectively), whereas no significant associations were found for the association of gender ($P=.07$), age ($P=.78$), and medical risk factors ($P=.60$) with AD-related preventive behaviors.

To examine Hypothesis 2 regarding the positive association between internet use and AD-related preventive behaviors, we added internet use to our model (see Model 2a). The prospective association of internet use was significant and positive ($P<.001$). Respondents who used the internet had higher AD-related

preventive behaviors compared with those who did not report this use. Therefore, this finding provided support for Hypothesis 2a regarding internet use. However, when controlling for internet use, gender emerged as a significant predictor of AD-related preventive behaviors such that women had higher AD-related preventive behaviors than men ($P=.03$). In addition, the adjusted R^2 (final step) in the sample was 7.7%.

To examine Hypothesis 2b regarding the positive association between perceived computer skills and AD-related preventive behaviors, we added perceived computer skills to our model (see Model 2b). The effect of perceived computer skills was positive yet insignificant ($P=.09$); indeed, the adjusted R^2 in the sample hardly changed compared with Model 1 and was only 4.5% ($P=.09$). Thus, this finding did not provide support for Hypothesis 2b regarding perceived computer skills.

Table 5. Hierarchical linear regression predicting Alzheimer disease–related preventive behaviors.

Predictors	Model 1 (n=1190)			Model 2a (n=1190)			Model 2b (n=1187)		
	B[a]	SE B[b]	β [c]	B	SE B	β	B	SE B	β
Constant	2.35	0.53	__[d]	2.14	0.53	—	1.96	0.57	—
Gender (women=1)	0.21	0.12	.05	0.26	0.12	.06[e]	0.23	0.12	.05
Age	–0.00	0.00	–.01	0.01	0.01	.03	0.01	0.01	.03
Education	0.23	0.04	.18[f]	0.13	0.04	.10[f]	0.21	0.04	.17[f]
Income adequacy	0.13	0.06	.06[g]	0.03	0.06	.01	0.09	0.07	.05
Medical risk factors	–0.03	0.05	–.02	–0.05	0.05	–.00	–0.02	0.05	–.02
Internet use	—	—	—	0.93	0.14	.22[f]	—	—	—
Perceived computer skills	—	—	—	—	—	—	0.07	0.04	.06
Adjusted R^2	0.043	—	—	0.077	—	—	0.045	—	—
R^2 change	—	—	—	.034	—	—	.002	—	—

[a]Unstandardized beta coefficient.

[b]Standard error for the unstandardized beta (B).

[c]Standardized beta coefficient.

[d]—: Not available

[e]$P<.32$.

[f]$P<.001$.

[g]$P=.04$.

Discussion

Principal Findings

Our findings indicate that internet use was significantly and positively associated with both knowledge on AD and AD-related preventive behaviors (Hypothesis 1). The prospective association between internet use and knowledge on AD held also when demographic attributes were controlled for (Hypothesis 2a). It is noteworthy that even though education and internet use were positively associated (r=0.46, $P<.001$), internet use still added to the explained variance in both knowledge on AD and AD-related preventive behaviors, after controlling for education and other demographic and medical risk factors (Hypothesis 2a), and internet use was a stronger predictor of knowledge on AD and AD-related preventive behaviors compared with education. Overall, the explained variance in knowledge on AD and AD-related preventive behaviors was significant yet relatively small (6.9% and 7.7%, respectively). Perceived computer skills were also significantly associated with both knowledge on AD and AD-related preventive behaviors (Hypothesis 1b). However, this bivariate prospective association did not hold in a multivariate analysis, when gender, age, education, perceived income adequacy, and medical risk factors were controlled for in predicting knowledge on AD and AD-related preventive behaviors (Hypothesis 2b). Overall, the explained variance was significant yet relatively small (6.9% and 7.7%, respectively).

Comparison With Prior Work

Our findings exemplify the capital-enhancing effect of using the internet in 2 domains: information acquisition and making more "responsible" choices [43,44]; these were both documented in the context of AD, relevant to people in middle and late adulthood. The findings indicate that internet users build personal capital and resources in the form of knowledge and behaviors. Our findings not only record first divide (ie, access) and second divide (ie, skills) variables' prospective association with a third divide (ie, outcomes), but also lend support to the sequentiality in the digital divide [45,46], namely, that access and skills in the digital arena (ie, digital access and skills reported in Wave 6 data collection) subsequently relate to offline outcomes in *another* domain (ie, knowledge and behavior in the health arena reported in Wave 7). The size of the explained variance in knowledge on AD and AD-related preventive behaviors attests to a relatively small effect of accrued capital gained from internet use, yet one similar to the small effects of internet use on other health processes [47] and of social capital on health, as documented in a recent meta-analysis [48].

Education was found to be a significant predictor of knowledge on AD and AD-related preventive behaviors. These findings echo recommendations regarding dementia prevention [2]; education, along with cognitive stimulation, is associated with building a cognitive reserve earlier in life. This reserve translates also into actual participation in health behaviors [49].

The study has several implications. First, by suggesting and testing mechanisms through which internet use may be associated with reduced dementia prevalence [12,14], namely, knowledge acquisition and preventive behavior, it signposts digital engagement as an intervention venue, recommended also by other researchers [44]. The intervention does not need to be

directive and focused on AD, as it seems that people arrive to this domain on their own.

Although it is unclear which specific digital activities are associated with enhanced knowledge on AD and AD-related preventive behaviors, opening the digital realm to more older adults is promising, and integrates into the evidence on the beneficial effects of cognitive stimulation. The scope of potential intervention focused on enhanced digital engagement/literacy is big, as only about one-half (642/1232, 52.11%, similar to SHARE respondents' average use [35]) of the respondents to this survey, a representative sample of households in this age bracket, had been digitally engaged in the preceding week, and almost one-third reported they never used a computer. Although many respondents own mobile phones, most often smartphones [50], they often do not realize its affordances. Internet use among this age group in Israel has risen in the past decade [30], but there is ample room for an additional increase.

Strengths and Limitations

This study has a number of strengths. First, the prospective association between internet use, knowledge on AD, and AD-related preventive behaviors is novel, and attests to the benefits accrued by internet use. It is one of the manifestations of the third digital divide in the health domain. Second, the longitudinal design of the study, establishing temporality, suggests directionality of the relationship between the variables. Internet use and perceived computer skills had both been measured in a previous data collection wave, and they predicted knowledge on AD and AD-related preventive behaviors. Most studies on internet use are not longitudinal, and do not afford drawing such a conclusion. A third major strength of the study is the representativeness of the sample, consisting of a relatively large number of respondents (n=1232).

However, certain limitations of this study should also be noted. Foremost, all the variables were self-reported and originated from a single source—the respondent. Some of the predictors are essentially reliable and valid (eg, demographic attributes), some are reported practices (eg, digital engagement) that are more prone to self-presentation bias, and some are inherently perceptions (perceived computer skills). The latter are moderately (though significantly) associated with actual performance, as can be inferred from reported and performed eHealth literacy [51]. This bias in perceived computer skills may explain the finding that it was not associated with knowledge nor behavior in multivariate analyses: it may not have measured computer skills accurately enough. Second, we cannot be completely confident in the directionality of the relationship between internet use, knowledge on AD, and AD-related preventive behaviors; the longitudinal measurement

of these variables does not guarantee that this was the actual sequence between them. Third, the 2 dependent variables exhibited relatively low reliability, probably as they employed dichotomous responses and covered different domains (eg, behaviors pertaining to diet, exercise, and social interaction). Lastly, the study did not examine the association of knowledge on AD and AD-related preventive behaviors with cognitive decline (though the latter was examined by other studies), nor whether knowledge on AD and AD-related preventive behaviors mediate the association between internet use and cognitive decline. Despite the limitations, the study is unique in that it documented—in a longitudinal design—how using the internet and having digital skills can generate positive outcomes for people in middle and late adulthood. The positive outcomes examined were knowledge on AD and behaviors which can modify the timing of AD, and the prospective design of the study allowed inferring the direction of the association: from internet and computer use to tangible benefits.

Future Directions

Future work could focus on unravelling what exactly in internet use afforded the reported benefits. This study did not track people's actual use of the internet but rather relied on their report of using it during the previous week. A more nuanced measurement of internet use (both eHealth and mHealth [mobile health]) could provide more precise information. For example, are the benefits derived from using knowledge and experiential accounts created by peers, such as in online health communities [16], aligned with Web 2.0 activities, or alternatively are the tangible benefits that result in obtaining information from traditional sources, such as hospitals, health maintenance organizations, and patients' associations, aligned with Web 1.0 consumption [52]? Adopting a functional approach [53], it is of special interest to unravel which digital activities are associated with AD-related preventive behaviors. Another intriguing direction is to examine subpopulations such as immigrants or minorities; knowledge on AD and AD-related preventive behaviors of subpopulations are of interest as well as the facilitating effect of internet use. Lastly, future research could focus on cognitive decline as the dependent variable, and test whether knowledge on AD and AD-related preventive behaviors indeed function as mediators between internet use and reduced dementia, as documented in recent findings [12,14,15]. Concomitantly, the mechanism through which internet use is associated with preventive behaviors could be further explored to examine whether knowledge mediates this association. Future research should avoid cross-sectional design, and hold onto the longitudinal design, to allow inferring the direction of the association.

Authors' Contributions

Conflicts of Interest

XSL·FO

RenderX

Multimedia Appendix 1
Knowledge on Alzheimer disease.
[DOCX File , 14 KB - aging_v4i2e25706_app1.docx]

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Abbreviations

AD: Alzheimer disease
SHARE: Survey of Health, Aging, and Retirement in Europe

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An Instrument for Measuring Social Participation to Examine Older Adults' Use of the Internet as a Social Platform: Development and Validation Study

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Abstract

Background: Older people's use of the internet is increasingly coming into focus with the demographic changes of a growing older population. Research reports several benefits of older people's internet use and highlights problems such as various forms of inequality in use within the group. There is a need for consistent measurements to follow the development and use of the internet in this group and to be able to compare groups both within and between countries, as well as follow the changes over time.

Objective: The aim of this study was to create an instrument to measure an older person's perception of the benefits of their online social participation, unconnected to specific applications and services. The instrument to measure internet social participation proposed in this paper builds on social participation factors and is a multidimensional construct incorporating both social relations and societal connectedness.

Methods: A short instrument for measuring social participation over the internet was created. An exploratory factor analysis (EFA) was conducted in a random selection of persons aged 65 years or older (n=193) on 10 initial items. Further validation was made by confirmatory factor analysis (CFA) in the remaining group (n=193).

Results: A 1-factor solution for the social internet score was decided upon after exploratory factor analysis (EFA; based on a random sample of half the data set). None of the questionnaire items were excluded based on the EFA, as they all had high loadings, the lowest being 0.61. The Cronbach α coefficient was .92. The 1-factor solution explained 55% of the variance. CFA was performed and included all 10 questionnaire items in a 1-factor solution. Indices of goodness of fit of the model showed room for improvement. Removal of 4 questions in a stepwise procedure resulted in a 6-item model (χ^2_6=13.985; χ^2/degrees of freedom=1.554; comparative fit index=0.992; root mean square error of approximation=0.054; standardized root mean square residual=0.025).

Conclusions: The proposed instrument can be used to measure digital social participation and coherence with society. The factor analysis is based on a sufficient sample of the general population of older adults in Sweden, and overall the instrument performed as expected.

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Introduction

Older adults' internet use is the focus of an increasing number of research studies [1]. Internet use has been reported to promote the well-being [2] and active aging [3] among older people and to act as a possible support for maintaining cognitive function [4,5]. Despite these benefits, there are also reports of a lower percentage of internet users in older age groups than in the whole population [6,7], creating a digital divide, leaving out many older adults from the benefits of the online world.

Research on this digital divide has initially been focused on actual internet access (first-level digital divide) and internet skills and use (second-level digital divide) [8]. However, with an increasing number of older people getting access to the internet, the focus has also shifted to a third-level digital divide in which the tangible outcomes of internet use are highlighted [8] and where actual users also differ in how they benefit from their online presence. One such outcome is the use of the internet to maintain social contacts and avoid loneliness [9-11].

The positive relationship between social participation and well-being and health is well documented [12,13]. Social participation has no universally agreed definition but is generally measured in terms of the quantity or quality of social interactions and connections [14]. In a study on older adults' social participation, Utz et al [15] classified it in the realm of organizational affiliations, friendship ties, kinship networks, social connectedness, social support, or social integration. Internet use has been generally acknowledged to have the potential to support such social affordance [16-19].

A possibility to measure the online social participation, unconnected to specific applications and services, would be of interest for comparing groups both within and between countries, and to examining changes over time. The instrument to measure internet social participation proposed in this paper builds on social participation factors and is a multidimensional construct incorporating both social relations and societal connectedness. It focuses on the subjective feeling of social participation free from references to specific applications and services.

Methods

Data Collection and Sample

Data were obtained from a sample of participants in the Swedish National Study of Aging and Care (SNAC). SNAC is a longitudinal cohort study of a representative sample of the aging Swedish population that started its data collection in 2001. It is a comprehensive, interdisciplinary study that investigates the health and living conditions of the Swedish population aged 60 years and older. A detailed outline of the SNAC study is available from Lagergren et al [20]. The present study sample is based on participants from 1 of the 4 regions in the SNAC study, the SNAC Blekinge (SNAC-B) cohort with individuals living in the municipality of Karlskrona.

As an addition to this study, it was seen necessary to further the efforts to gather information about older persons' use and experiences of societal digitalization. A first questionnaire was sent out in 2017, and the second slightly modified questionnaire

(the base for this study) was sent out in April 2019 to all participants in the SNAC-B study (N=733). A total of 581 persons responded, corresponding to a response rate of 79.3% (581/733). In the present study, only individuals who responded that they were information and communication technology users were included (n=393).

Out of the internet users, 388 were responders of at least one social participation score item. Of these, 21 persons had missing answers on at least one of the 10 questionnaire items in the social participation score (15 persons had 1 missing question; 3 persons had 2 missing; and 1 person each had 5, 7, and 9 missing). From the answers of the 388 responders, the following were the number of missing values for the 10 questions: 4, 3, 3, 8, 5, 5, 3, 3, 5, and 3, respectively. Finally, persons answering fewer than 5 questions were excluded, rendering the final number of participants to 386.

Instrument Development

In the first questionnaire sent out in 2017, there was a focus on older persons' affinity to technology, so-called technophilia [21], and this research was subsequently reported in JMIR. In further analysis of this initial research, the need was also found for an instrument that could measure experiences of the online social participation, unconnected to specific applications and services. This would be of interest to see changes over time between our cohorts (eg, asking about a specific application as Facebook use today could be changed to another application over time, but the underlying latent construct is the same). Social participation [14,15] was chosen as a theoretical framework incorporating a multidimensional construct with both social relations and societal connectedness.

A list of possibly interesting and relevant aspects of social participation and connectedness in an online environment was constructed from the theoretical framework and the control questions in the questionnaire (Table 1). From this, an initial 10-question instrument (5 questions in each domain) was composed by PA and JSB, who have expertise in the field of aging and the internet. This list was reviewed together with a third expert, in the psychology of aging, and different aspects and formulations were discussed and agreed upon.

The questionnaire was then pretested for face validity, coherence, and understandability with cognitive interviews [22] being conducted with the target group (a convenience sample of 6 individuals of both sexes ranging in age from 66 to 80 years). The interviewees were given the 10-item questionnaire and were encouraged to think aloud when they read the questions. The interviewer would also follow up with verbal probing (ie, questions about how well the interviewee understood the question) based on item wording, terminology, and if the structure was clear and easy to understand. Specifically, the questions "Can you repeat the question I just asked in your own words?", "Was there anything confusing about this question?", "What does the word [term] mean to you as it is used in the question?", and "Tell me what you thought when I asked about [topic of question]," were asked.

The item questions were then revised according to the feedback from the interviews with respect to the verbal probing.

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Especially important was to make sure that the questionnaire was using terminology relevant to older people using technology to ensure face validity. The questionnaire was translated into English using backward-forward translation from the original

Swedish version, by native-speaking translators in each direction.

The resulting questionnaire items can be found in Table 1.

Table 1. Initially suggested 10-question instrument.

Domain	English (translation)	Swedish (original)
Social relations	1. I think the internet helps me stay in touch with friends and family	1. Jag tycker att internet hjälper mig att hålla kontakt med vänner och familj
Societal connectedness	2. I think the internet helps me keep up to date with what's happening in society	2. Jag tycker att internet hjälper mig att hålla mig informerad om vad som händer i samhället
Societal connectedness [a]	*3. I think the internet makes me feel more included in society*	*3. Jag tycker att internet gör att jag känner mig mer delaktig i samhället*
Social relations	4. I think the internet makes me feel less lonely	4. Jag tycker att internet gör att jag känner mig mindre ensam
Societal connectedness	*5. I think the internet helps me to access meaningful activities*	*5. Jag tycker att internet hjälper mig att få tillgång till meningsfulla aktiviteter*
Social relations	*6. I think the internet helps me keep up my social network*	*6. Jag tycker att internet hjälper mig att hålla igång mitt sociala nätverk*
Societal connectedness	*7. I think the internet helps me reconnect to old memories and events of yesteryear*	*7. Jag tycker att internet hjälper mig att återknyta till gamla minnen och händelser från förr*
Societal connectedness	8. I think the internet helps me find pastimes and amusement	8. Jag tycker att internet hjälper mig att hitta nöje och förströelse
Social relations	*9. I think the internet helps me to expand and create new social networks*	*9. Jag tycker att internet hjälper mig att utöka och skapa nya sociala nätverk*
Social relations	*10. I think the internet makes me feel less isolated*	*10. Jag tycker att internet gör att jag känner mig mindre isolerad*

[a]The questions that made it into the final instrument are indicated by italics.

Statistical Analysis

In order to be able to include all participants who answered at least five questions on the social participation score, imputation was done on the missing values for the 10 items to be used in creating the social participation score. Thus, 26 missing values were imputed by using median imputation across the individuals. As the missingness was limited (close to 0.5%) it is not likely that the choice of imputation method would affect statistical analyses to any noticeable extent. To compare, a complete case analysis would result in excluding 5% of the 386 participants and was not preferable.

After imputation was carried out, a random sample (n=193) was drawn to perform an exploratory factor analysis (EFA), with the main aim of deciding on a single- or multiple-factor solution, and of delimiting the number of items making up the social participation score. The number of factors to include were decided based on the Cattell scree test [23] and Horn parallel analysis [24], along with inspection of the factors. After the EFA had been carried out, the Cronbach α coefficient was calculated for examining the internal consistency of the questionnaire items within a factor [25]. On the other half of the data (n=193), a confirmatory factor analysis (CFA) was performed, based on the structure proposed by the EFA. As the CFA was carried out on another data sample, it was possible to cross-validate the measurement model proposed by the EFA, as done by Kamin and Lang [26]. Before any of the factor analyses were carried out, both the Kaiser-Meyer-Olkin measure

of sampling adequacy, which calculated the proportion of the variance in the questionnaire items that might be caused by underlying factors [27], and the Bartlett test of sphericity, which tested the hypothesis that the items are unrelated [28], were performed. These tests were conducted on the complete data set (N=386).

Regarding sample sizes, Floyd and Widaman [29] recommend a sample size of at least 10 participants per parameter estimated (here meaning the number of questions in the questionnaire) for performing a CFA. The same recommendation is made by Nunnally [30] for the EFA. In the CFA, several goodness-of-fit measures were assessed: the chi-square statistic by itself and relative to the degrees of freedom (ideally <2 [31]), the standardized root mean square residual (SRMR; ideally <0.05 [31]), the comparative fit index (CFI; acceptable fit >0.95, [31]), and the root mean square error of approximation (RMSEA; ideally <0.05; acceptable fit 0.05-0.08, [32]). Modification indices (MIs) were evaluated to possibly improve the model by limiting the number of questionnaire items and to identify complex items in a similar manner to Hyde et al [33]. MIs are values corresponding to univariate score tests and reflect the model fit improvement that would be present if a constrained parameter were to be estimated as a free one [34]. In particular, we looked at MIs for covariances between questionnaire items within a factor in CFAs and hypothesized that for significant score tests, instead of allowing for covariances in the model between items, we could exclude 1 of 2 highly correlated items.

A total score, with continuous values from 1 to 5, of a 1-factor solution, was calculated with the nonrefined method of making a weighted sum score [35], with weights decided by the standardized factor loadings from the CFA. We decided not to use refined methods, such as regression scores or Bartlett scores, as a nonrefined method is more stable across samples [36]. The total score was used to delineate 5 different categories of 0.8 units each as the dependent variable in univariate ordinal logistic regression models [37]. This was done for evaluating associations between the social participation score and independent variables, such as gender and internet use frequency. Note that in such models, the magnitude of the β coefficients cannot be interpreted. Correlations between the social participation score and 3 other technical scores, TechPH ("an instrument for measuring older people's attitudes towards technology" [21]) and eHEALS ("measuring consumers' combined knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic health information to health problems" [38]), were also assessed, along with approximate *P* values. The first of the scores, consisting of two factors, was previously developed within our research group. Further validation of the score was made by evaluating correlations between the score (and the individual questions within the score) and other variables meant to measure neighboring (eg, usage of social networking sites) as well as diverse (eg searching of health-related information) quantities.

All statistical analyses were performed in SPSS (IBM Corporation) or R (R Foundation for Statistical Computing) software, using packages Psych, lavaan, REdaS, MASS, and Hmisc.

Results

Exploratory Factor Analysis

The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.91 for the complete data, and Bartlett test of sphericity was highly significant ($P<.001$). Thus it was appropriate to perform factor analyses.

A 1-factor solution for the social internet score was decided upon after the EFA (based on a random sample of half the data set). This was suggested by the bend in the scree plot, and also, only the first factor had an eigenvalue >1, although 3 factors were proposed based on the parallel analysis. However, it can be noted that the result from the parallel analysis was on the border of proposing a 1-factor solution: the eigenvalue for the second factor in the actual data was not much higher than that for the simulated or resampled data. When we inspected the factor solutions that had more than one factor, many items were cross-loaded on several factors, making the solutions difficult to interpret (Table 2).

Table 2. Two-factor solution with (standardized) cross-loadings from exploratory factor analysis on the sampled group (n=193).

Question	Factor 1 loadings	Factor 2 loadings
1. I think the internet helps me stay in touch with friends and family	0.36	0.66
2. I think the internet helps me keep up to date with what's happening in society	0.22	0.88
3. I think the internet makes me feel more included in society [a]	0.52	0.66
4. I think the internet makes me feel less lonely	0.68	0.35
5. I think the internet helps me to access meaningful activities	0.53	0.41
6. I think the internet helps me keep up my social network	0.7	0.42
7. I think the internet helps me reconnect to old memories and events of yesteryear	0.72	0.31
8. I think the internet helps me find pastimes and amusement	0.45	0.56
9. I think the internet helps me to expand and create new social networks	0.71	0.31
10. I think the internet makes me feel less isolated	0.84	0.26

[a]The questions that made it into the final instrument are indicated by italics.

The number of cross-loadings depends on which cutoff value to choose for item loadings to be kept within a factor. There is no general rule of thumb regarding this value, rather several different rules exist and have been reported in the literature [26,39,40]. To retrieve 2 factors without cross-loadings, a cutoff value of >0.52 would give such a solution. It can, however, be noted that Questions 3, 5, and 8 have similar loadings on both factors. Also, it is difficult to understand what the difference in theoretical construct between the 2 factors would be, given their included questionnaire items. Based on this, a 1-factor solution was decided upon. None of the questionnaire items were excluded based on the EFA (and the cutoff value for factor loadings was 0.5, the lowest value recommended by Hair et al [40]) as they all had high loadings, the lowest being 0.61 (Table

3). The Cronbach α coefficient was .92, and the 1-factor solution explained 55% of the variance.

Confirmatory Factor Analysis

A CFA was performed that included all 10 questionnaire items in a 1-factor solution (based on the second, nonsampled part of the data); the standardized factor loadings can be seen in Table 3). Results indicated that there is room for improvement based on the indices showing the goodness of fit of the model. After inspection of the model's MI values, it was found that some items had high correlations which could cause some of the model misspecifications. As the MI values represent score test statistics, by following a chi-square distribution of 1 degree of freedom, the values should be kept small if no model

misspecification were present. We used a stepwise procedure in which we removed 1 of the questionnaire items with the highest MI value (>10). When 1 item was removed, a new CFA was performed on which the new MI values were calculated. The problematic items were Questions 4 and 10 (MI=36.349), Questions 2 and 3 (MI=35.049), Questions 5 and 8 (MI=19.049), and Questions 1 and 6 (MI=11.589). Removing the questionnaire items with the lowest standardized factor loadings led to the exclusion of Questions 4, 2, 8, and 1. The removal of questions was agreed upon by medical and technical experts in the field. The standardized factor loadings in the CFA based on the 6 remaining questionnaire items are shown in Table 3.

Note that a parallel analysis (EFA) proposed a 1-factor solution for the 6 questionnaire items being left out of the 10 original ones.

Table 3. Standardized factor loadings from exploratory and confirmatory factor analyses for the 1-factor solution based on the original 10 questionnaire items and the chosen 6 items after exclusions. Based on the 2 different parts of the data: sampled (EFA) and nonsampled (CFA) groups.

Question	EFA[a] (n=193)	CFA[b] (n=193)	CFA with 6 items (n=193)
1. I think the internet helps me stay in touch with friends and family	0.69	0.58	—[c]
2. I think the internet helps me keep up to date with what's happening in society	0.69	0.59	—
3. I think the internet makes me feel more included in society [d]	0.82	0.73	0.69
4. I think the internet makes me feel less lonely	0.75	0.75	—
5. I think the internet helps me to access meaningful activities	0.68	0.78	0.75
6. I think the internet helps me keep up my social network	0.81	0.80	0.84
7. I think the internet helps me reconnect to old memories and events of yesteryear	0.75	0.80	0.80
8. I think the internet helps me find pastimes and amusement	0.71	0.72	—
9. I think the internet helps me to expand and create new social networks	0.75	0.80	0.84
10. I think the internet makes me feel less isolated	0.80	0.77	0.75

[a]EFA: exploratory factor analysis.

[b]CFA: confirmatory factor analysis.

[c]Not applicable.

[d]The questions that made it into the final instrument are indicated by italics.

Indices of goodness of fit of the model were improved for the 6-item model compared to the 10-item model. Following are the indices for the 6-item model: $\chi^2_6=13.985$; χ^2/degrees of freedom=1.554; CFI=0.992; RMSEA of approximation=0.054; SRMR=0.025).

The distribution of the social participation score among the 386 persons in the study is presented as means and fractions of participants receiving scores in 5 different ordered categories from 1 to 5, representing rounded score values of 1-1.8, 1.9-2.6, 2.7-3.4, 3.5-4.2, and 4.3-5, respectively (Table 4). Beta coefficients and P values from univariate ordinal logistic regression models, in which the categories 1-5 were used for the social participation score, are presented in Table 4.

Study participants with a medium level of education (finished secondary school, but without higher education except vocational training) had significantly lower social participation scores than did the participants with a low level of education (did not finish secondary school). A higher social participation score was also associated with more frequent use of the internet, as well as higher use of internet services.

Pearson correlation coefficients and approximate P values that compared the social participation score to the TechPH scores were divided into the factors TechEnthusiasm, TechAnxiety [21], and eHEALS [38], and were 0.480 ($P<.001$) for TechEnthusiasm; –0.159 ($P=.003$) for TechAnxiety, and 0.372 ($P<.001$) for eHEALS. Correlations comparing the social participation score (and its individual question items) to variables measuring a variety of internet-related quantities are presented in Table 5. The score is correlated to variables measuring, for example, whether the participant has been listening to web radio, participating on social networking sites, or following news reporting online. The score showed a lower or no significant correlation with health-related measures and no correlation with participation in online auctions or usage of Mobile BankID (Mobile BankID is an electronic identification solution in Sweden that allows companies, banks, organizations, and governments agencies to authenticate and conclude agreements with individuals over the internet).

Table 4. Distribution of social score among the study participants and associations between social score and independent variables presented as β coefficients from univariate ordinal logistic regression models.

Variable	Distribution, n (mean)	Fractions in categories 1-5	β value in ordinal logistic regression	P value
All	386 (3.05)	16, 21, 25, 23, 16	—[a]	—
Gender				
Men	186 (3.09)	17, 19, 23, 23, 19	Ref cat[b]	—
Women	200 (3.01)	15, 22, 27, 24, 13	−.15	.40
Age				
<75 years	195 (3.09)	13, 21, 28, 23, 15	Ref cat	—
≥75 years	191 (3.00)	19, 20, 22, 23, 16	−.14	.44
Education[c]				
Low	103 (3.24)	11, 22, 22, 20, 24	Ref cat	—
Medium	139 (2.88)	21, 19, 27, 23, 10	−.57	.01
High	124 (3.04)	15, 22, 23, 24, 15	−.29	.20
Internet use frequency				
Low	44 (2.3)	39, 30, 11, 14, 7	Ref cat	—
High	342 (3.14)	13, 20, 27, 24, 17	1.38	<.001
Use of internet services				
Low	55 (2.36)	42, 22, 15, 16, 5	Ref cat	—
Medium	240 (2.98)	14, 24, 28, 23, 12	1.15	<.001
High	91 (3.64)	5, 11, 23, 29, 32	2.27	<.001

[a]Not applicable.

[b]Ref cat: reference category.

[c]Education was categorized in three groups according to the previous Swedish education system, relevant for the age groups in this study: low, those who did not finish secondary school; medium, those who finished secondary school but no further education; high, those with some form of higher education.

Table 5. Pearson correlations between the social participation score (and its individual question items) to variables measuring a variety of internet-related quantities.

Item	Social sites[a], r	News and Media, r		Information[d], r	Activities[e], r	Economic utilities, r		Health utilities, r	
		Web radio[b]	News sites[c]			Mobile BankID, and other ID[f]	Buying and selling[g]	Web search[h]	EMR[i]
I think the internet makes me feel more included in society	0.291**	0.258**	0.313**	0.193**	0.179**	0.111*	0.046	0.169**	0.039
I think the internet helps me to access meaningful activities	0.189**	0.207**	0.152**	0.160**	0.168**	0.093	0.080	0.138**	0.104*
I think the internet helps me keep up my social network	0.366**	0.209**	0.207**	0.196**	0.109*	0.107*	0.031	0.090	0.102*
I think the internet helps me reconnect to old memories and events of yesteryear	0.264**	0.164**	0.204**	0.151**	0.157**	−0.029	0.038	0.095	0.067
I think the internet helps me to expand and create new social networks	0.401**	0.224**	0.199**	0.102*	0.166**	0.086	0.069	0.074	0.058
I think the internet makes me feel less isolated	0.266**	0.248**	0.230**	0.103*	0.104*	0.057	0.049	0.135**	0.110*
Internet social participation score	0.364**	0.264**	0.262**	0.182**	0.178**	0.084	0.063	0.140**	0.098

*Correlation is significant at $P<.05$ (2-tailed).

**Correlation is significant at $P<.01$ (2-tailed).

[a]Full question: Have you participated in social networking sites such as Facebook or Twitter and created a user profile and made posts or chatted?

[b]Full question: Have you been listening to web radio?

[c]Full question: Have you been looking at news sites?

[d]Full question: Have you been looking for information about products or services?

[e]Full question: Have you been playing or downloading games, pictures, movies or music?

[f]Full question: Have you been using Mobile BankID or any other electronic identification?

[g]Full question: Have you been selling goods or services through net auction sites like eBay?

[h]Full question: Have you been searching for information on diseases or treatments on official or private websites?

[i]Full question: Have you been looking at your electronic medical records (EMR) via an internet portal?

Discussion

Principal Results

We chose a 1D final factor structure for the social participation as supported by the scree plot but not entirely by the parallel analysis. However, in order to make the score user friendly, it was important to exclude factors with many cross-loadings, which otherwise would have led to difficulties in interpreting the underlying constructs. However, the 1D structure for the 6 final questionnaire items was supported by both the scree plot and the parallel analysis.

In removing the 4 questions (1, 2, 4, and 8), the loss of information was thought to be limited. By inspection of the questions, clear similarities can be seen in Questions 4 and 10 (feeling of loneliness and feeling of isolation), Questions 2 and 3 (being informed about society and taking part of society),

Questions 5 and 8 (access to meaningful activities and finding pleasure and amusement), and Questions 1 and 6 (keeping contact with friends and family and keeping up my social network). The goodness-of-fit indices were clearly improved after the simplification of questionnaire items.

The final instrument was shortened to 6 items in a 1-factor score, making it easy to use for any survey that measures digital social participation. It builds on social participation factors and has a multidimensional construct, incorporating both social relations and societal connectedness. Also, it focuses on the subjective feeling of social participation. This universal approach, unconnected to specific applications or services, suggests that its use will be able to compare different groups and examine changes over time.

The proposed digital social participation score showed no significant association with gender or age among older adults, thus demonstrating that it has the capacity to serve as a general

instrument. It complies well with assumptions about internet use: a higher social participation score is associated with more frequent use of the internet and higher use of internet services.

In different domains, the score correlates well with social internet activities and activities that promote social coherence and correlates poorly with more instrumental activities (eg, following news reports online or participating on social networking sites vs participating in online auctions or using Mobile BankID).

To conclude, we believe the proposed instrument can be used to measure digital social participation and coherence with society. The factor analysis is based on a sufficient sample of the general population of older adults in Sweden, and overall, the instrument performed as expected.

Whether it can be used to detect differences in outcomes such as loneliness, depression, or sense of coherence [41] needs to be shown in further studies. The instrument must also be validated in different contexts, such as in other populations and countries.

Limitations

Performing the final CFA on the data set that was used to redefine the theoretical model by the modification indices limited the validity of the goodness-of-fit measures. The social participation score should ideally be confirmed on another data set in a future study.

Acknowledgments

Conflicts of Interest

None declared.

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Abbreviations

CFI: comparative fit index
EFA: exploratory factor analysis
MI: modification index
RMSEA: root mean square error
SNAC: Swedish National Study of Aging and Care
SNAC-B: Swedish National Study of Aging and Care Blekinge
SRMR: standardized root mean square residual

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<u>Review</u>

Impact of the COVID-19 Pandemic on Older Adults: Rapid Review

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Abstract

Background: The COVID-19 pandemic has drastically changed the lives of countless members of the general population. Older adults are known to experience loneliness, age discrimination, and excessive worry. It is therefore reasonable to anticipate that they would experience greater negative outcomes related to the COVID-19 pandemic given their increased isolation and risk for complications than younger adults.

Objective: This study aims to synthesize the existing research on the impact of the COVID-19 pandemic, and associated isolation and protective measures, on older adults. The secondary objective is to investigate the impact of the COVID-19 pandemic, and associated isolation and protective measures, on older adults with Alzheimer disease and related dementias.

Methods: A rapid review of the published literature was conducted on October 6, 2020, through a search of 6 online databases to synthesize results from published original studies regarding the impact of the COVID-19 pandemic on older adults. The Human Development Model conceptual framework–Disability Creation Process was used to describe and understand interactions between personal factors, environmental factors, and life habits. Methods and results are reported following the Preferred Reporting Items for Systematic Reviews and Meta-analyses Statement.

Results: A total of 135 records were included from the initial search strategy of 13,452 individual studies. Of these, 113 (83.7%) studies were determined to be of level 4 according to the levels of evidence classification by the Centre for Evidence-Based Medicine. The presence of psychological symptoms, exacerbation of ageism, and physical deterioration of aged populations were reported in the included studies. Decreased social life and fewer in-person social interactions reported during the COVID-19 pandemic were occasionally associated with reduced quality of life and increased depression. Difficulties accessing services, sleep disturbances, and a reduction of physical activity were also noted.

Conclusions: Our results highlight the need for adequate isolation and protective measures. Older adults represent a heterogeneous group, which could explain the contradictory results found in the literature. Individual, organizational, and institutional strategies

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should be established to ensure that older adults are able to maintain social contacts, preserve family ties, and maintain the ability to give or receive help during the current pandemic. Future studies should focus on specific consequences and needs of more at-risk older adults to ensure their inclusion, both in public health recommendations and considerations made by policy makers.

Introduction

Background

Since the end of 2019, the SARS-CoV-2 outbreak has resulted in more than 71 million cases worldwide, as of December 16, 2020 [1]. Isolation and protective measures have been established by governments to varying extents around the world in order to mitigate the spread of the virus. These measures include physical distancing, use of face masks, handwashing, stay-at-home policies, and restrictions on social gatherings [2,3]. As a result, the general population has experienced drastic changes in day-to-day life [4]; high COVID-19–related fear [5]; and numerous psychological outcomes such as depression [6], increased sleep problems [7], and financial worries [8].

However, the extent to which the effects of COVID-19 reported by the general population are experienced by the aging population is not well documented. Isolation and protective measures are crucial for the aging population, who are at greater risk of COVID-19–related death [9]. However, isolation and protective measures may also amplify issues that are already present in older adults, such as loneliness, age discrimination, and excessive worrying [10-12]. Considering that physical distancing inevitably leads to some degree of social isolation, speculation towards the pernicious impact of physical distancing on the mental health, daily activities [12], and cognitive decline of older adults [11] is warranted. The COVID-19 pandemic may also amplify age discrimination by negatively impacting access to information, health care services, and support to informal caregivers and familial advocates [13,14].

According to the existing literature, although many older adults are now online [15,16], the majority still need assistance when using digital technologies and to access and assess information [17]. Furthermore, most vulnerable older adults do not have access to web resources or the required digital skills and knowledge for its use to be satisfying and efficient [15,18]. Digital technology is thus insufficient to reach vulnerable populations such as older adults [19].

The fear of contracting the virus could be an additional source of concern for this population, thus contributing to the overall anxiety—a mental health outcome already known to negatively affect the quality of life in older adults [10]. Thus, it is possible that the immediate and long-term effects of the COVID-19 pandemic are heightened for older adults as compared to other age demographics.

Since the beginning of the pandemic, there has been substantial concern surrounding older adults living in nursing home [20]. The percentage of nursing home residents with Alzheimer disease or other types of dementia is significant, reported to range between 45% and 75% [21-23]. It is possible that people with Alzheimer disease or other dementias are experiencing greater negative outcomes related to the COVID-19 pandemic.

A better understanding of the unique experiences of older adults during the pandemic is needed in order for governing bodies and health care providers to design adequate policies [13] and services as we advance. Therefore, data specific to the needs of older adults within the context of the present COVID-19 pandemic are urgently needed.

Objectives

The aim of this study is to synthesize the existing research on the impact of the COVID-19 pandemic, and associated isolation and protective measures, on older adults. Furthermore, we aim to investigate the impact of the COVID-19 pandemic, and associated isolation and protective measures, on older adults with Alzheimer disease and related dementias.

Methods

Protocol

Given the urgent need for adequate information, a rapid review protocol was chosen. This type of review is conducted using an accelerated systematic review method, which limits certain aspects of the methodology in order to provide evidence within a policy maker's timeframe [24,25]. This approach aligns with the available guidance for Cochrane Rapid Review Methods Group [25] and with the Practical Guide for Rapid Reviews to Strengthen Health Policy and Systems [26]. Methods and results are reported following the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) Statement [27]. The protocol for the present review was registered within the PROSPERO database (ID: CRD42020201814).

Conceptual Framework

The Human Development Model–Disability Creation Process (HDM-DCP) conceptual framework was used to describe and understand interactions between personal factors, environmental factors, and life habits [28]. The HDM-DCP model acknowledges the impact of the environment and the person on the execution of life habits. Personal factors include identity (facilitator or obstacle), organic systems (integrity or impairment), and capabilities (ability or disability). Environmental factors are stratified into societal (facilitator or obstacle), community (facilitator or obstacle), and personal (facilitator or obstacle) levels. Life habits consist of daily activities (social participation situation or disabling situation) and social roles (social participation situation or disabling situation). Each of these elements can be seen as a protective factor or as a risk factor for the individual. The HDM-DCP

framework allows observation of changes in these domains over a period of time (eg, the span of the COVID-19 pandemic). The framework puts into evidence social participation and social contacts, both of which may be greatly affected by pandemic-related isolation and protective measures.

Literature Search

Search strategies were developed by two authors (AL and NFB) and reviewed by two other authors (FR and ML). These strategies centered around three concepts: "COVID-19," "older adults," and "impact." The concept "COVID-19" was used to restrict the obtained results to those related to the present pandemic. According to the World Health Organization [29], older adults include people of 60 years of age and older. Therefore, in this study, the concept "older adults" included people aged 60 years and older, without excluding any diagnoses or conditions. The concept "impact" encompasses all three domains of the HDM-DCP model (ie, personal factors, environmental factors, and life habits) [28]. "Impact" variables can be reported by an individual, caregivers, family members, or health care workers, and may vary in the way that they are experienced or perceived. The following databases were used: MEDLINE via PUBMED; Embase, PsycINFO, and PsycARTICLES via Psycnet; and CINAHL and Ageline via

EBSCOhost. The searches were conducted on October 6, 2020. See Multimedia Appendix 1 for detailed search strategies used for each database.

Eligibility Criteria

The Population, Exposure, Comparator, and Outcomes (PECO) framework was used to develop the eligibility criteria used for the purposes of this review (see Table 1) [30]. Eligibility criteria were defined as follows: (1) peer-reviewed original papers with data related to our research question (opinion papers, reviews, methodological articles, preprints, and unpublished documents were excluded); (2) publication dates limited to 2019 and 2020, as the COVID-19 outbreak was first reported in 2019; (3) papers available in English or French; and (4) participants 60 years of age and older with any diagnosis except for COVID-19 survivors. The fourth criterion was applied in order to differentiate the effect of the pandemic from the physiological and health-related outcomes associated with a COVID-19 diagnosis. Furthermore, only papers that specified in the abstract the inclusion of older adults in the study were included. Outcomes that did not fit into the domains of the HDM-DCP framework (eg, knowledge about the spread of the disease) were excluded.

Table 1. Population, Exposure, Comparator, and Outcomes inclusion criteria.

Component	Description
Population (P)	People aged 60 years and older, excluding COVID-19 survivors
Exposure (E)	COVID-19 and its associated isolation and protective measures
Comparator (C)	Other age groups, before the pandemic, or none
Outcomes (O)	• Personal factors such as identity factors (facilitator or obstacle), organic systems (integrity or impairment), and capabilities (ability or disability) • Environmental factors such as societal (facilitator or obstacle), community (facilitator or obstacle), and personal (facilitator or obstacle) levels • Life habits such as daily activities (social participation situation or disabling situation) and social roles (social participation situation or disabling situation)

Study Selection and Data Extraction

Data retrieved from the databases were exported to Covidence [31]. Two reviewers independently screened the titles and abstracts of the obtained records. These reviewers then read the full text of the selected papers and determined whether they should be included. Any disagreement was resolved via consensus. Next, a single reviewer completed data extraction, which was then verified by another reviewer. The following variables were extracted: title, year of publication, country, study design, objectives, participant characteristics (eg, diagnosis and age), and outcomes. The references of the included papers were screened by the reviewers (one reviewer per study), and the titles and abstracts of additional papers were screened if relevant.

Level of Evidence Appraisal and Data Synthesis

Two reviewers established the level of evidence for each selected study, based on the levels of evidence classification of the Centre for Evidence-Based Medicine [32]. Due to the limited turnaround time, no risk of bias assessment was performed. A narrative approach consistent with the data synthesis of a rapid review [24] was used.

Results

Literature Search

The search strategy identified 19,053 records. A total of 13,452 records remained after duplicates (n=5601) were removed. Upon title and abstract screening, the number of papers reduced to 630, after the exclusion of 12,822 records. Thereafter, full-text screening resulted in a final inclusion of 135 records (Figure 1), following the exclusion of 495 others for various reasons.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) flow diagram.
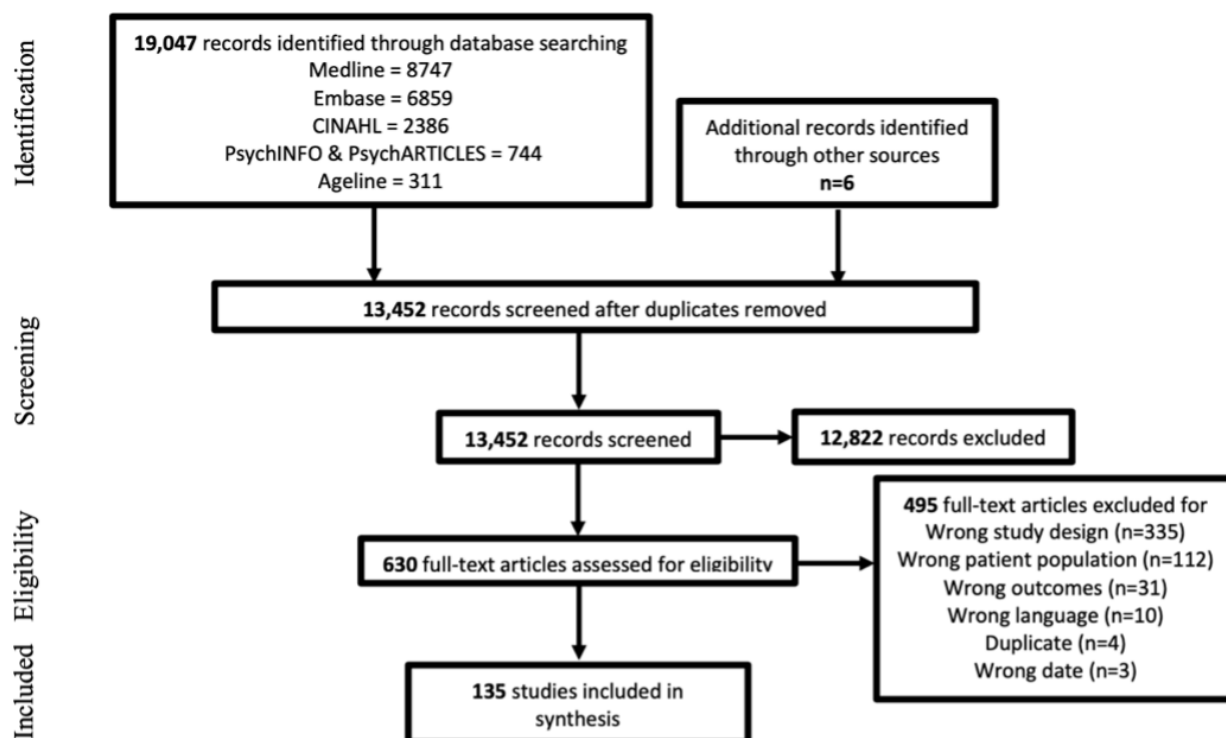
Characteristics of Included Studies

The selected records and their corresponding levels of evidence are shown in Table S1 of Multimedia Appendix 2. In all, 113 of 135 (83.7%) studies were determined to be of level 4 according to the Centre for Evidence-Based Medicine–Levels of Evidence [32] (transversal data collection), 20 (14.8%) studies were determined to be of level 2b (longitudinal studies), and 2 (1.5%) studies were of level 2b and level 4 (mixed study designs).

Of the 135 studies included, 40 (29.7%) studies included only older adults (≥60 years old) whereas 95 (70.3%) compared various age groups. Moreover, 15 (11.1%) studies included persons with specific conditions such as Alzheimer disease [33-35], Parkinson disease [36], frontotemporal lobar degeneration [37], severe cognitive impairments [38], ovarian cancer [39], gynecological cancer [40], patients with cancer actively treated with systemic therapy [41], pre-existing depression [42], chronic conditions [43], long-term respiratory conditions [44], migraine [45], epilepsy [46], and visual impairments [47]. A total of 29 (21.5%) studies were conducted in North America [40,42,43,48-73], 14 (10.3%) in China [46,74-86], 61 (45.1%) in Europe [33-38,41,44,87-139], 3 (2.2%) in Japan [140-142], 4 (3.0%) in Israel [143-146], 4 (3.0%) in Brazil [147-150], 4 (3.0%) in Australia [151-154], 2 (1.5%) in India [155,156], 1 (0.7%) in Malaysia [157], 2 (1.5%) in Kuwait [45,158], 1 (0.7%) in Saudi Arabia [159], 3 (2.2%) in Argentina [160-162], 1 (0.7%) in Cameroon [163], 1 (0.7%) in Russia [164], 1 (0.7%) in Ghana [47], 1 (0.7% in Cyprus [165], and 3 (2.2%) in multiple countries [39,166,167].

Outcomes of Included Studies

Personal Factors

Older adults reported a presence or worsening of psychological symptoms, and greater loneliness because of pandemic-related social isolation [33,38,47,49,51,52,56,57,62,63,77,78,84,89,90,99,105,114,117,128,135,139,140,148,156,160]. Compared to younger age, older age (ie, ≥60 years) was, however, associated with fewer psychological symptoms [39,44,50,54,57,59,64-67,74,77,89,95,97,98,101,107,109,111,114,116,120,121,124,125,127,136,138,147,151,153,157,158,161,162,165], lower loneliness [92,95,104,130,140,159], and better mental health and well-being [95,106,126,157,161,162]. Older adults were also shown to be better at regulating their emotions and coping with stressful events [44,61,68]. In contrast, 6 (4.4%) studies reported that older adults had more severe psychological symptoms than participants of other age groups [83,85,86,96,118,156], and some studies noted no psychological symptoms for most participants [42,79,119,165].

Several variables were associated with poor psychological health and well-being, including living alone [117], decreased social interactions [88], feeling close to death, high levels of COVID-19–related health worries [145], stress [70], health concerns and ageism [143], not having cognitive impairments [38], and male status [78]. In contrast, religious faith, exercise, self-care, and time spent in nature were associated with positive psychological well-being [70].

Various worries surrounding the current pandemic were reported in these studies [36,49,105,107,110,155]. For instance, older adults were more worried about COVID-19 [68,75,96,118,167], whereas younger individuals were more concerned about the

risks related to social isolation [164]. Older adults were less concerned for their emotional well-being, work goals, and finances [65], and they perceived they had lower chances of "running out of money" [53]. However, more worries about financial difficulties were reported in another study [164]. Older adults perceived the risks of COVID-19 (in comparison to that of the flu) to be higher [48,138], but aged men were less worried about COVID-19 (eg, contracting the virus, dying due to COVID-19, or disruptions to lifestyle) than their younger counterparts [48]. Their concerns were focused on others rather than themselves [144]. Anxiety associated with cancer was lower in older adults than in younger adults [41]. Expectations (eg, income decline, duration and long-term impact of COVID-19) were associated with an experience of stress, which was further associated with other negative effects [69]. Finally, the passage of time during the pandemic was found to be slower for older adults [115].

Regarding the impairment of organic systems, higher age was associated with poorer health status [80] and in some cases, a decline of functional status [163]. Decreases in mobility, functionality, vitality, and physical conditions were also noted [36,148]. An aggravation in neuropsychiatric and physical symptoms was reported in individuals with Alzheimer disease, dementia, and frontotemporal lobar degeneration, as well as in nursing home residents [34,35,37,93,139]. An exacerbation of migraine days and severity was observed among individuals with a migraine diagnosis [45]. One out of six older patients with epilepsy experienced increased seizures, but this frequency increased considerably among younger people with epilepsy [46].

Environmental Factors

Decreased social life and fewer in-person social interactions observed during the pandemic were occasionally associated with reduced quality of life and increased depression [42,63,128,139]. Some individuals continued to meet their relatives almost daily [36]. Furthermore, some studies reported on the negative impacts of the pandemic for caregivers [34,35].

Older adults reported unmet personal, domestic, or social needs [128]; difficulty finding help with functional needs such as bathing [62]; insufficient personal care [139]; decreased care rendered by caregivers [47]; and reductions in social support services hours [99]. Multiple barriers to care delivery were noted during this time [166]. For instance, one study reported that older adults were more likely to miss or cancel medical appointments [129], whereas another reported the opposite [60]. One study reported that treatment delays and postponed appointments were more common among older adults [130], whereas another reported this was more commonly observed among younger people [40]. More patients missed medical appointments during the pandemic as compared to the prepandemic timepoints [84,163], and rehabilitation services were discontinued for the majority due to the quarantine [160]. Finally, as compared to the previous years, psychiatry consultations for older individuals had reduced in one study [113] but reported to have increased in another [76].

Life Habits

Changes in sleep habits and sleep disturbances were reported to be affected by COVID-19 [37,56,84,87,105,134,160]. Of note, some studies indicated that sleep issues were lower in older adults than in younger adults [122,134,147].

Older adults reported a lower increase in unhealthy food intake, screen use, tobacco use [149], alcohol use [149,154], and cannabis use than did younger adults [123,152], in addition to a lower rise in unhealthy lifestyle changes or drinking [131]. One study indicated that the majority of older individuals consumed a balanced diet, limited their alcohol intake, and had adequate sleep patterns [82], whereas another study reported no change in alcohol use patterns [71]. This finding was contrasted by other studies that found that older adults increased binge drinking, alcohol frequency, alcohol consumption, and cigarette smoking [56,114,132]; changed their eating habits [132,148]; ate more [56,87]; and ate more often [87]. One study reported a higher consumption of unhealthy foods among older adults, as compared with participants of other age groups [149]. Food insufficiency increased in older adults during the pandemic, but to a lesser extent than that among younger adults [73], and decreased care resulted in hunger [47].

Changes in daily routine and plans were reported in a few studies [43,52,58]; however, one study noted no changes in the performance of daily habits among older adults [102]. Behavioral changes, such as buying more food and water than usual, going out less frequently, reducing social contacts, and staying away from public places were noted in several studies [36,47,58,146]. Unemployment increased in older adults, but at a lower rate than that in other age groups [72]. Higher age was associated with fewer sexual activities [108]. Some studies reported a decrease in physical activity [56,132,141,142,149] and a decline in attendance at physical activity workshops [133]. However, studies reported contradictory results regarding physical activity among older adults during the pandemic. Indeed, it was noted that older adults had the lowest levels of physical activity among all age groups [55,100]; however, they had the smallest decrease in physical activity [100], the lowest prevalence of insufficient physical activity [81] and were less likely to have changed their physical activity levels during the pandemic [137]. Moreover, physical activity was associated with higher resilience, positive affect, and lower depressive symptoms [94,141]. Older adults were also reported to have a lesser change in unhealthy movement behaviors [150].

A study indicated that a lot of time was spent learning about COVID-19 [87], and more time was spent using social media [56], internet [144], and electronic products [150]. One study reported a higher usage of electronic products by older people [149], whereas others reported contrasting findings [74,81]. Participants felt *blessed*, *lucky*, and *fortunate* to be able to stay in contact with others through social media [91]. Variation in game use by older adults did not differ from that observed in younger populations [167]. Older adults had fewer positive work events but more remote social interactions, social networks, and outdoor activities [65]. Finally, older adults engaged in more solitary activities and in fewer in-person activities [56].

One study reported that the majority of older adult travelers were planning to travel by air in the next year [103], whereas another found that older adults were canceling out-of-town trips [58]. The COVID-19 pandemic has presented significant challenges to most older adults [58], and compliance to hygiene recommendations was seen as a psychological burden by this population [148].

Discussion

Principal Results

Older adults are known to experience loneliness, age discrimination, and excessive worrying [10-12]. Therefore, we initially anticipated that they would experience greater negative outcomes related to the COVID-19 pandemic. However, this hypothesis was not uniformly supported by the available literature. The findings summarized within this review suggest that older adults experienced negative outcomes related to the pandemic, but to a lesser extent than their younger counterparts. Younger adults experienced greater psychological repercussions from isolation and feeling of loneliness [168]. There was indeed a correlation between young age and poor mental health [126], higher anxiety, depression, and stress [153]. This result may be explained by the daily experience of loneliness and social isolation among older adults prior to the pandemic [12], which in turn meant that COVID-19 led to fewer changes in their daily routine as compared to employed, younger adults. Another potential explanation is the influence of certain personal factors among older adults, for example, greater resilience that is associated with more purpose in life [112], better regulation of emotions, and better coping strategies in the case of stressful events [44,61,68]. These personal factors could explain the generally better psychological response by older adults throughout the COVID-19 pandemic. Additionally, these findings may be explained by sampling methods used in the available research. In other words, the isolation measures implemented in long-term care facilities may have caused additional barriers to conducting studies with residents. In our study sample, 16 (11.8%) studies were conducted among community dwelling older adults, 3 (2.2%) included older adults living in residential care facilities, 3 (2.2%) included older adults living in one of these two locations, and 113 (83.7%) studies did not detail this sampling information. Without uniform sampling methods, it is more difficult to draw strong conclusions. Older adults may have little to no access to technology [169], such as a computer or a smartphone, which are often required to participate in web-based surveys. The most isolated individuals may be the most difficult to reach, particularly if they lack access to social media or maintain minimal presence in public and community organizations—platforms often used by researchers to contact participants. Fewer opportunities to participate in surveys may explain the relative scarcity of research on vulnerable older adult populations, such as those with dementia or Alzheimer disease, during the present pandemic. In studies that compared different age groups, the proportion of aged individuals was often very small compared to other age groups. It is possible that the older adults who participated in surveys were healthy and had access to technology and, therefore, were not the most

vulnerable. This could explain why certain studies suggested that younger people were more impacted than older adults.

One study reported that anxiety symptoms in older adults were associated with ageism [143], something that the current pandemic seems to have exacerbated [170]. The COVID-19 pandemic has been characterized as an older adult problem, and social media, among other platforms, have been used by people to share ageist attitudes (eg, posts published with the hashtag "BoomerRemover") [171-173]. Greater awareness of age discrimination is needed to reduce these behaviors. There are other potential sources of anxiety among older adults, such as being unable to access support services since the onset of the COVID-19 pandemic [99]. More research is needed to understand the impact of ageism on older adults' well-being, as compared with other risk factors.

The impact of the pandemic on older adults can also influence their caregivers [34,35]. Indeed, family caregivers reported living with anxiety and fear [174] and having difficulty balancing caregiving challenges with their own needs [175] during this crisis. It is therefore important to consider the needs of the caregivers in future policies and in the implementation of isolation and protective measures.

The available literature offered different strategies for maintaining the well-being of older adults; these included using technology to ensure social connections, pursuing outdoor activities, and incorporating daily structure [176]. Different programs were also deployed during the pandemic with the aim of reducing social isolation through contact with a student volunteer who engaged in weekly phone calls with participants living in nursing homes [177] and a single call with participants living in long-term care facilities and in the community [178]. The use of technology to protect and improve mental health [179] and to maintain the health and independence [180] of older adults during this crisis was also discussed. The transformation of an on-site program into an online program for older populations [181] was found to be effective. Innovative programs should therefore be created with the goal of supporting vulnerable older adults and minimizing the long-term consequences and feelings of loneliness.

Physical activity should be promoted during the pandemic, especially for more at-risk individuals such as those living with chronic diseases [182]. Older adults should be guided to safe and accessible physical activity programs, selected according to the individual's level of autonomy, mobility, frailty, and health status, to avoid deconditioning during confinement. Physical activity is associated with a better quality of life [183] and decreased symptoms of depression in older adults [50], whereas increased inactivity could accelerate their physical decline [184]. Personalized physical activity programs with monitoring should therefore be made more accessible to this population to minimize deconditioning and help older adults maintain their physical and mental health, while ensuring their safety.

The secondary impacts of COVID-19 should be considered by governing bodies and institutions when taking action and making decisions about health care access and public health measures, both during the current pandemic and for future health crisis.

Mental health concerns have been reported among older adults [185], but few concrete actions have been taken to mitigate them.

Strengths and Limitations

Some studies classified older adults as including people below 60 years of age (eg, ≥50 years) [186-188]. Those results were excluded, along with potentially important data, to respect our eligibility criteria and to clearly differentiate the outcomes relative to older versus younger populations. Moreover, some studies focused on older adults with specific conditions, for example, Parkinson disease [36], cancer [39,40] or Alzheimer disease [33], which makes it difficult to differentiate the effects associated with their age from those associated with their condition. These studies were still analyzed, keeping in mind that individuals living with a variety of diagnoses are potentially more vulnerable to encounter negative outcomes related to the secondary effects of COVID-19. Some diagnostic keywords were selected because of the relationship between specific neurological conditions and higher age (eg, dementia and Alzheimer disease). This selection may have resulted in the omission of eligible studies that include older adults with other conditions such as cancer or cardiovascular diseases. However, a limitation in the selected keywords was needed to screen studies within a reasonable timeframe. In addition, the decision was made to exclude studies about COVID-19 survivors, because of the various physical and psychological changes that may be associated with the incidence of this condition. Contradictory results could also be attributable to the variance in health care systems and differences in isolation and protective measures implemented in various countries. Because of constant changing measures across countries, it would have been difficult, if not impossible, to analyze data in such a way. This aspect was, therefore, not considered in our data analysis in order to provide results in a reasonable timeframe. Future studies should take into consideration the country-specific variation in COVID-19 responses. Moreover, it is also possible that the sample age was not mentioned in the abstract or the title of the published papers, which would have resulted in the exclusion of the study during the first stage of screening.

Implication for Practice and Policy

Results obtained through this rapid review have highlighted the presence of psychological symptoms, decrease in social interactions, exacerbation of ageism, and the deterioration of physical conditions among older adult populations during the COVID-19 pandemic. It is essential that governing bodies and decision makers understand the needs of older adults when making choices regarding the implementation of social distancing measures. They should carefully choose their words when describing this pandemic, to avoid any form of age discrimination in the media.

Older adults represent a heterogeneous group, which could explain the contradictory results found in the sampled literature. Sample demographics should be considered in future studies to identify variables within older adult populations that could be associated with a poorer overall experience with the pandemic, and stronger conclusions could then be made. Indeed, studies that specifically target vulnerable age groups, such as adults living in rural areas [189] and deaf individuals [190], should be conducted to minimize the effects and long-term consequences in such populations. The impact of COVID-19 should be assessed separately according to various living environments in order to identify more at-risk individuals (eg, older adults in the community setting versus long-term care facilities). Future studies should also analyze different protective and risk factors among older adults. For example, it would be interesting to compare the effect of living alone versus living with others, of being in the younger range of the older adult demographic (eg, 60 years old) versus being in the latter range (eg, 85 years old), or of living independently at home versus living in a nursing home. Moreover, the general population could learn from older adults, regarding their resilience, regulation of emotions, and coping strategies, to improve their psychological response during this pandemic. Individual, organizational, and institutional strategies should be established to ensure that older adults are able to maintain social contacts, preserve family ties, and maintain the ability to give or receive help during this pandemic. The effectiveness of various strategies, such as making communication technologies more accessible, providing technology use training, and promoting technological innovations, should also be assessed to enable social interactions despite isolation and protective measures.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategies.
[DOCX File , 23 KB - aging_v4i2e26474_app1.docx]

Multimedia Appendix 2
Table S1. Synthesis of the 135 selected studies and their level of evidence.
[DOCX File , 113 KB - aging_v4i2e26474_app2.docx]

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Abbreviations

HDM-DCP: Human Development Model–Disability Creation Process
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-analyses

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