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Editorial

Mitigating the Effects of a Pandemic: Facilitating Improved Nursing Home Care Delivery Through Technology

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Abstract

The coronavirus disease (COVID-19) pandemic has been particularly challenging for nursing home staff and residents. Centers for Medicare & Medicaid Services regulation waivers are burdening staff and affecting how care is delivered. Residents are experiencing social isolation, which can result in physical and behavioral health issues, particularly for persons with dementia. These challenges can be addressed in part through technology adaptations. Full integration of electronic health record systems can improve workflow and care quality. Telehealth can improve access to outside providers, provide remote monitoring, and improve social connectedness. Electronic and audiovisual programs can be used for end-of-life planning and information sharing between nursing home staff and families. Online learning systems and other online resources provide flexible options for staff education and training. Investing in and adapting technology can help mitigate workforce stress and improve the quality of nursing home care during and after the COVID-19 crisis.

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nursing home; technology; social isolation; covid-19

Introduction

The coronavirus disease (COVID-19) pandemic has placed unprecedented strain on the US health care system, and the possibility that it could become endemic—meaning it will be a common dweller that regularly infects humans—suggests that this strain will persist for some time. As COVID-19 cases accelerate, health care workers are becoming more vital than ever, and they are rightly being hailed as heroes for their generous, brave dedication to caring for patients at the risk of their own health. Providing these heroes with resources to safely deliver high-quality care to their patients and themselves is imperative not only in acute care settings such as emergency

rooms and intensive care units (ICUs), but also in nursing homes, where staff provide care for vulnerable older adults in settings that are at risk for infectious disease outbreaks. Nursing home staff face unique challenges during the COVID-19 pandemic because they care for older adults with a high level of vulnerability to COVID-19 and experience constraints that far exceed those imposed in acute care settings. Telehealth strategies, automatic clinical decision-making reports, and other uses of technology commonly found in other care settings hold great promise to improve nursing home care and outcomes.

By 2030, almost 1 in 5 Americans will be 65 years or older [1], and today, >1.3 million people live in 15,600 nursing homes

[2]; in society, these people are some of the most frail and vulnerable to viral infections such as COVID-19 because they are older, have other medical conditions such as heart and respiratory disease, and live in group settings. US nursing homes are familiar with disease outbreaks, including seasonal influenza and norovirus; although COVID-19 shares similarities with these outbreaks, it will be more devastating because there are no approved therapeutics to slow the course of its toll on the human body and because there is currently no vaccine available to combat it.

Because of these vulnerabilities, nursing homes were early reporters of positive COVID-19 cases. The first reported COVID-19 death in the United States was a nursing home resident in Kirkland, Washington, reported on February 28, 2020. Nursing homes across the country and the Centers for Medicare and Medicaid Services (CMS) acted quickly; by March 13, 2020, they enacted guidelines to protect nursing home residents, including barring visitors and adding infection control measures that restrict communal activities, essentially isolating residents in their rooms. Despite these measures, COVID-19 infections spread quickly between nursing home residents and staff. As of April 29, 2020, more than 2700 Medicare-certified nursing homes across the country (1 in 6 facilities) acknowledged infections in residents or staff, and in some states, a majority of nursing homes have reported COVID-19 cases [3]. Nationally, COVID-19 death rates are higher for nursing home residents, who account for over half of deaths in some states [4].

Currently, nursing homes continue to battle COVID-19 infections among residents and staff, which is challenging how nursing homes provide care to our most vulnerable older adults. In addition to preventing the spread of COVID-19 within nursing homes, it is now necessary to plan for the admission of patients who were hospitalized with COVID-19 and are too debilitated to return to their homes. The recovery trajectories and continued health care needs of these patients are uncharted; however, increasing evidence points to long-term post-COVID-19 complications that may increase the complexity and length of rehabilitation [5].

During the COVID-19 pandemic, there has been much focus on personal protective equipment (PPE), the lack of testing and supplies, and the need for infection control training; however, this pandemic has also highlighted problems that nursing homes were already facing, such as frequent staff shortages and high turnover. It is important to take this opportunity to increase awareness of other aspects of care delivery within nursing homes that have been affected by the pandemic. These aspects of care delivery can be enhanced by leveraging strategies such as technology used in other areas of the healthcare system to improve nursing home care both now and in the future.

What challenges and issues do nursing homes face?

COVID-19 has presented unique challenges and highlighted ongoing issues faced by nursing homes in providing effective, compassionate, and safe care for vulnerable older adults in an

institutional home setting. While the strict regulatory controls currently in place for nursing homes have likely prevented further spread of COVID-19 and subsequent deaths, nursing home staff are being challenged with new work patterns, longer hours, and the need to find new ways to communicate with families. These measures pose additional risks for nursing home residents, such as isolation, which limits their mobility and social interactions. Furthermore, family members are not able to visit their loved ones, which can be particularly devastating when residents have dementia or are at end-of-life. Together, residents, families, and nursing home staff are facing unprecedented stress as they navigate these challenges and their own fears about the virus.

Impact of CMS Regulations on Care Delivery

Prior to COVID-19, the nursing home industry was highly regulated by CMS, which partners with state survey agencies to monitor every Medicare-certified and Medicaid-certified nursing home for safety and quality. Many of these challenges are related to CMS regulations on how nursing home care is delivered.

Regulation Waivers

During the COVID-19 pandemic, CMS has provided nursing homes with flexibility to decrease COVID-19 infection risk, emphasizing resident care over paperwork [6]. These waivers impact physical building requirements and relax minimum data set and staffing data submissions. Resident admission and discharge planning requirements are being waived. Quality assurance and performance improvement (QAPI) requirements are now focused on adverse events and infection control. Certified nursing assistant (CNA) certifications and annual in-service training requirements are being waived. Physicians can delegate any tasks and visits to physician assistants, nurse practitioners, or clinical nurse specialists who are acting within state scope of practice laws. Telehealth regulations have been relaxed, and billable physician visits can be conducted via telehealth, including telephone visits. Staying abreast of evolving CMS, Centers for Disease Control and Prevention (CDC), and state regulations and guidelines is challenging for an already stressed workforce. In particular, implementing new and difficult infection control guidelines, such as stopping congregant activities and preventing families from visiting their loved ones, is particularly stressful for staff, who recognize the impact on residents' general health and quality of life.

Staffing and Workforce Issues

Nursing home staff, including nurses, physical and occupational therapists, social workers, and direct care workers, often work at several different facilities; this increases the risk of acquiring and spreading COVID-19 between facilities, especially since many people who are positive for COVID-19 do not show outward symptoms. As the virus spreads among staff and residents, large numbers of nursing home personnel are remaining at home, contributing further to often pre-existing staff shortages. Some nursing homes must rely on agency staff at the risk of inconsistent care delivery and documentation. The relaxed CMS regulations support the hiring of new CNAs to fill vacancies; however, due to the lack of training requirements,

more staff are unprepared to work with nursing home residents during the pandemic. Further, staff must adjust to workflow changes resulting from residents being confined to their rooms and the added time required for implementing infection control practices. The negative impact of social isolation on the physical and mental health of residents further contributes to staff stress, particularly in the face of the probable endemic nature of COVID-19.

Infection Control Constraints

Nursing homes must ensure that they are adhering to infection control guidelines issued by a number of CDC, CMS, state, and local regulatory bodies [7]. New guidance and regulations are announced frequently and often appear to contradict those of other agencies. Every individual entering a nursing home must be screened for COVID-19 symptoms, and every resident must have their temperature checked daily [8]. Staff must wear masks the entire time they are in the nursing home, and if there are residents with COVID-19, full PPE must be worn when working with any resident [7]. Residents should wear masks when any staff member is in their room. These measures increase the time and difficulty of working with residents, increasing the difficulty of person-centered care and increasing the stress on staff and residents alike.

Impact on Residents

Under COVID-19 restrictions, nursing homes are closed to everyone but essential health care providers and staff. Congregant activities, including meals, are not allowed, and residents are mainly confined to their rooms. The consequences of isolation on the physical and mental health of nursing home residents will not be known for some time. However, anecdotal reports from staff and families suggest that residents' health is declining rapidly as a result of COVID-19 isolation. Below, we discuss several areas of particular concern.

Social Isolation

Because COVID-19 regulations prevent outside visitors and congregating of nursing home residents, the residents are socially isolated from each other and from family and friends. Social isolation itself is associated with increased loneliness, which has been associated with a plethora of behavioral and physical health issues, including increased depression and anxiety, increased risk of falls and hospitalization, and even death [9]. Residents living with dementia face particular challenges, as they often cannot understand why their routines are being disrupted and their activities curtailed. These disruptions, in addition to the lack of visitors who are often able to calm cognitively impaired residents, can result in a host of behavioral symptoms that staff have less time to address. Short-term consequences of social isolation are being reported anecdotally from health care providers, nursing home staff, and family members; these consequences include rapid decline in function and health (eg, dehydration, renal problems, and malnutrition), hopelessness and severe depression, and increases in suicidal ideation [10].

Increased Pressure Injury Risk

Nursing home residents are at increased risk for pressure injuries because they already have limited mobility and are now being

confined to their rooms. Residents will spend more time sitting or lying down; this increases the intensity and duration of pressure exposure, which are two factors that lead to pressure injury development [11]. The use of prone positioning in COVID-19 treatment further increases risk of pressure injuries, particularly on the face [12].

Increased Hospitalization Risk

As residents spend more time in their rooms, they are at risk for physical deconditioning, malnutrition (due to a lack of shared meals or assistance with eating), and depressive symptoms, all of which increase risk of hospitalization [13,14]. Dehydration and its associated risk of urinary tract infection and renal problems is also a concern due to the lack of shared meals and, potentially, to decreases in the amount of time staff have available for offering and encouraging oral hydration [15].

How can technology be leveraged to improve the care nurses deliver and keep nurses and residents safe?

Electronic Health Records

Electronic health record systems have been used in other health care settings to improve workflow and quality of care; however, full integration has been slower in nursing home settings. Enabling all nursing home staff to access and document records electronically provides an opportunity for real-time communication between staff members. However, many nursing homes only have computers at central nursing stations that are distant from resident rooms. For electronic charting to be efficient, adaptation of mobile charting platforms is needed, such as the use of tablets or point-of-care mobile workstations. The pandemic has also greatly stimulated the need to increase use of electronic medical record systems to collect data and use them for clinical decision-making in nursing homes. Several potential technology solutions are proposed below.

Standardized Documentation and Real-Time (On-Time) Reports to Improve Quality of Care

One example of successful implementation of health information technology is the On-Time Quality Improvement for Long Term Care (On-Time) program to decrease high pressure ulcer incidence rates in nursing homes [16-19]. Working with front-line staff, including CNAs, nurses, and dietary staff, project facilitators evaluated, streamlined, and designed standardized CNA documentation that incorporated best practice elements into daily charting. The goal was to facilitate consistently good preventive care using the daily information nurses need to target resources to residents at risk of developing pressure ulcers. The developed tools included a documentation form, a documentation completeness report, and four additional weekly clinical decision-making reports that helped identify residents at risk.

Development and testing were followed by incorporation of the On-Time tools into more than 10 different long-term care electronic medical record systems. Using electronic medical records to implement On-Time standardized documentation and clinical decision-making reports in nursing homes resulted in

enhanced quality improvement (QI) efforts; focusing staff on high-risk residents, improving team communication, and prompting timely interventions; providing a clear and practical process to maximize the role and contribution of CNAs in pressure ulcer prevention; and increasing CNA engagement with QI by showing them how their documentation, summarized in clinical reports, is used as a basis for proactive clinical decision-making. An evaluation of the On-Time Pressure Ulcer Prevention Program in 12 New York State nursing homes (3463 residents) found a large and statistically significant reduction in pressure ulcer incidence associated with the joint implementation of the four core On-Time reports [20-22].

Telehealth

Telehealth encompasses a broad range of electronic information and telecommunication technologies to support long-distance clinical health care and related activities through videoconferencing, internet-based applications, store-and-forward imaging, streaming media, and telephone-based services [23]. Telehealth approaches to improve care access and outcomes among older adults have been extensively studied and are associated with high degrees of patient and caregiver satisfaction [24]. Nursing home professional organizations such as LeadingAge have developed guidance regarding how to evaluate telehealth applications for use in long-term care [25]. Enhanced use of telehealth holds great potential to reduce burden on nursing home staff, enhance integration of specialty expertise care of nursing home residents, and enrich connections with family and friends, enhancing social connection during required physical distancing. For example, in acute care settings, use of tablets or telepresence robots has allowed staff to interact more with patients while reducing the duration of contact and use of PPE [26]; these devices have also been found to be acceptable to older adults [27]. Likewise, telehealth interventions connecting cardiologists to skilled nursing facility residents permit more frequent monitoring without direct visits and have been shown to reduce rehospitalization following heart failure [28].

Nursing homes should consider adopting telehealth approaches that have been successfully used in other health care settings to help keep nursing home residents safe and facilitate social connection while observing physical distancing. The Electronic Intensive Care Unit (eICU) uses two-way cameras and video monitors connected to a central hub for remote monitoring and care delivery [29]. Although this technology is primarily used for monitoring physiological processes, eICU staff also provide social support and “rounds” for patients to identify any unmet needs, which they communicate to ICU nurses. A similar process could be implemented in the nursing home setting, where video-enabled rounds, especially for residents who have tested positive for COVID-19, would allow staff to avoid donning and doffing PPE and enhance nursing home residents’ ability to express their needs and to experience regular human contact, albeit virtually. Video contact is particularly beneficial for residents with hearing impairment who rely on visual cues and mouth movements that are obstructed by PPE such as masks. Video-enabled rounding could also be used during mealtimes for residents who require prompting to eat and drink or for residents who simply desire company during meals.

Several barriers to expanded use of telehealth in nursing homes merit attention. First, older adults may be less familiar with tablets or mobile phones and may require initial face-to-face orientation to a new platform [30]. Use of tablets with “one-touch” connection features that permit adjustments of font size or volume and accommodate the use of device holders to compensate for arthritis or upper extremity weakness are recommended [31].

Using Technology in End-of-Life Care Planning

Now more than ever, information sharing between nursing home providers and staff, residents, and family members is particularly important at end-of-life to ensure resident preferences are respected. Since 2016, Medicare has reimbursed providers for formalized advance care planning discussions that can be conducted by telehealth visits [32]. Advance directives and other end-of-life documentation, such as the POLST (Physician Orders for Life-Sustaining Treatment), are useful in helping families and surrogates make decisions that are in keeping with the wishes of the dying resident and can guide the actions of nursing home staff. However, family members are often unaware of what was documented. Recent research has demonstrated that technology can be used to bridge this gap. An example is the use of Me & My Wishes videos of residents’ preferences for daily and end-of-life care that can be shared with designated family members and nursing home staff [33]. While filming and editing videos of nursing home residents discussing end-of-life preferences is likely not feasible during the COVID-19 pandemic, real-time discussions between residents, family members, and providers using tablet or smartphone technology are possible and would help ensure that care preferences are met. iPads are facilitating end-of-life conversations between hospitalized COVID-19 patients and family members [34] and could be used similarly in nursing homes both for decision-making and to allow families to say goodbye to loved ones.

Access to Technology to Promote Social Interaction

In addition to telehealth technologies, videoconferencing and tablet-based applications have been used to enhance social interaction among nursing home residents and family [35]. However, wide adoption has been impeded by limited wireless access within facilities as well as by financial limitations on access to devices [36]. ICU diaries, many of which are free or inexpensive, may have a role in the nursing home setting to facilitate communication during periods of physical/social distancing. These diaries are routinely used in hospitals to assimilate care information and to allow families and friends to maintain a connection, resulting in decreased anxiety and depression among ICU survivors and less posttraumatic stress in survivors’ families [37]. In addition to clinical information, ICU diaries include details about events occurring at home and in the community, enabling patients and their families to stay abreast of each other’s lives during periods of social distancing [38]. To make the above technologies available to residents who have mobility and sensory impairments, simple “hacks” to telemedicine equipment, such as placing monitors on flexible stands so that they can be moved in front of residents regardless of whether they are sitting, reclining, or lying in bed, could keep

this technology in reach of residents. Devices such as Apple TV can enlarge smartphone or tablet screens for easier viewing. Ensuring that hearing aids and eyeglasses are available should enhance older adults' ability to communicate with a wider array of friends and family.

Technology to Support Staff Education and Training

Relaxed guidelines for CNA training, the need to train new or agency staff quickly, and the increased workloads faced by nursing home staff increase the need for staff education and training. Technology can be leveraged to address these challenges and to avoid bringing staff together for training. Some nursing homes are already using learning management systems for staff training. Other online educational modules and training videos from reputable sources such as the CDC, health systems, and professional organizations can also be used. For example, training on donning and doffing PPE is needed, and demonstration videos that provide this training are available from a number of sources. The CDC recommends that nursing homes have a staff member available for every shift to monitor PPE use; this staff member could assess and approve staff

members' PPE use. Almost all of these online training programs can be accessed on a smartphone or tablet, which can help staff complete required training.

Conclusion

The unprecedented challenges of the COVID-19 pandemic place particularly great burdens on nursing home staff who are unfairly stigmatized and had the fewest resources in prepandemic times. At the same time, the dedication and sacrifice of the majority of nursing home staff go unnoticed. Today, more than ever, it is important that we support nursing home staff, particularly those providing direct care such as nursing, dietary, social, therapy, pharmacy, and custodial services, to our most vulnerable older adults in their time of greatest need. Technology presents opportunities to address the challenges these staff members are currently facing. We owe increased support to vulnerable older people and those who care for them, and we call for an investment in technology and other resources to support older people and their caregivers during the pandemic.

Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
CMS: Centers for Medicare & Medicaid Services
CNA: certified nursing assistant
COVID-19: coronavirus disease
eICU: electronic intensive care unit
ICU: intensive care unit
POLST: Physician Orders for Life-Sustaining Treatment
PPE: personal protective equipment
QAPI: quality assurance and performance improvement
QI: quality improvement

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Short Paper

Impact of Home Quarantine on Physical Activity Among Older Adults Living at Home During the COVID-19 Pandemic: Qualitative Interview Study

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Abstract

Background: Older adults and those with pre-existing medical conditions are at risk of death from severe acute respiratory syndrome coronavirus 2 (SARS CoV-2). In this period of quarantine, one of the reasons for going out is physical activity. This issue is important, as the impact of a sedentary lifestyle might be lower for children and young adults, but is far more severe for older adults. Although older adults need to stay at home because they have a higher risk of coronavirus disease (COVID-19), they need to avoid a sedentary lifestyle. Physical activity is important for older adults, especially to maintain their level of independence, mental health, and well-being. Maintaining mobility in old age is necessary, as it may predict loss of independence in older adults.

Objective: Our first objective was to evaluate the impact of this quarantine period on physical activity programs and on the physical and mental health of older adults. Our second objective was to discuss alternatives to physical activity programs that could be suggested for this population to avoid a sedentary lifestyle.

Methods: We conducted a qualitative survey using semistructured interviews with professionals (managers in charge of physical activity programs for older adults and sports trainers who run these physical activity programs) from the French Federation of Physical Education and Voluntary Gymnastics (FFPEVG) and older adults participating in a physical activity program of the FFPEVG. We followed a common interview guide. For analysis, we carried out a thematic analysis of the interviews.

Results: This study suggests that the COVID-19 epidemic has affected, before quarantine measures, the number of seniors attending group physical activity programs in the two study territories. In addition, despite the decline in their participation in group physical activities before the quarantine, older adults expressed the need to perform physical activity at home. There is a need to help older adults integrate simple and safe ways to stay physically active in a limited space. A national policy to support older adults for physical activity at home appears essential in this context.

Conclusions: Given the results of our study, it seems necessary to globally communicate how important it is for older adults to maintain physical activity at home. We are concerned about the level of independence and mental health state of older adults after the end of quarantine if there is no appropriate campaign to promote physical activity among them at home.

KEYWORDS

older adults; physical activity; COVID-19; social marketing

Introduction

After nearly 2 months of quarantine, France has approximately 132,000 people infected with coronavirus disease (COVID-19) and more than 25,000 deaths [1]. Older adults and those with pre-existing medical conditions are at risk of death from severe acute respiratory syndrome coronavirus 2 (SARS CoV-2) [2]. Studies agree that we are only at the beginning of an unprecedented health crisis affecting the population and especially older adults [3-5].

In this period of quarantine, one of the reasons for going out is physical activity [6]. However, this measure has been debated because it could lead to quarantine violation. This issue is important, as the impact of a sedentary lifestyle might be lower for children and young adults, but is far more severe for older adults. Although older adults need to stay at home because they have a higher risk of COVID-19 infection, they also need to avoid a sedentary lifestyle.

Physical activity is important for older adults, especially to maintain their level of independence [7], mental health, and well-being [8]. Physical inactivity among older adults is the fourth highest risk factor for mortality worldwide and a major contributor to disability [9]. Among people who do not engage in regular physical activity, the risk of functional decline is higher [10]. Maintaining mobility in old age is therefore necessary, as it may predict the loss of independence in older adults [11]. Insufficient physical activity during the quarantine period can therefore have deleterious effects on the mental and emotional health of older adults [12].

Our first objective was to evaluate the impact of this quarantine period on organizations conducting physical activity programs and on the physical and mental health of older adults. Our second objective was to discuss alternatives that could be suggested to this population to avoid a sedentary lifestyle.

Methods

Overview

We conducted a qualitative survey using semistructured interviews with professionals (managers in charge of physical activity programs for older adults and sports trainers who run these physical activity programs) from the French Federation of Physical Education and Voluntary Gymnastics (FFPEVG) and older adults participating in a physical activity program of the FFPEVG. We followed a common interview guide ([Multimedia Appendices 1 and 2](#)).

The interviewees were sports trainers and older adults who were participating in the Social Marketing and Physical activity in Elderly (SMAPE) study [13]. The main objective of the SMAPE study was to determine whether a social marketing program based on the promotion of group balance workshops for people aged 60 years and over increases their attendance rate in sessions

of “activities adapted physical skills.” This study was conducted in two French departments (Loire-42 and Haute-Loire-43). The FFPEVG organizes these group physical activity programs. The SMAPE study was suspended because of the quarantine implemented in France.

Data Collection

We asked the professionals about the impact of COVID-19 and quarantine on physical activity workshops and alternatives they could suggest. We also interviewed older adults about the importance they place on the physical activity before and during the quarantine and whether they were aware of other tools to continue physical activity at home. For analysis, we carried out a thematic analysis of the interviews.

Results

For this study, 8 professionals (with different professional roles) and 6 older adults participated. The professionals responded unanimously that because of the COVID-19 epidemic, attendance at physical activity workshops has declined. Three sports trainers estimated the drop in attendance by “about 20%, but it’s hard to tell because it’s uneven across the different workshops.” A majority also informed us that some participants “no longer wanted to have close contact” with the other participants and “no longer wanted to touch the equipment.”

Older adults who were no longer attending the workshops preferred to abstain from these workshops to avoid contact with other participants and potentially contracting COVID-19. A majority of the professionals told us that there was also influence from the families of these older adults, who, despite interest in such group physical activity, did not want their close ones to risk exposing themselves to the virus.

Following the first announcement to contain COVID-19 propagation in France, the medical commission of the FFPEVG decided to cancel all physical activity workshops held in its clubs until further notice. Professionals expressed concern that shutting down these activities could isolate some seniors, many of whom live alone and often away from their families:

I'm in the countryside, my husband died two years ago, so I don't want to do much . [Marcelle, 80 years old]

The professionals pointed out that there are alternative ways for older adults to perform physical activity at home. The FFPEVG proposed, for example, video clips on its website to help older adults exercise at home. However, none of the older adults were aware of the existence of online videos to encourage and assist them in performing physical activity at home:

No, I do not know of any tools. [Paulette, 84 years old]

Moreover, respondents were not interested in using online videos to perform physical activity:

If we want to continue (sport), we do it like this [without video]. [Renée, 91 years old]

All the older adults were receptive to the importance of physical activity for their health:

I find it quite interesting, especially for me, I have a lot of osteoarthritis. [Renée, 91 years old]

A majority continue to engage in physical activity at home:

I put C8, the channel (laughs) and I do the gym once in a while, and then some days I don't do it. It depends on how much time I have". [Denise, 73 years old]

Introducing physical activity into daily life requires the incorporation of a new culture into lifestyles that are provided, for example, in-group physical activity workshops:

I continue to do some things at home [based] on things I had seen and done there that I thought were good. [Renée, 91 years old]

However, for some, quarantine plays a limiting role in the practice of physical activity. For some, it is because of the material conditions:

Walk? Yes a little bit...we live on the side of the national road, it's not easy for us either. [Josianne, 71 years old]

Group physical activity creates social ties between people and encourages them to perform exercises. Therefore, being alone is an obstacle to performing physical activity:

On its own, it is less interesting. [Paulette, 84 years old]

Discussion

This study suggests that the COVID-19 epidemic has, before implementation of quarantine measures, affected the number of seniors attending group physical activity programs in the two study territories. This was mostly due to the fear of meeting potentially infected people.

Another result of our study is that despite the decline in older adults' participation in group physical activities before the

quarantine, they expressed the need to perform physical activity at home. Although quarantine is a measure to protect older adults from COVID-19, staying at home can lead to negative consequences such as reduced physical activity and sedentary behavior. It can also increase the risk of injury due to a lack of adapted equipment or poor knowledge of the physical exercises to perform. Moreover, social ties are essential to encourage older adults to perform physical activity [14]. Reduced social ties for older adults during quarantine could lead to a significant decrease in physical activity. In addition, loneliness could accelerate physical and cognitive decline in older adults [15].

The need for physical activity expressed by older adults raises the question of how older adults can be physically active in the current quarantine period. There is a need to help older adults integrate simple, safe ways to stay physically active in a limited space. A national policy to support older adults for physical activity at home appears essential in this context. In France, based on individuals' initiatives, local structures have sent booklets of physical activity advice and exercises to older adults.

There are currently several online physical activity support systems. Some of them are very interesting, such as FFPEVG video clips [16], the website of the French Ministry of Sports [17], or the United Kingdom National Health Service guide [18] aiming to encourage older adults to perform physical activity at home. Our study suggests that older adults do not want to use these online tools. Given the results of our study, it seems necessary to globally communicate how important it is for older adults to maintain physical activity at home. Among older adults, there are cultural, sociological, and economic differences that need to be considered when developing targeted messages that echo a target audience's existing views and practices, to produce more powerful persuasive effects. Behavioral segmentation can help better understand and target messages for high-risk subgroups [19] like older adults.

In conclusion, we are concerned about the level of independence and mental health status of older adults after the end of quarantine if there is no appropriate campaign to promote physical activity at home for them.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Interview guide for professionals.

[DOCX File, 20 KB - [aging_v3i1e19007_app1.docx](#)]

Multimedia Appendix 2

Interview guide for older adults.

[\[DOCX File, 20 KB - aging_v3i1e19007_app2.docx\]](#)**References**

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Abbreviations**COVID-19:** coronavirus disease**FFPEVG:** French Federation of Physical Education and Voluntary Gymnastics**SARS CoV-2:** severe acute respiratory syndrome coronavirus 2**SMAPE:** Social MARKeting and Physical activity in Elderly

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Original Paper

Impact of the AGE-ON Tablet Training Program on Social Isolation, Loneliness, and Attitudes Toward Technology in Older Adults: Single-Group Pre-Post Study

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Abstract

Background: The internet and technology can help older adults connect with family and friends. However, many older adults face obstacles to internet and technology use, such as lack of knowledge or self-efficacy.

Objective: The purpose of this study was to explore the impact of the AGE-ON tablet training program on social isolation, loneliness, and quality of life.

Methods: Adults aged >60 years took part in a series of 6 weekly workshops covering the basic features of a tablet. Before and after the program, social isolation, loneliness, social support, and quality of life were assessed. In addition, data on current tablet use and attitudes toward technology use were collected. Satisfaction with the program was also assessed at the end of the study using 6 Likert scale questions.

Results: The participants (N=32; mean age 76.3, SD 8.6 years) were predominantly female (n=20, 63%) and retired (n=30, 94%). The participants reported that they were highly satisfied with the program. After completing the program, no differences in social isolation, loneliness, social support, or quality of life were found. Frequency of tablet use increased and the attitudes of the participants toward technology improved.

Conclusions: The AGE-ON program resulted in increased tablet use frequency and may improve comfort and attitudes toward tablet use among older adults. This program may assist older adults in overcoming obstacles to internet and technology use to better connect with family and friends; however, further work targeting older adults who are socially isolated or at risk of social isolation is needed to more fully understand whether tablet training programs are beneficial in this population.

Trial Registration: ClinicalTrials.gov NCT03472729; <https://clinicaltrials.gov/ct2/show/NCT03472729>

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KEYWORDS

technology; older adults; tablet training; education

Introduction

Canada's cohort of adults over the age of 65 years is the fastest growing segment of the population. In 2018, 17.2% of the Canadian population was aged 65 and older; this segment is

expected to reach 20% by 2024 [1]. Social isolation and loneliness are growing concerns, as individuals are living longer and living alone, often far away from family members [2]. Social isolation is marked by living alone and having infrequent social contact and/or few social network ties [3]. Loneliness is a

subjective emotional experience in which there is dissatisfaction with the discrepancy between desired and actual social connections [4]. Both social isolation and loneliness are associated with poor quality of life [5] and premature mortality [6].

Use of the internet and technology has been proposed as a way for older adults to connect with family and friends, thus maintaining or even enhancing social connections, reducing loneliness and isolation, and improving quality of life [7-10]. The use of the internet for interpersonal communication and information seeking is positively correlated with life satisfaction and negatively correlated with depression in older adults [11]. However, older adults have barriers to internet and technology use, such as lack of knowledge and self-efficacy and concerns about privacy [12]. Although internet use among people over the age of 65 years is steadily increasing, older adults are still less likely to use the internet than younger age groups [13]. Internet use declines with increasing age, from 60% of persons aged 65-74 years to 29% of persons aged >75 years [14].

To date, several internet-based and computer-based training programs have been reported in the literature. A 2012 meta-analysis of 5 studies suggests that computer and internet training interventions can reduce loneliness in older adults, although the included studies reported small sample sizes and had high risk of bias [15]. More recently, a systematic review of interventions targeting loneliness and social isolation found that technology and community-engaged arts may be the most effective interventions to achieve these outcomes [9].

AGE-ON is a series of workshops developed in response to this literature by the Regional Geriatric Program Central (RGPC), based in Hamilton, Ontario. The goal of these workshops is to teach older adults with limited computer knowledge how to use tablet computers to connect with friends and family and gather information related to issues of importance to them. The primary objective of this study was to evaluate the effectiveness of this program at improving the participants' level of social isolation. The secondary objectives were to explore the impact of the program on loneliness and quality of life in older adults, the participants' comfort with and use of the tablet, and their satisfaction with the program.

Methods

Study Design

This is a single-group pre-post program evaluation of the existing AGE-ON program, which is administered by the RGPC. The study was registered prior to launch (ClinicalTrials.gov; NCT03472729). Our original intent was to conduct a randomized controlled trial with a wait-list control group; however, due to feasibility within the RGPC, namely lack of staff time and availability to host a second session at each location for wait-list control participants, this was not possible, and a single-group design was used. All procedures were reviewed and approved by the Hamilton Integrated Research Ethics Board, and all participants provided informed consent.

Participants

Eligible participants were English-speaking adults who expressed interest in the AGE-ON program. No exclusion criteria were applied. Recruitment was conducted via advertisements in local community newspapers, community postings, online postings, and social media targeting friends and caregivers of older adults from September 2018 to August 2019. All interested participants contacted the AGE-ON program coordinator at the RGPC, who provided information about the workshops and informed the participants about the research. Participation in the research component was optional and was not required to take part in the workshops. Participants did not receive compensation for their participation in the study; however, the program registration fee of CAD \$40 (US \$28.40) was waived for the participants.

Study Protocol

Participants attended 2-hour education sessions weekly over 6 consecutive weeks. Each session was facilitated by 1 instructor, with support from 2-4 volunteer university student mentors. The workshops were delivered in several settings, including retirement residences and an auditorium of a local hospital. The AGE-ON program, originally named iLive iLearn Well, was developed in 2014 by the RGPC to help older adults engage with technology and decrease perceived social isolation. The educational content was divided into 5 detailed modules, with 1 education session left free for review and participant-specific questions. The first week of classes focused on learning the basic features of an iPad (eg, powering on and off, volume, locating controls) and locating the variety of available apps. In subsequent weeks, participants learned how to use specific applications, including using the internet, taking and viewing photographs, sending and receiving emails, and using basic apps (eg, the Maps app, the Clock app, and Siri). The modules were accompanied by a participant workbook that included session content, homework, and additional information to help the participants learn the material. The homework assignments corresponded with the modules; they expanded on specific concepts and skills or prepared participants for future education workshops.

Outcome Measures

Quantitative data were collected at baseline and at the end of the 6-week program during the first and last AGE-ON sessions via paper questionnaires. Follow-up data were collected 1 month following the workshops by a telephone call with a trained research assistant (social support, attitudes toward technology, and tablet usage patterns only). The primary outcome was change in self-reported social isolation using the Duke Social Support Index (DSSI) [16]. The DSSI is an 11-item self-report scale that provides a measure of an individual's level of social isolation. Secondary outcomes included level of loneliness, determined using the De Jong Gierveld Loneliness Scale, which has been found to be a reliable and valid assessment of emotional and social loneliness [17]; quality of life, using the validated CASP-19 questionnaire [18] that is designed specifically for older adults with a focus on overall self-perceived quality of life; social support, using the 12-item Lubben Social Network Scale [19]; and comfort in using the

internet and iPad, using a variation of the Older Adults' Computer Technology Attitudes Scale [20] that was modified to be relevant to tablet use. The feasibility of the program was also assessed by collecting participant feedback on acceptability, participant satisfaction, and intent to continue use of the iPad, using a 6-point Likert scale. Demographic data were collected at baseline, including age, gender, education, employment status, marital status, living arrangement, and racial group.

Data Analysis

All statistical analyses were completed in SPSS version 9.4 (IBM Corporation). Baseline demographic data were summarized as mean and standard deviation or frequency and percentage where appropriate. Changes in outcome measures from baseline to end of study and 1-month follow-up were analyzed using the paired *t* test for continuous data and the chi-square test for dichotomous data.

Results

A total of 32 participants took part in the research study over 4 offerings of the program. No participants were found to be ineligible, but the method of recruitment was not tracked. The demographic characteristics of the study participants are presented in Table 1. The mean age of the 32 participants was 76.3 years (range 64-94); the majority were female (20, 63%), white (29, 91%), and retired (30, 94%). The individuals were well educated: of the 32 participants, 6 (19%) had a college or bachelor's degree and 11 (34%) had received a postgraduate degree or postgraduate training. Half the participants reported living with another person, such a wife, husband, partner, or children.

There were no significant differences in social isolation when measured either as a total score or as interaction or support sub-scores between baseline and end of study or at 1-month follow-up (Table 2). Moreover, no differences were found for loneliness, quality of life, or social support at 1-month follow-up. The participants' attitudes toward technology were not significantly different after they took part in the program (+3.9, 95% CI -2.4 to 10.3; $P=.22$) but did increase 1 month later (+10.1, 95% CI 3.6-16.6; $P=.004$).

The participants' self-reported frequency of tablet use increased from baseline to end of study; this increase was maintained at follow-up, changing from an average of several times a month to once a week (Table 3). There was also a significant increase in the number of reported uses of the tablet, from an average of 2.9 at baseline to 4.0 at end of study ($P=.001$) and at follow-up ($P=.002$). The most common tablet uses were email, seeking an answer to a specific question, internet browsing, and seeking health information. The only statistically significant difference between time points was an increase in the proportion of participants who used their tablet to seek health information (41.4% at baseline vs 62.1% at end of study, $P=.04$).

Overall, the participants were highly satisfied with the program, with 23 (71.9%) of the 32 participants finding the information useful, 22 (68.8%) indicating they would be interested in future workshops, and 25 (78%) reporting they would recommend the workshop to family and friends (Table 4). However, fewer participants reported that they intended to use (21, 66%) or had actually used (12, 38%) their iPad more because they took part in the program, and only 25 (56%) indicated that they shared the information learned with family and friends.

Table 1. Descriptive characteristics of the study participants at baseline (N=32).

Characteristic	Value
Age, mean (SD)	76.3 (8.6)
Gender, female, n (%)	20 (62.5)
Education, n (%)	
High school diploma, GED ^a diploma, or less	8 (25.0)
Some college, vocational, or training school after high school graduation	5 (15.6)
College or bachelor's degree	6 (18.8)
Postgraduate degree or training	11 (34.4)
Other	2 (6.3)
Employment status, n (%)	
Retired	30 (93.8)
Part-time employment	1 (3.1)
Other	1 (3.1)
Marital status, n (%)	
Widowed	13 (40.6)
Presently married or living with a partner	12 (37.5)
Divorced or separated	5 (15.6)
Never married	2 (6.3)
Living situation, n (%)	
With a wife, husband, or partner	12 (37.5)
Alone	10 (31.3)
In a retirement home	6 (18.8)
With children	3 (9.4)
With someone else	1 (3.1)
Racial group, n (%)	
White	29 (90.6)
Asian	1 (3.1)
Black or African American	1 (3.1)
Other	1 (3.1)

^aGED: General Educational Development.

Table 2. Quantitative outcomes at baseline, end of study, and follow-up.

Outcome	Baseline, mean (SD)	Change at end of study		Change at 1-month follow-up	
		Mean (95% CI)	<i>P</i> value	Mean (95% CI)	<i>P</i> value
Social support					
Total score	27.6 (3.9)	+0.3 (−1.1 to 1.8)	.61	+0.6 (−1.1 to 2.2)	.49
Interaction subscale	9.1 (1.9)	−0.03 (−0.6 to 0.6)	.91	+0.1 (−0.7 to 0.9)	.78
Support subscale	18.5 (2.9)	+0.4 (−0.8 to 1.5)	.53	+0.4 (−0.7 to 1.6)	.43
Attitudes toward technology	13.5 (14.3)	+3.9 (−2.4 to 10.3)	.22	+10.1 (3.6 to 16.6)	.004
Loneliness	31.9 (5.9)	+1.2 (−0.4 to 2.9)	.13	— ^a	—
Quality of life	40.4 (9.8)	+0.6 (−2.5 to 3.8)	.68	—	—
Social isolation	16.0 (5.8)	+0.1 (−1.6 to 1.9)	.87	—	—

^aNot measured.

Table 3. Participant tablet usage patterns before and after the AGE-ON program.

Usage pattern	Baseline (N=32)	End of study (N=29 ^a)		One-month follow-up (N=27 ^b)	
		Value	P value	Value	P value
Tablet use frequency, mean (SD)					
Frequency of tablet use ^c	2.9 (2.1)	4.0 (1.5)	.001	4.0 (2.0)	.002
Number of reported tablet uses	3.1 (2.4)	4.3 (2.1)	.06	4.4 (2.2)	.01
Tablet use type, n (%)					
Email	19 (65.5)	23 (79.3)	.37	21 (77.8)	.09
Instant messaging	5 (17.2)	10 (34.5)	.19	7 (25.9)	.09
Internet browsing	12 (41.4)	18 (62.1)	.26	21 (77.8)	.68
Audio or video calling	4 (13.8)	8 (27.6)	.28	8 (29.6)	.51
Reading the news	10 (34.5)	16 (55.2)	.24	9 (33.3)	.08
Reading an e-book	4 (13.8)	5 (17.2)	.06	5 (18.5)	.08
Answering a question	15 (51.7)	20 (69.0)	.78	21 (77.8)	.30
Seeking health information	12 (41.4)	18 (62.1)	.04	19 (70.4)	.40
Social media	9 (31.0)	7 (24.1)	.87	7 (25.9)	.24

^aThree participants did not complete the baseline checklist.

^bAn additional 2 participants were missing data at follow-up.

^cAssessed using a 6-point Likert scale: 1=never to 6=every day.

Table 4. Participant satisfaction with the AGE-ON program.

Survey prompt	Survey responses, n (%)		
	Strongly agree	Neutral	Strongly disagree
The information was useful.	23 (71.9)	6 (18.8)	0 (0)
I would be interested in future workshops.	22 (68.8)	7 (21.9)	0 (0)
I have shared the information I learned with family or friends.	18 (56)	9 (28)	2 (6)
I would recommend the workshop to family or friends.	25 (78)	4 (13)	0 (0)
Because of the workshop, I intend to use my iPad or tablet more.	21 (66)	7 (22)	1 (3)
Because of the workshop, I have used my iPad or tablet more.	12 (38)	7 (22)	1 (3)

Discussion

The purpose of this study was to explore whether taking part in a real world offering of a 6-week tablet training program for older adults reduced social isolation or loneliness or improved quality of life. Overall, despite high levels of satisfaction with the program itself, no changes were observed in our primary or secondary outcomes of interest.

These findings are in contrast to a 2012 meta-analysis that found a statistically significant decrease in loneliness scores in older adults when the results of 5 studies were pooled together, with an effect size of 0.56 [15]. Within this meta-analysis, the largest effects were found in studies that included individuals who were living in nursing home facilities and those who took part in adult day-care programs [21,22]. These participants may have started with higher levels of loneliness at baseline; thus, it would be more likely to see effects of the intervention on this outcome. The Lubben Social Support Scale utilized in this study

categorizes a person with a score of less than 12 as “at risk” for social isolation. Within our study, only 5 of 32 participants (16%) scored below this cutoff value at baseline, with a mean score across all participants of 16.0 (SD 5.8). Participants in the AGE-ON program were older adults who were interested in taking part in a tablet training program to learn this new skill and were not specifically identified because they were at risk for social isolation. Recruitment strategies were targeted at teaching older adults how to use tablet computers in a welcoming environment and were not targeted to lonely or socially isolated older adults. Therefore, it is possible that if this program were delivered to older adults who experience loneliness or who are at risk for social isolation, the findings with respect to this outcome would be different.

Our findings are similar to a previous study that found no difference in social isolation or self-esteem in older adults with psychiatric conditions who took part in twice-weekly internet and technology training over the course of 6 weeks [23]. These participants also reported high satisfaction with the program,

and the investigators suggested that a longer training program would be needed to see meaningful improvements. Another study found no difference in social support among older adults who were assigned to learn how to use social networks or an online diary website vs a wait-list control group [24]; these participants also rated the intervention favorably. A more recent updated systematic review of 25 studies of the effects of various types of information and communication technology on social isolation, social support, social connectedness, and loneliness and depression also found inconclusive results [25]. The types of interventions included in this review were broader and included items such as landline telephone-based befriending services and mobile phone instant messaging apps; the results indicated that the consistency of the findings with respect to social isolation or loneliness is more closely related to the population included than to the intervention used.

At the end of the 6-week AGE-ON program and 1 month later, the participants' attitudes toward technology were more favorable than at baseline; also, the participants self-reported that they used their tablets more frequently and for a wider variety of uses. Therefore, we are confident that the program was effective in helping to teach the participants how to use the iPad and that it met their learning needs. It is likely that the lack of change in social isolation and loneliness is not due to a failure of the program in teaching the participants to use the tablet properly but is rather due to the fact that using the tablet itself does not reduce social isolation or loneliness in this population. This is not surprising when we consider the types of activities for which the participants primarily reported using an iPad. The most common activities across all 3 time points were using email, finding the answer to a specific question, and seeking health information. Although email can be used to connect with others, other activities that would likely contribute more to feelings of social connectedness and reducing loneliness, such as audio or video calling, instant messaging, and social media, were reported by less than one-third of participants.

An emerging concern with respect to the use of technology is its ability to actually increase feelings of social isolation or loneliness in users. In a recent qualitative study of older adults aged ≥ 70 years who regularly used social media or social technology, the participants stated that while social media and technology use could certainly strengthen existing social relationships and bring depth and fun to social contacts, technology could also represent an obstacle to real human contact [26]. Encouragingly, in our study, we did not see negative changes in any of the measures of social isolation, loneliness, or social support; however, this is an important aspect that should be considered in future research.

Several methodological considerations limit the interpretation of our findings. First, as this was an evaluation of an ongoing community-based program, we were not able to randomize the participants to a control group. Second, this study included a convenience sample of highly motivated individuals who were offered free participation in a tablet training program and who mostly had access to a tablet of their own either at home or through a family member or friend. Thus, these results may be less applicable to the broader population. Finally, given the timeframe of the funding opportunity, we were only able to evaluate 4 offerings of the program in which 32 participants took part. Although a large sample would provide greater power to detect statistically significant differences, due to the consistent lack of change in any of the outcomes related to social isolation, loneliness, and social support, we do not believe a larger sample would alter our conclusions.

Overall, this study found that while older adults who took part in a tablet training program enjoyed the program and learned skills related to using a tablet computer and technology in general, participation in the program did not result in changes to social isolation, loneliness, or social support. Future work that specifically targets older adults who are socially isolated or at risk of social isolation is needed to more fully understand whether tablet training programs are beneficial in this population.

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Conflicts of Interest

None declared.

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Abbreviations

DSSI: Duke Social Support Index

RGPc: Regional Geriatric Program Central

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Original Paper

Clinician Perspectives on the Design and Application of Wearable Cardiac Technologies for Older Adults: Qualitative Study

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Abstract

Background: New wearable devices (for example, AliveCor or Zio patch) offer promise in detecting arrhythmia and monitoring cardiac health status, among other clinically useful parameters in older adults. However, the clinical utility and usability from the perspectives of clinicians is largely unexplored.

Objective: This study aimed to explore clinician perspectives on the use of wearable cardiac monitoring technology for older adults.

Methods: A descriptive qualitative study was conducted using semistructured focus group interviews. Clinicians were recruited through purposive sampling of physicians, nurses, and allied health staff working in 3 tertiary-level hospitals. Verbatim transcripts were analyzed using thematic content analysis to identify themes.

Results: Clinicians representing physicians, nurses, and allied health staff working in 3 tertiary-level hospitals completed 4 focus group interviews between May 2019 and July 2019. There were 50 participants (28 men and 22 women), including cardiologists, geriatricians, nurses, and allied health staff. The focus groups generated the following 3 overarching, interrelated themes: (1) the current state of play, understanding the perceived challenges of patient cardiac monitoring in hospitals, (2) priorities in cardiac monitoring, what parameters new technologies should measure, and (3) cardiac monitoring of the future, "the ideal device."

Conclusions: There remain pitfalls related to the design of wearable cardiac technology for older adults that present clinical challenges. These pitfalls and challenges likely negatively impact the uptake of wearable cardiac monitoring in routine clinical care. Partnering with clinicians and patients in the co-design of new wearable cardiac monitoring technologies is critical to optimize the use of these devices and their uptake in clinical care.

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KEYWORDS

technology; arrhythmia; monitoring; older people; cardiology; qualitative; wearable

Introduction

There is a proliferation in the design, development, and availability of novel consumer-grade wearable and app-based technologies for monitoring cardiac rate and rhythm. Yet, the optimal method and duration of monitoring remains unknown [1]. New devices include technologies such as AliveCor (a smartphone-based device with functionality to record a single point in time; a single-lead electrocardiogram) and Zio patch (a wearable adhesive patch to monitor heart rhythm for a prolonged duration). There is a growing demand for new health-monitoring technologies to assist clinicians in diagnosis, clinical decision making, treatment, and ongoing management of older adults [2]. This demand is driven by caring clinicians and by public interest in new technologies. Advanced age is a key risk factor in the development of heart failure, atrial fibrillation, and stroke, with a dramatically increased risk over the age of 80 years [3-5]. Novel wearable monitoring devices offer promise in detecting arrhythmia and monitoring cardiac health status, among other potentially clinically valuable parameters. Wearables are revolutionizing health care delivery, yet it is difficult to ascertain the number of health problems that these technologies may help to intervene and contribute to the provision of quality care [6]. Capabilities may include physiological and biochemical sensing, as well as motion sensing, which can be applied for diagnostic and ongoing monitoring [6,7]. Physiological monitoring by wearables could help in the diagnosis and treatment of a large number of individuals with cardiovascular, neurological, and pulmonary diseases. Further, home-based motion sensing might help prevent falls and maximize an individual's independence and community participation [8]. Wearables aim to improve quality of care and support health systems by triggering an alert based on abnormal parameters. They can aid in the diagnosis and treatment of illnesses in a timely and efficient manner. In particular, wearable technologies are increasing in popularity among cardiac patients, rehabilitation patients, and older patients. Due to the rapid pace of innovation, it is important to ensure that these technologies are suited to the individual needs of older adults. However, the clinical utility and usability from the perspectives of clinicians is largely unexplored. It is critical to explore the factors that impact translation from bench to bedside, upscale and sustainability of new devices in clinical practice. Further, there is a need to explore the use of cardiac monitoring devices to improve the detection and management of cardiovascular conditions and contribute to the improvement of the quality of life in older adults.

Aim

This study aimed to explore clinician perspectives on the use of wearable cardiac monitoring technology for older adults.

The 3 key objectives were (1) to explore clinical issues with current monitoring challenges, including barriers to use and uptake by older adults; (2) to explore priorities for the development of future technologies and identify the parameters of clinical importance; and (3) to explore the design of an "ideal device" for cardiac monitoring in older people.

Methods

Study Design

A descriptive exploratory qualitative design with semistructured focus groups involving clinicians was used.

Participant Selection

A convenience sampling technique was used to select study participants. Physicians, nurses, and allied health professionals working in tertiary-level hospitals who were available on the day of data collection were invited to participate in the face-to-face focus group discussion. Staff participated in a group that suited the daily routine of the clinical setting.

Setting

Physicians, nurses, and allied health professionals working in cardiology, rehabilitation, cardiac rehabilitation, and aged care services, at 3 major tertiary-level hospitals in Sydney, Australia, were invited to participate between May 2019 and July 2019.

Data Collection

Two expert facilitators, CF and LDH, conducted the focus groups. Both researchers are skilled in qualitative research methods and focus group facilitation. Prior to commencement of the focus group session, the facilitator highlighted the purpose of the group and outlined roles and responsibilities. Data were collected using audio recording, combined with field notes made at the time of the focus group interviews. Focus group sessions lasted 30-60 minutes to facilitate the conversation and reach data saturation. An interview guide was used to guide discussions. Probing questions were used when required by the facilitator to ascertain further information.

Interview Guide

The following questions were used to guide the focus group discussions:

1. Can you tell me about your experiences of cardiac monitoring in older people?
2. What are the issues with current cardiovascular monitoring technologies?
3. Why would this technology need to be replaced?
4. What clinical data or parameters do you want to measure in older people?
5. What health-related data do you want to capture when caring for older people?
6. How do you want the data to be presented or fed back to you?
7. What else would you like to know?
8. What is one bit of information that you would like to know that you can't get now?

Data Analysis

All focus group interviews were transcribed verbatim by research interns, and the transcripts were coded by 3 members of the research team. The data coders systematically read, searched, coded, and arranged. The Braun and Clarke [9] method of thematic analysis was used, and codes were clustered into groups before identification of any themes. Reducing the huge amounts of raw data from codes into categories and themes was

an iterative process, whereby the codes were subsequently assigned into categories before finalizing the overarching themes. Authors and members of the interviewee team were involved in the data analysis to ensure rigor and accuracy of the analysis and consensus.

Ethical Considerations

This study was approved by the Western Sydney Local Health District (Human Research Ethics Review Ref LNR/18/WMEAD/513) and received Western Sydney University external recognition approval (Human Research Ethics Review Ref H13228). This study was conducted in compliance with the principles of the Declaration of Helsinki [10]. Focus groups were conducted in a confidential area. Written informed consent was obtained from all participants.

Table 1. Baseline demographics of participants.

Focus group	Setting	Participants	Occupation
Group 1	Rehabilitation	n=13 (11 female, 2 male)	Nurses
Group 2	Cardiology and heart failure service	n=25 (4 female, 21 male)	Cardiologists Medical students Medical officers Allied health
Group 3	Cardiac rehabilitation service	n=6 (4 female, 2 male)	Allied health Nurses
Group 4	Aged care and rehabilitation	n=6 (3 female, 3 male)	Allied health Geriatricians Nurse
Total		n=50 (22 female, 28 male)	

The following 3 themes emerged that illustrated clinician perspectives on the use of wearable cardiac monitoring technology for older adults.

1. The current state of technology—understanding the perceived challenges of patient cardiac monitoring in hospitals
2. Priorities in cardiac monitoring—what new parameters could be clinically helpful
3. The ideal device—cardiac monitoring of the future

Theme 1: The Current State of Technology—Understanding the Perceived Challenges of Patient Cardiac Monitoring in Hospitals

This theme reflects the current challenges faced by clinicians in hospitals and the perceived areas of improvement in designing new technology for cardiac monitoring in older people. Three subthemes were clearly identified.

Subtheme 1: Physical Form and Function of Device

This subtheme includes all aspects of device structure and use that lead to negative experiences by either the user or the clinician. These aspects were as follows:

- Reduced accuracy of recorded data due to lead disconnection, movement interference, lack of continuous readings, interference, and false data
- Delirious patients pulling leads off

The funders of this research were not involved in the study design, data collection, analysis, or interpretation, and were not involved in the publication of the final manuscript.

Results

Principal Findings

A total of 4 focus groups were completed (Table 1). Participants represented physicians, nurses, and allied health staff working in 3 tertiary-level hospitals. All 4 focus group interviews were completed between May 2019 and July 2019. There were 50 participants, 22 female and 28 male. A diversity of professions was represented, including 5 cardiologists, 4 geriatricians, 10 allied health professionals, 15 junior and resident medical officers and students, and 16 nurses.

- Difficulty in use due to user not being technologically advanced
- Beeping causing anxiety and provoking panic

It's annoying because it's connected and it's got a wire. They don't read particularly well if they get loose. [Focus group 3, cardiac rehabilitation professionals]

A lot of data that the systems currently record is not real or not useful, so lots of interference from leads. [Focus group 4, aged care professionals]

A lot of our patients are older—anything too techy can get too frustrating. [Focus group 1, rehabilitation nurses]

People freak out when they hear beeping. [Focus group 4, aged care professionals]

Subtheme 2: Wearability of the Device

In terms of overall device wearability, patients do not like heavy devices around the neck, nor do they like leads and adhesives, as these get caught and feel restrictive. Concern was expressed about potential device-related skin and pressure injuries, hygiene, and infection control issues. In terms of device type selection, single-use and disposable devices were seen as wasteful and not ecologically friendly. It was also reported that hospitals often purchase cheap devices with short usable

lifespans. “We don’t need the dots and the leads and it’s quite heavy. Confused patients want to rip everything off.” (Focus group 4, aged care professionals.)

Subtheme 3: Device Data Management

Groups reported difficulty in interpreting the data produced, data overload, and alert fatigue. Questions were raised over ownership of data. “We just pick the parameters we would like and not have to use all the data available.” (Focus group 4, aged care professionals.)

Theme 2: Priorities in Cardiac Monitoring—What New Parameters Could Be Clinically Helpful

There was consensus from all clinicians for preference to select continuous monitoring over intermittent, where possible. These included blood pressure, pulse rate, heart rhythm, glucose level, oxygen saturation, mobility, and fluid status. The considerations around the best ways in which to provide these data to clinicians varied depending on the clinician role.

Continuous accurate data. It might actually help us find out why they are falling. [Focus group 1, rehabilitation nurses]

Patients are very individual and that ability to tailor that to that individual and their circumstances which are unique. [Focus group 4, aged care professionals]

If they are on fluid restriction...they could be having sneaky drinks on the side, you can’t keep track of exactly what their input is. [Focus group 1, rehabilitation nurses]

Theme 3: The Ideal Device—Cardiac Monitoring of the Future

The clinicians responded well to the idea of having input into what the ideal device would look like. The findings generated the following 2 core areas of consideration: (1) form, wearability, and characteristics, and (2) functionality.

Consideration 1: Form, Wearability, and Characteristics

The physical form of suggested technology included more obvious solutions, such as a watch, The physical form of suggested technology included more obvious solutions, such as a watch, tracker, iPad, smartphone, computer with internet page with a code linking to a device, sweat patches, mattress, and cushion-based technology. It appeared difficult for clinicians to think outside of the current health system parameter for design, which limited thinking at times. Sometimes it was challenging to generate thinking beyond the design of currently available devices. Wearability and characteristics were often described in single-word terms, such as comfortable, Velcro, waterproof, cleanable, small, lightweight, noninvasive, no beeping, wide and elasticized, alarm feature, wireless, easy to access and apply, and user-friendly.

Ideally nothing attached...no wires, no electrodes. Can shower in it. Easy to attach. [Focus group 4, aged care professionals]

Something quick, on the wrist. [Focus group 3, cardiac rehabilitation professionals]

Not too technologically advanced. Not wasteful. Hygienic. [Focus group 1, rehabilitation nurses]

Consideration 2: Functionality

Clinicians described functionality using phrases such as ability to interpret data and information to provide action, specific and tailored to individual patient needs, continuous real-time data to monitor change over time, flexibility in adjusting and setting own parameters and modify medications, communication fed back to patients, physical activity tracking, and ability to access data anywhere and anytime.

Change the parameters, so you aren’t going to constantly get alerts you don’t need. Something that would alarm to let you know. Reminder if you’ve not moved in a while, reminder to have a drink—passive prompts. [Focus group 1, rehabilitation nurses]

Kind of alarm setup, so if their stats dropped below a certain range or that their blood pressure was going up, down, heart rate’s going up. Show a visual picture...show them this is what’s happening, this is where you are, this is where you need to be. [Focus group 3, cardiac rehabilitation professionals]

Discussion

Findings generated the following 3 overarching, interrelated themes: (1) the current state of play, understanding the perceived challenges of patient cardiac monitoring in hospitals, (2) priorities in cardiac monitoring, and what parameters new technologies should measure, and (3) cardiac monitoring of the future, the “ideal device.”

Theme 1 elucidated the flawed design with current cardiac monitoring technology and how this inhibits gaining the full potential value of the best available data to inform patient care. Fundamental to this theme was the physical form and function of the device, and secondly, the management of data captured by the device [11].

A large proportion of cardiac monitoring devices used in hospitals and outpatient settings, such as Holter monitors, do not reflect the latest available technology; these technologies are frequently outdated relative to our personal technology at home [12,13]. The gap between commercially available technology and health service provision of technology is wide and could widen as the speed at which new consumer technologies entering the market increases [14].

Clinicians expressed frustration over the bulky and unattractive nature of the devices currently used in clinical settings, especially when comparing these devices with their own smartwatch or smart devices at home [15]. Adhesive skin dots, stiff cords, and a heavy, awkward battery pack may have never been that acceptable to patients, but they were tolerated relatively well at a time when this was the only method in which to collect and monitor such data [16].

Just as the physical and tactile design of health and monitoring technology has improved significantly, the way in which we receive, view, and are informed of data has changed immeasurably [14]. Our personal devices provide us with

attractive curated data, which, due to artificial intelligence and machine learning, has already filtered out unnecessary data and errors, such as artifacts. We are presented with graphical summaries and pictorials of what we need to know [17]. Therefore, when busy clinicians log on to view data from a device in clinical practice, the sense of frustration and dissatisfaction increases when they are faced with errors, artifacts, and missing or incomplete data [12].

Theme 1 is supported by literature that clinicians favor devices with a physical form that is unobtrusive and attractive, yet practical in terms of hygiene and affordability; they also favor a platform and system that are easy to use and that they have confidence in with respect to data management (privacy as well as the alerts generated from the data) [18,19].

Clinicians value how data collected from patients can inform their clinical practice [20]. Interestingly, clinicians value collecting data from several parameters, with no push to limit data collection from only one or two parameters. It appears that more parameters are better, providing relevant, accurate, and comprehensive understanding of a patient's condition [21]. This feature may add to design challenges for devices as they are expected to measure several physiological parameters, which could result in a physical design that is less streamlined than might be achievable with fewer parameters [22].

The future of health care and technology design requires multiple touch points from bench research to bedside patient use if future design is going to truly revolutionize care; it must meet the needs of users and support health professionals in their work [23]. Health data that are derived from wearable devices can frequently suffer from irregularities that affect the overall usefulness in care decision making and delivery [11]. Challenges of the current wearable technologies include lack of capacity to generate specific and accurate data, which could lead to anxiety and panic from the perspectives of the patient and the provider [19]. Wearable technologies can suffer from reliability problems [24], so ensuring accuracy is important for the generation of future data [25]. Interventions that are based on inaccurate data could put patient safety in jeopardy by inducing medication or procedural errors. Current technologies have some features that undermine patient comfort [14]. The benefit of these technologies could be limited if patients do not find them comfortable. Future technologies should prioritize the comfort of patients [15]. Wearable technologies could affect the physical, psychological, and social aspects of a patient's life [26]. Heavy devices, beeping, and devices that are difficult to clean could negatively affect user experience and sustainability of use [27]. Health care technologies are expensive. As a result, hospitals tend to buy cheaper devices that lack quality and have shorter lifespans [28]. Another critical challenge related to wearable technology is a lack of capacity to generate appropriate information that is unique to the patient [29].

Protecting patient health information, including medical and physiological data, is a major ethical obligation of health professionals and health care systems. Easy access to data generated from wearable technologies could lead to misuse of sensitive medical data [18,19]. These technologies also lack the

capacity to interpret and make sense of the data for further action [30]. This could keep patients dependent on health professionals for situations that patients could have resolved themselves.

Theme 2 highlights the essential design priorities in cardiac monitoring and the parameters that new technologies should measure. Form, functionality, wearability, and characteristics were highlighted as essential features for designers to consider (Multimedia Appendix 1). It has been recommended that emerging health technologies include features that can be tailored or individualized to a patient's condition [15,31]. Different patients have different cardiovascular conditions, and these wearable technologies should be capable of tailoring to each patient's uniqueness [21]. Health care professionals would also favor wearable technologies that can generate continuous and accurate data [20]. The ability to capture multiple parameters was preferred over single-parameter monitoring devices.

Theme 3 explored "the ideal device." The development of next-generation devices should include an iterative design with clinicians, patients, and end users. It was recognized by the groups that current cardiac monitoring technologies are heavy, uncomfortable, connected to wires, and easily damaged [12,13]. These technologies affect physical, psychological and social aspects of a patient's life, elements which should be considered in the development process [24,32-34]. The groups identified key recommendations for future devices. Health care professionals would prefer the ideal cardiac monitoring to be more comfortable, wireless, waterproof, and user friendly [35,36]. Wearable technologies with a capacity to provide accurate data continuously are highly valued by health care providers [15,37]. Our findings were similar to other research that highlights factors, including user-friendliness, satisfaction with design, comfort, and motivation, to be the important factors to enhance uptake [38]. It is important to tailor any monitoring solutions to meet the needs of individual patients, recognizing that one size does not fit all [38]. This is of particular importance for longer-term users, to enhance adherence to monitoring and wearability.

Conclusion

Existing wearable cardiac monitoring technologies for older adults do not fully address the needs of clinicians and their patients. A range of improvements are desirable to ensure these technologies have minimal impact on the patient (physically, psychologically, and socially). Substantial improvements in information provided by the device are desired. These improvements include the number of physiological parameters collected, reliability of data quality, continuity of data, capability of customizing data to individual patients, and a means of presenting data in an intelligible form that can impact patient care efficiently. These and other challenges will directly impact uptake in routine clinical care. Future acceptance of new wearable devices will rely on functionality and design for comfort as well as clinical accuracy. These must be considered early in the development process. Partnering with clinicians and patients in the co-design of new wearable cardiac monitoring technologies is critical to optimize the use of these devices and their contribution to patient care.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Themes.

[[DOCX File , 17 KB - aging_v3i1e17299_app1.docx](#)]

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Original Paper

Actual Use of Multiple Health Monitors Among Older Adults With Diabetes: Pilot Study

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Abstract

Background: Previous studies have reported older adults' perceptions of using health monitors; however, no studies have examined the actual use of multiple health monitors for lifestyle changes over time among older adults with type 2 diabetes (T2D).

Objective: The primary aim of this study was to examine the actual use of multiple health monitors for lifestyle changes over 3 months among older adults with T2D. The secondary aim was to explore changes in caloric intake and physical activity (PA) over 3 months.

Methods: This was a single-group study lasting 3 months. The study sample included participants who were aged ≥ 65 years with a diagnosis of T2D. Participants were recruited through fliers posted at the Joslin Diabetes Center in Boston. Participants attended five 60-min, biweekly group sessions, which focused on self-monitoring, goal setting, self-regulation to achieve healthy eating and PA habits, and the development of problem-solving skills. Participants were provided with the Lose It! app to record daily food intake and devices such as a Fitbit Alta for monitoring PA, a Bluetooth-enabled blood glucose meter, and a Bluetooth-enabled digital scale. Descriptive statistics were used for analysis.

Results: Of the enrolled participants (N=9), the sample was white (8/9, 89%) and female (4/9, 44%), with a mean age of 76.4 years (SD 6.0; range 69-89 years), 15.7 years (SD 2.0) of education, 33.3 kg/m² (SD 3.1) BMI, and 7.4% (SD 0.8) hemoglobin A_{1c}. Over the 84 days of self-monitoring, the mean percentage of days using the Lose It!, Fitbit Alta, blood glucose meter, and scale were 82.7 (SD 17.6), 85.2 (SD 19.7), 65.3 (SD 30.1), and 53.0 (SD 34.5), respectively. From baseline to completion of the study, the mean daily calorie intake was 1459 (SD 661) at week 1, 1245 (SD 554) at week 11, and 1333 (SD 546) at week 12, whereas the mean daily step counts were 5618 (SD 3654) at week 1, 5792 (SD 3814) at week 11, and 4552 (SD 3616) at week 12. The mean percentage of weight loss from baseline was 4.92% (SD 0.25). The dose of oral hypoglycemic agents or insulin was reduced in 55.6% (5/9) of the participants.

Conclusions: The results from the pilot study are encouraging and suggest the need for a larger study to confirm the outcomes. In addition, a study design that includes a control group with educational sessions but without the integration of technology would

offer additional insight to understand the value of mobile health in behavior changes and the health outcomes observed during this pilot study.

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KEYWORDS

mobile health; aged; lifestyle; self-management; diabetes mellitus, type 2

Introduction

Background

A total of 25.2% or 12 million older Americans (aged ≥ 65 years) have type 2 diabetes (T2D) [1,2]. Older adults are at substantial risk for acute and chronic microvascular and cardiovascular complications related to T2D, which is linked to higher mortality [2]. Older adults also endure many daily burdens associated with T2D management, for example, complex lifestyle management [3], adherence to medication [4,5], psychological effects [6,7], and financial impact [8,9]. In 2017, the direct and indirect costs attributed to T2D in the United States were US \$327 billion [10].

Lifestyle intervention, which focuses on decreasing energy intake and increasing physical activity (PA), is the most efficient nonmedical approach to self-management of T2D [11]. At present, achieving goals for dietary intake [12,13] and PA [1,14,15] remains challenging for many older adults with T2D. In a study with a large and diverse cohort of older adults with T2D ($n=2400$) from 16 US clinical sites, only a small percentage of older participants implementing intensive lifestyle interventions (33.7% at 1 year and 21.4% at 4 years) achieved or exceeded the national PA threshold for improved health (ie, ≥ 150 min per week), and a smaller percentage of older participants (20.2% at 1 year and 11.3% at 4 years) met the PA threshold of the American College of Sports Medicine (ie, ≥ 250 min per week) [15]. Moreover, older adults with T2D face challenges achieving dietary intake goals [12,13]. One study showed that more than 50% of older adults with T2D did not consider diet as part of diabetes management [13].

Numerous available and emerging technologies, such as wearable trackers, smartphone apps, and remote monitoring devices, can help older adults make lifestyle changes. One study demonstrated that wearable trackers and telehealth platforms can encourage older adults with hypertension to engage in healthier lifestyles [16]. Furthermore, a literature review

published in 2018 [17] indicated that more than 60% of elderly people were interested in the future use of wearable devices and the devices' potential to improve PA. Similar findings were found from two cross-sectional surveys [18,19] and a qualitative study [20]; these noted that older adults were willing to use health monitors to track health information. However, the limitation of the reported studies is that they only assessed older adults' perceptions of using health monitors; they did not examine older adults' actual use of multiple health monitors for complex lifestyle changes over time.

Objective

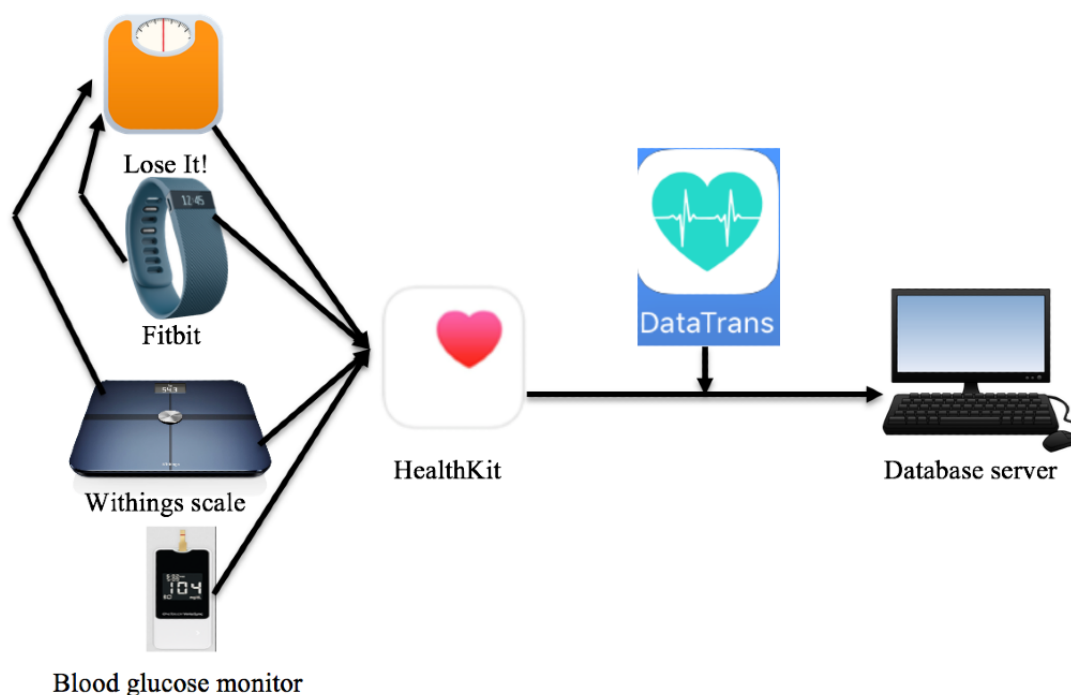
The primary aim of this study was to examine the actual use of multiple health monitors for lifestyle changes over 3 months among older adults with diabetes. The secondary aim was to explore changes in caloric intake and PA over 3 months.

Methods

Study Design

This was a single-group study lasting 3 months. The study was approved by the institutional review board at Boston College and the Joslin Diabetes Center in Boston. All participants provided informed consent and were given monitoring app and devices, including Lose It!, a self-monitoring smartphone app to record daily food intake; a Fitbit Alta for monitoring PA; a Bluetooth-enabled blood glucose meter; and a Bluetooth-enabled digital self-weighing scale. Participants also received a OneTouch Verio Flex meter and OneTouch Verio test strips for blood glucose monitoring. Data from all the provided monitoring devices were transmitted to the research center by synchronizing the device and app data from the HealthKit and then synchronizing to the DataTrans app (Figure 1). In addition, participants attended five 60-min, biweekly group sessions, which focused on self-monitoring, goal setting, self-regulation of behavior to support healthy eating and PA habits, and the development of problem-solving skills.

Figure 1. The infrastructure supporting remotely transmitted data collection.



Recruitment, Participants, and Settings

All participants were recruited through posted fliers from the Joslin Diabetes Center in Boston. Eligibility criteria included (1) previously diagnosed with T2D for 2 years or more, (2) aged 65 years or older, (3) BMI between 27 and 40 kg/m², (4) availability of wireless internet service at home, (5) prescribed insulin or oral medications for 1 year or more, (6) no changes in medications for 6 months or more before enrolling in the study, (7) used the Lose It! app on their computer or smartphone for the 5-day practice period, and (8) able to read and speak in English.

Individuals were excluded if they (1) were planning to frequently travel, vacation, or relocate within the next 6 months; (2) were unable to walk two blocks or had a lower limb amputation, severe arthritis, or other medical condition that prevented walking for exercise; (3) had severe complications of diabetes that interfered with self-management skills, such as renal disease (albumin/creatinine >300 µg/mg), severe peripheral diabetic neuropathy, severe peripheral vascular disease, symptomatic autonomic neuropathy, recent myocardial infarction (within the last 6 weeks), congestive heart failure, or other severe cardiac disease, or severe hypertension (systolic blood pressure >160/90 mm Hg); (4) were receiving current treatment for a serious mental illness (eg, schizophrenia, bipolar disorder, substance abuse, or eating disorders); (5) had severe visual, hearing, or cognitive impairments (eg, dementia and intellectual disability); or (6) were unable or unwilling to use the technology toolkit for data collection. All participants were required to obtain clearance from their primary care provider (PCP) before enrollment.

Protocol of Group Sessions

The five group sessions focused on (1) self-monitoring and goal setting, (2) healthy eating, (3) PA, (4) self-regulation of behavior to support healthy eating and PA habits, and (5) the development of problem-solving skills. All participants were taught to use self-monitoring devices 1 to 2 weeks before starting the group sessions. During the first group session, individualized goals for caloric intake were identified. In addition, participants were trained to observe how their weight changes corresponded with changes in dietary intake and PA. Participants were also counseled on monitoring their blood glucose at different times to identify when their blood glucose would be out of range, and they were taught to implement walking and dietary changes at particular times to improve blood glucose levels that were out of range. Such self-regulation skills were reinforced with guidance that aided in the development of the participants' problem-solving skills. Suggestions for changes in medication regimens, particularly insulin or hypoglycemic agents, were not part of the group sessions but were communicated to the participants' diabetes care providers. No intervention related to medication was performed by the study staff.

Measurements

Sociodemographic Data and Medical History

These data were collected using the self-administered sociodemographic and lifestyle questionnaire, which consists of 25 primary questions designed to assess standard sociodemographic and socioeconomic information, such as age, gender, marital status, education, employment status, income, and ethnicity or racial background. BMI (kg/m²) was calculated according to baseline weight and height. Baseline weight was measured using a digital scale (Tanita Corporation of America, Inc). Participants were asked to wear lightweight clothing while standing barefoot on the scale's footpads. Height (cm) was

measured with a stadiometer. Information on self-reported medical conditions, including hypertension, hyperlipidemia, diabetes, coronary artery disease, myocardial infarction, congenital heart disease, stroke, and congestive heart failure, was also collected. Cognitive status was assessed using the Montreal Cognitive Assessment, a brief screening tool for detecting cognitive dysfunction [21]. A total score of less than 26 typically indicates mild or more severe cognitive impairment (eg, dementia), whereas a total score of greater than or equal to 26 indicates intact cognition [22]. The information regarding medication changes was derived from the electronic medical records.

Actual Use of Technology

Participants' use of the provided Lose It! app, Fitbit Alta, self-weighing scale, and glucose meter was objectively determined based on date-stamped information; each day of use was coded binarily (use vs nonuse). The number of days per week that each device was used was then calculated. In addition, the proportion of participants who used each self-monitoring app and device per day was calculated.

Weight, Steps, and Energy Intake

Objectively assessed daily body weight data were transmitted via the provided Bluetooth-enabled scales. Daily weights were then used to calculate the percentage weight change relative to the baseline weight. Objectively assessed daily steps and self-reported daily energy intake were transmitted to the research server via the Fitbit Alta and Lose It! app.

Statistical Analysis

Descriptive statistics for continuous variables, such as age, BMI, and percentage change in weight, were reported as mean (SD). Categorical variables, such as gender, race, education, employment, and household income, were described using

frequency counts and percentages. Descriptive analyses were conducted using SPSS Statistics version 25 (IBM Corp).

Results

Among 14 approached participants, 5 were not eligible and 9 completed the study. The reasons for ineligibility (2/14, 14%) included difficulty commuting or parking and difficulty learning how to use the Lose It! app (2/9, 14%), fear of falling because of a health condition that prevented exercise (1/9, 7%), and personal circumstances (eg, sick family member and time conflict). All 9 participants attended all five group sessions.

Table 1 provides a description of the study sample (N=9). Most participants (8/9, 89%) were white, and 44% (4/9) participants were female. Participants were aged, on average, 76.4 years (SD 6.0; range 69-89 years), with 15.7 (SD 2.0) years of education. Participants were obese, with a mean BMI of 33.3 kg/m² (SD 3.1) and hemoglobin A_{1c} of 7.4% (SD 0.8; range 5.8%-8.6%). The mean duration of T2D was 14.4 years (SD 8.1). In addition to T2D, many participants had high blood pressure (8/9, 89%) and hyperlipidemia (6/9, 67%).

Over the 12 weeks (84 days) of self-monitoring, the mean percent days of using the Lose It!, Fitbit Alta, blood glucose meter, and scale were 82.7 (SD 17.6), 85.2 (SD 19.7), 65.3 (SD 30.1), and 53.0 (SD 34.5), respectively. **Figure 2** illustrates the mean number of days of self-monitoring by week. Over 12 weeks, participants consistently used the Lose It! app daily from the beginning of the study to week 6, but then there was a gradual decrease to 4 days per week at the end of the study. A similar pattern was seen in the Fitbit Alta use. There was a decline in the use of the glucose meter over 12 weeks, starting from 5.7 days per week to 2 days per week. Scale use started at 5 days per week, decreased to 2.6 days per week by week 6, increased to 4.7 by week 9, and then decreased to 3 days by week 12.

Table 1. Sample description (N=9).

Demographic characteristics	Values
Age (years), mean (SD)	76.4 (6.0)
Education (years), mean (SD)	15.7 (2.0)
Duration of type 2 diabetes (years), mean (SD)	14.4 (8.1)
BMI (kg/m ²), mean (SD)	33.3 (3.1)
Hemoglobin A _{1c} (%), mean (SD)	7.4 (0.8)
Gender, n (%)	
Male	5 (56)
Female	4 (44)
Race, n (%)	
White (non-Hispanic)	8 (89)
African American	1 (11)
Employment, n (%)	
Employed	2 (22)
Unemployed	7 (78)
Marital status, n (%)	
Married or living with other	6 (67)
Widowed, divorced, or other	3 (33)
Income, n (%)	
<US \$50,000	4 (44)
≥US \$50,000	5 (56)
Medical conditions, n (%)	
Hypertension	8 (89)
Hyperlipidemia	6 (67)
Heart problems	3 (33)
Fatty liver	3 (33)
Gout	3 (33)
Osteoarthritis	2 (22)
Mild cognitive impairment	4 (44)

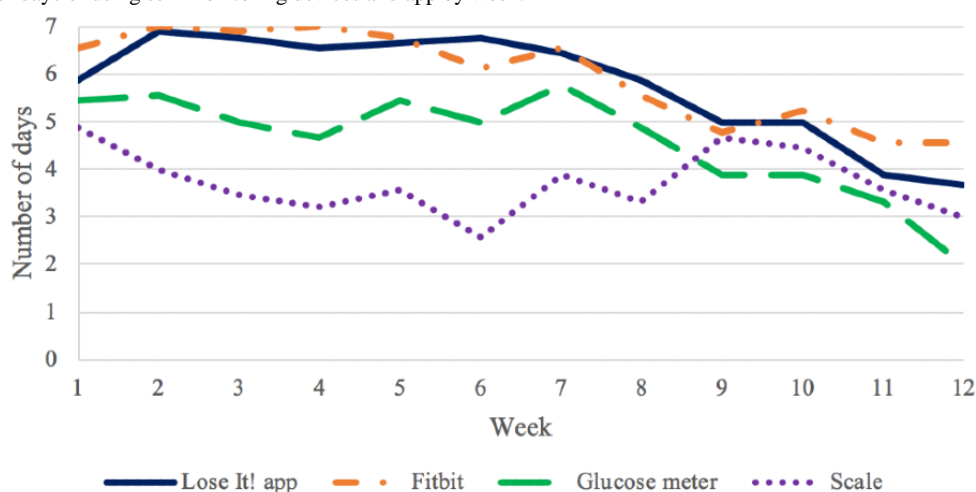
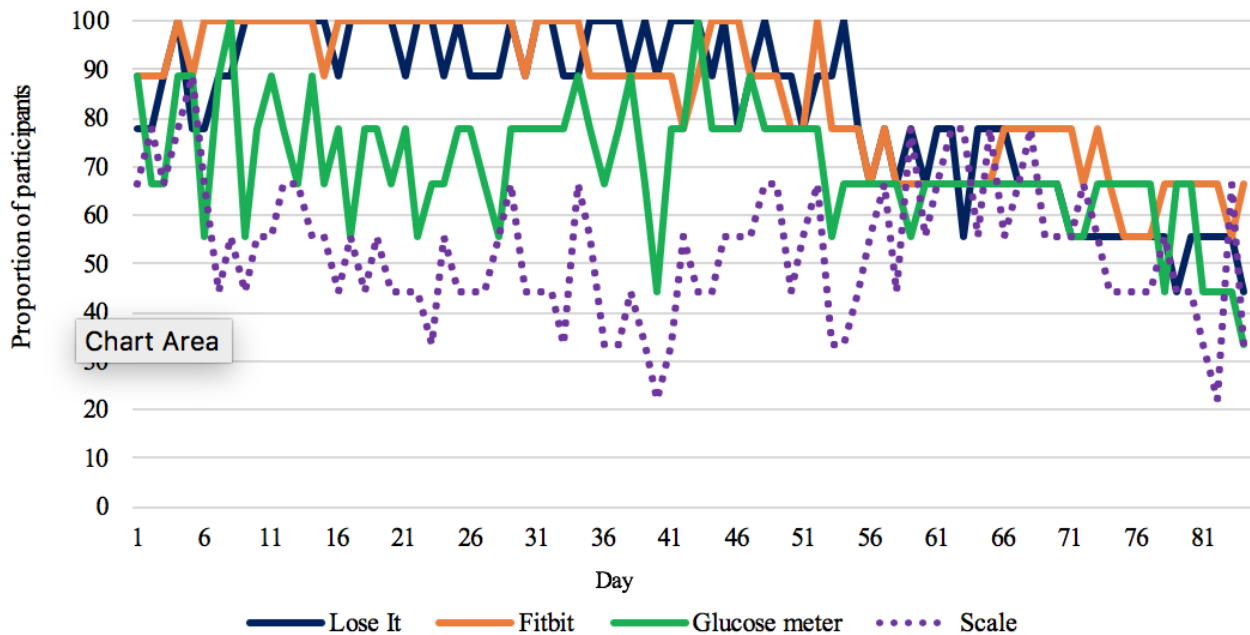
Figure 2. Number of days of using self-monitoring devices and app by week.

Figure 3 illustrates the proportion of participants using each of the self-monitoring devices each day. All participants used the Lose It! app for tracking their food intake and Fitbit Alta for tracking their PA during the first 8 weeks (56 days), and 60% to 80% of the sample continued using the 2 devices after the first 8 weeks. The proportion of the participants who used the

glucose meter and the scale was lower than that of the participants who used the Lose It! app and the Fitbit Alta during the first 8 weeks; however, the proportion of the participants who used the glucose meter and the scale was similar to that of the participants who used the Lose It! app and Fitbit Alta after 8 weeks.

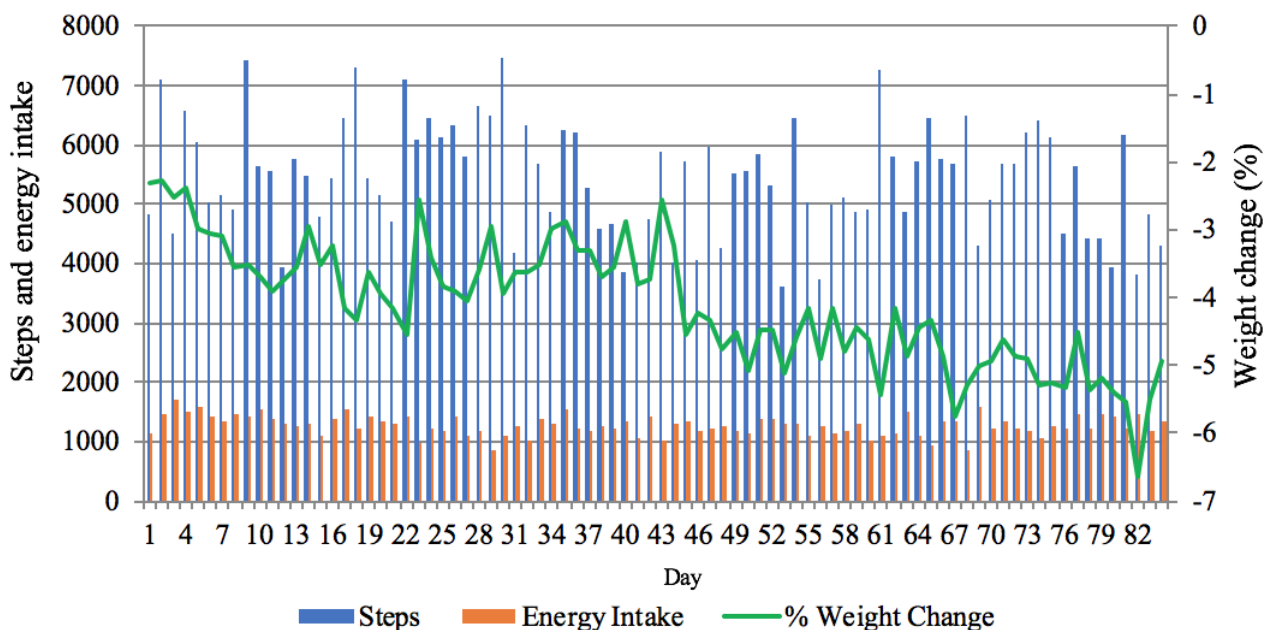
Figure 3. Proportion of participants using the self-monitoring device and app by day of monitoring.



From baseline to completion of the study (Figure 4), the mean caloric intake was 1459 (SD 661) at week 1, 1245 (SD 554) at week 11, and 1333 (SD 546) at week 12, whereas the daily step counts were 5618 (SD 3654) at week 1, 5792 (SD 3814) at week 11, and 4552 (SD 3616) at week 12. The mean percent weight loss from baseline to 12 weeks was 4.92% (SD 0.25). The dose

of oral hypoglycemic agents or insulin was reduced in 5 participants by their diabetes care providers, 4 participants' insulin prescriptions were reduced by 6 to 24 units and 1 participant's oral hyperglycemic agent prescription was reduced to a smaller dose.

Figure 4. Energy intake, steps, and percent weight loss relative to baseline by day of monitoring.



Discussion

Principal Findings

We conducted a single-group study to determine the usability of multiple health monitors among older adults with T2D. Our study participants were able to use multiple mobile health (mHealth) technology that is commercially available over a 12-week period to manage their daily lifestyle behaviors related to diet and PA. By leveraging multiple mHealth monitors, combined with group sessions, the results from our pilot study showed that improved lifestyle habits resulted in a healthy weight loss and reduced doses of insulin or other medications. Although this pilot study had a small sample size, the results are encouraging and suggest the need for a larger study to confirm the outcomes.

Comparison With Prior Work

The findings from this study are consistent with the reported research [23-25], which has demonstrated that older adults with T2D are willing to learn and use technology for disease management. Moreover, this study provides unique evidence that the older adults can use multiple devices. In particular, all participants in our sample used the Lose It! app for diet tracking and Fitbit Alta for PA tracking every day, particularly during the first 8 weeks of the study. One possible explanation for adherence is that using these 2 monitoring devices may have helped participants understand what their current diet and PA levels were compared with the goals they set with their health care team and how changes made to their diet and PA directly impacted their weight and blood glucose levels. Another possible explanation is that attendance to the biweekly group sessions, which included discussions about self-monitoring, healthy eating, PA, self-regulation skills, and problem solving, was beneficial in motivating participants to use the provided tools to support their lifestyle changes. The mean number of days participants used the scale was lower compared with the usage of the other devices. The suspected reason for missing weight data is loss of wireless internet connection; several participants reported that weight data did not transfer to their smartphone, although they did step on the scale.

Our study found that the use of mHealth by older adults with T2D resulted in lifestyle changes. This might be because of two potential reasons. First, our study guided participants' lifestyle behavior changes by using mHealth monitors to self-regulate and develop problem-solving skills [26,27]. Second, certain features of health monitors could offset some of the challenges of caring for an aging population that may face difficulty

achieving goals for multiple lifestyle changes. For example, participants were able to compare current dietary intake with goals by simply reviewing the bar or pie graphs that are automatically generated in the Lose It! app. The graphical displays may have enabled participants to more clearly see progress regarding adherence to their dietary goals [28] and may have been particularly useful for those with health and numeric literacy concerns [29].

Limitations and Strengths

The study has three main limitations; therefore, the results of this pilot study should be carefully considered. Owing to the small sample size, participants may not represent an older adult population with T2D cared for by community providers. The study should be replicated in an older population with T2D cared for by PCPs. Moreover, 2 participants in our study showed difficulty learning how to use the Lose It! app during the recruitment stage. As using a commercially available diet app such as Lose It! for diet monitoring might be relatively complex for some older populations, this issue needs to be further explored. Second, this was a single-group study, which lacked control of confounders for the behavior or outcome changes; however, the study's aim was to examine the usability of multiple health monitors for lifestyle changes. A future study using a randomized controlled design is needed to explore if and how the use of mHealth devices is more efficient in achieving improved T2D self-management outcomes compared with the standard self-management approach. Third, a majority of the participants were white and had a relatively high education level. The results might not be generalizable to other populations. However, our study has a unique strength: it is the first to demonstrate the daily use of multiple mHealth devices for diabetes management in older adults.

Conclusions and Implications

Although this pilot study had a small sample size, the results are encouraging and suggest the need for a larger study with a control group to confirm the outcomes. Future research should examine the motivation of older adults to use mobile apps to better self-manage their diabetes. A qualitative study of participants would collect valuable information to understand the role of social support in the context of the group setting in adopting and adhering to the use of new technologies. A study design that includes a control group with educational sessions without the integration of technology would offer additional insight to understand the value of mHealth in behavior changes and health outcomes observed during this pilot study.

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Conflicts of Interest

None declared.

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Abbreviations

- mHealth:** mobile health
- PA:** physical activity
- PCP:** primary care provider
- T2D:** type 2 diabetes

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Original Paper

The Feasibility and Utility of a Personal Health Record for Persons With Dementia and Their Family Caregivers for Web-Based Care Coordination: Mixed Methods Study

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Abstract

Background: Managing the complex and long-term care needs of persons living with Alzheimer disease and related dementias (ADRD) can adversely impact the health of informal caregivers and their care recipients. Web-based personal health records (PHRs) are one way to potentially alleviate a caregiver's burden by simplifying ADRD health care management

Objective: This study aimed to evaluate Personal Health Record for Persons with Dementia and Their Family Caregivers (PHR-ADRD), a free web-based information exchange tool, using a multiphase mixed methods approach.

Methods: Dementia caregivers (N=34) were surveyed for their well-being and perceptions of PHR-ADRD feasibility and utility at 6 and 12 months using close- and open-ended questions as well as a semistructured interview (n=8). Exploratory analyses compared participants' characteristics as well as PHR-ADRD use and experiences based on overall favorability status.

Results: Feasibility and utility scores decreased over time, but a subset of participants indicated that the system was helpful. Quantitative comparisons could not explain why some participants indicated favorable, neutral, or unfavorable views of the system overall or had not engaged with PHR-ADRD. Qualitative findings suggested that technology literacy and primary care provider buy-in were barriers. Both qualitative and quantitative findings indicated that time constraints to learn and use the system affected most participants.

Conclusions: Development and dissemination of PHRs for family caregivers of persons with ADRD should aim to make systems user-friendly for persons with limited time and technological literacy. Establishing health care provider buy-in may be essential to the future success of any PHR system.

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KEYWORDS

Alzheimer disease; technology; disease management; personal health record; family caregiving; informal caregiving; caregiver burnout; web-based intervention; assistive technology

Introduction

Background

In 2018, more than 16 million caregivers provided unpaid care to an estimated 5.8 million Americans living with Alzheimer disease and related dementias (ADRD) [1]. Population projections suggest that this need for assistance will expand as the number of persons aged 65 years and older with ADRD is projected to increase to 13.9 million in the United States by 2060 [2]. Unpaid spouses, children, and significant others assist with a host of complex needs, including basic daily care, symptom management, and care coordination [1]. The stress of providing this extensive care can lead to physical and mental health problems, burnout, and subsequent diminished care quality provided to persons living with dementia [3-7].

A range of interventions have been introduced to alleviate the adverse outcomes of dementia caregiving [1,2]. These interventions include programs to provide training in the management of dementia-related symptoms, bolstering resources through social support coordination, and respite designed to help caregivers maximize time free from care responsibilities [8-10]. More recently, interventions to alleviate caregiver burden and stress have leveraged modern technologies [11-13]. These technologies tend to focus on care recipients, including robotics for help with daily tasks [14,15] and socialization [16,17], remote devices aimed at promoting living at home with in-home monitoring devices [18,19], telemedicine [20,21], and other assistive technologies such as facial recognition software [22].

There is growing recognition of the need for assistive technology for caregivers of persons with dementia as well [13,23]. A number of cost-effective web-based options have emerged to support family ADRD caregivers, such as tailored education and resource portals [24-27]. Internet-based interventions are a low-cost mechanism to present education and provide support. A recent systematic review identified that the most successful internet-based interventions were multicomponent, tailored, and often involved contact with other caregivers as well as guidance from a coach. This resulted in improved decision making and self-efficacy and reduced depression and burden [28].

Objective

Personal health record (PHR) systems are a form of caregiver-focused technology leveraged to address prolonged and often-fragmented ADRD care needs. PHR systems take advantage of electronic health records (EHRs; or digital records of health information usually maintained at a care provider's institution) by consolidating information across institutions and offering easier access via web portals accessible by patients or, with permission, family members. Thus, the use of PHRs is a promising avenue for more effective coordination of ADRD health information between informal caregivers and health care professionals (eg, primary care physicians and case managers) and subsequent improved chronic disease management [29-32].

There remains little guidance regarding PHR systems or features that best support the complex and individualized care coordination needs of dementia caregivers. Personal Health

Record for Persons with Alzheimer Disease or Related Dementia and Their Family Caregivers (PHR-ADRD), a web-based care coordination tool, aimed to fill this gap.

Methods

Overview

This study examines the use of PHR-ADRD—a free web-based care coordination tool. A multiphase parallel convergent mixed methods pilot (QUAN+QUAL → QUAL) tested the feasibility and utility of the PHR-ADRD system to assist family caregivers in managing information and care during the course of ADRD [33]. Phase I used a different web platform and informed recruitment and health information access strategies for phase II [34], which is the focus of this analysis. This evaluation study of phase II aims to help elucidate the gap between development and implementation and successful adoption of care coordination tools such as PHR-ADRD among individuals providing care to persons with dementia.

Personal Health Record for Persons With Dementia and Their Family Caregivers Development

Phase I

The development of PHR-ADRD proceeded through 2 phases. In phase I, participants (N=13) tested the feasibility of Microsoft HealthVault, a similar PHR-ADRD as that used in phase II. HealthVault is a portal with manual entry or linkages with partnering health care providers for merging patient health care records into one profile, accessible anywhere via an internet-enabled device. Free features comparable with the PHR-ADRD platform used in phase II included maintaining basic demographics (eg, sex and blood type); health provider notifications; medicine and potential interaction information; as well as medical procedures performed, test results, and health condition histories [34].

Phase I revealed that a crucial barrier to the use of a PHR is access to health information from providers. Providers denied requests for information because a patient signature was illegible, refused to accept signatures from the person designated as having power of attorney, and frequently took 60 to 90 days to provide information, which was sometimes inaccurate and incomplete (eg, no images and test results). Historical medical records were also difficult to obtain if the physician or the health professional had retired. Another challenge that emerged during phase I was difficulty recruiting participants, potentially due to a lack of technological abilities, time commitment required to learn the system, fear of data security breaches, and lack of internet connectivity (especially in rural areas).

Phase II


At the conclusion of phase I [34], the research team partnered with a local developer to test their PHR platform (Alaska) for family caregivers of persons with ADRD using the same protocol but with increased attention to recruitment, technological assistance, and obtaining medical information. The phase II platform includes many of the basic features as the platform in phase I (eg, stores demographics; extensive health history, including conditions, immunizations, and test

results; and health provider message notifications), with the additional ability to authorize other caregiver users for shared access (Figures 1 and 2) [35].

Figure 1. Example Personal Health Record for Persons with Alzheimer Disease or Related Dementia and Their Family Caregivers informational screen—emergency profile.

- Home
- Basic profile
- Health views
- Emergency profile
- Weight management
- Measurements
- Health history
- Documents
- Health messages
- Apps & devices
- Sharing
- Record history


Print



Print wallet card


Print profile sheet

Share



Share emergency profile

Prepare



Find emergency apps

Carolyn Rowan
Birth date: 9/8/1946

Allergies [Add](#)

Name	Reaction	First Observed
Enalapril Maleate		...
Adhesive		...

Conditions [Add](#)

Name	Status	Onset Date	Stop Date
visual field defect nos		4/15/2013	...
Neuropsych testing		7/14/2014	...
Late effects of cerebrovascular disease, cognitive deficits		4/15/2013	...
Osteochondrodystrophy			...
Dementia			...
Osteoarthritis			...
Esophageal reflux			...

Figure 2. Example Personal Health Record for Persons with Alzheimer Disease or Related Dementia and Their Family Caregivers informational screen—health history.

The screenshot shows a web-based PHR interface. On the left is a sidebar with navigation options: Home, Basic profile, Health views, Measurements, Health history (selected), Allergies 2, Appointments, Conditions 28, Contacts, Family history, Immunizations, Insurance plans, Lab results 9, Medical devices, Medications 24, Procedure 15, Documents, Health messages, Apps & devices, Sharing, and Record history. The main area displays a table of conditions with columns for Name, Status, Onset Date, Stop Date, and Notes. A 'FILTER: All' dropdown and 'see sharing' link are at the top right. A context menu is open over the 'Dementia' entry, showing options: View details, No longer has this, Edit, Duplicate, Print, and Mark as confidential.

Name	Status	Onset Date	Stop Date	Notes
visual field defect nos		4/15/2013		...
Neuropsych testing		7/14/2014		...
Late effects of cerebrovas...		4/15/2013		...
Osteochondrodystrophy				...
Dementia				...
Osteoarthritis				...
Esophageal reflux				...
Major depressive disorder...				...
Cerebral infarction, left he...				...
Skin picking disorder				...
Obesity				...
Mitral and aortic heart val...		12/24/2009		...
Papanicolaou smear of cer...		June, 2011		...
Unspecified condition of t...		12/24/2009		...
History of stroke				...
Cataract nuclear				...
Hypercholesterolemia				...
Presbyopia				...
Hypertension				...
Myopia				...
Astigmatism				...
Diabetes Mellitus, Type II				...
Hearing loss: sensorineura...				...
Acute serous otitis media		2/13/2015		...

Attention to Recruitment

We adapted our recruitment strategy to address the limitations and challenges of phase I. In phase I, a study counselor identified and recruited family caregivers of persons with ADRD from a local dementia caregiver registry at the University of Minnesota. Phase II enhanced recruitment through more targeted communities and social network outreach. The phase II evaluation also leveraged the social networks of the PHR developer’s president/founder, a former health care advocate and employee of Minnesota’s Office Inspector General, to recruit participants.

Technological Assistance

Following the enrollment procedures, the PHR developer created a web-based profile for the ADRD caregiver on the PHR system and scheduled an in-person meeting for a hands-on tutorial at the caregiver’s home or on campus. In the meeting, the PHR developer worked with participants to link their profiles to health care providers, other family members, and local community services. The PHR developer was active in troubleshooting participants’ use of the system and encouraged usage with biweekly email and telephone prompts.

Obtaining Medical Information

The expertise of phase II PHR developers and the president/founder helped to actively obtain the care recipient’s medical information. They served as a key liaison between caregivers and providers throughout the study, particularly to obtain health records of persons with dementia when the caregiver was legally authorized to do so. Working directly with the PHR developer also enabled responsive changes in the

software to create more flexible data collection systems. It must be noted that for the phase II platform, a PHR does not need to be attached to an EHR to be used by the provider. If providers gave the necessary permission and access to care recipients’ health care data (either via electronic or paper records), this could be entered manually or automatically, depending on record format, into the PHR for use by the caregiver, other individuals, or health professionals, the caregiver could invite the PHR.

Procedure

After the initial screening for participant eligibility, informed consent from the caregiver and verbal assent from the person living with ADRD (where appropriate) were obtained, and the baseline survey was completed by the caregiver. Next, the participant met with the PHR developer to initialize use with the PHR and to familiarize them with the platform (refer to the *Technological Assistance* section).

Inclusion Criteria

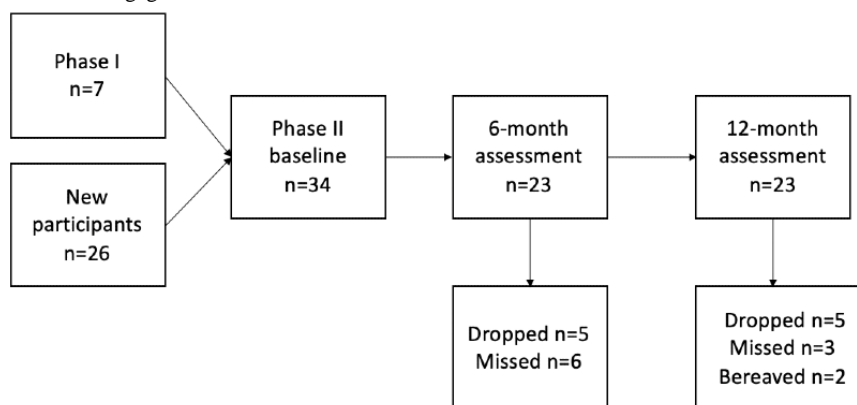
Inclusion criteria were as follows: (1) the care recipient had a physician diagnosis of ADRD; (2) the family member self-identified as someone who provided help to the person with ADRD because of their cognitive impairments; (3) the family caregiver indicated a willingness to use PHR-ADRD for care coordination purposes and access to an internet connection; and (4) the family caregiver provided at least 12 hours of in-person care per week to the person with ADRD at home, in an independent living setting, or in assisted living. As the PHR-ADRD system, surveys, and interviews were all in English, the sample was restricted to English-speaking participants. Some of the interested phase I participants were enrolled in the final

evaluation. The participant study flow and involvement are depicted in Figure 3.

Phase II caregivers were surveyed at baseline, 6 months, and 12 months regarding their well-being outcomes and physician interactions. Monthly surveys focused specifically on their use of the PHR-ADR system in the past month. Both quantitative

and qualitative data were collected regarding the use of PHR-ADR (N=34). At the end of the phase II study, a subsample of participants (n=8) was interviewed using a semistructured interview protocol. In addition, data were collected on provider interaction quality and ADR caregiver appraisals of their care situation, including self-efficacy and burden.

Figure 3. Participant enrollment and engagement flow.



Measures

The evaluation of PHR-ADR is grounded in well-established conceptual models of decision making and dementia caregiving. Encouraging patients of all ages to take an active role in their medical decisions is a keystone of modern practice [36-40], which is encapsulated in the shared decision-making model. This model is proposed to help patients make better clinical decisions and is premised on the belief that good decisions require time, structure, and adequate information [41,42]. In addition, outcome measures were informed by the stress process model, which suggests a mechanism of *proliferation* where the emotional stress of care provision to a person with dementia

(the primary stress) spreads to other life domains, which then may negatively influence the caregiver's mental or physical health and the care recipient's institutionalization [43-46]. Psychosocial resources or formal service use may help stem stress proliferation and protect dementia caregivers from negative outcomes.

Context of Care

Baseline variables included demographics of the caregivers and persons with ADR. Variables specific to the person living with ADR include time since they saw a doctor for memory problems, living arrangements, and their Medicaid status (Table 1).

Table 1. Baseline demographics of caregivers and care recipient dyads (N=34).

Variables	Total	Unfavorable (n=7)	Neutral (n=9)	Favorable (n=8)	Not engaged (n=10)	P value ^a
Caregiver						
CG ^b age (year), mean (SD)	65.4 (12.6)	68.7 (12.9)	62.9 (10.3)	63 (11.2)	67.4 (16.3)	.76
CG female, n (%)	24 (71)	3 (43)	7 (78)	7 (88)	7 (78)	.24
CG white, n (%)	33 (97)	7 (100)	9 (100)	8 (100)	9 (100)	— ^c
CG married, n (%)	28 (82)	7 (100)	8 (89)	6 (75)	7 (78)	.51
CG living children, mean (SD)	2.6 (2.2)	2.9 (2.0)	2.2 (1.4)	2.8 (2.7)	2.6 (2.8)	.95
CG bachelor's degree or higher, n (%)	31 (91)	7 (100)	8 (90)	6 (75)	10 (100)	.23
CG above median income, n (%) ^d	16 (47)	3 (43)	5 (56)	4 (50)	4 (44)	.95
CG employed, n (%)	14 (41)	3 (43)	5 (56)	3 (38)	4 (40)	.88
Care recipient						
CR ^e age (years), mean (SD)	77.6 (9.7)	76 (1.5)	73.4 (10.0)	84.1 (7.4)	77 (9.3)	.14
CR female, n (%)	17 (50)	5 (83)	2 (22)	6 (75)	4 (44)	.06
CR white, n (%)	32 (94)	6 (100)	9 (100)	7 (100)	9 (100)	—
CR married, n (%)	21 (62)	4 (67)	7 (78)	3 (38)	7 (7)	.34
CR living children, mean (SD)	3.2 (2.1)	3 (1.3)	2.2 (1.6)	4.4 (2.7)	3.4 (2.2)	.22
CR bachelor's degree or higher, n (%)	23 (68)	2 (33)	6 (67)	4 (50)	8 (80)	.27
CR above median income, n (%)	23 (68)	3 (50)	6 (67)	7 (88)	7 (78)	.45
CR activities of daily living, mean (SD)	1.5 (0.5)	1.6 (0.5)	1.4 (0.6)	1.5 (0.5)	1.5 (0.5)	.97
CR instrumental activities of daily living, mean (SD)	1.9 (1.0)	1.6 (1.1)	1.7 (1.0)	2 (1.2)	2.2 (0.6)	.50
CR RMBPC ^f frequency, mean (SD)	24.1 (0.1)	2.3 (0.4)	2.3 (0.6)	2.7 (1.0)	2 (0.2)	.42
CR cognitive impairment, mean (SD)	2.9 (0.8)	2.8 (0.9)	2.7 (0.8)	2.6 (0.8)	3.3 (0.6)	.27
CR Medicaid, n (%)	5 (15)	1 (17)	1 (11)	2 (25)	1 (11)	.85
Dyad						
CG is spouse of CR, n (%)	18 (53)	4 (57)	5 (63)	3 (38)	6 (60)	.74
CG and CR live together, n (%)	17 (50)	2 (33)	5 (56)	4 (50)	6 (67)	.65
CG first noticed CR memory problem, mean (SD), months	64.8 (26.4)	76 (36.1)	56 (32.1)	65.6 (2.6)	65.3 (17.1)	.57
CG first helped CR, mean (SD), months	36.2 (24.4)	45 (2.7)	32.3 (26.2)	4.3 (27.2)	31 (27.4)	.65
Time (months) since CR seen a doctor for memory problem, mean (SD)	48.3 (25.9)	45.8 (18)	44.1 (31.3)	48.8 (28.9)	52.8 (26)	.91

^aP values test if characteristic differs by favorability status, Fisher exact chi-square test, or analysis of variance, as appropriate.

^bCG: caregiver.

^c—: denotes no statistics were computed because these variables are constant.

^d≥80,000 for the caregiver and ≥30,000 for care recipient.

^eCR: care recipient.

^fRMBPC: Revised Memory and Behavior Problem Checklist.

Care Recipient Health and Cognitive Status

Care recipient health indicators include their dependence on assistance with *6 activities of daily living tasks* (Cronbach $\alpha=.89$) [47] and dependence on assistance with *6 instrumental activities of daily living tasks* (Cronbach $\alpha=.96$) [48,49]. An 8-item scale assessed the intensity of care recipients' memory

losses, communication deficits, and recognition failures at each time point (*cognitive impairment*; Cronbach $\alpha=.86$) [43,46]. The frequency of *behavioral problems* in persons living with ADRD was measured using the Revised Memory and Behavior Problems Checklist, which lists 30 common problems experienced by persons with ADRD (Cronbach $\alpha=.76$) [50].

Caregiver Self-Efficacy, Caregiver Distress, and Resources

An 8-item measure of *caregiver self-efficacy* was used. The 22-item *Zarit Burden Interview* measured caregiver emotional stress (Cronbach $\alpha=.92$) [51,52]. Two additional measures of subjective stress were used: a 3-item scale assessing caregiver experiences of the involuntary aspects of the caregiving role

(*role captivity*; Cronbach $\alpha=.78$) and a 3-item scale measuring caregivers' feelings of emotional and physical fatigue (*role overload*; Cronbach $\alpha=.83$) [43,46]. The 20-item *Center for Epidemiological Studies-Depression* scale measured caregivers' depressive symptoms (Cronbach $\alpha=.85$ to $.90$) [53,54]. An 8-item scale assessed the *socioemotional support* provided to the caregiver by relatives or friends at each time point (Cronbach $\alpha=.87$) [43,46] See Table 2.

Table 2. Baseline caregiver support, self-efficacy, and distress measures, (N=33),

Variables	Total	Unfavorable (n=6) ^a , mean (SD)	Neutral (n=9), mean (SD)	Favorable (n=8), mean (SD)	Not engaged (n=10), mean (SD)	P value
Socioemotional support	4.0 (0.8)	4.6 (0.5)	4.0 (0.7)	3.8 (0.7)	3.9 (0.9)	.25
Self-efficacy	3.6 (0.9)	3.7 (1.4)	3.8 (0.6)	3.6 (0.9)	3.4 (0.7)	.73
Burden	2.3 (0.8)	2 (0.8)	2.2 (0.8)	2.2 (0.8)	2.7 (0.8)	.38
Role captivity	2.8 (0.9)	2.4 (1.1)	3.2 (1.0)	2.8 (0.8)	2.7 (0.9)	.48
Role overload	2.8 (1.0)	3.3 (1.0)	3.1 (1.0)	2.6 (1.1)	2.6 (1.0)	.46
Center for Epidemiological Studies-Depression sum ^b	9.4 (7.6)	8.2 (4.2)	9.6 (8.0)	9.4 (1.1)	10 (7.7)	.98

^aOne *unfavorable* participant declined to answer these items.

^bCenter for Epidemiological Studies-Depression scores range from 0 to 30, and higher scores indicate more depressive symptoms.

Personal Health Record for Persons With Dementia and Their Family Caregivers Feasibility and Utility

Participants were sent a *monthly log* to assess how many days they used the system in the last month, the typical length of time they used it per session, whether they or a provider updated the information on it, and the reason for use. An open-ended question asked why they accessed the PHR-ADRD system in that month. At 6 and 12 months, participants answered via a web-based open- and close-ended survey, 5-point Likert scale *system review* questions about using the PHR-ADRD system

to coordinate care for their care recipients. The questions included (1) satisfaction with training, (2) content delivery and support, (3) other factors impacting the use of the PHR-ADRD system, and (4) how PHR-ADRD impacted care coordination across providers. All participants were approached at the conclusion of survey administration to complete a phone-based *semistructured interview* to expand on the utility of the PHR-ADRD system and to identify barriers to use. A full list of the open- and close-ended questions is given in Table 3 and Textbox 1.

Table 3. Most recent Personal Health Record for Persons with Alzheimer Disease or Related Dementia and Their Family Caregivers system review checklist by favorability status (N=24).

Variables	Total), mean (SD)	Unfavorable (n=7), mean (SD)	Neutral (n=9), mean (SD)	Favorable (n=8), mean (SD)	P value
The PHR-ADRD ^a was easy to use. ^b	3.4 (1.1)	2.2 (0.4)	3.6 (0.5)	4.0 (1.4)	.01
The information on the introductory screen of the PHR-ADRD was clear to me.	3.6 (1.0)	2.4 (0.5)	3.6 (0.5)	4.5 (0.8)	<.001
The information and screens that I completed on the PHR-ADRD was clear.	3.7 (1.1)	2.2 (0.4)	3.8 (0.5)	4.6 (0.5)	<.001
I was able to understand the options on the PHR-ADRD.	3.6 (1.0)	2.2 (0.4)	3.6 (0.5)	4.6 (0.5)	<.001
The [study counselor], was helpful to me when using the PHR-ADRD.	4.1 (1.1)	3.0 (1.2)	4.3 (0.7)	4.7 (0.8)	.01
I valued having the study counselor present to discuss the service options of the PHR-ADRD.	4.1 (1.2)	3.6 (1.7)	3.6 (0.9)	5.0 (0.0)	.05
After using PHR-ADRD, I was able to find something that looks as though it will meet my needs.	3.1 (1.1)	2.2 (1.0)	2.9 (0.4)	4.1 (0.9)	.001
After using the PHR-ADRD, I was able to find something that looks as though it will meet my relative's needs.	3.2 (1.0)	2.5 (1.0)	2.9 (0.4)	4.1 (0.9)	.003
My use of the PHR-ADRD led to more positive interactions/communication with my relative's primary care provider.	3.0 (1.2)	2.6 (0.5)	2.3 (0.7)	4.0 (1.3)	.006
There are time constraints to me being able to use PHR-ADRD (R) ^c .	3.4 (1.4)	4.0 (1.7)	3.5 (1.2)	2.8 (1.3)	.45
I am planning on using the PHR-ADRD regularly.	2.7 (1.3)	1.7 (0.5)	2.3 (0.7)	4.1 (1.1)	<.001
The information provided on the PHR-ADRD was clear and concise.	3.7 (1.0)	2.7 (1.0)	3.8 (0.5)	4.4 (0.8)	.002
I felt lost using the PHR-ADRD (R).	2.3 (1.2)	3.0 (1.4)	2.0 (0.0)	2.0 (1.5)	.32
I wish I would have known about PHR-ADRD sooner.	2.8 (1.2)	1.9 (0.9)	2.8 (0.7)	3.9 (1.2)	.003
After using the PHR-ADRD, I have more confidence providing care to my relative.	2.8 (1.2)	2.2 (0.8)	2.4 (0.7)	3.7 (1.5)	.04
The PHR-ADRD provided me with a sufficient number of options to support me.	3.3 (0.9)	2.6 (0.5)	2.9 (0.4)	4.3 (0.8)	<.001
The PHR-ADRD provided me with a sufficient number of options to support my relative.	3.3 (1.0)	2.8 (0.8)	2.8 (0.5)	4.3 (0.8)	.001
The overall layout, text, and design of the PHR-ADRD is very confusing to me (R).	2.4 (1.3)	4.0 (1.2)	2.0 (0.0)	1.4 (0.5)	<.001
I would be willing to use the PHR-ADRD on my own without [study counselor's] guidance.	3.2 (1.3)	2.2 (1.5)	3.1 (1.0)	4.3 (0.8)	.009
I would recommend PHR-ADRD to others in a similar situation as I am.	3.5 (1.1)	2.3 (1.1)	3.7 (0.5)	4.5 (0.5)	<.001

^aPHR-ADRD: Personal Health Record for Persons with Alzheimer Disease or Related Dementia and Their Family Caregivers.

^bHigher scores indicate more agreement with the item.

^cR: indicates that lower scores are better. Reverse scores were used for the favorability status allocation.

Textbox 1. Semistructured questions of Personal Health Record for Persons with Alzheimer Disease or Related Dementia and Their Family Caregivers (PHR-ADRD) feasibility and utility.

<p>Benefits and ease of use</p> <ul style="list-style-type: none"> • “Was the Personal Health Record for Persons with Alzheimer Disease or Related Dementia and Their Family Caregivers (PHR-ADRD) easy to use?” • “Why was the PHR-ADRD difficult to use?” <p>Functionality</p> <ul style="list-style-type: none"> • “Do you feel the services on the PHR-ADRD worked well for you? Why or why not?” • “Did the PHR-ADRD help you in interacting with your relative’s primary care provider? Why or why not?” <p>Caregiving impact</p> <ul style="list-style-type: none"> • “Did the PHR-ADRD help you feel more confident in providing care for your relative? Why or why not?” • “Do you think the PHR-ADRD has any effect on how you care for your relative?” <p>Other</p> <ul style="list-style-type: none"> • “Please add any other ways that the PHR-ADRD has been helpful to you or how you feel the PHR-ADRD could be improved.”
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Analysis

A total of 24 participants completed at least one PHR-ADRD system review checklist. The mean of the participants’ latest PHR-ADRD system review Likert sum score (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, and 5=strongly agree) was recoded into an overall favorability score by the top, middle, and bottom third percentiles, using 33.3% and 66.7% cutoff points. These corresponded to <3.03=unfavorable, 3.03-3.58=neutral, and >3.58=favorable groupings with group means 2.19 (SD=0.65), 3.22 (SD=0.14), and 4.31 (SD=0.61), respectively. The recoding procedure resulted in 7 unfavorable participants, 9 neutral participants, and 8 favorable participants with statistically significantly different checklist mean scores ($F_{2,21}=33.09$; $P<.001$). Ten more participants were coded as *not engaged* because they either were missing all follow-up surveys ($n=5$), left answers blank ($n=2$), or filled in all *not applicable* ($n=3$) for the PHR-ADRD system review checklist.

Baseline descriptive means and counts were compared among the unfavorable, neutral, favorable, and not engaged participants (analysis of variance [ANOVA] or chi-square analyses as applicable) to identify the characteristics and use experiences of those who liked or disliked the PHR-ADRD system. The PHR-ADRD system review checklist item mean scores were compared among the participants with checklist data (ANOVA). Analyses were performed using SPSS 25 (IBM Corp).

The brevity of comments on the PHR-ADRD monthly use questionnaire, the open-ended system review questions at the 6- and 12-month follow-up, and the semistructured interviews precluded a traditional in-depth qualitative thematic analysis. Instead, two coders read all qualitative data and selected quotes that provided insights into the quantitative patterns and suggested opportunities for future research.

Results

Sample Characteristics

A total of 34 caregiver-care recipient dyads were included in the survey. The baseline mean caregiver age was 65.4 (SD=12.6) years, about 70% (24/34) were female, nearly all had a bachelor’s degree or higher (31/34, 91%), and all were white. The baseline mean care recipient age was 77.6 (SD=9.7) years, 50% (17/34) were female, a majority had a bachelor’s degree (23/34, 68%), and all were white. Only 15% of the care recipients were on Medicaid. Half of the dyads were spouses (18/34, 53%); or living with each other (17/34, 50%). Caregivers had been helping their care recipient for an average of 36.2 months (or approximately 3 years; mean 35.2, SD 24.4 months). Other demographic characteristics are shown in [Table 1](#). In this study, caregivers were at the high end of socioemotional support and self-efficacy and reported low levels of burden, role captivity or overload, and depressive symptoms ([Table 2](#)).

Characteristics by Personal Health Record for Persons With Dementia and Their Family Caregivers Favorability

None of the baseline characteristics were significantly related to participants’ degree of favorability (unfavorable, neutral, favorable, or not engaged) toward PHR-ADRD, as shown in [Table 1](#). Furthermore, no statistically significant differences between the favorability status groups were indicated at baseline, 6-month, or 12-month follow-up measures of social support, self-efficacy, feelings of burden, role captivity, role overload, or depressive symptoms. Correlations and chi-square analyses using participants’ continuous mean PHR-ADRD review checklist utility scores yielded similar nonsignificant results. Altogether, this suggests that none of the quantitatively measured variables were related to PHR-ADRD experiences.

Participants who failed to engage with the technology suggested that they would have been more likely to view the technology favorably had their living arrangements or caregiving context

required more coordination across either caregiver or geographic location. For example, one caregiver explained that the technology would be most useful in cocaregiving situations where multiple caregivers share responsibility for providing care. In this context, the caregiver thought PHR-ADRDR would be especially useful when caregivers are not living in the same city. Another female participant felt that the tool would be beneficial to others but was not useful in her situation because her mother received her health care through the residential care facility where she lived:

I think it would have been really helpful, but we never actually had the opportunity to enter any information because it wasn't needed, but when I talk to other friends who are having all these family fights and issues because they don't know what's going on, or they don't have access to looking something up on the internet, I just think it would have been so incredibly helpful.

Nonetheless, this observation failed to come to bear in the quantitative data. Statistical analyses showed no difference in favorability or engagement by either living arrangement ($F_{3,33}=1.28$; $P=.73$) or spousal status ($F_{3,33}=1.66$; $P=.65$).

Personal Health Record for Persons With Dementia and Their Family Caregivers Feasibility and Utility

There was a statistically significant decrease ($t_{14}=4.21$; $P=.001$) in the overall mean PHR-ADRDR review checklist utility scores for the subsample that completed system reviews at both time points. The 12-month review checklist had a mean score of 3.84 ($SD=0.74$) and the 3-month checklist had a mean of 3.22 ($SD=1.06$) for a mean difference of -0.46 (95% CI -0.70 to -0.23).

Qualitative interviews provide insight into why PHR-ADRDR may have been useful for some caregivers and less useful for others. One interview respondent appreciated that the technology organizes everything in one place. The caregiver explained:

It's one place shopping. Everything is there for me. When we've gone to the hospital, all I've had to do is print out, or take my computer with me, his medications, his previous hospitalizations, all of his doctors contact numbers, the site is very easy to use...There's also a place to store all of the legal documents, his power of attorney, his medical directives, his POLST forms, and that's very helpful. You don't have to grab 100 papers if you need to use any of those documents.

She went on to explain that PHR-ADRDR also helped her husband stay engaged in his care:

I think he also likes the fact that when we need to go to the hospital, or some kind of medical thing, that he can tangibly hold on to the papers and feel like he's also part of the discussion.

Other caregivers found the tool useful for organizing medications, to-do lists, and appointments.

Despite these advantages, other users felt as though the technology was redundant and needlessly complex. One caregiver said that it was easier for her to call her adult children to provide updates rather than enter updates into PHR-ADRDR. She explained that the system's alert feature alerted users of updates but did not specify what was updated. This left users to search through PHR-ADRDR, looking for what had been updated. She elaborated:

I would put something in and they would get an alert, but they didn't know where I had put something in, under which category, and they didn't take the time to search out where I had put it.

Several caregivers said that they already had access to similar tools (eg, MyChart) through their health care provider and using the PHR-ADRDR was redundant.

Individual items were examined using correlations with participants' overall mean checklist scores and across favorability status groups using the tertile cutoffs (ie, unfavorable, neutral, or favorable) with an ANOVA approach (the *not engaged* participants had no PHR-ADRDR checklist scores and so were not included in these comparisons). All correlations were statistically significant with the exception of two items, which were mirrored in the ANOVA analyses. As shown in Table 3, only *I felt lost using the PHR-ADRDR* ($R^2=0.347$; $P=.12$) and *There are time constraints to me being able to use PHR-ADRDR* ($R^2=-0.218$; $P=.40$) were not associated with group status. Participants generally did not feel lost using PHR-ADRDR but did feel that time was a barrier to using the system.

Qualitative data echoed our finding that the time to learn and use PHR-ADRDR was a barrier. Caregivers noted in open-ended questions that they were too busy to use the PHR-ADRDR technology. In addition to the lack of time, this could indicate that the platform was too complicated and not user-friendly. For example, one participant reported that the system had *bugs* and discontinued using the system. In addition to the technology itself, users' level of comfort with technology is another potential explanation for the low engagement and favorability among some caregivers. According to one caregiver:

I think it's very worthwhile if you have relatives spread out around either the state, or the United States. I guess one thing that I had a problem with and this is my fault for not pursuing it- is, because I'm not that computer savvy, I didn't really know how to enter different reports we got from the doctor. I didn't know how to put that into the system.

There were no statistically significant differences in PHR-ADRDR use and engagement with the system between favorability groups as measured by mean days accessed, minutes spent during each access session, or times updated with health information (either by the CG or by a provider), as reported in the monthly logs (Table 4). The *not engaged* participants were significantly less likely to have filled out the monthly log in the first place ($F_{3,30}=4.88$; $P=.007$), which resulted in a lack of data for comparison of the monthly log items.

Table 4. Total Personal Health Record for Persons with Alzheimer Disease or Related Dementia and Their Family Caregivers use and log-use descriptives (N=34).

Variables	Total, mean (SD)	Range of responses	Unfavorable (n=7), mean (SD)	Neutral (n=9), mean (SD)	Favorable (n=8), mean (SD)	Not engaged (n=10), mean (SD)	P value
Number of monthly logs completed	3.4 (2.8)	0-8	3.6 (2.6)	5.0 (2.6)	4.3 (3.1)	1.0 (1.5)	.007
Total number of days the site was used ^a	8.7 (22.2)	0-96	1.3 (1.5)	3.1 (4.9)	24.5 (38.9)	— ^b	.12
Total minutes of each site visit	26.5 (16.4)	7-70	3.0 (9.0)	21.5 (8.9)	3.1 (27.5)	—	.72
Total number of times the caregiver or the care provider updated the site information	1.0 (1.4)	0-5	0.5 (0.5)	0.9 (1.2)	1.8 (1.9)	—	.23

^aNot engaged participants were only in the monthly log comparisons and therefore have missing data for the other comparisons.

^bMissing data.

Caregiver Provider Interaction

Favorable participants were most likely to agree that the use of the PHR-ADRD system *led to more positive interactions/communication with my relative's primary care provider*, whereas neutral and unfavorable participants were more likely to disagree ($P=.006$; Table 3). Very few caregivers updated or had their provider update the PHR-ADRD site with their medical information (total number of updates ranged from 0 to 5 over the whole study period), and it did not differ by favorability status ($P=.22$; Table 4).

Qualitative data point to a lack of provider buy-in as a barrier to PHR-ADRD engagement. One caregiver elaborated:

I think it's a brilliant program. I just think it needs to get started from the hospital/doctor standpoint...I wasn't able to really use the platform because my doctors and nurses and pharmacists didn't use it.

Another explained the barriers to using the platform and pointed to systemic barriers in the health care system:

I engaged several providers but ultimately hit a dead end each time. They won't share information directly with [the PHR-ADRD system], and they won't access the information even if they are entered by other healthcare providers. The responsibility falls onto the caregivers' shoulders to specifically request the information each time...This I find overly burdensome and that is why I finally gave up.

In all, participants were frustrated with entering their care recipients' medical information into the PHR-ADRD system and desired more buy-in from their providers to resolve this issue. Even favorable participants only updated or had their provider update their information about twice over the 12-month study period.

Discussion

Summary of Results

The PHR-ADRD system was neither extensively used nor favorably regarded by a majority of caregivers in the study, even with the PHR developer support and the use of a more interactive and flexible PHR platform. In particular, about

one-quarter of the enrolled participants were not engaged with the PHR-ADRD system to the extent that they did not fill out the system review checklist at any follow-up. Still, the users who did like the system (ie, the favorable group) consistently had positive reactions to all aspects of it, as seen in the items listed in Table 3.

Although a majority of older adults are interested in technological solutions to assist in caregiving [55], the dissemination and actual use of these tools has been less successful due to issues with web technology such as ease of use, availability of support, and computer literacy for both users and clinicians [56]. These issues seemed consistent in this PHR-ADRD study despite the system being designed with the goal of reducing the time needed to manage health information (eg, provider message notification capability and record access) and technology support provided by the developer. Participants still felt that there were time constraints and reported technological issues as barriers to effectively using the PHR-ADRD system. These findings align with a recent study that identified several ways in which another similar internet-based medical management tool was perceived as difficult to use: caregivers were reluctant to add another management tool to their already busy day-to-day activities, found the system itself difficult to use in terms of cognitive workload, and reported the system's tools to be of limited dynamic functioning [57]. Although this study's participants did not feel particularly lost using the PHR site, systems designed for ADRD caregivers need to pay extra attention to user interface design to equitably reduce cognitive and time burdens for users from all technological backgrounds [58].

Furthermore, concerns about privacy and confidentiality among ADRD caregivers and their care recipients may have limited the success of the PHR-ADRD tool [59]. A recent AARP survey found that about one-third of respondents did not trust health care companies to keep personal data secure on the web [55]. To allay these privacy issues, this project enlisted the help of the PHR developer to call or meet with participants to discuss their concerns. However, not all participants experienced the same benefits from this contact, as the helpfulness of this was perceived differently by favorability status. Building in administrative or advisory support for PHR systems that meet the needs of all users will increase the likelihood of favorability

reception and may alleviate concerns about privacy. In addition, PHR developers need to ensure privacy and confidentiality through high-quality security, employee training, and system audits [28].

Participants indicated that they may not have particular use for this kind of shareable medical platform. Over 93% (17/18) of the spousal caregivers in this study lived with their care recipient at baseline and so likely share less of the caregiving responsibilities with other family members. Family members who share caregiving responsibility with others may benefit more from the ability to manage and exchange medical data [18,60]. The qualitative data suggested that the tool may be more useful for those coproviding care and those whose care recipients are not residing in a long-term care facility. However, post hoc ANOVA analyses showed no difference in favorability or engagement groups by either living arrangement or spousal status.

In the future, systems such as PHR-ADRDR may be better received as more services are digitized, internet access is more universal, and the aging population becomes more technologically literate. EHRs are now used by more primary practices, and broadband penetration is making access to high-speed internet a reality for an increasing number of people, making such internet-based platforms for sharing medical information potentially more feasible [61,62]. Nonetheless, this study suggests there are still ongoing practical and translational issues regarding provider buy-in and the transfer of medical data into web-based systems such as PHR-ADRDR, particularly third-party platforms external to the health care system. Qualitative data indicate that lack of provider use and difficulty in sharing data across health care systems was a barrier to the usefulness of PHR-ADRDR. Negative provider PHR-related attitudes, extra work, and lack of reimbursement are potential reasons for the lack of provider buy-in and EHR facilitation. Provider buy-in may also allay potential privacy and security concerns [63]. This will have to be addressed even as the market moves into the development of user-friendly mobile phone apps [64].

Strengths

This was a multiphase, mixed methods approach to testing the PHR-ADRDR system, an internet-based medical health platform aiming to serve caregivers of persons living with dementia. This study attempted to build on the successes of its pilot phase to improve facets of the research design and PHR-ADRDR tool while giving voice to the caregivers (open-ended questions and interviews) with an eye toward continuous development. The PHR-ADRDR system itself was developed with a person-centered approach, geared toward shared decision making, and allowed

PHR-ADRDR caregivers and authorized users access to the medical data stored on the system. By leveraging the network and expertise of the PHR-ADRDR developer, the final evaluation was able to recruit a larger sample and make early changes to the software to enhance health data collection within the system. A previous relationship with the PHR-ADRDR developer for a limited number of participants did not appear to bias the results of the study, given the diversity of positive and negative reflections on the use of the system.

Limitations

Despite increased outreach efforts and time devoted to recruitment of ADRDR caregivers, this study still fell short of its original recruitment goal, both in terms of sample size (only 34 instead of 50) and diversity (all white participants). The general lack of diversity among older persons in Minnesota, where this study took place, limited recruitment in this regard. The nature of PHRs themselves may have limited recruitment and engagement as they currently require providers or caregivers to manually enter EHRs and do not appear as novel as other technology-based interventions such as in-home sensors or robotic aids. The small sample size may have limited the discovery of statistically significant differences to corroborate the qualitative findings. However, these exploratory analyses did demonstrate barriers that should be overcome before proceeding to a larger trial. The lack of significant findings should not be taken as definitive evidence that relationships do not exist. In addition, the follow-up and engagement of the participants was limited. Participant contact logs should be kept to evaluate whether technological and administrative support can improve PHR-ADRDR feasibility and utility. Finally, PHR use information was limited to self-report by the participant, which may have resulted in reporting bias.

Conclusions

The technological literacy of some participants, inherent complexity of a web-based PHR system, and lack of provider buy-in were considerable barriers to a majority of participants favorably engaging with this study's PHR-ADRDR system. Furthermore, the PHR-ADRDR system may not have been useful for those living with and providing sole care to their care recipient. Even so, a third of the participants found many facets of the system to be beneficial, such as medical document consolidation and portability. Future PHR-ADRDR development and adoption efforts should focus on reducing user interface complexity, increasing technological support, and improving provider buy-in and health record access so that these rapidly emerging dementia caregiver support tools can exert positive, meaningful benefits for people living with ADRDR and their family caregivers.

Conflicts of Interest

None declared.

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Abbreviations

ADRD: Alzheimer disease and related dementias

ANOVA: analysis of variance

EHR: electronic health record

PHR: personal health record

PHR-ADRD: Personal Health Record for Persons With Alzheimer Disease or Related Dementia and Their Family Caregivers

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Original Paper

Perspectives From Municipality Officials on the Adoption, Dissemination, and Implementation of Electronic Health Interventions to Support Caregivers of People With Dementia: Inductive Thematic Analysis

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Abstract

Background: Very few evidence-based electronic health (eHealth) interventions for caregivers of people with dementia are implemented into practice. As part of a cross-border collaboration focusing on dementia and depression in older people, two eHealth interventions for caregivers of people with dementia (“Myinlife” and “Partner in Balance”) were adopted by nine municipalities in the Euregion Meuse-Rhine.

Objective: This study aimed to (1) identify determinants for the implementation of eHealth interventions for caregivers of people with dementia in a municipality context and (2) formulate implementation strategies for these interventions.

Methods: Eight municipality officials were interviewed using open-ended, semistructured interviews about their background, thoughts on the implementation of the intervention, recommended strategies, and thoughts on eHealth in general. One additional municipality discontinued the implementation project and submitted answers to the interview questions via email. The interviews were transcribed and independently analyzed using inductive thematic analysis.

Results: The interviews provided information on the perspectives of municipality officials on implementing eHealth for caregivers of people with dementia in their local communities. Key findings from the inductive thematic analysis included the importance of face-to-face interviews in developing tailor-made implementation plans, the need for regular meetings, the enthusiasm of municipality officials to implement these interventions, the need for long-term sustainability planning through collecting data on the required resources and benefits, and the effect of name brand recognition in adoption.

Conclusions: The findings contribute toward filling the previously identified gap in the literature on the implementation context of eHealth interventions for caregivers of people with dementia. Municipality officials’ views indicated which implementation determinants they expected would influence the adoption, dissemination, and future implementation of eHealth interventions for caregivers of people with dementia in a municipal context. These insights were applied to tailored implementation strategies to facilitate the future implementation of interventions such as Myinlife and Partner in Balance.

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KEYWORDS

dementia; caregiver; internet; eHealth; implementation, senior friendly communities

Introduction

Electronic Health and Dementia Caregiving

Informal caregivers provide essential care to people with dementia, and this can have both positive [1] and negative effects on the caregivers' daily lives [2-4]. Previous research has shown that these positive effects can include an enriched relationship with the person with dementia, whereas the negative effects include burnout and social isolation. Electronic health (eHealth) interventions are *"treatments, typically behaviorally based, that are operationalized and transformed for delivery via the Internet"* [5]. eHealth interventions for caregivers of people with dementia have shown evidence of effectiveness at improving a wide range of negative outcomes for these caregivers, including the reduction of depressive symptoms, anxiety, and burden [6-9]. In addition to the evidence of their effectiveness for caregivers, eHealth interventions have the potential to meet the challenges faced by many modern health care systems as result of aging populations and declining birth rates [10]. For instance, eHealth interventions can provide a lower threshold to participation, more opportunities for personalization, instant delivery, real-time feedback, and increased accessibility for reaching more isolated populations who experience difficulties in gaining access to traditional services [11,12].

However, very few psychosocial interventions for caregivers of dementia find their way from effectiveness trial to practice [13], including eHealth interventions for caregivers of people with dementia [14]. Bringing these evidence-based interventions into practice would be beneficial in a number of ways, including a more efficient allocation of research resources, a reduction of unnecessary research replication, and their eventual benefit to caregivers through sustainable implementation. Previous research has pointed toward the absence of knowledge on the contextual environment as a significant barrier for health system planners and implementers in translating these interventions into practice [15,16]. For instance, as eHealth interventions bypass the traditional delivery methods and care structures, many health care professionals and governing bodies do not know how to implement the interventions and modify existing structures and norms to incorporate them [17]. An important reason for this absence of knowledge on contextual factors is the gold standard of randomized controlled trials (RCTs) as evidence, which often lack crucial, qualitative implementation data [18]. There has been a call for more realistic, efficient research designs that take the context of the eHealth intervention into account [19]. For eHealth, this involves gaining insight into the relevant aspects and actors of organizations and communities in the real-life contexts where the interventions will be implemented. An example of such an implementation context is municipalities looking to offer Web-based support to caregivers of people with dementia.

Study Aims

The aims of this study were twofold. First, this study aimed to gain insight into the views of municipality officials on the upcoming implementation of two eHealth interventions in their communities, to shed light on their reasons for adopting the technology and their strategies for dissemination and implementation. The two studied interventions were Myinlife, a Web-based platform to organize dementia care, and Partner in Balance, a Web-based course (see Methods). This study's findings will help identify potential implementation determinants and fill the knowledge gap in the environmental and contextual factors that influence sustainable eHealth adoption, dissemination, and implementation. Second, this study aimed to translate the insights from these interviews into implementation strategies, to aid researchers in implementing evidence-based eHealth for dementia caregivers. The definitions for these terms as employed in this study are *"the decision of an organization or a community to commit to and initiate an evidence-based intervention"* for adoption, *"the active approach of spreading evidence-based interventions to the target audience via determined channels using planned strategies"* for dissemination, and *"the process of putting to use or integrating evidence-based interventions within a setting"* for implementation [20].

Methods

Study Setting

This study took place in the context of the euPrevent Senior-Friendly Communities (SFC) project [21], involving 32 municipalities from the Euregion Meuse-Rhine. Here, a municipality refers to a town or district that has a local government. Municipalities' governing functions differ between countries, though in general they are responsible for local services that can include health care, education, recreation, and sport. This project ran from September 2016 to December 2019 and was implemented in the Euregion Meuse-Rhine, a border region covering parts of Belgium, Germany, and the Netherlands, which contains 150 municipalities. A total of 32 municipalities signed up to take part in the broader SFC project on a *first come, first serve* basis. The project first made an inventory of how the communities were already supporting their aging population and what they could still improve in this regard [22]. Afterward, municipalities chose activities from a so-called "activity buffet" consisting of 15 pre-existing activities. These activities addressed the mental health of older people, paying particular attention to dementia and age-related depression, including cultural activities such as a theatre production, a photo exhibition, consultations with experts on various topics, educational sessions on relevant topics and psychoeducation, creation, and organization of local social networks of elderly, and outreach activities. They also included two eHealth interventions to support caregivers of people with dementia: "Partner in Balance" and "Myinlife." On average, each municipality chose to implement four activities.

Studied Interventions

Partner in Balance

Partner in Balance is a blended care, 8-week, self-management intervention that helps caregivers of people with dementia adapt to their new roles. Detailed information about the program components and development is presented elsewhere [23]. In short, the blended care self-management program Partner in Balance consists of (1) a face-to-face intake session with a personal coach to familiarize participants with the program, choose Web-based modules, and set goals; (2) tailored Web-based thematic modules, including psychoeducation, behavioral modeling, reflective assignments, change plans, and email feedback from the coach over 8 weeks; and (3) a face-to-face evaluation session with the coach evaluating previously set goals. The coaches are health care professionals with experience in dementia care (eg, in the Netherlands, the Partner in Balance coaches are often dementia case managers). In a recent RCT, Partner in Balance was shown to be effective in improving caregivers' sense of competency, self-efficacy, and quality of life [23,24].

Myinlife

Myinlife is a Web-based platform for caregivers of people with dementia to involve their social network in organizing care and share positive caregiving moments. In the Netherlands, Myinlife has been integrated into the Alzheimer Netherlands website. Myinlife has the potential to simplify caregiving and provide caregivers with more control over their agendas [25,26]. The platform consists of the following functionalities: profile, circles, timeline, calendar, helping, personal messages, care book, and compass.

Study Design

In total, 9 of the 32 SFC municipalities opted to implement one of the two available eHealth interventions for caregivers of people with dementia in their communities: 6 municipalities chose Partner in Balance (4 in the Netherlands, 1 in Belgium, and 1 in Germany), whereas 3 chose Myinlife (2 in Belgium and 1 in Germany). The method of semistructured interviews was chosen because of its suitability to small-scale and flexible research, which matched the setting of this implementation study [27]. In each participating municipality, an open-ended, semistructured interview was conducted with the municipality official responsible for the implementation of the intervention. The interviews were on average 18.79 min long and took place in the period of about 6 months between the municipalities' decision to adopt the interventions and their actual implementation. The interview questions were about the municipality official's background, expectations concerning the implementation of the intervention, recommended strategies, and thoughts on eHealth in general. The complete interview guide can be found in [Multimedia Appendix 1](#).

Participants

In total, 8 in-person interviews were conducted. A ninth municipality chose to discontinue the implementation and delivered written answers to the interview. The reasons for this are discussed in the Results section. The officials interviewed in the remaining 8 participating municipalities had varying job descriptions. The majority described themselves as municipality policy officials, whereas some described themselves as employees responsible for specific activities concerning seniors, volunteers, demography, or specific local care facilities. [Table 1](#) lists some specific characteristics of the 9 communities who had chosen Myinlife or Partner in Balance from the activity buffet. As the participating municipalities wished to remain anonymous, any identifying information has been left out.

Table 1. Characteristics of the participating municipalities.

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

^aPopulation statistics sourced from the euPrevent Senior-Friendly Communities project [21,28].

Data Collection

Ethical approval for the study was granted by Maastricht University's Medical Ethical Oversight Commission under approval number 2018-0489. The 8 in-person interviews were conducted by one of the authors (HC) at each municipality's town hall or equivalent between July 2018 and December 2018. Each participant received an information sheet about the background and aims of the study, in addition to information on how their data would be processed and stored. Each participant agreed to and signed an informed consent form.

Interviews were conducted using a semistructured interview guide. Five interviews were conducted in Dutch, one in English, one in French, and one in German. The municipality that discontinued the implementation delivered written answers to the interview questions via email in Dutch.

Data Analysis

The interviews were transcribed verbatim using transcription tool F5 (dr. dresing & pehl GmbH). If conducted in a different language, transcriptions were translated into Dutch by two authors (HC and MS). The method of inductive analysis was

chosen to explore the current perspectives of municipality officials, as this domain has not been much researched, and there was little notion of the factors and themes that might emerge [29,30]. On the basis of the inductive analysis with no pre-existing categories or themes, individual codes were grouped into themes and categories. Afterward, the themes and categories were compared in a consensus meeting with another author (MD) to resolve any differences of opinion, resulting in the final thematic analysis. Thus, this method of inductive analysis served to inform the study's two objectives, which are explored using this study's results, previous findings, and relevant literature in the Discussion. Two authors (HC and MS) independently coded the interviews using the described inductive thematic analysis method and software tool Atlas.ti for Macintosh (Atlas.ti Scientific Software Development GmbH).

Results

Overview

Four main themes emerged from the inductive thematic analysis: the eHealth intervention, the users, the organization, and the wider context. Within the themes, categories and groups were formed (Table 2). These themes can be seen as concentric circles, where the constructs in each widening circle are further removed from the smallest circle. The circles all interact with and influence each other. For the purposes of clarity and as a reflection of the chronological process, the following sections will start by discussing the outermost circle (the wider context) and then work inward toward the innermost circles (the organization, the users, and the eHealth intervention).

Table 2. Interview themes and categories.

Theme	Categories and subcategories
1. Wider context	<ul style="list-style-type: none"> • 1.1 Municipality's context and political climate • 1.2 Bottom-up versus top-down push for eHealth^a • 1.3 Municipality values <ul style="list-style-type: none"> • 1.3.1 Staying close to the citizen • 1.3.2 Sustainability • 1.3.3 Valuing volunteers • 1.4 Societal factors <ul style="list-style-type: none"> • 1.4.1 Self-management in health care • 1.4.2 Sustainable integration with daily practice • 1.4.3 Brand value • 1.4.4 Increased needs for dementia care • 1.4.5 Political support for digital future
2. Organization	<ul style="list-style-type: none"> • 2.1 Internal: The municipality <ul style="list-style-type: none"> • 2.1.1 Implementation strategies • 2.1.2 Attitudes • 2.2 External: Collaboration with local organizations <ul style="list-style-type: none"> • 2.2.1 Emphasize added value to external organization • 2.2.2 Improving quality of care • 2.2.3 Financial sustainability planning
3. Users	<ul style="list-style-type: none"> • 3.1 Caregivers <ul style="list-style-type: none"> • 3.1.1 Dissemination: Through media, convincing through personal contact, gaining attention, events • 3.1.2 Involving users • 3.1.3 Personalization • 3.1.4 Involvement in the implementation • 3.2 Coaches <ul style="list-style-type: none"> • 3.2.1 Difficult to find/train/guide coaches • 3.2.2 Resource shortage • 3.3 Lack of users' digital abilities <ul style="list-style-type: none"> • 3.3.1 Caregivers • 3.3.2 Coaches
4. Intervention	<ul style="list-style-type: none"> • 4.1 Thoughts on eHealth <ul style="list-style-type: none"> • 4.1.1 Must keep modules up to date • 4.1.2 The Netherlands and Scandinavia at the forefront • 4.1.3 Risks around data leaks • 4.1.4 More familiarity with data systems than with apps • 4.1.5 Easier to reach people than traditional interventions • 4.2 Experiences with eHealth <ul style="list-style-type: none"> • 4.2.1 As a database for patient information • 4.2.2 In an educational context • 4.2.3 In the media • 4.2.4 No experience • 4.3 Expectations about future success of intervention implementation <ul style="list-style-type: none"> • 4.3.1 Ideal situation • 4.3.2 Expectations

^aeHealth: electronic health.

Wider Context

The term wider context refers to the social, political, and economic settings in which the municipality resides. The results of the inductive thematic analysis indicated that the municipality officials viewed a number of social, political, and economic factors as contributors to the choice to adopt Partner in Balance and Myinlife. Examples of this include the increase in older

people and dementia in the municipality, and the municipalities seeing the future as increasingly digital.

All over the community it's the digital things that are successful and also the future and so, it would be strange if the medical part doesn't take part.
[Respondent 6]

Furthermore, the fact that the intervention was evidence-based and had an academic “name brand recognition” resulting from its origins as a university research project, was a facilitating factor for some municipalities. Municipality officials mentioned that their choice of intervention depended on whether the intervention was in line with the values and policy of the municipality. In this regard, they mentioned that Myinlife and/or Partner in Balance matched their work on sustainability, caregiver support, and “staying close to the citizen.” When choosing which interventions to adopt for the project, the majority of municipalities reported having made the choice internally. However, two municipalities assembled a panel of lived-experience experts in dementia and caregiving and chose those activities which the panel identified as most relevant for their community. A final recurring theme regarding the choice to adopt the interventions was the bottom-up versus top-down approach to eHealth. Some respondents felt that eHealth is mainly pushed through top-down initiatives but that the population of their municipality does not express a desire for it.

Then you have the bottom-up or top-down approach, there is something to be said for the two of them. Now you started with the bottom-up, and yes, we are going to see how that goes and if that does not work, then we have to see if a top-down might become something. Then we have to see from which top we are going to start, so to speak. [Respondent 5]

The reasons for adopting Myinlife and Partner in Balance seemed similar for both interventions. It is interesting to note that municipalities that had chosen to implement Partner in Balance emphasized both the advantages of the intervention for the caregiver as well as for the coach.

Besides adoption, the wider context also played a role in planning the upcoming dissemination and implementation of the interventions in the communities. For instance, politically, imminent elections and the merging of three municipalities into one municipality made concrete planning difficult, as the budget and officials responsible might change.

Organization

When mapping the organizations involved in implementing Myinlife and Partner in Balance, the organizations were divided into two groups: internal (the municipality) and external (all local organizations they wanted to involve in the implementation). Concerning the internal attitudes of the municipality employees on the upcoming implementation, it appeared that the more familiar they were with the intervention, the more enthusiastic they were. Several long- and short-term implementation strategies were identified, such as appointing a contact person responsible for the intervention in the municipality, frequently checking up on and facilitating the intervention, and having a clear time plan.

It's not like it's ready-made. It's still about people, you have to remember that, you have to facilitate that, you have to motivate that. If you don't do that...everything depends on it, especially in this kind of work. If you think: Yes, now...I have thought it up

nicely and it will come naturally...that will not work.

[Respondent 2]

Concerning the external cooperation with local organizations, the responses showed that municipalities felt it was particularly important that the eHealth intervention should improve health care in their community. In particular, they hoped it would connect various links in the local care network. Examples of organizations the municipalities wished to collaborate with for the upcoming implementation were local care homes, case management organizations, geriatric departments of hospitals, caregivers' associations and support groups, general practitioners and other clinical professionals' practices, social work, dementia expertise centers, and home care organizations. The municipality officials expressed some wariness toward the Web-based aspect of the interventions and emphasized that the interventions would only be useful if there were demonstrable improvement in local health care services, although they noted that this would be hard to measure. This described external involvement of local organizations can also be seen as a kind of implementation strategy, and it was mentioned in every interview. For Myinlife, the external cooperation mostly served the purpose of aid in advertising and publicizing to disseminate the intervention to the target users. For Partner in Balance, the external cooperation with local health care organizations was an essential part of recruiting the platform's coaches, as they needed to have experience with both dementia and care.

But, yes, or that, will it make a difference later in care? When you talk about “care” - because that is central - I don't know, does [Myinlife] contribute to increasing the quality of care? [Respondent 4]

The respondents also foresaw significant barriers to implementation: Finding the time necessary to invest in publicizing and communicating about the intervention; finding coaches for Partner in Balance; convincing the older population of the platforms' advantages; and financially guaranteeing the sustainability of the interventions. The municipality that discontinued the implementation and subsequently submitted answers to the questions by email chose to focus on this topic. This municipality felt that the inability of Partner in Balance to guarantee what a license would cost after the project's end was a significant barrier. They also said the following:

There were too many unclear circumstances. Our neighbourhood teams had already started, the cooperating partners had full agendas and it was not clear what the costs were after the project. [Respondent 9]

Users

The theme *users* groups all statements from the municipality officials regarding who would be using the interventions. On the basis of their responses, two user groups were identified: the caregivers themselves and the coaches. The user group of the coaches is specific to Partner in Balance and does not apply to Myinlife. This finding of the coaches as a user group was interesting, as it had been expected that the coaches would be seen more as a part of the implementing staff described in theme category 3.2 (Table 2). However, it appeared that both the caregivers and the coaches were seen as target users of the

platform by the community officials, both of whom required recruitment with specific dissemination strategies.

So finding the coaches of course and maybe...finding the coaches is of course natural, but it is a real challenge...And, of course, reaching sufficient informal caregivers who want to sign up for this. [Respondent 4]

Concerning the recruitment of caregivers, municipality officials recommended focusing on younger caregivers, such as the children or grandchildren of people with dementia; involving local people with dementia and their caregivers in the implementation by consulting with them; being inclusive by trying to reach caregivers from all different backgrounds; and making sure the approach was personalized, as everyone has unique situations and needs. Specific dissemination strategies included media attention through both social media and press conferences, convincing local groups of the advantages of participation, and organizing face-to-face events. In this regard, the municipalities thought maintaining human contact was an essential part of the dissemination strategy. They proposed organizing stakeholder and caregiver meetings, rather than relying on digital and print communication.

I think, if we are going to focus purely on the partners of people with dementia, that we are only going to be able to reach very few people effectively. Because with a biased prejudice, maybe I am wrong, but I have this idea that older people are less open to web-based assistance than the younger generation. But I also know that there are many children who care for their mother or father with dementia, and we can reach them and if they have that knowledge they can hopefully also pass it on to the partner, so that we can also reach them directly. But I think that the online data is a difficult one. Plus, yes, it is now a one-off initiative - it has to be supported from [higher-up], and that must also remain on the agenda... [Respondent 5]

Concerning the recruitment of coaches, again, municipality officials stressed a lack of resources on the coaches' side, such as time and money, as a foreseeable barrier to effective dissemination and subsequently, implementation. As described in 3.2 (Table 2), most municipalities were keen to recruit both professionals and volunteers from local care organizations. However, one municipality also wanted to offer caregivers of people with dementia the chance to be coaches for Partner in Balance. They emphasized that it was important that these prospective lived-experience coaches would also be supported by a local dementia association. Furthermore, municipalities very often thought that both the caregivers and coaches of the target group would have a hard time with the Web-based aspect of the eHealth interventions.

Yes, most are actually received positively. The only thing is, we don't know how many people are going to respond, so is that going to take off? (laughing) That is also, a, a consideration, that you sometimes hear, that I have heard a few times. But there is enough interest for that kind of stuff? You will only

know that by trying and making it known and then seeing how much response there is. [Respondent 5]

Intervention

This theme describes the municipality officials' thoughts on both the chosen platforms specifically and on the idea of eHealth in general. Though they did expect the Web-based aspect of the interventions to be a complicating factor, there were predominantly positive attitudes toward eHealth. However, most had not yet worked with eHealth themselves and had only heard about it. Of those that did have experience with eHealth, it was common that they had come into contact with it in an educational context, such as at a university or in a training workshop. Respondents were, in general, more familiar with eHealth in the context of online databases for patient information than with apps. Taking into account the limited sample size, there were no obvious relationships between the age or job description of the participants and their experiences with eHealth. Most respondents were optimistic about the chances of successfully implementing the intervention in their communities, but some also felt that it would not be suitable for everyone, or that it could only be really successful in the future (but not right now). When asked what the ideal implementation of Myinlife or Partner in Balance in their communities would look like 2 years from now, municipality officials said they would like to see it be an integrated part of local care services. Some also gave indications of the minimum number of users they would like to be on the platforms. These were quite small, the largest number being 30.

Well, ideal for me would be that it is well known, that it is completely embedded in the guidance of caregivers. That it is well-known to everyone who is confronted with dementia, that you can also get support from it as an informal caregiver, in addition to the regular care of course, the most optimal care for the person with dementia themselves. I think that's important. And that we have enough coaches, who are motivated to do this motivated and who...experience this as a meaningful activity. [Respondent 3]

Discussion

Principal Findings

This study examined municipality officials' views on the adoption, dissemination, and implementation of evidence-based eHealth interventions for caregivers of people with dementia in their local communities. The resulting inductive themes provided interesting insights that helped meet this study's two objectives. First, these findings help fill the gap in the literature concerning the organizational and contextual factors that influence this process by identifying potential implementation determinants. Second, these findings aid the future implementation of eHealth interventions such as Myinlife and Partner in Balance by using these insights to formulate specific implementation strategies.

Mapping the Implementation Context and Identifying Potential Determinants

Regarding the first, more general objective of mapping the implementation context to identify determinants that influence implementation, the following lessons were learned. The first lesson concerns the level of enthusiasm, both from the municipality officials and the target groups. The interviews demonstrated that municipalities were enthusiastic about the idea of implementing eHealth to support caregivers of people with dementia in their communities. Indeed, nine out of 32 municipalities in the Euregion chose to adopt and implement the two eHealth interventions on offer in the activity buffet. Previous research has explored the views of stakeholders concerning the implementation of health technologies, including care professionals, managers within home care or social work organizations, technology designers, and policy makers [31,32]. However, to our knowledge, none have explored the views of municipality officials. Knowing that municipalities are enthusiastic about these interventions is important for future developers looking for a viable implementation environment for their interventions. For instance, municipalities in the Netherlands are responsible for supporting their local caregivers and have funds allocated for this [33]. As the municipalities seem to have positive attitudes toward eHealth, as well as available funds and incentives to support caregivers, implementing eHealth through municipalities seems to be a viable option, especially if they focus on caregiver support.

Belgian and German municipalities are not necessarily responsible for municipal caregiver support, although they do facilitate care support through collaboration with local organizations and health care providers [21]. It is, however, important to note that the municipalities did mention experiencing a top-down push for eHealth and doubted whether their current older population would have an interest in using these interventions. Research into older adults' attitudes toward eHealth interventions has shown mixed results [34-36], with evidence suggesting that older adults living in more rural areas (such as many of those included in this study) express less interest and capacity to use eHealth [37]. However, studies have also shown positive attitudes toward the use of eHealth both in older populations [38] and for younger caregivers [39]. Previous eHealth research has also mentioned enthusiasm from both target groups as well as the implementing organizations as an important implementation determinant [40].

The interviews demonstrated that, despite the Web-based and remote nature of eHealth interventions, the municipality officials all emphasized the importance of organizing face-to-face meetings with stakeholders and prospective users to facilitate a successful implementation. This builds on the findings from previously conducted Myinlife pilot studies, RCTs, and process evaluations, which showed a lack of effects on the trial's quantitative outcomes [25,41]. In particular, the process evaluation [26] provided qualitative insights that led to continued implementation of Myinlife, such as the overwhelmingly positive user experiences. For instance, the Myinlife process evaluation emphasized that online and offline support was necessary to facilitate the caregivers' knowledge of their own social support needs and available social capital.

This is in line with municipality official's views in this study, as they often mentioned the desire to organize meetings with the local caregivers. Future implementers should take into account that using events to promote the intervention and engage the target audience is recommended, especially for this older population, who might be harder to reach through online dissemination channels such as social media [42]. In addition, when comparing the concentric circles of influencing factors described here and in the Myinlife process evaluation [26], it is important to note that there is no circle discussing the influence of organizational factors in the Myinlife process evaluation. As is the case with many process evaluations, this is because of the fact that the process evaluation took place in a trial context, and there was no "external" implementation, as the implementation was carried out by the research team. However, it is important for researchers to consider these "internal" organizational factors in the process evaluation as well to facilitate the following implementation steps [14]. This need for more detailed information on the offline implementation aspect has been discussed in previous research [43] and would provide future implementers with useful information to make decisions regarding the viability of the intervention in its organizational context.

Next, the interviews also demonstrated that the municipalities considered the targeted recruitment of not only the caregivers but also of the coaches as an important contributor to successful implementation. Previously, the Partner in Balance process evaluation [44] had highlighted the importance of tailoring interventions to user characteristics and needs as well as the need for more research on the implementation process and context. Although the process evaluation did recommend an active role for health care professionals in guiding caregivers through the caregiving process, researchers had previously not considered the Partner in Balance coaches to be a part of the "user group." They had instead seen them as a part of the implementing organization. This is contrasted by the findings from this study, where municipality officials saw both the caregivers and the coaches as two separate user groups that required specific recruitment strategies. Although disseminating the intervention to coaches using specific implementation strategies is resource intensive, there is evidence to show that the addition of this "blended" aspect to an eHealth intervention significantly enhances outcomes [7,45,46].

The uncertainty around how long the interventions would continue to be available after the project and how much they would cost was a significant barrier. Indeed, this issue caused one municipality to discontinue the implementation of Partner in Balance. The necessity of long-term business modeling to ensure sustainable implementation of eHealth interventions is in line with previous research, both for dementia [47] and other populations [48]. In this regard, mapping the surrounding health care context and other financial stakeholders in relation to the intervention characteristics is essential, for instance by applying the Business Model Canvas [49]. Insight in whether and how much municipalities would be willing to pay is essential to sustainably implement these interventions.

Importantly, the responses from the municipality officials show that the "name brand" (in this case, the name of Maastricht

University and the Alzheimer Center Limburg) behind the eHealth intervention was an important factor in the decision to adopt the interventions. Not only the fact that they were evidence-based but also the fact that a reputable organization could vouch for the interventions was considered important. This is supported by previous research on health care provider adoption of eHealth [32] and emphasizes that developers of future interventions should consider highlighting the “name brand” value of their interventions, if applicable.

Finally, the process of conducting the qualitative, semistructured interviews with the municipalities was a very helpful exercise. These interviews helped avoid surprises in planning the later implementation by making expectations and agreements concrete. This fostered a sense of trust and understanding of the other parties’ needs. The interviews also allowed for the development of tailor-made implementation strategies, as recommended by Damschroder [50]. These tailor-made strategies also help provide a sense of ownership to the municipality, as they have a hand in designing them so that they fit the local context and stakeholders. Future eHealth developers looking to implement in municipalities or other organizations should consider holding similar “baseline interviews.”

Translating Insights Into Specific Implementation Strategies

Regarding the second, more specific objective of formulating implementation plans for eHealth interventions such as Myinlife and Partner in Balance, based on the insights into municipality implementation determinants, the following strategies can be applied to aid researchers in their future implementation into practice:

1. *Regularly contacting municipality officials:* There will be one municipality official responsible for implementing the interventions in the municipality as an official contact person. It is important that the research team has regular contact with this person by having regular meetings to create goodwill and a productive rapport.
2. *Organizing face-to-face meetings with both local stakeholders and caregivers:* It is important to organize events to provide caregivers with information on caregiving and offering eHealth as a support tool. The municipalities’ wish to organize events to disseminate and promote the interventions further underscore this point that eHealth interventions, whatever their original design or intent, necessitate some amount of human contact and personal tailoring. Each community will organize a stakeholder meeting and a caregiver meeting to embed the interventions in the local, unique care landscape.
3. *Making use of existing local services:* Local dementia services in each municipality will be contacted to be part of the eHealth project teams, as well as help with the recruitment of both caregivers and coaches. In addition, other local services will be contacted including nursing and mental health care services, as well as youth groups, professional training and apprenticeship schools, and hospitals.
4. *Regular eHealth project meetings:* Each municipality will have an eHealth project team in addition to the municipality

contact person. The contact person will be responsible for encouraging enthusiasm and increasing familiarity with the interventions and between team members. Members of the project team will include the municipality contact person, a representative from the research team, and the interested parties from the stakeholder and caregiver meetings.

5. *Promoting through online and offline campaigns:* In addition to the offline events, such as the stakeholder meetings, caregiver meetings, and eHealth project team meetings, municipalities will be encouraged to disseminate the interventions through any online channels they might have (such as websites, social media, and newsletters).
6. *Emphasizing name brand, evidence-based aspect:* All presentations and communication materials will emphasize the input of name-brand contributors, such as Maastricht University, Alzheimer Netherlands, ZonMW, the Alzheimer Center Limburg, INTERREG, and euPrevent.
7. *Collecting data to inform licensing model and ensure sustainability:* Describing the hours and financial resources needed during the project will help the municipalities decide whether the project will be sustainable in the future. These data will also help the research team and other future developers to budget for this need for continued, personalized support to the implementing organizations, informing sustainable business models and implementation plans. In this regard, it is important to consult with a local health authority to learn where their outcome priorities lie, so this can inform which data are collected.
8. *Tailoring more general strategies:* Each municipality’s implementation plan also includes strategies specific to the local population and services, such as collaborations with local technology companies and recruitment of local experts-by-experience as coaches. Given the finding that the health care and municipality context varies widely between countries, and even regions, certain aspects of the more general strategies will have to be tailored to the differing local services. For example, the Public Centers for Societal Welfare (*Openbaar Centrum voor Maatschappelijk Welzijn*) in Belgium are organized very differently and have different goals than the Dutch municipalities’ Law for Societal Support (*Wet Maatschappelijke Ondersteuning*) services.

The proposed strategies can help researchers in two ways. First, based on the experiences of this project, the strategies could help future researchers achieve a more successful collaboration with implementing organizations outside of the academic trial context. Second, applying these strategies could result in more much-needed data on the dementia eHealth implementation context, which many stakeholders (such as health insurers) claim is necessary for the scaling-up of these interventions. More generally, increasing the rate of successful, sustainable implementation of evidence-based eHealth interventions for caregivers of people with dementia can have significant societal advantages, including more targeted and efficient research funding, the possibility for caregivers of people with dementia to gain access to the interventions developed for them, as well as the opportunity for health care systems to provide more targeted, cost-efficient, and evidence-based Web-based dementia support [42].

Limitations

To our knowledge, this is the first study that explores the views of municipality officials on implementing eHealth interventions in their local communities. However, this study does have a few important limitations. First, with the exception of the municipality that chose to discontinue the implementation and submitted the answers to the interview questions by email, all of the participating municipalities had already chosen to implement eHealth in their communities. This results in the study's sample being biased to look favorably on eHealth implementation, as it does not take into account the views of those municipalities that did not choose these interventions. Furthermore, it is important to consider that this study interviewed municipalities that had signed up to be a part of the SFC project, and thus, could have been more motivated to successfully implement the interventions than "independent" municipalities might have been. Moreover, the SFC context limited the number of studied municipalities to those that had signed up to implement Partner in Balance and Myinlife, which resulted in a relatively small sample size and made it difficult to assess whether data saturation had been reached. Nevertheless, this study provides a useful overview of why the municipalities that opted to adopt these eHealth interventions did so, and many common themes were observed in the interviews. Second, as some of the authors were involved with the research institute that had developed both interventions and were responsible for their implementation, it is possible that the respondents were influenced to provide socially desirable responses. However, doubts and concerns were also expressed, and one municipality withdrew from the implementation, so there is reason to believe the municipalities still provided a

nuanced and truthful account of their views. In addition, the researchers had no advantage associated with municipalities choosing one eHealth intervention over the other, or instead of the other SFC activities. Finally, it is important to remember that all implementation plans were hypothetical at the time of interviewing, as they had not yet started implementing the interventions. Although this approach made it possible to offer tailored implementation strategies, it also presumably made it difficult for the respondents to provide insight based on their experiences with the two specific eHealth interventions, although they did discuss their views on eHealth in general (Table 2, theme 4.2). Future research will evaluate the effectiveness of the proposed strategies.

Conclusions

This study helps fill the gap in the literature concerning the implementation context of eHealth interventions for caregivers of people with dementia. The interviews provided information on how municipality officials view eHealth for caregivers of people with dementia and what they see as determinants of successful implementation. Proposed municipality implementation determinants included the enthusiasm from municipality officials to implement these interventions (despite a top-down push for them), the importance of face-to-face interviews in developing tailor-made implementation plans, regular face-to-face meetings with an eHealth project team, long-term sustainability planning by collecting data on required resources and benefits, and the facilitating effect of name brand recognition in adoption. Future research should collect data to inform pricing models to ensure long-term sustainability as well as evaluate the efficacy of the various proposed implementation strategies.

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Conflicts of Interest

Authors HC, FV, and MD were involved in the development of the studied eHealth interventions (Myinlife and Partner in Balance).

Multimedia Appendix 1

Interview guide for the semistructured qualitative interviews.

[DOCX File, 85 KB - [aging_v3i1e17255_app1.docx](#)]

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Abbreviations

eHealth: electronic health

RCT: randomized controlled trial

SFC: Senior Friendly Communities

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Original Paper

How Caregivers of People With Dementia Search for Dementia-Specific Information on the Internet: Survey Study

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Abstract

Background: During the last decade, more research has focused on web-based interventions delivered to support caregivers of people with dementia. However, little information is available in relation to internet use among caregivers in general, especially those caring for people with dementia.

Objective: The aim of this study was to evaluate the dementia-related internet use and factors that may be associated with its use among caregivers of people with dementia in Greece.

Methods: Secondary data from the Greek Dementia Survey of the Athens Association of Alzheimer's Disease and Related Disorders were collected from April to June 2017. A total of 580 caregivers of people with dementia participated in the study.

Results: The majority of the caregivers reported that they had used the internet in the previous 3 months (84.1%, 488/580). Nearly half of the caregivers (47.5%, 276/580) reported that they had received dementia services online. Bivariate analysis showed that a dementia-specific search of information was associated with age, education, kinship, and years of care. Age (odds ratio [OR] 2.362, 95% CI 1.05-5.33) and education (OR 2.228, 95% CI 1.01-4.94) were confirmed as predictors, with younger caregivers and those with higher educational attainment being more likely to search for dementia-specific information. Use of the internet to search for dementia information was only related to hours of care. The internet use by caregivers within the previous 3 months was associated with variables such as age, education, occupation, kinship, years of care, and self-reported impact on physical and social health.

Conclusions: Caregivers of people with dementia in Greece, as in the other southern European countries, are essential agents of the national health system. The existing short- and long-term respite care services are limited or nonexistent. Currently, caregivers receive mostly support and education from memory clinics and municipality consultation centers, which are mainly based in central cities in Greece. Despite the dementia awareness movement in Greece, there is still space to integrate the role of technology in the support and education of caregivers. Development of training programs for enhancing electronic health literacy skills as well as web-based services provision could support Greek caregivers in their everyday caring tasks.

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KEYWORDS

caregivers; internet; dementia; eHealth

Introduction

Caregivers of frail older people and people with dementia are a significant component of the national health care system across European countries [1]. Caring for a person with dementia is a demanding job, resulting in difficulty for caregivers to maintain their physical, psychological, and social health. Previous research indicates that caregivers are a more vulnerable group than the general population with problems ranging from social isolation; feelings of anger, guilt, grief, depression, and physical exhaustion; and difficulties in the reconciliation of work and care responsibilities [2-4].

The recent focus of research on web-based interventions supporting informal caregivers of people with dementia in their everyday tasks has revealed the role that these interventions will play in the coming years. Caregiver platforms providing psychoeducation, training, and other interventions, including telemedicine and other telehealth services such as mobile apps (eg, medication reminders, cognitive and reminiscence training, relaxation techniques, and forums), are only a few examples of the existing services that are accessed through the use of technology [5-9]. According to a recent scoping review [8], the majority of articles examining these interventions did not provide adequate information on use of the technology by caregivers after the end of the intervention. In the same review, the majority of the caregivers stated that the interventions were acceptable and usable. Therefore, there is a clear gap between the web-based interventions for caregivers and their overall web-based usage.

In the concept mapping presented by Chiu and Eysenbach [10], information and communication technology (ICT) factors, caregivers' needs, and style of use are three core categories that influence the use of web-based interventions for caregivers of people with dementia. The accessibility, required effort, and style of use (interactive or passive) in combination with the social support, caregiving beliefs, self-efficacy, and years of caregiving reflect the complexity in understanding caregivers' web-based service use. In this theoretical model, it is also relevant to add the component of electronic health (eHealth) literacy-related skills. Caregivers could benefit from the use of web-based services as they are cost-effective and easily accessible. However, this will only be successful if caregivers obtain or enhance their eHealth literacy skills. eHealth literacy is a concept that was initially defined by Norman and Skinner [11] in 2006, but the definition continues to trouble researchers [12].

Although studies have been performed to evaluate the factors influencing the health-related internet use of older people, little information is available on the specific population of family and other informal caregivers [13]. Research on the health-related internet use of older people confirms age and education as strong predictors of internet use, giving the advantage to younger and more educated people [14-18]. The number of electronic devices also seems to be a predictor of internet use [15]. Low income, low socioeconomic status, and racial/ethnic minorities are considered as predictors of internet nonuse [16]. Lack of skills when navigating the internet was

the most common problem identified within a sample of people with rheumatic diseases, including difficulty in operating the computer and internet browser, navigating and orientating, utilizing search strategies, evaluating relevance and reliability, adding personal content to the web, and protecting and respecting privacy [19].

Age, gender, and occupation are associated with frequency of internet use among caregivers, even though they typically use the internet less frequently than the general public [13,20]. Caregivers seem to prefer to search for information on disease-specific websites and those related to patient organizations out of habit and accessibility to influence the search for information online [21]. Nevertheless, the doctor remains the primary source of information [21]. In a study of caregivers online (ALZconnected [22]), the authors identified the need for caregivers of people with dementia to post more emotion-related posts; queries about the disease did not exceed 12% of the posts.

According to Piirto et al [23], internet access in Greece increased by 28% between 2009 and 2014, with 49% of daily users in 2014 comprising the age group of 16 to 74 years. This percentage increased to 85% in 2017, according to updated data from Eurostat [24]. Typical activities include reading the news, finding information, email, social networking, health information search, downloading software, and searching for a job. Three in four people in the age group of 65 years and over reported using the internet daily [25]. In Greece, only 5% of people in the age group above 55 years searched the internet once a week for health-related information according to the Flash Eurobarometer 404 survey conducted in 2014. These searches usually included health promotion topics (eg, diet, exercise) and information on specific diseases and treatments [26].

The aim of the present study was to investigate the dementia-related internet use by caregivers of people with dementia in a sample of caregivers in Greece and to determine possible factors that may influence internet use, and consequentially the use of web-based interventions. This study is part of a more extensive project for the development and implementation of training services for caregivers of people with dementia. Our main aims were to determine (1) the information-seeking behavior among caregivers of people with dementia in Greece with a focus on internet use (dementia-specific information on the internet or other sources, and use of web-based services); (2) whether information-seeking behavior differs according to caregiver sociodemographic characteristics; and (3) the preferred training delivery method for caregivers of people with dementia in Greece.

Methods

Study Design

This study followed a descriptive study design to identify associations among caregiver characteristics and information-seeking behavior with a focus on internet use. The methodology followed the Checklist for Reporting Results of Internet E-Surveys [27]. Secondary data obtained from the Greek Dementia Survey of the Athens Association of Alzheimer's

Disease [28], a password-protected survey, were analyzed. The Greek Dementia Survey represents the first study among caregivers of people with dementia at a national level to investigate the educational needs, care service awareness, and style of internet use.

The survey was distributed by email or in hard copy form provided by the social workers of dementia centers. The aim of the Greek Dementia Survey included identifying demographics, training needs, available services for caregivers, and type of web-based services used. In total, the Greek Dementia Survey included 40 questions using multiple-choice, dichotomized

responses (yes/no), or Likert-scale responses focusing on the caregivers' training needs. The items were developed as part of a literature review and the consensus meetings of the experts in this area, including stakeholders such as the Athens Association of Alzheimer's Disease and researchers focusing on dementia research. The electronic questionnaire was developed by the survey agency and was pretested within the research team (5 members). A survey agency organized the data collection from April to June 2017.

The data from 23 survey questions (including sociodemographic characteristics) were used for the present analysis (Textbox 1).

Textbox 1. Items included in the Greek Dementia Survey for the present analysis.

- Sociodemographic characteristics: gender, education, age groups, occupation, financial status, caregiver relationship to patient, family status, type of caregiver, and period of caring
- Self-reported impact of caregiving (1 item)
- Search for dementia-specific information (6 items), training delivery preferences, and caregivers' perceptions regarding the satisfaction derived from the information found
- Internet use for dementia-related information

1. "Do you or any close relative have internet access?"

2. "Have you used the internet in the previous 3 months?"

3. "Have you used a smartphone in the previous 3 months?"

4. "In the previous 6 months, have you received any dementia-related services (list) via the telephone, internet, face-to-face visit with an expert, or did not receive any such service?"

5. "If you have received any of the above services via the internet, please mention if it was accessed through a website, a social network, email, forum, video, blog FAQ, eLearning, teleconferencing, Quiz, or Chat."

Survey Administration

A total of 580 primary and secondary caregivers of people with dementia participated voluntarily in the survey by replying to online or to face-to-face questionnaires. No incentives were offered for the caregivers' participation. The sample was identified from Athens Association of Alzheimer's Disease registries and social media advertisement.

The survey was disseminated for 2 months through social media of the Athens Association of Alzheimer's Disease, and health care professionals also informed dementia daycare center members of the survey. For those with access to email, the survey was emailed through a link. A unique access code was provided to every participant. The access code was stored together with the survey results to eliminate duplicate entries. The participants could save their responses and return to complete the survey, or they could edit or clear the replies and initiate the survey another time. The survey comprised a total of 6 screens, including the consent page. The duration of the survey ranged from 5 to 23 minutes, with a mean time stamp of 10 minutes. If the caregivers could not access the internet, health care professionals of the dementia centers of the Athens Association of Alzheimer's Disease administered the survey as a face-to-face interview.

The inclusion criteria were as follows: caregivers over 18 years old, either primary or secondary (friend or family supporting the primary caregiver), of a person with dementia, helping the person in activities of daily living, and being capable of reading

and writing in the Greek language. As there is limited research on internet use among caregivers of people with dementia, we expanded the inclusion criteria to both primary and secondary caregivers, since age is a factor influencing internet use and secondary caregivers are usually children younger than the primary caregiver. After the questionnaires were submitted, a completeness check was performed. In total, 31 of the 580 surveys (5.3%) were incomplete.

Statistical Analysis

All data received by the email survey were entered manually into Statistical Package for the Social Sciences software (SPSS Inc, Chicago, IL, USA) by two researchers (NK and AM) who are staff members of the survey agency. Incomplete questionnaires were also analyzed. For analysis of the secondary data, descriptive statistics for caregiver characteristics and the replies received were computed. Bivariate analysis and binary logistic regression (backward conditional method) were performed.

Ethics Approval and Informed Consent

Permission to conduct the study was granted by the Scientific Committee of the Athens Association of Alzheimer's Disease, and was approved by the Executive Board on March 14, 2017.

Caregivers expressing interest in participating in the study were informed about the aim of the study, the length of time, and data storage by a researcher of the Athens Association of Alzheimer's Disease (NK). At the end of the study, only the

two data analysts (AM and AL), who are staff members of the survey agency, and the primary investigator (AE) had access to the data. Data will be stored for 5 years from the end of data collection. The researcher only used the email addresses of the caregivers to provide the link and the access code of the survey. The researcher (NK) invited the members of the Athens Association of Alzheimer's Disease to participate, and after obtaining their consent, emailed them the survey link and access code. The participants that were not members of the association were informed about the survey by the association's social media page and then emailed or messaged the researcher directly requesting the survey link.

Results

Female caregivers and adult children caring for their parents constituted the majority of the sample. The majority of the participants considered themselves to be primary caregivers who undertook all of the responsibility or shared equal responsibility rather than as secondary caregivers. Caregivers under 65 years old were most highly represented among age groups. Nearly half of the caregivers were employed and about a quarter of the participants were pensioners. The majority of the caregivers had attained tertiary-level education and were married or cohabitating with a partner. Regarding the duration of care, the majority of caregivers had been caring for fewer than 5 years, with about a third of participants being caregivers for more than 5 years. Nearly half of the participants reported living with difficulty or needing to borrow money (Table 1).

Caring tasks had a negative impact on the psychological and social health of the caregivers for 67.6% (392/580) and 57.1% (331/580) of the participants, respectively. The majority of the caregivers (94.7%, 549/580) searched for dementia information in multiple ways (telephone, internet, printed material, available services, health professionals), and among those who replied positively, 54.6% (300/549) frequently searched for information and only 19.3% (106/549) reported that the information they found met their needs.

Nearly two in three (59.7%, 346/580) of the participants considered education about dementia to be very important. Nevertheless, only a small percentage of participants stated a preference to receive the training from eLearning (114/580, 19.7%) or a videoconferencing tool (34/580, 5.9%). Over a third of the participants (218/580, 37.6%) stated a preference for a blended learning training program with both face-to-face seminars and eLearning courses, with a similar proportion

stating a preference for face-to-face training alone (207/580, 35.7%). The remaining participants indicated a preference for obtaining information from printed material (5/580, 0.8%) or other sources (0.5%).

Only a small percentage of the caregivers (5.3%, 31/580) did not access the internet. The majority of the caregivers reported that they had used the internet in the previous 3 months (84.1%, 488/580). They also reported that they used the internet mainly through smartphones or tablets (82.8%, 404/488) and almost half of the total sample (47.6%, 276/580) received dementia services online. Furthermore, the majority of caregivers reported that they had learned about available dementia services through the internet, followed by those informed by their doctor as a second source of information. The detailed breakdown of the sources of information is provided in Table 2.

Among the total sample, the majority of caregivers reported searching for online information about the disease (38.4%, 223/580), practical issues (23.3%, 135/580), available services (17.9%, 104/580), nonpharmacological interventions for people with dementia (10.7%, 62/580), and support and self-help advice for caregivers (7.8%, 45/580). They also reported that they do not frequently use the internet to interact with other caregivers or health care professionals to find out about financial issues, services related to patient safety, telemedicine, working caregiver support services, and mobility services for the person with dementia.

Caregivers who searched and used dementia services online within the previous 6 months mostly searched through websites (82.6%, 228/276), social media (28.3%, 78/276), and emails (21.4%, 59/276). The majority of caregivers searched in forums, blogs, or acquired information from videos, eLearning, teleconferences, quizzes, and chatrooms.

Regarding searching for dementia-specific information, we found statistically significant associations for women ($\chi^2=18.000$, $P<.001$), younger age ($\chi^2=10.865$, $P=.03$), higher education ($\chi^2=8.288$, $P=.02$), employed ($\chi^2=14.126$, $P=.007$), caring for a parent ($\chi^2=7.994$, $P=.012$), fewer hours of care ($\chi^2=17.698$, $P<.001$), and fewer than 5 years of care ($\chi^2=18.000$, $P<.001$) (Table 1).

Binary logistic regression analysis confirmed the associations of age and education. Caregivers under 65 years (odds ratio [OR] 2.362, 95% CI 1.05-5.33, $P=.04$) and those with more than 12 years of schooling (OR 2.228, 95% CI 1.01-4.94, $P=.05$) were more likely to search for dementia-specific information.

Table 1. Caregiver demographics and their association with dementia-specific information searching (N=580).

Characteristic	Respondents, n (%)	Dementia-specific information search			P value
		Frequently, n (%)	Occasionally, n (%)	Never, n (%)	
Gender					<.001
Women	430 (74.1)	244 (56.7)	166 (38.6)	20 (4.7)	
Men	150 (25.9)	55 (36.7)	84 (56.0)	11 (7.3)	
Age (years)					.03
<65	483 (83.3)	254 (52.6)	209 (43.3)	20 (4.1)	
66-85	93 (16.0)	44 (47)	38 (41)	11 (12)	
>86	4 (0.7)	1 (25)	3 (75)	0 (0)	
Education					.02
<12 years of secondary education	237 (40.9)	123 (51.9)	94 (39.7)	20 (8.4)	
Tertiary education	343 (59.1)	176 (51.3)	156 (45.5)	11 (3.2)	
Occupation					.007
Unemployed/student/homemaker	140 (24.1)	83 (59.3)	48 (34.3)	9 (6.4)	
Employed	299 (51.6)	141 (47.2)	148 (49.5)	10 (3.3)	
Pensioner	141 (24.3)	75 (53.2)	54 (38.3)	12 (8.5)	
Financial status^a					.48
Living comfortably	137 (23.6)	65 (94.9)	65 (47.4)	7 (5.1)	
Living with no major difficulties	174 (30)	85 (48.9)	82 (47.1)	7 (4.0)	
Living with difficulty/borrow money	259 (44.7)	144 (55.6)	99 (38.2)	16 (6.2)	
Family status					.85
Married/cohabitation	379 (65.4)	201 (53.0)	157 (41.4)	21 (5.5)	
Single/divorced	186 (32.1)	91 (48.9)	86 (46.2)	9 (4.8)	
Widowed	15 (2.6)	7 (47)	7 (47)	1 (7)	
Caregiver relationship to patient					.19
Child	389 (67.1)	202 (51.9)	171 (44)	16 (4.1)	
Spouse	112 (19.3)	62 (55.4)	41 (36.6)	9 (29)	
Other	79 (13.6)	35 (44)	38 (48)	6 (8)	
Type of caregiver					.02
Primary caregiver or sharing equally	396 (68.3)	215 (54.3)	156 (39.4)	25 (6.3)	
Secondary caregiver	184 (31.7)	84 (45.7)	94 (51.1)	6 (3.3)	
Hours of care per week^b					<.001
<20	301 (51.9)	136 (45.2)	154 (51.2)	11 (3.7)	
>20	279 (48.1)	163 (58.4)	96 (34.4)	20 (7.2)	
Period of caregiving (years)					.005
<5	389 (67.1)	183 (47.0)	181 (46.5)	25 (6.4)	
>5	191 (32.9)	116 (60.7)	69 (36.1)	6 (3.1)	

^aTen caregivers did not provide responses related to financial status.

^bMean 38.59, SD 45.92 (median 20).

Table 2. Source of information about available dementia services (N=388^a).

Source	n (%)
Internet	154 (39.7)
Doctor caring for the person with dementia	92 (23.7)
Event/seminar	76 (19.6)
Friend/acquaintance	74 (19.1)
Informational material, journal, or newsletter	71 (18.3)
Television	49 (12.6)
Family	36 (9.3)
Health care professional in dementia care	24 (6.2)
Radio	12 (3.1)
Paid caregiver	2 (0.3)
Other	6 (1.5)

^aThis table presents the responses of 388 caregivers who replied that they knew about the available dementia services.

Internet use by caregivers was associated with younger age ($\chi_1=141.27$, $P<.001$), higher education ($\chi_1=46.23$, $P<.001$), employed ($\chi_1=49.273$, $P<.001$), caring for a parent ($\chi_2=111.61$, $P<.001$), being married ($\chi_1=8.574$, $P=.01$), caring for fewer than 5 years ($\chi_1=6.70$, $P=.01$), caring for fewer than 20 hours per week ($\chi_1=12.83$, $P<.001$), and reporting a physical impact ($\chi_1=7.76$, $P=.005$) and a social health impact ($\chi_1=4.76$, $P=.03$). According to the binary logistic regression with the backward conditional method, age, education, kinship, and caring period were confirmed as significant predictors of internet use.

Caregivers in the age group under 65 years were almost 5 times more likely to use the internet in comparison with those of the age group 66-85 years. Caregivers with higher education (>12 years) and being children of the patient were 3 times more likely to use the internet, and caregivers with fewer than 5 years of caring were almost 2 times more likely to use the internet (Table 3).

Searching for dementia-related information online was only significantly associated with the hours of care ($\chi_1=10.461$, $P=.005$).

Table 3. Predictors of internet use based on binary logistic regression.

Independent variable	Odds ratio	95% CI	P value
Age (reference category: 66-85 years)	5.096	2.324-11.177	<.001
Education (reference category: <12 years)	2.940	1.669-5.178	<.001
Kinship (1) (reference category: spouse)	3.257	1.395-7.603	.006
Kinship (2) (reference category: other relatives)	3.387	1.523-7.531	.003
Caring period (reference category: >5 years)	1.788	1.027-3.112	.04

Discussion

Principal Findings

The present study aimed to identify the dementia-specific information-searching behaviors among caregivers of people with dementia in Greece using the internet or other sources, as well as their preferences regarding the web-based tools and modes of dementia training delivery. This topic is quite innovative for this specific population, as there is no relevant research available in Greece.

The Eurostat internet use report [24] indicated that Greece had one of the lowest percentages of internet use among people 16 to 75 years old in 2018. Thus, reporting the caregivers' search behavior is a first step to recognize this issue among caregivers and to raise awareness regarding the specific health and eHealth literacy skills that are important for adapting to the new

technological era. Age and education of this sample were associated with searches for dementia-specific information.

Age and education are two variables that are strongly related to health literacy levels, and the question related to the use of a dementia-specific information search could be considered as a screening question for this population regarding their health literacy. For caregivers to search for dementia-specific information, they require the necessary motivation, knowledge, and skills, which are the three core elements according to Soerensen et al [29] in the health literacy model.

Kim [13] examined the prevalence and searched for factors related to health-related internet use among caregivers of people with dementia based on responses to the question: "How often, if at all, have you gone on internet websites in the past year to find information and resources in any way related to being a caregiver for your care recipient?" Health-related internet use was associated with younger age, higher education, fewer hours

per week in caring tasks, emotional stress, and financial difficulties in comparison with nonhealth-related internet use. In the present study, searching for dementia-specific information on the internet was associated with hours of care; however, the percentage of caregivers searching for dementia-specific information on the internet was slightly lower than that reported by Kim (47.5%). In addition, internet use by caregivers was associated with age, education, kinship, and years of care. Caregivers participating in this survey responded that they did not use the internet as a source of interaction with other caregivers or health care professionals, and forums, chatrooms, blogs, eLearning, and videoconferencing were the least used services among caregivers. They also preferred a blended training approach with the use of face-to-face meetings and eLearning.

In Greece, apps tailored to caregivers' needs have only been developed in the last 4 years as part of European research projects, and with the collaboration of Alzheimer disease associations [9]. Disease-specific associations usually develop their own informational websites. An informative platform for caregivers of older people was also developed as part of a European-funded project [6]. Social media groups for caregivers were only created in the last 2 years in Greece. However, according to our results, caregivers do not frequently use these types of services. In a related study, networking with other caregivers, facilitating interactions, and developing technologies that reflect daily experiences were reported as essential needs of the internet use by caregivers and were considered to be more critical than searching for information on care provision [30]. Therefore, our finding may reflect the lack of skills for use of the specific services by this population in combination with the lack of web services in Greece tailored to the needs of caregivers. According to Chiu and Eysenbach [10], the accessibility, perceived effort required, social support, personal skills, and beliefs, as well as the years of caregiving and the way in which a person uses the internet are all factors that influence the pattern of ICT intervention use by caregivers. Therefore, eHealth literacy skills should also be added as part of personal skills. In addition, a fourth higher-order category needs to be added together with the ICT factors reflecting caregiving needs and style of use. This category would include perspectives of health care professionals of ICT use, who should be involved in the development, implementation, and dissemination of caregiver-specific ICT tools.

In Greece, as in other southeastern European countries, caregivers of people with dementia are essential agents of the national health system. The existing short- and long-term respite care services are limited if nonexistent. Currently, caregivers receive mostly support and education as part of the services of memory clinics and municipality consultation centers, which are usually based in the central cities in Greece. Despite the dementia awareness movement in Greece, there is still space to integrate the role of technology in the support and education of caregivers. In 2016, the first eHealth literacy study was performed among Greek citizens reporting the eHealth literacy levels among different age groups and concluding the importance of age and education as predicting factors [31]. Research regarding the eHealth literacy level among caregivers

of older people in Greece and Cyprus was only published for the first time in 2019 [32]. The caregivers in Greece and Cyprus reported a sufficient level of eHealth literacy skills (eHeals-Carer total score 29.70, SD 5.30, range 8-40) in comparison with available data [33-35]. We consider that the role of technology will become of great assistance among caregivers, as it will facilitate their everyday tasks, and may help to decrease the burden on the national health system. This could be achieved if caregivers enhance their skills to search for information and learn to evaluate and apply for them, not only from the internet but also from other sources. Nonprofit organizations and the existing dementia strategy could integrate training programs regarding the enhancement of health and eHealth literacy skills of caregivers of people with dementia in Greece, as the role of new technologies will become an integral part of our society in the coming years.

Limitations and Strengths

This study included a set of questions on searching for dementia-specific information either on the internet or from other sources as part of the Greek Dementia Survey and was distributed mainly through the online registries of the Athens Association for Alzheimer's Disease. Only a small number of participants answered the questions in hard copy form owing to difficulties in accessing or using the internet. Therefore, the low eHealth literacy caregivers were not adequately represented in the sample, who might provide clearer understanding of their difficulties in using everyday technology such as smartphones and apps.

Future studies could use a more heterogeneous sample with low or no knowledge of the internet to identify the needs of technology use in Greece. Despite this limitation, this is the first study among caregivers of people with dementia in Greece, which provides new knowledge of the internet use behavior and dementia-specific information-seeking online behavior for this population, laying the foundation for future research in this respect.

In Greece, as in other southeastern European countries, older people are not well accustomed to everyday technology. There are currently no available data of the internet use by people in Greece over 75 years old [36]. Children of people with dementia typically search for dementia-specific information to assist the primary caregivers. Primary caregivers, due to older age (in the case of spouses), may not know how to use the internet or are aware only of basic internet sources (eg, visiting specific websites to read the news or to play cognitive games). These factors could justify why the majority of the present sample included children caring for their parents.

Conclusions

Internet use through tablets and smartphones has become part of everyday life in the last 20 years. Nevertheless, there is variation in internet use according to gender, age, education, socioeconomic, and cultural factors. In the next few years, training programs will be developed to enhance the informal learning of digital skills among older adults mainly as part of European projects or national digital strategies. The population above 65 years old remains a broad age group that has fewer

opportunities in comparison with younger adults. This situation was partially confirmed by our study, since the age group that used the internet and searched for dementia information was mainly under 65 years old. Based on this finding, future interventions could implement the following three aspects: (1) nonprofit associations and vocational training organizations to provide tools to enhance the health and eHealth literacy skills of caregivers of people with dementia who are over 65 years old; (2) develop low-cost, easy to use ICTs tailored to the

specific needs of caregivers; and (3) raise awareness of ICT for caregivers among health care professionals. Future research should also focus on measuring the level of eHealth literacy among caregivers of people with dementia in Greece, identifying the specific technological needs in everyday life, and piloting training programs integrating the enhancement of health and eHealth literacy skills among caregivers and health care professionals.

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Authors' Contributions

All authors contributed equally to the writing of the paper. AE was involved in writing and statistical analysis, NM was involved in data analysis, AM was involved in writing the manuscript, and PS and EP supervised the study and contributed to writing and editing the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

eHealth: electronic health

ICT: Information and communication technologies

OR: odds ratio

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Original Paper

Developing a Plan for the Sustainable Implementation of an Electronic Health Intervention (Partner in Balance) to Support Caregivers of People With Dementia: Case Study

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Abstract

Background: Given the increasing use of digital interventions in health care, understanding how best to implement them is crucial. However, evidence on how to implement new academically developed interventions in complex health care environments is lacking. This case study offers an example of how to develop a theory-based implementation plan for Partner in Balance, an electronic health (eHealth) intervention to support the caregivers of people with dementia.

Objective: The specific objectives of this study were to (1) formulate evidence-based implementation strategies, (2) develop a sustainable business model, and (3) integrate these elements into an implementation plan.

Methods: This case study concerns Partner in Balance, a blended care intervention to support the caregivers of people with dementia, which is effective in improving caregiver self-efficacy, quality of life, and experienced control. The large-scale implementation of Partner in Balance took place in local dementia case-management services, local care homes, dementia support groups, and municipalities. Experiences from real-life pilots (n=22) and qualitative interviews with national stakeholders (n=14) were used to establish an implementation plan consisting of implementation strategies and a business model.

Results: The main finding was the need for a business model to facilitate decision-making from potential client organizations, who need reliable pricing information before they can commit to training coaches and implementing the intervention. Additionally, knowledge of the organizational context and a wider health care system are essential to ensure that the intervention meets the needs of its target users. Based on these findings, the research team formulated implementation strategies targeted at the engagement of organizations and staff, dissemination of the intervention, and facilitation of long-term project management in the future.

Conclusions: This study offers a theory-based example of implementing an evidence-based eHealth intervention in dementia health care. The findings help fill the knowledge gap on the eHealth implementation context for evidence-based eHealth interventions after the trial phase, and they can be used to inform individuals working to develop and sustainably implement eHealth.

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KEYWORDS

dementia; caregiving; eHealth; implementation; business modeling

Introduction

Dementia and Caregiving

The combination of an aging population and declining birth rate is proving to be a great challenge for many modern health care systems, resulting in rising costs and spending cuts [1]. In particular, policy makers express concerns about the rising costs of dementia care, as there are currently 50 million people with dementia, and this number is set to triple by 2050 [2]. Informal caregivers of people with dementia, such as spouses, friends, and other loved ones, provide a large part of the necessary care for people with dementia at home [3]. However, the informal caregiving process often results in chronic stress, leading to caregiver overburden, depression, and anxiety [4].

Electronic Health as a Potential Solution

Policy makers and governing bodies have expressed enthusiasm for electronic health (eHealth) as a solution to tackle these current health care challenges [5,6]. Various eHealth interventions have shown evidence of effectiveness at improving outcomes for the caregivers of people with dementia, such as self-efficacy and dementia knowledge, as well as reduced depressive and anxious symptoms [7-13]. eHealth interventions are defined as “treatments, typically behaviorally based, that are operationalized and transformed for delivery via the internet” [14]. eHealth interventions provide specific advantages to the caregivers of people with dementia, as they can be personalized and adapted to the stage of dementia and allow caregivers to receive psychoeducation without leaving the person with dementia home alone and to seek help without facing the stigma associated with dementia. For these reasons, eHealth is also mentioned as an important part of the Dutch *Deltaplan Dementie* [15] and in the council of the European Union’s dementia policies [16]. Of course, there are also specific challenges associated with implementing eHealth for the caregivers of people with dementia, including the advanced age of many caregivers. While many older adults show high digital literacy, impaired motor, cognitive, and perceptive abilities can constitute relevant barriers [17-19].

Implementing eHealth for the Caregivers of People With Dementia

Unfortunately, the implementation of evidence-based eHealth interventions into routine practice has proven challenging [20-22], and previous research has shown that very few eHealth interventions for dementia are implemented into practice [23]. Here, implementation is defined as “the process of putting to use or integrating evidence-based interventions within a setting” [24]. A lack of insight into eHealth interventions’ contextual determinants and process changes is an important factor in the slow implementation of many eHealth interventions [25]. Additionally, challenges in implementing eHealth include limited evidence of the demonstrable effects on improving health care outcomes, skeptical attitudes from health care professionals, lack of coordination and management of interventions within health care organizations, and the often peripheral position of potential end users in eHealth development [26]. Many of these issues result from problematic atheoretical implementation and insufficient implementation strategies [27], which are “methods

or techniques used to enhance the adoption, implementation, and sustainability of a clinical program or practice” [28]. This lack of successful implementation is an important missed opportunity for the health care system, as advantages of eHealth interventions for health care include the potential to widen access to more remote areas, lower thresholds for participation, improve quality through increased opportunities for personalization, improve service efficiency, and reduce costs [22,29]. To facilitate the sustainable success of these promising interventions, it has been argued that the development of a business model is paramount [30]. Here, a business model is defined as “the rationale of how an organization creates, delivers, and captures value” [31]. Business modeling can be seen as part of an effective implementation strategy, primarily through its potential to both aid sustainable financing and identify value drivers to ensure the relevance of the interventions to the target users [32]. Finally, it is important to note that the specific challenges experienced in implementing eHealth interventions for the caregivers of people with dementia can differ across settings. In this study, we explored the at-home setting of Partner in Balance, which is implemented through health care organizations.

The Intervention: Partner in Balance

One example of an eHealth intervention to support the caregivers of people with dementia is Partner in Balance. Partner in Balance is a web-based tool to support the caregivers of people with dementia at home, which is applied in a “blended” 8-week eHealth intervention. This “blended” aspect entails that Partner in Balance is delivered through a coach. These coaches are part of participating health care organizations (for example, dementia case management organizations), who have agreed to offer the Partner in Balance intervention to their clients. Partner in Balance coaches are required to have experience (1) in healthcare and (2) with dementia. The coaches are required to take part in a 2-hour Partner in Balance training course, were the intervention is presented and the coaches take part in various coaching exercises.

Afterwards, caregivers first meet coaches face-to-face for an intake session, where relevant modules are chosen to help the caregivers adapt to their new role. At home, the caregivers complete the chosen modules, which consist of caregiver tips, video vignettes, self-reflective assignments, and web-based feedback from the coach. Finally, the coaches and caregivers meet for an in-person evaluation session. Partner in Balance is currently available in Dutch, French, German, and English. The development and testing of Partner in Balance made use of the stepwise approach of the Medical Research Council (MRC) framework for complex interventions [33]. Information on the results of the needs assessment [34], pilot study [35], randomized controlled trial [36], and process evaluation [37] has been published previously. These last two studies showed that Partner in Balance increased caregiver self-efficacy, sense of competency, and quality of life, and was positively evaluated by both caregivers and coaches.

Aims and Objectives

This paper describes the implementation of Partner in Balance (an evidence-based eHealth intervention) as a use case to inform

developers of other evidence-based eHealth interventions for the caregivers of people with dementia. Using insights from real-life pilots and stakeholder interviews, the aim of this study was to shed more light on the implementation context and aid future researchers in the implementation of similar interventions. The specific objectives of this study are to (1) formulate evidence-based implementation strategies, (2) develop a sustainable business model, and (3) integrate these elements into an implementation plan.

Methods

Explorative Implementation

Real-Life Pilots

To acquire this insight, real-life pilot implementations of Partner in Balance in local care organizations were conducted. Here, the goal was to let the organizations implement Partner in Balance at their own discretion, free from the more rigid protocols of a randomized controlled trial. These pilots ran from September 2016 to September 2019. Organizations participating in the real-life pilots were recruited through two channels. First, Partner in Balance was offered as one of the 15 activities through the euPrevent Senior Friendly Communities (SFC) project [38]. In this project, 32 municipalities in the Netherlands, Germany, and Belgium had the option to implement Partner in Balance for free through local care organizations in their communities. Second, in 2017, Partner in Balance won the Dutch ZonMw *Medical Inspirer Prize* [39], resulting in public attention on the intervention and a small budget to implement Partner in Balance

in interested organizations for a limited time. During the real-life pilots, data were collected on the number and type of participating organizations, as well as the number of active coaches and participants.

Stakeholder Interviews

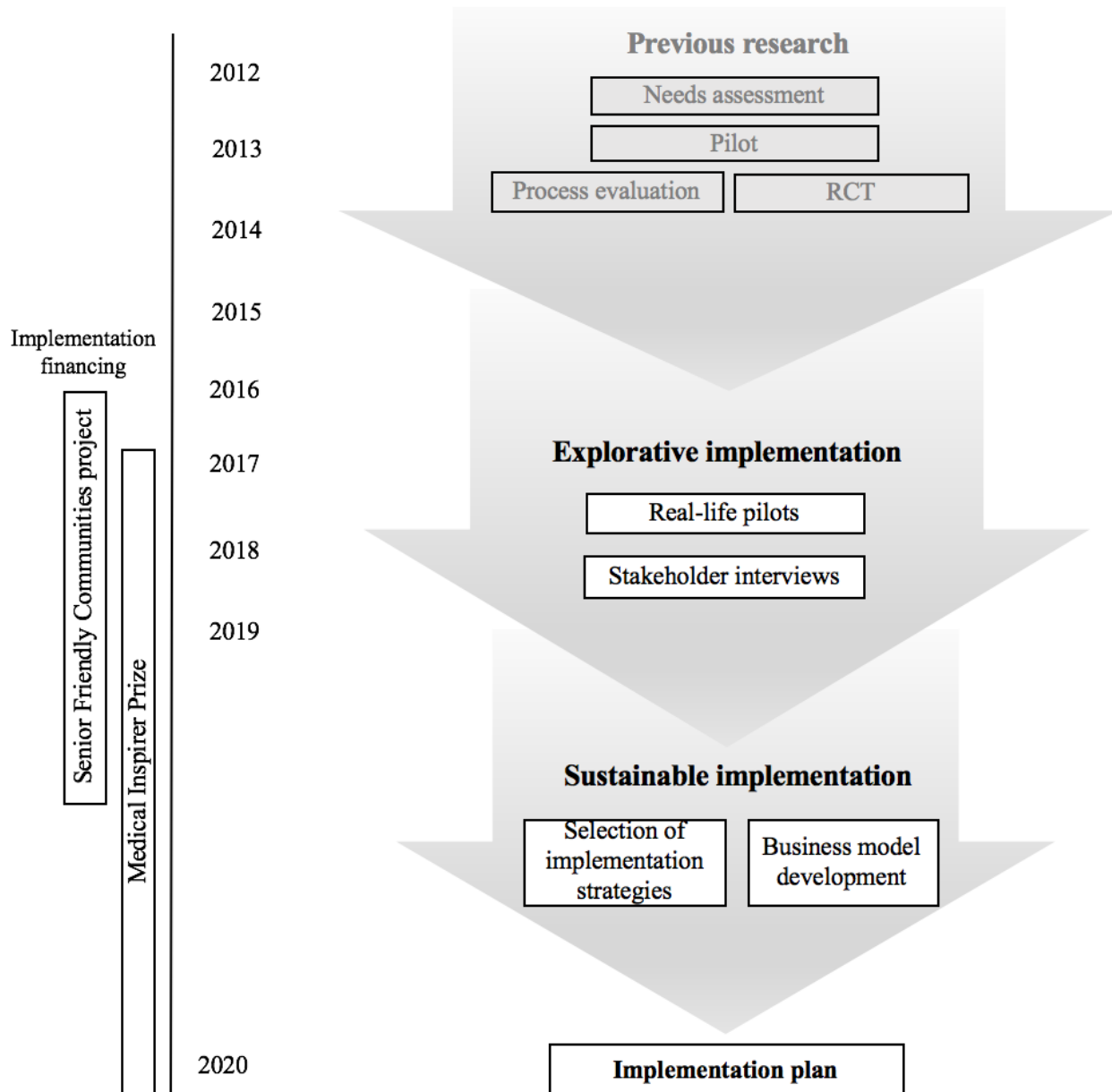
From April to June 2019, 14 semistructured qualitative interviews were conducted with stakeholders from patient organizations (n=2), a municipality implementing Partner in Balance (n=1), dementia case management organizations (n=2), mental health care providers (n=3), an eHealth expertise center (n=1), health insurers (n=3), an academic hospital (n=1), and a care research funding body (n=1). These interviews were all conducted in the Netherlands and in Dutch (10 in person and four via Skype). Participants signed an informed consent form. The interviews were recorded and transcribed verbatim. Two researchers (HLC and LMMB) applied inductive thematic analysis by independently coding the transcripts and subsequently grouping these codes into higher level categories and themes [40]. A meeting was held with a third researcher (MEdV) to discuss differences in coding and to reach a consensus. The stakeholder interview questions can be found in [Multimedia Appendix 1](#).

Sustainable Implementation

Overview

The goal of this project was to develop an implementation plan based on the information gathered during the explorative implementation. [Figure 1](#) presents an overview of the Partner in Balance implementation trajectory.

Figure 1. Partner in Balance development and implementation trajectory. RCT: randomized controlled trial.



Selection of Implementation Strategies

The first step in the development of the sustainable implementation plan was the selection of implementation strategies. Based on the information acquired in the previous research and explorative implementation phases, these strategies were formulated by researchers on the Partner in Balance implementation team, which consisted of researchers, the software partner, a coach organization, and the Knowledge Transfer Office.

The selection of strategies was guided by the consolidated framework for implementation research (CFIR) [41]. The CFIR is an established framework for mapping implementation and for eHealth interventions [42]. The CFIR aims to describe determinants, which can serve as barriers and facilitators, that affect implementation outcomes. The CFIR is made up of five domains (intervention characteristics, the outer setting, the inner setting, characteristics of individuals, and the process),

containing 39 implementation constructs. The CFIR has been used both to retrospectively evaluate implementation and to prospectively design future implementation strategies [43].

Development of a Business Model

The second component of this sustainable implementation plan was the development of a business model. The Partner in Balance business model was developed using the business model canvas [31]. The business model canvas is a popular framework that aims to develop new and document existing business models by mapping the value proposition, key activities, key resources, key partners, cost structure, customer relationships, distribution channels, and revenue of a product or service. The business model canvas has often been used to map business models for eHealth [32,44-46]. The Partner in Balance business model canvas was codeveloped and its face validity was jointly assessed with the involved software partner. The model was iteratively adapted by both parties in reaction to feedback from

potential clients. This was done to be able to offer participating organizations some certainties concerning the intervention's future availability and pricing, as this had already been reported in previous trials as a barrier to adopt the intervention in the future [37].

Ethical Approval

Ethical approval for these studies was granted by the Medical Ethical Oversight Commission of Maastricht University (approval number 2018-0489).

Results

Overview

The following section describes this study's findings from explorative implementation (real-life pilots and stakeholder interviews), while the subsequent section describes how these findings are integrated to achieve this study's objectives concerning sustainable implementation (devising implementation strategies and a business model). The final

section integrates these findings into a concrete implementation plan.

Explorative Implementation

Real-Life Pilots

Four and a half full-time equivalent researchers worked part-time on the implementation of the Partner in Balance project, recruiting organizations, providing technical and implementation support, managing relationships with organizations and the technology partner, planning and carrying out coach training, and developing new content modules. In the context of the SFC project, three municipalities in the Netherlands, one municipality in Belgium, and one municipality in Germany chose to implement Partner in Balance in their communities. The remaining 27 municipalities (84%) in the SFC project chose to implement other projects. In the context of the Medical Inspirer Prize, 19 organizations chose to implement Partner in Balance for their clients. [Table 1](#) provides an overview of some characteristics of the real-life pilots, including the finding that not all trained coaches ended up coaching participating caregivers.

Table 1. Overview of real-life pilots.

Real-life pilot characteristics	Value, n
Type of organization	22
Hospital	6
Company	1
Municipality	5
Case management organization	4
Mental health care organization	4
Care home	3
International research project	1
Total number of trained coaches	128
Total number of coached participants	122
Average number of participants per organization	10
Average number of coaches per organization	7

Stakeholder Interviews

The inductive interview analysis of interviews with potential stakeholders (n=14) resulted in five themes, with their own

categories and subcategories ([Table 2](#)). The aim of the interviews was to gain insights into stakeholders' views on barriers and facilitators to the sustainable implementation of Partner in Balance.

Table 2. Inductive interview themes.

Theme	Category (<i>examples of answers</i>)
1. Future of Partner in Balance	<p>1.1. Good content (<i>self-management, sustainability, blendedness, personalized, evidence-based, and positive health</i>)</p> <p>1.2. Need for Partner in Balance (<i>not suited for everyone, addition to offline services, psychoeducation, Partner in Balance is needed, an opportunity for a research project to grow, meets caregivers' needs, and digital factor is a challenge</i>)</p> <p>1.3. Extra Partner in Balance functions (<i>modules for new populations, extra workshops, chat function, more structural support, reminders when inactive, facilitator/contact person, forum, return meetings, and no changes necessary</i>)</p>
2. eHealth experiences	<p>2.1. Lack of suitable options</p> <p>2.2. Works better in younger adult populations</p> <p>2.3. Good investment</p> <p>2.4. Easier than physical services</p> <p>2.5. The provider has to be pushing the implementation</p> <p>2.6. Important to some health insurers</p> <p>2.7. Not often user-friendly</p>
3. Caregiving context	<p>3.1. Caregiving support (<i>where can caregivers go for support, often still new for care teams, importance of case management, and financing of caregiving support</i>)</p> <p>3.2. Policy</p>
4. Financial context	<p>4.1. Financing models (<i>public money, subscriptions, and licensing</i>)</p> <p>4.2. Potential financers (<i>caregiver, organization, municipality, labor market, and health insurer</i>)</p>
5. eHealth implementation process	<p>5.1. Purchase process (<i>pilots by providers, importance of municipality policy and budget, collaboration with organizations, and decision levels</i>)</p> <p>5.2 Evaluation criteria (<i>financial plan, form of eHealth, who is the eHealth owner, connection to research, and necessary information</i>)</p> <p>5.3 Outcomes of success (<i>waiting lists for care support go down, caregivers satisfied, less case management hours, more referrals, more caregivers supported, more caregivers able to safely live at home, positive real-time evaluations, more care efficiency, and acquisition of cost-effectiveness data</i>)</p>

Future of Partner in Balance

This first theme concerns the views stakeholders had on what was good about Partner in Balance and what could be improved in the future. The first category of this theme “good content” showed that all groups of stakeholders had positive attitudes toward the Partner in Balance content and thought many of its components were useful and timely. The second category refers to how stakeholders (especially policy makers and health care professionals) thought that Partner in Balance met caregiver needs, but emphasized that they saw it as complementary to and not as a substitution of face-to-face caregiving services. In the final category of this theme, stakeholders suggested options for additional Partner in Balance functions. These mostly centered around more contact and support, either online (through chat functions and forums) or offline (through meetings, symposia, and a contact person).

eHealth Experiences

The second theme discusses what stakeholders mentioned concerning the broader eHealth context. In the experience of health care professionals, eHealth is rather difficult to implement, especially in older populations. They also felt that the topic of eHealth was important to health insurers, and the implementation often needed to be pushed by the eHealth provider. Several groups of stakeholders mentioned that eHealth

is often not very user-friendly and saw this as an important barrier.

Caregiving Context

In the third theme “caregiving context,” stakeholders sketched the context in which dementia caregiving support usually takes place, as well as the associated challenges. These challenges included health care professionals’ unfamiliarity with the topic, as well as the importance of case management and how it (and dementia caregiver support in general) is organized. In terms of policy, a trend emerged across the different stakeholders. For policy makers, health care professionals, and health insurers, policy tended to focus less on caregiving and more on self-management, personalization, and positive health. These policy trends were in line with the Partner in Balance content, and this match between the intervention and current policy trends was considered a notable intervention selling point.

Financial Context

The fourth theme groups stakeholders’ views on the financial context of Partner in Balance. This included responses from policy makers on whether it was ethical to market an intervention developed with public money, as well as different options and calculations for various subscription and licensing models. Regarding the latter, large variations in the suggested price were observed, with caregiver contributions of €0 (US \$0), €1 (US \$1), €25 (US \$28), or €35 (US \$40) for a full course

(as a way to ensure adherence) and €200 (US \$226) to €700 (US \$791) paid by care organizations (including the costs of training, coaching hours, and hosting). However, the majority of stakeholders did not think that informal caregivers should be the ones paying for the intervention, but rather that this should fall to the care organizations, municipalities, or health insurers (no stakeholders suggested the intervention be somehow free for all parties). The health care professionals favored a yearly subscription model, where organizations could buy licenses for the desired number of participants. In the second category “potential financiers,” the Dutch national health care insurance system and how it relates to the municipal prevention mandate were the main topics of discussion. In particular, the classification of Partner in Balance as a tool for prevention (as buying a license could then be more suited to a municipality) or treatment (as buying a license could then be more suited to a health care insurer) was important. Other potential financing options were interested parties from the labor market (to combat loss of workforce to caregiver burden) and buy-in care networks (where local dementia care organizations group together in care networks).

eHealth Implementation Process

The final theme groups stakeholders’ statements on the process for their organizations to potentially adopt, disseminate, and implement new eHealth interventions for the caregivers of people with dementia. Concerning the first category “purchase process,” the policy makers emphasized the need for the intervention to be approved at many levels, including in the budget and policy (especially for municipalities), as well as the added value of testing interventions through pilots with local

collaborations. A number of evaluation criteria used by the organizations to decide whether to implement an intervention were discussed (Table 2). Most importantly, health insurers repeatedly mentioned the need for data on effectiveness and cost-efficiency. Interestingly, they emphasized that the data could be speculative and qualitative (and not necessarily longitudinal or randomized controlled). Useful outcomes with which health care organizations (such as dementia case managers) could measure implementation success were waiting list reduction, less case management hours, more referrals, more supported caregivers, more caregivers able to safely live at home, positive real-time evaluations, and more care efficiency.

Sustainable Implementation

Selection of Implementation Strategies

The devised implementation strategies were principally aimed at helping integrate Partner in Balance more into the coach organizations, as well as motivating and engaging these coaches and their management more effectively (domains of “inner setting” and “characteristics of the individuals”). This was based on the finding from usage data that not all trained coaches ended up coaching. In order to enhance the attractiveness of Partner in Balance to potential clients, more financial insights into the pricing and long-term business modeling of Partner in Balance were necessary (domain “characteristics of the intervention”). Additionally, strategies were formulated to streamline Partner in Balance administration and project management (domain “process”), as well as to expand and disseminate its use (domain “outer setting”). Table 3 lists the CFIR domains and corresponding implementation strategies.

Table 3. Partner in Balance implementation strategies and consolidated framework for implementation research domains.

CFIR ^a domain	Partner in Balance implementation strategy	Targeted CFIR subdomains	Operationalization
Characteristics of the intervention	Assess Partner in Balance's effect on an organization's care costs	Evidence strength and quality, relative advantage, adaptability, and complexity	Determine the intended effect on various aspects as follows: reduced experienced workload, shorter waiting time for case management, lower time investment for case manager, longer estimated period as full-time informal caregiver, less/later requirement for home care, and less/later crisis relief. Comparison of this longitudinal use of health care data during Partner in Balance deployment with a control group for the introduction of Partner in Balance using registered health insurers. Additionally, comparison of baseline measurement and follow-up measurement of maintenance time in a cohort of clients who receive Partner in Balance.
Characteristics of the intervention	Develop more detailed financial models	Cost, trialability, design quality and packaging, and interventions source	Determine the costs of required resources. Compare the necessary case management hours and waiting list before and after implementing Partner in Balance. Map responsible budgets.
Outer setting	Explore integrating Partner in Balance in case management in the Netherlands, as well as outside of Limburg	Cosmopolitanism, patient needs, and resources	Overview of bottlenecks and facilitators to offer Partner in Balance in the Netherlands, as well as outside of Limburg.
Outer setting	Subsidy applications and participation in networking and knowledge sharing events	External policies and incentives, cosmopolitanism, and peer pressure	Subsidy application involving crucial implementation partners in innovation clusters. Overview experiences and lessons learned by other innovation clusters.
Inner setting	Integrate Partner in Balance within Help with Dementia Limburg (case management organization)	Structural characteristics, organizational incentives and rewards, goals and feedback, and readiness for implementation	Prepared supervision plan for new clients in which the Partner in Balance offer is included as a fixed part.
Inner setting	Further development and embedding of inspiration sessions through integration in coach training	Tension for change, relative priority, and access to knowledge and information	Web-based inspiration session including video material in which case managers and caregivers explain the use and added value.
Characteristics of the individuals	Development of content for inspiration sessions and web-based coach training	Knowledge and beliefs about the intervention, self-efficacy, and individual stage of change	Inspiration session content and guide. Web-based coach training content.
Characteristics of the individuals	Pilot inspiration sessions and web-based coach training	Individual identification with the organization and other personal attributes	Custom inspiration session and web-based coach training based on feedback from current coaches.
Process	Evaluate coach training (by participants) plus evaluate web-based training	Reflecting and evaluating, as well as engaging (champions)	Overview of the number of chosen "live" or "online" trainings, including qualitative evaluation by participants on the quality, method, and content of the training.
Process	Disseminate progress	Engaging (formally appointed implementation leaders)	Short progress reports distributed among case managers (Help with Dementia newsletter) and nationwide (Alzheimer NL/dementie.nl).
Process	Write scientific publications and policy reports	Engaging (opinion leaders)	Scientific publications in peer-reviewed professional journals and policy reports (communication to contacts within the Ministry of Health, Welfare and Sport).
Process	Report to the public	Engaging (external agents of change)	Lay report
Process	Organize symposium	Engaging (external agents of change), reflecting, and evaluating	Symposium including communication and feedback of results to the society.
Process	Project coordination	Planning	Overview of project members in lead and coordination tasks.
Process	Define go and no go moments and possible next steps	Executing	Qualitative inventory of existing barriers and facilitators for scaling up and use.

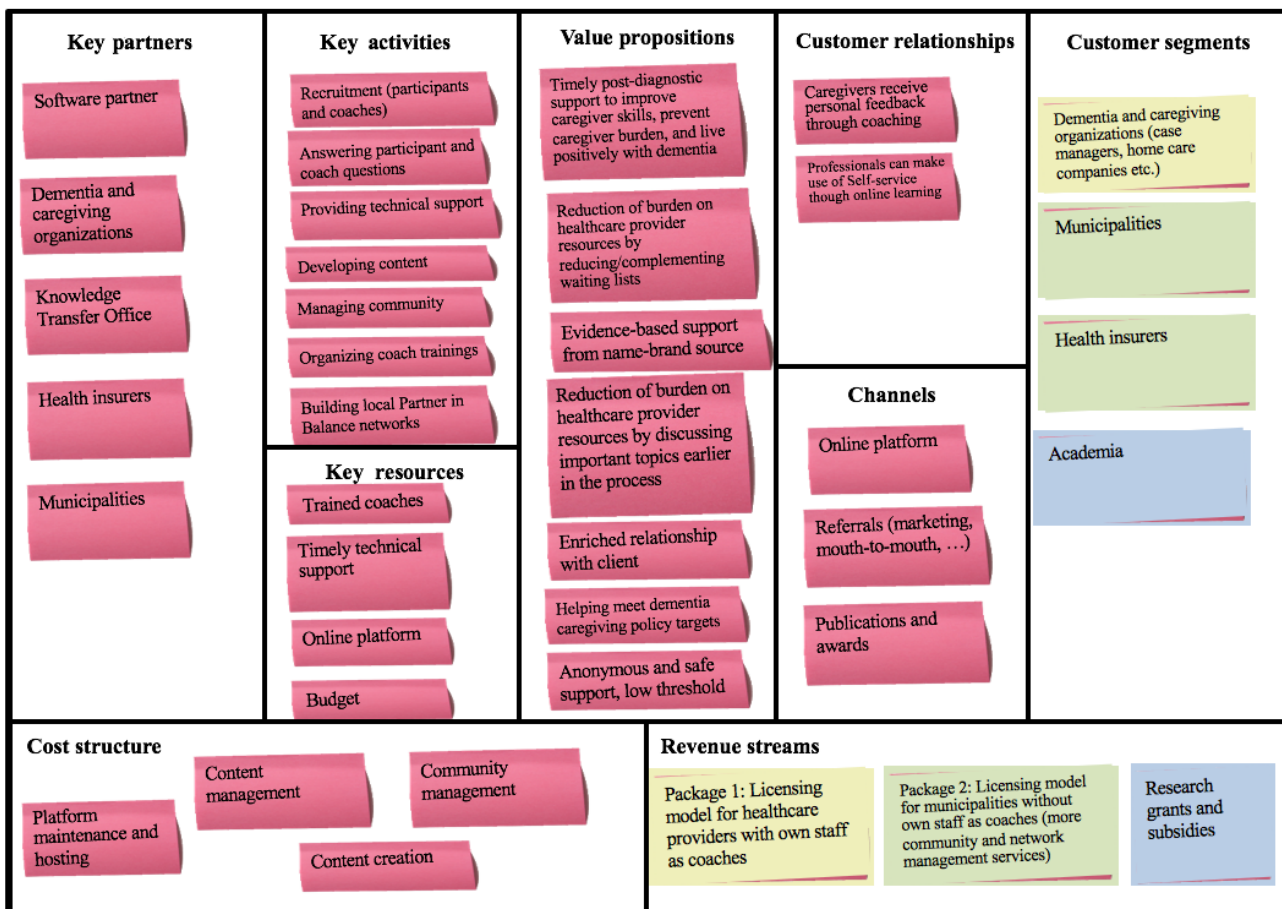
^aCFIR: consolidated framework for implementation research.

Development of a Business Model

Figure 2 presents a depiction of how sustainable implementation could hypothetically be achieved based on insights from the previous implementation phases and the stakeholder interviews. Partner in Balance has added value for caregivers, health care organizations, and municipalities (“value propositions”), and together with the “channels” and “customer relationships,” this helped the team form a better view of the intervention’s desirability to potential customers. In the proposed business model, three distinct types of customers were identified (“customer segments”). As a result, it was decided that two of these customer segments required specific licensing models (“revenue streams”). First, health care support providers, such

as case management organizations, require no help with recruitment as they can supply their own coaches in house and are targeted with package 1. Second, municipalities are targeted with a package that additionally includes identifying which local organizations can provide coaches (package 2). These revenue streams would in turn finance the main cost drivers of Partner in Balance described in “cost structure,” which are made possible by the “key partners,” “key activities,” and “key resources.” The development of this business model and collaboration with the Knowledge Transfer Office and the software partner are crucial to the sustainability of the implementation plan through its provisions for long-term financing of the Partner in Balance intervention.

Figure 2. Partner in Balance business model canvas. The nine elements help describe a firm's or product's structure by mapping its value proposition (middle element), infrastructure, (top left three elements), customers (top right three elements), and finances (bottom two elements).



Integration

The six components of the implementation plan are presented in this section. The operationalizations of the targeted CFIR subdomains were combined into components 1 to 5, while the business model canvas led to component 6. Based on these inputs, the components of the integrated plan for the sustainable implementation of Partner in Balance were as follows: (1) a ready-to-use Partner in Balance inspiration and intervention session format (live and online version and online coach training) to stimulate inner setting enthusiasm, (2) a guide for the implementing organization, in which Partner in Balance is included as a fixed offer in the first phase after diagnosis, (3) the writing of a report on financing options and

cost-effectiveness, (4) efficient communication of project results through different channels, (5) a coordination plan and division of responsibility, including risk management, and (6) a sustainability plan including a licensing model. This licensing model is currently structured for an organization to pay for coaching one client per payment. The coach’s organization and municipality chooses how many coach licenses they wish to buy. Additionally, implementation costs are charged depending on the type of package desired by the implementing organization.

Discussion

Addressing the Lack of Information on Long-Term Financing of the Intervention

In previous research, the Partner in Balance process evaluation [37] reported that initial implementation challenges were related to a lack of financing and time necessary to implement the intervention. The findings from this study's real-life pilots and stakeholder interviews made it possible to more precisely describe the previously identified issues and devise solutions by constructing a preliminary business model. In this study, stakeholders reported an unwillingness to commit resources to an intervention that might not be available in the future or that they might not be able to afford. This is in line with previous research that also advocated the application of business models to evidence-based interventions to facilitate long-term implementation [32,47]. Thus, this study contributes to literature on the implementation context by providing insights into this important implementation barrier, namely the lack of reliable pricing information for implementing evidence-based eHealth interventions to support the caregivers of people with dementia [48]. Additionally, the implementation strategies developed in this study using the CFIR helped ensure that the different components of successful implementation were considered in the business model.

Addressing the Lack of Information on the Organizational Context

There has been little research on the perspectives of the parties involved in the real-life implementation of evidence-based eHealth interventions for the caregivers of people with dementia [23]. For this reason, it was necessary to formulate a targeted implementation plan for Partner in Balance, which would help tailor Partner in Balance to this relatively underexplored dementia health care context. The implementation strategies and proposed business model resulted in an implementation plan that aimed to facilitate the integration of this evidence-based intervention into the organizational structures found in clinical practice. In this study, stakeholders in the domains of eHealth and dementia care perceived eHealth as difficult to implement and the usage data showed that 84% of SFC municipalities chose to implement other dementia-related projects instead of Partner in Balance, underscoring the role of organizations as gatekeepers in the implementation of evidence-based eHealth interventions for caregivers of people with dementia. This is in line with previous eHealth research that has cited the unfamiliarity of both implementing staff and the target population with web-based support tools as an important barrier to implementation [17,19]. Additionally, the fact that eHealth circumvents traditional health care delivery structures contributes to the difficulty many care organizations and governing bodies experience in implementing the interventions and adapting existing structures and norms to integrate them [49]. However, in the context of eHealth for dementia, the stakeholders did see Partner in Balance as needed and timely, particularly as it fits into current trending policy targets of self-management, personalization, and positive health, which have been advocated by the literature [50-52]. These

findings confirm that it is important to continue to investigate and accommodate the evolving role of dementia care professionals in the context of emerging eHealth innovations and consider embedding eHealth care education into training programs for health care professionals [53,54], as proposed by the strategies integrated into this study's implementation plan for Partner in Balance.

Recommendations From the Partner in Balance Case Study to Aid the Implementation of Future eHealth Interventions Supporting the Caregivers of People With Dementia

It is the authors' aim that the findings presented in this study also inform future eHealth interventions for the caregivers of people with dementia and facilitate more efficient development and implementation. We present the following recommendations based on the lessons learned throughout the various phases of the Partner in Balance implementation:

- (1) Health care organizations are often willing to pay for eHealth for their caregivers of people with dementia as long as the price of implementation is set, the evidence base is reliable, and the benefits to the organization are clear.
- (2) It is recommended to form an "innovation cluster" with dementia health care institutions (the implementers, such as dementia case management organizations) together with parties who can buy licenses (such as municipalities), while other organizations (such as health insurers) reimburse the health care organization's staff hours.
- (3) eHealth interventions to support the caregivers of people with dementia cannot be implemented as a ready-to-go one-size-fits-all project. Offline guidance and tailoring will always be necessary. Therefore, it is important to budget for this and identify which partners will be a part of the so-called "innovation cluster" to ensure a realistic implementation plan.
- (4) Finding a balance between these differing prioritizations and identifying which of the involved parties should be the financer and which should be the implementer in the dementia health care context are challenges best addressed early in the development process (preferably even before the effectiveness trial).
- (5) It is important to emphasize to potential eHealth buyers that eHealth should always be complementary to other offline dementia caregiving services and not a replacement of existing face-to-face services.
- (6) It is recommended to construct a preliminary business model canvas at the start of implementation (before the effectiveness trial) in order to identify all relevant partnerships, customer relationships, and revenue streams in the local dementia health care context. Doing this will allow researchers to create a product that is attuned to its specific market. If possible, it is also suggested to work with a commercial partner from the start. Using the business model canvas to inform our pricing and implementation plan was very helpful.
- (7) Future developers should incorporate an explorative implementation phase after the trial context. It is necessary to

flexibly explore different pricing models and iteratively address real-world implementation challenges prior to actually charging organizations.

(8) Using the CFIR helped to formulate implementation strategies targeted at many different aspects of implementation. It was particularly helpful in structuring thinking on project management, as well as the engagement of the implementing organization's staff and management.

This study has helped fill the knowledge gap concerning the implementation context for eHealth interventions for the caregivers of people with dementia in two important ways. It has added to the existing literature by providing an example of a business model to aid the implementation of an evidence-based eHealth intervention for the caregivers of people with dementia, as well as specific implementation strategies to facilitate integration into the dementia health care context. Future research should evaluate which types of implementation strategies are most successful at achieving long-term implementation. In particular, as concluded from the stakeholder interviews, a more in-depth cost-effectiveness study is needed to encourage more active participation from health insurers and health care organizations.

Strengths and Weaknesses

This study has unique and important strengths. First, this study made use of well-established theoretical frameworks to guide implementation, using the MRC framework for the development and evaluation of intervention effectiveness, as well as the CFIR and business model canvas. Second, despite its theory-driven approach, this study illustrated a practical and real-world representation of the implementation of an evidence-based eHealth intervention. By iteratively adapting the intervention and being able to adapt with more agility to implementation issues than is normally possible in a strict trial context, this study provided a realistic view of the implementation process and context.

This study also had several weaknesses. First, though it was intended as a "real-world" illustration of bringing an evidence-based eHealth intervention to the market, the actual implementation was still very much dependent on the researchers guiding and facilitating this implementation through the research project. However, this study still provides a useful overview of the steps necessary to construct a realistic

implementation plan. Second, several of the interviewed stakeholder had been involved in the Partner in Balance development in the past (four out of 14 stakeholders). This could have resulted in some positive bias to look favorably at the intervention's future implementation. However, the authors believe it was necessary to include some interview participants who had real knowledge of the working of Partner in Balance. Finally, people with dementia were not included as stakeholders in this study. This is because the intervention was developed together with the caregivers of people with dementia, and it exists in its current form as a result of their needs and wishes. The focus of this study's stakeholder interviews was on the surrounding implementation context and organizational determinants. Furthermore, the use experience of the intervention from the perspective of caregivers was explored in depth in the Partner in Balance process evaluation [37].

Future Research Areas

Future research will include an evaluation of the proposed implementation plan. In particular, as concluded from the stakeholder interviews, a more in-depth cost-effectiveness study is needed to encourage more active participation from health insurers and health care organizations.

Conclusions

Stakeholders saw eHealth as difficult to implement, but as an approach that is needed and timely, particularly as it fits into the current trends of self-management, personalization, and positive health. Applying the CFIR to devise theory-driven implementation strategies was primarily useful for targeting overlooked implementation aspects, such as ensuring effective and sustained engagement of coaches, streamlining project management, expanding and disseminating the intervention, and enhancing insights into pricing and long-term business modeling, in order to ensure sustainability. Insights from business modeling resulted in two different kinds of licensing agreements (one for municipalities and one for organizations). Finally, the authors recommend thoroughly exploring the organizational and health care contexts of the intervention and then forming "innovation clusters" (consisting, for example, of a technology developer, research team, intervention provider, and health insurer or other funder) from the start of eHealth development. This will help ensure that the intervention meets the needs of its target users (both the end users and the implementing staff).

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Stakeholder interview questions.

[[DOCX File, 13 KB - aging_v3i1e18624_app1.docx](#)]

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Abbreviations

CFIR: consolidated framework for implementation research

eHealth: electronic health

MRC: Medical Research Council

SFC: Senior Friendly Communities

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Original Paper

Descriptive Evaluation and Accuracy of a Mobile App to Assess Fall Risk in Seniors: Retrospective Case-Control Study

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Abstract

Background: Fall-risk assessment is complex. Based on current scientific evidence, a multifactorial approach, including the analysis of physical performance, gait parameters, and both extrinsic and intrinsic risk factors, is highly recommended. A smartphone-based app was designed to assess the individual risk of falling with a score that combines multiple fall-risk factors into one comprehensive metric using the previously listed determinants.

Objective: This study provides a descriptive evaluation of the designed fall-risk score as well as an analysis of the app's discriminative ability based on real-world data.

Methods: Anonymous data from 242 seniors was analyzed retrospectively. Data was collected between June 2018 and May 2019 using the fall-risk assessment app. First, we provided a descriptive statistical analysis of the underlying dataset. Subsequently, multiple learning models (Logistic Regression, Gaussian Naive Bayes, Gradient Boosting, Support Vector Classification, and Random Forest Regression) were trained on the dataset to obtain optimal decision boundaries. The receiver operating curve with its corresponding area under the curve (AUC) and sensitivity were the primary performance metrics utilized to assess the fall-risk score's ability to discriminate fallers from nonfallers. For the sake of completeness, specificity, precision, and overall accuracy were also provided for each model.

Results: Out of 242 participants with a mean age of 84.6 years old (SD 6.7), 139 (57.4%) reported no previous falls (nonfaller), while 103 (42.5%) reported a previous fall (faller). The average fall risk was 29.5 points (SD 12.4). The performance metrics for the Logistic Regression Model were AUC=0.9, sensitivity=100%, specificity=52%, and accuracy=73%. The performance metrics for the Gaussian Naive Bayes Model were AUC=0.9, sensitivity=100%, specificity=52%, and accuracy=73%. The performance metrics for the Gradient Boosting Model were AUC=0.85, sensitivity=88%, specificity=62%, and accuracy=73%. The performance metrics for the Support Vector Classification Model were AUC=0.84, sensitivity=88%, specificity=67%, and accuracy=76%. The performance metrics for the Random Forest Model were AUC=0.84, sensitivity=88%, specificity=57%, and accuracy=70%.

Conclusions: Descriptive statistics for the dataset were provided as comparison and reference values. The fall-risk score exhibited a high discriminative ability to distinguish fallers from nonfallers, irrespective of the learning model evaluated. The models had an average AUC of 0.86, an average sensitivity of 93%, and an average specificity of 58%. Average overall accuracy was 73%. Thus, the fall-risk app has the potential to support caretakers in easily conducting a valid fall-risk assessment. The fall-risk score's prospective accuracy will be further validated in a prospective trial.

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KEYWORDS

falls; seniors; fall risk assessment; app; mHealth; retrospective cohort study; discriminative ability

Introduction

Falls have a high prevalence among seniors, with 1/4 seniors aged 65 and above experiencing one fall per year [1-3]. Fall rates in nursing homes are higher than fall rates in the community. Rubenstein et al [4] provided an incidence rate of 1.7 falls per person, per year, for nursing facilities compared to an incidence rate of 0.65 falls per person, per year, for older people living in the community. The prevalence of fall-related injuries has also been found to increase with age [5]. Around 10-15% of falls result in a fracture [6]. Furthermore, fall-associated fractures among older people are significantly related to morbidity and mortality.

Due to demographic changes associated with an aging population, the number of falls among older adults is expected to rise considerably. A recent study even reported an increased rate of death from falls. These researchers investigated data from people who died as a result of a fall. The data showed that the rate of deaths from falls increased by an average of 3.0% per year during 2007-2016 [7]. Therefore, effective fall prevention strategies should be promoted and implemented.

Fall-risk assessment is a complicated task. Current scientific evidence suggests that a multifactorial fall-risk assessment, including an analysis of mobility as well as extrinsic and intrinsic risk factors, is crucial [1-3,8,9]. In Germany, the assessment of fall risk according to guidelines defining risk assessment and fall prevention procedures is mandatory in inpatient care [10]. However, this process includes a time-consuming and challenging subjective analysis of the patient's mobility status and a multitude of additional individual risk factors.

Thus, a smartphone-based application, Lindera Mobilitätsanalyse (Lindera GmbH, Berlin, Germany), was developed to facilitate fall-risk assessment. As a stand-alone software, this app enables nursing staff to perform a structured fall-risk assessment that conforms to regulatory standards [10].

Further app-based, fall-risk assessment tools have been identified in the literature [11-14]. One such fall-risk assessment app is the Aachen Fall Prevention Scale. This app is a self-assessment tool that consists of a simple questionnaire with a balance test that is self-assessed and evaluated. The app seeks to raise older adults' awareness of their fall risk. The Aachen Fall Prevention App was found to have a pooled sensitivity of 57.0% and a specificity of 76.7% [14]. A further fall-risk app is called Steady. This app consists of a health history questionnaire and five progressively more challenging mobility tasks to measure individual fall risk. This app was found to be highly usable among older adults but has not yet been evaluated in terms of validity, although the authors mention testing the app's validity as the next step for future research [11]. Both apps focus on individual seniors as users and assess mobility with challenging postural stability tasks. The Lindera mobility analysis was designed to support nursing staff and is the first fall-risk app that enables nurses to perform an objective, structured, fall-risk assessment that conforms to regulatory standards.

Fall-risk assessment tools should accurately discriminate fallers from nonfallers. Diagnostic accuracy relates to the fall-risk score's ability to discriminate between faller and nonfaller status. The discriminative performance of fall-risk assessments has frequently been quantified using measures such as sensitivity, specificity, and the area under the curve (AUC). The validity of each assessment tool should be evaluated to interpret the results correctly. Currently, the diagnostic test accuracy of most existing fall-risk assessment tools appears to be modest [1,15]. Overall diagnostic accuracy results must incorporate relative misclassification costs to account for the fact that false-negative and false-positive results are rarely clinically equivalent [16]. As there is always a trade-off between sensitivity and specificity, it is essential also to include the receiver operating curve. Measures of test accuracy can be limited by their dependence on the prevalence of an outcome. Measures that perform well among people for whom there is a strong suspicion that they have the condition being assessed (ie, the prevalence is close to 50%) will nearly always perform poorly in trying to identify people when the prevalence is low [17].

This paper aimed to study the discriminative ability of the fall-risk score with the aid of learning models. These models were evaluated based on relevant performance metrics, such as the receiver operating curve and its area under the curve, using a real-world dataset containing subjects with and without a previous fall history.

Methods

Study Design and Study Participants

The study was designed as a retrospective analysis of the Lindera user database. All study participants agreed to the collection of data presented in this publication by signing the terms and conditions for the use of Lindera as well as a written informed consent form. Lindera is compliant with the European Union General Data Protection Regulation. All data analyzed for the study were anonymized for statistical analysis.

The study sample consisted of seniors who completed a fall-risk assessment via the app between June 2018 and May 2019 and uploaded their data to the company's user database. The app only provides analyses for customers who have signed a data processing contract. The company's customers include nursing homes, outpatient nursing services, care support centers, and daycare institutions. Seniors were recruited and informed by nursing staff in these institutions.

To assure data quality and homogeneity among the study population, only participants aged 65 and above were analyzed, as this is seen as a relevant cut-off age for a higher occurrence of falls [18]. Furthermore, only seniors who provided information about their fall status over the last 12 months (faller or nonfaller) were included. Fall status was either self-reported or reported by nursing staff completing the assessment.

Due to the nonexperimental, retrospective, and anonymized study design, no ethical approval was needed.

Description of the Fall-Risk Score and Use of the App

Nurses can analyze a senior's mobility according to the Tinetti test criteria [19] via a smartphone camera and an underlying computer vision algorithm. This underlying algorithm is based on a combination of the convolutional pose machine (two-dimensional joint detection) and the VNect algorithm (three-dimensional joint and skeleton detection) [20,21]. Two procedures must be completed to provide a fall-risk assessment, the first of which is a smartphone-based video analysis, where a member of the nursing staff captures the senior's gait. The senior has to sit on a chair, stand up and walk about 3 meters toward the camera, then turn and walk back again. Seniors had to be able to perform this mobility test as a prerequisite for completing the full assessment. The use of walking aids was allowed (eg, walker, cane). After the mobility test, a questionnaire assessing further fall-risk factors had to be completed within the app. The questionnaires were either self-assessments or completed with the help of nursing staff. Only fully completed and uploaded assessments were analyzed. Nursing staff received a standardized training course by the Lindera customer success team on how to use the app and the questionnaire.

Every risk factor within the analysis is considered in the fall-risk score, which is a metric scale ranging from 0-100 points. Per validated fall-risk models that have shown a good diagnostic test accuracy [1,22] (STRATIFY [St. Thomas's Risk Assessment Tool In Falling Elderly Inpatients] Fall Risk Assessment Tool, Hendrich Fall Risk Model II, Downton Fall Risk Assessment), nine of the risk factors are given a double weighting (limited mobility, dizziness, visual and acoustic impairment, medication, cognitive impairment, depression, urge incontinence, fall history, and restlessness). Further evidence-based risk factors are weighted once (mobility-limiting comorbidities, foot disorders, comorbidities that lead to syncope, fear of falling, use of walking aids, and environmental hazards). Fall events were identified with an app-based question asking whether the senior had experienced a fall during the last 12 months. For a detailed description, please refer to the documentation of the scientific approach underlying the app [23]. To offer prevention strategies, an individualized fall prevention plan was provided with every analysis. The preventative measures were derived from an evidence-based recommendation database [23]. An individual fall-risk assessment and prevention plan were sent to each customer within 24 hours after they uploaded the analysis. An example prevention plan can be found in [Multimedia Appendix 1](#).

The fall-risk score assessment was completed using an app named Lindera Mobilitätsanalyse. The nursing staff was able to download the app for iOS (App Store) or Android (Google Play Store) mobile devices. The app was free to download, but to get the analysis results, care providers and study participants had to sign a data processing contract with the company and a declaration of consent following data protection law. The collaborating care provider covered the analysis costs. In Germany, care institutions have a prevention budget that provides a legal basis for them to fund appropriate solutions.

Data Collection

All data analyzed in this study were entered by the app's users and stored on company servers hosted by Deutsche Telekom and located in Bonn, Germany. The Chief Technology Officer of Lindera and backend employees had access to the database and extracted anonymized data for scientific evaluation. No identifiable patient information has been or will be shared.

Statistical Analysis

Descriptive Statistics

All statistical analyses were conducted using Python version 3.6.8 (Python Software Foundation, Wilmington, United States) with the aid of the Pandas library version 0.24.2. All modeling research was done using the scikit-learn machine learning library for Python, version 0.20.3. Python is widely used for conducting statistical analyses [24,25]. Descriptive statistics, including means, standard deviations, and distributions, were provided for all study variables and compared across groups (fallers vs nonfallers). To test for significant differences ($P < .05$) between groups, a two-sample, two-tailed t test was applied for metric variables, and a chi-squared test was applied for categorical data.

Model-Based Statistics

The ability to discriminate between fallers and nonfallers using the fall score feature alone was analyzed, prioritizing a high sensitivity. One of the best performance metrics for quantifying the accuracy of medical diagnostic tests, like the one considered here, is the receiver operating characteristic (ROC) [26-28].

To determine the ROC for the two-class classification model, we first calculated the confusion matrix for a predefined test dataset. Secondary performance metrics, like sensitivity, specificity, accuracy, and precision, can be easily calculated from the confusion matrix. Detailed descriptions of the concepts of the ROC, the confusion matrix, and secondary performance metrics, with a clear focus on the sensitivity-specificity trade-off, can be found in the supplementary materials section (see [Multimedia Appendix 2](#)).

In this study, we investigated and compared the following five models: Logistic Regression, Gaussian Naive Bayes, Gradient Boosting, Support Vector Classification, and Random Forest Classification. The primary reason for choosing these models was that they exhibit good selection capabilities over multiple model types and are well studied in applications of machine learning in the medical field [29,30] (for more details about the general theory and application of machine learning algorithms, see books by Hastie et al, Dangeti, and Bowles [31-33].) In all models used in the analysis, the fall score was the only independent variable used to predict the target output for each subject in the dataset, namely their classification into the nonfaller (0) or the faller (1) group.

The modeling pipeline was as follows. First, we partitioned the dataset into two subsets via a stratified random split. A total of 85% of the dataset went into a training-validation set (205 subjects) and 15% into a test set (37 subjects). We chose to perform a stratified split in order to ensure that the two classes had the same distribution in both subsets. Next, we performed

a stratified k-fold cross-validation (with $k=8$ splits) [34-36] on the training-validation subset, with the test set remaining untouched to enable the later evaluation of the final models on a real-world dataset. Details of the k-fold cross-validation can be found in the supplementary materials section (see [Multimedia Appendix 2](#)). The k-fold cross-validation helped us to identify a final form for each model and its mean cut-off probability for optimizing the sensitivity-specificity trade-off. We then trained these final models on the complete training-validation subset and calculated performance metrics based on the test dataset.

Results

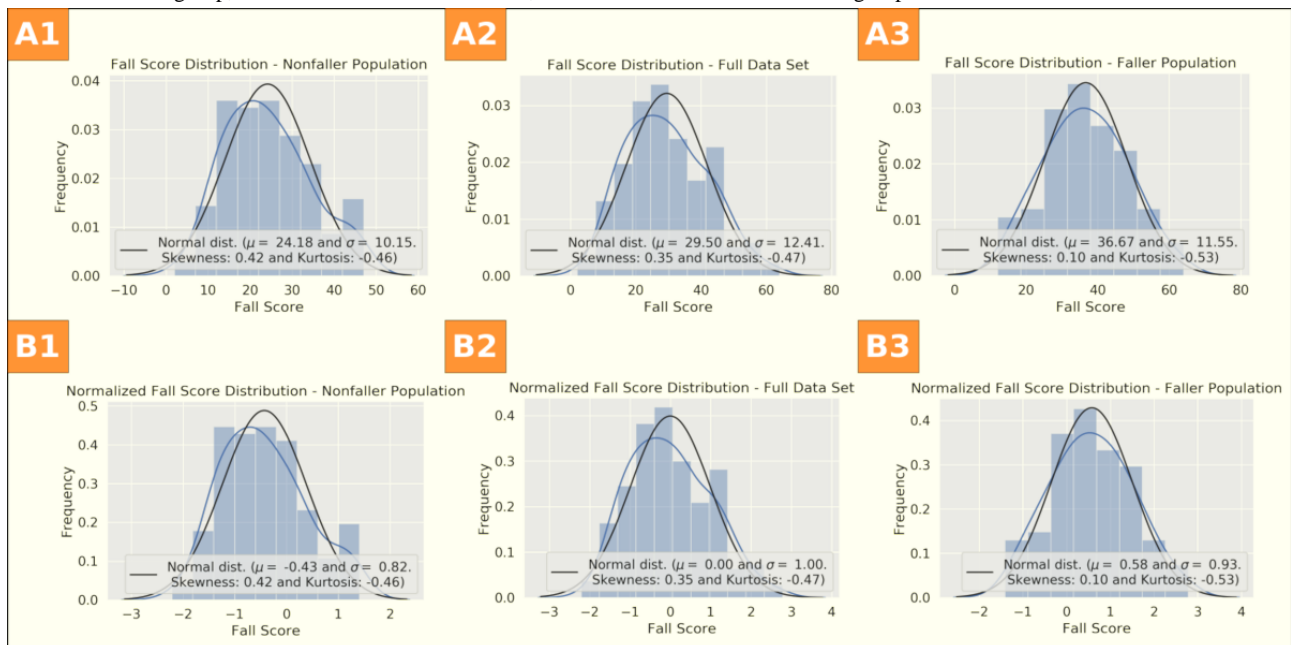
Descriptive Statistics

The sample had a mean age of 84.6 years (SD 6.7), and 169/242 participants (69.9%) were female. A total of 139 seniors (57.4%)

reported no previous falls (nonfaller), whereas 103 seniors (42.5%) reported at least one fall event in the last 12 months. There was no statistical difference in age ($P=.87$) or gender ($P=.41$) between fallers and nonfallers. Overall, 131 seniors (54.1%) were living in nursing homes, 34 (14.1%) in assisted living facilities, and 77 (31.8%) at home. There were 40 seniors (16.5%) who lived at home and received outpatient care.

The average fall-risk score was 29.5 points (SD 12.4). Fallers had an average fall-risk score of 36.7 (SD 11.6), while nonfallers had an average fall-risk score of 24.0 (SD 10.2). All analyzed subgroups showed a normal distribution (see [Figure 1](#)). There was a highly statistically significant difference in fall-risk scores between fallers and nonfallers ($P<.001$).

Figure 1. Fall-risk score histograms. Row A shows histograms for nonnormalized fall scores and Row B for standard-scaled fall scores. A1 and B1 show the nonfaller subgroup, A2 and B2 show the full dataset, and A3 and B3 show the faller subgroup.



We show the standard-scaled fall score distributions in [Figure 1](#). The normalized fall score distribution resembles a Gaussian distribution with a zero mean and standard deviation of one. Accordingly, the mean for the nonfaller subgroup is negative, while the mean for the faller subgroup is positive.

Skewness and kurtosis factors of the distributions are also shown in [Figure 1](#). Both are in a range corresponding with a normal distribution (skewness between -0.5 and $+0.5$).

Model-Based Statistics

The results of the k-fold stratified cross-validation are shown in [Table 1](#). The average sensitivity was around 85.0%. The average optimal cut-off probability was 0.32 (SD 0.06), and the corresponding cut-off fall score was 27.3 points (SD 3.4). A subject at or above that fall score value was classified into the faller subgroup on average.

Table 1. Results of the k-fold stratified cross-validation study (k=8).

	LR ^a model	GNB ^b model	GB ^c model	RF ^d model	SVC ^e model	Overall average (SD)
AUC ^f (SD)	0.76 (0.09)	0.76 (0.09)	0.75 (0.09)	0.74 (0.07)	0.74 (0.09)	0.75 (0.08)
Sensitivity, % (SD)	85.0 (4.0)	85.0 (4.0)	85.0 (5.0)	85.0 (5.0)	84.0 (4.0)	85.0 (4.0)
Specificity, % (SD)	49.0 (10.0)	49.0 (10.0)	54.0 (17.0)	50.0 (8.0)	51.0 (15.0)	50.0 (12.0)
Accuracy, % (SD)	71.0 (6.0)	71.0 (6.0)	68.0 (7.0)	66.0 (8.0)	71.0 (6.0)	70.0 (7.0)
Precision, % (SD)	56.0 (5.0)	56.0 (5.0)	59.0 (8.0)	56.0 (4.0)	56.0 (6.0)	57.0 (6.0)
Cut-off probability (SD)	0.31 (7.0)	0.29 (0.07)	0.38 (0.05)	0.34 (0.06)	0.27 (0.05)	0.32 (0.06)
Cut-off fall score points, mean (SD)	25.3 (3.3)	25.0 (3.0)	29.5 (3.4)	29.4 (6.0)	27.4 (1.4)	27.3 (3.4)

^aLR: Logistic Regression.

^bGNB: Gaussian Naive Bayes.

^cGB: Gradient Boosting.

^dRF: Random Forest.

^eSVC: Support Vector Classification.

^fAUC: area under the curve.

In a final step, we considered the models with the best average cut-off probabilities as the optimal models. These optimal models were then trained on the full training-validation set (85% of the complete dataset), while test metrics were calculated on

the remaining hold-out test set (15% of the complete dataset). Validation metrics for the individual models, together with the averages across all models, are presented in [Table 2](#).

Table 2. Results of the test set metrics for the final models.

	LR ^a model	GNB ^b model	GB ^c model	RF ^d model	SVC ^e model	Overall average (SD)
AUC ^f	0.9	0.9	0.85	0.84	0.84	0.86 (0.03)
Sensitivity, %	100.0	100.0	88.0	88.0	88.0	93.0 (6.0)
Specificity, %	52.0	52	62.0	56.0	57.0	58.0 (5.0)
Accuracy, %	73.0	73.0	73.0	70.0	76.0	73.0 (2.0)
Precision, %	62.0	62.0	64.0	61.0	67.0	63.0 (2.0)

^aLR: Logistic Regression.

^bGNB: Gaussian Naive Bayes.

^cGB: Gradient Boosting.

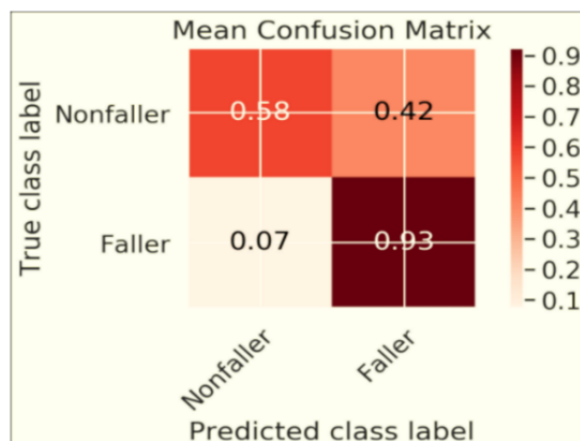
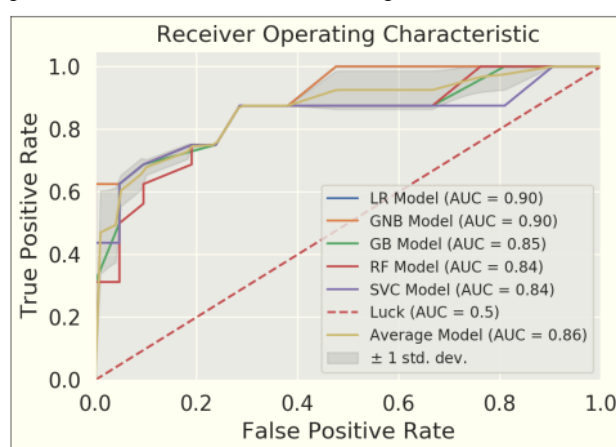
^dRF: Random Forest.

^eSVC: Support Vector Classification.

^fAUC: area under the curve.

[Figures 2](#) and [3](#) illustrate the main results of the finalized models, evaluated on the hold-out test set. The average confusion matrix is shown in [Figure 2](#). The models are quite sensitive (93% of the faller subgroup correctly classified to the faller group). [Figure 3](#) displays ROC curves for all five models

together with the average ROC curve. The mean AUC over all models is 0.86, and we can observe that most model ROC curves are located one SD above and below the average ROC curve (the grey area in the ROC plot). The high average AUC indicates that the fall score had very good separability.

Figure 2. Confusion matrix averaged over all five models.**Figure 3.** ROC curves and corresponding AUCs for the five models and the average over all five models.

Discussion

Study Findings

The study's main finding was that the fall-risk score exhibited a high discriminative ability to distinguish fallers from nonfallers across all six models evaluated. The models had an average AUC of 0.86, an average sensitivity of 93%, an average specificity of 58%, and an average accuracy of 73%. As discussed in the methods section, AUCs near 1 (0.8-0.9) indicate very good separability of the models and their corresponding features [26,37]. Thus, an average AUC of 0.86 indicates a very good discriminative ability of the fall score feature, which is further reinforced by the high average sensitivity of 93%.

Our results provide a descriptive evaluation of the designed fall-risk score for a sample of very elderly seniors with a mean age of 84.6 years old (SD 6.7). This high average age may be because more than half of the sample (54.3%) were nursing home residents. A total of 14.1% were living in assisted living facilities, and 16.1% received ambulant care. Thus, a large share of the investigated population was in high need of care. The high percentage of fallers (42.5%) in the sample may also be attributable to these demographic characteristics. There is currently only limited data on fall rates among seniors of very high age. Rapp et al [38] found retrospective one-year fall rates of 44.1% for women and 46.9% for men. Von Heideken Wägert

et al [39] reported a retrospective one-year fall prevalence of 45% in a cohort of seniors above age 85. Similarly, van Bommel et al [40] reported a fall rate of 44% for 85-year-old seniors. Moreover, 69.8% of the participants in the present study were female. This reflects the higher percentage of females in the elderly population, particularly at very high ages [41]. Hence, the sample seems to be representative of seniors of very great age for the discussed patient characteristics.

The average fall-risk score in this sample was 29.5 points (SD 12.4). The descriptive data analysis clearly shows that fallers had significantly higher fall-risk scores than nonfallers ($P < .001$). Moreover, the fall-risk scores in the evaluated groups were normally distributed, facilitating a good discriminative ability. This data can be used as reference values to judge and compare seniors' fall-risk scores. Furthermore, the dataset continues to grow as the use of the fall-risk assessment app continues, and reference values with an even higher sample size will exist in the future. Reference values for different subgroups will also be made available as the sample size increases.

Comparison With Prior Work

A large number of studies have evaluated the accuracy of fall-risk assessments [1,3,14,22,42]. Regarding AUC values, Lee et al [42] conducted a review of 31 studies and reported accuracy values for fall-risk assessments ranging from 0.62-0.89. More recently, Park et al [1] conducted a meta-analysis of 33

fall-risk assessment tools. They reported AUC values ranging from 0.76-0.97, sensitivity values ranging from 53%-89%, and specificity values ranging from 26%-90%. Based on criteria recommended by Olivier et al [43], fall-risk assessments with a sensitivity of $\geq 70\%$ are considered acceptable. Park et al reported specificities under 60% for nearly all evaluated assessment tools. Furthermore, Rasche et al [14] conducted a meta-analysis reviewing the latest fall-risk assessment measures and reported a mean sensitivity range of 57.0%-90.0% and a mean specificity range of 30.6%-84.3%. Average AUC values for the included fall-risk assessments ranged from 0.69-0.90. Consequently, the newly developed fall-risk score presented in this study achieves accuracy measures that are comparable to established fall-risk assessments.

It must be stated that all of our evaluated models achieved a specificity below 70%. This means that there is a tendency to report a higher risk of falling. This, in turn, could affect the fall prevention strategies recommended by the app. However, a lower specificity can be tolerated due to the noninvasive nature of fall prevention strategies, which often address general health issues. In other words, given the noninvasive nature of fall prevention interventions, falsely diagnosing someone as high risk is considered less detrimental than falsely categorizing someone as low risk (which would result in falls not being prevented). The primary goal of a fall-risk assessment tool is to identify people at a high risk of falling to minimize the occurrence of falls. Accordingly, we conclude that if a fall-risk assessment tool has a high sensitivity, it achieves its primary goal, even though the specificity is low. Thus, although the specificity is not ideal, the overall performance of the fall-risk score and its sensitivity-specificity trade-off meet the specific requirements of a tool for fall prevention.

The available research on the accuracy of fall-risk assessment tools exhibits high interstudy heterogeneity [1,22,42]. Because falls are multifactorial, it should be noted that all fall-risk assessments have imperfect accuracy. It is highly improbable that a single fall-risk assessment tool will be able to accurately assess all individually relevant risk factors and risk factor combinations. Nonetheless, these risk assessment tools can offer valuable help to clinicians and nursing staff and facilitate the identification of at-risk seniors and suitable interventions. Oliver et al stated that identifying and modifying risk factors seems to be the optimal strategy to prevent falls, as opposed to focusing only on risk prediction, which may be inaccurate and will not in and of itself prevent patients from falling [44]. Therefore, the evaluated fall-risk score is provided in combination with a tailored prevention plan for every senior assessed. Furthermore, a metric fall-risk score enables the quantification of fall risk, which could help to evaluate the effects of prevention strategies.

To assist health care professionals in understanding the fall-risk score, we suggest a cut-off value. In a precision-sensitivity study, a cut-off value of 27.5 points (SD 4.5) was shown to offer the best combination of sensitivity and specificity. Thus, seniors with a score higher than 27.5 points (SD 4.5) can be classified as having a high fall risk and should be prioritized in the implementation of prevention strategies. However, this cut-off value should be seen as merely a preliminary recommendation.

Evaluations of larger sample sizes with prospective data may lead to further adjustments in the recommended cut-off score.

Limitations

This study's limitations arise from its retrospective case-control study design, which makes it potentially vulnerable to selection bias. The potential for recall bias should also be considered. Recall bias refers to the increased likelihood that fallers will recall and report the presence of risk factors, whereas nonfallers are less likely to report risk factors [45]. Furthermore, this study evaluated data on retrospective fall status, which may have led to higher fall-risk scores among fallers. In other words, a past fall event may have led to higher values of the investigated risk factors (eg, limited mobility, fear of falling). These methodological issues will be addressed in further data analyses with a dataset that includes prospective data on fall status. A further methodological improvement could be the addition of a third group of frequent fallers. Frequent falls are associated with the most considerable risk of future falls [46] and could, therefore, provide insights about a high-risk population in need of the greatest support in terms of prevention strategies.

Moreover, there is a discussion in the fall-risk literature about the self-reporting of falls. One-year retrospective self-reporting of falls has been found to result in a slight underreporting [47,48]. Additionally, there is a need for a clear and simple definition of fall events from a methodological perspective [49]. The lack of a clear definition may have biased the assessment of fall events. A clear definition will become even more critical when the app is used without support from the nursing staff. Furthermore, our sample might not be representative of the broader population of older adults, and especially of community-dwelling older adults. Future research is needed to investigate the accuracy of the fall-risk score in further population segments.

Outlook

The digital assessment of fall risk has the potential to objectify and improve fall-risk assessment and reduce the subjectivity introduced by human judgment due to biases, prior knowledge, experience, preferences, and limited capacities to absorb information.

Various researchers have concluded that the validity of current fall-risk assessment tools is not enough [1,3,15]. Therefore, new approaches are needed. As the fall-risk assessment app's number of users grows, there is the potential to gain more in-depth insights from real-world data on the development of fall risk, fall-risk factors, different subgroups, and the effectiveness of fall prevention strategies based on large sample sizes. Gaining knowledge about effective fall-risk assessment and prevention in the geriatric population is critical considering current demographic challenges related to an aging population [50].

Conclusion

The descriptive statistics provided can be used as comparison and reference values for users of the fall-risk assessment app. The fall-risk score showed a high discriminative ability to distinguish fallers from nonfallers in all the evaluated models. On average, the models exhibited good accuracy, excellent

sensitivity, moderate specificity, and good AUC values. The fall-risk assessment app has the potential to support nursing staff in performing valid, systematic, and objective fall-risk assessments that can be used to identify relevant risk factors

and implement multifactorial prevention strategies. The fall-risk score's predictive validity will be further validated in future prospective trials, including larger sample sizes based on a growing real-world database.

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Conflicts of Interest

SR, AA, and SM are employees of Lindera.

Multimedia Appendix 1

Example prevention plan.

[PDF File (Adobe PDF File), 604 KB - [aging_v3i1e16131_app1.pdf](#)]

Multimedia Appendix 2

Details of model-based statistics.

[DOCX File, 217 KB - [aging_v3i1e16131_app2.docx](#)]

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Abbreviations

AUC: area under the curve

ROC: receiver operating characteristic

STRATIFY: St. Thomas's Risk Assessment Tool In Falling Elderly Inpatients

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Original Paper

The Roles of YouTube and WhatsApp in Dementia Education for the Older Chinese American Population: Longitudinal Analysis

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Abstract

Background: Dementia remains a stigmatized topic in the Chinese community.

Objective: This study aims to analyze and compare the usage of dementia educational YouTube videos and the modalities of video sharing over a 6-year period.

Methods: Dementia educational videos were uploaded to YouTube. Data was collected over a 6-year period. Results from the first 3 years were compared to those from the second 3 years using descriptive statistics and chi-square analysis.

Results: Over 6 years, the dementia educational videos generated a total watch time of 269,388 minutes, 37,690 views, and an average view duration of 7.1 minutes. Comparing the first and second 3-year periods of video performance data, there was a longer watch time (59,262 vs 210,126 minutes), more total views (9387 vs 28,303 views), and a longer average view duration (6.3 vs 7.4 minutes). Furthermore, WhatsApp has become a leading external traffic source and top sharing service, accounting for 43.5% (929/2137) and 67.0% (677/1011), respectively.

Conclusions: Over 6 years, YouTube has become an increasingly popular tool to deliver culturally sensitive dementia education to Chinese Americans. WhatsApp continues to be the preferred method of sharing dementia education and has become a top external traffic source to dementia educational videos. Taken together, these social media platforms are promising means of reducing the disparity in dementia knowledge in linguistically and culturally isolated populations.

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KEYWORDS

dementia; mental health; social media; geriatrics; health promotion; health education

Introduction

Social media has become a powerful means for health communication to and among the general public, patients, and health professionals alike [1]. Since its debut in 2005, YouTube has become one of the world's most popular social media platforms and a major contributor to the accessibility and dissemination of health information around the world [2].

Dementia is a progressive and irreversible neurocognitive disorder that severely impairs an individual's ability to independently function, which inadvertently causes tremendous burden to family members and caregivers [3]. Although no current therapy can reverse the steady cognitive decline, early

and accurate diagnosis has proven efficacious in prolonging quality of life and allowing both the patient and family time to adjust to changes [4]. Consequently, it is necessary to increase public awareness of this diagnosis to promote early intervention amongst all ethnic communities.

Dementia remains a stigmatized subject in the Chinese community, and the scant availability of language-appropriate and culturally sensitive education is a barrier to encouraging those affected from seeking help [5-7]. Work has been done to promote dementia awareness in the Chinese-American community via radio shows, television episodes, and short films [8-10]. Previous studies have demonstrated that YouTube has the potential to successfully deliver dementia education to the

older Chinese population [11-15]. In addition, studies have also identified WhatsApp as a promising means for disseminating such dementia education [16].

In this study, we aim to analyze how the Chinese-speaking public search for and share dementia educational videos and evaluate the usage of various social media platforms over time. To our knowledge, this is the first study to present such longitudinal data.

Methods

YouTube

A board-certified psychiatrist delivered 2 educational talk shows in Cantonese on a North American Chinese television station in Los Angeles, California. The content of the videos included discussing the background, management, and prevention of dementia. Real-time recordings were subsequently uploaded to YouTube as two 25-minute videos.

Sample

The sample of this study included YouTube video viewers over a 6-year period (January 2014-December 2019).

Statistical Analysis

Data was extrapolated from YouTube Analytics. A number of parameters were recorded including number of views, watch time, average view duration, devices used to view, traffic

sources, and modes and means of sharing via various social media platforms. Years 1 to 3 (January 2014-December 2016) and years 4 to 6 (January 2017-December 2019) were dichotomized. Descriptive statistics and chi-square tests were used to compare data collected between the first and second 3-year intervals.

This study used anonymous data collected by YouTube exclusively. A waiver for Institutional Review Board exemption was obtained through the University of California, Los Angeles-Human Subjects Protection Committee.

Results

In 6 years, the two videos of interest accrued a total watch time of 269,388 minutes and 37,690 views, resulting in an average view duration of 7.1 minutes. Broken down into two 3-year intervals, the data are as follows. The latter 3 years had increased performance in all parameters: longer total watch time increased number of views, and longer average view duration.

The average view duration on mobile devices (eg, mobile phone, tablet) between the former and latter 3-year intervals increased 17.0% from 6.9 minutes to 8.1 minutes. On the other hand, average view duration on computers increased 6.9% from 5.8 minutes to 6.2 minutes. There is a significant increase in mobile device usage compared to computer usage from the first 3-year window to the second 3 year window (66.6% vs 78.0%, $\chi^2_1=488.05$, $P<.001$) (Table 1).

Table 1. Devices used for viewing.

Devices	Jan 2014-Dec 2016			Jan 2017-Dec 2019		
	Minutes	Views	AVD ^a (min)	Minutes	Views	AVD (min)
Computer	18,292	3132	5.8	38,352	6226	6.2
Mobile device	40,970	6255	6.9	171,774	22,077	8.1
Total	59,262	9387	6.3	210,126	28,303	7.4

^aAVD: average view duration.

Comparing traffic sources, externally sourced views increased from 6.6% (621/9387 views) to 7.5% (2137/28,303 views) between the two 3-year periods. Of external sources, the top platforms remained Google search and WhatsApp, followed by Facebook. Over 6 years, traffic generated from Google search decreased from 1.5% to 1.1% of total views (138/9387 vs 302/28,303), Facebook generated traffic source decreased from 0.3% to 0.2% of total views (30/9387 vs 54/28,303), and WhatsApp traffic source increased from 0.6% to 3.3% of total views (59/9387 vs 929/28,303). Between the former and latter 3-year periods, WhatsApp traffic source surpassed that of

Google search with statistical significance (0.6% vs 3.3%, $\chi^2_3=225.78$, $P<.001$) (Table 2).

Table 3 shows the comparison between different sharing services. In comparing the two periods, there was a significant increase in usage of WhatsApp for sharing and movement away from sharing via email (66.4% vs 66.9%, $\chi^2_4=27.82$, $P<.001$).

Taken together, although there is a significant increase in traffic generated from WhatsApp between the 2 periods, WhatsApp remains more frequently used for sharing services than viewing capabilities (66.9% vs 3.3%, $\chi^2_1=33.3$, $P<.001$).

Table 2. Traffic sources.

Traffic sources	Jan 2014-Dec 2016			Jan 2017-Dec 2019		
	Minutes	Views	AVD ^a (min)	Minutes	Views	AVD (min)
Top 4 traffic sources						
Suggested videos	39,432	5288	6.6	128,448	15,942	8.1
YouTube search	9468	1696	5.6	8130	1606	5.1
Browse features	6642	954	6.9	46,680	6345	7.4
External	3228	621	5.2	11,400	2137	5.3
Top 4 external traffic sources						
Google search	600	138	4.3	1404	302	4.6
WhatsApp	336	59	5.7	4656	929	5.0
Facebook	222	30	7.4	378	54	7.0
Apple app	294	31	9.5	270	30	9.0

^aAVD: average view duration.

Table 3. Sharing services.

Sharing services	Jan 2014-Dec 2016, n=175 (times shared), n (%)	Jan 2017-Dec 2019, n=1011 (times shared), n (%)
WhatsApp	111 (66.4)	677 (67.0)
Email	23 (13.1)	39 (3.8)
Facebook	6 (3.4)	29 (2.8)
Text message	6 (3.4)	60 (5.9)
Other	29 (16.6)	206 (20.4)

Discussion

Principal Findings

As the power of social media increases, YouTube has become an indispensable e-mental health platform. In this study, we aimed to investigate the means that the Chinese-speaking public search for and share dementia education videos, and evaluate the usage of various social media platforms over time. Although prior studies have aimed to analyze the potential of YouTube and WhatsApp as means for disseminating dementia education, this is the first study to analyze data over a 6-year period—comparing the first and second 3 years—and provide statistical analysis of not only the trends in devices used for viewing but also the dynamic shift in traffic sources and usage of sharing services [11-16]. Overall, the latter 3 years had increased performance than the first 3 years including longer total watch time (59,262 vs 210,126 minutes), increased number of views (9387 vs 28,303 views), and longer average view duration (6.3 vs 7.4 minutes). Previous studies have reported a 6-minute median engagement time across online educational videos of varying lengths [17]. The increase in average view duration in the second 3-year period from 6.3 to 7.4 minutes demonstrates that the dementia educational videos were able to not only capture but also retain viewers' attention.

The chi-square analysis showed significant difference in our following analyses. Compared to computer use, average view duration on mobile devices remained and increased far more than on computers between the first and second 3-year intervals

(6.9-8.1 minutes). This demonstrates the increasing popularity of using a mobile device over a computer to watch the educational videos. Electronic health (eHealth) communication efforts should therefore ensure mobile device compatibility to maximize audience.

Analysis of traffic sources revealed that YouTube's suggested videos have consistently been the main source of traffic in the last 6 years. However, the analysis of external traffic sources revealed notable findings. Comparing the first and second 3-year periods, Google search traffic source remained relatively the same (1.5%, 138/9387 to 1.1%, 302/28,303 of views), Facebook generated traffic source decreased (0.3%, 30/9387 to 0.2%, 54/28,303 of views), and WhatsApp traffic source increased and even surpassed that of Google search (0.6%, 59/9387 to 3.3%, 929/28,303 of views). This demonstrates the significant rise in popularity of WhatsApp in the latter 3 years and suggests that WhatsApp could be the future platform for dementia education and eHealth communication alike.

Our study also demonstrates that WhatsApp has evolved into a leading means of sharing dementia knowledge among the Chinese American community. Between the first and second 3-year periods, WhatsApp and text message have both experienced increase in usage as sharing services, while Facebook and email have both dramatically decreased. Previous studies have suggested that WhatsApp is used more for its sharing capability than for its viewing function [16]. Our study confirms this finding and reinforces the claim with 6 years of longitudinal data. Not only has WhatsApp become the preferred

means of sharing dementia knowledge, but it has also exceeded Google search and has become the top external source of traffic.

Limitations

This study has several limitations. First is the lack of demographic information about the viewers. Because all video content was in Chinese and limited to US residents, it was assumed that our study population was largely Chinese American. The ability to collect demographic information would enable analysis of the impact of ethnicity and socioeconomic status on social media use. Second, because there was no measure of viewers' knowledge of dementia prior to and after watching the videos, we were unable to evaluate the effectiveness of the videos as an educational tool. Third, this study is a retrospective longitudinal analysis of data extrapolated from YouTube Analytics. As such, analysis was constrained to the variables and data collected by YouTube Analytics. In the future, prospective studies should focus on the role of WhatsApp in the dissemination of eHealth content. Last, as each video was 25-minutes long, there was a relatively short average viewing duration of 6.3 to 7.4 minutes. A shorter average viewing duration would preclude effective delivery of important

information. Shortening the video length and applying more engaging, interactive content could inherently improve viewer attention, viewing duration, and, ultimately, retention of educational content. Efforts to decrease stigma and negative perceptions toward dementia are essential to provide and coordinate care for the Chinese American population. Future directions include the continued study of the long-term impact that social media has in health communication to populations of interest.

Conclusion

YouTube has proven to be a valuable tool to deliver culturally sensitive dementia education to Chinese Americans, thereby reducing the disparity of dementia knowledge in linguistically and culturally isolated populations. WhatsApp continues to be a preferred method of sharing dementia education and has become a top external traffic source to dementia educational videos. Use of these findings and continued study of how social media can be used in health communication are imperative to work in disseminating knowledge, reducing stigma, and promoting early detection and treatment in the older Chinese American population.

Conflicts of Interest

None declared.

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Abbreviations

AVD: average view duration

eHealth: electronic health

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Original Paper

The Use of Internet-Based Health and Care Services by Elderly People in Europe and the Importance of the Country Context: Multilevel Study

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Abstract

Background: Digital health care is becoming increasingly important, but it has the risk of further increasing the digital divide, as not all individuals have the opportunity, skills, and knowledge to fully benefit from potential advantages. In particular, elderly people have less experience with the internet, and hence, they are in danger of being excluded. Knowledge on the influences of the adoption of internet-based health and care services by elderly people will help to develop and promote strategies for decreasing the digital divide.

Objective: This study examined if and how elderly people are using digital services to access health and social care. Moreover, it examined what personal characteristics are associated with using these services and if there are country differences.

Methods: Data for this study were obtained from the Special Eurobarometer 460 (SB 460), which collected data on Europeans' handling of and attitudes toward digital technologies, robots, and artificial intelligence, including data on the use of internet-based health and social care services, among 27,901 EU citizens aged 15 years or older. Multilevel logistic regression models were adopted to analyze the association of using the internet for health and social care services with several individual and country-level variables.

Results: At the individual level, young age, high education, high social class, and living in an urban area were positively associated with a high probability of using internet-based health and social services. At the country level, the proportion of elderly people who participated in any training activity within the last month was positively associated with the proportion of elderly people using these services.

Conclusions: The probability of using internet-based health and social services and their accompanying advantages strongly depend on the socioeconomic background. Training and educational programs might be helpful to mitigate these differences.

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KEYWORDS

eHealth; Europe; elderly people

Introduction

Health care systems in Europe and beyond are currently under pressure. Considering financial, demographic, and epidemiological developments, there is a need for new

approaches to deliver health care equally and cost effectively and with the best medical outcomes [1]. There are many hopes on technological solutions, in particular digital technology, which promises to deliver health care without restrictions in time and space and has the potential to transform health care systems and the health care industry. With this technology,

health information is obtained over the internet, vital signs are measured using smart devices and are directly sent to care providers, drugs are ordered over the internet, physicians are consulted from home, smartphone apps are used to manage chronic conditions, etc. Digital health care is an umbrella term for multiple buzzwords, including concepts like electronic health (eHealth), mobile health (mHealth), telemedicine, teleHealth, and many more. It can be defined as “the cultural transformation of how disruptive technologies that provide digital and objective data accessible to both caregivers and patients lead to an equal level doctor-patient relationship with shared decision-making and the democratization of care” [2].

Despite the potentials of digital health care, there are risks that lead to several challenges. In particular, the promise that all individuals will benefit equally needs to be questioned, as digital health requires not only infrastructure to use the internet, but also skills to operate digital technology [3,4]. Both, however, are unequally distributed across the population [5,6]. In this regard, a group of particular interest is elderly people. As decreasing fertility rates and increasing life expectancy are leading to demographic aging in North America, parts of Asia, and Europe, the absolute and relative numbers of old and very old (80 years or above) people are steadily increasing [7]. In addition, the elderly population is in particular need of health care and the possibilities and chances of digital health care for elderly people are particularly high [8]. However, there is a substantial part of the elderly population that does not use the internet, which is a precondition for using web-based health and social services.

When investigating influences on internet use for health and care services among elderly people, the following three aspects need to be considered: (1) factors influencing internet use in general; (2) factors influencing internet use for health-related purposes; and (3) factors influencing the capability to understand and process information, so-called eHealth literacy [3] or digital health literacy, which covers a set of skills to “search, select, appraise, and apply online health information” [4].

With regard to the first aspect, several studies reported that internet use declines with increasing age in Western societies [9,10]. Eurostat data for 2018 showed that 98% of EU-28 citizens aged 16 to 24 years used the internet within the last 12 months, but only 78% of those aged 55 to 64 years and 48% of those aged 65 to 74 years used the internet within the last 12 months [11]. There are differences between countries. Although the percentages have increased over the years, the use of internet technology by elderly people has declined with increasing age. This decline can be explained by several factors at not only the individual level, but also the “meso” and “macro” levels. At the individual level, factors, such as education [9,10,12] and income [9,10,13], are associated with digital divide. Moreover, male sex is associated with higher internet use, and age 65 years or above [10], health [13,14], and experience with computers during working life have an effect on internet use in old age [6,15]. At the “meso” level, social support is positively associated with internet use in old age. Those with a strong social network are more likely to use the internet, as they make use of internet and communication technologies to curate their network; in addition, individuals with a large social network

are more likely to be introduced to new technologies [16,17]. Moreover, support programs aimed at introducing elderly people to the internet have an effect [18]. At the “macro” level, several studies have shown a link between infrastructure and internet use. As individuals in rural areas often have less access to broadband or mobile connections, they are less likely to use the internet [10]. Another aspect that needs to be mentioned here is technical socialization. According to the “technology generation theory” [19], birth cohorts differ according to the technological devices they have used while growing up.

We were interested in exploring eHealth use in terms of using the internet to access health and social care services among those who were already on the internet. Considering the use of the internet for health purposes, previous research has revealed multiple influences on the use of new digital technologies to access health care by elderly people. There are, however, multiple overlapping factors. As for internet use in general, sociodemographic characteristics, such as gender (women are more likely to use the internet for health and social care than men), age, education, and household income, are associated with using the internet for health and social care services [20-25]. At the “meso” level, social networks are reported to have a positive effect [24]. At the “macro” level, previous results found that individuals in rural areas seem to use eHealth less often than those in more densely populated areas [24]. Although we did not encounter studies investigating the effect of the country context on the internet-based use of health and social care services, we assume that it has an influence. We assume that life-long learning programs have a comparable effect on eHealth use as on internet use in general. In rich countries, we hypothesize a high proportion of eHealth users and a high number of elderly people with the resources to access eHealth. The share of the national budget spent for elderly people is positively associated with eHealth use among elderly people, as more financial resources are provided. In addition, we hypothesize that in countries with a high proportion of elderly people, these elderly people represent a large group of customers for providers of eHealth and hence are a target for advertisements. Finally, as good access to the internet is a necessary condition to use digital health and social care services, we assume that the proportion of elderly people who use these services increases with an increase in a country’s quality of internet access.

It is important to determine if and how elderly people use the internet to access health care; what personal characteristics are associated with using eHealth; and whether there are country differences in access to eHealth, and if so, how can these be explained. To obtain this information, this study analyzed data from a Special Eurobarometer [26], using multilevel logistic regression. It investigated how many people in Europe use digital health care services. Furthermore, it explored which variables at the individual level and the country level are associated with a high probability of the use of digital health care services. Controlling for age, employment status, marital status, and self-perceived class, the study hypothesized that elderly women are more likely to use the internet to access health and social care (H1), elderly people with a high education level are more likely to use eHealth (H2), elderly people living

in urban areas are more likely to use eHealth (H3), and elderly people living alone are less likely to use eHealth (H4). At the country level, it hypothesized that elderly people in countries where life-long learning is more common are more likely to use eHealth (H5), elderly people in rich countries are more likely to use eHealth (H6), elderly people in countries where a large share of the welfare state's budget is spent on the elderly population are more likely to use eHealth (H7), elderly people in countries where demographic ageing is more developed are more likely to use eHealth (H8), and elderly people in countries where access to the internet is good are more likely to use eHealth (H9).

This study contributes to the field in several ways. First, the inclusion of individual as well as country level determinants of the probability of using digital health care services provides a more holistic picture of the potential of digitalization for health care among elderly people. The findings shed light on relevant disparities in the use of digital health care services among elderly people at the individual and country levels. The second contribution is the data used in the study, which were derived from a recent survey conducted in 2017. As digital technologies are changing quickly and new possibilities for digital health care provision are being developed constantly, regular monitoring of how elderly people use this approach is necessary. The third contribution is the comparative perspective. The inclusion of several countries in the analysis allows the identification of factors that foster and hinder the use of eHealth, which can be transformed into policy recommendations.

Methods

Data and Sample

The analysis in this study was conducted with data derived from the Special Eurobarometer 460 (SB 460) *Attitudes toward the impact of digitization and automation*, which collected data on Europeans' handling of and attitudes toward digital technologies, robots, and artificial intelligence, including questions on the use of internet-based health care in the year 2017. The SB 460 is part of the Eurobarometer program that includes several public opinion surveys among the citizens of the European Union on a variety of topics. For the SB 460, the TNS Political & Social network performed face-to-face interviews for 27,901 EU citizens aged 15 years or older. The interviews took place at the home of the interviewees and in their native language. Sampling was performed with a multistage random probability approach [26]. For the analysis of this study, the sample was restricted to adults aged 65 years or older who in general use the internet, which resulted in a sample size of 6900. In addition, it has the advantage of sufficient observational units (countries) at the upper level to conduct multilevel regression analyses.

Analysis Strategy

Multilevel logistic regression models were used to analyze the association of using the internet for health care services with several individual and country-level variables. Multilevel regression is an adequate tool of analysis when the data have a hierarchical structure with units at the lower level nested in

those at the higher level [27]; in this analysis, individual respondents nested in countries. However, as the data had a cross-sectional nature, no causal but only correlational relations can be derived from the results. The analysis was conducted using Stata 14 (StataCorp).

Measures

The variable for the use of digital health care services was based on the following question: *In the last 12 months, how often have you used, if ever, health and care services provided over the internet without having to go to the hospital or doctor's surgery (for example, by getting a prescription or a consultation online)?* The respondents could answer this question with any one of the following four predefined statements: *once, twice, thrice or more, and never*. Missing data were negligible (<1%, n=16). As over 83.87% (5787/6900) of the respondents reported never using internet-based health care services, the other three categories (once, twice, and thrice or more) were summarized into one category. This resulted in the dichotomous variable "use of digital health care services," with values of yes and no.

At the individual level, age, gender, education, social class, marital status, employment status, and urbanization degree were correlated with the use of digital health care services. Education was measured according to age on completion of education and was divided into the following three categories: younger than 15 years, 15 to 20 years, and older than 20 years. Social class was divided into the following three categories: high, medium, and low. Marital status was dichotomized into having a partner and not having a partner. Additionally, employment status was dichotomized into being employed and not being employed. Information regarding urbanization degree had the following three categories: rural area, towns and suburbs, and cities.

At the country level, we included five variables. The proportion of elderly people (aged 65 years or older) who had participated in educational or training activities within the last 4 weeks was used as a measurement for common life-long learning among elderly people. The gross domestic product per person was used to measure the economic development of the countries. To measure the spending for old age, we included the share of the national budget that was used for elderly people. The proportion of people older than 64 years to people younger than 65 years was used to measure how far demographic ageing in a country has progressed. Finally, the subdimension connectivity of the Digital Economy and Society Index was used to measure a country's access to the internet. Data for all five indicators were derived from Eurostat, the statistical office of the European Union [28].

Results

Descriptive Results

Figure 1 and Table 1 show how many elderly people are using internet-based health care services in different European countries. The highest rates were found in Scandinavian countries and Estonia, and the lowest rates were in Malta, Cyprus, and Germany.

Table 1. Use of internet-based health care services among elderly people (aged 65 years or older, N=6900).

Country	Users, n (%)	Nonusers, n (%)
Austria	14 (8.3)	176 (91.7)
Belgium	34 (11.8)	273 (88.2)
Bulgaria	11 (7.5)	149 (92.5)
Croatia	31 (25.8)	89 (74.2)
Cyprus	2 (2.5)	117 (97.5)
Czech Republic	14 (6.8)	183 (93.2)
Denmark	119 (38.9)	187 (61.1)
Estonia	126 (43.8)	161 (56.2)
Finland	144 (43.9)	187 (56.1)
France	13 (4.6)	273 (95.4)
Germany	24 (4.9)	491 (95.1)
Greece	11 (5.7)	176 (94.3)
Hungary	14 (4.6)	272 (95.4)
Ireland	9 (4.3)	206 (95.7)
Italy	23 (12.4)	166 (87.6)
Latvia	14 (6.9)	200 (93.1)
Lithuania	38 (11.2)	317 (88.8)
Luxembourg	22 (18.2)	100 (81.8)
Malta	7 (4.5)	157 (95.5)
Netherlands	78 (28.7)	200 (71.3)
Poland	30 (14.7)	165 (85.3)
Portugal	15 (8.0)	176 (92.0)
Romania	11 (10.5)	105 (89.5)
Slovakia	53 (21.6)	183 (78.4)
Slovenia	73 (26.7)	196 (73.3)
Spain	23 (10.3)	197 (89.7)
Sweden	103 (22.9)	338 (77.1)
United Kingdom	57 (14.5)	347 (85.5)

On comparing users and nonusers of eHealth (Table 2), users were on average younger (71.96 vs 73.04 years) and better educated (proportion of high education: 559/1113, 50.22% vs 1582/5787, 27.34%). In particular, among those from a high social class, there was a higher proportion of users than nonusers (162/1113, 14.56% vs 374/5787, 6.46%). Additionally, among

those in employment and with a partner, there was a higher proportion of users than nonusers (95/1113, 8.54% vs 324/5787, 5.60% and 684/1113, 61.46% vs 3152/5787, 54.47%, respectively). Among those in one-person households, there was a lower proportion of users than nonusers (366/1113, 32.88% vs 2246/5787, 38.82%).

Table 2. Characteristics of the users and nonusers of internet-based health care services.

Characteristic	Nonusers (N=5787), mean or n (%)	Users (N=1113), mean or n (%)	P value
Age (years)	73.04	71.96	.00 ^a
Gender			.22 ^b
Male	2676 (46.24)	536 (48.25)	
Female	3111 (53.76)	576 (51.75)	
Age when education was completed (years)			.00 ^b
<16	1855 (32.05)	153 (13.75)	
16-19	2350 (40.61)	401 (36.03)	
≥20	1582 (27.34)	559 (50.22)	
Social class			.00 ^b
Low	2868 (49.56)	354 (31.81)	
Medium	2545 (42.98)	597 (53.64)	
High	374 (6.46)	162 (14.56)	
Employment status			.00 ^b
Employed	324 (5.60)	95 (8.54)	
Not employed	5463 (94.40)	1018 (91.46)	
Marital status			.00 ^b
With partner	3152 (54.47)	684 (61.46)	
Without partner	2635 (45.53)	429 (38.54)	
Household size			.00 ^b
One	2246 (38.82)	366 (32.88)	
Two	3024 (52.26)	673 (60.47)	
Three	345 (5.96)	45 (4.04)	
Four or more	171 (2.96)	29 (2.61)	
Population density			.09 ^b
Rural area	1673 (28.91)	286 (25.70)	
Towns and suburbs	1974 (34.11)	390 (35.04)	
Cities	2140 (36.98)	437 (39.26)	

^at test.^bChi square test.

The results from the multivariate analysis are presented in [Table 3](#). The intraclass correlation of >0.16 shows that a substantial part of the dependent variable's variation was at the country level and the use of multilevel models is appropriate. At the individual level, the regression found no relevant association between gender and internet use for health and social care. Higher age was associated with less likelihood of using eHealth (OR 0.97, 95% CI 0.96-0.98, $P<.001$). The results also showed significant positive associations between education (16-19 years: OR 1.43, 95% CI 1.15-2.79, $P<.001$; ≥20 years: OR 1.95, 95%

CI 1.54-2.46, $P<.001$) and social class (medium: OR 1.45, 95% CI 1.23-1.71, $P<.001$; high: OR 2.00, 95% CI 1.53-2.61, $P<.001$) on one hand and use of eHealth on the other. Employment status, marital status, and household size were not associated with eHealth use. Population density was associated positively with eHealth use (cities: OR 1.23, 95% CI 1.02-1.48, $P=.03$). At the country level, only the proportion of elderly people who participated in educational activities was significantly associated with eHealth use (OR 1.06, 95% CI 1.01-1.13, $P=.02$).

Table 3. Regression findings regarding the use of internet-based health care services.

Variable	Model (N=6899)									
	M1		M2		M3		M4		M5	
	OR (SE)	95% CI	OR (SE)	95% CI	OR (SE)	95% CI	OR (SE)	95% CI	OR (SE)	95% CI
Individual-level variables										
Age	0.97 ^a (0.01)	0.96- 0.98	0.97 ^a (0.01)	0.96- 0.98	0.97 ^a (0.01)	0.96- 0.98	0.97 ^a (0.01)	0.96- 0.98	0.97 ^a (0.01)	0.96- 0.98
Gender (ref^b: male)										
Female	1.02 (0.08)	0.88- 0.19	1.02 (0.08)	0.88- 0.19	1.02 (0.08)	0.88- 0.19	1.02 (0.08)	0.88- 0.19	1.02 (0.08)	0.88- 0.19
Age (years) when education was completed (ref: <16)										
16-19	1.43 ^c (0.16)	1.15- 2.79	1.43 ^c (0.16)	1.15- 2.79	1.43 ^c (0.16)	1.15- 2.79	1.43 ^c (0.16)	1.15- 2.79	1.43 ^c (0.16)	1.15- 2.79
≥20	1.95 ^a (0.23)	1.54- 2.46	1.95 ^a (0.23)	1.54- 2.46	1.95 ^a (0.23)	1.54- 2.46	1.95 ^a (0.23)	1.54- 2.46	1.95 ^a (0.23)	1.54- 2.46
Social class (ref: low)										
Medium	1.45 ^a (0.12)	1.23- 1.71	1.45 ^a (0.12)	1.23- 1.71	1.45 ^a (0.12)	1.23- 1.71	1.45 ^a (0.12)	1.23- 1.71	1.45 ^a (0.12)	1.23- 1.71
High	2.00 ^a (0.26)	1.53- 2.61	2.00 ^a (0.26)	1.53- 2.61	2.00 ^a (0.26)	1.53- 2.61	2.00 ^a (0.26)	1.53- 2.61	2.00 ^a (0.26)	1.53- 2.61
Employment status (ref: employed)										
Not employed	0.92 (0.13)	0.70- 1.21	0.92 (0.13)	0.70- 1.21	0.92 (0.13)	0.70- 1.21	0.92 (0.13)	0.70- 1.21	0.92 (0.13)	0.70- 1.21
Marital status (ref: with partner)										
Without partner	0.81 (0.10)	0.63- 1.03	0.81 (0.10)	0.63- 1.03	0.81 (0.10)	0.63- 1.03	0.81 (0.10)	0.63- 1.03	0.81 (0.10)	0.63- 1.03
Household size (ref: one)										
Two	1.17 (0.15)	0.90- 1.51	1.17 (0.15)	0.90- 1.51	1.17 (0.15)	0.90- 1.51	1.17 (0.15)	0.90- 1.51	1.17 (0.15)	0.90- 1.51
Three	0.79 (0.16)	0.52- 1.17	0.79 (0.16)	0.52- 1.17	0.79 (0.16)	0.52- 1.17	0.79 (0.16)	0.52- 1.17	0.79 (0.16)	0.52- 1.17
Four or more	1.20 (0.29)	0.74- 1.93	1.20 (0.29)	0.74- 1.93	1.20 (0.29)	0.74- 1.93	1.20 (0.29)	0.74- 1.93	1.20 (0.29)	0.74- 1.93
Population density (ref: rural area)										
Towns and suburbs	1.11 (0.11)	0.92- 1.34	1.11 (0.11)	0.92- 1.34	1.11 (0.11)	0.92- 1.34	1.11 (0.11)	0.92- 1.34	1.11 (0.11)	0.92- 1.34
Cities	1.23 ^d (0.12)	1.02- 1.48	1.23 ^d (0.12)	1.02- 1.48	1.23 ^d (0.12)	1.02- 1.48	1.23 ^d (0.12)	1.02- 1.48	1.23 ^d (0.12)	1.02- 1.48
Country-level variables										
Life-long learning (M1)	1.06 ^d (0.03)	1.01- 1.13	N/A ^e	N/A	N/A	N/A	N/A	N/A	N/A	N/A
GDP ^f per person (M2)	N/A	N/A	1.00 (0.00)	0.99- 1.00	N/A	N/A	N/A	N/A	N/A	N/A
Spending for old age (M3)	N/A	N/A	N/A	N/A	1.03 (0.06)	0.90- 1.17	N/A	N/A	N/A	N/A
Old age ratio (M4)	N/A	N/A	N/A	N/A	N/A	N/A	1.03 (0.04)	0.94- 1.12	N/A	N/A
Connectivity (M5)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	1.01 (0.01)	0.99- 1.05

Variable	Model (N=6899)									
	M1		M2		M3		M4		M5	
	OR (SE)	95% CI	OR (SE)	95% CI	OR (SE)	95% CI	OR (SE)	95% CI	OR (SE)	95% CI
ICC ^g	0.16		0.18		0.18		0.18		0.17	

^a $P < .001$.

^bRef: reference.

^c $P < .01$.

^d $P < .05$.

^eN/A: not applicable.

^fGDP: gross domestic product.

^gICC: intraclass correlation coefficient.

Discussion

This study explored the determinants of internet-based use of health and care services among elderly Europeans, using data from the SB 460 and the multilevel regression technique. Our study focused on elderly people who were already using the internet and who went on the internet to use health and care services. We found that a large proportion of elderly people in Scandinavia and Estonia use the internet for health and care services and very few people in Malta, Cyprus, and Germany use the internet for these services. One explanation is the difference in broadband and mobile internet availability between these countries. Scandinavia and Estonia have a high number of households with internet access, whereas Malta, Cyprus, and Germany lag behind in terms of broadband availability [29]. Consequently, there is a need to offer proper infrastructure on a broad basis. Although the number of practicing physicians [30] does not seem to make a difference, the population density is comparably high in Malta, Cyprus, and Germany making it easier to access health and care services [31]. However, when living in rural areas, access to offline health care can be problematic and online services could help to make health and social care available even at long distances.

By analyzing the factors at the micro level, which seem to have an influence on the use of internet-based health and social care services among elderly people, we could confirm the results of previous research. In line with previous results, we found that users who are better educated and from a higher class are more likely to use these services [19]. We also found that elderly people in rural areas are less likely to use the internet for health and social services. This is in line with the results in the study by Torrent-Sellens et al, who used survey data from European citizens aged 16 to 74 years. Their data revealed that people living in less densely populated areas had a low propensity toward intensive eHealth use [24]. The results from the regression analyses showed that when controlling for potentially confounding variables, nonusers were older than users of internet-based health and care services. As shown by the results of other studies [9,10], age needs to be taken into account when analyzing eHealth use among populations. Several of our findings (those with high education are more likely to use eHealth, living in a city is positively associated with eHealth use, etc) seem to not apply to young cohorts.

In addition to scientific implications, political and societal implications can be drawn. The results underline several issues accompanying the spread of digital technology in general, but particularly in health care. Although internet-based health and care services have main advantages to support elderly people, policy makers and other stakeholders should also acknowledge that most elderly people do not use these services. Additionally, the probability to use these services does correlate with socioeconomic status and place of living. In particular, people with a low socioeconomic status and those living in rural areas seem to be at risk of being excluded from chances to use eHealth, although, in particular, the latter group could benefit from remote health services. This has the risk of increasing social inequality. Technology can cause or intensify social inequality and ultimately lead to social exclusion. Against this background, the capability of using modern technology itself can be seen as a dimension of social inequality [32]. Previous research has shown that people going on the internet for health services experienced improved outcomes with respect to their knowledge of health issues, health communication with medical professionals, decision-making about their health issues, and proper use of health services [23]. Consequently, this could lead to additional inequalities. As eHealth solutions are pushed at the national and EU level, policymakers should acknowledge these differences. The fact that elderly people often do not use the internet can itself be seen as one reason for the relatively low diffusion of eHealth in several countries [33]. Consequently, training and educational programs on how to use digital technologies in general and eHealth services in particular can support these elderly people who have little or no experience with eHealth. This argument is supported by the finding of this study that the proportion of elderly people participating in further education at the country level and the use of eHealth are closely related.

Our study has several limitations. First, it included a specific database. The Special Eurobarometer only includes one item that asks about eHealth (going on the internet to use health and care services). Hence, we could not draw any conclusions on the different facets of eHealth and could not provide detailed information on patterns of use. Second, we only investigated people who were using the internet and did not cover those not using the internet. We were mainly interested in exploring the personal characteristics of those using internet-based health and care services and macro factors potentially influencing the use.

This leaves room for a more detailed analysis including those not using the internet. Although we could confirm most of the results of previous studies and add new aspects to the discussion on the use of digital health by elderly people, there were several limitations. Third, the data used for the analysis were cross-sectional data; hence, no causal links could be made between the different variables. Fourth, the analysis was limited to European countries; however, demographic ageing and digitalization are global trends.

Despite these limitations, this study contributes to the field in three ways. First, the inclusion of individual- and country-level determinants of the probability of using digital health care

services provides a more holistic picture of the potential of digitalization for health care among elderly people. The findings shed light on the relevant disparities in the use of digital health care services among elderly people at the individual and country levels. Second, the data used in this study were derived from the most recent survey conducted in 2017. As digital technologies are changing at a fast pace and new possibilities for digital health care provision are being developed constantly, regular monitoring of how elderly people use these services is necessary. Third, there was a comparative perspective. The inclusion of several countries in the analysis allowed the identification of factors that foster and hinder the use of eHealth, which can be transformed into policy recommendations.

Conflicts of Interest

None declared.

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Abbreviations

SB 460: Special Eurobarometer 460

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Original Paper

A Smartphone App for Self-Management of Heart Failure in Older African Americans: Feasibility and Usability Study

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Abstract

Background: Mobile health (mHealth) apps are dramatically changing how patients and providers manage and monitor chronic health conditions, especially in the area of self-monitoring. African Americans have higher mortality rates from heart failure than other racial groups in the United States. Therefore, self-management of heart failure may improve health outcomes for African American patients.

Objective: The aim of the present study was to determine the feasibility of using an mHealth app, and explore the outcomes of quality of life, including self-care maintenance, management, and confidence, among African American patients managing their condition after discharge with a diagnosis of heart failure.

Methods: Prior to development of the app, we conducted qualitative interviews with 7 African American patients diagnosed with heart failure, 3 African American patients diagnosed with cardiovascular disease, and 6 health care providers (cardiologists, nurse practitioners, and a geriatrician) who worked with heart failure patients. In addition, we asked 6 hospital chaplains to provide positive spiritual messages for the patients, since spirituality is an important coping method for many African Americans. These formative data were then used for creating a prototype of the app, named Healthy Heart. Specifically, the Healthy Heart app incorporated the following evidence-based features to promote self-management: one-way messages, journaling (ie, weight and symptoms), graphical display of data, and customized feedback (ie, clinical decision support) based on daily or weekly weight. The educational messages about heart failure self-management were derived from the teaching materials provided to the patients diagnosed with heart failure, and included information on diet, sleep, stress, and medication adherence. The information was condensed and simplified to be appropriate for text messages and to meet health literacy standards. Other messages were derived from interviews conducted during the formative stage of app development, including interviews with African American chaplains. Usability testing was conducted over a series of meetings between nurses, social workers, and computer engineers. A pilot one-group pretest-posttest design was employed with participants using the mHealth app for 4 weeks. Descriptive statistics were computed for each of the demographic variables, overall and subscales for Health Related Quality of Life Scale 14 (HQOL14) and subscales for the Self-Care of Heart Failure Index (SCHFI) Version 6 using frequencies for categorical measures and means with standard deviations for continuous measures. Baseline and postintervention comparisons were computed using the Fisher exact test for overall health and paired t tests for HQOL14 and SCHFI questionnaire subscales.

Results: A total of 12 African American participants (7 men, 5 women; aged 51-69 years) diagnosed with heart failure were recruited for the study. There was no significant increase in quality of life ($P=.15$), but clinically relevant changes in self-care maintenance, management, and confidence were observed.

Conclusions: An mHealth app to assist with the self-management of heart failure is feasible in patients with low literacy, low health literacy, and limited smartphone experience. Based on the clinically relevant changes observed in this feasibility study of the Healthy Heart app, further research should explore effectiveness in this vulnerable population.

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KEYWORDS

heart failure; mobile health app; self-management

Introduction

Background

Self-monitoring, generally defined as the awareness of symptoms through measurements, recordings, and observations, is foundational to the successful management of any chronic health condition. Mobile health (mHealth) apps are dramatically changing how patients and providers manage and monitor chronic health conditions, especially in the area of self-monitoring [1]. In particular, mHealth apps provide patients with quick and easy access to real-time health information to assist in making health decisions (ie, when to call the physician or go to the emergency department) and improve patient outcomes. Recent studies suggest that use of mHealth apps is associated with reductions in mortality and hospitalizations, along with improved adherence to therapy and enhanced quality of life [2,3].

African American Patients With Heart Failure: A Vulnerable Population

Adults with heart failure represent a particularly vulnerable population that may benefit from mHealth apps, especially African American adults living in rural communities. Currently, heart failure is the leading cause of hospitalization for older adults, which can lead to an increased risk of complications and health care costs [4,5]. The highest rates of hospitalization for patients with heart failure are reported in the southeast of the United States, including South Carolina [6]. In addition to high poverty levels, African American patients with heart failure may experience other challenges that negatively impact their health status, including lack of insurance, limited or no transportation, and an inadequate supply of health care providers [7]. Conversely, overall health could be improved if health care providers harness the cultural basis of self-care in the African American population, such as spirituality, social support, and nonbiomedical healing traditions [8].

The use of mHealth apps has successfully assisted in the self-management of patients with heart failure [9,10]. However, there is limited literature to support the use of mHealth in the African American population [11-14], with few heart failure mHealth apps designed specifically for this population, who are typically sicker, poorer, less educated, and more affected

by comorbid conditions compared to other racial groups in the United States [15]. Therefore, there is a need for culturally appropriate mHealth apps to assist this vulnerable population of African American patients with heart failure.

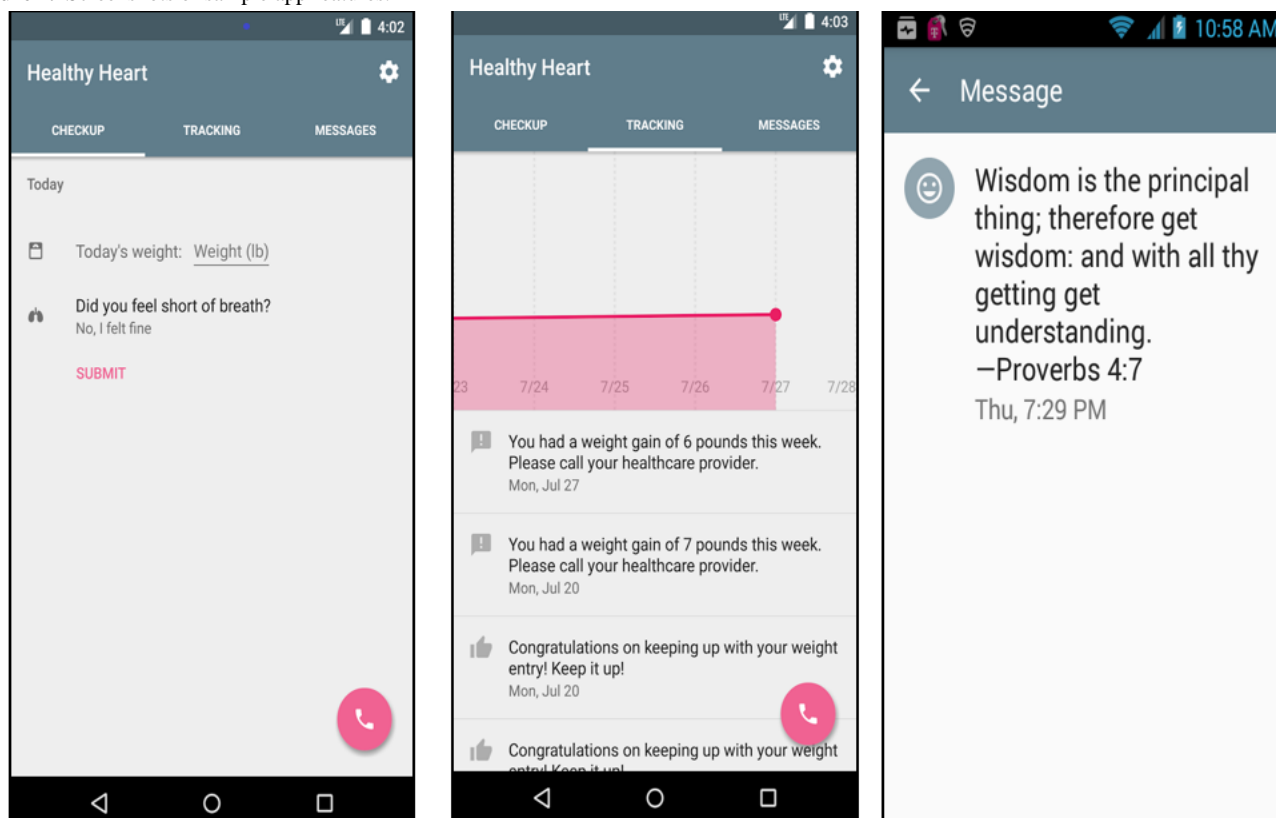
The purpose of this study was to design and describe the feasibility of the Healthy Heart app in African American patients with a discharge diagnosis of heart failure and assess impacts of using the app on quality of life and self-care.

App Development

To overcome these concerns and limitations, our team developed a prototype app, termed Healthy Heart, through an iterative design process with input from end users (ie, patients with heart failure and health care providers). The team consisted of nurses, social workers, and computer engineers. We adopted the situation-specific theory for behavioral change, which emphasizes the following three key components of self-management: (1) self-monitoring of symptoms, which helps patient to notice and focus on specific health problems; (2) health literacy, which educates patients about the role of healthy behaviors leading to desirable health benefits; and (3) confidence (self-efficacy), which is associated with making behavioral changes and taking actions to manage and improve one's health [16]. App development was also guided by emerging mHealth research to deliver interventions for self-management by fostering the cognitive and behavioral changes necessary to promote stability, health, and well-being in patients with heart failure [17,18].

Prior to app development, we used purposeful sampling to recruit 7 African American patients with heart failure and 3 African American patients with cardiovascular disease for qualitative interviews about their experience with heart failure. We also recruited 6 health care providers (cardiologists, nurse practitioners, and a geriatrician) who worked with heart failure patients. Using these formative data, we created a prototype of the Healthy Heart app incorporating the following evidence-based features to promote self-management: one-way messages, journaling (ie, weight and symptoms), graphical display of data, and customized feedback (ie, clinical decision support) based on daily or weekly weight. [Figure 1](#) displays screenshots of these main features.

Figure 1. Screenshots of sample app features.



The educational messages about heart failure self-management were derived from the heart failure teaching material provided to patients diagnosed with heart failure, and included information on diet, sleep, stress, and medication adherence. Sources for patient teaching included Agency for Healthcare Research and Quality Heart Failure Communication Tools [19], Health Topics, Heart Failure [20], and How to Reduce Sodium [21]. The information was condensed and simplified to be appropriate for text messages and to meet health literacy standards. Other messages were derived from interviews conducted during the formative stage of app development, including interviews with 6 African American hospital chaplains. We involved chaplains at this stage because spirituality is an important component of African American culture. For example, one motivational message was “Even when we go through things God is always there to lead us through troubling times in our lives” paraphrased from Psalms 46. The team conducted usability testing over a series of meetings between the nurses, social worker, and computer engineers.

Methods

Overview of Study Design

In this quasiexperimental pilot study using a one-group pretest-posttest design, 12 African American participants with a discharge diagnosis of heart failure used the Healthy Heart app. Prior to start of the study, Internal Review Board approval was received from the University of South Carolina and a locally owned, not-for-profit health care system.

Recruitment and Retention

Inclusion criteria were English-speaking African American men or women aged 50 years or older who received a diagnosis of heart failure and were discharged from the hospital to home care. Patients were excluded if they had a major cognitive impairment or a current diagnosis of psychosis. The home health nurse did not use a screening tool to determine cognitive impairment but instead used the discharge summary and her clinical judgment with the participant and family. Subjects who could not speak either English or a dialect of English were also excluded. Patients younger than 50 years of age were excluded from the study with no restriction on the upper age for participants.

The pool of potential participants comprised patients diagnosed with heart failure and discharged from the locally owned, not-for-profit health care system receiving 30 days of home health telemonitoring (ie, standard of care). Home health telemonitoring included an interactive monitor with direct connections to a scale and blood pressure cuff that automatically uploaded the data to a home health nurse. However, no additional visits were made to the patients after the monitor was installed and set up. The patients received telephone communication with the nurse if any of the measures were abnormal.

The home health nurses collaborated with the study team by querying the telemonitored patients of interest in participating in the Healthy Heart app study. Based on collaboration with the home health facility, we were unable to collect data about the number of patients approached. Recruitment occurred between November 2015 and September 2016. If interested, the patient signed a Health Information Portability and Accountability Act

release, which included contact information for the study coordinator, and received a fact sheet about the study. The study coordinator called the participants for a phone discussion that summarized and explained the study details, including the purpose, procedures, risks, benefits, and voluntary participation. Potential participants were encouraged to ask any questions. If the participant was interested, an appointment was scheduled for the study coordinator to visit the participant's home to obtain consent and administer the baseline study assessments. All participants were provided with an Android phone with the Healthy Heart app (ie, intervention) installed. This provided consistency and ease of instructing the participants on using the app. No monetary compensation was offered to the study participants; however, they were able to keep the low-cost study phone after the study period. In addition, a small thank you postcard and gift (approximately \$1 value) was mailed to the participants weekly to promote retention in the study.

Procedures

Once the study coordinator received verbal consent from the participant during the telephone conversations, the first home visit was scheduled within approximately 2 weeks after hospital discharge while the patient was still receiving telemonitoring from the home care nurse. During this home visit, the study coordinator obtained all baseline data.

A second home visit occurred approximately 1 week later in which the participant received the prepaid activated phone. The coordinator educated the participant about using the phone and Healthy Heart app. The study coordinator spent time teaching the participant (and caregiver if desired) how to turn the phone on and off, how to charge the battery, how to open the Healthy Heart app, and so forth. The US Department of Health and Human Services reports nearly 9 out of 10 adults in the United States have difficulty using everyday health information, and South Carolina ranks 39th in literacy in the country [22]. Based on our previous work with low-literacy, low-health literacy, and low-digital literacy patients, we anticipated that these participants would have low familiarity with using a smartphone or an app. Indeed, 7 of the 12 participants did not previously own a smartphone. Thus, we designed an instruction booklet written at a sixth-grade or lower reading level and used screenshots to explain each operation of the phone and each function of the app. In addition, the study coordinator assisted the participants with entering the phone numbers of the health care provider and pharmacy. On average, these visits lasted 1-2 hours. This home visit was timed so that the participant would have 1 week of overlap with the home health telemonitoring (ie, standard of care) and start of self-monitoring via the Healthy Heart app (ie, intervention). This overlap allowed the participants to become familiar with the app before stopping the telemonitoring for a seamless transition. The participant was instructed to call the coordinator if any questions arose. The coordinator called the participants about 2 weeks after the initial training to ascertain if they were experiencing any difficulties using the phone and the app. No additional visits for training occurred, but the coordinator was available during normal business hours via phone to assist with any usability or technical issues.

Six weeks after the initial assessment, a final assessment was completed, including the completion of assessment instruments obtained at baseline, the participants' perceptions of the phone and Healthy Heart app, and retrieval of data.

Description of the Intervention

The intervention consisted of the use of all app features continuously over 4 weeks. A total of 3 messages were sent daily: (1) a reminder to weigh every morning, (2) an educational message, and (3) motivational messages. Messages were repeated when the message bank had sent all messages once. The other two components of the app were journaling and customized feedback. Journaling consisted of the participant entering a daily weight and responding to a question about shortness of breath. The final component was customized feedback (ie, clinical decision support) that sent an alert message if the weight exceeded standards set by the home health protocol for monitoring heart failure. The message instructed the participant to call the health care provider if they experienced an increase of 2-3 pounds in a day or over 5 pounds in a week. Regardless of the amount of weight gained or lost, the participant could view a weekly graph of weight fluctuations.

Data Collection

Demographic and personal data were collected using a demographic data form adapted from a previous study [23]. Examples of personal data include living situation, instrumental social support, years since diagnosis, phone type, insurance type, and faith group. In addition, the participants were interviewed to ascertain their current recall of prior teaching on heart failure and current information on how to handle heart failure-related concerns. The interview consisted of yes/no and open-ended questions (eg, "Has anyone talked with you about the things you need to know in order to take care of yourself and your heart?").

The 14-item Centers for Disease Control and Prevention (CDC) Health Related Quality of Life Scale 14 (HRQOL14) was used to assess the participants' quality of life [24]. This scale has strong validity and reliability [25]. The following three modules of the HRQOL14 were utilized: core healthy days, activity limitations, and healthy days symptoms. The core healthy days (4 items) assessed (1) perceived general health, (2) number of days when physical health was perceived as poor, (3) number of days when mental health was perceived as poor, and (4) number of days when the respondent perceived activity limitations due to poor mental or physical health. Instructions for scoring followed the CDC guidelines [24]. The activity limitations module assessed more details about activity limitations due to poor health, including personal care and routine needs. The healthy days symptoms module was assessed only if the participant responded "no" to the activity limitation item in the healthy days module. For both the activity limitations and healthy days symptoms modules, we used the CDC Statistical Analysis System syntax for scoring [26].

The Self-Care of Heart Failure Index (SCHFI) Version 6 [16,27-29] subjectively assesses the participant in three areas: maintenance, management, and self-confidence, which are based on Riegel and Dickson's [16] conceptual model of heart failure

self-care. The instrument consists of 22 items rated on a 4-point scale with each subscale scored separately. Barbaranelli et al [27] recommended against reporting an overall score when a participant does not have a certain number of problems. The raw score ranges for each subscale are as follows: 10-40 for self-care maintenance, 4-24 for management, and 6-26 for self-care confidence. These ranges were all standardized to 0-100. Instructions for scoring and methods for handling missing data followed the method of Riegel and colleagues [28]. Reliability of the subscales ranged from low to adequate ($\alpha=0.56-0.80$) and construct validity was adequate [29].

Analysis

Descriptive statistics were computed for each of the demographic variables, overall and subscales for HQOL14, and subscales for the SCHFI using frequencies for categorical variables and means (SD) for continuous variables. Baseline and postintervention comparisons were computed using the Fisher exact test for overall health and with paired *t* tests for HQOL14 and SCHFI subscales.

Results

Recruitment

We enrolled 12 African American participants for this feasibility study. One participant was lost to follow up at the second assessment. Thus, 11/12 (92%) participants completed the study.

Demographic and Health Characteristics of the Sample

The main characteristics of our sample are summarized in Table 1. There were more men than women, and the age of participants ranged from 51 to 69 years. One quarter of the participants were married and the remaining participants were single, divorced, separated, or widowed. The majority of participants (10/12, 83%) graduated from high school. Over half of the participants (8/12, 67%) preferred not to answer about income or did not know their income. One third of the participants were on Medicare or Medicaid (4/12), one third had no insurance (4/12), one fourth had private insurance, and one third (4/12) did not know about insurance coverage. All participants (12/12, 100%) reported belonging to a church. Eleven of the 12 participants (92%) owned a cell phone, and 5/12 (42%) owned a smartphone. The majority of the participants received a diagnosis of heart failure less than one year prior to the study (7/12, 58%).

Table 1. Demographic and health characteristics of the study population (N=12).

Variable	Value
Age (years), mean (SD)	57.83 (1.68)
Gender, n (%)	
Male	7 (58)
Female	5 (42)
Marital status, n (%)	
Married	3 (25)
Not married	9 (75)
Education, n (%)	
Less than high school	2 (17)
High school	7 (58)
More than high school	3 (25)
Income, n (%)	
Do not know	2 (17)
Less than \$10,000	3 (25)
\$30,000-\$39,999	1 (8)
Chose not to answer	6 (50)
Years since diagnosis, n (%)	
<1	7 (58)
2 to 8	3 (25)
11 to 13	2 (17)

Heart Failure Care Activities

In the baseline assessment, most participants (11/12, 92%) stated that their health care provider (ie, doctor, nurse, or dietician) had discussed ways to manage their heart failure. All participants

reported weighing themselves daily, but 3/12 (25%) noted that they did not record their weight regularly. Six participants (50%) received instruction on specific limits for fluid intake and provided examples of 40 ounces, a quart, a gallon, or a liter. However, only 5/12 (42%) participants reported that they

followed the recommended fluid restriction. Participants gave a variety of answers when asked about salt restriction (eg, restricted salt altogether, do not eat much salt, or restricted to 200 mg per day).

Feasibility of App Usage

Participants with low digital literacy (ie, nonadopters of digital technology) initially struggled with phone and app operation. Anticipating this prior to phone distribution, we removed all nonessential apps from the phone to alleviate confusion about which app to use: the distributed phone only included the ability to call, a search engine app, and the Healthy Heart app. Nevertheless, participants had to practice several times during the training to understand how to answer the phone, make a

phone call, and open the app. They also needed to use the instruction booklet to help remember these steps in operating the phone. In spite of these barriers, over 60% of the data were successfully collected.

At the end of the intervention, we evaluated the participants' use of the phone and app to assist with future iterations of the app as well as to guide future research in working with this population. Unfortunately, we were unable to identify an evaluation tool specifically for mHealth apps and this population. For example, the Systems Usability Scale [30,31] was too broad to help us identify specific problems with the phone and the app. We asked closed questions that assessed potential problems with the phone and messages (ie, readability), and these results are summarized in [Table 2](#).

Table 2. Postintervention experience with the project and phone usage (N=11).

Question	Response	n (%)
Did you have any difficulty using the phone?	No	6 (55)
Was it easy to charge the phone?	Yes	10 (91)
Was it easy to read the message?	Yes	11 (100)
Was the font (size of the print) big enough?	Yes	10 (91)
Was the length of the message too long, not long enough, just right?	Just right	10 (91)
Have you used the phone to go online (search the web)?	Yes	4 (36)
Have you made any phone calls with this phone?	Yes	10 (91)
Have you sent any text messages?	Yes	4 (36)
Have you seen the Quick Dial feature (ie, that you can press to call your health providers)?	Yes	5 (46)
If yes, have you ever used the Quick Dial feature?	Yes	2 (18)
If not, would you use it if you need to contact your providers?	Yes	6 (55)

Quality of Life and Self-Care Heart Failure Index

For HRQOL14, at baseline, 5/12 (42%) of participants reported that their overall health was poor or fair, whereas at the postintervention assessment, 2/11 (18%) rated their health as poor or fair. No significant changes were found for any of the HQOL14 subscales. At baseline, participants reported a mean of 4 (SD 5.75, range 0-14) physically unhealthy days. Postintervention, the mean number of unhealthy days was reduced to 2.54 (SD 4.32, range 0-15). At baseline, respondents reported a mean of 1.42 mentally unhealthy days (SD 2.39, range 0-7), which increased postintervention to 3.18 (SD 9.02, range 0-30). At baseline, the mean number of days participants reported experiencing limitation in daily activities due to poor physical or mental health was 2.58 (SD 3.03, range 0-8), which decreased postintervention to 1.73 (SD 3.00, range 0-10). The

mean preintervention combined physical and mental unhealthy days was 5.41 (SD 7.54, range 0-21), which was similar to that postintervention at 5.54 (SD 9.95, range 0-30).

For the SCHFI, we were not able to analyze the management subscale due to participant responses. Per Riegel et al [28], if a participant responded "no" to experiencing trouble breathing or ankle swelling in the past month, then the management section of the SCHFI was not scored. Only 5/12 (42%) participants reported problems with one of these symptoms. Therefore, we compared baseline and postintervention scores for maintenance and confidence. No significant differences were found on either subscale. However, based on Riegel et al [28], the maintenance, management, and self-confidence scales showed clinically relevant improvement from baseline to posttest as the difference in the mean baseline score for maintenance and management was greater than 8 ([Table 3](#)).

Table 3. Analysis of subscales of Self-Care of Heart Failure Index.

Subscale	Baseline, mean (SD)	Postintervention, mean (SD)	P value	Difference score	Clinically relevant ^a
Maintenance (N=12)	63.33 (15.50)	72.70 (15.62)	.15	9.37	Yes
Management (N=9)	70.0 (7.07)	85.00 (14.36)	Presample too small ^b	15.00	Yes
Confidence (N=12)	83.86 (13.51)	90.90 (10.90)	.17	7.04	Approaches

^aClinical relevance defined as at least an 8-point difference in baseline to postintervention.

^bAt least half the items were missing from participant responses.

Hospital Readmission and Emergency Room Visits

During the final assessment, we ascertained information about emergency room and hospital readmissions. One participant reported admission to the hospital via the emergency room and another other participant reported an emergency room visit during the 6 weeks of the study. Six participants called their provider at least once based on instructions from the app.

Discussion

Feasibility

When working with a digitally naïve population with low literacy, we recommend careful consideration of the phone display (ie, simple and uncluttered) and the use of simple instructional materials. The use of screenshots instead of text in the instructional materials seemed to help participants understand how to use the phone and app. Although such work may be challenging, more research is needed on designing mHealth for this population. Our study makes a significant contribution toward the use of mHealth apps for managing a chronic disease in a health-disparate population. In this regard, we substantiated the work by Cajita et al [32] showing that older adults are willing to use mHealth technology.

Exploratory Findings

The Healthy Heart app did not significantly increase quality of life ($P=.15$), but did show clinically relevant changes in heart failure self-care maintenance, management, and confidence. Our preliminary findings are similar to those of Dang et al [33] who identified that an mHealth app is a feasible method of assisting health-disparate patients to manage their disease. However, in contrast to the results of their randomized controlled trial [34], our study participants showed clinically relevant changes in their ability to maintain and respond to heart failure symptoms, but did not show significant improvements in self-efficacy or quality of life.

The participants in our study had low rates of hospital readmissions and emergency room visits. This finding is consistent with a systematic review showing that that mHealth apps to manage heart failure may reduce heart failure-related hospital days [35]. However, our baseline findings regarding participant understanding are inconsistent with those of Spaling et al [36] who found that patients could recall advice about

self-care. Our participants' recall was not clear and often contained vague information. Our participants showed similar improvement in self-care to that found in the Spaling et al [36] study, although our change was not statistically significant.

Limitations

One limitation of the study is that we only tested the intervention (use of the app) for 4 weeks. This may not have allowed enough time for behavioral changes to be established and influence quality of life. Other limitations include the small sample size and the quasiexperimental nature of the study. However, previous studies suggest that a quasiexperimental design is appropriate when participants are unlikely to change their behavior without an intervention (ie, inclusion of a usual care group would not add information during pilot testing) [37,38]. Further, the impact of prior experience with telemonitoring (ie, standard of care) could have influenced the outcomes of this study. However, since we collected baseline data at the end of telemonitoring, we feel confident that our data reflected important improvements related to the use of the Healthy Heart app.

Conclusions

This study provides insights into the feasibility of mHealth apps among a disparate population with low literacy, low health literacy, and limited smartphone use. Additionally, the study provides essential lessons for the use of mHealth apps in this population. Providing instructions with screenshots with minimal text was a successful technique for training the participants on using the smartphone and Healthy Heart app. Furthermore, the inclusion of culturally appropriate messages potentially enhanced the acceptance of the Healthy Heart app. The initial focus groups with African American patients guided the development of the mHealth app to include culturally appropriate content. These findings suggest that patients want content that recognizes cultural differences. This study demonstrated clinically relevant changes in heart failure self-care maintenance, management, and confidence. As mHealth technology continues to advance, it is important to take into account how to address the needs of all patients, including those with low literacy, low health literacy, and limited smartphone use, as well as cultural differences. This study can provide some guidance on addressing these challenges for unique patient populations.

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Authors' Contributions

SH helped in conducting the study, data analysis, and writing and review of the article. SD and SA were involved in data analysis and writing and review of the article. PP was involved in conducting the study and writing and review of the article. HC and SL were involved in study concept, writing the grant, and writing and review of the article.

Conflicts of Interest

SH, SD, SA, PP, and HC have no conflicts to declare. SL has equity in the Health and Environment Group that received the grant.

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Abbreviations

- CDC:** Centers for Disease Control and Prevention
- HRQL14:** Health Related Quality of Life Scale 14
- mHealth:** mobile health
- SCHFI:** Self-Care of Heart Failure Index

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Original Paper

Digital Media as a Proponent for Healthy Aging in the Older Chinese American Population: Longitudinal Analysis

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Abstract

Background: Ensuring health literacy among underserved populations is essential amid an aging population. Accessible and appropriate (both culturally and linguistically) information is important when considering digital media education for older Chinese Americans.

Objective: This study aims to investigate how social media fare over time in disseminating health information and how we may most effectively educate this population.

Methods: For this study, 5 geriatric-themed educational videos about Parkinson disease, fall prevention, gastrointestinal health, oral health, and pulmonary disease were uploaded to YouTube. Data were collected over a 40-month period. Descriptive statistics and chi-square analysis were used to compare results from the first and second 20-month periods.

Results: In 40 months, the 5 videos in aggregate accrued 1171.1 hours of watch time, 7299 views, and an average view duration of 9.6 minutes. Comparing the first and second 20-month periods, there was a significant increase in mobile device usage, from 79.4% (3541/4458) to 83.3% (2367/2841). There was no significant difference in the usage of various external traffic sources and methods of sharing, with WhatsApp accounting for the majority of sharing in both 20-month periods.

Conclusions: Our study provides insight into where to focus future strategies to optimize digital media content, and how to best recruit, direct, and disseminate health education to an older adult Chinese American population. Combining the success of YouTube, social media, and messaging platforms such as WhatsApp can help to transcend cultural and linguistic barriers to promote healthy aging.

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KEYWORDS

geriatrics; health promotion; health education; social media; Parkinson disease; fall prevention; oral health; pulmonary disease; gastrointestinal health

Introduction

By the year 2060, there will be roughly 98 million Americans aged over 65 years, roughly 1 in 5 people, in large part due to the aging baby boom generation [1]. With aging come inevitable challenges of chronic diseases, falls, physical activity, oral health, and mental health concerns that can largely impact quality of life. Parkinson disease, the second-most common neurodegenerative disease after Alzheimer disease, is expected to affect nearly 1.2 million Americans by 2030 [2]. Similarly,

falls have become a leading cause of injury among older adults, with a projected 100,000 fatal falls per year and direct treatment costs expected to reach US \$101 billion by 2030 [3]. Challenges like these result in significant financial and emotional burden for families and caregivers, emphasizing the need to optimize care for this aging population in the coming decades.

The older adult population is not only growing, but also becoming more racially and ethnically diverse, making inequities in health and access to resources more apparent [4]. Nationally implemented healthy aging initiatives, programs,

and services therefore need to consider the unique needs of different subpopulations, and provide culturally and linguistically appropriate materials. Chinese Americans are one minority group that underutilize health resources; as a result, they are at risk for delayed diagnoses, and suboptimal treatment and management of a variety of chronic health conditions [5-7]. There remain cultural, educational, and linguistic barriers that present challenges in health literacy, access, and information dissemination [8,9].

Amid an aging population, distribution of health education over the internet and social media can contribute to healthy aging. Today, more and more Americans turn to the internet for health information. Social media has transformed into a platform for health communication among the general public, patients, and health professionals [10]. Among them, YouTube has become one of the world's most popular social media platforms [11]. Digital health education dissemination holds promise in helping to bridge cultural and linguistic barriers that have previously precluded populations from access to such information. It therefore behooves us to study how populations utilize and access digital health information to tailor how best to distribute and promote health literacy among underserved populations.

Previous studies have shown that YouTube is effective in delivering dementia knowledge to older Chinese Americans [12-14]. Another study has analyzed Twitter as a health information relaying platform [15]. Furthermore, Facebook advertising has proven promising for the dissemination of dementia and hypertension information [16,17]. In addition, more recent studies have suggested a rise in WhatsApp use among older Chinese Americans in sharing dementia education [18,19]. However, few studies have investigated other health education topics (even in aggregate) and the role of social media in their dissemination to this population. In this paper, we aim to determine the efficacy of YouTube as a medium for delivering a variety of aging-related health education resources, and study the change in modes of viewing and sharing across different social media platforms over time. To our knowledge, this is the first longitudinal study of 5 different geriatric-themed videos in the older Chinese American population.

Methods

YouTube

A board-certified psychiatrist delivered 5 geriatric-themed educational talk shows in Cantonese at the radio station KMRB AM1430 in Los Angeles. Real-time recordings were then individually uploaded to YouTube. Average video length was 36.4 minutes. Topics addressed include Parkinson disease, fall prevention, gastrointestinal health, oral health, and pulmonary disease.

Sample

The sample of this study included YouTube video viewers over a 40-month period (November 2016 to March 2020).

Statistical Analysis

Data were extrapolated from YouTube Analytics. Parameters recorded included number of views, watch time, average view duration, devices used to view, traffic sources, and modes and means of sharing via various social media platforms. The first and second 20-month intervals were dichotomized (November 2016 to July 2018, and July 2018 to March 2020). Descriptive statistics and chi square test were used to compare data collected between the first and second 40-month intervals.

This study used anonymous data exclusively collected by YouTube. A waiver for Institutional Review Board exemption was obtained through the Human Subjects Protection Committee of University of California, Los Angeles.

Results

In 40 months, the 5 videos in aggregate accrued a total of 1171.1 hours of watch time and 7299 views, and an average view duration of 9.6 minutes. A breakdown of each of the 5 video topics is shown in Table 1. Data were then dichotomized into two 20-month intervals: November 2016 to July 2018, and July 2018 to March 2020. Between November 2016 and July 2018, the recorded YouTube videos accrued a total of 738.6 hours of watch time and 4458 views, and an average view duration of 9.9 minutes. Between July 2018 and March 2020, there were 432.5 hours of watch time and 2841 views, and the average view duration was 9.1 minutes. Overall, the latter 20 months had a decrease in total watch time (738.6 versus 432.5 hours), the number of views (4458 versus 2841 views), and the average view duration (9.9 versus 9.1 minutes).

Table 1. Statistics of 5 videos over 40 months.

Video topics	Number of views	Hours watched	Average view duration (minutes)	Total video length (minutes)
Parkinson disease	3092	501.5	9.7	38
Falls	1990	352.6	10.6	37
Constipation and diarrhea	1076	112.4	6.3	27.5
Oral health	636	107.7	10.2	39
Pulmonary disease	505	96.9	11.5	40.5
Total	7299	1171.1	9.6	182

Average view duration on computers increased 13.0% from 8.4 to 9.5 minutes between the first and second 20-month periods. In comparison, average view duration on mobile devices (mobile phones and tablets) decreased 6.9% from 10.9 to 10.2 minutes. Despite an overall decrease in views in the second 20-month period, the relative usage of computers decreased from 20.6%

(917/4458) to 16.7% (474/2841), while relative mobile usage increased from 79.4% (3541/4458) to 83.3% (2367/2841). The increase in relative mobile device usage compared to computer usage from the first to the second 20-month period is statistically significant (79.4% versus 83.3%, $\chi^2_1=17.0$, $P<.001$; Table 2).

Table 2. Devices used for viewing videos.

Devices	November 2016 to July 2018			July 2018 to March 2020		
	Number of views	Hours watched	Average view duration (minutes)	Number of views	Hours watched	Average view duration (minutes)
Computer	917	129	8.4	474	74.7	9.5
Mobile device	3541	609.6	10.9	2367	357.8	10.2
Total	4458	738.6	9.9	2841	432.5	9.1

Looking at traffic sources, externally sourced views remained the same between the two 20-month periods: 6.9% (308/4458) and 6.9% (198/2841) of views, respectively. Of external sources, the top platforms were Facebook, Google search, and WhatsApp. Over 40 months, traffic generated from Facebook drastically decreased from 1.8% to 0% of total views (82/4458 versus 0/2841), Google search increased from 0.9% to 1.4% of total

views (41/4458 versus 39/2841), and WhatsApp decreased from 0.8% to 0.5% of total views (34/4458 versus 15/2841). Despite the significant drop in Facebook-generated traffic, there was no significant difference in traffic generated through Google search (0.9% versus 1.4%, $\chi^2_1=3.7$, $P=.06$) or WhatsApp (0.8% versus 0.5%, $\chi^2_1=1.7$, $P=.19$) between the two 20-month periods (Table 3).

Table 3. Traffic sources.

Traffic sources	November 2016 to July 2018			July 2018 to March 2020		
	Number of views	Hours watched	Average view duration (minutes)	Number of views	Hours watched	Average view duration (minutes)
Top 4 traffic sources						
Suggested videos	2024	375.9	11.1	917	161.4	10.6
YouTube search	945	102.7	6.5	790	98.4	7.5
Browse features	731	149	12.2	715	118.4	9.9
External	308	34.4	6.7	198	22.4	6.8
Top 4 external traffic sources						
Facebook	82	7	5.1	0	0	0
Google search	41	2.6	3.8	39	5.3	8.1
WhatsApp	34	6.4	11.3	15	0	12
Other	6	1.3	13	6	0.3	3

In the first 20 months, the videos were shared 107 times through various sharing services. In the second 20 months, the videos were shared 56 times, and WhatsApp was the most utilized

sharing method. However, comparing the two time periods, there is no significant difference in the usage of WhatsApp for sharing (54.2% versus 58.9%, $\chi^2_1=0.3$, $P=.56$; Table 4).

Table 4. Use of sharing services during both study periods.

Sharing services	November 2016 to July 2018 (N=107)	July 2018 to March 2020 (N=56)
	Shares, n (%)	Shares, n (%)
WhatsApp	58 (54.2)	33 (58.9)
SMS text messaging	7 (6.6)	1 (1.8)
Email	5 (4.7)	4 (7.1)
Facebook	1 (0.9)	1 (1.8)
Other	36 (33.6)	17 (30.4)

Discussion

Principal Findings

The majority of older adults have multiple chronic conditions [20]. Rather than focusing on a single condition or disease, this study is the first to analyze in aggregate the performance of 5 aging-relevant educational videos over 40 months. By investigating how older Chinese Americans are utilizing different platforms for viewing and sharing videos, we gain valuable insight into how we may tailor future health education dissemination to this population. Overall, the latter 20-month period had a decrease in total watch time (738.6 versus 432.5 hours), the number of views (4458 versus 2841 views), and average view duration (9.9 versus 9.1 minutes). A previous study determined that 6 minutes is the average engagement time for online educational videos of varying lengths [21]. Average view duration over the 40-month period was 9.6 minutes, demonstrating that these videos succeeded in maintaining viewers' attention and engagement.

Chi-square analysis revealed that mobile devices remain the top device used for viewing these educational videos; indeed, they experienced a statistically significant increase in usage from 79.4% (3541/4458) to 83.3% (2367/2841) over the 40 months, while computer usage decreased from 20.6% (917/4458) to 16.7% (474/2841). As there is a continued shift from computer to mobile device usage, ensuring mobile device compatibility in future digital health communication should be a priority. Furthermore, it becomes important to examine and understand any barriers and challenges that this population faces to better shape the design of future platforms and systems of health-related communication via mobile device. Barriers and challenges may include functional limitations such as visual or motor impairment, having low technology literacy, or being adverse to new methods. Work can be done to develop more user-friendly interfaces to maximize potential use among older adults. The development of user-friendly interfaces is not limited to only mobile device but extends to the development of future technologies such as voice-activated speaker devices, and the growing number of products on e-commerce platforms tailored for an aging population [22,23].

With regards to external traffic sources, while there was a significant decrease in Facebook-generated traffic, there was no significant change in Google search and WhatsApp traffic. Our study reveals an increase in Google search from 0.9% to 1.4% of total views (41/4458 versus 39/2841) and a decrease in WhatsApp from 0.8% to 0.5% of total views (34/4458 versus 15/2841). Although WhatsApp remains the top sharing service, there was no significant change in the amount of sharing that occurred between the two periods. Taken together, this study entertains questions of how to increase visibility via Google search amid a saturating field, and how to promote viewer sharing via WhatsApp. For example, future studies can investigate whether using long tail keywords (more specific keyword phrases) increase visibility via Google search.

It has previously been shown that digital recruitment via Facebook and, more recently, Instagram, is promising in directing individuals to health education materials [16,17,24].

However, the effects last only as long as the recruitment period. If strong and effective advertising is conducted at the beginning of a particular study period, the media in question could potentially experience longer-lasting visibility across future searches via Google. Work therefore needs to be done to devise novel or stronger methods of advertising (eg, Facebook, Instagram, or equivalent), and to publicize the availability of these resources to ensure enduring visibility and impact for years to come.

Finally, previous studies have shown that WhatsApp has become the preferred means of sharing dementia knowledge and is used more for its sharing capability than for its viewing function [18,19]. Although our data only provide a 40-month window into the performance of 5 different aging-themed educational videos, our study acknowledges WhatsApp's potential to become a successful platform for disseminating information for healthy aging to the older Chinese American population. As not only a social media platform, but also a personal messaging system, WhatsApp has the potential to reach a wide audience. With so many resources now available for the internet searcher, for any single resource to have a significant impact, the methods of dissemination and incentives for viewers to share need to evolve. Future studies could investigate the strategic placement of reminders to, for example, "share via WhatsApp if you found this useful." Other studies could incorporate the use of visual WhatsApp icons (specifically, the WhatsApp share button) to prompt and facilitate sharing via WhatsApp.

Limitations

There are several limitations in this study. As the videos used in this study were filmed in Cantonese, the audience was limited to those in the Chinese American population who are fluent in Cantonese. Furthermore, each video retained a rather short average viewing duration of 9.9 to 9.1 minutes, which is a fraction of the average video length of 36.4 minutes. Future studies should consider shortening video lengths and incorporating more interactive elements to increase audience engagement time with the goal of improved audience experience and greater retention of educational information. As a retrospective longitudinal analysis, data collected were limited to that collected by YouTube Analytics. Being able to design a prospective study would enable us to focus on WhatsApp as a sharing service, or the effectiveness of various recruitment methods.

Conclusions

The internet and usage of social media are continually evolving and changing the way in which we communicate health information among individuals and the medical community. YouTube is a promising and valuable tool to deliver culturally and linguistically appropriate health education to isolated populations. More studies need to be done to harness technologies now available on mobile devices with meaningful improvement in the health of older adults. In addition, future studies could investigate how WhatsApp can achieve its full potential as a top platform for health information dissemination. As such, further studies looking at both short- and long-term strategies and outcomes are necessary to learn how different populations of interest search for and disseminate information

to best be able to serve and deliver pertinent health education, ensure healthy aging, and promote healthy outcomes.

Conflicts of Interest

None declared.

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Original Paper

Existing Mobile Phone Apps for Self-Care Management of People With Alzheimer Disease and Related Dementias: Systematic Analysis

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Abstract

Background: Alzheimer disease and related dementias (AD/RD) are progressive neurocognitive disorders that currently affect approximately 50 million people worldwide. Mobile phone apps have been well-integrated into daily lives and can be used to deliver and promote health care. There is an increase in the use of technology to provide care and support to AD/RD patients and their families.

Objective: This study aimed to review apps designed for AD/RD patients and analyze the benefits of, and challenges to, such technological solutions.

Methods: A systematic approach was applied to review the availability, content, features, and quality of mobile phone apps to support self-care among AD/RD patients.

Results: The initial search for this review was conducted in January 2019, and the screening and analysis of the included apps were completed in May 2019. A total of 14 apps were included from an initial search of 245 apps. The top 3 features were alert (9/14, 64%), self-care tips (6/14, 42%), and social networking capacity (5/14, 35%). On average, the readability of the apps was a tenth-grade reading level (SD 3.06). The overall quality was 3.71 out of 5 (SD 1.37).

Conclusions: Our findings suggest that currently available apps for AD/RD patients may not meet complex needs and may be challenging to use, given the possible impaired communication ability associated with AD/RD. Therefore, high-quality apps need to be developed and rigorously evaluated for feasibility and efficacy.

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KEYWORDS

alzheimer disease; dementia; self-care; mobile phone apps

Introduction

Alzheimer Disease and Dementia Care

Alzheimer disease and related dementias (AD/RD) are progressive neurocognitive disorders that affect approximately 50 million people worldwide, a considerable number when it is taken into consideration that the patient population is projected to increase to 152 million by 2050 [1]. Patients with AD/RD must deal with multifaceted challenges in terms of physical, social, emotional, and cognitive perspectives. Cognitive function can be measured in a variety of domains, including attention span and concentration, intelligence, judgment, learning ability, memory, orientation, perception, problem solving, and psychomotor ability [2,3]. The majority of AD/RD patients also develop behavioral and psychological symptoms of dementia (BPSD), and some BPSDs, such as agitation, aggression, hallucination, and wandering, are considered quite challenging [4,5]. Furthermore, AD/RD patients are mainly elderly adults, making this group more vulnerable than those with other aging-related health issues [6].

Caring for AD/RD patients is complex and often results in depression, burden, and compromised health for the caregivers who provide their daily care and support [7-10]. It was also revealed that a caregiver's caregiving burden is positively associated with the level of dependence of patients with dementia [10]. Therefore, caregivers' burden can be reduced by a well-designed self-care support tool that meets the needs of the care recipients [5]. Thus, interventions that promote self-care among AD/RD patients may reduce caregivers' levels of burden and promote their health.

The Potential for Mobile Phones in Dementia Care

Mobile phone apps have become increasingly prevalent worldwide. The currently emerging mobile phone-based health apps are transforming health care and promotion, and are serving as a major wave in the reform of health care delivery systems [11]. According to the Healthy People 2020 Initiative, which uses data from the "Health Information National Trends Survey," increasing app usage can improve health outcomes and health quality, ultimately reducing health disparity and inequity [12]. In fact, nearly one-third of US adults use health apps with their accessible devices [13]. Nowadays, it is not only the younger generation with a natural inclination for technology who are using mobile phone apps, but also elderly people, who use these apps for the purpose of managing their health [14]. There is a great need, but also a great potential, for integrating mobile phone apps into the population of AD/RD patients for self-care.

Previous research has documented that 39% of adults aged 50 years or older have used mobile phone apps to access health information and manage their health [14]. Incorporating existing technology with mobile phone-based platforms is a highly feasible approach and has the potential to improve the quality of care and quality of life for AD/RD patients, which could potentially reduce public health costs and provide ways to find more efficient methods of sharing information. Thus far, technology has been used for addressing some symptoms of AD/RD, specifically forgetfulness [15]. The development of

mobile phone assistive apps targeting specific physical and cognitive impairments of AD/RD patients can foster their independence, reduce the burden of the caregivers, and delay or obviate their enrollment in institutions, thereby reducing the overall cost and burden of the health care system [16].

The development of an AD/RD app is a promising approach for addressing health disparities in AD/RD care, as these apps might be a valuable health care resource [17]. Usability and acceptability of apps are important to AD/RD patients. Previous studies have suggested that technology to support health care for elders must allow personalization in the design of mobile apps and tackle their poor readability by using technology [18,19]. However, if members of vulnerable populations, such as AD/RD patients, experience difficulties in using mobile health (mHealth) technologies, health disparities may increase [20].

Need for This Review

Mobile phone apps delivering health care-related information have been well integrated into people's daily lives for a number of conditions, and the use of technology focused on AD/RD care is increasing. The touch screen interface feature of a mobile phone allows easy operation for people with AD/RD because of its intuitive and simple operation design [2]. However, there has been a dearth of knowledge about how these apps meet the needs of AD/RD patients, and the quality and readability of the existing apps for dementia care lack sustainability because of technological advances and changes in health care guidelines and public information. Scientific literature to date has mainly focused on the use of apps from the perspective of caregivers, rather than patients with AD/RD [21-23]. Therefore, a comprehensive review of currently available apps addressing patients' complex needs is needed.

The major goal of this study was to systematically review the apps designed for AD/RD patients using the following aspects: (1) current availability, (2) content and features, and (3) quality. This study will inform continued research and promote the development of technology-based dementia self-care apps that will contribute to improving health care for patients with AD/RD and reducing the burden of their caregivers.

Methods

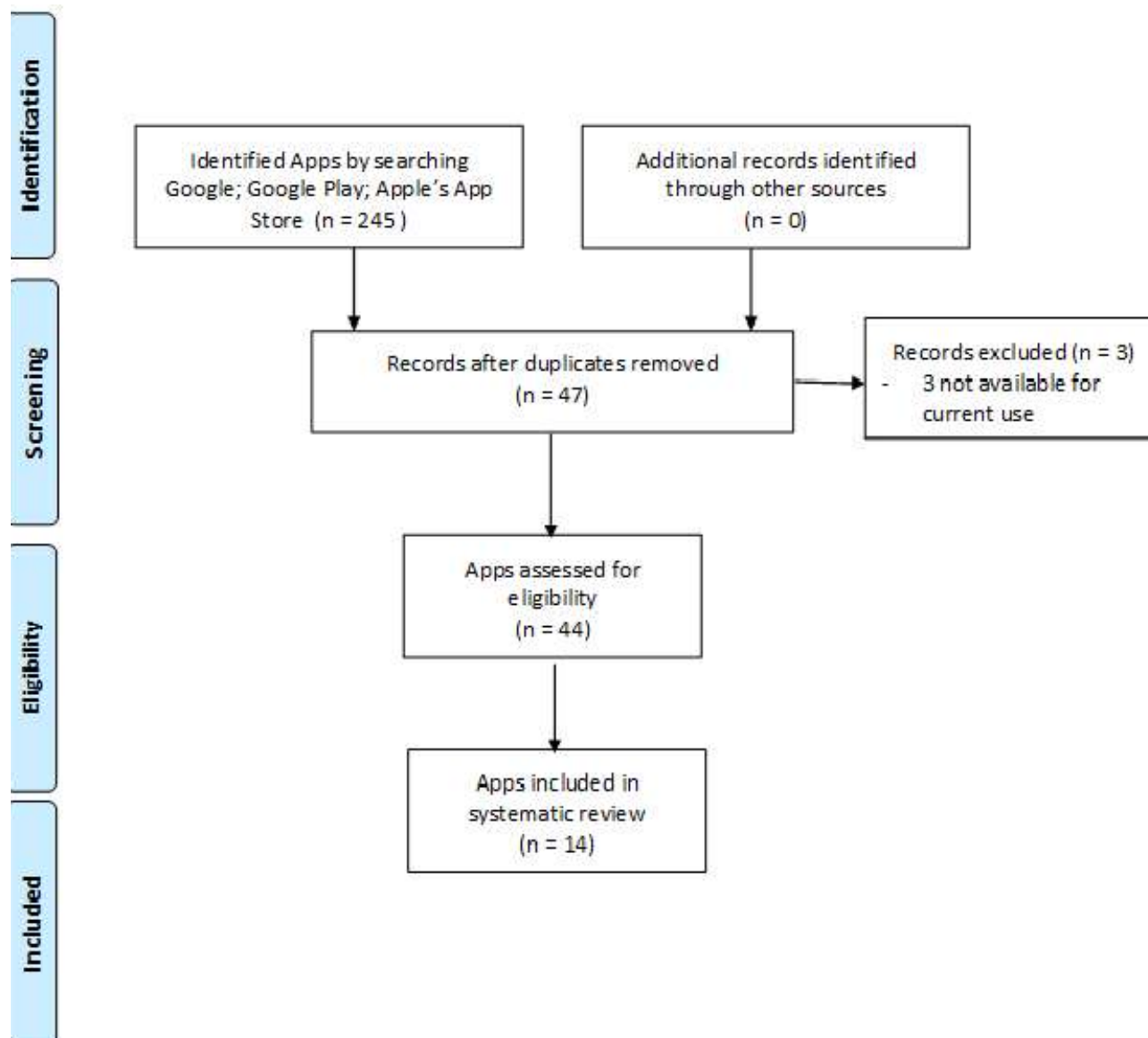
Searching Strategy and App Availability

A systematic approach was applied to review mobile phone apps for dementia care, which was informed by previous studies on caregiving technologies. For this study, multiple steps were taken to search and evaluate the apps. The following search terms were used: "dementia patients and smart phone app," "dementia patient and app," "Alzheimer's disease and smartphone app," "Alzheimer's disease and app," "dementia care and smart phone app," and "dementia care and app." Till January 2019, the initial search yielded 245 apps, and after duplicate apps were removed, 47 apps were left. After 3 apps were removed because of unavailability, 2 investigators (YG and FY) independently evaluated all 44 apps according to the eligibility criteria (Figure 1). In addition, the two investigators assessed the apps' readability, characteristics, and features (see

Figure 1). Any disagreement on the decision of an app was resolved through discussion until a consensus was achieved.

The availability of apps was searched in the Google Play Store and Apple's App Store.

Figure 1. App screening process.



Mobile App Characteristics

These apps were further screened to meet the following criteria: (1) available in English; (2) downloadable for current use (Google Play or Apple's App Store); (3) have a primary function of assisting AD/RD patients consistent with the needs identified by the literature; and (4) have a primary function of educating patients consistent with self-perceived needs of dementia care. The characteristics of included apps were coded by the app developer, country of origin, last date of update, mobile phone platform, and language.

Mobile App Features

The AD/RD patient support function was defined as an app feature for addressing one or more challenges faced by AD/RD patients, including memory, communication and language, ability to focus and pay attention, reasoning and judgment, and visual perception [24]. The AD/RD patient education function

was defined as app functions for teaching AD/RD patients about self-care skills, coping skills, and methods for using available services and building support systems for AD/RD caregiving [25-28].

Readability of Mobile Apps

The Automated Readability Index Calculator [29] was used to assess the readability of text appearing on the supporting Web pages associated with the included mobile phone apps (see [Multimedia Appendix 1](#)). The readability calculator for the US grade school system was applied as the grade level indicator, which includes 6 unique readability assessments: Flesch Kincaid Reading Ease, Flesch Kincaid Grade Level, Gunning Fog Score, Simple Measure of Gobbledygook Index, Coleman Liau Index, and Automated Readability Index.

Mobile App Rating Scale Assessment

The Mobile App Rating Scale (MARS) was used to independently assess the quality of apps. The MARS scale is a well-known standardized measurement tool for evaluating the quality of mobile apps related to health care [30-36]. Before starting the assessment, the reviewers discussed potential issues of conducting MARS assessments for dementia apps. The MARS contains 19 items that are rated using a 5-point scale (1=inadequate, 2=poor, 3=acceptable, 4=good, and 5=excellent) with the following 4 objective quality subscales: engagement (entertainment, interest, customization, interactivity, and target group), functionality (performance, ease of use, navigation, and gestural design), aesthetics (layout, graphics, and visual appeal), and information quality (accuracy, goals, quality of information, quantity of information, visual information, credibility, and evidence base). Subjective quality rating is also assessed by the MARS. An aggregate score of MARS was generated for the analyzed mobile apps. The validity and reliability were also tested [36].

Results

Summary

The initial search of this review was conducted in January 2019. The screening was started in February and completed in March 2019. Evaluation and analysis of included apps were completed in May 2019.

App Availability

Of the 245 apps identified, 14 met the eligibility criteria and were included in this report. After duplicates were removed, 44 of the remaining search apps did not have a primary function assisting dementia care, 10 did not have an AD/RD patient focus, 2 were not available in English, and 3 were not available in the Google Play Store or Apple's App Store. Of the 14 included apps, 11 (78%) were supported by both Google Play and Apple's App Store. In addition, 1 (1/14, 7%) app was available only in Apple's App Store, and 1 (1/14, 7%) was available only in Google Play.

Mobile App Characteristics

Of the 14 reviewed apps, 11 (78%) were developed by private, for-profit sectors, 2 (14%) were developed by a nonprofit foundation, and 1 (7%) was developed by an academic institution. Of the 14 apps, 7 (50%) were developed in the United Kingdom and 3 (21%) were developed in the United States. Of the remaining 4 apps, 3 were developed in other countries: 1 (7%) in Canada, 1 (7%) in Australia, and 1 (7%) in Norway; and 1 app could not have its country of origin ascertained. Additionally, 11 (78%) apps were free, with the exception of 3 that ranged from US \$0.99 to US \$4.99. However, 3/11 free apps included in-app purchase items, with costs ranging from US \$1.49 to US \$69.99. Of the 14 apps, 6 (42%) were recently updated in 2019, 1 (7%) was updated in 2017, and 7 (50%) were updated in 2015. As an eligibility criterion, all 14 apps were available in English, and 4 (28%) apps were available in multiple languages (Arabic, Danish, Dutch, Finnish, French, German, Hebrew, Italian, Japanese, Korean, Portuguese, Russian, Simplified Chinese, Spanish, and Turkish).

Mobile App Features

Of the 14 apps, each app had 1-5 features, with an overall mean of 2.35 features (SD 1.39) (Table 1). The alert or reminder function, such as wandering alert, appointment and medication reminder, and glucose monitoring, was the most common feature to assist patients with AD/RD with self-management. Another major common feature was that self-care tips were included, which shared general information about AD/RD and symptom management. In addition, five apps had social networking capacity, four apps were designed for documenting clinical information of care recipients, three apps were designed for medication management, two apps were designed for tracking patients' daily health behaviors (ie, diary), one app was designed as a monitoring device, one app was designed for storing clinical information to share with health care provider, one app was designed for receiving feedback from health care professionals, and one app was designed for connecting with community services.

Table 1. App availability, readability, characteristics, and features.

App availability, readability, characteristics, and features	Values
Mobile app availability, n (%)	
Both Google Play and Apple's App Store	11 (78)
Google Play	1 (7)
Apple's App Store	1 (7)
Mobile app characteristics, n (%)	
App developer	
Private for-profit sector	11 (78)
Private nonprofit foundation	2 (14)
Academic institution	1 (7)
Country of origin	
United Kingdom	7 (50)
United States	3 (21)
Other countries	3 (21)
Not available	1 (7)
Last date updated	
2018-2019	6 (42)
2016-2017	1 (7)
2014-2015	7 (50)
Mobile phone platform	
iOS	1 (7)
Android	2 (14)
Both	11 (85)
Cost	
Free	11 (85)
Purchase	3 (21)
Available language(s)	
English	14 (100)
Others	4 (28)
Mobile app content and features, n (%)	
Alert or reminder capacity	9 (64)
Self-care tips	6 (42)
Social networking capacity	5 (35)
Documentation of care recipient clinical information	4 (28)
Medication management	3 (21)
Track activities	2 (14)
Monitoring device	1 (7)
Storing clinical information to share with health care provider	1 (7)
Feedback from health care professionals	1 (7)
Links for community services	1 (7)
Quality and readability of mobile apps, mean (SD), range	
Readability of the text	10 (3.06), 6-16
Overall quality of the apps	3.71 (1.37), 3.12-4.20

App availability, readability, characteristics, and features	Values
Engagement score	3.88 (1.21), 3.37-4.24
Functionality score	4.21 (0.53), 3.92-4.32
Aesthetics score	4.14 (0.45), 4.09-4.31
Information quality score	4.04 (0.67), 3.98-4.11

Readability of Mobile Apps

The readability of the text of all 14 apps' websites was analyzed. On average, the text was readable by persons in the tenth grade (SD 3.06). Specifically, the websites were readable by persons in the levels of sixth grade (n=1), seventh grade (n=1), eighth grade (n=2), ninth grade (n=2), eleventh grade (n=2), twelfth grade (n=2), thirteenth grade (n=1), fourteenth grade (n=1), fifteenth grade (n=1), and sixteenth grade (n=1).

Mobile App Rating Scale Assessment

By using MARS, all included apps were assessed for each domain of the measure. The mean overall quality score of the apps was 3.71 (SD 1.37). The mean engagement score was 3.88 (SD 1.21), the mean functionality score was 4.21 (SD 0.53), the mean aesthetics score was 4.14 (SD 0.45), and the mean information quality score was 4.04 (SD 0.67) (Table 1).

Discussion

Mobile App Characteristics and Features

This study investigated current availability, content, features, and quality of apps designed to help elderly adults with AD/RD. In this review, 14 apps to assist older adults with AD/RD were analyzed. This review revealed that the major apps focused on general education tips, alerts, and social networking functions. Several apps addressed documentation of clinical information, medication management, and activity tracking. However, the cognitive, functional, and behavioral sequelae of dementia have not been fully addressed by these apps. According to this review, apps generally do not have adequate enough features to meet the complicated needs of patients with AD/RD.

However, the challenging behaviors of AD/RD patients can be modified, and their health can be promoted through adequate mobile technology-based interventions designed to meet the needs of these patients and their caregivers [5]. The evolution of mobile phone technology can have extensive influence on health care and promotion; therefore, apps focusing on dementia with comprehensive components may support AD/RD patients in meeting their needs [11,37-39]. For example, instant or real-time communication between AD/RD patients and health care systems is an important feature that should ideally be supported by these apps. Other suggested features include targeting the prevention of memory loss, communication and language skills, ability to focus, reasoning and judgment, visual perception, coping skills, and connectedness with the community [40]. Furthermore, clinical trials of these apps with measurable outcomes (eg, memory improvement and connectedness) are urgently needed to provide evidence for their efficacy.

In addition, with regard to content and its readability, access to high-quality AD/RD self-care via mobile phone apps is limited because of the high literacy level requirement of these apps. AD/RD may impair the language ability of patients, and dementia might result in defective linguistic reasoning, dwindling vocabulary, and changes in word association patterns [27]. Thus, AD/RD self-care apps must be designed with the patients' literacy and language ability in mind, as these patients might be at a particularly low literacy level for app usage. Previous studies have revealed that half of the AD/RD population potentially have difficulty reading words, sentences, and advertisement materials if the readability of text required is ninth grade or higher [40]. This study found that the readability of the reviewed apps varied from sixth grade to sixteenth grade, and only 13.3% (2/15) of the apps possessed readability levels lower than that of the ninth grade. Moreover, the ability to read does not guarantee understanding, or comprehension, of content, especially if the patient's discursive capacity to articulate meaning is impaired.

Previous research related to communication training for AD/RD patients has provided a direction for future app development. To warrant effectiveness, the apps for AD/RD patients need to provide clear and concise information, such as using a list or bullets [39]. Nonverbal communication is another evidence-based method to effectively communicate with AD/RD patients [40]. In the context of mobile phone apps, visual assistance, such as icons and pictures, might be helpful. Future research would benefit from evaluating the applicability of these techniques to mobile phone apps; effectiveness should also be tested.

Our study demonstrated that the quality of current AD/RD apps could be improved to provide high-quality AD/RD self-care assistance. The results from the MARS assessment showed that the quality of these apps widely ranged from 2.9-4.84 on a 5-point Likert scale. The range also indicated that the quality of these apps was generally acceptable. However, this wide range demonstrates the inconsistency related to the quality of these apps, which might cause hesitation in this already vulnerable patient population. Another finding from the MARS assessment was that most apps were rated from low to acceptable in the subcategory of engagement. Previous studies of caregiver apps found the same issue and attributed the cause to the design of the apps [24]. However, researchers in this study interpreted this finding from a different perspective. The assessment scale used in this study, MARS, was a simple and reliable tool for classifying and assessing the quality of mHealth apps [36]. Health apps with poor to acceptable engagement level might be chosen and used less by clients because of limited interactivity and customization, indicating poor app quality [24]. However, because of the nature of self-care apps used by

AD/RD patients, some of the scale items may not be applicable to these apps. For example, the cognitive impairment of AD/RD patients leads to the self-care apps being task-oriented. Moreover, engagement might be a low priority for these apps. Therefore, future research could develop a quality assessment scale for apps to be adopted by patients with cognitive impairments, even for AD/RD patients.

Furthermore, apps may be a particularly valuable resource for AD/RD patients with a minority background, who typically have low health care utilization rate [41]. None of the reviewed apps in this study provided culturally sensitive features, showing an exclusion of AD/RD patient users from a minority group, diminishing the life quality of this group, and further exacerbating health disparities. Culturally-sensitive interventions have been popularized because of a better chance of being implemented and sustained [42]. Research has shown that apps specifically targeting a given group or a community have a higher effectiveness than those apps designed for a general group/population [42,43]. Therefore, it is very important to make these apps culturally sensitive to minorities. In this study, few apps provided language options other than English. Culturally sensitive apps should consider AD/RD patients' needs with their preferred languages. However, to make an app culturally grounded for an underserved group, we need to go beyond language and incorporate the patients' ways of living by including their cultural values and religious beliefs.

Principal Findings

Our findings suggest that currently available apps for AD/RD patients may not meet complex needs and may be difficult to use given the possible impaired communication ability associated with AD/RD. Therefore, high-quality apps need to be developed and rigorously evaluated for feasibility and efficacy.

Limitations

One limitation of this study is that the researchers were unable to ascertain data security and privacy of apps for AD/RD patients. The cognitive impairment and age of the patient group put this already vulnerable group at increased risk of privacy breaches. Future research is planned to examine privacy policies and user data protection. Another limitation lies in the fact that the search for apps was very time-sensitive. Apps are being developed and launched at an unprecedented rate. We conducted two app searches in December 2018 and April 2019, and another supplementary search will be conducted in this study. A third limitation is that the researchers captured some level of divergence between the apps and the MARS assessment because the MARS assessment was not specifically designed for AD/RD care-related apps. For instance, MARS put many emphases on user engagement, whereas some AD/RD care apps are function-orientated. Future studies may aim to develop a more accurate measurement tool to test the quality of AD/RD care apps. Finally, we only included apps available in English. It is possible that this study excluded apps available in languages other than English.

Conclusions

This review provided a snapshot of the availability, content, features, and quality of current health care-related apps for AD/RD patients. There is an urgent need for high-quality comprehensive app systems or multifunction apps that are appropriate for the literacy and cognitive level of AD/RD patients. In light of the bias evident in existing apps, app developers should consider cultural aspects for future app development. In addition, future research should assess the effectiveness of these apps on the health condition and well-beings of AD/RD patients, caregivers, and the health care system with randomized clinical trials. The feasibility of integrating these apps in clinical care as well as within the health care policy arena opens more avenues for future research, dissemination, and implementation.

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Authors' Contributions

YG, FY, and HYL contributed to conceptualization. YG, FY, NR, and HYL contributed to methodology. YG, FY, FH, WL, NR, and HYL contributed to validation. FY and YG performed formal analysis. FY and YG contributed to resources. FY, YG, and HYL wrote the original paper. FY, YG, FH, WL, NR, and HYL wrote, reviewed, and edited the paper. YG and FY contributed to visualization. HYL supervised and contributed to funding acquisition. FY contributed to project administration.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Automated Readability Index Calculator and the Mobile App Rating Scale.

[PDF File (Adobe PDF File), 259 KB - [aging_v3i1e15290_app1.pdf](#)]

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Abbreviations

AD/RD: Alzheimer disease and related dementias

BPSD: behavioral and psychological symptoms of dementia

MARS: Mobile App Rating Scale

mHealth: mobile health

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Original Paper

A Dual-Pronged Approach to Improving Heart Failure Outcomes: A Quality Improvement Project

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Abstract

Background: Presently, 6.5 million Americans are living with heart failure (HF). These patients are expected to follow a complex self-management regimen at home. Several demographic and psychosocial factors limit patients with HF in following the prescribed self-management recommendations at home. Poor self-care is associated with increased hospital readmissions. Under the Affordable Care Act, there are financial implications related to hospital readmissions for hospitals and programs such as the *Program of All-Inclusive Care for the Elderly* (PACE) in Pinellas County, Florida. Previous studies and systematic reviews demonstrated improvement in self-management and quality of life (QoL) in patients with HF with structured telephone support (STS) and SMS text messaging.

Objective: This study aimed to evaluate the effects of STS and SMS on self-care, knowledge, medication adherence, and QoL of patients with HF.

Methods: A prospective quality improvement project using a pre-post design was implemented. Data were collected at baseline, 30 days, and 3 months from 51 patients with HF who were enrolled in PACE in Pinellas County, Florida. All participants received STS and SMS for 30 days. The feasibility and sustained benefit of using STS and SMS was assessed at a 3-month follow-up.

Results: A paired *t* test was used to compare the mean difference in HF outcomes at the baseline and 30-day follow-up, which demonstrated improved HF self-care maintenance ($t_{49}=0.66$; $P=.01$), HF knowledge ($t_{49}=0.71$; $P=.01$), medication adherence ($t_{49}=0.92$; $P=.01$), and physical and mental health measured using Short-Form-12 (SF-12; $t_{49}=0.81$; $P=.01$). The results also demonstrated the sustained benefit with improved HF self-care maintenance, self-care management, self-care confidence, knowledge, medication adherence, and physical and mental health (SF-12) at 3 months with $P<.05$ for all outcomes. Living status and social support had a strong correlation with HF outcomes. Younger participants (aged less than 65 years) performed extremely well compared with older adults.

Conclusions: STS and SMS were feasible to use among PACE participants with sustained benefits at 3 months. Implementing STS and SMS may serve as viable options to improve HF outcomes. Improving outcomes with HF affects hospital systems and the agencies that monitor and provide care for outpatients and those in independent or assisted-living facilities. Investigating viable options and support for implementation will improve outcomes.

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KEYWORDS

heart failure; mobile messaging; structured telephone support; self-care management; medication adherence; quality improvement

Introduction

Background and Significance

Heart failure (HF) is a clinical syndrome affecting 6.5 million Americans and is a growing problem around the world [1]. The gold standard of managing HF includes complex pharmacological, dietary, and device therapies that require self-management at home. Self-management can be defined as *daily activities that maintain clinical stability* [2]. For optimal health outcomes and stability, patients with HF must follow their prescribed self-management recommendations at home [3]. The most effective self-management strategies require patients to adhere to complex medication regimens, comply with diet and exercise recommendations, monitor symptom changes, and modify medications and behavior according to HF symptoms [4]. Individuals living with HF report significant negative effects on self-management at home with overall reduced quality of life; QoL [5]. In addition to the cost of human suffering, HF hospital readmissions are associated with over US \$17 billion annually [6]. Up to 12.5% of these readmissions have been identified as preventable [7]. Several psychosocial and socioeconomic factors limit the adherence of patients with HF to self-management at home [8]. The current guidelines recommend telephone follow-up within 3 days and a follow-up visit within 7 to 14 days of hospital discharge [3]. The ultimate goal of follow-up care is to employ innovative approaches to keep people out of the hospital and at home [3]. Despite effective medical and symptom management strategies that are available, a considerable gap exists in the ability to effectively manage HF at home. Poor symptom management results in increased re-admission and affects individuals' QoL [9]. A systematic review demonstrated that supporting people with HF at home using technology can reduce HF-related hospitalization and improve people's QoL with improved knowledge on HF self-care [10].

Old age and multiple comorbidities challenge the ability of patients with HF to learn and continue self-management practices at home [11]. Many older adults live alone and lack social support, tending to rely on others such as visiting nurses and home care services. Many states offer home care nursing for people with chronic diseases leveraging the federal program known as the *Program of All-Inclusive Care for the Elderly* (PACE) [12]. PACE provides comprehensive medical and social services to frail, community-dwelling elderly individuals, most of whom are dually eligible for Medicare and Medicaid benefits. Individuals aged 55 years or older and living in the service area of a PACE organization are eligible for home care nursing. The goal of PACE is to promote older individuals to live safely in the community. Financing for the program is capped, which allows providers to deliver all services that participants need rather than limit them to those reimbursable under Medicare and Medicaid fee-for-service plans [9]. The PACE model of care is established as a provider in the Medicare program and enables individual states to provide PACE services to Medicaid beneficiaries [12]. However, under the Affordable Care Act, there are financial implications related to hospital readmissions for hospitals and programs such as PACE in Pinellas County, Florida.

Therefore, a prospective pre-post quality improvement project was conducted to assess the feasibility and preliminary efficacy of a nurse-led telephone support intervention supplemented with mobile phone SMS text messages in older adults with chronic HF who were enrolled in PACE. Previous studies have tested the effects of structured telephone support (STS) in patients with HF, but the use of SMS in this population remains underexplored. The project was completed at the Sun Coast PACE at Pinellas County, Florida. The project included participants with HF enrolled in PACE. A dual pronged STS with daily SMS was implemented to examine improvement in HF self-care, knowledge, and QoL.

Rationale for Structured Telephone Support and Text Messaging

A systematic review of 49 qualitative studies found that much of the difficulty related to self-care management involved issues in remembering which self-care behaviors were appropriate or important to complete, as well as the harmful effects and perceived uncontrollability of HF symptoms [13]. A meta-analysis of 9 randomized clinical trials (RCTs) supported that individuals who received STS had a significantly lower risk of HF re-admission than controls (relative risk; RR 0.74; 95% CI 0.61 to 0.90) [14]. This is further supported by a review of 16 RCTs (n=5613) that exclusively implemented STS reduced HF-related hospitalization (RR 0.77, 95% CI 0.68 to 0.87; $P<.01$) [10]. A cost-effectiveness analysis of a 3-arm study, home visits with telephone calls (Home arm, n=196) and telephone calls only (Call arm, n=204), and control group that received standard care (Control arm, n=210) demonstrated that the telephone call arm had a higher probability of being cost-effective at 28 days and 84 days, whereas the home arm was less costly but less effective at 28 days and was dominating (less costly and more effective) at 84 days, indicating that a bundled intervention with home visits and telephone calls was less costly and more effective [15].

Given the increasing adoption and use of mobile technology, including text messaging in self-management of chronic diseases, a review on the use of mobile messaging for HF self-management was completed. Despite emerging evidence of mobile messaging use in several chronic conditions, the use of mobile messaging in HF has been limited. Among 60 patients with HF, daily messages from an interactive voice response system using an MP3 player with self-care management tips showed greater than a 50% reduction in the 30-day re-admission rate [16]. Similarly, a pre-post pilot study of patients with HF (n=15) reported that mobile messaging was easy to use 83% (12.5/15) and showed reduced pills missed 66% (10/15) and decreased salt intake 66% (10/15), with improved self-care maintenance (mean composite score increased from 49 to 78; $P=.03$) and self-care management (increased from 57 to 86; $P=.02$) at 4 weeks [17]. Mobile messaging was successfully used in cardiac rehabilitation [18], chronic health conditions [19], smoking cessation [20], weight loss [21], and medication adherence [22]. Therefore, the quality improvement project examined improvement in HF outcomes including self-care, medication adherence, and QoL after implementing STS with SMS among participants enrolled in PACE.

Methods

Overview

This project utilized a prospective pre-post design using a cohort of patients with HF enrolled in PACE in Pinellas County, Florida. Data were collected at baseline, 30 days, and 3 months. The sample included men and women with a clinical diagnosis of HF defined by the ICD-10-CM who were aged 55 years or above, a criterion for eligibility for PACE. The project was approved by the University's institutional review board (IRB). Participants enrolled in PACE at Sun Coast Pinellas County, Florida were contacted via telephone and scheduled for a visit at the Sun Coast PACE day care center or in their homes. During the visit, the consent was reviewed with the participant and all questions were addressed and answered. A copy of the signed consent document was sent home with those participants who requested that their family be made aware of the study and necessary requirements. The participants were then consented using the IRB approved consent form and were not coerced to participate. Participants were provided with explanations about the STS and SMS program in addition to the care offered by PACE. A sample of the SMS used with participants included questions and encouragement of HF best practices (see [Multimedia Appendix 1](#)). Participants were informed that participation was voluntary for this project and the required follow-ups to be scheduled would occur at 30 days and 3 months.

Intervention With Structured Telephone Support and Text Messaging

Once consented, all participants received STS 3 times a week over a 3-month period by an advanced registered nurse practitioner (APRN), who was a doctoral student. A standard protocol on delivering STS was developed to provide similar and consistent telephone support for all participants. Daily text messages on self-care tips on diet, exercise, HF symptom identification, and management as well as HF medications were also sent. Short messages on these topics with a total of 100 messages were developed and looped to be sent daily for 30 days. These messages were adapted for patients with HF and were similar to those utilized in studies using SMS for weight management. These messages were delivered automatically to participants' mobile phone via a computer system. Of the 51 participants, 47 had mobile phones that could receive SMS and 4 participants were given a mobile phone to use during the study period. The phones that were given for use in the project had service set up through a national carrier to cover the 3-month study period. All participants were shown how to receive and read SMS with instruction and return demonstration by the APRN to assess ability to participate. A weighing scale and sphygmomanometer were also available to use if the participant did not own one. We measured the feasibility of STS and SMS among PACE participants by tracking the number of participants who completed the study at 30 days and 3 months. The sustained benefit from STS and SMS was assessed by participants' scores at a 3-month follow-up.

Measurements

Once consented, participants completed standard, validated outcome measures including HF self-care, knowledge, medication adherence, and physical and mental health. In addition, participants completed demographic variables and the social support questionnaire.

Self-care behavior was assessed using the valid and reliable Self-Care of Heart Failure Index that comprises 15 items with 3 subscales rated on a 4-point response scale [23]. Reliability of the Self-Care Maintenance subscale was $r=0.56$, Self-Care Management was $r=0.70$, and Self-Care Self-Confidence was $r=0.82$ [23]. Multiple studies have tested this scale on persons with HF [24,25].

HF knowledge was measured using the Atlanta Heart Failure Knowledge Test, a standardized validated instrument that is utilized both in research and clinical settings [26]. The question has 30 questions with a possible 0-30 score. Content validity ratings on relevance and clarity were tested in patients and family members that ranged from 0.55 to 1.0, with 81% of the items rated from 0.88 to 1.0. Cronbach alpha was .84 for patients and .75 for family members [26].

Medication adherence was assessed utilizing the 8-item self-administered Morisky Medication Adherence Questionnaire (MMAQ). The MMAQ has a Cronbach alpha of .83 [27] and demonstrated a sensitivity of 95% and a specificity of 53% at a cut-off point less than 6 and a total score of 10, and higher scores indicate worse adherence [27].

Physical and mental health was assessed using the SF-12 questionnaire [28]. The SF-12 was compared with SF-36 among cardiac participants and found to be valid with a correlation coefficient of physical component summary (PCS-12/-36; $r=0.96$; $P<.001$) and mental component summary (MCS-12/-36; $r=0.96$; $P<.001$) scores [29]. Similarly, change scores between baseline and 12 months were highly correlated (PCS-12/-36; $r=0.94$; $P<.001$) and (MCS-12/-36; $r=0.95$; $P<.001$). Therefore, to reduce patient burden, we used the SF-12.

Demographic variables included age, gender, race, and living status. Social support was assessed using the Duke-UNC *Functional Social Support Questionnaire* (FSSQ) short-version, which has 8 items in a 5-point Likert scale (1=much less than I would like and 5=as much as I would like) with internal consistency ranging from 0.50 for useful advice to 0.85 for help around the house [30]. The higher average score indicates greater perceived social support.

Results

Data Analysis

Data were analyzed using SPSS for Windows (version 21.0, SPSS, Inc). Descriptive statistics with frequency and percentage for categorical variables such as gender, race, and living status and mean and standard deviation for continuous variables were computed. Paired t test statistics were completed to compare baseline data with 30-days follow-up data to examine the effect of the intervention with STS and SMS with changes in mean score.

Sample Characteristics

More than 100 records were reviewed to identify the patients with HF at PACE, and of those with the HF diagnosis, 85 were contacted for possible participation in the study over a 3-month period. A total of 51 eligible participants agreed and were enrolled in the study. Of those enrolled, about 90% (46/51) were

aged 65 years and older, and the mean age was 77.39 (SD 9.34) years; 65% (33/51) were females. One-half of the participants (51%, 26/51) lived alone and 23% (12/51) lived in an independent or assisted-living facility. The other participants lived with a spouse or family member. About 71% (23/51) were white and 24% (12/51) were African American (see [Table 1](#)).

Table 1. Sample characteristics of the participants.

Characteristics	Value
Age (years)	
Mean (SD)	77.39 (9.34)
>65, n (%)	46 (90)
Range	59-94
Gender, n (%)	
Male	18 (35)
Female	33 (65)
Race, n (%)	
Hispanic	2 (4)
Non-Hispanic white	23 (71)
Non-Hispanic black	12 (24)
Living status, n (%)	
Alone	26 (51)
Independent or assisted living	12 (23)
Lived with spouse or family member	13 (25)

Feasibility of Using Structured Telephone Support and Text Messaging

Calculating the number of participants who completed the study at 30-days and 3-month follow-up assessed feasibility of using STS and SMS. All 51 participants (100%) completed the study at 30 days and 3-month follow-up indicating feasibility to use STS and SMS in this population, which could be utilized in designing and conducting a larger study.

Potential Effect of Structured Telephone Support and Text Messaging on Heart Failure Outcomes

Owing to the sample size and lack of a control group, a dependent *t* test was used to compare baseline data with 30-day and 3-month follow-up data (see [Table 2](#)) to examine the effect of STS and SMS on HF outcomes. The results demonstrated that STS and SMS significantly improved HF self-care maintenance, self-care management, and self-care confidence and knowledge, medication adherence, and physical and mental health (Short-Form-12; SF-12) at 30 days and sustained improvement at 3 months with $P < .05$.

Table 2. Results of intervention at 3-month follow-up (n=51).

Outcomes	Baseline, mean (SD)	30-day follow-up, mean (SD)	3-month follow-up, mean (SD)	<i>t</i> test (<i>df</i>)	<i>P</i> value	Eta
Self-care maintenance	19.31 (3.61)	20.55 (3.13)	21.17 (2.92)	353.49 (49)	.01	0.935
Self-care management	9.67 (4.69)	10.16 (3.32)	22.72 (2.78)	438.24 (49)	.01	0.947
Self-care confidence	10.73 (3.70)	10.86 (3.57)	12.29 (2.85)	19.46 (49)	.01	0.443
Heart failure knowledge	23.98 (2.97)	27.82 (1.52)	28.84 (1.32)	91.19 (49)	.01	0.778
Medication adherence	3.14 (1.47)	2.84 (1.58)	2.78 (0.88)	6.84 (49)	.02	0.218
Short-Form-12	29.26 (2.88)	29.90 (2.90)	30.65 (2.41)	15.23 (49)	.01	0.383

Factors That Potentially Influenced Heart Failure Outcomes

An analysis was performed to examine the effect of age, gender, race, living status, and social support on HF outcomes. HF knowledge was found to have a significant association with age ($F_{1,49}=4.01$; $P=.05$; $\beta=.343$; $R^2=0.376$) indicating that those participants aged below 65 years had better HF knowledge.

Mental and physical health measured by SF-12 was also significantly associated with age ($F_{1,48}=5.47$; $P=.02$; $\beta=.277$; $R^2=0.328$) indicating that younger patients with HF were less depressed than older patients. Medication adherence was associated with social support measured by FSSQ ($F_{1,49}=5.03$; $P=.03$; $\beta=.305$; $R^2=0.093$). Those participants who lived with a spouse or family member had significantly improved self-care management ($F_{1,49}=-3.91$; $P=.01$; $\beta=.456$; $R^2=0.230$). Living status also was significantly associated with HF knowledge ($F_{1,49}=6.52$; $P=.01$; $\beta=.592$; $R^2=0.343$) and those who lived with a spouse or family member were less depressed as was evidenced by the SF-12 score ($F_{1,49}=16.47$; $P=.01$; $\beta=.502$; $R^2=0.252$).

Discussion

Principal Findings

We conducted a quality improvement project that demonstrated that the dual pronged intervention with STS and SMS improved HF self-care, HF knowledge, and medication adherence and decreased depressive symptoms. The use of STS and the delivery of SMS served as a health care coach for this patient population, many of whom are isolated owing to age, living status, and symptomatic HF. Mobile technologies can augment health coaching by empowering patients and coaches to maintain numerous avenues for communication through voice and text message communication. A total of 90 email messages were sent to participants over the 3-month period (see [Multimedia Appendix 1](#) for a sample of the messages). Participants were asked about the SMS and if they had received and understood the SMS. Questions were invited and requested during the STS communications.

Improvement in HF self-care was supported in a systematic review of 49 studies, which found that HF knowledge and self-care among HF participants, particularly regarding sodium reduction, medication adherence, weight monitoring, and physical activity, improved after STS [13]. These findings on improved self-care maintenance was also supported in a pre-post pilot study of patients with HF ($n=15$) that the text messaging improved self-care maintenance (mean composite score increased from 49 to 78; $P=.03$) and self-care management (mean composite score increased from 57 to 86; $P=.02$) at 4 weeks [17]. These findings are consistent with other research studies that supported improved medication adherence through the use of text messaging [31-33].

The findings also supported the assumption that living status and a higher level of social support had a strong correlation with HF self-care management and HF knowledge. The findings

were supported in a longitudinal observational study of patients with HF ($n=108$) that a higher level of social support correlated with better outcomes in self-care behavior and adherence to medication, diet, and exercise over time [34]. These results were also consistent with those from a multisite trial conducted in the Netherlands ($n=333$) that showed a high level of social support was the only significant predictor for improved outcomes ($\beta=-2.65$; 95% CI -4.45 to -0.85), as lower self-care scores reflect improved self-care [35].

The result of this project also indicated that those with good social support were less depressed (SF-12 score), and there was a strong association with depression and HF self-care [36]. Holzapfel et al [37] reported a significant association with self-care and age ($P<.05$), which was also similar among our participants as those aged below 65 years fared better in HF knowledge and were less depressed compared with those aged above 65 years [37].

STS and SMS are feasible interventions among PACE participants. The result from this project indicated that all 51 participants (100%) completed the study at the 30-day and 3-month follow-up, indicating feasibility and acceptability by PACE participants. Sustained benefits from using STS and SMS were demonstrated at the 3-month follow-up.

The use of mobile phones has incorporated the ability to provide unparalleled care for patients with HF as it serves to maintain communication with participants and is convenient for use by the elderly with little coaching.

Strength and Limitation

The study was completed at PACE, a member of Empath Health, a nonprofit integrated network of care supporting those challenged by chronic and advanced illness in the Tampa Bay region. Including participants enrolled at PACE served as a major strength and a limitation. PACE includes individuals above the age of 55 years, and thus 90% of the participants in the study were aged 65 years or older and 65% were females. PACE is an all-inclusive program, and patients with multiple physicians and obstacles with obtaining medications were not included along with a lack of generalizability to the overall population. Other limitations include the lack of a control group and use of self-reported measures and the outcome assessors and patients were not blinded. Hence, the possibility that the effects of the intervention were overestimated cannot be excluded. The small sample size was also a limitation; however, all study participants were able to complete the 3-month follow up.

Conclusions

Implementation of STS and SMS was relatively easy to implement in this population. The costs incurred for this project were mainly related to providing participants a mobile phone with service, weighing scales, or sphygmomanometers if they did not own one. We are extremely thankful for the funding from the American Association of Colleges of Nursing (AACN) that supported this project. However, to be realistic, one must be cognizant of the lack of mobile phone availability for participants. Facilities such as PACE may need to tap into available resources to provide mobile service to the elderly who

may live alone and educate them in using the service. HF symptom recognition and management are the mainstays of HF treatment, and interventions need to be tailored to improve self-care, knowledge, and QoL. Sustained benefits with improved knowledge with STS and SMS need to be evaluated for a longer period. The results were disseminated to the PACE administrators for review and possible adoption of this model not only in the management of patients with HF but also of other clients with chronic diseases receiving care at that facility.

Relevance to Clinical Practice

Nurses undertake many roles, including provision of direct care and clinical decision making. However, patient education and

coaching are independent functions and standards in nursing care. On the basis of the results of our study, self-care management interventions involving STS and SMS could effectively improve various aspects for HF outcomes. It is important to educate nurses and patients with HF regarding the most common problems related to self-care of those with HF and the effective way to utilize STS and SMS. The results can also help the administrators of agencies such as PACE, home care agencies, and independent living facilities to incorporate self-management interventions with STS and SMS into patients' daily treatment plan to prevent physical, psychological, and social problems that negatively affect patients' ability to care for themselves.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Sample of SMS text messages.

[[PDF File \(Adobe PDF File\), 29 KB - aging_v3i1e13513_app1.pdf](#)]

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Abbreviations

AACN: American Association of Colleges of Nursing
APRN: advanced registered nurse practitioner
CDC: Centers for Disease Control and Prevention
FSSQ: Functional Social Support Questionnaire
HF: heart failure
IRB: institutional review board
MCS: mental component summary
MMAQ: Morisky Medication Adherence Questionnaire
PACE: Program of All-inclusive Care for the Elderly
PCS: physical component summary
RCT: randomized clinical trial
STS: structured telephone support

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Original Paper

Mobile Apps to Support Caregiver-Resident Communication in Long-Term Care: Systematic Search and Content Analysis

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Abstract

Background: In long-term residential care (LTRC), caregivers' attempts to provide person-centered care can be challenging when assisting residents living with a communication disorder (eg, aphasia) and/or a language-cultural barrier. Mobile communication technology, which includes smartphones and tablets and their software apps, offers an innovative solution for preventing and overcoming communication breakdowns during activities of daily living. There is a need to better understand the availability, relevance, and stability of commercially available communication apps (cApps) that could support person-centered care in the LTRC setting.

Objective: This study aimed to (1) systematically identify and evaluate commercially available cApps that could support person-centered communication (PCC) in LTRC and (2) examine the stability of cApps over 2 years.

Methods: We conducted systematic searches of the Canadian App Store (iPhone Operating System platform) in 2015 and 2017 using predefined search terms. cApps that met the study's inclusion criteria underwent content review and quality assessment.

Results: Although the 2015 searches identified 519 unique apps, only 27 cApps were eligible for evaluation. The 2015 review identified 2 augmentative and alternative cApps and 2 translation apps as most appropriate for LTRC. Despite a 205% increase (from 199 to 607) in the number of augmentative and alternative communication and translation apps assessed for eligibility in the 2017 review, the top recommended cApps showed suitability for LTRC and marketplace stability.

Conclusions: The recommended existing cApps included some PCC features and demonstrated marketplace longevity. However, cApps that focus on the inclusion of more PCC features may be better suited for use in LTRC, which warrants future development. Furthermore, cApp content and quality would improve by including research evidence and experiential knowledge (eg, nurses and health care aides) to inform app development. cApps offer care staff a tool that could promote social participation and person-centered care.

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KEYWORDS

mobile apps; communication barrier; dementia; caregivers; long-term care; patient-centered care

Introduction

Background and Rationale

With the growing aging population, there are more people living with chronic conditions that contribute to physical, sensory (vision/hearing), and cognitive limitations. The complex health care needs of older adults living with chronic conditions may require the services offered in long-term residential care (LTRC) homes. Most LTRC residents (85%) are functionally dependent and require care staff assistance (eg, nurse and residential care aide) while completing activities of daily living (ADLs) [1], and 25% of residents live with dual sensory loss (hearing and vision) [2]. Besides physical and sensory limitations, an estimated 90% of residents live with some cognitive impairment, with 2 out of 3 residents living with Alzheimer disease and related dementias (ADRD) [1]. Furthermore, many residents experience communication difficulties associated with chronic conditions (eg, sensory loss, dementia, and stroke) and/or a cultural-language mismatch with care staff that can challenge interpersonal relationships, and care staffs' ability to meet residents' unique needs [3].

Implementation of a person-centered philosophy of care and person-centered interventions in LTRC depends on effective caregiver-resident communication [4]. Person-centered communication (PCC) involves sharing information and decisions between care staff and residents, being compassionate and empowering care provision, and being sensitive to resident needs, preferences, feelings, and life history [5]. By creating an environment that uses strategies and tools to enhance PCC, LTRC care staff can meet residents' unique needs and foster interpersonal relationships with the residents [6]. For example, care staffs' use of social and task-focused communication strategies (eg, greet the resident and provide one direction at a time, respectively) with residents living with dementia support the successful completion of ADLs [7,8]. Verbal and nonverbal behaviors (eg, use the resident's name and make gestures) contribute to positive communication between residents and care staff with different linguistic/cultural backgrounds [3].

Although guidelines for supporting person-centered language in LTRC exist [9], the LTRC setting faces many challenges that can act as barriers to PCC. One such challenge is language diversity. In countries that have a history of welcoming immigrants (eg, Canada, the United States, and Australia), care staff and residents with diverse linguistic and ethnocultural backgrounds often comprise LTRC settings [10-14]. For example, in Canada, most immigrant seniors live in urban areas (eg, Vancouver and Toronto), with approximately 50% of the Vancouver senior population being immigrants [15]. Similarly, it is common to find that English is not the first language of residential care aides, nor are they born in Canada [16]. Therefore, diversity in the LTRC setting is typical in major Canadian urban areas, leading to mismatches between care staff and residents' first language and/or ethnocultural backgrounds. The shortage of qualified care staff, low wages among residential care aides, and restrictions on who can provide specific types of care can lead to a reduction in the time needed to foster frequent, quality interpersonal interactions with

residents [17]. Finally, resource constraints inherent to the LTRC setting (eg, time and staffing) can lead to *task-focused* care rather than *person-focused* care and to fewer instances of caregiver-resident interpersonal interactions [18].

Several traditional approaches to supporting caregiver-resident communication have been tried in LTRC, including professional medical translator services for non-English-speaking residents, communication training programs [19], evidence-based communication strategies [7,8], employing bilingual care staff [20], and using augmentative and alternative communication (AAC) techniques, tools, and strategies (eg, communication boards and gestures). AAC can be used to address the needs of residents living with acquired communication disorders (eg, aphasia and dementia) by supplementing remaining speech abilities or replacing the voice output when speech is no longer viable [20,21]. Although the aforementioned supports can be beneficial, they are often inaccessible to caregivers or residents because of the limited time available for training and/or implementation during care routines, limited funding, and limited on-demand availability.

There is growing recognition of the potential role of technology in supporting the health care of older adults [21], with a focus on person-centered care [22-25]. In particular, the use of mobile communication technology (MCT), which includes mobile devices such as tablets and smartphones, along with their software apps, offers an innovative approach for supporting person-centered care. There are several advantages to using MCT in health care settings: (1) the devices are accessible, portable, small, lightweight, rechargeable, relatively easy to use, and inexpensive, have advanced features (eg, camera and sound recording), and have enough computing power to support web searching; (2) a variety of apps are available in the major app marketplaces; and (3) a wireless connection offers continuous, simultaneous, and interactive communication from any location [26].

In a short period, the availability of mobile apps has increased exponentially across the 2 largest app marketplaces: Google Play (Android platform) and the App Store (iPhone Operating System [iOS] platform). For example, in 2014, there were an estimated 2.6 million apps across the 2 marketplaces [27] and, by 2019, this number climbed to 5.5 million apps (111% increase) [28]. In addition to the convenience and commonplace of MCT, the appeal of using apps in health care may be because of the range of available built-in features that can support individuals' needs, preferences, and abilities (ie, person-centered care), including larger touch screen interfaces with tactile feedback, motion sensors, voice recognition, cameras, video recorders, and multimedia content (eg, images, sound, and text) [29]. App content can also be customized to support the unique needs of a target population. For example, apps designed for older populations can incorporate larger text and zoom capability; allow for preferred vocabulary, photos, and text; and have the options to save voice and video recordings. Thus, MCTs are useful tools for health care professionals and can support target populations with specific needs, such as those living with ADRD [29-32]. However, more information is needed to determine how these technologies could address specific challenges that caregivers encounter with target

populations (eg, dementia [33]) living in LTRC. Furthermore, given the rapidly changing landscape of the app marketplace (eg, new, updated, and removed apps), it is important to better understand the stability of apps in the marketplace. The longevity of apps has important implications in the LTRC context. For example, for training care staff to use an app that is subsequently removed from the marketplace would be a waste of financial resources. The first step to examining the use of MCT in the LTRC setting is to better understand the suitability of currently available commercial apps for supporting communication in the LTRC context and the stability of these apps over time.

Using mobile devices, along with AAC apps and language translation apps, collectively referred to as communication apps (cApps) in this paper, may offer an innovative approach to enhancing PCC in LTRC. In particular, cApps have the potential to support care staff and residents living with acquired neurogenic communication disorders [34] and/or linguistic/ethnocultural barriers [14] during daily activities. For example, cApps could be used as follows: (1) support residents' participation in their own care; (2) help identify, save, and share residents' individualized needs and preferences during care routines; (3) personalize activities and social engagement; (4) support information sharing between care staff and residents during daily care; (5) prevent and/or overcome communication breakdowns during ADLs by meeting residents' unique needs; and (6) promote social participation. However, to date, there appears to be no evidence about the availability of cApps that could support communication between care staff and LTRC residents during daily care routines. Recently, regulations and guidelines for the development and use of technologies in health care have been developed [35]. However, the existing commercially available apps were likely developed with limited regulatory oversight, resulting in little evidence for the validity and reliability of app content and questionable quality [36]. Therefore, we need to better understand the availability and the content quality of currently available cApps. This information will help to determine which cApp could be suitable for supporting caregiver-resident communication in LTRC.

Research Aims

This app review aimed to systematically identify and examine existing commercially available AAC and translation apps (ie, cApps) that care staff could access to support PCC with LTRC residents during daily activities. The specific objectives of this study were as follows:

1. To systematically identify commercially available apps designed for adults living with a communication impairment (AAC apps) and/or experiencing a language barrier (translation apps).
2. To assess cApp content (description of app characteristics and PCC features), with a focus on suitability and relevance to the LTRC setting.
3. To assess the quality of eligible cApps, with a focus on functionality, ease of use, and customization.
4. To recommend the top existing cApps best suited for supporting caregiver-resident communication during ADLs.
5. To replicate the review to better understand how a rapidly evolving app marketplace may impact the suitability and longevity of cApps in the LTRC setting over a 2-year period.

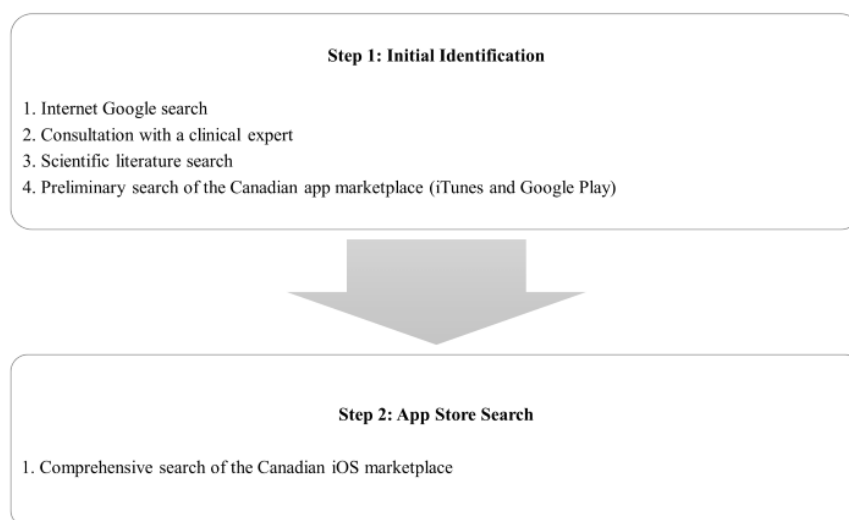
Methods

Identification Phase

Search Strategy

The systematic search for cApps in the Canadian marketplace was conducted between April and June 2015 and involved 5 steps: (1) internet search for AAC and translation apps using the Google search engine; (2) consultation with a speech-language pathologist (SLP) with expertise and knowledge in using AAC apps with adults living with a communication impairment (ie, clinical expert) to identify AAC apps recommended for use by adults living with a communication impairment; (3) scientific literature search focused on the use of mobile apps to support communication in the LTRC setting; (4) preliminary search of the official Canadian app stores of the 2 major operating systems (Android and iOS): Google Play and App Store; and (5) comprehensive search of the Canadian App Store (iOS platform; [Figure 1](#)).

Figure 1. Summary of the steps involved in the identification phase of the communication app reviews. Note that a consultation with a clinical expert and a preliminary search were not conducted for the 2017 review. iOS: iPhone Operating System.



Initial Identification

To gain a better understanding of the scope of the relevant and/or recommended AAC and translation apps available in the app marketplace, a Google search, a consultation with a clinical expert, a review of the scientific literature, and preliminary marketplace searches were completed. The Google search was conducted to help flag popular AAC and translation apps that should appear in the marketplace searches. The Google searches were done using a Google Chrome web browser by a single author (RW) on the same PC laptop computer (Windows 8; logged into a Google account) and involved separate searches for AAC apps and translation apps (Table 1). Google algorithms place the most relevant search results on the first result page and the majority of searchers stay on the first page [37]. To ensure comprehensiveness, the first 3 pages of the internet search results (50 results per page) were screened for links to specific apps and for links to websites that recommended apps useful for older adults living with a communication impairment or language barrier. Next, a consultation meeting with a clinical expert took place. The SLP shared a detailed spreadsheet of AAC apps that she used with her clients and identified which AAC apps would be appropriate for adults living with a

communication impairment in the LTRC setting. The scientific literature search was conducted to identify research reporting on the use of MCT to address the communication needs of vulnerable residents in LTRC. Searches were conducted in MEDLINE, AgeLine, and the Cumulative Index to Nursing and Allied Health Literature academic electronic databases in April 2015 and in February 2016 (RW). Broad search terms were used to capture subdomains of communication challenges/barriers, including language differences or aphasia. Free vocabulary (keywords) and controlled vocabulary (eg, Medical Subject Heading terms) were used for the combined concepts (Table 1). No date restrictions were applied to the searches and search results were limited to peer-reviewed academic literature and the English language. No relevant results were found in the literature searches. Finally, 2 reviewers (authors RW and DC) performed a preliminary search of both the App Store (iOS) and Google Play (Android) on a desktop computer to assess which marketplace appeared to have the highest inventory of AAC and translation apps. On the basis of information gathered from the Google search, the clinical expert, and the preliminary search of both market stores, the App Store (iOS) had the highest inventory of AAC and translation apps.

Table 1. Search terms used in Google Chrome and electronic databases.

Search location	Search terms (controlled and free vocabulary)
Google Chrome	
Function	
AAC ^a	augmentative and alternative communication apps for smartphones or tablets AAC apps for smartphones or tablet adult augmentative and alternative communication apps for smartphones or tablets adult AAC apps for smartphones or tablets AAC apps for smartphones or tablets for frail elderly AAC apps for smartphones or tablets for long-term care residents AAC apps for smartphones or tablets in hospital for patients communication app for adult patients
Translation	translation apps for smartphones or tablets translation apps for smartphones or tablets medical and health care translation apps
Electronic databases	
Population	
Older adults	<i>older adult*</i> , OR <i>aging</i> OR <i>ageing</i> , OR <i>aged</i> OR, <i>senior*</i> , OR <i>elder*</i> , OR <i>frail elder*</i> , OR <i>dementia</i> , OR <i>nursing home resident*</i> AND
Caregivers	<i>caregiver*</i> , OR <i>nurse*</i> , OR <i>nurse aide</i> , OR <i>health care aide*</i> AND
Communication barrier	<i>communication</i> , OR <i>communication barrier</i> , OR <i>communication aids for disabled</i> , OR <i>assistive technology</i> , OR <i>alternative and augmentative communication</i> , OR <i>AAC</i> , OR <i>communication disorder</i> , OR <i>communication impairment</i> AND
Intervention	
Mobile communication technology	<i>smartphone*</i> , OR <i>computer*-handheld</i> , OR <i>tablet computer*</i> , OR <i>cell* phone</i> , OR <i>portable computer*</i> , OR <i>mobile app*</i> , OR <i>software app*</i> , OR <i>computer software</i> , OR <i>app*</i> AND
Outcome	
Person-centered communication	<i>Person-centred care</i> , OR <i>Personhood</i> , OR <i>person-centred communication</i> , OR <i>communication strategies</i> , OR <i>person-centredness</i> AND
Setting	
Long-term residential care	<i>nursing home</i> , OR <i>long term care</i> , OR <i>institutional care</i> , OR <i>nursing home patient*</i> , OR <i>nurse-patient relations</i> , OR <i>nurse attitude*</i>

^aAAC: augmentative alternative communication.

App Store Search

For this study, the identification of AAC and translation apps that support interpersonal communication between LTRC residents and care staff during ADLs focused on a comprehensive search of the Canadian iOS marketplace: App Store for desktop computer searches and for mobile device searches (tablet and smartphone). AAC apps were searched in the medical, communication, education, lifestyle, and health and fitness categories of the App Store. Several keyword

searches were conducted, with the keywords “AAC,” “AAC communication,” “adult communication apps,” and “communication disability” returning most of the search results. The translation apps were searched in the medical education, health and fitness, reference, productivity, utilities, and business categories, using the keywords “translation apps,” “translate apps,” “medical,” and/or “health care translator apps,” and “multi-language translate.” To verify search results, 2 authors (RW and DC) performed independent searches for AAC apps

and for translation apps in the App Store, producing similar results.

Selection Phase

The iOS marketplace search results were exported to Microsoft Excel, and a single reviewer (DC) removed duplicates and screened the remaining apps (names/titles) for being foreign (ie, non-English title) and/or unrelated to interpersonal communication (eg, dictionary app). If the app's name did not clearly indicate that it was unrelated to communication or was foreign, the app was included for eligibility screening. For apps available in multiple versions, the complete version (ie, fully featured, no limitations, and no in-app purchase required) was included for eligibility screening and the less complete apps were marked as duplicates. In the case of apps with multiple versions that were identical except for the voice setting (male

or female), the adult female voice version was selected and the other version was marked as a duplicate. This decision was made because LTRC care staff are typically female [16].

Following the initial screening, the study's inclusion and exclusion criteria were applied (Textboxes 1 and 2). Two reviewers (authors RW and DC) independently applied the inclusion/exclusion criteria to approximately 20.0% of the apps (AAC: 36/181; translation: 4/18) by reviewing the App Store description. Following acceptable agreement, any disagreements were discussed, with final inclusion/exclusion decisions based on consensus. If needed, a third reviewer (JS) would assist in the inclusion/exclusion decision. A single reviewer (DC) applied the inclusion/exclusion criteria to all remaining apps. AAC apps and translation apps that met all the inclusion criteria, and none of the exclusion criteria, were included for metadata extraction, feature coding, and quality assessment.

Textbox 1. Inclusion criteria for communication apps study eligibility.

- Communication function: augmentative and alternative communication (AAC)
- The app's primary function is AAC for adults
- Communication was included as a keyword or in the text description of the app
- Can communicate basic needs (eg, feelings, emotions, preferences, and activities)
- Available in English
- Can support communication between a care provider and a patient in a health care setting
- Can be customized to support individual needs and preferences
- Includes all visual and auditory feedback functions (ie, images, text, and speech/sound)
- Communication function: translation apps
- The app's primary function is language translation
- Available in multiple languages
- Includes text-to-speech, speech-to-text, and speech-to-speech translation functions
- Could be used over the web and offline (eg, download language libraries for offline use)
- Option to save words/common phrases to a word bank on a tablet device
- Customization option (eg, save favorite words for quick access)

Textbox 2. Exclusion criteria for communication apps study eligibility.

- Communication function: augmentative and alternative communication (AAC)
- Requires substantial changes/modifications to use in the long-term residential care setting during the completion of activities of daily living (eg, need to import most images, create text and speech, add/delete built-in features)
- No longer available in the Canadian App Store
- Images are not adult appropriate (eg, child cartoon characters)
- Unrelated to communication with adults living with a communication difficulty
- Unrelated to communicating basic needs
- Does not include all visual and auditory feedback functions (ie, image, text, and speech/sound)
- Communication function: translation apps
- Does not support human-language translation
- Converting English to a single language was the only translation option
- Text-to-text was the only available feature of the app
- No longer available in the Canadian App Store

Evaluation Phase

Data Extraction for Content Analysis

Using a tablet device, a single author (DC) extracted the metadata content for all eligible AAC and translation apps from information provided in the Canadian App Store descriptions. In addition, if available, information was extracted from the developer's website and/or through reviewing web-based training modules or videos demonstrating the app. For content analysis, the authors (RW and JS) developed a detailed feature coding scheme to guide data collection for each cApp. For each cApp, extracted descriptive data were entered into a standard Microsoft Excel worksheet that contained the following metadata categories: (1) general description: search date, app name, app function, screenshot, keywords, and brief app description; (2) technical information: marketplace/platform, category, language, last software update, cost, and marketplace

longevity; (3) target user: general, living with a communication disability, living with aphasia, and other; and (4) other: upgrade with purchase, offline ability, technical support, translation function, and indication of informed design (ie, SLP, clinician, end user, and/or research was used to inform the development of the app).

On the basis of the extracted metadata, a set of secondary selection features were compiled for the AAC apps and for translation apps (Textbox 3). These secondary selection features were considered to be ideal characteristics of an app used in the LTRC setting (eg, a low-cost app with technical support would increase access and offer technical assistance to care staff) and were strongly considered during the identification of the cApps best suited to support PCC during ADLs in the LTRC setting. Evaluated cApps were identified as having a secondary selection feature by indicating *yes* or *no* for the presence or absence of a feature.

Textbox 3. Secondary selection features.

- Communication function: augmentative and alternative communication (AAC)
- Low cost (app <Can \$100 [US \$75.5])
- In the marketplace for at least two years (longevity/stability)
- Web-based and offline capabilities
- Technical support (email, phone, and web)
- Includes a translation function
- No cost/low cost for additional languages
- Communication function: translation apps
- Low cost (app <Can \$100 [US \$75.5])
- In the marketplace for at least two years (longevity/stability)
- Web-based and offline capabilities
- Technical support (email, phone, and web)
- No cost/low cost for additional languages

In addition, during the prepurchase review of the eligible cApps, data were collected on built-in and customizable features that support resident needs, preference, and feeling, as well as sharing of information between residents and care staff (eg, supports vision loss, option to add personal pictures, and two-way communication). All built-in and custom features were coded as being present (*yes*) or absent (*no*) in each app. The detailed feature coding scheme aided in the identification of cApps that included the highest number of PCC features (ie, built-in and customizable) relevant to the LTRC setting.

Quality Assessment

For both the AAC and translation apps, quality assessment rating criteria (Table 2) were derived from 3 dimensions of the Mobile Application Rating Scale [38] that were deemed relevant to this study: engagement (customization), functionality (ease of use), and aesthetics (graphic presentation and visual appeal). Each of the criteria was rated on a scale of 0 to 2 (0=*poor*, 1=*fair*, 2=*good* or 0=*not at all easy*, 1=*somewhat easy*, 2=*easy*). cApp quality assessment was conducted in 2 steps: a prepurchase quality assessment and a final quality assessment of purchased

cApps. During the prepurchase quality assessment step, 3 reviewers (authors RW, DC, and JS) independently applied the quality assessment rating criteria to the cApps by reviewing the store description, product tutorials/videos, or web-based videos (eg, YouTube) or by downloading freely available cApps. During the prepurchase evaluation, the initial quality assessment did not include ratings on sound quality (AAC) and translation accuracy because this information was typically unavailable without purchasing the app. All apps were assessed in alphabetical order. After ratings were complete, each reviewer judged whether the app was suitable for supporting communication in LTRC (*yes/no/possible*), followed by a decision to purchase/download the app for further evaluation (*yes/no/maybe*).

Following an independent review, the 3 authors convened to comparatively discuss the apps' initial quality assessment ratings and the apps' suitability for communication in LTRC. Collectively, the reviewers generated a shortlist of cApps that would be purchased/downloaded to undergo a final quality assessment. Although the cApp ratings were deemed important

to the purchase/download decision, cApps that included features appropriate for caregiver-resident communication in LTRC, as well as cApps with customization abilities, were given a higher degree of consideration in the purchase decision. In addition, if there were disagreements between reviewers' decision to purchase/download a cApp, the undecided cApp was included for further evaluation. Therefore, the approach taken to generate the shortlist could result in the purchase/download of a cApp

with a lower median initial quality assessment rating, as well as the decision not to purchase/download a cApp with a higher initial quality assessment rating. Two reviewers (authors DC and JS) independently documented their experience using each shortlisted cApp and completed the final quality assessment for the AAC and translation apps. All shortlisted apps were downloaded to an iPad Mini 4 device with an iOS 9 operating system and a 7.9" display for a direct user experience.

Table 2. Quality assessment rating categories for communication apps.

Communication function ^a	Categories ^{b,c,d}
Augmentative and alternative communication	<ul style="list-style-type: none"> • Sound quality: <i>How intelligible is the audio output?</i> • Graphic presentation: <i>What is the visual interface quality (image resolution detail [pixels] and image clarity)?</i> • Visual interface presentation: <i>What is the overall appeal of the app look (ie, color display, patterns, lines, scale, image/text type, image/text appropriateness, and display options)?</i> • Ease of use: <i>Overall, how easy is it to use the software interface (ie, app is intuitive to learn and requires minimal explanation to use; instructions are clear; simple, straightforward display; quick access to common features and commands; well-organized [layout] and easy to navigate)?</i> • Customization: <i>How easy is it to customize the app?</i>
Translation	<ul style="list-style-type: none"> • Sound quality • Graphic presentation • Visual interface presentation • Ease of use • Translation accuracy: <i>How accurate are the translated words/text</i>

^aThe maximum total score for the final quality assessment ratings=10 (augmentative and alternative communication and translation apps).

^bSound quality, graphic presentation, visual interface presentation, and translation accuracy were rated on a scale of 0 to 2 (0=poor, 1=fair, 2=good).

^cEase of use and customization were rated on a scale of 0 to 2 (0=not at all easy, 1=somewhat easy, 2=easy).

^dSound quality and translation accuracy were only applied in the final quality assessment of purchased/downloaded cApps.

Final Recommendation Phase

Following the independent assessment of all cApps, 3 reviewers (RW, DC, and JS) reconvened to discuss their experience with each app. The final selection of the most suitable cApps in the AAC category and in the language translation category was determined by research team consensus and was based on the combined findings of a three-stage comparative process involving the review of the extracted feature data, the initial quality assessment of eligible cApps, the user experience, and the final quality assessment of the purchased cApps.

Replication Review

The identification phase of the replication review took place in October 2017, and the evaluation phase was completed in July 2018. Apart from a consultation with a clinical expert, the identification phase involved the same methodological approach as the original 2015 review. Three trained research assistants completed the Google search, the comprehensive iOS marketplace search, and the initial screening (duplicates, foreign, and unrelated), while 1 author (RW) conducted the scientific literature search in October 2017. For the 2017 systematic app review, all search terms used in the Google search, in the comprehensive app store search, and in the literature search were identical to the terms used in the 2015 search (Table 1). As with the 2015 review, Google searches were performed using the Google Chrome web browser and involved separate searches

for AAC apps and translation apps. A single research assistant performed all AAC internet searches on the same PC laptop computer, and a single research assistant performed all translation searches on the same PC laptop computer. The literature search returned no relevant results. To replicate the 2015 review, only the Canadian App Store (iOS platform) was searched during the 2017 review.

Two reviewers (RW and DC) completed the selection, evaluation, and recommendation phases of the 2017 replication review. An agreement check was performed for eligibility assessment, whereby 2 reviewers independently assessed approximately 20.0% of the apps (AAC: 61/306; translation: 60/300). Following acceptable agreement, any disagreements were discussed, with final inclusion/exclusion decisions based on consensus and, if needed, a third reviewer (JS). A single reviewer (DC) applied the inclusion/exclusion criteria to all remaining apps. There were two instances in which the procedure for the 2017 replication review differed from the 2015 review. First, multiple versions of the same app (eg, lite [free] and pro [cost]) were treated as unique apps in the 2017 replication review because each version included different features and was anticipated to have varying quality levels. Therefore, a lite version may qualify for evaluation, whereas the pro version may not because of the higher cost. Apps that underwent software updates since the 2015 review were still considered the same version of the app. Second, secondary

selection features were applied to eligible cApps before the evaluation phase of the 2017 replication review to further narrow the pool of cApps that underwent quality assessment. Only cApps with all secondary selection features were evaluated in the 2017 review. As with the 2015 review, all quality assessment ratings were completed using an iPad mini 4 (iOS 12.2 operating system and 7.9" display).

Data Analysis

Descriptive statistics are used to summarize cApp characteristics, PCC features, and quality assessment ratings. To quantify change between the 2015 review and the 2017 replication review, the number and/or proportional increase/decreases are reported, with numbers/percentages presented from 2015 to 2017 (ie, from X to Y).

Results

Original Review

The 2015 App Store searches identified a total of 752 cApps (AAC=614; translation=138). The search terms AAC, AAC communication, and communication disability accounted for 90.4% (555/614) of all identified AAC apps. The search terms translation apps and translate apps accounted for 72.5% (100/138) of all translation apps identified in the initial search. After screening for duplicates, foreign, and unrelated apps, a total of 181 unique AAC apps and a total of 18 unique translation apps were identified. Figure 2 displays the 2015 search results, which was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram template [39]. After applying this study’s inclusion/exclusion criteria to the identified apps, 27 cApps were included in the study (Tables 3 and 4).

Figure 2. Flow diagram summarizing the results of the identification, selection, evaluation, and final recommendation phases involved in the 2015 communication app review. The presentation of results was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram template AAC: augmentative and alternative communication; ADLs: activities of daily living; LTRC: long-term residential care.

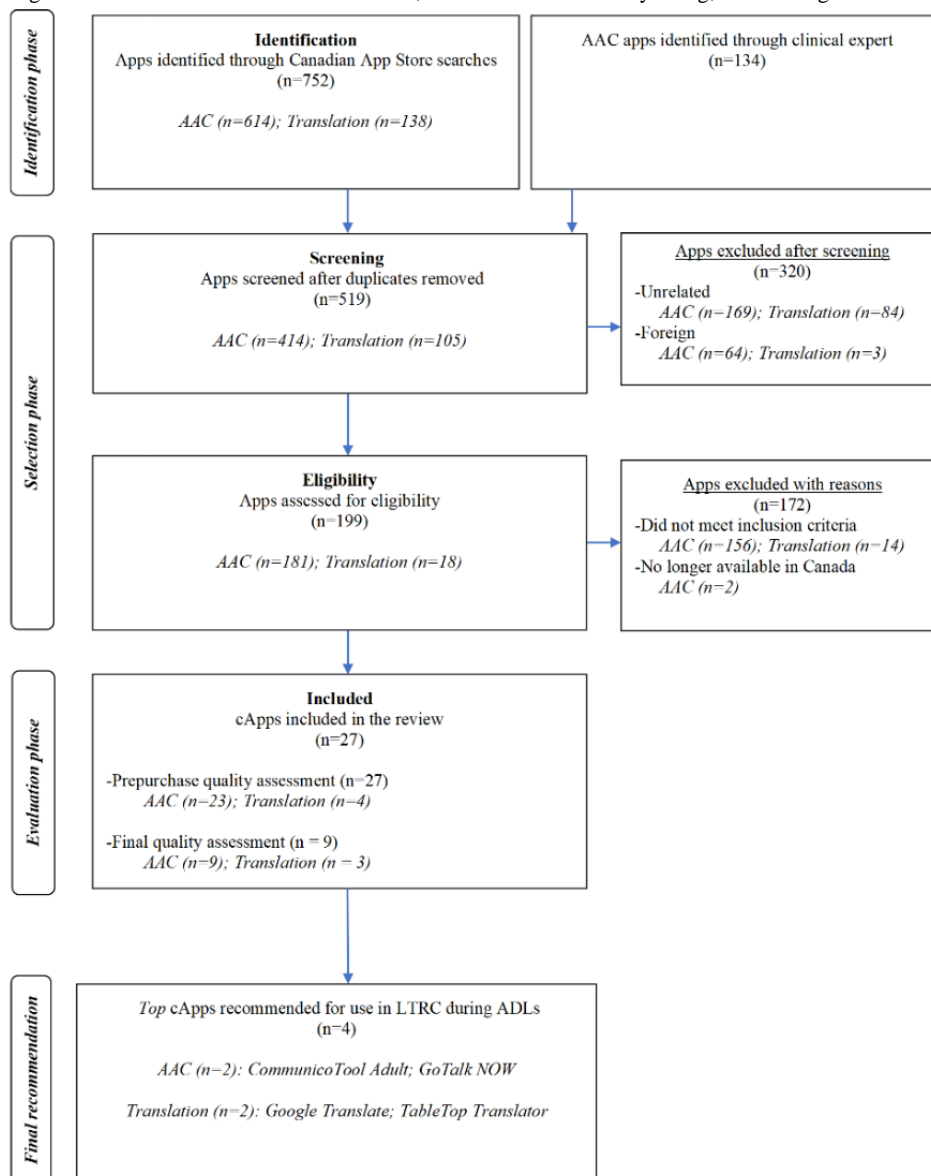


Table 3. List of communication apps evaluated in the 2015 review.

Category	Apps
Augmentative and alternative communication (n=23)	<ul style="list-style-type: none"> • Alexicom Elements Adult Home (Female)^a • App2Speak^{a,b} • AutisMate365^c • ChatAble^a • CommunicAide • CommunicoTool Adult^{a,d} • Compass (DynaVox) • Conversation Coach^{a,b,d} • Easy Speak—AAC^c • Functional Communication System^c • GoTalk NOW^{a,d} • iAssist Communicator^c • iCommunicate^a • image2talkb^{b,e} • MyTalkTools^{a,d} • PictureCanTalk^{a,c} • Proloquo2Go^a • Smart_AAC (med)^d • Sono Flex^{a,d} • SoundingBoard • Talkforme^c • TalkTablet^{a,d} • TouchChat AAC
Translation (n=4)	<ul style="list-style-type: none"> • Google Translate^{a,b} • iTranslate^{a,d} • SayHi Translate^c • TableTop Translator^{a,b}

^aIndicates that this app met study eligibility in the 2015 review and in the 2017 review.

^bIndicates that the same version of the app was evaluated in the 2015 and in the 2017 reviews.

^cIndicates that this app was no longer available in the marketplace during the 2017 review.

^dIndicates that a different version of the same app was evaluated in the 2017 review (eg, 2015: CommunicoTool Adult; 2017 CommunicoTool 2).

^eFor cApps with multiple versions, if a version of the cApp was evaluated in both the 2015 and in the 2017 review (eg, GoTalk NOW LITE and GoTalk Start different versions [ie, fewer features] of GoTalk NOW), it was not categorized as a newly evaluated cApp.

Table 4. List of communication apps evaluated in the 2017 replication review.

Category	Apps
Augmentative and alternative communication (n=25) ^a	<ul style="list-style-type: none"> • App2Speak • CommunicoTool 2 • Conversation Coach • Conversation Coach Lite^b • CoughDrop^c • Gabby^c • GoTalk NOW LITE^b • GoTalk Start^b • image2talk • iMyVoice Lite^{b,c} • iMyVoice Symbolstix^c • iSpeakUp^c • iSpeakUp Free^{b,c} • LetMeTalk^c • Mighty AAC^c • MyTalkTools Mobile Lite • SmallTalk Aphasia—Female^c • Sono Flex Lite^b • TAlkTablet CA AAC/Speech for aphasia^d • TalkTablet LITE—Eval Version^b • TalkTablet US AAC/Speech for aphasia^d • urVoice AAC—Text to speech with type and talk^c • Visual Express^c • Visual Talker^c • Voice4u AAC^c
Translation (n=17)	<ul style="list-style-type: none"> • Google Translate • Instant Translator—Converse^c • iTranslate Translator^c • iTranslator—Speech translation^c • iVoice^c • LINGOPAL 44^c • Microsoft Translator^c • Multi Translate Voice^c • Online—Translator.com^c • Voice Translator Reverso^c • Speak & Translate—Translator^c • TableTop Translator • The Interpreter—translator^c • Translator with Speech HD^c • Translator—Speak & Translate^c • TravTalk—Talking & Recording Phrasebook^c • Yandex.Translate: 94 languages^c

^aFor cApps with multiple versions, if a version of the cApp was evaluated in both the 2015 and in the 2017 review (eg, GoTalk NOW LITE and GoTalk Start different versions [ie, fewer features] of GoTalk NOW), it was not categorized as a newly evaluated cApp.

^bcApps that were newly evaluated in the 2017 review.

^cA free or low-cost version of a fully featured app that is available for a higher cost.

^dA different version of the same app.

Content Analysis

Extracted metadata for the evaluated cApps indicated that 91% (21/23) of AAC apps were only available for the iOS platform, while 50% (2/4) of translation apps were available for both the

iOS and the Android marketplaces. The majority of AAC apps (18/23, 78%) were categorized as *education* apps and most likely included one or more of the following keywords: AAC (18/23, 78%), communication disability (10/23, 43%), basic needs (4/23, 17%), or daily living (4/23, 17%). Half of the

translation apps (2/4) were categorized as *business* apps and all were labelled with the keyword *translate*. The majority of AAC apps (18/23, 78%) identified people living with a communication disability as the target user, whereas all translation apps (n=4) were designed for a general audience. Most AAC apps were available in English only (17/23, 74%), and the last software update was within 1 year (17/23, 74%). All translation apps' software was updated in the current year (ie, 2015). Some of the free AAC apps were limited versions of an app that could be upgraded with a purchase (eg, *CommunicAide (free)* and *CommunicAide Pro*, Can \$99.99 [US \$75.5]), and the majority (14/23, 61%) of AAC apps provided no indication of informed design. Only 17% (4/23) of the AAC App Store description and/or the developer's webpage indicated the inclusion of an SLP in the development of the app (*App2Speak*, *Chatable*, *CommunicAide Free*, and *CommunicoTool Adult*), while 9% (2/23) indicated research was used to inform the content (*Compass [DynaVox]* and *Proloquo2Go*), and 13% (3/23) included the end user (*Talkforme*, *image2talk*, and *MyTalkTools*).

Most of the AAC apps cost Can \$100 (US \$75.5) or less (17/23, 75%), were available in the marketplace for 2 years or more (18/23, 78%), and provided technical support (22/23, 96%; [Table 5](#)). All translation apps cost less than Can \$25 (US \$18.9), 3 out of the 4 apps provided technical support, and the majority (3/4, 75%) were available in the marketplace for 2 years or more. Although about half of the AAC apps indicated some offline functionality, only 1 translation app (*Google Translate*) had limited offline functionality. Although no AAC app included all secondary selection features, 83% (19/23) of the AAC apps

contained three or more of these features. *GoTalk NOW*, *SoundingBoard*, *AutisMate365*, *Conversation Coach*, *Functional Communication System*, and *MyTalkTools* contained the most of these features. Except for online and offline capabilities, 75% (3/4) of the translation apps included each of the secondary selection features.

Appraisal of PCC features indicated that 3 AAC apps (*GoTalk NOW*, *Talkforme*, and *MyTalkTools*) contained 11 or more of the built-in and custom features. Only 1 AAC app contained all 5 custom features (*GoTalk NOW*) and 1 AAC app included nearly all the built-in features (*Talkforme*). One translation app contained 86% (6/7) of all applicable features (*Google Translate*). Almost half of the AAC apps included 50% to 74% of the features that were deemed to support PCC, and 75% (3/4) of the translation apps contained some of the features ([Table 6](#)). Although all AAC apps indicated that they supported hearing loss (eg, speech rate adjustment, voice customization, and speech-to-text function), only 43% (10/23) supported vision loss (eg, high-resolution images, zoom function, and large images) and two-way communication (ie, conversation/interpersonal). All translation apps supported hearing and vision loss. Only 3 AAC apps included a built-in translation function (*Talkforme*, *MyTalkTools*, and *TouchChat AAC*). The majority of AAC apps included multiple display modes, natural voice output, and text-to-speech output. The ability to add personal photos/images and the option to add personal voice recordings were the most common custom features among the AAC apps, and all translation apps included vocabulary customization.

Table 5. Secondary selection feature summary of the evaluated communication apps (cApps; note: as the percentages were rounded, some categories may not add up to 100%).

Secondary feature	2015 review		2017 replication review		Change over time, (%) ^d	
	AAC ^a (n=23), n (%)	Translation (n=4), n (%)	AAC (n=25) ^b , n (%)	Translation (n=17) ^c , n (%)	AAC	Translation
Cost in Can \$ (low cost: app <Can \$100 [US \$75.5])						
Free	4 (17)	2 (50)	10 (40)	15 (88)	135	76
<\$25 (US \$18.9)	2 (9)	2 (50)	6 (24)	2 (12)	167	-76
\$25-\$49 (US \$18.9-US \$37)	7 (30)	0 (0)	4 (16)	0 (0)	-47	0
\$50-\$75 (US \$18.9-US \$37.8)	1 (4)	0 (0)	0 (0)	0 (0)	-100	0
\$75-\$100 (US \$37.8-US \$75.5)	3 (13)	0 (0)	1 (4)	0 (0)	-69	0
>\$100 (US \$75.5)	6 (26)	0 (0)	4 (16)	0 (0)	-38	0
In the marketplace for at least two years (longevity/stability) ^e	18 (78)	3 (75)	19 (76)	13 (76)	-3	1
Web and offline capabilities ^f	13 (57)	1 (25)	25 (100)	17 (100)	75	300
Technical support (email, phone, web)	22 (96)	3 (75)	25 (100)	16 (94)	4	25
Includes a translation function	3 (13)	N/A ^g	1 (4)	N/A	-69	N/A
No cost/low cost for additional languages	N/A	4 (100)	N/A	17 (100)	N/A	0

^aAAC: augmentative and alternative communication.

^bIn total, 11 AAC apps were evaluated in both the 2015 review and in the 2017 review.

^cIn total, 3 translation apps were evaluated in the 2015 review and in the 2017 review.

^dA negative percentage indicates a decrease in the percentage of cApps with the secondary feature over the 2-year period.

^eThe app copyright date was used to document marketplace longevity. In the absence of a copyright date, the oldest software update date was used.

^fFunctions/features available offline may be limited compared with the features available during app use over the web.

^gNot applicable.

Table 6. Summary of features that support person-centered communication (PCC) in the evaluated communication apps (cApps; this table describes PCC features found in the evaluated cApps during the 2015 review and in the 2017 replication review, as well as evaluates the percentage of cApps with a PCC feature between the 2015 and 2017 reviews. Data were extracted from the Canadian App Store description and during the prepurchase review of the cApps. Feature categories were not mutually exclusive; therefore, 1 app could have several built-in features and/or custom features).

Person-centered communication features	2015 review		2017 review		Change over time, (%) ^b	
	AAC ^a (n=23), n (%)	Translation (n=4), n (%)	AAC (n=25), n (%)	Translation (n=17)	AAC	Translation
Built-in features (n=9)						
Supports vision loss ^c	10 (43)	2 (50)	8 (32)	9 (53)	-26	6
Supports hearing loss ^d	23 (100)	4 (100)	25 (100)	16 (94)	0	-6
Multiple display representations ^e	20 (87)	4 (100)	25 (100)	11 (65)	15	-35
Natural sounding voice output ^f	16 (70)	3 (75)	17 (68)	11 (24)	-3	-68
Text-to-speech function	22 (96)	N/A ^g	25 (100)	N/A	4	N/A
Speech-to-speech function	2 (9)	N/A	1 (4)	N/A	-56	N/A
Translation function	3 (13)	N/A	1 (4)	N/A	-69	N/A
Available in multiple languages	8 (35)	N/A	11 (44)	N/A	26	N/A
Supports two-way communication ^h	10 (43)	3 (75)	7 (28)	7 (41)	-35	-45
Custom features (n=5)						
Can customize vocabulary ⁱ	7 (30)	4 (100)	17 (68)	12 (71)	127	-29
Can add/save personalized photos/images	18 (78)	1 (25)	19 (76)	3 (18)	-3	-28
Can to add/save personalized text	8 (35)	N/A	8 (32)	N/A	-9	N/A
Option to add/save personal voice recordings	15 (65)	N/A	15 (60)	N/A	-8	N/A
Can add/save personalized videos	4 (17)	N/A	6 (24)	N/A	41	N/A
Total number of features^j						
cApps ^k with all applicable features	0 (0)	0 (0)	0 (0)	0 (0)	N/A	N/A
cApps with most features (approximately 75% or more)	3 (13)	1 (25)	2 (8)	3 (18)	-38	-28
cApps with some features (approximately 50%-74%)	11 (48)	3 (75)	12 (48)	8 (47)	0	-37
cApps with few features (less than 50%)	9 (39)	0 (0)	11 (44)	6 (35)	13	N/A

^aAAC: augmentative and alternative communication.

^bPercent change calculation: [(percentage of 2017 apps with the feature–percentage of 2015 apps with the feature)/percent of 2015 apps with the feature]*100. A negative percentage indicates a decrease in the percentage of cApps with the person-centered communication feature over the 2-year period.

^cFeatures that support vision loss include high-resolution images, zoom function, and large pictures/text.

^dFeatures that support hearing loss include volume control, earbud option, speech rate adjustment, voice customizations, and speech-to-text function.

^eMultiple display representations indicate that the app includes two or more features: text, handwriting option, speech input, camera/photo pictures, images, symbols, and video.

^fInformation about voice output was not available for 4 AAC apps during the data extraction phase.

^gNot applicable.

^hSupports two-way communication means that the app could be used for caregiver-resident task-focused and/or interpersonal-focused communication (eg, conversation view).

ⁱOption to customize vocabulary includes saving frequently used words/phrases in the following manner: pages, favorite lists, history, and add personalized vocabulary.

^jA total of 14 person-centered features applied to AAC apps (built-in=9; custom=5). A total of 7 person-centered features were applicable for translation apps (built-in=5; custom=2).

^kcApp: communication app.

Quality Assessment

Initial quality assessment of the eligible cApps indicated that 7 AAC apps were highly rated: *Alexicom Elements Adult* (median 8), *TalkforMe* (median 8), *App2Speak* (median 7), *CommunicoAide* (median 7), *CommunicoTool Adult* (median 6), *Functional Communication System* (median 6), and *GoTalk NOW* (median 6). After considering secondary selection features and the initial quality assessment during a research team discussion, 9 AAC apps and 3 translations apps were shortlisted for purchase/download (Table 7). Following completion of the

final quality assessment ratings for each of the shortlisted cApps, *CommunicoToolAdult* and *GoTalkNOW* had the highest median ratings for AAC apps (Table 7). The research team reconvened for a final comparative review of the cApps. On the basis of consensus decisions, the top recommended cApps were finalized: *CommunicoTool Adult*, *GoTalk NOW*, *Google Translate*, and *TableTop Translator* (Multimedia Appendix 1). Although *TableTop Translator* and *SayHi* shared the same developer, the researchers selected *TableTopTranslator* because this app included more language options and the screen display supported two-way communication.

Table 7. Communication apps downloaded for final quality assessment ratings (the final quality assessment rating is based on the median rating of 2 reviewers. The maximum total rating score for cApps apps was 10).

cApp communication function and name ^a	Quality assessment ratings	
	2015 search (n=12)	2017 search (n=8)
Augmentative and alternative communication		
App2Speak	6.5	8.5
CommunicoTool Adult	9 ^b	8.5 ^{b,c}
Functional Communication System	5	N/A ^d
GoTalk NOW	7.5 ^b	8 ^{b,e}
iAssist Communicator	0	N/A
iCommunicate	3	N/A
image2talk	0	N/A
SoundingBoard	1	N/A
Talkforme	1.5	N/A
Translation		
Google Translate	8 ^b	9.5 ^b
iVoice Translator	N/A	9.5 ^b
Microsoft Translator	N/A	10 ^b
Online-Translator.com	N/A	8
TableTop Translator ^f	8 ^b	8.5
SayHi Translate	8	N/A

^aCommunication apps (cApps) are listed in alphabetical order.

^bTop recommended cApps for use in long-term residential care to support communication between residents and caregivers.

^c*CommunicoTool 2* was evaluated in the 2017 review.

^dNot applicable.

^e*GoTalk NOW LITE* was evaluated during the 2017 review.

^f*TableTop Translator* and *SayHi* shared the same developer.

Replication Review

Content Analysis

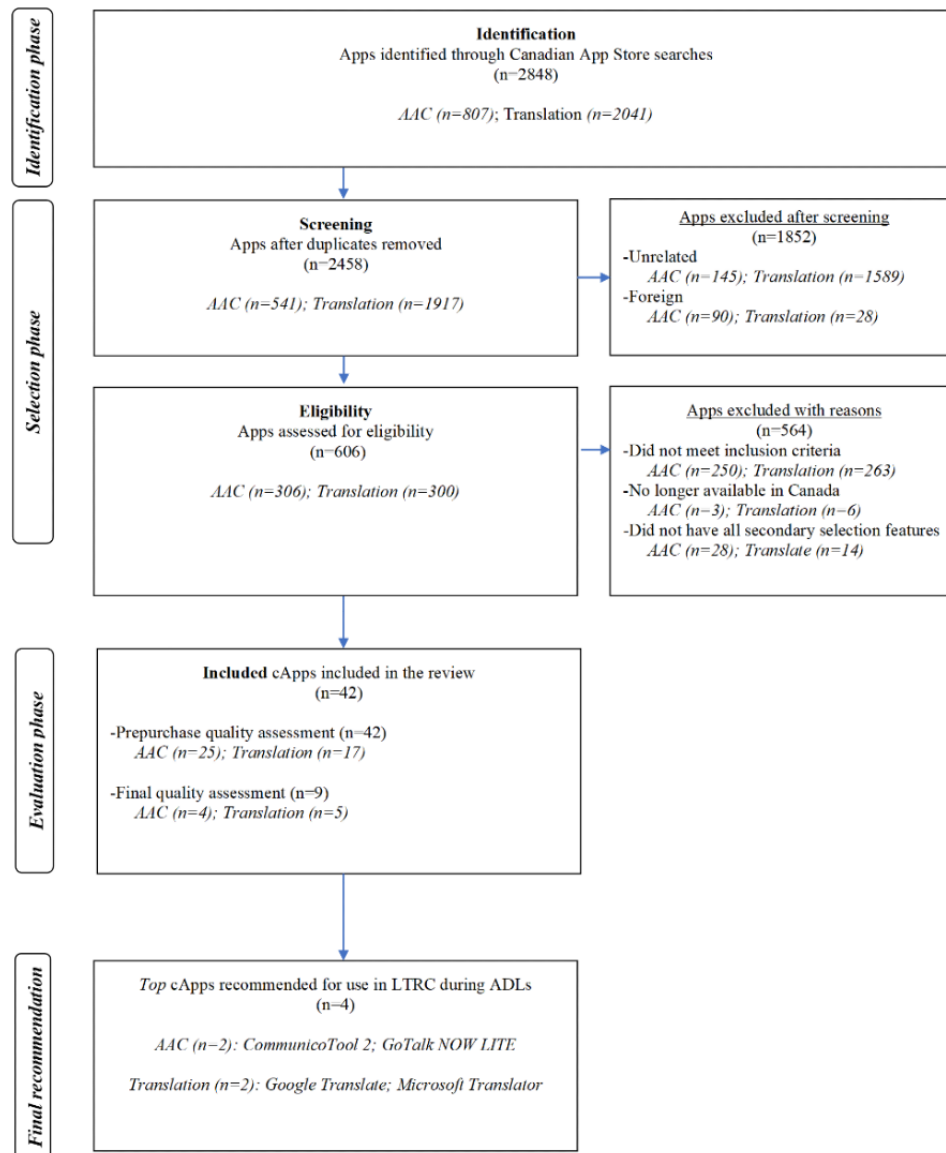
Following a comprehensive search of the App Store and the removal of duplicates, foreign, and unrelated apps, a total of 607 apps were screened for study eligibility (Figure 3). A total of 93 apps met the study's inclusion criteria. After applying the secondary selection features to further narrow down the pool of cApps, a total of 42 apps were evaluated (AAC: n=25; translation: n=17; Tables 3 and 4). In all, 36% (9/25) of the

evaluated AAC apps were a different version of the same app (eg, *Conversation Coach* and *Conversation Coach Lite*). A total of 28% (7/25) of the evaluated AAC apps were a low-cost or free version of an app that was also available in a fully featured version for a greater cost (Tables 3 and 4). None of the evaluated translation apps was a different version of the same app. The majority of the AAC apps were available only for the iOS platform (19/25, 76%), cost less than Can \$25 (US \$18.9) or were free (16/25, 64%), and were only available in English (14/25, 56%). Only 3 AAC apps indicated informed design (SLP: *Apps2Speak* and *Voice4u AAC*; end user: *image2talk*),

and only 1 AAC app included a translation function (*LetMeTalk*). Most translation apps were only available in the iOS marketplace (15/17, 88%), were available for 2 years or

longer (13/17, 76%), were free (15/17, 88%), and offered technical support (16/17, 94%). All translation apps had recent software updates and had some offline functions (Table 5).

Figure 3. Flow diagram summarizing the results of the identification, selection, evaluation, and final recommendation phases involved in the 2017 communication app replication review. The presentation of results was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram template AAC: augmentative and alternative communication; ADLs: activities of daily living; LTRC: long-term residential care.



The majority of cApps contained at least some PCC features (AAC: 14/25, 56%; translation: 11/17, 65%; Table 6). The AAC apps with the highest number of PCC features were *GoTalk NOW LITE* (11/14), *GoTalk Start* (11/14), and *CommunicoTool 2* (10/14). The translation apps with the highest number of PCC features were *Google Translate* (6/7), *TableTopTranslator* (6/7), *Translator with Speech HD* (6/7), *Microsoft Translator* (5/7), *Multi Translate Voice: Say It* (5/7), and *Voice Translator Reverso* (5/7). All AAC apps supported hearing loss, included multiple display representations, multiple output modes, and a text-to-speech function, while very few included a speech-to-speech function or a translation function.

Quality Assessment

All cApps that underwent final quality assessment were highly rated (Table 7). On the basis of researcher consensus, the following cApps were deemed to be best suited for supporting communication between residents living in LTRC and their caregivers during ADLs: *GoTalk NOW LITE*, *CommunicoTool 2*, *Google Translate*, and *Microsoft Translate* (Multimedia Appendix 1). Although *App2Speak* was rated higher than *GoTalk NOW LITE*, the app contained fewer PCC features than *GoTalk NOW LITE* (8 and 11, respectively) and fewer features than *CommunicoTool 2*. Importantly, *App2Speak* included only 2 custom features (add personal pictures and voice recordings) compared with *GoTalk NOW LITE*, which contained 4 custom features.

Stability of Evaluated Communication Apps Over Time

Between the 2015 review and the 2017 replication review, the number of AAC apps identified in the iOS marketplace increased by 31.4% (from 614 to 807) and the number of identified translation apps increased exponentially (from 138 to 2041; Figures 2 and 3). In all, 61% (14/23) of the eligible AAC apps in the 2015 review also met study eligibility in the 2017 review (Tables 3 and 4). Of the 2015 eligible/evaluated AAC apps, 35% (8/23) were no longer available in the marketplace in 2017. Two AAC apps identified in the 2015 review were excluded in the 2017 review because one required a substantial change for use in the LTRC setting and the other included images that were not adult appropriate (eg, child cartoon images; *SoundingBoard and TouchChat AAC*, respectively). Finally, 1 AAC app was excluded from the 2015 review but was deemed eligible in the 2017 review (*Gabby*). The images in *Gabby* were categorized as not adult appropriate in the original 2015 review; however, the updated version of *Gabby* contained images that were considered adult appropriate. Except for the *SayHi* app, which is no longer available in the App Store, all translation apps that were eligible in the 2015 review also met study inclusion in the 2017 review.

A similar number of AAC apps were evaluated in the 2015 and the 2017 reviews (n=23 and n=25, respectively). Of the 25 AAC apps evaluated in the 2017 review, 3 (12%) were the same version of the app evaluated in the 2015 review (*App2Speak, Conversation Coach, and image2talk*) and 9 (36%) were a different version of the same app evaluated in the 2015 review (eg, *Conversation Coach Lite* and *Sono Flex Lite*; Tables 3 and 4). Notably, *CommunicoTool Adult* (2015 review) was no longer available in the App Store and was replaced by *CommunicoTool 2* (2017 review). For this study, *CommunicoTool 2* was considered a different version of the same app because its features were quite like those of *CommunicoTool Adult*. Although *GoTalk NOW* was the only version of the app that was evaluated in the 2015 review, *GoTalk NOW, GoTalk NOW PLUS, GoTalk NOW LITE, and GoTalk Start* were all eligible versions of the same app in the 2017 review. After applying the secondary selection criteria, only *GoTalk NOW LITE* and *GoTalk Start* were evaluated in the 2017 review because these versions were classified as low cost (<Can \$100 [US \$75.5]). The cost of *GoTalk NOW* increased by 22% (from Can \$89.99 [US \$67.9] to Can \$109.99 [US \$83.1]). The number of evaluated translation apps increased by 325% in the 2017 review (from 4 to 17). Three of the four translation apps (75%) evaluated in the 2015 review were also evaluated in the 2017 review.

Stability of Communication App Features Over Time

Over the 2-year period, the majority of the evaluated cApps were only available for the iOS marketplace; however, the largest increase was observed in the percentage of AAC apps available across both iOS and Android platforms (167%; from 2/23, 9% to 6/25, 24%), and a decrease occurred among the translation apps (76%; from 2/4, 50% to 2/12, 12%). Between 2015 and 2017, the majority of AAC apps continued to indicate that adults living with a communication disability were the target user, while translation apps continued to target the general

users. There was a 44% increase in the percentage of AAC apps with no indication of informed design (from 14/23, 61% to 22/25, 88%), and the largest percent decrease was seen in AAC apps that included a translation function (69%; from 2/23, 13% to 1/25, 4%). For the secondary selection features (Table 5), only two remained stable over time across cApps: in the marketplace for 2 years or more and available technical support. The largest percent change increase was observed in AAC apps that were free (135%; from 4/23, 17% to 10/25, 40%) or cost less than Can \$25 (US \$18.9; 167%; from 2/23, 9% to 6/25, 24%) and in translation apps that included web-based and offline capability (300%; from 1/4, 25% to 17/17, 100%).

For PCC features, the overall percentage of AAC apps that included approximately 50% to 74% of the PCC features remained stable over the 2-year period (48%), whereas the percentage of evaluated translation apps with at least some PCC features decreased by 37% between 2015 and 2017 (from 3/4, 75% to 8/17, 47%; Table 5). Many of the custom PCC features included in AAC apps remained stable over the 2-year period, specifically features that supported hearing loss, used a natural sounding voice output, included a text-to-speech function, and offered an option to add/save personalized photos/images. Between 2015 and 2017, the largest percent increase occurred among AAC apps that included an option to customize vocabulary (127%; from 7/23, 30% to 17/25, 68%), whereas the largest decrease occurred for the percentage of AAC apps that included a translation option. Over the 2-year period, translation apps witnessed the largest decrease among the percentage of apps that included a natural sounding voice (68%; from 3/4, 75% to 11/25, 24%), whereas the percentage of translation apps that supported two-way communication decreased by 45% (from 3/4, 75% to 7/25, 41%).

Discussion

Principal Findings

This study's comprehensive review of cApps available in the iOS marketplace aimed to identify and assess the features and quality of cApps that would be most appropriate for use with residents living in LTRC homes. In addition, this study examined the stability/instability of cApps over a 2-year period. The 2015 review process culminated in selecting 2 AAC apps (*CommunicoTool Adult* and *GoTalk NOW*) and 2 language translation apps (*Google Translate* and *TableTop Translate*) that provided the most suitable overall content and usability features for enhancing communication between care staff and residents living in LTRC. For purposes of augmenting communication with images, video, sound, and text, these top 2 AAC apps contained features and functionality that promote a multimodal understanding of messages, appealing and high-quality images and audio/video capabilities, and the capacity to customize content to individuals. One of these AAC cApps, *GoTalk NOW*, has received an endorsement from researchers in the field of AAC [40]. The top 2 language translation apps in the 2015 review offered features that provided high-quality voices, accurate translation, the capacity to save commonly translated phrases, and versatility in translating across modalities (eg, text to speech). Together, these 4 cApps provide

a promising starting point for integrating communication technology into LTRC person-centered care practices. It is interesting to note that, during the predownload initial quality assessment, the top recommended cApps did not have the highest median quality assessment ratings. For example, *Alexicom Elements Adult*, *Talkforme*, *App2Speak*, and *CommunicAide* received the highest median rating for AAC apps, and *SayHi Translate* was the highest-rated translation app. However, once the shortlisted cApps were downloaded and used, the respective features, functionality, and usability of the top recommended cApps were judged to be superior to all the other downloaded apps. For example, *CommunicoTool Adult* included the option to have a human voice, the built-in photos were clear and relevant, and the app was customizable, and *GoTalk NOW* was easy to use, had several built-in and customizable features, and the stock pictures were relevant. *Google Translate* allowed for web-based and offline (ie, saved phrases) functions, was free, and was easy to use, whereas *TableTop Translator* supported face-to-face conversation with a unique split-screen function.

Overall, the majority of cApps evaluated in 2015 (20/27, 74%) demonstrated marketplace stability over a 2-year period. In the 2017 review, only one of the top recommended cApps from the 2015 review was replaced with a newly evaluated translation app, whereas the top AAC apps were different versions of the same app recommended in the 2015 review. The decision to recommend *Microsoft Translator* over *TableTop Translator* was based on several factors. The visual interface quality, the sound quality, and the visual interface presentation of *Microsoft Translator* were rated higher compared with *TableTop Translator*. Also, *TableTop Translator* uses Microsoft for translations, had not undergone any recent updates, and the app crashed several times while attempting to translate when using the app. Although *CommunicoTool Adult* was replaced by *CommunicoTool 2*, the newer version remained a top recommended cApp for use in the LTRC setting to support caregiver-resident communication during ADLs.

Although many of the AAC apps evaluated in 2015 and in 2017 include features and functionality that could support communication between LTRC staff and residents (ie, support hearing loss, included multiple display options, a text-to-speech function, add personal photos; technical support), less than half of AAC apps contained some (ie, 50%-74%) of these features. For instance, in both reviews, there was a limited number of evaluated AAC apps that supported two-way communication, included a speech-to-speech option or a translation function, supported vision loss, or provided options to add/save personalized text or videos. Moreover, the majority of AAC apps provided no indication of informed design, with less than 10% indicating SLP involvement in the design/development of the app. Importantly, it appears that none of the cApps, including the ones shortlisted in the 2015 and 2017 reviews, were specifically developed to support PCC, particularly with frail elderly residents living with sensory, motor, or cognitive impairments, and/or language barriers. For example, the stored voices linked to images in AAC apps (eg, speaking the word *orange* when clicking on image of orange) and translator's voices have not taken into account the potential impact of

speaker/listener dialect or accent, nor the use of male versus female voice, on residents' and staff's ability to understand the voice. The images on these apps are also generic, which means that some of the images are not relevant for the LTRC context because they have a different appearance than what is encountered in the resident's specific care environment (eg, dining area, shower, and meals or snacks). Using voices from the same dialect of the residents with voice qualities that accommodate to the high-frequency hearing loss of many residents, along with images that align with elderly residents' current and previous life experiences, is an important way to reduce the information processing demands of residents and maximize their familiarity with the content. In view of older adults' reluctance to learn new technologies, making the content as relevant and meaningful to their life experience and current needs should promote person-centered care and, thereby, greater acceptance of MCT and cApps during their daily activities.

All AAC apps that were evaluated in both the 2015 and 2017 reviews claimed to support hearing loss by offering volume control and input for listening devices (eg, earbuds). In addition, some AAC apps provided an option to adjust the speech rate, to customize the voice output, or to use a speech-to-text function. Although these features can enhance one's listening experience, the technical specifications are not capable of being adapted to different hearing loss profiles. Therefore, future apps found in the iOS marketplace should be designed to interface with hearing aid apps (eg, Mobile Ears) running on mobile devices [41]. The significance of meeting the hearing health needs of elderly residents in LTRC is apparent when considering that most residents in LTRC are living with hearing loss [42] and that failing to accommodate to their hearing loss can have repercussions on their cognitive and social well-being [2,43,44]. For example, Amieva et al [45] reported that people living with hearing loss who use hearing aids or other assisted listening devices are much less likely to experience cognitive decline than those who do not use hearing supportive devices. These authors also provided evidence that ensuring persons with hearing loss use their hearing aids is an important factor in the person's likelihood of using new technologies (eg, smartphone). Given that hearing aid use enables persons to engage in communication, it would follow that the use of other types of communication enhancement devices, such as cApps with features that support hearing, could be used in conjunction with hearing aids to help maintain cognitive and social functioning in aging and dementia. Future research is needed to explore the potential long-term benefits to cognitive and social health associated with regular use of hearing aids (or other assistive listening devices) and cApps in LTRC.

Many older adults in LTRC also experience significant declines in their vision [46]. This challenge can be addressed to some extent by ensuring residents are wearing appropriate corrective lenses and that the size of the images and text fonts is enough for each resident's vision needs. However, because MCT devices are small, the upper range of expanding images and text is highly constrained by the size of the device. Consequently, there is a need for accommodating the visual needs of residents while maintaining portability. One possible solution yet to be realized would be to pair the MCT device (eg, tablet) that care staff use

with special glasses for the resident that connect wirelessly to the MCT, allowing the image or text to be projected up close [47]. Another option, also yet to appear on the market, would be to use an MCT device that has an easy-to-use expandable/retractable display.

Other potential obstacles to overcome in using cApps effectively in LTRC relate to constraints on care staff in employing cApps during ADLs and on residents' physical abilities to interact via an MCT device. First, the demands on staff attending to multiple residents within a short period would require that the cApps be easily accessed in terms of activating a resident's customized cApp profile. This would entail having an *umbrella* home page that links to each resident's profile, a function that is currently not available on any cApps. Second, the staff are often engaged in care activities that require them to use both arms and hands, making it difficult to switch between care tasks and the use of an MCT device. Staff would need to plan their care activities in such a way that accessing the cApp does not interfere with the task or risk injury to either them or the resident. A related constraint is that care activities require staff to be very mobile, frequently bending over, while they assist residents during ADLs. These demands would make it necessary for the MCT device to be as small as possible so that it could be positioned in an easily accessed, yet secure, pocket/holster. As mentioned above, the size of an MCT device limits the size of images and text appearing on the cApp. This double-edged challenge of portability and resident user feasibility will require creative technical and functional solutions. As Reis et al [48] note, "technologies should complement and enhance service delivery and never impose themselves as an extra burden on already work-overloaded health professionals" [48]. Other challenges for successful use of cApps in LTRC include the need for care staff to have access to Wi-Fi, to be able to seamlessly update and transfer customized settings across different care staffs' MCT devices, and to be provided with ongoing training on how to effectively use MCT in a person-centered way during activities that are often physically and emotionally demanding.

From the resident's perspective, the use of technology for the current generation of residents is usually a novel experience and one that may be confusing and/or unappealing to them [49]. For this reason, it would be important to introduce cApps and MCT in a gradual fashion, perhaps beginning with a minimally demanding app such as passively listening to music [50,51]. Once a resident gets accustomed to the device, a caregiver can try out additional features and functions based on the resident's needs, abilities, and preferences. A second, and related, constraint for residents' use of cApps is their limited capacity to point to, touch, or drag/swipe because of their lack of familiarity with a cApp interface as well as their diminished fine motor skills and tactile sensitivities (see Armstrong et al [29] for a detailed discussion). Manufacturers of MCT devices and cApps should consider how the user interface could be more suitably adapted to accommodate older adults' motor and sensory capacities.

Limitations

Although this study is the first to systematically search the app marketplace to identify and evaluate AAC and translation apps

that would be suitable for use in the LTRC setting to support caregiver-resident communication, the review was limited to cApps found in the Canadian (English) iOS marketplace. Therefore, future research is needed to systematically review cApps available in additional platforms and app stores (eg, Google Play). To better understand the ways that cApps may change in the marketplace over time, we compared two time points: 2015 and 2017. Therefore, the percent changes reported in this study cannot be interpreted as trends in the marketplace. Finally, given the fast-changing landscape of the mobile app marketplace, future research should consider performing an app store search to verify the continued availability of the top recommended apps reported in this study.

Future Directions

To date, there is limited empirical research published on the use of mobile technology to support caregiver-resident communication in LTRC, and there is no available evidence to support the use of any of the identified cApps for caregiver-resident communication. Therefore, there is a need for future research to empirically examine the feasibility of using currently available cApps in the LTRC setting, as well as identify gaps in the use of this technology within different LTRC contexts. A better understanding of how care staff could use cApps to support PCC in LTRC should lead to improved quality of care and quality of life for residents living in LTRC homes.

Conclusions

The use of cApps may offer an innovative solution to support person-centered health care for residents living in LTRC homes. This study identified several cApps available in the App Store that aim to facilitate adult communication in general; however, very few cApps were designed with built-in features and custom features that would effectively support PCC in the LTRC setting. Although comparisons of our top-rated cApps demonstrated the inclusion of features that are potentially useful for supporting PCC, there was no indication that the currently available cApps were specifically designed for use in the LTRC setting to enhance caregiver-resident communication during ADLs. Furthermore, no cApp developer appeared to involve stakeholders (eg, clinicians, researchers, residents, and care staff) in the development and design process.

The ubiquitous nature of MCT (tablets/smartphones and their apps) and the growing use of mobile health in a variety of health care settings offer nurses and residential care aides an accessible and innovative tool to promote social participation and person-centered care. However, it is important to identify the availability and stability of commercially available cApps, as well as to conduct comprehensive reviews of the content and quality of existing apps, to ensure that cApps can be used to overcome communication barriers in the LTRC setting. Moreover, to improve the content and quality of cApps and to maximize the benefits of using mobile technology in care practices, it is imperative to include nurses and other care staff in the future development and design of cApps used in LTRC.

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Authors' Contributions

RW, AM, and JS contributed to the study conception and design. RW made significant contributions to all aspects of the study (data collection, data analysis, and reporting) and led the writing of the first draft of the paper. JS supervised the project, contributed to the development of data collection tools, evaluated the cApps (2015 review), assisted in the coordination of the study, and contributed to the first draft of the paper and revisions of the manuscript. DC performed the 2015 search, screened the apps, extracted extraction (2015/2017), evaluated cApps (2015/2017), and contributed to the first draft and paper revisions. AM commented on/revised the manuscript critically for important intellectual content. All authors take responsibility for the integrity of the data and the accuracy of the data analysis. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Screenshots of the top-recommended communication apps reviewed in 2015 and 2017.

[[PDF File \(Adobe PDF File\), 349 KB - aging_v3i1e17136_app1.pdf](#)]

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Abbreviations

- AAC:** augmentative and alternative communication
- ADL:** activities of daily living
- ADRD:** Alzheimer disease and related dementias
- cApp:** communication app
- iOS:** iPhone Operating System
- LTRC:** long-term residential care
- MCT:** mobile communication technology
- PCC:** person-centered communication
- SLP:** speech-language pathologist

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Corrigenda and Addenda

Correction: Existing Mobile Phone Apps for Self-Care Management of People With Alzheimer Disease and Related Dementias: Systematic Analysis

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The authors of “Existing Mobile Phone Apps for Self-Care Management of People With Alzheimer Disease and Related Dementias: Systematic Analysis” (*JMIR Aging* 2020;3(1):e15290) noticed several errors in the author information of their published article.

Author Fei Hu’s academic degree information has been corrected from “MD” to “PhD”.

Author Wei Li’s academic degree information has been corrected from “MD” to “MD, PhD”. Furthermore, the affiliation listed for author Wei Li has been revised from:

College of Engineering, University of Alabama, Tuscaloosa, AL, United States

to the following:

School of Health Professions, University of Alabama at Birmingham, Birmingham, AL, United States

The correction will appear in the online version of the paper on the JMIR website on May 19, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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