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Abstract

Background: Telemedicine is a potential option for caring for older adults with multimorbidity. There is a need to explore the perceptions about telemedicine among older adults with multimorbidity to tailor it to the needs of older adults with multiple chronic conditions.

Objective: This study aims to explore the perceptions about telemedicine among older patients with multimorbidity.

Methods: A qualitative study was conducted using semistructured interviews. The interview questions examined older adults’ perspectives about telemedicine, including their expectations regarding telemedicine services and the factors that affect its use. Thematic analysis was performed using NVivo (version 12; Lumivero). The study was reported using the Standards for Reporting Qualitative Research guidelines.

Results: In total, 29 patients with multimorbidity—21 (72%) female patients and 8 (28%) male patients with a mean age of 69 (SD 10.39) years—were included. Overall, 4 themes and 7 subthemes emerged: theme 1—perceived benefit of telemedicine among older adults with multimorbidities, theme 2—appropriate use of telemedicine for multimorbid care, theme 3—telemedicine system catering to the needs of older patients, and theme 4—respect patients’ decision to decline to use telemedicine.

Conclusions: Telemedicine for older adults with multimorbidity should focus on those with stable conditions. This can help increase access to care for those requiring continuous condition monitoring. A structured telemedicine program and patient-centered services can help increase patient acceptance of telemedicine. However, health care providers must accept the limitations of older patients that may prevent them from receiving telemedicine services.

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KEYWORDS
telemedicine; telehealth; chronic disease; multimorbidity; older adults; mobile phone


**Introduction**

**Background**

The COVID-19 pandemic has led to the emergence of telemedicine as a viable alternative to traditional, in-person care. Telemedicine has the potential to provide convenient medical care for patients with disabilities, transportation limitations, or busy schedules, enabling them to receive care from home [1-3]. It has become an increasingly valuable tool for delivering care to patients with multimorbidity, who require regular monitoring or adjustments to their treatment plans [4,5]. An emerging care model illustrates the integration of a patient-centered approach for individuals and chronic care model with multimorbidity. The model offers comprehensive care across various patient aspects and uses a multidisciplinary approach to address the complexity of managing multimorbidity [6]. Telemedicine can provide remote consultations and monitoring, provide patient education, and facilitate continuity of care [7,8].

In many countries, telemedicine has been promoted in the post–COVID-19 era owing to comparable health outcomes and favorable cost-effectiveness compared with in-person visits [9]. In Thailand, telehealth projects have been launched by the National Broadcasting and Telecommunication Commission of Thailand and the Thai Ministry of Public Health to improve health care services' accessibility and quality [10]. As Thailand has become an aged society, with approximately 12 million people aged ≥60 years [11], telemedicine can help improve the quality of life of older adults by promoting healthy behavior, enhancing social functioning, and reducing depressive symptoms [12,13]. Telemedicine can also improve health for older patients, who often have multimorbidity, by helping to provide continuous medical care [14].

However, the lessons learned from using telemedicine during the COVID-19 pandemic have documented challenges for both older patients and health care providers (HCPs), as it was an unfamiliar mode of treatment compared with in-person service [15]. In addition, the literature suggests that older patients may prefer in-person visits owing to the frustration caused by technological challenges when using telemedicine [16]. However, their perceptions and preferences regarding telemedicine remain poorly understood. Therefore, the needs of older patients for telemedicine should be explored [17].

Moreover, there are gaps in understanding telemedicine for those with multimorbidity [6,18]. Many studies showed the effectiveness of telemedicine, but most focused on the use of telemedicine for a single disease [19-21]. Managing patients with multimorbidity is an increasing challenge in primary care practice [22]. In multimorbidity, there are many interactions such as disease-disease, treatment-treatment, and disease-treatment, which increase the complexity of management [23,24]. The rising question is what is the appropriate use of telemedicine in caring for older patients with multimorbidity [25].

**Objective**

Our study aimed to explore the perceptions about telemedicine among older patients with multimorbidity. By understanding the perceptions about expectations, preferences, and barriers regarding telemedicine, the results can be used to develop telemedicine strategies to support the management of multimorbidity in the older population.

**Methods**

**Study Design**

A qualitative study of older adults with multimorbidity attending a primary care outpatient clinic at a university hospital in Thailand was conducted in 2021. The study used the Standards for Reporting Qualitative Research guidelines, which is a list of 21 items considered essential for complete, transparent reporting of qualitative research [26].

**Setting and Participants**

The Family Medicine Clinic at the Faculty of Medicine, Chiang Mai University, is a primary care clinic that provides general medical care for chronic diseases. Approximately 80% of all patients are older adults (aged ≥60 y) with multimorbidity. Multimorbidity was defined as the patient’s illness that includes the presence of multiple diseases or conditions, often with a cutoff of ≥2 conditions [27]. The most common conditions are hypertension, type 2 diabetes mellitus, and dyslipidemia. Approximately 90% of the patients had multimorbidity. Among those attending the clinic, the rate of controlled hypertension, type 2 diabetes mellitus, and dyslipidemia between August and October 2021 were 93.7%, 70.3%, and 79.8%, respectively.

Convenience sampling was used. Patients aged ≥60 years and diagnosed with at least 2 chronic conditions who were accessible and available were invited to participate in the study. The patients needed to have stable conditions, defined as being asymptomatic and not having any urgency or emergency conditions, according to the national clinical guidelines for managing hypertension [28], type 2 diabetes mellitus [29], and dyslipidemia [30].

**Telemedicine Service**

Telemedicine is the use of electronic information and communication technologies to provide and support health care when distance separates the participants [31]. In 2020, the Family Medicine Clinic in Thailand started a telemedicine service in response to the COVID-19 pandemic. After the COVID-19 pandemic, our facility continues to use telemedicine for delivering care to patients with chronic conditions. By considering patient safety, patients with moderate to well-controlled chronic conditions were approached to participate in the telemedicine service for continuous care [32]. In addition, it is essential to discuss with the patients the purpose of telemedicine and to address any limitations associated with its use [33]. In addition, the objective of telemedicine as ongoing care and limitations of telemedicine need to be discussed with the patients.

The clinic had adopted a published multimorbidity assessment checklist developed to help care for patients with multimorbidity.
The 20-item assessment checklist (Simple Multimorbidity Assessment Checklist for Primary Care) incorporates patient-centered concepts into managing multimorbidity in primary care settings, including assessment of the patient, review of all diseases and conditions, review of all treatments, review of clinical practice guidelines, assessment of interactions, understanding patient context and concerns, finding common ground, setting individual care plan, and continuity of care and follow-up visits. The checklist was also extended for use in the telemedicine service for assessing patients who were suitable for telemedicine and health caregiving.

The telemedicine service was provided via video or audio call, depending on the patients’ available devices and abilities. Physicians could collect patients’ medical histories and evaluate emergency or urgent conditions during the consultation. If any patient had conditions that required further evaluation, they were advised to come to the hospital. If patients did not require any further in-person assessment, medications were prescribed and delivered to the patient’s home via post.

Ethical Considerations
This study was reviewed and approved by the institutional ethics committee of the Faculty of Medicine, Chiang Mai University, Chiang Mai, Thailand (approval number 227/2021). All participants were informed about the research study and provided consent.

Data Collection and Analysis
Semistructured interviews were conducted between September and November 2021. The interview questions (Multimedia Appendix 1) focused on older patients’ perceptions about telemedicine, including their preferences regarding expectations from telemedicine services, and factors that affect its use, using the Unified Theory of Acceptance and Use of Technology framework [34]. This framework illustrates a comprehensive understanding of all the factors that affect people’s intentions to use the new technology. A research assistant, not involved in providing medical care, was trained in the interview method and interview questions by WJ and NB. Each interview lasted approximately 20 minutes and was conducted on-site. Interviewed information included baseline characteristics (age, sex, educational level, employment status, and their decision regarding telemedicine services) with permission for audio recording. Then, the interviews were transcribed verbatim. Data collection and analysis were performed iteratively by researchers. Recruitment ended when data saturation of the core analytic content had been achieved. Previous literature suggested that the sample size of 9 to 17 interviewees could help to reach saturation [35]. We further determined the sample size based on a previous study investigating the crucial factors for outpatient service selection among older adults. At least 16 patients were required to achieve data saturation [36]. Therefore, we considered collecting data from at least 16 patients until we achieved data saturation in the results [37]. Each transcript was evaluated multiple times to aid familiarization and understanding of the data. Descriptive analysis was used to describe the patient’s characteristics. For qualitative analysis, 2 independent researchers (NB and WJ) conducted inductive thematic analysis [38]. The preliminary results were then interpreted and discussed with KP, SP, NN, and CA. Codes were then developed based on patterns in the data. The identified codes were compared and discussed for similarities and differences until consensus was reached regarding the emergent themes and subthemes. Data analysis was performed using NVivo (version 12; Lumivero).

Results
Overview
In total, 29 older patients with multimorbidity participated. Of the 29 participants, 21 (72%) were women and 8 (28%) were men. The mean age was 71 (SD 7.17) years. The 2 most prevalent underlying diseases were dyslipidemia (27/29, 93%) and hypertension (25/29, 86%). Most patients had completed primary school (11/29, 38%) or had a bachelor’s degree (10/29, 35%). Of the 29 patients, 23 (79%) were retired and 6 (21%) were self-employed. Of the 29 patients, 18 (62%) patients were interested in using telemedicine, whereas 11 (38%) patients were not interested in telemedicine and rejected telemedicine when they were offered. Patients’ characteristics are summarized in Table 1.

From the semistructured interviews, 4 themes and 7 subthemes emerged. The themes and subthemes are summarized in Textbox 1.
Table 1. Patients’ characteristics (N=29).

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (y), mean (SD)</td>
<td>71 (7.17)</td>
</tr>
<tr>
<td><strong>Sex, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>21 (72)</td>
</tr>
<tr>
<td>Male</td>
<td>8 (28)</td>
</tr>
<tr>
<td><strong>Chronic conditions, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Dyslipidemia</td>
<td>27 (93)</td>
</tr>
<tr>
<td>Hypertension</td>
<td>25 (86)</td>
</tr>
<tr>
<td>Type 2 diabetes mellitus</td>
<td>9 (31)</td>
</tr>
<tr>
<td>Others</td>
<td>6 (21)</td>
</tr>
<tr>
<td><strong>Number of chronic conditions, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>19 (66)</td>
</tr>
<tr>
<td>3</td>
<td>7 (24)</td>
</tr>
<tr>
<td>4</td>
<td>1 (3)</td>
</tr>
<tr>
<td>5</td>
<td>2 (7)</td>
</tr>
<tr>
<td><strong>Educational level, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>No education</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Primary school</td>
<td>11 (38)</td>
</tr>
<tr>
<td>Secondary school</td>
<td>5 (17)</td>
</tr>
<tr>
<td>Vocational certificate</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>10 (34)</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>1 (3)</td>
</tr>
<tr>
<td><strong>Working status, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>23 (79)</td>
</tr>
<tr>
<td>Self-employed</td>
<td>6 (21)</td>
</tr>
<tr>
<td><strong>Decision regarding telemedicine, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Accept</td>
<td>18 (62)</td>
</tr>
<tr>
<td>Decline</td>
<td>11 (38)</td>
</tr>
</tbody>
</table>

Textbox 1. Summary of themes and subthemes.

**Theme 1: perceived benefit of telemedicine among older adults with multimorbidities**
- Convenient to access without the need for travel
- Minimize the risk of COVID-19 transmission

**Theme 2: appropriate use of telemedicine for multimorbidity**
- Telemedicine for monitoring stable conditions
- Enhancing the self-management of chronic conditions

**Theme 3: telemedicine system catering to the needs of older patients**
- Telemedicine services should be as similar as possible to in-person care
- Telemedicine services should adopt a clear protocol that includes in-person visits
- Supporting the development of technological skills and providing resources

**Theme 4: respecting patients’ decision to decline to use telemedicine for various reasons**
Theme 1: Perceived Benefit of Telemedicine Among Older Patients With Multimorbidity

Overview

The benefits of telemedicine were collected from older patients. They reported the reasons why telemedicine should be used and its benefits. These include eliminating the requirement for travel and reducing the risk of contracting COVID-19.

Subtheme 1: Convenient to Access Without the Need for Travel

The most mentioned benefit of telemedicine was eliminating the need for travel. Participants mentioned that telemedicine is convenient for accessing and receiving continuity of care. It can also save time and money, such as time spent in driving and finding parking. A patient mentioned that telemedicine reduces stress from long wait times at hospitals. It also eliminates the risk of driving accidents, especially in older patients with sensory problems owing to physiologic changes. In addition, there is no burden on family members or caregivers to come and drop them at the hospital:

...If we compare the advantages and disadvantages, there are more advantages, as it saves both time and cost. We don’t have to drive, look for parking spots, or wait in line [to meet the doctor and receive medication]. The advantages are greater. [Participant 13; female; aged 64 years; teacher; uncontrolled hypertension and obesity]

I like it because I don’t have to go to the hospital. It’s convenient. If I had to give [telemedicine] a score, it would be a ten because it’s convenient for me. I don’t have to drive there because I’m not good at driving right now. I have to ask my husband to take me there. [Participant 5; female; aged 72 years; housemate; well-controlled hypertension, type 2 diabetes mellitus, and dyslipidemia]

Because we don’t have to go to the hospital anymore. They send the medication to our house. It’s difficult to go to the hospital now. We have to ask our children to take us, but everyone is working. I want to receive the medication at home because I take this medication regularly. [Participant 26; female; aged 72 years; retired; well-controlled hypertension, type 2 diabetes mellitus, and dyslipidemia]

Sometimes, if I go to the hospital to see a doctor, I have to wait a long time, and it can be stressful. With video calls, I can talk for a long time. [Participant 23; male; aged 76 years; retired; uncontrolled type 2 diabetes mellitus, well-controlled hypertension, and dyslipidemia]

Subtheme 2: Minimize the Risk of COVID-19 Transmission

Patients perceive telemedicine as a helpful way to reduce the risk of SARS-CoV-2 infection by avoiding contact with individuals with infection at the hospital. By not having to physically go to the hospital, there is no need to wait in crowded areas for a physician or medication after treatment, resulting in decreased rate of contact:

I don’t have to go to places with many COVID-19 cases. My daughter also likes it because I don’t have to take risks. Using telemedicine is very good for me. [Participant 2; female; aged 72 years; self-employed; well-controlled hypertension, type 2 diabetes mellitus, and dyslipidemia]

Theme 2: Appropriate Use of Telemedicine for Multimorbidity

The participants felt that telemedicine should be used to care for patients with stable conditions in evaluating, monitoring, and providing health promotion. Participants also acknowledged the limitations of telemedicine in providing medical care, such as the inability to perform a complete physical examination or blood tests.

Subtheme 1: Telemedicine for Monitoring Stable Conditions

Patients feel confident in receiving telemedicine services when they have stable conditions because they have no abnormal symptoms, and the on-site care provided is only in the form of conversation to monitor their condition. Telemedicine services for those with stable conditions can resemble on-site care. Telemedicine services should include monitoring of clinical symptoms, vital signs, body weight, and behavioral factors. Consultation time is also required, so that patients can consult with their physician and inquire about their condition and receive follow-up care:

It’s just like when we see a doctor at the hospital. If we meet the doctor, we ask questions like this. We can also ask online like this and see each other’s faces; finding a doctor this way is good and convenient. The doctor called, and we talked. If we have any questions, we ask, and the doctor answers. It’s just like going to see a doctor. [Participant 18; female; aged 69 years; retired; well-controlled type 2 diabetes mellitus and osteoporosis]

However, some patients still believe that if they experience new or more severe symptoms, they prefer to receive treatment in an in-person setting for more detailed examinations or blood tests:

It’s [telemedicine] comprehensive, but only if I do not have severe symptoms... However, if the patient has more severe symptoms... it’s uncertain how effective the treatment [received through telemedicine] will be. [Participant 19; female; aged 66 years; retired; well-controlled hypertension and type 2 diabetes mellitus]

It’s [telemedicine] good. Luckily, there have been no issues during this period. But if any problems arise, I still have to go see a doctor. [Participant 15; female; aged 73 years; retired; uncontrolled type 2 diabetes mellitus and well-controlled hypertension]
Subtheme 1: Telemedicine Services Should Be as Similar as Possible to In-Person Care

When using telemedicine, patient concerns must still be evaluated, similar to in-person service. Some concerns may persist even after receiving telemedicine services. Presenting conditions can influence their physical or mental well-being, making it crucial for HCPs to thoroughly understand patients’ illnesses to ensure appropriate management. Some patients feel that video call feels more similar to an actual on-site visit than audio calls because they can see the facial expressions and gestures of the HCPs:

> Video calls would be better because the doctor can see the patient’s face and how they feel at that moment, whether they are feeling stressed or not. With video calls, I feel closer [to the doctor] and more comfortable... I usually don’t share things within my family unless it’s with the doctor. But with video calls, I feel more comfortable because I can see the doctor’s face, knowing that they care about me. I just want the doctor to call me and ask what I want to share or talk about. [Participant 1; female; aged 62 years; retired; well-controlled hypertension and type 2 diabetes mellitus]

Subtheme 2: Enhancing the Self-Management of Chronic Conditions

The patients perceive that they can take better care of themselves when telemedicine provides health care information specific to their health problems. Some patients suggested incorporating self-monitoring and health promotion features into the telemedicine platform. They believe in sharing self-management information with physicians to improve disease management, such as home monitoring of blood pressure and blood sugar levels. The platform could also provide specific knowledge for lifestyle modification, such as exercise videos or electronic brochures about food exchange lists. This enhances the potential for self-management:

> I normally check and record my blood sugar and blood pressure at home. Sometimes, I forget to bring the records to the hospital. However, in telemedicine, when the doctor calls, I can inform them of my records. [Participant 2; female; aged 72 years; self-employed; well-controlled hypertension, type 2 diabetes mellitus, and dyslipidemia]

Subtheme 2: Telemedicine Services Should Adopt a Clear Protocol That Includes In-Person Visits

Patients express concerns that telemedicine might replace traditional, in-person care, leading to a lack of access to physical examinations, blood tests, and additional symptom management. They desire telemedicine to complement a comprehensive multimorbidity management program while still having the option to see physicians in person at the hospital:

> Sometimes I want to meet with the doctor in-person to talk directly or ask questions. The doctor can know my symptoms if I communicate directly. If I say that it hurts here or it is swollen here, the doctor can touch it and examine it for evaluation. This is the basic step of diagnosing symptoms. I mean, I want to meet the doctor sometimes, but not frequently. It’s not like I don’t see the doctor for a year. I just want to see the doctor once or twice to feel reassured. [Participant 16; female; aged 74 years; retired; well-controlled hypertension, type 2 diabetes mellitus, and dyslipidemia]

Theme 3: Telemedicine Services Catering to the Needs of Older Patients

For an effective telemedicine service for older patients, it is crucial to address patient concerns and establish a clear management protocol based on their health status. Providing supporting resources, having good communication skills, and being aware of potential barriers arising from unfamiliarity with technology are also essential in meeting their needs.

Subtheme 1: Telemedicine Services Should Be as Similar as Possible to In-Person Care

When using telemedicine, patient concerns must still be evaluated, similar to in-person service. Some concerns may persist even after receiving telemedicine services. Presenting conditions can influence their physical or mental well-being, making it crucial for HCPs to thoroughly understand patients’ illnesses to ensure appropriate management. Some patients feel that video call feels more similar to an actual on-site visit than audio calls because they can see the facial expressions and gestures of the HCPs:

> Video calls would be better because the doctor can see the patient’s face and how they feel at that moment, whether they are feeling stressed or not. With video calls, I feel closer [to the doctor] and more comfortable... I usually don’t share things within my family unless it’s with the doctor. But with video calls, I feel more comfortable because I can see the doctor’s face, knowing that they care about me. I just want the doctor to call me and ask what I want to share or talk about. [Participant 1; female; aged 62 years; retired; well-controlled hypertension and type 2 diabetes mellitus]
uncontrolled type 2 diabetes mellitus and well-controlled hypertension

It’s possible to send the appointment time through LINE in advance; for example, if the doctor would come in the afternoon, someone would call in the morning to inform. The doctor could then ask about the symptoms very well. It was done quickly, in just a moment. [Participant 21; female; aged 75 years; retired; well-controlled hypertension and type 2 diabetes mellitus]

I asked about the cost of the medicine that sent text information by phone because I couldn’t contact the finance department. It’s very difficult. [Participant 18; female; aged 69 years; retired; well-controlled type 2 diabetes mellitus and osteoporosis]

I don’t know if they are doctors or not. To be honest, I don’t know who is calling me. But if it’s a video call, I can be more confident. [Participant 13; female; aged 64 years; teacher; uncontrolled hypertension and obesity]

Subtheme 3: Supporting the Development of Technological Skills and Providing Resources

Most participants had limited technological skills and relied on their children to assist in using electronic telemedicine devices. Only a small minority were proficient in using such devices, with some preferring mobile phone calls over video calls owing to incompatible smartphones or unfamiliarity with more complex devices such as tablets or PCs. However, some older individuals expressed willingness to learn with proper support:

If necessary, I need to adapt. I have to learn to use additional equipment because I don’t usually have a smartphone, so it might be difficult to learn. I can’t even turn it on. [Participant 9; female; aged 78 years; retired; well-controlled hypertension, type 2 diabetes mellitus, and dyslipidemia]

If it’s time for telemedicine, I have to try to adapt and learn gradually. [Participant 10; female; aged 71 years; retired; well-controlled hypertension, type 2 diabetes mellitus, and dyslipidemia]

Theme 4: Respecting Patients’ Decision to Decline to Use Telemedicine for Various Reasons

Older patients often reject telemedicine owing to various obstacles. They face challenges related to age-related physiological changes, including forgetfulness and cognitive difficulties such as finding phones or using video calls despite instructions. In addition, some patients do not regularly use electronic devices, whereas others feel burdensome relying on their children for telemedicine assistance. A few patients are unable to receive telemedicine service owing to their routine work commitments. Therefore, HCPs need to understand these obstacles and respect their decisions for declining telemedicine:

I don’t want to use telemedicine. It’s not difficult for me to see a doctor in person. If you teach me something, I will forget in three months. For example, when I wanted to take a video, my grandchild had to teach me ten times, but when I got home, I couldn’t remember. My memory has not been good for a few years. [Participant 12; male; aged 68 years; self-employed; well-controlled hypertension and type 2 diabetes mellitus]

Sometimes I am not with my phone. Like when I went to a restaurant, I forgot my phone there and didn’t realize it for three days. I think it’s a problem related to age, but if I were newly retired at 60-65 years old, I would be fine. But now that I’m nearly 80, I have problems, especially with memory and internet use. [Participant 23; male; aged 76 years; retired; well-controlled hypertension and type 2 diabetes mellitus]

If my child can help, that would be great. I need my child to be here because I don’t know much. I’m forgetful, but I don’t know if my child is available to help or not. I can’t do it if I’m alone because I have to care for two other older people who are 90 years old. It’s not easy for me because I have to take care of others as well. [Participant 4; female; aged 63 years; retired; uncontrolled type 2 diabetes mellitus, well-controlled hypertension, and dyslipidemia]

I can participate, but I am not familiar with it. I am old and have never used LINE [chat application] before. Trying to learn it now may be difficult because my memory is not very good, and I tend to forget things easily. Although my grandchildren have computers and mobile phones, I don’t want to bother them because they have to work all the time. If the doctor needs to call me, I have to ask my children. I don’t know if they’re available to answer or not. [Participant 8; female; aged 71 years; retired; uncontrolled type 2 diabetes mellitus and well-controlled dyslipidemia]

Discussion

Principal Findings

Summary

In this qualitative study, participants perceived telemedicine as beneficial because it eliminates the need for travel and minimizes the risk of COVID-19 transmission. Older adults view telemedicine as a safe and effective way to manage stable chronic conditions. It is recommended to include health promotion in telemedicine services to enhance self-management. Regarding catering to older patients’ needs, patients expressed that telemedicine should be presented as part of a continuous care program for multimorbidity, incorporating web-based monitoring with periodic in-person visits for physical examinations and laboratory screenings. Clear instructions, technological skills training, and access to resources such as equipment and caregivers are essential to make the program user-friendly for older patients. However, HCP should respect patients’ decision to decline telemedicine owing to various obstacles that older patients may face when using it.
Patients accepted telemedicine as an effective method to improve access to health care for older patients. Some older patients face difficulties when coming to hospitals, such as finding transportation and parking space, long waits for the physician, and long queues for receiving medication [16,36]. This is in accordance with the literature that positive perceptions about telemedicine include cost savings [39]. During the COVID-19 pandemic, receiving treatment through telemedicine services also helped to reduce the risk of infection transmission by reducing the risk of overcrowding of patients and the risk of exposure for those who may not need to come to the hospital [40]. Telemedicine would be a necessary solution for addressing problems regarding access to care in the event of new pandemics.

Several studies have shown that telemedicine can effectively improve the health care outcomes of older patients, particularly those with chronic conditions such as diabetes [19], heart disease [20], and asthma [21]. A study found that telemedicine consultations reduced hospitalization rates among older patients with chronic heart failure compared with standard care [41]. Another study found that telemedicine consultations for older patients with chronic obstructive pulmonary disease improved symptom control and quality of life and reduced hospitalization rates [42]. There is evidence supporting that telemedicine services have the potential to enhance self-management among patients and their families, including improving medication adherence among older patients with chronic conditions and improving disease control and patient satisfaction [43,44].

Older patients, who often have >1 chronic condition, constitute a key group who use the health systems [45]. Owing to the situation in Thailand, it will be a superaged society in the next few decades [46]. The older adults would be the main target for health care delivery. There are potential opportunities in digital health such as telemedicine, emphasizing the management of chronic diseases in Thailand [47]. Cost-effectiveness was also another reason in the long run for telemedicine compared with an in-person visit [4,48]. On the basis of patients’ perceptions obtained from our study and previous evidence supporting the health outcomes of telemedicine, we have the following 4 suggestions for enhancing telemedicine services tailored to the needs of older patients with multimorbidity.

**Identify the Target Population as Individuals With Stable Chronic Conditions**

Our study found that telemedicine is an accepted model for promoting continuous care for older patients with multimorbidity. In cases where patients have well-controlled chronic conditions and no abnormal symptoms, they can receive symptom monitoring and treatment through telemedicine [49].

Health care services for older patients with stable chronic diseases may not need to differ between telemedicine and in-person visits. The services should aim to monitor patients with stable conditions by regularly inquiring about their symptoms; offering self-care instructions at home (such as measuring blood pressure and blood sugar levels); and encouraging healthy behaviors such as medication adherence, maintaining a proper diet, and engaging in regular exercise. Telemedicine has the potential to replace nonurgent in-person medical visits for stable chronic diseases, as it can be used for symptom monitoring, detecting complications or disease progression, and prescribing medication delivery for stable chronic conditions [7,50].

**Telemedicine Services Should Be Designed to Closely Resemble In-Person Visits With Scheduled Periodic In-Person Visits**

Patients expressed concerns regarding the quality of care and maintaining the physician-patient relationship received through telemedicine. A previous study revealed that older patients perceived in-person visits as fostering a strong physician-patient relationship compared with telemedicine [16]. To address these concerns, telemedicine services should strive to deliver care that closely resembles an in-person visit in terms of the process and pattern of care. Telemedicine using video calls closely simulates an in-person visit over phone calls. It helps reduce medication errors, enhances diagnostic accuracy, and improves decision-making accuracy [51]. Telemedicine holds the potential to facilitate shared decision-making between patients and HCPs, thus promoting a patient-centered approach to care [52]. HCPs can also leverage telemedicine to provide education, promote behavior change, empower patients to take control of their health, boost their confidence, and ensure continuity of care [53].

Nevertheless, it is important to acknowledge the limitations of telemedicine. It is unable to perform comprehensive physical examinations and detailed laboratory tests, which means that it cannot fully replace in-person visits. Hence, it is crucial to integrate regular in-person visits with a physician at a hospital to adhere to standard medical practices. These in-person visits can be scheduled periodically on an annual basis, which can help instill confidence and satisfaction with the telemedicine services [54].

**Integrated Support Systems for Telemedicine, Including Clear Protocols, Caregiver Assistance, and Electronic Health Literacy Training**

When caring for older patients with multimorbidity through telemedicine, it is essential to establish a program that adheres to standard practices, incorporates clear protocols, and provides the necessary technical skills and resources. This will help ensure that telemedicine remains as a viable option beyond the COVID-19 pandemic, emphasizing ease of use and demonstrating its benefits. A well-defined service program enables patients to understand the process of care they will receive and empowers them to communicate their specific health needs [55]. In addition, telemedicine services for older adults may require assistance at various stages, including guidance for using tools such as smartphones, instruction for use, and involving caregivers in the process [56]. These supports could contribute to a smooth and more effective telemedicine experience for older patients and their caregivers.

**Develop Alternative Services for Older Adults Who Cannot Use Telemedicine**

Despite the potential benefits of telemedicine for the care of older adults, its use has some challenges and limitations. Some
older patients may face various obstacles in using telemedicine, such as declining vision, hearing, and memory owing to aging; difficulty in learning new skills; unfamiliarity with technology; and feeling burdened to ask for support, which can lead to rejecting telemedicine services [56]. In addition, telemedicine is unsuitable for unstable patients requiring emergent management and detailed physical examinations that cannot be conducted remotely [57]. Some specific clinical contexts or onset of new symptom in multimorbidity, such as hemiparesis, require a comprehensive examination for critical diagnostic accuracy and severity evaluation. If possible, an in-person visit would be more appropriate [58]. Thus, in-person visits or other alternatives should be available [7].

**Strengths and Limitations**

The study has several strengths and limitations. The strength of this study lies in its structured approach to gathering insights about various aspects of telemedicine service tailored to the need of older adults with multiple chronic conditions. The study results can provide valuable guidance about preparing and delivering telemedicine services for this population. However, there are still some limitations to be considered. First, participants were recruited from a single health care facility. The results may be affected by the nature of the health care system and the educational level and digital literacy level of the population. Further studies from different settings and regions are needed to tailor telemedicine services to the needs of older adults with multimorbidity. In addition, future studies could explore more experiences of HCPs providing telemedicine services to this population and identify strategies to address their challenges and concerns. Next, we did not include uncontrolled conditions in this study, and we did not include health care professionals. Further studies may include other telemedicine users. Another consideration point that could influence the results of this study is gender. Gender is associated with differences in digital health care behavior and plays a role in the adoption of health technologies. For example, women exhibit high tendency to access health care services, book physician’s appointments, and search for nutrition-related information. In contrast, men are more likely to explore options related to smoking cessation and use health apps for monitoring sleep patterns and blood pressure than women [59].

As there are various guidelines for telemedicine management, the platform used depends on the facility in each hospital setting. Having many telemedicine providers may disrupt the continuity of care owing to regulation and personal data protection [60]. Furthermore, there remains an inequity in access to care in telemedicine for vulnerable population, such as older people. A strategy to promote electronic health education and provide the necessary equipment to ensure telemedicine equity is needed [61]. Therefore, the use of telemedicine should be tailored depending on the setting and needs of the population and health system.

To ensure the sustainability of telemedicine for older patients with multimorbidity, HCPs should consider patients’ needs, expectations, and abilities when designing telemedicine systems. Importantly, the findings also suggest that HCPs should respect the decision of older patients who decline to use telemedicine owing to multiple obstacles and find alternative ways.

**Conclusions**

The study highlights the importance of personalized and patient-centered care [62], where providers should understand older adults’ needs, preferences, and limitations to tailor telemedicine services for the population. The use of telemedicine for older patients with multimorbidity should focus on those with stable conditions. For this population, telemedicine can help increase access to medical services for patients who require continuous monitoring and care. A structured program incorporating periodic in-hospital visits can help increase patient acceptance of telemedicine. However, HCPs must also understand the limitations of older patients owing to various factors that may prevent them from receiving telemedicine services.

**Acknowledgments**

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**Conflicts of Interest**

None declared.

**Multimedia Appendix 1**

Interview questions.

[DOCX File, 13 KB - aging_v7i1e52031_app1.docx]

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https://aging.jmir.org/2024/1/e52031


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Abbreviations

HCP: health care provider
Examining the Effect of Contactless Intergenerational Befriending Intervention on Social Isolation Among Older Adults and Students’ Attitude Toward Companionship: Content Analysis

Keya Sen¹, PhD; Nida Laheji¹, MHA; Zo Ramamonjiarivelo¹, PhD; Cecil Renick¹, JD; Randall Osborne², PhD; Brad Beauvais¹, PhD

¹School of Health Administration, Texas State University, San Marcos, TX, United States
²Department of Psychology, Texas State University, San Marcos, TX, United States

Corresponding Author:
Keya Sen, PhD
School of Health Administration
Texas State University
601 University Drive
San Marcos, TX, 78666
United States
Phone: 1 512 245 3508
Email: Keyasen@txstate.edu

Abstract

Background: Intergenerational friendship, a mechanism of social support, is an effective intervention to reduce the increasing risk of social isolation (SI) and develop companionship in the older adult population. The COVID-19 pandemic provided a unique opportunity to examine the psychosocial intervention of befriending via technology use as a primary form of contactless socialization.

Objective: The study aims to explore the effectiveness of the befriending intervention through a contactless, intergenerational service-learning project on older adult emotions, especially boredom and loneliness as the key attributes of SI, and on students’ attitude toward companionship.

Methods: During the months of January to April 2022, undergraduate students enrolled in a health administration course with a special focus on culture were asked to be involved in a contactless, intergenerational service-learning project (n=46). In this study, contactless intervention meant communication using the telephone and apps such as FaceTime and Zoom. Students were paired with older adults to have at least a 30-minute weekly conversation, for 8 weeks, via telephone or an internet-based app such as FaceTime. Students were asked to write a half-page diary after each interaction and a 1-page reflection at the end of the fourth week and at the end of the service-learning project. At the completion of the project, the researchers also surveyed the older adults to assess the impact of the project using a 5-item open-ended questionnaire. Following a heuristic approach and content analysis, student artifacts (110,970 words; 118-page, single-spaced Microsoft Word document) and the older adult surveys were analyzed using MAXQDA, (VERBI GmbH). Qualitative data were extracted to assess the impact of service learning on SI by measuring the attributes of boredom and loneliness among 46 older adults. Students’ attitudes toward companionship were also assessed using data from their diaries and reflections.

Results: Overall, three major constructs were identified: (1) meaningful engagement, defined as feeling safe, having increased confidence, and having reduced boredom; (2) internal motivation to participate in the weekly interaction, defined as discussion about daily life experience, level of happiness, and ability to exert personal control over the situation; and (3) intergenerational befriending, defined as perceived benefits from the friendly nature of the interaction, ability to comfortably connect with students, and positive feeling and attitude toward the student.

Conclusions: The contactless, intergenerational befriending intervention reduced boredom and loneliness among older adults and enhanced positive attitude and confidence among university students. Students helped older adults to develop digital skills for the use of apps and social media. Older adults showed interest in the intervention and shared their daily life experiences with the students, which helped to reduce the gap between generations. Findings indicate the effectiveness of an intergenerational service-learning intervention on SI reduction and increased positive attitude among college students.
Introduction

Background

The growing surge of the aging population has shone a spotlight on social isolation (SI). With increasing age, an increasing proportion of older adults experience chronic boredom and feelings of loneliness [1]. In addition, COVID-19 confinement and quarantine disturbed their lifestyle behaviors, making the aging population susceptible to high levels of stress and depression. SI is exacerbated when people are living alone, especially vulnerable older adults, experiencing the loss of family or friends, having comorbid or chronic illnesses, and facing sensory impairments. Even in residential settings and older adults’ living facilities, many older adults struggle to maintain their autonomy, self-determination needs [2], and competence as they are often disconnected from the broad community or dependent on unskilled nursing staff who lack social competence and training [2,3]. An intergenerational service-learning approach to befriending these individuals is an effective intervention to enhance their psychosocial well-being [4]. This approach demonstrates the importance of using reflective writing assignments to help university students deconstruct and reconstruct images, beliefs, and paradigms about older adults [5]. In addition, it is where the young individuals relate to older adults to discuss or share their life stories or day-to-day experiences to alleviate boredom, an attribute of SI [6].

Although SI is a global epidemic implying the absence of meaningful human relations and social connectedness, befriending is a psychosocial tonic to building social relationships and intergenerational friendships [7] that might reduce boredom and depression and significantly enhance the quality of life among older adults [8] and youth. The feeling of companionship is augmented when an intergenerational conversation is conducted purposefully, thereby negating the exacerbating consequences of SI such as boredom or even the feeling of loneliness. These negative subjective experiences result from discrepancies between an individual’s desires and perceptions about the quality of social relationships [9].

Intergenerational conversations are a gateway to enduring socialization for older adults and students [9]. The quality of life is enhanced as both generations engage in purposeful activities in a safe and friendly environment [8] to the satisfaction of each other’s psychosocial needs and well-being. Long-lasting intergenerational conversations can create a bonding between the older adult and the student, and it enhances the level of patience and builds social competence in youth, which are essential attributes to become skilled health care professionals in long-term care [10]. The social support provided by students can foster emotional health for the isolated, frail, older adult who is no longer at the center of a network of friends and acquaintances. Older adults with social connections have a high quality of life under social support [11], are motivated to work and engage in social activities, and have an inclusive attitude that promotes a healthy lifestyle [12]. Hence, they have low risk of conditions such as depression, addictive behaviors, or dementia [13]. With social connectedness, even in living alone situations, these individuals have life satisfaction, with high cognitive stability [10,14].

Facets of SI

SI is one of the most disruptive transformations that exacerbate the quality of life, affecting human behavior, perceptions, and experiences [10,15]. It is a condition that leaves one with feelings of boredom and loneliness that are detrimental to physical and mental health [7]. Loneliness among older adults is the subjective, distressed feeling of being alone or separated, whereas SI is the objective physical separation from the community [14,16]. In addition, boredom is an emotion that often triggers negative thoughts such as self-harm and anxiety, and it is profound when the surrounding environment is mostly empty [17]. Hence, boredom, compounded by the feeling of loneliness over a prolonged period, may result in depression [18], which is a mental disorder that can be controlled in a timely way by identification of the needs of individuals and restoration of successful attention in meaningful activities such as intergenerational conversations. More than 56 million adults aged ≥65 years live in the United States, accounting for approximately 16.9% of the nation’s population [19]. In this population, >7 million (13%) are socially isolated. Of those 7 million individuals, 1.3 million are severely socially isolated [5,7]. The crucial drivers of boredom [18,20], namely, lack of recreational opportunities; limited personal contacts; immobility; prescribed home office; and, especially, COVID-19 quarantine and isolation have dissuaded the everyday lives of older adults, triggering anxiety and monotony [4,16,21].

Boredom across the population increased significantly owing to the COVID-19 pandemic containment measures [22], and so did the behavioral intention to find information, access services, and connect socially [23]. For older adults, there is evidential increase of the benefits of technology interventions for social connectedness [10,24]. This may have helped the contactless, intergenerational, service-learning intervention to become especially effective, facilitating the feeling of companionship and social support that is felt bilaterally and actively by both parties [25].

Intergenerational Service Learning

Intergenerational service learning is an experiential learning, which is a course-based, credit-bearing, educational experience in which students participate in an organized, service-learning activity that meets identified community needs. Students reflect about the service activity to gain further understanding of a course content [26]. With an intent to develop a sense of companionship or friendship between both parties, the
intergenerational service-learning intervention brings the socially isolated older adults back on the periphery of social activities as they engage in conversations with college students [27]. Recurrent interactive sessions are useful to enhance the level of subjective well-being among older adults and connect them to the social network [28]. Alternatively, the service-learning sessions provide a broad appreciation of discipline and an enhanced sense of civic responsibility to the students while connecting them in purposeful activity with community members [29]. Requesting students to write diaries and reflections regarding their interactions with older adult adults is a key component of service learning [25,29]. Although it is less likely to see older individuals readily embracing service-learning sessions involving students or even social media sites when compared with young adults, adoption rates for contactless interactions with students among individuals aged ≥65 years have approximately doubled in the United States in the past 4 years [14,30].

**Intergenerational Befriending Approach**

This study used an approach that aims to bolster a long-lasting, genuine connection or relation between generations, especially college students engaged in service learning and older adults who are socially isolated [31]. This connection is based on shared experiences of daily living, which is reflected in the recurrent interaction based on the multicultural project. Although the intergenerational connection may develop over a contactless platform, it fosters a sentiment of compassion and empathy through focused interactions that add purpose and engagement for participants. The befriending idea is based on reciprocity and what benefits the older adult in a relationship [32]. The interactions are mostly based around topics that are meaningful to the older adult [10,33] and benefit the student to understand the biases of ageism. The idea is to make the older adult feel valued and cared for in a relation that is free from any kind of service delivery, obligation, or family ties [26,34].

**Contactless Socialization**

The quality of life comprises components such as health; well-being; peaceful existence; living in harmony; social engagement; life satisfaction; and keeping oneself busy with hobbies, volunteer service, or work [8,35,36]. The older adults were subjected to a harsher reality during the pandemic than younger adults as old age was affirmed as a risk for COVID-19 complications [37]. This contention promoted contactless socialization through contactless service-learning sessions via SMS text message, FaceTime, and emails that connected the older adults to wide social networks [38]. Although user confidence remained as a dominant issue when using technology such as a smartphone or tablet for interaction needs [39], the willingness and interest of older adults let students train them on the use of technology. The training also facilitated the use of mobile health and telemedicine among older adults, which greatly enhanced their health-related quality of life [40]. Hence, technology-based, contactless, service-learning sessions provided safe interaction for both parties, fostering social support and technology skill augmentation for the older adults [41]. Simple telephonic calls were used to build intergenerational friendships [13,38] connecting student helpers with their clients through personal life experience, interpersonal interaction, collaboration, and understanding [42].

**Study Purpose**

The study aimed to explore the effectiveness of the befriending intervention through a contactless, intergenerational, service-learning project on older adult emotions, especially boredom and loneliness as the key attributes of SI, and on students’ attitude toward companionship. Our approach was to forge an alliance and create an affective bond between the young student and the older adult to facilitate the possibility of friendship as they shared their life experiences and students engaged in technology training activities for the older adults regarding the use of apps and social media sites. The relationship that develops through befriending is seen as central to the experience while hypothesizing the facts that befriending would foster psychosocial well-being among older adults and that students’ attitudes toward older adults would become more positive throughout the service-learning course.

**Methods**

**Study Setting and Recruitment**

The research design was based on qualitative data analysis [43]. Data were collected through the survey of older adults and dialogues included in journal entries submitted by 46 undergraduate students enrolled in a Health Administration course. This core or required course had a special emphasis on cultural competency and diversity. The study followed 46 older adults, aged between 64 and 82 years, via intergenerational service-learning sessions during the months of January to April 2022. The older adults were recruited from residential facilities in Good Samaritan Society, Denton, Texas; Schertz Senior Living, Texas; Knowles Home, Nashville, Tennessee; Aguadilla Seniors, Puerto Rico; and Guadalajara Senior Center, Mexico. We selected these locations because these are the largest centers for older adults known to the researchers, and we asked the older adults in these centers to invite other participants known to them to participate in the study, to expand the sample size. The inclusion criteria for older adult participants consisted of the following: those who (1) were interested in socialization activities, (2) were aged >65 years, (3) could read English, and (4) were willing to participate in the study. The exclusion criteria were the following: older adults who (1) were aged <65 years, (2) were already engaged in >1 socialization activity, and (3) did not pass the “attention check” in a meeting with the researcher conducted before the intervention to assess their interests and identify careless respondents, thereby improving the data quality. The inclusion criteria of student participants were the following: all students enrolled in the health administration course irrespective of age or involvement in socialization activity. No exclusion criteria for students were determined.

**Data Collection Procedures**

The service-learning sessions are an essential component of the undergraduate Health Administration course that has culture as
a major topic. The course introduces undergraduate students to the historical and cultural development of health care in contemporary American society. During the months of January to April 2022 a total of 46 students were paired with 46 older adults from the abovementioned communities. Once a week, the students communicated with their assigned older adult partners and engaged in an unscripted conversation for at least half an hour, for a total of 8 weeks. Of the 46 pairs, 29 (63%) pairs engaged in telephonic conversations and 17 (37%) pairs engaged in internet-based conversations via casual calling app, such as FaceTime or Zoom. The risk of COVID-19 contamination restricted all possibilities of in-person meetings.

As part of service learning, students were required to create an artifact diary to document each conversation. Students were also asked to write a 1-page diary after each interaction with their older adult partners and 2 reflections. On the basis of the duration of the project, students were expected to write 8 diaries and 2 reflections, once at the end of their fourth interaction and then again at the end of their eighth interaction. The conversations were recorded by the students with their smartphones or technology used for internet-based interaction such as Zoom and then transcribed by the students.

As part of the study, older adults were surveyed (paper-based, 5-item open-ended questionnaire) by the researchers to determine their interest in conversation to reduce SI and evaluate the effectiveness of the project. This 1-time survey was mailed with return envelopes to the older adults at the end of the eighth interaction with students. Survey questions were open ended, so that older adults could write their answers. The students’ transcribed conversations, diaries, and reflections and the older adults’ answers to the open-ended questions in the survey were all used in the qualitative data analysis.

The open-ended survey questions for the older adults included the following: (1) Did you find the conversation interesting? If your answer is yes, please write a few lines what was interesting in the conversation. (2) Would you like to participate in our project again next semester?

The whole idea of the project was to provide a useful framework for befriending that may facilitate and create a meaningful bond between the young student and the older adult [44,45]. All questions were composed from previously validated survey instruments and contextualized for use in this study (refer to sources in Table 1). To assess older adult emotions, especially boredom and loneliness as the key attributes of SI, students focused on conversations (refer to definition in Table 1) based on life satisfaction and digital skill training in the context of meaningful engagement [46,47], internal motivation to participate in the intervention for both older adults and students [47-49], and human feelings in the context of intergenerational befriending or companionship [46,49,50]. Thus, in Table 1, we have presented 3 major constructs: meaningful engagement, internal motivation to participate, and intergenerational befriending.

<table>
<thead>
<tr>
<th>Table 1. Study constructs, definitions, and sources.</th>
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<tbody>
<tr>
<td>Construct</td>
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<tr>
<td>Meaningful engagement</td>
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<td>Internal motivation to participate</td>
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<td>Intergenerational befriending</td>
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**Ethical Considerations**

This contactless, intergenerational, befriending interventional study was approved by the institutional review board (protocol number 2022-7046) of the Texas State University. Written informed consent was obtained from all participants (students and older adults) before the intervention. Participants had the option to exit the intervention after reading the informed consent information or to provide consent to participate in the study. The confidentiality of the participants was properly protected during the intervention and data analysis. The study data were fully deidentified. All records pertaining to the intervention were securely protected in the university database with protected passwords, which were only accessible by the researchers. As this study was not grant funded, participants (undergraduate students and older adults) were not compensated for participating in this study.

**Data Analysis**

The older adults’ survey was mailed to the 46 older adult participants, and 21 (46%) returned the completed survey. Students’ diaries and reflections were collected at the end of the intervention (46/46, 100%), and all the files were used for data analysis. The qualitative data used in the study to extract the constructs and subconstructs were obtained from the 21 older adults’ surveys and 46 students’ diaries and reflections. Our analytic data included all the 110,970 words in a 118-page, single-spaced Microsoft Word document.
Following a heuristic approach [51] and content analysis, the data were coded using the qualitative text analysis software, MAXQDA by numbering each line of the dialogue [52]. The “Advanced Coding Method” in MAXQDA Standard was used for content analysis with major keywords that were allocated to data segments. The “Lexical Search” function located the keywords in all the text that define the 3 major constructs as identified in Table 1. Once the keywords of befriending, SI, boredom, socialization, engagement, and motivation were identified, the thematic coding of the relevant texts was performed using MAXQDA’s visual tool, “One Code Model.” We explored the frequency of words and terms used in the sources and analyzed their semantic contexts in a quantitative way. A differentiated word frequency analysis was performed using the “MAXDictio Module” [52]. The data were then classified into several groups to reveal trends and patterns of response to each question in the survey and in each topic of conversation between the older adults and students from the student dairies and reflections. Topically similar codes were grouped together and then narrowed by code segments using the option “Subcode Statistics” in the context menu of the “Code System” of MAXQDA. For example, the code “intergenerational befriending” was further subcoded as “comfortability,” “positive emotions,” and “perceived benefits.” Finally, using the MAXQDA function “Analysis Summary Grid,” thematic compilations were presented in “Participant Comment Tables.”

The use of heuristic inquiry [51,52] helped us to discover the nature of social phenomena, especially the intergenerational bonding that developed between participants, as we systematically coded the data. Owing to the complex nature of the emerging themes related to befriending and self-expression, heuristic inquiry appeared to be the most convenient method of sense making for this study. The heuristic depictions of the artifacts involved a synthesis of intuition and tacit understanding of researchers [53]. This understanding characterized the idea of befriending experience. The concepts that emerged from the study included relationship building, empathy, social interactions, and capacity for additional relational networks outside the family.

**Results**

In the older population of 46 adults, of which 19 (41%) were men and 27 (59%) were women, 3 main constructs were identified: intergenerational befriending, meaningful engagement, and internal motivation to participate in the program. According to the older adult participants, the perceived benefits of the friendly nature of intergenerational interaction were mainly the heightened feelings of comfort and reduced boredom. For both the student and older adult participants, trust in the interactions bolstered the positive emotions, enhancing the feeling of safety and social affinity. Table 2 displays the number of times the older adults’ and student participants’ specifics about the scope of befriending and engagement to reduce boredom. Meaningful engagement was described as “reduced boredom,” “feeling safe,” and “increased confidence.”

For a total of 253 times, the older adult participants mentioned that they were purposefully engaged, 96 times they reiterated their feeling of happiness, 58 times about feeling safe, and 98 times that there was an impressive increase in their level of confidence. Similarly, students mentioned 201 times that they were meaningfully engaged in the project, 91 times they felt happy, 55 times that they did not feel bored in the conversations with older adults, and 97 times about the increased level of confidence.

Intergenerational befriending was summarized as “comfortability” and “positive emotions.” The older adult participants specified 97 times that they benefited from the program and that they made new friends. For many older people, “engagement to reduce boredom” specified 97 times, was the main reason for participating in these conversations. Intergenerational sessions enhanced the motivation level of the older adults 277 times, with improvement in emotional health or positive emotions (specified 80 times). Having company was more of an antidote to reduce boredom (specified 90 times). The discussions about daily life experience led to emotive bonding and friendship. For the students, the befriending experience (specified 201 times) enhanced the feeling of comfort (specified 70 times) and positive emotions (59 times). Both the students and older adult participants looked forward to the sessions and considered it as a reason to get up in the morning.

The intergenerational service-learning intervention mainly covered two activities: (1) discussions about daily life experience to reduce the gap between generations and (2) digital training to help older adults to use social media sites and apps such as Facebook or Uber. The main attributes of SI targeted in this study, namely, boredom and loneliness, were minimized to some extent with the befriending approach as people felt safe and happy as they interacted with the students. Importantly, older adults were extremely interested in the technology training from students regarding how to use social media sites and apps such as Facebook and Uber. Tables 3 and 4 reflect the confirmatory statements of the older adults and students toward the valuable “befriending” component that engaged older adult participants substantially with the undergraduate college students in digital training and motivated them to share their life experiences safely. The attributes of hesitation and fear, which were noticed in the initial stages, turned to compassion, trust, respect, empathy, honesty, and warmth in the later stages, which are the most essential attributes of friendship.

The positive attitude and the dedication of the students toward the project helped the older adults to find social support and feel safe. On most occasions, activities were based upon the interest of the older adults. The opportunities for social interaction were possible as students were proactive and flexible with time and the needs of their older adult partners. The results revealed the importance of students’ positivity to support the older adults and the increased level of motivation for spontaneous interactions. The students created a friendly environment, or that of companionship, where the older adults had confidence that the discussions were appropriate based on their choices and preferences.

Another key finding was that older people define boredom and comfort differently and that there is a difference between the students’ perceptions and older adults’ perceptions related to interactions to alleviate boredom. Although befriending through
these sessions cannot compensate for the loss of an attachment figure, such as a close friend, spouse, or a significant other, which is common in old age, people with poor social skills are likely to have trouble in developing and maintaining relationships. Negative perceptions about age and aging, at societal and individual levels, have adverse effects on older adults’ health and well-being. Ageism, which means negative attitudes toward older adults, or unrealistic expectations about the intergenerational sessions can leave both the older adults and the young individuals with unmet social needs, resulting in increased boredom. Hence, the befriending approach must be understood from the individual’s subjective point of view.

Table 2. Constructs and subconstructs identified from the intergenerational service-learning intervention.

<table>
<thead>
<tr>
<th>Name of the constructs and subconstructs</th>
<th>Number of times specified by older adults (n=786), n (%)</th>
<th>Number of times specified by students (n=557), n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intergenerational befriending</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comfortability</td>
<td>79 (10.1)</td>
<td>70 (12.6)</td>
</tr>
<tr>
<td>Positive emotions</td>
<td>80 (10.2)</td>
<td>59 (10.6)</td>
</tr>
<tr>
<td>Perceived benefits</td>
<td>97 (12.3)</td>
<td>50 (8.9)</td>
</tr>
<tr>
<td>Internal motivation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling of happiness</td>
<td>96 (12.2)</td>
<td>91 (16.3)</td>
</tr>
<tr>
<td>Discussion about daily life experiences</td>
<td>181 (23)</td>
<td>86 (15.4)</td>
</tr>
<tr>
<td>Meaningful engagement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling safe</td>
<td>58 (7.4)</td>
<td>49 (8.8)</td>
</tr>
<tr>
<td>Increased confidence</td>
<td>98 (12.5)</td>
<td>97 (17.4)</td>
</tr>
<tr>
<td>Reduced boredom</td>
<td>97 (12.3)</td>
<td>55 (9.9)</td>
</tr>
</tbody>
</table>

Table 3. Comments of older adults about the key constructs.

<table>
<thead>
<tr>
<th>Key construct</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaningful engagement</td>
<td>&quot;Like to talk about you and the multicultural sensitivity project in the Zumba classes three times a week, and ballet classes twice a week.&quot; [Participant 2]</td>
</tr>
<tr>
<td></td>
<td>&quot;Feel glad, I seem to have more control on anger unlike before, we have opportunities for social interaction and there is less counterproductive behavior.&quot; [Participant 45]</td>
</tr>
<tr>
<td></td>
<td>&quot;She plays for the university’s basketball team. Since the university is so close to where I live, I get to attend all her games and is eternally grateful for this.&quot; [Participant 5]</td>
</tr>
<tr>
<td></td>
<td>&quot;The student group hosts a couple of social events every day, so there is always an event to attend and enjoy. Some of these events include- bingo, bible studies, stretching class, and physical fitness classes as well.&quot; [Participant 42]</td>
</tr>
<tr>
<td></td>
<td>&quot;She is physically very active, I enjoyed our zoom discussion last week, me and my husband, engaging in either yoga, meditation, or going on 30-minute walks.&quot; [Participant 16]</td>
</tr>
<tr>
<td>Internal motivation to participate</td>
<td>&quot;Family reunion was over; it was a good day of our weekly conversation and i-phone training.” [Participant 39]</td>
</tr>
<tr>
<td></td>
<td>&quot;Grateful to be able to wake up each morning and do the things that I enjoy, like art and seeing family and talking to my student friend over the phone.” [Participant 3]</td>
</tr>
<tr>
<td></td>
<td>&quot;Like to talk to you about school, do you enjoy the simple pleasures in life like cooking?” [Participant 28]</td>
</tr>
<tr>
<td>Intergenerational approach to befriending</td>
<td>&quot;Now look forward to our weekly conversations and app training sessions.” [Participant 40]</td>
</tr>
<tr>
<td></td>
<td>&quot;I don’t get to see my grandchildren as often as I would like, so having a person of the younger generation to talk to weekly reminds me a lot of them.” [Participant 25]</td>
</tr>
</tbody>
</table>
Table 4. Comments of students about the key constructs.

<table>
<thead>
<tr>
<th>Key construct</th>
<th>Comments</th>
</tr>
</thead>
</table>
| Meaningful engagement                        | • “At first the project was challenging, towards the end I felt relaxed, as I came to know the older adult partner more closely.” [Participant 9]  
• “She explained it so well, I never thought before that smoothie making could be so simple.” [Participant 11] |
| Internal motivation to participate           | • “She loves everything about her life. Our hobbies are the same. She is blessed to be healthy at her age, and she wouldn’t change a thing.” [Participant 12]  
• “My grandmother used to tell me similar things, to be able to wake up each morning and enjoy breakfast with family.” [Participant 1] |
| Intergenerational approach to befriending    | • “Feels nice to be in an interesting conversation and write diaries.” [Participant 46]  
• “So happy to help someone who sees her grandchild in me.” [Participant 45] |

Discussion

Summary

The befriending intervention delivered through the service-learning sessions promoted reciprocity and social support that enhanced the quality of life by fostering positive emotions and reduced boredom and loneliness. The intergenerational service-learning program fostered discussions about daily life experience that reduced the gap between generations and promoted companionship [54]. The proactiveness and dedication of the students for their project helped the older adults to find social support and feel safe and created a bonding between the generations with long-lasting friendships.

Meaningful Engagement

Through this specific intergenerational service-learning experiment, we found that most older adults try to keep themselves occupied through personal hobbies; talking to family over the phone; and occasionally, even work. Meaningful engagement was depicted well through the comments of older adult participant 42 who was happy and well engaged in programs and activities administered by the university such as telephone-based befriending and contactless luncheons with students. For these participants, social interaction through the service-learning program enhanced connectivity and reduced the risk of losing the motivation to maintain an active and healthy lifestyle. The conversations reduced the feelings of boredom and isolation that adversely affected their emotional health. These sessions helped the older adult to reengage in community networks and participate freely in cohesive neighborhood environments with other members of the older adult living facility. Older adult participant 2 found these sessions to be meaningful and interesting, explained the importance of these sessions to friends and community, and constantly spoke about the interactions in the Zumba and ballet classes 2 to 3 times a week. The intergenerational service-learning conversations toward the end of the project showed a heightened level of comfort for both the older adults and the youths and made the older adults feel that they are cared for while in conversation. Hence, they were not bored in their conversation with the students.

Internal Motivation to Participate

For the older adults, there is the need of a companion to share life experiences [55], which is profound when separated from the family owing to relocation, death of family members, or retirement [56]. The befriending activity reduced the boundaries between the 2 people involved, and the student befriender was asked to undertake tasks that the older adult wanted to do, such as using technology or having contactless visits during family reunion. This created a sense of internal motivation for older adult 40 to participate in the interactions. As students helped the older adults to interact with their family and share life stories, these interactive sessions fostered companionship that was of interest to the older adult and a reason for the student to find meaning and value in the conversations. Following the comments of older adult participant 25 and student participant 45, we found discussions about spouses to children and grandchildren and, for some, even to great grandchildren. All familial connections showed the importance of social support and motivated both parties in conversation on a day-to-day basis. Student participant 12 prayed for the well-being of his older adult partner and felt happy as he discovered a common hobby to talk about. Older adult participant 39 described her spouse returning from rehabilitation and mentioned that a welcome home party with her spouse’s family resulted in her having a good day. Older adult participant 5 revealed that she is eternally grateful to be able to attend her befriender’s basketball games; the joy and motivation to be able to socially connect seemed to have a positive effect on her well-being.

Intergenerational Approach to Befriending

Although several of the older adults in this study had various outlets to socialize such as hobbies, calling a friend, and family visits outside the intergenerational service-learning sessions, they still expressed appreciation toward the students for their time and companionship, which fulfilled the idea of befriending that we aimed for in this study. Student 45 noted that the older adult was nervous at the beginning but eventually looked forward to their weekly conversations, further mentioning that having someone from the young generation to talk to reminded her about her grandchildren whom she does not get to see often. In another instance, student participant 46 would write down events worth mentioning every week to discuss during the call. The overall evaluation of the intergenerational conversation was positive; older adult 40 wrote in the survey that she valued the ability to talk, listen, and share information with another...
human being whom she could trust and rely on. The befriending approach within these sessions appeared to expose the similarities between 2 different generations as the weeks passed. For example, student 28 revealed that he felt lucky to share the same religious and spiritual beliefs as the older adult partner. Similarly, student 42 stated that she and her older adult partner shared the same type of church. Most of the student’s reflections revealed the idea of reliability, compatibility, intimacy, and reciprocity in the conversations, which had a positive effect on promoting friendship and reducing boredom and loneliness for both parties. In addition, the program improved the youth’s social skills and assumptions related to one’s privacy and safety.

Limitations
This study has some limitations. Several students reported being unable to communicate with their partners at the beginning of the project owing to difficulty with older adults’ digital literacy, inability to answer phone calls or read SMS text messages, or inability to use apps such as Zoom or FaceTime. This ruled out the possibility of Zoom focus groups. In-person focus groups were also not possible owing to COVID-19 socialization restrictions. In some cases, there was dropout of older adults from the project owing to sickness or other health conditions. Although the authors clearly explained to the older adults that the service-learning project was completely contactless, some of them still preferred face-to-face interaction, which was not possible because of COVID-19 restrictions. Furthermore, student notes may not be free from bias. The findings from this study have limited generalizability because we used a sample of students from 1 course, and the results may not be applicable in other study settings. Variables such as overall health, stress, stigma, comorbid conditions, socioeconomic status, and discrimination were not considered while assessing older adult surveys or student artifacts in the study.

Conclusions
The need to feel important and be included in a large social group is vital regardless of age. The need is perhaps more during the later stages of life when one has more physical and mental challenges and is confined in living situations with very limited social networks. The effects of service-learning sessions on boredom and loneliness among older adults promoted interest in intergenerational practice to reduce SI and improved the feelings of companionship among both students and older adults as a long-term outcome of the intervention. Students identified the intergenerational component as a highlight of the health administration course, which increased their awareness of gerontological issues and knowledge about working with aging populations. The intervention enhanced students’ attitude toward companionship and gerontological practices via intergenerational befriending opportunities and digital training sessions. As students developed an interest in service-learning programs through frequent interactions with older adults, the social interaction component in the program amplified social connectivity via contactless interactions, phone conversations, and digital training sessions for older adults. Consequently, it reduced the risk of losing the motivation to maintain a self-image and an active and healthy lifestyle among older adults. This study was designed for periodic or postpandemic follow-up of the participants experiencing SI. Our results showed that older adults wished to maintain their social connectedness and access to technology and digital networks. Driven by a desire to communicate and access information that stemmed from the need to connect to friends, family, or other internet-based services such as mobile health or social media, older adults showed appreciation and gratitude toward the youth for taking an interest in their lives and, often, would look forward to their weekly conversations.

Acknowledgments
This study received no external funding. The authors are grateful to all the older adult study participants for their time and support in the study. The authors are grateful to Dr Stan Ingman for his assistance with the recruitment phase. The authors are also grateful to Dr Gayle Prybutok for helping with qualitative data analysis.

Data Availability
The institutional review board of this study does not allow data sharing because the data protection statement is an integral part of our institutional review board approval. Therefore, our data will not be made available.

Authors’ Contributions
KS was involved in conceptualization, methodology, validation, formal analysis, investigation, resources, data curation, writing, and original draft preparation. ZR and NL wrote and prepared the original draft. All other authors reviewed and edited the manuscript.

Conflicts of Interest
None declared.

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Abbreviations
SI: social isolation

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Determinants of Implementing an Information and Communication Technology Tool for Social Interaction Among Older People: Qualitative Content Analysis of Social Services Personnel Perspectives

Johanna Fritz, PhD; Petra von Heideken Wågert, PhD; Annelie K Gusdal, PhD; Rose-Marie Johansson-Pajala, PhD; Caroline Eklund, PhD
School of Health, Care and Social Welfare, Mälardalen University, Eskilstuna/Västerås, Sweden
*all authors contributed equally

Corresponding Author:
Johanna Fritz, PhD
School of Health, Care and Social Welfare
Mälardalen University
Box 883
Eskilstuna/Västerås, 72123
Sweden
Phone: 46 21101503
Email: johanna.fritz@mdu.se

Abstract

Background: Older people are particularly vulnerable to social isolation and loneliness, which can lead to ill-health, both mentally and physically. Information and communication technology (ICT) can supplement health and social care and improve health among the vulnerable, older adult population. When ICT is used specifically for communication with others, it is associated with reduced loneliness in older populations. Research is sparse on how the implementation of ICT, used specifically for communication among older people in social services, can be performed. It is recommended to consider the determinants of implementation, that is, barriers to and facilitators of implementation. Determinants related to older people using ICT tools are reported in several studies. To the best of our knowledge, studies investigating the determinants related to the social services perspective are lacking.

Objective: This study aims to explore the determinants of implementing the Fik® room, a new, co-designed, and research-based ICT tool for social interaction among older people, from a social services personnel perspective.

Methods: This study used an exploratory, qualitative design. An ICT tool called the Fik® room was tested in an intervention study conducted in 2021 in 2 medium-sized municipalities in Sweden. Informants in this study were municipal social services personnel with experience of implementing this specific ICT tool in social services. We conducted a participatory workshop consisting of 2 parts, with 9 informants divided into 2 groups. We analyzed the data using qualitative content analysis with an inductive approach.

Results: The results included 7 categories of determinants for implementing the ICT tool. Being able to introduce the ICT tool in an appropriate manner concerns the personnel’s options for introducing and supporting the ICT tool, including their competencies in using digital equipment. Organizational structure concerns a structure for communication within the organization. Leadership concerns engagement and enthusiasm as driving forces for implementation. The digital maturity of the social services personnel concerns the personnel’s skills and attitudes toward using digital equipment. Resources concern time and money. IT support concerns accessibility, and legal liability concerns possibilities to fulfill legal responsibilities.

Conclusions: The results show that implementation involves an entire organization at varying degrees. Regardless of how much each level within the organization comes into direct contact with the ICT tool, all levels need to be involved to create the necessary conditions for successful implementation. The prerequisites for the implementation of an ICT tool will probably change depending on the digital maturity of future generations. As this study only included 9 informants, the results should be handled with care. The study was performed during the COVID-19 pandemic, which has probably affected the results.
information and communication technology; implementation; determinants; social isolation; loneliness; organization; digitalization; facilitators; barriers; older people

**Introduction**

Older people are especially vulnerable to social isolation and loneliness, particularly because they are exposed to risk factors such as living alone and experiencing chronic illness [1]. There is robust evidence linking loneliness and isolation with physical decline; morbidity; increased mortality; and cognitive and mental health problems, such as depression and dementia; and increased risk of suicide [2-7]. Several studies point toward an increase in loneliness during the COVID-19 pandemic with stay-at-home orders and recommendations for social distancing [8-11], and the impact is particularly severe among people aged ≥80 years [12]. Information and communication technology (ICT) can supplement health and social care and improve health in the vulnerable, older population [4,13]. ICT is a part of welfare technology, which in one way or another, improves the lives of those who need it. When technology is used specifically for communication with others, it is associated with reduced loneliness [4,13-16] and increased well-being and life satisfaction [4] in older populations. Technology can improve social connectedness among older adults. The specific effectiveness rates favor ICT and videoconferencing [13]. Chen and Schultz [15] identified 4 important mechanisms for reducing social isolation using ICT: staying connected to other people, such as family and friends; gaining social support; participating in interesting activities; and boosting self-confidence. Studies show that ICT can support and maintain the social relationships and healthy and independent lives of older people at the individual level and should be prioritized as an early and preventive intervention in social services [17]. However, the use of ICT has been shown to decrease after 6 months of use [15,16]. Only few studies have investigated how the implementation of web-based social activities in social services can be performed. Thus, there is a need for sustainable, structured, and well-planned solutions for the implementation of ICT in social services.

To make ICT useful for older people, social services must consider the determinants for its implementation, that is, barriers to and facilitators of implementation. Determinants related to older people are reported in several studies. A literature review including 59 papers identified determinants related to this specific population’s adoption of technology, such as perceived usefulness, potential benefits, user friendliness, ease of learning, perceived costs and savings, knowledge about existence, availability in the market, technical support, social support, perceived emotional and psychological benefits, and relevance with their previous experiences [18]. Other identified determinants related to older people are gaps in ICT literacy, fear of making mistakes when learning the ICT tool [19], privacy concerns, technical difficulties, lack of user-friendly options designed specifically for an older population, and lack of experience in using technology [20,21]. However, implementation of ICT does not depend on the older people alone. Social services personnel have an important role in introducing ICT to older people and to support its use [22]. Thus, ways of working to introduce and support the use of ICT among older people need to be implemented in the social services and other services they offer. To the best of our knowledge, determinants of implementing an ICT tool for social interaction among older people related to the social services personnel perspective are lacking.

The readiness and maturity to adopt digitalization and new ways of working vary among the social services provided by Swedish municipalities, for example, in residential care services and home care services. Few older people receive access to welfare technology services despite the benefits [23]. It is a large step for an organization to move from a limited project to implementation in their organization. Konttila et al [24] identified determinants of importance for digitalization in health care but not specifically for the care of older people, related to professionals’ knowledge, skills, attitudes, and experiences and organizational and collegial support. One of the proposals from the Swedish Ministry of Health and Social Affairs [23] is that studies are needed to implement models for welfare technology in social services. A systematic review focused on facilitators and barriers that influence the implementation of welfare technology for older people, from the perspectives of older individuals, people with disabilities, informal caregivers, health and care personnel, organizations, infrastructure, and technology [25]. Overall, 6 themes of determinants were identified: capacity, attitudes and values, health, expectations of effects, shared decision-making, and identity and lifestyle. These determinants are within different levels in an organization and are consistent with other determinant frameworks for implementation [26,27]. However, most of the included papers in the systematic reviews of determinants for digitalization and implementation of welfare technology for older people [24,25] involved various types of technology, such as technology for smart homes, mobile devices in medicine and public health, self-care, medication, and surveillance systems, whereas ICT used specifically for communication among older people was not included. This study aimed to explore the determinants of implementing the Fik® room, a new, co-designed, and research-based ICT tool for social interaction among older people, from a social services personnel perspective.

**Methods**

**Design**

This study used an exploratory, qualitative design [28,29]. An exploratory design is appropriate for conducting studies in a field that is relatively underexplored and hence, an inductive approach was adopted [30].
The Fik@ room: An ICT Tool for Social Interaction Among Older People

The Fik@ room is a research-based ICT tool, in the form of a web platform for safe web-based social interaction, created and developed by researchers in coproduction with older people aged ≥60 years, municipal health and social care personnel, and an IT company, based on focus group interviews and workshops. The content and design of the Fik@ room was based on the needs and wishes expressed by older people [31]. The older people who participated in the development process in 2019 and 2020 expressed the importance of knowing that others visiting the Fik@ room were equal, that is, experiencing loneliness, and access to the Fik@ room was protected by an individual password. This log-in procedure contributes to increase the safety and the feeling thereof for the older people. All older people with access to the Fik@ room have received personal log-ins from a contact person from the municipality. People who received log-ins were older people who had experienced loneliness or social isolation [31]. The Fik@ room consists of digital coffee tables with seating for up to 4 people at each table (Figure 1). The older people can start conversations regarding topics of their own choice using video, voice, or chat. They can also post messages to each other on a bulletin board. In the Fik@ room, older people can meet new friends and socialize as a way of forming routines in their everyday lives. The Fik@ room focuses on meeting peers (people in the same situation) and offers the opportunity to meet and discuss subjects related to users’ interests. This foundation improves the quality of conversations in the Fik@ room and increases independence, participation, accessibility, and options for users to form their own social interactions as part of their everyday lives, which is associated with better quality of life for older people [17]. The Fik@ room is available on Google Play Store and Apple App Store (for iPad devices) but will not be available for logging in without permission from an authorized gatekeeper such as personnel in the municipality.

Figure 1. Illustration of a digital coffee table within the Fik@ room. The conversation theme of this table is sports, and in this example, only 1 person is attending.

Informants and Settings

The ICT tool was tested in an intervention study performed in May and June 2021 in 2 medium-sized municipalities in the middle of Sweden. The 2 municipalities were chosen because they are coproduction partners of the University and were both involved in the development of the Fik@ room. Informants in this study were social services personnel, with experiences of the intervention study and thus the implementation of this specific ICT tool in social services: municipal social services managers and social services personnel who recommended the ICT tool to older people in the intervention study (Table 1). The informants were chosen using a purposive sampling technique to capture different perspectives and experiences from the stakeholders in the implementation process, which provided the
process with experience-related information and theory-based knowledge. In total, 9 informants from the 2 municipalities agreed to participate, who were basically all the people involved in the implementation process. Municipality 1 had an ongoing digitalization project running in parallel with the intervention study. This means that the municipality was appointed by The Swedish Association of Local Authorities and Regions as 1 of 10 model municipalities, which would function as a model for the digitalization of care for older people. These 10 municipalities received extra financial support to enable time for knowledge dissemination. Together with The Swedish Association of Local Authorities and Regions, they support other municipalities with knowledge about digital services and welfare technology. Municipality 2 was not involved in the parallel, ongoing digitalization project.

Table 1. Characteristics of the informants and settings.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Municipality 1 (n=6)</th>
<th>Municipality 2 (n=3)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex of the informants, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2 (33)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Female</td>
<td>4 (67)</td>
<td>3 (100)</td>
</tr>
<tr>
<td><strong>Profession of the informants, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manager</td>
<td>2 (33)</td>
<td>1 (33)</td>
</tr>
<tr>
<td>Developer</td>
<td>1 (17)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>0 (0)</td>
<td>1 (33)</td>
</tr>
<tr>
<td>Technology supporter^a</td>
<td>2 (33)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Guide for older people^b</td>
<td>1 (17)</td>
<td>1 (33)</td>
</tr>
<tr>
<td>Ongoing digitalization project</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

^aTechnology supporters were IT experts, employed in the municipality, who prepared the iPad devices for the older people in the intervention study by installing SIM cards and connecting them to the network and installing the Fik@ room app.

^bGuides for older people were social services personnel with experience in IT, employed in the municipality, who worked at the meeting places for older people and supported the older individuals regarding the use of the iPad and the Fik@ room app.

**Data Collection**

Participatory workshops with 2 researchers acting as workshop leaders provided a valuable opportunity to learn together and discuss several perspectives. The informants both generated and analyzed data through a structured process for data collection and analysis that includes a combination of individual and group activities, inspired by the effect modifier assessment (EMA) method [32]. The EMA method consists of workshops and subsequent analyses. The workshop leaders facilitate the collection of information on past significant events; in this study, the event in focus was the introduction of the Fik@ room to older people. The method facilitates a combination of individual and group activities, which implies that all experiences from each informant is used and then developed in a group discussion. In this study, semiquantitative estimations were not used because all the determinants (barriers and facilitators) were considered important regardless of how many people had experienced them. The workshop guide (Multimedia Appendix 1) could be considered as a semstructured interview guide, but the workshop informants interactively influenced the interview guide by deciding what events and in what way the events are discussed. Each informant participated in 1 or 2 participatory workshops in August and September 2021, in groups of 3 to 6 participants. Each workshop began with casual conversation to help the informants feel at ease and more comfortable in the setting. The researchers served as workshop leaders to encourage a flow of discussion. To create a comfortable environment for the informants, the workshops were conducted separately for each municipality, ensuring that all the informants within a workshop were familiar with one another. The participatory workshop consisted of 2 parts. The first part focused on the determinants for implementing the ICT tool, and the workshop activities involved the identification of possibilities, obstacles, and challenges that were experienced during the intervention study. The first workshop leader (JF) asked the informants to individually note the possibilities, obstacles, and challenges on a paper in front of them and, thereafter, facilitated a group discussion regarding the same questions. The second workshop leader (CE) asked clarifying questions during the workshop and summarized the discussion at the end of the workshop. The second part started with a review of the first part, followed by the same individual and group processes as the first part, focusing on scenarios for the development of methods to support the implementation of the ICT tool. The workshop activities were regarding how to overcome the obstacles and reinforce the possibilities identified in the first part of the participatory workshop.

The workshops were performed using a web-based video communication tool, Microsoft Teams (Microsoft Corp). Municipality 1 performed the 2 parts of the workshop in separate sessions (2 hours each), and municipality 2 performed both the parts in the same session (2 hours). The informants’ professions were requested at the beginning of the first workshop. The workshops were video recorded using the Microsoft Teams video platform.
Data Analysis

The data were analyzed using qualitative content analysis with an inductive approach [33]. The recordings were transcribed verbatim. The text was read several times for familiarization. Meaning units related to the determinants for implementing the ICT tool for social interaction among older people from the perspectives of the social services personnel were identified, coded, and grouped into subcategories and categories according to similarities. Examples of the abstraction of categories from meaning units are shown in Table 2. The identification of meaning units and categorization were performed by the first author. To validate the analysis, part of the categorization was also performed by 2 other authors (CE and PvHW) separately. In addition, the analysis was regularly discussed and validated among all the authors during the process to achieve consensus.

Table 2. Examples of the abstraction process: meaning units, codes, subcategories, and categories.

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Code</th>
<th>Subcategory</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>...That they [the personnel] have a login so when they are there, they [personnel and older person] can talk to each other at a table [within the ICT tool] just like we did.</td>
<td>Be able to log in to the ICT tool</td>
<td>Be able to show the tool</td>
<td>Be able to introduce the ICT tool in an appropriate manner</td>
</tr>
<tr>
<td>If it had been as usual [before the pandemic] then we would have done the same at home visits, and it would have been much easier because then you can show this leaflet, talk about it, and sell it in a better way, so it would have been much better.</td>
<td>Easy to show in person</td>
<td>Be able to show the tool</td>
<td>Be able to introduce the ICT tool in an appropriate manner</td>
</tr>
<tr>
<td>The pandemic, of course, because it has not been possible to visit people. They have not wanted to let us in, and not even homecare staff have been able to visit some people. They have declined home care and arranged help in another way because they do not want to expose themselves to the coronavirus.</td>
<td>The pandemic hindered in-person visits</td>
<td>Be able to show the tool</td>
<td>Be able to introduce the ICT tool in an appropriate manner</td>
</tr>
</tbody>
</table>

aICT: information and communication technology.

Ethical Considerations

This study was conducted in accordance with the Declaration of Helsinki [34] and Swedish Ethical Review Act [35]. However, according to the act, ethics approval by the Swedish Ethical Review Authority is not needed when, for example, sensitive personal data are not collected (ie, when interviewing staff to determine how they perform their work), as in this study. However, the intervention study (in which older people were study participants) has obtained ethics approval by the Swedish Ethical Review Authority (Dno 2020-06640). Participation was voluntary, and all informants provided their verbal consent after receiving verbal and written information. Furthermore, they were allowed to withdraw at any time without consequences.

Results

Overview

The results included 7 categories of determinants for implementing the ICT tool: be able to introduce the ICT tool in an appropriate manner, organizational structure, leadership, digital maturity of the social services personnel, resources, IT support, and legal liability (Textbox 1). The results are presented using the categories as headings, and the subcategories are italicized in the text.
 textbox 1. categories and subcategories of determinants for implementing the information and communication technology (ict) tool for social interaction among older people.

be able to introduce the ict tool in an appropriate manner

- to tailor the information
- be able to show the ict tool
- to let the user practice
- the personnel need to have knowledge about the ict tool

organizational structure

- a system for effective communication
- clear roles

leadership

- the manager’s engagement
- enthusiasts

the digital maturity of the social services personnel

- the personnel’s digital skills
- the attitudes among the personnel varied

resources

- costs
- time
- access to transport

it support

- accessibility
- follow-up system

legal liability (no subcategories)

be able to introduce the ict tool in an appropriate manner

older people need to be informed about the existence of the ict tool. reaching all potential users with information about the tool was a challenge that the informants did not know how to address. they found that written information sent via mail reached many potential users and was easy to distribute. however, when introducing the ict tool to an older person, the informants found it important to tailor the information, for example, the amount of information that the older person was able to receive, according to their knowledge and attitude toward ict. knowing the person and meeting in person facilitated tailoring compared with written information and web-based meetings:

i have to know how to structure the conversation with the person i am calling, and i also have to do that when i call the person because i have to hear what status the person has, how should i handle the person, i.e., how should i structure my conversation so that i establish good communication with the person. i must choose my conversational tone mode, how i present it, and how i tell it, a lot is about structuring the conversation and i have to do that immediately when i get in touch with the person. [informant 4]

when introducing the ict tool, the informants found it important to be able to show the tool. to enable this, the personnel also needed to have the prerequisites to log in to the ict tool, which was not always a matter of course. the personnel also needed to have access to their own account, and the program needed to be installed in their digital equipment. to reduce older people’s fear of digital tools, the informants found it important to let the users practice using digital tools in a playful manner. getting acquainted with digital equipment, such as tablets or computers, through playing games, watching movies, or reading newspapers can improve the ease of use of other digital tools such as the ict tool. some meeting places for older people offered these practices and integrated digital tools into their daily services. during the covid-19 pandemic, in-person visits were not always possible but were considered a prerequisite for showing and practicing the ict tool:

to dare to use the tablet...to use it for something they are familiar with, read the newspaper or whatever it may be, as a first step. it may not be the ict tool that is the first step, but it may be the next step when they have learned to use the tablet. a game can be a little
easier or reading the newspaper can be an easier way to start using it and then you take the next step. [Informant 7]

To be able to provide information regarding the ICT tool, personnel need to have knowledge about it. The informants perceived the written information regarding the ICT tool as useful for understanding the purpose of the tool. However, it was difficult to inform older people about a tool without knowing how it looked or how it worked. Having both seen and tried the tool made the personnel more confident when informing older people about it:

It was great that we got to try the ICT tool first, because it also makes it easier when you are out with the user to show them how it works because you actually know what the picture looks like, how the sound sounds, what happens with the sound if we sit too close to each other. So, I thought it was great, you need to try it first. [Informant 6]

Organizational Structure

When implementing the ICT tool, the informants perceived it as important to have a system for effective communication within the organization. A secure electronic communication system regarding personal data worked appropriately for communication among different parts of the organization regarding lists of potential users, who to call, who would visit whom, information needed for home visits, and so on. After the personnel had visited an older person, they used the same system for feedback about the visit and to document whether further support was needed. The informants also highlighted the importance of feedback among different levels within the organization, such as to the management team by whom new decisions could be made:

Lists were created so that we had a structure on which we had called, who would go to whom, all the information needed to make a home visit and even be able to write when you had been there, and it was a completed project...So, it was a very good structure in the lists. [Informant 3]

Spontaneously, I would say that some structure will be required for the recruitment of these [older] people. [Informant 2]

The informants expressed that clear roles facilitated the implementation of the ICT tool. Clarity about whom to ask regarding a special issue, whom to ask for support, and so on makes the work more efficient. Similarly, the person who holds the role knows what duties come with the role. They experienced that the implementation was facilitated if the selected personnel performed the introduction, skills training, and support of the ICT tool:

I thought a bit about this regarding whom to contact and so on. It should be incredibly clear, both for our users but for the employees as well. They should not have to think “who are we to contact to get support for this?” but there must be somewhere very, very clear so it can be done quickly, so that you do not have to run around and look and waste time looking for who to contact. [Informant 7]

Leadership

The informants expressed that the manager’s engagement was important to the implementation, and it became obvious when engagement was lacking. A manager who was open to the ICT tool and interested in its implementation spread their engagement to the rest of the working group. According to the participants, another success factor was having enthusiasts or champions as leaders. These were selected personnel with a clear mandate within the organization who had extra knowledge about ICT, who worked actively regarding its implementation, and who regulated the entire process:

That it is someone who owns the question, who has the question on their table, who is the one who then ensures that it is followed up, and the continuity of the whole thing I think is very important. [Informant 6]

The Digital Maturity of the Social Services Personnel

The implementation of the ICT tool was affected by the social services personnel’s digital skills. According to the informants, some of the personnel did not know how digital equipment worked, such as a tablet, which hindered them from informing others about and supporting the use of the ICT tool:

The personnel couldn’t use a tablet either, you had to give them basic instructions on how to press the button to start it up. Of course, there were also those who were very talented. But you might think that it is only the older people that don’t have the skills, but it is actually the personnel too. [Informant 3]

The informants expressed that the attitudes among the social services personnel varied. Some were very interested, and the implementation was conducted smoothly. In other parts of the organization, the personnel did not even talk about the ICT tool. The informants thought that an ICT tool that can be used by both older people and personnel would create great interest among the personnel compared with a tool that can be used only by older people. For example, the personnel could conduct lectures or discussions about health-related subjects, such as diet and exercise, within the ICT tool. The informants thought that this digitalization investment had a positive impact on personnel’s attitudes toward digital tools, which provided synergies and paved the way for the implementation of this specific ICT tool:

Yes, but what if we can have a table where we can talk about health and diet, and those who want to can come in and hear, listen, or participate in discussions. [Informant 2]

Resources

Implementation requires resources of various types. In this case, the informants highlighted resources regarding costs, time, and access to transportation. They expressed concern about the costs that would be required to gain access to the tool and support. The implementation of the ICT tool would be at the expense of something else. According to the informants, a
payment model based on different fees, depending on what is included, may facilitate implementation:

If you start from the scenario that it is the municipalities that in some way buy a license or something similar for the ICT tool, then the payment model itself could be for a lower amount if the municipality itself, so to speak, moderates what is said and not, and perhaps a higher amount then if it is a company who would be responsible for it.  
[Informant 5]

Implementation takes time, and some of the most time-consuming parts, as mentioned by the informants, were sending and following up on information letters, delivering tablets, creating log-ins, and showing users what to do. The informants felt that time had been allocated at different levels (eg, to key individuals within the digitalization investment area of the model municipality):

It does not matter what we are going to do, time is required. And if you have decided to make a change like this, you should be aware that time is needed. So, it is obvious that it is something that really needs to be considered if it would be implemented somewhere else as well. That you actually make sure you have that time and resources, it costs to implement something, but in the end, it can generate so much more.  
[Informant 7]

Access to transportation is a prerequisite for home visits. The informants experienced that there are always cars available as a means of transportation for home visits.

IT Support

The accessibility of the support, both for the users and personnel, was perceived as important for implementing the ICT tool. Contact information needed to be available, and it was preferable if all support could be reached using the same contact method (eg, the same phone number or email address). In addition, time needs to be allocated for support. According to the informants, support not only involved direct contact with the user but also involved communication with and recurring feedback between the supporters and the personnel. Support could be provided through various forums to increase accessibility, such as during home visits, at meeting places for older people, or at the public library. Support could also be provided via other digital media, which hindered accessibility, as the requested support was sometimes related to the difficulties in handling the digital equipment itself and, thus, also the digital support. During the COVID-19 pandemic, the accessibility of support was particularly limited, as digital support could not be received owing to some users’ lack of skills, and the older people did not accept home visits owing to the risk of spreading the infection:

What needs to be strengthened is time, it is the key that we have talked about. It was also what was difficult, but we also saw that what still worked well was when there was allocated time for various steps: time to be at home with the user to practice and provide support and follow-ups, but also time for communication with personnel and recurring feedback: to ask how it works out. So, I think that resources and time really need to be strengthened, then you have all the prerequisites to succeed.  
[Informant 6]

The personnel lacked a follow-up system for support. They expressed a need to be able to follow up regarding whether the user had used the ICT tool to facilitate implementation. It was not possible to assess whether the older person understood how to use the ICT tool after a short introduction. The informants suggested that it should be possible to obtain information about the number of log-ins on the ICT tool to be able to follow up with users who have few log-ins:

It would be interesting to get feedback on if these users have not been in at all. Then you could have maybe called them and asked: How are you? Do you want more help?  
[Informant 9]

Legal Liability

The informants expressed doubts about whether the municipalities complied with the legislation if the ICT tool was offered by the municipality and used inappropriately, such as the use of racist statements. There was a concern that the municipality cannot guarantee that nothing inappropriate is said within the ICT tool without some form of supervisory function. Therefore, it was proposed that a moderator of the ICT tool could perform that function:

If the municipality buys it, we stand as some form of guarantor, we also have a responsibility not to release that freely, but to have some form of moderating function that can support what is said. Because racist statements may be used, for example, and then we also have a responsibility to take care of it.  
[Informant 5]

Discussion

Principal Findings

The results included 7 categories of determinants for implementing the ICT tool. Being able to introduce the ICT tool in an appropriate manner concerns the personnel’s options for introducing and supporting the ICT tool, including their competencies in using digital equipment. Organizational structure concerns a structure for communication within the organization. Leadership concerns engagement and enthusiasm as driving forces for implementation. The digital maturity of the social services personnel concerns the personnel’s skills and attitudes toward using digital equipment. Resources concern time and money. IT support concerns accessibility, and legal liability concerns possibilities to fulfill legal responsibilities.

Comparison With Previous Studies

Determinants of implementing ICT tools related to older people have been reported in several studies and systematic reviews [18-21]. The novelty of our study lies in its knowledge about the determinants of implementing a new, co-designed, and research-based web platform, customized specifically for older adults, from a social services personnel perspective. The
determinants identified in this study are concretized to increase the understanding of specific factors that influence the implementation of an ICT tool for social interaction among older people. Damschroder et al [27] and Flottorp et al [26] highlighted several domains of determinants, including factors related to the implemented intervention itself (in this case, the ICT tool) and patient factors. These 2 domains are not presented in our results but are reported in a related article [22]. The social services personnel’s view about the determinants identified in this study were mainly related to the interaction between the personnel and older individual, and organizational factors. Our findings differ from those of other studies describing older people’s views about determinants, which were mainly related to their own capacity, attitudes, and health-related benefits and the usefulness and ease of learning the technical tool [18-22]. However, the interaction between the professional and the older individual relates to strategies for supporting older people to overcome barriers mentioned as determinants by the older people themselves. Thus, although the determinants mentioned by social services personnel and older people differ, they are logically interconnected. The 7 categories of determinants reported in the study correspond to the following domains reported in the paper by Flottorp et al [26]: individual health professional factors; professional interactions; incentives and resources; capacity for organizational change; and social, political, and legal factors. Some of the factors within these domains were not mentioned as determinants by the informants in our study, such as the continuing education system, assistance (external) for organizational change, contracts, and political stability. As they were not mentioned by the informants, we interpreted them to be of less importance in this specific case.

Most of the identified determinants in our study were related to contextual factors at different levels, which confirms that contextual determinants play an important role in implementation [36]. Nilsen and Bernhardsson [36] highlighted contextual factors as determinants at the micro (interaction between the professional and patient), meso (the organization), and macro (influences from the wide environment) levels. The micro-meso-macro framework for analysis is a useful way of understanding the determinants of implementation, as implementation is a multilevel phenomenon [37]. In this study, the contextual determinants mostly involved the micro (be able to introduce the ICT tool in an appropriate manner) and meso levels (organizational structure, leadership, resources, and IT support). Only 1 category was identified at the macro level (legal liability). The Lancet and Financial Times Commission on Governing Health Futures 2030 [38] recommends interventions at the macro level to facilitate the digitalization of health and social care to achieve future health and well-being. From the perspective of the personnel, the impact of the identified determinants likely differs. As macrolevel determinants were not mentioned by the informants to the same extent as microlevel and mesolevel determinants, it could be assumed that macrolevel determinants were not perceived to have as great an impact as micro- and mesolevel determinants on the implementation of the ICT tool.

A category of determinants that we identified, the digital maturity of the social services personnel, was related to individual health professional factors according to the checklist by Flottorp et al [26] and, in particular, knowledge, skills, and cognition. A lack of digital competence has been identified across all professions within social services in Sweden, and the development of the personnel’s competence is stated to be a success factor when implementing welfare technology in social services [23]. Konttila et al [24] recommend that learning how to use technical devices should be integrated into the personnel’s daily work by providing education and sufficient time for learning. In previous studies, knowledge and skills primarily focused on digital and technical aspects. However, our results in the category, be able to introduce the ICT tool in an appropriate manner, also emphasize the importance of the personnel’s pedagogical knowledge and skills in teaching older people how to use an ICT tool. This introduces additional demands on the personnel that must be considered when implementing an ICT tool in social services.

Our results are consistent with the barriers to and facilitators of the implementation of welfare technology identified by Zander et al [25]. All our identified determinants correspond to the themes reported by Zander et al [25] regarding capacity, attitudes, and values. In addition, we identified enthusiasts, as part of the leadership category, as an important driving force for implementation, which was not explicitly mentioned by Zander et al [25]. However, similarity can be seen with the theme of participation, as Zander et al [25] discussed the importance of involvement in the development, decision-making, and implementation processes as a facilitator of implementation. A theme of determinants that Zander et al [25] identified but were not identified in our results was expectations. Expectations were seen as a barrier to the implementation of welfare technology and were related to fear that the technology would affect the quality of care, threats to professional identity, and fear of losing jobs. It is possible that the ICT tool in our study was not perceived as a threat against the personnel’s professional role, as it did not directly affect the quality of care or replace the care provider. It is also important to remember that the technology used in the literature review by Zander et al [25] did not include ICT used specifically for communication among older people, which can explain the differences in the results.

According to our results, enthusiasts seemed to be an important facilitating determinant for implementation. Enthusiasts can also be described as champions or local opinion leaders, depending on whether they are appointed by the management or considered informal, educationally influential leaders appointed by peers [39]. In our results, we interpret enthusiasts more consistently with the definition of champions. However, it remains unclear whether the enthusiasts only function through managerial status and process or also function through social influence, such as an opinion leader. To support implementation, the evidence for the role of local opinion leaders is more robust than that for champions, and it seems that involvement of local opinion leaders is an effective implementation strategy [39,40]. To understand the impact mechanisms of enthusiasts, the role and significance of enthusiasts need further clarification.

One of the 2 municipalities included was a model municipality for the digitalization of care for older people, which contributed
to an important difference between these municipalities. The informants from the model municipality expressed the determinants by describing their own experiences as facilitators (eg, their experiences regarding how a system for effective communication among personnel facilitated the implementation of the ICT tool). The other municipality talked about the same determinant as a barrier, that is, the lack of a system for effective communication. It was obvious that the digitalization project positively influenced the implementation of the ICT tool, which also confirms the importance of determinants related to the organization. Although the ICT tool was supposed to be easy to use for older people [31], it is still important to have an organizational structure to support the older people in using the ICT tool. Previous studies highlight the importance of a shared vision within the organization for the implementation and involvement of leadership [25]. These determinants were perceived by the informants in the model municipality. They also experienced other facilitators identified in previous studies, such as a system for communication, clearly defined roles, enthusiasts, access to IT support, and resources that facilitated the implementation [24,25]. Digital maturity appears to be great in the model municipality, which also affected the implementation of the ICT tool.

Implementation is more likely to be successful if implementation strategies are chosen based on an assessment of determinants (facilitators and barriers) of implementation [40]. However, when selecting the implementation strategies, consideration must also be given to the effectiveness of different strategies based on well-designed studies and systematic reviews, the phases—implementation or maintenance—of the actual implementation process [41], and the theoretical underpinnings of the implementation [42,43]. Our findings can contribute to increasing the understanding of the complexity of implementing an ICT tool for social interaction among older people in municipal settings and guide the choice of implementation strategies.

Several studies have explored the determinants of using ICT tools, often in relation to older people. ICT tools can mean different types of technology that are used in health and social care and used by older people outside health and social care. Most ICT tools studied are not designed specifically for older people [18-21,23-25]. In this study, determinants are explored in the model municipality, which also affected the implementation of the ICT tool. Previous studies highlight the importance of a shared vision within the organization for the implementation and involvement of leadership [25]. These determinants were perceived by the informants in the model municipality. They also experienced other facilitators identified in previous studies, such as a system for communication, clearly defined roles, enthusiasts, access to IT support, and resources that facilitated the implementation [24,25]. Digital maturity appears to be great in the model municipality, which also affected the implementation of the ICT tool.

Strengths and Limitations

As determinants for improving professional practice have been identified at different levels [26,41], we wanted to include the informants involved in the implementation of the ICT tool in different ways. The combination of informants working with leadership and informants working directly with the older people in different ways enabled a comprehensive understanding of the determinants of the implementation of an ICT tool for social interaction among older people in municipal settings. It would have been desirable to have more informants from municipality 2. Although the study only included 9 informants, these informants had specific experiences pertinent to the study’s aim by being involved in the intervention study that introduced the Fik® room to older people. Taken together with the specific phenomenon in question and a narrowly defined objective, the data were considered to have sufficient information power [44].

The use of participatory workshops inspired by the EMA method [32] contributed to a systematic approach to data collection and opportunities to learn from each other. The combination of individual and group activities meant that all experiences from each informant were used and developed in group discussions, which contributed to multifaceted and rich data. By including a second part of the workshop, focusing on how to overcome obstacles and reinforce the possibilities identified in the first part of the workshop, we were able to further use the informants’ thoughts and experiences.

Owing to the COVID-19 pandemic, the workshops were performed using the web-based video communication tool, Microsoft Teams. Although conducting qualitative studies over the internet facilitated the informants’ participation, it also involved some challenges [45]. A challenge was the informants’ familiarity with technological hardware and software. In this case, the informants had access to a reliable internet connection and a computer with a microphone and camera. The video communication tool, Microsoft Teams, was chosen because the informants were already familiar with this program because it was used in their organizations. All the informants (9/9, 100%) used digital communication tools in their daily work and were familiar with how to communicate using them. Another challenge is that web-based interviews seem to generate short responses and less contextual information [45], which could also apply to web-based workshops. Compared with in-person workshops, web-based groups need to be small, and 4 to 6 participants are recommended [45]. Therefore, we included a maximum of 6 informants in each workshop group. It might be a limitation that the informants in the workshops knew each other. A power imbalance might have occurred between managers and employees, which might have limited the issues that were raised for discussion during the workshops. However, the opinion of the 2 researchers participating in the workshops was that the informants spoke freely regarding the barriers to and facilitators of implementing the ICT tool. The fact that the implementation of the ICT tool was a project might have stimulated the informants to speak more freely than they might have done if the ICT tool was implemented as compulsory working task.

An exploratory design was considered appropriate for conducting research in this relatively underexplored field and thus, we adopted an inductive approach [30]. The choice of design was made to stimulate an open and creative discussion to enable the identification of new areas of determinants. In hindsight, a deductive approach would also have been possible to use because our results proved to be consistent with the checklist by Flottorp et al [26]. However, the use of the inductive approach contributed to a deep understanding of the determinants of implementing an ICT tool for social interaction among older people.
The findings present the determinants for the implementation of an ICT tool for social interaction among older people in municipal settings, but the determinants related to the ICT tool itself and older people are presented in a related article [22]. This division may complicate the possibility of obtaining an overall picture of the current determinants of importance for the implementation of the ICT tool. To make this easy for the reader, we refer to the related article by Gusdal et al [22] in the text.

The careful description of the data collection process and illustration of the findings with quotations increased the confirmability of the findings. Trustworthiness was strengthened through regular discussions among the authors during the analyses. The agreement between our findings and those of previous studies regarding the determinants of implementation in general [26] and implementation of welfare technology for older people in particular [25] increases the credibility of our findings, which is an important strength of our study and indicates wide transferability of the findings to the implementation of other ICT tools for older people in other contexts. However, the trustworthiness and transferability of the study results should be considered with caution because there were only 9 informants from 2 municipalities involved. Despite the small sample size, the study revealed important aspects to be considered when implementing ICT tools in municipality social services.

This study was conducted during the COVID-19 pandemic. The purpose was not to relate the results to the situation of older people specifically during the pandemic. However, the pandemic has probably affected the results in different ways. The problem of loneliness among older people increased during the COVID-19 pandemic [9-12], which increased the need for new solutions for communication among older people. This may have affected the attitude of both the older people and the personnel participating in this study toward ICT tools. The difficulties with meeting older people in person are also strongly associated with the restrictions during the pandemic and might have affected the results as the personnel did not have the prerequisites to meet older people and introduce the ICT tool (and the hardware) in the same way as without the pandemic and physical restrictions. Therefore, determinants with a direct connection to the pandemic are not as relevant during periods without a pandemic.

Conclusions

The ICT tool discussed in this study will be used by older people in their homes for the purpose of social interaction. Although the ICT tool is for use by older people in their homes, with limited involvement of others, the results show that the implementation involves an entire organization at different levels. Specifically, the following may be required: ability of the personnel to introduce and support the ICT tool, including their competencies in using digital equipment; structure for communication within an organization; leadership as a driving force; sufficient resources; and possibilities to fulfill legal responsibilities. Regardless of how much each level within the organization comes into direct contact with the ICT tool, all levels need to be involved to create the necessary conditions for successful implementation. The prerequisites for the implementation of an ICT tool will probably change depending on the digital maturity of future generations. As this study only included 9 informants, the results should be considered with caution. The study was performed during the COVID-19 pandemic, which has probably affected the results.

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Data Availability

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

Authors’ Contributions

JF, CE, AKG, RMJP, and PvHW were involved in the methodology of the study. JF and CE conducted the workshops. JF conducted the content analysis and wrote the original draft. CE, AKG, RMJP, and PvHW supported the analysis and contributed to reviewing and editing the paper.

Conflicts of Interest

Coauthors CE, AKG, RMJP and PvHW own equity in the Fik® room, a company that might benefit from this study’s findings. The company was founded after the data collection of this study and aims to make the Fik® room available for its target audience. The first author (JF) led data analysis and manuscript preparation to ensure objectivity in the research.

Multimedia Appendix 1

Workshop guide.

[PDF File (Adobe PDF File), 110 KB - aging_v7i1e43999_app1.pdf ]
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Abbreviations

EMA: effect modifier assessment
ICT: information and communication technology

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Development and Usability Testing of a Mobile App–Based Clinical Decision Support System for Delirium: Randomized Crossover Trial

Jiamin Wang¹,²*, PhD; Meihua Ji²*, PhD; Yuan Han³, MSN; Ying Wu², PhD

Abstract

Background: The 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium (3D-CAM) is an instrument specially developed for the assessment of delirium in general wards, with high reported sensitivity and specificity. However, the use of the 3D-CAM by bedside nurses in routine practice showed relatively poor usability, with multiple human errors during assessment.

Objective: This study aimed to develop a mobile app–based delirium assessment tool based on the 3D-CAM and evaluate its usability among older patients by bedside nurses.

Methods: The Delirium Assessment Tool With Decision Support Based on the 3D-CAM (3D-DST) was developed to address existing issues of the 3D-CAM and optimize the assessment process. Following a randomized crossover design, questionnaires were used to evaluate the usability of the 3D-DST among older adults by bedside nurses. Meanwhile, the performances of both the 3D-DST and the 3D-CAM paper version, including the assessment completion rate, time required for completing the assessment, and the number of human errors made by nurses during assessment, were recorded, and their differences were compared.

Results: The 3D-DST included 3 assessment modules, 9 evaluation interfaces, and 16 results interfaces, with built-in reminders to guide nurses in completing the delirium assessment. In the usability testing, a total of 432 delirium assessments (216 pairs) on 148 older adults were performed by 72 bedside nurses with the 3D-CAM paper version and the 3D-DST. Compared to the 3D-CAM paper version, the mean usability score was significantly higher when using the 3D-DST (4.35 vs 3.40; P<.001). The median scores of the 6 domains of the satisfactory evaluation questionnaire for nurses using the 3D-CAM paper version and the 3D-DST were above 2.83 and 4.33 points, respectively (P<.001). The average time for completing the assessment reduced by 2.1 minutes (4.4 vs 2.3 min; P<.001) when the 3D-DST was used.

Conclusions: This study demonstrated that the 3D-DST significantly improved the efficiency of delirium assessment and was considered highly acceptable by bedside nurses.

Trial Registration: Chinese Clinical Trial Registry, ChiCTR-IOR-17,010,368, https://www.chictr.org.cn/showproj.html?proj=17671

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KEYWORDS

delirium; 3D-CAM; older adults; clinical decision support system; nurse; 3-Minute Diagnostic Interview for Confusion Assessment Method-Defined Delirium

Introduction

Delirium is a common complication that is highly prevalent among hospitalized older adults; it can affect up to 40% of hospitalized older patients [1,2]. Delirium is associated with many adverse outcomes, including cognitive and functional impairment, increased hospital stay, care burden, and mortality, and therefore leads to increased care needs and poor prognosis [3,4]. The severity of the adverse consequences of delirium are positively correlated with the severity and duration of delirium [5]. Therefore, early recognition of delirium is essential for timely management of delirium to improve the patient’s prognosis [6].

Although many clinical guidelines and representative societies have recommended the use of standardized assessment tools for daily delirium screening in clinical practice, delirium is still...
poorly recognized among hospitalized older adults [6,7]. A previous study has shown that up to 66% of older adults with delirium went unrecognized in routine practice [8]. The possible reasons for underdiagnoses of delirium include communication barrier, inadequate use of the screening tools, and a lack of education on and conceptual understanding of delirium [9].

The Confusion Assessment Method (CAM) has been used as the reference standard for delirium screening [10]. However, the use of the CAM to assess delirium requires a combination of cognitive testing and subjective judgment based on clinical experience. Lemière et al [11] found that the sensitivity on the daily use of the CAM by bedside nurses was only 30%. Therefore, to overcome the feasibility issues associated with the use of the CAM, Marcantonio et al [12] developed the 3-Minute Diagnostic Interview for CAM-Defined Delirium (3D-CAM) based on the key features of the CAM and simplified the evaluation process. The 3D-CAM was perceived as easy to use, and it had a sensitivity of 92% to 100% and a specificity of 88% to 94% among studies that were tested in different ethnic groups [12-15]. Kuczmarska et al [15] has identified that the 3D-CAM is appropriate for delirium assessment in general wards.

However, a previous study has shown that the use of the 3D-CAM by bedside nurses in routine practice demonstrated relatively poor usability, with multiple errors (such as human error, misunderstanding of item content, and incomplete or missing nursing records) during assessment [16]. The assessment of alteration on attention and thinking must be combined with cognitive assessment. During the process, nurses need to memorize, calculate, and make a judgment according to the patient’s response, which is prone to human errors. Meanwhile, the patient’s consciousness status needs to be compared with the assessment results at admission by reviewing the patient’s medical records. With these identified challenges, nurses often fail to complete the assessment successfully due to communication problems and difficulties in finding or loss of related materials. Moreover, due to the limited knowledge level on delirium among clinical nurses, adding prompts or cues to the items can effectively improve nurses’ identification of delirium, in addition to providing training on basic delirium knowledge before the use of the 3D-CAM [16]. Therefore, there is an urgent need to develop and adopt innovative ways to promote prompt delirium assessment in routine practice both effectively and accurately.

Several studies have reported that a clinical decision support system (CDSS) with some degree of autonomy may help solve this issue and improve the accuracy and adequacy of delirium assessment among bedside nurses [17,18]. Marcantonio et al [19] developed a brief app-based delirium identification tool, and it has shown good performance. Based on the Confusion Assessment Method for Intensive Care Unit (CAM-ICU), mobile apps have also been developed for delirium screening of patients in intensive care units (ICUs), and they showed acceptable usability and accuracy when used by bedside nurses [20-22]. Therefore, in this study, we aimed to develop the Delirium Assessment Tool With Decision Support Function Based on the 3D-CAM (3D-DST) and to evaluate its usability among older patients by bedside nurses.

Methods

Ethical Considerations

The research protocol and secondary data analysis were approved by the institutional review committee of Capital Medical University (2015SY49). This was a substudy under a clinical trial, which was registered at the Chinese Clinical Registry (ChiCTR-IOR-17,010,368). Verbal informed consent was obtained from each participant before the start of the program, and participants had the right to withdraw during the study. The data were anonymized. The study protocol was safe and reliable and did not provide any compensation to the participants.

Design and Development of the 3D-DST

Previous Work

The 3D-CAM was translated into Chinese in a previous study and validated by nurse researchers; it showed acceptable sensitivity and specificity among hospitalized Chinese older patients [23].

Phase 1: Analysis of Problems in the Use of the 3D-CAM

The task walkthrough method was used to fully address the end users’ needs and achieve the overall goal of automatic delirium evaluation [16].

Phase 2: Design of the 3D-DST

In this phase, we first formed a multidisciplinary team that included experts with rich experience in delirium assessment. Bedside nurses, nursing researchers, software engineers, and user interface designers who were specialized in developing nursing information systems (NISs) were involved in the designing phase. The 3D-DST was designed and developed following the American Medical Informatics Association usability design principle [24]. Details of the design principle are shown in Multimedia Appendix 1.

Evaluation Process Analysis and Optimization of the 3D-DST

Based on the evaluation content and rules of the original 3D-CAM, this study scrutinized and analyzed the 3D-CAM evaluation process, identified the best path, and reoptimized and standardized the 3D-CAM evaluation process. By optimizing the 3D-CAM evaluation process, only the necessary paths to support the delirium evaluation were reserved, unnecessary links were eliminated, and the assessment was standardized to reduce intermediate errors; thus, a clinical decision-making system for delirium screening was established. Automatic evaluation logic jumps were incorporated into the system design according to the evaluation rules. Based on the problems identified by bedside nurses and the overall goals of the system, the key functional modules of the 3D-DST were initially drafted in mind-mapping software (Xmind software, version: 3.7.4.0; XMIND LTD).
User Interface Design of the 3D-DST

Overview

The interface design was completed in several steps. First, we used AxureRP (Axure Rapid Prototyping) to draft the logical diagrams, workflow, functional components, and user interfaces of the 3D-DST. Second, we made a web page to facilitate communication with engineers and team members. This was achieved via WuliHub (a domestic data hosting and sharing platform), and the interface prototype diagram and interaction components drawn by AxureRP were uploaded into this web browser–based demonstration scheme. Via WuliHub, a set of HTML files were generated based on the interface prototypes and interaction schemes drawn by AxureRP; they were compressed and uploaded to the platform for easy sharing. Third, following the American Medical Informatics Association interface design principle, the order of the evaluation content of each interface was determined based on the evaluation content and the optimal evaluation process of the 3D-DST. Finally, the prototype design of the evaluation interface of the 3D-DST was completed with the identified functions, including evaluator registration, log-in authentication, and user log out. Corresponding functional assessment modules were also developed, along with the result-reporting interface. The 3D-DST was designed by following the existing delirium assessment system [23], with easy access and a friendly display; for example, the patient’s identification was obtained by scanning their wristband, and different color selection, buttons, and information composition were used to increase its feasibility and usability.

Phase 3: Architecture and Development of the 3D-DST

In this phase, the system architecture, databases related to personal information and assessment data, and the user interfaces were identified. The 3D-DST was developed to fit on Android-compatible devices (Huawei nova 3), as the personal digital assistant used in clinical practice was largely based on the Android system rather than the iOS system in China.

We used Java, Spring Boot, and RouYi-Vue to program the backend framework and Vue for the front-end framework. Mysql was used to formulate the databases. GitLab and Docker were used to release the 3D-DST. To make the 3D-DST system more stable, the model-view-viewmodel (MVVM) was used as the architecture scheme. The synchronization between view and model was completely automatic without human interference, the data maintenance was completely managed by the MVVM, and the operating environments were Linux and Windows [25,26]. To maintain information security, the 3D-DST set a cookie scheme with a time limit. The users needed to log in and verify their identity again when the cookie expired.

Usability Evaluation of the 3D-DST

Overview

The usability of the 3D-DST was evaluated using the acceptance questionnaire, and the results were compared to the 3D-CAM paper version when it was used by bedside nurses. The questionnaire included 6 domains regarding usability: perceived usefulness, ease of use, ease of learning, trustworthiness, intention to use, and satisfaction. The performance of the app was evaluated on 4 domains and compared to that of the 3D-CAM paper version, which included the successful completion rate of delirium assessment (proportion of nurses who completed the assessment correctly when they used the 3D-CAM paper version and the 3D-DST), evaluation completion time (time used to complete the assessment), the number of mistakes made during assessment against the results from a researcher, and satisfactory evaluation using an acceptance questionnaire.

Design, Setting, and Participants

This study was conducted among 72 bedside nurses from 3 tertiary hospitals in Beijing, China. Eligible patients from 3 internal medical wards (neurology, respiratory, and cardiology) and 1 surgical ward (orthopedic) of the study hospitals were assessed by participating bedside nurses using both the 3D-DST and the original 3D-CAM paper version. All participating patients and bedside nurses provided informed consent before study initiation.

Following convenient sampling, bedside nurses who met the following criteria were included in the usability testing phase: (1) registered nurse with a valid license; (2) had more than 1 year of working experience and had been working continuously in their department for more than 3 months; and (3) willing to participate in this research. Hospitalized older adults who were aged 65 years or older and could communicate effectively in Mandarin were included in the study, and those with identified severe visual or hearing impairment were excluded from delirium assessment. Nurses who declined to participate during the study period were also excluded from the final analysis.

Usability Evaluation

The usability evaluation of both the 3D-CAM paper version and the 3D-DST was conducted using the usability testing questionnaire designed by Feng et al [27]. The content validity index scores for the 3 areas in the questionnaire (topic suitability, topic importance, and content clarity) were 1.00, 1.00 and 0.96, respectively. Since the dimensions for evaluating the usability of the CAM-ICU and 3D-CAM are similar, the questionnaire can also be used to evaluate the usability of the 3D-CAM. In this study, we revised several items of the questionnaire to make it suitable for the 3D-CAM paper version or the 3D-DST. For example, we changed the item “I think this tool meets the requirements of ICU nurses for a delirium assessment tool” to “I think this tool meets the requirements of nurses for a delirium assessment tool in general wards.” In addition, the term “CAM-ICU” in the items evaluating the ease of use was replaced with “3D-CAM.” The reliability of the revised questionnaire was tested for overall internal consistency, and the Cronbach α coefficient was 0.907. The questionnaire was rated on a 5-point Likert scale ranging from “1=strongly disagree” to “5=strongly agree.” A higher score indicated better user acceptance. The usability evaluation was evaluated on 6 domains: perceived usefulness, ease of use, ease of learning, trustworthiness, intention to use, and user satisfaction. To evaluate the acceptability of the 3D-DST, items to evaluate the interfaces of the app were added to the questionnaire, so the
usability questionnaire contained 26 and 43 items for the 3D-CAM paper version and the 3D-DST, respectively.

Before study initiation, researchers used a computer program to generate random numbers and made an assignment sequential table. Eligible bedside nurses were numbered according to the order they participated in. One group of nurses (Group A) used the 3D-CAM paper version first to evaluate 3 patients (initial evaluation at admission and follow-up assessments during the patients’ hospitalization, including assessments of possible cognitive impairment or identified delirium). Subsequently, the same group of bedside nurses used the 3D-DST to evaluate patients with a similar admission diagnosis after 24 hours to avoid the impact of short-term memorization on the evaluation process. Conversely, nurses from the other group (Group B) used the 3D-DST first and then the 3D-CAM paper version second to evaluate 2 different sets of patients (3 patients per nurse). Nurses who participated in the study only assessed patients admitted in the wards where they worked. A nurse researcher conducted training sessions for all bedside nurses on the use of the 3D-CAM and the 3D-DST before their assessments; the nurse researcher also selected the eligible patients based on their admission diagnosis prior to being approached. Usability testing of both the 3D-CAM paper version and the 3D-DST was carried out when each set of assessment was completed (Figure 1).

Figure 1. Flowchart of participant recruitment and participation. 3D-CAM: 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium; 3D-DST: Delirium Assessment Tool With Decision Support Function Based on the 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium.
Performance of the 3D-DST

During each assessment, 1 experienced nurse researcher observed the performance of bedside nurses and completed the patients’ delirium screening using the 3D-CAM paper version at the same time. The successful completion rate of delirium assessments in terms of the proportion of correctly identified delirium, whether using the 3D-CAM paper version or the 3D-DST by bedside nurses, was recorded. In addition, the number of mistakes made during the assessments (compared to the researcher’s assessment results) and the evaluation completion time were also recorded for each nurse. Nurses were blinded to the researcher’s assessment results.

Sample Size

The highest score for each item of the usability questionnaire was 5 points (the higher the score, the better the usability). We expected that an average score of 4 or more would be achieved when the 3D-DST was used by bedside nurses, which is 1 point higher than the average score of the 3D-CAM paper version. With the SD being 1.0 and \( \alpha = 0.05 \), at least 54 bedside nurses were needed to achieve 90% power. Considering that a quarter of bedside nurses might not be able to complete the study, a final sample of 72 nurses was required for this study.

Data Analysis

SPSS software (version 21.0; IBM Corp) was used to perform the data analysis. Normally distributed variables were presented using the mean and SD, whereas nonnormally distributed variables were presented using the median and range. Categorical variables were presented with frequencies and proportions as appropriate. The \( \chi^2 \) test or Fisher exact test was used to compare the differences between nurses’ baseline data (different age groups, sex, etc) and the evaluation success rate. The comparison of evaluation completion time, the total usability score, and the impact of the sequential use of the 3D-CAM paper version and the 3D-DST between 2 groups were achieved using ANOVA. A nonparametric test was used to test the differences between the scores of each domain of the usability questionnaire and the order of using the 2 types of assessments. \( P < 0.05 \) was considered statistically significant.

Results

Design and Development of the 3D-DST

Phase 1: Analysis of Problems in the Use of the 3D-CAM Paper Version

Several problems were identified with the use of the 3D-CAM paper version by bedside nurses, including human errors, insufficient or incorrect understanding of the assessment contents, and incomplete or failed retrieval of the relevant information from the nursing record [16]. In developing the 3D-DST, the delirium evaluation process was simplified as unnecessary steps were automatically omitted after sorting out the procedural results related to specific features of the 3D-CAM. The evaluation processes of the 3D-CAM paper version and the 3D-DST are shown in Multimedia Appendices 2 and 3.

Phase 2: Design of the 3D-DST

The 3D-DST was installed on mobile phones with an Android (8.1.0) system, 128 GB, 8-core processor, and 1.8 GHz. Three evaluation modules were incorporated into the 3D-DST, reflecting the inquiry, observation, and selective evaluations. The evaluation interfaces (Figure 2) of the 3D-DST included 8 evaluation pages and 16 different evaluation result interfaces (3 delirium-positive interfaces and 13 delirium-negative interfaces).
Auxiliary reminders based on the common mistakes reported by nurses in phase 1 were added to the system. In overcoming these burdens, the 3D-DST was developed to include reminders on the correct answers regarding items 1, 2, and 5. Nurses only needed to check whether the patient’s response was consistent with the reminder or not. As the 3D-DST can automatically record and retrieve previous evaluation results, item 22 was not displayed in the 3D-DST but was incorporated into the algorithm of the 3D-DST, and the result was generated automatically. To address issues associated with “incorrect understanding of item content,” cues were incorporated into the 3D-DST to facilitate better understanding of the contents of related items (11 through 20) during assessment.

In the development of the 3D-DST, we also included functions to automatically retrieve necessary information from the record for comparison, which was incorporated into the 3D-DST. Nurses using the 3D-DST do not need to manually search and compare the previous evaluation results, which could increase the successful completion rate of the assessment.

**Usability Evaluation of the 3D-DST**

A total of 72 bedside nurses completed the usability testing of the 3D-DST. The demographic characteristics of participating bedside nurses are shown in Table 1. They were mainly female (n=67, 93%), with 44 (61%) nurses holding a bachelor’s degree. A total of 148 patients were evaluated by nurses in this study.
with 98 (66%) being female and a mean age of 76 (SD 7.18) years.

**Table 1. Demographic characteristics of the participating bedside nurses.**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Group A (n=36), n (%)</th>
<th>Group B (n=36), n (%)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age group (years)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-30</td>
<td>20 (56)</td>
<td>20 (56)</td>
<td>.93</td>
</tr>
<tr>
<td>31-47</td>
<td>16 (44)</td>
<td>16 (44)</td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td>&gt;.99</td>
</tr>
<tr>
<td>Female</td>
<td>33 (92)</td>
<td>34 (9)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3 (8)</td>
<td>2 (56)</td>
<td></td>
</tr>
<tr>
<td><strong>Education level</strong></td>
<td></td>
<td></td>
<td>&gt;.99</td>
</tr>
<tr>
<td>Junior college</td>
<td>12 (33)</td>
<td>13 (36)</td>
<td></td>
</tr>
<tr>
<td>College and above</td>
<td>24 (67)</td>
<td>23 (64)</td>
<td></td>
</tr>
<tr>
<td><strong>Work experience (years)</strong></td>
<td></td>
<td></td>
<td>.71</td>
</tr>
<tr>
<td>&lt;5</td>
<td>15 (42)</td>
<td>16 (44)</td>
<td></td>
</tr>
<tr>
<td>5-10</td>
<td>11 (31)</td>
<td>9 (25)</td>
<td></td>
</tr>
<tr>
<td>≥11</td>
<td>10 (28)</td>
<td>11 (31)</td>
<td></td>
</tr>
</tbody>
</table>

A total of 432 delirium assessments (216 pairs) were performed by the bedside nurses on 148 older adults with the 3D-CAM paper version and the 3D-DST, of which 38 (26%) older adults were confirmed as delirium positive by a nurse researcher using the 3D-CAM paper version.

The mean usability scores of bedside nurses using the 3D-CAM paper version and the 3D-DST were 3.40 (SD 0.43) and 4.35 (SD 0.31), respectively, with the score of the 3D-DST being 0.95 points higher than that of the 3D-CAM paper version (P<.001). The median scores of the 6 domains of the satisfactory evaluation questionnaire for nurses using the 3D-CAM paper version and the 3D-DST were above 2.83 points and 4.33 point, respectively. As shown in Table 2, the median scores on the ease of use, ease of learning, and trustworthiness were 1 point higher than the other 3 domains (P<.001). The total satisfactory score of the 3D-DST was higher than that of the 3D-CAM paper version (P<.001), whereas the order of assessments, whether using the 3D-CAM paper version first or the 3D-DST first, had no effect on the results.
The assessment success rate of the 3D-CAM paper version was a little lower compared to that of the 3D-DST (203/216, 94% vs 212/216, 98.1%; \(P=.045\)). The median time of assessment using the 3D-CAM paper version was 2.1 minutes longer than that of the 3D-DST (4.4 vs 2.3 min; \(P<.001\)). The overall performances of the 3D-DST and the 3D-CAM paper version are displayed in Table 3.

### Table 3: Comparison of the performances between the 3D-CAM\(^a\) paper version and the 3D-DST\(^b\) by bedside nurses.

<table>
<thead>
<tr>
<th>Performance</th>
<th>Nurses, n</th>
<th>Assessments, n</th>
<th>Group A</th>
<th>Group B</th>
<th>(P) value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Successful completion rate, n/N (%)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.045</td>
</tr>
<tr>
<td>3D-CAM paper version</td>
<td>72</td>
<td>216</td>
<td>103/108 (95.4)</td>
<td>100/108 (92.6)</td>
<td></td>
</tr>
<tr>
<td>3D-DST</td>
<td>72</td>
<td>216</td>
<td>107/108 (99.1)</td>
<td>105/108 (97.2)</td>
<td></td>
</tr>
<tr>
<td><strong>Human errors, n</strong></td>
<td></td>
<td></td>
<td>6</td>
<td>9</td>
<td>.62</td>
</tr>
<tr>
<td>3D-CAM paper version</td>
<td>72</td>
<td>N/A(^c)</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>3D-DST</td>
<td>72</td>
<td>N/A</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Evaluation completion time (min), median (IQR)</strong></td>
<td></td>
<td></td>
<td>4.45 (2.5-5.4)</td>
<td>4.35 (2.4-5.3)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>3D-CAM paper version</td>
<td>72</td>
<td>203</td>
<td>2.25 (1.25-3.55)</td>
<td>2.35 (1.4-3.6)</td>
<td></td>
</tr>
<tr>
<td>3D-DST</td>
<td>72</td>
<td>212</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(a\)3D-CAM: 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium.

\(b\)3D-DST: Delirium Assessment Tool With Decision Support Function Based on the 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium.

\(c\)N/A: not applicable.
Discussion

Principal Findings
This study described the development process of a CDSS based on the 3D-CAM and evaluated its usability in delirium screening among older patients. Our results demonstrated that the 3D-DST was perceived as highly satisfactory with acceptable usability when used by bedside nurses, and it improved the completion rate and reduced the evaluation completion time when bedside nurses used the app among older patients.

CDSSs are tools incorporated with a significant clinical knowledge base and are designed to provide users (health care professionals, patients, and caregivers) with an intelligent way to assist in clinical decision-making [28]. Previous studies have found that well-designed CDSSs are effective and can improve clinical outcomes and health processes [29]. Therefore, it is very important to ensure the quality of CDSSs and avoid unpleasant situations when deploying unreliable systems.

Functional suitability is a very important feature when developing CDSSs; it refers to the extent to which a system meets the stated and implied requirements through its functional components under certain conditions [30-32]. In our study, the 3D-DST is aimed to connect with the hospital information system or NIS, so that it can automatically retrieve the patients’ information via the hospital information system. The 3D-DST can obtain information by scanning the QR code on the patient’s wristband, which allows the 3D-DST to be easily integrated into the portable NIS and facilitates efficient delirium assessment by bedside nurses.

As indicated by the study results, the median scores on the ease of use, ease of learning, and trustworthiness of the 3D-DST were over 1 point higher than those of the 3D-CAM paper version. It was demonstrated that the development of the 3D-DST met the requirements of bedside nurses, improving the acceptability and usefulness of the screening tool. There were several possible reasons. First, the 3D-DST was designed through process optimization, which incorporated strategies such as automatic evaluation logic jumps, embedded prompts, automatic comparison function, etc. The design process made full use of information technologies, such as automatic recording, calculation, and other intelligent functions, that could effectively solve the problems identified by nurses when they used the 3D-CAM paper version. The 3D-DST was well accepted by bedside nurses, the burden on the memorization of information was reduced, and the ease of use of the 3D-CAM was improved. Second, nurses only needed to complete the evaluation process by following the interfaces and the embedded prompts. Nurses did not need to learn the specific instructions, and the system could automatically record, calculate, and output the results, therefore improving this tool’s learnability and scalability. Third, since the content of the 3D-CAM is mostly a routine assessment, nurses needed less training time to use the tool. Moreover, with reduced time to complete the delirium assessment, nurses perceived the 3D-DST as highly acceptable, which generated trustworthiness and solved the existing problems associated with the use of the 3D-CAM paper version.

The improvement of the perceived usefulness, intention to use, and satisfaction scores was less than 1 point when comparing the 3D-DST with the 3D-CAM paper version. This could be attributed to the following reasons. The scores on these 3 domains of the 3D-CAM paper version were considerably high. Perceived usefulness was mainly evaluated based on nurses’ knowledge of delirium assessment, whereas intention to use mainly referred to whether nurses were willing to use the tool and whether the nurses could accept the method of using the tool or not, notwithstanding the evaluation completion time. Since this study was only conducted in a short period of time, nurses may not fully understand and appreciate that the 3D-DST can standardize the assessment process and improve the recognition rate and accuracy of the delirium assessment. In the future, the duration that the nurses use the 3D-DST should be extended before the acceptance evaluation. Furthermore, the intention to use the 3D-DST and satisfaction perceived by nurses may be affected by organizational factors.

Our study found that the 3D-DST had a slightly higher successful completion rate than the 3D-CAM paper version in assessing delirium among bedside nurses (212/216, 98.1% vs 203/216, 94%; P=.045). In the 3D-DST, reminders of the correct responses for items 1, 2 and 5 (objectively testing patients’ cognition) were incorporated into the app, which can increase the accuracy of the delirium assessment, reduce the information processing time, and improve nurses’ work efficiency. When nurses evaluate delirium using the 3D-DST, the system will automatically record and generate the evaluation results without manual input; this prevented possible human errors that are introduced by the nurses. The 3D-DST also added prompts that aimed to reduce the assessment failure rate caused by incorrect or inadequate understanding of the content of the items. By integrating prompts into the 3D-DST, it may have contributed to the reduced failure rate among bedside nurses by guiding and standardizing the assessment process; thus, insufficient knowledge and possible human errors are fully addressed during the assessment. Therefore, the 3D-DST improved the success rate of the delirium assessment. With assistance of CDSSs, decision-making can be incorporated into the routine assessment to guide nurses to complete the assessment successfully with standardized procedures [33-35].

The advantages of the study are multifactorial. The 3D-DST was developed to solve the problems associated with the use of 3D-CAM paper version in routine practice by nurses. The research team included multidisciplinary members such as delirium assessment experts and software development engineers, and we used a combination of multiple architectures to ensure the stability of the system during the development process. In addition, in evaluating the usability and performance (completion rate, time required for completing the assessment, and the number of human errors made by nurses during the assessment) of the 3D-DST, both subjective and objective approaches were used by comparing the 3D-CAM paper version with the 3D-DST among bedside nurses, which showed the promising results of the 3D-DST.

This study also has several limitations. First, each bedside nurse only used the 3D-CAM to evaluate 6 patients, which may have limited the nurses’ possibility to evaluate all types of patients.
with different admission diagnoses in general wards. Therefore, our result may not be generalizable to other clinical settings. Second, this study only applied a quantitative approach to evaluate the usability of the 3D-DST; interviews can be added to explore the usability of the 3D-DST among bedside nurses in the future. Third, during the usability testing phase, some usability issues in our system may not be adequately reflected due to limitations in the patients’ admission types and the limited number of assessments. Fourth, bedside nurses were not physically involved in the interface design process, which may have affected the usability of the interface. However, we have examined the problems and issues associated with the use of the 3D-CAM paper version among bedside nurses, and the 3D-DST was developed to address these problems by including experienced nursing researchers during the development process, so the results should not be affected. Finally, this study did not analyze the accuracy of the 3D-DST in assessing delirium, as this was not required for the study objectives at this stage, and it was completed as a separate study.

**Conclusion**

This study demonstrated that the 3D-DST was perceived as highly acceptable and useful in assisting bedside nurses to identify delirium among older adults in routine practice. The integration of this app with existing health systems could enhance its positive impact on the efficiency and accuracy of delirium screening in the future.

**Acknowledgments**

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**Authors' Contributions**

JW contributed to conceptualization, methodology, software, and writing—original draft. MJ contributed to writing—review and editing. YH contributed to conceptualization, methodology, software, validation, formal analysis, and investigation. YW contributed to conceptualization, methodology, software, validation, resources, writing—review and editing, supervision, project administration, and funding acquisition.

**Conflicts of interest**

None declared.

Multimedia Appendix 1

Details of the design principle.

[DOCX File, 13 KB - aging_v7i1e51264_app1.docx ]

Multimedia Appendix 2

Evaluation process of the original 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium (3D-CAM) paper version.

[PNG File, 162 KB - aging_v7i1e51264_app2.png ]

Multimedia Appendix 3


[PNG File, 330 KB - aging_v7i1e51264_app3.png ]

Checklist 1

CONSORT-eHEALTH checklist (V 1.6.1).

[PDF File, 1742 KB - aging_v7i1e51264_app4.pdf ]

**References**


Abbreviations

3D-CAM: 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium
3D-DST: Delirium Assessment Tool With Decision Support Function Based on the 3-Minute Diagnostic Interview for Confusion Assessment Method–Defined Delirium
CAM: Confusion Assessment Method
CAM-ICU: Confusion Assessment Method for Intensive Care Unit
CDSS: clinical decision support system
ICU: intensive care unit
MVVM: model-view-viewmodel
NIS: nursing information system

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Original Paper

Digital Storytelling Intervention for Enhancing the Social Participation of People With Mild Cognitive Impairment: Co-Design and Usability Study

Di Zhu¹,², MAP; Abdullah Al Mahmud¹*, PhD; Wei Liu²*, PhD

¹Centre for Design Innovation, Swinburne University of Technology, Melbourne, Australia
²Beijing Key Laboratory of Applied Experimental Psychology, National Demonstration Centre for Experimental Psychology Education, Beijing Normal University, Faculty of Psychology, Beijing Normal University, Beijing, China

* these authors contributed equally

Corresponding Author:
Abdullah Al Mahmud, PhD
Centre for Design Innovation
Swinburne University of Technology
John St Hawthorn Melbourne, VIC 3122 Australia
Phone: 61 392143830
Email: aalmahmud@swin.edu.au

Abstract

Background: Community-based social participation has shown promise in delaying cognitive decline in older adults with mild cognitive impairment (MCI) who are at risk of developing dementia. Although group storytelling interventions have proven effective, the need for a skilled workforce to support people with MCI can limit broader community implementation. Technology-based interventions may offer a solution to this limitation by replicating the abilities of therapists.

Objective: This study aims to co-design a digital storytelling intervention and evaluate its usability.

Methods: This co-design process involved 3 stages, engaging people with MCI (n=12), their caregivers (n=4), and therapists (n=5) in Beijing, China. In the first stage, we used card sorting and voting methods to identify potential incentives for social participation and target the specific abilities that people with MCI wanted to enhance. In the second stage, we conducted brainstorming sessions with people with MCI and their caregivers to identify the potential features of a digital storytelling application named Huiyou (“meeting new friends” in Chinese). Finally, we assessed Huiyou’s usability with people with MCI and therapists, leading to iterative improvements based on the usability findings.

Results: We uncovered a crucial link between boosting the self-confidence of people with MCI and their ability to address social participation challenges. Notably, we identified memory improvement and enhanced language expression as key factors for effective communication with grandchildren. Subsequently, participants suggested features and interfaces to address these challenges, leading to the development of Huiyou, a group-based digital storytelling application featuring functions such as generating story materials, conducting memory retrieval activities, and sharing stories. It received an “excellent” rating in the User Experience Questionnaire benchmark, displaying high levels of attractiveness, dependability, stimulation, and novelty. People with MCI achieved an average task completion rate of 87% (n=19; SD 0.13) of the 22 tasks. However, feedback from people with MCI and therapists highlighted usability issues in navigation, activity management, user interface, and feature optimization, indicating a need for improved accessibility and efficiency.

Conclusions: The co-design approach contributed to developing the Huiyou prototype, supporting community-based social participation. User feedback highlighted the potential of Huiyou to enhance well-being and facilitate meaningful social interactions while maintaining crucial existing relationships.

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KEYWORDS
co-design; digital storytelling; people with mild cognitive impairment; MCI; technology-based intervention development; dementia; mobile phone

Introduction

Background
Social participation has proven efficacious in decelerating the progression of dementia from mild cognitive impairment (MCI) [1], particularly in low- and middle-income countries [2]. To enhance social participation among older adults with MCI, researchers are engaged in reducing the obstructions to social participation [3] and creating and customizing a variety of constructive social activities [4]. To expand social participation, researchers have explored an assortment of interventions aimed at improving memory, communication, and familial relationships among older adults with MCI [5]. Social participation is considered at different levels: societal, community, relationship, and individual levels [6]. Community involvement is defined by its significance and the sense of satisfaction it generates in people’s lives as well as its potential for creating social support [7]. Older adults reported that technology could assist them in maintaining social connections [8]. For example, researchers used cameras, enabling people with MCI to memorialize their daily lives [9]. Most interventions concentrate on enhancing cognitive abilities [10] or facilitating recreational and sports activities [11]. The former relies upon participants’ strong motivation to participate in interventions, whereas the latter has less impact on cognitive ability. Storytelling tools can simultaneously enhance cognitive abilities and create a novel form of social interaction. Incorporating storytelling as a therapeutic intervention possesses enormous potential for improving health care outcomes and promoting well-being among people with MCI [12]. Studies have demonstrated that socially isolated people with MCI may experience lower psychological well-being and exhibit more negative states of mind than older adults considered to have cognitive normality [13]. Owing to cognitive impairments, people with MCI may experience lower psychological well-being and exhibit more negative states of mind than older adults considered to have cognitive normality [13].

However, these storytelling interventions often lack a focus on community-based social activities, primarily being individual interventions without emphasis on interpersonal interactions. Furthermore, community-based programs depend on skilled facilitators, such as therapists or social workers, to maintain quality. For instance, providing training for facilitators before they lead a group reminiscence program ensures expertise in techniques and effective program management [20]. In integrative group storytelling therapy, participants exhibited strong social integration, supported one another, displayed valuable life skills, and fostered positive self-worth and institutional loyalty during reminiscing and feedback sharing [21]. Consequently, participants felt supported and experienced a sense of belonging when performing digital group activities [22]. Community-based social participation relies on facilitators who organize activities and provide support in securing spaces and promoting events. Therefore, using a technology-based storytelling intervention to boost community-based social engagement can enhance community belonging.

The 3 main features of a digital storytelling application are multimedia material editing, memory recall, and story sharing. Some memory retrieval interventions may combine multiple functions of the interventions, such as people with MCI simultaneously reminiscing and sharing their recollections [23]. Challenges in using technology remain an unsolved issue; people with MCI typically exhibit lower digital literacy [24]. Most storytelling programs include training sessions before the intervention, such as storytelling classes [25], as mostly commercial, off-the-shelf technology is used to support digital storytelling [12], and these programs require digital literacy for multimedia editing and digital storytelling. Some studies required trained volunteers [26] or caregivers [23,27] to support people with dementia in developing stories. However, these settings are intended to enable people with MCI to adapt to existing environments and interactive tools rather than customizing the software to their specific needs (thus enhancing the usability of the storytelling application while simultaneously reducing learning costs). The applicability of these methods for memory retrieval among adults with MCI is currently not fully understood [28]. Therefore, our aim was to co-design a technology-based group memory retrieval intervention, which is a key form of digital storytelling intervention, to support social participation. We also investigated how to design user-friendly storytelling applications to manage digital resources and reduce learning costs for people with MCI.

Theoretical Framework
Co-design pertains to the collaborative involvement of people (users and stakeholders) in the design of a product or service [29]. Co-design workshops for interventions for people with MCI involve people with MCI, caregivers, and therapists in designing the intervention programs, providing unique perspectives. Involving users in design sessions helps engineers and researchers better understand requirements. A co-design approach would be helpful in identifying the requirements for
designing technology-based group memory retrieval interventions for people with MCI. In our study, the development of the storytelling prototype was guided by 2 behavioral and theoretical frameworks to raise participants’ awareness about their social health behaviors and tailor adequate actions for behavior change, namely the Behavior Change Wheel [30] and Theoretical Domains Framework (TDF). Beginning with the Behavior Change Wheel, a behavioral analysis enables intervention designers to select particular areas for exploration, thereby guiding the development of the digital storytelling approach. TDF deepens the understanding of psychological and behavioral factors influencing effective interventions. This integration aligned our application’s features with identified behavior change strategies, fostering a comprehensive approach to promoting social health. In addition, a communication strategy called MESSAGE (an acronym representing 7 key communication strategies, each encapsulated by its initial letter; within each strategy, specific suggestions are aimed at enhancing effective communication: maximizing attention [M], focusing on expression and body language [E], keeping it simple [S], providing support for their conversation [S], assisting with aids [A], getting their message [G], and encouraging and engaging in conversation [E]) [31] was used to support digital storytelling communication. Considering the critical importance of providing caregivers with effective tools to bolster memory and communication abilities in individuals with dementia [32], the implementation of specific communication strategies between people with MCI and the Huiyou application is paramount.

**Methods**

**Ethical Considerations**

The Swinburne University of Technology’s Human Research and Ethics Committee provided ethics approval for this research (20226525-11105) on September 26, 2022. All workshop participants provided written informed consent to participate and gave permission for their audio recordings and sketches to be used in publications. All methods were performed in accordance with relevant guidelines and regulations. We collected no identifying information from the research participants, such as their names or email addresses. Each participant was assigned a unique ID number to ensure their anonymity. In addition, we provided informed consent forms, including a project information sheet, to uphold their privacy rights.

**Research Team**

The research team is a collaborative ensemble of specialists in human-computer interaction, user experience, and design, each contributing their distinct expertise to the success of the project. AAM has an extensive background in design research and human-computer interaction, and WL has engaged in and performed research on user experience extensively. DZ is a doctor of philosophy student specializing in design.

**Sample**

A social work organization named Jingshilaonian, located in Beijing, China, expressed willingness to participate in this research. Situated within the Tiantongyuan community in Beijing, this institution specializes in providing psychosocial support, mental health services, and daily activity assistance to older adults, including those with MCI. Jingshilaonian played a vital role by assisting us with the recruitment and screening of people with MCI by administering the Montreal Cognitive Assessment, as developed by Nasreddine [33]. The inclusion criteria for people with MCI encompassed independent community dwelling, age >65 years, no visual or hearing impairments, and adequate reading ability. The exclusion criteria for people with MCI included significant neurological conditions, such as stroke or brain injury, because of potential confounding effects. Caregivers had no specific inclusion criteria. For therapists, the inclusion criteria were postgraduate qualifications and >3 years of experience in social interventions.

To engage participants, we collaborated with the organization’s manager to distribute information sheets to people with MCI and their caregivers, inviting them to participate in the study. We co-designed a storytelling intervention with people with MCI (n=12), their caregivers (n=4), and therapists (n=5) in Beijing, China. The brainstorming stage and rough prototyping stage for the intervention were attended by people with MCI and caregivers in a group setting, and the user testing stage was attended by people with MCI and therapists. People with MCI (n=12) were aged 65 to 77 (mean 69.91, SD 4.20) years, and their average Montreal Cognitive Assessment-Chinese version score was 23.58 (SD 1.38). A total of 4 caregivers participated in the workshops. Table 1 summarizes the demographics of people with MCI.
Table 1. Demographics of participants with mild cognitive impairment (n=12).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Values</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3 (25)</td>
</tr>
<tr>
<td>Female</td>
<td>9 (75)</td>
</tr>
<tr>
<td><strong>Age (y), mean (SD)</strong></td>
<td>69.92 (4.20)</td>
</tr>
<tr>
<td><strong>Age (y), n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>65-69</td>
<td>5 (42)</td>
</tr>
<tr>
<td>70-74</td>
<td>6 (50)</td>
</tr>
<tr>
<td>75-79</td>
<td>1 (8)</td>
</tr>
<tr>
<td><strong>Educational background, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>2 (17)</td>
</tr>
<tr>
<td>High school</td>
<td>3 (25)</td>
</tr>
<tr>
<td>Junior high school</td>
<td>7 (58)</td>
</tr>
</tbody>
</table>

Procedure

Overview

We adopted the co-design stages proposed by Robinson et al [34], namely scoping (stage 1), participatory design workshops (stage 1), and prototype development (stage 2). After developing the prototype, we conducted a usability evaluation (stage 3; Figure 1). The specific tools and procedures used can be found in the protocol paper [14].

Figure 1. The process of data collection. MCI: mild cognitive impairment; UEQ: User Experience Questionnaire.

Stage 1: Intervention Idea Brainstorming Workshops

In this initial phase, it took 45 minutes to uncover the essential aspects of significant social participation for people with MCI and their caregivers. This stage involved a sequence of 4 workshops designed to identify the most compelling benefits, role models, and barriers related to social participation. By prioritizing these aspects, we sought to deepen our understanding of the significance of social participation for people with MCI and enhance the quality of data for the subsequent phase. During each workshop, people with MCI and caregivers voted on the most compelling benefits and role models, and people with MCI selected 2 abilities that they wished to improve. These insights were critical for informing the design of our digital storytelling intervention.

Stage 2: Prototyping Workshops

Building on the insights gained from stage 1, we focused on collaborative brainstorming sessions involving people with MCI and their caregivers in stage 2. The goal was to explore the design and interaction logic of the interface through 60-minute workshops. Digital storytelling interventions involve recalling
past actions, events, and feelings using physical prompts. In addition to building on the insights gained from the literature review of digital storytelling interventions, we identified the main features of digital storytelling applications as story creation, memory retrieval, and story sharing [12]. Furthermore, we found that the themes of stories significantly impacted the storytelling experience [35]. Therefore, the research team proposed 4 primary properties for potential features of the digital storytelling intervention: identification of preferred storytelling themes, support for story material generation, memory retrieval, and story sharing. Participants were encouraged to describe, illustrate, or display sample interfaces on their mobile devices. Figures 2-6 were generated during the prototyping workshops by participants and facilitator DZ. The key objectives were to define the program’s main goals; propose relevant features, interactions, workflow, and interface elements; and create rough prototypes to visualize the intervention’s interfaces and interactions. The outcomes of this stage provided the foundation for designing the prototype of our digital storytelling application.

Figure 2. A sketch showing browsing and reminiscing topics and details.

Figure 3. A sketch of (A) material addition entry point indicated by a “+” icon and (B) adding material description of story materials.
Stage 3: User Testing

We created the Huiyou prototype based on the insights and ideas gathered from stages 1 and 2. To evaluate the application’s usability, we identified 22 specific tasks aligned with its features and interaction logic. These tasks were meticulously selected to ensure that the intervention’s primary objectives, including enhancing social connection and community participation for people with MCI, could be effectively achieved. Participants, including people with MCI and therapists, engaged in usability testing sessions, where they completed these tasks and provided feedback on their experiences. The usability test session was 45 minutes long. Feedback gathered from these sessions included task success rates, concerns, and preferences. We also collected data on individual task completion rates and task completion with facilitator assistance. In our usability testing, we used a comprehensive approach to evaluate the features and subtasks of the Huiyou intervention. For instance, in testing the
story sharing feature, participants were tasked with actions such as entering the speech mode, locating speech prompts, assessing speech length on the page, and identifying the screen projection button. If participants independently interacted with the interfaces successfully, the facilitator recorded it as task completion without assistance. However, if participants encountered difficulties in completing a task even after thoroughly examining the entire interface, the facilitator intervened by offering predefined tips, such as suggesting checking the bottom of the screen. In such cases where participants were able to successfully interact with the interfaces with the facilitator’s assistance, the facilitator recorded it as completion with facilitator assistance. Following this, we initiated an iterative design process to refine and enhance the user interfaces (UIs) based on participant feedback, ensuring the application’s usability and effectiveness.

Data Collection
Qualitative data were gathered through interviews, sketches, and focus group discussions at different stages of the research via audio recordings. In stage 1, focus group discussions were conducted to analyze the prioritized aspects of social participation. Stage 2 involved brainstorming activities during which participants generated sketches and discussed the potential features of Huiyou. In stage 3, participants’ feedback was collected through self-reporting during usability testing and structured interviews. It is important to note that the Chinese version of the User Experience Questionnaire (UEQ) had previously undergone psychological validation [36]. A total of 22 usability tasks were used to evaluate task completion, providing a comprehensive approach to gaining valuable insights into the user experience of Huiyou and effectively assessing its usability.

Data Analysis
Qualitative data analysis followed a thematic analysis approach [37,38]. Two individual researchers reviewed and coded the interview transcripts and organized the codes into themes using NVivo (version 12.0; Lumivero) [39]. Labels, such as “Stage 1-group 2-people with MCI number 2,” were used to distinguish different groups and participants.

In the design phase, the research team used the JiShiSheJi design to create the interface. After usability testing, a redesign phase was initiated, involving a detailed analysis of participant feedback and interview responses. These data were systematically summarized to identify improvement areas. An iterative design process was then used to enhance the UIs by incorporating participants’ feedback. This approach ensured that the final version of Huiyou aligned better with the needs and preferences of people with MCI.

Quantitative data analysis involved calculating completion rates using Excel (Microsoft Corp) to determine the average completion rate and feature rankings. The UEQ results were assessed using the UEQ Handbook [40], whereas the UEQ Data Analysis Tool Version 12 was used to compute mean values, SD, and CI for various usability dimensions of attractiveness, ease of use, efficiency, dependability, stimulation, and novelty.

We also used Excel to calculate the mean values of task completion rates with and without assistance.

Results
The key findings from each stage of this study are summarized as follows.

Stage 1 Findings: Intervention Idea Brainstorming Workshops
Overview
Our exploration unfolded into 3 distinctive themes, each shedding light on a crucial aspect of participants’ experiences. We examined how social participation can be a powerful catalyst for enhancing physical health and fostering lifelong learning. Through the inspiring stories of confident older adults who wholeheartedly embraced challenges, our second theme showcased exemplars of unreserved social participation. Finally, we delved into the primary barriers people with MCI aimed to overcome, with a particular focus on memory, language expression, and the mastery of essential smartphone skills.

Enhancing Physical Health and Lifelong Learning Through Social Participation
Most participants with MCI (8/12, 67%) regarded social participation as an approach to maintaining physical health. They found that attending social activities can enhance their health status because they are less prone to catching colds when actively participating in social activities. People with MCI pay more attention to physical health; therefore, the benefits of physical health may attract people with MCI to participate in social activities.

Most participants with MCI (8/12, 67%) reported that engaging in activities with older adults positively impacted their physical well-being; these activities, such as exercise programs or outdoor group activities, helped improve their physical condition, increased their mobility, and supported their overall health. In addition, the social interaction involved in these activities afforded them a support system, along with accountability and the motivation to stay active and adopt a healthy lifestyle. In agreement with this, participants stated the following:

"Engaging with others and staying socially active can help improve my physical health. It encourages me to stay active, spend time with people, and motivates me to maintain a healthy lifestyle." [Stage 1, G2-P3]

Few participants with MCI (3/12, 25%) emphasized the value of lifelong learning and intellectual stimulation; participating in social activities provided these participants with a platform for communication, exploration, and the imparting of knowledge. By engaging in collaborative social activities and exchanging ideas with others, they were encouraged to continuously learn and discover new things. One of the participants commented the following:

"Engaging in social activities can improve my mental health by allowing me to interact with others, receive emotional support, reduce feelings of loneliness, and..."
enhance positive emotional experiences. [Stage 1, G1-P2]

People With MCI Admire Peers Who Face Challenges Confidently

Most participants with MCI (9/12, 75%) admired older adults who displayed the confidence to attend various activities. Interacting with confident older adults allowed these participants to gain a new perspective on aging and life experiences; they were inspired to embrace challenges, overcome impediments, and approach life with a positive mindset:

They give me strength and inspiration, demonstrating passion and a positive attitude in caring for others, making me believe that I can still have a fulfilling and meaningful life even in challenging circumstances. [Stage 1, G3-P3]

People With MCI Want to Improve Their Memory and Language Deficit and Smartphone Skills

Table 2 indicates that most people with MCI wish to improve their memory and expression of language, as participants mentioned that memory affects them frequently and that language expression can affect communication with their grandchildren. Of the 12 participants with MCI, 7 (58%) prioritized the improvement of memory, as this affected them the most:

I have poor memory; as I spoke, I forgot where I was talking. Therefore, I want to improve it first. [Stage 1, G2-P2]

Table 2. The top 3 barriers identified (N=24).

<table>
<thead>
<tr>
<th>Barriers to overcome</th>
<th>Votes, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory ability</td>
<td>7 (29)</td>
</tr>
<tr>
<td>Language expression</td>
<td>5 (21)</td>
</tr>
<tr>
<td>Smartphone use</td>
<td>4 (17)</td>
</tr>
</tbody>
</table>

*Each person with mild cognitive impairment had 2 votes; in total, there were 24 votes from the 12 participants.

Of the 12 participants with MCI, 5 (42%) mentioned that their storytelling ability also affected communication, mainly when talking with their grandchildren:

My education level is limited, and I hope I can improve my language skills so that I can tell my granddaughter vivid stories. [Stage 1, G3-P1]

Among the 12 participants with MCI, 4 (33%) felt that using a smartphone was difficult, and some (3/12, 25%) people with MCI believed that the requirement for the ability to navigate a smartphone might prevent them from further social participation:

As I get older, I cannot use many functions of my phone. I always have to consult others, but it is more convenient to learn them myself. [Stage 1, G2-P3]

All the participants with MCI (12/12, 100%) selected smartphones as the suitable device on which to install the application because they all had access to a smartphone, with only a few participants reporting that they owned an iPad (Apple Inc); smartphone was viewed as the more favorable option, being more portable than tablets or computers:

I have a smartphone; if the application could be installed on my phone, it would be more convenient since I carry the phone all the time. [Stage 1, G2-P2]

In summary, the benefits of social participation for people with MCI included the improvement of physical health through engagement in activities, the fostering of a support network, and increased confidence among older adults. Memory and language expression were the primary barriers they wished to improve and were crucial for their communication with their grandchildren. Furthermore, their smartphone skills required enhancement to facilitate continued social participation.

Stage 2 Findings: Prototyping Workshops

Overview

Following the analysis of the findings from stage 1, the research team believed that the creation of a group-based digital storytelling intervention would be beneficial for improving memory, language expression, and smartphone use skills, and eventually, it could enhance social connection and participation. We have outlined the findings regarding the 4 primary features of the digital storytelling application as follows.

Preferred Storytelling Themes for Sharing With Others

All the participants with MCI (12/12, 100%) stated that they would like to share recent activities, including hobbies (as well as the changes they perceived around them), social activities, and current politics. Hobbies were most commonly cited because the participants were eager to share them with others and had invested much time and effort in them. The participants with MCI reported the following:

I enjoy content related to technology, as well as driving. I like observing different cars; whenever a related topic arises, I cannot stop talking about it. [Stage 2, G2-P2]

Moreover, participants suggested receiving memory retrieval themes to ensure a well-defined topic to reminisce and allow them to gather relevant materials beforehand, expediting the process for smoother implementation.

Design of the Story Material Generation

After defining the storytelling themes, users could generate story materials by obtaining topics for memory retrieval, collecting materials, adding material descriptions, and integrating materials for further story sharing. The facilitator encouraged participants with MCI to create sketches; however,
only 4 (33%) of the 12 participants with MCI were inclined to do so (Figures 5 and 6). Consequently, the facilitator assisted those who were unwilling to draw in visualizing their ideas.

Figure 2 presents a sketch for browsing a topic for memory retrieval; on the left side of the page, there are a search bar for exploring events at the top and a list of events, including images, the name of the event, and its description at the bottom. The user navigates the list of events via a scrolling mechanism. Adjacent to each event entry is a registration button. The page on the right offers 2 options for displaying the activity. Option A displays only a text-based summary of the subject matter. By contrast, option B displayed a more significant activity schematic with introductory text provided underneath:

> For example, for my son’s wedding, just get a few photos, just two or three. [Stage 2, G2-P3]

The material collection feature enhances content by providing explanatory details and enriches the collection by sourcing pictures from various internet platforms. Recording snippets of information further aids by capturing valuable insights. In addition to collecting the target content, participants also suggested recording fragmented information informally. Figure 3 presents a sketch of an entry point for the supplementary material at the bottom of the page, indicated by a plus icon, which reveals 3 input methods when clicked. The input methods include voice input, text input, and video input:

> The function of voice recognition is very convenient. With just a press of a button, recording starts, and in the end, it can be converted into text for preservation, making it easy to view later. [Stage 2, G1-P2]

The adding material description feature aims to optimize the collection of data by associating individuals with each story (Figure 3); for instance, the developmental stages of the country, timeline, and the type of activities connecting people with MCI with the country’s developmental stages and arranging them chronologically and by different activities for easy navigation. Participants recommended the provision of a framework of memories to aid them in refining the story; for example, participants could select the time stage, such as the founding of the People’s Republic of China in 1949, and the stage of their life at the selected time, such as youth, middle-age, working, or retired. The choice of location is provided using a map. Finally, participants can apply labels for characters, including their avatars and names. One of the participants explained this as follows:

> We can label the key characters that appear inside. [Stage 2, G3-P2]

> I like to categorize these [materials] by age and objectively exist since I am willing to use classification methods that are specific, not easily confused, preferably objectively present, and not prone to misunderstanding. [Stage 2, G3-P3]

The integrating material feature aims to create a cohesive memory retrieval experience by uploading selected materials to the topic in question and adjusting sequences to promote a seamless and engaging narrative flow (Figure 4). The participants provided 2 options: option 1 displayed the candidate photos in the first row, and below, each theme was listed, with the corresponding material dragged and dropped into the theme; and option 2 allowed users to select the order of presentation after choosing the related theme. One of the participants with MCI commented the following:

> After uploading these photos, we need to associate them with the story to be told based on different story themes. Before sharing, we could easily change the sequence of the materials. [Stage 2, G2-P1]

Memory Retrieval Activity Design Through Facilitation Strategies

The digital storytelling application uses various strategies to enhance the experience in the memory retrieval function. It has 3 features: a story presentation, group discussion, and story summary.

During story presentation, the digital storytelling application has cheat sheets for recall, minimizing interruptions by using timers, promoting interactive discussions, and creating permanent records. Mobile technology facilitates the easy capture of memories, forming meaningful connections with cherished life events. Preparing a cheat sheet with helpful tips can provide valuable guidance to ensure a smooth and engaging memory retrieval experience (as shown in Figure 5). The cheat sheet might present either keyword prompts or corresponding content. A cue word switches to the content of the corresponding material, depending on the selected content format:

> Sometimes [my] memory is poor, and this software can provide a cheat sheet to prevent me from forgetting what I need to share at the moment. [Stage 2, G1-P2]

During the session, avoiding interruptions allowed participants to immerse themselves fully in their nostalgic journey, and a visual timer helped them manage their time effectively:

> You can only limit the time. One is that most of the time, how many people cannot all stand on the same question, or you cannot all stand on your own time for a few minutes. [Stage 2, G4-P2]

During a group discussion, the approach integrates memory retrieval with open discussion groups. Encouraging participants to pose questions by raising their hands fosters an interactive and dynamic environment (Figure 6). During the presentation, each participant has an avatar, and the Wi-Fi signal strength is displayed next to the avatar. If the participant has a question they wish to ask, they may raise their hand, and a small, raised hand icon is displayed next to their profile. These discussions can be informal, fostering a sense of engagement in shared experiences and collective memories:

> Ask each other questions. This form is quite good. Ask each other because it is to discuss different opinions on a subject, and this is the best way. Yes, if there are no different opinions, this question may be a little biased. [Stage 2, G3-P3]

> I want to ask questions. If you want to ask questions that I am interested in, I can also raise my hand and answer them. [Stage 2, G1-C1]
The story summary feature aims to make memory retrieval more tangible; facilitators can generate records or memories from the discussions, providing a lasting and meaningful resource for participants to cherish and revisit:

Currently, mobile phones are very convenient. When I take a group photo and see everyone’s photos, I can recall what happened at that time. I also like to keep a diary and can simply remember one or two sentences. [Stage 2, G4-C1]

**Story Sharing to a Broader Audience**

To share the records of their recollections with the desired person or group, participants suggested using WeChat (Tencent Holdings Limited), which allows for the convenient and efficient sharing of memories, ensuring that the memory retrieval experience can be cherished and enjoyed by those involved. Most participants with MCI (8/12, 67%) wished to share this experience with certain persons or groups, primarily through WeChat:

Based on different themes, [we can] send today’s activities to corresponding people, such as those with common interests or children. Share with them through WeChat and let them know the latest situation as well. [Stage 2, G2-P3]

However, one of the people with MCI showed no interest in sharing the content with others:

At this age, I’m not willing to share with more people; at least subjectively, I have no intention to please anyone. [Stage 2, G1-P2]

In summary, Table 3 outlines the key functionalities and features of the memory log system, along with valuable suggestions for their implementation. To generate materials, the inclusion of memory topics aids in focused preparation. Collecting materials might include adding explanations to materials, collecting pictures from the internet, and the informal recording of fragments of discussions. While adding material description, users could add details such as time, location, and key characters to the material. Users could integrate materials into each presentation by changing the sequence of materials. During memory retrieval, facilitators can benefit from cheat sheets, minimize interruptions, and use visual timers in presentations. Open discussions, hand raising, and interactive dialogues further enrich the experience. Summarizing these records enhanced memory retention. Sharing options, such as WeChat, extend the impact beyond the scope of the audience.

Table 3. The main features of Huiyou identified from stage 2 (ie, prototyping workshops).

<table>
<thead>
<tr>
<th>Functionalities and features</th>
<th>Suggestions to implement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Generating story materials</strong></td>
<td>• Inform the topic and collect relevant materials in advance</td>
</tr>
<tr>
<td>Obtain a topic for memory retrieval</td>
<td>• Add a description to each record</td>
</tr>
<tr>
<td>Collect materials</td>
<td>• Collect pictures from others via the internet</td>
</tr>
<tr>
<td>Add material description</td>
<td>• Casually record fragmented information</td>
</tr>
<tr>
<td>Add essential character to each material</td>
<td>• Add essential character to each material</td>
</tr>
<tr>
<td>Link to the sequential steps of the country’s development</td>
<td>• Follow the timeline to show the content</td>
</tr>
<tr>
<td>Categorize by different activities</td>
<td>• Categorize by different activities</td>
</tr>
<tr>
<td>Integrate materials</td>
<td>• Upload selected materials to the target topic</td>
</tr>
<tr>
<td>• Change the sequence of the materials</td>
<td></td>
</tr>
<tr>
<td><strong>Memory retrieval activity</strong></td>
<td>• Prepare a cheat sheet to obtain tips</td>
</tr>
<tr>
<td>Story presentation</td>
<td>• Avoid interruptions during the presentation</td>
</tr>
<tr>
<td>Group discussion</td>
<td>• Set visual timer</td>
</tr>
<tr>
<td>• Combine memories and discuss</td>
<td></td>
</tr>
<tr>
<td>• Raise hands to ask questions</td>
<td></td>
</tr>
<tr>
<td>Story summary</td>
<td>• Open discussion</td>
</tr>
<tr>
<td>• Generate a record or memory</td>
<td></td>
</tr>
<tr>
<td><strong>Sharing story</strong></td>
<td>• Share the record via WeChat (Tencent Holdings Limited)</td>
</tr>
</tbody>
</table>

**Developing the First Prototype of Huiyou**

The first digital prototype of Huiyou (Figure 7) was produced in JiShiSheJi [41], a web-based free software prototype design and development tool, following an iterative process of co-design workshops and feedback collected from the meetings. The software name 会友, Huiyou, derived from the Pinyin pronunciation, means “meeting new friends” in Chinese. It is
inspired by a classic quote from Confucius in the Analects: “A gentleman seeks friendship through literature and reinforces goodness through friendship.” This statement emphasizes the idea that individuals cultivate friendships through literary exchange and support virtue through companionship. The name reflects a positive vision of fostering social connections through literature, friendship, and benevolence. Users can leverage technological means through the software to expand their social circles, facilitating deeper communication and connections with others. The name embodies the social nature of the software and its goal of promoting friendship. Huiyou effectively stores memories from daily life and encourages people with MCI to reminisce and discuss favorable memories with new friends.

Huiyou has 2 main features: supporting people with MCI to conduct self-reflection daily (preparing materials with cues) on certain topics and facilitating group memory retrieval (presenting a story and promoting a discussion with group members). Two innovative aspects of Huiyou are embedded memory retrieval for capturing daily life and its ability to collect recent, valuable memories. Another such feature is combined self-reflection and group reflection to enhance social interaction during the discussion, in addition to sharing and participating in social activities outside the home.

**Figure 7.** Huiyou prototype: home page.

**Activity preparation progress**
- Each activity has 3 tasks
- The icon of the completed task will change to the main color

**Obtain reminiscing topic**
- Inform the topic and collect relevant materials in advance

**Recent memory**
- Show the memory created during the recent storytelling session

As Figure 8 illustrates, the process of registering an activity on the Huiyou application begins with the user navigating from the home page to the activity page, where they can browse and select the activity they wish to register for; they then upload the material and edit it on the active page. When an event is about to commence, the user enters the event details page from the home screen. Next, they enter the activity and encounter a start screen for analyzing memories. The activity may be recorded and shared with others. If the user has any issues with the software, they can click the help button to discover operation guidelines.
Stage 3 Findings: User Testing

Results From Task Analysis

Through this comprehensive usability testing stage, we identified minor areas of improvements in the interaction logic and interface layout to optimize user experience. In the 22 tasks, the participants scored an average success rate of 59% without assistance and 87% with assistance from the facilitator. Most challenges were identified to be associated with the direction of interaction; after knowing the direction, the success rate increased. Table 4 lists 5 tasks within the Huiyou digital storytelling application that demonstrated notably high usability, with completion rates exceeding 90% when performed individually. These tasks included “upload pictures” and “recording new materials,” both of which achieved perfect task completion rates of 100% with facilitator assistance. In addition, tasks such as “entering speech mode,” “find speech prompts,” and “insert a group photo after the event” also exhibited exceptional usability, with 92% individual task completion rates and 100% task completion rates with facilitator assistance.

This effectively communicates that within the Huiyou digital storytelling application, 5 tasks have a completion rate ≤75%, indicating the need for improvement. Tasks such as “add material description,” “browse registration activities,” and “switch the view of the activities” exhibited relatively lower individual task completion rates of 8%, whereas the presence of a facilitator notably enhanced completion rates to 58%. Similarly, the “judge whether the speech is too long on the page” and “enter the activity interface” tasks had initial completion rates of 25%, which significantly improved to 75% with facilitator assistance. These findings emphasize areas where the application’s UI and task guidance may benefit from refinement to ensure a more user-friendly and accessible experience, particularly for people with MCI.
Table 4. Task descriptions and completion rates of people with mild cognitive impairment (n=12).

<table>
<thead>
<tr>
<th>Features and task</th>
<th>Task completion without assistance, n (%)</th>
<th>Task completion with facilitator assistance, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Generating story materials</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upload pictures</td>
<td>11 (92)</td>
<td>12 (100)</td>
</tr>
<tr>
<td>New materials for text input</td>
<td>6 (50)</td>
<td>10 (83)</td>
</tr>
<tr>
<td>New materials for voice input</td>
<td>7 (58)</td>
<td>10 (83)</td>
</tr>
<tr>
<td>Record new materials</td>
<td>12 (100)</td>
<td>12 (100)</td>
</tr>
<tr>
<td>Add material description</td>
<td>1 (8)</td>
<td>7 (58)</td>
</tr>
<tr>
<td>Add material tags</td>
<td>9 (75)</td>
<td>11 (92)</td>
</tr>
<tr>
<td>Edit material permissions</td>
<td>5 (42)</td>
<td>11 (92)</td>
</tr>
<tr>
<td>Enter my material</td>
<td>9 (75)</td>
<td>11 (92)</td>
</tr>
<tr>
<td>Change the sequence of materials</td>
<td>7 (58)</td>
<td>12 (100)</td>
</tr>
<tr>
<td>Browse registration activities</td>
<td>3 (25)</td>
<td>9 (75)</td>
</tr>
<tr>
<td>Enter the activity interface</td>
<td>6 (50)</td>
<td>9 (75)</td>
</tr>
<tr>
<td>Switch the view of the activities</td>
<td>1 (8)</td>
<td>7 (58)</td>
</tr>
<tr>
<td>Sign up for activities and add groups</td>
<td>5 (42)</td>
<td>9 (75)</td>
</tr>
<tr>
<td>View task progress</td>
<td>6 (50)</td>
<td>12 (100)</td>
</tr>
<tr>
<td>Enter task</td>
<td>10 (83)</td>
<td>11 (92)</td>
</tr>
<tr>
<td><strong>Memory retrieval activity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enter speech mode</td>
<td>11 (92)</td>
<td>12 (100)</td>
</tr>
<tr>
<td>Find speech prompts</td>
<td>12 (100)</td>
<td>12 (100)</td>
</tr>
<tr>
<td>Judge whether the speech is too long on the page</td>
<td>3 (25)</td>
<td>9 (75)</td>
</tr>
<tr>
<td>Find the screen projection button</td>
<td>9 (75)</td>
<td>12 (100)</td>
</tr>
<tr>
<td><strong>Sharing story</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insert a group photo after the event</td>
<td>11 (92)</td>
<td>12 (100)</td>
</tr>
<tr>
<td>Use help features</td>
<td>4 (33)</td>
<td>10 (83)</td>
</tr>
</tbody>
</table>

Results From the UEQ

When comparing the ratings to the UEQ benchmark [36], it was noted that the application falls within the average and above range, suggesting that there is room for improvement. The combined ratings for all users, including both people with MCI and therapists organized by the value of each UEQ item can be seen in Figure 9, wherein the average score pertaining to attractiveness is 2.073 (SD 0.82), ease of use is 1.609 (SD 1.15), efficiency is 1.5 (SD 0.85), dependability is 1.875 (SD 0.76), stimulation is 1.813 (SD 0.96), and novelty is 1.703 (SD 1.33). In the results obtained from the UEQ (7-point positive and negative scale; Figure 9), participants with MCI expressed favorable opinions about Huiyou, perceiving it as an enjoyable (mean 2.7, SD 0.6), supportive (mean 2.3, SD 0.7), clear (mean 2.5, SD 0.7), and friendly (mean 2.3, SD 0.8) application. However, they found learning challenging (mean 1.5, SD 1.9) and somewhat complex (mean 0.9, SD 2.1).
**Results From Usability Testing**

On the basis of the interviews conducted and feedback collected during usability testing, we identified 15 usability issues to improve (Table 5). These issues were linked to the features of the application, including the home page and navigation, sign-up activities, adding material descriptions, changing the sequence of selected materials, sharing stories, uploading material, UI and design, and picture gallery. The main change was made to the home page (resolving the first usability issue in Table 5), addressing the user feedback that there was a lot of information on the home page and that the activity entrance was not clear, making it difficult to locate it quickly. One of the participants with MCI mentioned the following:

*I’m not sure how to find the activities I want to participate in. The location of the activities should be more prominent. Those generated memories don’t necessarily have to be on the first page.* [Stage 3, P3]

Therefore, notable enhancements included moving activity records to a separate tab, thereby streamlining the navigation and organization processes. In addition, more activity entries were added to the home page, providing users with a broader range of options. We followed all recommendations to redesign the Huiyou application.
### Table 5. Usability issues and recommendations.

<table>
<thead>
<tr>
<th>Features and issues</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home page and navigation</strong></td>
<td></td>
</tr>
</tbody>
</table>
| There is a lot of information on the home page, and the activity entrance is not clear | • Show the activities list. Each activity may have a different status: ongoing activity (in a dark green rounded rectangle) and waiting to start (in a gray rounded rectangle)  
• Move the entrance of the “casually record fragmented information” feature from being suspended in the lower right corner to being fixed in the lower center |
| Category activity is hard to find | • Move activity records to a separate tab  
• Add more entries on the home page |
| **Sign-up activities** | |
| Activity registration setup issues | • Display activity registration first, followed by recent activities |
| **Adding material description** | |
| Unable to understand the edit permissions | • Change the heading to “invite others to edit” |
| Unable to find materials and view photos that have already been uploaded | • Integrate the image library and add tags  
• Allow easy switching and searching for images |
| Unable to understand content edit functions | • Change to content description, integrating the description on 1 page, including time, location, characters, events, and others  
• User should be able to add pictures’ tags from material, including family, friend, sightseeing, group photo, and item |
| **Changing the sequence of selected materials** | |
| Unable to sort materials | • Provide operating instructions and make the font color of the instructions more eye-catching  
• Provide support for 2 sorting methods: drag and click |
| **Sharing story** | |
| The “share the screen” button is too small | • Make the screen projection button larger and highlight the color more prominently |
| Face-to-face discussions require no “raise hand” button | • Remove the “raise hand” button for inquiries in face-to-face discussions |
| **Uploading material** | |
| No need to find internet resources | • Delete the option of “upload material through internet” |
| **User interface and design and picture gallery** | |
| Need colorful and simple icons | • Update icons to be colorful, eye-catching, and more solid |
| The return icon is not prominent | • Increase the size of the return icon  
• Change the dark background of the “help” icon to a lighter background |
| Keyboard input and voice input | • Default voice input |
| The picture gallery contains too much information | • Reduce the number of images displayed in galleries and preset some images in advance |

### Discussion

#### Principal Findings

This study outlines the process and outcomes of co-designing and prototyping Huiyou, a digital storytelling application intended to facilitate social engagement and enhance the cognitive well-being of people with MCI in community-based settings. Insights collected from usability testing shed light on both strengths and areas for improvement in terms of user-friendliness and accessibility within the application’s design and functionality. Furthermore, some functions have been simplified, including the path for uploading material without internet resources. People with MCI may take 15 minutes to collect the materials they want to present and 10 minutes to present their stories. Each story is original, proposed by people with MCI, and they may ask for the support of volunteers or caregivers. The storytelling process has 2 phases: preparation of materials and memory retrieval. Emphasizing the recollection...
of recent memories was found to encourage social engagement and foster a sense of belonging. Huiyou, the storytelling application used in this study, facilitated material generation by providing preset content prompts and allowing independent material collection, setting it apart from other interventions. During the memory retrieval activity, participants used personalized cues and multimedia elements, triggering meaningful conversations and connections. This study’s findings suggested that storytelling themes for people with MCI should revolve around recent positive experiences and significant life periods. Notably, the application scored highly in attractiveness, dependability, stimulation, and novelty, although it required ease of use and efficiency enhancements. Recommendations for interface design included emphasizing crucial elements, minimizing cognitive complexity, and streamlining information presentation for improved user accessibility and experience.

Comparison With Prior Work
This research highlights the importance of selecting storytelling themes that evoke recent positive experiences for people with MCI in China. The emphasis on significant life stages and changes, excluding marital experiences, is supported by existing literature [37]. Surprisingly, the study observed a keen interest among older male adults in political subjects, deviating from expectations based on previous research on political engagement among older Chinese adults [42]. It is proposed that prioritizing recent positive memories through Huiyou can encourage social engagement, fostering a sense of belonging and participation among people with MCI. Huiyou facilitates the storytelling process for people with MCI through self-collected materials rather than preset content prompts [43,44], engaging them to share their stories. According to the Capability, Opportunity, and Motivation–Behavior (COM-B) system, Huiyou aims to enhance psychological capability, create social opportunities, organize social activities regularly, and reinforce reflective and automatic motivations. In addition, the following TDF components were embedded in the prototype: skills, social role and identity, beliefs about capabilities, goals, memory, attention and decision processes, and social influences. For example, Huiyou incorporates behavior change strategies in the TDF that involve social influence [45], such as group discussions that monitor group progress. As the therapists said, these design features can foster peer pressure, enhancing adherence to task completion and effectively facilitating the establishment of social connections. During group discussions, Huiyou implements the MESSAGE communication strategy to involve people with MCI actively. For instance, it allows users to add notes to materials, which are then displayed on the screen during memory retrieval. Unlike other interventions, Huiyou enables users to collect and arrange materials themselves, enhancing their sense of accomplishment and reducing the need for external support. The application’s approach of facilitating material generation and arranging sequences aims to stimulate positive memories and encourage active engagement during the memory retrieval process. Therefore, Huiyou supports people with MCI in arranging the display sequences of materials, as OurStory does [23]. In memory retrieval activities, a substantial number of stimuli are prepared in advance and presented randomly to prompt older adults to narrate stories [46]. However, this approach relies on the divergent thinking abilities of older adults. Unfortunately, this method does not support the possibility of multiple stimuli coming together to form a more complete story. Unlike older adults with dementia, people with MCI possess the autonomy to select cues for their storytelling, fostering interpersonal connections and evoking positive emotions [47]. Personal topics serve as effective memory tests, enhancing storytelling and social memory [48]. Huiyou uses visual cues, music, and various technological platforms to stimulate memory retrieval and trigger discussions among older adults. By encouraging the recall of recent positive memories and promoting group discussions [49], Huiyou enhances the confidence of people with MCI, empowering them to actively participate in social interactions and community activities. Group discussions not only provide opportunities for self-expression but also foster reflection and inspiration from shared social experiences. Sharing recent memories via Huiyou fosters dialogue and active social engagement among individuals with MCI. They can either share their stories during group reminiscing sessions or record and distribute their memories to family and friends. Unlike some interventions that lack a structured approach to memory retrieval [50], Huiyou allows for the systematic recording and sharing of stories [51], primarily using WeChat as the chosen platform for its broad reach among friends and family.

Usability Issues of Huiyou
On the basis of the UEQ benchmark results diagram, Huiyou earned a place in the “excellent” category [36]. These insights serve as invaluable pointers for refining the user experience of the application. People with MCI typically adhere to a top-to-bottom, left-to-right reading pattern [52], emphasizing the importance of placing essential interactive elements at the center or the top of the screen. Furthermore, adopting a more noticeable design approach, such as incorporating colored buttons, may be beneficial. The cognitive complexity experienced by people is influenced by the quantity of content displayed on a single screen. Even subtle variations in interface design demand additional information processing time for people with MCI. To mitigate cognitive strain, it is advisable to minimize the amount of information displayed on each screen and segment tasks into more manageable steps.

Limitations
One limitation was the small number of participants with MCI throughout the study. To mitigate the impact of a small sample size, the research team invited the same participants to engage in multiple stages of the study, gathering diverse research data, including interview outcomes, hand-drawn interfaces, and usability task data, and introduced the perspective of caregivers of people with MCI. Reusing the participants was an efficient approach to prototype development and, to some extent, mitigated the impact on people with MCI as well as clinician time. Another limitation was that the Huiyou prototype was redesigned based on the participants’ feedback; however, in this study, we did not evaluate the refined prototype. In the future, field testing with people with MCI will be used to measure the effectiveness of the tool in improving social participation.

https://aging.jmir.org/2024/1/e54138
Conclusions

We described the co-design processes of developing a digital storytelling intervention, Huiyou, in collaboration with people with MCI and caregivers. We then evaluated the user experience of the application based on the feedback of people with MCI, caregivers, and therapists. Huiyou incorporates story-sharing themes that align with the needs of people with MCI in China. These themes foster common topics and evoke positive emotions without delving into excessive privacy. Unlike traditional reminiscence therapy, it is confined to memory enhancement during intervention sessions, neglecting other potential intervention times. Huiyou transforms reminiscence into an everyday activity that individuals can engage in at their own convenience. This provides more opportunities to collect and cherish fond memories. Huiyou excelled in usability testing, earning an “excellent” rating in the UEQ benchmark for attractiveness, reliability, stimulation, and novelty. However, there is room for improvement in accessibility and efficiency. By combining social participation with the fostering of relationships and the stimulus to contact friends, the application not only promotes individual well-being but also meaningful social interactions and maintains vital relationships for people with MCI.

Acknowledgments

The authors would like to thank all the staff, people with MCI, and caregivers who were involved in this project.

Authors' Contributions

AAM and DZ conceptualized this study. DZ collected and analyzed the data. AAM directed several rounds of feedback and contributed significantly to the manuscript’s writing and revision. AAM and WL supervised the project. All the authors examined and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Higher resolution version of Figure 8.

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Abbreviations

**COM-B**: Capability, Opportunity, and Motivation–Behavior

**MCI**: mild cognitive impairment

**MESSAGE**: maximizing attention, focusing on expression and body language, keeping it simple, providing support for their conversation, assisting with aids, getting their message, and encouraging and engaging in conversation

**TDF**: Theoretical Domains Framework
Experiences of Older Adults, Physiotherapists, and Aged Care Staff in the TOP UP Telephysiotherapy Program: Interview Study of the TOP UP Interventions

Rik Dawson¹; Heidi Gilchrist¹; Marina Pinheiro¹; Karn Nelson²; Nina Bowes³; Cathie Sherrington¹; Abby Haynes¹

¹Institute for Musculoskeletal Health, Sydney Musculoskeletal Health, Sydney Local Health District, The University of Sydney, Camperdown, Australia
²Whiddon, Sydney, Australia
³Uniting AgeWell, Melbourne, Australia

Corresponding Author:
Rik Dawson
Institute for Musculoskeletal Health, Sydney Musculoskeletal Health
Sydney Local Health District
The University of Sydney
PO Box M179, Missenden Road
Missenden Road
Camperdown, 2050
Australia
Phone: 61 403895186
Email: rik.dawson@sydney.edu.au

Abstract

Background: Telehealth provides opportunities for older adults to access health care. However, limited research exists on the use of telehealth within aged care services, particularly regarding physiotherapy-led fall prevention and mobility programs. Understanding the experiences and interactions of older adults, physiotherapists, and aged care service providers is crucial for the scale-up and sustainability of such essential programs. The TOP UP study, a hybrid type 1 effectiveness-implementation randomized controlled trial in aged care, used a supported multidisciplinary telephysiotherapy model to motivate older adults to engage in exercises to improve mobility and reduce falls.

Objective: This qualitative substudy aims to achieve 2 primary objectives: to describe the experiences and acceptability of the TOP UP intervention for older people, physiotherapists, and aged care support workers and managers and to gain an in-depth understanding of program implementation.

Methods: A purposive recruitment strategy was used to select 18 older adults who participated in the TOP UP intervention, ensuring variation in age, gender, residential status (home or residential aged care), geographic location, and cognitive levels. In addition, 7 physiotherapists, 8 aged care support workers, and 6 managers from 7 different aged care provider partners participated in this study. Semistructured interviews were conducted to explore stakeholders’ experiences with the TOP UP program, gather suggestions for improvement, and obtain insights for the future implementation of similar telephysiotherapy programs. The interview framework and coding processes were informed by behavior changes and implementation frameworks. Data were analyzed using an abductive approach, informed by 2 behavioral change theories (Capability, Opportunity, Motivation, and Behavior Model and Self-Determination Theory) and the Nonadoption, Abandonment and Challenges to the Scale-Up, Spread and Sustainability of Health and Care Technologies framework.

Results: All participants (n=39) reported high levels of acceptability for the TOP UP program and cited multiple perceived benefits. The thematic analysis generated 6 main themes: telephysiotherapy expands opportunity; tailored physiotherapy care with local support enhances motivation; engaging, older adult–friendly educational resources build capability; flexible reablement approach fosters autonomy; telephysiotherapy is safe, effective, and acceptable for many; and organizational commitment is required to embed telehealth. The motivation to exercise was enhanced by Zoom’s convenience, use of tailored web-based exercise resources, and companionable local support.

Conclusions: This study highlights the inherent value of telephysiotherapy in aged care, emphasizing the need for investment in staff training, local support, and older adult–friendly resources in future telephysiotherapy iterations. TOP UP represents a
convenient and flexible web-based care model that empowers many older adults to receive sustainable, high-quality care precisely when and where they need it.

**Trial Registration:** Australian New Zealand Clinical Trials Registry (ANZCTR) ACTRN 1261000734864; https://anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12621000734864

*(JMIR Aging 2024;7:e53010)* doi:10.2196/53010

**KEYWORDS**

physiotherapy; telehealth; telephysiotherapy; exercise; aged care; qualitative methods; behavior change; technology; virtual care

**Introduction**

**Background**

The proportion of older people in the population is increasing worldwide. From 2020 to 2050, the number of older people aged ≥60 years will double to 2.1 billion, representing 22% of the world’s population [1]. By 2050, the number of people aged ≥80 years is expected to triple to 426 million [1]. Older people experience poor mobility and higher rates of falls than younger people, leading to significant morbidity, mortality, and poor quality of life [2-4]. Poor mobility and falls are 2 of the biggest cost drivers in hospital and aged care services [2,5]. In 2021, a total of 10.7% of people aged ≥65 years living in the Organization for Economic Co-operation and Development countries received long-term care, either at home or in care facilities, costing these governments 1.5% of the gross domestic product [6,7]. Aged care spending has increased over the last 15 years in most Organization for Economic Co-operation and Development countries, and population aging will continue to increase the demand on stretched health care systems [7].

Strong evidence supports the effectiveness and cost-effectiveness of physiotherapy-led exercise programs for enhancing mobility and reducing falls in aged care settings [8]. However, the Australian Royal Commission into Aged Care highlighted significant barriers to accessing mobility-promoting and fall prevention interventions delivered by allied health professionals, such as physiotherapists [9]. Qualitative evidence suggests that (referred and defined in this manuscript as telephysiotherapy) could be a feasible, acceptable, and effective approach for delivering mobility and fall prevention programs to older adults living in the community [10]. Telephysiotherapy could be particularly advantageous in increasing access and convenience for people with travel constraints and mobility limitations or who live in regional and remote areas [11].

Telerehabilitation that has provided telephysiotherapy has been found to have similar effectiveness compared with in-person rehabilitation services for community-dwelling older people, and it shows no increased risk of adverse events [12]. However, there is no evidence supporting the effectiveness, cost-effectiveness, and implementation feasibility of telephysiotherapy for improving mobility, reducing falls, and enhancing the quality of life for older adults receiving aged care services in their homes or residential aged care.

Telehealth is currently being used in aged care, but there is limited guidance on how best to implement it [13]. Hybrid effectiveness and implementation research has been shown to accelerate research translation into clinical practice [14]. Implementation research explores the experience of a complex intervention such as telehealth and its relationship to other factors, such as intervention engagement and adherence, perceived effectiveness, acceptability, and self-efficacy, which can support implementation translation [15].

**The TOP UP Trial**

TOP UP is designed to provide a scalable solution for delivering physiotherapy exercise interventions via telehealth to improve mobility, reduce falls, and enhance the quality of life in aged care. The TOP UP program was developed in collaboration with our aged care partners, physiotherapists, and aged care service users and their caregivers. A series of workshops identified potential facilitators to improve older people’s engagement with technology and motivation to exercise. The program’s co-design was also influenced by behavior change models, such as Self-Determination Theory (SDT) [16] and the capability, opportunity, motivation, and behavior (COM-B) framework [17].

TOP UP is investigating synchronous and asynchronous care to optimize both personalized health care and self-directed exercise [18] in aged care settings. It involves the delivery of real-time physiotherapy assessments through videoconferencing (synchronous telehealth) using the Zoom app (Zoom Video Communications Inc) by older adults receiving aged care services at home or in residential care. These service users are given access to evidence-based exercise videos on the TOP UP website and the StandingTall app (asynchronous telehealth) to support their exercise program. Each participant has the weekly support of a trained aged care worker to help them access the Zoom app and follow the exercise program. The outcomes being measured include effectiveness (mobility, falls, and quality of life), cost-effectiveness, and implementation measures (acceptability, reach, fidelity, dose delivered, and adoption).

The program is being tested in a hybrid type 1 effectiveness-implementation randomized controlled trial. Older adults were screened by their aged care service providers. Eligibility criteria included the age of older people (≥65 years); possessing sufficient physical, sensory, cognitive, and English language skills to participate; and having individual consent or possess sufficient physical, sensory, cognitive, and English language skills to participate; and having individual consent or consent from the person responsible. Those with terminal or unstable illness, with severe dementia, having participated in a similar physiotherapy program in the previous year, or being unable to walk 10 m were excluded from the study. A total of 242 participants were recruited from a screening pool of 1348 aged care service users (older people).

A total of 242 participants (120 per group) will provide 80% power to detect a 0.9 point between-group difference in 12-point
Short Physical Performance Battery test scores at 6 months (assuming SD 2.8, \( P=.05 \), and 20% dropouts) [19]. A 0.5-point between-group difference in the Short Physical Performance Battery test was considered clinically significant. This sample size was expected to be sufficient to detect between-group differences of 10% to 15% for the secondary outcome measures. Quantitative data analysis is expected to be completed in 2024.

Participants randomized to the intervention group received 10 videoconference physiotherapy sessions over 6 months using the Zoom app and received an individualized balance and strength exercise program. These exercise programs are based on the World Health Organization 2020 guidelines on physical activity and sedentary behavior [20] and the Otago exercise programs [21]. Existing aged care support staff, called “coaches,” have been trained to supervise participants to access the technology and provide “hands-on” exercise support once per week with the assistance of exercise videos designed by the research team. The waitlist control group receives a 3-month version of the program once the intervention period at each site is completed.

To inform the successful development of programs such as TOP UP, it is essential to examine not just if but how and why TOP UP worked (or not) and what strategies could best improve it. The aim of this paper was to use interview data to provide detailed insights into the experiences of older people, physiotherapists, coaches, and aged care managers with the telephysiotherapy intervention. The objective was to understand how contextual factors mediate the delivery of the TOP UP program and to produce transferable lessons for the potential use of future telephysiotherapy in aged care [22].

Methods

Study Design and Context

This study used a qualitative, descriptive approach through semistructured one-on-one interviews [23]. Qualitative description is increasingly used in conjunction with effectiveness and implementation trials and aims to present a straightforward description of participants’ experiences [24]. The analysis is grounded in the participants’ own words, making the results accessible to vulnerable groups, valid, highly translatable, and useful for refining interventions [25]. Qualitative description sits within a constructivist paradigm, considers multiple meanings, and recognizes that the research process is never neutral [26]. To strengthen the research rigor, we included triangulated data sources (by drawing on perspectives of different stakeholder groups) and a reflective discussion of emergent findings among the multidisciplinary research team [27].

Conceptual Framework

We used 2 behavior change theories, COM-B and SDT, and the Nonadoption, Abandonment and Challenges to the Scale-Up, Spread and Sustainability of Health and Care Technologies (NASSS) framework to provide a conceptual “lens” to inform data collection and analysis [28]. The COM-B model of behavior change proposes that to engage in a behavior such as exercise (B), a person must be physically and psychologically capable (C) and have the opportunity (O) to engage in the behavior, as well as the motivation to do so (M). COM-B simplifies complex factors and recognizes that to modify behavior, we need to address at least one of these components [17]. SDT focuses on the motivation underpinning behavior change, positing that effective programs must support autonomy, competency, and relatedness [16]. The NASSS framework is an evidence-based, theory-informed, and pragmatic framework that can help predict and evaluate the success of a technology-supported health program. It consolidates multiple implementation frameworks, targeting key issues relating to the implementation and uptake of telehealth at the microlevel of individual staff and consumers, the mesolevel challenges of organizational engagement and adoption, and macrolevel policy and regulatory factors (Figure 1) [28].
Recruitment and Data Collection

At the initial TOP UP recruitment, all aged care service users, coaches, physiotherapists, and aged care managers received an information sheet inviting them to participate in an interview for this qualitative study. After participants read the informational letter and confirmed their interest in participating in an interview, they received an informed consent letter to be signed by themselves or their person responsible before the interview appointment. A list of potential aged care service users and their coaches and physiotherapists was created in consultation with 3 of our aged care partners (Ashfield Baptist Homes, Whiddon, and Uniting AgeWell).

A purposive recruitment strategy was used to select 18 older adults who participated in the TOP UP intervention, ensuring variation in age, gender, residential status (home or residential aged care), geographic location, and cognitive levels. All 39 participants contacted agreed verbally and in writing before and on the day of the Zoom interview. None of the participants declined to participate in the interviews. The interviews were conducted 3 to 6 months after the interviewees commenced the program. Recruitment was stopped at the point when data adequacy had been reached, that is, when we judged that we had sufficient rich data across our purposive sample with which to answer our research questions [29].

The interview guide was created in consultation with the wider research team and representatives from our aged care partners (Multimedia Appendix 1). Interview questions targeted concepts from the COM-B model, SDT, and NASSS framework (described earlier). Specific questions explored the relative value of the different components of TOP UP (eg, Zoom, exercise videos, and the level of support provided). Questions regarding its implementation and effectiveness were also included. We also asked interviewees to identify local and potential system-wide barriers and facilitators to the successful adoption of telephysiotherapy, such as TOP UP and other programs aimed at delivering fall prevention and mobility programs in aged care. We used open-ended questions and active listening to confirm our understanding of the interviewees’ perspectives. RD and KN conducted the interviews individually on Zoom. They were
involved in the delivery of the program, so to reduce sociability bias, interviewees were encouraged to critique the TOP UP program and its implementation to identify improvements [30].

Aged care participants had a family member or someone familiar to them from their aged care organization that was not their coach to assist them with connection to the Zoom app and to support them through the interview. The participants were reminded that they could stop the interview at any time. No repeat interviews were conducted. RD and KN completed memos after the interviews and met to discuss the data and the emerging thematic content. Interview audio recordings were automatically transcribed using Zoom’s free transcription service, and transcripts were corrected by RD. Transcripts were not returned to the participants.

Data Analysis

The transcripts and interview field notes were uploaded to NVivo 12 (Lumivero) for data management and coding [31]. The transcripts were coded by one researcher (RD) using an inductive analytical approach. RD drafted an initial thematic framework drawing on emergent themes in the data and was informed by domains from the NASSSS framework. In total, 2 researchers (RD and AH) tested and refined the coding framework on 2 manuscripts, adding codes and modifying existing codes from inductively identified concepts in the data. RD coded the remaining data. RD, CS, and AH met regularly to discuss emergent codes and themes.

Recurrent themes were generated from reading across the coded data and reviewed against concepts from SDT [16] and the COM-B framework [17,29] to understand how aspects of the TOP UP program influenced exercise engagement. An early overview of the findings was discussed with all coauthors and our consumer representative to explore a wider range of possible thematic interpretations and to help ensure that we had answered our research questions, including considering the implications of our findings. Disagreements were resolved through discussion. The criteria for reporting qualitative research was descriptively described. The transcripts were coded by one researcher (RD) using an inductive analytical approach. RD drafted an initial thematic framework drawing on emergent themes in the data and was informed by domains from the NASSSS framework. In total, 2 researchers (RD and AH) tested and refined the coding framework on 2 manuscripts, adding codes and modifying existing codes from inductively identified concepts in the data. RD coded the remaining data. RD, CS, and AH met regularly to discuss emergent codes and themes.

Ethical Considerations

Ethics approval for this qualitative substudy was included in the TOP UP study approval granted by the Ethics Review Committee at the Sydney Local Health District Research Ethics and Governance Office, Concord, Australia (approval number CH62/6/2021-009). The trial was registered with the Australian New Zealand Clinical Trials Registry (ACTRN 1261000734864).

Results

Participants

In total, 39 people participated in semistructured interviews: 18 (46%) aged care service users who completed the TOP UP program, 7 (18%) aged care physiotherapists, 8 (21%) coaches, and 6 (15%) aged care managers. Interviews took an average of 19 (range 8-53) minutes. These service users were aged from 70 to 93 (median 87.5) years at the start of the intervention; 11 (61%) were female and 7 (39%) were male; 11 (61%) used a 4-wheeled walking frame to walk and 7 (39%) did not need a walking aid to walk; 7 (39%) lived in metropolitan cities in New South Wales and 11 (61%) lived in rural or remote areas in New South Wales and Victoria; 6 (33%) had mild to moderate cognitive impairment and 12 (77%) had no cognitive impairment; all had multiple comorbidities (median 7, range 2-11); and 10 (56%: median 1, range 1-7) had one or more falls in the last 12 months. The median Technology Readiness Index score was 2 out of 5 (range 1-3.9), which classified aged care users as technology avoiders, people who tend to have a high degree of resistance and a low degree of motivation to use technology [33]. A total of 4 (22%) aged care service users had used phone-based telehealth before with their general practitioner, but none had used a videoconferencing app such as Zoom before the study or used telehealth to receive physiotherapy.

Of the 7 physiotherapists interviewed, 4 were based in metropolitan areas and 3 were based in rural areas. A total of 4 coaches supported aged care service users from residential aged care, and 4 coaches supported aged care service users from home aged care. In addition, 1 aged care manager worked at a remote residential aged care site, 1 managed a rural residential aged care site, and 4 were home care managers from rural areas.

Main Findings

Overview

Our qualitative analysis revealed that all interviewees found the TOP UP program to be acceptable and would recommend similar telephysiotherapy programs to other older people receiving aged care services. Thematic analysis generated 6 key themes related to the experiences of TOP UP. We also compiled evidence of these experiences to identify and manage emergent possibilities, uncertainties, and interdependence that could guide the adoption of telephysiotherapy in aged care using the NASSSS framework. Quotations were used to illustrate each theme. We annotated the quotes for anonymity with aged care service users referred to as P1, P2, and so on, and other stakeholders are descriptively described.

Theme 1: Telephysiotherapy Expands Opportunity

Theme 1 highlights the expanded opportunities for accessing the physiotherapy that TOP UP provided. TOP UP minimized barriers to physiotherapy access related to travel and associated costs:

Travel in country areas is just too hard and having telehealth in the home makes it so easy to do. I can’t do a 70 km round trip – it is too expensive. [P10]

This was also echoed by service users whose significant disabilities created access barriers:

Because of my health, there’s no way I can go out to see a physio. One, I’ve got to get someone to take me, like a relation, or pay someone to take you, it’s not practical. It’s hard to park anywhere near the physio, you’ve got to walk, so by the time you get to the physio you’re exhausted. [P1]
efficiently, improving opportunities for older adults receiving aged care services to receive physiotherapy where and when they need it:

Some people need to be able to see a physio quickly, and we can provide telehealth services quickly, it is so efficient. [Home care physiotherapist, metro]

TOP UP had the greatest impact on rural and remote services, especially in areas where telehealth has the potential to address chronic health inequity issues related to workforce shortages:

Our town has a physio that visits once a month. Recently, one of our residents had a fall so I called the clinic and found out that we can’t get an appointment to take our resident to see a physio for 6 weeks, if someone has a fall like this, we just can’t wait six weeks. Telehealth really helps us. [Residential manager, remote]

Theme 2: Tailored Physiotherapy With Local Support Enhances Motivation

Regular local support was identified by all interviewees as important for enhancing older people’s confidence to try the exercise program and to support their motivation to “stick with” the program, including coping with TOP UP’s increasing challenge over time. Many interviewees across the 4 stakeholder groups explained that it was not just physical and technological support that the coaches offered (eg, providing stand-by assistance while performing balance exercises and managing the Zoom app) but also companionship and emotional support:

I can’t get out much and I began to look forward to the weekly session with my care worker as I really appreciated the support, she gave me to do something positive for my health. My coach understood what was going on in my life and she gave me the confidence to keep doing the exercises. [P12]

All the physiotherapists interviewed indicated that the coaches’ “hands-on” support was vital to the success of the program, as it helped to build capability and confidence. Importantly, TOP UP was a tailored program in which physiotherapists were able to modify exercises according to the individual needs of each service user, mirroring the person-centered approach typical in-person physiotherapy sessions. This tailored approach was particularly important to aged care service users whose health changes required program adaption:

My physio understood that I needed a break when I had some surgery, but was ready for me when I got back home and quickly helped me regain the fitness that I had lost in the hospital. [P18]

The TOP UP program used technology and behavior change techniques to maximize program adherence. Zoom provided physiotherapists with a platform to deliver individualized real-time health coaching and goal setting, which has been shown in the literature to increase participant adherence [34]. Interview data indicated that these techniques were being used across program implementation, consistent with the behavior change theory:

Physiotherapists start with building external motivation by setting goals, by encouraging them, and highlighting their progress we help them develop internal motivation to keep going. If we can motivate them internally, half the job is done, and exercise will become a routine and a lifestyle habit. [Home care physiotherapist, metro]

Further evidence emerged that these techniques were having the desired effect:

Their motivation seemed to improve when they reached their goals, and they wanted to keep on trying. Their motivation is the most important thing. [Residential coach, metro]

However, it was the combination of live tailored physiotherapy with enthusiastic and companionable local support that seemed to both develop confidence and underpin motivation:

The individual sessions on Zoom were important, so I could ask some questions about how I was doing, and having my physio give me some individual feedback was important for my confidence to keep exercising. My coach has made it possible, and her support has been great, she is so lively, and she exercises with me which makes it fun, we had such a laugh, she keeps me motivated, and she takes the monotony out of it. If you are not having fun, it is not worth it. [P10]

The previous quote also highlights the vital role of enjoyment in exercise and how this can be enhanced with a trained support worker acting as a coach. This may be especially important for engagement in the TOP UP program, given that many of the physiotherapists interviewed suggested that telehealth requires more time to develop a therapeutic alliance. Therapeutic alliance refers to how people experience the empathy of clinicians, and research shows that a strong therapeutic alliance is connected to positive treatment adherence and results in physical therapy [35]:

It’s not until you get to the fourth or fifth telehealth session that people start getting to really know you and feel like you can be an advocate for them. I think that telehealth does allow for a personal connection which adds to exercise adherence. [Physiotherapist, home care, rural]

TOP UP physiotherapists and coaches’ person-centered approach to goal setting, highlighting progress during the program and celebrating any achievements, seemed to enhance the aged care service user’s motivation to exercise:

TOP UP helped me care about my future before I just didn’t care. I loved the way the physio explained things to me carefully, so I understood. I really appreciate having the support worker exercise with me and reinforce what to do, and how to do the exercises. All of this made me feel like I mattered and now I can walk further, do my shopping, which is a big improvement. [P12]
**Theme 3: Engaging, Older Adult–Friendly Educational Resources Build Capability**

Interviewees expressed enthusiasm for the instructional videos that were designed to support high-quality independent exercises throughout the program. The videos incorporated exercises modeled by an older person, slow-paced dialog in a warm conversational style, natural lighting to maximize visibility, minimal visual distractions, and gentle humor, all of which seemed to increase exercise engagement by older people. In the following quotes, 2 participants describe the importance of “seeing” another older person in web-based videos:

> It was great to see an older person do the exercises, really motivating to see someone my age doing the program. The videos were at the right pace, and I like how they got harder over time. It was fun. [P17]

> The exercise videos are motivating because I feel like I am doing it with someone – it’s interactive and fun. Following a book can be boring. [P5]

Many stakeholders commented positively on the video design that incorporated slow demonstration and simple dialog that aimed to teach aged care service users how to perform safe and effective home exercise:

> The physiotherapist in the videos demonstrated the exercises slowly and explained things easily. I was really surprised how the residents were able to follow everything without any help. [Residential coach, metro]

> Having online exercise resources really helps because people aren’t familiar with exercise techniques, they can follow their prescribed video and it helps keep their exercise dose up. [Home care physiotherapist, regional]

Many of the physiotherapists interviewed commented that the TOP UP program was complex and challenged participants to navigate different apps and printed resources such as exercise diaries while using Zoom. They suggested that simpler telephysiotherapy programs (or simpler mechanisms for accessing program components) could be developed to enhance the user experience and minimize program dropout. One physiotherapist commented:

> I think having an easy to navigate, no fuss system where our clients can look up an exercise, record their exercise program and any problems they may have had, a fall, etc. I think an app where physiotherapists could get access to this information easily during a session and to help prepare for another session would be useful. [Home care physiotherapist, rural]

**Theme 4: A Flexible Reablement Approach Fosters Autonomy**

TOP UP is designed to encourage older adults to take a lead in their program planning; flexibility is emphasized, including choices about what resources to use (printed and web-based) and what skills they wish to develop that would enable them to engage in activities they found most important:

> I liked how it started easily, and I moved my way up the program. There is structure to the program, and you commit to it. I often plan to do a session but if something comes up, I make an appointment with myself to make sure I do it another time. [P16]

> I liked that I could stop and start the videos according to my own needs on the day. [P1]

This can be described as a reablement approach, and the physiotherapist and coaches were encouraged to build the aged care service users’ physical capability and support them in transferring their new skills to access other activities in their community independently:

> Residents lack enough physical activity here, sometimes we are short staffed, and sometimes the staff don’t have time to help. It was great to see our residents on the TOP UP program improve their mobility and begin to walk to different activities on their own. [Residential manager, rural]

All stakeholders valued the reablement approach, and it was reported that TOP UP seemed to be a catalyst for reablement, as many of their clients began to engage in more socialization with friends and families and embrace other physical activities as they became stronger and more mobile:

> Physios and coaches can work together to ensure that the participant becomes independent and autonomous in their use of telehealth and do more exercise as the program progresses. As they improved, we had discussions with them and their coach about how they could do more outdoor walking. [Home care physiotherapist, rural]

> I was surprised about the other quality of life benefits of telehealth, talking to their physio on zoom, seeing their support workers in this new way, learning how to get out and about in the community, all seemed to reduce social isolation, which is so important for our customers. [Home care manager, rural]

**Theme 5: Telephysiotherapy Can Be Safe, Effective, and Acceptable for Many**

Most interviewees regarded TOP UP as a safe, effective, and acceptable program. Interviewees reported positive physical and quality of life improvements:

> I think it’s fabulous. I wouldn’t have imagined that I would be given the opportunity to get physio. Physically, I can walk further. My breathing is better. I’m stronger, it gives you more independence. [P1]

> Telehealth has not only helped my customer’s strength, mobility and coordination, but it seemed to help their overall quality of life, they seemed happier and more confident to walk. [Residential care manager, rural]

Many interviewees reported that the combination of physiotherapist-led instructional exercise videos and supervision by trained support workers increased the safety of the TOP UP:

> I think having a physio run exercises in the videos gives the intervention more authority, frees up my...
time to motivate the residents and keep them safe. [Residential coach, remote]

I think having the care worker there with the client to help set up Zoom, hold the iPad, and angling the video so I can see them clearly makes the program safer and more successful. [Home care physiotherapist, rural]

However, TOP UP was not considered to be suitable for all aged care service users. All stakeholders agreed that telehealth presents challenges for frail clients in residential aged care, who often have higher levels of mobility and sensory and cognitive disability. A total of 2 cognitive and sensory impaired aged care service users found using Zoom to “see” their physiotherapist frustrating and as a result, pulled out of the program:

First of all, not all dementia residents get used to it, and second, people with hearing and vision problems struggle to follow. [Residential aged care manager, rural]

Some physiotherapists would hesitate to use telehealth without local support for those aged care service users with high fall risks:

For people who are mostly independent I wasn’t worried, but if I did have someone who was who was frailer and there was no one there with them I was worried they might fall. [Home care physiotherapist, regional]

Some aged care service users and managers suggested that although telephysiotherapy is a good secondary option, they would still prefer in-person physiotherapy, especially for older adults with more complex needs:

I prefer a blend of face-to-face physio and telehealth. I need some hands-on physio from time to time to manage the arthritis in my back, but I liked the telehealth program because I could follow the physio exercise videos at home, it was so convenient. [P18]

It appears that a hybrid model that incorporates a blend of face-to-face physiotherapy and web-based exercise resources, such as exercise videos, was viewed as particularly acceptable for those with significant health challenges:

I don’t know if someone with severe dementia or disabilities would be able to access telehealth. I also think a lot of clients would like a hybrid telehealth model starting with a face-to-face assessment. [Home care physiotherapist, rural]

Finally, our screening process uncovered many technological hesitations and potential telehealth data concerns that prevented the recruitment of many potential aged care service users into the TOP UP trial:

There is some hesitancy around technology use due to recent cybersecurity anxiety in the community— for example the Optus and Medibank breaches. [Home care manager, rural]

Theme 6: Organizational Commitment Is Required to Embed Telephysiotherapy

Interviewees explained that considerable organizational commitment is required to embed telehealth programs such as TOP UP in aged care. Sufficient investment is required to train staff, conduct more meetings with their physiotherapy service providers to plan for the development of a new service, such as telephysiotherapy, prioritize TOP UP sessions within busy service schedules, and, where necessary, direct funds toward supportive technology. Some coaches and physiotherapists commented that the use of devices such as large iPads and smart televisions enhanced telehealth engagement by improving the visibility and hearing experience of service users:

Zoom worked well when we connected the iPad to the TV, we were able to turn the volume of the TV up so the resident could hear better. It also gives a bigger picture as well, so they can see the physio better. [Residential care coach, rural]

However, such equipment can be costly, and telehealth-specific funding was raised by physiotherapy, aged care managers, and coaches as a key condition for ongoing sustainability of telephysiotherapy in aged care:

I think that maybe there needs to be funding support. Telehealth is an important and easy way to increase access and uptake. One physio could service several homes in a full-time caseload. [Residential care physiotherapist, rural]

TOP UP required 3 people to be available for appointments (the older person, their coach, and the physiotherapist on Zoom); thus, scheduling was more challenging than 2-person face-to-face health care interactions:

There are always challenges whenever it comes to scheduling, especially during COVID when we were short of staff. But if you have a good relationship with your physiotherapy provider, who is responsive to time slot suggestions, then our scheduling team could work their magic and get it all booked. [Home care manager, rural]

Training was provided to older adults to increase their confidence using an iPad, our website, and relevant apps (Zoom and StandingTall). Coaches were trained to increase their level of comfort by navigating the TOP UP website and Zoom. Physiotherapists were trained to deliver effective telephysiotherapy assessments using Zoom and provided strategies to enhance relationship development with older adults and their coaches. All interviewees highlighted this training as an important factor in overcoming “telehealth hesitancy” both for service users and program providers:

There was a lot of telehealth hesitancy at the beginning, but with education they slowly got quite comfortable in doing it. [Home care physiotherapist, metro]

There is a need to have some general training so we [physiotherapists] know how to use it [telehealth technology] effectively: make sure your voice is coming through, how to pace instruction so our clients
The coaches and customers need training to know how to set up a shot, to make sure that they are visible to ensure that the client becomes independent and autonomous in their use of telehealth. [Home care physiotherapist, rural]

All stakeholders indicated the need for specific investment into better internet connectivity to ensure the sustainability of future telephysiotherapy programs:

I’ve found is there are still a lot of places in rural Australia where older people don’t have fast Internet, they don’t have smart TVs, or they don’t have the technology that metro places have. People are ready to engage with telehealth, but there’s no infrastructure in rural areas. [Residential physiotherapist, metro]

Some aged care service managers and physiotherapists indicated that more frequent and more detailed web-based exercise training programs would be useful to improve the skill level of a wider group of support staff:

It is very important to have lots of staff trained. For example, if the regular coach is sick, another staff member could take over and keep the program going. [Home care manager, rural]

Implementation Guidance Through the Lens of the NASSS Framework

TOP UP appears to be well positioned for sustainable adoption, and learnings from this study have informed the translation of telephysiotherapy services by our aged care partners into practice. Table 1 uses the NASSS framework to help explain TOP UP’s successes and failures and explore the facilitators required to embed similar telephysiotherapy programs in aged care.
**Table 1.** An overview of TOP UP implementation guidance in relation to the Nonadoption, Abandonment and Challenges to the Scale-Up, Spread and Sustainability of Health and Care Technologies framework domains.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Definition of domain</th>
<th>Implementation guidance derived from study findings</th>
<th>Illustrative quotes from interviewees</th>
</tr>
</thead>
<tbody>
<tr>
<td>The condition</td>
<td>The suitability of the participant’s attributes/needs and their interaction with the intervention.</td>
<td>TOP UP is suitable for aged care service users with mobility challenges who can walk short distances. It is not suitable for those with significant sensory and cognitive disability.</td>
<td>“Someone with severe dementia or severe disabilities would not be able to have that skill to access telehealth.” [Residential coach, rural]</td>
</tr>
<tr>
<td>The technology</td>
<td>Technical features related to the usability of telehealth and its support requirements.</td>
<td>TOP UP requires access to the internet via an iPad or similar device. Aged care service users do not need technical skills due to the weekly support they received from trained care workers to help them use the iPad, navigate Zoom, and access exercise videos on a website. However, basic technological skills were often developed, which increased autonomy.</td>
<td>“One of my clients is really good with technology but other clients need my help to turn on the iPad and follow the program.” [Residential coach, metro]</td>
</tr>
<tr>
<td>The value proposition</td>
<td>The value proposition of telehealth for upstream end users (aged care service providers) and downstream users (physiotherapists and their clients).</td>
<td>All stakeholders saw telephysiotherapy as a valuable addition because of its convenience and perceived effectiveness, especially for those with poor mobility or who are living in rural or remote areas. The value proposition for telehealth to treat musculoskeletal pain is less as stakeholders prefer a more “hands-on” experience. A hybrid model would add value for some.</td>
<td>“Telehealth would save us time and travel and help us to see more people.” [Home care physiotherapist, regional]</td>
</tr>
<tr>
<td>The adopter system</td>
<td>The ongoing investment required to support the telehealth intervention and the ongoing acceptability of stakeholders.</td>
<td>TOP UP requires consistent investment in training, human (physio, coaches), and physical infrastructure (devices, fast internet, senior-friendly exercise resources) to create sustainable success. However, high levels of system support are likely to be reinforced as positive returns on investment due to their perceived positive impacts on mobility and well-being.</td>
<td>“TOP UP is more than just a fall prevention program, it offers a truly enabling focus where our clients can build their strength and balance and get out into the community again. I think many of our clients could benefit from telehealth.” [Home care manager, rural]</td>
</tr>
<tr>
<td>The organization</td>
<td>An organization’s capacity to embrace the telehealth intervention and the supports required to establish and maintain it as a viable service offering.</td>
<td>Not all aged care services chose to participate in TOP UP because of the perceived burden of working with technology. Providers who joined TOP UP wanted to investigate telehealth’s impact on access to fall prevention and mobility programs, in areas where there are physiotherapy shortages. Providers offered considerable support via technology provision, extra administration support for scheduling of telephysiotherapy sessions, and enough care workers to support the program.</td>
<td>“I was surprised at how easy telehealth was to get started. We gave the clients an iPad and the assistance the care workers gave them was important to help them engage with telehealth. Our scheduling team are fantastic, and they managed to solve the scheduling challenges really well.” [Home care manager, rural]</td>
</tr>
<tr>
<td>The wider context</td>
<td>The wider organizational and policy impacts on telehealth uptake and sustainability.</td>
<td>Stakeholders agreed that funders need to provide telehealth-specific funding and education for interventions such as TOP UP to reduce technology hesitation and improve telehealth systems that enhance its adoption and sustainability.</td>
<td>“I feel that people would be greatly advantaged if there was a separate pocket of funding for allied health so that we could afford to deliver ongoing telehealth” [Home care manager, rural]</td>
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</table>

**Discussion**

**Principal Findings**

This study, which included participants such as older adults, physiotherapists, aged care support workers, and managers in the TOP UP trial, offers valuable insights. Our thematic analysis identified key factors for the telephysiotherapy program’s acceptability, including advice from physiotherapists, consistent support from trained care workers, older adult–friendly web-based exercise resources, and a flexible reablement approach. The interview data supported multiple themes, suggesting that the synergistic integration of these ingredients within the TOP UP contributed to its high acceptability. The discussion explores the impact of single components and emphasizing their combined contribution to TOP UP’s acceptability.

**TOP UP Study Is Acceptable**

Acceptability is an important consideration in the design and implementation of complex health care interventions, such as TOP UP [36]. Our findings align with the increasing body of literature indicating acceptance of telehealth among older adults in community settings despite high levels of technology hesitation [37,38]. A cohort study of a telehealth program incorporating physiotherapy for rural older adults found that telehealth was safe (no adverse events) and feasible (average telehealth attendance 85%) [38]. A 2021 cross-sectional survey of health care providers further affirmed increasing telehealth acceptability over time among homebound older adults [39].

**Barriers and Facilitators Related to Telehealth Adoption**

TOP UP identified several barriers and facilitators that enabled aged care service users to overcome high levels of technology...
hesitation and, if appropriately addressed, could improve the translation of telehealth programs into aged care [40]. TOP UP’s qualitative findings are reflected in the literature, which demonstrate that barriers related to this population’s innate technology hesitation and greater sensory, physical, and cognitive impairments could be addressed by the provision of local support, internet-connected devices, fast internet, and appropriate telehealth training can mitigate these barriers [39,41,42].

A recent US survey of physician providers of homebound older adults during the COVID-19 pandemic revealed that a significant proportion of their patients were technology avoidant [39] (only a third of their patients had used video-based telehealth before, 310/873, 35.5%). Among patients who had not used telehealth before, providers deemed that one in 4 (153/563, 27.5%) of their patients would not be able “interact over video” due to cognitive or sensory impairments. This survey found other barriers: providers lacked knowledge of their patients’ internet connectivity, and participants faced financial constraints in obtaining internet plans and were unable to pay for internet plans or video-capable devices. Similar findings emerged in the TOP UP, where most trial participants had limited access (10/18, 56%) to video-capable devices, limited telehealth experience (4/18, 22%), and low telehealth readiness (Technology Readiness Index 2 out of 5). Addressing barriers related to the purchase of telehealth infrastructure and providing local support can facilitate wider acceptance within aged care settings.

A recent qualitative exploration of factors influencing acceptability in dementia management revealed that videoconferencing had potential benefits over in-person appointments by improving access to care for those with mobility limitations and reducing the stress associated with clinic appointments [43]. A crucial insight from this study emphasized the necessity of technical support and telehealth training involving information on how to access and use different telehealth apps and tips for setting up the video camera for maximum visibility. Similarly, another study examining telehealth’s role in enhancing oncology care for older adults emphasized that appropriate technology training integrated into the screening process and program delivery could enhance telehealth adoption [44]. These studies align with TOP UP’s findings that emphasized the delivery of appropriate education at screening and recruitment to reduce technology avoidant behaviors, preprogram technology training to support adoption, and training to troubleshoot any emerging technology issues to enhance sustainability.

TOP UP demonstrated that behavior change training for physiotherapists and coaches in health coaching techniques, motivational interviewing, and collaborative goal setting can facilitate telehealth adoption. Behavior change training has been shown to increase therapeutic alliance and enhance exercise program outcomes in other studies [45]. A strong therapeutic alliance has been identified as a crucial facilitator in previous telehealth interventions [46]. In our study, physiotherapists, coaches, and aged care service users found telehealth suitable for effective behavioral change coaching and suggested that specific training on skills to enhance therapeutic alliance is important to augment telehealth acceptability. Specific examples included targeted training on using Zoom emojis to acknowledge client achievements and building a personal connection through virtual tours of the older person’s home and garden. However, they noted that establishing a successful therapeutic alliance through telehealth demands more time compared with in-person sessions, potentially increasing program costs.

**Telehealth Can Provide Key Ingredients for Behavior Change**

TOP UP was co-designed to incorporate the COM-B model to create positive behavior changes related to exercise adherence [17]. Recent data from the Australian Institute for Health and Welfare have shown the critical significance of addressing insufficient physical activity in older individuals, given their 50% contribution to 2.5% of the overall disease burden in Australia [47]. Consequently, increasing motivation and opportunities for exercise in this demographic is crucial in mitigating the adverse health consequences stemming from sedentary behavior [19] and in supporting the efficiency of the health care system [48]. TOP UP’s tailored approach and use of older adult–friendly resources appeared to increase the capability (C) of older adults to exercise. The program provided increased opportunities (O) for exercise by facilitating increased access to physiotherapists. Furthermore, TOP UP heightened motivation (M) through its reablement approach, goal-setting mechanisms, and cultivation of enjoyment via companionable coaching [16].

The TOP UP program strategically incorporated the principles of SDT to promote increased exercise adherence. According to SDT, intrinsic motivation thrives when individuals perceive a sense of autonomy and control over their activities [49]. Our study findings suggest that the aged care service users valued the opportunity to regain independence through self-directed exercise. The TOP UP program effectively nurtured feelings of competence through its personalized and progressive exercise routines program, fostering a sense of relatedness through local support and the rapport established during the telephysiotherapy sessions that actively promoted enjoyment. This observation aligns with the systematic review by Teixeira et al [50] on SDT and exercise adherence, affirming the positive correlation between intrinsic motivation, enjoyment, personal achievement, and heightened program acceptability.

Our study has provided insights into the potential explanatory effects of the social learning theory by Bandura [51] and Motivational Theory of Role Modeling in supporting the high acceptability of TOP UP. The social learning theory by Bandura [51] underscores the significance of observation and imitation in driving behavior change. When individuals perceive the modeled behavior as valuable, and the model possesses an admired status while being relatable, the likelihood of behavioral change increases. In this context, physiotherapists, esteemed as exercise professionals in the community [52], played a crucial role in enhancing the perceived value of the TOP UP program. Furthermore, the Motivational Theory of Role Modeling highlights another critical aspect of TOP UP’s acceptability [53]. Many interviewees emphasized the importance of including older adults as role models in exercise videos. Both theories
suggest that the inclusion of older role models was a pivotal factor inspiring behavioral change, explaining the positive reception of TOP UP exercise videos.

**Scale-Up and Sustainability of Telephysiotherapy in Aged Care**

Telehealth has emerged as a prominent method for implementing scalable health care interventions, a trend that has intensified during the COVID-19 pandemic [54]. However, the challenge of sustaining these programs is pressing, as is evident from reports of high participant attrition rates in telehealth-led exercise programs [55]. Successfully delivering cost-effective exercise programs to frail older adults with multiple comorbidities in the aged care environment is challenging and complex, demanding significant resourcing [8]. Insights gained from the NASSS framework [28] underscore the need for careful screening of older adults for telephysiotherapy participation and the provision of targeted training to all stakeholders to enhance its feasibility. Our analysis indicates that while TOP UP was acceptable, a hybrid model of virtual care that combines in-person initial assessments, subsequent synchronous telephysiotherapy sessions for program progression, and the integration of local support and older adult–friendly web-based exercise resources may further increase telephysiotherapy uptake and sustainability in aged care.

Although the cost-effectiveness analysis of TOP UP is pending, our qualitative observations indicate that establishing telephysiotherapy programs requires substantial investment in both physical and human infrastructure. The telehealth literature discusses the critical role governments play in developing policies and guidelines to foster telehealth adoption [56]. Our interviews revealed a consensus on the need for dedicated funding for telehealth to enhance adoption and sustainability.

**Strengths, Limitations, and Future Studies**

This qualitative study had several strengths. It triangulates empirical data relating to the uptake and sustainability of telephysiotherapy in aged care from 4 perspectives: older adults receiving physiotherapy within aged care services, physiotherapists, trained support workers who deliver the intervention, and aged care managers who are charged with case management and overseeing aged care service resource allocation and delivery. Our partnerships with aged care providers and their ongoing input in the research have enabled us to develop a deep understanding of how the TOP UP program was delivered in aged care and, if proven effective, this will speed up its translation into wider practice [14].

Qualitative research serves as a valuable tool for refining program design, deepening insights into the outcomes of quantitative research, and offering valuable guidance for enhancing the implementation of complex interventions such as telephysiotherapy in aged care [26]. In this study, we adopted a broad sampling strategy aimed at delivering a rich description of diverse intervention experiences, enlisting the perspectives of 18 older adults encompassing a range of sociodemographic characteristics distributed across 10 distinct sites. Moreover, the inclusion of independent physiotherapists, separate from both the aged care service partners and the research team, in our study design may have reduced potential social desirability bias, enhancing the credibility of our findings [30].

Several limitations of this study necessitate careful consideration. TOP UP excluded participants from culturally and linguistically diverse backgrounds and thus presented a notable gap in our understanding of their experiences. To address this gap, future trials that prioritize the inclusion of culturally and linguistically diverse communities are required. In addition, although the interviewee cohort was purposefully selected to encompass maximum variation, it is essential to acknowledge that this pool primarily consisted of individuals who voluntarily participated in the trial, potentially predisposing them to higher levels of exercise engagement and receptiveness to telehealth. Consequently, this may limit the generalizability of our findings.

Several aged care service users and coaches were interviewed by either a physiotherapist or aged care service provider who delivered the program. This can lead to social desirability biases, which may undermine the credibility of the study results [57]. Given this context, aged care service users and staff might hesitate to openly share negative experiences with their interviewers despite the research team’s assurances that their feedback would have no bearing on their ongoing care or employment status. To mitigate this bias, interviewees made concerted efforts to positioning themselves as eager learners, actively encouraging interviewees to share their “insider” perspectives on quality improvement and expressing genuine appreciation for any criticism offered. Future larger-scale mixed methods studies should be designed to enhance research quality and further explore the impact of telephysiotherapy uptake and sustainability in aged care while carefully addressing social desirability bias.

This study suggests a need for the development of simplified telephysiotherapy exercise programs to facilitate greater adoption in aged care. A recent scoping review conducted in 2021, examining the barriers and facilitators to the use of telehealth by older adults, found several impediments associated with current technology, including challenges related to small screens, text size, small icons, insufficient color contrast between text and background, and complex functionality [58]. The review also identified ease of use as a key facilitator of telehealth adoption. Some TOP UP stakeholders interviewed indicated a preference for simplified functionality tailored to this demographic. Respondents expressed a desire for telehealth programs that incorporated TOP UP program features such as Zoom, exercise diaries, and videos, into one user-friendly application. These findings advocate for further research aimed at enhancing the user experience.

**Conclusions**

This interview study explored the program experiences of aged care service users, physiotherapists, and aged care staff involved in the TOP UP trial, a telehealth-led exercise program designed to improve mobility, reduce falls, and enhance quality of life. All stakeholders indicated high program acceptability, underscored by its safety, and perceived effectiveness. The thematic analysis uncovered key insights: TOP UP’s provision of convenient access to physiotherapy services for aged care...

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*(page number not for citation purposes)*

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recipients, the positive impact of tailored physiotherapy coupled with local support on exercise motivation, the effectiveness of engaging older adult–friendly resources in fostering program adherence, and the facilitation of greater independence through a flexible reablement approach. This study emphasizes the importance of sustained organizational commitment for the successful implementation of telephysiotherapy programs, such as TOP UP, highlighting the need for training and external funding to ensure telephysiotherapy’s adoption and sustainability.

Acknowledgments
RD receives scholarship funding and JO receives salary support from the National Health and Medical Research Council–funded Centre for Research Excellence—Prevention of Fall-related Injuries. MP holds a National Health and Medical Research Council of Australia Early Career Fellowship. KN is employed by Whiddon and NB is employed by Uniting AgeWell. The TOP UP study was funded by Dementia Australia and Aged Care Research and Industry Innovation Australia. The funders and organizations had no role in the trial design and will not have any role during its execution, analyses, interpretation of the data, or decision to submit the results.

Data Availability
The data sets generated during this study are not publicly available because of the confidentiality promised to the participants as part of the informed consent process. However, data sets are available from the corresponding author upon reasonable request.

Authors' Contributions
All authors reviewed the thematic analysis. RD, AH, and KN drafted the semistructured interview guide. RD drafted the manuscript as the lead author. All authors critically revised the manuscript for intellectual content.

Conflicts of Interest
RD receives scholarship funding, and JO receives salary support from the National Health and Medical Research Council–funded Centre for Research Excellence—Prevention of Fall-related Injuries. MP holds a National Health and Medical Research Council of Australia Early Career Fellowship. KN is employed by Whiddon, and NB is employed by Uniting AgeWell. All other authors declare no other conflicts of interest.

Multimedia Appendix 1
Semistructured interview guide.
[DOCX File, 17 KB - aging_v71e53010_app1.docx]

Multimedia Appendix 2
The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.
[DOCX File, 16 KB - aging_v71e53010_app2.docx]

References


Abbreviations

COM-B: capability, opportunity, motivation, and behavior
NASSS: Nonadoption, Abandonment and Challenges to the Scale-Up, Spread and Sustainability of Health and Care Technologies
SDT: Self-Determination Theory

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Characteristics and Range of Reviews About Technologies for Aging in Place: Scoping Review of Reviews

Abstract

Background: It is a contemporary and global challenge that the increasing number of older people requiring care will surpass the available caregivers. Solutions are needed to help older people maintain their health, prevent disability, and delay or avoid dependency on others. Technology can enable older people to age in place while maintaining their dignity and quality of life. Literature reviews on this topic have become important tools for researchers, practitioners, policy makers, and decision makers who need to navigate and access the extensive available evidence. Due to the large number and diversity of existing reviews, there is a need for a review of reviews that provides an overview of the range and characteristics of the evidence on technology for aging in place.

Objective: This study aimed to explore the characteristics and the range of evidence on technologies for aging in place by conducting a scoping review of reviews and presenting an evidence map that researchers, policy makers, and practitioners may use to identify gaps and reviews of interest.

Methods: The review was conducted in accordance with the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews). Literature searches were conducted in Web of Science, PubMed, and Scopus using a search string that consisted of the terms “older people” and “technology for ageing in place,” with alternate terms using Boolean operators and truncation, adapted to the rules for each database.

Results: A total of 5447 studies were screened, with 344 studies included after full-text screening. The number of reviews on this topic has increased dramatically over time, and the literature is scattered across a variety of journals. Vocabularies and approaches used to describe technology, populations, and problems are highly heterogeneous. We have identified 3 principal ways that reviews have dealt with populations, 5 strategies that the reviews draw on to conceptualize technology, and 4 principal types of problems that they have dealt with. These may be understood as methods that can inform future reviews on this topic. The relationships among populations, technologies, and problems studied in the reviews are presented in an evidence map that includes pertinent gaps.

Conclusions: Redundancies and unexploited synergies between bodies of evidence on technology for aging in place are highly likely. These results can be used to decrease this risk if they are used to inform the design of future reviews on this topic. There is a need for an examination of the current state of the art in knowledge on technology for aging in place in low- and middle-income countries, especially in Africa.

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KEYWORDS
aging in place; technology; gerontechnology; assistive technology; gerontology; geriatric; geriatrics; older adult; older adults; aging; aging; scoping; review methods; review methodology; older people; evidence map; evidence mapping
Introduction

Background

The World Health Organization (WHO) estimates that the global population aged 60 years and older will increase from 12% to 22% between 2015 and 2050, with the most dramatic increase in low- and middle-income countries (LMICs) [1]. This will change the age composition in populations globally. Demographic aging refers to shifts in the age composition of populations where the proportion of the population that consists of older people grows significantly. The fact that people are now living longer than ever and that they are expected to continue doing so is the result of positive developments in public health and survival [2]. Yet, demographic aging is also one of the key challenges of our time [3].

This concern is caused by how demographic aging will impact nation states. As people grow older, they tend to become increasingly reliant on both formal and informal care. For instance, older people are more likely to have functional limitations, need assistance with everyday tasks, and need medical care [4-6]. Moreover, older individuals have lower incomes, which compound the challenges of their increasing need for care [7]. As a result, nation states have a variety of systems in place to care for older people, including systems of shouldering the cost of that care.

In countries where welfare and care systems are heavily subsidized, demographic aging is predicted to lead to heavy financial strain and a decreased quality of life for older people, unless solutions that cater to the need to maintain good health and affordable health care into a longer set of retirement years are developed [8]. Still, the adverse consequences of demographic aging will be even greater in LMICs. In LMICs, welfare systems often function poorly or are nonexistent, meaning that the burden of caring for older people falls on families or on the older individuals to care for themselves. This has caused concerns that LMICs will “grow old before growing rich” [7].

To neutralize the overwhelming demand for health care, solutions are needed to enable older people maintain their health for longer and postpone or avoid disability and dependency [1,9,10]. Against this background, interest in technology that enables older people to age in place while maintaining their dignity and quality of life has grown rapidly over the past 2 decades [11].

Aging in place is a concept that refers to the shared responsibility of individuals and public authorities to enable older people to continue to live safely, relatively independently, and comfortably in the community either in their current home or in appropriate housing, regardless of age, income, or level of competence [1,12-14]. The idea is that policies and public services should address the challenges posed by demographic aging by finding alternatives to traditional forms of older adult care and creating solutions that are less resource-intensive. In welfare states where health and care services are heavily subsidized, this shift toward less resource-intensive solutions generally refers to options that maintain a high quality of life for older people while simultaneously preventing or delaying the need to relocate to a nursing home or becoming dependent on care [15], as well as to solutions that minimize the use of resources in nursing homes and other forms of formal care, without compromising their quality. Meanwhile, in LMICs, the main challenge is that welfare systems are weak and even nonexistent. Assistive technology and related services are marginal and not available for the majority, particularly for the poor rural populations. Ensuring assistive technology for all, including the growing number of older adults, requires resources and build-up of competence through a sustainable systems approach [16]. In this context, innovations are needed in service delivery, and community-based models as well as adaptation of existing assistive technology and development of new and contextually relevant assistive technology are needed to ensure that older people live well and as autonomously as possible [17].

Technologies that enable aging in place encompass a wide variety of technologies designed to monitor or support the health and activities of older people or strengthen their contact with others [11,15]. In some cases, older people are the intended users, but technology can also be used to establish links between older adults and their circles of care. Technologies for aging in place include both high- and low-tech solutions, including but not limited to mobility devices, information and communication technologies, assistive technologies, sensor technology, telemedicine, health monitoring, games, wearables and medication reminders, and the internet of things [15,18-27].

Rationale

Alongside the interest in technology that can enable older people to age in place, the number of publications on this topic has increased dramatically. In this context, literature reviews can be important tools for researchers as well as practitioners, policy makers, and decision makers who need to navigate current debates and access syntheses of the available evidence. Yet, to date, there is no review of the available published reviews that provide an overview of the range and characteristics of the evidence on technology for aging in place.

While reviews of reviews on technologies for aging in place do exist, they typically limit the scope to health conditions, diseases, technologies, or caring practices, for instance, by focusing on the self-efficacy of older people using technology to self-manage chronic obstructive pulmonary disease, hypertension, heart failure, or dementia at home [28]; on the effects of digital technologies on older people’s access to health and social care [29]; on the promotion of physical activity in older people using mobile health (mHealth) and eHealth technologies [30]; or on how mHealth technology may support aging in place [31] and procedures of user-centered usability assessment for digital solutions [32].

Objective

The objective of this review of reviews is to explore the characteristics and the range of evidence on technologies for aging in place by conducting a scoping review of reviews in accordance with the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for
Scoping Reviews) [33]. The PRISMA-ScR checklist is available in Multimedia Appendix 1.

By exploring the included reviews, we are particularly interested in what year and in which journals they are published, which review methods that characterize reviews in this field, and whether there are any reviews that are explicitly concerned with LMICs. By LMICs, we mean the countries identified by the Organization for Economic Co-operation and Development as having low-income or middle income economies, which may be updated from time to time by the Organization for Economic Co-operation and Development [34]. In exploring the range of evidence presented in reviews on technologies for aging in place, we are particularly interested in which types of populations, technologies, and problems they have been concerned with.

**Methods**

**Eligibility Criteria**

We included literature reviews in English about technology for older people or older adult care, including informal care, that we were able to access. To ensure the quality of our sources, we limited our scope to peer-reviewed literature reviews that have been published in academic journals. For the same reason, we only included reviews where the methods were clearly described. We did not apply any limits to the year of publication.

**Information Sources**

Our method of selecting databases included making a list of the most relevant journals in the field that the authors were aware of (Multimedia Appendix 2). The complete list was sent to a panel of experts consisting of members from the WHO and the International Society of Gerontechnology, who were asked to add any potentially relevant journals missing from the list. After the list was considered complete, the authors identified the databases where these journals were indexed. The final selection of databases was Web of Science (Table 1), PubMed (Table 2), and Scopus (Table 3). The searches in Web of Science and Scopus were conducted on September 13, 2022, and the search in PubMed was conducted on September 14, 2022.

### Table 1. Web of Science—core collection (n=1741).

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<th>Results</th>
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<td>4,027,248</td>
</tr>
<tr>
<td>(TS=ai) OR TS=(&quot;ag$ in place&quot;) OR TS=(gerontechnology) OR TS=(&quot;assisted living&quot;) OR TS=(&quot;assist* tech&quot;) OR TS=(assist* device*) OR TS=(&quot;tele*&quot;) OR TS=(&quot;welfare tech&quot;) OR TS=(&quot;digital* health&quot;) OR TS=(&quot;digital* care&quot;) OR TS=(&quot;smart hom&quot;) OR TS=(&quot;smart hea&quot;) OR TS=(mobile health) OR TS=(mhealth) OR TS=(ehealth) OR TS=(robot*)</td>
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### Table 2. PubMed (n=2402).

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### Table 3. SCOPUS (n=3131).

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<td>TITLE-ABS-KEY ( ( &quot;old* per*&quot; ) OR ( &quot;old* peo*&quot; ) OR ( &quot;old* age*&quot; ) OR ( &quot;old* adu*&quot; ) OR ( &quot;old* use*&quot; ) OR ( geriatric ) OR ( &quot;aged per*&quot; ) OR ( &quot;aged peo*&quot; ) OR ( &quot;aged use*&quot; ) OR ( aging ) OR ( elder* ) OR ( senior ) OR ( retire* ) OR ( pension* ) ) OR ( &quot;later life&quot; ))</td>
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<tr>
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<td>3131</td>
</tr>
</tbody>
</table>

### Search

A search consisting of the terms “older people” and “technology for ageing in place” with alternate terms was conducted using Boolean operators and truncation. The search was adapted to the rules for each database.

### Selection of Sources of Evidence

The search resulted in a total of 7274 identified studies, that is, 3131 from Scopus, 2402 from PubMed, and 1741 from Web of Science. We used Covidence (Veritas Health Innovation) to organize the review process. After 1827 duplicates were identified and removed, 5447 studies were screened using the eligibility criteria (see Textbox 1). The original list of eligibility criteria contained items 1-7. However, after we identified a retracted paper, we decided to add exclusion criterion 8 “retracted paper.” The title and abstract screening resulted in the exclusion of 4973 studies. The full-text screening resulted in the further exclusion of 130 studies, and the remaining 344 studies were included in the data charting process. Figure 1 illustrates this process.

### Textbox 1. Eligibility criteria.

#### Inclusion criteria
- Literature reviews
- Journal paper
- Peer-reviewed research
- Able to source full text
- Methodologically sound
- About technology for aging in place
- English

#### Exclusion criteria, with a short label for Covidence
- Not a literature review—Papers that do not review the literature
- Not a journal paper—Anything that is not a paper meaning: book chapters, conference proceedings, protocols, reports, preprints, etc
- Not research—editorials, opinion pieces, press, etc
- Unable to source—currently unable to access full text currently
- Method not described—Reviews that do not clearly describe their methods
- Thematically irrelevant—Not about technology for aging in place
- Not in English
- Retracted paper
Data Charting Process and Data Items

The data were extracted using the data extraction template feature in Covidence. The extraction of data was organized in line with our objectives and research questions. Tables 4 and 5 provide an overview of the relationship between the research questions and the extracted data.

**Table 4.** Research questions and charted data that relate to the characteristics of reviews on technologies for aging in place.

<table>
<thead>
<tr>
<th>Research question</th>
<th>Extracted data</th>
</tr>
</thead>
<tbody>
<tr>
<td>During what years were the reviews published?</td>
<td>Year of publication</td>
</tr>
<tr>
<td>In which journals have the reviews been published?</td>
<td>The name of the journal where they are published</td>
</tr>
<tr>
<td>Which review methods characterize the reviews?</td>
<td>The named review methods they refer to</td>
</tr>
<tr>
<td>Is there an explicit concern with LMICs?</td>
<td>If they refer explicitly to LMICs (yes or no)</td>
</tr>
</tbody>
</table>

LMIC: low- and middle-income countries.

**Table 5.** Research questions and charted data that relate to the range of evidence in reviews on technologies for aging in place.

<table>
<thead>
<tr>
<th>Research question</th>
<th>Extracted data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Which populations are they concerned with?</td>
<td>The population specified in the review</td>
</tr>
<tr>
<td>Which types of technology are they concerned with?</td>
<td>The technology specified in the review</td>
</tr>
<tr>
<td>What type of problems are they concerned with?</td>
<td>The issues of interest specified in the review</td>
</tr>
<tr>
<td>What is the relationship between the populations, problems, and technologies the reviews have dealt with</td>
<td>The type of technology and the issues of interest specified in the review</td>
</tr>
</tbody>
</table>

All authors participated in the choice of databases and establishing the search terms and eligibility criteria. EL constructed the search string and conducted the final search. All authors participated in the screening process. The full-text papers were extracted by the authors JMB, MG, and AHE. All authors participated in the data synthesis and presentation of the findings.

**Results**

**Characteristics of Evidence on Technologies for Aging in Place**

Multimedia Appendix 3 shows an overview of the data and sources that correspond to this section. The number of reviews of evidence on technology for aging in place has increased dramatically over the past few years (Table 6). The earliest review included in our search was published in 2001 [35]. A total of 20 reviews were published between 2001 and 2010. By comparison, 142 reviews were published between 2015 and 2020. Note that the table only includes reviews published before September 13, 2022, when our search was conducted.

From 2020 to 2021, there was a near doubling in number of reviews. Since our search was conducted at the beginning of September 2022, the figure does not show the full extent of published reviews in 2022. However, it is likely that the trend will continue upwards. The included reviews were published in 183 unique journals. Of those, most journals have only published 1 or 2 reviews since 2001. Only 12 journals have published more than 5 reviews in total since 2001 (Table 7).
Table 6. Number of reviews by year of publication (n=344).

<table>
<thead>
<tr>
<th>Year of publication</th>
<th>Reviews, n</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001</td>
<td>1</td>
</tr>
<tr>
<td>2002</td>
<td>0</td>
</tr>
<tr>
<td>2003</td>
<td>0</td>
</tr>
<tr>
<td>2004</td>
<td>1</td>
</tr>
<tr>
<td>2005</td>
<td>1</td>
</tr>
<tr>
<td>2006</td>
<td>0</td>
</tr>
<tr>
<td>2007</td>
<td>5</td>
</tr>
<tr>
<td>2008</td>
<td>4</td>
</tr>
<tr>
<td>2009</td>
<td>6</td>
</tr>
<tr>
<td>2010</td>
<td>2</td>
</tr>
<tr>
<td>2011</td>
<td>4</td>
</tr>
<tr>
<td>2012</td>
<td>8</td>
</tr>
<tr>
<td>2013</td>
<td>12</td>
</tr>
<tr>
<td>2014</td>
<td>14</td>
</tr>
<tr>
<td>2015</td>
<td>6</td>
</tr>
<tr>
<td>2016</td>
<td>16</td>
</tr>
<tr>
<td>2017</td>
<td>23</td>
</tr>
<tr>
<td>2018</td>
<td>23</td>
</tr>
<tr>
<td>2019</td>
<td>33</td>
</tr>
<tr>
<td>2020</td>
<td>47</td>
</tr>
<tr>
<td>2021</td>
<td>88</td>
</tr>
<tr>
<td>2022</td>
<td>50</td>
</tr>
</tbody>
</table>

Table 7. Overview of 12 journals that have published 5 or more reviews on technologies for aging in place since 2001.

<table>
<thead>
<tr>
<th>Journals</th>
<th>Reviews, n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Interventions in Aging</td>
<td>5</td>
</tr>
<tr>
<td>Healthcare</td>
<td>5</td>
</tr>
<tr>
<td>Assistive Technology</td>
<td>6</td>
</tr>
<tr>
<td>Journal of Telemedicine and Telecare</td>
<td>7</td>
</tr>
<tr>
<td>Maturitas</td>
<td>8</td>
</tr>
<tr>
<td>JMIR Aging</td>
<td>10</td>
</tr>
<tr>
<td>International Journal of Environment Research and Public Health</td>
<td>11</td>
</tr>
<tr>
<td>Sensors</td>
<td>11</td>
</tr>
<tr>
<td>The Gerontologist</td>
<td>11</td>
</tr>
<tr>
<td>Disability and Rehabilitation: Assistive Technology</td>
<td>13</td>
</tr>
<tr>
<td>International Journal of Medical Informatics</td>
<td>16</td>
</tr>
<tr>
<td>Journal of Medical Internet Research</td>
<td>17</td>
</tr>
</tbody>
</table>

The reviews refer to 15 unique types of review methods. Of these, the most common were systematic reviews (n=144) and scoping reviews (n=60). The third most common review method was to provide a detailed account of the procedures but refrain from referring to a specific type of review method (n=98). While there were only 13 integrative reviews and 6 narrative reviews, the fact that most other review methods only occurred once or twice made the narrative reviews common by comparison (Table 8).
Table 8. Overview of the data analysis methods used in the included reviews.

<table>
<thead>
<tr>
<th>Data analysis method</th>
<th>Reviews, n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systematic review</td>
<td>144</td>
</tr>
<tr>
<td>Scoping review</td>
<td>60</td>
</tr>
<tr>
<td>Integrative review</td>
<td>13</td>
</tr>
<tr>
<td>Narrative</td>
<td>6</td>
</tr>
<tr>
<td>Mini-review</td>
<td>5</td>
</tr>
<tr>
<td>Review of reviews</td>
<td>5</td>
</tr>
<tr>
<td>Rapid review</td>
<td>2</td>
</tr>
<tr>
<td>Umbrella review</td>
<td>1</td>
</tr>
<tr>
<td>Targeted review</td>
<td>1</td>
</tr>
<tr>
<td>Meta-interpretive review</td>
<td>1</td>
</tr>
<tr>
<td>Focused literature review</td>
<td>1</td>
</tr>
<tr>
<td>Descriptive review</td>
<td>1</td>
</tr>
<tr>
<td>Clinical review</td>
<td>1</td>
</tr>
<tr>
<td>Critical interpretive synthesis</td>
<td>1</td>
</tr>
<tr>
<td>Conceptual review</td>
<td>1</td>
</tr>
<tr>
<td>Comprehensive review</td>
<td>1</td>
</tr>
<tr>
<td>Comparative literature review</td>
<td>1</td>
</tr>
<tr>
<td>Reflective review</td>
<td>1</td>
</tr>
<tr>
<td>Unspecified</td>
<td>98</td>
</tr>
</tbody>
</table>

Only 1 review referred explicitly to LMICs [36]. This review aimed to identify policy gaps in the delivery and availability of assistive health technology and medical devices for aging populations, particularly in LMICs, and found that practical, life-enhancing support for older people through assistive health technology, medical technology, and related health and social services is a neglected issue.

Range of Evidence on Technologies for Aging in Place Populations

Multimedia Appendix 4 shows an overview of data and sources that correspond to this section. Some reviews dealt with more than one type of population.

Table 9. Overview of the populations in 253 reviews that described the population in terms of people and the roles they play in the context of aging.

<table>
<thead>
<tr>
<th>Populations</th>
<th>Reviews, n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older people</td>
<td>220</td>
</tr>
<tr>
<td>Formal caregivers</td>
<td>1</td>
</tr>
<tr>
<td>Formal caregivers and informal caregivers</td>
<td>2</td>
</tr>
<tr>
<td>Informal caregivers</td>
<td>5</td>
</tr>
<tr>
<td>Older people and formal caregivers</td>
<td>5</td>
</tr>
<tr>
<td>Older people, formal caregivers, and informal caregivers</td>
<td>4</td>
</tr>
<tr>
<td>Older people and informal caregivers</td>
<td>16</td>
</tr>
</tbody>
</table>

In total, 73 reviews described the population in terms of older people as well as individuals from other age groups, with a particular diagnosis or health problem. These reviews included studies about people of different age groups with different cognitive impairments exclusively (n=41) or in combination with other health problems (n=2). Notably then, these reviews...
included evidence based on studies of younger people as well as older people. Table 10 provides an overview of the diagnoses and health problems that these reviews used to conceptualize the populations.

Table 10. Overview of the diagnoses and health problems used to conceptualize the population in reviews about older people and others with a particular diagnosis or health problem (in total n=73 reviews).

<table>
<thead>
<tr>
<th>Diagnoses and health problems</th>
<th>Reviews, n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>1</td>
</tr>
<tr>
<td>Cardiovascular diseases</td>
<td>1</td>
</tr>
<tr>
<td>Cardiovascular diseases, diabetes, and asthma</td>
<td>1</td>
</tr>
<tr>
<td>Chronic conditions</td>
<td>7</td>
</tr>
<tr>
<td>Cognitive impairments</td>
<td>41</td>
</tr>
<tr>
<td>Cognitive impairments, cardiovascular diseases, and chronic obstructive pulmonary disease</td>
<td>1</td>
</tr>
<tr>
<td>Cognitive impairments, neurological disorders, falls, and cardiovascular disease</td>
<td>1</td>
</tr>
<tr>
<td>Complex needs</td>
<td>1</td>
</tr>
<tr>
<td>Decline in hand grip and dexterity</td>
<td>1</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
</tr>
<tr>
<td>Falls</td>
<td>4</td>
</tr>
<tr>
<td>Falls and frailty</td>
<td>1</td>
</tr>
<tr>
<td>Frailty</td>
<td>6</td>
</tr>
<tr>
<td>Frailty and decreased hearing</td>
<td>1</td>
</tr>
<tr>
<td>Hip injuries</td>
<td>1</td>
</tr>
<tr>
<td>Loneliness and social isolation</td>
<td>2</td>
</tr>
<tr>
<td>Mental health</td>
<td>2</td>
</tr>
</tbody>
</table>

Types of Technology

Multimedia Appendix 5 shows an overview of the data and sources that correspond to these results. Some reviews dealt with more than one type of technology.

We identified 69 different types of technology that reviews have been concerned with and 5 substantive strategies that the reviews have used to conceptualize the technology with which they are concerned. Two of the 345 reviews used other strategies for conceptualizing technology. One was about co-designed technologies [37]. The other was about what they termed as consumer technology as well as smart environments [38].

The first and most common strategy (n=140 reviews) is to refer to technology by using descriptive technical terms such as “sensors” [39-48], “artificial intelligence” [49-52], “GPS” [53-55], or “games” [56-60]. The reviews that used this strategy covered 31 different types of technology exclusively or in combination with each other. Most of these reviews were focused on robots or robopets (n=47), information and communication technology (n=23), smart environments (n=17), or sensors (n=10).

The second strategy (n=65) is to conceptualize technology by the purpose of the technology in relation to a disease or type of health challenge that the technology addresses or is believed to be able to address, for instance, by using terms such as “technology for dementia” [61-70], “technologies for social connectedness” [71-75], “technology for frailty” [76-78], “technology for safety” [79], or “technology for falls” [60,80-84]. Most of the reviews that relied on this strategy dealt with assistive technologies (n=28).

The third strategy (n=30 reviews) is to refer to technologies in terms of their intended purpose in caring services or practices that they are part of. Such terms include “teleophthalmology” [85], “monitoring technologies” [86,87], “telerehabilitation” [88-93], “technology for home health care” [94,95], or “technology for pain management” [96]. Most reviews that relied on this strategy were concerned with telerehabilitation (n=7) or technology for health information (n=6).

The fourth strategy (n=29 reviews) is to describe the type of technology by using umbrella terms that broadly refer to the use of technology to enable older people to age in place, for instance, by defining the technology of interest in terms of “technology for ageing in place” [11,97-99], “gerontechnology” [100-102], “welfare technology” [103-105], “technology for healthy ageing” [106,107], or “technology for older people” [22,32,108-112].

The fifth strategy (n=75 reviews) is to describe the type of technology the review is concerned with by way of concepts that refer to the use of technology as part of a broad range of caring services, strategies, and practices, such as, for instance,
telecare [113-119], telemedicine [120-125], e-interventions [126], or eHealth [127-143]. Most reviews that used this type of concept to describe the technology they are concerned with dealt with mHealth (n=18), eHealth (n=17), or telehealth (n=18).

**What Types of Problems Have the Reviews Dealt With?** Multimedia Appendix 6 shows an overview of the corresponding data and sources. Some reviews dealt with more than one type of problem. We identified 49 unique problem topics and 4 principal types of problems.

The first type of problem is related to different types of care services or caring practices (n=60 reviews). Most of these reviews dealt with problems related to the context of home care (n=30), caring practices in nursing homes or other long-term care institutions (n=11), or rehabilitation (n=7). By contrast, other topics occurred only once or twice, that is, problems related to caregiver burden [144,145], dementia care [146], emergency care services [147], informal care [148], and health information services [149,150].

The second type of problem is issues related to the management of health-related issues or diseases in the context of aging in place (n=128 reviews). Of those, most dealt with problems related to cognitive impairments either exclusively (n=61) or in combination with one or several other health problems (n=10), that is, cognitive impairment and mental health [151-155], or cognitive impairment, stroke, cardiovascular disease, and falls [156]. Other problems that were featured relatively frequently included falls and balance–related issues (n=19), frailty (n=8), chronic conditions (n=8), and depression (n=5). Meanwhile, other problems related to the management of other health-related issues and diseases featured only once or twice, despite being common health challenges for older people (for instance, Parkinson’s disease [157,158], malnutrition [159], dental health [160], eye diseases [85], and pain [96,161]).

The third type of problem relates to the experience of aging in place (n=82 reviews). The most common topics in this category were loneliness, including social isolation or connectedness (n=21 reviews), older peoples’ self-care or self-management (n=19 reviews), and active aging (n=16 reviews). Other topics in this category include healthy aging [106,111,137,162-165], information needs [166], quality of life [97,167-173], quality of life and older people’s self-care and self-management [174,175], and activities of daily living exclusively [176-179] or in combination with other topics such as loneliness [180,181], or quality of life [182].

The fourth type of problem relates to the research and development of technology. This was the most common type of problem (n=285 reviews). The overwhelming majority of reviews that dealt with this type of problem were concerned with barriers and drivers of use and acceptability (n=114), the effect or implications of technology (n=86), or the combination of these 2 topics (n=21). Other common topics included uptake or scalability (n=15), user involvement (n=11), ethical considerations (n=14), feasibility (n=10), and cost-effectiveness or use (n=7).

Notably, problems related to home care (n=30), loneliness (n=21), cognitive impairments (n=71), barriers and drivers of use and acceptability (n=114 reviews), and the effect or implications of technology (n=86) have been heavily emphasized. Meanwhile, others such as cost-effectiveness or use of technologies (n=7), health information needs (n=1), malnutrition (n=1), dental health (n=1), eye diseases (n=1), and pain management seem underprioritized by comparison.

**What Are the Relationships Between the Problems, Technologies, and Populations That the Reviews Have Dealt With**

Multimedia Appendix 7 shows an evidence map that provides an overview of the relationships between problems, technologies, and populations that the reviews have been concerned with. Some reviews deal with more than one population, technology, and type of problem. Multimedia Appendix 8 shows an overview of the corresponding data and sources.

As illustrated in the evidence map (Multimedia Appendix 7), many reviews draw on an evidence base that is not specific to older people or their caregivers.

This is particularly notable in the reviews on the following topics: barriers and drivers of use and acceptability, cognitive impairment, and the effect or implications of technology. The same observation applies to the following types of technology such as assistive technologies, robots, technology for dementia, technology for falls, technology for frailty, telehealth, and technology for Alzheimer disease.

**Summary of Evidence**

In exploring the range and characteristics of reviews on technology for aging in place, we found that the number of reviews, as well as the pace at which they are published, has increased dramatically over time. While some journals such as JMIR Aging, Disability and Rehabilitation: Assistive Technology, the Journal of Medical Internet Research, and The Journal of Medical Informatics have published more reviews on this topic than others, the literature is scattered over 183 unique journals. Most reviews on this topic are systematic reviews (n=144).

In exploring the range of reviews on technology for aging in place, we identified 3 principal ways that reviews have dealt with populations. Specifically, the 3 ways are describing the population in terms of older people or different types of caring roles (n=253), in terms of people affected with a particular health condition or diagnosis (n=73), or not specifying the population (n=43). These may be considered as methods of conceptualizing populations. We identified 88 unique types of technology that the reviews have dealt with. We also found that there are strong tendencies for reviews to synthesize the evidence on broad and unspecific categories of technology such as “ICT” or “robots” rather than to concentrate on a particular device (a notable exception is a review on personal alarms [183]). Moreover, we identified 5 strategies that the reviews draw on to conceptualize technology. Those strategies are to (1) refer to technology by using descriptive technical terms; (2) conceptualize technology by way of the purpose of the technology about a disease or health issue; (3) refer to technologies in terms of their purpose in caring services or...
practices; (4) use umbrella terms that broadly refer to the use of technology to enable older people to age in place; and (5) use concepts that refer to the technology as part of caring services, strategies, and practices. We also identified 4 principal types of problems and 49 unique subtypes of problems that the reviews have dealt with. The four principal types are problems related to (1) different types of care services or caring practices, (2) the management of health problems or diseases, (3) the experience of aging in place, and (4) the research and development of technology. The evidence map (Multimedia Appendix 6) demonstrates the relationships between the populations, technologies, and problems studied in the reviews and illustrates the gaps. Notably, many of the reviews on the most studied technologies and problems draw on studies that are not specific to older people or the context of aging in place, either by not specifying the population at all or by including studies on patients of all ages, meaning that topics studied only by such reviews should also be considered gaps.

Discussion

Summary of Evidence

Together, these results speak to the need for regularly updated overviews of ongoing debates in the field. However, they are also illustrative of the challenges that such overviews must overcome. For instance, the lack of conceptual hegemony means that any attempt to describe the technologies that the reviews have been concerned with in purely technical terms fails to grasp the diverse ways that technology is understood in this field. A more fruitful approach is to categorize them according to the different ways that they understand and deal with technology. Used as methodological tools, the strategies of defining populations, conceptualizing technology, the typology of problems, and the overview of the relationships presented here can inform the design of future reviews and enable researchers to purposefully identify gaps and publications that are likely to be of relevance to each other despite conceptual differences that may obscure their similarities.

It is notable that only 1 review was explicitly concerned with LMICs, considering that the greatest growth in older people globally will be in LMICs [1], particularly in Africa where the population of 60 years and older is expected to increase by more than 100% by 2050 [184]. Similarly, it is notable that in the included reviews, relatively little attention has been paid to formal and informal caregivers. Both formal and informal caregivers play important roles in the context of technology for aging in place. Both formal and informal caregivers frequently speak and act on behalf of older people, especially older people with cognitive impairments when technology developers seek to identify user needs or evaluate the usefulness of the technology [185-188]. In doing so, they act as gatekeepers who shape what types of technology are developed and offered to older people, and equally important, which are not [109]. Both formal and informal caregivers are often the intended users of technology that is meant to enable older people to age in place. Thus, the politics of their lives and working conditions as well as the quality and type of care they are able to provide to older people are shaped by what the technology affords and prohibits [189-191]. Yet, the purpose of the technology is aimed at the needs of the older person or efficiency-related goals in care organizations rather than the improvement of the care workers’ working environment or care burden. Additionally, like all users, both formal and informal caregivers are not just impacted by technologies that enter their lives but they also shape the technology in turn [188,192-199], meaning that the implications that the technology will have in practice are never given beforehand and must always be studied in the context of use [185,187,200,201]. Finally, both informal and formal caregivers must frequently improvise and adapt the technology to render it functional [192,202-205]. Thus, both formal and informal caregivers play important roles in shaping the practices, politics, and services that the technology affords or delimits in the lives of older people who age in place. These roles have been thoroughly described in the literature. Yet, they seem overlooked in reviews on technology for aging in place.

It is problematic that so many reviews concerned with problems related to technologies for aging in place draw on an evidence base that is not specific to older people. Older people frequently have other needs than younger people even when they share a diagnosis because the aging body presents specific challenges, which increase the risk of illnesses, falls, disability, and death [206]. It is therefore unlikely that reviews that do not focus explicitly on older people are able to grasp and address the specificity of the challenges that older people face as part of aging in place. This primarily concerns reviews on the topics of barriers and drivers of use and acceptability, cognitive impairment, and the effect or implications of technology. It also concerns reviews about assistive technologies, robots, technology for dementia, technology for falls, technology for frailty, telehealth, and technology for Alzheimer disease. While these topics and technologies have frequently been addressed, the value that reviews that do not specify their population or that base their arguments on studies of people of all ages (see Multimedia Appendix 6) is limited, and there is a need for more targeted and age-specific syntheses reviews to better address the unique requirements of older individuals and their caregivers. The strong tendency for reviews in this field to concentrate on broad and unspecific categories of technology, such as “ICT” or “robots” means that there is no straightforward way for practitioners to use these reviews as support in decision-making processes regarding the potential usefulness and challenges related to specific devices.

Limitations

Despite the many methodological strengths of the design of a scoping review of reviews, there are some limitations to be considered. These include the potential for bias in the review process, the difficulty ensuring the quality and reliability of the included reviews, and the potential for the review to be influenced by the perspectives and priorities of the researchers conducting the review. Considering the broad eligibility criteria chosen for this review, the results may be considered representative of the characteristics and range of evidence on technologies for aging in place. However, the inclusion of more databases could have expanded the data set even further, and potentially relevant literature that does not use the term aging in place explicitly may have been missed. Moreover, this review...
has not sought to explore or synthesize the results of the included reviews nor have we considered the quality of the included reviews.

**Conclusions**

The number of published reviews on this topic in the past few years in combination with the rate at which they are published suggests that redundancies and a lack of fruitful synergies between them are likely. The breadth of variation concerning how reviews have dealt with populations, conceptualizations of types of technology, and problems demonstrates the conceptual differences that must be bridged to remedy this problem.

Together, these results underscore the necessity for improved coordination and collaboration among reviews while also recognizing the potential benefits of more standardized vocabularies.

The insights gained from the methods of dealing with populations, strategies for conceptualizing types of technology, and the types of problems identified in this study may be used methodologically to identify commonalities and connections that may otherwise be obscured by differing conceptual frameworks.

There is an urgent need for an examination of the current state of the art in knowledge regarding technology for aging in place in LMICs. Developing a deeper understanding of the conditions surrounding aging in LMICs, especially in Africa, and the implications those conditions have for the roles that technology may play and not play in the lives of older people and their circles of care should be an essential focus of the research agenda.

**Acknowledgments**

The scoping review was conducted by SINTEF as part of a collaboration among SINTEF, WHO, and the International Society for Gerontechnology (ISG) that aim to ensure an emphasis on older people within the current global momentum on AT. The authors would like to thank Espen H Aspnes, former vice president of ISG who leads Pillar II in this collaboration, to which the result of this review contributes. We also wish to thank Professor Sue Levkoff (ScD, MSW, SM), College of Social Work, the University of South Carolina. Endowed chair in SeniorSMART, as well as other members of the International Society for Gerontechnology (ISG) and The WHO contributed to discussions and workshops during the planning stage of this review. For their contributions to the selection of databases, we especially thank Dr Callista Kahonde, researcher and assistant lecturer at Stellenbosch University; Centre for Disability and Rehabilitation Studies, and Anna Spånt Enebuske, MSSc and research officer at The Swedish Municipal Workers’ Union. Finally, we thank our colleague Sandra Klonteg MSc, SINTEF Digital, for her contributions during the data extraction phase, and Mr Sebastian M Bergschöld for his contributions to the evidence map. This study was funded by SINTEF.

**Conflicts of Interest**

None declared.

Multimedia Appendix 1
PRISMA-ScR Checklist.
[DOCX File, 56 KB - aging_v7i1e50286_app1.docx ]

Multimedia Appendix 2
Journals to guide the selection of databases.
[PDF File (Adobe PDF File), 116 KB - aging_v7i1e50286_app2.pdf ]

Multimedia Appendix 3
Characteristics of evidence on technologies for ageing in place.
[XLSX File (Microsoft Excel File), 68 KB - aging_v7i1e50286_app3.xlsx ]

Multimedia Appendix 4
Populations.
[XLSX File (Microsoft Excel File), 62 KB - aging_v7i1e50286_app4.xlsx ]

Multimedia Appendix 5
Types of technology.
[XLSX File (Microsoft Excel File), 69 KB - aging_v7i1e50286_app5.xlsx ]

Multimedia Appendix 6
Types of problems.

Multimedia Appendix 7
Evidence map.

Multimedia Appendix 8
Relationships between problems technologies and populations.

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Abbreviations

LMIC: low- and middle-income country
mHealth: mobile health
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Review
WHO: World Health Organization

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Refining Cultural Adaptations of a Behavioral Intervention for Latino Caregivers of People Living With Dementia: Qualitative Interview Study in Washington State

Celeste N Garcia¹, BA; Miriana C Duran¹, MPH, MD; Magaly Ramirez¹, MS, PhD
Department of Health Systems and Population Health, University of Washington, Seattle, WA, United States

Corresponding Author:
Magaly Ramirez, MS, PhD
Department of Health Systems and Population Health
University of Washington
3980 15th Avenue North East
Seattle, WA, 98195
United States
Phone: 1 2065439773
Email: maggiera@uw.edu

Abstract

Background: In the United States, Latino caregivers of individuals with dementia face unique challenges and an elevated risk of adverse health outcomes. Despite the increasing prevalence of Alzheimer disease and related dementias among Latino adults, few evidence-based interventions are tailored to their cultural context. To address this gap, we examined the cultural adaptations required for the STAR caregivers (STAR-C) virtual intervention, an evidence-based intervention that educates family caregivers to manage behavioral and psychological symptoms of dementia. While STAR-C has shown effectiveness, neither the original in-person nor the virtual intervention considered the distinct experiences of Latino caregivers, who often bring culturally significant values into caregiving interactions.

Objective: This study’s objective was to test and refine the preliminary cultural adaptations of the STAR-C web-based training modules for Latino caregivers of people living with dementia.

Methods: Through qualitative interviews with 15 Latino caregivers in Washington State, we identified key adaptations to enhance the cultural relevance of the web-based training modules.

Results: The interviews highlighted 4 main themes for adaptation: the delivery of the STAR-C web-based training modules, comprehensive dementia education, simplified problem-solving strategies, and prioritizing caregiver well-being.

Conclusions: This study’s findings informed the development of culturally adapted STAR-C web-based training modules that aim to provide tailored support to Latino caregivers. While further research is needed to assess the efficacy of these adaptations, our work contributes to bridging the gap in dementia caregiving for Latino families, potentially reducing health disparities and enhancing health care services for this population.

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KEYWORDS
caregivers; caregiver; caregiving; carer; carers; STAR-C; STAR caregiver; internet; web-based; online; educational; education; family care; family; families; informal care; adaptation; adaptations; cultural; culturally; module; modules; training; Hispanic; Hispanics; Spanish; Latin; Latina; Latinas; Latinos; Latinx; Latino; dementia; qualitative research; Alzheimer disease; qualitative Alzheimer; experience; experiences; attitude; attitudes; opinion; perception; perceptions; perspective; perspectives; aging; older adults; old age; mental health; neuro; ageing; geriatrics; gerontology; geriatric; interview; eHealth; digital health; alzheimers; memory; memory loss; care giving; Hispanic or Latino; mobile phone

Introduction

Latino caregivers of people living with dementia are at an increased risk of experiencing adverse health impacts due to caregiving, yet few evidence-based interventions have been developed to support Latino families [1]. In the United States, Latino adults are 1.5 times more likely to develop Alzheimer disease and related dementias (ADRD) compared to non-Latino
White adults [2]. The disparity is due in large part to the health conditions (eg, cardiovascular disease, diabetes, high blood pressure, and obesity) and socioeconomic factors (eg, chronic exposure to economic and social adversity, lower levels and quality of education, and discrimination) that are more prevalent in Latino populations and are associated with cognitive decline [2,3]. The number of Latino people living with dementia is expected to increase to 3.5 million by 2060, leading to a rise in Latino adults caring for family members with ADRD [4]. Although evidence-based caregiver interventions exist, they often fall short in meeting the unique cultural needs of Latino families [1,5,6]. There is an urgent need to develop culturally appropriate evidence-based interventions that address the unique challenges faced by Latino caregivers of people living with dementia and consider the sociocultural context in which they provide care.

STAR caregivers (STAR-C) is an in-home intervention that involves training health professionals to teach family caregivers strategies to manage behavioral and psychological symptoms of dementia (BPSD) [7,8]. Caregivers learn to monitor symptoms, identify possible environmental or interpersonal triggers, and develop effective responses. They also learn strategies for communicating with people living with dementia in a way that supports positive affect and prevents or minimizes problems, increasing pleasant events to improve mood, and improving the support caregivers receive from informal and formal networks. STAR-C is demonstrated to reduce the frequency and severity of BPSD, as well as improve burden, depression, and reactivity to symptoms in caregivers [7]. Recently, STAR-C was reconfigured as a virtual intervention to facilitate large-scale implementation in clinical settings. The virtual intervention, coined STAR-C Virtual Training and Follow-up is being tested in an ongoing trial at Kaiser Permanente Washington [9,10]. For 6-8 weeks, caregivers complete 6 web-based training modules asynchronously and have six 30-minute weekly telephone check-ins with a coach (ie, master’s-level social worker or mental health counselor). In addition, support from coaches is provided, as needed, via secure messaging in the Kaiser Permanente Washington patient portal for up to 6 months.

The STAR-C virtual intervention was timely given the COVID-19 pandemic, which shed light on the urgent need for digital health strategies that offer support virtually [11]. Many social and health care services for older adults and their family caregivers shifted from in-person to digital platforms to expand reach during the pandemic [12]. Neither the in-person or virtual STAR-C interventions, however, were developed with explicit consideration of the experience of Latinos providing care to a family member living with ADRD. Caregiver interventions for Latinos need cultural adaptations because cultural values and beliefs, such as familismo (dedication and commitment to family) and respeto (respect) play a pivotal role in shaping caregiving interactions with people living with dementia, experiences, and perceptions of support [13]. The goal of performing cultural adaptations to evidence-based interventions such as STAR-C is to promote more favorable experiences with the intervention and alleviate the health disparities associated with dementia caregiving among vulnerable populations.

To address the gap in the lack of culturally appropriate evidence-based interventions for Latino caregivers, we sought to culturally adapt the content of the web-based training modules of the STAR-C virtual intervention for Latino caregivers. In our previous study, we identified what cultural adaptations to the STAR-C web-based training modules are needed for Latino caregivers and we designed preliminary adaptations [14]. Preliminary adaptations included expanding the content of the web-based training modules to improve understanding of dementia; revising language that was viewed as stigmatizing, offensive, or culturally inappropriate; and adding cultural examples to reflect the range of family involvement in caring for people living with dementia and multigenerational living [14]. It is unknown, however, whether these modifications sufficiently align with the intended goals of cultural adaptation [15]. In addition, it is unknown whether there are additional opportunities to further enhance the cultural relevance of the STAR-C web-based training modules for Latino families. Therefore, the objective of this study was to test and refine the preliminary cultural adaptations of the STAR-C web-based training modules for Latino caregivers of people living with dementia.

**Methods**

**Ethical Considerations**

This study was granted approval by the institutional review board at the University of Washington (STUDY00009534). Participants in this study gave their verbal or written consent for their involvement. All the data we collected from participants was labeled with a unique study identification number and not the participants’ name or any other information that could identify participants. The contact information of participants was kept in a password-protected file and computer. All data collected from participants were kept confidential and accessible only by our study team. We did not use participants’ names in reports of study findings, REDCap (Research Electronic Data Capture; Vanderbilt University) surveys, or audio recordings of interviews. Instead, we labeled everything with this study’s identification number. We destroyed data that identified participants when we finished recruitment.

**Overview of This Study’s Design**

Figure 1 [16] illustrates our approach to the cultural adaptation of the STAR-C web-based training modules within the context of the Discover, Design + Build, Test framework. In our previous study, we conducted a qualitative study to gather information about needed cultural adaptations to the web-based training modules for Latino caregivers (the “Discover” phase) [14]. We then used the findings from the qualitative study to brainstorm ideas for preliminary cultural adaptations (the “Design” phase). In this study, we developed low-fidelity prototypes of the culturally adapted STAR-C web-based training modules and tested the prototypes with Latino caregivers (the “Build” phase).
Figure 1. The cultural adaptation of STAR-C web-based training modules within the context of the Discover, Design + Build, and Test Framework. STAR-C: STAR caregiver.

Participant Selection
We carried out semistructured qualitative interviews in Washington State with 15 Latino caregivers of people living with dementia who spoke Spanish or English. Caregivers were considered eligible if they self-identified as Hispanic or Latino, were aged 21 years or older, were a child, spouse, or partner, or close friend of someone diagnosed with dementia, lived with the diagnosed individual or within a 5-mile radius, and provided a minimum of 8 hours of weekly care. Our recruitment strategy involved 3 approaches. Initially, we identified potential participants through the electronic health record system at University of Washington Medicine. Additionally, we circulated flyers in both Spanish and English across various locations, including a UW Medicine specialty clinic, a primary care practice-based research network, the Alzheimer Association Washington State Chapter, and local tiendas in Latino communities. Lastly, we used media platforms like local Spanish and English radio stations and newspapers to discuss the impact of dementia on the Latino population and publicize this study. A member of this study’s team screened for eligibility the individuals who showed interest in joining this study and arranged interviews for those who met the eligibility requirements. Caregivers received a compensation of US $45 for taking part in this study.

Description of the Low-Fidelity Prototypes
In the STAR-C Virtual Training and Follow-up intervention, caregivers receive 1 web-based training module per week for a period of 6-8 weeks. Textbox 1 describes the topics of the web-based training modules. The core components of the intervention include dementia education, strategies for effective communication, Activators-Behaviors-Consequences (ABC) problem-solving, pleasant events, and caregiver support.

Textbox 1. Topics of STAR caregivers (STAR-C) web-based training module.

| Week 1: Understanding dementia, realistic expectations about behavioral treatments for behavioral and psychological symptoms of dementia, and strategies for effective communication. |
| Week 2: Activator, Behavior, Consequence (ABC) approach to problem-solving, including rationale and development of an ABC plan for target behaviors that caregivers identify. |
| Week 3: Review of ABC plan (revise if needed). |
| Week 4: Pleasant events and managing negative thinking. |
| Week 5: Review of ABC plan and pleasant events schedule (revise if needed). |
| Week 6: Caregiver support strategies for coping with caregiving and maintaining gains. |

We created 3 low-fidelity prototypes of the culturally adapted STAR-C web-based training modules in both English and Spanish for testing among study participants. The low-fidelity prototypes were in the form of videos of recorded presentations with images, text, and voice-over. The videos featured short excerpts from various STAR-C web-based training modules. The first video consisted of educating Latino family caregivers on dementia and problem-solving using the ABC approach. This video explained the STAR-C program, dementia, its causes, walked through each step of the ABC approach for problem-solving in dementia, and concluded with a caregiving example of the ABC approach. The second video featured some modifications, including the addition of information about dementia stages, common behaviors exhibited by people living with dementia, and importance of self-care. We also enhanced the visual aesthetics and design of the lessons to make them more visually appealing and added humor. In the third video, we maintained the core content from the previous versions but incorporated interactive images and examples to increase engagement and interactivity. Figures 2 and 3 provide an example of the low-fidelity prototypes.
Figure 2. Culturally adapted STAR-C web-based training module—understanding Alzheimer and related dementias, with a focus on disproportionate impact on Latinos. STAR-C: STAR caregiver.

What is dementia?

- Dementia impacts many families in our community.
- Latinos are more likely than other racial or ethnic groups to get dementia.
- In the US, 1 out of 8 Latinos over 65 has dementia.

Figure 3. Culturally adapted STAR-C web-based training module—ABC acronym. ABC: Activators-Behaviors-Consequences; STAR-C: STAR caregiver.

ABC problem-solving

The ABCs of how to solve problems you face when caring for someone with memory loss.

The goals of this session are to:

- Introduce the ABCs:
  - Activators (causes)
  - Behaviors
  - Consequences

- Come up with specific plans to help change behaviors.

Data Collection

Study participants received the low-fidelity prototypes (ie, videos) via text message, WhatsApp Messenger, or email, depending on their preference, and were asked to watch the video at home on their own time prior to the scheduled qualitative interview. A bilingual or bicultural staff member trained in qualitative research techniques conducted interviews from January to August 2022. These interviews were held virtually, and they took place in either Spanish or English based on the participant’s choice. Each interview spanned 30 to 60 minutes in length and was audio recorded and transcribed verbatim by a professional service.

The staff member used semistructured interview guides. For the first 5 interviews, the interview guide asked general questions pertaining to likes and dislikes, queries about the program’s dementia content, examination of the ABC problem-solving strategy, assessment of the provided caregiving example, and a series of questions delving into video accessibility, design, and duration. For the subsequent 5 interviews, we revised the interview guide by adding questions focused on participant preferences, such as whether they preferred watching or listening to the video content, their favored method of receiving the videos, and their ideal video length. Finally, after another subsequent 5 interviews, we revised the interview guide again by incorporating additional inquiries centered around evaluating the images within the videos and improving viewer engagement.

Data Analysis

We analyzed the transcripts in their original languages, either Spanish or English, using the qualitative data analysis techniques described by Saldaña [17]. We began by reading through all the transcripts and writing analytic memos to reflect on the
content—n...g insights, thoughts, and emerging patterns. We then...deductive codes from a pre-established codebook to the interview transcripts (“protocol coding” [17]). The pre-established codebook was used in a prior qualitative study of STAR-C and was composed of codes representing components of the cultural treatment adaptation framework [14,18]. As an illustration, the codebook contained codes like “Materials and Semantics,” “Cultural Examples and Themes,” and “Therapeutic Framework” to capture cultural adaptations that were needed in the delivery of the intervention. In the next step, we applied inductive second-order codes to capture the details of participants’ feedback (“subcoding” [17]). For example, one of the inductive subcodes under “Materials and Semantics” was “Different BPSD examples” since multiple participants had suggested including in the intervention materials problem-solving examples for different BPSD. Afterward, we grouped the deductive and inductive codes into a smaller number of candidate themes that represented opportunities to improve the cultural adaptations of STAR-C (“pattern coding” [17]). We examined the interrelationship across and within the candidate themes and made refinements to ensure that excerpts within themes cohered and that each final theme was distinct from the others. Finally, we developed a statement to describe each of the themes, which are presented in the following section. To manage this coding process, we used Dedoose (version 8.1.8; SocioCultural Research Consultants, LLC).

**Results**

**Overview**

Table 1 provides the characteristics of Latino caregivers who participated in this study and a description of their caregiving situation. The average age of caregivers was 48.9 (SD 11.1) years, 13 (87%) identified as women, 7 (47%) were the adult children of the people living with dementia, and 12 (80%) provided 35 hours or more of care per week.
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Family caregivers (N=15), n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years), mean (SD)</td>
<td>48.9 (11.1)</td>
</tr>
<tr>
<td>Mexican, Mexican American, or Chicano</td>
<td>15 (100)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Woman</td>
<td>13 (87)</td>
</tr>
<tr>
<td>Man</td>
<td>2 (13)</td>
</tr>
<tr>
<td><strong>Occupational status</strong></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Employed</td>
<td>5 (33)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1 (7)</td>
</tr>
<tr>
<td>Homemaker</td>
<td>5 (33)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (20)</td>
</tr>
<tr>
<td><strong>Highest level of educational attainment, mean (SD)</strong></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>4 (27)</td>
</tr>
<tr>
<td>High school</td>
<td>5 (33)</td>
</tr>
<tr>
<td>Vocational or technical training</td>
<td>2 (13)</td>
</tr>
<tr>
<td>Some college</td>
<td>1 (7)</td>
</tr>
<tr>
<td>College graduate</td>
<td>2 (13)</td>
</tr>
<tr>
<td>Postgraduate</td>
<td>1 (7)</td>
</tr>
<tr>
<td><strong>Devices owned</strong></td>
<td></td>
</tr>
<tr>
<td>Smartphone</td>
<td>14 (93)</td>
</tr>
<tr>
<td>Tablet</td>
<td>5 (33)</td>
</tr>
<tr>
<td>Laptop</td>
<td>7 (47)</td>
</tr>
<tr>
<td>Computer</td>
<td>6 (40)</td>
</tr>
<tr>
<td>Owns any device</td>
<td>15 (100)</td>
</tr>
<tr>
<td><strong>Caregiver’s relationship to person living with dementia, mean (SD)</strong></td>
<td></td>
</tr>
<tr>
<td>Adult child (eg, daughter)</td>
<td>7 (46.7)</td>
</tr>
<tr>
<td>Spouse or partner</td>
<td>5 (33.3)</td>
</tr>
<tr>
<td>Other relative</td>
<td>3 (20)</td>
</tr>
<tr>
<td><strong>Care provided per week (hours)</strong></td>
<td></td>
</tr>
<tr>
<td>35 or more</td>
<td>12 (80)</td>
</tr>
<tr>
<td>5-14</td>
<td>3 (20)</td>
</tr>
<tr>
<td><strong>Number of years providing care, mean (SD)</strong></td>
<td>3.7 (2.4)</td>
</tr>
<tr>
<td>Caregiver and person living with dementia living together, mean (SD)</td>
<td>10 (66.7)</td>
</tr>
</tbody>
</table>

The qualitative analysis revealed adaptations that were needed in the (1) delivery of the STAR-C virtual intervention, (2) “dementia education” core component, (3) “ABC Problem-Solving” core component, and (4) “caregiver support strategies” core component. The sections below describe the need for these adaptations from the perspective of caregivers, as well as the changes that were made to the STAR-C web-based training modules in response to caregiver feedback.

**Theme 1: Adaptations to the Delivery of the STAR-C Virtual Intervention**

**Design Videos to be Accessible via Audio Only**

Latino caregivers reported that they liked that the STAR-C videos combined visuals with narration. They reported that the narration helped to reinforce the visual content and vice versa. They said this combination of visuals and narration was engaging because it helped to hold their attention and made it easier for them to learn the content. For example, 1 Spanish-speaking caregiver said:
The thing is that audio and seeing the image are also easier in this type of application. It became more practical and easier for me to learn and understand compared to just reading and seeing it without any—well, at least in my opinion, my brain doesn’t work the same way, I believe, but I liked the idea that you can see it, like imagine it, and create that idea.

However, while the ideal would be to watch the STAR-C videos, some caregivers mentioned that this may not always be practical. They said that they were often occupied with errands, household, and caregiving work, and that it would be nice in these circumstances to be able to listen to the video. For that reason, the caregivers suggested that the videos be designed to be accessible via audio only. Further, 1 Spanish-speaking caregiver stated:

Since sometimes one doesn’t have much time to sit down and take the time to be looking at the screen. So, I put everything in the background while I do my daily tasks.

In response to caregivers’ feedback, we modified the narration script to ensure that it was independent of visuals and accessible via audio only. The narration focused on providing clear and descriptive explanations of the visual content. Instead of relying on visuals to convey information, the narration script described the key elements, actions, and visuals present in the video. This approach would enable caregivers to form a mental image and grasp the content without needing to see the visuals.

Make Videos Accessible on Multiple Platforms

Latino caregivers expressed a preference for having various methods of accessing the STAR-C videos, including phone applications such as Facebook Messenger, WhatsApp Messenger, YouTube, and other platforms. Caregivers desired video access through platforms they used regularly and were easily accessible on their preferred devices. For example, 1 Spanish-speaking caregiver stated:

No, but I hardly use my email. I do check my email, but almost all the information I receive, I receive it through WhatsApp. And then, I can see it right away without any problem.

A few caregivers encountered technical difficulties when attempting to access the videos such as lack of Wi-Fi access in their homes or limited storage on their phones, requiring troubleshooting. For example, 1 caregiver said she could not view the videos initially because her phone’s storage was full. Once the caregiver emptied her phone’s storage, she was able to view the videos. In addition, while the caregiver could view the videos on her computer, she did not have Wi-Fi at home and would need to connect the computer to her phone’s hotspot.

In response to caregivers’ feedback, we considered various options to accommodate preferences and technology access, to ensure optimal accessibility to the STAR-C videos. We would offer caregivers the option to receive the STAR-C videos on phone applications like Facebook Messenger, WhatsApp Messenger, and YouTube, as these are commonly used platforms for communication and information exchange. We would also optimize the video formats to reduce file sizes. Finally, we would offer troubleshooting support to assist caregivers who may face technical challenges while trying to view the videos.

Enable Caregivers to Easily Share Videos With Family Members

According to caregivers, the content in the STAR-C videos had a positive impact on communication and information sharing among caregivers and other family members who assist with caregiving. For that reason, caregivers expressed a strong desire to share the video content with their extended family, including siblings and other relatives involved in caregiving responsibilities. Sharing the videos empowered caregivers to improve their caregiving practices. For example, 1 Spanish-speaking caregiver explained:

Moreover, right away, I allowed myself—I don’t know if it was allowed, but I sent that information to my sisters-in-law and they were like, ‘Wow, wait, so I’m going to treat my dad like this, so I can stop this. So, I got irritated by this.’” My sisters said, “I got it now,” because we truly are alone, there really isn’t much of a tool at hand that leads you to something like this, and even though it might seem small, a few minutes of video, it was truly very good. So, I can’t imagine everything that’s going to come [in the future with STAR-C]. Really, I appreciate it, truly.

Another Spanish-speaking caregiver highlighted the need for education and support at the individual level. They indicated that the program’s benefits extended beyond their immediate family, potentially benefiting other caregivers in similar situations. The caregiver explained:

I believe what we were missing was educating ourselves more about this… It could be the entire family, because it was in Mexico where my mom, the rest of my siblings, and I were. We were all taking care of dad, and sometimes, even then, we couldn’t manage. We were like five adults and my dad.

In response to caregivers’ feedback, we decided that it would be appropriate to encourage Latino caregivers participating in the research study to share the STAR-C videos with other family members if they wished, regardless of whether the other family members were also enrolled in the research study. In addition, we decided to welcome other family members within the same family to enroll as study participants if they were interested and met the eligibility criteria. The program’s content could serve as a catalyst for discussion, knowledge exchange, and support among primary caregivers and their extended network of caregivers.

Theme 2: Adaptations to the “Dementia Education” Core Component

Expand Content to Improve Caregiver Understanding of Dementia

Latino family caregivers expressed the need for expanded content in the “Dementia Education” core component to enhance their understanding of dementia. They highlighted the importance of delving deeper into the nature of the disease, its progression, and the various stages it entails.
Several caregivers identified common misconceptions about Alzheimer disease and memory loss in the Latino community, expressing surprise at the late stages of dementia when physical limitations manifest. They stressed the necessity of detailed information to comprehend the evolving challenges faced by people living with dementia. Caregivers emphasized the significance of incorporating this expanded content to enhance their knowledge and foster a more holistic understanding of dementia.

But that part surprised me a lot, which is that the body itself forgets its needs. And it’s the final stage. And I would like it if they did include the stages of Alzheimer’s or dementia. Because for most people, if you tell them, it’s like “oh, they forgot things or put something in the wrong place or they get lost.” But the final stage is the one that very few people know about, it’s what happens when your body, even if it gives signals, you don’t recognize them. It’s like a baby who can’t tell you they’re thirsty, they’re hungry, their stomach hurts, and things like that. So, that’s when it gets complicated and obviously, the end is near.

In response to caregivers’ feedback, we further expanded the content of the first video focused on teaching caregivers about ADRD. Our goal was to provide a comprehensive understanding of dementia, untangling its root causes and distinguishing it from the natural aging process. We describe the different stages of dementia to offer Latino caregivers a better understanding of the importance of understanding the frustrations experienced by both caregivers and people living with dementia and the need to approach interactions with empathy and compassion.

Caregivers indicated the need for comprehensive education on reducing their own risk of developing dementia. They highlighted the importance of understanding the impact of dementia while also learning about strategies to combat it. A Spanish-speaking caregiver said:

The thing is, for example, I’m looking at my husband’s case and I think about myself, and I think, “Well, what can I do to prevent what happened to my husband from happening to me?” Because what will happen if I develop dementia? What will happen to both of us? So, I would like to have more information. What can I do to avoid this? Because I am his caregiver.

Another Spanish-speaking caregiver, after learning about the prevalence of dementia among Hispanics in the STAR-C video, expressed the need for more information on prevention and early signs. They said:

That’s really good [the information in the module]. I was genuinely surprised when it said that one in every eight Hispanics has or will develop, right? So, it’s a bit alarming, and I think, wow, I don’t know, I would like to know more about whether there would be any way to prevent it. It would be great to have more information about prevention or the signs—as it says there, some forgetfulness is normal, certain forgetfulness, right? Like now, being busy with a thousand things, I forgot, and believe me, it happens to me, but I know it’s because I have a lot on my plate and I try to do them all. But I would really like if there was information about whether there’s any way to prevent this condition.

Caregivers’ feedback confirmed our previous findings about the need to modify the STAR-C content to include
comprehensive education on dementia. In response to caregivers’ feedback, we will also be providing caregivers with information on reducing their own risk of developing the condition. By providing caregivers with guidance and knowledge on prevention strategies, STAR-C can empower them to take proactive steps in safeguarding their cognitive health and that of their loved ones.

Theme 3: Adaptations to the “ABC Problem-Solving” Core Component

Simplify the “ABC” Problem-Solving Acronym in Spanish

The “ABC” problem-solving approach in the STAR-C program was regarded as helpful by some Latino caregivers, who found the provided examples to be effective and relatable. However, it was acknowledged that understanding the acronym (“Activators, Behaviors, Consequences”) could be a bit challenging for others. Further, 1 Spanish-speaking caregiver explained why she liked the ABC problem-solving approach:

So, I found the video to be very original, very realistic. It was done very well because I felt identified. The three ways they presented it, in A, B, and C, personally, it felt very real to me, I loved it, almost perfect, because these are situations that do happen and changes that we do need to make. From the beginning, we don’t know how to do it, but with this video or the app that they’re going to develop, it seems very practical to me because it will provide a lot of tools and strategies to people who have no idea how to go about it. Like us in the beginning, we were learning as we went through each day.

Another Spanish-speaking caregiver initially faced challenges in understanding the ABC acronym but gained clarity once the video explained it further.

Yes, some of those words were a bit difficult for me to understand, but later on, it was explained what each of them meant.

Further, 1 Spanish-speaking caregiver reported that while they could understand the content, including the ABC acronym, well due to their extensive Spanish language skills, they acknowledged that a person with limited education might struggle to understand it clearly.

I can understand it perfectly, but I think I can understand because I have a very good Spanish. I was a Spanish teacher for many years, so my language and vocabulary are quite extensive. However, I believe that if the same video had to be heard by someone with limited education, they probably wouldn’t understand it, at least not clearly.

These quotes highlight the caregivers’ perspective on the need to simplify the “ABC” problem-solving acronym in Spanish. While some caregivers found the explanations of each letter in the acronym helpful, others reported that individuals with limited education may potentially face challenges in understanding the acronym. In response to caregivers’ feedback, we simplified the ABC acronym to enhance comprehension and accessibility for a wider range of caregivers. Initially, the ABC acronym was translated as A for “activadores” (activators), B for “comportamiento” (behavior), and C for “consecuencias” (consequences). However, based on the feedback received, we took an additional step to simplify it entirely in Spanish, resulting in the revised form as “las 3 Cs” (the 3 Cs) representing C for “causas” (causes), C for “comportamiento” (behavior), and C for “consecuencias” (consequences).

Add More Problem-Solving Examples With Different BPSDs

Caregivers conveyed a strong desire for the STAR-C program to incorporate a greater variety of problem-solving examples that cover different BPSDs. While some caregivers appreciated the existing examples, they emphasized the importance of including a more extensive range of stories and behaviors to address the diverse challenges encountered in dementia care. For example, 1 Spanish-speaking caregiver stated:

I liked everything, the only thing is that I would like them to add a bit more different stories, with different behaviors.

Another Spanish-speaking caregiver shared their personal experience with their mother’s behavior and the importance of addressing such situations.

Yes, my mom experiences a lot of panic episodes, and I didn’t see that in the video, so in my own way, I handled panic situations in her illness, like waking up at night in a panic: “Where am I? Who am I? Where are we?” So, I didn’t see in the video strong things like that, like screaming, situations where you don’t know what to do as a family member, so you just hug them. I hugged my mom, I hugged her, I hugged her, and I said, “Calm down, we’re okay. I’m your daughter, we’re here.” I mentioned the house, the surroundings, everything. But she has those night panics out of fear very often.

These quotes underscore the caregivers’ interest in having a more extensive selection of problem-solving examples that address various BPSDs, such as aggression and panic attacks. In response to caregiver’s feedback, we will include a broader range of scenarios and behaviors, so that caregivers can gain invaluable insights and strategies to effectively manage the diverse challenges associated with BPSDs.

Demonstrate Problem-Solving With Real People

Latino caregivers reported a desire for more realistic and relatable problem-solving examples in the STAR-C program. They suggested incorporating videos featuring real interactions between caregivers and persons living with dementia to enhance the learning experience. Further, 1 Spanish-speaking caregiver explained:

Perhaps, in the example—I mean, I don't know how much of the video or program is left [to be developed], but maybe, I don't know, perhaps the depiction of two people acting out the situation, maybe it would look much more professional or
They emphasized the need for caregivers to take regular breaks. Participants collectively acknowledged the importance of caregiver rest, support, and self-care, so that caregivers can be better equipped to provide optimal care to their loved ones.

**Discussion**

**Principal Results**

This study’s objective was to test and refine the preliminary cultural adaptations to the STAR-C web-based training modules for Latino caregivers. Our qualitative analysis identified key adaptations required in (1) the delivery of STAR-C, (2) the “dementia education” core component, (3) the “ABC problem-solving” core component, and (4) the “caregiver support strategies” core component. Caregivers expressed a desire for STAR-C videos to be accessible through audio-only formats, and they highlighted the importance of making the videos available on various platforms, including those commonly used in their community. They also emphasized the need for the videos to be easily shareable with family members to enhance communication and caregiving practices. In response, we tailored the narration script to facilitate audio-only access and optimized video formats for widespread accessibility. Moreover, caregivers requested comprehensive education on dementia prevention and understanding the disease’s stages, advocating for expanded content within the “Dementia Education” core component. This resulted in additional content aimed at enhancing caregivers’ understanding of dementia progression and challenges. To further foster empathy, caregivers suggested highlighting the importance of viewing the world from the perspective of individuals living with dementia. Consequently, we incorporated elements emphasizing empathy into the program. Caregivers also sought to incorporate strategies for reducing the risk of developing dementia, leading to the inclusion of content addressing preventive measures. Within the “ABC Problem-Solving” core component, caregivers expressed a need to simplify the “ABC” acronym in Spanish and expand problem-solving examples. We responded by simplifying the acronym and incorporating more problem-solving scenarios to cater to diverse challenges. Additionally, caregivers desired realistic problem-solving examples featuring real interactions between caregivers and persons with dementia. Lastly, caregivers emphasized the importance of caregiver well-being, prompting us to underscore self-care, rest, and seeking support to ensure caregivers’ mental and emotional health is prioritized. These adaptations collectively refine the STAR-C web-based training modules for Latino caregivers and provide a culturally tailored, evidence-based intervention to support dementia caregiving in this community.

**Comparison With Prior Work**

Our study identified several key adaptations needed to enhance the cultural relevance and effectiveness of the STAR-C web-based training modules for Latino caregivers. Notably, caregivers expressed a strong desire for videos to be accessible through audio-only formats, a finding that aligns with a study
conducted among Hispanic participants from Spain [19], where a similar preference for audio accessibility was observed. The importance of making videos available on various platforms, as highlighted in our study, is also consistent with research where caregivers expressed openness to learning caregiving information from diverse sources and settings [20].

The cultural adaptations identified in this study to enhance the relevance and effectiveness of the STAR-C web-based training modules for Latino caregivers may have applicability to caregivers from other racial and ethnic minority groups as well. For example, collectivist and familism values tend to be strong in Asian cultures that emphasize family and community interdependence [21,22]. As such, making the STAR-C videos easily shareable with family members to facilitate communication and coordinated caregiving practices may also resonate with Asian caregivers.

Furthermore, our study aligns with prior research by emphasizing the need for comprehensive education on dementia prevention and understanding the disease’s stages [20,23]. In a study conducted among various ethnic groups, including Hispanic or Latinos, African Americans, and Asian Americans, it was found that a common lack of knowledge about the early signs of Alzheimer disease existed [23]. This knowledge gap underscores the importance for comprehensive dementia education, a point that resonates with our study’s findings. Additionally, another study similarly stressed the importance of greater education regarding the diversity and spectrum of dementia-related symptoms [20].

Caregivers also strongly advocated for simplifying the ABC acronym in Spanish, adding more problem-solving examples, and demonstrating problem-solving with real individuals. These adaptations align with a study assessing Spanish language health information via videos [24], which found that participants preferred videos featuring increased actor participation, as it enhanced their ability to relate the content to real-life situations.

Limitations

Our study has limitations worth noting. First, the low-fidelity prototypes of the STAR-C web-based training modules (ie, videos) we used in this study lacked the realistic appearance and comprehensiveness of the full virtual STAR-C program. This may have limited our ability to obtain accurate perceptions and feedback, as caregivers might not have fully understood or engaged with the low-fidelity prototypes as they would have with a higher-fidelity version of the full STAR-C program. As a next step in this research, we plan to pilot test high-fidelity prototypes of the STAR-C web-based training modules. Second, caregivers’ feedback about STAR-C is influenced by their personal preferences and experiences, which may result in us inadvertently prioritizing features or solutions that appeal to the specific subgroup of Latino caregivers participating in this study rather than broader populations of Latino caregivers. We tried to address this limitation by interviewing a diverse group of caregivers including both male and female caregivers (most Latino caregivers tend to be women), caregivers of different ages and family roles (ie, spouse vs child caregiver), and caregivers with different educational backgrounds.

Conclusions

This study addresses a critical gap in the field of dementia caregiving, particularly for Latino caregivers who face unique challenges and disparities in health outcomes. The culturally adapted version of the virtual STAR-C program represents a significant step forward in bridging this gap. Our findings highlight the importance of tailoring interventions to meet the specific needs of Latino caregivers, considering cultural values and beliefs that shape caregiving interactions and experiences. The key adaptations we needed to make to the STAR-C web-based training modules, including accessibility improvements, expanded dementia education, enhanced problem-solving strategies, and a focus on caregiver well-being, underscore the importance of cultural adaptation of evidence-based caregiver interventions for Latino families. While further research is needed to assess the efficacy of these adaptations, we believe that the virtual STAR-C intervention has the potential to improve health care services and health outcomes for Latino people living with dementia and their family caregivers. By addressing the pressing need for culturally adapted evidence-based interventions, we aim to promote more favorable experiences with the intervention and ultimately reduce the health disparities associated with dementia caregiving in this community. This work contributes to the broader mission of advancing health care services for older adults by using technological innovations, serving the interest of health professionals and family caregivers of older adults.

Acknowledgments

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Conflicts of Interest

None declared.

References


Abbreviations
- **ABC**: Activators-Behaviors-Consequences
- **ADRD**: Alzheimer disease and related dementias
- **BPSD**: behavioral and psychological symptoms of dementia
- **REDCap**: Research Electronic Data Capture
- **STAR-C**: STAR caregiver

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Expectation, Attitude, and Barriers to Receiving Telehomecare Among Caregivers of Homebound or Bedridden Older Adults: Qualitative Study

Pansiree Onseng\textsuperscript{1}, MD; Wichuda Jiraporncharoen\textsuperscript{1,2}, MSc, MD; Sasiwimon Moonkayaow\textsuperscript{1}, MD; Pimchai Veerasirikul\textsuperscript{1}; Nutchar Wiwatikunupakarn\textsuperscript{1,2}, MD; Chaisiri Angkurawaranon\textsuperscript{1,2}, MD, PhD; Kanokporn Pinyopornpanish\textsuperscript{1,2}, MD

\textsuperscript{1}Department of Family Medicine, Chiang Mai University, Chiang Mai, Thailand
\textsuperscript{2}Global Health and Chronic Conditions Research Group, Chiang Mai University, Chiang Mai, Thailand

Corresponding Author:
Kanokporn Pinyopornpanish, MD
Department of Family Medicine
Chiang Mai University
110 Intawarorot Rd., Sripum, Muang
Chiang Mai, 50200
Thailand
Phone: 66 53935462
Fax: 66 53289306
Email: kanokporn.pinyopo@cmu.ac.th

Abstract

Background: In recent years, telehomecare has become an increasingly important option for health care providers to deliver continuous care to their patients.

Objective: This study aims to explore the expectations, attitudes, and barriers to telehomecare among caregivers of homebound or bedridden older adults.

Methods: This qualitative study used semistructured interviews to explore caregivers’ perspectives on telehomecare for homebound or bedridden older adults. The study adhered to the SRQR (Standards for Reporting Qualitative Research) guidelines. Participants were selected using convenience sampling from caregivers of homebound or bedridden older adults with experience in both in-person home visits and telehomecare services provided by the Department of Family Medicine at Chiang Mai University, in an urban area of Chiang Mai Province in Northern Thailand. Semistructured interviews were conducted. The interviews were audio recorded with participant consent and transcribed verbatim. The framework method was used, involving multiple readings of transcripts to facilitate familiarization and accuracy checking. The study used the technology acceptance model and comprehensive geriatric assessment as the analytical framework.

Results: The study included 20 caregivers of older adult patients. The patients were predominantly female (15/20, 75%), with an average age of 86.2 years. Of these patients, 40\% (n=8) of patients were bedridden, and 60\% (n=12) of patients were homebound. Caregivers expressed generally positive attitudes toward telehomecare. They considered it valuable for overall health assessment, despite recognizing certain limitations, particularly in physical assessments. Psychological assessments were perceived as equally effective. While in-person visits offered more extensive environmental assessments, caregivers found ways to make telehomecare effective. Telehomecare facilitated multidisciplinary care, enabling communication with specialists. Caregivers play a key role in care planning and adherence. Challenges included communication issues due to low volume, patient inattention, and faulty devices and internet signals. Some caregivers helped overcome these barriers. The loss of information was mitigated by modifying signaling equipment. Technology use was a challenge for some older adult caregivers. Despite these challenges, telehomecare offered advantages in remote communication and resolving scheduling conflicts. Caregivers varied in their preferences. Some preferred in-person visits for a broader view, while others favored telehomecare for its convenience. Some had no strong preference, appreciating both methods, while others considered the situation and patient conditions when choosing between them. Increased experience with telehomecare led to more confidence in its use.

Conclusions: Caregivers have positive attitudes and high expectations for telehomecare services. Although there may be barriers to receiving care through this mode, caregivers have demonstrated the ability to overcome these challenges, which has strengthened
their confidence in telehomecare. However, it is important to enhance the skills of caregivers and health care teams to overcome barriers and optimize the use of telehomecare.

**KEYWORDS**

telehomecare; telemedicine; telehealth; caregivers; older adults; attitudes

**Introduction**

Thai society has come to recognize the challenge of the aging society and that there is a rapid growth in the number of homebound or bedridden older adult patients with chronic diseases [1]. Homebound refers to a state in which one’s life space is limited to their residence, yet they retain the ability to move within their home. On the other hand, being bedridden is a condition in which a person has experienced significant physical weakness and can no longer move about freely, thus being confined to their bed. These 2 statuses are typically caused by the patient’s comorbidities and often result in the need for comprehensive care and caregiver [2-4]. As a result, coordinated health care services are essential for these individuals, and home health care services have been found to be effective in improving patient outcomes. A long-term care policy has been implemented to provide home care and social support for this population [1,5]. These services are particularly useful for doctors to assess a patient’s living conditions and have been shown to decrease hospitalization, improve physical and psychosocial health, and enhance the overall quality of life for older adults [6,7].

Telemedicine has emerged as a potential solution to bridge the gap between homebound or bedridden patients and health care services [8]. By allowing health care providers to connect with patients remotely, telemedicine can reduce travel costs, provide convenience, and help control the spread of the pandemic [9]. However, there are also disadvantages and challenges associated with this technology, such as the lack of face-to-face communication between doctors and patients and the need for patients to have the technical skills to use these devices [1]. These factors may make the home visit system unsustainable [10].

Over the past 3 years, the COVID-19 pandemic has further highlighted the need for telemedicine, as in-person home visits have been interrupted and transformed into telehomecare for patients requiring continuous health care at home [11-13]. Telehomecare is a form of telemedicine that combines videoconferencing and health monitoring between homebound or bedridden patients and home health care providers [14]. In order to conduct telehomecare for homebound or bedridden older adult care, the caregiver has the main role of helping monitor the patient and communicate all information to health care teams. Therefore, if the caregivers are also older adults and are not proficient with technology, this can pose a barrier, especially for patients living in remote areas [15].

Prior studies on the perception or perspective of the use of telemedicine in caring for older adults have primarily focused on the viewpoints of physicians [16,17] and older adult patients [18,19], rather than caregivers. Physicians have also reported perceiving advantages in the use of telemedicine for older adults, including the reduction of postponed care, the promotion of timely care, enhanced physician efficiency, improved communication with both patients and caregivers, the alleviation of patient travel burdens, and the facilitation of health outreach and educational efforts [17]. The use of technology for health care in older adults could be influenced by their age and the complexity of diseases they face [19], impacting their acceptance of technology [20] and use behavior [21]. It has been noted that the technological acceptance of patients and providers appears to have positive effects on patient outcomes, including self-management and readmissions. The literature also indicates that family caregivers play a vital role in assisting the patient’s decision to adopt and engage with technology [22]. Physicians are aware that caregivers have a role in deciding whether to use telehealth services [16]. Overall, it is important to assess caregivers’ genuine perspectives and suggestions.

A recent study from the United States has explored family caregivers’ perceived benefits and barriers to telemedicine visits for community-dwelling older adults with chronic diseases [23]. Caregivers reported effectiveness in increasing access and continuity of care, but they also expressed concerns about their older relatives’ ability to access and use the technology independently and difficulty in establishing patient-provider rapport. However, these results could be different in Thailand and among families of older adults with more limited capacity, such as the homebound or bedridden population. Thus, this study aims to investigate the expectations, attitudes, and barriers concerning telehomecare among caregivers of homebound or bedridden older adults. Specifically, it will explore caregivers’ expectations regarding the perceived usefulness of the service in delivering comprehensive care for older adults with limited mobility; the barriers that affect the perceived ease of using the service; and their overall attitudes toward the care provided, including their preferences. The results of this study will provide useful insights for the creation of effective care plans for homebound or bedridden older adult patients and their caregivers.

**Methods**

**Study Design**

This study was a qualitative study, using semistructured interviews to investigate the perspectives of using telehomecare for homebound or bedridden older adults, as perceived by their caregivers. The study was reported according to the SRQR (Standards for Reporting Qualitative Research) guidelines [24].

**Ethical Considerations**

Ethical approval was obtained through the Medical Ethical Committee of Chiang Mai University, Chiang Mai, Thailand.
(227/2021). Informed consent was obtained from all participants. The privacy and confidentiality of human participants were rigorously protected throughout this study. Data were either anonymized or deidentified, as applicable, to safeguard the identity of participants. Participants in the study received a monetary compensation of 100 (US $2.7) for their participation.

**Recruitment**

Participants were selected using convenience sampling from caregivers of homebound or bedridden older adult patients who had experience with both in-person home visits and telehomecare services provided by the Department of Family Medicine at Chiang Mai University. The samples were selected from a list of families of older adults who had received care within the past 2 months. Research assistants reached out to these families via phone calls until the total expected sample size was achieved. The study was conducted in an urban area of Chiang Mai Province in Northern Thailand. Inclusion criteria were that participants must be the primary caregiver and speak Thai, while caregivers with communication difficulties were excluded. The researchers expected to recruit at least 20 participants to achieve data saturation, based on similar qualitative studies [25].

**Textbox 1. The interview guide.**

- How long has your family been receiving home care and telehomecare?
- What was the main reason for switching from in-person care to telehomecare?
- Do you perceive telehomecare as useful for your family?
- As a caregiver for an older adult patient, do you feel confident about receiving care for the patient through telehomecare?
- Can you compare the effectiveness of care between in-person home visits and telehomecare for older adult patients?
- Are you satisfied with these services? Which one do you prefer and why?
- What do you see as potential barriers or concerns regarding the use of telehomecare for caring for older adult patients?

**Data Collection**

Semistructured in-depth interviews were conducted between November 2021 and March 2022. There were two parts to data collection as follows: (1) participant characteristics and (2) in-depth interviews about the perspectives of using telehomecare for homebound or bedridden older adults. The patient interviews were conducted in Thai by a single researcher (PO) who was trained in the interview method and interview questions by the qualitative researchers (KP and WJ). Each interview was conducted in a private counseling room to help ensure comfort and confidentiality. Each interview was audio recorded with the participant’s consent, followed by verbatim transcription. PO and KP subsequently reviewed the audio record, and any issues that needed further exploration were discussed. Participant characteristics including sex, age, occupation, relationship with the patient, and the duration of care as the caregiver were recorded. Patient diagnoses and homebound or bedridden status were also gathered. Open-ended interview guides were designed and then piloted to make sure that participants were allowed to share their thoughts freely. The interview guide was described in Textbox 1.

**Data Analysis**

We followed the framework method for the analysis of qualitative data [26]. Each transcript was read multiple times by the 2 researchers (PO and KP) to aid familiarization and to check the accuracy of each transcript. The key elements of the technology acceptance model and comprehensive geriatric assessment for older adult patient care were used as the analytical framework to help identify key issues, concepts, and themes. The study aimed to address the 2 main research questions, which align with the technology acceptance model in the context of providing care for older adults from the perspective of caregivers. The technology acceptance model is the theory that suggests the predictors toward the acceptance and rejection to use technology. These predictors include (1) perceived usefulness and (2) perceived ease of use which are influenced by, for example, technology anxiety or experience, subjective norms, expectations, trust, cultural diversities, and technology characteristics [27]. These factors, in turn, shape attitudes toward using telehomecare services.

The first question focused on perceived usefulness (expectation), incorporating comprehensive geriatric assessment to determine whether telehomecare is suitable for providing comprehensive home-based care for older adults. Comprehensive geriatric assessment is usually carried out while providing care for older adults at home to increase the understanding of an older person’s care needs and preferences and to help in finding common goals of care [28,29]. Its three key elements include (1) comprehensiveness (physical, psychological, and environmental issues); (2) multidisciplinarity; and (3) person-centered goal setting. The second question concentrated on the perceived ease of use of telehomecare for caregivers caring for older adults. This encompassed concerns and perceived barriers.

To explore our research questions, we adopted the framework method, which used a combined approach, incorporating both deductive and inductive elements for the analysis [26]. The deductive approach was applied to the preexisting theories, specifically the technology acceptance model and comprehensive geriatric assessment. Meanwhile, the inductive approach was used to analyze the expectations, attitudes, and barriers associated with telehomecare among caregivers of homebound or bedridden older adults.

The researchers compared the identified codes and discussed the similarities and differences until they reached a consensus on the emergent themes and subthemes. Then, the preliminary
results were interpreted with WJ and CA. All authors read and contributed to the manuscript. NVivo (version 12; QSR International) was used for data analysis. Descriptive analysis was used to describe participant characteristics, including frequency, percentage, mean, and SD. The results were presented to caregivers to receive their feedback.

**Results**

**Sociodemographic Data of Caregivers**

A total of 20 caregivers were recruited, of which 25% (n=5) were male and 75% (n=15) were female, with an average age of 59.5 (SD 14.27) years. Fourteen (70%) of the caregivers were identified as the children of the patients, 15 (75%) caregivers had at least a bachelor’s degree or equivalent level of education, and the average duration of patient care was 3.3 (SD 2.9) years. Table 1 provides a summary of the general information about the caregivers. The average interview duration was 28.45 minutes, ranging from 20 to 47 minutes.

**Table 1.** Sociodemographic data of caregivers (N=20).

<table>
<thead>
<tr>
<th>Item</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5 (25)</td>
</tr>
<tr>
<td>Female</td>
<td>15 (75)</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>59.5 (14.27)</td>
</tr>
<tr>
<td>Range</td>
<td>26-87</td>
</tr>
<tr>
<td><strong>Relation to patient, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>2 (10)</td>
</tr>
<tr>
<td>Siblings</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Child</td>
<td>14 (70)</td>
</tr>
<tr>
<td>Grandchild</td>
<td>3 (15)</td>
</tr>
<tr>
<td><strong>Highest education, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Primary school</td>
<td>2 (5)</td>
</tr>
<tr>
<td>Secondary school</td>
<td>3 (15)</td>
</tr>
<tr>
<td>Bachelor’s degree and higher</td>
<td>15 (75)</td>
</tr>
<tr>
<td><strong>Duration of receiving home health care (years)</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>3.3 (2.9)</td>
</tr>
<tr>
<td>Range</td>
<td>1.5-15</td>
</tr>
</tbody>
</table>

**Health Status of Older Adult Patients**

The majority (15/20, 75%) of patients were female, with an average age of 86.2 (range 66-95) years. Among these patients, 8 (40%) patients were bedridden and 12 (60%) patients were homebound. The most common comorbidities included hypertension (15/20, 75%), dyslipidemia (7/20, 35%), dementia (7/20, 35%), and stroke (6/20, 30%). Additionally, 45% (n=9) of patients reported needing assistance for using technology, while 40% (n=8) of patients indicated that they were unable to use technology.

**Caregivers’ Expectations, Attitudes, and Barriers Toward Telehomecare**

**Overview**

Based on the interviews, it was found that caregivers of older adult patients have specific attitudes and expectations toward taking care of the older adult by using telehomecare. They see it as a valuable service for overall health assessment, although they acknowledge limitations in certain aspects. Communication and device usability challenges were noted, but there is a clear advantage to telehomecare in specific cases compared with in-person visits. Confidence in this service is widespread, yet individual preferences are influenced by family circumstances and situations. Multimedia Appendix 1 shows the framework matrix. The details are provided in the following sections.

It is a Service That Provides an Overall Assessment of a Patient’s Health, but Some Aspects May Be Limited

When surveying caregivers’ perceived usefulness toward telehomecare for older adult patients within the comprehensive geriatric assessment framework, differing attitudes emerged. Overall, caregivers displayed a favorable attitude toward telehomecare, despite some limitations in specific areas.
Physical Assessment
With regard to the physical assessment of the patients, telehomecare can be more limited than in-person home visits. However, caregivers can mitigate this by providing clearer information through photos and videos.

Similar to the case of my mother’s mole which turned into a malignant tumor, it was not noticed clearly through VDO call. [Participant 019]
It doesn’t affect me. If grandma has a pain or where there is any wound, the doctor will ask to take pictures or ask her to walk around to observe the symptom through video call. [Participant 014]

Psychological Assessment
Caregivers believe that psychological assessments yield similar outcomes through both telehomecare and in-person visits, as doctors can ask questions and provide privacy for patients during an assessment session.

It’s not different. The doctor asks the same questions, such as “Are you worried about anything?” or “Would you like me to help you with anything?” [Participant 017]

Environmental Assessment
In-person visits offer a broader environmental assessment experience compared with telehomecare, leading to more precise advice on home environment modification. However, caregivers have found ways to use telehomecare effectively, such as walking around with the device.

If the doctor was to visit in person, they would be able to see the home environment and provide advice on how to improve it. If it is stuffy, smelly, unsightly, not suitable for the patient, then the doctor can suggest more than a VDO call. This is because sometimes we don’t show the home environment as much. [Participant 013]

Multidisciplinary Care
Telehomecare facilitates engagement with specialists such as dieticians and physiotherapists, thus enhancing patient care.

The telehomecare allows us to have more knowledge from other members of the health care team, especially about how to do physical therapy and how to manage the diet for the patient. [Participant 015]

Goal of Care and Care Planning
Caregivers play a key role in facilitating communication and treatment plan adherence during telehomecare, ensuring patients follow prescribed plans effectively.

We’re able to keep up with the treatment plan even during telehomecare because when the doctor has a video call with my grandma, I always listen and take notes, and then I go over what the doctor has told her. I take notes of it all. [Participant 002]

Communication and Device and Usability Limitations Are Also Challenges
In telehomecare, despite the content, care processes, and follow-ups remaining the same, challenges still arise. The main barriers are related to communication and issues with the equipment, but most caregivers are capable of handling these challenges.

Communication
Challenges include low volume from either the patient or health care worker, low patient inattention, and faulty devices, leading to unclear communication. Caregiver presence during sessions can help overcome these barriers.

Grandma’s voice is quite soft. She can’t speak loud making it difficult for the doctor to hear [Participant 002]
During telehomecare, if mother is sitting and trying to listen, it may be necessary for a caregiver to be present to help explain things, as she may have a reduced ability to listen and understand due to her age and weakening internal systems. [Participant 015]

Technologies and Signaling Systems
Loss of information may occur in telehomecare, but some caregivers have modified or changed the signaling equipment and environment to enhance it, resolving this issue.

The sound is a bit lacking, but it’s probably my Internet. After changing the Wifi, it’s better. My mother’s room lacks internet signal. [Participant 007]
Barriers? There are some when we use VDO call. Because the phone is old, and we changed the area where we put the phone, so we received a call late. We don’t use Wifi. [Participant 018]

Ability to Use Technology
Older caregivers may encounter difficulties due to their unfamiliarity with technology, affecting their ability to use telehomecare equipment.

I am not good at using the smartphone. Sometimes they ask me to take pictures of this and that area and I don’t really know how to shoot and am not very proficient in using the device. [Participant 013]

There is an Obvious Advantage of Telehomecare in Limited Cases Rather Than In-Person Home Visits
Despite some challenges and difficulties, telehomecare offers a clear advantage by providing a means of communication in remote areas.

Scheduling Conflicts
Telehomecare can resolve scheduling conflicts caused by caregiver appointments, enabling remote participation when in-person visits are not possible.

There are times when the older adult patient is not at home during the appointment time. Recently, Grandma was at the center. But we communicated through Line in this group. And then we turn on the
Inconvenient Home Settings

Telehomecare is convenient when the patient’s home is not suitable for visits, for example, the home space is not suitable for the health care team to visit, or traveling to the home of the patient is inconvenient. It is especially effective when assessments rely on the caregiver alone, as outcomes remain similar without the need for travel.

It’s convenient. We don’t have to prepare anything. It’s the same. The appointment time doesn’t need to be made, just only when she is unable to sleep. [Participant 017]

Limited Participation of the Patient

It is also effective when assessments rely solely on the caregiver, for example, when the patient has limited participation in conversation, as outcomes remain similar without the need for travel.

...I think it’s convenient for both parties. Maybe the patient is taking a nap when the team visit, so eventually the doctor didn't talk to grandma anyway but to me. [Participant 016]

Everyone is Confident About This Type of Service, but Their Preference Depends on the Family Circumstance and Situation

Overview

When asked about transitioning from in-person home visits to telehomecare, all participants (100%) expressed confidence in receiving telehomecare. Caregivers believed it was similar to in-person visits and met their expectations for health care services. For instance, suggestions about how to reduce health risk behaviors, providing physical therapy advice, managing diet, and offering psychological support for both patients and caregivers.

I feel confident because if we have any problems, we can ask just like how we did when the doctor came, but the disadvantage is that the doctor does not see the patient in person but everything else is the same [Participant 016]

The preference of individual caregivers toward the in-person home visit versus the telehomecare service model is due to personal experiences and all aspects gained during both forms of services. These can be divided into 3 categories.

Preference for In-Person Home Visit

Some caregivers prefer in-person visits because they provide a broader view. These visits allow for a more comprehensive understanding of the patient’s living conditions, environment, evolving symptoms, and overall well-being. In addition, from the direct experience of caregivers, it is easier to identify additional abnormalities during in-person visits that may require treatment. Eight caregivers preferred in-person home visits because they could see more of the overall picture of the patient and the environment.

Because the last time the doctor and the nurse came to visit the house, they gave me notice and later, mother had discovered a mole that protruded into a malignant tumor; we didn’t know it. We thought it was a normal wart. Here, in-person home visits are very helpful, because sometimes caregiver doesn’t know what it is. [Participant 019]

Preference of Telehomecare

Two caregivers prefer telehomecare over in-person visits because it is more convenient as they require less preparation. Often, during home visits, the patient may be sleeping and most of the communication is with the caregiver.

She prefers a VDO call because it is convenient for both doctor and patient. Sometimes the patient will be taking a nap. Most of the patients as old as grandma start napping a lot. If the doctor comes and grandma is not talking to him anymore, she’ll take a nap. This is a waste of the doctor’s time. [Participant 016]

Preference for Both Methods

Five caregivers had similar preferences for both forms of services. They appreciated that both approaches provided an equivalent level of service and treatment, meeting their expectation and goals of health care services during examinations and treatment processes.

I like both. I had no problems with both of them. Through VDO calls, we also get what we need for patient care - medicines and lab results. For me, I don’t have a preference for either method because the specific advantages are different. [Participant 003]

Additionally, some of the caregivers had no preference between in-person home visits and telehomecare as they found advantages in both methods depending on the situation, such as the current pandemic situation and the patient’s condition.

It can be both. But now the doctor says that during the COVID pandemic, he still needs to communicate through VDO call as it is good for both sides. As for the in-person home visit, it provides a visual interaction, but during A VDO call, we still have talking, interviewing, asking questions, providing the health care process which is similar kind of work as well. [Participant 014]

Discussion

Principal Findings

The study discovered that telehomecare is not the same as in-person visits. It may present certain difficulties and barriers, particularly in the aspects of assessment, interaction, and technology use. Despite these barriers, it has the potential to fulfill requirements and bolster trust among those caregivers who provide care to older adults at home to a similar extent as a face-to-face visit. The majority of patients prefer both forms
of care, but it is important to adapt use to fit specific circumstances and conditions.

**Comparison With Prior Work**

The caregivers of homebound or bedridden older adults expressed positive attitudes toward telehomecare and are prepared to familiarize themselves with this service, comprehending its limitations and the need for its use instead of in-person visits. The previous scope review for patients receiving the telehomecare service at home found that patients desire telehomecare as a supplementary channel, offering easier access to health services from the health care team. This can enhance symptom management and encourage greater self-care [30]. Additionally, I study shows that telehomecare patients have greater expectations of telehomecare for the quality and efficiency of patient care, a positive relationship with the team, reduced travel costs [31], and a sense of continuous health monitoring and reassurance from their health care team [32]. If these concerns are addressed in patient care, it will heighten the confidence and satisfaction of both patients and their families.

Moreover, previous studies have found that the majority of participants with a negative attitude toward telehomecare services need more face-to-face health checks than those monitored by telehomecare. This is because they did not have a sense of touch as in in-person visits and were not familiar with using devices. This caused barriers. Conversely, those who are already comfortable with the technology tend to have a more favorable view and see telehomecare as a convenient option, eliminating the need for physically transporting patients to a hospital [8]. These findings align with the results of this study.

**Recommendations for Enhancing Telehomecare Services**

Based on these results, there are 4 recommendations for enhancing telehomecare services as provided in the following sections.

The Provider Should Enhance the Patients’ or Caregivers’ Skills to Do Self-Health Assessment

Our study results revealed that it is possible to conduct an overall assessment of a patient’s health through telehomecare, but there may be limitations in assessing certain aspects, such as physical assessment. Telehomecare’s limitations make it hard to conduct comprehensive videoconferencing or telephone-based health checks, leading to potential medical errors. To ensure effective patient care, family members and caregivers must be involved [33]. Educating them on symptom recognition and initial assessments can help detect abnormalities early, leading to prompt notification for further assessment by the health care team [23]. It is important to provide training and education to caregivers on how to effectively use telemedicine services, as it can improve their skills in self-observing symptoms and mental health management. Telehomecare can also be used to educate and promote self-care, which can lead to better health outcomes for patients. Various channels, such as phone calls, websites, apps, or chats, can be used to provide additional health care skills to caregivers [34,35].

**The Health Care Team Should Enhance Their Skills on Telehomecare Services for Patients at Home**

A technical problem has been reported as an issue. Therefore, it is crucial for the health care team to possess the necessary skills in telehomecare services to assist patients and their families when they encounter such problems in order to enhance ease of use. It has been suggested that health care teams possess the following skills when delivering telehomecare services [36]: (1) determining when to use telemedicine and assessing the ability of patients and caregivers to use it; (2) proficiency in assessing and caring remotely for patients; (3) effective communication and relationship-building with patients, caregivers, and families; (4) professionalism; (5) basic understanding of information technology; (6) knowledge of laws and privacy protection; (7) ethical considerations; (8) awareness of patient’s safety; and (9) awareness of accessibility and service culture. All of these knowledge and skills required by the health care team impact the provision of effective services which are of utmost importance. In some countries, such as the Netherlands, core competencies have been defined for nurses to ensure the effective implementation of telehealth [37].

The key findings from this study suggest that the health care team should know how to assess the situation and select the appropriate service models, whether it could be in-person home visits or telehomecare based on the experience. Although service users have different preferences, circumstances and necessities should be considered. According to the study by Doraiswamy et al [38], it was noted that telehomecare services had previously been used for noncommunicable diseases. However, during the current pandemic, they have become increasingly important for diagnosis, symptom monitoring, rehabilitation physiotherapy, and reducing the spread of pathogens as well [38]. Despite these advantages once the outbreak situation improves, telehomecare services should only be provided in appropriate cases. Patients with positive attitudes toward telehomecare services; who have used technology and have previously received in-person medical treatment; and have difficulties traveling to the hospital due to distance, finances, or health issues are typically considered suitable for telehomecare services. In addition, the content discussed during the telehomecare services should not be of a sensitive nature, particularly in the case of relationships with the caregiver [39]. It is important to ensure that the patient has a suitable place to receive telehomecare services without distractions and can provide the necessary information to the health care team.

The preferences of patients and their families are a crucial factor in choosing the right telehomecare service. It is important for the physician to consider various aspects, including the patient’s health, family preferences on service models, and the current social situation. Health care providers should engage in conversations with older adult patients and their caregivers regarding the advantages and disadvantages of telehealth, enabling patients to make informed choices between in-person and telemedicine options [23]. This is to make an informed decision and ensure patient satisfaction with the chosen service in the future.
The Barriers, Especially Those That Are Fundamental to Providing Telehomecare Services, Should Be Removed as Much as Is Feasibly Possible

In our study, we found that barriers to telehomecare can originate from patients themselves, including soft speaking voices or inadequate communication devices. Technology-related barriers, such as poor signal quality or connectivity issues, may also occur. To mitigate these issues, providers and recipients may need to invest in proper equipment, use a microphone that can absorb speech well, and place equipment in the right position to optimize the internet signal [33]. Additionally, the financial aspect of the service should also be considered, it may be useful to have a system to restore certain devices from the service provider but must be weighed against the expenses of the service provider side as well.

Some caregivers struggle to use communication devices, which can cause interruptions in telehomecare services. Patients may also feel incapable of learning to use these devices, according to a study by Huang et al [8]. Thus, telehomecare teams should be knowledgeable about the devices used, inquire about any concerns, and provide assistance to build confidence in using them. To ensure accessibility to all areas, it is recommended to develop strong internet signal towers to support telehomecare for the national benefit.

Interestingly, this study found that the majority of caregivers for older adult patients were highly educated children, with great potential to use technology better than the patient. However, they may still have limitations in using communication devices and technology [40]. Health care providers should not judge their ability based on age or education, and even frail older adults can be trained with help from nurses and caregivers [41]. Each family should be evaluated on a case-by-case basis, and appropriate assistance provided.

Services Should Also Be Provided to Meet Expectations Regarding the Management of Health Problems

Caregivers of older adult patients often have specific expectations from their health care providers, such as recommendations to enhance the patient’s overall health, psychological support, and reducing transportation costs. Our findings support that caregivers perceive telehomecare as useful and prefer it when their expectations are met during the service delivery. Offering services that meet the expectations of patients and their caregivers helps improve the health care aspect and engage in service involvement, which leads to a reduction in hospitalization rates [41,42]. The health care team should strive to meet these expectations to maintain the trust of patients and their families in the telehomecare health care service to the same extent as in an in-person home visit.

Strengths

The strength of this study is that the study involved caregivers with experience in both in-person home visit and telehomecare, allowing for comparison of both services. The study also focused on in-depth aspects related to caring for the bedridden older adults who may have limitations in receiving services.

Limitations

However, there are also limitations to this study. For instance, the information obtained through interviews by health care teams or personnel from the hospital may be biased. To mitigate this, the researchers took measures to ensure that the interviewer was not involved in the treatment of any of the patients and caregivers interviewed. The interview process for participants using convenience sampling may involve selecting individuals who are readily available or easy to reach, potentially leading to a sampling bias. However, the data reach its saturation. Additionally, the sex of participants was 75% (n=15) female, which may yield different insights compared with settings with varying sex ratios among caregivers. However, in Thailand, the majority of caregivers for older adults are female, with a prevalence ranging from 70% to 90% [43-45]. This ratio is similar to that in our study. Given the slight tendency for male individuals to hold slightly more favorable attitudes toward technology use than female individuals, although not substantially [46], it is important to note that this sex imbalance among caregivers should not significantly impact the study’s results. The participants of this study were mainly caregivers of older adults with stable chronic illnesses. Caregivers of patients with more complicated illnesses or the terminally ill may have different attitudes or expectations. We did not include the attitudes of the medical service team with regard to this aspect. These attitudes may affect the outcomes of services and treatment as well, which may be subject to further study. Last, conducting a study comparing telehomecare with no care would underscore the significance of home-delivered care. However, since our initial aims did not include a comparison of these 2 populations, we did not collect data from individuals who have not received the service. It may be worthwhile to consider further research involving families of older adults with health conditions that limit their function but are unable to obtain home care services. Nevertheless, obtaining information about this population could be challenging.

Conclusion

In conclusion, telehomecare is a viable option to supplement in-person home visits. It has the potential to provide quality health care services to patients and allow health care teams to offer treatment and advice remotely. Caregivers have shown a positive attitude toward telehomecare, which is comparable in effectiveness to in-person visits. Despite potential challenges, telehomecare can be a useful alternative in situations where in-person visits are not possible. However, it is important to enhance the skills of caregivers and health care teams to overcome barriers and optimize the use of telehomecare.
Acknowledgments
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Data Availability
The data sets generated or analyzed during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest
None declared.

Multimedia Appendix 1
Framework matrix.

References


Abbreviations

SRQR: Standards for Reporting Qualitative Research

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The #SeePainMoreClearly Phase II Pain in Dementia Social Media Campaign: Implementation and Evaluation Study

Louise I R Castillo, MSc; Vivian Tran, MSc; Mary Brachaniec, MAHSR; Christine T Chambers, PhD; Kelly Chessie, PhD; Alec Couros, PhD; Andre LeRuyet; Charmayne LeRuyet; Lilian Thorpe, MD, PhD; Jaime Williams, PhD; Sara Wheelwright; Thomas Hadjistavropoulos, PhD

1Department of Psychology and Centre on Aging and Health, University of Regina, Regina, SK, Canada
2Centre on Aging and Health, University of Regina, Regina, SK, Canada
3Department of Psychology and Neuroscience, Dalhousie University, Halifax, NS, Canada
4Centre for Pediatric Pain Research, IWK Health, Halifax, NS, Canada
5Department of Pediatrics, Dalhousie University, Halifax, NS, Canada
6Santa Maria Senior Citizens Home, Regina, SK, Canada
7Faculty of Education, University of Regina, Regina, SK, Canada
8Department of Community and Epidemiology, University of Saskatchewan, Saskatoon, SK, Canada
9Trusted Marketing Services, Saskatoon, SK, Canada

Corresponding Author:
Thomas Hadjistavropoulos, PhD
Department of Psychology and Centre on Aging and Health
University of Regina
3737 Wascana Parkway
Regina, SK, S4S 0A2
Canada
Phone: 1 306 585 4457
Fax: 1 306 337 2321
Email: hadjistt@uregina.ca

Abstract

Background: Social media platforms have been effective in raising awareness of the underassessment and undertreatment of pain in dementia.

Objective: After a successful pilot campaign, we aimed to scale our pain-in-dementia knowledge mobilization pilot initiative (ie, #SeePainMoreClearly) to several social media platforms with the aid of a digital media partner. The goal of the initiative was to increase awareness of the challenges in the assessment and management of pain among people with dementia. A variety of metrics were implemented to evaluate the effort. Through this work, we endeavored to highlight key differences between our pilot initiative (which was a grassroots initiative), focusing largely on Twitter and YouTube, and the current science-media partnership. We also aimed to generate recommendations suitable for other social media campaigns related to health or aging.

Methods: Evidence-based information about pain in dementia was summarized into engaging content (eg, videos) tailored to the needs of various knowledge users (eg, health professionals, families, and policy makers). We disseminated information using Facebook (Meta Platforms), Twitter (X Corp), YouTube (Alphabet Inc), Instagram (Meta Platforms), and LinkedIn (LinkedIn Corp) and measured the success of the initiative over a 12-month period (2020 to 2021). The evaluation methods focused on web analytics and questionnaires related to social media content. Knowledge users’ web responses about the initiative and semistructured interviews were analyzed using thematic analysis.

Results: During the course of the campaign, >700 posts were shared across all platforms. Web analytics showed that we drew >60,000 users from 82 countries to our resource website. Of the social media platforms used, Facebook was the most effective in reaching knowledge users (ie, over 1,300,000 users). Questionnaire responses from users were favorable; interview responses indicated that the information shared throughout the initiative increased awareness of the problem of pain in dementia and influenced respondent behavior.

Conclusions: In this investigation, we demonstrated success in directing knowledge users to a resource website with practical information that health professionals could use in patient care along with pain assessment and management information for
caregivers and people living with dementia. The evaluation metrics suggested no considerable differences between our pilot campaign and broader initiative when accounting for the length of time of each initiative. The limitations of large-scale health campaigns were noted, and recommendations were outlined for other researchers aiming to leverage social media as a knowledge mobilization tool.

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KEYWORDS
knowledge translation; Twitter; older adults; Facebook; knowledge mobilization

Introduction

Background

Social media platforms play an important role in academic dissemination and have untapped potential as knowledge mobilization (KM) tools that can allow researchers to interact directly with the public worldwide [1]. KM encompasses activities involved in the synthesis and dissemination of research information; this process includes knowledge synthesis, dissemination, transfer, exchange, and cocreation by researchers and knowledge users [2]. Knowledge users, such as older adults and their families, are increasingly turning to web-based platforms (eg, Twitter [subsequently rebranded as X] and Facebook) to share and obtain information [3,4]. Health-related initiatives on social media networks have successfully raised awareness about a host of topics (eg, mental health, breastfeeding, and cancer) [5]. For example, a nationwide HIV prevention campaign (#PrEP4Love) garnered >40 million views across various social media platforms [6].

Researchers have supplemented social media KM initiatives with other web-based KM methods (eg, web-based repositories, educational videos, and community groups) [7,8]. Despite the innovation of this approach, the sustainability of social media health campaigns is contingent upon different factors (eg, continued content generation and ongoing funding) [9]. As such, there is a growing need for partnerships with digital media experts to aid in health KM. A notable example of this is the work by Chambers [10], who mobilized knowledge about pediatric pain within the context of a science-media partnership through her #ItDoesntHavetoHurt campaign. The initiative demonstrated worldwide impact and great success in producing and disseminating digital evidence–based content tailored to the needs of parents and health professionals, obtaining 1.3 million Twitter impressions, 5.5 million hashtag mentions, and >250,000 views of her YouTube video [10]. Impact was also demonstrated through indices of adoption and changed practices [10].

Although researchers have attempted to track the reach and impact of social media for KM through web metrics and the use of social listening software [11,12], very little research has been conducted using social media for KM in older adults with dementia. To address limitations in the reach of traditional KM campaigns and a gap in the literature, we launched and evaluated the pilot #SeePainMoreClearly (phase I) social media KM campaign with messages that reached >2,376,853 unique individuals on Twitter [9]. The goal of the pilot initiative was to increase awareness of the challenges in the assessment and management of pain among people with moderate to severe dementia with limited ability to communicate [13,14]. Moreover, we aimed to disseminate information on evidence-based approaches to effectively assess and manage pain in this population (eg, [15-18]). To maximize uptake, we created a web-based repository of pain assessment and management information [19]. We also prepared an engaging 2-minute YouTube video with evidence-based information about pain in dementia [20].

The script for the video was created and modified with input from health professionals, caregiver partners, researchers, and knowledge user organizations. The pilot campaign was evaluated by tracking social media and web metrics and by conducting qualitative analyses of social media posts in response to the #SeePainMoreClearly campaign over a 5-month period. #SeePainMoreClearly demonstrated substantial reach with >5,000,000 hashtag impressions on Twitter. The short video was viewed >50,000 times, and our web-based repository was visited by people in >55 countries. Moreover, the content analysis of social media posts (ie, tweets) from users who used the hashtag or responded to our messaging and content posted on Twitter were favorable. Many users expressed support for the initiative and increased advocacy for improved pain care for people living with dementia.

Our findings showed the effectiveness of web-based KM methods in reaching very broad international audiences quickly. Perhaps most importantly, without counting the posts that were produced by members of our team, the initiative doubled the number of posts made on the topic of pain dementia on Twitter during the campaign period as compared with a control period of the previous year [9]. It is important to note that the #SeePainMoreClearly pilot campaign took place in 2019, before the COVID-19 pandemic. The pilot #SeePainMoreClearly was a grassroots initiative in which a small number of researchers prepared engaging materials and disseminated them on their own with support from several knowledge user organizations that agreed to help disseminate the message. A lesson from the pilot #SeePainMoreClearly experience was that although KM grassroots campaigns can be very successful, lengthier social media campaigns (run solely by researchers) would not be sustainable, as involvement can be very time-consuming for researchers who generally must attend to multiple other obligations. A partner with digital media expertise and time to dedicate resources is necessary for a sustainable large-scale KM campaign. Hence, we sought and obtained funding to support such a partnership.
Objectives
The primary purpose of this study was to launch and evaluate a longer (12 months instead of 5 months) #SeePainMoreClearly campaign with expanded social media platform coverage (eg, Twitter, Instagram, Facebook, and LinkedIn as opposed to just Twitter) with the following additional objectives:

1. Track the reach of a larger social media KM campaign over a 12-month period on various platforms (eg, Facebook, Twitter, Instagram, and LinkedIn)
2. Evaluate the impact of the campaign on knowledge users’ (eg, patient, caregiver, health professional, and policy maker) knowledge
3. Evaluate the impact of a science-media partnership on our pilot campaign in meeting knowledge users’ needs
4. Outline recommendations to develop and scale social media KM initiatives.

We expected the results to demonstrate a large scope and breadth of our campaign, resulting in a large number of visits to our resource website [19]. Moreover, we predicted that our results would demonstrate the value of a science-media partnership as a strategy for improving KM in the area of pain in dementia. We contrast the experiences of the digital media partnership campaign with the pilot #SeePainMoreClearly campaign. The findings from this project can inform subsequent evaluations of social media as a KM tool.

Methods

Ethical Considerations
The ethical process involving contact with human participants (eg, questionnaires and semistructured interviews) was approved by the University of Regina Research Ethics Board (#REB 2020-036).

Identification and Engagement of Digital Media Partner

Given the nature of our funding, we were restricted to identify a digital media partner within our home province. As such, a web search was conducted to identify potential locally based digital media partners that listed social media promotion as part of their services. We then communicated with 2 of the firms that, based on their websites, seemed highly experienced with social media marketing and described the nature of our work to confirm that they understood the needs of our project and that they were interested in partnering with us for the campaign. Our institution required us to subject the project to an open competitive bidding process before awarding the contract. This process allows qualified bidders to submit proposals and budgets. The 2 firms with which we had communicated were invited to submit their proposals. On the basis of this process, the best qualified bidder who offered competitive pricing was selected from a total of 3 bidders.

Development of Content and the Campaign
We worked with the selected digital media partner to develop the campaign content and KM strategy as well as to collect social media analytics in response to our campaign. An iterative process was implemented with team collaborators (eg, caregiver partners, researchers with knowledge of the content area, media experts, and health care professionals) with the aim of developing lay summaries of evidence-based information about pain in dementia. Specifically, a series of web-based meetings with members of the team were coordinated to identify pertinent information about pain assessment and management among older adults with dementia, which served as the basis of the campaign’s content. Accordingly, the general topics agreed upon by the team were as follows: (1) the feasibility of regular pain assessments, (2) available guidelines for pain assessment, (3) resources for informal caregivers, (4) effects of psychotropic medication in long-term care (LTC), (5) validated pain assessment tools, (6) implementing regular pain care in LTC, (7) gaps in education for health professionals and ways to address this challenge, (8) effects of untreated pain in dementia, (9) pain care during the COVID-19 pandemic, (10) cost of untreated pain for the health care system, (11) benefits of regular pain assessments, and (12) effective ways to assess pain in dementia. Once the general topics were identified, information was gathered that corresponded to established guidelines (eg, [17,18,21,22]) or was supported by published research in leading peer-reviewed journals. Specific evidence-based information was selected by our team, which included content experts and caregivers with lived experience. Next, the team developed lay summaries (eg, 200-300 words) of the evidence present in the literature covering each aforementioned topic (eg, [17,18,21,22]). Several rounds of refinement were conducted by team members. Following this, the team developed 8 cross-cutting messages and key points (Multimedia Appendix 1) divided by the target group (eg, health professionals, policy makers, and public or families). These messages were then relayed to the digital media team as the basis for the messaging developed for the campaign. The digital marketing team developed a series of images and posts for each target group. Moreover, a short animated (ie, 2-minute long) video was created for each target group (eg, family, health care professionals, researchers, and policy makers). The animated videos were posted on the web page and on social media platforms. Examples of the content and posts are shown in Figure 1. Blog posts written by team members and people with lived experiences related to the topics outlined in this section were shared throughout the initiative. A total of 42 blog posts [23] were created and posted on the web page of this project.
Figure 1. Digital content samples shared throughout the initiative.

**Dissemination Strategy**

Unlike the pilot campaign [9], which focused on Twitter and YouTube, information was disseminated on 5 social media platforms used for the campaign: Facebook (Meta Platforms), Twitter (X Corp), YouTube (Alphabet Inc), Instagram (Meta Platforms), and LinkedIn (LinkedIn Corp).

A total of 756 posts were shared across Facebook, Twitter, Instagram, and LinkedIn, and 5 videos were posted on YouTube over a 12-month period (ie, October 1, 2020, to September 30, 2021). A key goal of the dissemination strategy was to direct knowledge users to the web-based repository to share further information and resources about pain in dementia [19]. We designed the content (eg, social media posts, images, and short animated videos) to be of interest to our target groups. Moreover, we developed social media posts to gain the attention of specific target groups (eg, by including an image with the statement Resources for researchers prominently displayed). As with the pilot initiative, the #SeePainMoreClearly hashtag was used to maximize the reach of the content and information. We leveraged events (eg, the International Day of Older Persons in October, World Alzheimer Awareness Month in September, and Alzheimer Awareness Month in January) to develop tailored content. The total amount of money spent on post promotion and advertisements was CAD $29,793.86 (US $22,133.06); the vast majority of this amount was spent on Facebook and Instagram, CAD $26,384 (US $19,599.96), Twitter, CAD $3045 (US $2262.05), and LinkedIn, CAD $364.86 (US $271.04).

**Evaluation of the Campaign**

**Engagement and Reach of the Initiative**

**Web Analytics**

A longitudinal data collection strategy was used to obtain web and social media metrics over a 12-month campaign period (ie, October 1, 2020, to September 30, 2021). For the website, the number of content viewers and pages views were tracked using Google Analytics [24]. For our analysis, we reported a descriptive count (eg, count of total engagement, reach, and impressions) of all web and social media analytics. Google Analytics was used to collect data from the website. To clarify how Google Analytics works, each time a user visits a web page, a tracking code by Google Analytics collects information on how that user interacted with the page [25]. Google Analytics then aggregates and organizes this information in the Google Analytics portal as a report detailing different metrics (eg, the count of web page visits and the number of pages viewed). Similarly, the social media metrics were aggregated by each social media platform. This information was accessed through...
the social media platform’s website (eg, Facebook Analytics). Web and social media analytics were exported and reported.

**Social Media Analytics**

The reach, scope, and engagement of the initiative and web-based repository were monitored through social media metrics (eg, web analytics, hashtag analytics, and social media analytics). Similar metrics have been used in previous research to quantify the impact of social media initiatives [10,12]. The number of impressions (ie, the number of times users have seen the web-based content), reach (ie, the number of unique users who have seen the web-based content), and engagement (ie, the number of comments, retweets, “likes,” and shares) were extracted using the analytics provided by each platform. Not all analytics were available for each social media platform (eg, reach was not available for LinkedIn). Analytics were summarized based on three sources of information: (1) analytics of only paid posts provided by the social media platform, (2) analytics of the total number of posts (ie, paid and unpaid) provided by the social media platform, and (3) third-party social media analytics manager (eg, CloudCampaign) provided by the digital marketing team. Moreover, our digital media partner could only obtain data for specific periods (eg, year-long data could not always be obtained) for some platforms owing to limitations in the sources of information. Nevertheless, attempts were made to encompass the entire evaluation period. Depending on the data source, data were provided from (1) October 1, 2020, to September 3, 2021; (2) October 1, 2020, to November 2, 2020; or (3) November 3, 2020, to September 30, 2021. Thus, the reported numbers varied as a function of the period. The Keyhole social media monitoring (also known as social listening) software [26] was used to collect the metrics and analytics for the #SeePainMoreClearly hashtag on Twitter.

**Knowledge Users’ Responses to the Initiative**

**Semistructured Interviews With Knowledge Users**

Individuals who viewed and engaged with the content (eg, responded to social media posts or added their own commentary when reposting content shared throughout the initiative) on social media were invited to participate (ie, research personnel contacted back to users who responded to social media posts and invited them to participate in interview) in semistructured interviews with a researcher to gain an understanding of their perceptions about the initiative. Moreover, invitations (ie, through social media posts or recruitment posters) to participate in the interview were circulated across social media platforms. All participants recruited through social media posts were asked to contact the research team to indicate their interest. The interviews were conducted over Zoom (Zoom Video Communications Inc) audio-only and covered the following topics: perceptions about the initiative, quality of information and messages disseminated, and impact of the initiative on knowledge and behavior (Multimedia Appendix 2). Zoom’s automated transcription feature was used to facilitate the transcription of the interviews. The transcription was then reviewed with the interview audio recording to ensure accuracy. NVivo (version 12; Lumivero) software [27] was used to facilitate the coding reliability thematic analysis [28]. Two independent researchers initially organized a subset of data into clusters based on commonalities and recurring ideas to develop a coding book [28]. Consistent with a coding reliability thematic analysis approach, themes were developed inductively and aligned with the data collection questions of the study [28]. Themes that emerge from this analysis can be viewed as a summary of the participant responses. Codes were developed after data familiarization, while keeping the data collection questions in mind. Two coders individually coded a subset (3/13, 20%) of the data to develop a coding book. They grouped each line of text into clusters and then into higher-level codes (ie, themes). The coders then met to discuss and finalize the coding book. Discrepancies between the coding researchers and decisions to merge or split categories were discussed throughout the process until a consensus was reached. The developed coding book was applied to the remaining data to identify the prevalent categories and obtain a frequency count of the identified themes. To ensure rigor in our analysis, we conducted consistency checks on the coded themes and categories (eg, discussing discrepancies between coders) and maintained ongoing communication among coders throughout the process to establish consensus. Moreover, a randomly selected subset of data was coded to assess intercoder agreement. Triangulation was considered through the different perspectives (eg, health professionals, caregivers, and people with dementia) obtained in this study and the use of a mixed methods approach (ie, use of interview and numeric questionnaire data). A primary coder coded the entire data set, and a secondary coder coded a subset of the data to establish intercoder agreement. The second coder coded a randomly selected 20% (3/13) of the participant data. NVivo calculates a κ coefficient to evaluate agreement as follows: total units of agreement between the 2 coders minus the expected frequency of the agreement occurring by chance, divided by the total units within the source minus the expected frequency of the agreement occurring by chance [29].

**Social Media Comments About the Campaign**

Social media analytics do not provide information about the content of the comments in response to our initiative (ie, whether users liked or disliked the content). As such, we analyzed the responses to the initiative to better understand users’ perception of our campaign. To assess the perception of a wider sample of knowledge users, comments by web users in response to the posts made during the campaign across Facebook, Twitter, Instagram, and LinkedIn were collected manually and subjected to a coding reliability thematic analysis, consistent with the method outlined in the Semistructured Interviews With Knowledge Users section. The aim was to understand the type of comment (ie, opinion, personal experiences, and information) in response to the content shared to determine prevalent themes.

**Overview of Evaluation Questionnaires**

A brief survey was circulated across the campaign’s social media platforms to receive feedback about users’ perception of the content and information shared during the initiative. The participants were recruited via invitations on social media platforms. For example, social media posts were created to encourage participants to provide their input on the initiative by clicking on the link that directed users to the questionnaires. The link to the questionnaire was also available on the website for this project. Individuals who accessed the surveys were
asked to indicate the group they belonged to (1) caregiver, family member, or friend of a person with dementia, (2) person living with dementia, (3) public, (4) health professional, or (5) policy maker. Demographic information questions about participant age, gender, country, relationship with the person living with dementia, and type of health care provider (ie, for individuals who identified as a health care professional) were collected and outlined using descriptive and frequency statistics.

**Pain in Dementia Evaluation Questionnaire**

A short questionnaire, used in the pilot campaign evaluation [9], was used to solicit anonymous responses from various knowledge users. The survey included both general and specific questions for the general public, health professionals, and caregivers of people with dementia. Most responses were provided along 7-point Likert scales (eg, 1=not very likely to 7=very likely) and focused on viewers’ opinions about the initiative, content, and likelihood of using the information provided. Descriptive statistics were calculated for the Likert scale items in the evaluation questionnaire.

**Information Assessment Method for All**

Users’ perception of the content and potential benefit of the information were assessed using the IAM4all (Information Assessment Method for All) [30]. The IAM4all consists of 6 general questions assessing information relevance and use, with nested follow-up questions depending on participant responses. Accordingly, the IAM4all is a 28-item self-report questionnaire designed to measure 4 levels of outcomes associated with receiving or seeking web-based information: situational relevance, cognitive impact, information use, and health benefits. Each item is rated based on agreement to a question (ie, yes, no, or possibly). Content validity of the IAM4all has been substantiated through a review of the theories of information science and feedback from knowledge users (eg, laypersons, health professionals, and experts) [30]. Descriptive and frequency statistics were used to calculate the means and SDs for the items in the questionnaire.

**Web-Based Discussions About Pain in Dementia**

The level of web-based discussions about pain in dementia was determined by examining the number of posts on Twitter and Facebook. Three periods of comparison were established: (1) a precampaign period (ie, a 7-month period following the end of the pilot campaign and before the start of #SeePainMoreClearly phase II, March 1, 2020, to September 30, 2020); (2) a campaign period (October 1, 2020, to September 30, 2021); and (3) a postcampaign period (ie, a corresponding 7-month period following the end of #SeePainMoreClearly phase II, October 1, 2021, to April 30, 2022). Searches for unique (ie, not retweets or reposts) tweets on Twitter containing the hashtags “#pain #dementia” AND/OR key words “pain dementia” were conducted for all 3 periods using the Keyhole software. A catalog of all the tweets during the specified periods was collated on a spreadsheet by Keyhole. A similar method could not be used to obtain Facebook posts on Keyhole (ie, this feature was not available on Keyhole for Facebook posts); hence, a manual search using the aforementioned keywords was conducted for all 3 periods. That is, the specific keywords were typed in the search bar on Facebook, and the period (eg, precampaign period, campaign period, and postcampaign period) was specified in the search filter. Posts for each platform across the 3 periods were cataloged. The following types of posts were excluded: (1) pertaining to pain as a metaphor (ie, using “pain” as a metaphor for psychological distress, such as in the context of grief “I feel your pain”), (2) unrelated to the problem of pain in dementia, (3) shared by our own research group, and (4) not in the English language.

**Results**

**Engagement and Reach of the Initiative**

**Web Analytics**

Over 60,000 users from 82 countries viewed the web-based repository website, which resulted in 83,247 page views over the 12-month period (ie, October 1, 2020, to September 30, 2021). In examining the manner (ie, how people found the website) in which users were directed to the website, a majority of users (ie, 51,693 users) were directed to the website through links (ie, posts including a link to the website) from social media platforms. Other users directly typed the website link (ie, 6927 users) or searched the website link (ie, 2152). A small number of website users (ie, 116 users) were referred by other sites (ie, partnering organizations linking the web-based repository website on their web page). The blog web pages were viewed 59,919 times. Of the blogs posted during the project, the article written (on the request of our team) by an acclaimed author, Louise Penny, in which she relayed her experiences caring for her husband who lived with dementia [31], garnered most of the views (ie, received 33,226 views).

**Social Media Analytics**

The analytics are summarized in Table 1 based on the 3 sources of information and data periods described in the Methods section. The advertisements that were initiated on Facebook could also be posted on Instagram based on advertisement specifications. To maximize reach, the digital media team specified advertisements on Facebook and Instagram to be displayed on all available placements and to the specified targeted audiences. This includes Facebook and Instagram feeds (ie, advertisements displayed on the user’s feed), in-stream advertisements for videos, search results, and external apps and sites (ie, advertisements displayed to audiences on additional websites and mobile apps, such as newspaper websites). That is, advertisements initiated on Facebook could be displayed on Facebook, Instagram, or to external websites or apps connected to Facebook, resulting in increased impression and reach than organically derived engagement. The advertisements analytics (eg, impression and reach) on Facebook and Instagram differs from Twitter and LinkedIn as a function of the data source (ie, paid impression or reach on Facebook and Instagram are higher because they capture not just impression or reach derived on Facebook and Instagram but also on third-party websites such as newspaper websites; Table 1).
Table 1. Summary of the social media analytics for the #SeePainMoreClearly campaign.

<table>
<thead>
<tr>
<th>Period</th>
<th>Metric</th>
<th>Facebook, n</th>
<th>Twitter, n</th>
<th>Instagram, n</th>
<th>LinkedIn, n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Period 1</td>
<td>Impressions</td>
<td>4,100,000</td>
<td>724,200</td>
<td>4883</td>
<td>8538</td>
</tr>
<tr>
<td></td>
<td></td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Reach</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Instagram advertisement analytics</td>
<td>138,833</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Twitter/Instagram/LinkedIn only analytics</td>
<td>—</td>
<td>4420</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Facebook only analytics</td>
<td>1,313,485</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Engagement</td>
<td>282,704</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Cloud Campaign</td>
<td>—</td>
<td>977</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Period 2</td>
<td>Impressions</td>
<td>519,929</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Reach</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Engagement</td>
<td>630</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Period 3</td>
<td>Impressions</td>
<td>871,800</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Reach</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Engagement</td>
<td>2125</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
</tbody>
</table>

a Some analytics could not be obtained for specific platforms because they were not available. Moreover, the digital marketing team could only obtain data for specific periods (eg, year-long data could not be obtained) for some platforms owing to limitations in the sources of information. Nonetheless, efforts were made to capture the entire period.

b Period 1=October 1, 2020, to September 30, 2021.

c “Facebook overall analytics”=generated from paid and unpaid impressions on Facebook and third-party websites such as newspaper websites that are part of the Facebook advertising display network across Canada.

d Data for this period or metric were not applicable or not available.

e “Twitter/Instagram/LinkedIn only analytics”=analytics based on unpaid posts circulated only on Twitter, Instagram, or LinkedIn.

f On Instagram, the period 1 impressions only include impressions for unpaid posts posted on Instagram. It does not include paid posts that were posted on Facebook but reached Instagram audiences.

g “Twitter/LinkedIn advertisement analytics”=analytics based on paid posts circulated on Twitter and LinkedIn.

h “Instagram advertisement analytics”=the analytics are based on paid posts that were posted on Facebook but reached Instagram audiences based on specified target audiences.

i “Facebook only analytics”=based on paid and unpaid posts that were circulated only on Facebook.

j Cloud Campaign (ie, third-party social media monitoring software): these analytics are based on unpaid posts circulated individually on Twitter, LinkedIn, and Instagram. The Cloud Campaign analytics from Facebook includes analytics of paid and unpaid posts circulated only within Facebook.

k Period 2=October 1, 2020, to November 2, 2020.

For a graphical illustration of the analytics, refer to Multimedia Appendix 3. Social media analytics indicated that 1,313,485 people were reached by the content shared on the Facebook page created for this project (Table 1). The #SeePainMoreClearly hashtag on Twitter (eg, obtained by Keyhole) was used by 540 users, resulting in 2835 posts. Moreover, the hashtag reached 1,691,440 users and gained 8,592,929 impressions and 8696 engagements. The 4 animated videos developed during the initiative were viewed over 257,000 times across the web page and social media platforms. The views for each video were as follows: 106,055 (family), 102,407 (health care professionals), 42,731 (policy makers), and 5911 (researchers). The pilot campaign video was also disseminated during phase II of the campaign across social media platforms and received 45,637 views (ie, 43,870 views on Facebook, 1043 on Twitter, 709 views on YouTube, and 15 views on Instagram).

Knowledge Users’ Responses to the Initiative

Semistructured Interviews

Overview

A total of 13 knowledge users who interacted with the initiative’s posts participated in semistructured interviews. All participants provided informed consent. Participants had varied perspectives: 1 participant had lived experience of dementia, 4 participants had family members living with dementia and were health professionals, 4 participants were caregivers, and 4 were clinicians. A thematic analysis was conducted by 2 separate coders to establish an intercoder agreement. A randomly selected 20% (3/13) subset was coded by a second coder to assess for agreement. Overall agreement was excellent (k=0.81). Five themes emerged from the data: (1) increased awareness about the problem of pain in dementia, (2) perceived barriers to pain management, (3) increased knowledge and changes in behavior, (4) value of social media as a method of scientific dissemination, and (5) suggestions for improvement.

Increased Awareness About the Problem of Pain in Dementia

A majority of participants expressed positive views about the initiative, particularly about the manner in which the content was shared throughout the initiative and the resulting increased awareness about the problem of pain in dementia. One participant noted the importance of the information shared during the initiative:

Overall as a whole, I really liked it. I like the messaging that comes out of it, and I think it’s something really important to continue doing...I don’t think there’s a real understanding about pain and older adults. I like the messaging and I think it’s something that’s really important for us, as well as a society to promote.

Participants also expressed that the information shared during the initiative highlighted the experiences of older adults with dementia and pain. A person indicated that they thought the initiative was “great” because “the more information that can get out to caregivers, the better it will be for the residents [and] the people that have loved ones at home.” Furthermore, the initiative brought awareness to an underdiscussed problem of pain in dementia. For example, one participant stated:

Oh it’s good thing to put out here, something that people haven’t really thought about even the health care system and [pain in dementia] is a huge problem...so to bring it to the forefront is good, it needs to be brought to the forefront.

Overall, participant responses described a lack of prior understanding related to the experience of pain in dementia and the need for increased awareness about this topic.

Some individuals commented on the significance of the specific messages shared throughout the campaign in raising awareness about pain in dementia. For example, a participant noted the following:

I love what you’re doing. It’s a concern that everybody has, and why I call you a niche [because] it is a subject that people haven’t traditionally thought of.

Similarly, one participant expressed that the messaging on the videos were informational. This participant noted the following:

I guess one thing that stood out to me so much was the video of the man who seemed very angry. And so, I think back of all the people who’ve been labeled as the “angry person” could be the person in pain. And I think that message really hit me the most on pain.

Several participants expressed that the messaging shared during the initiative changed their perception about the problem of pain in people with dementia. A person commented on the videos:

You know one thing I did really like is the video with the gentleman that they thought was being kind of aggressive...I thought that video was really good but then on the other side [you] have the gentleman communicating how he is feeling. That was really good because that was really eye-opening.

Perceived Barriers to Pain Management

Knowledge users described various barriers that they have experienced in managing pain in their clinical practice or as a family member caring for a person living with dementia. The barriers encountered by knowledge users centered on inadequate pain assessments conducted in their practice or of their family member and relative living with dementia. For example, a health care professional reported the inadequate frequency of pain assessment in their facility:

You know, often in Ontario anyway, where I live, assessments in long-term care are done quarterly on clients and that’s, you know, that’ll be an all-encompassing assessment but certainly pain is part of that evaluation and, I mean, four times a year is not even close to being adequate to properly address and intervene if someone is living with pain.

In light of inadequate pain assessment practices, caregivers are often left to advocate for their family member or relative living...
with dementia. A caregiver in the study expressed the importance of families in advocating for assessment for their loved one:

I realized I don’t know if [my mother] might have tooth decay in her teeth [or if it] would be hurting her, and I don’t know how to figure that out. And I don’t think anyone else is checking. Yeah, because I think the lesson of my story here is that I am more likely to assess pain in my mom than her [care providers]

Participants described lack of continuing education and awareness as significant barriers to improving practices in LTC settings. For instance, a participant indicated the following:

I think there’s certainly a lack of understanding and education by many health care professionals who are working with older adults who live with dementia, so I think a barrier is getting that education, well, I mean, it’s an opportunity for people to have more education but a barrier is kind of reaching the people.

Participants also indicated that the lack of education of the public at large was a significant barrier to improving current practices:

I think the barrier is the lack of education, the lack of knowledge that people with dementia can have pain and express it in a different way. So, I think that the lack of education of health care workers, but the public in general.

Insufficient education about the topic means that health professionals or caregivers of persons with dementia may not be aware of the signs and symptoms that can indicate pain. A caregiver in the study reflected on this notion and shared their lack of knowledge about the signs of pain in her mother living with dementia:

I mean I can think back to my mother who had two strokes. And after the second one, she used to scream all the time. She used to scream. And she never spoke to anyone, but she screamed. And when I questioned the doctor, if could she be in pain, he was so sure that she was not. It doesn’t manifest that way. And so, I think back like, “was she in pain all the time?” When she screamed louder when we came, was it a plea for help. I think lot about that.

Increased Knowledge and Changes in Behavior

Participants described the positive impact of the information on their knowledge and behavior. Some participants noted that the information shared during the initiative influenced their awareness and advocacy in their personal life or in clinical practice. Health professionals indicated that they found gaps in their own practice as a result of viewing the content shared in this initiative. A participant said the following:

It made me more aware of the gap in pain assessment with people like my mom. And then it also made me more aware that the onus then is on me as a caregiver to do it, and I feel woefully inadequate, that fact that I encountered the research has made me realize that it’s me doing the diagnostic [work] and I have no medical skill at all.

Greater insight into their own behavior was also reported by the participants. A clinician noted the following:

It also made me more aware for myself in my own practice...so that’s changed my practice in that way. To be more cognizant that behaviors the patient is displaying could be manifested due to pain. So, I need to ask the caregivers and ask the family, “Has he or she changed in behaviors in any way recently?” “Have you noticed, you know, a consistent type of behavior? Is it a specific time of day, is it related to something?” So that I could look more into pain and assessing it in a roundabout way, rather than asking them straight, “Do you think that your husband or wife is in pain?”

Other participants indicated that the initiative largely impacted their perspective on this issue (eg, “I would say it’s definitely changed the viewpoint”). Finally, participants indicated that they shared the knowledge they obtained with others:

I share things that you guys put out there, if you look back at my timeline, you’ll see periodically I make reference to you guys.

Similarly, one participant noted the following:

I forward all this information off to my colleagues that work in this [area] that are even more focused in the nursing aspect that would have a more direct impact on client care needs.

Value of Social Media as a Tool for Scientific Dissemination

Participants underscored the importance of leveraging social media to share research information in the age of the internet. Participants expressed that sharing evidence-based information fosters trust and credibility among users seeking information on social media platforms. For example, one participant noted the following:

I think it has a lot of positive benefits. Where to start? After this past year right, social media and technology were probably utilized more than they ever have been. So, I actually think it’s a really great way to disseminate that information. And then further to that too, because I’ve been following all your accounts for a while, just there again, yeah, the quality of the content is also really good. So, with that being said, it creates that credibility and that trust. And then that also really feeds into where social media sometimes isn’t the most trusted source. So, I do think that it’s been a really great way to get that information out there.

Participants also acknowledged the salience of social media platforms that needs to be further leveraged for scientific dissemination (eg, “social media certainly in light of COVID, like it is the way that information gets disseminated right now so I think it’s very appropriate and it is a strength that you’re on various platforms sharing resources”). Other participants
expressed the importance of health initiatives in combating misinformation over the web:

**I think a lot of times there’s a lot of misinformation for people and families and health care practitioners and [they] want to have some valid research-based information for best practices and when you do things like this and have it more accessible then it’s easier for people to gain the right information and make the best decisions for their family members or their clients that they can.**

Other participants commented on the reach that social media platforms hold in raising awareness of issues in a short amount of time and connecting knowledge users across the world. One participant indicated the following:

**It’s brilliant, social media has always been very, very good at distributing information. Creating awareness. Highlighting anything in social media catches the eye of the person. Because people are looking for answers.**

In particular, one participant commented on the utility of Facebook targeting specific demographic groups:

**I think, using social media is great, you know, the thing about Facebook, is that it is now an older person’s social media and people often think that that young people are caregivers of people with dementia. But it’s not always so—it’s old people who are caring for people with dementia. Facebook is good because most of us use Facebook.**

### Suggestions for Improvement

Finally, participants made suggestions about scaling and improving the initiative. One participant said the following:

**I think it would be effective for you to reach out to the Alzheimer’s Society...I would love to see you partner with them in an active way on their media.**

One participant suggested focusing on reaching individuals who may not be directly reached by the initiative. For example, one participant noted individuals who may not be using or cannot access social media platforms:

**I think smaller communities don’t have the access or don’t know about it. I mean now we do have the Internet and that sort of thing which is fabulous but lots of time we don’t even know it’s out there.**

As another example, one participant stated the following:

**It’s the reachability...say like you know, even for me, it was from [someone else] that I found out about this, I have never seen it while using any of the social media account before. And like that largely depends on my browsing habits too right? But it’s the reachability that you guys have to concentrate on.**

Other participants suggested incorporating information to traditionally delivered pain education:

**And so, if there was a way, we could get this added into a pain curriculum, I think that would be excellent, because I never had it in my course, and I’ve learned from this.**

In clinical practice, one participant expressed the following:

**Well, I think, for so many people with dementia, their care is being provided by people with minimal education or I should say varying levels. If [people could get] a little certificate put into their little portfolios that would show, they have completed a course in pain assessment for people with dementia and that would somehow be an incentive for them as workers.**

### Social Media Comments

#### Overview

A total of 895 comments were included in the analysis. Most of the comments were retrieved from Facebook (eg, 822/895, 91.8%), followed by Twitter (eg, 68/895, 7.6%), and a small subset was comments by users on Instagram (eg, 5/895, 0.6%). A randomly selected 20% (179/895) subset was coded by a second coder to assess for agreement. The overall intercoder agreement was excellent (ie, k=0.80). Six themes emerged from the analysis: (1) positive comments in response to the initiative, (2) sharing their personal experiences in response to the content, (3) criticisms about and suggestions to improve pain management practices, (4) responses related to the COVID-19 pandemic, (5) negative comments in response to the content, and (6) advertisements.

#### Positive Comments in Response to the Initiative

Many users provided positive comments in response to the content. Facebook users expressed empathy in response to the content shared in the form of comments (eg, “I am praying for you” and “Amen”) and with the use of “emojis” (eg, praying emoji and red hearts). Other respondents commented on the importance of the initiative. For instance, a user on Facebook provided a comment noting the following:

**The work you are doing is so important to all.**

As another example, other users commended the initiative (eg, “such an important campaign #seepainmoreclearly”). Blog posts written by care partners in which they relayed their experiences as caregivers stimulated various positive discussions about the initiative. For example, a user commented “thanks for bravely sharing your experience with having a spouse with dementia, what a difficult journey, I enjoy [your books] so much!” in response to Louise Penny’s blog post shared on social media. As another example, a user expressed the following:

**Thank you for this information which is truly important. Your story is important to open our minds to an area of Alzheimer’s that many did not think of.**

#### Sharing Their Personal Experiences in Response to the Content

Other users responded to the initiative by sharing their personal experiences with the posted content. For example, one user stated the following:

**My family went through this when my dad was only in his early 50s...no one had heard of**
Alzheimer’s...this disease is so sad and robs the family of so much. I’m glad there’s more support for families now, and wish we’d had more support when we needed it.

Another user expressed their experience of caring for their mother:

I wonder this all the time. My mom is nearly 101 and has dementia. She rarely expressed having pain. But how can she not when she is quite hunched over and has arthritis.

Other individuals provided additional commentary on the shared information. A user emphasized the importance of pain assessment:

People with dementia, people unable to clearly explain [their] pain, we need to look for clues daily that would help us determine if something out of the norm is going on.

Criticisms About and Suggestions to Improve Pain Management Practices

Critical comments about current practices or advocating for improved practices were also present. For instance, a user expressed the following in response to a post:

There is a problem with doctors overlooking any kind of pain.

Another user pointed out the issue of resource limitations in LTC facilities (eg, “staffing is a huge issue which needs a timely resolution”). Moreover, a user indicated that “seniors deserve much more than the less of minimum care they get.” Other users provided suggestions to improve practices:

There are so many kinds of dementia, each with their own stages. We need more access to good education and support for home care to help families cope.

Another user stated the following:

Pain assessment only on admission and then every 3 months? Pain must be assessed whenever there is the slightest indication of pain. A formal assessment every 3 months should reflect how effective the measures were.

Responses Related to the COVID-19 Pandemic

As the campaign occurred during the COVID-19 pandemic and disseminated vaccination information related to residents in LTC, a subset of the comments was related to the pandemic. Some users noted the negative ramifications of isolation in LTC (eg, “I am sick of the lockdowns in care homes. Not being able to take them out for a day for visits...is absolutely insane. They are suffering terribly over this, and it has to stop.’’). Other comments denounced the significance of vaccines (eg, “the fake pandemic was created for the COVID vaccines”).

Negative Comments in Response to the Content

A subset of the comments expressed negative responses to the information shared. A few of these comments perpetuated stereotypes about older adults (eg, “people with dementia still feel pain?”) or dementia (eg, “reading this is enough to get dementia”). A user expressed disagreement with one of the information shared:

We assess residents for pain every time we see them. We are not stupid; we can tell when someone is in pain.

Do any of you work in LTC facility? Staff in dementia units are trained to look for any behavioral issues that may arise from pain.

Advertisements

Finally, a small subset of comments was from users advertising a product or information (eg, “Dementia and Alzheimer’s affects so many. Please don’t forget to check out my podcast, if you haven’t already” and “Can we help your loved one/care home/hospital/nursing home in UK with our free mp3s preloaded with the music of their own choice? Contact me asap please click on the link.”).

Responses to the Evaluation Questionnaires

The demographic characteristics of the knowledge users who responded to the questionnaires are presented in Multimedia Appendix 4. The majority of the survey respondents were caregivers of people living with dementia. Moreover, most respondents indicated that they had found the #SeePainMoreClearly campaign on Facebook and were living in Canada. Not all participants who responded to the survey completed all the questionnaires; therefore, the number of respondents is indicated in Tables 2 and 3. Table 2 outlines the respondents’ impression of the campaign. Across respondent groups, respondents endorsed a favorable impression of the campaign, a great likelihood of sharing information with others, and the use of social media for KM. Of note, the question regarding the new information provided by the content was rated lowest in each respondent group. Table 3 outlines the descriptive statistics based on the responses to the 6 general questions assessed by the IAM4all questionnaire. As noted in Table 3, responses indicated that most individuals (eg, 138/178, 77.5%) indicated the likelihood of using the information for themselves or someone else. Moreover, 77.1% (131/170) of the individuals expressed benefitting from the information shared during the initiative.
Table 2. Respondents’ impression of the campaign.

<table>
<thead>
<tr>
<th></th>
<th>Caregivers</th>
<th>Public</th>
<th>Health professional</th>
<th>Person living with dementia</th>
<th>Researcher</th>
<th>Policy maker</th>
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</thead>
<tbody>
<tr>
<td><strong>Overall impression of the campaign</strong></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Value, mean (SD)</td>
<td>4.67 (1.63)</td>
<td>4.33 (1.49)</td>
<td>5.16 (1.72)</td>
<td>4.18 (1.72)</td>
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<td></td>
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<tr>
<td>Value, n&lt;sup&gt;c&lt;/sup&gt;</td>
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<td>24</td>
<td>25</td>
<td>11</td>
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<tr>
<td><strong>Level of new information provided</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Value, mean (SD)</td>
<td>3.91 (1.83)</td>
<td>4.21 (1.74)</td>
<td>4.04 (2.09)</td>
<td>3.50 (2.07)</td>
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<td></td>
</tr>
<tr>
<td>Value, n&lt;sup&gt;c&lt;/sup&gt;</td>
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<td>24</td>
<td>25</td>
<td>10</td>
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<td><strong>Impact on information-seeking behavior</strong></td>
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</tr>
<tr>
<td>Value, mean (SD)</td>
<td>4.90 (1.89)</td>
<td>4.33 (1.76)</td>
<td>4.84 (1.82)</td>
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<td>25</td>
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<td></td>
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<tr>
<td><strong>Using social media for scientific dissemination</strong></td>
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</tr>
<tr>
<td>Value, mean (SD)</td>
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<td>5.00 (1.67)</td>
<td>5.44 (1.53)</td>
<td>5.00 (1.83)</td>
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<tr>
<td>Value, n&lt;sup&gt;c&lt;/sup&gt;</td>
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<td>25</td>
<td>25</td>
<td>10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup>Ratings are based on a 7-point scale, ranging from 1 (not at all) to 7 (very much): “Overall, how much did you like the image/clip/video?”

<sup>b</sup>Cell sizes <5 were not reported to protect the confidentiality of the participants.

<sup>c</sup>n=not all participants who responded to the survey completed all the questionnaires in the study; this number represents the number of participants who answered this question.

<sup>d</sup>“Did the video/image/clip provide you with new information?”

<sup>e</sup>“Are you likely to seek additional information about pain in dementia (and its assessment) as a result of watching this video/viewing this content?”

<sup>f</sup>“It takes an average of 17 years until professionals start to use important research results into their practice Do you think social media (e.g., Twitter) is a good way to spread important health information to caregivers of people with dementia/to people with dementia?”
Table 3. Survey responses to the IAM4all\(^a\) questionnaire (N=190).

<table>
<thead>
<tr>
<th>Question</th>
<th>Respondents, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Why did you look for this information?(^a,b)&quot;</td>
<td></td>
</tr>
<tr>
<td>To answer a question about the health of someone else (total number of respondents=190)</td>
<td>116 (61.1)</td>
</tr>
<tr>
<td>To satisfy my curiosity about a health matter (total number of respondents=172)</td>
<td>108 (62.8)</td>
</tr>
<tr>
<td>To find choices different from those given by a health professional (total number of respondents=172)</td>
<td>61 (35.5)</td>
</tr>
<tr>
<td>To follow-up on the information given by a health professional (total number of respondents=168)</td>
<td>52 (31)</td>
</tr>
<tr>
<td>To prepare myself before talking to a health professional (total number of respondents=168)</td>
<td>50 (29.8)</td>
</tr>
<tr>
<td>To help me decide if I should see a health professional (total number of respondents=169)</td>
<td>40 (23.7)</td>
</tr>
<tr>
<td>To answer a question about my health (total number of respondents=177)</td>
<td>30 (17)</td>
</tr>
<tr>
<td>&quot;Did you find the information you were looking for?&quot; (total number of respondents=181)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>73 (40.3)</td>
</tr>
<tr>
<td>Yes, but I did not understand it</td>
<td>15 (8.3)</td>
</tr>
<tr>
<td>No, I did not find it</td>
<td>72 (39.8)</td>
</tr>
<tr>
<td>No, but I found something else</td>
<td>21 (11.6)</td>
</tr>
<tr>
<td>&quot;What did you think about this information?(^a,b)&quot;</td>
<td></td>
</tr>
<tr>
<td>Now I want to learn more about this health matter (total number of respondents=161)</td>
<td>112 (69.6)</td>
</tr>
<tr>
<td>Now I know something new (total number of respondents=163)</td>
<td>79 (48.5)</td>
</tr>
<tr>
<td>I am reminded of something I already knew (total number of respondents=157)</td>
<td>76 (48.4)</td>
</tr>
<tr>
<td>This information says I did, or I am doing the right thing (total number of respondents=158)</td>
<td>66 (41.8)</td>
</tr>
<tr>
<td>Now I am reassured (total number of respondents=158)</td>
<td>66 (41.8)</td>
</tr>
<tr>
<td>I am not satisfied with this information (total number of respondents=153)</td>
<td>33 (21.6)</td>
</tr>
<tr>
<td>I think there is a problem with this information (total number of respondents=151)</td>
<td>14 (9.3)</td>
</tr>
<tr>
<td>I think this information could be harmful (total number of respondents=148)</td>
<td>2 (1.4)</td>
</tr>
<tr>
<td>&quot;Did you or will you use the information for yourself?&quot; (total number of respondents=178)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>55 (30.9)</td>
</tr>
<tr>
<td>No, not for myself, but I used it for someone else</td>
<td>83 (46.6)</td>
</tr>
<tr>
<td>No, I did not use this information for myself or for someone else</td>
<td>40 (22.5)</td>
</tr>
<tr>
<td>&quot;Did you (do you expect to) benefit from this information?&quot; (total number of respondents=170)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>131 (77.1)</td>
</tr>
<tr>
<td>No</td>
<td>39 (22.9)</td>
</tr>
<tr>
<td>Did something negative come out from using this information? (total number of respondents=148)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>4 (2.7)</td>
</tr>
<tr>
<td>No</td>
<td>144 (97.3)</td>
</tr>
</tbody>
</table>

\(^a\)IAM4all: Information Assessment Method for all.

\(^b\)Refers to participants who answered “Yes” with possible choices of yes, no, or possibly.

Comparison of Web-Based Discussions About Pain in Dementia

The extent of discussions about pain in dementia was assessed by examining the total number of posts on Twitter and Facebook. After excluding posts pertaining to pain as a metaphor, unrelated to the problem of pain in dementia, shared by our own research group, and not in the English language, the number of tweets that were retained doubled from the precampaign period compared with during the campaign period (see Multimedia Appendix 5). A similar increase was also observed on Facebook. The number of discussions about pain in dementia decreased in the postcampaign period compared with during the campaign period (see Multimedia Appendix 5). The number of excluded posts in each period is summarized in Multimedia Appendix 6.
Discussion

Principal Findings

Social media allows the immediate dissemination of information to a large number of knowledge users. Although our relatively short pilot KM campaign (phase I) was successful, its longer-term continuation by researchers alone was not feasible owing to competing demands. As such, we partnered with a digital media company to launch phase II of the #SeePainMoreClearly campaign with expanded social media platform coverage. The goal of the initiative was to increase awareness of the challenges in the assessment and management of pain among people with dementia. We codeveloped key messages with partners (eg, health professionals, caregivers, and researchers) that served as the basis of our messaging.

Our findings demonstrated the effectiveness of social media KM methods in reaching very broad audiences over a 12-month period. Evidence of positive impact on knowledge users’ knowledge was demonstrated. The participants described positive perceptions in response to the information shared throughout the initiative. Survey respondents (eg, caregivers, health professionals, researchers, the public, and people with dementia) endorsed a favorable impression of the campaign. Overall, our initiative highlighted the advantages of using a science-media partnership (eg, collaboration with digital media experts, resources to develop tailored content and resources, and consistent dissemination of information). However, broad social campaigns require extensive resources and time commitments. We outline the recommendations to address these areas.

The current (phase II) initiative involving a science-media partnership was different in several regards from our pilot campaign that focused only on Twitter and a YouTube video. In comparison with the pilot campaign [9], visits to our web-based repository substantially increased in phase II, even when considering the difference in the lengths of the 2 campaigns. Phase II used extended evaluation metrics through the inclusion of interviews, in addition to social media analytics, questionnaires, and the analysis of social media responses over a 12-month period. Hashtag analytics on Twitter across the 2 phases were comparable, despite differences in the length of evaluation (eg, 5 months vs 12 months). We observed lower outside organization engagement during phase II of our initiative, which could have contributed to lower phase II engagement when accounting for the length of evaluation. Moreover, our social media presence was greater in phase II compared with our pilot campaign.

Overall, our findings demonstrated the effectiveness of social media KM methods in reaching very broad audiences quickly. In this study, we demonstrated success in directing knowledge users to a resource website with practical information for health professionals, caregivers, and people living with dementia. For instance, over 60,000 users from 82 countries viewed the web-based repository website over the 12-month period. In particular, the blog posts shared during the project attracted many readers. The blog web pages were viewed 59,919 times, providing evidence for their reach. This is comparable with other KM efforts showing the use of blogs as an engaging way of connecting to targeted users [32].

The reach and engagement of users on social media platforms also provided evidence for the success of the initiative in raising awareness about the problem of pain in dementia. Information shared on Facebook was successful at reaching a wide range of audience, with 1,313,485 people reached by the content shared on the Facebook page. However, it should be noted that some analytics (eg, reach and engagement) could not be obtained from social media sites (eg, LinkedIn) because these analytics were not provided by the platform. This limits our ability to deduce the full extent of engagement on these platforms. Nonetheless, the number of impressions on Facebook was the highest (eg, 4,100,000) compared with Twitter, Instagram, and LinkedIn. This is consistent with previous research showing extensive reach and engagement on Facebook compared with other platforms [6,33]. In contrast, Neil-Sztramko et al [34] conducted an awareness campaign targeted toward working caregivers and found that although Facebook posts generated the most reach, the quality of the engagement was low. The topic area, targeted audience, and length of evaluation could explain the differences between our findings and those of previous research. We observed the lowest reach and engagement on Instagram and LinkedIn. This is not surprising given that our primary audience comprised caregivers of people with dementia who tend to be older [35,36]. Older adults have shown a preference for Facebook in comparison with other social platforms [37]. Taken together, our findings suggest that Facebook may be the most suitable platform for disseminating information related to pain in dementia.

Our findings extend our pilot evaluation by including in-depth interviews with knowledge users who interacted with the campaign in addition to the analysis of social media analytics and evaluation questionnaires. Many interview participants indicated positive perceptions in response to the information shared throughout the initiative. Moreover, the participants expressed that the significance of the initiative was in bringing awareness to an underdiscussed problem. The interview participants acknowledged the utility of social media as a tool for scientific dissemination. Many participants noted the importance of leveraging social media to share research information. Other participants expressed the importance of health initiatives in combating misinformation over the web. Quantitative responses to the surveys also supported this view. Survey respondents endorsed the use of social media as a way of spreading important health information to caregivers of people with dementia and to people with dementia. We found evidence of the information and resources impacting caregivers of people with dementia for their reach during the initiative.
The initiative stimulated web-based discussions about pain in dementia. Consistent with themes that emerged from social media responses on Twitter during the pilot campaign [9], many web users expressed positive comments in response to the initiative. In particular, expressions of support were prevalent in both the pilot and phase II of our campaign. Many web users who responded to the content disseminated during the campaign shared their personal experiences or added commentary to the posted content. In addition to sentiments of advocacy for better care, which was observed in our pilot campaign, social media comments in response to phase II of our campaign also highlighted criticism and suggestions to improve practices related to pain management in dementia. Users highlighted the need for access to continuing education and support for staff and families to increase the frequency of pain assessment in LTC. This demonstrated meaningful engagement by users in response to posts. Increased discussions also highlighted negative responses about the information shared (eg, perpetuating stereotypes about older adults and dementia), which was not observed in the pilot campaign. Differences in themes that emerged between the pilot and phase II could be due to the broader reach of phase II (eg, inclusion of Facebook), as the pilot campaign only examined responses using the #SeePainMoreClearly hashtag on Twitter. We also found increased discussion about pain in dementia during the initiative on Twitter and Facebook in comparison with before and after the initiative. However, this discussion was not sustained months following the end of the campaign. This highlights the importance of continuous and meaningful engagement to maintain gains made by an initiative. Given our methodology, we collected a substantially lower number of posts on Facebook in comparison with Twitter. This discrepancy is likely owing to the manual search that was conducted to obtain Facebook posts in comparison with the data that were easily pulled by Keyhole for Twitter posts. Depending on a user’s privacy settings, posts shared on personal or private accounts are excluded when conducting a general search on Facebook.

Limitations and Directions for Future Research

A particular strength of this study is that the content shared during the initiative was developed collaboratively with family caregiver partners, researchers, media experts, and health care professionals. Various measures were also used to assess not only the web-based reach of the initiative but also the perceptions of knowledge users. Nonetheless, we acknowledge that the use of social media for KM research represents a new area that does not lend itself to strict scientific control in the evaluation of its effectiveness. We adapted a more nuanced approach in developing partnerships and using multimodal approaches to show the impact in different ways. Although we aimed to assess the impact on users’ knowledge and behavior, we did not directly evaluate behavior change. Future research should examine the associated behavior outcomes (eg, increased pain assessment) in addition to the spread of information (eg, analytics). It is also difficult to measure the impact of the initiative at an organizational or policy level. This could be an important avenue for future research. Individuals in our interview and surveys expressed their intention to use the information; however, the adoption and use of information was not obtained. Perhaps, a follow-up assessment of how or whether knowledge users applied learned information could be investigated. Moreover, the effectiveness of social and web modalities in creating meaningful changes in knowledge and behavior is subject to further examination. Notably, the landscape of social media is constantly changing, and researchers will need to adapt to these changes if they want to leverage this modality. For example, social media can be used to spread health misinformation [38]. Using social media for KM health efforts can also be used to combat false and unscientific web-based information. As such, ensuring the quality of scientific evidence disseminated on the web should be considered in the development of social media-based dissemination efforts. Although these findings may not be generalizable to other KM initiatives, our investigation adds to the growing body of knowledge leveraging social media as a KM tool.

**Recommendations**

Our study highlighted the successes and challenges of social media KM initiatives. When comparing the pilot with the scaled initiative (phase II), there appears to be no considerable difference with regard to views, impressions, or reach when accounting for the length of time of each initiative (5 months vs 12 months). Although this scaled initiative demonstrated success in garnering a large reach across social media platforms, broad initiatives such as phase II of our campaign require extensive resources and time commitment, which may not be feasible for researchers in the long term. The following recommendations are proposed to assist researchers and partners who may be interested in developing and maintaining a web-based KM initiative:

1. Researchers could collaborate with established communication and marketing departments at their institution or other digital media partners to aid in digital and social media outreach of research information and internal and external advertising. Granting agencies may be able to allocate funds for such purposes.

2. Facebook and Twitter appear to be the most relevant platforms for KM for the topic of pain and dementia. However, researchers from other disciplines may find other platforms more helpful in reaching their target audience. For example, if a researcher’s area of research is adolescent mental health, Instagram or TikTok and the use of stories may increase engagement among knowledge users. Although we found success in using multiple social media platforms, it may be more sustainable to pool resources on 1 or 2 of the most used platforms based on the target audience.

3. Investments in targeted and paid advertisements can be an effective mechanism to increase the exposure and engagement of campaign posts at a low cost per engagement [39,40].

4. Our initiative highlighted the importance of codeveloping the initiative with partners of our intended target groups. Many of our partners developed blog posts about their lived experience, which generated the most engagement. As such, personalized blog posts and opportunities for knowledge users to share their experiences (ie, turning comments on)
can be an easy and cost-effective way to stimulate discussions.

5. The success of our pilot initiative was largely influenced by partnering with professional organizations that helped disseminate information and resources to their audiences. Engagement from external organizations was lower during phase II of our initiative, potentially contributing to the overall decrease in engagement. We observed that external organizations were more inclined to retweet our content when it originated from our individual researcher accounts rather than from a generic SeePainMoreClearly social media account. Researchers should collaborate with organizations within their specific area of interest who can support in meaningfully engaging with their targeted audiences. Connecting with trusted messengers (eg, influencers, people with lived experience, and large followings) could help to penetrate targeted groups.

Conclusions
We partnered with a digital media partner to launch phase II of the #SeePainMoreClearly campaign with expanded social media platform coverage. The goal of the initiative was to increase awareness of and provide resources related to the challenges in the assessment and management of pain among people with dementia. Although this scaled initiative demonstrated success in garnering large reach across social media platforms, broad initiatives such as phase II of our campaign (reported in this manuscript) require extensive resources and time commitments, which may not be feasible for researchers in the long term. Researchers should leverage collaborations with their institutions to aid in the digital media outreach of research information. Furthermore, granting agencies should consider allocating more funds for such KM purposes. Our initiative highlighted the importance of codeveloping KM efforts with the partners of our intended target groups and working with professional organizations to disseminate information to our target audience. Collaborations with people with lived experiences and professional organizations will be key to the success of any future KM effort. Our study adds to the growing body of knowledge that leverages social media as a KM tool.

Acknowledgments
This study was supported by funding from the Saskatchewan Centre for Patient-Oriented Research (#345325) and the Saskatchewan Health Research Foundation (#23629).

Authors' Contributions
TH wrote the grant application that supported this research; played a key role in project conceptualization, knowledge mobilization (KM) messaging, analytic direction, and manuscript writing; and oversaw all aspects of this study. LIRC prepared the first draft of this manuscript and played a key role in project conceptualization, data collection, data analysis, and KM messaging. MB, a partner with lived experience as a caregiver, played a key role in KM messaging; provided input in the manuscript; and contributed to team discussions. VT contributed to data analysis. CTC was a consultant on research design and development, provided detailed feedback on the manuscript, and participated in team discussions about project progress and development. SW, a digital media partner, oversaw the collection of web analytics and digital dissemination. All authors participated in team discussions that directed this work, provided input on multiple aspects of the project (eg, social media dissemination strategy) and messaging content, and reviewed and approved the manuscript.

Conflicts of Interest
None declared.

Multimedia Appendix 1
Key points (cross-cutting messages).
[DOCX File, 21 KB - aging_v7i1e53025_app1.docx]

Multimedia Appendix 2
Interview moderator guide.
[DOCX File, 15 KB - aging_v7i1e53025_app2.docx]

Multimedia Appendix 3
Summary of the social media analytics for the #SeePainMoreClearly campaign.
[DOCX File, 28 KB - aging_v7i1e53025_app3.docx]

Multimedia Appendix 4
Demographic characteristics of the survey respondents.
[DOCX File, 15 KB - aging_v7i1e53025_app4.docx]
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Abbreviations

IAM4all: Information Assessment Method for all
KM: knowledge mobilization
LTC: long-term care
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Original Paper

Barriers to and Facilitators of Older People’s Engagement With Web-Based Services: Qualitative Study of Adults Aged >75 Years

Annemarie Money1,2, BA, MSc, PhD; Alex Hall1, BA, Grad Dip, MSc, PhD; Danielle Harris1,2, BSc, MSc; Charlotte Eost-Telling1,2, BSc, MSc, PhD; Jane McDermott1, BA, MA; Chris Todd1,2,3,4, BA, MA, PhD

1School of Health Sciences, University of Manchester, Manchester, United Kingdom
2National Institute for Health and Care Research, Applied Research Collaboration Greater Manchester, Division of Nursing Midwifery and Social Work, Faculty of Biology, Medicine and Health, Manchester, United Kingdom
3Manchester Institute for Collaborative Research on Ageing, The University of Manchester, Manchester, United Kingdom
4Manchester University NHS Foundation Trust, Manchester, United Kingdom

Corresponding Author:
Annemarie Money, BA, MSc, PhD
School of Health Sciences
University of Manchester
5th Floor, Jean McFarlane Building
Manchester, M13 9PL
United Kingdom
Phone: 44 0161 306 7777
Email: annemarie.money@manchester.ac.uk

Abstract

Background: The COVID-19 pandemic has accelerated the shift toward the digital provision of many public services, including health and social care, public administration, and financial and leisure services. COVID-19 services including test appointments, results, vaccination appointments and more were primarily delivered through digital channels to the public. Many social, cultural, and economic activities (appointments, ticket bookings, tax and utility payments, shopping, etc) have transitioned to web-based platforms. To use web-based public services, individuals must be digitally included. This is influenced by 3 main factors: access (whether individuals have access to the internet), ability (having the requisite skills and confidence to participate over the web), and affordability (ability to pay for infrastructure [equipment] and data packages). Many older adults, especially those aged >75 years, are still digitally excluded.

Objective: This study aims to explore the views of adults aged >75 years on accessing public services digitally.

Methods: We conducted semistructured qualitative interviews with a variety of adults aged ≥75 years residing in Greater Manchester, United Kingdom. We also interviewed community support workers. Thematic analysis was used to identify the key themes from the data.

Results: Overall, 24 older adults (mean age 81, SD 4.54 y; 14/24, 58% female; 23/24, 96% White British; and 18/24, 75% digitally engaged to some extent) and 2 support workers participated. A total of five themes were identified as key in understanding issues around motivation, engagement, and participation: (1) “initial motivation to participate digitally”—for example, maintaining social connections and gaining skills to be able to connect with family and friends; (2) “narrow use and restricted activity on the web”—undertaking limited tasks on the web and in a modified manner, for example, limited use of web-based public services and selected use of specific services, such as checking but never transferring funds during web-based banking; (3) “impact of digital participation on well-being”—choosing to go to the shops or general practitioner’s surgery to get out of the house and get some exercise; (4) “the last generation?”—respondents feeling that there were generational barriers to adapting to new technology and change; and (5) “making digital accessible”—understanding the support needed to keep those engaged on the web.

Conclusions: As we transition toward greater digitalization of public services, it is crucial to incorporate the perspectives of older people. Failing to do so risks excluding them from accessing services they greatly rely on and need.

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KEYWORDS
digital exclusion; digital inclusion; older people; technology; aged; web-based; internet
Introduction

Background

The shift toward digital technologies to provide access to essential and nonessential public services, such as health care, public administrative services, utilities, financial services, and leisure, has been accelerated by the COVID-19 pandemic [1-3]. In many countries, including the United Kingdom (the setting for the research reported in this paper), this shift has also been driven by national policy in attempts to maintain access to essential services during periods of social lockdown [4-6]. Many social, cultural, and economic activities, such as appointment or ticket booking, have transitioned to web-based platforms [7], whereas many COVID-19-related initiatives, such as booking and recording COVID-19 tests and vaccinations, were primarily offered through digital platforms to the public. In particular, during the COVID-19 lockdown periods, being on the web became critical for maintaining social ties and combating loneliness [8-10].

This may be convenient for many people, and there is evidence to show that digital inclusion, accelerated by the pandemic, has increased in recent years [11]. However, although in the United Kingdom, the “digital divide” (the gap between those who do and those who do not have access to new forms of information technology [12]) may have narrowed in recent years, the impact has not been felt equally and has widened for some groups [13,14]. The digital divide remains especially wide for older adults aged ≥75 years; this is further exacerbated by living alone, having a limiting long-term condition, and being financially susceptible [15,16]. An analysis of the English Longitudinal Study of Ageing data conducted early in the pandemic (June and July 2020) showed that 45% of adults aged 52 to 64 years and 41% of adults aged 65 to 74 years used the internet more since the COVID-19 outbreak, but only 24% of those aged >75 increased their use and 9% were using it less [17].

Digital exclusion, in its broadest definition [15], relates to three connected aspects: (1) access, that is, whether individuals have access to the internet at home or elsewhere; (2) ability, that is, having the skills and confidence to participate over the web; and (3) affordability, that is, the ability to pay for infrastructure (equipment) and adequate data packages [16]. In the United Kingdom, recent data from the national communications regulator (Ofcom) suggests that 6% of UK households do not have home internet access, but this figure rises to 26% of people aged ≥75 years [18]. It is also acknowledged that an additional 2 million households are experiencing financial difficulty, and this will likely increase given the cost-of-living crisis from 2021 to 2023 [19,20]. Digital exclusion is viewed as a “super” social determinant of health [21] as it impacts a variety of areas of life, including leading to poorer health outcomes [22,23] and challenges with employment, housing, education, and finance. It disproportionately affects many people, including people with low incomes, people living in social housing, people living with disabilities, people in rural areas, and people for whom English is not their first language, as well as other marginalized groups. Although all these factors are important indicators of who is likely to be digitally excluded, age remains the biggest indicator.

According to data from the UK Office for National Statistics for 2020, a total of 99% of adults aged 16 to 44 years were recent internet users compared with only 54% of adults aged ≥75 years [24]. It is vital to understand the complexities of how digital exclusion exacerbates health and social inequalities so that adequate responsive action can be considered. For example, it is not simply the case that ensuring internet connectivity will mitigate digital exclusion. There is a need to understand structural challenges; financial barriers; digital literacy; and other aspects, such as the impacts of various health conditions and disabilities and concerns about privacy and data protection [25-28].

A recent scoping review explored the barriers to and facilitators of older people’s digital engagement across the spectrum of nonuse through sustained use [29]. This review found that there are substantial overlaps between barriers and facilitators; for example, lack of knowledge of digital technologies is a barrier, prior knowledge is a facilitator, perceived lack of personal capability is a barrier, and a positive attitude toward oneself is a facilitator. The review also found a substantial gap regarding the determinants of technological nonuse. Although this review provides a thorough scope of the literature, it included studies involving participants with a mean age of ≥65 years and did not offer any further stratification by age. There is a need for a more nuanced focus on older groups of older people. Current insights into digital technology use often exclude a specific focus on people aged ≥75 years. The coverage of age groups in several major reports and surveys often stops at the age of 74 years or includes all people aged ≥65 years as 1 homogeneous age category [30].

Objectives

Given the increased risk of digital exclusion among older age groups and the fact that this may have been exacerbated by the COVID-19 pandemic, it is vital to gain a deeper understanding of the use, attitudes, and preferences of people aged ≥75 years.

In the United Kingdom, this gap has been recognized as a policy priority. In Greater Manchester, a city-region in North West England with a population of 2.867.800 in 2021, as many as 1.2 million residents are estimated to be limited digital users because of exclusion or personal preferences, with a substantial proportion of these being people in later life. To address this digital divide, the Greater Manchester Combined Authority (GMCA) established a Digital Inclusion Action Network and Taskforce in October 2020 [31], with the ambition to make Greater Manchester a 100% digitally enabled UK city-region. Older adults aged ≥75 years were included as a critical population group for targeted action related to digital inclusion. The aim of the paper is to report findings from a qualitative study exploring the views of adults aged ≥75 years on accessing web-based public services.

Methods

Study Design

The National Institute for Health and Care Research Applied Research Collaboration Greater Manchester was commissioned by the GMCA to gather insight into the barriers to and
facilitators of older adults’ (>75 y) digital participation within the region. To address this, we conducted semistructured qualitative interviews with adults aged ≥75 years residing in Greater Manchester.

**Sampling, Recruitment, and Data Collection**

Purposive and convenience sampling were used to identify and recruit participants. Adapting to web-based rather than face-to-face data collection during the COVID-19 pandemic lockdown meant that we had to use an approach that allowed us to use our existing networks and recruit via several third-party organizations affiliated with the GMCA Ageing Hub. We recruited a range of older adults; these included older adults who were fully engaged and participating in many web-based activities (often enrolled in a local support program), those who were just starting to receive support to get on the web, those who were previously engaged but were now lapsed users, and those who had no interest in getting on the web or using a computer or device at all. We also recruited community support workers to learn from the approaches they used to continue to engage with their communities, particularly during the COVID-19 pandemic period (2020 to 2022) [32].

Data were collected via semistructured interviews (conducted by AM) with a topic guide (Multimedia Appendix 1) developed from a rapid review of the literature [33] and from input from the project oversight team.

**Data Analysis**

Interviews were audio recorded, transcribed, and exported to NVivo Pro (version 12) software for data management [34]. Using a thematic analysis approach [35], initial themes were identified from the transcripts and indexed to develop the analytical categories. Via a process of constant comparison [36], these categories were reviewed and refined by 2 researchers (AM and DH), and any ambiguities in the coding framework were reconciled by a thorough discussion with the research team. All interviews were then fully coded using NVivo Pro for qualitative analysis (AM and DH).

**Ethical Considerations**

Ethics approval was granted by the University of Manchester Proportionate Research Ethics Committee (2021-12638-20811). All interviews were conducted virtually (by telephone or other remote means agreed upon with the participants) at a time convenient to the participants; the participants provided informed consent before data collection. The data were collected between October 2021 and February 2022. All data provided was anonymised by the research team with any personal identifying information removed. All participants received a £15 ‘Love2Shop’ voucher as a thank you for their participation in the interview.

**Results**

**Overview**

The final sample comprised 26 interviews: 92% (24/26) with older adults aged >75 years and 8% (2/26) with community digital support officers. The older adult sample had a mean age of 81 (SD 4.54; range 75-91) years; 58% (14/24) of the participants were female, 96% (23/24) were White, and 4% (1/24) were of South Asian background. Participants were sampled from 4 (40%) of the 10 local authority areas in Greater Manchester, 75% (18/24) of the participants were users of the internet (to some degree), and interviews lasted on average 23 (SD 8.51; range 8-60) minutes.

A total of 5 themes were identified as being key in understanding the barriers to and facilitators of motivation, engagement, and participation in using web-based public services. The key themes and subthemes are presented in Textbox 1 and discussed in detail in the subsequent sections.

**Textbox 1. Key themes and subthemes identified via thematic analysis.**

- **Theme 1: initial motivation to participate digitally**
- **Theme 2: narrow use and restricted activity on the web**
  - Preference for choice of access
  - Narrow use driven by fear
  - Lack of interest in learning new digital skills and tasks
- **Theme 3: impact of digital participation on well-being**
- **Theme 4: the “last generation”?**
- **Theme 5: making digital accessible**
  - One-to-one support
  - Mitigating physical impairments

**Theme 1: Initial Motivation to Participate Digitally**

Among older adults who were using the internet, it was evident that their decision to do so was often driven by a particular, recent need that motivated them to go on the web. Unsurprisingly, given that COVID-19 pandemic lockdowns reduced face-to-face social contact [32], one of the major motivators related to maintaining social connections and gaining skills to be able to connect with family and friends in other parts of the world. A participant stated the following:
Another participant said the following:

"A participant stated the following: the web, with some noting that if they did not do it over the web, it would involve them going to the surgery, "which is a bus ride away." However, when asked about the prospect of ordering prescriptions and shopping. A participant said the following:

That’s the most brilliant thing I’ve ever used, Amazon. You don’t even have to go outside the door."

[Participant 13, female, aged 75 years]

Theme 2: Narrow Use and Restricted Activity on the Web

Preference for Choice of Access

Although three-quarters (18/24, 75%) of the older adults interviewed were digitally engaged (to some extent), many of them were “narrow” users [11,15], in that they participated only in a handful of web-based activities or tasks. The participants reported very little interaction with web-based public administrative services (eg, local and national government services such as disabled parking applications, passport applications, driving licenses, and benefit applications). The participants were more positive about some aspects of web-based health services, particularly ordering prescriptions. When asked why they preferred to order prescriptions over the web, some commented that the system is “straightforward to use” and that they “find it very useful” to be able to order over the web, with some noting that if they did not do it over the web, it would involve them going to the surgery, “which is a bus ride away.” However, when asked about the prospect of more public services moving to web-based access, most participants—both those who used the internet and those who did not—were in consensus that digital should not be the only option provided by organizations to access a service, for a variety of reasons. A participant stated the following:

The jabs that I had, it was telling me to go online, that’s an example, and I phoned up my doctor’s surgery and said, look, I can’t go online, right, so they did the appointment for me. And also I had a bit of an argument with [large retail pharmacist named] and other stores like [pharmacy chain] because the flow thing, you know the flow thing, [Lateral Flow Test—rapid antigen test for COVID-19] you’ve got to go online although you didn’t get any because they were sold out, they were out of them all the time...it’s just ridiculous, nobody thinks about the older people."

[Participant 14, male, aged 83 years]

Another participant said the following:

Personally I don’t think you can beat seeing the doctor face to face, they can pick up on your body language, colour of your skin. I think there’s lots of things that you can pick up on face to face. So, I do think seeing the doctor face to face is essential for the majority, I really do. I think going online for some things is good, but I do think if you’re not very sure about what you’re doing, I think...I would imagine it could cause a lot of stress, if there’s no alternative..."

[Participant 24, female, aged 76 years]

Narrow Use Driven by Fear

Many participants adopted a granular approach to use, in which they had specific and limited web-based tasks they would undertake within particular domains of activity, such as banking or shopping. For example, many were happy to log on to banking apps or websites and view their balance—that is, to monitor their account—but stopped short of undertaking any transactions. Reasons for this limited use included a concern about having personal details “out there,” pressing the wrong button and sending the money to the wrong place, and a fear of being scammed. A participant stated the following:

...No, I won’t do finance at all, PayPal or anything. I really don’t trust it because there are so many scams around, erm, I just think it’s too easy, if you press the wrong button and its gone to Timbuktu, no I definitely won’t have anything to do with online banking, and it’s a shame because I know that I would shop online and it would save a trip to the Post Office or the bank or whatever, but I just wouldn’t trust it..."

[Participant 7, female, aged 79 years]

Another participant stated the following:

...I know I’ve got the banking online on the tablet if I want to use it for transactions, but I’m just quite happy seeing what I’ve got at the moment. I don’t really feel confident enough to do transactions. I always worry, God if I do something wrong, I’m in trouble."

[Participant 24, female, aged 76 years]

In addition, another participant said the following:

I just feel as though I don’t want to be divulging too much information about myself to the wide world, if you know what I mean."

[Participant 11, female, aged 87 years]

Community digital support officers highlighted fear and concerns around the safe sharing of personal information as a key barrier to engagement among older adults. In particular, media reports highlighting scams and frauds were deemed to exacerbate this barrier. The community officers were aware of the need to inform people of the potential risks, but “more positive campaigns about [the benefits of] using the internet [for older people] are needed” (digital support officer 2), as the negative stories reported on television were seen to deter older adults from benefiting from available web-based services. They reported that the word “scam” really “puts fear into older persons” and the media “cherry pick” the very worst scams to the point that people are convinced that these are happening on their very doorsteps:

...And this is no joke, I have had people say to me that they think there are people outside their house on a laptop in their car, you know they are parked on the..."
street trying to use their Wi fi to scam them. That sort of thing. [Digital support officer 1]

**Lack of Interest in Learning New Digital Skills and Tasks**

Where participants did use web-based services, once their initial needs had been met and they had gained the necessary skills to complete an activity, many lacked interest or were reluctant to undertake additional tasks or learn new activities. They were happy to maintain the skills and knowledge gained to undertake the tasks or activities that initially prompted them to get on the web. A participant stated the following:

I wouldn’t use it for much really. I’m not ambitious about it. I have done what I wanted to do and anything else that I gained, it’s a bonus. [Participant 10, female, aged 91 years]

Another participant stated the following:

Are there any tasks that you haven’t yet done online that you think you might want to try or you want to do in the future? [Interviewer]

No, because I can use the computer and I can use the phone and the tablet for anything that I personally need to do. [Participant 20, male, aged 76 years]

In addition, another participant said the following:

And are there things that you would want to do, that maybe you don’t yet know how to do, or you’d need some support to be shown how to do it? [Interviewer]

I don’t think so. I think I do what I need to do… [Participant 13, female, aged 75 years]

**Theme 3: Impact of Digital Participation on Well-Being**

For some participants, who were not digitally engaged and had no interest in getting on the web, social connections and social interaction were cited as a reason for not engaging. One participant stated the following:

No, I just think I’ve never been interested. I feel that if I did use something I’d be on my own doing it, and I don’t like being on my own. Years ago I had one of these knitting machines and I had it for a while, and I hated it because it meant I was sat on my own knitting, and I don’t want to do that. I like to go out and meet people while I can. [Participant 3, female, aged 90 years]

Another participant stated the following:

This is the problem, lots of people don’t talk anymore. They know…they don’t know any other way of corresponding, getting in touch with people. I mean they go on the internet. They text, they don’t talk…I mean you go out for a walk and you can more or less guarantee at least 50 per cent of people walk around with their phone. [Participant 5, male, aged 83 years]

The participants also spoke about digital engagement in relation to aspects of physical and mental well-being. For example, for some, not using web-based services, such as to make a general practitioner (family physician in the United Kingdom) appointment, was seen as a positive because they had to get “out of the house” and, in doing so, had the benefit of getting “a little bit of exercise.” For others, there was the acknowledgment of the advantages of being able to shop over the web during lockdowns, but now that restrictions had lifted, they had reverted to their preference to shop in person, which again was seen as an opportunity for exercise. Others talked about how it was sometimes “too easy” to depend on the internet to find out information that they could not immediately call to mind, and this was spoken about in terms of brain health and keeping the mind active. A participant stated the following:

So, in terms of doctors’ appointments and things, you can still get to the surgery or you could ring. Is that something that you prefer to do? [Interviewer]

Yes, I can ring on my landline and talk to a receptionist, or just toddle myself down to the surgery and go face to face with them, you know…Not that I would get an appointment any quicker with the doctor but, you know…And it gives me a little bit of exercise. [Participant 18, female, aged 79 years]

Another participant stated:

I’ve gone back to going out because you get a little bit of exercise, you know. So yeah, I don’t shop for groceries online anymore, no, I always go to the shop. [Participant 20, male, aged 76 years]

Another participant stated the following:

...A couple of days ago, it sounds ridiculous this…I thought, what’s the name of that pub at the top of Lancashire Road? I mean, what the hell I thought about that for, and I could not for the life of me, and I thought, no...remember it, because you do know it. And this morning, it’s come to me, The Hinds Head it’s called. [Participant 13, female, aged 75 years]

Okay, so you resisted the urge to find out? [Interviewer]

I did, yes, I did. I thought, no, that’s too easy. [Participant 13, female, aged 75 years]

**Theme 4: The “Last Generation”?**

Many participants, particularly those who were not on the web, spoke about barriers regarding generational issues and how they felt they might be the “last generation” to experience difficulty with digital participation:

...But I do think that we’re the last generation, almost the last generation that this will affect. Because from being babies now they have iPads now and what-have-you, don’t they? It’s just second nature to them. It puts you to shame when you watch them. [Participant 12, female, aged 81 years]

This often went hand-in-hand with the perception that these difficulties were unique to their generation and that the younger generations experienced little difficulty in adapting to or embracing new technology. A participant stated the following:

Well, do you know what, to be honest with you, I could say I’m at the end of a generation. Because if you
think of the youngsters today now and you think of...like my sons have no problem with this, that’s another generation, and then the one below that is the youngsters, yeah, this will never happen again...it’s unlucky, I’m at the end of a generation. [Participant 14, male, aged 83 years]

Another participant stated the following:

The youngsters, from school onward, they know nothing but the internet. So everything is being geared toward them. And we older people, in my generation, have had to start learning various things which become harder and harder. It’s second nature to younger people, to the 30s, 40s. [Participant 5, male, aged 83 years]

Theme 5: Making Digital Accessible

For those older adults who were participating (to some extent) in web-based activities, it was important to discuss barriers and facilitators that might require consideration to keep older adults engaged and supported.

One-to-One Support

Participants emphasized the importance of having patient assistance while navigating tasks on the web. They also highlighted the value of receiving written instructions and having tasks demonstrated multiple times. The participants also valued the one-to-one support given to them but stressed that this needed to be ongoing support, noting that sometimes they would “get the hang of” one task (eg, shopping) only to find that the next time they logged on to the website, the landing page may have changed, which would “throw them off” and result in them feeling unsure whether they could continue in the manner they had been shown. A participant stated the following:

I’d love someone to sit and show me so I can write it down and if I get stuck I know how to do it myself. [Participant 19, female, aged 82 years]

Other participants stated the following:

She writes things down for me, because I can’t always remember what I’ve been told. If I’ve got it there in black and white then I can follow it. It does help. [Participant 2, female, aged 76 years]

Yeah, sometimes it doesn’t click immediately and you need them to go over it again. So you need somebody who’s got a little bit of patience. [Participant 21, male, aged 78 years]

...I could do this before and now I’m having too many problems. And it’s the same with...so what it is, is what they call navigating the website becomes more difficult when they change the format, and that I find very, very annoying. [Participant 8, male, aged 75 years]

You know, the system I have for my laptop, when they start changing things I get very annoyed and I think, oh, I’ve got to figure out how to get out of that or whatever it is, yes...I’m just getting really annoyed when I have to figure out how all of these things work again. [Participant 1, female, aged 76 years]

Mitigating Physical Impairments

In addition, we asked respondents about physical impairments that might currently (or potentially in the future) make digital participation difficult. Arthritis, cataracts, Parkinson disease, diabetes, and tremors were all listed as having an effect on current internet use. Regarding future impact, although acknowledging uncertainty about how this could develop—“my eyes are not great. Yeah, I don’t know how that’s going to go.” (participant 1, female, aged 76 y)—many of the respondents were quick to point out potential solutions to overcome these; for example, some had already been shown how to locate and use the microphone function in Google Assistant, how to use predictive text, and how to increase the font size of the text on the screen. Many respondents had already taken these issues into consideration when deciding on the type of device to use. A total of 61% (11/18) preferred to use tablets, and this was for several reasons, including their portability and ease of use. One participant stated the following:

I also like the fact that I can have it on my knee in the lounge or the chair that I’m in. [Participant 19, female, aged 82 years]

Discussion

Principal Findings

The aim of this project was to explore the views of adults aged ≥75 years on accessing web-based public services in response to a policy initiative to further understand older people’s digital behavior and engagement. The analysis of the semistructured interviews identified 5 themes that were key to understanding some of the barriers and facilitators experienced by the older adults participating in this project. The key facilitators included responses to meeting certain needs (particularly during national lockdowns) such as food shopping, ordering prescriptions, and staying connected with family and loved ones. The identified barriers included fear of scams and misuse of personal information, lack of ongoing support to maintain or learn new skills, preference for face-to-face interactions (especially for health appointments), and a wider generational belief (held by many) that difficulties getting on the web were “unique” to their generation and that older adults found it difficult to adapt or embrace new technology. Crucially, we also found that the potential unintended consequences of the benefits offered by digital technologies to access public services could be seen as a barrier to their use. In particular, this included their ease of access to information and their convenience, which were seen to reduce the need for people to engage cognitively elsewhere or to leave the house, thereby denying them exercise and social interaction opportunities.

Theoretically, there are several models that attempt to explain digital engagement and uptake. Two of the most well-known and widely used are the Technology Acceptance Model [37] and the Unified Theory of Acceptance and Use of Technology [38]. However, these models are primarily used to quantify the acceptance of technologies rather than to provide qualitative
insights [29]. One straightforward categorization to facilitate an understanding of different “types” of older adults’ digital behavior suggests they may fall into 1 of 4 groups—“engaged,” “disheartened,” “transitional,” or “uninterested” [39]. “Engaged” refers to those older adults who believe they are capable of learning and perceive a value in using digital technology, that is, believe the internet is useful to them personally. “Disheartened” users also believe the internet to be useful and usually have more need for digital services but are worried about safety and associated risks and feel less confident in their ability and skills. “Transitional” older adults often have the highest need for use of digital services, but they are frequently lapsed users with narrow, if any, experience of digital engagement other than for social media purposes. “Uninterested” older adults do not perceive value in web-based activity and often have others access websites on their behalf. They usually have strong social connections and can be resistant to using the web. Although these categories are helpful in starting to think about digital behavior and potentially offer insights into how to support different “types” of older adults, the interviews presented here show that older adults’ digital behavior may not always be neatly classified into 1 type of user versus another. A large proportion of the respondents could be classified as digitally “engaged” in the sense that they were keen to go on the web, felt capable of learning, and had many of the skills deemed “essential” [40] for digital participation.

However, it was not possible to map these older adults to 1 “type” as there was often an overlapping of categories (particularly “engaged” and “disheartened”), which required a more nuanced understanding of what digital participation means for older adults. During discussions around the motivations behind getting on the web for our older adults (particularly during the pandemic), the initial “engagement” was evident; however, this engagement for many appeared to ebb away, and subsequently, many of them fitted the descriptions for other categories, for example, “disheartened” users. Although many of our older adults admitted a perceived value in accessing the internet and participating digitally (ie, “engaged”), a lack of confidence, lack of support, or fear of sharing information would often result in them becoming “disheartened,” disengaging from aspects of internet use, and not taking full advantage of the services available to them (eg, restricted use of web-based banking). Understanding that many older adults will not “fit” into 1 category highlights the need for a more individualized and nuanced approach to tailoring digital support services [41].

When considering the wider impacts of digital technology transformation, older adults’ limited use of web-based activities such as banking and concerns over data protection were also amplified by a lack of confidence and skills. Added to this were the needs of older people to get out and to socialize, with health-related appointments, shopping, and banking forming part of how participants stayed active and well in their communities. Work undertaken with a range of individuals, including older adults, during the pandemic found that a move to internet-based general practitioner and health appointments was sometimes problematic for this group for a variety of reasons, including a lack of skills and confidence, no interest in engaging on the web, and a lack of trust [42-44]. In addition, web-based platforms provide a very limited 2D view of a person and their circumstances [45,46]. As such, it is critical that people are encouraged to leave their homes and are able to access and attend face-to-face appointments. We already know that far too many older people are sedentary and do not achieve the recommended levels of physical activity [47,48]. This worsened during the COVID-19 pandemic, negatively impacting health [49]. Therefore, adding to this burden by substituting physical activity with digital engagement should be avoided.

The pandemic and its successive lockdowns have moved much public and social activity to web-based platforms. Digital exclusion is often discussed in terms of “hard” (eg, never having used the internet or having no internet access) or “soft” (eg, improving digital engagement, skill level, or confidence) [7]. These changes driven by the pandemic are said to have improved “hard” exclusion for the general population. However, in terms of improving the “softer” areas of exclusion, the pandemic has done little to close the digital divide, particularly for older adults [50]. There is evidence to show rates of internet use increasing faster among younger cohorts and declining among older cohorts, demonstrating the digital divide naturally closing in time as generations who experience high levels of digital exclusion are replaced by younger generations who embrace and adapt to technological change [51,52]. This idea came through strongly in the interviews conducted, with many older adults expressing this view. However, it was not clear whether they attributed this to the impact of the rapid digitalization brought about by the pandemic or to the impact of a more general move toward digitalization over a longer period. However, the rapid development of technology combined with an individual’s changes in physical health has been shown to worsen feelings of being unable to keep up or feeling too old to embrace new technology among older adults [53]. There is also the view that older adults can often internalize agism [54] and accede to the stereotype that they are not able to master technology and so do not attempt it. It seems plausible that the rapid increase in digitalization during the pandemic may have exacerbated these feelings of being left behind, but it is also important to note that inaccurate perceptions of young people as fluent technology users may be driven by a broad range of factors, including media representation, agism, and other social constructs related to digital inclusion and exclusion. Although the impact of the 2020 to 2023 COVID-19 pandemic brought many of these issues to the forefront in discussions around digital participation and the impact of the divide for older adults, these are not new issues related only to older adults’ experiences during the pandemic [50].

This study highlights several digital technology features that have delivered positive outcomes for people aged ≥75 years. Among those we interviewed, there was a preference toward using tablets [55] as well as a willingness to order prescriptions and engage in web-based shopping. Shared learning across public institutions on aspects of digital technology transformation that have been delivered successfully for adults aged >75 years would be beneficial. For example, what can we learn from the experience of web-based ordering of prescriptions that could inform other public service digitalization infrastructure and processes? There is also the importance of
ensuring digitalized services are fully accessible to all, including those living with long-term health conditions that may impact their ability to use digital devices (eg, arthritis) or access content easily (websites, text, etc). For older adults who wish to participate on the web, building confidence in undertaking tasks, such as banking, via support that is task focused and repeated is crucial [56,57].

**Strengths and Weaknesses**

Current data and insight into digital technology use may exclude people aged ≥75 years or may lack a specific focus on this age group. Often, available data on older adults’ use stops around the age of 74 years or it provides information on all individuals aged ≥65 years. Given the increased risk of digital exclusion among older age groups and the fact that this may have been exacerbated by the COVID-19 pandemic, it is vital to gain a deeper understanding of the use, attitudes, and preferences of people aged >75 years. Although this research was relatively small in number, its strength is that it focuses on those aged >75 years (average respondent aged 81 years). A key message to take away from the work is one of choice: that those aged ≥75 are not digitally homogenous but rather require a range of options, both digital and nondigital, that will enable them to engage in ways that work best for them and do not further exacerbate digital inequalities [23,58-60]. A key finding adding to the literature [29] is that the benefits of technologies, such as ease of access to information and convenience, may actually have unintended consequences that put older adults off using them. This includes a desire among some participants to continue to access some public services in person for the indirect benefit of physical activity while doing so. This finding is particularly important in light of other healthy aging policies that promote physical activity to improve disability-free life expectancy [61].

Future research should investigate the experiences of older adults from ethnic minority groups. Although this study aimed to be as inclusive as possible, the recruitment of older adults from diverse ethnic minority groups proved challenging. It would also be beneficial to examine the influence of age-related sensory changes on digital inclusion. Investigating the preferences and experiences of older adults with hearing or visual impairments would provide valuable insights. Physical distancing and stay-at-home restrictions during pandemic lockdowns meant that our recruitment strategy had to be adapted to make use of our existing networks and ties with third-party organizations to be able to recruit older adults for the study. A reliance on web-based means of recruitment resulted in a more digitally engaged sample of older adults being recruited than originally intended, although the levels of engagement varied among the older adults. In an ideal setting, a study of this nature would have been conducted with older adults in a face-to-face setting rather than via telephone or video interviews [62-64]. However, data collection during the COVID-19 pandemic meant this approach was not possible, and this will have had an impact on the final sample of older adults, with a larger proportion of adults who were digitally engaged taking part.

**Conclusions**

The shift to digital delivery of public services, both throughout the pandemic and more generally as a driving force for future service provision, requires a focus on the needs and preferences of older people so that they are not excluded from service access. Mitigation against digital exclusion is a core component of 1 of the strategic priorities to reduce health inequalities across England [52]. It is vital that the needs and preferences of people of all ages are considered, particularly those aged >75 years, who are often underrepresented in research. Attempts to classify “types” of digital users may be a useful heuristic for thinking about digital engagement, but the boundaries between categories are permeable and complex. Those aged ≥75 years are not a digitally homogenous group but rather require a range of options, both digital and nondigital, that will enable them to access services without further exacerbating digital inequalities.

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**Authors’ Contributions**

The conceptualization and design of the study was undertaken by AM, JM, and AH. Data collection was undertaken by AM. AM and DH coded and analyzed the data. AM drafted the original paper as first author and DH, JM, AH, CET, and CT worked on reviewing and editing subsequent drafts. All the authors have read and agreed to the published version of the manuscript.

**Conflicts of Interest**

None declared.

Multimedia Appendix 1
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Abbreviations

GMCA: Greater Manchester Combined Authority
The Implementation Success of Technology-Based Counseling in Dementia Care: Scoping Review

Dorothee Bauernschmidt1*, Dr rer medic; Janina Wittmann1*, MSc; Julian Hirt2,3, Dr rer medic; Gabriele Meyer1, Dr phil; Anja Bieber1, Dr rer medic

1Institute of Health and Nursing Science, University Medicine Halle, Martin Luther University Halle-Wittenberg, Halle (Saale), Germany
2Center for Dementia Care, Institute of Nursing Science, Department of Health, Eastern Switzerland University of Applied Sciences, St Gallen, Switzerland
3Department of Clinical Research, University Hospital Basel, University of Basel, Basel, Switzerland
* these authors contributed equally

Corresponding Author:
Anja Bieber, Dr rer medic
Institute of Health and Nursing Science
University Medicine Halle
Martin Luther University Halle-Wittenberg
Magdeburger Straße 8
Halle (Saale), 06112
Germany
Phone: 49 345 557 4427
Email: anja.bieber@uk-halle.de

Abstract

Background: Implementing technology-based counseling as a complex intervention in dementia care poses challenges such as adaptation to stakeholders’ needs and limited resources. While studies have examined the effectiveness of technology-based counseling, its successful implementation remains largely unexplored.

Objective: We aimed to review the knowledge about the implementation success of technology-based counseling interventions for people with dementia and their informal caregivers.

Methods: We conducted a scoping review and systematically searched CINAHL, the Cochrane Library including the Cochrane Central Register of Controlled Trials, MEDLINE, PsycINFO, and Web of Science Core Collection databases (April 2021) in combination with citation searching and web searching (November 2021). Studies reporting on technology-based counseling interventions for people with dementia or their informal caregivers were included, irrespective of the design. We used the conceptual framework for implementation outcomes to operationalize implementation success and applied the outcomes acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability as categories to inform data extraction. We identified dimensions within the categories and synthesized results narratively and graphically.

Results: We included 52 publications reporting on 27 technology-based counseling interventions. The studies were conducted in 9 countries and published between 1993 and 2021. As the design of the included studies varied, the number of participants and the type of data reported varied as well. The intervention programs were heterogeneous and ranged from single counseling interventions (such as helpline services) to counseling as part of a multicomponent program. Telephone, email, videoconferencing, social media (respectively chats), and web-based platforms were used for delivering counseling. We found data on appropriateness for all interventions and data on acceptability for most interventions, describing aspects such as consumer-perceived usefulness and helpfulness of services, as well as satisfaction. Information on the other categories of adoption, feasibility, fidelity, implementation cost, penetration, and sustainability was fragmented.

Conclusions: The scope and depth of information on conceptual categories of the implementation success of technology-based counseling for people with dementia and informal caregivers varied. The data only partially covered the concept of implementation success, which highlights the need for a systematic evaluation accompanying the implementation. The application of theoretical approaches for implementation and adherence to the framework for developing and evaluating complex interventions are required to promote the implementation of complex interventions and to comprehensively assess implementation success.

Trial Registration: PROSPERO CRD42021245473; https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=245473

https://aging.jmir.org/2024/1/e51544
Introduction

During the course of dementia, people with dementia, their families, and informal caregivers may need professional support to deal with the consequences of the disease [1-4]. Supportive interventions [5] are complex in their development, delivery, and impact, as they involve multiple components, aim at multiple outcomes, and are delivered in different settings. In addition, a broad range of skills are required of those who deliver the interventions [6] in dementia care.

Counseling for people with dementia and their informal caregivers is a supportive intervention that can be defined as conversational therapy in which a trained therapist listens to the person, enhances the individual’s ability to cope with the effects of dementia, and provides information and education [7,8]. Counselors provide information about the disease and support service options, offer the opportunity to share and discuss feelings or problems, and can enhance problem-solving and coping skills [9,10]. In the context of dementia, counseling services provided by professionals and tailored to individuals aim at various outcomes, such as reducing depressive symptoms and perceived burden, improving quality of life and self-efficacy, and encouraging the uptake of support services in the community [11]. Counseling interventions are therefore complex interventions comprising several components, such as specific training for providers, tools and instruments to individualize services, or different ways to access the available services [9,11]. Information and communication technologies may improve accessibility to counseling [12,13], and this aspect gained importance during the COVID-19 pandemic when remote counseling offered the possibility of providing support without the risk of infection [10,14].

To successfully translate complex interventions into practice, various challenges need to be overcome. Implementation can be defined as an “actively planned and deliberately initiated effort with the intention to bring a given intervention into policy and practice within a particular setting” [15]. The challenges described in implementing eHealth interventions in dementia care include adapting the interventions to match the skills and abilities of the target population, achieving user friendliness in the context of rapidly evolving technology, and addressing users’ concerns about security issues, especially when personal information is disclosed [16]. In implementing organizations, the lack of staff resources or the lack of interaction with staff as well as the reluctance of the provider to use the technology may impede implementation [16]. Furthermore, financial and time constraints can also act as barriers to implementation [16]. In the wider context, aspects such as stakeholders’ limited capabilities to support innovation or preferences for classically delivered care were identified as significant barriers [16].

Another challenge in the implementation of complex interventions is to operationalize and measure the success or effectiveness of implementation efforts. In a Cochrane Review on remotely delivered information, training, and support (including counseling) for informal caregivers of people with dementia, the authors found information on various aspects indicating implementation success such as acceptability, user satisfaction, or fidelity of implementation. As the indicators and assessment areas varied substantially across studies, data synthesis could not be conducted [9]. There are theoretical approaches that facilitate a comprehensive evaluation of implementation efforts [15]. One of them is the conceptual framework for implementation outcomes introduced by Proctor et al [17], which provides implementation-specific outcomes for assessing implementation success.

While there are studies investigating the effectiveness of technology-based counseling [8,9,11], the extent to which these interventions are successfully implemented remains unexplored. To address this gap in knowledge, we aimed to review the evidence and pursue the question of what is known about the implementation success of technology-based counseling interventions for people with dementia or their informal caregivers.

Methods

Design

According to the methodological approach of scoping reviews [18], we aimed at mapping evidence of implementation success to provide a comprehensive overview. We followed the methodological guidance [18] of the Joanna Briggs Institute and structured our report according to the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) [19].

Protocol and Registration

This scoping review is embedded in the project “Technology-based counselling in dementia (TeCoDem),” for which a protocol has been developed [7] and registered with the international prospective register of systematic reviews (PROSPERO CRD42021245473; see the section Deviations From the Protocol).

Eligibility Criteria

We included studies, irrespective of their design in English and German, that reported on technology-based counseling interventions for people with any type and severity of dementia or their informal caregivers. Interventions had to be tailored to individuals and provided remotely by professionals using various information technologies. Studies on people with mild cognitive impairment as well as studies on standardized interventions, such as cognitive behavioral therapy, on genetic counseling, and on counseling regarding diagnostics or screening for dementia were excluded. We also excluded studies describing interventions that focus mainly on care coordination or case
management. Furthermore, publications reporting exclusively on the development of interventions were excluded [7].

**Information Sources and Search Strategy**

We searched CINAHL, the Cochrane Library including the Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE via PubMed, PsycINFO via Ovid, and the Web of Science Core Collection databases (last search: April 22, 2021) without any filters and limiters. We systematically developed a search strategy that contained 3 components: *dementia, technology, and counseling*. Corresponding search terms and synonyms (eg, *dementia/Alzheimer, technology/electronic, counselling/counseling/consultation*) were identified through an orienting search using MEDLINE via PubMed, and we checked entry terms given in the Medical Subject Headings browser. The strategy was peer-reviewed by applying the Peer Review of Electronic Search Strategies [20]. In addition, we performed forward and backward citation searches of included studies and pertinent reviews via Scopus (last search: October 7, 2021) and a web search via Google and Google Scholar (last search: November 26, 2021) [21,22]. Full database-specific search strategies are provided elsewhere [7].

**Selection of Sources of Evidence**

Titles, abstracts, and full texts were independently screened by 2 reviewers (out of AB, JH, and DB) using the Rayyan web browser. The strategy was peer-reviewed by applying the Peer Review of Electronic Search Strategies [20]. In addition, we performed forward and backward citation searches of included studies and pertinent reviews via Scopus (last search: October 7, 2021) and a web search via Google and Google Scholar (last search: November 26, 2021) [21,22]. Full database-specific search strategies are provided elsewhere [7].

**Data Charting Process and Data Items**

A targeted and uniform extraction sheet was developed and consented to by the research team. We extracted study and design characteristics (year of publication, country where the study was conducted, objectives, number of participants or contacts) and assessed the technology-based counseling interventions by applying criteria from the Template for Intervention Description and Replication checklist [24] and from the revised Criteria for Reporting the Development and Evaluation of Complex Interventions guideline [25] to obtain a comprehensive overview of the interventions and their components. Data extraction on implementation success was guided by the conceptual framework for implementation outcomes, which comprises the implementation outcomes acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability [17]. We adapted the definitions of the outcomes by specifying the intervention of interest and adjusting it to the research interest of our scoping review. Adaptations were consented to by the review team. The original and adapted definitions are listed in Table 1.

**Synthesis of Results**

Data on the implementation success of technology-based counseling interventions were summarized by applying the framework mentioned in the preceding section [17]. The following 8 conceptually distinct implementation outcomes were resolved by discussions within the review team.

### Table 1. Original and adapted definitions of implementation outcomes.

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Original definition according to Proctor et al [17]</th>
<th>Adapted definition for our review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptability</td>
<td>“Acceptability is the perception among implementation stakeholders that a given treatment, service, practice, or innovation is agreeable, palatable, or satisfactory.”</td>
<td>Acceptability is the perception among implementation stakeholders of technology-based counseling that the intervention is agreeable, palatable, or satisfactory.</td>
</tr>
<tr>
<td>Adoption</td>
<td>“Adoption is defined as the intention, initial decision, or action to try or employ an innovation or evidence-based practice.”</td>
<td>Adoption is defined as the intention, initial decision, or action to try or employ a technology-based counseling intervention.</td>
</tr>
<tr>
<td>Appropriateness</td>
<td>“ Appropriateness is the perceived fit, relevance, or compatibility of the innovation or evidence based practice for a given practice setting, provider, or consumer; and/or perceived fit of the innovation to address a particular issue or problem.”</td>
<td>Appropriateness is the perceived fit, relevance, or compatibility of the technology-based counseling intervention for the given practice setting, provider, and consumer; and/or perceived fit of the intervention to address a particular issue or problem.</td>
</tr>
<tr>
<td>Feasibility</td>
<td>“Feasibility is defined as the extent to which a new treatment, or an innovation, can be successfully used or carried out within a given agency or setting (Karsh 2004).”</td>
<td>Feasibility is defined as the extent to which the technology-based counseling intervention can be successfully used or carried out within a given agency or setting.</td>
</tr>
<tr>
<td>Fidelity</td>
<td>“Fidelity is defined as the degree to which an intervention was implemented as it was prescribed in the original protocol or as it was intended by the program developers (Dusenbury et al. 2003; Rabin et al. 2008).”</td>
<td>Fidelity is the degree to which a technology-based counseling intervention was implemented as it was prescribed in the original protocol or as it was intended by the program developers.</td>
</tr>
<tr>
<td>Implementation cost</td>
<td>“Cost (incremental or implementation cost) is defined as the cost impact of an implementation effort.”</td>
<td>Implementation cost is the cost impact of an implementation effort.</td>
</tr>
<tr>
<td>Penetration</td>
<td>“Penetration is defined as the integration of a practice within a service setting and its subsystems.”</td>
<td>Penetration is defined as the integration of a technology-based counseling intervention within a service setting.</td>
</tr>
<tr>
<td>Sustainability</td>
<td>“Sustainability is defined as the extent to which a newly implemented treatment is maintained or institutionalized within a service setting’s ongoing, stable operations.”</td>
<td>Sustainability is defined as the extent to which an implemented technology-based counseling intervention is maintained or institutionalized within an organization’s ongoing, stable operations.</td>
</tr>
</tbody>
</table>

Quotations from the included studies were extracted and assigned to the outcomes by 1 reviewer (out of DB or JW) and cross-checked for accuracy by another reviewer (out of DB or JW). Any discrepancies were resolved by consensus between these 2 reviewers.
were used as conceptual categories to operationalize implementation success: acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability.

Our approach to data synthesis involved the following steps:

1. Concept specification: identification of dimensions in the definition of each conceptual category: as these conceptual categories incorporate various aspects [17] and therefore represent multidimensional concepts, a concept specification was performed by determining the dimensions of the categories [26,27]. Dimensions are defined as characteristics according to which empirical facts can be distinguished [28]. The 2 reviewers (DB and JW) independently identified dimensions matching the attributes of the conceptual categories [27] described by Proctor et al [17] with the characteristics of the extracted data. Consensus on the dimensions was reached through discussion between the 2 reviewers.

2. Reduction of data and assignment to dimensions in analysis matrices: the extracted data were reduced without paraphrasing and assigned to the dimensions using tables as analysis matrices.

3. Specification of the level of analysis: we specified the level at which data were provided (level of analysis: consumer, provider or providing institution, organization, setting, and administration), as indicated by Proctor et al [17].

4. Narratively synthesizing of findings and graphical presentation: findings were narratively synthesized and presented in the form of a net diagram.

Each synthesis step was cross-checked (DB and JW) and consent was obtained from the review team.

Study characteristics and characteristics of the included interventions are presented in narrative and tabular forms.

**Deviations From the Protocol**

The prespecified method of conducting a Qualitative Comparative Analysis on the conditions of successful implementation of technology-based counseling interventions [7] could not be realized because of the heterogeneity of the data found in the literature. In addition, reports that were not written in English or German were excluded because of a lack of professional translation resources.

**Results**

**Selection of Sources of Evidence**

The electronic database yielded 6387 records. After removing duplicates, we screened the titles and the abstracts of 3775 records, reviewed 277 full texts for eligibility, and included 35 records. We identified 3614 records from additional sources and assessed 151 full texts, of which 17 were included. Finally, 52 publications [29-80] reporting on 27 technology-based counseling interventions were included (Figure 1).

![PRISMA Flowchart](https://aging.jmir.org/2024/1/e51544)

**Characteristics of Sources of Evidence**

Interventions ranged from single counseling interventions, such as helpline services, to multicomponent programs combining nontechnology-based components, such as day care for people with dementia, with technology-based counseling for informal caregivers. All 27 interventions [29-80] focused on informal caregivers, mostly in combination with people with dementia, and 4 also addressed professional caregivers [29-32,34,35,37,40]. Counseling was provided by professionals...
from different disciplines, such as psychologists, geriatricians, or nurses. If volunteers were involved, they were professionally supervised or had received training. The technologies used for delivery included telephone, email, videoconferencing, social media, and chats, as well as web-based platforms. Additional (personalized) information material was frequently offered and delivered via email or postal mail. We differentiated the following types of interventions (refer to Table S1 in Multimedia Appendix 1): counseling via telephone or email and counseling via videoconferencing; web-based psychosocial intervention: information, communication, and counseling; videoconference- or telephone-based counseling combined with tele-monitoring or psychoeducation; and technology-based counseling as part of a comprehensive program with nontechnology-based components.

The design of the included studies varied (refer to Table S2 in Multimedia Appendix 1). Studies applying a quantitative descriptive design mostly focused on users’ demographics, topics discussed and advice provided in counseling sessions, and satisfaction with services. Few of the included studies exclusively focused on implementation, and we found process evaluation reports [79,80] related to 2 interventions. Furthermore, the publication type of the included reports varied greatly, as we aimed to depict the broad spectrum of interventions. In addition to research reports, we identified abstracts, letters to the editor, and practical project reports.

The interventions are displayed in Table S2 in Multimedia Appendix 1 and characteristics of the included studies are described in Table S3 in Multimedia Appendix 1.

Results of Individual Sources of Evidence

Table 2 provides an overview of the data extracted from the included studies.

The label (“✓”) indicates the presence of data without any information on content or scope. None of the interventions included reported data in all categories. The information available ranged from 1 to 7 conceptual categories for each intervention (also refer to the analysis matrices in Multimedia Appendix 1).
Table 2. Overview of reported data on conceptual categories.

<table>
<thead>
<tr>
<th>Intervention</th>
<th>References</th>
<th>Data extracted for conceptual categories</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Acceptability</td>
</tr>
<tr>
<td>Admiral Nurse Helpline</td>
<td>[29-32]</td>
<td>✓</td>
</tr>
<tr>
<td>ADS Helpline</td>
<td>[33]</td>
<td>✓</td>
</tr>
<tr>
<td>Alzheimer Helpline</td>
<td>[34,35]</td>
<td>✓</td>
</tr>
<tr>
<td>Alz-i-Connect</td>
<td>[36]</td>
<td>✓</td>
</tr>
<tr>
<td>CANDID</td>
<td>[37]</td>
<td>✓</td>
</tr>
<tr>
<td>Care Consultation</td>
<td>[38]</td>
<td>✓</td>
</tr>
<tr>
<td>Care Consultation Plus</td>
<td>[38]</td>
<td>✓</td>
</tr>
<tr>
<td>Care Consultation/Care Consultation Plus</td>
<td>[38]</td>
<td>✓</td>
</tr>
<tr>
<td>Coyne comparator</td>
<td>[39]</td>
<td>✓</td>
</tr>
<tr>
<td>Coyne experimental</td>
<td>[39]</td>
<td>✓</td>
</tr>
<tr>
<td>Coyne</td>
<td>[39]</td>
<td>✓</td>
</tr>
<tr>
<td>Helpline Alz Ass East Massa</td>
<td>[40]</td>
<td>✓</td>
</tr>
<tr>
<td>Natale</td>
<td>[41]</td>
<td>✓</td>
</tr>
<tr>
<td>ODCC</td>
<td>[42]</td>
<td>✓</td>
</tr>
<tr>
<td>Sabat</td>
<td>[43]</td>
<td>✓</td>
</tr>
<tr>
<td>Salfi nonanonym</td>
<td>[44-46]</td>
<td>✓</td>
</tr>
<tr>
<td>Salfi anonym</td>
<td>[44-46]</td>
<td>✓</td>
</tr>
<tr>
<td>Salfi</td>
<td>[44-46]</td>
<td>✓</td>
</tr>
<tr>
<td>FITT-C</td>
<td>[47-53]</td>
<td>✓</td>
</tr>
<tr>
<td>FITT-D</td>
<td>[54]</td>
<td>✓</td>
</tr>
<tr>
<td>NVAMP</td>
<td>[55]</td>
<td>✓</td>
</tr>
<tr>
<td>ICSS</td>
<td>[56-61]</td>
<td>✓</td>
</tr>
<tr>
<td>InformCare</td>
<td>[62-64]</td>
<td>✓</td>
</tr>
<tr>
<td>Link2Care</td>
<td>[65]</td>
<td>✓</td>
</tr>
<tr>
<td>Online Coaching</td>
<td>[66]</td>
<td>✓</td>
</tr>
<tr>
<td>De Cola</td>
<td>[67]</td>
<td>✓</td>
</tr>
<tr>
<td>Laver</td>
<td>[68,69]</td>
<td>✓</td>
</tr>
<tr>
<td>RCTM</td>
<td>[70-73]</td>
<td>✓</td>
</tr>
<tr>
<td>Dementelcoach</td>
<td>[74-79]</td>
<td>✓</td>
</tr>
</tbody>
</table>
Synthesis of Results

Acceptability

We defined acceptability as the perception among implementation stakeholders of technology-based counseling that the intervention is agreeable, palatable, or satisfactory [17]. Within the data related to the conceptual category (reported for 20 interventions [29-36,38,40,43-69,74-80]; refer to Table 2), we identified the dimensions measures to promote acceptability and impact, which can be further differentiated into impact of parts of the service and impact of the overall service. Measures to promote acceptability were reported, specifically from the perspective of the organizations. These were mainly aimed at promoting acceptability among providers, for example, through supervision, debriefings, or training. The impact on parts of the respective intervention or service was described from the perspective of both the provider and the consumer. The provider reported satisfaction with their role, whereas the consumer described individual parts of the service, including the helpfulness of the conversations, the competence of counselors, accessibility, materials, etc. The impact on the overall service was reported from the provider’s perspective, namely, satisfaction with the experience of the team members. Other interventions reported on the impact of the overall service from the consumer’s perspective, illustrated by relief, satisfaction with the intervention, or comfort with the service.

Adoption

Adoption is defined as the intention, decision, or action to use an intervention [17] (reported for 12 interventions [29-32,36,37,40,42,47-54,65,67-69,74-80]; refer to Table 2). Dimensions of adoption were organizational motive, mode of decision, and uptake of interventions motivated internally or externally. The motives of organizations included their commitment to helping families affected by dementia, connecting individuals to helpful information, providing access to support services, and providing support. Some authors described organizational motives in more general terms by referring to aspects that need to be addressed, for example, increased service demands or restrictions in the living conditions of people with dementia in the community. The mode of decision was characterized in different ways: as a response to developments in the setting, such as mobility restrictions or the increasing use of the internet in the target groups; as consent to participate at the organizational level; or as permission sought and obtained to implement the program. External reasons for the uptake of the specific intervention were evidence of the effectiveness of the intervention found in the literature or evidence indicating that the previously used mode of delivery needed to be adapted. Internally motivated uptake is based on the development, modification, or advancement of one’s own interventions.

Appropriateness

Appropriateness is understood as the perceived fit [17] of technology-based counseling for stakeholders, the setting, and the problems addressed. We defined the dimensions overall compatibility with stakeholder needs, tailoring to individuals, skills and instruments for enhancing fit, and concepts for fit for this conceptual category and found extensive information for all interventions [29-80]. If assignment of the quotes to experimental and comparator interventions was not possible, we assumed that the information was applicable for both interventions (refer to Table 2).

The dimension overall compatibility with stakeholder needs comprises information on accessibility, availability, tailoring to consumer groups, and usefulness of service. In the area of accessibility, the ways to access were described, ranging from the use of a single technology to multiple ways via email, telephone, and videoconferencing, or in combination with home visits. The availability of counseling in terms of service hours, for instance, permanently or during regular working hours on weekdays, was discussed against the background of availability when needed or in times of crisis. From the perspective of organizations, providers, and consumers, technology-based counseling was viewed as a mode of delivery that can solve logistical issues such as making appointments or long-distance travel. People who are homebound can access support without leaving their homes, and caregivers do not have to arrange substitute care. The limitations of remote delivery, such as the loss of context or consumers’ different capacities for using technology, were discussed from the perspective of the provider.
and the consumer. In addition, the advantages and disadvantages of anonymous services and services in which providers know the caregiver or the person with dementia are debated. Tailoring to consumer groups included services focusing on early-onset dementia or rare diseases, considering cultural and ethnic backgrounds, and providing multilingual services. To ensure the usefulness of the services, the appropriate amount and delivery of information were discussed. Tailoring to individuals included statements from the perspective of the provider that services were individualized, personalized, adapted, or flexible and aimed at responding to or addressing individual clients' needs by offering the most appropriate intervention or the best approach to resolve problems. Providers' skills for enhancing fit were described as specialist communication or counseling skills based on the training, knowledge, or experience of the person providing the service. Instruments used in organizations for enhancing fit comprise assessment instruments, information material, or written summaries of counseling sessions, such as letters, scripts, or proposals for individual use. Concepts for fit were reported from the providers' perspective and described in terms of person-centered and holistic approaches by applying techniques such as validation or empathetic understanding and psychological strategies to enhance coping and problem-solving processes.

**Feasibility**

We defined feasibility as the extent to which technology-based counseling can be successfully used [17] and identified the dimensions practicability, factors impeding feasibility, and factors promoting feasibility (reported for 13 interventions [29-32,36,39,40,43,47-64,68-79]; refer to Table 2). The practicability of the interventions was stated from the perspective of the provider, the organization, or the setting. The quotes refer to the general practicability of the intervention, stating its successful application or conceptual clarity. Practicability was also discussed with reference to the use of technology. Factors impeding feasibility comprised general aspects such as lack of financial and staff resources, technology-related aspects such as legal standards and technical challenges, and the lack of visual and nonverbal cues when counseling was delivered via telephone. Special training of providers to overcome technical problems or to compensate for technology-related issues was reported as a factor promoting feasibility.

**Fidelity**

Fidelity is the degree to which an intervention was implemented as prescribed or intended [17] (reported for 9 interventions [29-32,37,38,40,47-54,62-64,68,69]; refer to Table 2). We determined formalization of intervention and quality assurance in delivering the intervention as dimensions of fidelity. Formalization of intervention was addressed by mentioning standardized manuals, guidelines, frameworks, protocols, or assessments. Proceedings for quality assurance in delivering the intervention comprised senior staff supervision to ensure adherence to the protocol and monitor fidelity, the analysis of audiotaped counseling sessions, and the use of adherence and competence scales.

**Implementation Cost**

On the basis of Proctor et al [17], we defined the conceptual category implementation cost as the cost impact of an implementation effort reported from the perspective of a provider or the providing institution (reported for 3 interventions [36,62-64,74-79]; refer to Table 2). We identified the dimensions cost impact of delivery because of complexity of intervention, cost impact of implementation because of complexity of implementation strategy, and cost impact because of varying complexity of settings. Data on the first dimension comprised the costs of delivering the complex intervention and its financing through previously paid travel costs. The costs of the implementation strategy were illustrated by the impact of existing and lacking financial resources for staffing on the implementation process. Within the third dimension, failed expansion or implementation because of a lack of resources was exemplified.

**Penetration**

Within the conceptual category of penetration, defined as a step of integrating the technology-based counseling intervention into the service setting ([17] reported for 11 interventions [29-37,40,62-65,67,74-80]; refer to Table 2), we identified 3 dimensions: collaboration with stakeholders, access to the service, and spread. Data from interventions describe cooperation with stakeholders to implement the intervention, initiated either by the implementing organization itself or jointly through cooperation with other stakeholders in the setting. Access to the service occurred through referrals from other stakeholders in the setting, for example, physicians, or through information from other sources, such as telephone books or newspapers. From the perspective of the implementing organization, the degree of utilization of the intervention by different professional groups (eg, physicians, social workers, and nurses) was described. The level of spread was reported from the perspective of the implementing organization as well as the setting and is often reflected as the regional spread of interventions, for example, at the national or international level.

**Sustainability**

Following Proctor et al [17] and consequently Steckler et al [81], we understand sustainability (reported for 13 interventions [29-38,40,42,47-53,62-67]; refer to Table 2) as the final phase of the diffusion process in which innovations become entrenched in organizations. We were able to identify specifications of the data in 3 dimensions: routinization, passage, and incorporation. These dimensions were mainly reported from the perspective of the implementing organization; once, the perspective of the administration was also taken. The data on the dimension routinization provided information on the permanence and the degree to which the intervention was established, especially related to the number of versions of the intervention developed, the stakeholders involved, or the period from the start of the program. The duration varied greatly, ranging from a recent introduction to a multiyear build-up with many contacts. Statements were found in the interventions indicating maintained information from other sources, such as telephone books or newspapers. From the perspective of the implementing organization, the degree of utilization of the intervention by different professional groups (eg, physicians, social workers, and nurses) was described. The level of spread was reported from the perspective of the implementing organization as well as the setting and is often reflected as the regional spread of interventions, for example, at the national or international level.
行政视角也被考虑，指的是研究项目结束后支持的中断，以及项目的终止。例如，这个维度通过整合另一个目标群体或扩展到另一个地区得到了澄清。例如，对现有结构的最终整合旨在维持干预，描述了服务的传播方式。形成的结构。

**Graphical Presentation of Synthesized Data**

图2展示了数据的合成图形。数据对概念性的实施成功类别进行了寻求，用于27项干预（蓝色线）。数据被提取的干预数量由红色线表示。虽然适宜性和可接受性类别基本覆盖，但其他领域的大部分内容仍被忽略（参见图2）。

**Discussion**

**Principal Findings**

我们旨在回顾有关基于技术的咨询服务实施成功的知识。在我们的筛选审查中，我们纳入了52篇报道了27项干预的文献。干预是多样化的，从单个咨询服务，如热线，到作为多组件程序的一部分的咨询服务。为了操作化实施成功，我们使用了概念框架中实施结果的8个结果[17]作为概念性类别。只有少数研究评估了实施。实施结果的报告被发现是零散的，信息的全面性差异很大。总体上，报告的重点是在适宜性和可接受性结果上，这可能是因为为了适应脆弱的目标群体，人们投入了巨大努力。

作为我们的数据显示，接受性在视角上不一致：数据报告了提升接受性的措施，但仅从提供者的视角。同时，从提供者的视角报告影响的代表性不足。这已经讨论过在文献中，实施的融合存在困难[16]。报告的信息显示了采纳的重要性，这取决于组织动机和选择的干预类型。在成功的实施中。实施努力。我们发现决策来自行政决策者对可持续性的影响，限制了干预的实施。

增加行政决策者的实施干预的投入热情，通过推广对特定干预的熟悉，并利用品牌认知的影响，可能有助于长期承诺[82]。在一些情况下，特定干预的采纳是基于对其有效性的证据，需要进一步的有效性试验来扩展决策制定有关技术咨询服务实施的证据。

提供的数据在适宜性方面包含了最大量的信息，记录了针对特定目标而采取的努力。除了对一般提高接受性的措施的提升外，提供者的态度和工具，以及个别提供者应用的策略，已经讨论过了在文献中，实施的融合存在困难[16]。报告的信息显示了采纳的重要性，这取决于组织动机和选择的干预类型。在成功的实施中。实施努力。我们发现决策来自行政决策者对可持续性的影响，限制了干预的实施。

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were described. Tailoring and personalizing counseling services to individuals’ needs has been associated with the usefulness of information and support [55-65]. The benefits and limitations of using technology for delivering counseling are discussed against the background of statements by consumers who would have preferred a different mode of communication with counselors [36]. On the basis of participants’ attrition, González-Fraile et al [9] reported that remote support or training interventions appear to be less acceptable to informal caregivers of people with dementia than control interventions, which may limit their applicability in community settings. Further research is needed to determine whether services that are accessible both face to face and technology-based can provide appropriate accessibility and improve the perceived fit of the target populations.

Information on feasibility comprised the successful implementation of interventions. Although factors impeding feasibility, such as legal issues and technical challenges, were reported, we found no information on failed or unsuccessful implementation. Barriers to the implementation of eHealth interventions described in the literature are, among others, the lack of digital literacy in the target population and staff’s uncertainties and insecurities about their coaching competences [83]. According to Proctor et al [17], the concept of feasibility is typically “invoked retrospectively as a potential explanation of an initiative’s success or failure.” Thus, a more comprehensive reporting of factors promoting or impeding feasibility may inform the implementation of interventions in future projects and may contribute to increasing the implementation success of technology-based counseling interventions.

Ways of formalizing the interventions to ensure fidelity in the delivery of interventions were mentioned, but manuals or guidelines were not made accessible along with publications. In addition, measurements to ensure fidelity were described for some interventions, but the results of assessments, as well as details on aspects where deviations occurred, were not reported. After critically reviewing the literature on the use of fidelity implementation frameworks in early intervention, Lemire et al [84] also stated gaps in defining and assessing implementation fidelity. Drawing on preexisting conceptualizations, the authors proposed a definition of fidelity that comprises the 4 components: adherence, exposure, quality, and participant responsiveness [84].

The cost impact of implementation efforts was rarely reported for the included interventions. Factors that influence the costs are the complexity of the specific intervention, the strategy used for implementation, and the delivery setting [17]. Despite the costs incurred in setting up the technical infrastructure, the costs for remote delivery were lower than when counseling was provided face to face [36,68,69]. Owing to the lower costs, eHealth interventions are considered suitable for widespread implementation [16]. The provision of information on implementation costs is essential to compare the cost impact of different interventions and to inform decisions regarding the uptake of a specific intervention [17].

The data reported on penetration often indicates access to the service in multiple ways, which seems to match the preferences and capabilities of consumers. As reported by Jelly et al [85], caregivers use dementia support services primarily when services are able to meet consumers’ individual needs. However, it is important to keep in mind that, from an organizational point of view, these extended access options need to be served simultaneously. In particular, cooperation with other stakeholders seems to be central to integrating counseling services into a service setting, but this was only highlighted by some authors in the included publications.

The sustainable anchoring of diffusion processes is described as a difficult phase in the implementation process of support services for caregivers of people with dementia. The reasons for this include a lack of understanding of the barriers to sustainable implementation in practice and a lack of long-term funding [86]. The problem is substantiated in that, as long as researchers focus on measuring the effectiveness of the interventions, the potential goal is not fully realized. However, there are models that can support this sustainable implementation [87].

There are several theoretical approaches, such as generalized theories, models, or frameworks, that address different aspects of implementation [88]. Frameworks “describe more loosely structured constellations of theoretical constructs... or prescriptive approaches for accomplishing implementation goals” [88]. By providing clarity in terms and definitions [88], frameworks contribute to shared language in implementation research. There are different types of frameworks focusing on processes or determinants or evaluations [88]. Evaluation frameworks, such as the conceptual framework for implementation outcomes introduced by Proctor et al [17] and the Reach, Efficacy, Adoption, Implementation, Maintenance (RE-AIM) planning and evaluation framework [89,90], offer guidance on identifying results that can be used to evaluate implementation efforts [88]. While the RE-AIM framework describes outcomes across 5 domains (reach, effectiveness, adoption, implementation, and maintenance) [90], Proctor et al [17] present the concept of 8 implementation outcomes, which are differentiated from service system and treatment outcomes. Implementation outcomes are defined as “the effects of deliberate and purposive actions to implement new treatments, practices, and services” and are reported from different levels of analysis (eg, the provider or the consumer perspective) [17]. Serving as conceptual categories of the implementation success [17], these outcomes provided the appropriate approach to operationalize the object of interest—the implementation success of technology-based counseling interventions in dementia—in our review.

To increase the clarity of terminology used in implementation research, Proctor et al [17] proposed the definitions of 8 conceptually distinct implementation outcomes as a “working taxonomy,” including different aspects of implementation success and thus creating a comprehensible framework.

The use of outcomes as conceptual categories was sometimes challenging in our case. The mapping of the extracted data, in particular, was sometimes difficult because of the conceptual
similarity of some outcomes, for example, penetration and sustainability, and the inconsistent use of terminology found in the literature. When determining the levels of analysis, we sometimes included additional perspectives, as described by Proctor et al [17].

Altogether, the lack of process evaluation studies, the fragmented reporting, and the unclear use of terms and concepts made it impossible to determine the extent of implementation success of technology-based counseling interventions in dementia care. Because of the impaired comparability of data, we were not able to assess how the different types of interventions affect the conceptual categories of acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability. For instance, we found data on appropriateness for all interventions, but the consumer-perceived usefulness of services was referred to for only 5 interventions. These 5 interventions comprised helplines that provided counseling via telephone [29-32,55] and web-based psychosocial interventions that provided information, communication, and counseling [56-65]. The reported information does not allow any conclusions to be drawn on how the types or components of interventions have an impact on implementation success. Gaining further insight into this issue is important for developing future interventions that can be implemented successfully.

Adherence to the framework for developing and evaluating complex interventions [6] may help overcome these problems, as proper process evaluation and exploration of conditions for implementation are recommended. The update to the Medical Research Council guidance states that “[e]arly consideration of implementation increased the potential of developing an intervention that can be widely adopted and maintained in real-world settings” [6] and thus can increase the success of implementation efforts. In addition, the conceptual clarity of the terms and concepts used in implementation research is needed to enhance transparency. This can be achieved by applying theoretical approaches that “encapsulate as generalized theories, models, or frameworks” [88]. The consistent use of terms not only creates clarity but also forms the basis for better reporting on the success of implementation efforts, as Lengnick-Hall et al [91] proposed as the first of 6 practical recommendations for improved implementation outcomes reporting.

**Strengths and Limitations**

We followed a theory-driven approach to review the available evidence on implementation success. As we examined a broad topic with evidence emerging from studies in various designs, a scoping review proved appropriate. We performed a comprehensive and methodologically rigorous systematic literature search and included a variety of technology-based counseling interventions for people with dementia and their informal caregivers. Differentiating counseling from interventions focusing on education and information or from psychotherapeutic approaches brought challenges that we overcame through intensive discussions in the review team. Although we were able to include a considerable number of publications, it was not possible to make reliable statements about the implementation success of technology-based counseling interventions in dementia because of the inconsistent database as well as the heterogeneity in terminology and concepts.

**Conclusions**

We applied 8 conceptually distinct categories to operationalize the implementation success of technology-based counseling interventions for people with dementia and their informal caregivers. We found considerable data for the categories appropriateness and acceptability, and limited data on sustainability, feasibility, adoption, penetration, fidelity, and implementation cost. There is an imbalance in the scope and depth of the reported data on the conceptual categories, and the data extracted from the included publications only partially covered the concept of implementation success.

This highlights the need for a systematic evaluation accompanying the implementation of technology-based counseling interventions in the context of dementia. Adherence to guidelines for the development and evaluation of interventions and to guidelines or recommendations for reporting conceptualizations, measurements, and results on implementation outcomes is needed to expand knowledge on the effectiveness of implementation efforts and may foster the implementation of complex interventions in diverse contexts.

**Acknowledgments**

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**Authors’ Contributions**

DB, JW, JH, GM, and AB conceived the idea of the manuscript and made substantial contributions to this scoping review. JH and AB conducted the literature search. DB, JW, JH, and AB conducted study selection and data extraction. DB, JW, JH, and AB conceptualized and operationalized the object of interest. DB and JW conducted the data analysis and synthesis. DB and JW were involved in the drafting of the manuscript. DB, JW, JH, GM, and AB revised the manuscript for important intellectual content. All authors read and approved the final manuscript.
Conflicts of Interest

None declared.

Multimedia Appendix 1

Description of included intervention programs, description of studies reporting on included intervention programs, and analysis matrices.

[DOCX File, 181 KB - aging_v7i1e51544_app1.docx]

Multimedia Appendix 2

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist.

[DOCX File, 89 KB - aging_v7i1e51544_app2.docx]

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Abbreviations

PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews

RE-AIM: Reach, Efficacy, Adoption, Implementation, Maintenance

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Review

Patient and Public Involvement in Technology-Related Dementia Research: Scoping Review

Pippa Kirby1,2,3, BA, MSc; Helen Lai2,3, BSc, MRes; Sophie Horrocks2,4, MA, MSc; Matthew Harrison2,4, MA, MEng; Danielle Wilson2,3, BSc; Sarah Daniels2,3, MSc; Rafael A Calvo5, PhD; David J Sharp2,3, BA, MBBS, PhD; Caroline M Alexander1,6, MCSP, MSc, PhD

1Department of Therapies, Imperial College Healthcare NHS Trust, London, United Kingdom
2UK Dementia Research Institute, Care Research and Technology Centre (UK DRI CR&T), London, United Kingdom
3Department of Brain Sciences, Faculty of Medicine, Imperial College London, London, United Kingdom
4Helix Centre, Institute of Global Health Innovation, Imperial College London, London, United Kingdom
5Dyson School of Design Engineering, Imperial College London, London, United Kingdom
6Department of Surgery and Cancer, Imperial College London, London, United Kingdom

Corresponding Author:
Helen Lai, BSc, MRes
UK Dementia Research Institute
Care Research and Technology Centre (UK DRI CR&T)
9th Floor, Sir Michael Uren Hub, White City Campus, Imperial College London
86 Wood Lane
London, W12 0BZ
United Kingdom
Phone: 44 20 7594 9755
Email: h.lai18@imperial.ac.uk

Abstract

Background: Technology-related research on people with dementia and their carers often aims to enable people to remain living at home for longer and prevent unnecessary hospital admissions. To develop person-centered, effective, and ethical research, patient and public involvement (PPI) is necessary, although it may be perceived as more difficult with this cohort. With recent and rapid expansions in health and care-related technology, this review explored how and with what impact collaborations between researchers and stakeholders such as people with dementia and their carers have taken place.

Objective: This review aims to describe approaches to PPI used to date in technology-related dementia research, along with the barriers and facilitators and impact of PPI in this area.

Methods: A scoping review of literature related to dementia, technology, and PPI was conducted using MEDLINE, PsycINFO, Embase, and CINAHL. Papers were screened for inclusion by 2 authors. Data were then extracted using a predesigned data extraction table by the same 2 authors. A third author supported the resolution of any conflicts at each stage. Barriers to and facilitators of undertaking PPI were then examined and themed.

Results: The search yielded 1694 papers, with 31 (1.83%) being analyzed after screening. Most (21/31, 68%) did not make clear distinctions between activities undertaken as PPI and those undertaken by research participants, and as such, their involvement did not fit easily into the National Institute for Health and Care Research definition of PPI. Most of this mixed involvement focused on reviewing or evaluating technology prototypes. A range of approaches were described, most typically using focus groups or co-design workshops. In total, 29% (9/31) described involvement at multiple stages throughout the research cycle, sometimes with evidence of sharing decision-making power. Some (23/31, 74%) commented on barriers to or facilitators of effective PPI. The challenges identified often regarded issues of working with people with significant cognitive impairments and pressures on time and resources. Where reported, the impact of PPI was largely reported as positive, including the experiences for patient and public partners, the impact on research quality, and the learning experience it provided for researchers. Only 4 (13%) papers used formal methods for evaluating impact.

Conclusions: Researchers often involve people with dementia and other stakeholders in technology research. At present, involvement is often limited in scope despite aspirations for high levels of involvement and partnership working. Involving people with dementia, their carers, and other stakeholders can have a positive impact on research, patient and public partners, and
researchers. Wider reporting of methods and facilitative strategies along with more formalized methods for recording and reporting on meaningful impact would be helpful so that all those involved—researchers, patients, and other stakeholders—can learn how we can best conduct research together.

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KEYWORDS
dementia; technology; patient and public involvement and engagement; co-design; coproduction

Introduction

Background

Worldwide incidence of dementia is increasing. In the United Kingdom alone, there are approximately 1 million people living with dementia, with this figure expected to double by 2050 [1]. The total cost of care for people with dementia in the United Kingdom in 2019 was £34.7 billion (US $44.1 billion), with an expected increase to approximately £94 billion (US $119.5 billion) by 2040 [2]. Technology is increasingly cited as a means of supporting people with dementia and their formal and informal carers and reducing some of this economic burden.

“Digitally enabled care” is a core component of the National Health Service Long Term Plan [3]—it is felt that technology has the potential to facilitate aging in place and reduce unplanned hospital admissions, with consequent economic benefits as well as improved health outcomes and quality of life [4,5]. Smart home systems, assistive technology devices, and other technologies are being developed with aims including supporting safety in people’s homes; enabling early detection of deterioration or ill health; supporting activities of daily living; and facilitating access to treatment, leisure activities, or social participation [5-8].

Despite rapid advancements in technology, the implementation of health and care–related technology for people with dementia has been slow, and there is increasing recognition of the many challenges in this area [9-11]. These challenges include ethical issues regarding privacy, autonomy, safety, and trust and the risk of creating or exacerbating health-related bias and inequality [12-16]. Researchers and technology developers must also understand the complex and changing needs of individual circumstances—there is a need for research to center on the person and their support network rather than on the technology itself if it is to be successful [17]. Therefore, understanding users’ perspectives is fundamental if we are to develop technologies that are acceptable, effective, and ethical [5,10,18,19]. One way to achieve this is through patient and public involvement (PPI).

PPI describes a partnership between patients, the public, and researchers in the research process itself. It is often described as research conducted “with” or “by” service users rather than research “about” or “for” them [20]. In addition to being seen as an ethical imperative, PPI aims to improve the efficiency and value of health research, recognizing that those with lived experience of health conditions or services will bring knowledge and experience that may increase the relevance of studies, improve recruitment and retention of participants, and improve dissemination of research findings [20-22]. PPI is now seen as an essential part of health and social care research—the Health Research Authority strongly advises PPI because of its likelihood of improving research quality and addressing the Research Ethics Committee’s key considerations [23]. Stakeholder engagement is a key part of the guidance from the International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use [24], and the National Institute for Health and Care Research (NIHR) makes it a condition of research funding [21]. The NIHR describes different approaches to involvement with increasing levels of power and influence for members of the public, from consultation (least power) to coproduction and user controlled (most power) [20].

PPI in dementia-related research has been gathering pace in recent years. Historically focusing more on the involvement of carers or other stakeholders, this has changed with more studies involving people with dementia themselves [25,26]. It is now well established that this supports and promotes a person-centered model of health care [27-31]. PPI should be conducted in a manner that promotes equality, diversity, and inclusion [20]. The NIHR emphasizes the need for researchers to enable the involvement of underrepresented groups and adapt their PPI approaches and activities to ensure accessibility for all groups affected by the project [32]. When planning and carrying out PPI in dementia research, this means the consideration of all groups affected by aging and dementia from diverse ethnic, racial, linguistic, geographic, and socioeconomic backgrounds.

The principle of stakeholder involvement is not unique to PPI. To understand the principles of terms such as “co-design” and “coproduction” within PPI, it is important to appreciate the context in which these terms have developed beyond just the health care sector. Within technology innovation, there has been a steady and increasing emphasis over the past 50 years on ensuring that a “human-centered” approach is taken to developing a new product or service [33]. Human-centered design emphasizes the need for fostering deep empathy with the people one is designing with, bringing end users into the design process as early as possible. Co-design can be a method of human-centered design. Co-design also stems from the 1970s, from a Scandinavian movement of participatory design, in which scientists, technologists, and design researchers acknowledged that “the people destined to use the system [must] play a critical role in designing it” [34]. Wider adoption of these human-centered design approaches has been seen in the last 15 years with methodologies such as the Design Council’s “Double Diamond” [35] helping visualize this iterative approach to innovation and wider adoption across nondesigners.

Considering the context of technology within health and social care, it is not surprising that practitioners from health and social care, it is not surprising that practitioners from health and
The objectives of this scoping review were as follows:

1. To describe the approaches to PPI used to date in technology-related dementia research, exploring who is involved, when, and how.
2. To describe the reported barriers to and facilitators of effective PPI in this area, and
3. To examine and report on the impact of PPI in this area.

Methods

Review Type
To gather the available literature in this area, a scoping review was conducted. Scoping reviews are often used in preference to systematic reviews in cases in which the body of literature is likely to be large and heterogeneous and to answer broad questions (such as “what is known about this concept?”) [44]. They are a useful way to map out the evidence, as opposed to systematic reviews, which often bring together literature on a particular subject with a more defined question, for example, about the efficacy of interventions [45]. The PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) guidelines [44] were followed to ensure appropriate reporting.

Search Strategy and Eligibility Criteria
A search strategy was developed and used a search string consisting of words related to dementia; technology designed to support health, care, or well-being; and PPI. Knowing that the terminology used varies considerably, definitions were kept broad, in particular of “patient and public involvement,” adapting and building on existing search strings from previous reviews [11,19,25,41,42]. Our definition of technology was similarly broad. Assistive technology may be described as “products or systems that support and assist individuals with disabilities, restrict mobility or other impairments to perform functions that might otherwise be difficult or impossible” [46]. We included any type of assistive technology as well as, more broadly, any technology that could be deemed to be a part of technology-enabled care (such as telehealth systems, telecare, telemedicine, and self-care apps) [47]. Inclusion criteria were developed (Textbox 2). PPI activities do not usually require ethics approval [20], yet we did not exclude those who sought ethics approval so as to ensure that we captured a range of approaches.

Textbox 1. National Institute for Health and Care Research “Guidance on co-producing a research project”—key principles.

1. Sharing of power—the research is jointly owned and people work together to achieve a joint understanding
2. Including all perspectives and skills—making sure the research team includes all those who can make a contribution
3. Respecting and valuing the knowledge of all those working together on the research—everyone is of equal importance
4. Reciprocity—everyone benefits from working together
5. Building and maintaining relationships—an emphasis on relationships is key to sharing power” [32]
Textbox 2. Inclusion and exclusion criteria.

<table>
<thead>
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<th><strong>Inclusion criteria</strong></th>
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<tr>
<td>Research about dementia (any type) or mild cognitive impairment</td>
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<tr>
<td>Research focused on technology designed to support the health, care, or well-being of people with dementia or their carers</td>
<td></td>
</tr>
<tr>
<td>Research describing ways in which patients or other stakeholders were actively involved in the research process itself (not only as research participants)</td>
<td></td>
</tr>
<tr>
<td>Full text available in English</td>
<td></td>
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<tr>
<td>Any publication date up to the end of 2022</td>
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<th><strong>Exclusion criteria</strong></th>
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<tbody>
<tr>
<td>Dementia only mentioned incidentally (eg, primary focus was Parkinson disease)</td>
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<tr>
<td>Technology in which target beneficiaries are not people with dementia, family or carers (eg, web-based education programs for health care workers)</td>
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<tr>
<td>Studies in which the patients or stakeholders are positioned as research participants only (eg, participants in a qualitative study) and are not actively involved in conducting the research</td>
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<tr>
<td>Reviews</td>
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<td>Opinion pieces</td>
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<td>Conference abstracts</td>
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**Data Sources and Charting Process**

The search was conducted in 4 databases: MEDLINE, PsycINFO, Embase (using Ovid), and CINAHL (using EBSCO). All papers published until the end of 2022 were included. Abstracts had to be available in English, and opinion pieces and reviews were excluded (refer to Multimedia Appendix 1 for the full MEDLINE search string). The search was last conducted in January 2023. References were exported to EndNote (Clarivate Analytics) and then to Covidence (Veritas Health Information) [48] for screening. After the removal of duplicates, 2 reviewers (PK and HL) screened the titles and abstracts against the eligibility criteria. The full texts were then further screened for eligibility. The 2 reviewers then independently charted the data from the included studies using a predesigned extraction table. For the first 10 papers, detailed discussions were held to clarify interpretations of PPI. Subsequent discussions were held to reach a consensus where required. A third author (CMA) was available if a consensus was not reached. As the purpose of this review was to provide an overview of existing evidence regardless of quality, no formal appraisal of methodological quality was conducted, in line with guidance [45]. Facilitators of and barriers to effective PPI were grouped and analyzed by the first author to draw out themes, which were then refined in discussion with the other authors. The impact of PPI, where described, was summarized and categorized into impact on the study, impact on the patient and public partners, and impact on the research team.

Initial database searching identified 1689 records, with an additional 5 found through hand searches following references from papers identified in the initial search. After removal of 695 (41%) duplicates, the remaining 999 abstracts were screened. Most of these (915/999, 91.6%) did not meet the eligibility criteria (were not about dementia, involvement in research, or technology). Determining whether papers described active involvement in the research process or merely involvement as participants was frequently unclear from the abstracts alone, and the authors erred on the side of inclusion here, in line with guidance. When analyzing full texts (84/999, 8.4%), not meeting the “involvement in research” criteria was the most common reason for exclusion (25/53, 47% of the papers excluded at this stage). A total of 31 papers were included in the scoping review. Figure 1 shows the flow of information for this process.
Results

Study Characteristics

Of the 31 papers included in the review (Table 1), most (n=18, 58%) were published between 2020 and 2022. Only 13% (4/31) were published before 2010. Most papers were authored by groups from multiple disciplines, for example, authors from design engineering backgrounds and health sciences and health care professionals. A total of 13% (4/31) of the studies included patient or public partners as coauthors [17,49-51]. In total, 21 of the studies originated in Europe, including 10 (48%) from the United Kingdom. Others were from Canada (7/31, 23%) and Australia (3/31, 10%), and 1 of the studies (1/31, 3%) included discussions of collaborations with groups in Ireland, Hong Kong, Brazil, and India [52].

Table 1 also outlines the stakeholders involved, the stage or stages of the research they were involved in, and the methods used for this involvement. When determining which stage of research stakeholders were involved in, the authors mapped involvement onto NIHR stages of research in which PPI might typically take place (eg, “design of the research”). Where Table 1 states “did not fit model,” this was because participants were positioned as both coresearchers and research participants. This is explored further in the following sections (Table 2).

A range of technologies were described with varied purposes (Textbox 3), apart from in Liddle et al [17], which did not focus on any one type.
Table 1. Study characteristics describing the technology, stakeholder involvement, stage of the research process in which the involvement took place, role of the stakeholder, and methods used to involve patients and the public.

<table>
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<tr>
<th>Study, year</th>
<th>Origin</th>
<th>Technology type and purpose</th>
<th>Stakeholders involved</th>
<th>NIHR(^a) stage of research in which PPI(^b) took place</th>
<th>Role of stakeholders involved</th>
<th>PPI methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Davies et al [53], 2019</td>
<td>United Kingdom</td>
<td>Website to provide information and peer and professional support for caregivers of people with dementia toward end of life</td>
<td>Research development group including 6 HCPs(^c), 2 members of a dementia charity organization, and 1 carer</td>
<td>Design of the research, undertaking and management of the research, and analysis of data</td>
<td>Refining the aims of the wider project and steering the project throughout</td>
<td>Steering group, group meetings, and 1:1 meetings</td>
</tr>
<tr>
<td>Kort and van Hoof [54], 2014</td>
<td>The Netherlands</td>
<td>Website with information about home modifications for people with dementia and their family caregivers</td>
<td>3 dyads (people with dementia+carer) and, separately, a group of 20 (carers or residential home staff)</td>
<td>Did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Observations, consultation rounds, and questionnaire</td>
</tr>
<tr>
<td>Schikhof et al [55], 2010</td>
<td>The Netherlands</td>
<td>Monitoring system in residential home for people with dementia to detect anomalies (eg, panicking and falls)</td>
<td>8 nursing home staff members and 13 family representatives (as proxies for people with dementia)</td>
<td>Did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Interviews, workshops for prototype testing, informal group meetings, and focus groups</td>
</tr>
<tr>
<td>Muñoz et al [56], 2022</td>
<td>Canada</td>
<td>Virtual reality game to support engagement in exercise for people with dementia</td>
<td>7 people with dementia or MCI(^d), 5 older adults without dementia, industry partners, and HCPs</td>
<td>Design of the research and undertaking and management of the research; elements did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Prototype testing and interviews (people with dementia or MCI and older adults), research group meetings (HCPs), and focus group (older adults without dementia, members of the research team, and industry representatives)</td>
</tr>
<tr>
<td>Eisapour et al [57], 2020, also with reference to Eisapour et al [58], 2018, and Eisapour [59], 2018</td>
<td>Canada</td>
<td>Virtual reality game to support engagement in exercise for people with dementia</td>
<td>HCPs and 3 people with dementia</td>
<td>One PPI representative involved in the main research team, presumed to be throughout; other elements did not fit model</td>
<td>Contributing to the iterative design process and involved in the main research team</td>
<td>Focus groups, observations, informal discussions in care home, and prototype testing; one member of the original focus group subsequently joined the research team</td>
</tr>
<tr>
<td>Hanson et al [60], 2007</td>
<td>Sweden</td>
<td>Home computer-based education and support program providing information, support tools, and exercises for people with dementia and their carers</td>
<td>7 people with dementia</td>
<td>Did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Group meetings to develop support program content and computer skills tuition for group members</td>
</tr>
<tr>
<td>Orpwood et al [61], 2004</td>
<td>Finland and others part of the ENABLE project</td>
<td>Various assistive technology devices: picture gramophone, calendar, tap monitor, lost object locator, gas cooker monitor, and night-light</td>
<td>Family carers (as proxies for people with dementia), paid carers, and older adults without dementia</td>
<td>Did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Informal group meetings and focus groups</td>
</tr>
<tr>
<td>Study, year</td>
<td>Origin</td>
<td>Technology type and purpose</td>
<td>Stakeholders involved</td>
<td>NIHR stage of research in which PPI took place</td>
<td>Role of stakeholders involved</td>
<td>PPI methods</td>
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<tr>
<td>Kort et al [62], 2019</td>
<td>The Netherlands</td>
<td>Various projects described: a smart pill box and real-time location systems (also a website as documented separately [51])</td>
<td>People with dementia and carers (past or current)</td>
<td>Did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Varied between projects: observations, consultations, storytelling, focus groups, and “thinking aloud” sessions</td>
</tr>
<tr>
<td>Hendriks et al [63], 2017, also with reference to Hendriks et al [64], 2014</td>
<td>Belgium</td>
<td>System for monitoring the mealtimes of people with dementia in a care home using sensors and data input by carers into the app</td>
<td>Industry representatives, academics and HCPs, professional carers, people with dementia, and informal carers</td>
<td>Did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Meetings, feedback sessions with HCPs or professional carers, integration of research team into daily life at care home, and group “mapping” sessions with people with dementia and carers</td>
</tr>
<tr>
<td>Orpwood et al [65], 2007</td>
<td>United Kingdom</td>
<td>Various technology projects: music player, video streaming of outside world scenes into the homes of people with dementia, conversation prompter for people with dementia, and “sequence support” tool for prompting ADLs</td>
<td>Varied across projects: people with dementia; carers; and other “user representatives,” including academics from the social sciences, engineering, and dementia organizations</td>
<td>Did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Varied across projects: user surveys, co-design workshops, observations, 1:1 user testing, and interviews</td>
</tr>
<tr>
<td>Savitch et al [66], 2012</td>
<td>United Kingdom</td>
<td>Website providing information about assistive technology for people with dementia</td>
<td>People with dementia and, separately, a steering group that also included 1 person with dementia</td>
<td>Steering group: detail not given; elements did not fit model</td>
<td>Contributing to the iterative design process (people with dementia); steering group also provided input throughout</td>
<td>Interviews, focus groups, co-design workshops, and involvement in steering group meetings</td>
</tr>
<tr>
<td>Perkins et al [52], 2022</td>
<td>United Kingdom, Ireland, Hong Kong, India, and Brazil</td>
<td>Web-based delivery of CST</td>
<td>4 people with dementia, 4 family carers, 4 service managers, and 8 CST group facilitators from the United Kingdom and Hong Kong; additional stakeholders in India</td>
<td>Design of the research and undertaking and management of the research</td>
<td>Designing and developing a protocol (people with dementia, carers, service managers, and CST facilitators) and field-testing of the protocol and subsequently giving feedback following testing (CST facilitators)</td>
<td>Focus groups (web-based); CST facilitators then tested the protocol with people with dementia in 5 countries; interviews with CST facilitators following field-testing</td>
</tr>
<tr>
<td>Hwang et al [67], 2015</td>
<td>Canada</td>
<td>Animated videos for prompting people with dementia with ADLs</td>
<td>6 family carers</td>
<td>Did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Co-design workshops first to develop the concept and then refine the designs; 2 home visits for paper prototype evaluation</td>
</tr>
<tr>
<td>Oksnebjerg et al [68], 2019</td>
<td>Denmark</td>
<td>An app to support self-management for people with dementia, including a calendar and diary</td>
<td>4 people with dementia, 4 family carers, and 4 paid carers</td>
<td>Did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Co-design workshops</td>
</tr>
<tr>
<td>Study, year</td>
<td>Origin</td>
<td>Technology type and purpose</td>
<td>Stakeholders involved</td>
<td>NIHR&lt;sup&gt;a&lt;/sup&gt; stage of research in which PPI&lt;sup&gt;b&lt;/sup&gt; took place</td>
<td>Role of stakeholders involved</td>
<td>PPI methods</td>
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<tr>
<td>Hung et al [50], 2021</td>
<td>Canada</td>
<td>PARO, a commercially available robot seal that uses AI&lt;sup&gt;c&lt;/sup&gt; to support the social and emotional needs of the people with dementia interacting with it</td>
<td>5 “patient and family partners”</td>
<td>Undertaking and managing the research, analysis of data, and dissemination of research findings</td>
<td>Supporting data collection, thematic analysis of data, and authoring of the paper</td>
<td>Supporting data collection with some patients or particular settings, analysis (4 × 1-h thematic analysis group sessions), and coauthoring the paper</td>
</tr>
<tr>
<td>Rathnayake et al [37], 2021</td>
<td>Australia</td>
<td>A mobile health app that provides information about dementia, care strategies, and tips for managing ADLs</td>
<td>Carers, HCPs, and IT experts</td>
<td>Did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Web-based survey, interviews, and co-design workshops</td>
</tr>
<tr>
<td>Kowe et al [69], 2021, also with reference to Kowe et al [70], 2022</td>
<td>Germany</td>
<td>Sensor-based activity management system</td>
<td>6 family carers</td>
<td>Analysis of data</td>
<td>Supporting thematic analysis of interview data</td>
<td>30-min group analysis session or workshop</td>
</tr>
<tr>
<td>Daly Lynn et al [51], 2021, also with reference to Daly Lynn et al [71], 2019, and Daly Lynn et al [72], 2022</td>
<td>United Kingdom</td>
<td>Smart home system for people with dementia in supported living</td>
<td>Peer researchers: 7 older adults without dementia; steering group: including 2 people with dementia, 1 family carer, and 2 dementia organization employees</td>
<td>Undertaking and management of the research, analysis of data, and dissemination; steering group: detail not given</td>
<td>Peer researchers: conducting interviews with research participants and supporting data analysis; steering group: ensuring that the voice of older people was central to the project and coauthoring the paper</td>
<td>2-d training for peer researchers, conducting interviews jointly with a member of the research team, group thematic analysis session, and evaluation forms</td>
</tr>
<tr>
<td>Banbury et al [73], 2021</td>
<td>Australia</td>
<td>Virtual support program to provide information and peer support for carers of people with dementia</td>
<td>6 family carers</td>
<td>Did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Co-design workshops and group meetings (all virtual) following the Double Diamond approach</td>
</tr>
<tr>
<td>Fox et al [74], 2022</td>
<td>United Kingdom</td>
<td>A mobile health app that delivers memory tests throughout the day to monitor cognition changes</td>
<td>7 people with dementia, 7 family carers, and a PPI officer</td>
<td>Did not fit model</td>
<td>PPI officer as “proxy patient representative” in the research team; people with dementia and carers contributed to the iterative design process</td>
<td>Co-design workshops; PPI officer part of the main research group</td>
</tr>
<tr>
<td>Rai et al [75], 2020</td>
<td>United Kingdom</td>
<td>Virtual delivery of CST</td>
<td>People with dementia and family carers</td>
<td>Did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Consultation meetings and co-design workshops</td>
</tr>
<tr>
<td>Owens et al [76], 2020</td>
<td>Consortium spanning organizations in Europe and the United States</td>
<td>Remote monitoring and measurement technologies for people with dementia</td>
<td>People with dementia and family carers</td>
<td>Did not fit model</td>
<td>Design of the research</td>
<td>Provision of feedback on researchers’ literature review, group discussions, workshops, and other meetings of the patient advisory board</td>
</tr>
<tr>
<td>Study, year</td>
<td>Origin</td>
<td>Technology type and purpose</td>
<td>Stakeholders involved</td>
<td>NIHR stage of research in which PPI took place</td>
<td>Role of stakeholders involved</td>
<td>PPI methods</td>
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</tr>
<tr>
<td>Stavropoulos et al [77], 2021</td>
<td>Greece, with involvement from multiple countries across Europe</td>
<td>A range of commercially available wearable devices</td>
<td>11 people with dementia and 10 carers from 11 countries across Europe</td>
<td>Design of the research</td>
<td>Reviewing devices and providing information to guide the design of future research, aiming to make it more relevant and accessible and improve participant experience</td>
<td>One-off 2.5-h session including presentations, roundtable discussions, hands-on experimentation, and voting</td>
</tr>
<tr>
<td>Liddle et al [17], 2022</td>
<td>Australia</td>
<td>No specific technology discussed—study explored factors related to engagement with technology for people with dementia and carers</td>
<td>15 people with dementia and carers (living experience expert reference group); 4 of them (2 people with dementia and 2 carers) were also members of the core research team and were listed as coauthors</td>
<td>Design of the research, undertaking and management of the research, analysis of data, and dissemination of research findings</td>
<td>Setting research priorities, supporting the design of interviews and developing the topic guide, thematic analysis of data, reflexivity sessions with the research team, and writing up of the study</td>
<td>Group sessions, discussions and meetings with reference group, group analysis sessions, and discussions of reflexivity</td>
</tr>
<tr>
<td>Hassan et al [78], 2017</td>
<td>United Kingdom</td>
<td>A range of commercially available wearable devices</td>
<td>&gt;30 in total: people with dementia or MCI, carers, people with early-onset dementia (aged &lt;65 y), and older adults without dementia</td>
<td>Design of the research</td>
<td>Contributing to research design (producing guidelines to optimize design and improve acceptability) and informing procurement decisions</td>
<td>Exploratory workshops in groups according to diagnosis (people with dementia+carers, people with early-onset dementia, and older adults without dementia), individual 1:1 meetings (people with MCI), and opportunities for stakeholders to try the devices at home</td>
</tr>
<tr>
<td>Jacklin et al [79], 2020</td>
<td>Canada</td>
<td>A wearable (wristband) for capturing movement-related behaviors (eg, falls, wandering, and agitation)</td>
<td>Indigenous community representatives, carers, community elders, and health and social care workers</td>
<td>Did not fit model</td>
<td>Informing the design of the research to ensure that culturally appropriate and inclusive methods are used</td>
<td>Community-based participatory research approach, focus groups (with carers), and preparation meetings with the Community Advisory Council to plan the research and ensure that appropriate methods are used</td>
</tr>
<tr>
<td>Ghafurian et al [80], 2022</td>
<td>Canada</td>
<td>App to support professional carers in communicating with people with dementia in nursing homes</td>
<td>17 professional carers and 1 nurse</td>
<td>Did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Survey, focus groups, and co-design workshops</td>
</tr>
<tr>
<td>Berge et al [81], 2022</td>
<td>Norway</td>
<td>Tablet-based music app primarily used as a relational tool to support positive interactions between people with dementia and carers</td>
<td>People with dementia or other psychiatric conditions, carers, and HCPs</td>
<td>Did not fit model</td>
<td>Contributing to the iterative design process</td>
<td>Observations, interviews, and 2 focus groups; user testing of a prototype with 4 older adults with dementia or other psychiatric conditions</td>
</tr>
</tbody>
</table>
### Table 2. Patient and public involvement (PPI) in the different stages of research as recommended by the National Institute for Health and Care Research [21] (n=31).

<table>
<thead>
<tr>
<th>Stage of research</th>
<th>Studies with PPI at this stage, n (%)</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design of the research and development of the grant application</td>
<td>7 (23)</td>
<td>PPI representatives (here a “Patient Advisory Board”) supported research planning and design, giving feedback on relevance and priorities [76].</td>
</tr>
<tr>
<td>Undertaking and management of the research</td>
<td>7 (23)</td>
<td>PPI representatives, here termed “peer researchers,” collected data for the study interviewing people with dementia [51].</td>
</tr>
<tr>
<td>Analysis of data</td>
<td>6 (19)</td>
<td>PPI representatives were part of interview data analysis and discussions of reflexivity [17].</td>
</tr>
<tr>
<td>Dissemination of research findings</td>
<td>4 (13)</td>
<td>PPI representatives coauthored the paper [49].</td>
</tr>
<tr>
<td>Did not fit model</td>
<td>21 (68)</td>
<td>PPI representatives were positioned both as co-designers along with the research team and as research participants testing the prototype [81].</td>
</tr>
</tbody>
</table>

**Notes:**

aNIHR: National Institute for Health and Care Research.
bPPI: patient and public involvement.
cHCP: health care professional.
dMCI: mild cognitive impairment.
eADL: activity of daily living.
fCST: cognitive stimulation therapy.
gAI: artificial intelligence.
### Types of technologies and their purposes.

<table>
<thead>
<tr>
<th>Technology Type</th>
<th>Purposes</th>
</tr>
</thead>
</table>
| Sensor monitoring systems (including smart home monitoring systems) | • Safety alerts  
• Monitoring (of health, activity, behavior, and cognition) |
| Wearables       | • Safety alerts  
• Monitoring (of health, activity, behavior, and cognition) |
| Apps            | • Monitoring (of health, activity, behavior, and cognition)  
• Self-management  
• Exercises  
• Information provision or education  
• Supporting social interaction  
• Social and emotional well-being |
| Miscellaneous assistive technology devices (not wearables and not app based, eg, gas cooker monitor or smart pill box) | • Safety alerts  
• Self-management  
• Leisure access  
• Supporting social interaction  
• Social and emotional well-being |
| Websites        | • Information provision and education  
• Accessing peer support  
• Accessing professional support |
| Videoconferencing platforms | • Therapy delivery  
• Information provision and education  
• Accessing peer support |
| Virtual reality games | • Exercises |

### Who Was Involved?

Studies involving only 1 stakeholder group in their PPI activities were in the minority (5/31, 16%), and many (17/31, 55%) involved ≥3 different stakeholder groups, with the range of these shown in Multimedia Appendix 2. Family carers were the most frequently involved group (27/31, 87% of the studies), followed by people living with dementia (23/31, 74%). Most papers gave little detail about recruitment methods or the background of their PPI representatives. Where papers mentioned attempts to recruit diverse viewpoints, this generally referred to involving different stakeholder perspectives (eg, patients as well as carers and health care professionals), and where inclusivity was dwelled on, this usually referred to the involvement of people living with dementia. Some papers mentioned the linguistic mix or geographical spread of those involved, in particular [52,76,77]. Discussions of racial or ethnic diversity within PPI groups were almost entirely absent. There was one exception [79] in which the inclusion of First Nations representatives was central to the study.

### When Were They Involved?

The NIHR recommends PPI throughout the research cycle, highlighting in particular 4 key areas where PPI can take place [21]. The studies in this review were mapped to these stages, as shown in Table 2. In total, 29% (9/31) of the studies had involvement from patient and public partners at multiple stages throughout the research cycle [17,49-53,56,57,66], although...
sometimes a lack of detail on methods meant that this multistage involvement was presumed (eg, description of a steering group providing oversight “at key milestones” [66] without further description).

As shown in Table 2, a total of 68% (21/31) of the sources did not fit into this NIHR description. These were papers describing a co-design or participatory design process in which the stakeholders involved were both the “co-researchers” or “co-designers” and yet were also positioned as research participants. Typically, these studies involved stakeholders in the iterative design process of a technology prototype. Participants collaborated with the research team on the design process while also being positioned as study participants, for example, being observed testing prototypes or providing feedback as part of interviews. Their involvement could not clearly be classified as designing the research (the study protocol having been designed before their input) or quite as “undertaking/managing the research” as they were the targets of data collection, not involved in the process of collecting them themselves. However, as the authors positioned these stakeholders as collaborators or co-designers along with the research team, these studies were not excluded in the same way that others were when they were more clearly set up as qualitative studies (eg, a focus group to collect end users’ views on technology where ethics approval had been sought for this research process).

How Were They Involved?
Approaches to PPI varied (Table 1). Every paper mentioned at least one form of group activity for their involvement work. Varying terms were used for this—co-design workshops and focus groups were the most frequently mentioned, along with group meetings, group discussions, prototype testing sessions, consultation rounds, group consultations, informal meetings, group feedback sessions, and workshops. Most papers (26/31, 84%) described more than 1 type of activity. In addition to group activities, many conducted interviews [37,49,51,52,55,56,65,66,81,82], observations [54,57,62,65,81,82], or surveys or questionnaires [37,54,65,80,82,83]. A total of 19% (6/31) of the studies set up steering groups that were regularly involved in the research process, described variously as a research development group [53], living experience expert reference group [17], steering group [51,66,71], and patient advisory board [76,77], although details were minimal or absent about what this entailed. A total of 19% (6/31) of the papers [17,49-51,74] described some form of integration of patient and public partners (or, in 1 case, a PPI officer as proxy for the PPI group itself [74]) into the main research team, although, again, details were often very minimal about what this entailed. In total, 13% (4/31) of the papers were coauthored by patient and public partners [17,49-51].

Barriers to and Facilitators of Effective PPI
A total of 74% (23/31) of the papers included at least some reporting of either facilitators or barriers faced when conducting PPI. In many cases, this reporting was minimal, for example, listing one challenge the team faced. Only 26% (8/31) of the papers had what we considered to be a more thorough discussion of barriers or facilitators [51,56,60,63,64,69,70,73,74,78] (the papers by Hendriks et al [63,64] refer to the same study, as do those by Kowe et al [69,70]). Barriers and facilitators were grouped into themes (Textboxes 4 and 5). Facilitators often focused on ways to achieve richer, more meaningful involvement, for example, working with multiple stakeholder groups and creating a trusting, supportive group dynamic. The barriers identified principally regarded issues with working with dementia as a condition as well as practical issues such as time and budget.
Textbox 4. Facilitating effective patient and public involvement (PPI).

**A person-centered approach: choices and adaptability in involvement**

1. Prioritizing the well-being and positive experience of those involved [60,77]
2. Offering choices and being led by those involved (how to take part, methods, environment, and level of involvement) [17,69,82]
3. Use of extra time and flexibility for people with dementia, including modification of activities to make them more accessible, acknowledging that there will be no *one-size-fits-all* [60,77]

**Building the group: rapport, trust, and equality**

1. Spending time developing group relationships, finding commonalities, and building connections within the team [51,73,77]
2. Building time for chatting and eating together. Informality helps build rapport and flatten hierarchies [60,63,65]
3. Use of a nonresearcher as facilitator [69]
4. Being face-to-face rather than web-based [77]
5. Use of small groups [60]

**Multiple viewpoints**

1. Including views from multiple stakeholder groups as a way of improving the quality of involvement work and the richness of the data gathered [78,82]
2. Planning a range of methods to recruit and work with different groups (carers, people with dementia, health care professionals, and others) seen as important [82]
3. Considering ways of involving seldom heard groups—from practical adaptations (researchers traveling and not asking patient and public partners to do so) [80] to cultural considerations [79]
4. Group members from different backgrounds learning from each other [65]
5. Support to access different groups was beneficial (eg, working with community organizations or having managerial support to enable staff to take time away from their main role [56])

**The right environment**

1. Considering accessibility and proximity to local amenities and transport [60,78]
2. Considering who owns the environment—researchers going to those involved (eg, integrating into nursing home environment) may help create a greater sense of equality, flatten hierarchies, and support researchers’ understanding of the group they are working with [56,63,80]
3. Being face-to-face enabled hands-on workshops, improved group dynamics, and reduced technology barriers [77,78]
4. Web-based environments enable geographically diverse groups to come together and may keep discussions more focused [73]

**Support and training**

1. Having facilitators or members of the research team who are skilled and experienced working with people with dementia [60,78]
2. Providing training for patient and public partners (eg, data collection, thematic analysis, and computer skills) [51,60]
3. Supporting patient and public partners with adequate time to reflect and debrief with members of the academic research team [51]
4. Using paper prototypes to overcome technology barriers [66]
5. Providing adequate support for people with dementia (family carers [60] or modified activities [60,77,78])

**Pragmatism and compromise**

1. Proxy involvement (of family, PPI officers, and nursing home staff) used in place of people with dementia (or people with moderate to severe dementia) in cases in which their involvement was not seen as feasible [55,61,74]
2. One-to-one sessions found to be easier to organize than group sessions [53]
3. Virtual meetings may be easier to organize than face-to-face meetings [73]
Textbox 5. Barriers to effective patient and public involvement (PPI).

The nature of dementia
1. Cognitive impairments seen as too great a barrier to attempt PPI with people with dementia [55,61]
2. Input from people with dementia described as very minimal [62]
3. Attempts at adaptations unsuccessful [63,64]
4. Variations in presentation making it difficult to plan a particular approach or manage a group [63,64]
5. Carers and people with dementia both overestimating the abilities of the latter [63,64]
6. Unreliable historians— for example the challenge of interpreting someone’s account of their ability to participate in activities of daily living while they also recount recent interactions with long-dead relatives [63,64]
7. The emotional load faced by researchers working with this group, including challenges such as being asked for support or advice out of their scope [63,64]

Inequality of relationships within the group
1. Some authors highlighted issues with patient and public partners feeling undervalued or not equal within the team; this applied to those without dementia [51,63], though dementia was also seen as an additional barrier to a sense of equality [63,64]
2. Lack of payment for PPI also contributed to this, as well as the limited scope or lack of defined roles and responsibilities for patient and public partners [63,69]

Time pressures
1. Researchers’ time pressures—co-design or other involvement activities as time-consuming processes that can be difficult to manage alongside the time pressures of a research study [75,81,83]
2. Family carers’ time pressures—busy schedules and stressful lives [37,69]
3. Staff time pressures—nursing home staff and health care professionals’ strict shift patterns and limited flexibility for time away from work [80], in some cases exacerbated by the COVID-19 pandemic [52]
4. Limited time resulting in reduced or inadequate training for patient and public partners [51,69]
5. Rapport building in the group suffering as a result of lack of time [51,56]

Recruitment and diversity
1. Small numbers of people involved resulting in reduced diversity of opinions and a poorer representation of stakeholders [56,57,75]
2. Challenges with generating interest in the study or reaching particular groups [74,78] and COVID-19 causing staffing pressures [52] and a lack of face-to-face options for people with dementia [82]

Processes and communication
1. Communicating complex content (the ethics of smart homes, technology use, and design processes) was particularly challenging for people with dementia [62,68]
2. Use of jargon terminology by researchers was a barrier for all patient and public partners (not only those with dementia) [63,69]
3. Methods of communication—use of phone for people with dementia was limiting [82], and sending too many emails was unpopular [56]
4. Processes for PPI members experienced as boring or repetitive (eg, completing multiple assessments), especially when combined with a lack of communication about the purpose or the results of their input [56]
5. Lack of involvement and communication early in the study resulting in stakeholders having less of a connection or understanding of the project or feeling that their contributions were less valued [51,63]

Impact of PPI
Although most papers (28/31, 90%) implied or briefly commented that stakeholder involvement had some impact on their study (usually on the iterative design process), this was sometimes without any description of what the impact was. Where any details were given, as was the case in 52% (16/31) of the papers [51,54-57,60,61,63,69,73-79], the results are summarized in Textbox 6.
Textbox 6. Impact of patient and public involvement (PPI) activities.

Impact on the research

- PPI activities helped set groups’ research agendas, with clearly defined stakeholder priorities for research [76,77]. PPI data were identified as something that can be shared with and used by the wider research community when planning research [77].
- Involvement in research design resulted in a set of recommendations that the authors hope will improve the acceptability for research participants [78] and in specific cultural adaptations and approaches [79].
- Involvement in data collection was reported as adding richness to the data on account of the rapport and connections that peer researchers built with the people with dementia they were interviewing [51].
- Many papers (21/31, 68%) commented that the methods used (eg, co-design and participatory design) had an end result that was in some way grounded in the views or priorities of users but often with minimal detail. In total, 13% (4/31) of the papers [55,57,74,75] gave detail about the extent to which user groups drove the development or design of technology, reflecting on the value of their input.
- Coresearcher involvement in a thematic analysis workshop made for a more robust analysis, with differing perspectives between the research team and coresearchers showing the need for more PPI at the analysis stage in the future [69]. The limited impact that PPI activities had at the analysis stage was also reflected on, citing inadequate time and training for coresearchers resulting in brief and surface-level group analysis sessions [51,69].

Impact on patient and public partners

- Feedback on positive experiences of patient and public partners was provided in general terms [74,78]. Positive relationships between team members were developed, with feelings of mutual respect as well as the value of finding connections being reported [51,56,73].
- Some reported empowerment and satisfaction with the project and their role in it [54,60,61].
- Patient and public partners developed new skills [51].
- Negative experiences were reported on, including finding tasks boring or repetitive or processes complex [56]. Some papers also reported that patient and public partners felt underinvolved [51] or not treated as equal partners [63].

Impact on the academic research team

- Researchers gained a deeper understanding of the needs and priorities of the group they were seeking to conduct research with and for [79].
- Researchers developed a sense of connection with and respect for other disciplines or stakeholders they had not previously worked with [60,65].
- One paper reflected on the emotional burden associated with close working with people with dementia and the need for support for researchers as well as the people with dementia themselves [64].
- The initial challenges of stepping back when sharing responsibility with peer researchers was reported on, which became easier with experience [51].

In general, no formal methods were used for evaluating the impact of PPI activities. Where papers reported on impact, it was usually limited to the authors’ reflections, including when reporting on the impact on patient and public partners. In the case of 13% (4/31) of the papers [51,56,63,73], the authors reported seeking direct feedback from those who had been involved, for example, in the form of interviews; evaluation forms; or, in 3% (1/31) of the studies, a much more extensive retrospective analysis using formalized methods [63].

Discussion

Principal Findings

In this scoping review, we set out to explore the concept of PPI in technology-related dementia research. The papers reviewed in this study revealed that dementia researchers are embracing PPI, with varied and sometimes ambitious methods, values centered on inclusivity and coproduction, and involvement of a range of stakeholder groups. We found that approaches often blurred boundaries between those involved as “researchers” and those involved as “participants” so that most studies’ (21/31, 68%) PPI activities did not fit into a strict definition of PPI, for example, as set out by the NIHR [32]. Although the involvement activities being undertaken demonstrate this to be a rapidly expanding and developing field, the brevity in the reporting of such activities (often without comments on the impact of PPI) perhaps highlights the need for clearer reporting guidelines. Where mentioned, the impact of PPI was generally reported as being positive on research quality, patient and public experience, and the learning experiences provided to researchers. We comment further on our objectives in the following sections.

Objective 1: To Describe the Approaches to PPI Used to Date in Technology-Related Dementia Research (Exploring Who Is Involved, When, and How)

We found that there was a narrative across many of the included papers about the value of involvement and coproduction methods, with many authors describing their aspiration for high levels of involvement with a sense of partnership and equality with stakeholders. A few consciously excluded people with dementia from this aspiration, citing cognitive impairments as making it either practically or ethically too challenging to involve this group. These views were chiefly expressed in older papers (before 2010). More recent papers were broadly inclusive, with some describing their efforts to involve people with dementia along with other stakeholder groups such as...
carers, health care professionals, and older adults without dementia. Sometimes, these groups were involved in similar ways, and sometimes, there were 2 very separate approaches, for example, a set of workshops with people with dementia and carers and more extensive involvement of health care professionals or others without dementia in the research process (eg, playing a role in designing the protocol or as members of a steering group). The fact that a significant majority (26/31, 84%) involved more than one stakeholder group, with many involving ≥3 groups (17/31, 55%), reflects the value placed on hearing from multiple viewpoints.

Despite this widespread acknowledgment of the value of collaborative or coproduction methods, it was not always clear from the papers to what extent their methods reflected these values. Some used methods that perhaps lend themselves better to a consultative approach (such as one-off focus groups or surveys) rather than a collaboration or coproduction approach [20]. Consultative methods have some value in enabling researchers to find out more about people’s views and experiences. They are also relatively easy to organize (often one-off events as opposed to longer-term involvement), meaning that they are a practical way of hearing from a wide range of stakeholders [20]. However, these methods mean that involvement will always be more limited in scope—there is no 2-way discussion, and there is the risk of disengagement from stakeholders who feel that their views are not being listened to [20], as indeed was reported by Hendriks et al [63]. Where stated methods or approaches may have enabled more of a partnership approach to take place (eg, the use of a series of co-design workshops or involvement of a steering group), the brevity of the write-up often prevented us from understanding whether or how this happened.

The most common methods of involvement were through some form of group activity such as focus groups, workshops, prototype testing sessions, or roundtable discussions. Every paper mentioned some form of group activity such as these, with or without other methods. Involvement often occurred at just one stage of research—most commonly, this was contributing to the design of a prototype but with no involvement either before or after this (eg, in protocol design, recruitment, analysis, or dissemination), although there were exceptions to this, with studies involving patients or the public throughout multiple stages of the research.

Most studies (26/31, 84%) used multiple methods of involvement. There will be practical reasons for using different methods, some suiting particular groups or settings more than others, especially when we consider involving people with dementia and the flexibility of approach that this requires. Tiersen et al [82] described many different methods in their paper, reflecting that this “resulted in triangulation of investigators, methods and data sources to develop a more comprehensive understanding of the phenomena being studied.” The use of multiple methods also allowed for more flexibility of involvement, with some able to take on a more active or sustained role than others as able or desired. This was cited as an aspiration or suggestion for future PPI by groups who did not have such flexible approaches, such as Kowe et al [69]. The paper by Liddle et al [17] described the flexibility of roles and high levels of involvement. Their “Living Experience Expert Reference Group” involved 15 people with dementia and carers, of whom 4 (2 people with dementia and 2 carers) were also integrated into the main investigator team. Roles included helping set research priorities, developing the interview topic guide, analysis of data, reflexivity sessions, and the write-up of the study. Shadarevian et al [49] and Hung et al [50] also described the integration of stakeholders into the main research group, mentioning roles in undertaking and managing the research along with analysis and dissemination, although there was little detail about the methods used for this involvement. PPI in data collection was rare. It was described in most depth by Daly Lynn et al [51], who worked with “peer researchers” (older adults without dementia) to interview research participants with dementia about their experiences with smart home living, with an insightful write-up detailing both the positive experiences and the challenges they faced.

Finally, although the notion of diverse viewpoints being included in PPI was often celebrated, this almost always referred to the inclusion of a variety of stakeholder groups (eg, patients, carers, and health care professionals). In general, there was very little explicit discussion of the demographics of PPI representatives. To reduce health-related inequalities and bias, researchers should consider not only how to involve people with dementia but also the demographics of this heterogeneous population, explicitly seeking ways to involve underrepresented groups.

**Objective 2: To Describe the Reported Barriers to and Facilitators of Effective PPI in This Area**

The general lack of evaluation or reflections on barriers to and facilitators of involvement means that the themes described in this paper result from a minority of studies, with most derived from just 26% (8/31) of the studies [51,56,60,63,69,73,74,78]. Themes drawn out broadly matched those frequently documented in the literature [11,25,41,42], in particular barriers such as time and budget, recruitment issues, and the specific challenges of adapting activities to be suitable for people with dementia.

Facilitators tended to focus on the manner in which activities were carried out (eg, how informality helped flatten hierarchies) rather than on specific methods or approaches, such as focus groups or interviews. The themes here mirror the key principles of coproduction outlined by the NIHR [21,32]. The NIHR emphasizes that coproduction does not require a specific method but a more nuanced focus on interpersonal skills, relationship building, and power sharing (Textbox 1) [32]. However, although many papers stated the need for approaches using these principles or claimed to have worked with such values in mind, details about what was done were often limited. We would welcome further and more detailed reporting on these activities so as to build the knowledge base among research teams and enable more high-quality PPI to be conducted in the future with this population. As also emphasized by Hendriks et al [64], there is a need for more than anecdotal evidence in the literature about how to involve people with dementia—the lack of guidelines or a strong evidence base makes progression challenging.
The barriers identified reflect the challenging nature of PPI in technology-related dementia research. Time and resources were frequently cited as limiting factors. Some studies avoided the challenge of making PPI activities accessible to people with dementia by not involving them at all. Hendriks et al [64] detailed the challenges of involving people with dementia in a particularly frank manner. They reported on the difficulty of sufficiently modifying activities to make them accessible, difficulties with variability in dementia presentations, and overestimation of abilities by people with dementia and their family carers. They went as far as to say that “the differences between the designer and the person to design for are too big to speak about equality in participation” [64]. A few papers highlighted the complex topics under discussion (eg, smart home technology, ethics, and design processes) and the difficulty of translating these issues into something someone with dementia could understand and contribute to [62,63,68]. Kort et al [62] went as far as to say that the complexity of content meant that input from people with dementia was very basic, commenting that “the actual participation in the project was deemed more important than the actual contribution.” Although pessimistic sounding in tone at times, these honest admissions of the challenges faced and the inability of researchers to overcome them to a meaningful degree help the research community understand the current landscape of PPI in technology-related dementia research. They reinforce the need for significant investment to be made for the involvement of people with dementia to be successful. This is not merely in the creation of accessible resources or the provision of the right environment. Rather, it may be that significant cultural shifts need to take place for researchers to be able to plan and conduct effective coproduction based on the key principles of power sharing, inclusivity, respect, reciprocity, and relationship building [32]. It seems likely that researchers would benefit from significant training and support in understanding power dynamics and coproduction as well as support to learn more about how to work with people with cognitive impairments.

**Objective 3: To Examine and Report on the Impact of PPI in This Area**

Papers with more than a brief comment on the impact of involvement were scarce in this review, mirroring the findings by Suijkerbuijk et al [41] as well as the findings of those studies considering PPI in dementia research more broadly [25,26,42,84]. A few papers, notably those by Daly Lynn et al [51], Muñoz et al [56], Banbury et al [73], and Hendriks et al [63,64], provided valuable discussions and evaluations of impact.

Where papers reported on the impact of their involvement work, the results were largely positive. The studies demonstrated that PPI can have a positive impact on research quality at multiple stages of the research cycle as well as on those taking part. To achieve this, the authors reflected on the need to involve multiple stakeholder groups and use multiple methods of involvement to provide a person-centered and flexible approach in which people feel well supported and valued for their contribution. To do this evidently requires significant investment of time and resources. Even those papers detailing what we considered to be relatively high levels of involvement spoke about the need for more time and resources, for example, to improve levels of training or offer more formalized PPI roles [51,69].

It was helpful to see negative experiences with PPI also reported [56,63,64]. These are often missing from the literature [85] but provide helpful learning points. Another area that received little attention is the emotional impact of PPI on researchers. This was commented on briefly by Hendriks et al [64] but otherwise did not feature in the studies we reviewed, although it has been noted as a feature of PPI in dementia research more broadly [43,84]. The emotional impact on researchers might be seen as both positive and negative—as a research community, it would be helpful to recognize and value the learning and increased empathy that can come from close working with patient and public partners. It is also important to recognize the potential distress or emotional burden felt by researchers, which might be associated with this relationship, in particular for those unused to working with people in cognitive decline [43]. It is important that future studies consider these impacts and that researchers as well as patient and public partners have access to adequate training and support.

Across most studies (27/31, 87%), formal or standardized methods were not used to capture impact. Reporting was generally limited to the authors’ personal reflections. In only 13% (4/31) of the papers did the authors report seeking direct feedback from those who had been involved, for example, in the form of interviews or evaluation forms [51,56,63,73]. Hendriks et al [63] included a detailed evaluation of impact. This team retrospectively analyzed their participatory design process, mapping out the decision-making process at each stage of the project and considering the extent to which co-researchers had been involved and, therefore, whether participation had been truly meaningful. They also interviewed some of those who had been involved and analyzed themes that emerged. There is a risk that reporting on the impact of PPI can lead to an overvaluing of that which is easily measured but of little meaning (such as the number of people involved) instead of these more complex issues such as research culture or power relations [85]. Therefore, this example by Hendriks et al [63] reflecting on and evaluating the power dynamics at play and the processes that took place is particularly commendable.

In the future, it would be helpful for all involved—researchers, patients, and the public—if there were more recording and reporting of the impact of involvement to help all parties understand if, when, how, and why partnership working is beneficial [20,43]. Capturing this in a meaningful way is the challenge ahead of us [85,86]. A focus on the dialogue and the learning is felt to be helpful—Russell et al [85] recommend exploring “the complexity and richness of this relationship, using methods that emphasise illumination rather than measurement, and asking when, why, and with whom the dialogue happens or fails to happen.”

**Defining PPI: Challenges We Faced in This Review**

One of the challenges we faced was the varying terminology and approaches used to involve groups in research. We applied a broad definition of “involvement” and, therefore, included papers using co-design or participatory design processes, as described, for example, by Hendriks et al [63]. Within a
participatory design approach, there is a deliberate blurring of
the roles of “designer” and “end user.” When written up in a
research context, this can lead to a blurring of the roles of
researcher, designer, end user, and research participant. From
a PPI perspective, it is not usually considered appropriate for
people involved in research to also be research participants as
this can compromise both the researcher and person involved
[20]. However, the NIHR gives the example of participatory or
action research as a possible exception to this rule, and it was
often these types of studies that we reviewed. Nevertheless, it
was often difficult to determine which studies met our inclusion
criteria, in part because of this mixing of roles and because of
lack of detail in the methodology sections. Where studies explicitly used qualitative research methods (stating a qualitative
approach and collecting data for analysis with appropriate ethics
approval), they were excluded from this review. However,
details were often missing, or sometimes subsections of a study
appeared to be qualitative, whereas other sections were framed
more like PPI activities. Terminology could not be relied on as
it was applied inconsistently among studies. Similarly,
information about ethics applications was not always available,
and we did not use this as part of the inclusion and exclusion
criteria. Had we used a stricter definition of PPI, we would have
excluded a significant portion of the literature (21/31, 68% of
the studies in this review). We felt that doing this would result
in a misrepresentation of the type of involvement work being
carried out and in missing key learning points from these studies.

Strengths
We used a comprehensive search strategy considering all types
of technology, all types of dementia, and many terms for “patient
and public involvement” to reflect the different types of
involvement in the field, building on search strategies from
other reviews [11,19,25,41,42] that at times had been narrower
in scope (eg, looking at “patient and public involvement” but
not “co-design”). The 2 reviewers overcame the difficulty of
defining PPI through regular communication and close working
throughout the screening stages, consulting with a third member
of the team where required. The review is further strengthened
by multidisciplinary team input, with representatives from health
care and health sciences as well as from design and technology
backgrounds, which we hope ensures that our reflections and
conclusions are of interest and applicable to a wide range of
disciplines.

Limitations
We did not conduct a gray literature search. Doing so might
have resulted in a broader range of accounts of involvement
being included. In addition, we did not involve patients or the
public in this review, which may have contributed additional
perspective and depth. However, we have planned and started
recruitment for a much broader PPI strategy for our research
center. The results of this review will be shared with our steering
group so as to jointly consider how the findings should inform
our PPI work as a center.

Conclusions
At present, most involvement in technology-related dementia
research is limited in breadth (often to just 1 stage in the research
cycle) and depth (often consultative rather than with any sharing
of power). We see across the literature shared aspirations of
high levels of meaningful involvement in research, and it is
encouraging to see some evidence of this being put into practice,
with some reporting on methods used for involvement and the
impact this has. Where papers gave details, it appears that a
flexible approach with multiple methods used at different stages
of the research cycle may be the most successful, tailoring
methods to the various groups or individuals involved and
facilitating greater depth or breadth of involvement according
to people’s wishes and abilities. When this is done well, PPI
can have a positive impact on both the research and those
involved. This evidently will take significant time and resources,
particularly if the approaches used are to move beyond
consultations to collaboration or coproduction. Wider reporting
of methods and facilitative strategies along with more formalized
methods for recording and reporting on meaningful impact
would be helpful so that all those involved—researchers,
patients, and other stakeholders—can understand and learn how
best to jointly conduct research.

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Authors’ Contributions
PK wrote the manuscript. PK and HL developed the protocol with supervision from CMA and SD. PK and HL screened the
results and extracted the data with third-author support where necessary from CMA. All authors reviewed and contributed to the
final manuscript.

Conflicts of Interest
None declared.

Multimedia Appendix 1
Detailed search strings used for the different databases.
[DOCX File , 22 KB - aging_v7i1e48292_app1.docx ]
Multimedia Appendix 2
Stakeholder groups included as part of patient and public involvement activities.
[ PNG File , 76 KB - aging_v7i1e48292_app2.png ]

Multimedia Appendix 3
PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) checklist.
[ DOCX File , 83 KB - aging_v7i1e48292_app3.docx ]

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Abbreviations

NIHR: National Institute for Health and Care Research
PPI: patient and public involvement
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews
Promoting Personalized Reminiscence Among Cognitively Intact Older Adults Through an AI-Driven Interactive Multimodal Photo Album: Development and Usability Study

Xin Wang, PhD; Juan Li, PhD; Tianyi Liang, BSc; Wordh Ul Hasan, BSc; Kimia Tuz Zaman, BSc, MSc; Yang Du, PhD; Bo Xie, PhD; Cui Tao, PhD

1Department of Computer Science, North Dakota State University, Fargo, ND, United States
2Department of Computer Systems and Software Engineering, Valley City State University, Valley City, ND, United States
3School of Nursing, The University of Texas at Austin, Austin, TX, United States
4School of Information, The University of Texas at Austin, Austin, TX, United States
5D Bradley McWilliams School of Biomedical Informatics, UTHealth Houston, Houston, TX, United States

Corresponding Author:
Juan Li, PhD
Department of Computer Science
North Dakota State University
Quentin Burdick Building Room 258
1320 Albrecht Boulevard
Fargo, ND, 58105
United States
Phone: 1 7012318562
Fax: 1 7012318255
Email: J.Li@ndsu.edu

Abstract

Background: Reminiscence, a therapy that uses stimulating materials such as old photos and videos to stimulate long-term memory, can improve the emotional well-being and life satisfaction of older adults, including those who are cognitively intact. However, providing personalized reminiscence therapy can be challenging for caregivers and family members.

Objective: This study aimed to achieve three objectives: (1) design and develop the GoodTimes app, an interactive multimodal photo album that uses artificial intelligence (AI) to engage users in personalized conversations and storytelling about their pictures, encompassing family, friends, and special moments; (2) examine the app’s functionalities in various scenarios using use-case studies and assess the app’s usability and user experience through the user study; and (3) investigate the app’s potential as a supplementary tool for reminiscence therapy among cognitively intact older adults, aiming to enhance their psychological well-being by facilitating the recollection of past experiences.

Methods: We used state-of-the-art AI technologies, including image recognition, natural language processing, knowledge graph, logic, and machine learning, to develop GoodTimes. First, we constructed a comprehensive knowledge graph that models the information required for effective communication, including photos, people, locations, time, and stories related to the photos. Next, we developed a voice assistant that interacts with users by leveraging the knowledge graph and machine learning techniques. Then, we created various use cases to examine the functions of the system in different scenarios. Finally, to evaluate GoodTimes’ usability, we conducted a study with older adults (N=13; age range 58-84, mean 65.8 years). The study period started from January to March 2023.

Results: The use-case tests demonstrated the performance of GoodTimes in handling a variety of scenarios, highlighting its versatility and adaptability. For the user study, the feedback from our participants was highly positive, with 92% (12/13) reporting a positive experience conversing with GoodTimes. All participants mentioned that the app invoked pleasant memories and aided in recollecting loved ones, resulting in a sense of happiness for the majority (11/13, 85%). Additionally, a significant majority found GoodTimes to be helpful (11/13, 85%) and user-friendly (12/13, 92%). Most participants (9/13, 69%) expressed a desire to use the app frequently, although some (4/13, 31%) indicated a need for technical support to navigate the system effectively.
Conclusions: Our AI-based interactive photo album, GoodTimes, was able to engage users in browsing their photos and conversing about them. Preliminary evidence supports GoodTimes’ usability and benefits cognitively intact older adults. Future work is needed to explore its potential positive effects among older adults with cognitive impairment.

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KEYWORDS

aging; knowledge graph; machine learning; reminiscence; voice assistant

Introduction

As the proportion of older individuals rapidly grows, an increasing number of older individuals are becoming concerned about their physical and mental well-being [1]. Steptoe et al [2] found that a decline in health is associated with a negative psychological state. In addition, aging is closely associated with various psychosocial stress factors, such as loneliness, personal losses, and lower socioeconomic status [3]. These factors may increase the risk of developing mental health disorders. In recent years, increasing evidence suggests that psychological well-being could be a potential asset for healthy aging [4].

Reminiscence therapy stands as a profound approach, rooted in a deep understanding of cognitive and emotional processes, designed to elevate the psychological well-being of older adults. This therapy transcends the mere recall of life histories, encompassing both oral and written narratives, in a multisensory journey that engages sight, sound, taste, touch, and smell [5-7]. It extends beyond a mere collection of activities, encompassing the contemplation of photographs, immersion in music, and the sharing of narratives about pivotal life events [5-8]. The underlying success of reminiscence therapy lies in its capacity to stimulate long-term memory, playing a pivotal role in fostering overall well-being, an attribute particularly invaluable for those grappling with short-term memory challenges [9]. As individuals review and discuss evocative materials, including vintage videos, cherished photographs, or sentimental household artifacts, they embark on a path to not only retrieve memories but also enhance their self-esteem, nurture interpersonal skills, and enrich their psychosocial well-being [4,10]. This is rooted in the therapy’s ability to harness the profound impact of these sensory stimuli. Significantly, the American Psychological Association recognizes the therapeutic potential of reminiscence therapy, attesting to its ability to ameliorate mental health conditions, elevate mood, and mitigate agitation, especially among individuals coping with Alzheimer disease or dementia [5].

Research by Tam et al [4] indicates that reminiscence intervention not only produces positive effects among older adults with dementia but also benefits cognitively intact older adults. For instance, it reduces the depressive symptoms of cognitively intact older adults, significantly improves their life satisfaction, and promotes their self-esteem, psychological well-being, and happiness.

Reminiscence interventions, whether administered within health care facilities such as hospitals, assisted living communities, or nursing homes, or within the familial cocoon of private homes, are bolstered by the skillful orchestration of trained professionals and caregivers [5,7,11]. In health care settings, psychologists, social workers, and specialists in geriatric care often take the helm in conducting these interventions, drawing upon a wealth of materials that hold personal significance for older adults. The tailored application of these materials, including photos, videos, and cherished objects, becomes a key facet in rekindling memory and reminiscence. These interventions can be adjusted to individual or group settings, finely attuned to the unique needs and preferences of older adults [5,11,12]. In private residences, reminiscence interventions are executed with dedication by family members, caregivers, or volunteers [5]. They use similar materials as those found within health care facilities, including familial photographs and cherished keepsakes, as a conduit to memory stimulation and the initiation of reminiscing. Nevertheless, conducting these interventions at home can be challenging due to a shortage of human resources [11]. Caregivers and family members, juggling numerous responsibilities, may find their time and resources stretched thin, underscoring the need for innovative approaches, such as the one proposed in this study, to bridge this gap.

To overcome the challenges of limited resources and specialized training in performing reminiscence interventions, flexible and effective computer-based interventions are highly beneficial [13-15]. We designed, developed, and tested GoodTimes, a personalized interactive multimodal photo album mobile app for cognitively intact older adults. It can be used on smartphones and tablets, providing older adults with on-the-go access to their photos as well as those provided by family members. This intelligent digital photo album allows users to browse and query photos in various orders, including chronological order, by location, by event, or by specific family members. To enhance the reminiscing experience, a voice assistant (VA) interacts with the user, providing information about the picture, such as the family members in the picture, the special moment, and the location. The VA also asks questions, answers user questions, and responds to user comments, creating a setting where special memories can be remembered and enjoyed. To ensure the user’s comfort and avoid any distress, the VA will not mention anything about depression or other challenges that older adults may be facing. Older adults can use the app independently, but it is also beneficial for families, caregivers, and assisted living staff to share the mobile app with the older adult they care for. Overall, GoodTimes is a convenient and effective tool that can be used anytime, anywhere, with or without caregiver support, for cognitively intact older adults. This user study indicates that after using this app, users reported engaging in enjoyable conversations with the app.
Methods

Ethics Approval
This study was reviewed and approved by the institutional review board of NDSU. The IRB Protocol number is IRB0004419.

Overview
GoodTimes is built on artificial intelligence (AI) technologies, including image recognition, natural language processing, knowledge graph, logic, and machine learning, to provide an interactive and personalized experience for older adults. The system architecture is illustrated in Figure 1. The app can be accessed through smartphones and tablets, and users can interact with it using their voice or fingers. The VA, which uses automatic speech recognition and natural language understanding technologies, converts the user’s voice into a text request. The conversation management module then processes the user’s request through 2 steps: user intent identification and dialogue management (DM). First, the user intent identification matches the user’s text request with predefined intents and dialogue states to create an input frame. Then, the DM module executes the dialogue policy based on the dialogue state graph and updates the dialogue state.

Figure 1. System Architecture.

There are 2 types of communication requests: personal requests, which involve questions and answers related to the user’s personal information, and general requests, which do not necessarily involve personal information. Examples of personal questions include “Who is in the photo?” and “What is the story behind this photo?” General requests include knowledge not necessarily related to the user’s personal information, for example, a commonplace or a piece of widely known artwork. For instance, the AI may provide an answer about art collections in the Louvre Museum in Paris.

To handle general requests, we fine-tuned a Generative Pre-Trained Transformer (GPT; OpenAI) [16], a powerful neural language model. For personal requests, we have designed our own personal knowledge engine to provide tailored responses. Backend services of our personal knowledge engine are requested based on the user’s intent, and these services are supported by a semantics-based query engine and reasoning engine. These engines work over a knowledge graph, which is the brain of the system. The knowledge graph contains facts, relationships, and rules about photos, people, places, time, and stories. The search and reasoning engines link the dialogue with a specific photo, user profile, and context to enable personalized services. Finally, the DM module generates responses using the speech act and content selected based on the input frame.

The system maintains a library of photos that can be uploaded by the older adult user’s family members and caregivers. Metadata of a photo, such as people, animals, location, time, and special events, are also saved in the knowledge. Family members get involved in uploading, sharing, and explaining the photos, promoting collaboration, and having fun. Involving family members in the photo album can improve their relationship, help family members learn more about older adults, and facilitate reminiscence interventions for older adults, with or without caregiver support.

Constructing an Open Personal Knowledge Graph
The “brain” of the system is a comprehensive knowledge graph [17] that contains knowledge about the user and the photos. All the knowledge is represented as a graph in which data is modeled as nodes (vertices) and links (edges) between them. Nodes in our knowledge graph are normally a person, place, location, or thing, and links are how they are connected or related. Figure 2 shows an example knowledge graph about an older adult, Bob. In this graph, Bob, Alice, Cat, Person, Attraction, and Golden Gate Bridge are nodes. They are connected by many different relationships. For example, Alice is Bob’s wife, and Bob is the father of Cat. Alice, Bob, and Cat are persons. Bob visited the Golden Gate Bridge, which is an attraction. This example graph shows many things and relationships about Bob. It is used by the system to explain the story of the picture, including the people inside the picture, their relationships, where they visited, etc.
Graphs are used to model knowledge because they can encode real-world knowledge as “things” (not “strings”) and their interrelationships. This enables the system to communicate with users by analyzing what the words in a sentence actually mean rather than simply analyzing strings of characters. In addition, structuring knowledge in the form of graphs allows knowledge to evolve over time. New “things,” relationships, and external knowledge can be easily added or linked to the existing graph. In our system, we extend the core knowledge graph with external knowledge graphs, such as Wikidata [18,19], to extend our knowledge. Furthermore, reasoning and navigation can be performed over knowledge graphs.

**Knowledge Graph Construction**

First, we built a high-level ontology working as the schema of the knowledge graphs. Then, we create a knowledge graph by instantiating the ontology with detailed instances retrieved from uploaded photos (with metadata) and user surveys and external knowledge graphs, such as Wikidata. Using ontology would allow logical inference for retrieving implicit knowledge rather than only allowing queries requesting explicit knowledge. We proposed a “Who-What-When-Where” model as the foundation of this album ontology. “Who” represents the person in or not in the photo but related. “What” points to the story related to a photo. “When” specifies the time when the photo was taken, which can be a date, a social occasion, or a historical monument. “Where” describes the place where the photo is taken. Figure 3 shows a major part of the ontology. This ontology is instantiated with instances through photo metadata extraction, tagging extraction, image recognition, and social media extraction.

The ontology serves as schema-level knowledge used to instantiate instances or individuals, thereby creating a comprehensive knowledge graph. Instance information is collected through various means, such as automatically extracting metadata from photos or through manual input or voice-based question and answer. Through these processes, a detailed knowledge graph like the one shown in Figure 2 can be generated.
Figure 3. Part of the photo album ontology.

Semantic Rule Definition

In order to facilitate logical inference and gain new insights from the knowledge graph, we have established a set of rules and used logical reasoning over the ontology. We provide a few examples of these rules below, noting that some are specified within the ontology itself, while others are created separately using Semantic Web Rule Language [20-22]. For clarity, we present all rules using the same first-order logic [22] format.

Relatives:

If x is the husband of y, then y is the wife of x, and vice versa:

$$\forall x, y \; \text{Husband}(x, y) \iff \text{Wife}(y, x)$$

If x is the mother or father of y, then x is also the parent of y, and vice versa:

$$\forall x, y \; (\text{Mother}(x, y) \lor \text{Father}(x, y)) \iff \text{Parent}(x, y)$$

If z is the parent of both x and y, and x is not the same as y, then x and y are siblings:

$$\forall x, y, z \; (\text{Parent}(z, x) \land \text{Parent}(z, y) \land x \neq y) \Rightarrow \text{Sibling}(x, y)$$

If x is the parent of y, and y is the parent of z, then x is the grandparent of z:

$$\forall x, y, z \; (\text{Parent}(x, y) \land \text{Parent}(y, z)) \Rightarrow \text{Grandparent}(x, z)$$

Social Relations:

Time:

$$\forall x, y, z \; \text{Time}(x) \land \text{Time}(y) \land \text{Time}(z) \land \text{Before}(x, y) \land \text{Before}(y, z) \Rightarrow \text{Before}(x, z)$$

$$\forall x, y \; \text{Time}(x) \land \text{Time}(y) \land \text{Before}(x, y) \Rightarrow \text{After}(y, x)$$

Location:
Photo co-occurrence Relations:

\[
\forall p, l, t, ph \quad (\text{Person}(p) \land \text{Location}(l) \land \text{Time}(t) \land \text{Photo}(ph) \land \text{PersonInPhoto}(p, ph) \land \text{PhotoTakenAtLocation}(ph, l) \land \text{PhotoTakenTime}(ph, t)) \Rightarrow \text{Visited}(p, l, t, ph)
\]

//Person p1 and p2 visited location l at time t together

\[
\forall p1, l, t, ph \quad \text{Person}(p1) \land \text{Person}(p2) \land \text{Visited}(p1, l, t, ph) \land \text{Visited}(p2, l, t, ph) \Rightarrow \text{VisitedTogether}(p1, p2, l, t)
\]

Dialogue Management

The photo album's VA is a machine learning-based system that enables users to engage with it through natural conversation. The VA is capable of understanding user intents from free text, answering questions, and asking questions for a specific purpose. To promote reminiscence intervention, GoodTimes guides users in recalling their memories by asking them photo-related questions and responding based on their answers. The VA facilitates personalized questions during the dialogue flow and can route natural conversations with users. A photo album with a VA can help older adults feel more connected to their past present, providing them with a sense of familiarity and comfort, which is especially important for older adult users. Our dialogue flow management includes the following key points to facilitate engaging interactive conversation: VA-driven conversation, intent recognition, context management, personalization, and empathy incorporation.

VA-Driven Conversation

In our app, the VA initiates and guides the conversation. The conversation between the VA and the user begins with a friendly greeting or prompt, followed by a series of questions that revolve around the “Who-What-When-Where” themes but are not limited to them. These questions are designed to elicit specific information about the photos from the user and jog their memory. We use techniques including contextual prompts, confirmation prompts, and error handling to let the VA control the dialogue flow.

The VA provides prompts or suggestions to the user based on the current context of the conversation. For example, if the user talks about a specific photo, the VA can suggest related topics or questions to keep the conversation flowing smoothly. The VA uses confirmation prompts to confirm the user’s intent or response to a question. This is useful when the VA needs to verify information before moving on to the next question or action. When the user provides incorrect or invalid input, the VA will provide appropriate responses, including rephrasing a question or prompt, asking for clarification, or providing an explanation of what the VA is looking for. By using these techniques, the VA can guide the conversation in a way that ensures the user provides the necessary information while keeping the conversation under control.

Intent Recognition

There are 2 ways to identify the user’s intent. One is to fine-tune a GPT to let it specify the intent or use our designed intent identification model (IIM). In our implementation, we used our own IIM as the main method, as GPT is more expensive. In our IIM, the VA uses the natural language processing algorithm, part of speech tagging [23], to break down a sentence or phrase into its constituent parts, such as nouns, verbs, and adjectives. Then, it uses named entity recognition [24] to extract important information such as the user’s intent, entities (relevant keywords or phrases), and context from these components. We use machine learning algorithms (eg, our previous proposed algorithm [25]) to analyze the user’s input and match it with the most relevant intent. To train the model, we provide sample user inputs and assign them to specific intents. The VA then uses these examples to learn patterns in the data and improve its ability to recognize user intent over time.

Context Management

The VA also keeps track of the conversation’s context, including previous statements made by the user and the VA’s responses. This helps to ensure that the VA’s responses are relevant to the current conversation. Context management in the VA of the interactive photo album is critical to providing a seamless and personalized user experience. VA uses a context stack to manage the context of the conversation. For example, suppose the user is looking at a photo of a trip to Paris taken in front of the Louvre Museum. In that case, the VA can use this information to provide related suggestions or ask follow-up questions, such as “Did you see Leonardo da Vinci’s Mona Lisa in Louvre?” These questions are generated by prompting GPT using our knowledge graph and previous conversation history as context. The VA also needs to be able to handle changes in context, such as if the user switches to talking about a different topic. In such cases, the VA must recognize the change in context and adjust its responses accordingly. Overall, effective context management is crucial to creating a personalized and engaging experience for users interacting with the VA in the interactive photo album.

Personalization

The VA personalizes the conversation by considering multiple factors, including the user’s preferences, personal profile such as name, age preferences, and conversation history. The very basic form of personalization is addressing the user by name to make the conversation more personal and engaging. In addition, the VA will use knowledge in the knowledge graph to address people or things in the photo. For example, the VA will use the information stored in the knowledge graph to refer to people or things depicted in the photos. For instance, if the user’s mother is shown in the photo, the VA may address her as “your mother, Susan,” as her name is known from the knowledge graph. Similarly, if the user’s pet dog is in the photo, the VA may refer to the dog by its name, “Buddy.” Additionally, suppose the knowledge graph indicates that the user has a close relationship with a particular person. In that case, the VA can refer to them with a personal term, such as “your dear friend, John.” This personalization can enhance the user’s experience and create a more natural and engaging conversation. Also, the VA uses the conversation history to tailor the conversation. For example, if
the user has previously shown a preference for a particular type of photo or event, the VA can use this information to recommend similar photos or events.

**Empathy Incorporation**

The VA incorporates empathy into dialogue to create a more natural and engaging conversation. This involves understanding and responding to the user’s emotional state, using appropriate tone and language, and showing concern for the user’s needs and feelings. Older adults and people with Alzheimer disease may have difficulty understanding complex sentences or abstract concepts [26]. Our VA uses simple, clear language to make sure they understand what the VA is saying. The VA always tries to be patient and understanding when asking older adults about photos. The VA gives positive feedback when the user answers questions correctly or remembers important information. If they provide incorrect answers, the VA will gently correct them and provide additional context or information. It is also important to repeat questions if they are not answered correctly, as older adults may need more time to process and remember information. Asking related questions, such as about memories of a trip shown in the photo or the hobbies of a person in the photo, can also be helpful in stimulating memories and encouraging conversation. Overall, we try to create a comfortable and positive environment for older adults to share their memories and stories.

**Conversation Using Knowledge Graph**

The knowledge graph is the source of information for conversing with users and is stored in Neo4j [27-29], a graph database that the VA uses to ask and answer questions about photos. Cypher [27-29], Neo4j’s query language, is used by the VA to navigate the graph and generate questions and responses. Natural language queries and answers from users are converted into Cypher queries. For example, if a user asks, “Who is in this photo?” the VA can convert this into a Cypher query that retrieves all people in the photo. To generate photo-related questions, Cypher first locates a specific photo node based on certain criteria. Relevant properties are then extracted from this node to generate a question, with the property value serving as the standard answer. Cypher can also query for a relationship linked to this node, creating a directional triple consisting of the photo node, a relationship, and another node. The knowledge graph uses directional triples (node-relationship-node) to express semantic data as subject-predicate-object. For more complex questions with multiple bindings, Cypher enables searching for nearby nodes and relationships by limiting the number of hops and specific relationships.

To keep the conversation engaging, the VA can ask follow-up questions related to the previous topic. For instance, if the previous query was about Mary, the VA might ask, “Do you remember Mary’s hobby?” by using the previous query result (ie, Mary) as the subject or object of a new triple. The new question is generated based on this triple, with the other node or relationship serving as the question and the remaining element in the triple as the standard answer. In addition, GPT [30,31] is used to generate related questions and content, which will be discussed further later on.

**GPT as a Complement**

GPT is the state-of-the-art large language model used for various natural language processing tasks, including “question answering.” One of the main advantages of GPT is its large amount of pretrained knowledge, which enables it to understand and generate natural language text with high accuracy. However, the cost of using GPT could be prohibitive for some applications, including our system. Despite this limitation, we still benefited from GPT’s capabilities by using it to provide complementary functions. For example, we used GPT to help identify user intent if our IIM was not confident about its result. Moreover, GPT was used to enhance the conversational experience by generating follow-up questions and responses. For instance, if a user asks a question about a particular topic, GPT can generate related questions or statements that may help the user explore the topic further.

To ensure that the responses generated by GPT are relevant and accurate, we provided appropriate context for the conversation. One way to achieve this is by leveraging our local knowledge graph and conversation history as a source of relevant information. By converting the knowledge graph database into a triple format (subject, predicate, and object), we could index the triple file using semantic embeddings, which represent text data in a continuous vector space. This allows for efficient comparison and retrieval of similar text items while preserving semantic relationships between words and phrases. To generate embeddings, we used the pre-trained embedding model “Bidirectional Encoder Representations from Transformers” [32], resulting in a single vector embedding. These embeddings were then used in semantic search, enabling efficient and cost-effective searching. When a user query was received, we converted it into semantic embeddings and matched them with the embeddings of the knowledge graph using cosine similarity. This helped us identify the most relevant or related information sources in our knowledge graph that are related to the user’s query. Once we had identified the most similar embeddings in our local knowledge base, we used them as context or query input for the GPT model. This context provides GPT with relevant information from our local knowledge base, allowing it to generate relevant responses. In summary, while GPT may not be used extensively in our system due to its cost, it can still provide valuable complementary functions that enhance the user experience and help us better understand the user’s intent.

**Prototype System**

We have implemented GoodTimes as an Android-based app using a mobile app development framework called Flutter [33]. The app includes a VA that uses Google’s Dialogflow [34] to understand natural language. When the VA identifies what the user wants, it uses Google Cloud Functions to interact with a backend server built with Spring Boot [35]. This server connects to a Neo4j database that stores information in the form of a knowledge graph. We used LangChain (Harrison Chase) [36], a Python package, to integrate OpenAI’s GPT language models with the knowledge graph. Specifically, we used the GPT-3.5 Turbo model and defined the GPT language model using the LLMPredictor class and the input prompt format using the
PromptHelper class. The user has the option to interact with the app using either voice commands or touch input.

**Use-Case Study**

We conducted a use-case study to evaluate the functionality of our interactive photo album app before deploying it to real users. This involved identifying and analyzing specific scenarios in which the app could be used, such as browsing photos, sharing them with friends and family, and asking questions related or unrelated to the photo. By examining how the app was used in these scenarios, we were able to identify areas for improvement to make it more user-friendly. The creation of fictional users for the use cases involved careful consideration of relevant characteristics and demographics aligned with this study’s objectives. Factors taken into account included age, gender, cultural background, language proficiency, cognitive and physical abilities, technological familiarity, and more. This iterative process allowed for refinement based on the specific goals and requirements of our research or design project.

Let us consider a fictional character, Bob, who is 79 years old and has memory challenges that affect his ability to remember things. As part of our use case, we presented Bob with a collection of photos encompassing significant moments such as his granddaughter Sara’s birthday party, his memorable trip to Paris with his wife, and heartwarming memories with his beloved pet dog, Lucy.

**Figure 4** exemplifies the interaction between Bob and the VA, showcasing their communication regarding photos in the album. This particular example demonstrates the VA’s capability to engage with Bob and help him remember significant moments. In the conversation, Bob and the VA discuss a photo from Sara’s birthday party. Initially, Bob is unsure of the people in the photo. The VA kindly reminds him that it is Sara in the picture, which prompts Bob’s memory. The VA provides additional information about the event, refreshing Bob’s memory and filling in the gaps. The VA also helps Bob recall his trip to Paris. This interaction highlights the VA’s ability to serve as a helpful reminder and facilitator of memory recall. By engaging in conversations and providing contextual information, the VA helps Bob reminisce about important occasions and people in his life. This feature demonstrates the valuable role the VA plays in aiding individuals with memory challenges by providing gentle reminders and support.

In addition to the previously mentioned use cases, we conducted evaluations on 12 additional scenarios for our app. The diverse range of use cases demonstrated the app’s potential as a valuable tool for helping older adults cherish their memories and enhance their overall well-being.

![Figure 4](https://aging.jmir.org/2024/1/e49415)

In addition to the previously mentioned use cases, we conducted evaluations on 12 additional scenarios for our app. The diverse range of use cases demonstrated the app’s potential as a valuable tool for helping older adults cherish their memories and enhance their overall well-being.
User Study

We conducted a user study to evaluate the usability and features of the GoodTimes app. Participants were recruited through convenience sampling using various digital communication channels, such as phone calls, social media, and email. To accommodate participants’ preferences, the study sessions were conducted in person at locations including their homes, local coffee shops, or parks. These sessions were conducted individually, allowing for personalized interaction and feedback.

At the beginning of each session, participants were provided with an overview of the study objectives and the app’s key features. Written consent was obtained from each participant, following the approved study protocol by the institutional review board of North Dakota State University. A video demonstration was presented, and participants were given approximately 30 minutes of hands-on practice with the app. A researcher was present to address any questions during the session. Following the interaction, participants completed a set of questionnaires to provide feedback on their experience, which took approximately 15 minutes to complete. This approach enabled us to gather comprehensive insights into the app’s usability and user experience.

The questionnaire consists of 2 main parts. The first part focused on participants’ experiences with the app’s features, including their interactions with the intelligent agent and their emotional responses to the digital photo gallery. They rated their experiences with 5 statements on a Likert scale ranging from “strongly agree” to “strongly disagree.” The survey included questions developed by the research team based on previous research and expert opinions.

The second part focused on the overall usability of the app, and open-ended questions were used to identify areas for improvement. In this part, we used a subset of the System Usability Scale (SUS) to assess the app’s usability. The SUS is a widely recognized and validated instrument for evaluating the usability of interactive systems. We selected 5 relevant SUS questions out of a total of 10 and included them in our survey.

In our evaluation of the app’s usability and user experience, we used statistical analyses to objectively understand participant feedback. Specifically, we used a 1-sample 2-tailed t test, a parametric test used to determine if the sample mean significantly differs from a known or hypothesized population mean. Given that our data was interval in nature and derived from Likert-scale responses, the 1-sample t test was particularly apt. The hypothesized population mean in our context was the neutral point on our scale, allowing us to discern whether participants’ responses significantly leaned toward agreement or disagreement.

Results

Participants

The user study included a total of 15 participants, with 13 of them completing the survey. Out of the 12 studies conducted, 11 were in-person sessions, while 1 was conducted on the web through Zoom (Zoom Video Communications) as per the participant’s preference. The participant demographics are summarized in Table 1. Among the participants, 8 fell in the age range of 55-64 years, 2 were in the age range of 65-74 years, and 3 were in the age range of 75-84 years. In terms of gender distribution, there were 8 male participants and 5 female participants. Regarding education, 3 participants held a PhD degree, 4 participants had a master’s degree, 3 participants had a bachelor’s degree, 1 participant had a college degree, and 2 participants had completed high school.

Table 1. Demographic information of the participants.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Participants, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
</tr>
<tr>
<td>55-64</td>
<td>8 (62)</td>
</tr>
<tr>
<td>65-74</td>
<td>2 (15)</td>
</tr>
<tr>
<td>75-84</td>
<td>3 (23)</td>
</tr>
<tr>
<td>≥85</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Man</td>
<td>8 (62)</td>
</tr>
<tr>
<td>Woman</td>
<td>5 (38)</td>
</tr>
<tr>
<td><strong>Highest educational degree</strong></td>
<td></td>
</tr>
<tr>
<td>PhD</td>
<td>3 (23)</td>
</tr>
<tr>
<td>Master’s</td>
<td>4 (31)</td>
</tr>
<tr>
<td>Bachelor’s</td>
<td>3 (23)</td>
</tr>
<tr>
<td>College degree</td>
<td>1 (8)</td>
</tr>
<tr>
<td>High school</td>
<td>2 (15)</td>
</tr>
<tr>
<td>Less than high school</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>
**Evaluation Outcomes**

In order to evaluate the GoodTimes app, we conducted a user study with 13 older adult participants to collect feedback on their experiences with the app and its usability. Table 2 encapsulates participants’ feedback on their conversational experiences with the VA. The outcomes revealed an overwhelmingly positive response to their interaction experience with the VA. A significant majority of participants (12 out of 13) endorsed the efficacy and relevance of the VA in their conversations. Specifically, 8 participants were in strong agreement that the VA disseminated pertinent information, while the remaining 5 concurred with this sentiment. Furthermore, a compelling majority (11 out of 13) expressed strong affirmation regarding the VA’s accuracy in sharing memory-related information. In terms of the VA’s language clarity and appropriateness, 12 participants were either in strong agreement or in agreement, indicating near-universal approval.

The $P$ value, a measure of statistical significance, provides robust statistical validation of these findings. For instance, the statement “The VA provided relevant information” had a $P$ value of <.001, suggesting that the observed results are extremely unlikely to have occurred by chance alone. Similarly, the almost identical $P$ values for “The VA provided correct information” and “The VA’s language is appropriate and easy to understand” (both $P$<.001) underscore the authenticity and significance of these findings. A $P$ value below the typical threshold of .05 indicates a significant difference from the expected neutral response. This provides strong evidence that participants genuinely felt the statements were accurate descriptors of their experiences.

Table 3 depicts a profound capacity to foster positive emotions and reminisce among the study participants. It was noteworthy that every participant either agreed or strongly agreed that the app invoked cherished memories. Moreover, a substantial majority signaled their agreement or strong agreement with the app’s efficacy in reviving memories of dear ones, such as friends and family. Impressively, a significant 11 out of 13 participants articulated that the app augmented their happiness.

In Table 3, $P$ values offer compelling evidence of these perceptions. For the statement “Brings a lot of Good Memories,” a $P$ value of <.001 indicates an exceptionally significant result, suggesting the overwhelmingly positive feedback was not a mere coincidence. The sentiment “accelerates thinking about friends and family” also received a $P$ value of <.001, reinforcing the strong affirmation of the app’s ability to stir memories of loved ones. Furthermore, the feedback “Makes me happy” also manifested a $P$ value of <.001, emphasizing that a significant number of participants derived joy from the app’s use. These $P$ values, being well below the conventional .05 threshold, bolster the claim of the app’s potent capability to enhance emotional health through memory stimulation.

During the usability assessment phase of our survey, we gauged the app’s interface using standardized usability prompts. Table 4 depicts an overview of the results on app usability. The results elucidated a prevailing sentiment of approval among respondents concerning the app’s usability. Notably, a significant desire was expressed to engage with the system regularly, as indicated by a $P$ value of <.005, which suggests this sentiment was not merely by chance. Additionally, the system’s helpfulness and its design simplicity garnered significant endorsement, as evidenced by the compellingly low $P$ values of <.001, respectively. This denotes a genuine appreciation for the system’s functionality and design among users.

### Table 2. Participants’ feedback on their conversational experience with the voice assistant (VA).

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree, n</th>
<th>Agree, n</th>
<th>Neutral, n</th>
<th>Disagree, n</th>
<th>Strongly disagree, n</th>
<th>Mean (SD)</th>
<th>2-tailed $t$ (df)</th>
<th>$P$ value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conversation was pleasant</td>
<td>8</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>4.3846 (0.9608)</td>
<td>5.1959 (12)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Conversation was fluent and natural</td>
<td>4</td>
<td>7</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>4.0769 (0.8623)</td>
<td>4.5029 (12)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>The VA provided relevant information</td>
<td>8</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4.6154 (0.5064)</td>
<td>11.5016 (12)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>The VA provided correct information</td>
<td>11</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4.8462 (0.3755)</td>
<td>17.7272 (12)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>The VA’s language is appropriate and</td>
<td>11</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4.8462 (0.3755)</td>
<td>17.7272 (12)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

### Table 3. Participants’ feedback on their emotional response to app usage.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree, n</th>
<th>Agree, n</th>
<th>Neutral, n</th>
<th>Disagree, n</th>
<th>Strongly disagree, n</th>
<th>Mean (SD)</th>
<th>2-tailed $t$ (df)</th>
<th>$P$ value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brings a lot of Good Memories</td>
<td>10</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4.7690 (0.4385)</td>
<td>14.5455 (12)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Accelerates thinking about friends and</td>
<td>10</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>4.6920 (0.6304)</td>
<td>9.6773 (12)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Makes me happy</td>
<td>5</td>
<td>6</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>4.1538 (0.8987)</td>
<td>4.6290 (12)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>
Another commendable finding was the respondents’ confidence in using the app without external technical assistance. This was statistically supported by a $P$ value of .03, reflecting a valid level of user self-assurance. However, the topic of needing technical support to operate the system did receive varied responses. Interestingly, the statement “I think that I would need the support of a technical person to be able to use this system” had a $P$ value of .49, indicating that this sentiment was not statistically significant and could likely be attributed to random variability.

**Discussion**

**Principal Results**

We designed, developed, and tested an interactive photo album app called GoodTimes that uses AI technology to engage in conversations with users and tell stories about pictures, including family, friends, and special moments. The app was developed using state-of-the-art AI technologies, including image recognition, natural language processing, knowledge graph, logic, and machine learning. We constructed a comprehensive knowledge graph that models the information required for effective communication, including photos, people, locations, time, and stories related to the photos. We then developed a VA that interacts with users by leveraging the knowledge graph and machine learning techniques.

In order to evaluate the GoodTimes app, we conducted a use-case study to verify its various functions in different real-life scenarios. Additionally, we conducted a user study with 13 older adults to collect feedback on their experiences with the app and its usability. We found that the feedback from our participants was highly positive, with 92% (12/13) reporting a positive experience conversing with GoodTimes. All participants mentioned that the app invoked pleasant memories and aided in recollecting loved ones, resulting in a sense of happiness for the majority (11/13, 85%). Additionally, a significant majority found GoodTimes to be helpful (11/13, 85%) and user-friendly (12/13, 92%). Most participants (9/13, 69%) expressed a desire to use the app frequently, although some (4/13, 31%) indicated a need for technical support to navigate the system effectively.

**Limitations**

Our research has some limitations that we aim to address in future work. First, we plan to increase family members’ active involvement in the process of using the app by making it easy and enjoyable for them to upload pictures and record their voices. Additionally, the findings may not be generalizable to both cognitively impaired and cognitively intact older adults due to the small convenience sample used in this study.

To better understand the potential of our app as a supplementary tool for reminiscence therapy, we plan to deploy the app to their homes or assisted living environments, allowing them to use it for an extended period of time. By doing so, we can observe the app’s impact over time and gain valuable insights into how it can provide emotional and mental stimulation to improve their quality of life.

**Comparison With Previous Work**

Previous research has shown that reminiscence therapy, which involves the use of photos and videos to stimulate long-term memory, can improve the emotional well-being of older adults [5,37]. However, providing personalized reminiscence therapy can be challenging for caregivers and family members.

Various studies have investigated technology as a means of supporting reminiscence therapy for older adults. For instance, Chen et al [38] developed an app that used a lifelogging device to capture photos and videos and presented them in a timeline format, resulting in improved quality of life and cognitive function for participants. However, this approach is limited to recent events and can be inconvenient for users to wear many devices. Additionally, the mashup process requires significant caregiver involvement.

Another study by Tsao et al [39] developed an augmented reality app that allows users to interact with virtual versions of their memories. The app was found to increase participants’ sense of control and satisfaction with their lives. The study by Schoneveld [40] developed an AR photo album prototype to facilitate communication between a person with dementia and their caregiver, family member, or friend, aiming to evoke more details and elements of memory and contribute to additional discussion material. The prototype has shown positive results in low- and high-fidelity prototype testing with experts and proxy testers. Another study [41] created digital reminiscence

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**Table 4. Overview of results on the app’s usability.**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree, n</th>
<th>Agree, n</th>
<th>Neutral, n</th>
<th>Disagree, n</th>
<th>Strongly disagree, n</th>
<th>Mean (SD)</th>
<th>2-tailed $t$ (df)</th>
<th>$P$ value</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would like to use this system frequently</td>
<td>0</td>
<td>9</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>3.6154 (0.6504)</td>
<td>-</td>
<td>3.4115 (12)</td>
</tr>
<tr>
<td>I think the system is very helpful</td>
<td>4</td>
<td>7</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>4.0769 (0.8623)</td>
<td>-</td>
<td>4.5029 (12)</td>
</tr>
<tr>
<td>I think the system design is very simple and easy to use</td>
<td>4</td>
<td>8</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>4.2308 (0.5991)</td>
<td>-</td>
<td>7.4073 (12)</td>
</tr>
<tr>
<td>I feel very confident about using the system</td>
<td>4</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>3.7692 (1.0919)</td>
<td>-</td>
<td>2.5400 (12)</td>
</tr>
<tr>
<td>I think that I would need the support of a technical person to be able to use this system</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>6</td>
<td>1</td>
<td>2.7692 (1.1658)</td>
<td>-</td>
<td>0.7138 (12)</td>
</tr>
</tbody>
</table>

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(page number not for citation purposes)
and music therapies using prompts such as photos, videos, and music. The study focused on the rural population, which has reduced access to dementia care services.

Compared with these studies, our GoodTimes app uses AI technology to engage in conversations with users and tell stories about pictures, including friends, family members, and special moments. This personalized approach aims to provide a more engaging and emotionally supportive experience for older adults, requiring minimum efforts from caregivers. This study’s results showed that the app was well-received by participants, who found it helpful, easy to use, and enjoyable. In conclusion, while previous research has shown the benefits of reminiscence therapy for older adults, our GoodTimes app adds a new dimension to the field by using AI technology to provide a personalized and engaging reminiscence therapy experience.

Conclusions

In conclusion, this study demonstrated the potential of the GoodTimes app to provide personalized reminiscence therapy to older adults, improving their emotional well-being. The use-case study and user study results showed that the app was well-received by participants and provided a helpful, easy-to-use, and enjoyable experience. Although this study has some limitations, such as the need for a larger sample size and a longer evaluation period, we plan to address these limitations in future work. Our GoodTimes app adds a new dimension to the field of reminiscence therapy by using AI technology to provide a personalized and engaging experience. Overall, we believe that the GoodTimes app has the potential to positively impact the lives of older adults and their families.

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Conflicts of Interest

None declared.

References


Abbreviations

- **AI**: artificial intelligence
- **DM**: dialogue management
- **GPT**: Generative Pre-trained Transformer
- **IIM**: intent identification model
- **SUS**: System Usability Scale
- **VA**: voice assistant

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