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Original Paper

Comparison of the Mental Burden on Nursing Care Providers With and Without Mat-Type Sleep State Sensors at a Nursing Home in Tokyo, Japan: Quasi-Experimental Study

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Abstract

Background: Increasing need for nursing care has led to the increased burden on formal caregivers, with those in nursing homes having to deal with exhausting labor. Although research activities on the use of internet of things devices to support nursing care for older adults exist, there is limited evidence on the effectiveness of these interventions among formal caregivers in nursing homes.

Objective: This study aims to investigate whether mat-type sleep state sensors for supporting nursing care can reduce the mental burden of formal caregivers in a nursing home.

Methods: This was a quasi-experimental study at a nursing home in Tokyo, Japan. The study participants were formal caregivers who cared for residents in private rooms on the fourth and fifth floors of the nursing home. In the intervention group, formal caregivers took care of residents who used sleep state sensors on the fourth floor of the nursing home. The sleep state sensors were mat types and designed to detect body motion such as the frequency of toss and turning and to measure heartbeat and respiration. One sensor was placed on a bed in a private room. When body motion is detected, the information is instantly displayed on a monitor at a staff station. In addition, the mental condition of the formal caregivers was measured using a validated self-reported outcome measure—the Profile of Mood States (POMS), Short-Form, 2nd edition. Formal caregivers in both groups received the POMS at baseline, midpoint (week 4), and endpoint (week 8) to identify changes in these domains. The primary outcome was the difference in total mood disturbance (TMD) of the POMS at baseline and week 8.

Results: Of the 22 eligible formal caregivers, 12 (intervention group) utilized sleep state sensors for 8 weeks. The remaining 10 formal caregivers (control group) provided nursing care as usual. As for the primary outcome of the difference between TMD at baseline and week 8, TMD in the intervention group improved by –3.67 versus 4.70 in the control group, resulting in a mean difference of –8.37 (95% CI –32.02 to 15.29; P=.48) in favor of the intervention.

Conclusions: The present 8-week study showed that sleep state sensing for elderly residents might not be associated with reduced mental burdens on formal caregivers in nursing homes.

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KEYWORDS

long-term care; caregiver burden; nursing homes; aged; information technology; sensors

Introduction

The aging of society is rapidly increasing and expanding in the world. According to the United Nations, there were 703 million persons aged 65 years and older in 2019 worldwide, and the number of older adults is projected to double to 1.5 billion in 2050 [1]. Population aging has been fastest in East and Southeast Asia, Latin America, and the Caribbean [1]. For instance, Japan has the highest proportion of older persons in the world; in 2019, 28.1% of the population (or 35.6 million) was 65 years and older [2]. By 2065, 1 in 2.6 people will be 65 years and older in Japan [2]. Such rapid demographic changes leave countries with insufficient long-term care resources to tackle the challenges associated with an aging population.

In accordance with the aging population in Japan, there has been an exclusive increase in the demand for long-term care [3,4]. The increasing need for long-term care has brought about an increased burden on formal caregivers [5,6]. In particular, the formal caregivers in nursing homes had to deal with exhausting labor (ie, long hours, overtime work, and late-night work). The mental and physical fatigue is severe and also undermining their health, resulting in migraines, depression, and backache [6-9]. To cope with the heavy labor, the Japanese government promoted the utilization of the Internet of Things (IoT) to support formal caregivers [10].

IoT means that everything can be accessed anytime and anywhere, and that applications work without human intervention, as long as there is internet [11]. To date, IoT application studies for health care use include IoT devices for tracking human activities in primary health care centers [12], for medication compliance among older outpatients [13,14], for intensive health guidance among outpatients with diabetes mellitus [15], and for home-based health care [16]. Although research activities on the use of IoT devices to support long-term care for older adults exist, there is limited evidence on the effectiveness of these interventions among formal caregivers in nursing homes [17-19]. In this study, we investigate whether sleep state sensors for supporting long-term care can reduce the mental burden of formal caregivers in a nursing home.

Methods

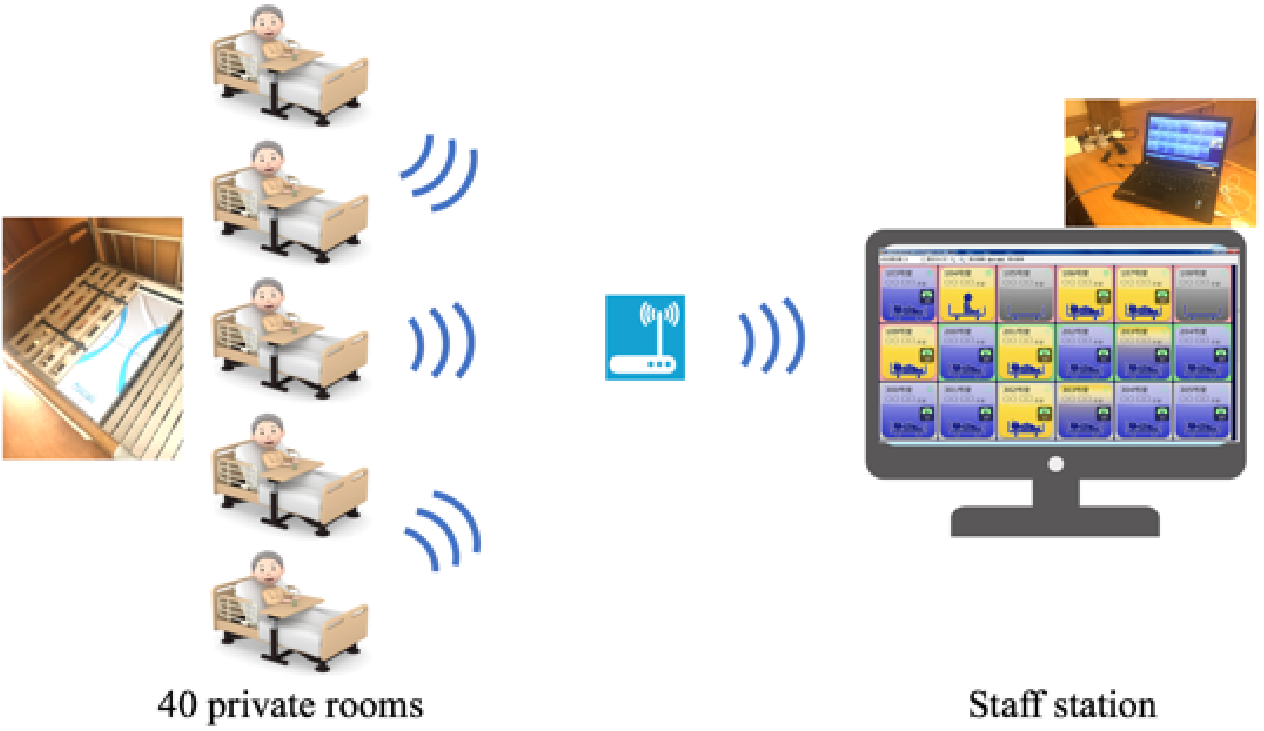
Study Design and Participants

We conducted a quasi-experimental study to examine the effects of sleep state sensors for supporting formal caregivers at a nursing home. The participants were eligible if they were formal caregivers, aged at least 20 years, and worked at a nursing home. Participants are excluded from the study if they plan to leave the job within 8 weeks. In this study, we investigated whether long-term care for residents using mat-type sleep state sensors that detect the resident's sleep state reduces the caregiver's mental burden compared with usual care.

Procedures

An intervention group received sleep state sensors to provide long-term care for residents in all 40 private rooms on the fourth floor of a nursing home in Zenkoukai, Tokyo. The sleep state sensors were mat types and designed to detect body motion such as the frequency of toss and turning and to measure heartbeat and respiration. One sensor was placed on a bed in a private room. When body motion is detected, the information is instantly displayed on a monitor at a staff station. The monitor showed the sleep state (ie, awake or asleep) and action state (ie, lying, sitting, or leaving bed) of the residents at all times. When formal caregivers cared for residents in each private room, they checked the sleep and active state of the resident on the monitor and visited the private room (Figure 1). For instance, in the intervention group, when the visiting the room for elimination care, the formal caregiver checked the resident's sleeping or waking status on display and visited the room for elimination care when the resident was awake as much as possible. By contrast, formal caregivers in the control group (on the fifth floor of the nursing home) provided long-term care for residents as usual.

Figure 1. Overview of the sleep state sensors.



The sensors were expected to allow the formal caregivers to check the status of each resident in each private room of nursing homes in real time on PCs at the staff station, thus enabling them to provide care efficiently. Furthermore, by accumulating these records, it was possible to understand the rhythm of each resident's life. As a result, it was expected that care plans can be formulated to match the rhythm of each resident's life.

In addition, the mental condition of the formal caregivers was measured using self-reported outcome measures, the Profile of Mood States (POMS), Short-Form, 2nd edition (POMS 2) [20,21]. POMS 2 was published in 2012 to assess transient feelings and mood, and has already been validated by Heuchert and McNair [20]. The Japanese version of the POMS 2 scale has already been validated for reliability and validity [22,23]. Participants in both groups received the POMS at baseline, midpoint (week 4), and endpoint (week 8) to identify changes in these domains. The POMS assessed mood states of individuals, or transient, fluctuating feelings and enduring affect states [20,21].

Outcome

The primary outcome was the difference at 8 weeks in the total mood disturbance (TMD) of the POMS. Referring to previous studies, we set the duration of the sensor-based intervention at 8 weeks [24,25]. The TMD indicated the extent to which formal caregivers experienced overall negative or positive affect, or the degree of overall mood disorder, where a higher score is indicative of the bad mood. The TMD was a composite score of 5 negative mood states (ie, anger-hostility, confusion-bewilderment, depression-dejection, fatigue-inertia, tension-anxiety) and a positive mood state (ie, vigor-activity). As for the TMD and negative mood states, higher scores could indicate a problem. Regarding the positive mood states, lower scores indicate a problem. Regarding clinically significant differences, we considered a difference of 8 points or more in the TMD as clinically significant, referring to previous studies [26]. The secondary outcome was the change at 3 time points (ie, baseline, week 4, week 8) of the TMD to clarify the change of the mental burden immediately after the introduction.

Statistical Analysis

For the primary analysis, we performed an analysis of covariance (ANCOVA), which is a blend of analysis of variance (ANOVA) and general linear regression to evaluate differences between groups. We conducted the ANCOVA using POMS 2 (eg, TMD), intervention, measurement timing, and an interaction term between intervention and measurement timing. For secondary outcomes, the difference between the intervention and control groups was analyzed using ANCOVA. For the PMD at the baseline, midpoint (4 week), and endpoint (8 week), we used a repeated ANOVA to assess the change of TMD in the intervention and control groups. A *P* value less than .05 was considered statistically significant. Statistical analysis was performed using Stata, version 16.0 (StataCorp).

Ethical Approval

Medical ethical approval was obtained from the Medical Ethical Committee of Tokyo Medical and Dental University (M2017-228-2). All participants gave written consent for participation in the study.

Results

A total of 25 formal caregivers were recruited; however, 1 formal caregiver in the intervention group and 2 formal caregivers in the control group discontinued because of leaving the job at the nursing home. Among the 22 formal caregivers, the median age was 31 years (IQR 28-37 years); 9 (41%) formal caregivers were women versus 13 (59%) men. The median working period at the nursing home was 59 months (IQR 14-92 months). Among the 22 formal caregivers, 12 (55%) were certificated care workers (ie, those who have national qualifications). Tables 1 and 2 present the baseline characteristics of the formal caregivers and older persons, respectively, by the intervention and control groups.

Table 1. Baseline characteristics of the formal caregivers.

Population	Intervention group (n=12)	Control group (n=10)	*P* value
Age (years), median (IQR)	31 (28-32)	32 (30-55)	.27[a]
Sex, n (%)			.19[b]
Women	3 (25)	6 (60)	
Men	9 (75)	4 (40)	
Working period[c] (months), median (IQR)	57 (7-74)	76 (34-93)	.31[a]
Certifications, n (%)			.85[b]
Certificated care worker	7 (58)	5 (50)	
Other	2 (17)	1 (10)	
None	3 (25)	4 (40)	

[a] Mann-Whitney *U* test.

[b] Fisher exact test.

[c] Working period at the nursing home.

Table 2. Baseline characteristics of the older persons.

Population	Intervention group (n=40)	Control group (n=40)	*P* value
Age (years), median (IQR)	87 (82-91)	87 (82-91)	>.99[a]
Sex, n (%)			.79[b]
Women	32 (80)	30 (75)	
Men	8 (20)	10 (25)	
Care need levels, n (%)			.81[b]
1	0 (0)	0 (0)	
2	0 (0)	1 (3)	
3	9 (23)	9 (23)	
4	15 (38)	17 (43)	
5	16 (40)	13 (33)	

[a] Mann-Whitney *U* test.

[b] Fisher exact test.

Among the 22 formal caregivers, 12 were assigned to the intervention group, and 10 to the control group. Out of the 12 formal caregivers in the intervention group, 50% (n=6) experienced positive TMD at the endpoint (ie, week 8). Of the 10 formal caregivers in the control group, 50% (n=5) also experienced positive TMD at the endpoint (ie, week 8). As for the primary outcome of the difference between TMD at baseline and week 8, TMD in the intervention group improved by –3.67 versus 4.70 in the control group, resulting in a mean difference of –8.37 (95% CI –32.02 to 15.29; *P*=.48) in favor of the intervention. Although significant differences were not observed (see above) between the intervention and the control groups, the sign of regression coefficients was negative.

Table 3 shows the effect of the intervention on secondary outcomes. The change in anger-hostility from baseline to 8 weeks in the intervention group improved by –0.84 versus 0.90 in the control group, resulting in a mean difference of –1.73 (95% CI –7.43 to 3.96; *P*=.54; Tables 1 and 2). The change in depression-dejection in the intervention group improved by –0.16 versus 1.60 in the control group, resulting in a mean difference of –1.77 (95% CI –6.49 to 2.96; *P*=.45). The change in tension-anxiety in the intervention group improved by –0.91 versus 0.20 in the control group, resulting in a mean difference of –1.12 (95% CI –6.58 to 4.34; *P*=.68). Significant differences were not observed (see above) in 5 negative mood states (ie, anger-hostility, confusion-bewilderment, depression-dejection, fatigue-inertia, tension-anxiety) and a positive mood state (ie, vigor-activity).

Table 3. Mean difference in change of the Profile of Mood States.

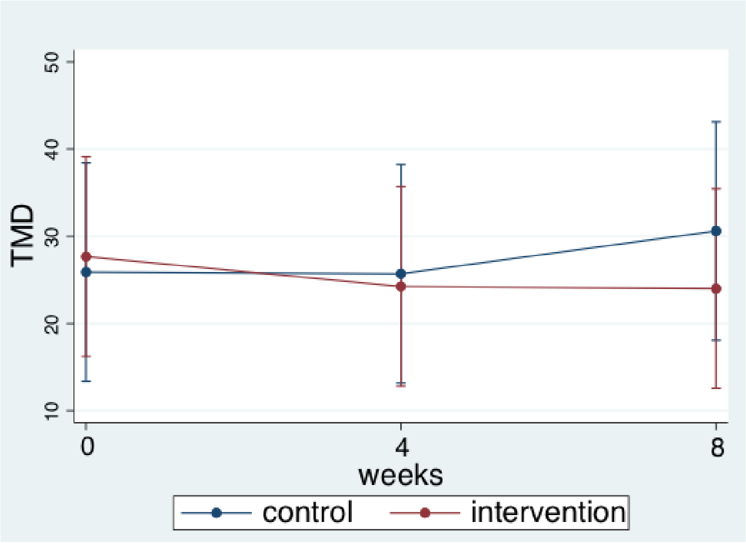
Parameter	Baseline[a]		Week 8[a]		Mean difference in change (intervention vs control) (95% CI)	*P* value[b]
	Intervention (n=12)	Control (n=10)	Intervention (n=12)	Control (n=10)		
Total mood disturbance	27.67 (25.27)	25.9 (13.55)	24.00 (19.29)	30.60 (9.92)	–8.37 (–32.02 to 15.29)	.48
Anger-hostility	5.67 (5.43)	6.00 (4.69)	4.83 (4.41)	6.90 (2.95)	–1.73 (–7.43 to 3.96)	.54
Confusion-bewilderment	7.58 (5.82)	5.00 (3.26)	7.42 (3.84)	6.00 (2.86)	–1.17 (–6.42 to 4.09)	.66
Depression-dejection	6.33 (4.29)	4.60 (2.73)	6.17 (4.08)	6.20 (3.46)	–1.77 (–6.49 to 2.96)	.45
Fatigue-inertia	8.17 (5.92)	9.60 (4.13)	6.92 (5.77)	9.70 (3.85)	–1.35 (–7.78 to 5.08)	.67
Tension-anxiety	8.83 (5.52)	7.80 (3.57)	7.92 (4.17)	8.00 (3.52)	–1.12 (–6.58 to 4.34)	.68
Vigor-activity	8.92 (4.89)	7.10 (4.06)	9.25 (4.90)	6.20 (4.77)	1.23 (–4.71 to 7.18)	.68

[a] Mean (standard error).

[b] Analysis of covariance.

For the PMD at the baseline, midpoint (4 weeks), and endpoint (8 weeks), we used a repeated ANOVA to assess the change of TMD in the intervention and control groups. The results indicated that the mean differences (intervention vs control) at the baseline, midpoint, and endpoint were 1.77 (95% CI –15.20 to 18.73; *P*=.84), –1.45 (95% CI –18.42 to 15.52; *P*=.87), and –6.6 (95% CI –23.57 to 10.37; *P*=.44), respectively (Figure 2).

Figure 2. Change of the TMD from baseline to week 8. TMD: total mood disturbance.



Discussion

Principal Findings

We investigated whether sleep state sensors for supporting long-term care can reduce the mental burden of formal caregivers in a nursing home. The primary outcome was the difference from baseline to endpoint (week 8) on the TMD of the POMS, or the degree of overall mood disorder. As the result of this study, the TMD in the intervention group improved by –3.67 versus 4.70 in the control group, resulting in a mean difference of –8.37 (95% CI –32.02 to 15.29; *P*=.48). No significant difference was observed in the study.

In contrast to previous studies with sensors [27-29], utilization of mat-type sleep state sensors was not associated with improving burdens of formal caregivers in the nursing home. Notably, the scales to measure mental condition in the previous study were different from those used in this study; for example, the Satisfaction with Work Questionnaires, the Satisfaction with Life Scale [30], and the Life Satisfaction Questionnaire were used previously [31]. One possible reason for the lack of association between utilization of sleep state sensors and TMD of formal caregivers may be time-lag bias; that is, the impact of using sleep state sensors might appear much later. In our study, the mean differences in change (intervention vs control) at baseline, midpoint, and endpoint were 1.77 (95% CI –15.20 to 18.73; *P*=.84), –1.45 (95% CI –18.42 to 15.52; *P*=.87), and –6.6 (95% CI –23.57 to 10.37; *P*=.44), respectively. Although significant differences were not observed, the mean differences in change (intervention vs control) increased gradually. Thus, further studies over a longer duration would be needed to investigate the association [29, 32, 33].

As for the 5 negative mood states (ie, anger-hostility, confusion-bewilderment, depression-dejection, fatigue-inertia, and tension-anxiety) and a positive mood state (ie, vigor-activity), the greatest change in the intervention group occurred in the fatigue-inertia category. By contrast, there was little change in the fatigue-inertia category in the control group. The use of sensors may therefore be related to reducing fatigue. In future studies, we need to research the differences in the changes in each item.

According to an interview with some formal caregivers in the intervention group, the timing of checking the residents' condition on the monitor was when they did routine rounds to check on the residents' health at night, and when they provided excretory care during the day. They then adjusted the time of care when the resident was asleep. Thus, change in the timing of care provision might enhance the quality of care and improve the satisfaction of residents [34-36]. In addition, it was expected to be useful for countermeasures against infectious diseases because the residents' condition can be ascertained without visiting the room. Further studies about enhancing the quality of care and combating infectious diseases are needed to investigate the effect of the intervention. Moreover, further research on the mechanism of how sensor use would impact care is needed.

Limitations

Several limitations of this study need to be noted. First, the participants were selected from just 1 nursing home in Tokyo, Japan. Thus, our results cannot be generalized because selection bias may be present. Second, random assignment could not be performed, which may have caused selection bias. Third, the small sample size of this study must be noted. Fourth, the follow-up period might be insufficient, and we did not take into account the time-lag bias. Finally, we cannot completely eliminate the effects of potential confounding factors, including socioeconomic status and educational status of formal caregivers. However, to the best of our knowledge, this is the first study to explore the impact of mat-type sleep state sensors on formal caregivers in a nursing home in Japan, which would contribute to the development of future research on long-term care.

Conclusions

For an 8-week study in a nursing home, sleep state sensing for elderly residents might not be associated with reduced mental burdens on formal caregivers. The findings imply that further studies over a longer duration would be needed to investigate the association between the utilization of mat-type sleep state sensors and reduced mental burdens on formal caregivers in nursing homes.

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Authors' Contributions

All authors have contributed substantially to the conception and design, or collection of data; SI drafted the article and performed the statistical analysis; KK, H-PT and YO performed the interpretation of the data; H-PT, KK, and YO revised the article critically for important intellectual content. All authors have approved the final version to be published.

Conflicts of Interest

None declared.

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Abbreviations

ANCOVA: analysis of covariance
ANOVA: analysis of variance
IoT: internet of things
POMS: Profile of Mood States
TMD: total mood disturbance

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Original Paper

The Usability and Impact of a Low-Cost Pet Robot for Older Adults and People With Dementia: Qualitative Content Analysis of User Experiences and Perceptions on Consumer Websites

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Abstract

Background: Worldwide, populations are aging exponentially. Older adults and people with dementia are especially at risk of social isolation and loneliness. Social robots, including robotic pets, have had positive impacts on older adults and people with dementia by providing companionship, improving mood, reducing agitation, and facilitating social interaction. Nevertheless, the issue of affordability can hinder technology access. The Joy for All (JfA) robotic pets have showed promise as examples of low-cost alternatives. However, there has been no research that investigated the usability and impact of such low-cost robotic pets based on perceptions and experiences of its use with older adults and people with dementia.

Objective: The aim of our study was to explore the usability and impact of the JfA robotic cat, as an example of a low-cost robot, based on perceptions and experiences of using the JfA cat for older adults and people with dementia.

Methods: We used a novel methodology of analyzing a large volume of information that was uploaded by reviewers of the JfA cat onto online consumer review sites. Data were collected from 15 consumer websites. This provided a total of 2445 reviews. Next, all reviews were screened. A total of 1327 reviews that contained information about use of the JfA cat for older adults or people with dementia were included for analysis. These were reviews that contained terms relating to “older adults,” “dementia,” and “institutional care” and were published in the English language. Descriptive statistics was used to characterize available demographic information, and textual data were qualitatively analyzed using inductive content analysis.

Results: Most reviews were derived from consumer sites in the United States, and most reviewers were family members of users (ie, older adults and people with dementia). Based on the qualitative content analysis, 5 key themes were generated: prior expectations, perceptions, meaningful activities, impacts, and practicalities. Reviewers had prior expectations of the JfA cat, which included circumstantial reasons that prompted them to purchase this technology. Their perceptions evolved after using the technology, where most reported positive perceptions about their appearance and interactivity. The use of the robot provided opportunities for users to care for it and incorporate it into their routine. Finally, reviewers also shared information about the impacts of device and practicalities related to its use.

Conclusions: This study provides useful knowledge about the usability and impact of a low-cost pet robot, based on experiences and perceptions of its use. These findings can help researchers, robot developers, and clinicians understand the viability of using low-cost robotic pets to benefit older adults and people with dementia. Future research should consider evaluating design preferences for robotic pets, and compare the effects of low-cost robotic pets with other more technologically advanced robotic pets.

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KEYWORDS

social robot; pet robots; low-cost robot; dementia; older adults; qualitative research; qualitative content analysis

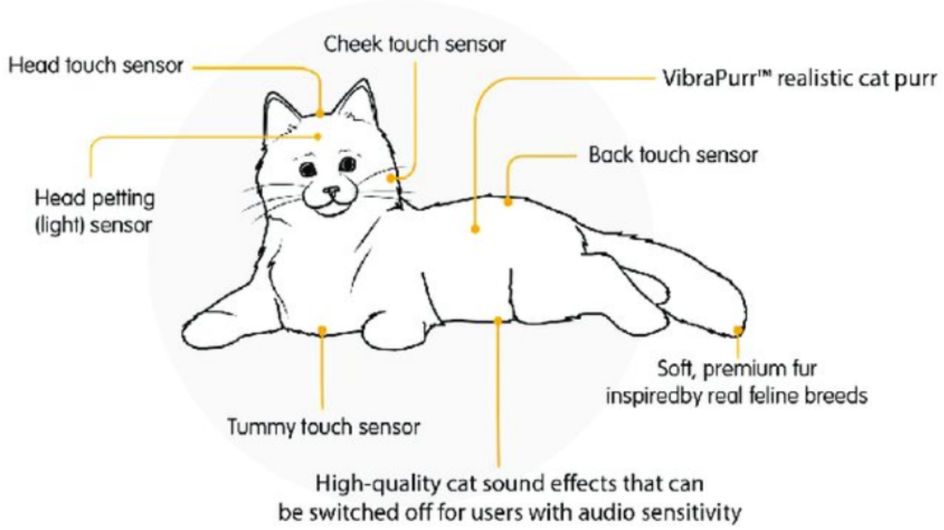
Introduction

Worldwide, the population is aging exponentially. Since the prevalence of dementia greatly increases with age, the corresponding number of people with dementia is also on the rise [1]. Older adults and people with dementia are especially at risk of social isolation and reduced psychosocial health [2]. Social robots, such as robotic pets, are innovative technological solutions that are being developed and deployed to address the psychosocial needs of this population [3]. They are defined as autonomous or semiautonomous devices that are socially evocative and socially receptive [4], with the ability to interact with humans in a socially appropriate manner [5]. Pet robots are developed to simulate and substitute animal-assisted therapy [6]. Although animal-assisted therapy can benefit the social and emotional health of older adults and people with dementia by providing companionship, eliciting relaxation, and reducing loneliness [7,8], the use of live animals can pose several challenges. For instance, there is potential for transmission of zoonotic diseases, animal aggression, and compromised animal welfare [9]. Therefore, the use of a robotic alternative is seen as a novel way to enable older people and people with dementia to reap the psychosocial benefits of animal-assisted therapy, while potential adverse effects are avoided. Overall investigations into their effects have demonstrated positive benefits for older adults and people with dementia. Their use was found to have positively affected physiological indicators through improved sleep, improved oxygenation and cardiac status, reduced use of psychotropic drugs, improved mood, and improved social engagement [10-12]. PARO, a robotic seal, was the most studied robotic pet. Other pet robots include AIBO (robotic dog), JustoCat and NeCoRo cat (robotic cats), and Pleo (robotic dinosaur). However, the affordability of the robots is one key issue that has been widely flagged as a concern by multilevel stakeholders [13-15]. For instance, the JustoCat costs approximately US $1350 and PARO costs about US $6000. The substantial cost of such technology can reduce innovation dissemination [16], posing the ethical concern of unequal access [17]. Therefore, there is a need to explore lower costed alternatives.

The Joy for All (JfA) robotic pets have been identified as low-cost and commercially available innovations that have been used for older people and people with dementia [18]. They contain sensors to respond to touch and light, through movements and vocalizations, with the purpose of providing social interaction (Figures 1 and 2). Because they are capable of autonomous responses to stimuli for the purposes of social interaction, they should be considered as social robots. As one unit of the JfA robotic pet costs between US $110 and US $130, they are significantly more affordable. Synthesized findings from a recent review showed that despite being less-technologically advanced than other robotic pets, the JfA robotic pets showed promising benefits to address the psychosocial needs of older adults and people with dementia [18]. This included improved mood and affect, improved social interaction, companionship, and other well-being outcomes [18]. The lower cost of the technology also appeared to influence the ways in which the robotic pets were being used. For example, in contrast to other higher-costed pet robots that have been shared among users [12], most older adults and people with dementia that were included in the study owned their own JfA pet [18]. This implied that the affordability of the JfA pets had an influence on the accessibility to and adoption of this technology. Furthermore, individual ownership of social robots was suggested as a way to mediate the issue of infection control by reducing the potential for transmissible diseases from shared use. This is especially relevant in residential care settings in light of the COVID-19 pandemic, where a recent study has advised against the sharing of pet robots [19]. The review also found that while a few studies used both the JfA cat and dog for older adults and people with dementia, most only used the JfA robotic cat. A study by Bradwell et al [20] presented similar findings, where the JfA robotic cat, among 7 other alternatives, was chosen by older adults as their most preferred robotic pet.

Figure 1. Joy for All robotic pets.

Figure 2. Touch interaction capabilities of the Joy for All cat. Used with permission from Joy for All.



Despite its potential as a therapeutic device, there is a lack of research to understand the usability and impact of the JfA cat based on perceptions and experiences of its use with older adults and people with dementia. As such, this study aims to explore the perceptions and experiences of using the JfA cat for older adults and people with dementia, using user-generated content published on consumer websites. This is a novel methodology that will be described below.

Methods

Study Data

The data used for this research are located on public platforms (ie, consumer review sites). Therefore, informed consent for this study was not obtained. However, as the use of direct quotes from consumer reviews could potentially make them identifiable, the quotes that were illustrated in this study were minimally amended to ensure users' anonymity. This study was approved by the National University of Ireland Galway Research Ethics Committee (reference number R20.JUN.12).

Focus on User-Led Content

To date, most research that aims to understand experiences using social robots has traditionally been researcher driven [10]. By contrast, this study utilized the large volume of information uploaded by users of the JfA cat onto publicly accessible online consumer review sites. These sites contain a sizeable body of anecdotal evidence from users who have purchased and used lower costed pet robots. These individuals shared detailed accounts of their experiences, for the primary benefit of other potential users who might be seeking to gather information about the product. Examining this valuable source of information during the study was an opportunity to develop knowledge shifting away from regarding researchers and health care professionals as the sole producers of information toward eliciting the voice and empowerment of nonprofessionals [21]. This approach has been used in other research fields, such as business or consumer research, however it is a novel methodology in the field of health and social sciences which allowed for an examination of user-led content.

Data Collection: Data Sources and Search Strategy

Data collection involved 3 key steps. First, online consumer review sites were identified through a Google search, using the search terms “Joy for All cat” and “user review”. The researcher's (WK) internet browsing history and cookies were cleared, and the search was conducted in the incognito mode. Next, the first 100 consumer sites identified from the Google search that contained consumer reviews of the robotic cat were selected as data collection sites. All reviews were manually extracted into Microsoft Excel. This step was essential to ensure a clear audit trail, as the content of a webpage may change depending on what the researcher searches for and researcher's location [21]. Consumer reviews of all languages that were submitted up to July 24, 2020, were extracted using a standardized data extraction form (Multimedia Appendix 1) containing the following data fields: (1) review title, (2) review text, (3) star rating given, and (4) review date. Demographic information about users of the technology, such as their age group, diagnoses, and setting, was also collected if these data were available. If these were not available, the data field was left empty. To ensure anonymity, no potentially identifying information, such as the reviewing authors' name and photo attachments, was collected. Finally, all reviews were screened to identify the sampling frame for data analysis.

Inclusion and Exclusion Criteria

Reviews were included if they contained information about the use of the robotic cat for older adults or people with dementia in any settings and were published in the English language.

As not all reviews contained information regarding users' age and diagnoses, innovative approaches had to be undertaken to ensure that all relevant reviews were adequately considered for inclusion. First, as the average age of becoming a grandparent is between 50 and 69 years in several countries [22-24], it seemed reasonable for the researcher to include reviews that mentioned about the use of the robotic cat for this group (ie, grandparents) as older adults. Next, reviews that contained information about the use of JfA cat in institutional care were also included, as the large majority of people living in assisted living facilities or care homes are of an older age group [25-29].

Hence, reviews that met any of the following inclusion criteria were included in the sampling frame:

- Included terms related to older adults, such as “older adult”, “elderly”, “elder”, “senior”, “grandmother”, or “grandfather” or explicit comment that users of the JfA robotic cat are aged 60 years and above
- Contained terms related to dementia, such as “dementia”, “Alzheimer’s disease”, “memory loss”, “memory problems”, “cognitive impairments” or “cognitive issues”, “memory care”
- Contained terms related to institutional care, such as “nursing home”, “assisted living facility”, “retirement home”
- Published in English language

All reviews that did not meet these inclusion criteria were excluded. Reviews that were included were cleaned and formatted on Microsoft Excel before being exported into NVivo 12 (QSR International) for data analysis.

Data Analysis

Descriptive statistics was applied to characterize the number of reviews, available demographic information about users of the JfA cat, and the average star ratings given by users. Textual data were qualitatively analyzed using inductive content analysis, as described by Hsieh and Shannon [30], on the NVivo12 software. This method of data analysis was chosen as it guides systematic categorization of large volumes of text-based data and facilitates the identification of patterns of occurrences [31].

The data analysis proceeded as follows: First, 3 coders (WK, SW, and PH) immersed themselves in the data by reading all data repeatedly to obtain a sense of the whole and to allow new insights to emerge [31,32]. The first 5% of reviews were read word by word by each coder, who independently generated key thoughts or concepts for each phrase, and labeled them using descriptive and low-inference codes [33,34]. After that, all coders met to discuss similarities and differences, and agreed on codes that formed the initial coding scheme [30]. Next, this coding scheme was tested by WK, SW, and PH, who independently coded another 10% (n=137) of all data using the coding scheme. Data that did not fit into an existing code were assigned a new code. After this, intercoder reliability test (ICR), using the kappa coefficient (κ), was conducted to assess the similarity between the coding produced by the authors. Although there is no set consensus on what proportion of data should be analyzed to yield a reliable estimate of ICR [35], an analysis of 10%-25% of the data set is typical [36]. Conducting this test allowed the rigor and transparency of the coding framework to be ascertained [36-38]. The kappa coefficient of 0.60 was obtained, which demonstrated substantial agreement between coders [39]. Following this, all coders met to discuss and agree upon the final coding framework. In particular, they ensured that all data within the codes and categories were distinctive and that they had good coherence [40,41]. The final coding scheme (Multimedia Appendix 2) was tested by WK and SW, who independently coded another 5% (n=66) of the data set. Strong intercoder reliability was established (κ=0.7). Thereafter, the coding framework was applied to the remaining reviews by WK. Research rigor was ensured through prolonged engagement with the data [42], and frequent meetings with all coders throughout the creation of the coding framework, and to develop and refine the codes and categories.

Results

Overview

Figure 3 shows the flowchart that reports the data identification and collection. A total of 100 websites were identified, of which 15 were consumer review sites for the JfA robotic cat (Table 1).

Figure 3. Flowchart (identification of reviews).

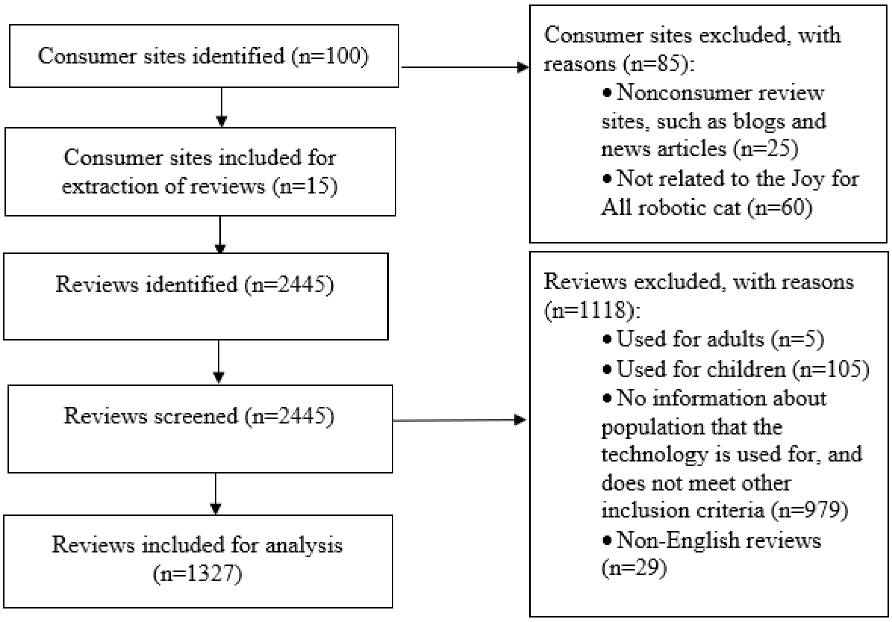


Table 1. Consumer sites and reviews identified.

Consumer review sites (source)	Number of reviews
Amazon (total: 6 sites)	2068
Joy For All	214
Best Buy	25
MindCare Store	7
Eugeria	5
Caregiver Products	5
Alzstore	32
Alzproducts	10
QVC	79
Walmart	0

Description of Reviews

A total of 2445 consumer reviews were submitted over a 5.5-year period from December 4, 2015, to July 24, 2020. Of these, 1327 reviews met the inclusion criteria and were included for data analysis. Most reviews were derived from consumer sites from the United States (n=948), Canada (n=132), the United Kingdom (n=80), and Australia (n=13). Most reviews contained information about review date and star rating (n=1309). Overall, the number of reviews increased steadily from 2015 to 2020, and its average star rating was 4.75 (Table 2).

Table 2. Star rating and number of reviews across the years.

Year of review	2015	2016	2017	2018	2019	2020
Number of reviews	15	180	222	228	372	292
Average star rating	4.13	4.63	4.86	4.74	4.76	4.76

Review Authors and Users of the Robotic Cat

Information about the review authors and users is presented in Table 3. Most review authors were family members of the primary users of the JfA cat. The majority were children (n=770), grandchildren (n=120), and partners (n=52) of older adults or people with dementia. Only 2% (n=22) of all reviewers identified themselves as users of the robotic cat. Information about the relation of other review authors with the older person or person with dementia was not available in 247 (18.61%) cases.

Table 3. Information about review authors and users.

Information	Sample size, n (%) (N=1327)
Review authors	
Relationship to users	
Family members	1038 (78.22)
Children	770 (58.03)
Grandchildren	120 (9.04)
Partners	52 (3.92)
Other relatives	96 (7.23)
Self	22 (1.66)
Others (friends, care workers)	6 (0.45)
No information	247 (18.61)
Users	
Age/diagnosis	
Older adults	586 (44.16)
People with dementia, cognitive impairment or memory issues	687 (51.77)
Gender	
Female	988 (74.45)
Male	121 (9.12)
No information	218 (16.43)
Setting	
Long-term care facilities	399 (30.07)
Memory care facilities	56 (4.22)
Retirement homes	16 (1.21)
Other care facilities	49 (3.69)
Own homes	19 (1.43)
No information	788 (59.38)

The JfA cat was described as being for the use for older adults in 44.16% (586/1327) of reviews, while 51.77% (687/1327) described their use for people with dementia, cognitive impairment, or memory issues. The majority (n=1109) contained information about users' gender, of which 89.09% (n=988) were females. Less than half (n=539) provided explicit information about the setting in which the device was used (Multimedia Appendix 3). Most were used in care settings, including long-term care facilities (n=399), specialized memory care facilities (n=56), retirement homes (n=16), or other care facilities (n=49).

Qualitative Findings

Themes

Five themes were generated from the qualitative analysis: (1) prior expectations, (2) evolving perceptions, (3) meaningful activities, (4) impact of the robotic cat, and (5) practical aspects surrounding the use of the JfA cat. Table 4 shows the main themes, subthemes, and their prevalence in the data. It also provides information on exemplar codes and representative quotes in each subthemes. We will describe the themes in the following sections.

Table 4. Main themes, subthemes, and exemplar codes.

Main themes and subthemes	Prevalence, n (%)[a]	Examples of exemplar quotes *(code)*
Prior expectations		
Circumstances	390 (29.39)	*When my 89-year-old mother was sent to a nursing home after a hospital stay, she lost her residence of 25 years, and worst of all, she lost her beloved orange tabby (can’t have a live cat).*
Expectations	182 (13.72)	*I was sceptical when I first heard that a mechanical cat like this could provide comfort and relief from anxiety for an elderly person suffering dementia (uncertainty and scepticism).*
Perceptions		
Appearance	364 (27.43)	*You can feel the bumps on the body through the fur (not lifelike).*
Interactivity	418 (31.50)	*It’s ingeniously designed, with the movements coming at a seemingly random cycle, just like a real animal. The meowing is the only weakness, it doesn't really sound like a cat, but the purring is spot on (positive comment about interactivity).*
Expectations met	415 (31.27)	*It did way more than I thought it could. Seemed like I found new things it could do for 3 days before I found everything (exceeded expectations).*
Ambivalence or rejection	114 (8.59)	*I bought this for my grandma, and she was very upset by it. She's in her late 80's and has slight dementia but she still got offended by this kitty. I took the cat home with me since she was so upset. I wasn't trying to insult her (rejection).*
Meaningful activities		
Companionship	270 (20.35)	*Now Brutus (name for the JfA cat) is helping my grandma not to feel completely alone (companionship).*
Doing something (activities)	500 (37.68)	*She takes it everywhere she goes, it rides along in her basket in her walker (taking it to places).*
Facilitation and support	75 (5.65)	*She wants it to purr, but gets upset if it meows too much. So we put it on mute so it still moves it’s head and eyes and arm and purrs but doesn’t get annoying (facilitation and support).*
Treating the robot cat as if it were real	70 (5.28)	*We talked to Mom/Grandma and let her know we were going to try to get her cat fixed. She is very concerned that we are going to take her cat away, but we assured her that we would try very hard to not take it away from her (attachment).*
Topic of conversation	78 (5.88)	*Both cat and grandfather are now quite popular. With dementia, I am not sure if he knows the cat is not real. Needless to say this cat has helped to improve my grandfather’s social interactions as many people come to check out the cat (topic of conversation).*
Impacts		
Positive impacts on users	1000 (75.36)	*Mom who has dementia & suffers from sundowner syndrome. Her cat’s meowing & purring (an impressively large repertoire of vocalizations) and the many movements it makes in response to touch, motion & sound provide the perfect kind of distraction my Mom needs in those PM hours (a welcome distraction).*
Negative impacts (users)	20 (1.51)	*She cried the other day because she thought it died (someone turned it off), she picked it up and cried for hours (negative impact on users).*
Positive impacts (others)	111 (8.36)	*My Mum is in a residential care manor and one of the other residents saw the cat and her daughter bought her one. All the residents love them (positive impacts on others).*
Negative impacts on others/caregivers	3 (0.23)	*When the care home residents saw the cat, there was a near riot because they all wanted to hold it and stroke it at the same time (negative impact on others).*
Practicalities		

Main themes and subthemes	Prevalence, n (%)[a]	Examples of exemplar quotes *(code)*
Positive aspects	409 (30.82)	*We have had it for a few weeks now and have yet to replace the batteries. The cat goes into sleep mode when it is not touched for several minutes which saves the battery life. It is reactivated as soon as one of the sensors in the back or head are touched (battery life).*
Negative aspects	118 (8.89)	*The product is ONE STAR in terms of reliability. My FIL loved it so much he broke it. We think he held the head too tightly, and ultimately the servos broke. The cat still meows and purrs, but it no longer rolls onto its back and the eyes no longer open (not robust).*
Suggestions for improvement	51 (3.84)	*One thing they missed though, is the movement a cat makes when you scratch under her chin...You know, head back so you can really get in there. And if they are reading this...they could make it a smart cat with an app and everything. It would be cool if you could talk to it or give it commands and it responds (suggestions for improvement).*

[a] Based on a total of 1327 reviews.

Prior Expectations

This theme describes the circumstances which prompted reviewers to acquire the JfA robotic cat for the older person or person with dementia, and reviewers' perceptions of this technology prior to its use. Some reviewers (223/1327, 16.80%) commented that users had previous experience with or liked cats or other animals. However, users were now unable to own a live animal due to circumstantial or personal reasons (181/1327, 13.64%), such as institutional restrictions in residential care facilities and reduced physical or cognitive capacities.

> *Recently my 93 mother's dementia progressed to the point that she required assisted living in a nursing home. She was devastated that she could not take her two cats with her. She misses them more than anything.* [Reviewer 108]

Other reviewers indicated that they were prompted to purchase the JfA cat due to concerns about loneliness and isolation (102/1327, 7.69%), especially for intended users who lived alone or in residential facilities. The impact of COVID-19 measures was discussed in more recent reviews, where reviewers shared that visitation and activity restrictions exacerbated feelings of isolation. As such, expectations were focused on the users' likes of animals, and hopes that it might provide comfort, companionship, and improve their overall quality of life.

> *When my family was faced with having to admit my 91-year-old Granny to a memory care facility it was devastating for us to think of her in there all alone and sad....* [Reviewer 8]

> *Due to the pandemic and imposed isolation and restrictions, all enrichment activities such as visiting music, games, exercises, therapy animals were ceased. Residents were no longer allowed to eat with other residents. We hoped the therapy cat would provide some comfort.* [Reviewer 13]

A few reviewers (70/1327, 5.28%) reported skepticism about the usefulness of the robotic pet, and concerns about how users would perceive it or respond to it.

> *I braced myself for a dismissive laugh, a 'what the hell did you get this for, what a waste of money'.* [Reviewer 335]

> *At first, I was hesitant because I was worried that she (my mother) would be insulted if I gave her a 'toy'.* [Reviewer 146]

Perceptions

This theme describes perceptions about the appearance and interactive features of the JfA cat, and whether it has met reviewers' expectations. Perceptions about its appearance were mainly positive (312/1327, 23.51%), as reviewers commented about its life-likeness, size, and weight as resembling a real cat. Reviewers (357/1327, 26.90%) also commented about the device's realistic movements and vocalizations, especially its purring. Some pointed out that their JfA cat looked similar to users' previous cats. The robotic cat has sensors to respond to light and touch, however, its vocal and movement responses are nonprogrammable and are unpredictable. Some reviewers perceived its unpredictability as behaviors that resembled a live cat.

> *At intervals, this cat flicks its ears, raises a paw to its face as if it's washing, turns it head when touched, blinks its eyes, and partially closes its eyes; and purrs and meows when it's head and back are petted. It also rolls back to expose its belly, and what is funny about the cat, is that the moments are unpredictable, and spontaneous just as if it were real.* [Reviewer 394]

However, a few reviewers were negative in their comments (105/1327, 7.91%). The robotic cat was thought to be hard to the touch, which reduced its cuddliness and realism. The meowing sound of the cat was perceived as sounding like a person imitating its meow, and some movements were perceived to be mechanical looking and sounding. Although most reviewers said that not being life-like did not influence the interaction that users had with the technology, others commented that users' acceptance of the device was negatively impacted.

> *She (my mother) doesn't seem to notice the battery pack which is quite hard but likes to pet it (JfA cat) and keeps it on her bed at night.* [Reviewer 588]

> *The facial and ear movements do make some mechanical noise, but they're not that loud and don't detract from it. The one thing that I could do without is that occasionally the front half twists and rolls back, then after a few minutes it comes back up. That's*

> *when you hear the loud motor really kick in and I find it to be an unnatural movement.* [Reviewer 215]

> *While she (my mother) seemed to like the cat at first, she noticed the jerky movements and mechanical sounds it makes when it turns its head and she didn't like this. Three weeks after giving it to her she says that it's a beautiful cat, but that there's something wrong with it.* [Reviewer 262]

Perceptions of the JfA cat sometimes evolved with its use. Although most reviewers who discussed about their expectations of the robotic cat perceived it to have met or exceeded their prior expectations and fitted the needs of users (182/1327, 13.72%), some considered that the JfA cat may not be suitable for everyone. Similarly, a few users were ambivalent or had negative perceptions, and rejected the technology (72/1327, 5.43%).

> *We didn't know if (my father) would like it, scoff at it, or soon get bored with it. His eyes lit up the moment it (JfA cat) was taken out of the box.* [Reviewer 171]

> *My elderly aunt found the cat "creepy" and wanted no part of it. I can see how some elderly people would like this mechanical replica, but she didn't like it.* [Reviewer 161]

Meaningful Activities

This theme describes the engagement in meaningful activities with the JfA cat. Use of the JfA cat provided opportunities to supervise or provide care for older people and people with dementia (500/1327, 37.68%). Activities included holding, petting or brushing it, talking to it, keeping it on their laps, sleeping with it, and taking it to places. Some activities, such as naming the cat after their previous pet or loved ones, also provided an avenue for users to reminisce about past experiences. The robot's interactivity also appeared to be perceived as behaviors of reciprocity, which facilitated users to continue engaging with it.

> *She (my mother) no longer speaks and appears somewhat catatonic. We were looking for ways to 'reach' her since talking to her and trying other activities were fruitless. We gave her this cat and got a glimpse into our mom again! The purring, meowing and movements awakened my mom and she came alive.* [Reviewer 763]

> *He (my dad) stroked her head, tail and back. He wanted to know her name. We told him she needed him to pick one for her. She became Fluffy! She meowed...He meowed back and laughed....* [Reviewer 167]

In some instances, the JfA cat was perceived to replace a lack of activity or participation, or replace undesirable or restless behaviors. Reviewers also commented that it provided companionship, and some users developed an attachment toward it.

> *She (my mother) has stopped looking for her kids at night and she is focused on taking care of her cat.* [Reviewer 1060]

> *She (my mother) will hang onto it (JfA cat) for dear life and not want to give it back to us. She has it with her at all times except at meals and during structured activities.* [Reviewer 763]

The JfA cat also provided users with a topic of conversation with others, including family members, friends, care providers, and residents within care facilities. Some passers-by would stop to interact with the user, talking about the JfA cat. This suggests that the robotic pet provided different opportunities for interactions.

> *She (my mother) had great difficulty speaking but would ask for "baby" every morning, would meow back at the cat and carry on an indecipherable conversation everyday.* [Reviewer 641]

> *I was delighted that not only did she (my mother) find it wonderful, but she also had the experience that all the dementia patients in her facility, including the nurses, are doting and cooing at the kitty cat. I was pleased that it brought her comfort and joy from the attention she got as well as the kitty itself.* [Reviewer 651]

Users varied as to whether they considered the JfA cat to be real. Reviewers (74/1327, 5.58%) mentioned that users were aware that this was not a live cat, but still enjoyed the device. While some commented about explicit attempts to introduce or remind users that the JfA cat is a robotic device, others suggested that users should treat it as a real cat. Some users who were not aware that the JfA cat was a robotic device treated it as if it were a live animal (70/1327, 5.28%) and tried to feed it with food and water, which dirtied it. Such perceptions also caused anxiety among some users, who became concerned that it would not eat or drink, or that it would escape. The device's vocalizations caused concerns among some users (70/1327, 5.28%), who became worried that the cat was upset. Some also exhibited distress when the robotic cat was not moving.

> *It's unclear whether she (my mother) believes it (JfA cat) is real or not - but we avoid clarifying that it isn't, and all try to act interact with it in front of her as though it is real, and of course we helped her pick a name!* [Reviewer 594]

> *Dad was nervous his cat would escape and get lost or that no one had given her food or water and she'd die. Mom had to stop him from bring Fluffy water (i.e., dumping it over her).* [Reviewer 167]

Impact of the Robotic Cat

This theme describes how the JfA robotic cat impacted the primary user and the caregiver. Most reviewers (874/1327, 65.86%) reported that users exhibited positive emotions. These included expressions of love and affection toward the robotic cat, expressions of joy, and improved mood. Several reviewers (228/1327, 17.18%) also commented that use of this technology was calming, provided comfort, and gave users a sense of purpose.

> *She [my mother] now has a reason to get out of bed in the morning and is back to her old self again.* [Reviewer 554]

> *I would say this week has been his calmest, happiest, most relaxed, enjoyable week in possibly three or more years! Because of this life-like, mechanical companion designed exactly for people like him.* [Reviewer 167]

> *She never slept through the night. Usually, I am up with her constantly, but we actually had to wake her this morning. She actually went to sleep with her cat cuddled in her arms.* [Reviewer 160]

The reviewers and other caregivers were also impacted. Reviewers shared about positive emotions and physical relief that they, their family members, and care staff experienced from observing users' interactions with the robotic cat (161/1327, 12.13%). Amidst these feelings, some reviewers shared about a sense of conflict or dilemma in watching users interact with a robotic device.

> *The amount of joy this has brought her - and me watching her interact with the cat - is priceless.* [Reviewer 265]

> *Now honestly for some in my family the idea that my mom is in love with a mechanical cat and believes it is real can be a distressing and shocking new reality. But to see her joy with this cat and to occasionally use it as a diversion when she sundowns or when she goes through an angry phase is priceless.* [Reviewer 530]

The JfA cat was also reported to have a positive impact on other people (111/1327, 8.36%), such as users' neighbors, or other residents in their care facility, who also enjoyed the technology.

> *She enjoys sharing it with all the other residents, and they agree that petting this purring cat is very soothing and relaxing.* [Reviewer 146]

Practical Aspects of Its Use

This theme describes comments about the facilitation that was rendered to support users' interaction with the JfA cat, overall experiences of the technology, and technical aspects of its use. Some reviewers provided mediation and supported users who perceived it to be a real animal (75/1327, 5.65%). Actions included reassuring users that the JfA cat was well taken care of, keeping it on mute or turning it off at night when users fell asleep, preparing spare batteries and being ready to prepare to change them as needed, and regularly cleaning food stains off its mouth. A few mentioned the use of a waterproof bib on the JfA cat's neck, and creating artificial feeding stations. Some reviewers also commented that they purchased an additional robotic cat as a back-up device.

> *It was purring a lot last night and I heard him telling the cat "shhhhh". I looked over and he's looking it in the eyes and shhhhing it. So I turned the cat off for a while.* [Reviewer 722]

> *I've got her (JfA cat) a collar and made her a tag and a feeding station (thank you hot glue and modge podge), so that he can care for her the way years of instinct and memories tell him he should.* [Reviewer 167]

Overall, most reviewers (409/1327, 30.82%) reported positive experiences. This included comments about satisfaction, and comments that they would recommend this device to others.

> *If you have someone in your life living with dementia or Alzheimer's, or something similar, please consider...this for that person. I haven't seen my grandmother that happy since before she became sick.* [Reviewer 180]

Nevertheless, some reviewers (118/1327, 8.89%) shared negative experiences, which included comments about the technical aspects of its use. Experiences about the JfA cat's technical performance were mixed. While some reviewers shared that the technology was durable and lasted for over a year at the time of review (32/1327, 2.41%), others commented that it only lasted for a week to 8 months (48/1327, 3.62%). Others elaborated that the short lifespan of the device was sometimes attributed to users' behaviors, such as attempts to feed it or holding it too tightly, which hindered or damaged the device's mechanics. Such issues led to disappointment among some reviewers.

> *Grandma holds it so tight that when the cat wants to put its paw up or roll on its back, she is preventing the movement. Now, it sounds like the motor has been damaged.* [Reviewer 344]

> *It's really sad that this cat did not last. My elderly mother is devastated....Really, really, really disappointed.* [Reviewer 207]

Some reviewers also raised concerns about difficulties cleaning the robotic cat and maintaining its cleanliness.

> *Ours is showing wear around the cat's mouth as grandma keeps insisting on feeding it real food...so I am cleaning it ALOT with dove soap, water and a washcloth.* [Reviewer 265]

> *It is difficult to clean Lucette's (name for the JfA cat) fur. Elderly people do tend to be like children and stroke their pets with sticky hands.* [Reviewer 108]

Finally, some reviewers (51/1327, 3.84%) suggested how the JfA cat could be improved. These included improvements to its appearance, such as having more cushioning to make it softer to hold, having a more realistic "meowing" sound, and more interactive movements. Reviewers also commented that the device should be more durable and customizable, and suggested that volume controls or options to turn off the movement of the cat while keeping its sounds on should be made available.

Discussion

Principal Findings

This is the first study to use a novel web-based approach to explore the usability and impact of a low-cost robotic pet for older adults and people with dementia, based on perceptions and experiences of its use. Most of the review content was derived from consumer sites that were based in the United States, and most reviewers were family members of older adults and people with dementia. Overall, most reviewers had positive perceptions and experiences of using the JfA cat and found it to be beneficial and practical for older adults and people with dementia. Nevertheless, not all were satisfied with this technology.

Users' previous experiences of pet ownership were frequently reported as a circumstantial reason for purchasing the JfA cat for the intended user. This finding aligns with previous findings that users' like of animals influenced their acceptance of a robotic pet [43]. Therefore, it may be worth screening users' likes and dislikes of animals as a predictor to gauge their acceptance of the robotic pets [44]. Reviewers also acknowledged that pragmatic deterrents, such as institutional regulations and a lack of capacity to care for a live animal, propelled them to seek robotic alternatives. This echoes the proposition that a recognition of the relative advantage of an innovation can facilitate its adoption [45].

Most perceptions about the JfA cat were positive, which suggests its design as a familiar animal was acceptable. In previous studies, familiarly designed robotic animals, such as the JustoCat and the NeCoRo cat, were also well received by older adults and people with dementia [46,47]. Likewise, other studies have highlighted preferences for familiarly designed pet robots [20,48,49]. These findings contrast with the notion that people are more likely to accept less familiarly designed robots because they would have fewer prior conceptions or expectations [50]. However, this hypothesis has not been widely evaluated, as few studies have investigated design preferences of older adults or people with dementia. Indeed, in most research studies, participants were typically given a single pet robot to engage with, which was selected based on the needs of the research rather than the preference of the participants. In line with a person-centered approach to care [51], older adults and people with dementia should be given the autonomy to choose their preferred robotic pet design. People with dementia, especially in the advanced disease stages, may not be able to articulate their preferences for pet design. However, they should still be given opportunities to participate in decisions relating to their care [52], to allow for the maintenance of self-identity, dignity [53], and personhood [54]. Moving forward, more considerations should be made to identify pet robot design preferences of individuals.

Use of the robotic cat offered older adults and people with dementia opportunities to participate in meaningful activities. Older adults and people with dementia participated in an array of activities with the JfA cat, such as talking to it and about it, cuddling, and stroking it. These findings resonate with results from studies which used other robotic pets [46,48,55,56], suggesting the potential of the JfA cat to elicit similar activities. Other activities identified included brushing the cat, sleeping with it, and taking it to places. Some reviewers supported these meaningful activities by getting a brush for users to brush the cat, and getting a cat bed and a personalized collar to allow for easier identification in care facilities. Such activities were not reported in previous studies and appeared to be unique to this study. This might be attributed to more opportunities for interaction with the cat over an extended period, made possible due to individuals owning their own robotic cat and not sharing it with others. Individual ownership may have provided users with the opportunity to take ownership of the robotic pet and be actively involved as care providers, in contrast to their traditional role as passive recipients of care [57]. Furthermore, the consistent and proximate presence of the JfA cat might have enabled such additional activities involving its use to be scaffolded naturally.

The relationship between engagement in meaningful activities and health outcomes has been established [58-62]. Similar to findings from previous studies [10-12,18], participating in activities with the JfA cat elicited positive emotions among users, and also provided comforting and calming effects. This is an important finding, because it highlights the potential of the JfA cat to elicit therapeutic benefits that are similar to costlier and more technologically sophisticated robotic pets. This raises an important question—In consideration of potential cost benefits, what degree of technological sophistication is required for a robotic pet to be therapeutic? Further research and randomized controlled trials should be conducted to evaluate and compare the effectiveness of low-cost robotic pets on the mental and social health of older adults and people with dementia, with other more technologically advanced robots.

The movements and vocalizations of the JfA cat appeared to be perceived positively by users as behaviors of reciprocity. Reciprocity, or the give and take that occurs between individuals, can influence the maintenance of social relationships [63,64]. This may explain why interactive robotic pets have been able to elicit more user engagement as compared with noninteractive or plush alternatives [65,66]. Interestingly, the lack of predictable responses to touch and movement was interpreted by some users as resemblant of a live cat's behavior, and was well received. Nevertheless, the JfA cat's interactive features also resulted in some negative impacts, particularly among those who perceived it as a live animal. When the robotic cat ran out of batteries, some users exhibited emotional distress as they perceived it to be dead. The meowing sounds worried or caused annoyance to some users, who sometimes perceived the robotic cat to have unmet needs. Similar issues have also been raised previously in relation to other robotic pets [13,48,67,68]. Furthermore, some users became concerned that the cat was not eating and attempted to feed it. These issues may be due to individual ownership of the robotic cat, where perceived responsibility for pet care may place a burden on people with cognitive impairment [69]. In such instances, reviewers provided mediation and support. This suggests that unattended, prolonged interactions with the robotic pet may have the potential to cause negative impacts. In turn, this raises the question as to what amount of robot–human interactions, especially for people with cognitive impairments, should be conducted completely without the support of caregivers. Findings from this study suggest some degree of facilitation and mediation by caregivers may still be necessary.

The JfA cat also positively impacted caregivers, providing them with a sense of relief and positive emotions, which included feelings of happiness and contentment. There is currently a lack of research that has focused on how robotic pets impact caregivers. More research is needed to increase understanding, especially since one of the key premises for developing social robots is to supplement and support the care of older people with dementia [66].

Finally, despite the overall positive perceptions and experiences, some reviewers reported negative opinions about the cat's design. This included comments about its "hardness" and lack of sophistication, such as audible mechanics during movements and unrealistic "meowing" sounds. These issues did not appear to influence most users' interaction with the robotic cat, suggesting that reviewers may have a higher expectation than the end users in wanting the robotic cat to behave more realistically and autonomously. Nevertheless, these issues resulted in the rejection of this technology by a minority of users. Comments about the robustness of the technology were mixed, with some reviewers being dissatisfied with its durability. Some elaborated that users' handling of the JfA cat, such as holding it too tightly or dropping it, affected its functioning. The relatively short longevity of the device has potential to cause negative impacts such as emotional distress, especially among users who have developed an attachment toward it [70]. The understanding of such issues are useful to inform future robot development to ensure technological robustness [18].

Limitations

Despite the valuable new knowledge that was generated through this study, there are limitations that should be acknowledged. Data that were used for this study were self-reported information that was gathered through publicly available sources. The anonymity of users makes it difficult to verify the authenticity of the content, and to verify the ages and diagnoses of the users of the robotic cat. Most reviewers were family members, and as such, their perceptions and experiences might differ from actual opinions of the primary end user (ie, older adults or people with dementia). Although most included reviews were shown as verified purchases, it is not possible to confirm the authenticity of review or distinguish potentially deceptive reviews. There could also be a bias in terms of the representation of data, as not all consumers will upload their reviews on consumer websites. Nevertheless, given the analysis of the large number of reviews from multiple websites across a 5-year period, as well as the richness of the data contained in these reviews, it may be reasonable to infer that the findings from this study represent real-world perceptions and experiences of using the JfA cat for older adults and people with dementia.

Conclusion

This study provides important knowledge about the usability and impact of a low-cost robotic pet for older adults and people with dementia based on perceptions and experiences of its use. It analyzed user-driven content to access a unique perspective toward an understanding of this phenomenon. We found that circumstantial reasons, such as inability to care for a pet, have prompted the use of the robotic cat, and that familiarly designed robotic pets can be accepted by older adults and people with dementia. Although the JfA cat is less technologically advanced than other robotic pets, its interactive features were generally well received. Use of the JfA cat facilitated participation in meaningful occupations, as it provided older adults and people with dementia opportunities to participate in various activities. These activities elicited positive psychosocial impacts on both users and caregivers. Nevertheless, facilitation by caregivers may be necessary to monitor for and mitigate potential negative impacts. Although perceptions and experiences were mainly positive, negative aspects of the JfA cat's design and interactivity were raised. Experiences of its durability were also mixed, which highlights the need to improve the technical robustness of this device.

These insights are vital in helping researchers, robot developers, and clinicians to understand the viability of using low-cost robotic pets to benefit older adults and people with dementia. Future research should consider evaluating design preferences for nonfamiliarly versus familiarly designed robotic pets. It will also be valuable to conduct a randomized controlled trial to compare the impacts of low-cost robotic pets with other more technologically advanced robotic pets, to understand any similarities or differences of their impacts on the mental and social health of older adults and people with dementia. A process evaluation may also be conducted to identify factors that may explain any outcome variations. This has the potential to influence equal access to technology if their impacts on the psychosocial health of users are comparable.

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Authors' Contributions

WQK conceptualized the research, developed the review questions and review design, and collected the data. WQK, SW, and PH coded and analyzed the data. Preliminary results were discussed with RMD. WQK initiated the first draft of the manuscript. All authors read the draft and provided critical feedback. All authors approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Data extraction form.

[XLSX File (Microsoft Excel File), 29 KB - aging_v5i1e29224_app1.xlsx]

Multimedia Appendix 2
Coding framework.
[DOCX File , 36 KB - aging_v5i1e29224_app2.docx]

Multimedia Appendix 3
Settings.
[DOCX File , 16 KB - aging_v5i1e29224_app3.docx]

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Abbreviations

ICR: intercoder reliability test
JfA: Joy for All

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Original Paper

Exploring Older Adults’ Adoption and Use of a Tablet Computer During COVID-19: Longitudinal Qualitative Study

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Abstract

Background: As mobile computing technology evolves, such as smartphones and tablet computers, it increasingly offers features that may be particularly beneficial to older adults. However, the digital divide exists, and many older adults have been shown to have difficulty using these devices. The COVID-19 pandemic has magnified how much older adults need but are excluded from having access to technologies to meet essential daily needs and overcome physical distancing restrictions.

Objective: This study sought to understand how older adults who had never used a tablet computer learn to use it, what they want to use it for, and what barriers they experience as they continue to use it during social isolation caused by the COVID-19 pandemic.

Methods: We conducted a series of semistructured interviews with eight people aged 65 years and older for 16 weeks, investigating older novice users’ adoption and use of a tablet computer during the nationwide lockdown due to COVID-19.

Results: Participants were gradually yet successfully accustomed to using a tablet computer to serve various daily needs, including entertainment, social connectedness, and information-seeking. However, this success was not achieved through developing sufficient digital skills but rather by applying the methods they were already familiar with in its operation, such as taking and referring to instruction notes.

Conclusions: Our findings imply that older adults without digital literacy can still benefit from a digital device for quality of later life if proper traditional methods they are already familiar with are offered in its use.

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KEYWORDS
older adults; tablet computer; technology acceptance; mental model; longitudinal study; COVID-19

Introduction

Overview

Thanks to rapid technological advancements and decreasing costs, mobile devices are becoming accessible to more older adults, which led the aging population to become the fastest-growing group of technology adopters [1]. The statistics show that internet usage among US residents aged 65 years and older has surged from 43% in 2010 to 75% in 2020 [2], and more than 61% of this population owned a mobile phone as of 2020 compared to only 18% in 2010 [3]. Along with mobile phones, the number of tablet users is also on the rise, with roughly 50% of US adults owning a tablet computer in 2021 [3]. The increased ownership of a tablet computer is particularly promising for older adults since a larger screen size is positively associated with older adults’ technology adoption rate [4]. For older adults with impaired vision and reduced dexterity, a larger screen size and better screen resolution are crucial for device usability. Thus, tablets with a larger screen than mobile phones have been more appealing to senior users [5].

However, the digital divide by age still exists, as only 39% and 18% of older adults own a mobile phone and a tablet computer, respectively [3]. This trend is not different in European countries: 35% of people aged 65 years and older did not own a mobile phone, in contrast to over 98% of those aged 18 to 45 years that did own a mobile phone in the United Kingdom in 2020 [6]. Furthermore, digital literacy to use mobile devices comfortably is negatively related to age [7], and older adults often encounter numerous challenges in using new technologies [8-11]. Socioeconomic status is another crucial factor contributing to the digital divide. Approximately 40% of adults with lower incomes (households earning less than US $30,000 a year) do not have home broadband services or a computer, and a majority of them are not tablet owners [12]. By comparison, each of these technologies is nearly ubiquitous, if not multiple of each of these technologies, among adults in households earning US $100,000 or more a year [12]. When age and socioeconomic status are combined, it becomes evident that low-income older adults are most likely to face a digital divide [13].

The COVID-19 pandemic has magnified the importance but lack of access to mobile devices by older adults [14,15]. The mandated shelter-in-place and social distancing orders transformed most tasks that have been performed through face-to-face means into virtual formats. For instance, local organizations and community associations shifted their information distribution and outreach efforts from offline to online platforms, and in-person meetings and events are substituted with virtual methods of communication. While a shift to digital enabled people to stay connected and informed amid the nationwide lockdown, many older adults who were already experiencing social isolation and loneliness were excluded from digital services, which significantly degraded their quality of everyday lives [16-18]. Consequently, efforts to increase older adults' access to technology have been spurred by both nonprofits and public agencies.

One such effort was carried out by the Housing Authority of the City of Elizabeth, a low-income housing organization in the greater New York area, to distribute over 100 tablets to low-income senior residents to enhance their access to service and information online in the fall of 2020. Although this effort was well-received by the residents, it raised a subsequent concern about the sustainable use of this technology because most recipients were first-time tablet users. They needed to gain sufficient digital skills and develop technological self-efficacy to use a tablet.

We conducted weekly semistructured interviews for 16 weeks with eight senior residents who received a tablet computer to serve two goals: (1) practically, to help the recipients learn digital skills to comfortably use a tablet; and (2) theoretically, to investigate how older novice users learn and develop digital skills over time. From this study, we aimed to answer the following research questions:

1. What do older adults use a tablet for during COVID-19?
2. What challenges do they experience when using a tablet, and how do they progressively cope with those challenges?
3. What are the factors that affect older adults' learning of digital skills?

To date, the prospect of older adults' learning to use mobile devices has been extensively discussed in the literature. However, most studies relied on self-reports of past experiences [19,20] or quasiexperiments on various learning modes [21,22]. This paper contributes to the literature by investigating, for 4 months, the real-world context of how older adults who are new to tablet technology progressively learn digital skills to perform desired tasks on a tablet.

Our findings revealed that our participants were willing to learn and successfully use a tablet for entertainment, social connectedness, and information-seeking purposes as the study proceeded. However, it was not through acquiring sufficient digital skills, despite their continuous learning endeavor, but through incorporating the method they are already familiar with in its operation: pen and paper. The underlying issue with difficulty in acquiring digital skills was the lack of a proper mental model of how a tablet works. These findings can be used as design guidelines to promote the sustained use of emerging personal technologies to support the aging society. To the best of our knowledge, this is the first study that investigated the progressive use of a tablet computer among novice older users through a longitudinal field deployment study.

Literature Review

Background

Digital literacy is a set of skills and knowledge required by individuals to use digital devices to access and use digital information effectively [23]. As today's young adults who are savvy users of current digital devices become older, they will not experience much difficulty in using them. However, the digital divide will continue to exist because computing technology continues to advance, and new digital devices will continue to emerge. Perhaps one of the earliest research topics on older adults' technology use was investigating their use of automatic teller machines in the late 1990s [24]. Moreover, researchers are still investigating older adults' use of emerging technologies (eg, wearables [25], voice assistants [26]).

Information and communication technologies are becoming an integral part of our everyday lives as information and services are increasingly delivered and consumed online [27]. In particular, access and use of mobile devices such as smartphones and tablets are vital rather than an option, since these are used as a primary gateway to obtain needed information and services for many daily tasks [28]. Consequently, a growing number of older adults are expected to use mobile devices to fulfill some of their everyday needs. However, unlike younger generations, older adults did not grow up with technologies that are prevalent today. Many older adults are not familiar with new technologies and thus have difficulties in using them. Therefore, there has been an emerging focus on helping the aging population learn to use mobile devices.

Older Adults and Technology Acceptance

Much research has sought to comprehend technology use and acceptance by older people using existing theories of technology adoption such as the technology acceptance model (TAM) [29] and the unified theory of acceptance and use of technology (UTAUT) [30] (eg, [31-33]). Although these theories are widely used to evaluate user attitudes toward the acceptance of technology in general, limitations exist because they lack sufficient consideration on age-specific or age-related factors.

To overcome such limitations, researchers have extended these theoretical frameworks to specifically account for older adults' technology acceptance behaviors [8,11,34-36]. Details may differ in these extended frameworks, but one common factor that distinguishes older adults from their younger counterparts in technology acceptance is the special learning needs that older adults have when using new technology.

For example, Renaud and van Biljon [35] postulated the senior technology acceptance model (STAM) expanding on TAM [35]. STAM introduced an incorporation phase in which older adults explore and experiment with new technology to estimate the perceived ease of learning and use for technology acceptance. Similarly, Kim et al [34] developed a theoretical model that extends TAM and UTAUT to explain how older adults accept or reject mobile devices. This model comprises an additional phase, intention to learn, with three affecting factors (self-efficacy, conversion readiness, peer support) that determine the acceptance of mobile devices among older adults. They further validated this model through a comparative study with younger adults [37]. Third, Barnard et al [8] proposed a model of technology acceptance and rejection for older adults, which emphasized the facilitating conditions to learn a technology, such as a friendly space for trial and error and provision of a manual, as a decisive factor for seniors' technology adoption.

As learning has been found to be crucial for older adults' technology acceptance, researchers have sought ways for older adults to effectively learn to use new technology, which we explain in the next section.

Older Adults' Learning to Use Mobile Devices

Researchers have investigated various modes of learning to determine older adults' preferences when learning to use mobile devices. For instance, Pang et al [21] conducted a design prove study of an interactive help kiosk, Chiu et al [38] conducted a focus group of a small-group tutoring approach, LoBuono et al [39] observed the utility of intergenerational learning by college students, and den Haan et al [40] ran a field study of peer-to-peer community learning. Although findings from these studies were mixed as to which learning methods older adults preferred or found effective, they share a common preference: a collaborative approach implemented by peer support, interpersonal communication, and community-based programs. In contrast, independent learning was preferred for its ability to control learning speed and avoid bothering family and friends, although its effectiveness is limited.

In summary, mobile devices are becoming essential for healthy aging and independent living, but many older adults experience various challenges with respect to using new technology. Learning is imperative in overcoming those challenges, although empirical evidence on how older novice users learn and develop digital skills for their sustained use of mobile devices is limited. This paper contributes to this body of literature by exploring what challenges older novice users experience when learning to use a tablet computer and how they cope with those challenges over time through a longitudinal field study.

Methods

Ethical Considerations

The study was approved by the Rutgers Institutional Review Board (Pro2020002565), and informed consent was obtained from all participants before participating in the study.

Participants

For participant recruitment, we collaborated with the Housing Authority of the City of Elizabeth, an affordable housing community located in the greater New York area that the first author has a long-established research collaboration with. This community manages 1322 public housing units of various types, including single units, family housing, and senior complexes, approximately 1000 of which are for a low-income senior and disabled population. To improve older adults' access to technology during COVID-19, this organization raised a fund to distribute free tablet computers to senior residents. As a result of this effort, about 100 senior residents in this housing community received a free tablet in the fall of 2020. Among those who received a tablet, we recruited participants to take part in this study. When giving out a tablet, a recipient was asked if they were interested in participating in this study. Upon agreement to participate, we installed the Zoom app on their tablet before giving it out. Three inclusion criteria for participation were age being over 65 years, English-speaking, and being a first-time tablet owner.

In total, we recruited 10 participants (6 females and 4 males), ranging in age from 65 to 80 years (mean age 71.6, SD 4.9 years; see Table 1). Nine participants lived by themselves and one participant lived with a partner. With respect to general technology use, six participants owned a smartphone, four participants owned a flip phone, six participants owned a computer, and one participant owned an eBook (Kindle). All participants said that they frequently used computers for information searching and email. Seven participants said they had used a tablet but never owned it, and three said they had never used a tablet. The self-identified ethnicity of all participants was Black or African American. Two participants withdrew within the first month of the study due to losing interest in the study. The other eight participants completed the study for the entire study duration.

Table 1. Participant demographics.

Participant ID	Age (years)	Gender	Devices owned	Occupation before retirement	Study duration
P1	65	Male	Smartphone, computer	Machine operator	Completed
P2	66	Female	Flip phone, computer	Nurse aid	Completed
P3	71	Female	Smartphone	Customer service	Completed
P4	80	Male	Smartphone, computer	Tax preparer	Completed
P5	74	Female	Smartphone, computer	Paraprofessional	Completed
P6	68	Female	Flip phone	Customer service	Completed
P7	72	Male	Smartphone, computer	Sales	Completed
P8	78	Female	Flip phone, computer, eBook	Homemaker	Completed
P9	69	Male	Smartphone	Sales	Dropped
P10	73	Female	Flip phone	Customer service	Dropped

Data Collection

Participants were told to freely use a tablet as much or as little as they wanted throughout the study period, and we conducted a weekly semistructured interview for 16 weeks between fall 2020 and spring 2021. All interviews were conducted virtually via the Zoom video-conferencing app. For those who did not know how to use Zoom, we conducted the first interview over the phone and provided step-by-step instructions for launching the app and then switched to Zoom for the rest of the first interview.

Our interview protocol consists of two sessions: the first half of each interview explored participants' daily use of a tablet and their reflection on its use, and the second half was devoted to providing in-person instruction on using a tablet for various features. For the first session, we investigated what older adults wanted to use a tablet for, what difficulties they faced when using it, and how they coped with those difficulties. To explore these spaces in different stages of use, we constructed three sets of open-ended interview questions by phase. In the first phase (weeks 1 to 4), we focused on understanding initial impressions, needs, and difficulties in using a tablet. In the second phase (weeks 5 to 14), we explored the user experience in-depth, including usage patterns, the needs and challenges, and strategies to cope with breakdowns. In the third phase (weeks 15 and 16), we focused on the overall reflection on users' interaction with a tablet. Each session lasted from 30 to 60 minutes. Next, for the second session, we asked participants if they wanted to learn any feature and provided step-by-step instructions for the feature. We did not prepare any instruction material but provided impromptu verbal explanations on how to perform a requested task. This session lasted about 30 minutes.

In addition, participants filled out a short survey to inform us about their basic demographic information, including age, household type, occupation before retirement, and devices owned. All interviews were audio-recorded and transcribed. Participants who completed the study were compensated with a US $160 gift card upon completion. Those who withdrew were partially compensated, and the amount was prorated by the duration of participation.

Data Analysis

We analyzed our interview data using thematic analysis to reveal patterns across data sets. Thematic analysis is a method for identifying, analyzing, and reporting patterns and themes within qualitative data [41]. We selected thematic analysis because it enables investigating explanatory conceptual themes associated with older adults' use of a tablet over time. The thematic analysis process involves open coding, axial coding, and selective coding for theme identification.

First, we conducted open coding to identify concepts that are significant, such as abstract representations of events, objects, happenings, and actions that emerged from the data. For open coding, each author separately created a set of codes for a selected interview transcript. All authors then met and compared a list of individually generated codes to validate, cross-validate, and consolidate the codes. We iterated this process four times when we were convinced that the coding process had saturated. Using the consolidated codebook, the first author then coded the rest of the interview transcripts. Next, we categorized the related concepts created by open coding into conceptual phenomena using axial coding. Phenomena refer to repeated patterns of events, happenings, actions, and interactions, representing people's responses to problems and situations. Lastly, we followed the selective coding process to integrate all concepts extracted from axial coding into a single storyline through building relationships.

Results

Overview

In the first interview, all participants said that they used to engage actively in the events and activities organized by a local senior center before COVID-19, which constituted most of their physical activities and social interactions. Thus, unsurprisingly, they all expressed increased feelings of loneliness and social isolation due to social distancing and shelter-in-place orders during COVID-19.

> *I used to go to the senior center every day and play games. I can't do that anymore. My daily routine now, because of the pandemic, is not a real good routine because I am home all day. The biggest joy I have in*

> *life now is going to Shoprite and buying my groceries once a week. And we wave at each other if there are any of my friends there.* [Participant (P) 2, Interview (W) 1]

> *Before the COVID-19 hit, I was part of the senior center where I used to go four times a week. I was into the ceramics classes, exercises, and all kinds of different activities at the center. Now, I'm always in the house.* [P6W1]

> *I'm so used to going to the senior center. Now we can't go to the center. Now I have a tablet, so I could still play bingo and talk to my friends. But being in person is much better for us so that you can get up and talk to people and have refreshments.* [P7W1]

Fortunately, most participants quickly acknowledged that a tablet could serve as an outlet for sustaining a quality life and remaining connected with other people amid COVID-19 within the first couple of weeks of the study. Consequently, they tried to make good use of a tablet to fulfill various needs throughout the study. While many of these efforts were successful, several participants failed to gain sufficient digital literacy to comfortably use a tablet even upon completion of the 4-month-long training. In what follows, we report the findings on our participants' purposes, perceived benefits, and challenges of using a tablet. While these are not much different from tablet use in general, our findings show empirical evidence of older novice users' adoption and use of a tablet over time.

Purposes and Benefits of Using a Tablet

Entertainment: Playing Mobile Games

The most common topic of questions about tablet use in the first phase of the study was how to install mobile game apps. Some participants were already playing mobile games on their smartphones and asked to help install the same apps to their newly received tablets, and others asked how to find and install new mobile games on a tablet. Similarly, the most common use of a tablet was for playing mobile games. To our opening question of each interview, "what did you use your tablet for this past week?", the prevalent answer throughout the study was playing a mobile game.

> *Before COVID, I didn't play the game, because I didn't have a tablet. Since I have my tablet now, I'm playing lots of games. Because of COVID, I am forced to sit down and learn things that I didn't have to do before, like playing a game. Now, even if we start going back out, I will probably carry my tablet wherever I go and use it.* [P2W8]

People usually play mobile games to spend leisure time or alleviate boredom [42]. However, our participants did not mention any of these as their intention of playing mobile games. Instead, they emphasized and made clear that they played mobile games for constructive purposes such as engaging in challenges, gaining a feeling of accomplishment, and keeping active mentally and physically. We are uncertain if the noted intentions were genuine or due to a response bias where a respondent exhibits the purposeful presentation of self to fit into socially desirable attitudes or please an audience [43]. What we are certain of is that our participants were conscious of the potential benefits that playing mobile games can bring to them. The downside is that they played only a couple of simple games, even though numerous mobile games have been designed for cognitive, physical, and hedonic benefits for healthy aging. Although the excerpts below mentioned some other games, Bingo and Scribble were two games that all participants stated they played throughout the study.

> *I play a few games every day like Bingo, Scribble, and Candy Crush on my tablet to keep my brain active and my coordination back and forth. I try to keep on challenging myself with the games.* [P3W2]

> *I like to play a challenging game on a tablet, like three-word matching games, because I had many strokes. Playing games keeps my brain active, keeps your eyes and hands move, and it makes you keep thinking.* [P7W3]

> *I have an app called Happy color on my tablet that I play all the time. It has all different pictures on it, and you just color them by the number that's noted. I love to play that because it's comforting and soothing to me.* [P8W4]

In general, the entertainment purposes of using a mobile device are fulfilled by various activities, ranging from playing games to listening to music, watching TV and videos, and reading books [42]. However, none of these, other than playing mobile games, was brought up by our participants throughout the study, except for one participant mentioning their attempt, but failure, to install a TV app in week 12. In fact, we introduced and provided instructions for using many recreational features mentioned above during the interviews, and their initial responses to these features were positive. However, we had not received any comment about using them throughout the study.

> *I tried to install a TV app, Pluto TV, on my tablet. But I wasn't successful because they asked for a password, and I didn't know what password I have.* [P5W12]

Social Connectedness: Video Chats and More

Because all interviews were to be conducted virtually via Zoom, a video-chatting app, we offered instructions on using it during the first interview until participants fully understood how to use it. They then used Zoom at least once a week to participate in this study for 4 months. These efforts must have enabled our participants to utilize Zoom comfortably and effectively as the study proceeded. Participants unanimously expressed excitement, satisfaction, and a positive outlook for using Zoom to socialize with others and overcome loneliness during COVID-19 throughout the study. Although video-chatting platforms cannot substitute for face-to-face interaction, they still provided those who felt a loss of connection with a way to connect with friends and loved ones safely.

> *I was by myself for 14 days. The only time I can talk to anybody now is when I zoom on a tablet earlier today. It was a nice experience because we saw more people. It was keeping me from being lonely. It's helping me stay in touch with people and to get things*

> *done. Now it's another part of my life that I'd like to keep using.* [P6W3]

> *We haven't been in person since we closed down in March. So that was very instrumental in getting these tablets. The most important thing I'm having a tablet for is being able to reach out and talk to other people. This tablet is like my best friend now. He goes with me everywhere. I got to give it some name.* [P7W4]

> *I was all by myself. But once I was on the Zoom, it has affected my life tremendously. I can see the seniors who I used to see at the center. A lot of seniors are homebound and very lonely. So, just to be able to be in touch with the other seniors is very meaningful to us. Seeing them is a way of alleviating a lot of the loneliness from being alone.* [P3W5]

Another common purpose of using Zoom was religious socialization, which is an essential part of many participants' social activities. One of the popular answers to our interview question "what did you use your tablet for this past week?" was attending virtual church services.

> *I zoom for my church services on Sunday. I haven't gone back to my church yet because the pastor had a COVID and came back, but they weren't taking temperatures or social distancing. But every Sunday, you can watch on zoom the pastor live-streams. You can't see anybody but the pastor, but you still receive whatever he's preaching about.* [P1W4]

A key concern or complaint that participants had with using Zoom was that many other seniors were still unfamiliar with or did not know how to use Zoom. Our participants gained sufficient in-person training and step-by-step guidance on using Zoom from participating in this study. However, many older adults lack access to these resources. Since having more people on video-chatting platforms is essential for virtual socialization, participants sought ways to help other seniors use Zoom.

> *There's a lot of seniors that have a tablet but just don't zoom. I wanted to host a zoom meeting with some of the seniors I know for some of those classes. How do I do that? Do they charge you for that?* [P1W5]

> *Today was a good meeting (for the senior center's class). We had almost 16 seniors, which was phenomenal. As time goes by, we're getting more on the zoom meetings. We still have some that are having a problem getting on and still don't understand. So, someone has to go to their house and show them how to get on.* [P6W7]

> *The lady who just moved in upstairs was by herself. Last week, I came down to help her get on our Zoom meeting. The lady was really depressed when we spoke to her. She broke down and was crying on zoom. We all told her that we're all here for her and will call her if necessary. That made her feel much better, and I felt much better too.* [P7W10]

There are many video-chatting platforms other than Zoom, namely FaceTime, Skype, Google Meet, Microsoft Team, WebEx, and many more. Banskota et al [44] showed that older adults used FaceTime and Skype most frequently while in isolation during COVID-19. However, our participants only used Zoom throughout the study and nothing else. We consider three factors that must have contributed to their heavy reliance on Zoom for virtual socialization: (1) they learned how to use Zoom but no other apps and (2) FaceTime and Skype are generally used among friends and loved ones [44], whereas (3) our participants mostly connected with other seniors via virtual meetings organized by a senior center or a church for which Zoom is the primary tool used.

Besides, our participants fulfilled their needs for social connectedness not only by directly talking to others via video-chatting apps. Equally valuable was to share meaningful and helpful information with friends and loved ones. We received numerous questions on how to send digital data of various formats (eg, pictures, messages, news) to other people throughout the study. Even though it was an indirect experience, sharing digital data still gave older adults a sense of being connected to and engaging with others.

> *I want to send a picture I take on the tablet to other people. How do I do that? Can you teach me how to send them to like my granddaughter?* [P4W4]

> *I love sending inspirational cards to my friends in the morning. I send them wonderful things to uplift everyone's spirit. Doing that makes me feel connected to them.* [P2W5]

> *Someone emailed me the vaccine information. And I wanted to share it with my friend, and so I forwarded it to her and said, you just click on the link. But she couldn't find the link in my email. I didn't know how to give her the live link.* [P3W8]

Information Seeking: Google and YouTube

Participants did not ask much about what to use a tablet for when they were first introduced to it, except for playing mobile games and using Zoom. Thus, we spent a great deal of the second session of the first-phase interviews introducing various apps, including but not limited to Google and YouTube, and explaining how to use them.

Participants started mentioning their information-seeking experiences after a few weeks of the study had lapsed. As the study proceeded, participants spent more time sharing their experiences of searching and retrieving various types of information when answering our interview question "what did you use your tablet for this past week?" The topics of information participants searched for encompassed an extensive range of informational needs and everyday activities, ranging from cooking to gardening, health care, home improvement, food, shopping, and many more.

> *I like looking at different types of cooking on YouTube. This morning, I went to YouTube and put "how to cook turkeys" in the search bar. And it brought up a lot of different ones. What I liked is that I can set my tablet up on the counter and follow the recipe from the tablet. I've never done that before. I used to make a copy and follow it.* [P8W6]

> *I use my tablet every day nowadays to check out different sites. For example, Facebook gives me information about food distribution, vaccine, testing, stimulus checks, etc. Last week, I looked up Google to see if I could take the COVID shot while rehabbing from having a flu shot. So that was a good resource to find out.* [P7W9]

> *Whenever I need information about my gardening, I take the tablet and put a question into Google, and I get my answer. The other day when a branch broke off from one of my blueberry bushes, I went into Google to find out how to replant it.* [P1W10]

We identified two interesting aspects of our participants' tablet use for information-seeking. First, in contrast to many entertainment features that we introduced but were rarely used, participants quickly adapted to and increasingly used the features for information-seeking as the study proceeded. We attribute this to older adults' substantial informational needs for independently managing everyday life as much as their impending emotional needs for socialization. Second, although the general purposes of using YouTube range widely from information-seeking to education, entertainment, exercise, and more [45], participants used YouTube only to retrieve practical information. We introduced YouTube as "a place where you can watch videos online" to participants; nevertheless, they watched YouTube videos only to fulfill their informational needs. Many possible reasons can account for this usage pattern (eg, lack of interest, unfamiliarity with browsing, not knowing what is available), although our data did not present any concrete reason. Further studies are required to examine older adults' use of YouTube.

Challenges and Coping Strategies for Tablet Use

Dealing With Challenges Due to Forgetfulness

The most prevalent difficulty that all participants experienced and asked for help with was managing passwords. In the first few interviews, participants spent most of the second sessions asking for help logging in to different apps and websites. Some participants could not log in to certain services because they did not have an account, and some could not because they did not remember their password, all of which we quickly resolved by helping them create a new account or find a password. What we struggled with the most was when the password a participant remembered did not work. We asked them to retry multiple times, which made them feel confusion, frustration, and decreased confidence. Some services became deactivated after several login trials, and thus we helped them proceed with extra steps for reactivation. However, many of them gave up after a few failed attempts and told us that they did not want to use it anymore. After several similar incidents, we realized that the password participants remembered was, in fact, for a different service in most cases (eg, using a tablet's passcode for Google login).

> *I have a password that I set up, but it keeps telling me it's the wrong password. So, I have to check into that. I know that's what I set up but don't know why it's not accepting it. I probably had to do forgot password and set up another one.* [P4W2]

As the study proceeded, participants gradually got used to managing multiple accounts and passwords through repeated instructions, although not through memorization. Except for relying on the autocomplete feature, a common strategy was to keep written records of accounts and passwords. In fact, writing down passwords is an old and widespread practice [46,47], and some of our participants already kept a written record of their passwords. We observed that novice participants also quickly developed a practice of keeping their newly created account information on paper and resorted to written copies of passwords for logins. However, its effectiveness and sustainability were questionable.

> *People tell you don't use the same password. So, I have so many different passwords. And I have a diary with all of my passwords in it. I have to see the diary to find the password so that I can do whatever I want to do.* [P2W2]

> *When I create an account, I write its password on a piece of paper. And then I lay the paper over here or over there, and I don't use it for long. And then when I have to use it, I don't know what the password was. And by then, the paper is gone.* [P3W2]

One effective way to extend this practice is to digitize written records, as mentioned by P1 in week 4, although nobody else mentioned this.

> *I wrote all my passwords and the names of apps on a piece of paper and took a picture of it. So, if I need to find a password, I go to my photos gallery and pull up my password and the name of the app.* [P1W4]

Unsurprisingly, none of our participants was aware of any password-managing tool, and we did not consider introducing it to them either, because it was too complicated for them to use. In addition, privacy and security concerns relating to keeping written copies of passwords were never brought up, which confirms prior work showing that older adults are unaware of and susceptible to privacy and security risks associated with technology use [48].

We also observed that keeping written records of information was used not only for managing passwords. Most participants kept written instructions for various features we taught and counted on those whenever needed (eg, adjusting screen brightness, changing font size). In all, participants relied heavily on a traditional pen-and-paper method to cope with their forgetfulness throughout the study.

> *The only thing that bothers me is that I can't get the tablet connected to my printer. I'm so used to making copies of instructions. Do I need some type of a cord to connect a tablet to the computer and then print?* [P5W3]

> *I wrote down the steps of changing the font size on stickies. Stickies are now all over my place. Until I get more familiar with how to do it, I need to follow the notes.* [P3W7]

> *When I find a recipe on YouTube, I sometimes want to print it out. But it didn't show me where I can make a copy. I didn't want to lose it and having to start all*

> *over again. But I don’t know how to print it out from my tablet.* [P6W6]

Dealing With Challenges Due to Unfamiliarity With New Technology

Because most participants had never used a tablet before, we anticipated that a lack of self-efficacy, one of the most significant psychological challenges for older adults’ technology adoption [34], would prevail, at least in the first few weeks of tablet use. As expected, participants reported many experiences of having a fear of making mistakes or not reversing them after making mistakes.

> *The thing I’m afraid of the most with the tablet is that I may hit the wrong button because I didn’t want to mess up something. The other day, I was writing an email. And maybe I hit something that I was not supposed to, and lost the email. I didn’t know how to get it back. Someone said draft or something, but I don’t know where to find it.* [P3W3]

> *When she (a friend) sent me an email, I could barely read it because it was so small. So, she explained to me how to enlarge it. Then, it became so large that it overruns the page. But I didn’t want to go back and change the font because I didn’t have confidence that I was proficient enough to change font size without making a mistake. What if I hit the wrong something and mess up everything?* [P7W4]

The second prevalent topic that participants asked for help with, following managing passwords, was adjusting the settings on a tablet and apps, such as display brightness, font size, screen timeout, volume, and screen orientation. In contrast to the questions about password management, which gradually decreased in frequency as the study proceeded, the questions about controlling the settings persisted throughout the study. Unfortunately, we did not find any evidence of participants becoming used to managing most settings, even after 4 months of training. As mentioned previously, most participants resorted to step-by-step instruction notes they wrote down on paper when adjusting settings. Furthermore, whenever participants tried a new app, they experienced similar difficulties setting it up and asked for help even in the later phase of the study.

> *I was trying to play a new mobile game, but its screen was vertical. I wanted horizontal. At one point, it did fine. But then I got stuck in vertical. And I couldn’t get it out of vertical when I played the came next day. Is there a way to change it?* [P1W8]

> *Today, I went on Zoom for a chair exercise. There were five people on including the instructor. All of our boxes were pretty big. I wanted to make them smaller so that I could see the instructor bigger. But I didn’t know how to resolve that.* [P5W11]

Even though participants counted on written notes for most operations, their self-efficacy still improved significantly as the study proceeded. Regardless of relying on written notes, successfully operating intended functions for themselves increased their confidence in using a tablet, which positively influenced their willingness to try new things on a tablet. For this, repeated trials were mandatory, which participants considered not a burden but a process.

> *I’m in my 70s, and this was the first time that I managed to be on Zoom for myself. I think three or four times will make it better. I’m not grasping things as fast as I used to. I have to do it many times to be more competent in what I’m doing.* [P3W2]

> *When my friend was trying to teach me how to put Zoom on my phone, she just gave up. Finally, I am on Zoom now!* [P4W2]

> *I felt very nervous (of using a tablet). But as it went along, I did pretty good. I still would like to have more practice so that I feel more confident within myself. After you get a certain age, you don’t retain a lot of things, and a lot of things are harder to do. And when you start something, and you conquer it, it makes you feel good. I haven’t conquered the tablet, but I’m not as afraid to use it as I was initially.* [P5W13]

In the last interview, most participants expressed gratitude and satisfaction with participating in this study for having an opportunity to gain in-person instructions on using a tablet for an extended period. However, this approach is not scalable or widely available. Our participants proceeded with repeated trials supported by our research team by participating this study, but many older adults lack access to this type of support.

> *It was a blessing that I had the opportunity to work with. I learned a lot from this 4-month program with you. You are patient which was great for a senior so that they felt comfortable in trying to learn in this stage of their life.* [P8W16]

Discussion

Principal Findings

Extensive research has sought to elucidate the challenges older adults face when adopting new technology. Consequently, various factors were identified and discussed, such as perceived usefulness, usability, affordability, compatibility, accessibility, reliability, support availability, learning efforts, and self-efficacy [49]. Our study provided a unique and lived environment where low-income seniors who had no prior experience with a tablet received one for free and gained support to use it to fulfill essential needs during the nationwide lockdown due to COVID-19. This unique circumstance eliminated many of these challenges and magnified two factors: learning efforts and self-efficacy. Our findings show that participants gained sufficient self-efficacy to use a tablet comfortably, not by acquiring digital skills but rather by developing ways to address the challenges. This section discusses a possible reason for their difficulty in obtaining digital literacy despite continuous learning endeavors and a strategy to manage the challenges.

Difficulty in Learning: Lack of a Mental Model

Prior work shows that older adults are able and willing to learn how to use new digital devices [19,34,50]. Our findings confirm that our participants were eager to learn to use a tablet, and successfully used it primarily for entertainment, social connectedness, and information-seeking purposes. However, they did not acquire digital skills to retain and transfer despite repetitive instructions. We consider one reason for this issue to be related to our instruction not guiding to construct a proper *mental model* of how a tablet works.

A mental model refers to “some kind of understanding of how a device works in terms of its internal structure and processes” [51]. Prior research demonstrates that having a proper mental model improves performance on learning and retaining the operating procedures for an unfamiliar piece of equipment [52]. A key to constructing a mental model is to make the learning experience meaningful: the more “meaningful” a learning experience is, the faster it is learned and the better it is retained [53]. In contrast, rote learning focuses on delivering fragments of knowledge, often in isolation from any context [54].

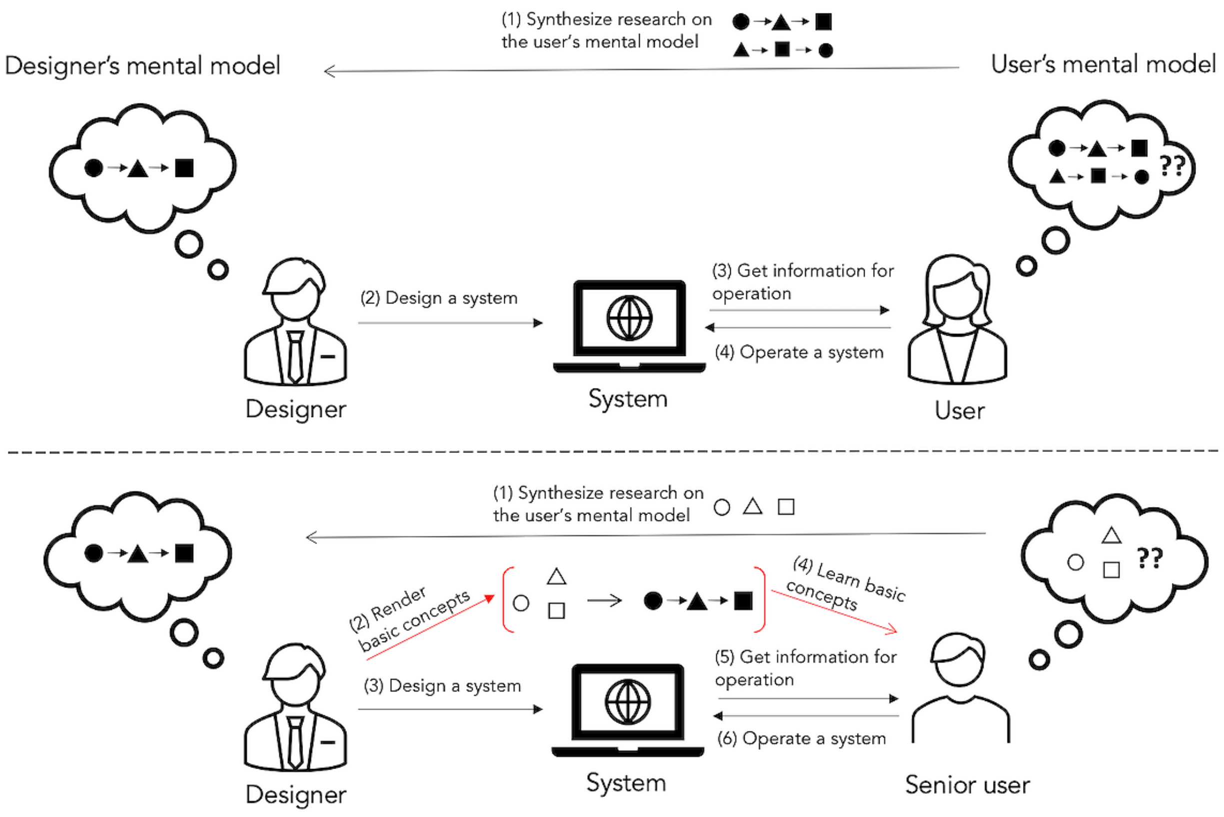
The mode of instruction we offered to our participants was close to rote instruction, delivering the actions required to perform a task (eg, a sequence of buttons to press) without descriptive information of how a device works. In fact, this type of instruction is common in describing how to operate a digital device. For instance, below is a standard instruction for adjusting a mobile device’s font size, which we used to help participants change the font size on their tablet screen. This instruction can be informative to those who have a basic knowledge of how a device works.

1. On your tablet, open the Settings app
2. Tap Accessibility > Font size
3. Use the slider to choose your font size

We initially had a naïve approach of using this rote instruction mode to teach our participants to use a tablet. Later, we realized that this instruction did not contain “meaningful” information for our participants to retain. Our participants, novice older users who were even foreign to some of the terms used, had difficulty understanding, following, and memorizing the instruction. They often needed extra explanations, such as the location of an action item or how to operate a stated action.

The need to bridge the gap in mental models between users and designers is well documented in the fields of human-computer interaction [55]. Research has shown that this gap can be closed by synthesizing a user’s mental model in design. However, this model is not applicable to those who are void of any mental model, such as older novice users. Although various learning modes have been investigated for older adults’ preference and effectiveness [21,39,40], little has been sought to support senior users to construct a basic mental model of how a device works. In consequence, we propose an additional phase in the conceptual modeling process for older novice users: a learning phase through which a senior user can obtain a basic concept of how a system works (see Figure 1). To implement this, not only senior users need to learn the basic concept, but also designers need to render and offer the basic concept that older adults can learn from.

Figure 1. Top: Norman’s conceptual modeling process ([55], page 16). Bottom: a proposed conceptual modeling process for a designer and a senior user. To support a senior user who lacks a basic mental model of a digital device, the designer should first render basic concepts based on a synthesis of research and then design a system. A senior user should first learn basic concepts and then use the system.



Solution to Cope With Difficulties: Facilitating Traditional Methods

Efforts have been devoted to developing new digital devices to support the aging population. However, for many older adults, what they are already familiar with might be the best tool to use without fear of making mistakes, a burden to ask others for help, or stress in learning how to use it.

As the study proceeded, all participants increasingly used a tablet comfortably to perform the various activities they intended. However, we observed that this success was not through gaining sufficient digital literacy. While our research team's in-person instruction must have contributed to their increased tablet use somehow, the most helpful method we observed was to count on what they were already familiar with: pen and paper. Instead of struggling with comprehending and retaining information of using a tablet, participants took notes of necessary details from our instruction and used them later when needed. Despite its scalability and sustainability concerns, pen-and-paper was the easiest, fastest, most efficient, and most reliable method of support for our participants in using a tablet.

Emerging technologies have tremendous potential to support the everyday activities and independence of older adults. However, such potential can be realized only when older adults use them. Because they are exposed to new technology at the later stage of their lives, it is inevitable that they are not familiar with and thus need to learn today's digital devices. While we believe older adults can better understand and retain knowledge to use a digital device once they construct a mental model, effort is still required to learn how to use it. Therefore, we argue that it is important to deliberate on incorporating existing methods that older adults are already familiar with into the design of new digital devices. An excerpt below demonstrates how one participant easily uses GoGoGrandparent, a call-in rideshare support service for transportation.

> *I have the app (for a ride) that I use all the time but it's not Uber or Lyft. It is called GoGoGrandparent. All I have to do is call them, and they ask me if I want someone to pick me up at my home. If I do, press one and then they tell me how long it will be before an Uber driver gets to my house and what kind of car they're driving.* [P7W11]

In the end, the goal is not to make older adults learn to use a digital device but to make their lives of better quality. While researchers have sought to enhance older adults' digital literacy to use a digital device, our findings demonstrate that older adults can benefit from what a digital device offers without much digital literacy if they can integrate a method they are already familiar with in its operation, at least in the short term. Increased use of a digital device will eventually lead to improving digital literacy. Hence, more research is needed to determine how to incorporate the methods older adults are familiar with into designing new technology.

Limitations and Future Work

Our findings must be evaluated within the context of several limitations. First, we used convenience sampling by recruiting participants from a low-income senior-housing community in an urban region of the United States. Thus, our participant pool may not represent the aging population in general. Selection bias or possible homogeneity of participant characteristics (eg, location, culture, socioeconomic status) might have influenced the responses in the interviews. Second, we acknowledge that our findings might not be exclusive to older adults. However, we did not conduct any comparative study between people in different age groups. Thus, we do not have any evidence to argue whether people in other age groups might encounter a similar learning process as experienced by our participants. Lastly, all participants used the same model of a tablet, whose interface design might have influenced user experience.

We believe our findings could be generalizable to older adults' adoption and use of any personal computing technologies (eg, computer, smartphone). However, we are cautious of overgeneralization because we did not validate our findings on other technologies and thus lack scientifically significant evidence to argue its generalizability. Hence, the next step is to examine the generalizability of our findings by conducting similar studies on other technologies and through an extensive literature review of relevant studies.

Conclusion

As technology becomes an integral part of our everyday lives, older adults are increasingly expected to use digital devices to access information and services. Now, the COVID-19 pandemic brought needed attention to a long-standing problem: a digital divide that puts technology out of reach for many seniors, which significantly increased loneliness and social isolation among older adults. As a collaborative effort with a local community organization, we distributed tablets to low-income senior residents to help them access essential services and needed information online during the nationwide lockdown in the United States. This study aimed to serve two goals: practically, to help the recipients learn digital skills to use a tablet, and theoretically, to investigate how older novice users learn and develop digital skills to use a tablet comfortably over time. The findings demonstrate that our participants were willing to learn and successfully use a tablet for entertainment, social connectedness, and information-seeking purposes. However, it was not through acquiring sufficient digital skills but rather by incorporating the method they are already familiar with in its operation. We consider, among other things, that the lack of a proper mental model of how a tablet works prevented them from building digital skills despite repetitive instructions. We are hopeful that our results will encourage future studies to reduce the digital divide and improve the aging population's access and use of emerging digital devices for a better quality of later life.

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Conflicts of Interest

None declared.

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Abbreviations

STAM: senior technology acceptance model
TAM: technology acceptance model
UTAUT: unified theory of acceptance and use of technology

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Original Paper

The Use of Technology Among Persons With Memory Concerns and Their Caregivers in the United States During the COVID-19 Pandemic: Qualitative Study

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Abstract

Background: Stay-at-home orders and other public health measures designed to mitigate the spread of COVID-19 have increased isolation among persons with memory concerns (PWMCs: individuals diagnosed with cognitive impairment or Alzheimer disease or related dementias). The pandemic has also exacerbated challenges for family members who care for PWMCs. Although technology has demonstrated the potential to improve the social connections and mental health of PWMCs and their family caregivers (CGs), previous research shows that older adults may be reluctant to adopt new technologies.

Objective: We aimed to understand why and how some PWMCs and their CGs altered their use of mainstream technology, such as smartphones and fitness trackers, and assistive technology to adapt to lifestyle changes (eg, increased isolation) during the COVID-19 pandemic.

Methods: Using data collected in 20 qualitative interviews from June to August 2020 with 20 PWMCs and family CG dyads, we assessed changes in and barriers to everyday technology use following the implementation of COVID-19 mitigation strategies in the United States. Zoom videoconferencing was utilized to conduct the interviews to protect the health of the participants who were primarily older adults.

Results: Using qualitative thematic analysis, we identified 3 themes that explained motivations for using technology during a pandemic: (1) maintaining social connections, (2) alleviating boredom, and (3) increasing CG respite. Results further revealed lingering barriers to PWMC and CG adoption of technologies, including: (1) PWMC dependence upon CGs, (2) low technological literacy, and (3) limitations of existing technology.

Conclusions: This in-depth investigation suggests that technology can provide PWMCs with more independence and offer CGs relief from CG burden during periods of prolonged isolation.

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KEYWORDS

social isolation; dementia; caregiving - informal; aging in place; caregivers; aging; elderly; pandemic; COVID-19; mental health; technology use; health technology

Introduction

Persons with memory concerns (PWMCs: individuals formally diagnosed with mild-to-moderate cognitive impairment or Alzheimer disease [AD] or Alzheimer disease–related dementias [ADRD]) and their family members who care for them experience significant challenges in their daily lives. Before the COVID-19 pandemic, PWMCs were likely to experience social isolation as changes in memory, social roles, and personality occurred [1]. Family caregivers (CGs) of PWMCs also had an increased risk of social isolation before the pandemic [2].

COVID-19 is a respiratory illness spread mainly through respiratory droplets and direct contact that is more likely to result in severe illness or death for older adults. Due to the unknown nature of COVID-19 at the time and rapid global spread, many services such as in-home aides and adult day services quickly closed at the onset of the pandemic [3]. This sudden absence of or disruption to home- and community-based services shifted the burden of continuous and comprehensive care to family CGs and intensified their existing challenges [4-6]. Since the onset of the pandemic, research has shown that CGs of PWMCs have experienced increased stress related to the exacerbation of PWMCs' behavioral, psychological, or dementia symptoms [5]. The increased burden and stress family CGs experienced during the initial stages of the pandemic were related to the amount of social support they received, the level of help the PWMCs required to complete activities of daily living, and the level of CGs' concern about the pandemic [7,8]. Throughout the course of the pandemic, many CGs have indicated concerns about a rapid decline in the cognitive functioning of PWMCs, due, in part, to the lack of social interaction [9].

Various types of technology have been used in research with PWMCs and family CGs. Assistive technology, designed specifically to assist PWMCs and their CGs perform a task, is associated with improved cognitive abilities and increased autonomy among PWMCs [10]. Mainstream technologies, such as Zoom or fitness trackers, also offer benefits to this population, such as by supporting social and physical functioning [11]. The use of technology to communicate with friends and family members allows for social connection while social distancing. Remote socialization, such as through web-supported Zoom videoconferencing, is associated with increased positive emotions and decreased agitation among PWMCs [10]. Information and communication technology use is positively associated with social connection and social support, as well as reduced social isolation among older adults [12].

In a prior study, 71% of CGs expressed interest in technology to support caregiving tasks [13]. However, interest in any given technology does not guarantee adoption. A technology's perceived value and perceived impact on quality of life, an individual's confidence in their ability to learn the technology, and social network support of technology use are key hurdles that influence technology adoption in this population [14,15]. Additionally, adoption of technologies for PWMCs and their CGs tends to be low due to barriers such as cost, complexity, inflexibility, a lack of awareness, and even age, income, and education [11,16,17].

During the COVID-19 pandemic, particularly during stay-at-home orders, the use of technology was necessary to sustain social connection and physical and mental health. Public health measures, such as social distancing, may have altered the perceived value of certain technologies on quality of life among many community-dwelling PWMCs and CGs. For example, telehealth medical visits were deemed feasible and acceptable to PWMCs and their CGs during the pandemic [18]. Social network support may have further influenced the uptake of certain technologies during the pandemic to maintain social connections. Therefore, previously identified barriers to technology adoption could have been outweighed by the increased social isolation and desire to maintain health among some PWMCs and their CGs.

The aim of this study was to investigate how and why some PWMCs and their CGs living in the community changed their mainstream and assistive technology use during the COVID-19 pandemic in the United States. Additionally, we aimed to understand how some PWMCs and their CGs used technology to adapt to isolation during the pandemic.

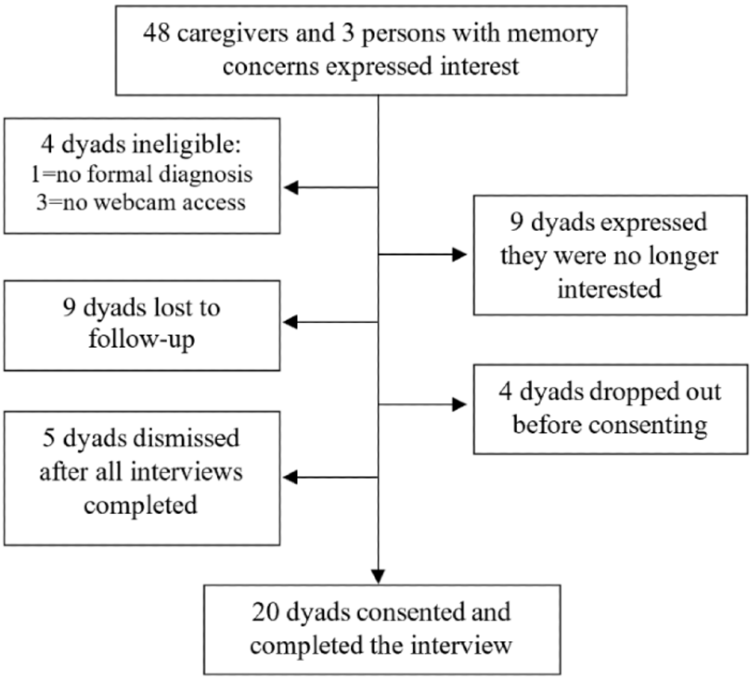
Methods

Recruitment

In total, 20 PWMCs and their CGs who lived in the community were recruited in the United States to assess (1) how their technology use shifted in response to the COVID-19 pandemic and (2) the impact that shift had on social isolation. Each PWMC-CG dyad was recruited to participate in a semistructured qualitative interview over Zoom videoconferencing. Although Zoom interviews were utilized to protect the health of older adult participants who were more likely to develop severe illness if they contracted COVID-19, this may have introduced selection bias by only including more technologically literate participants who could use Zoom [3]. Selection bias is discussed further in the Discussion section. Participants were recruited through the University of Minnesota Caregiver Registry, a list of family members of PWMCs and health professionals who have agreed to learn about research participation opportunities available on behalf of the senior author's project team. We emailed all individuals in the registry, inviting them to participate in the study. Participants were also recruited through email advertisements in professional networks and at memory clubs and adult day programs for PWMCs.

To be eligible to participate, the PWMCs had to speak English, have no history of a serious mental illness (ie, any major psychiatric disorder), and have a diagnosis of AD/ADRD or mild-to-moderate cognitive impairment by a physician. To be eligible, CGs had to speak English, be 21 years of age and over, and self-identify as someone who assists the PWMCs because of their memory loss. Because the interviews were conducted via Zoom, 3 dyads were considered ineligible since neither member of the dyad had access to a working web camera and microphone. One dyad was ineligible because the PWMC had never received a formal diagnosis of AD/ADRD or cognitive impairment. Figure 1 describes study participant flow. In total, 40 participants were enrolled and participated in the dyadic interviews conducted by authors EA and AM. The study was approved by the University of Minnesota Institutional Review Board (STUDY00006318).

Figure 1. Study participant flowchart.



Data Collection Procedures

Qualitative interviews were conducted from June 25 to August 6, 2020. Before an interview began, the CGs and PWMCs had to provide verbal consent or assent. PWMCs' capacity to consent was evaluated by administering the Mini-Cog and the University of California, San Diego (UCSD) Brief Assessment of Capacity to Consent (UBACC) [19,20]. The PWMCs provided verbal consent if they had a Mini-Cog score of 3 or higher and a UBACC score of 14.5 or higher. PWMCs provided verbal assent if they scored 2 or lower on the Mini-Cog or less than 14.5 on the UBACC. Once consent or assent was obtained, we administered a brief survey to CGs and PWMCs to determine age, sex, race, ethnicity, education, income, employment status, living arrangement, relationship to each other, and disease progression of the PWMCs.

Qualitative interviews adhered to a semistructured protocol focusing on 4 major topics: (1) technology use pre-COVID-19, (2) technology use during the COVID-19 pandemic, (3) adoption of specific technologies during the pandemic, and (4) facilitators and barriers to technology adoption. See Multimedia Appendix 1 for the semistructured interview questions. Interviews were audio-recorded, and direct observation notes were completed within 24 hours of each interview to document impressions of the participants' location, level of comfort with Zoom technology, any nonverbal behaviors of importance, and how the PWMCs and CGs interacted.

Data Analysis

Audio recordings were professionally transcribed and organized in NVivo 12 (QSR International). Interview transcripts and direct observation notes were thematically analyzed using Braun and Clarke's 6 steps of thematic analysis: (1) familiarization, (2) generation of initial codes, (3) search for themes, (4) review themes, (5) define and name themes, and (6) write-up of themes analyzed [21]. An iterative process was followed to continually identify themes, linkages, and explanations, which were compared to create a codebook. Researchers then identified textual elements that emerged repeatedly (ie, codes); these codes were clustered into larger categories that were used to construct major thematic elements from the text. All authors reviewed the codebook to refine and clarify codes and themes. Next, EA and AM independently coded a subset of the interviews and revised the codebook after comparing codes and discussion with the full authorship team. EA coded the interview transcripts, and author JM reviewed the coded material and revised it, as necessary, to ensure accuracy and replicability. The iterative process of developing codes and themes ensured that saturation was achieved and the data were characterized appropriately. Peer debriefing, negative case analysis, and clear audit trails enhanced transparency and rigor in the analysis [22].

Results

Participants

In total, 20 dyads participated in the study (Table 1). Most PWMCs were male (14/20, 70%), and most CGs were female (14/20, 70%). In addition, 16 (80%) of the 20 dyads were spouses/partners, while the other dyads were siblings or parents/adult children. Furthermore, 18 (90%) of the 20 PWMCs lived with their CGs. Half (n=10) of the PWMCs were diagnosed with AD or early-onset AD, 6 (30%) were diagnosed with mild cognitive impairment, and the remaining 4 (20%) were diagnosed with other types of memory loss.

Table 1. Demographics of participants in the study.

Characteristics	Entire sample (N=40)	PWMCs[a] (N=20)	CGs[b] (N=20)
Age (years), mean (range)	72.23 (37-88)	74.75 (57-88)	69.70 (37-86)
Race, n (%)			
White	38 (95.0)	19 (95.0)	19 (95.0)
Black/African American	2 (5.0)	1 (5.0)	1 (5.0)
Ethnicity, n (%)			
Hispanic	1 (2.5)	0	1 (5.0)
Non-Hispanic	39 (97.5)	20 (100.0)	19 (95.0)
Gender, n (%)			
Female	20 (50.0)	6 (30.0)	14 (70.0)
Male	20 (50.0)	14 (70.0)	6 (30.0)
Employment status, n (%)			
Employed	4 (10.0)	N/A[c]	4 (20.0)
Retired	15 (37.5)	N/A	15 (75.0)
Homemaker	1 (2.5)	N/A	1 (5.0)
Education, n (%)			
High school degree	5 (12.5)	4 (20.0)	1 (5.0)
Some college	12 (30.0)	5 (25.0)	7 (35.0)
Bachelor’s degree or more	23 (57.5)	11 (55.0)	12 (60.0)

[a] PWMC: person with memory concerns.

[b] CG: caregiver.

[c] N/A: not applicable.

Qualitative Analysis

Overall, 6 themes were identified that highlight why and how CGs and PWMCs altered their technology use during the COVID-19 pandemic. We present them in 3 groups: (1) facilitators of technology use, (2) barriers to technology use, and (3) overcoming challenges. Technological devices commonly used by participants were smartphones, smartwatches, computers, tablets, smart TVs, and assistive technology designed for PWMCs, such as pill dispensers.

Facilitators of Technology Use During the COVID-19 Pandemic

Due to stay-at-home orders and other public health measures to reduce the spread of COVID-19, PWMCs and CGs experienced physical and social isolation. Engagement with technology alleviated some of the negative outcomes of isolation by (1) sustaining social connections, (2) reducing boredom, and (3) increasing CG respite. These themes are presented with quotes and associated pseudonyms in Table 2 and discussed in more detail later.

Table 2. Facilitators of technology use during the COVID-19 pandemic for PWMCs[a] and their CGs[b].

Theme	Description	Exemplary quotes
Sustaining social connections	CGs and PWMCs were motivated to use technology to maintain social connections that would have otherwise been diminished during the pandemic.	• "It's a necessity if we want to keep in touch with people. We can't go visiting family all the time. So, it makes us feel good to be able to see them and, like with you, have a conversation. We're not so isolated." [Lisa, F[c], 77 years, CG] • "They're about 6 of us that'll text back and forth to one another a few times during the week." [Tristan, M[d], 71 years, PWMC] • "We have a night set aside weekly that we all just kind of check-in with each other, just a videoconference." [Hazel, F, 75 years, CG]
Reducing boredom	CGs and PWMCs used online games and streaming services and browsed the internet to promote entertainment and engagement.	• "I got put on a game that I was playing constantly. That's what got me by." [Peyton, F, 37 years, CG] • "We really have been very, very isolated, so when there's nothing to do, you spend more time on ways to reach out to people or just to get information." [Rick, M, 73 years, CG] • "For the first time a few months ago, we subscribed to Netflix and we're taking advantage of that . . . there's no more going to theaters." [Darius, M, 82 years, CG]
Increasing CG respite	CGs used technology to alleviate or reduce caregiving tasks to potentially create more time for respite.	• "When you have . . . 3 or 4 appointments on certain weeks, and then other weeks, there are 12 appointments. So, without technology [Slack], you can't have your job and coordinate all these things." [Louis, M, 47 years, CG] • "I signed up for the GPS[e] [watch] thing. That's worth a million dollars, you know . . . if he wants to go out by himself and I can track him" [Judy, F, 62 years, CG] • "I am using the computer more for food purchases, but we still do go out, and then again, I'm using the watch to track where he's at." [Lily, F, 64 years, CG]

[a] PWMC: person with memory concerns.

[b] CG: caregiver.

[c] F: female.

[d] M: male.

[e] GPS: Global Positioning System.

Sustaining Social Connections

Almost every participant expressed how the pandemic changed how they connected with friends and family. Most of the participants started using Zoom or other videoconferencing technology during the pandemic, while some reported using videoconferencing before the pandemic to keep in touch with family or friends. Many participants indicated new or increasingly frequent engagement with others through computer-mediated communication (CMC), with some even communicating with family members with whom they had lost contact. Half of the dyads reported increased online social engagement, which helped maintain social connection and reduced negative effects of prolonged isolation. April (female [F], 62 years, CG) shared how she used videoconferencing to maintain some aspects of her social connections and said,

> *My mental health would definitely suffer without the technology of the Zoom meetings and videoconferencing capabilities.*

Both PWMCs and CGs realized the importance of social connections during isolation and the importance of sustaining social connections through CMC.

Participants emphasized that ensuring the PWMCs remained socially connected through CMC use was important for mental health and to possibly slow dementia progression. Louis (male [M], 47 years, CG) shared his concern for his father's lack of social connection during the pandemic:

> *When you have the connections, then you remember people's names or who they are. If you don't see people for a long time, then you start to forget who they are.*

For those with the ability and resources to use CMC, it was instrumental in allowing PWMCs to maintain social connections during the pandemic.

Participants also mentioned an increase in the use of other technologies to stay connected, such as photo-sharing apps (eg, Snapchat), texting, and emailing. Barb (F, 86 years, CG) noted she does "a little more texting . . . and more email, because now they're sending all this stuff of what you can do while you're at home, instead of going to adult day [programs]." CGs and PWMCs demonstrated myriad ways in which they adapted to the isolation using different technologies to maintain social connections.

Reducing Boredom

Using technology to reduce boredom was common among participants. Some engaged more passively with technology through streaming movies and music. Some participants were actively engaged with technology by attending online classes, playing memory games, exercising to workout videos, or searching for medical facts. Layla (F, 72 years, PWMC) expressed gratitude for the numerous entertainment options available:

> *If we were going through this pandemic in the 1940s, it'd be an absolute mess, and [now] you can watch TV and see what's going on and all that stuff . . . it's a hard time, but in a sense there's still things we can do.*

Reducing boredom was important for isolated CGs and PWMCs staying at home, which led to the increased use of existing technology and the adoption of new ones, along with continued cognitive engagement.

Increasing Caregiver Respite

Some CGs and PWMCs adopted new technologies that offered convenience while in the home, such as telehealth visits, grocery delivery services, and Global Positioning System (GPS) technology. These technologies reduced stress and saved time for CGs. Peggie (F, 60 years, CG) leveraged technology for telehealth visits and said,

> *I actually kind of like if we don’t really need to be in the office for a visit. It takes a lot less time . . . versus driving back and forth and waiting.*

Telehealth visits offered CGs conveniences, as did online shopping. Lisa (F, 77 years, CG) began ordering groceries online because

> *Before [the pandemic], I had freedom for, like, a 4-hour slice twice a week. Eight hours where I could get out and do errands that I needed to do, and now I don't have that, and I don't like to leave Myles alone for any length of time. So, I just order my groceries online, and then I go pick them up or my daughter will pick them up for us.*

Online shopping allowed CGs who usually shopped in person to not worry about leaving their relative in the car or at home alone for an extended period.

The loss of adult day programs and in-home care visits made finding personal time difficult for some CGs. In some cases, GPS technology provided CGs respite, while still allowing them to attend to the health and safety of the PWMC when needed. CGs, like Rick (M, 73 years) shared how he used GPS watch technology to track his wife who exercised outside without him being present. Rick said,

> *If Layla was walking and she didn't come back when I thought she should, and I had no clue where to look for her, that would be incredibly stressful!*

The GPS watch provided Rick and his wife free time and a sense of independence. Another CG, Judy (F, 62 years) explained that when her relative wore a GPS watch it gave her “peace of mind.” Christa (F, 63 years, CG) shared that she used tracking technology because her relative lived in a different city and therefore was not able to know where her relative always was without the help of GPS. Through the adoption of technology, some CGs were able to find ways to create respite time for themselves.

Barriers to Technology Use During the COVID-19 Pandemic

Managing the COVID-19 pandemic in conjunction with caring for someone with memory concerns presented its own set of challenges, as did using new technology. Barriers that impacted CG and PWMC technology use included (1) limitations of existing technology, (2) technological literacy, and (3) the dependence on CGs to use technology. These themes are presented with quotes and associated pseudonyms in Table 3 and discussed in more detail later.

Table 3. Barriers to technology use during the COVID-19 pandemic for PWMCs[a] and their CGs[b].

Theme	Description	Exemplary quotes
Limitations of existing technology	CGs and PWMCs experienced various frustrations and difficulties using technology during or prior to the pandemic due to technological limitations.	• “Sometimes, you have a hard time hearing on Zoom . . . and it’s harder to focus. So you have to really focus on the screen.” [Louis, M[c], 47 years, CG] • “Sometimes, he does text . . . he does have parkinsonism, where he does now have more motor issues, [and] it’s hard for him to tap on the phone.” [April, F[d], 62 years, CG] • “People with memory loss can’t [usually] use a smartphone, and so, they’ve had to go to, like, a flip phone just because it keeps it simple . . . I get confused once in a while on the apps, but not too often.” [Lee, M, 77 years, PWMC]
Technological literacy	CGs and PWMCs varied in how familiar they were using technology.	• “I have a newer cell phone, and it does more than what I can do . . . I’m not using everything that’s available there.” [Lily, F, 64 years, CG] • “Lief was really very familiar with technology early on . . . he’s significantly lost his ability to navigate, with how rapidly changing technology has been.” [April, F, 62 years, CG] • “I don't like apps and the security aspect of apps. I don't trust it . . . because I don't really understand it.” [Judy, F, 62 years, CG]
Dependence on CGs to use technology	PWMCs varied in their level of dependence upon their CGs to use technology.	• “He is coming to me to help him with [the smart TV], which is okay. He's not as frustrated with asking for help as he used to be, but that's a thing that sometimes creates anxiety.” [Lily, F, 64 years, CG] • “Charles sometimes gets frustrated at the new technologies. I have to keep helping him with it.” [Annmarie, F, 73 years, CG] • “I might have to have instructions, but if I use it enough, it’ll go.” [Charles, M, 77 years, PWMC]

[a] PWMC: person with memory concerns.

[b] CG: caregiver.

[c] F: female.

[d] M: male.

Limitations of Existing Technology

Most technologies were not designed to suit the needs and abilities of PWMCs. Challenges for PWMCs using CMC included the absence of nonverbal cues, system lag-time issues, and difficulty learning, which resulted in less satisfaction in social interactions while using the technology. CMC can cause PWMCs to become confused or frustrated due to the lack of nonverbal cues and lag-time issues. Peggie (F, 60 years, CG) explained that

> *Not being able to see the body language, and engaging people appropriately, I think, is harder . . . for someone like [my husband], who maybe is having some challenges getting the words out . . . on a video it's harder.*

Although some technologies were designed for PWMCs, a few CGs expressed that they were still too complicated and caused stress and confusion. Peggie shared that her husband’s memory loss support group was over the phone because the group members were unsuccessful in joining the videoconference due to difficulty learning new technology. Dementia severity impacted the ability to learn new technologies and limited the types of technologies that were useful to PWMCs.

Technological Literacy

CGs and PWMCs in the sample varied in their familiarity and comfort with technology; some participants felt well versed or tried to stay up to date on new technologies, while others tried to avoid using any and did not stay up to date. Rick (M, 73 years, CG) explained that

> *Layla and I use computers every day. We have iPhones, iPad, 2 laptops, Apple, [and] an iMac. We have Amazon echoes. We have cameras and security devices. Our thermostat . . . we do all that stuff.*

Conversely, Gary (M, 77 years, CG) had a nonsmartphone cellular device, and while he used the computer regularly, the interview was his first video call. One PWMC regularly wrote blog posts and used CMC, such as social media with friends, while Myles (M, 85 years, PWMC) said,

> *I’m what is known as computer illiterate, so I have a difficult time using the telephone.*

Lack of familiarity with older technology frequently precluded adoption of new technology.

Most CGs expressed interest in using new technology to benefit themselves and their relatives yet were often too intimidated to try. Peyton (F, 37 years, CG) shared,

> *I'm not really good with it . . . I want to stay up to date, but I don't know what I'm doing.*

Less technologically literate participants were frequently intimidated by various aspects of technology. Some participants chose not to use any technology that required more than passive use, such as downloading an app. The level of technological literacy prior to the pandemic impacted how likely a participant was to adopt a new technology during the pandemic.

Some CGs who were less technologically literate were able to seek out and try new technology with the help from others within their social network. April's (F, 62 years, CG) uptake of new technologies was driven by her children:

> *I wouldn't even consider it if my kids didn't say "Hey, look at how cool this works . . . you should get this, Mom."*

Another CG, Barb, (F, 86 years) shared how her granddaughter often helped her learn a new technology, such as Zoom. Less technologically literate participants whose social networks reinforced the use of new technology were able to realize the benefits it had in their lives.

Dependence on Caregivers to Use Technology

Over half of the dyads shared various ways in which the PWMC was dependent on the CG to utilize technology. Annmarie (F, 73 years, CG) would completely set up Zoom so the PWMC could use it, while other PWMCs used technology independently and relied on their CGs only when problems arose, such as a screen going blank. Some CGs like Peggie (F, 60 years, CG) expressed a desire for the PWMCs to be more independent using technology:

> *I would really love it if he didn't have to say, "Peggie, can you come help me make this happen?"*

To maintain a technology's usefulness, a CG had to be readily available, have time to teach the PWMC how to use it, and reinforce its use.

Overcoming Challenges

Participants who were motivated to try a new technology and overcame the associated challenges reported increased social connection, reduced the caregiving burden, and, in some instances, increased PWMC independence. Some CGs began using technology to promote learning and cognitive engagement among their relatives during the pandemic. For example, Zoom meetings and viewing pictures on Facebook helped to stimulate memory and mental capabilities to maintain recognition and memories of friends and family. Throughout the interviews, there were examples of PWMCs learning a new technology and gaining independence. Lisa (F, 77 years, CG) explained how she used to set up calls on her husband's hearing phone so that he could call other people:

> *But since COVID he started using it himself . . . I said [to Myles], "That's a little bit of freedom that you've got back."*

These fragments of increased PWMC freedom were able to slightly reduce caregiving burden despite increased stress and isolation.

Discussion

Principal Findings

The COVID-19 pandemic forced a shift in technology adoption for those who were fortunate enough to have access to it. Yet, CGs and PWMCs were not always willing to try new technology to assist them due to barriers such as each person's level of technological literacy, the dependence on the CG for use, and limitations of the technology. For CGs and PWMCs who adopted new technology or adapted existing technology, technology was perceived as more useful during the pandemic than before, specifically in relieving boredom, maintaining social connections, and increasing CG respite.

Comparison With Prior Work

Our research affirms that social network support, perceived value, perceived impact on the quality of life, and confidence in the ability to learn a new technology are all important influences of technology adoption [14,15]. Each of these influences played a role in technology adoption among PWMCs and CGs during the pandemic. Our research also highlights the role of technology in reducing the caregiving burden during the pandemic, along with increasing PWMC independence. GPS technology seemed to minimize CG stress by reducing the likelihood of PWMCs getting lost [23]. Similar to findings by Øderud et al [24], our research also shows that GPS technology provides CGs with respite time, while allowing PWMCs to enjoy their freedom and outdoor activities safely.

Studies suggest that assistive technology can reduce the caregiving burden yet may also pose an additional burden when technology adoption and use require too much CG help [25]. Such results are consistent with our findings that CGs are unlikely to adopt burdensome technology. In a review of 56 studies, assistive technology was perceived as removing CG stress and burden overall, although no significant change in the caregiving burden was reported in any of the 16 (29%) quantitative studies included in the review [23]. This discrepancy in CG burden results may be due to insensitivity of existing quantitative outcome measures [26]. Perhaps alternatively, no single device or app is comprehensive enough to reduce the caregiving burden, and instead, a combination of technologies is required to significantly reduce burden.

Technology can foster social connections for CGs and PWMCs by counteracting the impact of diminished social support and interactions during the pandemic. A systematic review of 25 publications concluded that information and communication technologies (ICT) can be an effective way of reducing social isolation among older adults; however, it is not suitable for all older adults [12]. Prior to the pandemic, technological interventions to reduce social isolation were understudied [27]. Not only are more ICT interventions being developed to reduce loneliness and increase social participation during the pandemic, but older adults also have a more positive view of ICT interventions now in contrast to before the pandemic [28].

Preliminary findings are showing promising results; in a qualitative study, researchers demonstrated that virtual memory cafés, where PWMCs and CGs remotely interact with other PWMCs and CGs, were able to support the social connectedness of PWMCs and CGs during the COVID-19 pandemic [29].

Recommendations

The findings emphasize the importance of incorporating technological barriers of PWMCs and their CGs into the design process. Although dependence on the CG to use technology cannot be eliminated entirely, it should be avoided or minimized through mindful design. Therefore, it is important to engage both the PWMC and the family CG during each stage of the design process. Additionally, it is likely not feasible for technology developers to improve a users' technological literacy. However, testing new products by CGs and PWMCs at various stages of dementia progression could highlight difficulties for less technologically literate users. This codesign process is important for any technology used by older adults yet is most important for technology designed specifically for PWMCs.

Limitations

Limitations of this research include factors that may make the study population different from the general population. Participants were recruited through email, and they had to be willing and able to participate in interviews over Zoom, which could have led to selection bias. Participants may be more likely to use Zoom and other technologies than individuals who would have only been recruited in a nontechnological manner or did not have the capability to participate in a Zoom interview. Since income, education, and race/ethnicity are major influences of technology adoption, it is important to note that this sample was highly educated, had a median income higher than the national median income, and primarily identified as non-Hispanic White [30]. Additionally, we did not include PWMCs living in long-term care, and no PWMCs were in the later stages of dementia. Due to these differences, participants in this study may have different patterns of technology use/disuse compared to other CGs and PWMCs, all of which likely limit the generalizability of the findings. The results are hypothesis generating, and future research should engage a more racially and ethnically diverse population of CGs and PWMCs and include participants with lower incomes, educational attainment, and technological literacy.

Conclusion

This research contributes to the literature on this population's technology usage. Much of the existing literature focuses solely on assistive technology, while our research points out that mainstream technologies, such as smartphones or Zoom, were predominately used by this sample. Further research is needed to examine how mainstream technologies are used to support PWMCs and CGs in their everyday lives and to compare whether those who adopted more technology during the pandemic coped better with isolation than those who did not alter their technology usage.

Our research found that the COVID-19 pandemic resulted in an increase in technology use among many participants. These findings emphasize the importance of technology use among CGs and PWMCs, particularly during isolation, to provide relief from caregiving burden and afford PWMCs more independence.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Semistructured interview questions.
[PDF File (Adobe PDF File), 42 KB - aging_v5i1e31552_app1.pdf]

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Abbreviations

AD: Alzheimer disease
ADRD: Alzheimer disease–related dementias
CG: caregiver
CMC: computer-mediated communication
F: female
GPS: Global Positioning System
ICT: information and communication technologies
M: male
PWMC: person with memory concerns
UBACC: University of California, San Diego Brief Assessment of Capacity to Consent

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Original Paper

Understanding Current Needs and Future Expectations of Informal Caregivers for Technology to Support Health and Well-being: National Survey Study

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Abstract

Background: There are approximately 6.5 million informal (unpaid) caregivers in the United Kingdom. Each caregiver plays a critical role in the society, supporting the health and well-being of those who are ill, disabled, or older and who need frequent support. Digital technologies are becoming a ubiquitous part of everyday life for many, but little is known about the *real-world* impact of technology for those in a caring role, including the abilities of technologies to address the mental and physical impacts of caregiving.

Objective: This study aims to understand the current and future technology use of caregivers, including digital technologies used to care for themselves and the person they look after.

Methods: We codeveloped a wide range of questions with caregivers and care professionals and delivered this survey both on the web and in paper format (eg, using social networks such as Twitter alongside *in-person* events). Questions were focused on providing care and looking after caregiver health and well-being. Analyses focused on both quantitative outcomes (frequency counts and Likert questions) and explored free text entries (thematic analysis).

Results: From 356 respondents, we identified that caregivers were receptive to, and largely positive about current and future use of technology both for their own care and their caring role (eg, checking in from distance). There were notable concerns, including the risk that technology could replace human contact. We identified several key areas for future work, including communication with health and social care professionals, and the potential for technology to help caregivers with their own health. We also identified several stakeholders (eg, care workers, pharmacy staff, and general practitioners) who could act as suitable points for technology signposting and support.

Conclusions: Caregivers are a transient, often difficult to reach population, and this work has collated a large body of knowledge across a diverse group of individuals. Many caregivers, like the rest of society, are realizing the benefits of using everyday technology to help deliver care. It is clear that there is already a high level of dependency on technologies, where future expectations will grow. However, many barriers to digital technology use remain, including a lack of ongoing technology support. Preventive measures linked to technology that can help look after a caregiver's own health appear acceptable, particularly for communicative tools. This collated caregiver knowledge is a call for all stakeholders—academics, policy makers, and practitioners—to take note of these specific challenges, and to ensure that caregiver voices are both heard and fully integrated within the emerging digital health agenda.

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KEYWORDS

caregiving; technology; health; well-being; digital health; co-design; mobile phone

Introduction

Background

Informal (unpaid) caregivers play a critical role in society, supporting the health and well-being of those who are ill, disabled, or older who need frequent support. Caregivers are the biggest health care provider in the United Kingdom alone, with an estimated 6.5 million informal caregivers (ie, approximately 10% of the total population), with an economic impact of approximately US $77-US $182 billion per year [1,2]. Globally, an aging and growing population means that the number and economic contribution of caregivers appear to grow considerably in the years ahead.

Collectively, caregivers are diverse. Each situation is unique, varying across geographic location, conditions cared for, cumulative time spent caring, available support (social, health care, or otherwise), and information received [3]. Reaching and understanding this *silent workforce* is not straight forward, as many caregivers take many years to—or may never—identify with the term of being a *caregiver* [4]. Although the tasks that caregivers undertake differ (eg, specific needs, hours spent caregiving, and support available [5-7]), the commonalities in experience are the physical and mental stresses, which are considerable and unrelenting. The cumulative load of caregiving steadily impacts the health and well-being of caregivers, and for many, caregiving is associated with a broad range of acute and chronic mental and physical conditions [8-10]. Accordingly, there are urgent calls at national and multinational levels to find ways to support caregiver needs through cost-effective, sustainable, and preventive solutions [11,12]. Such calls have accelerated the development of many innovative approaches, such as those directed toward digital health and wellness technology-based solutions [13].

The development of solutions based on digital health and wellness technology is increasing across a wide range of approaches, including telehealth, mobile health, wearables, and health analytics as well as digitalized (eg, paperless) health systems [14,15]. Technology support for health and well-being is also increasingly prominent within community care where technologies, such as webcams, personal alarms, GPS trackers, and voice technologies are helping many caregivers regularly manage aspects of safety, communication, care, and sustaining independence for as long as possible [13].

Study Aims

In a growing continuum of digital possibilities, understanding theoretical models of moderators and mediators for technology use is of significant interest to all stakeholders [16]. Nevertheless, our global understanding of the barriers and enablers for *real-world* technology use for caregivers is still surprisingly sparse [17-19]. Given the considerable prominence of caregivers within our health and social care workforce, this study aims to collect evidence on the current and future technology use of caregivers, both for their own health and well-being, and the person or persons they look after within the context of the United Kingdom.

Methods

Overview

The Supported Carer Project survey involved delivering a comprehensive survey to help inform current understanding of the use of digital technology among caregivers, both for caregiver health and those cared for. As we did not find one already in existence, we co-designed a novel survey with caregivers. This survey was designed to be used across the United Kingdom to capture both current and future needs and how digital health technologies might be able to meet these needs.

Inclusion Criteria and Survey Co-design

Our inclusion criteria reflected our broad interests and included all informal caregivers aged ≥18 years. We used a broad definition of an informal caregiver, *people that provide unpaid care by looking after an ill, older or disabled family member, friend, or partner*. We did not specify the minimum number of hours per week caregivers needed to be caring for. Ethical approval was received from the Department of Computer & Information Science at the University of Strathclyde. Our survey collated information on basic demographics, health needs, and explored perspectives on technology for both caregivers and those being cared for (including interactions with health and social care professionals). Our survey questions (Multimedia Appendix 1) were codeveloped through consultation with key study partners who had significant experience working in the caregiver domain (Health and Social Care Alliance Scotland [The ALLIANCE] and Carers Scotland as part of Carers UK). Questions were developed iteratively, and the scope and approach of our survey was critiqued by 3 individual caregivers and 5 professionals from caregiver organizations to ensure that the length, wording, and scope were appropriate. No questions were mandatory, so responses vary across each question discussed. The survey consisted of four key sections: (1) the demographic details of you as a caregiver (7 questions); (2) you as a caregiver and technology use (13 questions); (3) the demographic details of the person that you care for and health and social care service use (26 questions); and (4) technology use for the person you care for (50 questions). Caregivers could add multiple people cared for should they care for more than one person, up to a maximum of 4 people.

Survey Distribution and Consent

The distribution of our survey involved convenience sampling. More specifically, we shared the web-based version of our survey through social media channels (eg, Twitter), and email distribution through networks accessible to our third sector partners. The survey was promoted using email and social media networks connected to The ALLIANCE [20] and Caregivers Scotland as part of the Caregivers United Kingdom [21]. Paper copies of the survey were also distributed at conferences and professional events from The ALLIANCE and Carers UK (Scotland), which were posted back to us. In addition, the UK Alzheimer's Society agreed to share this survey using their web-based message board systems, *Talking Point*. The survey was available from June 21, 2018, to September 28, 2018. Consent was implied in both digital and paper format after participants read, acknowledged, and accepted the initial terms of the anonymized survey.

Data Handling and Analyses

Our survey was constructed using Qualtrics Software, where we stated that any data entered must not contain any identifiable information. These efforts were paralleled in a paper format. As free text entry methods could not prevent identifiable information from being entered, data were treated as confidential at all times and retained within encrypted, password-protected sources. Qualitative analyses were performed using thematic analysis and deep dives [22]. All quantitative analyses (frequencies and summary statistics) were performed using R Studio (version 1.1.456).

Results

Demographic Information of Caregivers and Those Cared for

We received 356 caregiver responses (total sample size but individual question responses vary) in our survey, and the demographics of caregivers and those cared for are summarized in Table 1. Caregivers who completed our survey varied in age, but most commonly between 45 and 54 years (135/356, 37.9% of responses), predominantly female (288/354, 81.3% vs 60/354, 16.9%) and self-reported as White (335/354, 94.6%). Of the 331 responses for this specific question, 234 (70.7%) of our respondents were located in Scotland, 74 (22.3%) in England, 17 (5.1%) in Wales, and 6 (1.8%) in Northern Ireland. Regarding the highest level of education, 56.2% (200/356) of respondents had obtained a degree or equivalent, and 22.2% (79/356) had completed higher education. Regarding the number of people cared for, 72.9% (210/288) of participants were caring for 1 person, 22.2% (64/288) were caring for 2 people, 4.2% (12/288) were caring for 3 people, and 0.7% (2/288) were caring for 4 or more people. A total of 34.2% (121/354) of caregivers were working full-time, 25.4% (90/354) were part-time, and 40.4% (143/354) were not working, of which 90 (ie, 90/354, 25.4% of all caregivers responding) had to give up work because of caregiving. Caregivers varied in the number of years spent caregiving, ranging from less than a year (5/309, 1.6%) to over 20 years (34/309, 11%). Four participants responded to our survey via post (4/356, 1.1%) with all other responses via our web link.

Our survey responses included information from 359 individuals cared for, where information differed considerably from that among caregivers in both age and gender (Table 2). Those cared for were most commonly either <35 years (99/359, 27.6%) or >65 years (193/359, 53.8%), and males and females cared for were 51.1% (181/354) and 47.7% (169/354), respectively. The ethnicity of those cared for was very similar to that of caregivers. Among individuals cared for (where sufficient detail was given for 355 individuals; Multimedia Appendix 2) over 20 different conditions were listed, and the most common conditions were dementia (109/355, 30.7%), older needs (106/355, 29.8%), and mental health conditions (74/355, 20.8%). Similarly, the types of specific health problems reported varied considerably across those cared for. From 258 responses, 99 (38.4%) reported precise hand movement problems, 66 (25.6%) speech impairments, 66 (25.6%) deafness or hearing loss, and 40 (15.5%) were blind or had sight loss. A total of 44.2% (114/258) of responses indicated that there were *other* sensory issues. We were able to explore 106 of these (free text responses), where mobility was a specific problem for 29.2% (31/106) of respondents. Overall, this subgroup of responses was diverse and problems related to both physical (eg, "nerve damage" and "physically weak") and psychosocial health issues (eg, anxiety or memory).

Table 1. Study sample and population characteristics of caregivers.

Demographics	Caregivers, n (%)
Age (years; N=356)	
18-24	4 (1.1)
25-34	17 (4.8)
35-44	56 (15.7)
45-54	135 (37.9)
55-64	100 (28.1)
65-74	28 (7.9)
75-84	13 (3.7)
≥85	1 (0.3)
Prefer not to say	2 (0.6)
Gender (n=354)	
Female	288 (81.4)
Male	60 (16.9)
Other	3 (0.85)
Prefer not to say	3 (0.85)
Ethnicity (n=354)	
White	335 (94.6)
Mixed/multiple ethnic groups	3 (0.85)
Asian/Asian British	4 (1.13)
Black/African/Caribbean/Black British	0 (0)
Other	4 (1.12)
Prefer not to say	8 (2.3)
Highest level of education (N=356)	
Degree or equivalent	200 (56.2)
Higher education	79 (22.2)
Other qualifications	18 (5.1)
School qualifications	52 (14.6)
No qualifications	5 (1.4)
Do not know	2 (0.6)
Number of years caregiving (n=309)	
<1	5 (1.6)
1-2	36 (12)
3-4	54 (17.5)
5-6	53 (17.2)
7-8	28 (9.1)
9-10	24 (7.8)
10-16	41 (13.3)
>16-20	34 (11)
>20	34 (11)

Table 2. Study sample and population characteristics of people cared for.

Characteristics	People cared for, n (%)
Age (years; N=359)	
0-15	49 (13.7)
16-24	32 (8.9)
25-34	18 (5)
35-44	9 (2.5)
45-54	25 (7)
55-64	31 (8.7)
65-74	39 (10.9)
75-84	81 (22.6)
≥85	73 (20.3)
Prefer not to say	2 (0.6)
Gender (n=354)	
Female	169 (47.5)
Male	181 (50.8)
Other	1 (0.3)
Prefer not to say	5 (1.5)
Ethnicity (n=356)	
White	334 (93.8)
Mixed/multiple	7 (2)
Asian/Asian British	5 (1.4)
Mixed/multiple	1 (0.3)
Black/African/Caribbean/Black British	2 (0.6)
Other	7 (2)

Technology for Caregivers’ Own Health and Well-being

Current Interest

Caregivers were asked about their level of agreement to use technology to help with their own health and well-being. Of the 277 responses, 92 (33.2%) of respondents strongly agreed, 102 (36.8%) agreed, 67 (24.2%) neither agreed nor disagreed, 12 (4.3%) disagreed, and 4 (1.4%) strongly disagreed:

> *Being able to access support or some form of mental health support would be ideal. Being a carer is tough and you focus most of your time on the person you care for but forget you also need care.* [Participant quote on using technology for own health and well-being]

Caregivers interpreted help from digital technologies in many different forms. Our analysis identified themes across concepts of relaxation, meditation, memory prompts, communication (both with health and social care professionals and peers), entertainment and tools, such as fitness trackers to encourage or inform healthy lifestyle choices (Textbox 1). Arguments to support the use of technology to support health and wellness were based on convenience, accessibility, and accuracy: being able to use digital tools quickly to find answers on a regular basis. Exploring the free text of caregivers who were not interested in using technology for their own health (ie, 16 caregivers who disagreed or strongly disagreed that they had an interest) highlighted many concerns regarding technology. Time (and money) were barriers to use for 5 respondents, and technologies that operate in silos outside of health and social care are of limited use. Concerns were also raised that technology can become a *gimmick*. Technologies were highlighted as a concern where they reinforce a concept of *failure*: technologies that assess progress and activity relating to one’s own health and well-being can resonate with feelings of a lack of achievement.

Textbox 1. Caregiver quotes for using technology for own health and well-being. Caregivers rated their agreeability regarding their level of interest “to use technology to help me with my own health and well-being.” Quotes are examples of further details given from participants grouped according to level of agreement.

Strongly agree

- “Being able to access support or some form of mental health support would be ideal. Being a caregiver is tough and you focus most of your time on the person you care for but forget you also need care.”

Agree

- “It is all very useful- but won’t encourage you to meditate or exercise. You have to want to do it, for it to be effective. When you are isolated, depressed and stressed—you still need human interaction.”

Neither agree nor disagree

- “I don’t know how it would help. I fear it going wrong.”

Disagree

- “Gimmicks like these tech devices are of little interest to me. I do make extensive use of the internet to connect with other caregivers and share information and social chatter.”

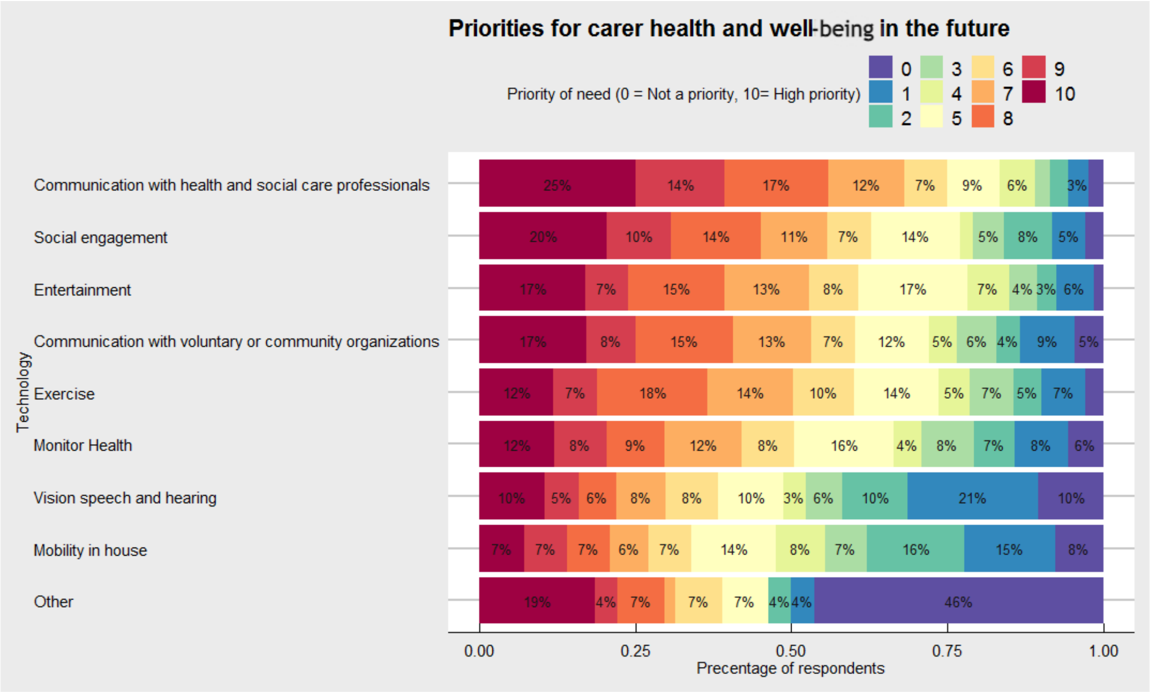
Strongly disagree

- “There is enough to deal with already. The thought of my phone telling me to go for a walk fills me with dread. Yet more to fail at.”

Future Interest

When individuals were asked where they would like to see a focus on future technologies for caregiver health and well-being, we identified that there was a wide range of needs for future priorities (Figure 1). In parallel with the themes identified for current use, the most commonly reported future needs were around the themes of communication with health and social care professionals (62/247, 25.1%) of respondents rated this as the highest priority need). Other high-priority needs identified (ie, 10 out of a possible 10) for caregiver health and well-being were technologies focused on social engagement (51/245, 20.8%), entertainment (44/253, 17.4%), and communication with voluntary or community organizations (41/239, 17.2%). Some 54 respondents noted that not all of their needs were captured within the predefined eight categories. We explored these data and identified 24 diverse responses. Examples included, *accessing research and best practice recommendations* and *medication management*. Others were more interested in mental health aspects such as *rebuild my self-esteem* and *mental health monitoring advice and support*.

Figure 1. Summary figure of how caregivers would like to see future technologies support them with their own health and well-being in percentage. Color indicates priority of need where 0=not a priority (violet) and 10=highest priority (maroon).



Technology for Delivering Care

Current Interest

We gathered 238 responses on the agreement level regarding interest for caregivers to use technology within their caring role. We observed that 39.5% (94/238) strongly agreed, 33.6% (80/238) agreed, 21.8% (52/238) neither agreed nor disagreed, 3.4% (8/238) disagreed, and 1.5% (4/238) strongly disagreed. Through free text responses (Textbox 2), caregivers commonly noted several key benefits, including digital devices (eg, tablets, smartphones, or laptops) allow ease of access to information, checking in from distance (eg, Skype), supporting isolation, communication, entertainment (eg, Netflix), and help with simple reminders for care duties such as medications:

> *Caring comes down to people and we must get the focus back on to people, not technology!* [Participant quote on using technology for caring role]

Some caregivers reported knowledge of web-based learning and support modules. Concerns from caregivers included that reaching health and social care professionals remains difficult, and that the use of technology can be stressful for those cared for (eg, provoking anxiety). Technologies are also limited in their suitability for progressive conditions.

Textbox 2. Caregiver quotes for using technology in caring role. Caregivers were asked to rate their level of interest for using technology to help them with their caring role. Quotes are examples of further details given from participants grouped according to level of agreement.

Strongly agree

- "In order for me to continue be able care at home I need technology. Simple as that."

Agree

- "Living in a fairly isolated community and reliant on a car for appointments, shopping and visiting friends, technology such as video links, and FaceTime are helpful."

Neither agree nor disagree

- "With dementia it is only useful in the early stages."

Disagree

- "I care for someone with very complex mental health problems and technology would raise his already extreme anxiety I suspect."

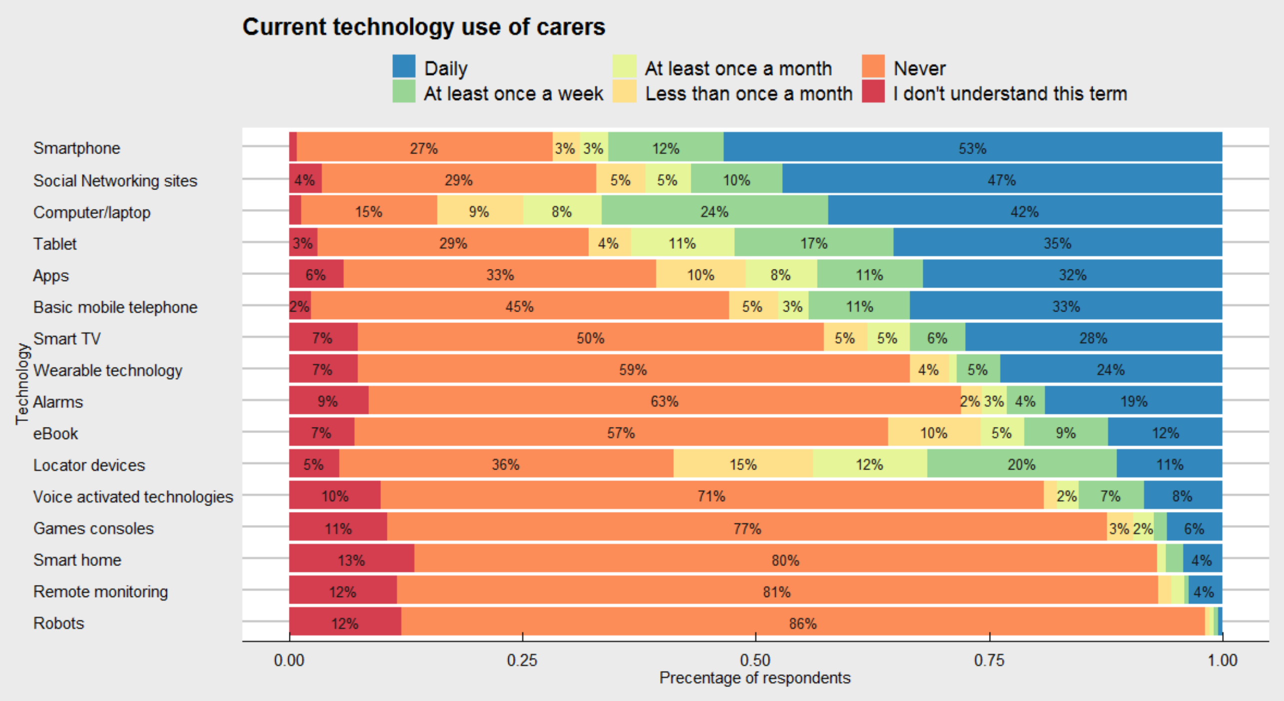
Strongly disagree

- "Caring comes down to people and we must get the focus back on to people, not technology!"

Type of Technology and Frequency of Use Within Caring Role

We asked caregivers about the type and frequency of technology they use for their caring role and they most commonly reported smartphones, computer or laptop use, and social networking sites with 65.8% (154/234), 66.5% (151/227), and 59.8% (128/214), respectively, reporting at least once weekly use (Figure 2). Many technologies have been used sporadically; for example, locator devices (eg, Google Maps and GPS) are used at least to some degree by 57.3% (130/227) of caregivers but are commonly used weekly or monthly. Regarding frequency of use, caregivers were twice as likely to have never used wearable technology as opposed to using it daily. The use of platforms specific for gaming was limited (eg, PlayStation or Xbox) and was used by 5.9% (13/218) of caregivers daily. Such use was not limited to younger ages but included involvement from caregivers aged 55 to 64 years. Perhaps tellingly, a lack of understanding of terminologies used in our survey was often associated with caregivers never using a specific technology to help them in their caring role (eg, robots, smart homes, and remote monitoring).

Figure 2. Current technology use of caregivers to conduct their caring role. The x-axis represents cumulative percentage use, whereas the y-axis represents the different types of technologies. Frequency of use was grouped into: (1) Daily, (2) At least once a week, (3) At least once a month, (4) Less than once a month, (5) Never and (5) I don't understand this specific technology term. TV: television.



Confidence and Support for Technology

We asked caregivers about their confidence levels when selecting the most appropriate technologies. Of the 238 responses, 25 (10.5%) strongly agreed, 82 (34.4%) agreed, 69 (28.9%) neither agreed nor disagreed, 51 (21.4%) disagreed, and 11 (4.6%) strongly disagreed that they were confident in selecting the most appropriate technologies for their caring role. A range of qualitative comments supported such statements (Textbox 3), particularly around barriers to adoption, such as that technology moves so fast, technology is often aimed at younger markets, and that information is lacking. Enablers for high confidence in selecting technology commonly involved caregivers who had a particular background in technology, a family member to hand with technology expertise, and the ability to search for solutions through computers or the internet:

> *No one has helped me. It was all down to Google and common sense.* [Participant quote on confidence for using technology for caring role]
>
> *I DO NOT want more technology in my caring role, there is more than enough and it is a failure* [Participant quote on support for using technology for caring role]

We also asked caregivers whether there was sufficient support and training for technology resources and services to help them in their caring role. Of the 236 responses, 6 (2.5%) strongly agreed, 33 (13.9%) agreed, 102 (43.2%) neither agreed nor disagreed, 67 (28.4%) disagreed, and 28 (11.9%) strongly disagreed. A range of qualitative comments supported these statements (Textbox 4), including financial restrictions, lack of visibility or existence of support, a need for self-sufficiency within the caring role, inability to accommodate all users (eg, older caregivers), and lack of overall support for caregivers with technology just being one component of this.

Textbox 3. Caregiver quotes regarding confidence for using technology in caring role. Caregivers rated their confidence about selecting the most appropriate technologies for their caring role. Quotes are extracts of further comments given from participants grouped according to level of agreement.

Strongly agree

- “I like technology and try to find ways to adopt and adapt it for my use.”

Agree

- “I can find my way around most technologies.”

Neither agree nor disagree

- “Not always sure what will be most effective.”

Disagree

- “I just don’t know anything about what might be available.”

Strongly disagree

- “No one has helped me. It was all down to google and common sense.”

Textbox 4. Caregiver quotes regarding support and training for using technology in a caring role. Caregivers rated whether there was sufficient support and training for technology resources and services to help them in their caring role. Quotes are examples of further details given from participants grouped according to level of agreement.

Strongly agree

- “I do not want more technology in my caring role, there is more than enough and it is a failure.”

Agree

- “I find I can access the information I need—I do wonder though, if it is as accessible to everyone?”

Neither agree nor disagree

- “Feel I have everything I need or can afford.”

Disagree

- “I have never been offered or had discussed any info on tech enabled care from anyone in Social Work or NHS.”

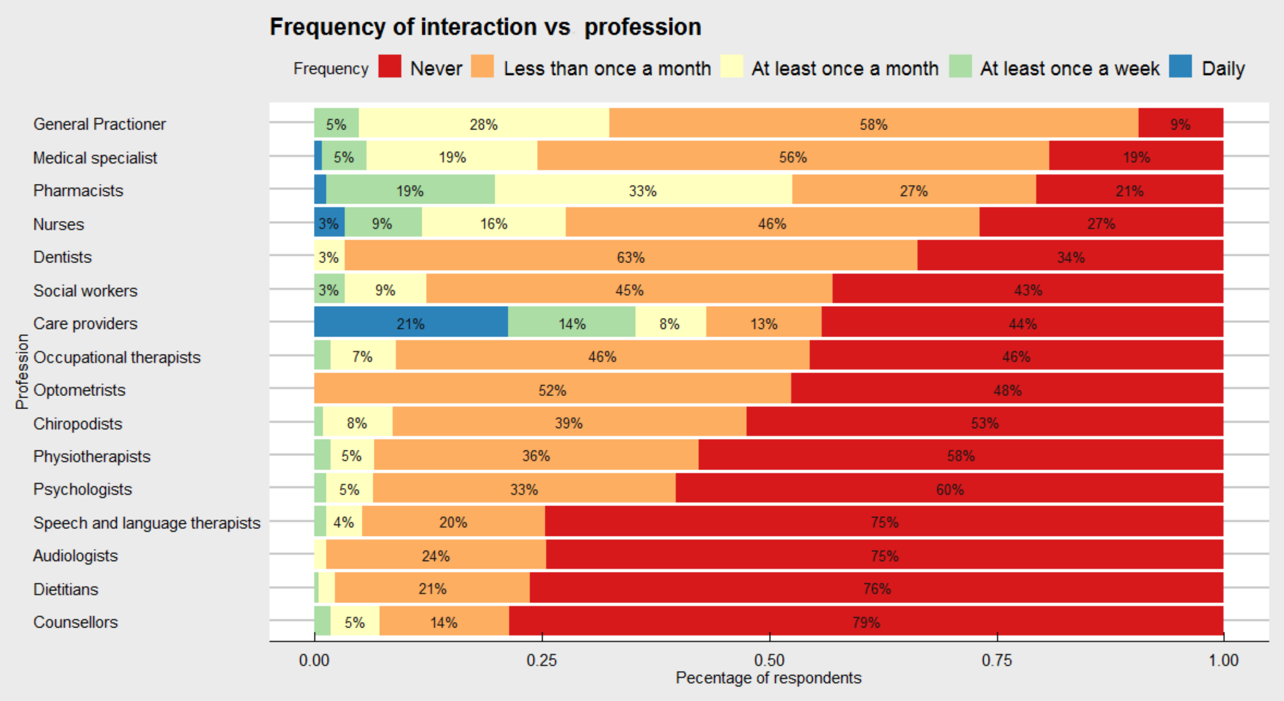
Strongly disagree

- “There is a general lack of support, let alone for tech stuff.”

Health and Social Care Professional Interactions

We explored the types of health and social care professionals that caregivers interacted with as part of their caring role (Figure 3). The results revealed that a particularly common point of contact overall was the role of general practitioners, where 27.5% (73/265) reported interactions at least once a month and 4.9% (13/265) reported interactions at least once a week. Semiregular contact was made by 58.1% (154/265) of caregivers, whereas 9.4% (25/265) of respondents reported *never* interacting with this professional group. Pharmacists were a professional group that commonly interacted with caregivers, where 79.3% (192/242) of caregivers reported at least some interaction. More specifically, this included 1.2% (3/242) of caregivers who reported daily interactions, 18.6% (45/242) reported weekly interactions, and 32.6% (79/242) reported monthly interactions. Conversely, caregivers were less likely to interact with counselors and dietitians, with 78.7% (177/225) and 76.3% (171/224) of caregivers reported that they never interacted with these professional groups, respectively. The frequency of reach of some health and social care professionals was notably high within specific subgroups of caregivers. For example, although 55.7% (136/244) of respondents of caregivers interacted with care providers, it was common that these were very regular interactions (52/244, 21.3% daily and 34/244, 13.9% weekly).

Figure 3. Frequency of health and social care professional interactions for caregivers. The x-axis represents cumulative percentage of interactions, whereas the y-axis represents the different health and social care professional groups Frequency of use was grouped into: (1) Daily, (2) At least once a week, (3) At least once a month, (4) Less than once a month, (5) Never.



Future Interests

When we asked caregivers about their priorities for caring, there was relatively little variance between many of the prespecified categories used (Figure 4). The most common priorities highlighted (ie, 10 of a possible 10) included: *checking in from distance* (65/185, 35.1%), *communication with health and social care professionals* (64/203, 31.5%), and *transport* (eg, help outside the house to move more easily and independently; 57/193, 29.5%). Interestingly, there was also a relatively strong need for activities of daily living (eg, sitting and sleeping; vision, speech, and hearing; and social engagement). Innovations regarding exercise and entertainment to help caregivers with their caring role were comparatively less desirable compared with other aspects, with 13.2% (26/197) and 14.9% (29/194) of caregivers stating this as a greater priority need.

We extended these questions to understand how caregivers make decisions about whether to purchase future technologies (Figure 5). Here, we identified that study participants most commonly allocated the highest desirability (ie, 10 of a possible 10) to reliability (107/220, 48.6%), ease of use (102/220, 46.4%), and accessibility (100/211, 47.4%). Comparatively, less important considerations were enjoyment of use (31/197, 15.7%), integration with other services (23/191, 12%), and design considerations (8/193, 4.1%).

Figure 4. Priorities for future technologies to help caregivers to undertake their caring role. Color indicates priority of need where 0=not a priority (violet) and 10=highest priority (maroon).

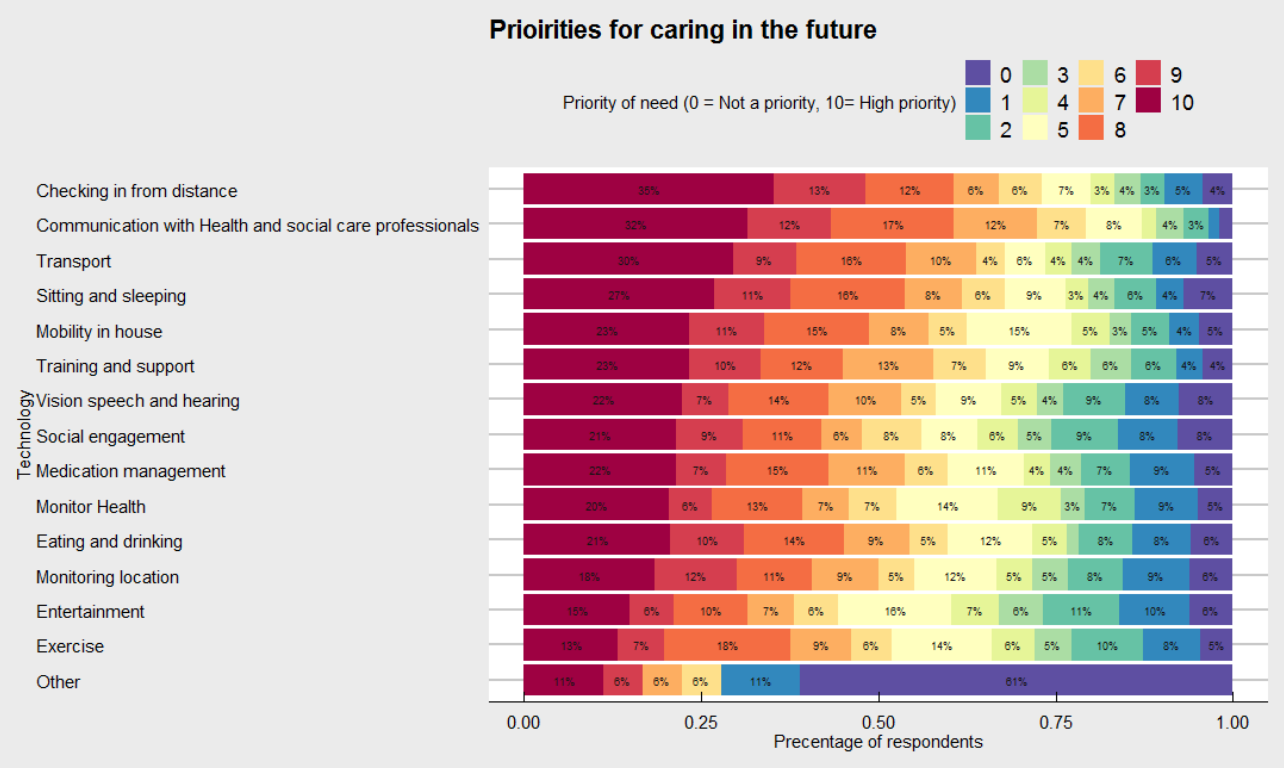
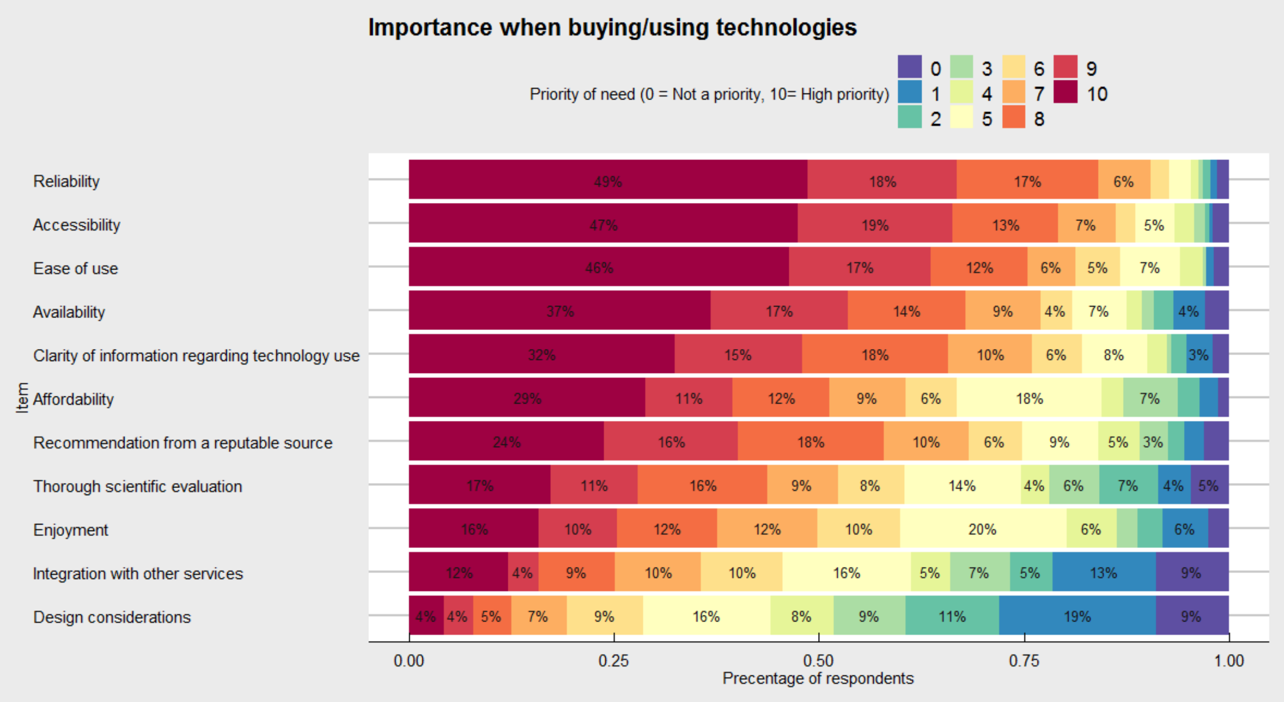


Figure 5. Priorities when deciding whether (or not) to buy future technologies. Color indicates priority of need where 0=not a priority (violet) and 10=highest priority (maroon).



Discussion

Principal Findings

We set out to improve collective knowledge on current and future technology use of caregivers, both for their own health and well-being, and the people they look after within the context of the United Kingdom. To our knowledge, our work is one of the largest surveys of its kind to focus specifically on the use of current and future digital health technologies to support the health and well-being of the UK caregivers and those cared for. Our sample was considerable in size, diversity, and level of detail recorded; caregivers varied in age, employment, gender, and conditions cared for. In agreement with cross-sectional evidence [3], our sample of caregivers was predominantly female; however, given sufficient sample size, it is of note that this finding may not always be paralleled across all age groups (eg, male caregivers are particularly common at the ages of ≥65 years [23]). The findings suggest that technologies play a diverse role in informal care settings where most, but not all, caregivers are largely positive about the potential. Such positivity is not without reservation, as technology can also be a negative force. Ongoing support is clearly lacking, and real-world value and implementation is limited as caregivers face challenges across cost, sustainability, availability, and reliability.

Limitations

Our study had several limitations. First, given that caregivers are often hidden within the society, selection biases remain challenging to avoid. For example, our self-reported ethnicity data reflect the UK national statistics, where 94% of UK caregivers identify as White [24]. Moreover, as critical questions remain regarding the extent of the additional challenges that ethnic minorities face, it is pertinent that both research and policy strategies continue to reach these groups. Most of our survey respondents were highly educated; however, this may not be representative of the general population. Work conducted by the New Policy Institute in 2014 (based on the Office of National Statistics Family Resources Survey) found that 70% of working-age people caring for 20 hours a week or more did not have qualifications above the General Certificate of Secondary Education level [24]. Our methods of recruitment (using existing social networks, such as Twitter) may also have encouraged specific conditions (eg, dementia and cancer) or populations (eg, greater number of years of formal education) to respond. Our postal replies were few, and we did not explore how individuals found our initial web link to the survey in detail. Nevertheless, our work still represented over 20 different conditions, and 14% of those cared for were under the age of 16. Understanding caregiver needs in more rare conditions remains vital [25]; however, it falls out of the scope of this work. Although the development of a survey promoted on the web has helped us reach many people in a relatively short time frame, those averse to digital health technologies may be underrepresented. There are also inherent biases associated with convenience sampling; our participants were predominately based in Scotland, reflecting our local links and networks. Very few of our participants were new to caregiving. Although the extensive experience of our respondents is advantageous for gaining long-term insights, further work is needed to understand how challenges differ within those who are new to caregiving, particularly with respect to information seeking. Finally, to ensure anonymity of responses, we are not able to explore geographic, socioeconomic, or deprivation indices in further detail: important avenues for future work.

Interpretation and Future Directions

There are several findings from this work that are pertinent to understanding caregiver demographics. Here, we build on technology use for caregivers by exploring in detail what makes caregivers receptive to technology across confidence, support, exploring health professionals involved, and the drive to look after their own health and well-being both now and in the future [26,27]. Most caregivers who responded to our survey regularly used smartphones, social networking sites, and computers or laptops to support their caring activities at least once a week (with many using such devices daily). This work adds to the current evidence that caregivers are not simply an *extension* of the health and social care service, but a diverse group given little attention and support [16]. Our results have demonstrated that caregivers do not just crave but also need much stronger and more meaningful links to our health and care professionals, which hold particular weight given the context of COVID-19 and risk of future pandemics. Technology could easily support such links, but the risk of rejection from professional health staff and caregivers could severely impact implementation. Careful, caregiver-led solution design is nonnegotiable if we are to support those most in need, including those who are isolated or have less experience in digital and health literacy. Particularly useful points of contact for this could include signposting and some limited support from: general practitioners, those working within professional caring roles, or a pharmacy setting.

This work highlights lessons in that regularity of use may not always represent perceived usefulness, for example, many caregivers make use of locator devices (eg, Google Maps and GPS) and laptops weekly or monthly (opposed to daily). It could be particularly fruitful to understand such relationships in more depth within future work and why many apps and technology solutions become left *behind*. Both digital divide and health literacy levels are important considerations. Despite sharing brief descriptors, concepts such as *Internet of Things* devices or *robots* can be alien to respondents and, accordingly, few participants reported use. Further work is now required to (1) ensure that caregivers are provided with knowledge and awareness of what technology is available; (2) achieve sustainable models of support; and (3) identify how research and policy can extend the utility of both new and existing technologies, including isolated or poorly represented groups.

Throughout the work conducted, there were several notable concerns raised about current and future technologies (eg, costs and timeliness of solutions), which aligns with other literatures [28]. Both our own findings and others [29-31] have highlighted the high degree of isolation that caregivers face. Successful innovation and technologies are strategies that can tackle this problem, including connecting caregivers to supportive environments, such as family, friends, and health and social care professionals. Furthermore, our work parallels both policy and research findings elsewhere (eg, in dementia technology charters, web-based resources, and the UK government policy documents) that technology should not replace human contact [32-34]. Given that a shrinking UK health care workforce appears all but inevitable [35], innovative solutions (both technology-based and otherwise) are required. This work highlights that caregivers need to be involved from concept initiation all the way through to the postevaluation stages.

Our work also informs state-level actors and health and social care providers. Caregivers demonstrated confidence in choosing technologies for their needs, but the need for support to use technologies was highlighted throughout. However, the delivery of this objective is complex. There are key questions regarding *who* should provide this support in the longer term. Although the potential for care providers and pharmacists to deliver technology supports is clear (ie, professionals who regularly interact with caregivers), careful consideration of workload, resources and training, and overall interest and acceptance is required. In addition, it is somewhat concerning that so few individuals are able to access the vital (and often preventive) support delivered by other professionals, such as counselors and nutritionists. The absence of access may not necessarily be associated with the absence of need. Perhaps indicative of the high need for technology solutions is that caregivers ranked *thorough scientific evaluation* relatively low regarding priority. Taken together, there is an urgent need to protect caregivers from purchasing unproven or unsafe technologies to bridge gaps in care, as highlighted in recent dementia reviews [36].

Finally, the collective message from caregivers is that having a wide array of unsupported gadgets (new or existing) cannot address core needs in day-to-day caregiving. Well-established technologies are still not reaching caregivers in a satisfactory form (eg, checking in for distance and communication tools). Caregivers frequently face health and well-being challenges alone, highlighted by a need for *communication with health and social care professionals* and are urgently looking for solutions regardless of the quality of science or how personalized technologies can be made. Continued co-design and consultation is required to improve current and future systems and technologies in a transparent manner, particularly given the significant reform and change that is well underway [37].

Conclusions

Digital technologies appear to be largely acceptable for caregivers. As we look to the future, this work suggests that caregivers are calling for solutions that augment the human touch, connecting caregivers to those cared for (including at distance), friends and family, and health and social care professionals. Quality is key: unsupported and unreliable technologies remain problematic (and may not enhance safety or well-being), where finding and using technologies is often compounded by time pressures. Technological developments remain fragmented, and it is critical that new horizons collectively deliver on empowering caregivers with skillsets, knowledge, and tools to help their day-to-day role. Moreover, this work reiterates the need for all stakeholders, including academics, policy makers, and practitioners, to recognize the invaluable role that caregivers play in communities and to ensure that this group become equal coarchitects of the emerging digital health agenda.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey example distributed to study participants (paper format).
[DOCX File , 248 KB - aging_v5i1e15413_app1.docx]

Multimedia Appendix 2
The number of different health conditions cared for across the sample.
[DOCX File , 14 KB - aging_v5i1e15413_app2.docx]

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Original Paper

Refining a Digital Therapeutic Platform for Home Care Agencies in Dementia Care to Elicit Stakeholder Feedback: Focus Group Study With Stakeholders

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Abstract

Background: Persons living with dementia require increasing levels of care, and the care model has evolved. The Centers for Medicare and Medicaid Services is transitioning long-term care services from institutional care to home- or community-based services, including reimbursement for nonclinical services. Although home care companies are positioned to handle this transition, they need innovative solutions to address the special challenges posed by caring for persons living with dementia. To live at home longer, these persons require support from formal caregivers (FCGs; ie, paid professionals), who often lack knowledge of their personal histories and have high turnover, or informal caregivers (eg, family or friends), who may have difficulty coping with behavioral and psychological symptoms of dementia. The Generation Connect platform was developed to support these individuals and their formal and informal caregivers. In preliminary studies, the platform improved mood and influenced caregiver satisfaction. To enhance platform effectiveness, Generation Connect received a grant from the National Institutes of Health Small Business Innovation Research to improve clinical outcomes, reduce health care costs, and lower out-of-pocket costs for persons living with dementia who receive care through home care agencies.

Objective: This study aims to evaluate information elicited from a series of stakeholder focus groups to understand existing processes, needs, barriers, and goals for the use of the Generation Connect platform by home care agencies and formal and informal caregivers.

Methods: A series of focus groups were conducted with home care agency corporate leadership, home care agency franchise owners, home care agency FCGs, and informal caregivers of persons living with dementia. The qualitative approach allowed for unrestricted idea generation that best informed the platform development to enable home care providers to differentiate their dementia care services, involve informal caregivers, improve FCG well-being, and extend the ability of persons living with dementia to age in place. Using the Technology-Enabled Caregiving in the Home framework, an inductive and iterative content analysis was conducted to identify thematic categories from the transcripts.

Results: Overall, 39 participants participated across the 6 stakeholder focus groups. The following five overarching themes were identified: technology related; care services; data, documentation, and outcomes; cost, finance, and resources; and resources for caregivers. Within each theme, the most frequent subthemes were identified. Exemplar stakeholder group statements provided support for each of the identified themes.

Conclusions: The focus group results will inform the further development of the Generation Connect platform to reduce the burden of caregiving for persons living with dementia, evaluate changes in cognition, preserve functional independence, and promote caregiver engagement between these individuals. The next step is to evaluate the effectiveness of the revised platform in the National Institutes of Health Small Business Innovation Research phase 2 clinical trial to assess the efficacy of its evidence-based interventions and market viability.

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KEYWORDS

dementia; technology; mobile app; home care; focus groups; qualitative research; digital therapeutics; value-based care; aging in place; caregiving

Introduction

Background

Owing to the degenerative nature of the disease, persons living with dementia require escalating support for their care and are increasingly vulnerable to institutionalization. The historical model for providing care to persons living with dementia has involved the heavy use of facility-based care at great financial and social costs to the Centers for Medicare and Medicaid Services and persons living with dementia and their families [1,2]. On average, the total per-person Medicaid payments for persons living with dementia aged >65 years are 23 times higher than Medicaid payments for other Medicare beneficiaries [1]. In 2020, the national cost of caring for people with Alzheimer disease and related dementias (ADRD) is projected to reach US $305 billion, with 67% (US $206 billion) paid by Medicare and Medicaid to cover health care and long-term care payments for people with ADRD [1]. As such, over 50% of persons living with dementia die in nursing homes or medical facilities [3].

Caregiver Roles for Persons Living With Dementia

Persons living with dementia overwhelmingly want to age in place and avoid institutionalization [4]. To live at home longer, persons living with dementia require support from (1) formal or clinical caregivers (ie, paid professionals), who often lack knowledge of persons living with dementias' personal histories and have high turnover rates, or (2) informal or nonclinical caregivers (eg, family or friends), who may have difficulty coping with behavioral and psychological symptoms of dementia (eg, aggression and anxiety) [5]. To address this need, the Centers for Medicare and Medicaid Services is transitioning long-term care services from institutional care to home- or community-based services, including expanding Medicare Advantage (MA) plans to include nonclinical services as reimbursable supplemental benefits [6].

The importance of those who engage with persons living with dementia to deliver such care services will become amplified as the demand for nonclinical home care services increases worldwide. Such expansion of services is certainly welcome, as evidence currently supports the benefits of nonclinical home care providers on patient outcomes [7]. Research findings demonstrate that nonclinical providers can reduce behavioral and psychological symptoms of dementia and health care costs through consistency of care and person-centered engagement [8]. However, home care providers reported a mean caregiver turnover rate of 82% in 2018 [9], which often translates into prevalent service disruptions. In addition, home care providers lack solutions to ensure that frontline nonclinical caregivers have the necessary knowledge of persons living with dementia's personal histories to implement evidence-based care methods [9]. Even with appropriate knowledge, nonclinical providers typically lack systems and processes to demonstrate improved clinical outcomes and cost savings [10,11]. This current struggle represents a promising opportunity for nonclinical home care providers to have access to user-friendly, easily implementable data collection tools.

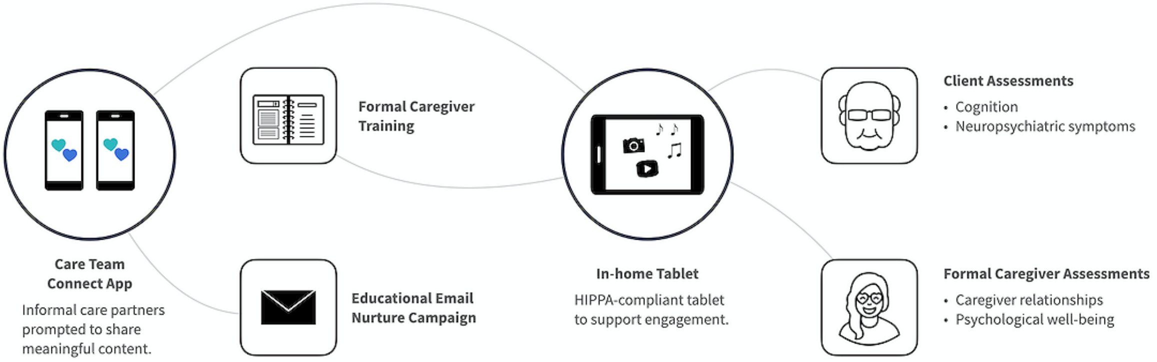
The use of information communication technologies (ICTs) by frontline care staff to enhance patient care and record clinical outcomes is common in hospitals, long-term care facilities, and skilled home health care [12]. However, ICT use by frontline caregivers in nonclinical home care is rare. A small number of providers are exploring solutions for family connectivity and remote care; however, there have been no known technology solutions for frontline caregivers that specifically address the use of digital therapeutics to enhance social engagement and data collection for both persons living with dementia and their caregivers.

Development of a Technology-Based Data Collection Tool

Generation Connect, a gerontology-focused software development company, developed a digital therapeutic platform to support informal and formal caregivers (FCGs) in the care of persons living with dementia (Figure 1).

The Generation Connect platform was originally conceptualized to enhance the informal caregiver's understanding of evidence-based nonpharmacological interventions and support FCGs in facilitating person-centered care. The Generation Connect platform focuses on the following three key technology initiatives to address barriers to aging in place: (1) the deployment of specially configured tablets to enhance persons living with dementia's engagement routines, (2) the development of an application to improve collaboration between home care providers and informal caregivers, and (3) the creation of assessment tools to streamline data collection related clinical outcomes for persons living with dementia and their caregivers. The Generation Connect platform is intended for its design to be used across all stages of dementia. Current users tend to be in the moderate to later stages of dementia; however, future efforts are being planned to broaden its usage for persons living with dementia in the earlier stages.

Figure 1. Generation Connect platform configuration. HIPPA: Health Insurance Portability and Accountability Act.



Generation Connect partnered with the University of Wisconsin–Madison to determine how care providers' use of computer tablets to engage persons living with dementia improved their mood and influenced caregiver satisfaction [13,14]. This preliminary research motivated further exploration of (1) complications saving client preferences, (2) the inability to digitally engage informal caregivers while maintaining the Health Insurance Portability and Accountability Act (HIPAA) compliance, and (3) the lack of systems for collecting clinical data.

To begin addressing the insights gained from these preliminary studies, Generation Connect received a feasibility grant funded by the National Institute on Aging from the National Institutes of Health Small Business Innovation Research (NIH SBIR) phase 1. The purpose of this grant was to develop an innovative technology solution that could eventually help improve clinical outcomes, reduce health care costs, and lower out-of-pocket costs for persons living with dementia who receive care through home care agencies. Through the NIH SBIR grant, Generation Connect sought to enhance the platform to address the following three key technology initiatives: (1) develop platform features that prompt care teams (informal caregivers and FCGs) to participate in evidence-based engagement strategies (eg, music, reminiscing, and socialization), (2) deploy HIPAA-compliant tablets to help care teams personalize these engagement routines, and (3) integrate clinically validated assessment tools into care routines.

Objectives

As part of the initial exploration and discovery phase of this grant, a series of focus groups were conducted with key project stakeholders, including (1) home care agency corporate leadership, (2) home care agency franchise owners, (3) home care agency FCGs, and (4) informal caregivers of persons living with dementia. The purpose of this phase of the project is to evaluate the information elicited from the series of stakeholder focus groups conducted by the Generation Connect design team to develop a better understanding of existing processes, needs, barriers, and goals for the use of a digital therapeutic platform by home care agencies and informal caregivers.

Methods

Overview

A formal qualitative approach [15] allowed for the unrestricted generation of ideas that would best position the Generation Connect platform to enable home care providers to differentiate their dementia care services, involve informal caregivers, improve FCG well-being, and extend the ability of persons living with dementia to age in place. Focus group participants completed an electronic survey before engaging in the focus group sessions, which included a section explaining the study and requiring their consent to participate.

Ethics Approval

This study was approved by the WCG institutional review board (IPCDCDA-2020).

Focus Group Participants

The following stakeholder categories represented the focus group participants:

- Franchise owners (organization A): it was a national home care agency with 565 independently owned and operated units. A partnership with Generation Connect in 2018 involved an alpha pilot to deploy the Generation Connect platform in 10 markets, which continues to be used in clients' homes. These owners also participated in testing the platform and recruited clients for this NIH SBIR project. These home care leaders had direct experience in implementing the Generation Connect platform as part of their home care services. These individuals provided unique insights into how the Generation Connect platform influenced clinical outcomes for clients and FCG, business outcomes, and FCG satisfaction and company culture.
- FCGs (organization A): it was a group of 15 professional caregivers with experience using the Generation Connect platform as part of the alpha pilot mentioned in item 1. These frontline care workers had direct experience using the Generation Connect platform among people with dementia. FCG often lacked a personal relationship with the people with dementia but had more dementia-related experience than other FCGs.

- Informal caregivers (receiving services from organization A): it was a group of 4 women caring for their fathers with memory loss who have experience using the Generation Connect platform as part of their loved one's care. These stakeholders could be seen as more directly reflecting the perspective of the person with dementia, as recruiting people with dementia was unfeasible for this study. Family caregivers have extensive, and often complex, relationships with the care recipient and other family members. These family members had direct experience using the Generation Connect platform as part of receiving home care services and provided a valuable perspective on how Generation Connect platform use could affect home care services.
- Franchise owners (organization B): it was a medical and nonmedical home care provider, with over 500 independently owned and operated units in the United States and 130 abroad. These home care leaders did not have experience using the Generation Connect platform but had agreed to participate in phase 1 pilot testing. They were specially selected by the corporate leadership team because of their past experience in implementing caregiver technologies and specialty dementia care programs. They can provide unique insights regarding the challenges of clinical implementation, business strategy, and impact on company culture for such programs. These owners also participated in testing the Generation Connect platform and recruited clients for the NIH SBIR project.
- Corporate leadership team (organization B): Generation Connect partnered with organization B to recruit owners for participation in phase 1 activities to deploy and pilot test the Generation Connect platform. Similar to organization A, they are one of the largest franchisors (≥650 locations) and have experience piloting caregiver technology initiatives across their franchise network.
- Corporate leadership team (organization C): a national home care franchisee, with ≥600 independently owned and operated units in the United States and nearly 480 abroad. Generation Connect had been involved with organization C on consulting projects involving senior technology, but the organization had no previous experience using the Generation Connect platform. As one of the largest home care franchisors (≥1100 locations), with extensive experience in implementing national tech initiatives, they can provide unique insights into moderators and mediators of widescale Generation Connect platform adoption across the franchise network.

Participant Recruitment

Participants with direct knowledge of existing processes, needs, and barriers related to dementia care in the home were purposefully selected to participate in the focus group sessions. For the corporate focus groups, Generation Connect sent an invitation to our primary point of contact from organizations B and C, inviting corporate leaders to participate. Both organizations are national leaders in nonmedical home care and have recent experience implementing technology initiatives at the corporate level. Our contacts recruited colleagues that provided the most helpful insights. It was an open invitation for corporate leadership within the organization. Corporate leaders from organization B helped recruit franchise owners from within the network to participate in focus group and product testing. For the franchise owners' focus groups, we invited all home care owners who opted to participate in phase 1 pilot testing. It was an open invitation to local franchisee leadership staff. Each organization had at least one director-level employee who participated in the focus groups. For the FCG focus group, home care leadership invited 17 FCGs with experience using the Generation Connect platform to be involved in the focus group; of the 17 FCGs, 15 (88%) decided to participate. For the informal caregiver group, each of the 4 organization A owners involved in phase 1 offered 1 family member with previous experience using the platform the opportunity to participate in the focus group, and all 4 accepted.

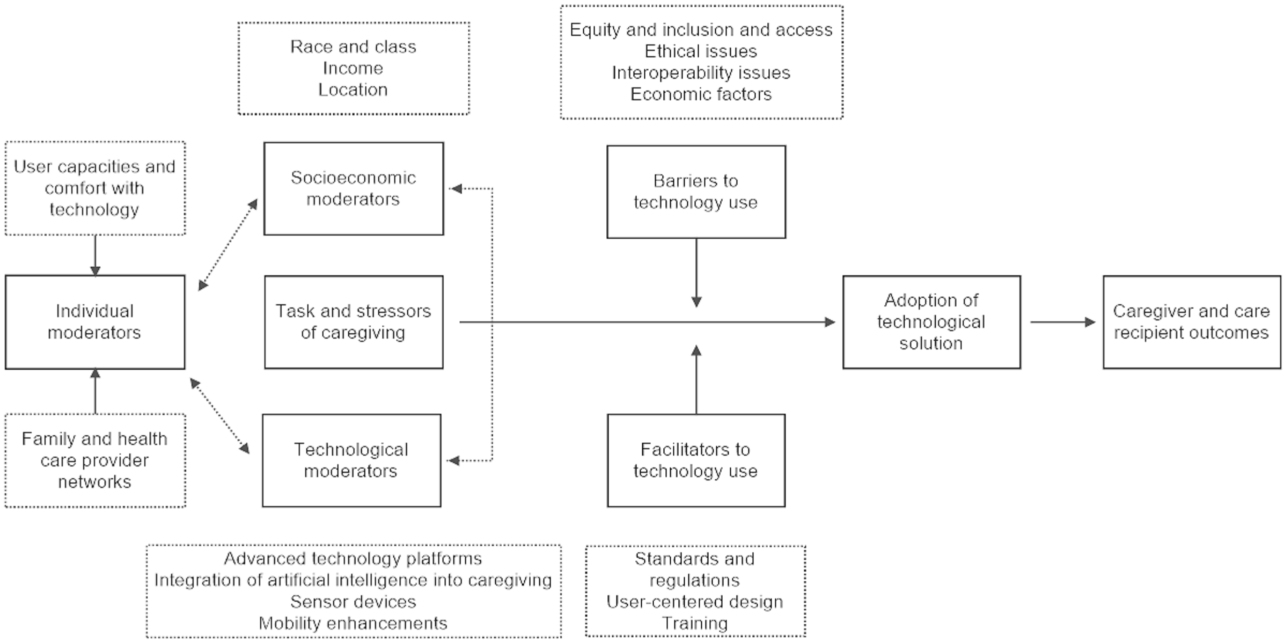
All participants from organization A, including franchise owners, FCGs, and informal caregivers, had firsthand experience using a pilot version of the Generation Connect platform. Although the franchise owners of organization B had no previous experience using the Generation Connect platform, they had experience implementing a variety of dementia care and technology initiatives.

Interview Guide Development

Interview guides for each stakeholder group were developed by the research team. Guide development was informed by Technology-Enabled Caregiving in the Home (TECH) [16], which is the theoretical framework that guides this research (Figure 2).

The TECH framework examines the characteristics that could influence FCGs' adoption of technological platforms that, in turn, can contribute to persons living with dementia and caregiver outcomes. Thematic model domains include (1) individual, socioeconomic, or technical moderators; (2) barrier or facilitator mediators; and (3) technology-related measurement issues. This model provides a *map of thinking* as the basis for broader adoption of caregiving solutions [16]. Influencing caregiving through such moderating and mediating pathways to improve caregiving outcomes has the benefit of promoting technological solutions throughout the system of caregiving.

Figure 2. Technology-Enabled Caregiving in the Home framework (adopted from a study by Lindeman et al [16]).



The interview guides were distributed internally for review, involving team members without clinical or domain knowledge, to ensure that they were easy to comprehend and interpreted uniformly. Then they were refined based on reviewers' feedback. This refinement process involved nonsubstantive improvements in readability and understandability to prompt unequivocal responses more directly from participants. The resulting guides were structured for 1-hour–long interviews.

Focus Groups

Between November 2020 and January 2021, the Generation Connect staff conducted a total of 6 focus groups with stakeholders. For confidentiality and proprietary reasons, focus groups with home care corporate leaders and home care franchise owners and case managers were conducted separately. This separation helped ensure that members of both stakeholder groups would feel more comfortable in freely sharing information about their company. Owing to the COVID-19 pandemic, all focus groups were conducted via a HIPAA-compliant version of GoTo's GoToMeeting, an internet-based meeting platform. Dates and times for interviews (conducted by MP or DD) were scheduled based on the convenience of each participant. The interviews of focus group participants generally followed the structure of the focus group guides and questions related to the themes relevant to each stakeholder group (Table 1).

Table 1. Focus group question categories by recipient.

Focus group question categories	Question category included in the recipient focus group			
	Corporate leaders	Franchise owners and case managers	Formal caregivers	Informal caregivers
Person-centered dementia care or care service	✓	✓	✓	✓
Social determinants of health	✓			
Approach to Medicare Advantage	✓	✓		
Caregiver staff		✓		
Tracking outcomes		✓		
Living with dementia				✓
The role of technology in client care	✓	✓		
Technology-assisted caregiving			✓	✓

Analysis of Interview Data

Focus group meetings were automatically transcribed by GoToMeeting. The transcript was reviewed, verified for accuracy and anonymity, and deidentified by the Generation Connect staff. All deidentified transcripts were then made available to the University of Wisconsin–Madison researchers through upload to a secure university network server to further control for data security and confidentiality. A general inductive and iterative content analysis approach was used to generate the development and identification of thematic categories from the interview data. These themes were derived according to the relevant TECH factors (individual, socioeconomic, or technical moderators; barrier or facilitator mediators; and technology-related measurement issues) and the various TECH variable domains within each factor. The inductive approach is a systematic procedure for analyzing qualitative data that are commonly used in health and social science research and evaluation [17]. An experienced qualitative coder (AG) independently coded all interview transcripts while developing a preliminary coding scheme to capture themes related to caregiver, patient and family, work system, and programmatic factors. Effort was made to ensure that the initial list of codes avoided overlap and reduced redundancy whenever practicable.

Once the transcripts were reviewed and coded, and all the codes and subcodes were compiled, they were transferred to another researcher (MG). The researcher then independently read the transcript to validate both the coding (ie, the interview content that was assigned to a code) and the list of codes. After the initial validation process, the researchers met to compare their coding results. The researchers sought consensus to resolve discrepancies in coder agreement to ensure more accurate coding; 100% consensus was achieved across all codes and subcodes. In the final stage of this coding process, the same 2 researchers again evaluated the extracted content within each code for consistency and were then forwarded to Generation Connect staff (MP) for review, which resulted in no additional changes and represented the final validation of the codes and subcodes and their application to the interview text. The final coding dictionary consisted of five main codes, with 40 subcodes across the main themes: care services, cost, finance, resources, data, documentation, outcomes, resources for caregivers, and technology.

This phase 1 study did not meet the criteria for an Applicable Clinical Trial; therefore, it was not registered on ClinicalTrials.gov.

Results

Overview

A total of 39 participants were interviewed during the 6 stakeholder focus groups. The following five overarching coding themes were identified and are presented here in order of frequency: (1) *technology related*; (2) *care services*; (3) *data, documentation, and outcomes*; (4) *cost, finance, and resources*; and (5) *resources for caregivers*. For each coding theme, the most frequent subthemes served as the key finding for this paper. In addition, after the broad themes and key findings are provided, a separate section titled *Other Relevant Findings* is offered to highlight content that was frequently elicited from a particular stakeholder group or that represented unique or noteworthy implications. Table 2 demonstrates the frequency with which the various themes and subthemes were represented and the extent to which individual stakeholder groups contributed to each.

Exemplar statements obtained through focus group transcripts are listed for each stakeholder group that offered feedback for a particular subtheme, to provide qualitative support for each of the coding domains. When necessary, interview participants' quotations were edited to remove nonsubstantive interjections or repetitive words or phrases or connect partial phrases that were eventually stated in their entirety.

Table 2. All identified focus group themes and frequencies.

Identified theme	Corporate (n=196), n (%)	Formal caregiver (n=94), n (%)	Franchise owner (n=222), n (%)	Informal caregivers (n=38), n (%)	Total (n=550), n (%)
Care services	53 (27)	22 (23.4)	47 (21.2)	12 (31.6)	134 (24.4)
Ability to react to changes	2 (3.8)	2 (9.1)	8 (17)	3 (25)	15 (11.2)
Addressing family needs	1 (1.9)	0 (0)	2 (4.3)	0 (0)	3 (2.2)
Assess and support cognition or mental health	12 (22.6)	0 (0)	6 (12.8)	0 (0)	18 (13.4)
Expanding care services	6 (11.3)	0 (0)	2 (4.3)	0 (0)	8 (6)
Individualized care	7 (13.2)	1 (4.5)	12 (25.5)	0 (0)	20 (14.9)
Maintaining patient in home	1 (1.9)	0 (0)	0 (0)	0 (0)	1 (0.7)
Patient and family engagement	15 (28.3)	2 (9.1)	12 (25.5)	1 (8.3)	30 (22.4)
Preparation for personal care rather than clinical care	4 (7.5)	0 (0)	1 (2.1)	0 (0)	5 (3.7)
Response to patient	1 (1.9)	17 (77.3)	4 (8.5)	8 (66.7)	30 (22.4)
Variability of care services	4 (7.5)	0 (0)	0 (0)	0 (0)	4 (3)
Cost, finance, and resources	33 (16.8)	3 (3.2)	44 (19.8)	2 (5.3)	82 (14.9)
Administrative burden	3 (9.1)	0 (0)	3 (6.8)	0 (0)	6 (7.3)
Cost issues	5 (15.2)	0 (0)	10 (22.7)	1 (50)	16 (19.5)
Cost options	11 (33.3)	1 (33.3)	1 (2.3)	0 (0)	13 (15.9)
Dedicated staff	2 (6.1)	0 (0)	5 (11.4)	0 (0)	7 (8.5)
Medicare Advantage or other programs	10 (30.3)	0 (0)	14 (31.8)	0 (0)	24 (29.3)
Need for resources	1 (3)	2 (66.7)	1 (2.3)	1 (50)	5 (6.1)
Turnover issues	1 (3)	0 (0)	10 (22.7)	0 (0)	11 (13.4)
Data, documentation, and outcomes	38 (19.4)	8 (8.5)	36 (16.2)	7 (18.4)	89 (16.2)
Demonstration of value	15 (39.5)	0 (0)	3 (8.3)	0 (0)	18 (20.2)
Demonstration of value (patience)	0 (0)	0 (0)	4 (11.1)	0 (0)	4 (4.5)
Documenting patient routines and incidences	1 (2.6)	2 (25)	1 (2.8)	7 (100)	11 (12.4)
Need to document outcomes	17 (44.7)	0 (0)	13 (36.1)	0 (0)	30 (33.7)
Need to document outcomes (standardization)	1 (2.6)	0 (0)	0 (0)	0 (0)	1 (1.1)
Need to document outcomes, with some limitations	1 (2.6)	0 (0)	0 (0)	0 (0)	1 (1.1)
Sharing information and resources	3 (7.9)	6 (75)	15 (41.7)	0 (0)	24 (27)
Resources for caregivers	15 (7.7)	21 (22.3)	31 (14.0)	3 (7.9)	70 (12.7)
Allocating caregiver services	2 (13.3)	0 (0)	7 (22.6)	0 (0)	9 (12.9)
Benefit of experience	0 (0)	6 (28.6)	5 (16.1)	0 (0)	11 (15.7)
Caregiver support and mentoring	0 (0)	0 (0)	5 (16.1)	0 (0)	5 (7.1)
Need for training and education	13 (86.7)	15 (71.4)	14 (45.2)	3 (100)	45 (64.3)
Technology	57 (29.1)	40 (42.6)	64 (28.8)	14 (36.8)	175 (31.8)
Acceptance of technology	6 (10.5)	3 (7.5)	7 (10.9)	1 (7.1)	17 (9.7)
Acceptance of technology and barriers to use	4 (7)	2 (5)	1 (1.6)	3 (21.4)	10 (5.7)
Acceptance of technology, but not universal	0 (0)	0 (0)	1 (1.6)	0 (0)	1 (0.6)
Benefit of family contributing content	4 (7)	1 (2.5)	3 (4.7)	3 (21.4)	11 (6.3)

Identified theme	Corporate (n=196), n (%)	Formal caregiver (n=94), n (%)	Franchise owner (n=222), n (%)	Informal caregivers (n=38), n (%)	Total (n=550), n (%)
Benefit of personalized content	7 (12.3)	11 (27.5)	11 (17.2)	3 (21.4)	32 (18.3)
Benefit of technology	19 (33.3)	10 (25)	20 (31.3)	1 (7.1)	50 (28.6)
Benefits of technology, mostly but not always	0 (0)	1 (2.5)	0 (0)	0 (0)	1 (0.6)
Benefits of technology, with some limitations	1 (1.8)	0 (0)	5 (7.8)	0 (0)	6 (3.4)
Challenges of technology	5 (8.8)	9 (22.5)	9 (14.1)	1 (7.1)	24 (13.7)
Expanding personalization options	2 (3.5)	3 (7.5)	1 (1.6)	2 (14.3)	8 (4.6)
Expanding technology	3 (3.5)	0 (0)	5 (7.8)	0 (0)	8 (4.6)
Integrating technology into standard care	6 (10.5)	0 (0)	1 (1.6)	0 (0)	7 (4)

Theme 1: Technology Related

Overview

The purpose of the focus group interviews was to elicit feedback that would ultimately help guide the development and refinement of a tablet-based innovative technology (the Generation Connect platform) to be used with patients with dementia. As a result, it is not surprising that technology-related content was the prevailing thematic area (occurring 175 times). The stakeholder focus group participants provided feedback about a wide range of issues related to technology—from the degree of acceptance by patients, family members, and caregivers to its benefits and challenges and the positive implications of expanding various aspects of technology into patient care activities. As indicated by the listed subthemes, this theme is characterized by a variety of categories, including desire to involve technological advances as an expected part of standard patient care.

Key Finding 1: Benefits of Technology

One-third of all instances of *technology-related* content were specific to the benefits of technology, that is, this subtheme tended to illustrate the extent to which various technological programs enhanced patient care or family engagement. The *benefits of technology* subtheme was primarily endorsed by corporate leaders and franchise owners and case managers, although FCGs also viewed it as a benefit. It was rarely mentioned among informal caregivers, which is more a function of the questions asked rather than not accepting or having a negative view of technology.

Key Finding 2: Engagement, Training, and Impact

As for the corporate leader focus group participants, they were asked to speak to making engagement between the caregiver and the person with dementia part of the care plan. The specific question was “Is [engagement] something you guys have seen in your network or something that’s on your radar as part of the training and approach, you guys are taking the dementia care?”

> *How do you get people to personalize care, period, and to learn and to make better days? That’s the thing. And it’s the hardest thing, but if you can figure it out with this app, we’re, we’re interested.* [Corporate Staff 2, December 3, 2020]

The same corporate leader reflected a similar sentiment when asked to consider their in-house training resources and their strategy for not only developing proprietary resources but also leveraging third-party resources to supplement the training:

> *But we have a lot of caregivers that are learners. They, just, they wanna learn more, want to know more. So that’s why we’ve offered this additional platform, that was third party. And we’ve also, we’ve put it sort of on demand, so that they can take it whenever. There, it’s convenient for them, and in any setting.* [Corporate staff 2, December 3, 2020]

When franchise owners were asked about an aspect of dementia care that they were most proud of, one responded:

> *So, I would say that’s the thing that we’re probably most proud of...is the way that we have been able to engage clients and their family members...In some cases, family members who really weren’t that involved became much more involved, um, as a result of this, of this program. So, we have family members who, you know, maybe lived at a farther distance, and this became the catalyst for them really becoming involved in the care. And just the checking in on their loved one, and it gave them a way to...create memories, by sharing old memories, and then seeing how their loved one reacts to it by the entries into the [Generation Connect] platform. It was just a really, I’m very proud of the way that this tool has helped, not only the clients, but also the family members to really create new memories and have a memorable experience.* [Franchise owner and case manager, location C, November 11, 2020]

Key Finding 3: Challenges Limit Benefits of Technology

There were also a few occasions (n=7) when various stakeholders acknowledged the benefits of technology but additionally admitted that the realization of those benefits can be somewhat undermined by particular challenges that limit their effects:

> *I mean, we do a lot of education on the care team and who all that involves and as family caregivers there’s the primary and the secondary caregiver and then even those, beyond that, that can support in various*

> *ways. So, I would say that it's probably done in more like an educational forum and then I would agree, that homecare tablet really does allow for more family connection even just...the social aspects. Maybe it's not helping with the direct care but just connecting the families. We've seen a lot of great success with that.* [Corporate staff 1, December 3, 2020]

> *Again, it really depends...on the caregiver or client technology. If we're able to do a HIPAA compliant we are definitely using that, but in some cases they don't have an iPad working, we are using the caregiver cell phone which sometimes the caregivers have technology glitches on their end and maybe you can't get it a Zoom meeting going.* [Franchise owner and case manager, location H, November 11, 2020]

> *My clients that I worked with and did a lot of zooming with, I had to keep educating the family, like how to get things to work, right, because they got a little bit dependent on me being able to know how to do this. And they wanted to be able to use it too. And I have to keep telling them, OK, this is where you go for this. It was hard sometimes to keep saying it...There were times that my client was just got tired quickly.* [FCG, location A: CG 3, November 12, 2020]

However, it is reassuring that the various benefits of technology were considered prevalently among stakeholders.

Theme 2: Care Services

Overview

Unsurprisingly, content related to patient care services was frequently mentioned (134 times) throughout the discussions with all stakeholder groups, as improvements in patient care underlies the objective of this technology-based project and these services. In addition to general aspects of caregiving practice, this theme encompassed attributes of clinical care, including the use of formal cognitive or mental health assessments. The care services that were mentioned also extended to family members and efforts to improve their interactions with the patient.

Key Finding 1: Patient and Family Engagement

Input from all stakeholder groups informed this subtheme and identified the variety of ways in which engagement with patients and families took place. Such activities range from a thorough review of the patients' care plan with their families to helping family members interact with their loved ones with dementia, either through direct involvement or through technology:

> *Specifically, we walk through the whole care plan and all of the activities that we're going to do to massage and exercise that cognition while also taking care of all the ADLs and the IADLs that we have to manage during that visit. Then we ask the family, basically, to enter into an agreement or a contract with us at that, I understand, this care plan, and I understand that this is different.* [Corporate staff 1, February 2, 2021]

> *We've tried to use that meet and greet kind of program that [Location G Owner 7] was talking about. But we have found that every time we set up, know, a plan or rule that says, "that's what we're going to do," it doesn't work…If we have a real serious dementia situation...that it's going to be challenging, then we absolutely will have [Location B Dementia Specialist] go there and introduce and even stay the whole first shift with that caregiver, in order to make sure that the transition works.* [Franchise owner and case manager, location B, January 22, 2021]

> *So, she was going through a lot with her family, was going through a loss. I wanted to make sure that it was truly the family agitating her, and not just her demeanor. Over time, once I started to realize what exactly was agitating her and making her days more difficult, I initially started by bringing it up with the office...But eventually, I did start to have some discussions with [family], just to let them know that, obviously, their intentions are in the right place. But...it's very difficult for them to see sometimes the repercussions of the things that they're saying, the things that they're doing, especially when their family member is in a facility or is far away because they might see them for a few minutes, but who's there for the rest of the day. So, thankfully, I've, I've gotten a little bit better with being able to address those things with them because I have created a really good relationship with the family.* [FCG, location E: CG1, November 12, 2020]

> *I think, with my sister living in Texas, it would have been great, as [Location A: Family 1] said, to comment back, to be able to have a conversation with a caregiver. The other thing is that it would have been super helpful to know which caregiver posted what comment about my mom. Because, that would have helped us to figure out who's using it, and who's not.* [Informal care partner, location C: family 1, November 17, 2020]

Key Finding 2: Response to Patient

All stakeholder groups contributed information that was relevant to responses to patients, although corporate leaders mentioned this only once. This subtheme could apply to either caregivers' and family members' responses to patients (Table 3), with the objective of interacting with patients in a manner that does not exacerbate the patients' emotional state or result in family members' anxiety.

Table 3. Direct quotes responding to the patient from the caregiver and family member perspectives.

Staff	Caregiver response to the client	Family member response to the patient
Corporate staff	None	“So, a lot of time, and I think that’s what makes our cognitive support program special, that we really do work and educating the family. Through that process, but that also might mean that they’re not willing to accept that their loved one needs to be in this type of receiving this type of care. So, there’s a lot of just human elements that we’re dealing with in this as well.” [Corporate staff 1]
Franchise owner and case manager	“You know, it’s been nice to have access to an engagement tool where we can engage in a different way with our clients. We’ve had a couple particular situations where the caregivers have really embraced the concept of the iPad and have had one-on-one training with [Cofacilitator] from Generation Connect, which has been really awesome. And really helped them to develop and get a better understanding of how to really use the iPad to better engage the clients and just seeing the caregiver’s just come up with more creative ideas of how to use the iPad.” [Franchise owner and case manager, location B]	“We do get, sometimes, you get [a patient] who is just so resistant and the family member gives up. That mean, you know, the care recipient only wants that family member around them, uh, attempts to throw everybody out. And the family member just decides that it’s not worth, the hassle.” [Franchise owner and case manager, location B]
Formal caregiver	“So, what I try to do is, I try to redirect, I have a patient now. Who, she’ll tell me, did my husband died? And I will tell her, yes. I heard he was such a jokester, why don’t you tell me about a joke? And even though she, it’s kind of like she’s reliving the grief every time to hear that she died it’s bringing up happy memories, uh, know how he was when he was alive.” [Formal caregiver, location C: CG[a]2]	“The client’s family. Daughter in-law and son she lived with were very well educated. He was a professor. She was a registered nurse. And when I would come, they would argue with her all the time, and it made me feel like I was the bad guy because I would go along with it. If she told me, ‘the moon was made of green cheese,’ but they would argue all the time with her. And I know, [my manager], she gave them lots of videos and lots of links to look at. but they just wanted nothing to do with that. If they were there the whole time that I was there with them, I was exhausted mentally and physically, and I mean there were times I left there crying, because I was so upset with them. And then, the client that I had just before this one, I couldn’t have had a better support system with a son and daughter-in-law, I mean, it’s just phenomenal. She was a teacher and I forget what he did, architect. But, you know, I just, yeah, I just feel the mind has to be open to the heart or vice versa to be able to understand the daughter of my client now.” [Formal caregiver, location A: CG2]
Informal care partner	“Building on what [Location F: Family 1] said when I first noticed changes in my dad. I wanted him understand things logically. So, I would argue with him and try to make him see my point of view, which only led to not good situations. And my case worker through [home care company] sort of suggested to redirect. If we’re talking about something, mentioning something else, can redirect the conversation’s show that his mind would go on something else, not what we were talking about, and gradually, I learned to just go with the flow.” [Informal care partner, location E: Family 1]	“I did a little bit of reading, but to me, it just started feeling that [it] was the only choice, you know, because I really wasn’t interested in having an argument with my dad, you know. I didn’t need to win him over to my point of view. So, I think that was just a little bit, for me, it just seemed like a natural thing to do. I think my sister, I think she, just, over time, also saw that there wasn’t any percentage in it...we were not able to convince him of this factual thing, or that actual thing, and so I think she’s, that, just over time, she also kind of, I don’t know, maybe she saw me do it, but it also could just have come to her. She just has a different personality. She’s a more, she’s a more logical, analytical person so that you know that was her, her go-to’s – we’ll lay out the facts. I have a different way of being in the world. And so, I’m more interested, I’m more looking like, ‘well, what’s, you know, what’s the relationship here, what’s connected?’” [Informal care partner, location F: Family 1]

[a] CG: caregiver.

Theme 3: Data, Documentation, and Outcomes

Overview

Corporate leaders and franchise owners and case managers were much more likely to offer information about *data, documentation, and outcomes* than FCGs and informal care providers. In total, all stakeholder groups referenced this theme 89 times. Overall, such feedback related largely to the use and value of cataloging changes in patients’ mood or behavior to evidence the effects of treatment. However, there was also an interest in communicating about sharing information and resources and in factors that can undermine such sharing to caregivers or family members.

Key Finding 1: Need to Document Outcomes

This subtheme reflected the same pattern of responses as the overall thematic category, with only the corporate leader and franchise owner and case manager stakeholder groups having input about the *need to document outcomes*. Much of this feedback was elicited from direct questions about efforts to quantify patient care outcomes and the limitations of such efforts:

> *Our operating system is the one that every home care company uses, and so we track a care plan and we track the tasks that are done every day. But where the outcome is...the seniors' needs, or goal, and the family's goal. And that's an, a text box. And so, that's one issue where we're, you know, we can't really match what the goal is with the "what's happening."...also the way our systems are set up – they're not built, for pulling outcome data, [and] it's hard to track hospitalizations when there's nowhere to capture where, when they had their last hospitalization before they became one of our clients, for example.* [Corporate staff 2, December 3, 2020]
>
> *We track incidents and falls for the Department of Health. We have to have an incident book if somebody falls or something happens. So, we try to track those to see, you know, just for that reason, clearly, if somebody is falling a lot, we try to figure out why and make changes on it, you know, so, we'll just keep track of it in our system, client file. No, that's about it.* [Franchise owner and case manager, location G, November 11, 2020]

Key Finding 2: Feasibility of Using Technology to Document Outcomes

Although there was prevalent recognition of the utility of outcome measurement, 1 focus group member brought up a specific constraint relating to this objective:

> *But, right now, so we actually input into our operating software, ways that they could track...mile markers...But our Franchisees actually have to go in and check the mile markers. And then they have to do the assessment repeatedly, so that they can see where they're at on the mile markers. And we actually have care plan associated with all four of those different ability levels that a client will go into, based on where they're at in the journey, based on their ability level, and what they're likely able to do, and what they're likely not able to do, based on their disease progression. The problem is tracking. So, right now, to [corporate staff 4]'s point, I can't get that information to a family unless our franchisees regularly monitor assess and are input that information into our software.* [Corporate staff 1, February 2, 21]

In addition, when questioned about the potential for standardization of assessment forms in the system, as a means to consistently compare among franchises, it was admitted by one stakeholder that standardization was not feasible at the present time: "But there is no standard assessment form either" [Corporate staff 2, December 3, 2020].

Theme 4: Cost, Finance, and Resources

Cost, finance, and resources represents the most unique theme (with 82 identified instances), where most of the relevant content was obtained from corporate leaders and franchise owners and case managers. In addition to the issues most relevant to this theme, other related content involved discussions about the benefit of having staff members who are dedicated to specific activities or responsibilities, factors influencing staff turnover, and MA and other reimbursement programs, most of which involve some amount of administrative burden.

This most frequent subtheme was derived from focus group questions related directly to the topic of MA. Such questions elicited quite elaborate responses related to the pros and cons of this reimbursement policy, which is illustrated most thoroughly with the following corporate leader stakeholder feedback:

> *I mean, the biggest issue right now is just reimbursement, and hours, right? So, you're exactly right, Your last comment. It is true. There's, we're seeing more demand than we've ever seen. Why in the world would we waste the time on Medicare Advantage when the reimbursement isn't? We can't pay our caregivers, so there's no margin. You're getting 20 hours, a quarter of care, which really doesn't have any sort of impact on outcome anyway. The only reason that we're even, and we do participate in a few Medicare Advantage plans, but ultimately, the only reason is to collect the data on why shouldn't we do it anymore.* [Corporate staff 3, February 2, 2021]
>
> *We, actually, I should say we billed, but did not get paid through some Medicare Advantage plans. And the motivation is, it's really, it's kinda like long term care in my mind. You're billing a policy that somebody has paid into and it helps them get the care they need, right? That type of thing. We had, previously, probably, most of the people on here don't do this anymore. We had done an assignment of benefits or policies and we're phasing that out. Some of them, you know, obviously will keep the ones that we still do an assignment of benefits for, but we won't be doing that anymore, because an insurance company will always pay their member before they'll pay us. So, that's one of the reasons we're phasing it out. But I think the idea behind it is it gives care to people that might otherwise not be able to afford it or might not even want - if they understand the benefit. It might help them remain independent and at home longer, if they utilize those benefits that they have.* [Franchise owner and case manager, location F, January 22, 2021]

Theme 5: Resources for Caregivers

Unsurprisingly, content related to patient care services was frequently mentioned during the stakeholder discussions (70 times), as improvement in patient care is the objective of this technology project and these services. Despite the different subthemes, the concepts within this theme universally highlighted the importance of training and support as a key function in maintaining the ongoing use of the Generation Connect platform.

Despite the general view that technology has its uses and advantages, it was evident from focus group responses that home care provider staff and family members have a *need for training or education*, especially in relation to technology. Although there were particular questions designed to elicit information about education or training needs, some of the content was forthcoming naturally when describing other aspects of patient care. The need for training and education was endorsed relatively evenly across corporate leaders, franchise owners and case managers, and FCGs; however, informal caregivers also provided relevant feedback about their need for dementia-related knowledge. Table 4 details the perspective of the focus group participants related to training and education related to technology and caregivers or family members' knowledge about dementia.

Table 4. Direct quotes responding to the need for training and education related to technology or knowledge about dementia.

Staff	Training or education related to technology	Training or education related to caregivers' or family members' knowledge about dementia
Corporate staff	"But I do know that that the caregivers play a big role and there's a lot of training that the office does for the caregivers to say, you know, this is what the tablet is. This is how you can engage. And the caregivers, I think there's an app specifically for the caregiver on the tablet, so they're interacting with it regularly for like things like clocking in and out, and those types of things, so that automatically I would imagine a lot of times prompts engagement too with the client, because the caregiver's interacting with it so regularly. I think another neat function is that the tablet has like scrolling pictures on it, so when it's charging even, it's kind of like a rotating picture frame. So, I think that that in and of itself to kind of prompts interaction with it, especially if there's a new photo that they haven't seen before. But I would imagine for those living with dementia, probably is more caregiver interaction." [Corporate staff 1]	"I would say that another addition, though, to the proprietary training following the Alzheimer's Dementia Care evidence-based practices was about assessments, which we always do, but this training that we've updated, took that to another level and sort of explained how important it is. That's what we've always explained, that it is important. But now, we've actually said, here's how we can do it." [Corporate staff 2]
Franchise owner and case manager	"I think the biggest thing for us is just continuing to keep the education piece on all staff. So, our frontline workers being trained in dementia care, because you never know when you're going to have an opportunity, where current client, they're taking care of, starts experiencing, signs, and symptoms. So, you know, I think, the, earlier we catch it on, then, the better partnership we have with the frontline staff and the families. And that's kind of a goal that I've been doing in the community, you know, barring this year, is educating people and, you know, trying to bring technology into it." [Franchise owner and case manager, location H]	"Now one of the things we're very proud of is the fact that we do a lot of one-on-one dementia care. I'm a certified dementia trainer with the Alzheimer's Association, so all of our caregivers go through training with me before they can put out in the field. We also have great mentoring programs." [Franchise owner and case manager, location D]
Formal caregiver	"So, we've just had a lot of success with it. The only difficult part has been making it work with providing links for the family. I, I don't know if maybe there's some type of re-education that can go on with the family, and using the care team Connect app. Or if there's just...because I, I navigate the relatively well. So I don't typically look into it. I don't know if you guys have like a tutorial section of the apps, that the family would be able to use to educate themselves more on how to navigate the app. But I know that sometimes, they've had difficulties, so, they've had a hard time finding where to upload photos, where to click the link, so that they can join Zoom calls, But, but, overall, I mean, the Zoom calls and face timing has gone really, really well." [Formal caregiver, location E: CG[a]1]	"So, thankfully, I've gotten a little bit better with being able to address those things with them because I have created a really good relationship with the family. It kind of has fallen back on me. It was just having those conversations with them. Sometimes it works, sometimes it doesn't. It's kinda one of those hit and miss things, but a lot of it falls back, just to the fact that the families usually just don't have the amount of education that we do, and aren't always open to the education that we can give them, just because they don't, they don't really see the, the depth, that it really has. They don't see how much we've actually had to learn about it. They only see a surface level of us telling them, that, their actions are making the family upset. Your words are making them upset, then they get offended. So, I feel like, I feel like if I had more resources to be able to give them more resources to be able to direct them to, it would make things a lot easier. I just said that resources were really important for them." [Formal caregiver, location E: CG1]
Informal care partner	"Would you be able to load videos like a video of my grandson running through the yard because I have not been able to figure out how to post a video? I can do photos, but I have not figured out videos...I just need a lesson." [Informal care partner, location A: family 1]	"So, I do think that there's so many things about my parents getting older and having health problems, and these mental problems, and all of these things. And I, often, my sister today, we'll just look at each other, will say, we cannot be the only ones, we're not the only ones. And yet, it's so hard, it's so hard to find. Where is that training? Where are those resources? It is, it's not, it's not at all easy, and, as this disease becomes, I think, at some point, it will be epidemic. We're going to live, everyone is going to live so long that our population is going to be filled with people who have this disease. And maybe just the sheer volume of folks will help bring. Bring this topic and, and these, this, this training, and these ideas more into the mainstream, I have to say, I, I was very uncomfortable telling anyone that My dad has Alzheimer's, at all for...I felt a lot of shame about that, which is really unfortunate." [Informal care partner, location F: family 1]

[a]CG: caregiver.

Other Relevant Findings

A number of other issues warranted discussion because they were identified frequently from a particular stakeholder group or else represent unique or noteworthy implications. Multimedia Appendix 1 summarizes these issues by stakeholder group and provides exemplary quotes.

Discussion

Principal Findings

The focus group findings highlight the complex and dynamic implications of providing care for persons living with dementia in their homes. More importantly, this study contributes to the growing literature on how technology can support care for people with dementia living in the community [18,19] and the importance of a user-centered design approach [20]. Overall, the stakeholder group participants share a widespread belief about the benefits of technology in general and about the Generation Connect platform, specifically with regard to the platform's support efforts for caring for individuals with dementia in their homes. In general, this finding supports the benefit of technology acceptance for promoting technology use [21-24]. It is clear that in this case, familiarity breeds acceptance, with many FCGs reporting using the Generation Connect platform during their shifts. In doing so, they tended to notice a range of improvements in client behaviors and client relationships. Our results reinforce earlier findings suggesting that direct interaction with technology is associated with increased familiarity [25] and that increased engagement is related to improved outcomes [26]. Most importantly, FCGs believed that iPad use helped them connect with clients and facilitated enjoyable experiences. These results were found although the Generation Connect platform was largely used with clients in later stages of dementia and with more severe symptoms.

Corporate members and franchise owners were particularly enthusiastic about the possibility of providing individualized care, and the platform under development reinforces this approach with its personalized content and ability to expand patient personalization options. Such results support the key value of personalization when designing technology for people with dementia [27], which is associated with improved social engagement, mood, activities of daily living, and the caregiver and participant relationship [14,28,29]. More generally, the direct involvement of key stakeholders aligns with recommendations from an earlier position paper calling for the direct involvement of stakeholders when designing technology for people with dementia to support meaningful use [18]. However, formal and informal caregivers have somewhat different opinions about the benefits of individualized care on patient outcomes in the Generation Connect platform. FCGs considered most of the app features to have potentially positive implications. However, the ability to routinely share updates with family was not believed to be as important as other platform characteristics. This finding may represent an area for further consideration or exploration to understand why this feature of the Generation Connect platform was not as widely accepted. Informal caregivers' opinions were similar, in general, about the benefits of the Generation Connect platform regardless of how often they used it. Understanding the advantages of individualized care seems an essential issue for convincing FCGs to adopt it into their routine care practice.

Despite the general acceptance of the Generation Connect platform, challenges need to be considered and addressed for broad and successful adoption. For example, a noticeable perception from informal caregivers was that less frequent users tended not to see a difference in caregiver interactions. This finding suggests the need for more direct communication with informal caregivers and even FCGs about the potential immediate and sustained benefits of the Generation Connect platform that can be derived from repeated use of the technology. In addition, acceptance of technology was not universal. Oftentimes, patients' use of the Generation Connect platform was determined by their previous comfort with technology, but family members certainly indicated that they could play an important role in assisting patients so they could benefit from engaging with content on the device.

Feedback about challenges and limitations to the benefits of technology largely reinforced the need to provide informational resources to mitigate the influence of knowledge deficits. Across the stakeholder groups, participants generally understood that education or training is necessary to better prepare caregivers for the broader use of technology and that it would be beneficial for some family members to receive similar content. In particular, corporate staff and franchise owners consistently expressed a belief in the importance of training to ensure that FCGs can provide appropriate and clinically valuable care to individuals with dementia, which could include patient engagement through technology. As a result, strategic training efforts are required to incorporate the Generation Connect platform into standard care practices.

Although it is feasible to address many of the identified technology-related challenges and shortcomings through additional education, cost remains a relevant limiting factor. Identified cost issues ranged from insufficient reimbursement for care services to the financing of technology hardware and internet services. However, external environmental changes targeting expanded broadband access, or increasing technology affordability and accessibility, may reduce cost burdens.

Finally, corporate members and franchise owners considered patient outcomes and the documentation of such outcomes as worthy of investigation, which can be aided by the Generation Connect platform. However, feedback suggests that corporate members may require more direct evidence of the benefits of using the Generation Connect platform to record and track client outcomes before committing to the technology. Franchise owners, on the other hand, not only recognized the importance of tracking client outcomes but also were more likely to already be engaged in such activities.

Strengths and Limitations

The focus groups conducted for this study phase provided important insights into the mindsets of various key stakeholders about the viability of using tablet technology and the Generation Connect platform to facilitate approaches to reduce ADRD symptoms and strengthen caregiver and persons living with dementia engagement. However, the number of focus groups was limited, and many of the focus group participants had prior experience using the Generation Connect platform. This purposeful participant selection was considered necessary, given the objective of this project phase to elicit feedback about the Generation Connect platform that would help guide its construction content refinement and expanded adoption.

In addition, response bias is possible because of the stakeholder focus groups. However, Generation Connect staff attempted to mitigate potential bias by (1) using a standardized interview protocol emphasizing that the forums were meant to elicit feedback that should relate both to positive and negative experiences and (2) structuring focus groups to control for the effects of organizational hierarchy (eg, franchise owners were provided separate forums from FCGs who may work within those franchises). Finally, more comprehensive feedback from the FCG focus group could have been attained through an intentional recruitment strategy that included FCGs who declined to use the Generation Connect platform when presented the opportunity, to compare to the feedback from FCGs with experience using the platform. Similarly, a few home care franchises failed to operationalize the Generation Connect platform in the pilot testing session. Including these individuals in the focus group could have resulted in more comprehensive feedback and insights into the limitations on or barriers to the adoption of the platform at the franchise level.

Conclusions

It is encouraging that the Generation Connect platform can help address many of the issues identified through stakeholder focus group interviews. Further development of the Generation Connect platform capabilities for nonclinical home care will be informed by stakeholder feedback to reduce the burden of caregiving for persons living with dementia, evaluate changes in cognition, preserve functional independence, and promote engagement between persons living with dementia and caregivers. Successful completion of this overall project, leading to a finalized platform, is planned as the basis for a larger NIH SBIR phase 2 clinical research trial to assess the efficacy of evidence-based interventions and the market viability of the Generation Connect platform. Specifically, the principal aim of the phase 2 project will be to quantify the economic impact (eg, reduced hospital or emergency department admissions, falls, and care transitions) and clinical outcomes (eg, decreased anxiety, depression, and isolation) and support or accelerate home care network efforts to standardize data collection around these key outcomes. Demonstrated effectiveness through a clinical trial would reinforce the Generation Connect's go-to-market objective of commercializing the Generation Connect platform in the home care industry as a viable ICT solution to improve clinical outcomes, reduce turnover, extend client length of stay, and support emerging MA plans.

This study revealed key discoveries that are essential to consider for future projects, which are as follows: (1) early intervention and collaboration between FCGs and family members who are providing care; (2) great variability exists across national franchise networks in their ability to adopt and commercialize technology solutions; and (3) providers have systems in place to track clinical data and outcomes, but they are limited in scope and lack standardization and interconnectedness. Importantly, the insights gained from this study will prove critical to informing our approach for the phase 2 outcomes research and future commercialization efforts.

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Conflicts of Interest

DD, RL, and MP work for Generation Connect, which is a gerontology-driven technology company with an intergenerational team that works together with forward-thinking care organizations to build engagement solutions that promote person-centered care through technological innovation.

Multimedia Appendix 1
Exemplary quotes associated with other issues identified from the focus groups.
[DOC File , 59 KB - aging_v5i1e32516_app1.doc]

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Abbreviations

ADRD: Alzheimer disease and related dementias
FCG: formal caregiver
HIPAA: Health Insurance Portability and Accountability Act
ICT: information communication technology
MA: Medicare Advantage
NIH SBIR: National Institutes of Health Small Business Innovation Research
TECH: Technology-Enabled Caregiving in the Home

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Original Paper

Mobile Device Ownership, Current Use, and Interest in Mobile Health Interventions Among Low-Income Older Chinese Immigrants With Type 2 Diabetes: Cross-sectional Survey Study

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Abstract

Background: Chinese immigrants suffer a disproportionately high type 2 diabetes (T2D) burden and tend to have poorly controlled disease. Mobile health (mHealth) interventions have been shown to increase access to care and improve chronic disease management in minority populations. However, such interventions have not been developed for or tested in Chinese immigrants with T2D.

Objective: This study aims to examine mobile device ownership, current use, and interest in mHealth interventions among Chinese immigrants with T2D.

Methods: In a cross-sectional survey, Chinese immigrants with T2D were recruited from Chinese community centers in New York City. Sociodemographic characteristics, mobile device ownership, current use of social media software applications, current use of technology for health-related purposes, and interest in using mHealth for T2D management were assessed. Surveys were administered face-to-face by bilingual study staff in the participant's preferred language. Descriptive statistics were used to characterize the study sample and summarize technology use.

Results: The sample (N=91) was predominantly female (n=57, 63%), married (n=68, 75%), and had a high school education or less (n=58, 64%); most participants had an annual household income of less than US $25,000 (n=63, 69%) and had limited English proficiency (n=78, 86%). The sample had a mean age of 70 (SD 11) years. Almost all (90/91, 99%) participants had a mobile device (eg, basic cell phones, smart devices), and the majority (n=83, 91%) reported owning a smart device (eg, smartphone or tablet). WeChat was the most commonly used social media platform (65/91, 71%). When asked about their top source for diabetes-related information, 63 of the 91 participants (69%) reported health care providers, followed by 13 who reported the internet (14%), and 10 who reported family, friends, and coworkers (11%). Less than one-quarter (21/91, 23%) of the sample reported using the internet to search for diabetes-related information in the past 12 months. About one-third of the sample (34/91, 37%) reported that they had watched a health-related video on their cell phone or computer in the past 12 months. The majority (69/91, 76%) of participants reported interest in receiving an mHealth intervention in the future to help with T2D management.

Conclusions: Despite high mobile device ownership, the current use of technology for health-related issues remained low in older Chinese immigrants with T2D. Given the strong interest in future mHealth interventions and high levels of social media use (eg, WeChat), future studies should consider how to leverage these existing low-cost platforms and deliver tailored mHealth interventions to this fast-growing minority group.

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KEYWORDS

technology use; Chinese immigrants; type 2 diabetes; mHealth; health disparities; immigrant health; diabetes; mobile health; intervention; smartphone; immigrant

Introduction

Type 2 diabetes (T2D) in Chinese Americans is a significant health concern for the US health care system [1-3]. According to a recent epidemiological survey, 43.1%, or 1 out of every 2, Chinese Americans in New York City (NYC) have T2D or prediabetes [3]. The majority of Chinese Americans with T2D are foreign-born older immigrants with limited English proficiency and health literacy [3-6].

Once diagnosed with T2D, Chinese immigrants demonstrate poorer self-management and worse glycemic control [4,5,7-9], and are more likely to develop end-stage renal disease [7,10]. In a recent study of racial and ethnic minorities with T2D in NYC [5], Chinese immigrants performed an average of 3.80 (SD 0.13) capillary glucose checks per week, compared to 11.88 (SD 0.57) checks per week for Hispanic individuals and 10.29 (SD 0.29) checks per week for Black individuals. The mean number of yearly hemoglobin A_{1c} (HbA_{1c}) checks was 1.16 (SD 0.15) for Chinese immigrants, 3.31 (SD 0.14) for Hispanic individuals, and 3.23 (SD 0.18) for Black individuals [5].

Diabetes self-management education and counseling programs are effective interventions for diabetes control [11,12]. However, numerous factors limit the access of such programs to Chinese immigrants. While 76.6% of Chinese immigrants report limited English proficiency [13], there is a shortage of language-concordant clinicians and limited language access or medical interpretation [14-17]. Differing cultural norms may limit the relevance and effectiveness of diabetes care and counseling delivered by non-Chinese clinicians or interpreters [6,14,18-20]. Moreover, comprehensive diabetes counseling is impeded by the limited amount of time patients are able to spend with clinicians [15]. As a result, Chinese immigrants often report having unmet information needs for their T2D management [15,17].

Mobile health (mHealth) technology may be a promising way to address some of the previously mentioned barriers and reduce T2D health disparities. Research demonstrates SMS text messaging–based interventions improve glycemic control in patients with T2D, including minority populations [21-24]. SMS text messaging and social media strategies may be particularly relevant for immigrant populations given their high social needs to stay connected with their families and friends in their home countries [25]. To our knowledge, no studies have examined social media–based mHealth interventions in Chinese immigrants with T2D. Little is known regarding access to, use of, and attitudes toward mHealth in this fast-growing immigrant population. While it is often assumed that underserved, low-income immigrant communities have limited access to technology or would not have interest in telehealth programs [26], there is a paucity of empirical data on these subjects. With the rapid growth of telehealth programs over the past few years, it is critical to understand immigrant communities’ access to technology, use of technology for disease management, and interest in future mHealth programs. To address this knowledge gap, this study aims to examine mobile device ownership, social media use, current use of mHealth interventions, and interest in using such technology for T2D management among Chinese immigrants.

Methods

Conceptual Framework

This pilot study was informed by the National Institutes of Health (NIH) Stage Model for Behavioral Intervention Development [27] and the National Cancer Institute’s (NCI) Health Information National Trends Survey (HINTS) framework [28]. The NIH Stage Model posits that Stage 0 formative data is critical and can provide important preliminary data to inform Stage I intervention development and evaluation. There is a dearth of culturally tailored interventions to address T2D disparities in low-income older Chinese immigrants. This pilot study examined whether this underserved immigrant population has access to technology and how they access health information. These are critical formative data to collect before allocating resources to developing or testing an intervention.

In addition, we used the HINTS framework [28] to guide the choices of survey questions. Based on the HINTS framework, patients’ health information–seeking behavior is affected by various factors, including patient characteristics (eg, age, gender, socioeconomic status), prior experience with information-seeking, attitudes toward the source, and other contextual factors (eg, access to mobile technologies and Wi-Fi).

Study Design

For this cross-sectional study, Chinese immigrants with T2D were recruited from 4 community centers in Chinatown areas in NYC. Study flyers were posted in the community centers. Community leaders introduced the study at social events sponsored by the centers, and interested participants self-referred to study staff who attended the events.

To be eligible for the study, participants had to (1) self-identify as a Chinese immigrant or Chinese American, (2) be 18 years of age or older, (3) self-report that they had been diagnosed with T2D over a year ago, and (4) be currently self-managing T2D at home. This study was approved by the New York University Grossman School of Medicine Institutional Review Board. All participants provided signed informed consent. All study materials were available in English, Mandarin, and Cantonese. Surveys were administered face-to-face by bilingual study staff in the participant's preferred language. Participants received US $20 gift cards as an incentive for completing the survey.

Measures

Sociodemographic Characteristics

Age, gender, marital status, education, income, employment status, duration of residence in the United States, language spoken at home, and English proficiency were assessed.

Technology-Related Questions

Measures on technology use were adapted from the HINTS framework, including questions assessing access to technology, current social media use, current use of technology for health management, interest in mHealth interventions, and family or friends' involvement and interest in mHealth interventions.

Access to Technology

Using questions adapted from the HINTS framework, we assessed mobile device ownership (basic cell phones, smartphones, tablets, or none) and access to Wi-Fi at home (yes, no, or don't know/not sure). For those who owned a smartphone or tablet, we also asked whether they had an unlimited text messaging plan.

Current Social Media Use

Current use of social media platforms and SMS text messaging was assessed by asking participants whether they currently used WhatsApp, WeChat (a Chinese version of WhatsApp), basic text messaging, Facebook, or other social media platforms.

Current Use of Technology for Health Management

We assessed the extent to which participants relied on technology by asking them to identify their primary source of information for diabetes-related questions. Response options included health care providers; the internet; family, friends, or coworkers; newspapers; and do not seek help. We also asked whether they had used the internet to search for diabetes-related information in the past 12 months and whether they had used mobile phones or computers to watch a health-related video in the past 12 months.

Interest in Future mHealth Programs

Participants were asked whether they would be interested in participating in a future mHealth program for T2D self-management.

Family and Friends' Involvement and Interest in mHealth Interventions

Given the importance of family ties in the Chinese culture [6,18,20], we assessed participants' perceptions of their family's or friends' interest in mHealth interventions. Specifically, we asked whether participants discussed their T2D with others and if so, whether these family members or friends would be interested in receiving mHealth interventions to better support the patient in their T2D self-management efforts.

Statistical Analyses

We recruited 101 participants between April 2018 and July 2018. Data analyses were limited to 91 participants with complete data from the technology use survey. Descriptive statistics were used to examine the distribution of sociodemographic variables in addition to technology ownership and use, whether participants had accessed a health-related video, and attitudes toward mHealth interventions. Means and standard deviations were calculated for continuous variables. Frequencies and percentages were reported for categorical variables. Sample characteristics were summarized. We performed all analyses with SPSS, version 25.0 (IBM Corp).

Results

As shown in Table 1, the sample was composed of primarily low-income, married, foreign-born, elderly females with limited education, who had long-standing T2D. Most participants reported having lived in the United States for nearly 2 decades and having limited English proficiency.

Table 1. Sample characteristics (N=91) and access to technology, current use, and interest in mHealth interventions among older Chinese immigrants with type 2 diabetes.

Characteristic	Value
Age in years, mean (SD)	70 (11)
Age >65 years, n (%)	61 (67)
Gender, n (%)	
Female	57 (63)
Male	34 (37)
Currently married, n (%)	68 (75)
High school education or less, n (%)	58 (64)
Annual family income, n (%)	
≤US $25,000	63 (69)
≥US $25,000	12 (13)
Declined to answer or don’t know	16 (18)
Employment status, n (%)	
Currently employed	30 (33)
Not employed, not working	9 (10)
Retired	52 (57)
Foreign-born, n (%)	91 (100)
Number of years living in the United States, mean (SD)	19 (14)
Limited English proficiency	78 (86)
Mobile device ownership, n (%)	
Basic mobile phone	20 (22)
Smartphone	72 (79)
Tablet	49 (54)
Has a mobile device (basic mobile phone or smart device)	90 (99)
Has a smart device (smartphone or tablet)	83 (91)
Social media platforms (including text messaging) currently used by participant , n (%)	
WeChat	65 (71)
Basic SMS text messaging via cellular carrier	62 (68)
WhatsApp	4 (4)
Has Wi-Fi installed in home, n (%)	66 (73)
Has unlimited SMS text messaging plan, n (%)	
Yes	36 (40)
No	41 (45)
Don’t know	13 (14)
Did not answer	1 (1)
Primary source of diabetes-related information, n (%)	
Health care provider	63 (69)
The internet	13 (14)
Family, friends, or coworkers	10 (11)
Newspapers	4 (4)
Do not seek help	1 (1)
Has used the internet to look for information about diabetes in the past 12 months, n (%)	21 (23)

Characteristic	Value
Has watched a health-related video in the past 12 months, n (%)	34 (37)
Is interested in receiving mHealth interventions for T2D, n (%)	69 (76)
Has family/friends to talk to about their T2D, n (%)	62 (68)
Family/friends interested in receiving mHealth interventions to better support participant[a], n (%)	50 (81)

[a] This question was only assessed as a follow-up item among 62 participants who reported that they had family or friends to talk to about their T2D. The percentage was calculated accordingly.

Nearly all participants had a smart mobile device, and nearly three-quarters had Wi-Fi access at home. The most commonly used social media platform was WeChat, followed by basic text messaging. Very few participants used WhatsApp, and none reported using Facebook, Twitter, or Instagram.

The majority reported that their primary source for diabetes-related information is health care clinicians, with few participants reporting their first sources of information are the internet, family, friends, or coworkers. Less than one-quarter of the sample reported using the internet to search for diabetes-related information in the past 12 months. About one-third of the sample reported that they had watched a health-related video on their cell phone or computer in the past 12 months.

Despite the fact that the majority of participants were low-income older immigrants with limited education, over three-quarters expressed interest in receiving T2D management mHealth interventions in the future. About two-thirds reported having family or friends to talk to about their T2D. Of these, a large majority agreed that family or friends would be interested in receiving mHealth interventions to learn how to best support them in their efforts to manage their T2D.

Discussion

Principal Findings

To the best of our knowledge, this is the first study that provides data on technology ownership, current use, and interest in mHealth interventions in underserved Chinese immigrants with T2D. Although the majority of study participants were older immigrants with low income and limited education, they demonstrated high mobile device ownership and familiarity with a particular social media platform (ie, WeChat). This finding is consistent with a previous study reporting high social media use among immigrant populations to connect with their families and friends in their home countries [25]. Our data are also consistent with recent survey results from the Pew Research Center showing that about 95% of White, Hispanic, and Black American adults owned a cell phone and 80% had a smartphone [29]. The wide availability of mobile devices suggests a promising platform to increase access and deliver diabetes messaging and support to this underserved population [30]. Of particular note, Chinese immigrants are familiar with WeChat, a popular free Chinese social media app, and rarely used WhatsApp, Facebook, or Twitter. These data suggest that researchers may want to consider leveraging WeChat for this population in the future.

Despite high smart device ownership and internet access, the use of technology for health-related purposes was low in our sample. While about 70% of US adults considered the internet as their top source for health information [31], only 14% (13/91) of participants in our sample did, with the majority relying on health care providers. Compared to about 80% of US adults using the internet to search for health-related information [32], less than one-quarter of our sample (21/91, 23%) did so in the past 12 months. One interesting finding to note is that while the use of the internet to search for health-related information was much lower in our sample than the general US population, the proportion of participants who had watched a health-related video in the past 12 months was comparable [33]. This may be related to the high use of WeChat in our sample, which permits sharing of videos via chat windows. Our study found that almost 80% (69/91, 76%) of this relatively elderly sample reported interest in receiving mHealth videos in the future to help with T2D management. Taken together, these data suggest future researchers may want to consider leveraging multimedia strategies (eg, brief videos) to increase access and uptake of T2D-related education and counseling in this population.

The success of T2D management depends largely on the social and environmental contexts in which patients live and perform diabetes self-care [34,35]. When patients with T2D live in a supportive family context (eg, the family embraces a lifestyle consistent with the needs of the patient with T2D), they are more likely to receive social and emotional support for self-management, adhere to diabetes self-care requirements, and achieve better glycemic control [36]. Patients with T2D living in nonsupportive family environments (eg, family members undermine the patient’s efforts) have more difficulty initiating and sustaining recommended diabetes self-care behaviors, experience more diabetes-related distress, and report lower self-efficacy for self-management success [36,37]. Involving family members may be a useful strategy, given our finding that most participants discussed their T2D with family and friends, and believed their family and friends would be interested in receiving mHealth-based guidance to better support the participant’s self-management efforts.

Our findings provide valuable implications in the era of the COVID-19 pandemic. It is well-documented that COVID-19 disproportionately affects racial and ethnic minorities and immigrant communities [38-40]. The social isolation and loneliness resulting from prolonged safety measures (eg, social distancing, stay-at-home orders) is particularly concerning for older individuals and those with T2D who are at high risk of poor COVID-19 outcomes [41]. A high rate of mobile device ownership and strong interest in mHealth interventions among older Chinese immigrants with T2D may represent a window of opportunity for low-cost mHealth interventions to reduce diabetes burden and improve self-management outcomes in this rapidly growing immigrant group in the era of COVID-19.

Limitations and Strengths

There are several limitations to be acknowledged. This study involved a relatively small, convenient sample. Participants were recruited from the NYC metropolitan area, limiting generalizability to other locations. Because recruitment was accomplished through community-based organizations, the results may not be representative of all Chinese Americans receiving care through primary care or hospital settings. Participants in this study had, on average, lived in the United States for almost 20 years. These results may not be applicable to newly arrived immigrants who might be less acculturated or less familiar with western approaches for T2D management.

Several strengths should also be noted. To the best of our knowledge, this is the first study that provides data on technology use in older low-income Chinese immigrants with T2D. These data are particularly relevant during the COVID-19 pandemic. Our data on the high usage of WeChat and basic text messages and rare usage of WhatsApp suggested future researchers may consider choosing linguistically and culturally tailored platforms to engage racial and ethnic minorities. In addition, Chinese immigrants have been reported to be a hard-to-reach population for research participation [42,43]. We partnered with several trusted community organizations and successfully recruited 101 Chinese immigrants within 4 months (April 2018 to July 2018).

This study is important in that it focuses on a fast-growing, yet significantly understudied immigrant population [44]. While telehealth and telemedicine programs are rapidly growing in the era of the COVID-19 pandemic, low-income, underserved populations, particularly older immigrants with limited English proficiency, are often overlooked because it is assumed that they do not have access to technology and have limited interest in telehealth programs [26]. This study serves as a first step to dispel these myths and demonstrates that access to technology is not a major issue and that interest in mHealth programs is high. Our research team is currently testing a WeChat-based culturally and linguistically tailored diabetes video program in this underserved, older, low-income immigrant population.

Conclusions

This study addressed a critical gap in the literature with regard to technology ownership and use of and attitudes toward mHealth in a relatively older immigrant population with T2D. While current telehealth use remained low, the high mobile device ownership and social media use and strong interest in mHealth programs suggests that mHealth may be a promising approach to deliver health education and increase access to diabetes support to this fast-growing minority group. This study also provides timely preliminary data in the era of COVID-19 as older immigrant communities are among the hardest hit populations. With the rapid shift to telemedicine strategies, it is important for health care policymakers, clinicians, community partners, and researchers to consider how to leverage existing technologies to reduce health disparities and increase access to health care in this underserved population.

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Conflicts of Interest

None declared.

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Abbreviations

HbA_{1c}: hemoglobin A_{1c}
HINTS: Health Information National Trends Survey
mHealth: mobile health
NCI: National Cancer Institute
NIH: National Institutes of Health
T2D: type 2 diabetes

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Original Paper

COVID-19's Influence on Information and Communication Technologies in Long-Term Care: Results From a Web-Based Survey With Long-Term Care Administrators

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Abstract

Background: The prevalence of COVID-19 in the United States led to mandated lockdowns for long-term care (LTC) facilities, resulting in loss of in-person contact with social ties for LTC residents. Though information and communication technologies (ICTs) can be used by LTC residents to support their socioemotional needs, residents must have access to ICTs to use them.

Objective: This study explored ICT access and use in LTC facilities and how LTC facilities adapted to try to enhance social connections for their residents during the COVID-19 pandemic.

Methods: LTC administrators in South Carolina (United States) were invited to complete a web-based survey exploring ICT access and use in LTC facilities and whether access and use changed as a result of the COVID-19 pandemic.

Results: LTC administrators (N=70, 12 nursing homes [NHs], and 58 assisted living facilities [ALFs]) completed the web-based survey. Since March 2020, a total of 53% (37/70) of the LTC facilities have purchased ICTs for residents' use. ICTs have mainly been used for videoconferencing with family members (31/36, 86%), friends (25/36, 69%), and health care providers (26/36, 72%). NHs were 10.23 times more likely to purchase ICTs for residents' use during the COVID-19 pandemic than ALFs (odds ratio 11.23, 95% CI 1.12-113.02; *P*=.04). Benefits of ICT use included residents feeling connected to their family members, friends, and other residents. Barriers to ICT use included staff not having time to assist residents with using the technology, nonfunctional technology, and residents who do not want to share technology.

Conclusions: Our results suggest that over half of the LTC facilities in this study were able to acquire ICTs for their residents to use during the COVID-19 pandemic. Additional research is needed to explore how residents adapted to using the ICTs and whether LTC facilities developed and adopted technology integration plans, which could help them be prepared for future situations that may affect LTC residents' engagement and communication opportunities, such as another pandemic.

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KEYWORDS

COVID-19; pandemic; socioemotional needs; long-term care; nursing home facility; assisted living facility; elderly; older adults; information and communication technologies; support; emotion; needs; access; connection; communication; engagement

Introduction

As a result of the COVID-19 pandemic, nursing homes (NHs), assisted living facilities (ALFs), and other long-term care (LTC) facilities were required to restrict access to the public since March 2020 [1]. Many of these communities were not prepared to operate in this type of emergency as they were faced with personal protective equipment and staff shortages [2]. LTC facilities were even less prepared for the increased socioemotional needs, which arose for residents due to the loss of in-person contact with family and friends because of the mandated facility lockdown [3-5].

Loneliness and social isolation have long been salient issues for LTC facilities [6,7]. Change in residence, the death of family members and friends, and increased medical needs have been associated with increased loneliness and isolation among LTC residents [6,8-13]. As a way to address residents' quality of life, LTC facilities abide by federal regulations to facilitate resident communication opportunities with people within and outside of the facility. For example, nursing homes are federally mandated to provide telephone access for each resident and are required to provide internet access if it is available at the facility [14]. In addition to following federal regulations, some LTC facilities have also started to incorporate information and communication technologies (ICTs) for residents' use in the facility [15-17]. ICTs are devices and applications that provide the potential for unlimited connectivity and communication through technology such as desktop computers, laptops, tablets, smartphones, the internet, social media platforms, and videoconferencing [16,18]. Some segment of LTC residents can use ICTs, although residents' age, education level, interest in technology, and level of care may influence ICT use (Seifert A and Cotton S, unpublished data, 2021) [19,20].

The advent of the COVID-19 pandemic and the mandated LTC lockdowns necessitated that LTC facilities determine ways to help residents stay engaged with their social ties [21] and continue to receive medical care [22-24]. Most studies examining how the COVID-19 pandemic has affected the lives of older adults have concentrated on community-dwelling adults. Among the COVID-19–related studies on LTC [25]**,** the main focus has been on the medical circumstances (eg, cases, outbreaks, and personal protective equipment) pertaining COVID-19 [2,26-41], LTC employees [2,42-47], communication with family members [36,48], or provision of training on LTC issues related to the COVID-19 pandemic [24,49,50].

Among studies focusing on ICT access and use by LTC residents since the onset of the COVID-19 pandemic, almost none have examined ICT changes that facilities have implemented to address the potential socioemotional impacts on residents. ICTs have been used for telehealth purposes in medical screening and health care management of LTC residents [48,51-53]. A few studies have examined how LTC residents used ICTs for social purposes to communicate with those outside of the LTC facility. Telephone calls were reported by family members of LTC residents as the primary method of communication with LTC residents [54,55], followed by texting [54] and videoconferencing [54,55] during the mandatory lockdown. However, LTC residents reported that they preferred videoconferencing with family members rather than telephone calls [56]. Telephone calls were also employed in outreach interventions targeting LTC residents at risk for social isolation during the COVID-19 pandemic [57,58].

Three studies have assessed ICT availability in LTC facilities and use by LTC residents during the COVID-19 pandemic [3,48,59]. Montgomery et al [3] examined ICT use among a sample of 365 nursing home residents and found that 40% of the respondents owned a device, 47% indicated that their nursing home had computers or tablet devices, and 67% said that their nursing home offered free unlimited access to the internet via Wi-Fi. Ickert et al [59] evaluated the ICT resources in 10 care homes in Canada and found that all 10 care homes had tablet devices available for use. However, barriers to use existed, including the following: (1) age of the tablets, which could prevent videoconferencing apps from updating, or image disturbances during videoconferencing and (2) weak Wi-Fi infrastructure resulting in all videoconferencing having to occur in one area of the care home. Staff members were the critical link in facilitating video communication between residents and their family members. Staff members scheduled the videoconferencing visits, helped residents to the area in the home where they could participate in the videoconference call, assisted residents in using the tablets, and cleaned the tablet devices after each use. Marin et al [48] surveyed a staff member at each of the 46 ALFs in Rhode Island, which received donated tablets. Of the 46 ALFs, 11 of the staff members completed a web-based survey 2 weeks after the tablets were distributed. Survey responses indicated that the tablets were predominately used by residents to video chat with their family members (90.9%).

Though these 3 studies provide some insights into availability and use of ICTs in LTC facilities, they do not offer insights into how LTC facilities adapted during the pandemic to lessen potential social isolation and loneliness among their residents. To address this deficiency, this study explored (1) how LTC institutions modified technology access in their facilities and (2) the challenges that arose with these adaptations.

Methods

Recruitment and Data Collection

At the onset of the COVID-19 pandemic, the state of South Carolina placed contact limitations for residents of NHs and ALFs (known as community residential care facilities in South Carolina) [60]. Hence, we included both NHs and ALFs in this study as they experienced the same government-mandated restrictions.

LTC administrators in South Carolina were invited to complete a web-based survey from November to December 2020 to explore ICT access and use in LTC facilities and whether access and use changed as a result of the COVID-19 pandemic. Email contact information for 193 NH and 496 ALF administrators was obtained from the South Carolina Department of Health and Environmental Control (DHEC) website [61]. LTC administrators were recruited to participate in the Qualtrics survey through email, which included a secure weblink to access the survey. After sending the initial email request for participation, follow-up emails were sent at 3 days and 13 days. The Qualtrics survey was composed of 20 pages with 1-3 questions per page, there were adaptive questions based on the response to other items, and the survey took approximately 20 minutes to complete. During the survey, participants were able to review and change their answers using a back button. In total, 70 LTC administrators (12 NHs and 58 ALFs; 1 participant per site) completed the Qualtrics survey. Informed consent, which included the estimated time to complete the survey, data protection, the purpose of the study, and the principal investigator, was reviewed prior to the start of the survey. Participation was voluntary, and LTC administrators who chose to participate in the study clicked “yes” in agreement and began the survey. No incentives were offered for participation. This study was reviewed and approved by the university institutional review board.

Measures

Facility Characteristics

Participants were first asked general information about their LTC facility. The type of LTC facility was determined by the name of the facility, “What is the name of your facility?” and which type of LTC facility the name was associated with on the DHEC website [61]. Where the facility was located in South Carolina was assessed by an open-ended question, “In which city is your facility located?” The number of employees was measured with 2 questions: “How many full-time employees does your facility have?” and “How many part-time employees does your facility have?” Response options for both questions ranged from 1 to 100 in intervals of 1 with the final response option of “more than one-hundred.” The bed count was assessed numerically with the question, “How many beds does your facility have?” and then converted into size groups (>50 beds, 51-149 beds, 150 or more beds) following standard categorization [62]. Bed occupancy was measured by two questions: “What percentage of beds was occupied in February 2020, prior to COVID-19, in your facility?” and “What is the percentage of beds occupied now in your facility?” For both questions, response options ranged from 5 to 100 in intervals of 5. Facility ownership was assessed by the measure, “What is the ownership type of your facility?” with 3 response options (for profit, nonprofit, and federal or state).

ICT Access and Use

Facility technology preparedness was measured with the question, “How technologically prepared was your organization to address the social distancing need for residents as a result of COVID19?” Response options included the following: “Fully prepared,” “Mostly prepared,” “Somewhat prepared,” and “Not prepared.” We then assessed the facility technology capabilities with response options of “Yes,” “No,” or “Do not know”, to the following questions: “Does your facility have internet access?” “Does your facility have WiFi?” “Are residents able to access the internet?” “Are residents able to access WiFi?” and “Does your facility have a dedicated employee who helps residents with technology needs/issues?” Technology provided by the facility for residents’ use, prior to the COVID-19 pandemic, was assessed with one question, “Prior to February 2020, which type of technology did your facility provide for residents’ use?” Response options included the following: “TV,” “Radio,” “Desktop computers,” “Laptops,” “Smartphones,” and “Tablets”; respondents could select all that applied. Residents’ technology use was measured with a “Yes” or “No” response to “My residents use these technologies: Laptops, tablets, and smartphones.” The participants who responded “No” were then prompted with the follow-up question, “Why do you think that residents in your facility do not use laptops/tablets/smartphones?” Response options included, selecting all that apply, the following: “Do not have a need,” “Poor WiFi/bandwidth capability/capacity,” “Physical infrastructure of building,” “Cost is prohibitive,” or “Other (please specify).”

Changes in Facility ICTs, Access, and Use Since the Onset of the COVID-19 Pandemic

Next, we asked technology-related questions about use in the LTC facility since the COVID-19 pandemic. Technology spending was assessed through four questions: (1) “How much did your organization adjust its technology spending for residents due to COVID-19?” with response options including “Increased spending by more than 50%,” “Increased spending by 25-50%,” “Increased spending less than 25%,” “No change,” and “Decreased spending”; (2) “Since February 2020, has your facility purchased new technology for residents’ use?” with response options including “Yes” and “No.” The participants who responded with “Yes” were then prompted with four follow-up questions: “Which technology has been purchased for residents’ use?” with response options including “Laptops,” “Tablets,” “Cellphones,” “Smartphones,” or “Other (please specify)”; and “What type(s) of funds were used to purchase these devices?” with response options including (select all that apply) “Donation,” “the CMS COVID-19 Communicative Technology grant,” “Facility funds,” or “Other (please specify).” An open-ended question was asked: “Why was this new technology purchased?” Lastly, we asked, “How did residents learn to use this technology?” with response options including “Staff member helped them learn,” “Learned on their own,” “Another resident helped them learn,” and “Other (please specify).” New technology used by residents was assessed through three questions: (1) “How has this technology provided by your organization been used by residents?” with response options including (select all that apply) “Playing games,” “Video conferencing,” “Email,” “Searching for information,” “Shopping,” and “Other (please specify).” The number of residents using the technology was measured by two questions: “What percentage of residents have used this technology?” and “What percentage of residents have been unable to use the technology provided by your organization due to health or other impairments?” with response options for both questions ranging from 5 to 100, in intervals of 5.

Benefits and Barriers to ICT Use

Finally, resident changes since using technology were measured with two questions including (1) “Have there been any positive changes since residents started to use the new technology?” with response options including (select all that apply) “Decreased negative behaviors from residents,” “Residents socializing more,” “Residents feel connected to family members,” “Residents feel connected to friends,” “Family members feel connected to other residents,” and “Other (please specify)” and (2) “Have there been any negative changes since residents started to use the new technology?” with response options including (select all that apply) “Staff don’t have time to assist residents with technology,” “Broken technology,” “Stolen technology,” “Infection spread due to sharing technology,” “Residents do not want to share technology,” and “Other (please specify).”

Analysis

Questionnaires that had been completed up to 73% or more were included in the analysis. Given the exploratory nature of this study and the small sample size, the data were initially analyzed descriptively. A binary logistic regression model was used to investigate whether facility characteristics (ie, type, ownership, and bed size) influenced ICTs purchased during the COVID-19 pandemic. In line with the aim of this study, exploring ICT changes in LTC facilities during the pandemic, the dependent variable was the binary measure that assessed whether facilities purchased ICTs for residents' use during the COVID-19 pandemic.

Results

Facility Characteristics

The LTC facilities (N=70) were located throughout South Carolina in the Upstate (25/70, 36%), Low Country (18/70, 26%), Midlands (15/70, 21%), and Pee Dee regions (12/70, 17%) (Table 1 and Figure 1). The majority of the facilities were for-profit ownership (54/70, 77%). In total, 58 of the facility administrators that responded were from ALFs, with the remaining 12 administrators being from NHs. In total, 44% (31/70) of the facilities had a medium bed size (26-100 beds). Half of the ALFs (29/58) had 25-100 beds, while 83% (10/12) of the NHs had greater than 100 beds. Prior to the COVID-19 pandemic, administrators reported that, on average, 82% (SD 24.4%) of the beds were occupied (Table 2). Since the COVID-19 pandemic, administrators reported, on average, 74% (SD 23.4%) of the beds have been occupied. The facilities had, on average, 37 full-time employees (SD 35.6) and 14 part-time employees (SD 31.1). Most of the administrators (37/70, 57%) thought that their facility was at least mostly technologically prepared to address the social distancing needs for their residents that arose as a result of the COVID-19 pandemic.

Table 1. Facility characteristics.

Characteristics	Total (n=70), n (%)	Assisted living facilities (n=58), n (%)	Nursing homes (n=12), n (%)
Region in South Carolina			
Low Country	18 (26)	17 (29)	1 (9)
Midlands	15 (21)	12 (21)	3 (25)
Pee Dee	12 (17)	8 (14)	4 (33)
Upstate	25 (36)	21 (36)	4 (33)
Ownership type			
For profit	54 (77)	44 (76)	10 (83)
Nonprofit	13 (19)	11 (19)	2 (17)
Federal or state	3 (4)	3 (5)	0
Bed size			
Small (fewer than 25 beds)	22 (31)	22 (38)	0
Medium (26-100 beds)	31 (44)	29 (50)	2 (17)
Large (101 or more beds)	17 (25)	7 (12)	10 (83)
Facility technology preparedness[a]			
Fully prepared	13 (20)	11 (20)	2 (20)
Mostly prepared	24 (37)	21 (39)	3 (30)
Somewhat prepared	23 (35)	18 (33)	5 (50)
Not prepared	5 (8)	5 (9)	0

[a] Missing data from 3 assisted living facilities and 2 nursing homes.

Figure 1. Proportion of long-term care facilities participating in this study by regions in South Carolina, United States.

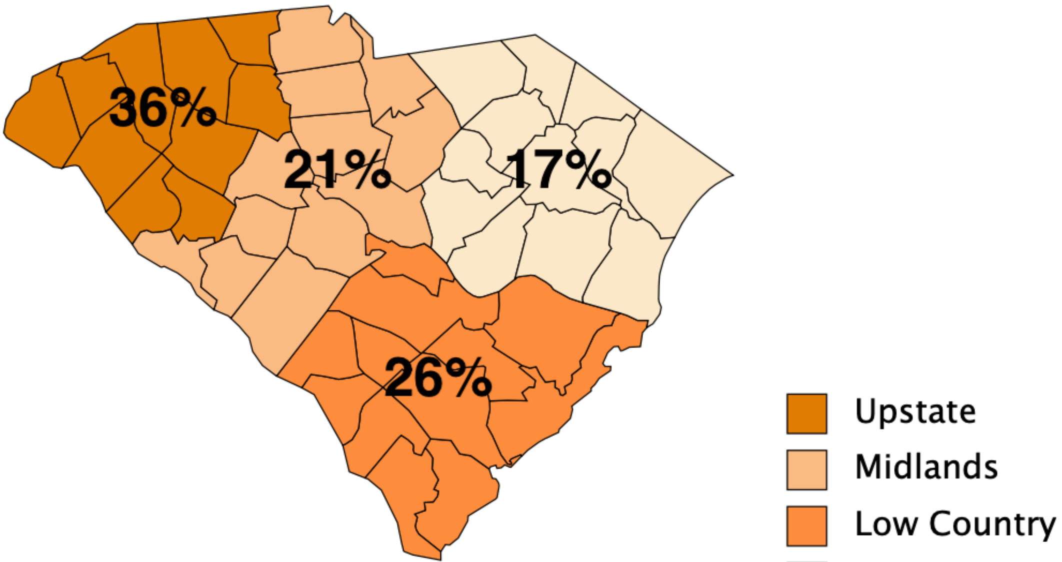

Table 2. Additional facility characteristics.

Characteristics	Score, mean (SD); range
Percent of beds occupied prior to COVID-19	
Total	82.21 (24.4); 5 to 100
Assisted living facilities	80.34 (26.4); 5 to 100
Nursing homes	91.25 (4.8); 80 to 95
Percent of beds occupied during COVID-19	
Total	73.93 (23.4); 5 to 100
Assisted living facilities	73.73 (25.5); 5 to 100
Nursing homes	75.83 (8.2); 60 to 90
Full-time employees	
Total	37.5 (35.6); 1 to ≥101
Assisted living facilities	25.6 (26.1); 1 to ≥101
Nursing homes	95 (9.6); 75 to ≥101
Part-time employees[a]	
Total[a]	14.5 (19.1); 1 to 76
Assisted living facilities[a]	11.7 (29.6); 1 to ≥101
Nursing homes	44.2 (22); 15 to 76

[a] Missing responses from 7 assisted living facilities.

ICT Access and Use

Most of the facilities provided internet (69/70, 99%) and Wi-Fi (66/70, 94%) access, although not all of them allowed residents to access the internet (59/69, 86% compared to 99% who had internet access) and Wi-Fi (57/66, 86% compared to 94% who had Wi-Fi access). Prior to February 2020, the top 2 ICTs provided by LTC facilities for residents' use were televisions (65/67, 97%) and radios (53/67, 79%; Table 3). In total, 33 of the 70 (47%) facilities have a dedicated employee to provide ICT support to residents. In total, 59% (38/64) of LTC administrators reported that their residents used laptops, 78% (50/64) of LTC administrators reported that their residents used tablet devices, and 96% (61/64) of LTC administrators reported that their residents used smartphones. Of the LTC administrators who reported that their residents did not use laptops, tablet devices, or smartphones, the predominant reasons for nonuse were lack of need (18/35, 51%) or prohibitive cost (7/35, 20%).

Table 3. Access to and use of information and communication technologies.

Technologies	Total (N=70), n (%)	Assisted living facilities (n=58), n (%)	Nursing homes (n=12), n (%)
Internet or Wi-Fi			
Facility has internet access	69 (99)	57 (98)	12 (100)
Residents able to access the internet	59 (86)	47 (82)	12 (100)
Facility has Wi-Fi	66 (94)	54 (93)	12 (100)
Residents able to access the Wi-Fi	57 (86)	46 (85)	11 (92)
Information and communication technologies available for residents to use[a]			
Television	65 (97)	55 (98)	10 (91)
Radio	53 (79)	47 (84)	6 (55)
Tablet device	24 (36)	19 (34)	5 (45)
Smartphone	20 (30)	17 (30)	3 (27)
Desktop computer	20 (30)	15 (27)	5 (45)
Laptop	17 (25)	12 (21)	5 (45)
Dedicated employee to help residents with information and communication technologies	33 (47)	27 (48)	6 (50)
Information and communication technologies that residents use[b]			
Smartphones	61 (96)	49 (94)	12 (100)
Tablet devices	50 (78)	38 (73)	12 (100)
Laptops	38 (59)	27 (52)	11 (92)
Reason why residents do not use information and communication technologies			
Do not have a need	18 (51)	17 (50)	1 (100)
Cost is prohibitive	7 (20)	7 (21)	0
Poor Wi-Fi, bandwidth capability, or capacity	6 (2)	2 (6)	0
Other (cognitive ability, do not know how, physical disabilities, not supplied by family, or no interest)	11 (31)	11 (32)	0

[a] Missing responses from 2 assisted living facilities and 1 nursing home.

[b] Missing responses from 6 assisted living facilities.

Changes in Facility ICTs, Access, and Use Since the Onset of the COVID-19 Pandemic

Since the onset of the COVID-19 pandemic and the subsequent lockdown of LTC facilities, 61% (43/70) of the LTC administrators reported an increase in technology spending at their facility (Table 4). A majority (37/70, 53%) of the LTC facilities reported purchasing ICTs for their residents. The main way the ICTs were purchased was by using facility funds (29/37, 78%). Though Centers for Medicare and Medicaid Services funding was provided for COVID-19 communicative technology grants for NHs, only 45% (5/11) of the nursing home administrators reported using this source of funding to purchase ICTs for their residents. ALF administrators also reported using personal funds, donations, and a small business loan. The top three ICTs purchased by LTC administrators for their residents (nonmutually exclusive) were tablet devices (27/37, 73%), smartphones (8/37, 22%), and laptops (8/37, 22%). In an open-ended question, 35 of the 37 administrators who purchased ICTs during the COVID-19 pandemic reported that the primary reason for purchasing ICTs was to help residents communicate with their family members. Additional reasons for purchasing ICTs included enabling telehealth and providing a secure communication channel for their staff.

Table 4. Changes in access to and use of information and communication technologies at facilities since the onset of the COVID-19 pandemic.

Changes	Total (N=70), n (%)	Assisted living facilities (n=58), n (%)	Nursing homes (n=12), n (%)
Change in technology spending			
No change	27 (39)	27 (47)	0
Increased spending less than 25%	20 (29)	16 (28)	4 (33)
Increased spending by 25%-50%	15 (21)	10 (17)	5 (42)
Increased spending by more than 50%	8 (11)	5 (9)	3 (25)
Facility purchased information and communication technologies for residents' use			
Yes	37 (53)	26 (45)	11 (92)
No	33 (47)	32 (55)	1 (8)
Among participants who reported purchasing information and communication technologies for residents' use:			
Funds used to purchase information and communication technologies			
Facility funds	29 (78)	21 (81)	8 (73)
The Centers for Medicare and Medicaid Services COVID-19 communicative technology grant	5 (14)	0	5 (45)
Donations	3 (8)	3 (12)	0
Other (personal funds, small business loans, and residents provided for self)	4 (11)	4 (15)	0
Information and communication technologies purchased			
Tablet devices	27 (73)	16 (62)	11 (100)
Smartphones	8 (22)	6 (23)	2 (18)
Laptops	8 (22)	7 (27)	1 (9)
Cellphones	1 (3)	1 (4)	0
Other (Facebook portal, Amazon Echo, Nucleus, Eversound technology, headsets, cords to connect tablets and phones to televisions, and smart televisions)	8 (22)	8 (31)	0
How information and communication technologies have been used by residents[a]			
Videoconferencing with family members	31 (86)	21 (81)	10 (100)
Videoconferencing with healthcare providers	26 (72)	19 (73)	7 (70)
Videoconferencing with friends	25 (69)	16 (62)	9 (90)
Playing games	10 (28)	8 (31)	2 (20)
Shopping	9 (25)	6 (23)	3 (30)
Searching for information	8 (22)	6 (23)	2 (20)
Email	4 (11)	2 (8)	2 (20)
Other (Pleasure, Telehealth)	3 (8)	3 (12)	0
How residents learned to use information and communication technologies[a]			
Staff-assisted	35 (97)	25 (96)	10 (100)
Self-taught	6 (17)	3 (12)	3 (30)
Other resident–assisted	4 (11)	3 (12)	1 (10)
Other	1 (3)	0	1 (10)
Do not know	1 (3)	1 (4)	0

[a] Missing response from one nursing home.

Administrators reported that, on average, 42% (SD 30.4%) of the residents used the technology provided by facilities and 25% (SD 26.4%; Table 5) of the residents were not able to use the technology provided by the facility owing to health or other impairments. Per the LTC administrators, residents have predominately used the newly purchased ICTs for videoconferencing with family members (31/36, 86%), health care providers (26/36, 72%), and friends (25/36, 69%). Residents have also used the ICTs for entertainment such as playing games (10/36, 28%), shopping (9/36, 25%), and searching for information (8/36, 22%). Though most of the LTC facilities did not have a dedicated person to assist residents with technology use, administrators reported that residents mainly learned to use the ICTs with help from LTC staff members (35/36, 97%).

Table 5. Additional changes in access to and use of information and communication technologies among facilities since the onset of the COVID-19 pandemic.

Additional changes	Residents (%), mean (SD); range
Used the technology provided by the facility	42.6 (30.4); 0-100
Unable to use the technology provided by the facility owing to health or other impairments	25.1 (26.4); 0-95

Benefits of and Barriers to ICT Use

The most commonly reported benefits reported by LTC administrators were that using ICTs helped residents feel connected to their family members (26/34, 77%) and friends (16/34, 47%), and using ICTs allowed the residents to socialize more with others (11/34, 32%; Table 6). Administrators noted barriers to ICT use, such as staff not having time to assist residents with technology, broken technology, and residents who did not want to share technology, although these barriers were each reported by <25% (9/34) of respondents.

Table 6. Benefits of and Barriers to the use of information and communication technologies.

	Total (N=34), n (%)	Assisted living facilities (n=24), n (%)	Nursing homes (n=10), n (%)
Benefits of using information and communication technologies			
Residents feel connected to family members	26 (77)	17 (71)	9 (90)
Residents feel connected to friends	16 (47)	11 (46)	5 (50)
Residents are socializing more	11 (32)	9 (38)	2 (20)
Decreased negative behaviors from residents	7 (21)	6 (25)	1 (10)
Residents feel connected to other residents	5 (15)	4 (17)	1 (10)
Other (eased some anxiety for residents and family)	2 (6)	2 (8)	0
Barriers to using information and communication technologies			
Staff do not have time to assist residents with technology	5 (15)	2 (8)	3 (30)
Broken technology	4 (12)	2 (8)	2 (20)
Residents do not want to share technology	2 (6)	1 (4)	1 (10)
Other (not enough devices and staff to help with tech use and residents with dementia)	3 (9)	2 (8)	1 (10)

Results of Binary Logistic Regression Analysis: Relationship Between ICT Purchase During the COVID-19 Pandemic and Facility Characteristics

Binary logistic regression analysis suggest that NHs, compared to ALFs, were 10.23 times more likely to purchase ICTs for residents' use during the COVID-19 pandemic (odds ratio 11.23, 95% CI 1.12-113.02; *P*=.04). None of the other facility characteristics were related to whether LTC facilities purchased ICTs. The overall results of binary regression analysis for ICTs purchased during the COVID-19 pandemic are shown in Table 7.

Table 7. Results of binary logistic regression analysis for the relationship between the purchase of information and communication technologies and facility characteristics.

	Odds ratio (SE; 95% CI)	*P* value
Type (nursing home)	11.23 (1.18; 1.12-113.02)	.04
Ownership		
For profit	1.85 (1.28; 0.15- 22.87)	.63
Nonprofit	0.72 (1.39; 0.05-10.82)	.81
Bed size	1.00 (0.01; 0.99-1.01)	.68

Discussion

Principal Findings

This study is unique in that it presents an institutional perspective regarding how LTC facilities attempted to use ICTs to help address the socioemotional needs of their residents during the COVID-19 pandemic. Although there were some LTC facilities that, prior to the pandemic, provided ICTs for residents' use, corroborating the findings from other prior studies [15,17,19], the advent of the lockdowns led many of the South Carolina facilities in this study to purchase ICTs.

NH administrators had higher odds of reporting that they purchased ICTs than ALF administrators. However, neither facility size nor ownership type were related to whether ICTs were purchased. Larger samples with more diversity in facility size, particularly among NHs, as well as other facility characteristics, might reveal differences that were obscured due to the homogeneity in NH respondent facility sizes in this study.

Since the onset of the COVID-19 pandemic, most of the LTC facilities in this study purchased ICTs, primarily tablet devices (27/37, 73%), to help enhance resident connection with social ties during the pandemic. Less than a quarter of the LTC facilities purchased smartphones or laptops for residents to use to communicate with friends, family, and health care providers during the lockdown. Although most of the LTC facilities did not have dedicated staff to assist residents in using ICTs, more than 95% (35/37) of the administrators in this study reported that staff helped residents learn to use ICTs during the pandemic to communicate with social ties and related reasons. This suggests that LTC facilities should consider having staff available to assist residents with using ICTs, thus confirming what other studies have suggested [16,18].

Though the LTC administrators in this study reported ICT use by their residents primarily for communication with their social ties, the majority (26/36; 72%) reported that residents used the ICTs for telehealth purposes. Given the high risk of COVID-19 among older adults, telehealth could be an important way for older adults to continue health care with minimal risks. While research is needed to explore how telehealth is used by LTC facilities and LTC residents in more detail, interventions are also needed to help older adults learn to use ICTs to effectively use in general and for telehealth services in particular [16,18].

Strengths and Limitations

This is one of the few studies examining administrators' technology adaptations during the COVID-19 pandemic. The results of this study illustrate the importance of staff members for helping residents to be able to use ICTs, as well as the fact that almost none of the facilities had a dedicated staff person to assist with technology needs at the time of this study. This suggests that facilities should take into account the technological needs of their residents and provide ongoing support to help them maintain their ICT use; prior research has noted the importance of ongoing technical support for older adults to be able to continue to use ICTs over time [16,18,20].

While this study sheds light on ICTs purchased and used in LTC facilities since the start of the pandemic, the data were collected from LTC facilities in South Carolina, which limits the generalizability of this study. Consistent with the LTC industry, our sample is predominately for profit LTC facilities. However, the majority bed size for both the ALFs and NHs in this study is not representative of the LTC facilities in South Carolina or the United States. Although 50% (29/58) of the ALFs in this study were medium-sized facilities (26-100 beds), the majority of ALFs in the United States (65%) and in South Carolina (46%) are small facilities (25 beds or less). In addition, 83% (10/12) of the NHs in this study were large facilities (101 beds or more), while the majority (64%) of NHs in the United States and in South Carolina (49%) are medium-sized facilities (26-100 beds) [63]. We acknowledge that the number of NHs that participated in the study was very small (n=12). Given the small number of NH administrators in the sample, the results for NHs should be taken with caution. It may be the case that a selection effect occurred with NHs who utilized ICTs in their facilities being more likely to respond to our ICT focused survey. Alternatively, perhaps larger NHs are more likely to have ICT access for their residents.

We found that prior to February 2020, there were NH administrators who reported that their residents used laptops (11/12, 92%), tablets (12/12, 100%), or smartphones (12/12, 100%). However, the number of NH administrators who reported residents having these was very small (n=12). Assisted living administrators also noted that prior to February 2020, their residents used laptops (27/58, 52%), tablet devices (38/58, 73%), and smartphones (49/58, 94%). Given the presence of greater health conditions among NH residents [64,65], compared to ALF residents, we would have expected that smaller percentages of NH residents would have been reported to use ICTs than what was reported in this study.

While the exploratory results of this study are informative in helping to illustrate the range of actions taken and administrators' perceptions of these ICT use impacts on residents, additional data with larger and more diverse samples of LTC administrators as well as other staff members and residents are needed to ascertain if and how various types of LTC facilities adapted to the COVID-19 pandemic to help residents maintain connections to their social ties. Future research should investigate the types and degree of ICTs available for residents' use in a national sample of LTC facilities, as well as identifying how LTC administrators adapted the ICTs available to LTC residents.

Conclusions

LTC facilities were not adequately prepared to support the socioemotional needs of their residents in the event of a federally mandated facility lockdown [3]. ICT use can be a useful tool to help LTC residents maintain contact with social ties either during a pandemic or during nonpandemic times. However, LTC facilities and residents must have ICTs available to use, residents must be skilled in using ICTs, and support must be available to ensure continued use for residents to reap the benefits of their use. We encourage LTC facilities to develop technology integration plans to prepare for future situations that may affect LTC residents' interaction and communication opportunities, such as another pandemic, and to facilitate residents' use in the present time.

Authors' Contributions

SRC and AMS designed the study. AMS analyzed the data. All authors contributed to and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

ALF: assisted living facility
DHEC: South Carolina Department of Health and Environmental Control
ICT: information and communication technology
LTC: long-term care
NH: nursing home

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Original Paper

Older Adults’ and Clinicians’ Perspectives on a Smart Health Platform for the Aging Population: Design and Evaluation Study

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Abstract

Background: Over recent years, interest in the development of smart health technologies aimed at supporting independent living for older populations has increased. The integration of innovative technologies, such as the Internet of Things, wearable technologies, artificial intelligence, and ambient-assisted living applications, represents a valuable solution for this scope. Designing such an integrated system requires addressing several aspects (eg, equipment selection, data management, analytics, costs, and users’ needs) and involving different areas of expertise (eg, medical science, service design, biomedical and computer engineering).

Objective: The objective of this study is 2-fold; we aimed to design the functionalities of a smart health platform addressing 5 chronic conditions prevalent in the older population (ie, hearing loss, cardiovascular diseases, cognitive impairments, mental health problems, and balance disorders) by considering both older adults’ and clinicians’ perspectives and to evaluate the identified smart health platform functionalities with a small group of older adults.

Methods: Overall, 24 older adults (aged >65 years) and 118 clinicians were interviewed through focus group activities and web-based questionnaires to elicit the smart health platform requirements. Considering the elicited requirements, the main functionalities of smart health platform were designed. Then, a focus group involving 6 older adults was conducted to evaluate the proposed solution in terms of usefulness, credibility, desirability, and learnability.

Results: Eight main functionalities were identified and assessed—cognitive training and hearing training (usefulness: 6/6, 100%; credibility: 6/6, 100%; desirability: 6/6, 100%; learnability: 6/6, 100%), monitoring of physiological parameters (usefulness: 6/6, 100%; credibility: 6/6, 100%; desirability: 6/6, 100%; learnability: 5/6, 83%), physical training (usefulness: 6/6, 100%; credibility: 6/6, 100%; desirability: 5/6, 83%; learnability: 2/6, 33%), psychoeducational intervention (usefulness: 6/6, 100%; credibility: 6/6, 100%; desirability: 4/6, 67%; learnability: 2/6, 33%), mood monitoring (usefulness: 4/6, 67%; credibility: 4/6, 67%; desirability: 3/6, 50%; learnability: 5/6, 50%), diet plan (usefulness: 5/6, 83%; credibility: 4/6, 67%; desirability: 1/6, 17%; learnability: 2/6, 33%), and environment monitoring and adjustment (usefulness: 1/6, 17%; credibility: 1/6, 17%; desirability: 0/6, 0%; learnability: 0/6, 0%). Most of them were highly appreciated by older participants, with the only exception being environment monitoring and adjustment. The results showed that the proposed functionalities met the needs and expectations of users (eg, improved self-management of patients’ disease and enhanced patient safety). However, some aspects need to be addressed (eg, technical and privacy issues).

Conclusions: The presented smart health platform functionalities seem to be able to meet older adults’ needs and desires to enhance their self-awareness and self-management of their medical condition, encourage healthy and independent living, and provide evidence-based support for clinicians’ decision-making. Further research with a larger and more heterogeneous pool of stakeholders in terms of demographics and clinical conditions is needed to assess system acceptability and overall user experience in free-living conditions.

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KEYWORDS

smart health; remote monitoring; requirement elicitation; older population; age-related chronic conditions; healthy aging; Internet of Things; mobile phone

Introduction

Background

Currently, 22% of the total population in Europe is aged >65 years, and this number is estimated to increase to 51% by 2070 [1]. More than 50% of the existing older adults have ≥3 chronic disorders (eg, hypertension, heart disease, and diabetes) that negatively affect their quality of life (QoL) and independent living [2]. The multiple comorbidities of chronic conditions with co-occurring age-related cognitive and behavioral changes make older adults frail, with a consequent increased risk of geriatric syndromes, hospitalization, and disability. Hence, the aging population is expected to be a great challenge for health care systems and represents a perfect target for developing new smart health platforms [3].

Smart health is a concept that refers to the multidimensional change that medical care is facing as a result of the integration of mobile devices (eg, smartphones), wearables (eg, fitness bands), and smart medical devices (eg, smart blood pressure monitors). These instruments enable the collection of massive amounts of health-related data that, when analyzed with artificial intelligence models, can provide insights for a personalized intervention. Smart health systems have become increasingly feasible in recent years because of the remarkable technological advancements in processing power, network infrastructures, and big data analytics, leading to a high level of information processing [4]. Big data may offer many advantages in the health care sector [4-6]: they are decisive in the prevention and early detection of diseases, risk monitoring, definition of tailored interventions based on a patient-centered over a disease-centered approach, objective reporting and evidence-based medicine, reduction of social and medical costs, and public health surveillance.

Over the past decade, the needs of the aging society have been investigated, and several smart health solutions have been proposed. The ultimate goal of smart health systems devoted to the older population is to encourage healthy lifestyles, increase autonomy, facilitate social inclusion, guarantee continuity of medical therapy even at home, and provide remote monitoring and teleconsulting. Technologies capable of monitoring an individual's activities and behaviors [7-9] have been developed to promote healthy habits (eg, active living and healthy nutrition). For better management of age-related diseases, devices supporting a proper intake of medication [10,11] have been suggested, and mobile apps providing remote monitoring [5], cognitive training [12], and psychological support [13-15] have been proposed. In addition, systems enabling the monitoring of home environmental conditions [16,17] or the detection of falls [9,18] have been designed to increase the safety of older adults.

The use of smart health solutions by the older population has been widely explored in the current literature [19-22]. In that regard, the attractiveness, ease of use (eg, understandable and simple language and easy access to information), and perceived added value of the technology (eg, relevant and valuable functionalities) are considered facilitators of the adoption of new technology for older adults [21,23]. Other enablers lie in an individual's adequate education to the use of technology because of prior experience with digital devices and mobile apps and in the curiosity toward the new technology [23]. The presence of support for older adults in learning to use the technology positively predisposes them to the use of new technological solutions [23]. In contrast, the literature suggests that the main barriers to the prolonged use of technology by older adults are issues in the usability of the system and perceived irrelevance of an application or a device with a resulting sense of the uselessness of the entire technology [23]. Moreover, the physical and functional age (ie, a combination of physiological, psychological, and social age determined by measures of functional capability indexed by age-normed standards), the absence of instructions or guidance, computer anxiety, and lack of confidence can lead to premature abandonment of those solutions by older populations [21,24,25]. Furthermore, relative to their use, older adults expressed privacy concerns, disapproval of possible excessive control from the caregivers, and lack or reduction of social interaction [20,21].

An important step in the design process of technology for community-dwelling older adults is to collect and address the needs of all involved stakeholders (eg, older patients, caregivers, and clinicians) [19,20,26]. A recent study [27] on a telepsychiatry service suggested that clinicians' concerns must be considered and addressed in the design and development of a service targeted for older adults. Another work [28] highlighted that poor involvement of the health care team in the development of an assistance and intervention service leads to reduced treatment adherence for patients [28]. Hence, all end users have to be involved in the design and implementation phases of a smart health platform for the older population.

However, research exploring attitudes, perceptions, expectations, and concerns about smart health technologies of both older adults and clinicians is limited, and users' well-being is often treated as a secondary outcome by assistive technology designers [29]. Moreover, the focus of most studies has been on exploring a single device (eg, tablet) [21] or function (eg, telemonitoring of daily activities) [20,26,27] and not a platform or a system including different devices and services.

Objective

This study, conducted within the Horizon 2020 European project *SMART BEAR*, addresses the aforementioned limitations. The idea underpinning this project is the implementation of an affordable, accountable, and privacy-preserving innovative platform (ie, SMART BEAR platform), integrating off-the-shelf smart and medical devices. The focus of developing such a platform is to support the healthy and independent living of aging people with five prevalent health-related conditions: hearing loss, cardiovascular diseases, cognitive impairments, mental health issues, and balance disorders. For every medical condition, the platform intends to provide the end users with remote monitoring and intervention based on several functionalities that may improve their QoL and facilitate disease management. More specifically, the platform aims to fulfill five objectives: (1) promote patients' self-awareness of health status, (2) promote patients' self-management of their own health conditions, (3) encourage patients' active living, (4) enable patient's independent living, and (5) provide evidence-based support for clinicians' decision-making.

Within this context, this study aims to collect key requirements for the SMART BEAR platform design by involving both older adults and clinicians. Specifically, the objective of the study is 2-fold; we aimed to understand stakeholders' beliefs, attitudes, needs, expectations, and concerns about the SMART BEAR platform (*objective 1*) and to evaluate the proposed solution with a small group of older adults (*objective 2*). The paper is structured as follows: the methodology, methods, data collection, sample population, and data analysis are described in the *Methods* section; results obtained are reported in the *Results* section; and discussion on the insights gained is narrated in the *Discussion* section. The paper ends with the conclusions, limits, and future work being presented.

Methods

Overview

A 2-phase experimental procedure was designed to address the objectives of this study. The first phase (*requirements collection*) was devoted to gaining a comprehensive understanding of the behaviors and perceptions of both clinicians and older adults, as well as exploring environmental factors that influence their adoption of the technology (*objective 1)*. Once this process was completed and the collected data were analyzed, the main functionalities to make the SMART BEAR platform effective and adoptable by the end users could be identified. The second phase (*evaluation*) was intended to provide an overall assessment of the designed platform and its functionalities (*objective 2*).

Methodology

The methods used to gather clinicians' and older adults' data can be distinguished into two categories: *focus group* and *web-based questionnaire*.

A *focus group* activity can be defined as a discussion within a small group of people (eg, 4-10 participants) about a specific topic led by a well-trained facilitator (eg, a psychologist or a researcher able to stimulate an active engagement of participants in the debate). Although it is a time-consuming activity, the focus group is well-appreciated in medical research as it represents a valid method for collecting qualitative and quantitative information. Conversely, *web-based questionnaires* allow gathering information from a large sample in a short period; it is easy to fill in remotely using a computer or a smartphone, and its answers are simple to analyze as a more structured survey.

To establish the content and structure of the methods used in the study, a draft of questions was first created according to preliminary informal interviews conducted with experts (eg, neuropsychologists, geriatricians, and engineers). Then, a brainstorming session was conducted to decide which questions to include or exclude (eg, "Is this question really needed?"). The brainstorming was helpful in avoiding the temptation to include questions without critical evaluation of their contribution toward the achievement of the study objectives. Finally, special attention was given to the wording, length, order, and format of questions (eg, several factors such as the age of the target respondents were considered, and the font size of the questionnaires was adapted accordingly). The questions were organized and worded to encourage respondents to provide accurate, unbiased, and complete information.

Requirements Collection Phase

The *requirements collection* phase included three subsequent activities: first, a focus group activity with clinicians (*focus group for clinicians*) was conducted to collect qualitative exploratory information for a better understanding of how the SMART BEAR platform can benefit older adults and their physicians. Clinicians with various medical specialties (eg, geriatricians, cardiologists, psychiatrists, neurologists, and psychologists) were encouraged to participate in the activity. Indeed, their experience with older patients and their caregivers may offer valuable perspectives on the problems faced in clinical practice and how the technology may facilitate the management of prevalent age-related conditions. Moreover, they were invited to debate about the *intrinsic capacity* (IC) model [30] introduced by the World Health Organization, according to which the individual's functional abilities need to be considered to ensure a comprehensive characterization of older patients. Second, a structured questionnaire was issued via the web to a large sample of clinicians (*web-based questionnaire for clinicians*) to learn about their beliefs, attitudes, and expectations on the SMART BEAR platform. In the third phase, a web-based questionnaire was set up and disseminated among older adults (*web-based questionnaire for older adults*) to collect their feedback and impressions about the SMART BEAR platform.

Evaluation Phase

The *evaluation* phase included a focus group activity with older adults using a storytelling approach (*focus group for older adults*). The participants, as potential users of the SMART BEAR platform, were invited to answer structured questions while observing archetypal users (ie, users with similar age and clinical conditions) experiencing the proposed technological solution and its functionalities.

Experimental Procedure

During the *requirements collection* phase, once the participants' demographic data were gathered, 5 areas were investigated overall through the *focus group for clinicians*, *web-based questionnaire for clinicians*, and *web-based questionnaire for older adults* (Table 1). In detail, in the *focus group for clinicians*, the facilitator (ie, a neuropsychologist) explored four areas of interest for clinicians (ie, impact of disease in everyday life, remote monitoring, use of technology in medical practice, and about SMART BEAR) by administering a set of 33 open-ended questions to the participants (Multimedia Appendix 1). Instead, the *web-based questionnaire for clinicians* comprised 13 closed, multiple-choice questions to guarantee clarity, brevity, and usability of the questionnaire, given its web-based nature. The questions were selected from among those used in the *focus group for clinicians*. They covered 3 of the 4 areas of clinicians' interest (ie, impact of disease in everyday life, being a very broad and complex topic, was excluded to avoid an excessive workload for the respondents).

Furthermore, free-form comment boxes were added to gather further participants' insights. The *web-based questionnaire for clinicians* (Multimedia Appendix 1) was published on the Limesurvey platform, and its link was spread through the internal mailing lists of Istituto di Ricovero e Cura a Carattere Scientifico (IRCCS) Policlinico Ca' Granda (Milan, Italy), Ospedale Maggiore (Crema, Italy), and IRCCS Ospedale San Raffaele (Milan, Italy). Similarly, for the *web-based questionnaire for older adults*, the multiple-choice, close-ended questions structure was preferred, and 35 questions were selected to cover the areas targeted for older adults (ie, impact of disease in everyday life, remote monitoring, older adults' relationship with technology, and about SMART BEAR). The questionnaire for older adults (Multimedia Appendix 1) was published on the Limesurvey platform, and the link was shared among the contacts of clinicians, colleagues, and older participants of previous research projects.

Table 1. Investigated areas and used methods for each phase.

Phase	Clinicians	Older adults
Requirements collection phase (areas)		
Impact of disease in everyday life	Focus group	Web-based questionnaire
Remote monitoring	Focus group and web-based questionnaire	Web-based questionnaire
Older adults' relationship with the technology	N/A[a]	Web-based questionnaire
Use of technology in medical practice	Focus group and web-based questionnaire	N/A
About SMART BEAR	Focus group and web-based questionnaire	Web-based questionnaire
Evaluation phase (interventions)		
Physical training	N/A	Focus group: S_1[b]
Diet plan	N/A	Focus group: S_1
Monitoring of physiological parameters	N/A	Focus group: S_1
Psychoeducational intervention	N/A	Focus group: S_2[c]
Monitoring of the mood	N/A	Focus group: S_2
Cognitive training	N/A	Focus group: S_2
Hearing training	N/A	Focus group: S_2
Environment monitoring and adjustment	N/A	Focus group: S_2
Evaluation phase (transversal functions)		
Data visualization	N/A	Focus group: S_1 and S_2
Gamification	N/A	Focus group: S_1 and S_2
Regular report	N/A	Focus group: S_1 and S_2
Regular report to clinician	N/A	Focus group: S_1 and S_2
Suggestion	N/A	Focus group: S_1 and S_2
Reminder	N/A	Focus group: S_1 and S_2
Data access to caregiver	N/A	Focus group: S_1 and S_2
Teleconsulting	N/A	Focus group: S_1 and S_2

[a] N/A: not applicable.

[b] S_1: Carlo's story.

[c] S_2: Lidia's story.

According to the data collected in the *focus group for clinicians*, *web-based questionnaire for clinicians*, and *web-based questionnaire for older adults* and their analysis, 8 interventions and 8 transversal functions of the SMART BEAR platform were proposed and assessed in the *evaluation* phase through the *focus group for older adults'* activity (Table 1). It comprised a discussion based on a narration where the contents of the research questions are merged with the story of personas (ie, archetypal users). This method was selected as it encourages the identification of the participants with the protagonist, which facilitates the comprehension of the proposed technology use. Moreover, it enables participants to bring new ideas and personal insights into the discussion. In more detail, 2 stories (Carlo's story and Lidia's story; Multimedia Appendix 1), describing 2 personas (ie, Carlo and Lidia) interacting with the platform and making use of specific interventions and transversal functions, were presented and discussed. More specifically, in each story, different interventions were illustrated according to the protagonist's problems (eg, physical training is offered in Carlo's story as Carlo conducts a sedentary lifestyle). The presented interventions were evaluated in terms of usefulness (ie, *Do you find it useful to meet your needs*?), credibility (ie, *Do you think or feel it credible*?), desirability (ie, *Would you find it desirable*?), and learnability (ie, *Would you be able to learn to use it*?). Transversal functions were presented in both stories because of their versatility and evaluated in terms of usefulness and desirability.

Sample Population

An overall sample of 148 participants (Figure 1), comprising both clinicians (118/148, 79.7%) and older adults (30/148, 20.3%), took part in the study. The research was designed in accordance with the European Union Guidelines for Clinical Practice and the current revision of the Declaration of Helsinki. The study was approved by the Ethics Committee of the University of Milan (nr. 50.20 on May 14, 2020). All participants provided informed written consent before enrollment in the study.

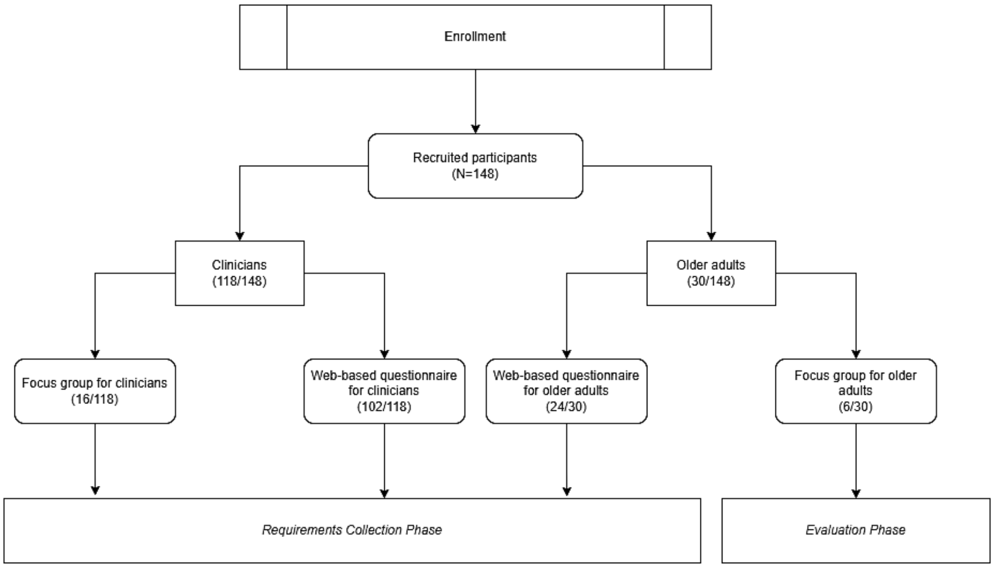
As shown in Figure 1, clinicians (16/118, 13.6%) with expertise in all medical domains from two hospitals, IRCCS Policlinico Ca' Granda and Ospedale Maggiore, were involved in the *focus group for clinicians*. A focus group was planned in each hospital. More specifically, 56% (9/16) of participants took part in the first focus group at Policlinico Ca' Granda (*focus group 1 for clinicians*), whereas the second focus group was performed with the involvement of 44% (7/16) of medical experts at Ospedale Maggiore in Crema (*focus group 2 for clinicians*). Each focus group lasted approximately 90 minutes and was conducted in a specifically furnished room at the hospital's premises. The focus groups were led by a neuropsychologist, whereas 2 biomedical engineers took notes.

Physicians (102/118, 86.4%) with expertise in ≥1 of the medical condition of interest were enrolled from IRCCS Policlinico Ca' Granda, Ospedale Maggiore, and IRCCS San Raffaele Hospital for the following step of the study (ie, filling the *web-based questionnaire for clinicians*).

Participants aged ≥65 years with any of the target age-related conditions were recruited for the last 2 activities through word-of-mouth communication. In particular, of the 30 older adults, 24 (80%) participated in the *web-based questionnaire for older adults'* activity in the *requirements collection* phase, and 6 (20%) took part in the last *focus group for older adults'* activity in the *evaluation* phase.

The *focus group for older adults* was conducted by a neuropsychologist and 2 bioengineers in a medical office in Chiesa in Valmalenco (Sondrio, Italy) and lasted approximately 90 minutes. More specifically, the neuropsychologist conducted the discussion of the topics, and the 2 bioengineers took notes of the discussions and occasionally intervened to obtain a better explanation of concepts that emerged from the discussion. Users' comments and feedback were collected in dedicated sheet forms.

Figure 1. Sample population diagram.



Data Analysis

The collected data were digitalized (*focus group for clinicians* and *focus group for older adults*) or exported (*web-based questionnaire for clinicians* and *web-based questionnaire for older adults*) in Microsoft Excel (Microsoft Corporation).

A separate content analysis was conducted on the qualitative data gathered in the *requirements collection* phase (*focus group for clinicians*, *web-based questionnaire for clinicians*, and *web-based questionnaire for older adults*). Every answer was assigned to a group of common opinions or preferences to allow the conversion of qualitative information into quantitative data. Then, the quantitative data collected in the *focus group for clinicians* and a *web-based questionnaire for clinicians* referring to the same questions were combined to gain the clinicians' overall outcomes. Hence, a frequency analysis was conducted, and the results, in terms of the number of occurrences and related percentage values, were reported separately for each area investigated and involved stakeholders (clinicians or older adults).

At the end of the *requirements collection* phase analysis, researchers with heterogeneous expertise (eg, biomedical engineers, neuropsychologists, geriatric specialists, and computer scientists) formed a working group to design the functions and interventions of the smart health platform. For this purpose, the design considered the project's objectives; namely, to address the five areas of the IC model (ie, locomotion, cognition, vitality, sensory, and psychology). The results obtained in the *requirements collection* phase allowed for the assessment of the impact of such technology on the life of the target population in terms of needs satisfaction and technology acceptance. Moreover, implementation factors were considered, resulting in the endorsement of consumer technology. The working group debated on the possible solutions to reach these objectives and finalized the design by identifying 8 interventions and 8 transversal functions, which constitute the subject for the *evaluation phase*.

Here, a content analysis was conducted for qualitative data, and a frequency analysis was conducted for quantitative data. The results obtained in that phase were reported only in terms of percentage as a small group of older adults participated in the *focus group for older adults*.

Results

Requirements Collection Phase

Focus Group for Clinicians Sample Population

A group of 16 clinicians (8/16, 50% women) between the ages of 27 and 64 years (mean 42, SD 13 years) was recruited for the *focus group for clinicians* (ie, 7/16, 44% physicians; 3/16, 19% geriatricians; 3/16, 19% cardiologists; 1/16, 6% surgeons; and 2/16, 12% medical scientists). They all agreed that high blood pressure, ischemic disease, cardiac arrhythmias, imbalance, hearing loss, falling, dementia, depression, anxiety, and stress are the principal clinical problems that challenge older adults' everyday lives. The most treated medical conditions were high blood pressure (12/16, 75%), ischemic heart disease (10/16, 63%), arrhythmias (9/16, 56%), dementia (9/16, 56%), depression (7/16, 44%), falls (6/16, 38%), imbalance (6/16, 38%), anxiety (6/16, 38%), stress (3/16, 19%), and hearing loss (2/16, 13%).

Web-Based Questionnaire for Clinicians Sample Population

A sample of 102 participants completed the *web-based questionnaire for clinicians*. Approximately 98% (100/102) of the respondents expressed their area of expertise (ie, 59/102, 57.8% had expertise in geriatrics; 7/102, 6.8% had expertise in surgery; 6/102, 5.8% had expertise in general medicine; 4/102, 3.9% had expertise in neurology and physiotherapy; 2/102, 1.9% had expertise in cardiology, emergency medicine, and internal medicine; and 1/102, 0.9% had expertise in ear, nose, and throat, psychiatry, gastroenterology, pathological anatomy, urology, rheumatology, nephrology, radiology, psychology, odontology, endocrinology, oncology, and nutrition). The most frequently treated medical conditions by the surveyed clinicians were dementia (68/102, 66.6%), hypertension (64/102, 62.7%), falls (58/102, 56.8%), arrhythmias (55/102, 53.9%), ischemic heart disease (50/102, 49%), anxiety and depression (46/102, 45%), imbalance (39/102, 38.2%), stress (21/102, 20.5%), and hearing loss (9/102, 8.8%). Regarding the frequency of visits, 25.4% (26/102) of the sample declared that they visited their older patients more than once per month, 31.3% (32/102) visited every 1 to 3 months, 34.3% (35/102) visited every 6 months, and 9.8% (10/102) visited once per year.

Web-Based Questionnaire for Older Adults Sample Population

A total of 24 participants (16/24, 67% women) aged >65 years completed the *web-based questionnaire for older adults*. The sample was distributed as follows: 67% (16/24) in the 65 to 70 age range group, 17% (4/24) in the 71 to 75 age range group, 8% (2/24) in the 76 to 80 age range group, and 8% (2/24) in the >81 years group. Most respondents (16/24, 67%) declared that they lived with someone (all of them claimed to share their home with their spouse and 5/24, 21% with their progeny as well). The medical conditions prevalent among participants were hypertension (9/24, 38%), cardiovascular disease (6/24, 25%), anxiety (4/24, 17%), hearing difficulties (3/24, 13%), arrhythmias (4/24, 17%), balance disorders (2/24, 8%), and depression (1/24, 4%). Instead, 21% (5/24) of participants claimed to have experienced none of the abovementioned disorders.

A description of stakeholders involved in the first phase of the experimental procedure (*focus group for clinicians*, *web-based questionnaire for clinicians*, and *web-based questionnaire for older adults*) clustered according to the medical condition treated or experienced is summarized in Table 2.

Table 2. Requirements collection phase medical conditions treated or experienced (N=142).

Medical conditions	Clinicians (n=118), n (%)	Older adults (n=24), n (%)
Hearing loss (ie, tinnitus and unreceptiveness)	11 (9.3)	3 (12.5)
Cardiovascular diseases (ie, arrhythmias, ischemic heart disease, and hypertension)	82 (69.5)	16 (66.7)
Cognitive impairments (ie, dementia)	77 (65.3)	0 (0)
Mental health problems (ie, anxiety, depression, and stress)	68 (57.6)	4 (16.7)
Balance disorders (ie, imbalance and falls)	68 (57.6)	2 (8.3)
None	0 (0)	5 (20.8)

Area 1: Impact of Disease on Everyday Life

Table 3 summarizes the clinician (*focus group for clinicians*) and older adult (*web-based questionnaire for older adults*) inputs related to the *impact of disease in everyday life*.

All clinicians (16/16, 100%) agreed on the impact of age-related disorders on older adults' daily living activities, and approximately all of them (13/16, 81%) considered that a personalized intervention was required. Approximately all participants (15/16, 94%) suggested that the family members of the older person were most affected by the onset of the disease. Specifically, according to clinicians, 88% (14/16) of caregivers report having mental health problems (eg, burnout, depression, and sleeping difficulties). Other issues encountered by caregivers in handling the patient, as observed by clinicians, are the reconciliation of their own commitments and time with the needs of the patient (eg, daily assistance, scheduling medical appointments, and bringing them to the appointments), the experience or know-how to manage the disease or the adverse clinical situations, therapy management, and supervision. The whole group (16/16, 100%) suggested that a significant barrier for older adults in their disease management is therapy compliance. Thus, the clinicians claimed that these issues have a relevant impact on caregivers' mental health (ie, caregivers often report stress and anxiety).

Older adults reported effects on cardiorespiratory functions (6/24, 25%), sleep (6/24, 25%), and diet (3/24, 13%) for the vital area, whereas impact on sight (7/24, 29%), hearing (4/24, 17%), and smell (4/24, 17%) were observed for the sensorial area. Impacts on anxiety (7/24, 29%), depression (1/24, 4%), irritability (5/24, 21%), energy (5/24, 21%), and sociality (2/24, 8%) were found within the psychological area, whereas effects on balance (2/24, 8%), locomotion (3/24, 13%), and muscle strength (6/24, 25%) were noticed in the motor area. With regard to the cognition area, participants reported memory (10/24, 42%), attention (5/24, 21%), and language (1/24, 4%) difficulties. Most of the older adults (17/24, 71%) declared that no help was needed to manage their medical condition. However, the remaining 29% (7/24) were used to asking for help (3/24, 12% sometimes and 4/24, 17% rarely) in daily living activities (eg, personal hygiene and visiting the physician). Moreover, participants declared that they visited the clinician more than once per month (7/24, 29%), every 1 to 3 months (7/24, 29%), every 6 months (8/24, 33%), and less than once per 5 years (2/24, 8%). They joined their clinician on phone calls (18/24, 75%), written messages (10/24, 42%), and webpages (1/24, 4%).

Table 3. Results related to the impact of disease in everyday life (N=40).

Intrinsic capacity model areas	Clinicians (n=16), n (%)	Older adults (n=24), n (%)
Vital area (eg, cardiorespiratory functions, appetite, and autonomy)	15 (94)	13 (54)
Sensorial area (ie, vision, hearing, and smell)	6 (38)	11 (46)
Psychological area (eg, anxiety, depression, euphoria, and irritability)	13 (81)	17 (71)
Motor area (eg, balance, locomotion, coordination, and strength)	9 (56)	14 (58)
Cognitive area (ie, memory, attention, and language)	10 (63)	10 (42)

Area 2: Remote Monitoring

On the basis of the discussion stimulated among clinicians during the focus group, it was found that the most adopted intervention for older adults with the targeted clinical conditions seemed to be outpatient monitoring (96/118, 81.3% of clinicians), and only in some cases (30/118, 25.4% of clinicians), hospitalization was considered necessary.

Furthermore, 2.5% (3/118) of clinicians reported at the *focus group for clinicians* to have experience with remote monitoring of older patients, and the most monitored parameters were blood pressure and therapy compliance. The most commonly used means for remote communication were phone calls (74/118, 62.7%), emails (52/118, 44%), and WhatsApp communication (47/118, 39.8%). However, one of the clinicians reported feeling stressed from remote monitoring.

Regarding older adults, only 58% (14/24) of the interviewees used remote monitoring devices; in particular, 54% (13/24) of the participants claimed to use a smart blood pressure monitor, whereas 4% (1/24) stated that they used an electrocardiogram monitor. Table 4 shows the primary outcomes related to *remote monitoring* from clinicians (*focus group for clinicians and web-based questionnaire for clinicians*) and older adults (*web-based questionnaire for older adults*).

Table 4. Results related to remote monitoring (N=142).

Parameters considered useful	Clinicians (n=118), n (%)	Older adults (n=24), n (%)
Blood pressure	85 (72)	12 (50)
House temperature	13 (11)	1 (4.2)
Air pollution	11 (9.3)	3 (12.5)
ECG[a]	37 (31.4)	0 (0)
Fall detection	74 (62.7)	2 (8.3)
Heart rate	65 (55.1)	5 (20.8)
Glycemia	47 (39.8)	0 (0)
Social interaction frequency	42 (35.6)	2 (8.3)
Diet habits	68 (57.6)	8 (33.3)
Levels of noise exposure	13 (11)	1 (4.2)
None	0 (0)	4 (16.7)
Other		
Physical activity	8 (6.8)	10 (41.7)
Cognitive functions	68 (57.6)	—[b]
Weight	1 (0.8)	—
Medication adherence	1 (0.8)	—
Behavioral changes and mood	50 (42.4)	3 (12.5)
Sleep quality	3 (2.5)	8 (33.3)
Pain	1 (0.8)	—
Eyesight	1 (0.8)	—

[a] ECG: electrocardiogram.

[b] Not available.

Area 3: Older Adults' Relationship With Technology

Multimedia Appendix 2 provides the results from the *web-based questionnaire for older adults* related to *older adults' relationship with technology*.

Area 4: Use of Technology in Medical Practice

Table 5 illustrates the clinicians' results (*focus group for clinicians and web-based questionnaire for clinicians*) related to the *use of technology in medical practice*.

As reported in Table 5, smart devices were considered useful in medical practice by most participants (107/118, 90.7%). However, 42.4% (50/118) of the clinicians never used smart devices in clinical practice, whereas only 5.1% (6/118) used them all the time. The same percentage of participants (50/118, 42.4%) did not suggest any of the proposed or other devices, whereas 1.7% (2/118) of clinicians judged the use of a device to recognize the patient's position and movement (eg, GPS tracking device) as significant. Monitoring of a person's sleep quality and oxygen saturation was also suggested by a participant.

Table 5. Results related to the use of technology in medical practice (N=118).

Use of technology	Clinicians, n (%)
Technology is useful in medical practice	107 (90.7)
Frequency of use	
Never	50 (42.4)
Rarely	34 (28.8)
Sometimes	14 (11.9)
Often	14 (11.9)
Everyday	6 (5.1)
Apps and devices prescribed or suggested	
Nutrition app	20 (16.9)
Physiotherapy app and smart devices	23 (19.5)
Smart hearing aids	10 (8.5)
Smart pillboxes	23 (19.5)
Physical activity app and smart devices	23 (19.5)
Smart blood pressure tracker	32 (27.1)
None	50 (42.4)
Other: movement tracking	2 (1.7)
Other: oxygen saturation and sleep quality app	1 (0.8)

Area 5: About SMART BEAR

Most clinicians (108/118, 91.5%) would recommend their patients to participate in the SMART BEAR project. Moreover, almost all participants would like to receive regular reports regarding the patients' health status. More specifically, they preferred daily reports (8/118, 6.7%), weekly reports (58/118, 49.1%), and monthly reports (35/118, 29.6%). Approximately 11.8% (14/118) of the participants would like to receive a report only if an abnormality was detected, whereas 1.7% (2/118) of the participants did not answer. During the *focus group for clinicians*, 94.1% (111/118) of the clinicians expressed interest in sending the reports to the patient, 75.4% (89/118) of them suggested sending the reports to both physicians and patients, and 38.1% (45/118) suggested sending the reports to the patient and caregiver.

Even older adults (18/24, 75%) expressed interest in receiving periodic reports about their own health status (weekly reports were preferred by 4/24, 17%, whereas monthly reports were favored by 20/24, 83%). In addition, they would like their own clinician (8/24, 33%), wife or husband (9/24, 38%), son or daughter (7/24, 29%), or none (4/24, 17%) to have access to the content of those reports. Regarding how to receive the reports, written messages (17/24, 71%), voice messaging (3/24, 13%), and email (9/24, 38%) were indicated. Approximately 63% (15/24) of the older adults showed an interest in notifications and suggestions that the platform could generate based on the collected data. This information was expected to be shared with the spouse (11/24, 46%), son or daughter (6/24, 25%), physician (2/24, 8%), and friend (2/24, 8%), whereas some (3/24, 13%) of participants preferred that no one had access to such notifications and suggestions. The expressed preferred ways of receiving notifications and suggestions were written messages (18/24, 75%), voice messaging (2/24, 8%), and email (10/24, 42%).

Table 6 reports the main clinicians' (*focus group for clinicians and web-based questionnaire for clinicians*) and older adults' (*web-based questionnaire for older adults*) inputs related to about SMART BEAR.

At the end of the *requirements collection* phase, the outcomes gained by considering both clinicians' and older adults' opinions and suggestions were mapped to the domains of the IC model to define a list of interventions and transversal functions worth including in the platform.

Table 6. Results related to about SMART BEAR (N=142).

About SMART BEAR	Clinicians (n=118), n (%)	Older adults (n=24), n (%)
Participation in SMART BEAR project	108 (91.5)	16 (66.7)
Expectations		
Less unnecessary visits	40 (33.9)	3 (12.5)
Enhanced patient’s safety	39 (33.1)	9 (37.5)
Better self-management of patients’ health status	77 (65.3)	10 (41.7)
Better patient’s social interactions	37 (31.4)	4 (16.7)
None	2 (1.7)	3 (12.5)
No answer	2 (1.7)	—[a]
Other		
Enhanced patient’s autonomy	—	3 (12.5)
Enhanced patient’s confidence	55 (46.6)	4 (16.7)
Improved patient’s health status	12 (10.2)	—
Improved patient’s diet habits	28 (23.7)	2 (8.3)
Improved patient-physician communication	9 (7.6)	—
Time saving	23 (19.5)	6 (25)
Money saving	19 (16.1)	2 (8.3)
Concerns		
Privacy	19 (16.1)	5 (20.8)
Change of routine	28 (23.7)	3 (12.5)
Erroneous measurements	37 (31.4)	4 (16.7)
Erroneous notifications (suggestions by platform)	31 (26.3)	3 (12.5)
Technical issues of the devices	60 (50.8)	7 (29.2)
Education on devices and platform use	75 (63.6)	2 (8.3)
Increased stress for the user	25 (21.2)	5 (20.8)
None	4 (3.4)	6 (25)
No answer	1 (0.8)	—
Other: decreased patient’s referral to private practice	2 (1.7)	—

[a] Not available.

Evaluation Phase

A total of 6 participants took part in *the focus group for older adults* (5/6, 83% women) in the *evaluation* phase. One of the participants was aged <70 years, whereas the others were in the 71 to 75 age range group. The education of this sample was heterogeneously distributed (ie, 1/6, 17% elementary school; 2/6, 33% middle school; 1/6, 17% high school; and 2/6, 33% in university). Half of the sample declared that they lived alone, whereas the other half stated that they lived with their spouse. Regarding the medical conditions experienced by participants, they claimed to have experienced hypertension (6/6, 100%), anxiety (3/6, 50%), cardiovascular diseases (1/6, 17%), and hearing loss (1/6, 17%).

The results of the assessment of the SMART BEAR platform interventions and transversal functions are reported in Table 7.

Overall, participants evaluated the platform positively, and all participants agreed that the objectives would be achieved. In particular, in their opinion, the SMART BEAR platform would enhance self-awareness of users’ health status (6/6, 100%), support self-management of users’ health conditions (6/6, 100%), promote active living both physically and cognitively (6/6, 100%), facilitate independent living (5/6, 83%), and enable evidence-based support for clinicians (6/6, 100%).

Table 7. Older users' assessment of SMART BEAR functions in the evaluation phase (N=6).

Functions of SMART BEAR platform	Usefulness, n (%)	Credibility, n (%)	Desirability, n (%)	Learnability, n (%)
Interventions				
Physical training	6 (100)	6 (100)	5 (83)	2 (33)
Diet plan	5 (83)	4 (67)	1 (17)	2 (33)
Monitoring of physiological parameters	6 (100)	6 (100)	6 (100)	5 (83)
Psychoeducational intervention	6 (100)	6 (100)	4 (67)	2 (33)
Monitoring of the mood	4 (67)	4 (67)	3 (50)	3 (50)
Cognitive training	6 (100)	6 (100)	6 (100)	6 (100)
Hearing training	6 (100)	6 (100)	6 (100)	6 (100)
Environment monitoring and adjustment	1 (17)	1 (17)	0 (0)	0 (0)
Transversal functions				
Data visualization	6 (100)	N/A[a]	5 (83)	N/A
Gamification	6 (100)	N/A	5 (83)	N/A
Regular reports	6 (100)	N/A	5 (83)	N/A
Regular report to clinician	4 (67)	N/A	5 (83)	N/A
Suggestion	6 (100)	N/A	6 (100)	N/A
Reminder	6 (100)	N/A	6 (100)	N/A
Data access to caregiver	2 (33)	N/A	2 (33)	N/A
Teleconsulting	6 (100)	N/A	5 (83)	N/A

[a] N/A: not applicable.

Discussion

Principal Findings

The goal of this study was 2-fold; we aimed to understand stakeholders' beliefs, attitudes, needs, expectations, and concerns about the SMART BEAR platform (*objective 1*) and to evaluate the proposed solution (*objective 2*) with a small group of older adults.

Regarding *objective 1*, a thorough comprehension of clinicians' and older adults' perceptions of the SMART BEAR platform was pursued through the investigation of five areas: *impact of disease in everyday life* (area 1), *remote monitoring* (area 2), *older adults' relationship with the technology* (area 3), *use of technology in medical practice* (area 4), and *about SMART BEAR* (area 5).

Impact of Disease in Everyday Life

The results obtained in the *requirements collection* phase showed that clinicians agreed on the impact that age-related conditions have on older adults' daily living activities, which was also confirmed by the interviewed older adults. More specifically, the effects on all the areas investigated within the IC model were reported by both clinicians and older participants: psychological area (13/16, 81% clinicians and 17/24, 71% older adults), vital area (15/16, 94% clinicians and 13/24, 54% older adults), motor area (9/16, 56% clinicians and 14/24, 58% older adults), cognitive area (10/16, 63% clinicians and 10/24, 42% older adults), and sensorial area (6/16, 38% clinicians and 11/24, 46% older adults). More specifically, older adults complained of anxiety, irritability, reduced energy, problems in vision, hearing, memory, attention difficulties, cardiorespiratory problems, and sleep disorders. However, the older adults who answered the questionnaire did not acknowledge the impact of the age-related conditions on their vital areas as severely as the interviewed clinicians assessed their patients. This might be because of a more objective overview of the vital problems from the clinicians (ie, objective medical examination and appropriate measurement of vital signs) than the subjective older adults' self-awareness. Although input from clinicians is fundamental to the design of an assistive technology, this discrepancy supports the importance of tailoring the smart health platform to the needs of a specific patient. In fact, as it emerged from the literature review, one of the most frequent causes of technology abandonment in older adults is the lack of perceived relevance of the service [23].

The onset of chronic diseases in the older population has important consequences for family members as well. Indeed, clinicians (ie, 14/16, 88% of participants in the *focus group for clinicians*) underlined that the complex management of the patient (eg, daily assistance and medical appointments) might lead caregivers to mental health problems (eg, sleeping difficulties, burnout, and depression), as confirmed by the literature [31,32]. Nevertheless, only 29% (7/24) of the older adults in *web-based questionnaire for older adults* declared to need help from family members for routine activities (eg, personal hygiene and visits to the physician). This incomplete overlap between clinicians' and older adults' feedback is in line with the relatively low limitations that older respondents have reported on their autonomy. This may be explained by the age of the sample population (20/24, 83% of older adults were aged <76 years, whereas more severe comorbidities were generally observed in more advanced age). The age distribution of older participants, in turn, could be because of the method used for data collection (ie, web-based questionnaire), which requires a certain autonomy and familiarity with the technology.

Use of Technology in Medical Practice

The outpatient approach for age-related disorders is the most preferred and used by interviewed clinicians. This is probably why most of them (107/118, 90.7%) considered the technology useful in medical practice (Table 5). These results are in line with those of the current literature [33,34]. In particular, objective measurements provided by smart medical devices are very appealing for medical experts as they can ensure support in decision-making for the clinician, help for the caregiver, and timely interventions for the patient. This study suggests that the most used devices in clinical practice are smart blood pressure trackers (32/118, 27.1%), physical activity and physiotherapy applications or devices (23/118, 19.5%), smart pillboxes (23, 19.5%), and nutrition applications (20/118, 16.9%). Furthermore, applications that are able to monitor sleep quality and track position were also indicated to cope with older adults' sleeping difficulties and cognitive problems. Instead, smart hearing aids were suggested or prescribed by only 8.5% (10/118) of clinicians, and such data might be due to the expertise of the clinicians involved in this study (ie, only a few of them, 11/118, 9.3%, deal with hearing impairments; Table 2). However, the use of smart devices in the current clinical practice is still uncommon (50/118, 42.4% of clinicians never use smart devices; Table 5), and it is mostly explained by the difficulties met by the older population in technology adoption [21,25].

Older Adults' Relationship With Technology

Older adults who took part in the study suggested being quite confident with the technology use (Multimedia Appendix 2). Only 8% (2/24) of the participants found some difficulties in using it, and none judged it as obstructive to everyday life. However, it is important to note that although the totality of participants regularly uses a smartphone, a decreasing trend in the use of more modern devices can be observed (ie, 15/24, 63% uses smart television, 9/24, 38% uses smartwatches, and 6/24, 25% uses smart lamps and smart thermostats). Nevertheless, this apparent resistance to the latest generation of devices can be overcome, provided that the technology is found valuable. Indeed, most participants were positively predisposed to use new technology if considered helpful, and none expressed themselves against adopting a useful device. Such findings are also confirmed by Vaportzis et al [21].

Remote Monitoring

Both clinicians and older adults agreed on the importance of remote monitoring. However, greater participation in identifying parameters useful for remote monitoring was observed from clinicians rather than older adults (ie, 4/244, 1.6% of older participants did not express any suggestions about measurement to monitor remotely; Table 4). The interest of health care professionals in monitoring blood pressure (85/118, 72%), heart rate (65/118, 55.1%), and diet habits (68/118, 57.6%), as well as physical activity and sleep quality, are in line with the typologies of devices and applications that they recommend to patients in their clinical practice. Further interest was also shown in devices that may detect falls (74/118, 62.7%) and monitor patients' therapy adherence and mood, cognitive functions, and behavioral changes of the latter. In this way, it is indeed possible to increase older patients' safety, provide concrete support for their caregivers in the management of the therapy, and help older adults face loneliness and social exclusion. Even older adults considered blood pressure (12/24, 50%), diet habits (8/24, 33%), and heart rate (5/24, 21%) measurements to be relevant. On the other hand, fall detection was not considered crucial (it was judged useful for 2/24, 8% of older respondents), which may be explained by the low rate of motor problems in the older adults' sample (Table 2). Similarly, social contact frequency tracing aroused little interest in older adults (2/24, 8%) as it felt intrusive. Clinicians registered some concerns about remote monitoring; they complained about the shortage of time to answer patients' phone calls and lack direct interaction with the patient. In addition, they stated that the symptoms remotely reported by patients could be misleading (ie, subjective) and hence misinterpreted in the absence of a visit in person. Finally, they said they were worried about potential false positives (ie, receiving alarm values from the device that could be normal for a specific patient).

About SMART BEAR

Smart health platforms, such as SMART BEAR, have attracted interest from both stakeholders. Most of them (108/118, 91.5% of clinicians and 16/24, 67% of older adults) expressed interest in participating in the project. The main expectation from using the SMART BEAR platform is a better self-management of patients' health status (77/118, 65.3% of clinicians and 10/24, 42% of older adults; Table 6). Both clinicians and older adults were aligned with the expectation that the SMART BEAR platform may increase patient safety (39/118, 33.1% of clinicians and 9/24, 38% of older adults). In contrast, it appears that only clinicians expected that this platform might reduce patients' unnecessary visits (40/118, 33.9% of clinicians and 3/24, 13% of older adults) and increase patients' social interactions (37/118, 31.4% for clinicians and 4/24, 17% for older adults). Clinicians also awaited enhanced patient confidence and improved patient-physician communication. However, the latter seems to be more concerned with the use of such a platform than older adults (ie, 4/118, 3.4% of clinicians vs 6/24, 25% of older adults declared to have none of the proposed concerns). Moreover, a difference in the typology of concerns reported by stakeholders was observed (Table 6). For example, the health care professionals' sample was especially concerned with education on devices and platform use (75/118, 63.6%), which is in contrast observed for only a few (2/24, 8%) of the older adults. In fact, no particular criticalities in using the technology were reported by the older people involved in the study, which may be because of the age distribution of the sample or participants' underestimation of the difficulties in using technological devices. Conversely, poor usability and improper functioning of the platform (eg, technical issues of devices, erroneous measurements, and notification and suggestion by the platform) caused concerns for both stakeholders. Furthermore, a small group of both clinicians and older adults (ie, 25/118, 21.2% of clinicians and 5/24, 21% of older adults) reported that the use of the proposed technology could lead to increased stress for the users. In particular, older adults (ie, 5/24, 21% of older adults vs 19/118, 16.1% of clinicians) were worried about privacy issues, which is fully understandable as it is subject to monitoring provided by the platform [20,21].

With regard to objective 2, the usefulness, credibility, desirability, and learnability of the SMART BEAR functions for its end users were assessed. The results obtained in the evaluation phase showed that the presented technology could address all the expected goals. Moreover, most of the proposed interventions were well-accepted by older adults. In more detail, all participants evaluated cognitive training (intervention 6) and hearing training (intervention 7) as useful, credible, desirable, and easy to learn. A very positive assessment of usefulness and credibility was also gained for physical training (intervention 1), monitoring of physiological parameters (intervention 3), and psychoeducational intervention (intervention 4). However, some doubts about the ease of use of such functionalities, with special regard to physical training and psychoeducational intervention, were revealed by older adults. The possibility of monitoring diet habits (intervention 2) was found useful by most people (5/6, 83%) but not as attractive as it was judged invasive (it was considered desirable only for the 1/6, 17%; Table 7).

In contrast, almost all participants who judged the monitoring of mood as useful (intervention 5) would like to have it (ie, 4/6, 67% and 3/6, 50%, respectively; Table 7). Such functionality has been judged effective in gaining a greater awareness of the patient's own condition. Nonetheless, uncertainty about a computer-based interaction on emotions and states of mind was raised (eg, "describing my mood using a smartphone without a person to person communication is unfriendly"). In addition, participants reported concerns that such an intervention (ie, intervention 5) may be time consuming and too burdensome (eg, to fill in a web-based questionnaire weekly). The environment monitoring and adjustment (intervention 8) received a negative assessment; indeed, only 17% (1/6) considered it valid and credible, and none would like to use it (eg, "it is difficult to accept a change in the own routine when the age is advancing" and "it is challenging to find the environmental conditions that fit well with all family members"). However, such functionality (ie, intervention 8) was considered helpful for less autonomous individuals. Relative to transversal functions, they were believed advantageous and desirable, although some preferences could be observed. The idea of receiving notifications and suggestions (transversal function 5) and the reminders (transversal function 6) from the platform were highly appreciated by all older users. Furthermore, the possibility of visualizing data (transversal function 1), access gamification dynamics (transversal function 2) for an enhanced motivation in pursuing the program, get information (eg, trend and statistics) about their own behaviors and health status through regular reports (transversal function 3), and seek a medical teleconsultation using the platform (transversal function 8) were thought helpful by everyone but undesirable by one of the participants because of poor confidence in the technology. Sharing regular reports with clinicians (transversal function 4) was found desirable by 83% (5/6) of participants but useful by 67% (4/6) of participants as they had some doubts that the clinician would agree to use this feature (ie, it takes considerable time). Finally, the possibility of sharing the data collected by the platform about their health parameters, activities, and behaviors with caregivers (transversal function 7) was widely discussed among older adults, and the willingness to safeguard their privacy and to feel independent but also the desire not to worry their loved ones and a light embarrassment in using gerontological technologies were reported. All these factors led most older participants (4/6, 67%) to consider data access to caregivers useless and undesirable.

Conclusions, Limitations, Strengths, and Future Works

In the era of personalized medicine, several benefits are expected from innovative smart health technologies that are able to ensure a continuous and noninvasive remote monitoring of the patient. For example, an early diagnosis; a data-driven approach in medical assistance; a closer and more trustful physician–patient relationship; and improved self-management, autonomy, and safety of the patient are desired.

In this study, clinicians' and older adults' perspectives about a smart health platform were gathered to design a solution (ie, the SMART BEAR platform) that fits all end user requirements well. The obtained results showed that the SMART BEAR platform represents a suitable solution for improving older adults' QoL, reducing the burden of age-related chronic conditions for both patients and caregivers, and providing objective reporting to the clinician for evidence-based medicine. Moreover, it offers useful insights so that smart health can become a widespread reality. For instance, devices and applications specifically targeted for the older population should not contain stigmatizing symbols, thus avoiding negative feelings in older adults with a consequent failed adoption of the technology. In addition, users' needs and expectations to meet and concerns to address and solve were defined. For example, the service needs to offer adequate training and technical support for end users to be endorsed by clinicians. Finally, several functionalities for a successful smart health platform were suggested, such as psychoeducational interventions and gamification elements.

This study used a mixed approach, adopting qualitative (ie, focus groups) and quantitative methods (ie, questionnaires with close-ended questions). This approach has limitations, as it does not allow a complete comparison between the data obtained with different methods; however, it is most effective for gaining insights into the issue. In fact, focus groups enable open discussions in which researchers can explore a subject with experts. Conversely, web-based questionnaires are a powerful method for maximizing participation in an investigation, thus consolidating or disproving assumptions formulated during the first exploratory phase. The following collection of technology requirements was based on data from a large sample. The designed platform has features that appeal to at least a consistent group of experts and a smaller group of possible users. Ultimately, focus groups become useful again to validate the elaborated concept and gain a detailed impression from potential end users. However, the sample of older adults was limited in comparison with the sample of clinicians, and this may be a limitation that can hardly be overcome because of the difficulty in reaching that population in large numbers. Moreover, it should be noted that the obtained outcomes could have been affected by the characteristics of the participants involved (ie, age groups and age-related conditions were not equally covered by participants).

Regarding research positioning, the authors mainly faced cultural challenges because of demographic differences between the research group and the group under study; that is, older adults. Geriatric medical specialists were essential to adopt a fitting framework for understanding the problem and the objectives of this research. This allowed researchers to design the study methodology and tools by adopting a holistic, person-centered approach instead of the traditional disease-based approach. This point of view was supported by the technical–biological background of the authors with a biomedical engineering degree, especially in studying how novel technological interventions would be able to support the individual’s well-being. As this study involved the active participation of older adults, the researchers tried to consider possible biases when the surveys were designed and conducted. This aspect was particularly important for the validation of the proposed design in focus groups when technology was discussed with participants who probably had very limited experience with it. Hence, the mediation of a neuropsychologist ensured that a common understanding was created with the participants and that possible adverse outcomes such as misunderstandings and frustration were avoided. Overall, heterogeneity in the academic background was the key strength of the research group.

Future works comprising further experimental activities with more and varied stakeholders (ie, clinicians and older adults distributed heterogeneously concerning the age, sex, and medical conditions treated or experienced and also their caregivers) are needed to investigate the acceptability and the overall user experience of the future developed platform in free-living conditions.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Material used in both the requirements collection phase and the evaluation phase.

[DOCX File , 1114 KB - aging_v5i1e29623_app1.docx]

Multimedia Appendix 2

Results from the web-based questionnaire for older adults related to older adults’ relationship with technology.

[DOCX File , 25 KB - aging_v5i1e29623_app2.docx]

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Abbreviations

IC: intrinsic capacity
IRCCS: Istituto di Ricovero e Cura a Carattere Scientifico
QoL: quality of life

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Original Paper

Socioeconomic Disparities in the Demand for and Use of Virtual Visits Among Senior Adults During the COVID-19 Pandemic: Cross-sectional Study

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Abstract

Background: The COVID-19 pandemic has limited the provision of in-person care and accelerated the need for virtual care. Older adults (65+ years) were 1 of the highest user groups of in-person health care services prior to the pandemic. Social distancing guidelines and high rates of mortality from coronavirus infections among older adults made receiving in-person health care services challenging for older adults. The provision of virtual care technologies can help to ensure continuity of care and provide essential health care services during the pandemic to those at high risk of contracting the COVID-19 coronavirus, including older adults. It is also essential to understand and address potential socioeconomic, demographic, and health disparities in the demand for and use of virtual care technologies among older adults.

Objective: The objective of this study is to investigate socioeconomic disparities in the demand for and use of virtual visits during the COVID-19 pandemic among older adults in Canada.

Methods: A cross-sectional web survey was conducted with 12,052 Canadians over the age of 16 years, selected from Leger's Léger Opinion panel from July 14 to August 6, 2021. Associations between socioeconomic factors and the demand for and use of virtual visits were tested using $\chi 2$ tests and logistic regression models for telephone visits, video visits, and secure messaging. Weighting was applied using the 2016 census reference variables to render a representative sample of the Canadian population.

Results: A total of 2303 older adults were surveyed. Older adults expressed the highest demand for and use of telephone visits, following by video visits and secure messaging. eHealth literacy was positively associated with the use of all 3 virtual care modalities. Higher income was negatively associated with the use of video visits (odds ratio [OR] 0.65, 95% CI 0.428-0.974, *P*=.03). Having no private insurance coverage was negatively associated with use of secure messaging (OR 0.73, 95% CI 0.539-0.983, *P*=.04), but living in a rural community (OR 0.172, 95% CI 1.12-2.645, *P*=.01) and being born outside of Canada (OR 0.150, 95% CI 1.041-2.173, *P*=.03) were positively associated with the use of secure messaging. Higher education (OR 0.078, 95% CI 0.633-0.97, *P*=.02) and being non-White (OR=0.054, 95% CI 0.312-0.92, *P*=.02) were negatively associated with the use of the telephone.

Conclusions: This study found that compared to video visits and secure messaging, the demand for and use of telephone visits were more prevalent among older adults during the pandemic. The gaps between the demand for and use of video and secure messaging services remain substantial. Our results highlight socioeconomic disparities among older adults that could potentially explain this trend. Lower income and a lower education level may act as barriers for older adults in acquiring the skills and technologies necessary to use more complex solutions, such as video and secure messaging. In addition, higher eHealth literacy was found to be critical for older adults to successfully navigate all types of virtual visit technologies.

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KEYWORDS

virtual care; virtual visit; COVID-19; survey; virtual care demand; virtual care use; older adults; elderly care; aging; digital health; pandemic

Introduction

The COVID-19 pandemic has posed unprecedented challenges for Canadians and the Canadian health care system. As in-person visits halted due to social distancing guidelines in the beginning of 2020, there has been a rapid expansion and uptake of virtual care technologies by the health care system to meet patient needs. Virtual care technologies can be defined as "any interaction between patients and/or members of their circle of care, occurring remotely, using any forms of communication or information technologies, with the aim of facilitating or maximizing the quality and effectiveness of patient care" [1]. Virtual care can be conducted via virtual visits through modalities, including telephone visits, video visits, or secure messaging interactions with a health care provider. Virtual visits have the potential to expand access to care for patients, especially during the COVID-19 pandemic. In Ontario, primary care provision quickly shifted to virtual with a 56-fold increase in virtual visits between March and July 2020 [2]. Between January and August 2021, virtual visits accounted for 35% of all most recent patient-reported visits, with 78% conducted via the telephone, 19% via videoconferencing, and 3% via secure messaging [3].

The declaration of the COVID-19 pandemic and social distancing measures disproportionally affected older adults above the age of 65 years. Older adults were particularly affected by COVID-19 due to prevalent health conditions related to age that lead to more severe clinical outcomes when infected with COVID-19. Data from Statistics Canada indicate that between March 2020 and May 2021, older adults accounted for 93% of the deaths attributed to COVID-19 [4]. Prior to the pandemic, older adults were among the highest health service users [5,6]. Age-related health factors, such as multimorbidity and limitations on functional capacity, make routine as well as urgent health care critical for the well-being of older adults. Older adults may experience challenges with accessing health services due to physical capacity limitations, financial barriers, and deteriorating psychological conditions [7]. The COVID-19 pandemic posed additional challenges for older adults, such as misinformation, physical and psychological isolation, and limitations to routine activities [8].

There is a paucity of research that assessed the impact of COVID-19 on health system utilization by older adults and the barriers and facilitators related to the demand for and use of virtual visits. International studies have indicated that during the COVID-19 pandemic, the number of routine health care services have decreased for older adults [9]. Findings from the recent Commonwealth Fund survey on older adults suggest as many as 32% of Canadian older adults with multiple chronic conditions had to cancel or postpone at least 1 appointment due to the pandemic [10]. Evidence emerging from Ontario suggests that because of a quick shift to virtual care, older adults maintained higher levels of care during the pandemic despite the absence of in-person care in many care settings [2]. Presently, there is a lack of knowledge about how older adults have navigated the health care system during the pandemic and their demand for and use of virtual visits to substitute or supplement in-person care. The purpose of this study is to investigate potential disparities in the demand for and use of virtual visits among older adults by assessing the associations between socioeconomic characteristics of older adults with self-reported demand for and use of telephone visits, video visits, and secure messaging services during the COVID-19 pandemic.

Methods

Study Population and Design

The 2021 Canadian Digital Health Survey is a cross-sectional, web-based survey of 12,052 Canadians, conducted in both English and French through computer-assisted web interviewing technology. The survey was commissioned by Canada Health Infoway (Infoway) and conducted by Léger. The Léger Opinion (LEO) panel was used for this survey. LEO is Léger's proprietary panel with nearly 500,000 representative panelists from all regions of Canada based on a representative sample of Canadian citizens with internet access. LEO's panelists were randomly selected using random digital dial samples, and panelists from more hard-to-reach target groups were also added to the panel through targeted recruitment campaigns. The survey questionnaire was created by Infoway, but the administration of the survey and the cleaning and coding of the survey data were conducted by Léger and then transferred to Infoway for analyses. A consent statement was presented to respondents at the beginning of the survey, and informed consent was obtained as part of the survey. No personal identifier was included in the data set to Infoway, and no personal health information was collected as part of the survey. Testing of the online survey was conducted by both Infoway as well as Léger staff. A small monetary incentive was offered to survey participates by Léger. The survey collected questions on demographic, socioeconomic and health characteristics as well as the self-reported demand for, and use of, digital health services, among other questions. In total, 68 questions were included in the survey.

Based on the respondent's default language of choice, the survey was presented to respondents in either English or French. Data collection took place from July 14 to August 6, 2021. Using 2016 Canadian Census data, Leger's methodologists applied weighting according to region, age, and gender to render a representative sample of the Canadian population. A margin of error cannot be associated with a nonprobability sample in a panel survey. For comparison purposes, a probability sample of this size would have a margin of error of ±0.895%, 19 times out of 20. For more details on the survey, please refer to a comprehensive report published by Infoway [3].

Measures

Use of virtual visits was determined by the self-reported answer to the question "Have you used _____ in the last 12 months?" and the demand for virtual care was determined by the self-reported answer to the question "Are you interested in accessing _____, whether you currently have access or not?" The demand for and use of telephone visits, video visits, and secure messaging were assessed separately with the same questions.

Socioeconomic Factors

Tables 1-4 outline the socioeconomic, health-related, and demographic factors, as well as the eHealth Literacy Scale (eHEALS) used to measure eHealth literacy, respectively. Household income reports the self-reported household income before tax in the past year. Education level reports the self-reported highest level of education obtained, including qualification obtained outside of Canada, and responses were collapsed into secondary education or less; college diploma or trade certificates; undergraduate degree; graduate degrees, including paramedical professional degrees; other; none of the above; and prefer not to answer. Community size was measured using the question “How would you describe the community you live in?” and responses were rural, small, medium, or large population centers, and urban centers. The population size for a rural community was defined as less than 1000 people. The population size for small, medium, and large population centers was defined as 1000-19,999 people, 20,000-99,999 people, and 100,000-999,999 people, respectively. An urban center was defined as 1 million people and over. Immigrant status was assessed with the question “Are you a Canadian citizen?” Language at home reports the language spoken on a regular basis at home. Employment status reports the current employment status, and responses were collapsed into working, including full- and part-time employment; unemployed, including homemakers, disabled, and students; retired; other; and prefer not to answer. Health coverage was based on the question “Which of the following best describes the type of health insurance coverage you currently have?” and the categories were collapsed into public coverage only, private coverage, no coverage, and don’t know and prefer not to say. Private coverage includes insurance plans paid for by the respondent, a family member, an employer, or an association.

Table 1. Socioeconomic characteristics of older adults and bivariate associations with the demand for and use of virtual visits, 2011 Canadian Digital Health Survey (N=2303).

Factors	All n (unweighted, weighted)=(2303, 2454), weighted %[a]	Use[b] n (unweighted, weighted)=(1149, 1245), weighted %	Versus have not used, χ^2 (*df*)	*P* value	Demand[c] n (unweighted, weighted)=(1773, 1902), weighted %	Versus have no interest, χ^2 (*df*)	*P* value
Household income (CAD $)[d]	N/A[e]	N/A	12.5 (7)	.08	N/A	29.9 (7)	<.001
24,999 or less	9.7	8.8	N/A	N/A	8.5	N/A	N/A
25,000-49,999	22.9	21.8	N/A	N/A	21.9	N/A	N/A
50,000-79,999	23	22.3	N/A	N/A	22.9	N/A	N/A
80,000-99,999	14.1	15.6	N/A	N/A	14.9	N/A	N/A
100,000-149,999	12.7	12.5	N/A	N/A	13.3	N/A	N/A
150,000-249,999	4.8	5.5	N/A	N/A	5.4	N/A	N/A
250,000 or more	1.0	1.2	N/A	N/A	1.1	N/A	N/A
Prefer not to answer	11.9	12.3	N/A	N/A	12	N/A	N/A
Education level	N/A	N/A	21.2 (6)	.01	N/A	39.9 (6)	<.001
Secondary or less	22.3	20.9	N/A	N/A	20.8	N/A	N/A
College or trade	32.1	31.3	N/A	N/A	31.5	N/A	N/A
Undergraduate degree	29.3	30.6	N/A	N/A	30.7	N/A	N/A
Graduate degree or more	13.4	15.1	N/A	N/A	14.7	N/A	N/A
Other	1.1	1.0	N/A	N/A	1.2	N/A	N/A
None of the above	1.3	1.0	N/A	N/A	1	N/A	N/A
Prefer not to answer	0.4	0.1	N/A	N/A	0.2	N/A	N/A
Community size	N/A	N/A	10.5 (4)	.03	N/A	0.6 (4)	.97
Rural	10	9.9	N/A	N/A	10	N/A	N/A
Small population center	18.2	16.6	N/A	N/A	18	N/A	N/A
Medium population center	19.6	18.4	N/A	N/A	19.5	N/A	N/A
Large population center	29.9	30.9	N/A	N/A	30.1	N/A	N/A
Urban center	22.3	24.2	N/A	N/A	22.4	N/A	N/A
Immigration status	N/A	N/A	1.4 (2)	.50	N/A	2.7 (2)	.26
Canadian citizen by birth	82.9	82.3	N/A	N/A	82.6	N/A	N/A
Canadian citizen by naturalization[f]	16.0	16.8	N/A	N/A	16.5	N/A	N/A
Not a Canadian citizen	1.0	0.9	N/A	N/A	0.9	N/A	N/A
Language spoken at home	N/A	N/A	12. 6 (2)	.01	N/A	1.5 (2)	.68
English	76.1	78.4	N/A	N/A	76.6	N/A	N/A
French	22.0	98.6	N/A	N/A	21.6	N/A	N/A
Other	1.9	1.4	N/A	N/A	1.8	N/A	N/A
Employment status	N/A	N/A	7.9 (4)	.44	N/A	2.2 (4)	.97
Working full-time or part-time	13.5	13.1	N/A	N/A	13.7	N/A	N/A
Unemployed	2.0	2.0	N/A	N/A	2.1	N/A	N/A
Retired	83.2	83.6	N/A	N/A	83.1	N/A	N/A
Other	1.1	1.4	N/A	N/A	1.1	N/A	N/A
Prefer not to answer	0	0	N/A	N/A	0	N/A	N/A

Factors	All n (unweighted, weighted)=(2303, 2454), weighted %[a]	Use[b] n (unweighted, weighted)=(1149, 1245), weighted %	Versus have not used, χ^2 (*df*)	*P* value	Demand[c] n (unweighted, weighted)=(1773, 1902), weighted %	Versus have no interest, χ^2 (*df*)	*P* value
Health care coverage	N/A	N/A	74.3 (4)	<.001	N/A	28.2 (4)	<.001
Public coverage only	54.5	61.1	N/A	N/A	56.2	N/A	N/A
Private coverage	36.6	34.0	N/A	N/A	36.2	N/A	N/A
No coverage	6.4	3.8	N/A	N/A	5.4	N/A	N/A
I don't know	1.7	0.6	N/A	N/A	1.3	N/A	N/A
Prefer not to answer	0.9	0.5	N/A	N/A	0.8	N/A	N/A

[a] Percentages are weighted and have been rounded and may not total 100.

[b] Older adults who have used of at least 1 type of virtual visit modality in the past 12 months.

[c] Older adults who have expressed the demand for at least 1 type of virtual visit modality.

[d] A currency exchange rate of CAD $1=US $0.78 is applicable.

[e] N/A: not applicable.

[f] Data not available due to low cell count in response categories.

Table 2. Health-related characteristics of older adults and bivariate associations with the demand for and use of virtual visits, 2011 Canadian Digital Health Survey (N=2303).

Factors	All n (unweighted, weighted)=(2303, 2454), weighted %[a]	Use[b] n (unweighted, weighted)=(1149, 1245), weighted %	Versus have not used, χ^2 (*df*)	*P* value	Demand[c] n (unweighted, weighted)=(1773, 1902), weighted %	Versus have no interest, χ^2 (*df*)	*P* value
Access to a family physician	N/A[d]	N/A	28.2 (1)	<.001	N/A	32.8 (1)	<.001
Yes	93.9	96.3	N/A		95.0	N/A	
Chronic conditions							
Chronic pain	15.5	18.3	14.5 (1)	<.001	16.7	8.4 (1)	.004
Cancer	5.4	5.5	0.1 (1)	.79	5.6	0.7 (1)	.40
Diabetes of all types	17.1	19.7	12.9 (1)	<.001	16.9	0.2 (1)	.63
Chronic obstructive pulmonary disease (COPD)	4.9	5.3	1.11 (1)	.30	5.0	0.4 (1)	.53
Arthritis	30.1	34.6	24.8 (1)	.001	30.9	2.9 (1)	.09
Cardiovascular disease (CVD)	7.3	8.4	5.2 (1)	.02	7.5	0.6 (1)	.45
Alzheimer disease or any other dementia	0.2	0.3	N/A	N/A	0.3	N/A	N/A
Developmental disability	0	0.1	N/A	N/A	0	N/A	N/A
Drug or alcohol dependency	1.0	1.5	4.6 (1)	.04	1.3	5.2 (1)	.02
Obesity	11.5	13.7	12.0 (1)	.001	12.3	4.9 (1)	.03
Learning disability	0.6	0.6	0.1 (1)	.80	0.7	N/A	N/A
Emotional, psychological, or mental health conditions	7.2	8.9	11.5 (1)	.001	7.9	5.5 (1)	.02
Physical disability	7.1	8.3	6.1 (1)	.02	7.1	.001 (1)	.98
Sensory disability	8.5	10.0	7.2 (1)	.01	9.1	4.2 (1)	.04
3 or more chronic conditions	14.0	17.2	21.1 (1)	.009	15.0	6.6 (1)	.01
SRH[e]	N/A	N/A	26.6 (5)	<.001	N/A	13.5 (5)	.02
Excellent	7.0	5.3	N/A	N/A	7.1	N/A	N/A
Very good	32.1	29.1	N/A	N/A	32.3	N/A	N/A
Good	40	43.2	N/A	N/A	39.8	N/A	N/A
Fair	16.9	17.9	N/A	N/A	17	N/A	N/A
Poor	3.8	4.3	N/A	N/A	3.7	N/A	N/A
Prefer not to say	0.2	0.2	N/A	N/A	0.1	N/A	N/A
SRMH[f]	N/A	N/A	9.7 (5)	.09	N/A	6.5 (5)	.26
Excellent	26.4	24.7	N/A	N/A	25.7	N/A	N/A
Very good	37.0	37.0	N/A	N/A	37.4	N/A	N/A
Good	26.3	27.9	N/A	N/A	26.4	N/A	N/A
Fair	8.6	9.0	N/A	N/A	8.7	N/A	N/A
Poor	1.5	1.5	N/A	N/A	1.7	N/A	N/A
Prefer not to say	0.1	0.0	N/A	N/A	0.1	N/A	N/A

[a] Percentages are weighted and have been rounded and may not total 100.

[b] Older adults who have used of at least 1 type of virtual visit modality in the past 12 months.

[c] Older adults who have expressed the demand for at least 1 type of virtual visit modality.

[d] N/A: not applicable.

[e] SRH: self-rated health status.

[f] SRMH: self-rated mental health status.

Table 3. Demographic characteristics of older adults and bivariate associations with the demand for and use of virtual visits, 2011 Canadian Digital Health Survey (N=2303).

Factors	All n (unweighted, weighted)=(2303, 2454)	Use[a] n (unweighted, weighted)=(1149, 1245)	Versus have not used	Demand[b] n (unweighted, weighted)=(1773, 1902)	Versus have no interest
Age (years)					
F (*df*)	N/A[c]	N/A	1.72 (1)	N/A	3.19 (1)
P value	N/A	N/A	.19	N/A	.07
Mean (SD)	71.51 (5.13)	71.39 (5.05)	N/A	71.41 (5.04)	N/A
Gender identity, χ^2 (*df*), *P* value	N/A	N/A	10.8 (2), .06	N/A	4.6 (2), .46
Man, weighted %[d]	45.3	42.5	N/A	45.4	N/A
Woman, weighted %	54.5	57.3	N/A	54.4	N/A
Other/prefer not to answer, weighted %	0.1	0.3	N/A	0.3	N/A
Ethnic identity, χ^2 (*df*), *P* value	N/A	N/A	14.9 (2), .31	N/A	17.9 (2), .16
White, weighted %	92.1	93.3	N/A	92.9	N/A
Non-White, weighted %	6.8	4.7	N/A	5.1	N/A
Other, weighted %	1.5	1.5	N/A	1.2	N/A
Prefer not to answer, weighted %	1.1	0.6	N/A	1.0	N/A

[a] Older adults who have used of at least 1 type of virtual visit modality in the past 12 months.

[b] Older adults who have expressed the demand for at least 1 type of virtual visit modality.

[c] N/A: not applicable.

[d] Percentages are weighted and have been rounded and may not total 100.

Table 4. eHEALS[a] used to measure eHealth literacy of older adults and bivariate associations with the demand for and use of virtual visits, 2011 Canadian Digital Health Survey (N=2303).

Factor	All n (unweighted, weighted)=(2303, 2454)	Use[b] n (unweighted, weighted)=(1149, 1245)	Versus have not used	Demand[c] n (unweighted, weighted)=(1773, 1902)	Versus have no interest
F (*df*)	N/A[d]	N/A	2.725 (1)	N/A	13.78 (1)
P value	N/A	N/A	.10	N/A	<.001
Mean (SD)	25.95 (6.98)	26.69 (6.81)	N/A	26.59 (6.67)	N/A

[a] eHEALS: eHealth Literacy Scale.

[b] Older adults who have used of at least 1 type of virtual visit modality in the past 12 months.

[c] Older adults who have expressed the demand for at least 1 type of virtual visit modality.

[d] N/A: not applicable.

Health-Related Factors

Diagnosed chronic health conditions were assessed with the question “Do you have _____ diagnosed by a health professional?” Respondents who indicated “yes” were counted for each chronic condition. Self-rated mental health status (SRMH) and self-rated health status (SRH) were measured by asking respondents, “In general, how would you rate your overall physical/mental health?” Access to a family doctor was assessed through the question “Do you have a family doctor or regular place of care, such as a health center or a family medical/medicine group?” The responses were dichotomized into yes and no/don’t know.

Demographic Factors

Age was calculated based on the respondents’ year of birth and survey date. Gender was self-reported and categorized into man, woman, and other/prefer not to answer. Ethnicity was based on the question “Which ancestry category best describes you?” and responses were collapsed into White, non-White, other, and prefer not to answer.

eHealth Literacy

eHealth literacy was measured using the eHEALS, an 8-item self-assessment tool designed to measure respondents' knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic health information to health problems [11]. Originally developed to assess eHealth literacy levels among youth and youth workers by Skinner and Norman [11], the scale has since then been adapted to a variety of settings, population groups, and multiple languages [12]. Each question measures an aspect of perceived eHealth literacy and is scored on a Likert scale ranging from 1 to 5. Scores are summed to derive an overall eHealth literacy score that ranges from 8 to 40 for each respondent. A higher eHEALS score represents higher self-perceived eHealth literacy.

Statistical Analysis

Bivariate Associations

SPSS Statistics version 24 (IBM) was used for descriptive analyses [13]. Descriptive statistics were calculated for older adults, older adults who used at least 1 type of virtual visit modality in the past year, and older adults who expressed a demand for using at least 1 type of virtual visit modality. Bivariate associations between the demand for and use of virtual visits and socioeconomic, demographic, and health characteristics of older adults were assessed using χ^2 tests for categorical variables and the *t* test for continuous variables. Respondents who used at least 1 modality of virtual visit were compared to respondents who had not used any virtual visit in the past 12 months, and respondents who expressed a demand for at least 1 type of virtual visit were compared to respondents who did not express a demand for any virtual visit modalities.

Adjusted Logistic Regressions

SAS version 9.4 (SAS Institute) was used for logistic regression analyses [14]. Using the use and demand for telephone visits, video visits, and secure messaging as outcome variables, multivariable logistic regressions were conducted to assess associations with socioeconomic characteristics of older adults. Socioeconomic characteristics included in the model were household income (below and equal to CAD $80,000 before tax vs above CAD $80,000; note that a currency exchange rate of CAD $1=US $0.78 is applicable), education (less than undergraduate degree vs at least an undergraduate degree), community size (rural vs other), immigration status (not born in Canada vs born in Canada), language at home (English vs other), employment status (retired vs other), and health insurance coverage (no private insurance vs has private insurance). We adjusted for demographic and health factors using gender (male vs female/other), SRH (excellent/very good vs good/fair/poor/prefer not to say), SRMH (excellent/very good vs good/fair/poor/prefer not to say), ethnicity (non-White vs White), and chronic conditions (3 or more vs less than 3). In addition, we included eHealth literacy measured with eHEALS [11] to assess its impacts on the demand for and use of virtual visits. Adjusted models containing all the variables together were used to evaluate the odds of expressing the demand for and use of telephone, secure messaging, or video visits as a function of socioeconomic variables. No interactions were found between gender, SRH, SRMH, income, education, ethnicity, community, immigration status, language, employment status, insurance coverage, number of chronic conditions, and eHealth literacy.

Results

Sample Description

All reported percentages and related absolute numbers were weighted. A total of 2303 older adults were surveyed, which represents 19.11% of the total sample of 12,052 from the 2021 Canadian Digital Health Survey. The proportion of older adults who expressed a demand for telephone visits was the highest, followed by video visits and then secure messaging. Similarly, the proportion of older adults in our sample who have used telephone visits within the past year was the highest, followed by video visits and secure messaging. Overall, 1902/2454 (77.51%) older adults expressed a demand for at least 1 modality of virtual visit, and 1245/2303 (54.06%) used at least 1 modality of virtual visits in the past 12 months. The mean age of respondents was 71.51 years (SD 5.13), 1111/2454 (45.27%) respondents identified as male, and 2303/2454 (93.85%) respondents reported having a family physician or a regular place of care. In addition, 30.11% (739/2554) older adults reported having arthritis, followed by diabetes and chronic pain, and 344/2454 (14.02%) respondents reported having 3 or more chronic conditions. Just over one-third of respondents rated their health status as either excellent or very good, and over half of the respondents rated their mental health status as excellent or very good. More than half of the older adults surveyed reported their household income before tax to be below CAD $80,000, over half of the respondents reported not having an undergraduate degree, almost all the respondents self-identified as White, and 9.98% (245/2454) reported living in rural communities. Approximately 82.89% (2034/2454) of respondents were born in Canada, 1867/2454 (76.08%) surveyed respondents reported speaking English at home, 2042/2454 (83.21%) respondents were retired, and 896/2454 (36.51%) respondents had private health coverage. The average eHealth literacy score for older adults in our sample was 25.95 (SD 6.97).

Bivariate Associations for Demand for and Use of Virtual Care

The proportion of older adults who expressed a demand for at least 1 modality of virtual visits was 1902/2454 (77.51%) respondents, and the proportion of older adults who used at least 1 modality of virtual visits last year with their health care provider was 1245/2303 (54.06%) respondents (Table 1). Bivariate associations between the demand for and use of virtual care and socioeconomic, demographic, and health characteristics are shown in Tables 1-3. Significant associations were found between both income ($P<.001$) and education ($P<.001$) with the demand for virtual visits. No other socioeconomic factors were found to be significantly associated with the demand for virtual visits, except for health coverage ($P<.001$). For the use of virtual visits, a significant association was found with education ($P=.01$) but not for income ($P=.08$). Other socioeconomic factors associated with the use of virtual visits included community size (*P*=.03), home language (*P*=.01), and health coverage (*P*<.001). Compared to older adults who did not express a demand for any virtual visit modalities, older adults who expressed a demand were more likely to have a family physician (1807/1902 [95%] vs 497/552 [90%], *P*<.001), have 3 or more chronic conditions (285/1902 [15%] vs 61/552 [11.1%], *P*=.01), and be diagnosed with chronic pain, drug or alcohol dependence, a learning disability, or a sensory disability. In addition, significant associations were found between the demand for virtual visits and SRHS, household income, education, and health care coverage. Compared to older adults who did not use any modality of virtual visits in the past 12 months, older adults who used virtual visits were also more likely to have a family physician (1199/1245 [96.31%] vs 1100/1209 [90.98%], *P*<.001), have 3 or more chronic conditions (212/1245 [17.03%] vs 133/1209 [11%], *P*<.001), and be diagnosed with chronic pain, diabetes, arthritis, cardiovascular disease, obesity, emotional, a psychological or mental health condition, a physical disability, or a sensory disability. eHealth literacy scores were higher among those who expressed a demand for virtual visits (26.59 vs 23.74, *P*<.001) and higher among those who used virtual visits in the past 12 months (26.69 vs 25.18, *P*=.01).

Adjusted Logistic Regression Model to Assess Determinants of Demand for Virtual Care

Table 5 displays the adjusted logistic regression findings on factors associated with the demand for telephone visits, video visits, and secure messaging. Socioeconomic factors associated with the use of telephone visits, video visits, and secure messaging were tested with 3 multivariable logistic regression models. Older adults with an annual income of less than CAD $80,000 were less likely to express a demand for video visits (odds ratio [OR] 0.56, 95% CI 0.44-0.72, *P*<.001), secure messaging (OR 0.77, 95% CI 0.61-0.98, *P*=.04), and telephone visits (OR 0.74, 95% CI 0.57-0.97, *P*=.03). Similarly, older adults without an undergraduate degree were less likely to express a demand for video visits (OR 0.62, 95% CI 0.50-0.77, *P*<.001), secure messaging (OR 0.71, 95% CI 0.58-0.88, *P*<.001), and telephone visits (OR 0.68, 95% CI 0.54-0.86, *P*<.001). Other factors that were significant included ethnicity, language, insurance coverage, digital health literacy, and gender. Being non-White and an English speaker at home were negatively associated with the demand for video visits and secure messaging but not for telephone visits. Having no private insurance (OR 1.21, 95% CI 1.01-1.47, *P*=.04) and having more chronic conditions (OR 1.52, 95% CI 1.16-1.99, *P*<.001) were positively associated with the demand for telephone visits. Older adults with higher eHealth literacy, reflected by a higher score on the eHEALS, were more likely to express a demand for video visits (OR 1.04, 95% CI 1.03-1.06, *P*<.001), telephone visits (OR 1.04, 95% CI 1.03-1.06, *P*<.001), and secure messaging (OR 1.05, 95% CI 1.04-1.06, *P*<.001).

Table 5. Factors associated with the demand for virtual visits, 2011 Canadian Digital Health Survey (N=2303).

Factors	Video, OR[a] (95% CI)	Messaging, OR (95% CI)	Telephone, OR (95% CI)
Household income (CAD $80,000 and below vs above CAD $80,000[b])	0.56 (0.44-0.72)	0.77 (0.61-0.98)	0.74 (0.57-0.97)
Education (less than undergraduate degree vs undergraduate degree or more)	0.62 (0.50-0.77)	0.71 (0.58-0.88)	0.68 (0.54-0.86)
Community (rural vs other)	1.04 (0.79-1.37)	1.05 (0.80-1.38)	1.15 (0.85-1.55)
Immigration status (immigrant/not a citizen vs born in Canada)	1.19 (0.95-1.51)	1.14(0.91-1.44)	1.01 (0.79-1.30)
Language (English vs other)	0.78 (0.64-0.96)	0.71 (0.58-0.86)	1.23 (1.00-1.52)
Employment (retired vs other)	0.91 (0.73-1.13)	0.91 (0.73-1.14)	0.94 (0.74-1.20)
Insurance (without private insurance vs with private insurance)	1.03 (0.86-1.22)	1.00 (0.84-1.19)	1.21 (1.01-1.47)
Gender (male vs female/other)	1.11 (0.93-1.32)	1.19 (1.00-1.41)	0.94 (0.78-1.13)
SRH[c] (excellent/very good vs good/fair/poor/prefer not to say)	1.15 (0.95-1.39)	1.1 (0.91-1.33)	0.97 (0.79-1.19)
SRMH[d] (excellent/very good vs good/fair/poor/prefer not to say)	0.95 (0.79-1.15)	0.87 (0.72-1.05)	0.97 (0.79-1.20)
Ethnicity (non-White vs White)	0.59 (0.35-1.00)	0.54 (0.32-0.93)	0.61 (0.36-1.03)
Chronic disease (3 or more vs less than 3)	1.02 (0.81-1.30)	1.1 (0.87-1.40)	1.52 (1.16-1.99)
eHEALS[e] score (8-40)	1.04 (1.03-1.06)	1.05 (1.04-1.06)	1.04 (1.03-1.06)

[a] OR: odds ratio.

[b] A currency exchange rate of CAD $1=US $0.78 is applicable.

[c] SRH: self-rated health status.

[d] SRMH: self-rated mental health status.

[e] eHEALS: eHealth Literacy Scale.

Adjusted Logistic Regression Model to Assess Determinants of Use of Virtual Care

Table 6 displays the adjusted logistic regression findings on factors associated with the demand for telephone visits, video visits, and secure messaging. Unlike its associations with demand, a lower income was not significantly associated with the use of secure messaging or telephone visits but was negatively associated with video visits (OR 0.64, 95% CI 0.43-0.95, *P*=.03). A lower level of education was found to be negatively associated with use of telephone visits for older adults (OR 0.78, 95% CI 0.63-0.97, *P*=.02). Other socioeconomic factors that increased the odds of using video visits were being an English speaker (OR 1.99, 95% CI 1.30-3.03, *P*<.001) and being born outside of Canada (OR 1.67, 95% CI 1.18-2.36, *P*<.001). Older adults who were born outside of Canada (OR 1.50, 95% CI 1.04-2.17, *P*=.03) and those who resided in rural communities (OR 1.72, 95% CI 1.12-2.65, *P*=.01) had higher odds of using secure messaging during the past year, while older adults who did not have private insurance had lower odds of using secure messaging (OR 0.73, 95% CI 0.54-0.98, *P*=.04). Interestingly, having no private insurance increased the odds of using telephone visits for older adults (OR 1.41, 95% CI 1.19-1.68, *P*<.001). Being an English speaker was positively associated with use of telephone visits (OR 1.27, 95% CI 1.04-1.55, *P*=.02). Other health and demographic factors associated with the use of telephone visits included having more than 3 chronic conditions (OR 1.55, 95% CI 1.22-1.96, *P*<.001) and being non-White (OR 0.54, 95% CI 0.31-0.92, *P*=.02). Similarly with demand, eHealth literacy was positively associated with the use of video visits (OR 1.03, 95% CI 1.01-1.05, *P*=.01), secure messaging (OR 1.04, 95% CI 1.01-1.06, *P*<.001) and telephone visits (OR 1.03, 95% CI 1.01-1.04, *P*<.001).

Table 6. Factors associated with the use of virtual visits, 2011 Canadian Digital Health Survey (N=2303).

Factors	Video, OR[a] (95% CI)	Messaging, OR (95% CI)	Telephone, OR (95% CI)
Household income (CAD $80,000 and below vs above CAD $80,000[b])	0.64 (0.43-0.95)	0.70 (0.46-1.07)	0.81 (0.64-1.03)
Education (less than undergraduate degree vs undergraduate degree or more)	0.70 (0.48-1.02)	0.82 (0.56-1.22)	0.78 (0.63-0.97)
Community (rural vs other)	0.95 (0.58-1.56)	1.72 (1.12-2.65)	0.96 (0.73-1.26)
Immigration status (immigrant/not a citizen vs born in Canada)	1.67 (1.18-2.36)	1.50 (1.04-2.17)	1.12 (0.89-1.40)
Language (English vs other)	1.99 (1.30-3.03)	1.23 (0.84-1.80)	1.27 (1.04-1.55)
Employment (retired vs other)	0.97 (0.68-1.40)	1.44 (0.95-2.17)	1.07 (0.86-1.33)
Insurance (without private insurance vs with private insurance)	1.08 (0.80-1.45)	0.73 (0.54-0.98)	1.41 (1.19-1.68)
Gender (male vs female/other)	0.81 (0.60-1.09)	1.03 (0.76-1.40)	0.77 (0.65-0.91)
SRH[c] (excellent/very good vs good/fair/poor/prefer not to say)	0.86 (0.61-1.20)	0.89 (0.63-1.25)	0.68 (0.56-0.82)
SRMH[d] (excellent/very good vs good/fair/poor/prefer not to say)	1.03 (0.75-1.43)	0.85 (0.61-1.19)	1.13 (0.93-1.37)
Ethnicity (non-White vs White)	0.55 (0.20-1.53)	0.51 (0.17-1.57)	0.54 (0.31-0.92)
Chronic disease (3 or more vs less than 3)	1.73 (1.21-2.49)	1.27(0.86-1.88)	1.55 (1.22-1.96)
eHEALS[e] score (8-40)	1.03 (1.01-1.05)	1.04 (1.01-1.06)	1.03 (1.01-1.04)

[a] OR: odds ratio.

[b] A currency exchange rate of CAD $1=US $0.78 is applicable.

[c] SRH: self-rated health status.

[d] SRMH: self-rated mental health status.

[e] eHEALS: eHealth Literacy Scale.

Discussion

Principal Findings

This study investigated the demand for and use of virtual care by older adults from a cross-sectional web survey of Canadians during the COVID-19 pandemic. Bivariate associations suggest that older adults' demand for virtual care is partially driven by the need for health services caused by health conditions (ie, multimorbidity) and partially associated with eHealth literacy levels. Patients with more chronic conditions and worse SRHS were more likely to express a demand for virtual visits. eHealth literacy and socioeconomic factors known to be associated with eHealth literacy among older adults, such as education and income [15,16], were also significantly associated with the demand for virtual visits. The demand for all types of virtual visit modalities was negatively associated with income and education. Older adults with low household income and less education had lower odds to express a demand for virtual visits. In addition, our results suggested that older adults who were non-White and who were English speakers had lower odds to demand video visits and secure messaging. Compared to video visits and secure messaging, a greater proportion of older adults from our sample expressed a demand for telephone visits. The same trend was observed for the use of telephone visits: a greater proportion of older adults have used telephone visits during the past 12 months. We identified multiple socioeconomic, demographic, and health factors associated with the demand for and use of specific virtual care modalities. Specifically, data showed that older adults with lower education and lower income had lower odds of expressing a demand for virtual visits. Additionally, older adults without private insurance coverage had lower odds of using secure messaging. eHealth literacy was a significant predictor of the demand for and use of all modalities of virtual visit.

The literature looking at patient characters and its association with the demand for virtual care among older adults is scarce. A recent report by Health Canada found that individual socioeconomic status, including income and education, plays a key role in influencing access to virtual care [16]. One recent US study looking at interest in telehealth visits for individuals aged 50-80 years found that when compared to individuals with a high school degree or less, those with at least an undergraduate degree are less likely to show interest in telehealth [17]. The same study also found that White individuals have the lowest level of interest [17]. Variations in payment models between Canada and the U.S. could, in part, explain the difference in findings on ethnicity and education. Non-White and individuals with less education in the U.S. could face greater barriers when it comes to paying for in-person visits and other costs associated with an in-person visit (eg, transportation, job flexibility). The Canadian public health care system eliminates direct costs associated with in-person visits, making virtual care a complementary service rather than a substitute to in-person visits. Another US study that investigated the disparities in virtual care use by older adults suggested that non-White patients are less likely to have video visits when compared to White patients [18]. The association between ethnicity and the use of virtual visits seems to be more nuanced than what has been studied thus far. Additional research is needed to ensure that older adults who are ethnic minorities have access to all types of virtual care modalities.

Lower reported usage of video visits and secure messaging services may be related to financial and technological barriers, such as a lack of digital equipment, internet access, and al ack of skills to navigate technology [19]. Consistent with the past literature, participants with low household income are less likely to conduct a video visit [20,21]. A recent Infoway analysis demonstrated that higher-income groups were more likely to use virtual care when compared to lower-income groups [22]. Considering that some video visits were offered by private and for-profit vendors during the pandemic, it is likely that income would become a barrier to using virtual health technologies that are not covered under the public payment plan. In addition, cohort research looking at virtual care usage during the pandemic has suggested a digital divide between telephone and video use based on race, income, and age. Studies have found that older, lower-income individuals use more telephone, while White, higher-income individuals use more video [18,20,23]. The proliferation of private services could also explain the association between insurance status and the use of secure messaging. In response to COVID-19, temporary billing codes were established by all provinces and territories, with the exception of Nunavut [24]. Most provinces provide billing codes to cover synchronous visits through telephone and video, but coverage for secure messaging is sparse [24]. The use of secure messaging services might therefore be limited by private health insurance coverage, as our study suggests. This could also explain the positive association between chronic conditions and the use of video and telephone visits. Older adults with multiple chronic conditions would likely require more health services, and virtual visits as well. The financial barriers associated with the use of secure messaging might explain the lack of significant associations between secure messaging and chronic condition status.

In line with past research, our data show that eHealth literacy is an important driver/constraint for the use of virtual care [15,25]. The past literature on the digital divide suggests that older adults disproportionally suffer adverse consequences from a lack of technological access and literacy [15,26]. Older adults typically face challenges in accessing virtual care due to a lower use of digital health technologies, a lack of motivation to use technology, and a lack of technological equipment and broadband access [20,25]. This could explain the low prevalence for the use of secure messaging and video visits from our study. Secure messaging and video visits are more complex technologies when compared to telephone visits and require the users to have higher levels of digital as well as digital health literacy, which might pose as barriers of access for older adults [27]. In addition, physical barriers, such impaired cognition, hearing, vision, and dexterity, may also cause problems for older adults in using more complex technologies, such as video visits and secure messaging [19]. The observed prevalence is consistent with findings from the U.S., suggesting that older age was associated with lower usage of video and telephone usage during the pandemic [20] and that the majority of virtual visits conducted by older adults during the COVID-19 pandemic were via audio technologies [18]. Older adults from marginalized groups may face additional challenges using complex technologies due to language barriers and income constraints. Patient outcome studies have suggested that the use of telemedicine among older adults can lead to high levels of patient satisfaction and acceptance [19]. Unless programs and policies are put in place to promote digital health technology uptake among older adults, exacerbating the current digital divide will likely lead to more inequities. Our finding adds to the emerging evidence base advocating for improved patient eHealth literacy to close the digital divide and the associated inequalities.

Limitations

Our study suffers from a few limitations. The Canadian Digital Health Survey is a web survey and therefore may limit participation by older adults with limited access to technological equipment and the internet. Therefore, our findings might skew toward older adults with more internet and technology access. Second, the study population was weighted to render a representative sample of the Canadian population. As a result, our sample was predominantly White and therefore may have had more access to technology than other ethnic/culture groups. We did not collect information on the duration or completion of the health encounter and therefore cannot assume that these virtual visits were all successfully completed. The chronic condition of respondents was self-reported. Although our survey question prompted respondents to only report chronic conditions as diagnosed by a health care professional lasting for more than 6 months, it is possible that respondents reported self-diagnosed chronic conditions. Health care utilization was self-reported and may be impacted by recall error, although past research has shown that bias and variance of recall error of health care usage were minimized for the 12-month recall period [28].

Conclusion

Despite limitations, this study provides novel insights into potential drivers and barriers that determine the demand for and use of virtual visits among older adults during the COVID-19 pandemic. We found that despite high levels of demand to access virtual visits among older adults, the rates of usage are much lower, especially for video visits and secure messaging. Lower usage of complex technologies could be caused by financial barriers, inadequate eHealth literacy, a lack of technological equipment and broadband access, and physical limitations. In addition, socioeconomic inequities associated with the use of secure messaging and video services emphasize the need to regulate the proliferation of private, for-profit virtual care vendors. Other socioeconomic and demographic disparities, such as ethnicity, immigration status, and education, that may pose challenges to accessing virtual visits for older adults should be carefully investigated to reduce existing inequities in health service access and health outcomes. Future studies should test the extent to which virtual care can deliver improvements in access to health care services as well as patient experience among older adults.

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EY contributed to the study conception and design, data analysis and interpretation, manuscript preparation, manuscript review, and manuscript editing. SH contributed to manuscript review.

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Conflicts of Interest

None declared.

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Abbreviations

eHEALS: eHealth Literacy Scale
Infoway: Canada Health Infoway
LEO: Léger Opinion
OR: odds ratio
SRH: self-rated health status
SRMH: self-rated mental health status

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Original Paper

Development of a Community-Based e-Health Program for Older Adults With Chronic Diseases: Pilot Pre-Post Study

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Abstract

Background: Chronic diseases may impact older adults' health outcomes, health care costs, and quality of life. Self-management is expected to encourage individuals to make autonomous decisions, adhere to treatment plans, deal with emotional and social consequences, and provide choices for healthy lifestyle. New eHealth solutions significantly increase the health literacy and empower patients in self-management of chronic conditions.

Objective: This study aims to develop a Community-Based e-Health Program (CeHP) for older adults with chronic diseases and conduct a pilot evaluation.

Methods: A pilot study with a 2-group pre- and posttest repeated measures design was adopted. Community-dwelling older adults with chronic diseases were recruited from senior activity centers in Singapore. A systematic 3-step process of developing CeHP was coupled with a smart-device application. The development of the CeHP intervention consists of theoretical framework, client-centric participatory action research process, content validity assessment, and pilot testing. Self-reported survey questionnaires and health outcomes were measured before and after the CeHP. The instruments used were the Self-care of Chronic Illness Inventory (SCCII), Healthy Aging Instrument (HAI), Short-Form Health Literacy Scale, 12 Items (HLS-SF 12), Patient Empowerment Scale (PES), and Social Support Questionnaire, 6 items. The following health outcomes were measured: Montreal Cognitive Assessment, Symbol Digit Modalities Test, total cholesterol (TC), high-density lipoproteins, low-density lipoproteins/very-low-density lipoproteins (LDL/VLDL), fasting glucose, glycated hemoglobin (HbA_{1c}), and BMI.

Results: The CeHP consists of health education, monitoring, and an advisory system for older adults to manage their chronic conditions. It is an 8-week intensive program, including face-to-face and eHealth (*Care4Senior* App) sessions. *Care4Senior* App covers health education topics focusing on the management of hypertension, hyperlipidemia, and diabetes, brain health, healthy diet, lifestyle modification, medication adherence, exercise, and mindfulness practice. Content validity assessment indicated that the content of the CeHP is valid, with a content validity index (CVI) ranging 0.86-1 and a scale-CVI of 1. Eight participants in the CeHP group and 4 in the control group completed both baseline and post intervention assessments. Participants in the CeHP group showed improvements in fasting glucose, HbA_{1c}, TC, LDL/VLDL, BMI, SCCII indices (Maintenance, Monitoring, and

Management), HAI, and PES scores post intervention, although these changes were not significant. For the participants in the control group, the scores for SCCII (management and confidence) and HLS-SF 12 decreased post intervention.

Conclusions: The CeHP is feasible, and it engages and empowers community-dwelling older adults to manage their chronic conditions. The rigorous process of program development and pilot evaluation provided valid evidence to expand the CeHP to a larger-scale implementation to encourage self-management, reduce debilitating complications of poorly controlled chronic diseases, promote healthy longevity and social support, and reduce health care costs.

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KEYWORDS

eHealth; self-management; older adults; chronic disease; community care; elderly; community; innovation; development; pilot; evaluation; health literacy; empowerment; feasibility; engagement

Introduction

The life expectancy of Singaporeans has increased from 76.1 years in 1990 to 84.8 years in 2017 [1]. Multiple socioeconomic factors impact the quality of life among older individuals, including functionally limiting diseases [2]. It is estimated that Singaporeans spend the last 10.6 years in poor health conditions owing to a higher prevalence of chronic diseases [1]. These commonly include diabetes, hypertension, and lipid disorders, which may severely impair the quality of life [3]. Not only the quantity of time spent alive but also quality of life are important. For community-dwelling older adults with chronic diseases, self-management is essential to their quality of life [4]. They are more susceptible to further cognitive impairment, which could drastically compromise their ability of performing self-care [5,6]. Hence, self-management programs allowing early detection and prevention of cognitive impairment can substantially improve healthy aging [7].

Self-management refers to daily activities that individuals take for themselves and families to stay healthy and to care for long-term illness [8]. Individuals are more involved in their self-care and given the opportunity to adopt an active program suitable for their medical conditions [9]. Effective self-management helps older adults to experience improved health outcomes and to reduce medical cost [10].

Self-management is expected to make the health care system more patient-centric by shifting responsibilities toward individuals in terms of making autonomous decisions, adhering to treatment plans, and dealing with emotional and social consequences caused by their medical conditions [9]. It also provides choices for individuals to live in an active and healthy lifestyle. Self-management requires older adults to have a good understanding of the disease itself, the prescribed medication, as well as other procedures related to self-care [11]. Health literacy is the capacity of individuals to obtain, process, and understand basic health information and the services needed to make appropriate health decisions [12]. Hence, improvement in health literacy of chronic disease management empowers older adults to have access, understand, and use health information to make decisions when performing self-management [13]. According to the SIGNS Study conducted by the Centre for Ageing Research and Education, health illiteracy is prevalent among the older Singaporeans [14]. With improved health literacy, community-dwelling older adults are expected to improve their self-management skills [13], helping them to make decisions on suitable health practice and strategies to cope with their chronic diseases.

Additionally, social support from family, friends, and neighbors serves as a complementary strategy for enhancing an individual's self-management skills [15] by providing relevant information, emotional support, and practical help [16]. Social support is closely related to health behavior and health outcomes. For people who have lower economic status or educational levels and who are more socially isolated, educational and counseling interventions developed for their self-management of chronic diseases may be less effective [17]. In this context, social support can significantly compensate for their inequality in health [15]. Daviglus et al [18] developed the concept that family and social network supports play an essential role in keeping the chronic disease under control. Hence, social support significantly contributes to the adherence to the treatment plan as well as self-management behavior [19].

The modern health care system leverages on innovation and technologies to empower patients and families in self-care. Compared to conventional approaches to patient education, new eHealth solutions such as mobile health, web-based learning, and telehealth significantly increase patients' health literacy and empower them in self-management [20-22]. Multiple studies have shown that eHealth solutions have positive impacts on chronic disease management through effective patient education and increased medication adherence [23,24]. Therefore, eHealth is actively promoted powered by information technology. Health illiteracy among the older population has negative health outcomes and increases health care costs [14]. It is a critical issue for a rapidly aging population in a technology-driven society.

In an aging population, it is necessary to shift the health care landscape toward the community to ease the burden of acute hospitals [25,26]. Such community health care support is provided by multidisciplinary primary care teams to promote effective self-management [27,28]. Having health professionals constantly motivate and support patients to manage the chronic conditions signifies a supportive relationship, thus promoting effective self-management for patients to pursue [28]. In light of the aforementioned gaps and the potential use of technology in bridging these needs, this study aims to develop a Community-Based e-Health program (CeHP) for older adults with chronic diseases and to conduct a pilot evaluation prior to a full-scale interventional program.

Methods

Research Design

This study describes a systematic 3-step process of developing the CeHP, coupled with the use of a smart device application. A pilot study with a 2-group pre- and posttest repeated measures design was adopted.

Setting

Subjects were recruited from Community Nurse Posts at two senior activity centers (SACs) within the neighborhood in the east region of Singapore. The strategic location ensures that the nursing service is convenient and accessible for the older adults living in the community. The services consist of health screening, individual and group health coaching, health and geriatric assessment, chronic disease monitoring and education, care referral and coordination, and complex nursing care [29].

Developing the Intervention

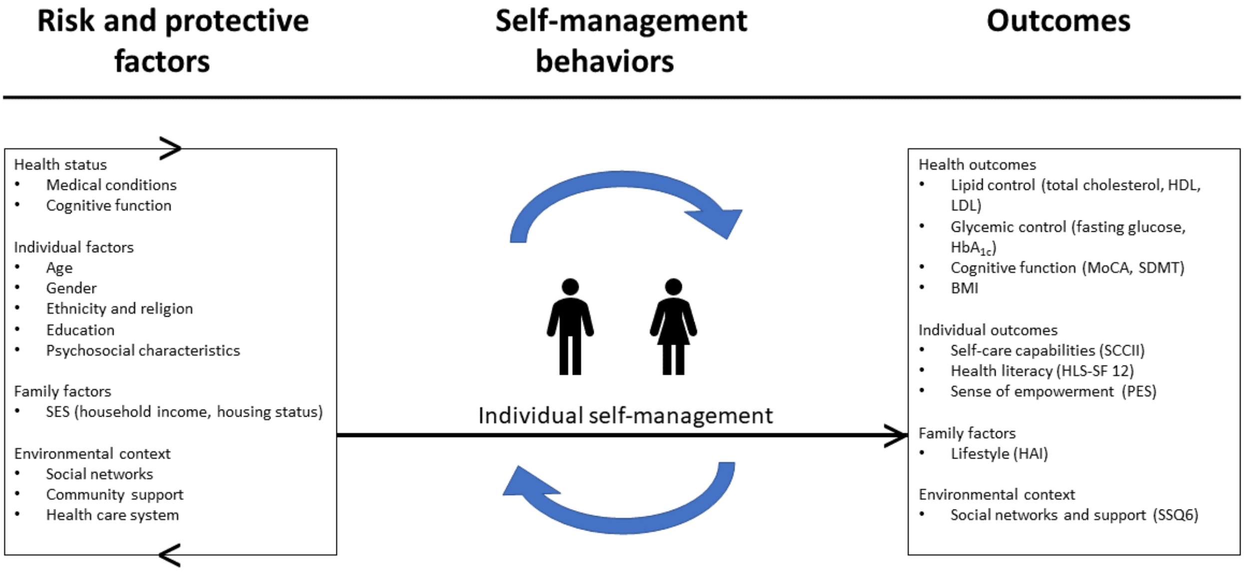
Development of the CeHP consisted of a systematic 3-step process: theoretical framework, a client-centric participatory action research process, content validity assessment and pilot testing.

Theoretical Framework

A systemic scoping review identified the focus of the theoretical approaches was behavior change in most of the self-management programs (SMPs). The most frequently used theory was the social cognitive theory, where the participants' self-efficacy increased as a result of the SMPs, and evidence showed that the associated behavior change could affect various health outcomes [30]. Building on the theoretical foundation, we adopted the concept of self-management, which can capture the complexity of living with medical conditions and managing it in an individual's everyday life [31]. A diverse body of knowledge reflects a number of factors that influence the individual's self-management. The factors influencing self-management are categorized into (1) health status: medical condition; (2) individual: age, gender, self-efficacy, integration, diversity; (3) family: socioeconomic status, family function; and (4) environmental: social networks, community, and health care system [32].

The individual's self-management is interactive and influences a variety of health outcomes, especially for individuals living with chronic conditions. In our study, the following outcomes in relation to the factors are measured: (1) health outcomes: cognitive function (Montreal Cognitive Assessment [MoCA], Symbol Digit Modalities Test [SDMT]), lipid profile (total cholesterol [TC], high-density lipoprotein [HDL] cholesterol, and low-density lipoprotein [LDL]/very-low-density lipoprotein [VLDL] cholesterol), glycemic profile (fasting glucose and glycated hemoglobin [HbA_{1c}]), and BMI; (2) individual outcomes: sociodemographics, self-care capabilities (Self-care of Chronic Illness Inventory [SCCII]), health literacy (Short-Form Health Literacy Scale, 12 Items [HLS-SF12]), empowerment (Patient Empowerment scale [PES]); (3) family outcomes: lifestyle (Healthy Aging Instrument [HAI]); and (4) environmental outcomes: social networks and support (Social Support Questionnaire, 6 items [SSQ6]) (Figure 1) [32]. Self-management may influence how environmental resources, such as health care system and community support, are accessed and utilized, and the nature of interactions with health care professionals. Reasonable targets could be set with the potential to alter the behavioral changes and health outcomes. For example, interventions may target at psychosocial factors, family functioning, or working with the individuals to develop and enhance the self-management capabilities. Hence, CeHP is targeted at working with the individuals to develop and enhance their self-management capabilities.

Figure 1. Self-management framework. HAI: Healthy Aging Instrument, HbA_{1c}: glycated hemoglobin, HDL: high-density lipoprotein, HLS-SF 12: Short-Form Health Literacy Scale, 12 Items, LDL: low-density lipoprotein, MoCA: Montreal cognitive assessment, PES: Patient Empowerment Scale, SCCII: Self-care of Chronic Illness Inventory, SDMT: symbol digit modalities test, SES: socioeconomic status, SSQ6: Social Support Questionnaire, 6 items. [32].



Client-Centric Participatory Action Research Process

CeHP was developed to promote older adults' self-management capabilities with their chronic conditions. CeHP was designed through a 3-stage iterative, client-centric, participatory action research process [33]. First, a front-end analysis was conducted to identify the unique health care needs of older adults and initial design ideas through focus groups and literature search. Second, a preliminary design of the intervention was developed from the literature and focus group findings. Finally, we iteratively incorporated revisions and refinements on the basis of client-centric feedback, which was collected during usability sessions.

Stage 1: Front-End Analysis

A comprehensive search and evaluation of existing eHealth interventions were carried out. Evaluation from the evidence-based literatures provided a fundamental understanding of the current interventions. A systematic review examined community-based SMPs for older adults with chronic conditions and evidenced that SMPs involved fostering skills to improve problem-solving, health behavior, and disease management [34]. However, this review highlighted that SMPs need to broaden the strategies to be more patient-centered by helping older adults manage the impact of the conditions on their daily lives, and to provide strategies for managing interacting symptoms, treatments, and everyday problems due to the high prevalence of multiple morbidities in older adults [34]. A recent meta-analysis provides evidence that educational intervention is effective to improve the health literacy of the perceived severity and susceptibility of the patients' medical conditions, and perceived benefits of the treatment, and increased medication adherence among adult patients diagnosed with hypertension, hyperlipidemia, or diabetes [35]. The educational interventions consist of face-to-face counseling with the participants on the diseases, complications, medications, side effects, adherence, lifestyle changes, self-monitoring, and self-management skills [35].

We have conducted a meta-analysis on the technology-based interventions on diabetes, and the results indicate that technology-based psychosocial interventions had significant effects on diabetes distress, self-efficacy, and HbA_{1c} levels in adults with type 2 diabetes mellitus (T2DM) [36]. The technology-based interventions consist of telephone-based health coaching, telemonitoring, computer-assisted self-management, web-based programs and tools, and mobile apps. Nevertheless, an integration of technology-based psychosocial interventions into usual care can enhance treatment for older adults with T2DM [36]. In the current COVID-19 pandemic situation, telehealth applications have provided solutions to facilitate the care of older adults with chronic conditions, and the medical apps delivered virtual assessments and treatments, improved medication adherence for older adults, and supported the health care professionals during the pandemic [37].

Our researchers conducted focus groups with older adults to explore their needs regarding eHealth. Three focus group discussions were conducted, and the thematic analysis was carried out. Three major themes emerged from the analysis: (1) personal approach in living with chronic diseases (older adults applied positive thinking and accepted the needs to change their habits and follow the instructions of health care professionals); (2) navigating health-related information (older adults obtained health information from health care professionals, health talks from reputable organizations, experiences of friends or family, internet resources, talk shows in the media, and web-based videos); and (3) decision-making on sieving credible eHealth information (older adults often experienced online health resources are overwhelming and confusing, they either turn to health care professionals for advice or use own experience and knowledge to judge the reliability and credibility of the web-based health resources). Details of the qualitative study will be published in a subsequent paper. In addition, our recent scoping review also highlighted the concerns of older adults on the barriers of web-based interventions, such as the lack of access and proficiency in technology, or the lack of interest in the use of digital technologies [37].

Stage 2: Design and Development

With inputs from the literature and focus groups, the researchers developed the preliminary contents of the CeHP. Based on client-centric design suggestions, the following principles guided the development of the CeHP: (1) the intervention must be designed for older adults, (2) the content must be related to the specific health knowledge deficits that were identified during focus group and literature evaluations, and (3) the content needs to be delivered in a brief and skimmable format to fit the attention span and cognitive capabilities of the older adults. The details of the contents are presented in the Results section.

Stage 3: Formative, User-Centric Evaluation

Formative evaluation took the form of multimodal usability testing [38,39] which sought to elicit feedback on applicability, content, ease of use, acceptance, and time to complete the modules. Feedback was collected from the participants during the development of the intervention on the usage information and usability testing, which were subsequently used to further extend and refine the intervention [40].The formative evaluation generated input regarding revisions and modifications that informed the design and development of the CeHP.

Content Validity Assessment

A committee of experts was formed to evaluate the content validity of the CeHP, including 2 nurse clinicians, 2 physicians, a dietician, a physiotherapist, and a pharmacist, specifically on the clinical relevance and quality of the contents. They rated the contents from 1 (not relevant/appropriate/comprehensive) to 4 (very relevant/appropriate/comprehensive). Content experts were required to provide feedback if they had rated any learning point 2 and below on any of the aspects.

Pilot Test of the Study Intervention

Sampling and Recruitment Process

Convenience sampling was used. Recruitment was carried out through word of mouth and recruitment poster at 2 SACs. The inclusion criteria were as follows: (1) age ≥55 years; (2) being able to understand and communicate in either English or Chinese (Mandarin); (3) being able to give consent to participate; (4) living within the community setting; (5) being diagnosed with at least one of these chronic conditions (hypertension, hyperlipidemia, or diabetes mellitus); and (6) being able to commit to the 8-week CeHP. The exclusion criteria are as follows: (1) having severe cognitive impairment; (2) having severe psychiatric disorders; (3) having severe vision impairment; and (4) having severe hearing impairment. Participants in the intervention group were recruited from SAC 1, and they completed the CeHP regimen. Participants in the control group were recruited from SAC 2, and they continued with their usual recreational programs. Recruitment was carried out at 2 SACs at different physical locations to minimize contamination between the two groups.

Data Collection Procedure

The questionnaires were administered at two time points: baseline and post intervention. Two trained researchers conducted face-to-face sessions. The questionnaires were conducted in the participants' preferred language, either English or Chinese (in the participant's preferred dialect). Each session lasted 45-60 minutes. Each participant was given a cash reimbursement after completing questionnaires and providing blood samples. A maximum of 9 mL of blood in ethylenediaminetetraacetic acid (EDTA) blood tubes was collected from every participant at each time point. The responses were recorded using the web-based e-Survey platform approved by the university. Sociodemographic and clinical data such as age, gender, ethnicity, marital status, employment status, education, housing type, morbidities, alcohol intake, smoking status, and physical activity were recorded. Clinical data such as TC, HDL, LDL/VLDL, fasting glucose, HbA_{1c}, and BMI were also measured before and after the intervention.

Psychosocial Measures

The SCCII [41] assesses the process of self-care by individuals with a variety of chronic conditions. It consists of 30 items with 5-point Likert scales to evaluate self-help behavior, symptom management, health-seeking behavior, and self-care confidence. The HAI [42] focuses on how healthy and active lifestyle among the elderly is considered. The HAI includes nine components: Being self-sufficient and Living Simply, Managing Stress, Having Social Relationships and Support, Making Merit and Good Deeds, Practicing Self-care and Self-awareness, Staying Physically Active, Staying Cognitively Active, Having Social Participation, and Accepting Aging. HAI has 35 items on a 5-point scale. A higher score represents greater healthy aging levels. The HLS-SF 12 measures the competency of an individual when dealing with health-related information [43]. It consists of three domains including health care, disease prevention, and health promotion. The PES [44] is a 15-item scale developed to assess empowerment and the patient's sense of control over their illness experience [45]. The SSQ6 measures the number of people providing support to an individual and the satisfaction level of the individual who received the support [46].

Brief Cognitive Tests

The MoCA is a screening instrument to detect mild cognitive impairment [47]. A study has shown that MoCA may be relatively more sensitive in detecting characteristic cognitive deficits due to cardiovascular diseases prevalent in Asian elderly, and it takes approximately 12 minutes to complete [48]. The SDMT is a sensitive processing speed test and is added to supplement MoCA for optimal cognitive screening. The SDMT is widely used and takes approximately 5 minutes to complete [49]. Cognitive ability affects the self-care behavior of patients with chronic disease. Assessment of cognitive function through the MoCA and the SDMT may help inform interventions to improve the self-care behavior in these patients.

Bioassay Procedures

Upon collection of blood samples, the EDTA tubes were centrifuged at 1500 *g* for 5 minutes at room temperature to separate plasma from other blood components. After centrifugation, plasma was collected, aliquoted in different tubes, and stored at –80°C for downstream analyses. Plasma glucose level was measured using the glucose assay kit (Sigma Aldrich, MK286) whereas TC, HDL, and LDL/VLDL levels were measured using the AF HDL and LDL/VLDL assay kit (Sigma Aldrich, MK331) in accordance with the manufacturer's protocol. Absorbance was measured at 570 nm using the SpectraMax M2 microplate reader (Molecular Probes). Plasma glucose level and TC, HDL, and LDL/VLDL levels were calculated from the standard. HbA_{1c} levels were determined using a Beckman UniCel DxC600 Chemistry Analyzer (Beckman Coulter), with hemoglobin levels measured using a colorimetric method at 410 nm, and glycation levels measured using a turbidimetric immunoinhibition method at 340 nm.

Data Analysis

Descriptive statistics, including mean (SD) and percentages, were used to summarize the demographic information and outcomes at baseline and post intervention. A paired samples *t* test was used to examine the difference between the baseline and postintervention periods and to compare outcome measures before and after implementation among participants. All analyses were conducted using RStudio (version 1.1) implementing R (version 3.4) [50], and the significance level was set at 5%.

Ethical Issues

Ethical approval was obtained from the university's institutional review board (H-20-028) and the hospital's Centralised Institutional Review Board (Ref 2020/2051). Researchers explained the purpose of the study to potential participants. Informed consent was obtained from the participant prior to data collection. The participants were reassured that participation in the study was voluntary, and withdrawal from the study would not result in any negative consequences. Confidentiality and anonymity were maintained as no identifiers were recorded in the questionnaires.

Results

Outline of the Community-Based eHealth Program

The CeHP consists of health education, monitoring function, and an alert and advisory system for older adults to manage their chronic conditions (Figure 2). The CeHP is an 8-week intensive program, consisting of face-to-face and eHealth (*Care4Senior* App) sessions. Face-to-face session covers health education topics such as diet, exercise, and brain health, which are available in *Care4Senior* App. *Care4Senior* App can be installed on smart devices. *Care4Senior* has unique features including a health library, daily care, exercises, quizzes, interactive videos, and administrative platform (Figure 3). *Care4Senior* consists of health education topics focusing on management of hypertension, hyperlipidemia, and diabetes, brain health, healthy diet, lifestyle modification, medication adherence, exercise, and mindfulness practice (Figure 4). Each module consists of animated videos of conversations between a fictional elderly couple, and health education topics. A prototype of *Care4Senior* App has been developed by the technical team.

Figure 2. Conceptual outline of the Community-Based e-Health Program.

Figure 3. Care4Senior App - Main Screen.

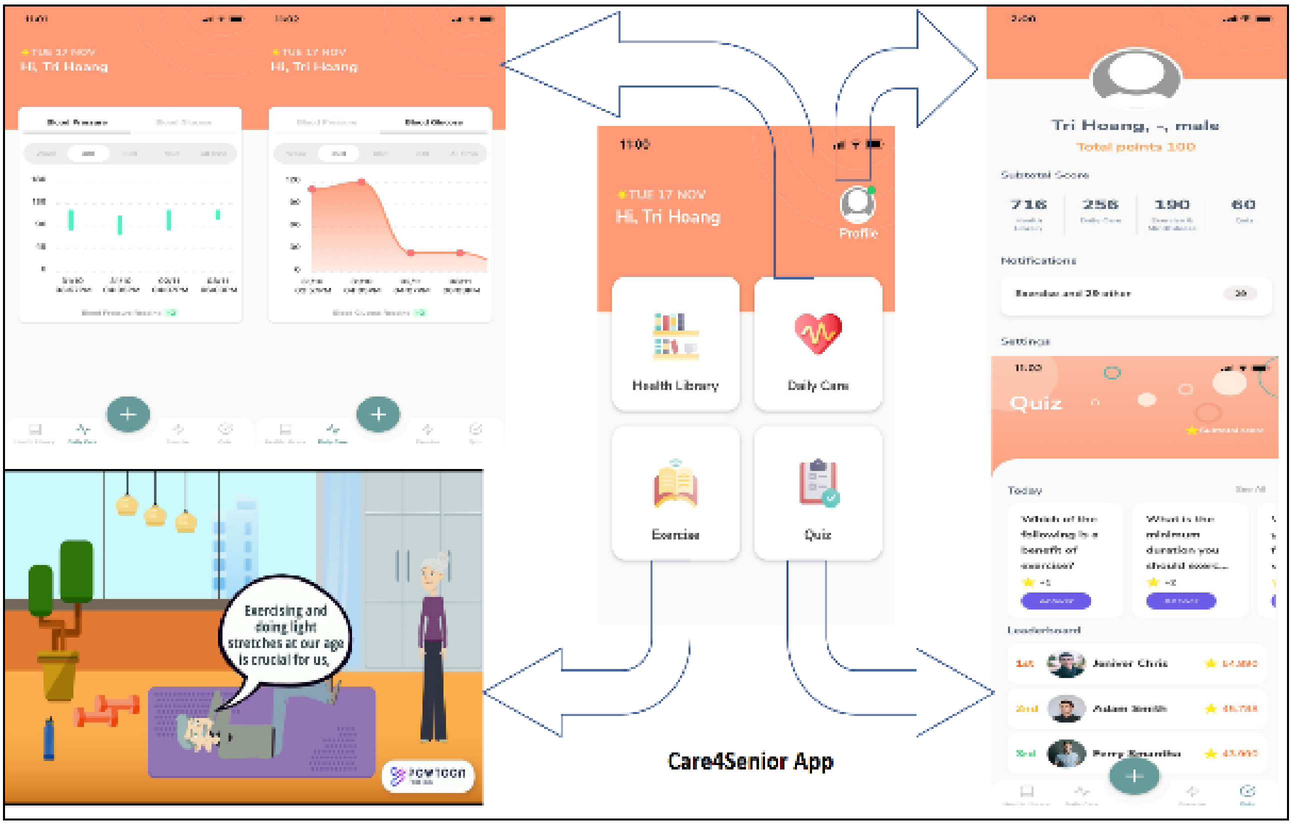
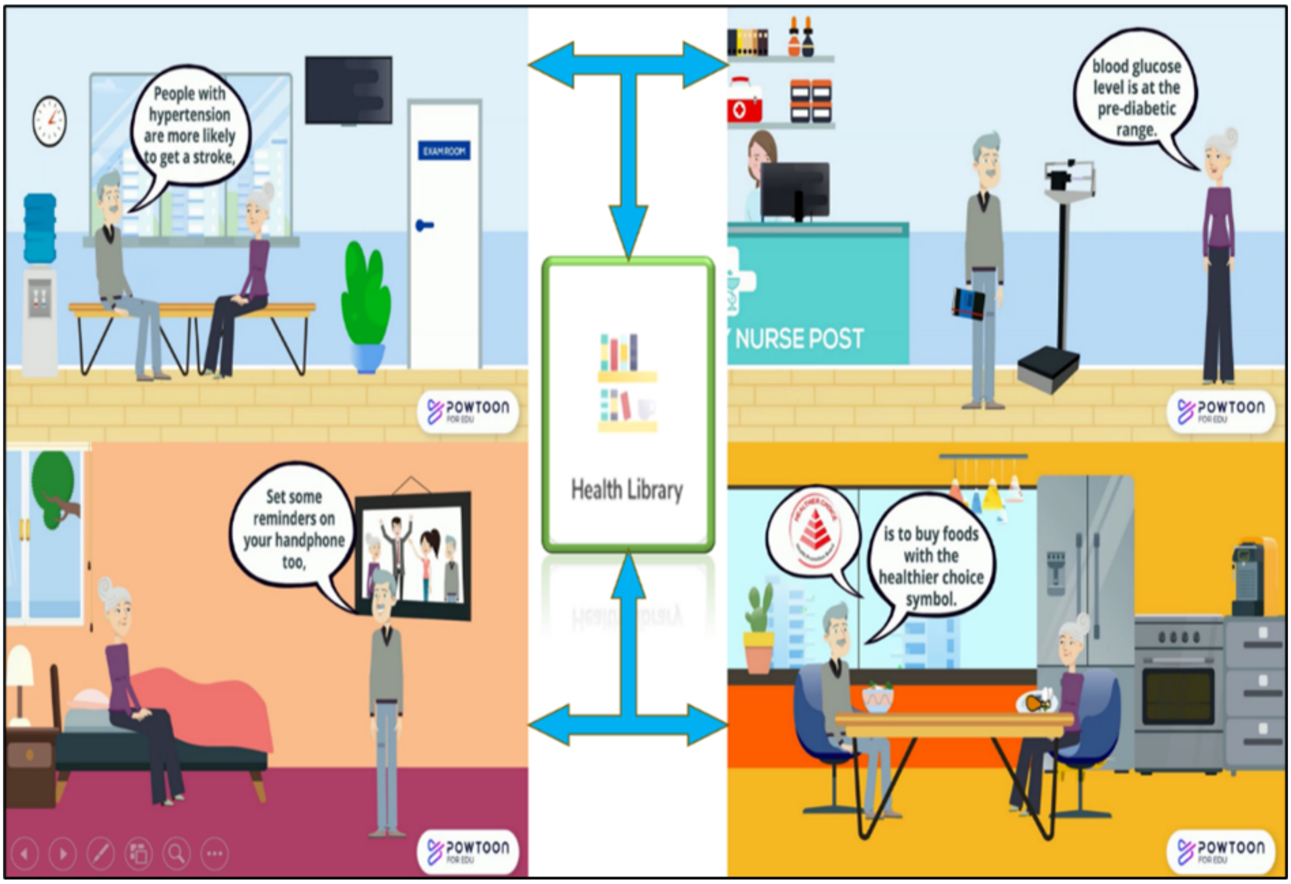


Figure 4. Care4Senior App - Health Library.



Mode of Delivery

During the intervention, the research team conducted weekly face-to-face training and evaluated the participant's competency in using the *Care4Senior* App. The older adults could then continue with the *Care4Senior* App at home. Researchers monitored participants' App usage closely via the administrative platform of the App; for example, blood pressure and glucose entry, and quiz status. A reminder was sent to the participants through the phone if their blood pressure and glucose reading were not entered or were beyond the normal range. The CeHP provides a platform to improve the overall clinical outcomes for older adults living with chronic diseases by empowering them with self-care skills.

Results of the Content Validity Test

The content validity index (CVI) was calculated, and only when both item-CVI and scale-CVI values were above 0.8, the content of the program would then be considered valid [51,52]. Our results indicate that the content of CeHP is valid since item-CVI ranged 0.86-1 and the scale-CVI was 1. Positive feedback has been received from 7 content experts that the CeHP is well-structured and covers common chronic diseases, which are helpful for older adults to gain knowledge about self-management through medication compliance and lifestyle modification. Nevertheless, content refinement was carried out for those items rated below 2. The item-CVI for revised content became 1 after reassessment by content experts. Based on the feedback, the research team fine-tuned the contents to ensure accuracy. Meanwhile, there were also concerns that the content might be overwhelming for the participants. Content experts suggested rephrasing certain terminologies for participants with lower literacy levels. Researchers readjusted the font size, reduced wordy contents, and added more pictures to be more senior-friendly.

Results From the Pilot Evaluation

Among all screened and invited participants, a total of 15 participants enrolled in the pilot study. However, owing to drop-outs, 8 participants in the intervention (CeHP) group and 4 in the control group completed both baseline and postintervention assessments. Figure 5 shows the recruitment and program flow. Table 1 shows demographic and clinical characteristics of the participants. The Student *t* test and Pearson chi-square test revealed no significant difference between CeHP and control group participants. The mean age of the participants was 74.4 years (CeHP group) 69.75 years (control group). All participants in the CeHP group were of Chinese ethnicity, and 7 of them (88%) were female. One participant in the control group is of Malay ethnicity, and 50% of the participants were female. All participants stayed in public housing and were independent and ambulating. All participants had at least one of the chronic illnesses (hypertension, hyperlipidemia, or T2DM). Participants in the CeHP group were mostly compliant with the seminar regimes except when they had other commitments such as medical visits or work (attendance rates are shown in Table S1 in Multimedia Appendix 1). Participants also rated the design and user-friendliness of the app as above average on a 5-point scale (Table S2 in Multimedia Appendix 1).

Figure 5. Flowchart of participant recruitment for the Community-Based e-Health Program (CeHP).

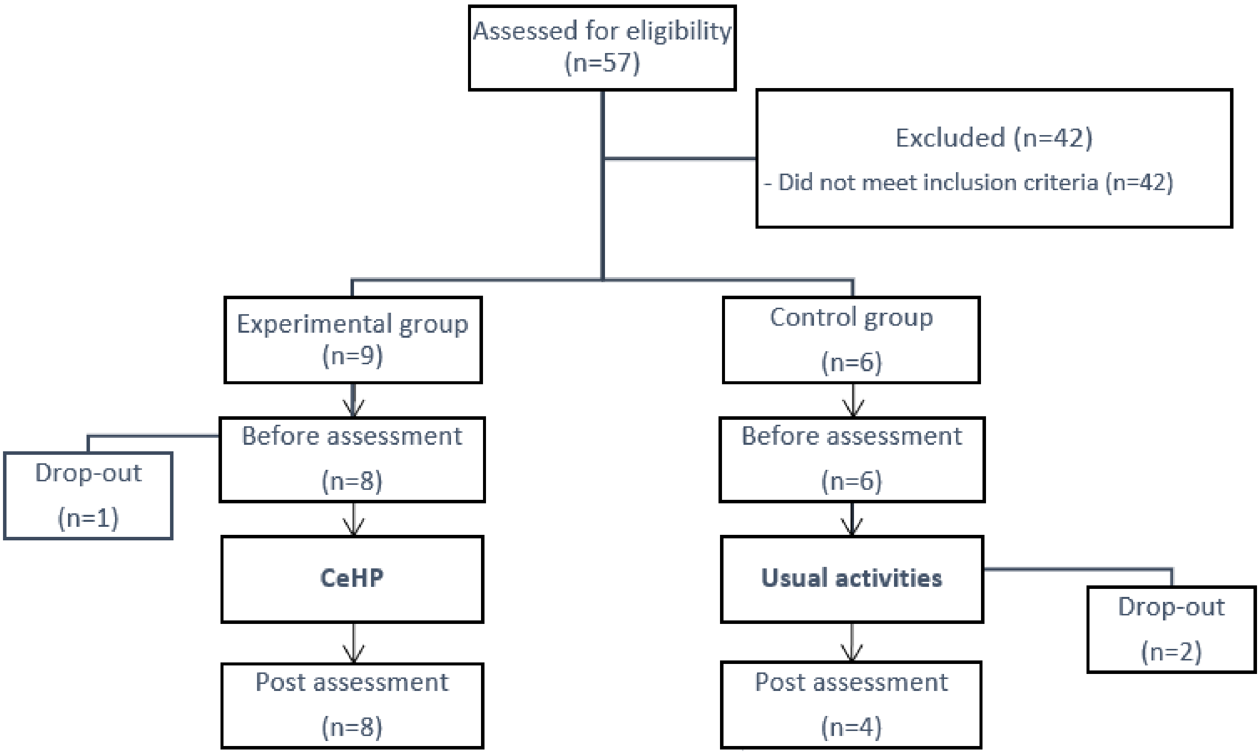


Table 1. Demographic and clinical characteristics of participants in pilot evaluation.

Variables	Community-Based e-health Program group (n=8)	Control group (n=4)	*P* value[a]
Age (years), mean (SD)	74.4 (6.22)	69.75 (8.34)	.38
Gender, n (%)			.48
Male	1 (12.5)	2 (50)	
Female	7 (87.5)	2 (50)	
Race, n (%)			.71
Chinese	8 (100)	3 (75)	
Malay	0	1 (25)	
Marital status, n (%)			.22
Single, separated, or divorced	3 (37.5)	0	
Married	1 (12.5)	2 (50)	
Widowed	4 (50)	2 (50)	
Highest education level, n (%)			>.99
None or primary education	6 (75)	3 (75)	
Secondary school and above	2 (25)	1 (25)	
Employment status, n (%)			>.99
Working	1 (12.5)	0	
Not working or retired	7 (87.5)	4 (100)	
Housing type, n (%)			.15
HDB[b] studio apartment	3 (37.5)	4 (100)	
HDB 3-room apartment and above	5 (62.5)	0	
Living status, n (%)			.28
Alone	4 (50)	0	
With others	4 (50)	4 (100)	
Physical exercise, n (%)			.71
>3 times per week	8 (100)	3 (75)	
Never	0	1 (25)	
Current smoker, n (%)	0 (0)	1 (25)	.71
Regular drinker, n (%)	0 (0)	1 (25)	.71
Hypertension, n (%)	6 (75)	4 (100)	.78
Hyperlipidemia, n (%)	7 (87.5)	3 (75)	>.99
Type 2 diabetes, n (%)	3 (37.5)	4 (100)	.15

[a] Age was compared using the Student *t* test, whereas other categorical characteristics were compared using the Pearson chi-square test or the Fisher exact test.

[b] HDB: Housing and Development Board.

Table 2 shows the psychosocial, cognitive, and blood test findings before and after the intervention. Participants in the CeHP group demonstrated improvements in fasting glucose, HbA_{1c}, TC, LDL/VLDL, BMI, 3 of 4 SCCII indices (in the following domains: Maintenance, Monitoring, and Management), and HAI and PES scores, though the changes are not significant. Among control group participants, the scores for the two domains (Management and Confidence) from SCCII and HLS-SF 12 decreased after the intervention. The participants' (control group) fasting glucose and TC levels were also higher post intervention than during baseline assessment; however, these differences were not significant.

Table 2. Mean scores of study outcomes.

Measures	Community-Based e-Health Program group (n=8), mean (SD)			Control group (n=4), mean (SD)		
	Baseline	Post intervention	*P* value[a]	Baseline	Post intervention	*P* value[a]
Psychosocial measures						
Self-care of Chronic Illness Inventory indices						
Maintenance	85.94 (10.83)	93.36 (4.85)	.09	83.59 (4.69)	87.5 (14.66)	.56
Monitoring	67.29 (24.53)	70.0 (13.09)	.81	52.92 (13.77)	63.5 (16.56)	.28
Management	54.0 (10.47)	61 (8.21)	.13	60 (10.83)	54 (12.44)	.18
Confidence	87.81 (9.95)	87.5 (10.69)	.95	83.13 (10.08)	78.75 (12.67)	.37
Healthy Aging Instrument	147.63 (17.07)	149.75 (6.82)	.68	136.25 (23.26)	148.25 (15.59)	.10
Patient Empowerment Scale	40.63 (3.38)	43.75 (8.31)	.29	39.50 (2.08)	47.25 (7.54)	.08
Social Support Questionnaire, 6 items satisfaction total score	29.63 (4.44)	28.75 (4.56)	.61	27.75 (5.68)	28.25 (4.79)	.70
Health Literacy Survey Short Form (HLS-SF12) Index	30.56 (3.32)	30.38 (4.03)	.78	29.51 (6.35)	26.39 (6.0)	.06
Cognitive tests						
Montreal cognitive assessment total score	25.13 (3.40)	23.13 (4.36)	.20	19.75 (3.30)	20.0 (5.72)	.87
Symbol digit modalities test score	27.5 (9.68)	26.0 (14.25)	.56	18.75 (2.99)	19.75 (3.59)	.51
BMI	25.19 (3.76)	24.78 (4.06)	.35	25.36 (3.48)	.20	.68
Biomarkers						
Fasting glucose (mg/dL)	90.77 (28.32)	84.12 (13.47)	.26	110.54 (24.95)	124.88 (71.36)	.58
Glycated hemoglobin (%)	6.49 (0.84)	6.31 (0.60)	.11	8.13 (0.49)	7.18 (0.63)	.07
Total cholesterol (mg/dL)	115.30 (7.76)	114.99 (4.76)	.94	110.29 (8.12)	111.53 (9.14)	.68
High-density lipoprotein cholesterol (mg/dL)	35.36 (10.46)	31.38 (7.41)	.29	31.20 (5.83)	32.21 (4.52)	.80
Low-density lipoprotein/very-low-density lipoprotein cholesterol (mg/dL)	103.91 (10.49)	99.10 (16.24)	.25	93.69 (12.55)	88.86 (17.35)	.28

[a] *P* values determined through the Student paired *t* test.

Discussion

Principal Findings

This paper illustrates a systematic 3-step process of developing a community-based health education program coupled with the use of a smart-device application. Development of the intervention consists of a theoretical framework, a client-centric participatory action research process, and psychometric testing. The rigorous process ensured the validity of the intervention, and explicitly reporting the detailed description of the intervention could facilitate replication of the intervention in the future.

The prevalence of chronic diseases is increasing among the older population. Hypertension, hyperlipidemia, and T2DM are the most common chronic conditions among community-dwelling older adults. The progression of diseases and impact on quality of life can be tapered off by active treatment and self-management. By promoting health literacy and awareness of community health resources, it is feasible to reduce debilitating complications of poorly controlled chronic conditions and subsequent hospitalization, which contributes to the burden of the health care system [53].

The results from the pilot test revealed that the CeHP was feasible and potentially effective in improving self-management capabilities of older adults. The pilot test demonstrated improvements in fasting glucose, HbA_{1c}, TC, LDL/VLDL, BMI, SCCII indices, HAI scores, although these changes were not significant, which could be due to a small sample size. eHealth interventions have gained popularity among older adults in the recent years. Research has shown that daily monitoring via eHealth interventions increased older adults' confidence, control, awareness in managing their conditions, prompted more communication with their doctors, and using monitoring records to review their medications [53,54]. Hence, participants were more proactive in managing their conditions.

The results of the pilot test showed improvements in the PES score, albeit not significant. Research has shown that eHealth interventions improved older adults' self-efficacy for health-decision making and patient-provider communication [55]. As a result, older adults are empowered to take charge in managing their chronic conditions. eHealth interventions have shown improvement in chronic disease self-management and reduced health care utilization [56], which evidenced that eHealth interventions are feasible to be implemented among community-dwelling older adults and are beneficial in reducing health care costs.

With the high attendance rate (86% in average), high overall satisfaction toward the App (75%), and positive user feedback (Multimedia Appendix 1), the pilot test provided evidence that CeHP has excellent features as a senior-friendly App to deliver health-related information to the older adults. With the rapid adoption of information technology in health care, more technology-based interventions will be utilized in the delivery of care. Older adults are a large consumer group for health care services. Hence, service providers need to consider various aspects to facilitate uptake, such as user-friendly e-interventions for older adults and appropriate user training [55].

It is noteworthy that many older adults are not technologically savvy despite the rapid increase in internet-based users among the older adult population [55]. Hence, older adults may require training and support initially in using eHealth interventions [57], as observed by our researchers during the pilot study. Research has shown that older adults are more confident in maneuvering the internet after undergoing the training [56,58]. Portz and LaMendola [57] reported that the average duration of web-based participation among older adults was longer than that in younger cohorts, which could be an indication that older adults tend to be committed to eHealth programs to improve their health outcomes. Multiple studies have shown that older adults living alone reported poor health, which could predict increased hospital utilization [56]. By attending face-to-face group seminar sessions, participants may gain social support from fellow groupmates, which may serve as a complementary strategy for enhancing individual’s ability of self-management through social network to better manage chronic diseases [15,16,18,19].

A systematic review reported that eHealth programs provide support and feedback for a healthy lifestyle and highlighted the evidence on the facilitating factors and barriers [59]. The barriers are lack of motivation and support; however, strong motivation, adequate support, and feedback are facilitating factors for the continuity of eHealth programs [59]. The most frequent motivator is feedback from professionals or peers on the extent to which people have achieved their goals. Hence, eHealth interventions can tap on the resources from volunteers in the community to provide support to the participants. Prior training is necessary to equip the peer volunteers with essential skills [53].

The larger-scale intervention after this pilot evaluation will be compared against a control group in a randomized controlled trial. Owing to low education level in older adults (75% with primary school of below in the pilot trial), we anticipate barriers for these older adults to use technological devices. This will be countered by having face-to-face sessions to teach the older adults in using the *Care4Senior* App. In addition, the app was also developed in both English and Chinese (Mandarin) languages to cater to the needs of elderly population in Singapore.

Limitations

As a pilot evaluation, this phase of the study was carried out to assess its feasibility and refine its structure and operations. The results of the pilot test may be biased owing to the small sample size and the predisposition of the participants being already health conscious. The 8-week duration may also be too short to elicit significant changes in health behaviors that improve health outcomes.

Conclusions

A large proportion of older adults are living with multiple chronic diseases, and thus managing their health in the community is a major public health concern. The CeHP engaged and empowered older adults living in the community to manage their chronic conditions. The rigorous process of program development and pilot evaluation provided valid evidence to extend CeHP to a subsequent larger-scale trial to encourage self-management, reduce debilitating complications of poorly controlled chronic diseases, promote healthy longevity and social support, and reduce health care costs. In the future, eHealth interventions can tap on the resources from volunteers in the community to provide support to the older adults.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Face-to-face seminar attendance rates and participants’ ratings regarding app design and user-friendliness.

[DOCX File , 17 KB - aging_v5i1e33118_app1.docx]

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Abbreviations

CeHP: Community-based e-Health Program
EDTA: ethylenediaminetetraacetic acid
HAI: Healthy Aging Instrument
HbA_{1c}: glycated hemoglobin
HDL: high-density lipoprotein
HLS-SF 12: Short-Form Health Literacy Scale, 12 Items
LDL: low-density lipoprotein
MoCA: Montreal Cognitive Assessment
PES: Patient Empowerment Scale
SAC: senior activity center
SCCII: Self-care of Chronic Illness Inventory
SDMT: Symbol Digit Modalities Test
SMP: self-management program
SSQ6: Social Support Questionnaire, 6 items
T2DM: type 2 diabetes mellitus
TC: total cholesterol
VLDL: very-low-density lipoprotein

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Original Paper

Investigation of Carers' Perspectives of Dementia Misconceptions on Twitter: Focus Group Study

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Abstract

Background: Dementia misconceptions on social media are common, with negative effects on people with the condition, their carers, and those who know them. This study codeveloped a thematic framework with carers to understand the forms these misconceptions take on Twitter.

Objective: The aim of this study is to identify and analyze types of dementia conversations on Twitter using participatory methods.

Methods: A total of 3 focus groups with dementia carers were held to develop a framework of dementia misconceptions based on their experiences. Dementia-related tweets were collected from Twitter's official application programming interface using neutral and negative search terms defined by the literature and by carers (N=48,211). A sample of these tweets was selected with equal numbers of neutral and negative words (n=1497), which was validated in individual ratings by carers. We then used the framework to analyze, in detail, a sample of carer-rated negative tweets (n=863).

Results: A total of 25.94% (12,507/48,211) of our tweet corpus contained negative search terms about dementia. The carers' framework had 3 negative and 3 neutral categories. Our thematic analysis of carer-rated negative tweets found 9 themes, including the use of weaponizing language to insult politicians (469/863, 54.3%), using dehumanizing or outdated words or statements about members of the public (n=143, 16.6%), unfounded claims about the cures or causes of dementia (n=11, 1.3%), or providing armchair diagnoses of dementia (n=21, 2.4%).

Conclusions: This is the first study to use participatory methods to develop a framework that identifies dementia misconceptions on Twitter. We show that misconceptions and stigmatizing language are not rare. They manifest through minimizing and underestimating language. Web-based campaigns aiming to reduce discrimination and stigma about dementia could target those who use negative vocabulary and reduce the misconceptions that are being propagated, thus improving general awareness.

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KEYWORDS

patient and public involvement; dementia; co-production; misconceptions; stigma; Twitter; social media; Alzheimer's Disease

Introduction

The World Alzheimer's Report [1] highlighted the damaging negative attitudes about dementia, "as the resulting shame, guilt, hopelessness, and social exclusion, lead to delayed diagnosis [2], inability to cope, decreased quality of life [3] and increased burden of dementia (eg, excess disability [4])." These issues also extend to friends, family, and caregivers of individuals with dementia, as they become the target of stigmatizing views "by association" [5]. Myths and misconceptions about dementia can also lead to a lack of open communication [6]. The use of devaluing words, such as "demented" is especially common on social media platforms such as Twitter [7], and many tweets contain language that ridicules the disease and therefore perpetuates the associated stigma [8]. Twitter is a popular international social media service, with the vast majority of tweets being public and thus reaching a wide audience [9]. It also has a high prevalence of stigma towards dementia [10] and therefore lends itself to investigations into misconceptions.

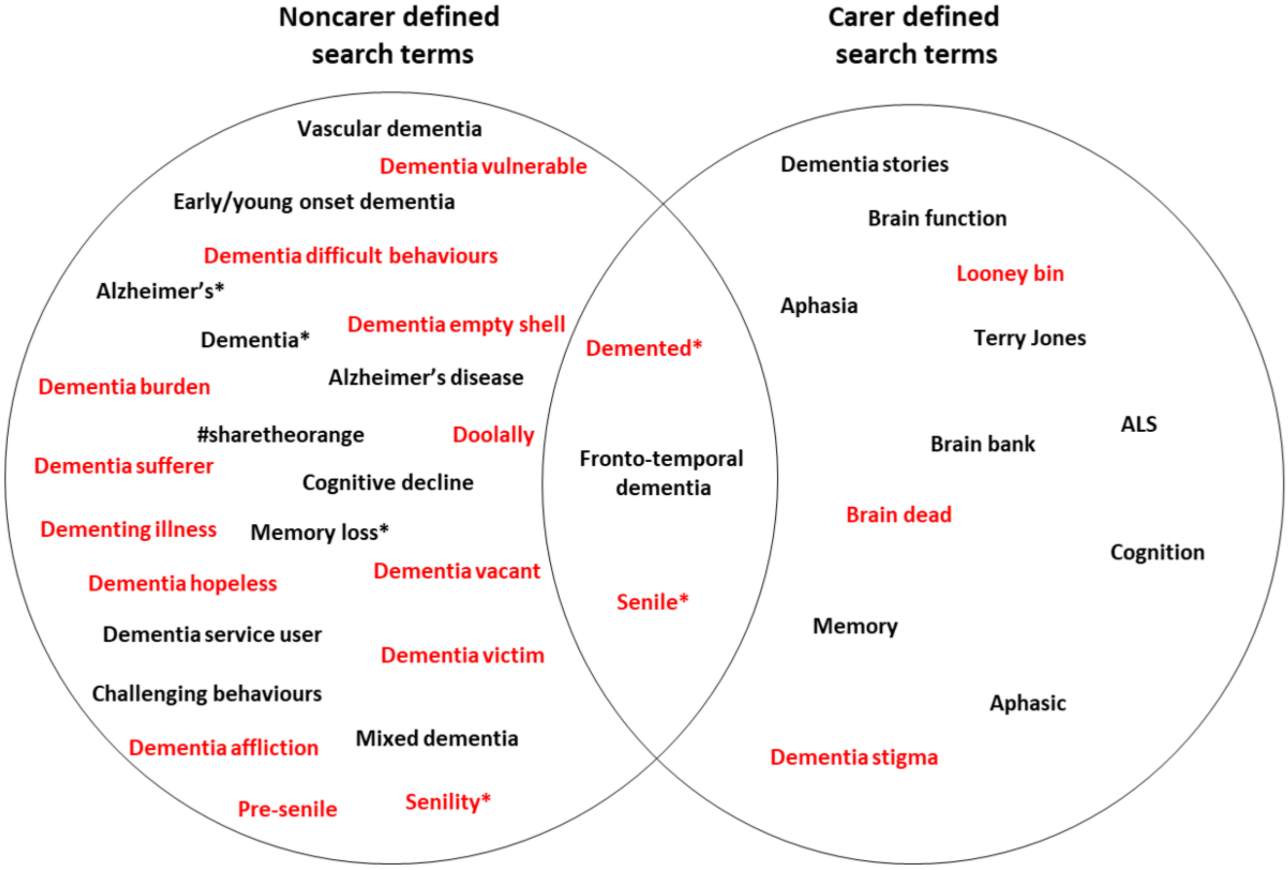
Given the multiple negative consequences, it is surprising that little is known about the prevalence of public misconceptions on social media. Improving the overall knowledge base for dementia, especially a detailed understanding of the types of misconceptions, can provide a baseline from which to challenge misconceptions and stigma [11]. Although previous work examined types of dementia-related conversations on Twitter from the researchers' perspective [12-14], none have taken the views of those with lived experience into account to understand misconceptions. We argue that involvement through participatory methods is the first step to understanding the social media content that perpetuates dementia misconceptions and stigma. This study overcomes this gap by codeveloping a framework with carers to understand, in detail, the forms of dementia misconceptions on Twitter.

Methods

Design

This was a mixed methods study using participatory methods [15,16] with carers of people with dementia. We held 3 focus groups with carers to identify search terms for data collection and generated an initial framework of misconceptions. Search terms (Figure 1) from carers, the literature, researchers' Twitter searches, and dementia awareness campaigns were used to extract tweets (described next in "Tweet Collection and Screening") and carers' feedback iteratively refined the framework. Carers then individually categorized tweets into the framework and their interrater reliability was examined. The final framework was used by service user researchers (researchers with lived experience of using mental health services) to analyze tweets that carers categorized as negative.

Figure 1. Neutral (black) and negative (red) search terms, as defined by carers and noncarers (eg, through researchers' own Twitter search, or the literature). Words with an asterisk were taken from Oscar et al [8].



Participants and Recruitment

Participants were recruited if they had experience caring for someone with a diagnosis of dementia. We recruited from (1) a research advisory group, MALADY [17], made up of dementia carers, and (2) Join Dementia Research, a United Kingdom–wide web-based platform hosted by the National Institute for Health Research (NIHR). Participants were included if they were at least 18 years old and were dementia carers who could give capacity to consent. A total of 7 carers were recruited and invited to take part in as many of the research activities as possible.

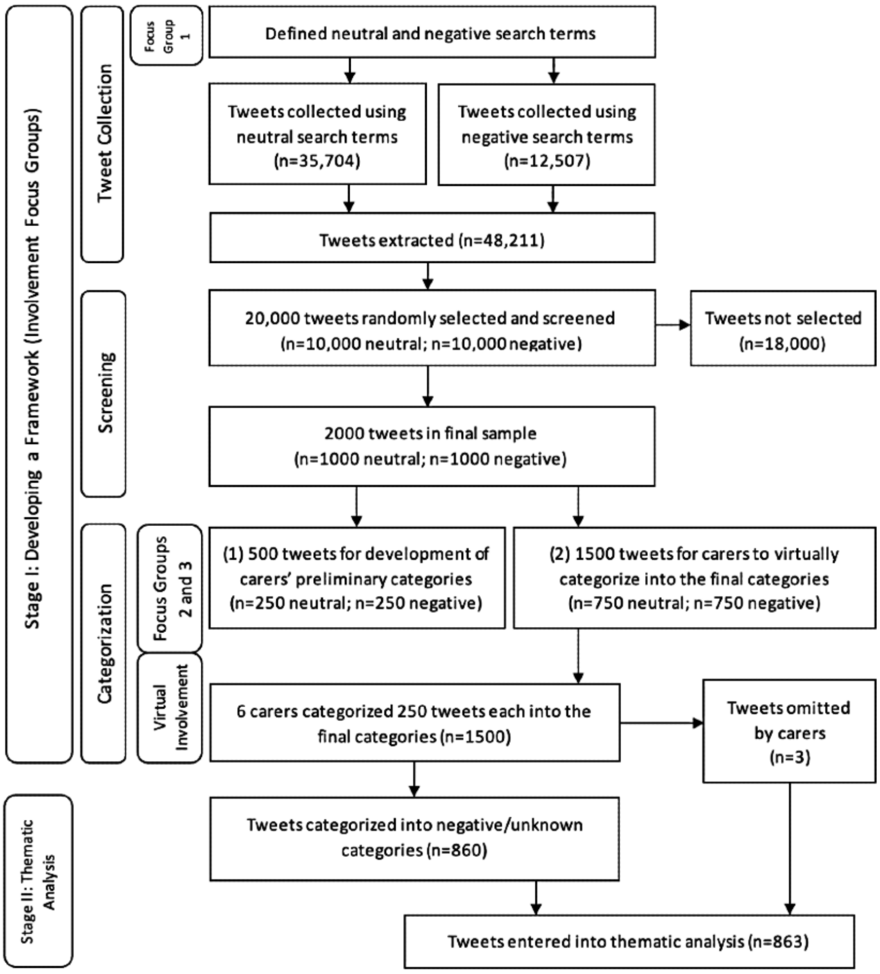
Patient Involvement

Dementia carers were involved as participants and were involved in the design, project management, and data analysis for this paper; they are also authors of this paper.

Tweet Collection and Screening

Publicly available tweets originating from across the world were extracted in real time between February 4 and 7, 2020, using Twitter's streaming application programming interface (API). The connection to Twitter's API was made via Python's open source Tweepy library (Python Software Foundation). Tweets were captured if they contained any occurrence of the English dementia search terms identified by carers, those previously cited by Oscar et al [8], or words identified in tweets from patient advocacy groups or awareness campaigns. Most words were directly associated with dementia (see Figure 1), but some words or phrases not specific to dementia were also included because carers thought they related to negative aspects of dementia. Through a discussion with carers, there was a lack of agreement on what differentiated a positive term from a neutral term; therefore, we asked the carers to simply categorize words as either negative or neutral (which included positive) search terms. All search terms were then defined by carers as negative or neutral. The stages of analysis are shown in Figure 2. A total of 48,211 tweets were collected, 35,704 using neutral search terms and 12,507 using negative search terms (see Multimedia Appendix 1 for a breakdown of tweet collection). To manage this data set, 10,000 neutral and 10,000 negative tweets were randomly selected. From these 20,000, we selected 2000 tweets (1000 negative and 1000 neutral) that met the following criteria: (1) written in English, (2) made clear reference to dementia, (3) had a comprehensible meaning (ie, not a Uniform Resource Locator [URL] or a random string of words generated by a bot), and (4) were neutral or negative. These 2000 tweets were given to carers to carry out 2 tasks. First, carers coded a subsample of tweets (n=500) and subsequently refined their initial framework. Then, carers were given the remaining 1500 tweets to code into the final categories (see Figure 2 for an overview). This number and the types of tweets were defined through discussion with the carers on the burden tweet rating would place on them.

Figure 2. Tweet extraction and categorization, outlining the number of tweets extracted, screened, not selected, and categorized by carers.



Ethical Approval and Procedure

The study was granted ethical approval from the King's College London Psychiatry, Nursing and Midwifery Research Ethics Committee on December 4, 2019 (HR-19/20-14565). The procedure consisted of 2 stages.

Stage I: Developing a Framework (Involvement Focus Groups)

Carer involvement was spread across 3 focus groups. Each group followed a prespecified structure, which incorporated strategies to facilitate coproduction [18]. These focus groups took place in person (Multimedia Appendix 2).

The process of building the framework fell into 3 steps. In step 1, focus group members (n=4) described their experiences, browsed Twitter in order to generate a list of dementia search terms, and categorized the search terms as either negative or neutral (Figure 1). In step 2, the researchers generated an initial framework. In both focus groups 2 and 3, carers (n=5) categorized 250 tweets randomly selected from the sample of 2000 into themes, refined them, and created new ones (Multimedia Appendix 3). The final framework included all their feedback. Finally in step 3, 6 carers were each emailed a different set of 250 randomly collected tweets, and they categorized their set of tweets independently into the final framework. Each tweet was coded only into one category. This step was carried out via email due to the COVID-19 pandemic. Interrater reliability was assessed by each of the 6 carers categorizing 50 rated tweets (10 tweets from each of the 5 other carers). The total number of tweets used for the assessment of interrater reliability was 300.

Stage II: Qualitative Analysis of Tweets

We focused our analysis on the tweets that carers categorized as negative and tweets that carers were unsure of or missed. See Figure 2 for a breakdown of tweet extraction and categorization.

Data Analysis

An interrater reliability analysis using the kappa statistic was performed to determine consistency among carer raters in the final development of the framework. We report the average kappa score across all carers and the range.

Service user researchers carried out a thematic framework approach [19] for the qualitative analysis of the tweets. All tweets that the carers categorized into negative framework categories as well as those categorized as "other" or "I don't know," and the tweets the carers omitted, were thematically analyzed as one data set, employing an inductive, holistic methodology. This process involved (1) familiarization with the data by reading through the tweets, (2) coding the tweets, (3) combining the relevant tweets together, (4) examining the codes (ie, the framework categories) to identify themes, (5) reviewing and refining the themes, and (6) defining and naming the themes. Two researchers independently conducted this analysis using NVivo 12 for Windows (QSR International), identifying themes and subthemes within the framework created by the carers. The researchers compared their coding, and any discrepancies were resolved through discussion between the researchers. A guidance document (Multimedia Appendix 4) was written with the criteria used by the 2 researchers to categorize the tweets, which was used by a third researcher to ensure consistency of the coding process when resolving any coding disagreement.

Results

Participant Characteristics

Carer participant characteristics are summarized in Table 1. See Multimedia Appendix 5 for the breakdown of carer attendance at each focus group. We found 25.94% (12,507/48,211) of our total data set contained misconceptions or stigmatizing language originating from our negative search terms.

Table 1. Participant characteristics, N=7.

Characteristics	Values
Gender, n (%)	
Female	5 (71)
Male	2 (29)
Age (years), mean (SD)	63.33 (11.79)
Ethnicity, n (%)	
White British	6 (86)
Black/Black British	1 (14)
Employment status, n[a] (%)	
Retired	3 (50)
Employed (part-time)	1 (17)
Self-employed	1 (17)
Receiving Employment and Support Allowance (ESA)	1 (17)
Length of time spent being a carer (years), mean (SD)[a]	8.83 (6.59)

[a] For this category, n=6 as there is 1 missing data point; percentages have been calculated accordingly.

Carer Influence on the Framework (Focus Groups 1 to 3)

Carers' feedback from focus groups 1 to 3 was used to construct 6 finalized categories: 3 neutral categories (lived experience, organizational and community group statements, and individual comments on dementia-related topics) and 3 negative categories (minimizing or underestimating words/statements; dehumanizing, weaponizing, or outdated words/statements; and incorrect or questionable words/statements).

Final Tweet Categorization

In step 3, 6 carers categorized 250 tweets each, but 3 tweets were not categorized, leaving 1497 categorized tweets. See Table 2 for the number of tweets falling into each category.

There was fair agreement between carers across 6 categories (3 neutral and 3 negative) on average in the framework (κ=0.43; range 0.067-0.7). Agreement was better when we aggregated the data to investigate agreement between neutral and negative categories, but there was still evidence that carer views differed (κ=0.92; range 0.5-1).

Table 2. Carer attribution of tweets into each framework category (categories 1-3: neutral; categories 4-6: negative), n=1497.

Categories	Tweets categorized to each category, n (%)
1. Lived experience	97 (6.48)
2. Organizational and community group statements	308 (20.57)
3. Individual comments on dementia-related topics	232 (15.50)
4. Minimizing or underestimating words/statements	19 (1.27)
5. Dehumanizing, weaponizing, or outdated words/statements	662 (44.22)
6. Incorrect or questionable words/statements	96 (6.41)
7. Other[a]	34 (2.27)
8. I don't know[a]	49 (3.27)

[a] For the purpose of categorization, 2 additional categories were created: other (for tweets that clearly did not belong in any of the other categories) and I don't know (for tweets that carers thought might belong in one of the categories, but were uncertain about).

Qualitative Analysis of Tweets

A total of 863 tweets were thematically analyzed from the 3 negative categories (minimizing or underestimating words/statements; dehumanizing, weaponizing, or outdated words/statements; and incorrect or questionable words/statements), as well as those categorized as "other" and "I don't know." All the coding discrepancies were resolved between the service user researchers. The summary of the final framework of themes is shown in Table 3 and Multimedia Appendix 6 with example tweets.

The majority of tweets were specifically insults targeted towards politicians (469/863, 54.3%), and a large portion contained general dehumanizing, weaponizing, or outdated words/statements (n=143, 16.6%). Dehumanizing language featured heavily in the tweets about politics (63/863, 7.3%), and the most frequently found words in the tweets featured American politicians alongside the words "senile" and "demented."

Table 3. Carer defined framework categories, and their researcher defined themes and subthemes, showing the number of tweets coded to each theme and framework category and their percentage of the total number of tweets analyzed, n=863.

Framework categories, themes, and subthemes	Tweets, n (%)	Tweets coded to each framework category, n (%)
Minimizing or underestimating words/statements	1 (0.1)	21 (2.4)
Jokes	14 (1.6)	
Painting a negative picture	3 (0.3)	
Unintentionally minimizing	3 (0.3)	
Dehumanizing, weaponizing, or outdated words/statements	143 (16.6)	737 (85.4)
Celebrities	34 (3.9)	
Politics	63 (7.3)	
Weaponizing diagnoses	4 (0.5)	
Insults targeted towards politicians	469 (54.3)	
Unintentionally weaponizing	24 (2.8)	
Incorrect/questionable words and statements	0 (0)	34 (3.9)
Armchair diagnoses	21 (2.4)	
Cures/causes of dementia	11 (1.3)	
Assumptions about politicians	2 (0.2)	
Neutral	64 (7.4)	64 (7.4)
Unclear	7 (0.8)	7 (0.8)

Minimizing or Underestimating Words/Statements

Tweets in this framework category made light of dementia, using nonoffensive words (eg, "selective dementia") in a way that did not convey the seriousness of the condition. This was further nuanced by some tweets using dementia-related terms to make jokes about people's unusual behavior or painting a negative picture of dementia. In these cases, tweets suggested that people with the condition have a poor quality of life, as if they are just waiting until "death ends your misery," or are inherently a danger to themselves or others. Some tweets in this theme unintentionally minimized the severity of dementia, without using weaponizing language. These suggested that those diagnosed do not in fact have dementia, and elderly people should not be expected to "remember her relatives' birthdays."

Dehumanizing, Weaponizing, or Outdated Words/Statements

Tweets in this framework category used stigmatizing and weaponizing words to ridicule dementia or people with dementia, most frequently using "demented" or "senile." The vast majority of these tweets were related to politics. Most were insults targeted towards politicians, most frequently Donald Trump ("Demented Don") and Nancy Pelosi ("Nancy is a senile…woman"); however, Joe Biden also had many such insults targeted towards him ("Biden is senile"). Some tweets used weaponizing language casually to make weaponizing diagnoses of politicians (eg, tweeting that a politician "has senility"). The majority of these were about Donald Trump. Many tweets also referred to "demented democrats" generally. Tweets in this theme used this weaponizing language about celebrities, frequently Bette Midler. Some tweets used weaponizing terms unintentionally in reference to behaviors the user does not like, such as being "in bed before 11.30pm."

Incorrect/Questionable Words and Statements

This framework category represents tweets that contained misconceptions around dementia. Most frequently, these took the form of armchair diagnoses, suggesting that somebody, likely a public figure, has dementia in a way that is not malicious. Most referenced Donald Trump; however, other politicians were also named, such as Bill Clinton, Ronald Reagan, and Joe Biden. Many used their personal experience of a client or relative's dementia diagnosis as justification for their armchair diagnosis, reasoning that they have "lived with it with my Mom." Additionally, these tweets speculated on causes of dementia, including "vegan diet and carbs," or provided suggestions for cures that appeared anecdotal or were not supported by research findings.

Neutral

These tweets were judged by the researchers to not portray any negative attitudes towards dementia. One tweet referred to a film "Cecil B Demented," with several others reporting on reputable scientific results in the field of dementia.

Unclear

This framework category contained tweets that the researchers could not categorize into other themes. Often, their meaning could vary depending on connotation, and it was unclear whether they were making light of dementia or legitimately referring to somebody with the condition (eg, "I thought he was brake checking me for a second but then I realized his dementia was effecting his motor skills").

Discussion

Principal Findings

There is limited qualitative research investigating dementia misconceptions on Twitter, with most literature focusing on content relating to dementia awareness [12,20] or supporting people with dementia [13,21]. To our knowledge, this is the first participatory study focusing on dementia misconceptions on Twitter to develop a framework to categorize misconceptions. We found that dementia misconceptions and weaponizing terms are prevalent and problematic on Twitter.

From the tweets extracted on dementia, 25.94% (12,507/48,211) were negative. We then extracted a sample representing half negative and half neutral tweets and validated this categorization by carers' ratings. They rated just over half of the tweets (777/1497, 51.90%) as displaying negative attitudes, which is slightly over the 50% (750/1500) of these tweets extracted using negative search terms. Most negative tweets were insults targeted towards politicians. Our prevalence of negative tweets (12,507/48,211, 25.94%,) is similar to previous work by Oscar et al [8], who found 21% of their Alzheimer disease–related tweets (N=6583) used Alzheimer disease–related words to perpetuate stigma. Their analysis was carried out by 2 researchers manually coding only 311 tweets across 6 broad categories (metaphorical, personal experience, informative, joke, ridicule, organization). Our participatory work focuses on the end-user views—the carers' ratings and views of misconceptions. We found an overlapping theme in "jokes," but through our qualitative analysis, we were able to highlight that jokes manifest as minimizing or underestimating words or statements. This high prevalence of misconceptions and stigma in tweets is mirrored in research investigating other neurological conditions. For example, McNeil et al [22] found 41% of tweets using the word "seizure" were derogatory in nature, and likewise found ridicule or jokes were common in these tweets. These misconceptions towards dementia are also widespread in the general population and are not exclusive to views disseminated on social media. Crisp et al [23] found that over half of the UK adults surveyed expressed negative attitudes towards people with dementia, including that they were unpredictable, hard to talk to, and feel things in a different way than other people.

We employed an inductive methodology to categorize each tweet into 1 theme. This approach has also been applied in previous qualitative research [12], but others adopted deductive approaches (with categories decided a priori) to categorize almost 70% of tweets to multiple dimensions [8]. We made the conscious decision to involve carers from the very beginning to develop a framework based on their experiences, and then employ an inductive approach for our qualitative analysis. This was important as this is the first piece of research to focus specifically on dementia misconceptions on Twitter, but it also ensured that we captured the meaning of the tweet from the recipient's viewpoint (taking an emic perspective [24]), particularly given that tweets are short snippets of text which can lack context.

Implications

This study has significant public health implications. We provide terms that carers of people with dementia consider to be misconceptions or stigmatizing towards dementia. Therefore, social media platforms should incorporate these terms into their algorithms to enable users to filter out any tweets containing these negative terms. As these terms have been generated by carers after conducting Twitter searches, their validity is reinforced as they have been rated as negative by the people they affect the most.

Additionally, these terms could be used to identify Twitter users who propagate these attitudes and target them in an awareness campaign to reduce their misconceptions. This would aim to promote awareness of the use of words which can perpetuate stigma around mental illness, benefiting the reduction of stigma related to any mental illness [25].

Strengths and Limitations

Understanding what constitutes stigmatizing or weaponizing language on Twitter requires the incorporation of personal perspectives, but this approach is rare. Previous studies investigating misconceptions or stigma in mental health have rarely consulted with service users or carers [8,26,27]. Our participatory methods ensured that our framework is grounded in the personal perspective of those who will be affected by the poor use of language.

Our sample of tweets thematically analyzed by researchers (n=863) is larger than those in previous studies, such as Cheng et al [12] (n=398) and Oscar et al [8] (n=311), and this broader sample provides a better understanding of the prevalence and forms of dementia misconceptions on Twitter. However, many of our tweets were related to American politics; therefore, future work should consider using a broader time period to understand whether this effect is one of time (an election period) or one of American politics in general. The timing of tweet collection will have affected the prevalence of tweets relating to politicians and the rate may be lower if tweets are collected at other times.

Additionally, we extracted tweets during UK office hours and, therefore, overnight events would have been captured the following morning. This may not have allowed us to capture the initial conversations surrounding controversial events. This work only focuses on Twitter and Twitter users, who may not represent the general population [28] or users of other social media platforms. Future work should investigate misconceptions on other social media platforms and in the wider general public.

Our carer group was small and consisted predominately of White British participants, and there was mixed agreement by carers on what constitutes misconceptions and stigma. We found that agreement about tweet categories was greater when assessing whether a tweet was negative or neutral, rather than its individual category; some tweets could be interpreted as stigmatizing by one person, but not by another. Our findings reflect the heterogeneity in neurological and mental health conditions, combined with societal and cultural factors, which shape how individuals communicate and understand their mental health [29]. We propose that future work ensures not only a larger group, but also a more diverse group of carers, patients, and members of the public classify tweets, and that clinical, social, and cultural data are used to understand some of their personal reactions.

Conclusion

This study demonstrates the importance of coproduction in assessing dementia misconceptions. Contributions from people with lived experience and carers can provide a perspective that may be overlooked by researchers. We highlight the high frequency of misconceptions or weaponizing language used in dementia-related tweets. The most commonly used terms are "demented" and "senile" to disparage American politicians including Nancy Pelosi, Donald Trump, and Joe Biden. These findings may prove to be useful to inform a campaign aiming to reduce these misconceptions, correct people's misunderstandings of dementia, and highlight the effect their words have on carers of, and people with, dementia.

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Data Sharing

Data available upon request from SJ.

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Authors' Contributions

Data collection was carried out by SJ, CO and DM. DM and CO facilitated involvement focus groups. Thematic analyses were carried out by SMJ, GH and SE. Data were interpreted by SJ, SMJ, GH, SE, and TW. SJ, SMJ, GH, SE and TW wrote the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Number of tweets collected in each extraction round.
[DOCX File , 20 KB - aging_v5i1e30388_app1.docx]

Multimedia Appendix 2
Breakdown of focus group content.
[DOCX File , 20 KB - aging_v5i1e30388_app2.docx]

Multimedia Appendix 3
Preliminary themes with carer feedback .
[DOCX File , 22 KB - aging_v5i1e30388_app3.docx]

Multimedia Appendix 4
Guidance document explaining coding as provided to third coder.
[DOCX File , 24 KB - aging_v5i1e30388_app4.docx]

Multimedia Appendix 5
Breakdown of carer attendance by focus group.
[DOCX File , 24 KB - aging_v5i1e30388_app5.docx]

Multimedia Appendix 6
Framework categories and themes with their subthemes, showing example tweets for each theme.
[DOCX File , 26 KB - aging_v5i1e30388_app6.docx]

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Abbreviations

API: application programming interface
NHS: National Health Service
NIHR: National Institute for Health Research
URL: Uniform Resource Locator

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Original Paper

Using Twitter to Examine Stigma Against People With Dementia During COVID-19: Infodemiology Study

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Abstract

Background: During the pandemic, there has been significant social media attention focused on the increased COVID-19 risks and impacts for people with dementia and their care partners. However, these messages can perpetuate misconceptions, false information, and stigma.

Objective: This study used Twitter data to understand stigma against people with dementia propagated during the COVID-19 pandemic.

Methods: We collected 1743 stigma-related tweets using the GetOldTweets application in Python from February 15 to September 7, 2020. Thematic analysis was used to analyze the tweets.

Results: Based on our analysis, 4 main themes were identified: (1) ageism and devaluing the lives of people with dementia, (2) misinformation and false beliefs about dementia and COVID-19, (3) dementia used as an insult for political ridicule, and (4) challenging stigma against dementia. Social media has been used to spread stigma, but it can also be used to challenge negative beliefs, stereotypes, and false information.

Conclusions: Dementia education and awareness campaigns are urgently needed on social media to address COVID-19-related stigma. When stigmatizing discourse on dementia is widely shared and consumed amongst the public, it has public health implications. How we talk about dementia shapes how policymakers, clinicians, and the public value the lives of people with dementia. Stigma perpetuates misinformation, pejorative language, and patronizing attitudes that can lead to discriminatory actions, such as the limited provision of lifesaving supports and health services for people with dementia during the pandemic. COVID-19 policies and public health messages should focus on precautions and preventive measures rather than labeling specific population groups.

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KEYWORDS

coronavirus 2019; social media; stigma; dementia; ageism; COVID-19; Twitter; bias; infodemiology; attention; risk; impact; misinformation; belief; cognition; cognitive impairment

Introduction

The COVID-19 pandemic is taking a serious toll on people with dementia and their care partners. In Canada, dementia is the most common comorbidity, accounting for 36% of all COVID-19-related deaths [1]. Increased age, medical frailty, and health conditions often associated with dementia increase the risk for complications from COVID-19 [2,3]. Consequently, increased COVID-19 risk and vulnerability for people with dementia have been emphasized by governments, health care clinicians, the general public, and traditional news media (eg, radio and television news, print media, and affiliated websites) using a 1-to-many communication structure (ie, 1 verified individual or group is the publisher of information for many consumers) [4-7].

Beyond dissemination of information by traditional news media outlets, Twitter and other forms of social media (eg, Facebook, YouTube, Instagram) have been used extensively by individuals during the pandemic in a many-to-many communication structure (ie, any individual can be both a publisher and a consumer of information) to share messages about COVID-19 [7,8]. Social media is generally described as internet-based channels of mass personal communication fostering perceptions of interactions among users, deriving value predominantly from user-generated material and content [9]. For example, people have been using Twitter to share opinions, fears, and beliefs regarding the COVID-19 pandemic. However, a consequence of this many-to-many communication structure is that any member of the network can share inconsistent, contradictory, or even false information about the pandemic. Accordingly, this messaging can lead to COVID-19 misconceptions, false information, and stigma (eg, stereotypes, negative beliefs, and discriminatory behavior) toward individuals or groups that are often already marginalized [10,11].

Recently, an emerging body of literature has identified COVID-19-related stigma and ageism against older adults in social media discourse [12,13]. Ageism reflects how we think, feel, and act toward others or oneself based on age [14]. The model of stigma communication [15,16] identifies 4 types of message content (mark, group labeling, responsibility, and peril): (1) a mark to classify people in a stigmatized group, (2) descriptions or labels of the stigmatized group as a separate entity from the rest of society (eg, us vs them), (3) assigning responsibility for placement in the stigmatized group, and (4) cues to imply that the stigmatized group is a peril or threat to society that needs to be addressed through collective efforts. In 2021, a study analyzing 536 tweets under the #BoomerRemover hashtag reported issues of intergenerational conflict, ageism, and stigma toward older adults during the pandemic [17]. Another study examining 351 tweets about older adults during the COVID-19 pandemic found that almost 88 (25%) of the tweets had stigma, ageism, or potentially offensive content toward older adults [18]. Stigma against older adults is not limited to the pandemic. In 2017, Oscar et al [19] analyzed tweets on Alzheimer disease and reported that 21% of the tweets fostered stereotypes and stigma.

Addressing stigma against dementia on social media is important because it can have severe implications, including depression, anxiety, fear, social isolation, feelings of shame, and a decreased quality of life for people with dementia and their care partners [20-25]. Research shows that stigma against dementia can negatively impact interactions with health care providers, experiences in acute care settings, and access to specialist services and delay a timely dementia diagnosis [24,25]. However, a timely diagnosis enables people with dementia to acquire support services, obtain relevant information, plan for the future, and access pharmaceutical treatments that may improve their cognition and quality of life [21].

Apart from the 1 study by Oscar et al [19], there is a paucity of research exploring social media discourse related to stigma against dementia, especially in the context of the COVID-19 pandemic. Furthermore, the unknown effects of COVID-19 may perpetuate fear, blame, and false beliefs, leading to increased stigmatization against marginalized groups, especially for groups deemed as being more at risk to the virus, such as people with dementia. Examining how stigma manifested on social media during the pandemic may deepen our understanding of the methods and content used to facilitate stigma communication against people with dementia and their care partners.

With over 330 million monthly users [26], Twitter presents a novel opportunity to expand the repertoire of qualitative research approaches and data collection methods [27] by using a comprehensive, publicly available data set for infodemiology. Infodemiology (ie, information epidemiology) is defined by Eysenbach as the study of the distribution and determinants of health information on the internet to inform health professionals and health policy [28]. Given the high volume of active users, Twitter provides an innovative means for understanding different COVID-19 perspectives that may have been ignored or concealed due to the current challenges of conducting in-person research during the pandemic. Using Twitter data, the objective of this study was to examine social media discourse on stigma against people with dementia during the pandemic.

Methods

Ethics

Drawing on existing Twitter studies, there is a general consensus that tweets can be used for research without requiring ethical approval, because analyzing publicly available text on social media platforms, such as Twitter, is generally not considered human subject research [18,19]. Because tweets posted on the Twitter website are located within the public domain, ethics approval was not obtained. However, we removed any identifying information related to usernames or handles (eg, @name) to help protect the anonymity of the Twitter users.

Recruitment

Tweets were collected on Twitter using the GetOldTweets application in Python from February 15 to September 7, 2020. Search terms for the tweets included dementia or Alzheimer disease used in combination with COVID-19, coronavirus, or COVID, resulting in 20,800 tweets. Nonoriginal tweets and retweets were excluded from the study. Filters were applied to exclude irrelevant tweets (eg, spam, advertising), resulting in 5063 (24.34%) tweets. The 5063 tweets were analyzed by a group of coders [29], with 1743 (34.43%) tweets identified for stigma-related coding. Given that the tone of the tweets can be difficult to interpret, our process for identifying stigma-related tweets for inclusion was broadly based in attempts not to overlook any relevant tweets. Specifically, our inclusion criteria included tweets that perpetuated stigma (eg, political dementia–related insults, assigning blame to people with dementia, self-stigma, stereotypes or labeling people with dementia, and misinformation about dementia), tweets that devalued the lives of older adults or people with dementia, and tweets that challenged stigma against people with dementia. The 1743 tweets were extracted into a Microsoft Excel spreadsheet for data analysis. An Excel spreadsheet was used to support ease of use among the large research team because it did not require additional training in order to use the software.

Data Analysis

The 1743 tweets were analyzed using thematic analysis after line-by-line coding, a qualitative method that identifies key topics and patterns in the data, with the objective of identifying the overarching themes [30]. To develop a robust codebook, 4 researchers (authors JDB, MEO, SF, ALC) read and re-read 100 (4.74%) tweets multiple times to become immersed within the Twitter data and develop the initial codes. The stigma communication model [15,16] was used in the development of our initial codebook by including codes such as the mark (eg, a mark to classify people in a stigmatized group), responsibility (eg, assigning blame by making attributions about the lifestyle or actions of people with dementia), peril (eg, suggesting that people with dementia are a social, physical, or economic threat to society), and group labeling (eg, descriptions or labels of people with dementia as separate from the rest of society). The codebook contained definitions, cues, and tweet examples for each of the codes. Pilot tests were conducted to test intercoder consistency with the researchers independently coding the same tweets and then meeting to compare coding and further revise the codebook (eg, deleting or adding additional codes for emerging themes). After multiple meetings, the codebook was further refined by merging or deleting any overlapping or unused codes. The final version of the codebook consisted of 6 codes: (1) devaluing the lives of older adults (eg, “old and dying anyways”), (2) responsibility/blame (eg, “dementia COVID economy”), (3) false information (eg, COVID-19 vaccine causes dementia), (4) political dementia–related stigma (eg, “dementia Joe”), (5) self-stigma (eg, “don’t save me, save my grandchildren”), and (6) challenging stigma against dementia (eg, “it’s a scandal how dementia patients are treated”).

Once the codebook was completed, the researchers met with the coding team. The coding team consisted of 12 coauthors, who received 4.5 hours of coding training (eg, individual practice coding exercises, collaborative team coding to identify and address any coding challenges or questions, team meetings to discuss specific coding questions, and partner coding activities). After the coding training was completed, the 1743 tweets were divided among the 12 coders. Each coder received 268 (15.38%) tweets, which allowed for each tweet to be independently coded by 2 different coders to ensure intercoder reliability. Any coding challenges or discrepancies were resolved through collaborative discussion and consensus.

After coding was completed, team meetings were held to conduct thematic analysis [30] by examining the primary themes and subthemes that emerged from reviewing the researchers’ reflexive memos [31] and re-reading the tweets under each of the codes. All the researchers were experienced in thematic analysis, and 1 trainee (author KSG) was mentored by working in direct collaboration with the research team. Reflexivity was used to recognize the researchers’ positionality in terms of their own judgments and beliefs to help ensure that these did not influence the analysis [30]. An additional team meeting was held to reach group consensus on the overarching themes and to identify exemplar tweets (eg, accessible, no acronyms) for publication.

Rigor

Three measures were used to ensure rigor in our research. First, the research team used reflexive memos to record notes about emerging patterns, themes, and relationships during the coding process [31]. Second, multiple coding (eg, each tweet coded independently by 2 coders) was used to provide cross-checks in the interpretation of the tweets by independent researchers [32]. Moreover, having each tweet coded independently by 2 reviewers helped to ensure intercoder reliability, with an average of 86% agreement between the coders. The intercoder reliability was determined by calculating each percentage of agreement between the 6 different pairs of coders (eg, 2 independent coders for each code) and then taking each of the 6 pairs’ percentage of agreement numbers to calculate the overall group average. Third, team-based analysis and regular meetings were used as a form of peer debriefing, where the team reviewed the codebook, asked questions about the coding process, and provided in-depth feedback and suggestions to ensure the research accurately reported the findings [33].

Results

Main Themes Identified

Based on our thematic analysis, 4 main themes were identified: (1) ageism and devaluing the lives of people with dementia, (2) misinformation and false beliefs about dementia and COVID-19, (3) dementia used as an insult for political ridicule, and (4) challenging stigma against dementia.

Ageism and Devaluing the Lives of People With Dementia

Stigma communication includes processes such as marking some people as different, group labeling to delineate how some people are separate from society, assigning responsibility or blame by making attributions about a group’s actions or way of life, and implying that this group is a peril to society [15,16]. In this sample of tweets, the group labels "poorer quality of life" and "death by COVID-19" were frequently applied to people with dementia, with implications that death by COVID-19 would be a welcome alternative to dying with dementia:

> *I know two people that have died from Covid. One was 80 with severe dementia and in a nursing home and the other was 35 and topped herself due to lockdown. I know what one was "unnecessary"*

Some of the ageist group labeling intersected with negative views of long-term care (LTC) homes:

> *The life expectancy in LTC (long-term care) is not even 30 months. You're there to die a slow death from Alzheimer's, basically. My neighbour refused treatment for pneumonia for her husband so he wouldn't have to go to the bitter end. Covid is actually a better death than dementia.*

In addition, it is important to note the language used when describing dementia in these quotes (ie, "severe") and in the following quote "full blown":

> *That's one of the really selfish elements of it, because you can guarantee that attitude would change when staring death in the face. Saying that, my granny is 95, in a home, with full blown dementia. Quick Covid death clearly not a disaster there*

These tweets present LTC homes or nursing homes as a place where individuals with dementia face a "slow death" and imply limited quality of life. The tweets also suggest that the lived experience of dementia is the same for all older individuals despite having many remaining abilities when first diagnosed and vastly different lived experiences of dementia based on one's available personal, social, and environmental resources [34]. The tweets do not account for the quality of life as experienced by persons with lived experience of dementia and how the nature of quality of life can change as the disease progresses [35].

In addition to group labeling, the tweets communicated the notion of peril or threat of dementia to the general public. Not only were the lives of people with dementia devalued, but the idea of having dementia as a diagnosis and the possibility that one might die of dementia was reported as a threat (eg, potential diagnosis or death from dementia being the threat) in some of the tweets. For example:

> *Honestly if I knew I had dementia and was still in charge of myself I'd go out and try and find corona carriers to shake hands with. This coming from someone who watched a close relative existing for 10yrs, NOT LIVING just existing It's horrible. :(*

The following tweet has a similar message:

> *I would consider Covid a blessing if I was in a care home. They don't call pneumonia "the old man's friend" for nothing. A slow dementia death is way way worse.*

In both these cases, the tweeters identify as being threatened by dementia, portray dementia as "not living" or a condition with no quality of life, and feel that a COVID-19 death would be preferable. Restricted resources during the pandemic exacerbated the perception that the life of a person with dementia was less valuable:

> *You have one hospital bed. You can either give to a decrepit 93 yr. old nursing home resident with dementia who's only realistic COVID outcome is death or a 40 yr. old previously healthy father of 2 young kids who may stand a chance of survival - you choose.*

One tweet specifically alluded to the economic threat of a future dementia diagnosis:

> *. . . I know this is not a popular view - but I would not want to live in a home with dementia and swallow up my kid's inheritance. I'd much, much rather die of COVID than that.*

Group labeling reinforces differences between persons with Alzheimer disease and those without Alzheimer disease, which discriminates those with dementia, as it is the end point of stigma.

Misinformation and False Beliefs About Dementia and COVID-19

Some tweets about COVID-19 and dementia propagated misinformation about dementia. Misinformation about dementia included perpetuating false beliefs that the COVID-19 vaccines (or vaccines in general) cause dementia or labeling COVID-19 as a cause of dementia. The language in these tweets is consistent with the stigma communication model's processes of responsibility and peril [15,16].

> *The flu killed more people in 2018 than the corona virus has and we have a flu vaccine that contains Aluminium and Mercury which has been linked to Dementia and Alzheimers*

Did you know; the coronavirus vaccine causes dementia and homosexuality? FAR worse than the virus itself! As a mother of 5-oop . . . make that 3, I can't support the corona vaccine! and neither should you! Spread the word across Facebook!

> *My friend's daughter, age 30, has COVID DEMENTIA and COVID COPD - but she is not a statistic unless she dies and many people are not tested.*

By perpetuating misinformation about dementia, the end result is that society may view persons with dementia with only negative attributes, and it helps separate "us" from "them." This view may lead persons with dementia to experience stigma.

Dementia Used as an Insult for Political Ridicule

Despite use of a filter that referred to the US presidential candidates for the 2020 election by name (Donald Trump and Joe Biden, and synonyms), many tweets remained that were relevant to the theme of insult and political ridicule because these tweets used the term "dementia" in a pejorative manner. The use of dementia as a form of personal attack is an attempt to diminish and devalue others, but it also devalues the lived experiences of those with dementia and their carers. The following examples are tweets that used the term “dementia” with the aim of insulting 1 of the presidential candidates. The stigma communication [15,16] in these tweets is characterized by marking, which refers to an attribute or feature attributed to an individual and “marks” them as different.

> *To be fair, #DementiaJoe thinks he's running for the US Senate, but I bet your news coverage didn't show that gaffe. Do you really think America is going to elect a cop hating, socialist crook with dementia over the man who built the greatest economy since Reagan, before Covid?*

> *Was unemployment down until covid? Was the economy booming? . . . there’s 2 brutal truths, right there, you’re willing to destroy us all, yourselves included to put a guy with obvious dementia in the WH. That’s insane, and that’s the “brutal truth” of it . . .*

> *More than 60M Americans voted in 2016 to have us led by a malignant narcissist whose dementia was visibly progressing. A shocking percentage of these traitors will vote to re-elect him—and the GOP—even as their redneck family and friends die from COVID-19. America is broken.*

Others used the term “dementia” as an insult to imply diminished abilities to perform duties of their job, underscoring how stigma against dementia can include depicting incompetency.

> *No because the mf has dementia and is unfit too speak in front of a crowd or debate anyone! Covid 19 was a fucking hoax too crash the economy and then you’ve created race wars too deflect off democratic crimes! We know you’re going to rig the election in order to win!!*

Others used dementia as an insult to dismiss their target’s viewpoint by suggesting they are cognitively compromised.

> *Yea, in an alternate reality he might be, but not on this planet in this lifetime. What is it you think is best? He’s blatant racism? The blatant nepotism? Blatant corruption? The way he has allowed Covid to kill our people and destroy the economy? You must have dementia*

Challenging Stigma Against Dementia

One theme emerged in contrast to the others, namely that of challenging the stigma against dementia in association with the COVID-19 pandemic. Tweets condemned the derogatory language, directly critiqued negative behaviors, and voiced concerns that ageism and stigma against persons with dementia were exacerbated during the pandemic. For example, some questioned the lesser value placed on deaths of those with dementia who contracted COVID-19.

> *It really feels like a portion of the population, we're not supposed to care about their deaths. They're less worthy, or disposable somehow. I imagine someone with dementia or terminal cancer also suffering with end stage severe Covid-19 and my heart breaks.*

Some tweets referenced deficits in formal care experienced by persons with dementia and how these have been highlighted by the COVID-19 pandemic. For example, a tweet stated,

> *It’s a national scandal how dementia patients are treated. COVID-19 took her in the end .*

Tweets brought attention to systemic issues around health care access and availability for people with dementia by describing how they deteriorated due to COVID-19 pandemic conditions.

> *The elder care situation is abhorrent even in the best of times. I witnessed firsthand options in USA for a self pay mother and father w/ dementia and is very dismal. The culture devaluation of elders and economic vulture capitalism has created a living nightmare. Covid amplifies*

Further, people wrote tweets as a call to action, directly confronting negative stereotypes of dementia. Some tweets presented accurate facts about dementia to contradict myths or stereotypes. Other tweets asserted a need to change our attitudes and actions with respect to care provision and treatment of older adults with dementia, both generally and specifically regarding the pandemic.

> *Watched Ross Kemps living with dementia last night. What a great family, dementia isn’t just an old persons illness it can affect anyone at any age. We need to get a hold on this illness, people have hurt long enough. Covid has increased the pain, people need support. @AlzSocNI*

> *#COVID should make us re-examine how we treat the #elderly we will ALL be old one day. We #warehouse people. It’s #shameful and at @SavonixInc we are dedicated to the #dignity of our #elderly #ethics #nursinghomes #dementia*

Discussion

Principal Findings

During the pandemic, significant social media discourse has focused on COVID-19 and people with dementia [13,17,18]. In this study, we examined Twitter data to understand stigma against people with dementia during the COVID-19 pandemic. Drawing on Smith’s [15,16] model of stigma communication, we identified 4 main themes: ageism and devaluing the lives of people with dementia (eg, group labeling), misinformation and false beliefs about dementia and COVID-19 (eg, peril and responsibility), dementia used as an insult for political ridicule (eg, marking), and challenging stigma against people with dementia. Overall, our study sheds light on stigma against dementia during the COVID-19 pandemic and highlights opportunities for policy and research to address this moving forward.

In our research, we found that Twitter users reported that the lived experience of dementia was the same for all individuals. For example, people with dementia were stereotyped as a homogeneous group of people who were highly vulnerable and at the end stages of their lives. However, research has demonstrated that dementia does not progress in a linear fashion and, most notably, that it varies from person to person [35-37]. Similar stereotypes focusing on frailty and COVID-19 vulnerability among older adults have been found in public health campaigns and traditional news media [5,6,38-40]. These stereotypes serve to perpetuate COVID-19 stigma against older adults and people with dementia. Consequently, COVID-19 policies and public health campaigns should focus on precautions and preventive measures rather than labeling specific population groups.

In several tweets analyzed in this study, there was an assumption that people with dementia were better off dying from COVID-19 than continuing to live with dementia, an assumption that can lead to experienced, perceived, anticipated, or internalized stigma. More specifically, death was described as a welcomed means to end the pain and suffering of people with dementia. This assumption is also embedded throughout the literature prior to the pandemic. For example, in existing studies conducted with caregivers, the death of a person with dementia has been described as the best solution because it ends the person's pain and suffering due to dementia [41,42]. However, this "solution-based focus" on death is extremely problematic, leaving little scope for developing COVID-19 policies and programs to improve the quality of life for people with dementia. More specifically, how we view and discuss deaths of people with dementia shapes how policymakers, health clinicians, and the public value the lives of people with dementia. Consequently, this type of discourse may influence who is prioritized for treatment in the context of COVID-19 [43].

Although many tweets had stigmatizing content, tweets also challenged stigma against dementia. For example, some tweets provided accurate facts about dementia, highlighting systemic COVID-19 issues faced by people with dementia or directly confronting myths and stereotypes against dementia. This unifying and supportive discourse against stigma and ageism has also been found in other studies [13,17,44,45]. The World Health Organization [21] suggests that sharing accurate information is key to dispelling myths and stereotypes about the disease. Moreover, research suggests that stigma against dementia is related to fear and a lack of understanding about the disease [20,46]. Consequently, there is a growing need for dementia education and awareness campaigns targeted toward digital media [47] and specifically toward Twitter and other social media platforms.

Recent studies show that policymakers, clinicians, and public health officials are increasingly using Twitter to share and gather information on the COVID-19 pandemic [8,48]. However, because Twitter messaging includes opinions as well as information that may be false or inaccurate, precautions must be taken in interpreting the data, especially given the dementia-related stigma identified in our study. Smith et al [49] assert that when stigmatizing discourse is shared with the general public and "influential others," it becomes a collective norm with policy and practice implications. Specifically, stigma perpetuates misinformation, pejorative language, and patronizing attitudes that can lead to discrimination against people with dementia. Evidently, recent reports highlight discriminatory actions related to the limited provision of medical services, inadequate access to health care information, and restricted access to COVID-19 treatment options and lifesaving supports for people with dementia during the pandemic [50,51]. Accordingly, our findings have practical implications for policymakers and clinicians because they highlight the need for sensitivity to avoid dementia-related stigma, discriminatory actions, and ageist attitudes about COVID-19.

Urgent action is needed to address stigma to improve the quality of life for people with dementia and their care partners [21,22,25,45]. It is essential that people with dementia not be defined by their disease but be instead recognized as individuals with the same human rights as any other person [52,53]. Moreover, people with dementia must be included in critical discussions on COVID-19 programs and policies, especially around the provision of medical services and lifesaving supports. Rather than focusing on stereotypes and stories of risk and suffering, policymakers, clinicians, and the general public must understand that people with dementia are diverse and able to lead meaningful lives. Moving forward, further research is required to identify the contributing factors, implications, and interventions to address stigma against dementia on social media and beyond.

Limitations

Although our study provides valuable information about perceptions of COVID-19 and stigma against dementia, it is not without limitations. First, our interpretation of each tweet is limited by our lack of knowledge about the author's tone, intention, and purpose. For example, important details and contextual information (eg, background, culture, confounding factors) may not be included within the 280-character-limit tweet, making the tone and intention of the tweet difficult to assess. To help rectify this issue, each tweet was coded independently by 2 reviewers to reduce the likelihood of misinterpreting the meaning of the tweets. Despite this measure taken in our study, there is still room for interpretative error. Readers of tweets are also limited in their ability to infer tone, intention, and purpose, so there is value is our analysis that assesses and reports on the content of tweets that are being distributed to the public. As such, future research with qualitative interviews or focus groups with people with dementia or their care partners may provide more comprehensive and in-depth information regarding COVID-19 and experienced stigma against dementia.

Second, no sociodemographic or geographic information (eg, ethnicity, age, sex, gender, income, country) of the tweeters was collected in our study and accordingly limits our ability to further evaluate stigma beyond describing the Twitter discourse. For example, because no data were collected on sex or gender, it is difficult to make specific inferences or draw conclusions regarding stigma against dementia in relation to sex or gender during the pandemic. Further research is needed to explore the stigma against dementia in relation to sociodemographic information, including sex and gender.

Third, our data present a snapshot in time because they focused on tweets posted from February 15 to September 7, 2020. Consequently, it is possible that our findings would change if a different time frame was selected, such as during subsequent waves of the pandemic, after the US presidential election had occurred, or after vaccine availability [12]. Further research is necessary to examine longitudinal changes in dementia-related stigma across the duration of the pandemic, across different sociopolitical climates, and across different time frames within the pandemic.

Finally, it is possible we would have discovered more stigma-related tweets if our scraping strategy had not required dementia, COVID-19, and some description of familial or friendly relationship status. We used a reference to US political candidates by name as a filter for the initial study because these were tweets that perpetuated stigma, and although the secondary analysis for the study discovered this theme of stigma perpetuation, it is not clear whether tweets that referred to US political candidates by name were qualitatively different from those that informed the “dementia as an insult for political ridicule theme.”

Conclusions

During the pandemic, there has been significant social media attention focusing on the increased COVID-19 risks and impacts for people with dementia and their care partners. Unfortunately, much of this discourse has amplified issues of preexisting ageism and stigma against people with dementia. Our study identified 4 themes related to dementia-related stigma and COVID-19, ranging from misinformation and false beliefs to challenging stigma against dementia. Consequently, social media has been used to spread stigma, but it can also be used to challenge these negative beliefs, stereotypes, and false information.

Our findings reveal that dementia education and awareness campaigns are urgently needed to target social media to address stigma. When stigmatizing discourse of dementia is widely shared and consumed amongst the public, it has public health implications. How society talks about dementia shapes how policymakers, clinicians, and the general public value the lives of people with dementia. Stigma perpetuates negative attitudes, patronizing language, and false information that can lead to inequitable access to lifesaving supports and health care services. Thus, COVID-19 policies and public health messages should focus on precautions and preventive measures instead of labeling people with dementia. Consequently, it is essential that people with dementia not be defined by their disease during the pandemic but be instead recognized as diverse individuals who are able to live meaningful lives with the same human rights as any other person.

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Authors' Contributions

MEO conceived the idea with JDB. MEO and RJS devised the Twitter scraping approach, and RJS scraped for tweets. JDB, MEO, SF, and ALC devised the codebook. JDB, MEO, SF, ALC, AC, KSG, LEB, JB, SG, KSM, DB, HMO, and LP each coded and double-coded tweets. All authors contributed example tweets and participated in the thematic analysis. JDB wrote the first draft of the manuscript, and all authors revised the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

LTC: long-term care

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Original Paper

One-Year Postfracture Mortality Rate in Older Adults With Hip Fractures Relative to Other Lower Extremity Fractures: Retrospective Cohort Study

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Abstract

Background: Hip fracture in older adults is tied to increased mortality risk. Deconvolution of the mortality risk specific to hip fracture from that of various other fracture types has not been performed in recent hip fracture studies but is critical to determining current unmet needs for therapeutic intervention.

Objective: This study examined whether hip fracture increases the 1-year postfracture mortality rate relative to several other fracture types and determined whether dementia or type 2 diabetes (T2D) exacerbates postfracture mortality risk.

Methods: TriNetX Diamond Network data were used to identify patients with a single event of fracture of the hip, the upper humerus, or several regions near and distal to the hip occurring from 60 to 89 years of age from 2010 to 2019. Propensity score matching, Kaplan-Meier, and hazard ratio analyses were performed for all fracture groupings relative to hip fracture. One-year postfracture mortality rates in elderly populations with dementia or T2D were established.

Results: One-year mortality rates following hip fracture consistently exceeded all other lower extremity fracture groupings as well as the upper humerus. Survival probabilities were significantly lower in the hip fracture groups, even after propensity score matching was performed on cohorts for a variety of broad categories of characteristics. Dementia in younger elderly cohorts acted synergistically with hip fracture to exacerbate the 1-year mortality risk. T2D did not exacerbate the 1-year mortality risk beyond mere additive effects.

Conclusions: Elderly patients with hip fracture have a significantly decreased survival probability. Greatly increased 1-year mortality rates following hip fracture may arise from differences in bone quality, bone density, trauma, concomitant fractures, postfracture treatments or diagnoses, restoration of prefracture mobility, or a combination thereof. The synergistic effect of dementia may suggest detrimental mechanistic or behavioral combinations for these 2 comorbidities. Renewed efforts should focus on modulating the mechanisms behind this heightened mortality risk, with particular attention to mobility and comorbid dementia.

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KEYWORDS

hip; fracture; mortality; aging; older adults; elderly; mortality risk; electronic health record; EHR; survival probability; postfracture mortality rate; fall; bone; injury; dementia; diabetes; type 2 diabetes; trauma; treatment; comorbidity; mobility

Introduction

Recent studies suggest a 17%-25% 1-year mortality rate following hip fracture or its surgical repair in older adults [1-4]. However, hip fracture has rarely been compared against other fracture types in elderly cohorts to understand its specific impact on mortality risk and the unique vulnerabilities associated with it. Since previous studies have suggested that, under specific conditions, fracture location can impact mortality risk [5,6], a comparison of hip fractures against other fracture types may help inform postfracture medical care to target high-risk patient populations more specifically.

This study comprehensively compared 1-year mortality rates following fractures of the hip, upper humerus, and lower extremities to determine whether mortality risks differed by fracture type or fracture region in the elderly population as a whole. In addition to simple comparisons of 1-year mortality rates associated with different fracture types and combinations across elderly cohorts, we also used propensity score matching across cohorts to reduce the impact of confounding factors. We hypothesized that hip fracture would result in greater 1-year mortality rates compared to fractures that did not similarly impact mobility.

This study also examined the extent to which the age-associated comorbidities of dementia and type 2 diabetes (T2D) increase 1-year postfracture mortality rates. Dementia has been identified as a major risk factor for hip fracture [7], is associated with increased mortality risk after hip fracture [8], and is linked to increased postoperative complications following hip fracture repair [9]. Similarly, T2D has been identified as a fracture risk factor [10], with insulin treatment status additionally modifying the region-specific fracture [11,12]. Importantly, both dementia and T2D are associated with increased mortality risk irrespective of fracture [13-15] and, by comparing different fracture types/combinations in individuals with the same comorbidity, we were able to deconvolute each specific fracture's mortality rate to determine whether dementia or T2D act synergistically with the fracture to exacerbate mortality outcomes.

Methods

TriNetX Queries

Data were acquired through queries performed in the TriNetX database (TriNetX, Cambridge, MA, USA) using the Diamond Network on fractures that occurred from January 1, 2010, to December 31, 2019 (queries were last updated the week of March 28, 2021; this update was to capture patients with fractures within these time frames whose records were added later). Follow-up of patients included 2020 data, despite changes to the age-adjusted mortality rate that year [16], to keep the results as complete and updated as possible. The Diamond Network contains electronic medical record (EMR) and medical and pharmacy claims data [17] from over 200 million de-identified patients across the United States and its territories. Patients without an assigned sex were ignored, as those missing this information likely had an incomplete medical record; TriNetX explicitly defines the sex of patients but does not include gender data. Males and females were divided into age cohorts spanning 10-year intervals (60-69, 70-79, and 80-89 years). To minimize the risk of patient identification, the TriNetX database does not report patients' data once they exceed 90 years of age. Since we were interested in mortality rates within the first year following hip fracture repair, cohorts ended at 89 years of age.

Codes from the *International Classification of Diseases, Tenth Revision* (ICD-10) were used for fracture diagnoses, and patients were identified as having a hip fracture if a code of S72.0, S72.1, or S72.2 was present in their record. Hip fractures were compared to fractures of the upper humerus (S42.2); regions near the hip (lumbar vertebra, S32.0; sacrum, S32.1; coccyx, S32.2; ilium, S32.3; acetabulum, S32.4; pubis, S32.5; ischium, S32.6); nonhip regions of the femur (femur shaft, S72.3; lower femur, S72.4); knee and lower leg (patella, S82.0; upper end of tibia, S82.1; tibia shaft, S82.2; lower end of tibia, S82.3; fibula shaft, S82.4); and talus, malleoli, and foot (medial malleolus, S82.5; lateral malleolus, S82.6; talus, S92.1; metatarsal, S92.3; great toe, S92.4; lesser toe, S92.5). Fracture codes below the hip that were broadly categorized as "other" or "unspecified" were not included. The upper humerus was chosen as a control for hip fracture since both fractures occur at anatomically similar torso-appendage junctures. The other fracture sites impact mobility to varying degrees and were chosen based on reports that mobility limitations play a critical role in the mortality risk of older adults [18,19]. Comparisons were also performed between the hip fracture grouping and each of the other listed individual fracture codes. In a respective query, only 1 fracture event among the pooled fracture types or for the individual fracture type was allowed to occur from 60 to 89 years of age, but we did not actively exclude individuals who had simultaneous, or even subsequent, fractures across, or outside of, our groupings, even though certain combinations are predicted to worsen outcomes [20,21]. In addition, although we removed individuals who experienced multiple fracture events of the same kind or grouping from 60 to 89 years of age to reduce confounding variables, some of these removed individuals may have fractured a different bone under the same code or pool of codes or the same bone contralaterally, and it may not be a repeated fracture of the same type. The analysis did allow for the same fracture to have occurred prior to 60 years of age. The incidence of each fracture type or grouping within the specified decade was initially established across sex and age, and the percentage of individuals in each sex and age cohort deceased from 1 day to 1 year postfracture was determined by dividing the number of individuals deceased by the total population with same-day deaths subtracted. Since the TriNetX database cannot report information for cohorts with 10 or fewer individuals, the number of same-day deaths had to be determined by subtracting the deaths that occurred from 1 day to 1 year from the deaths that occurred within 1 year for the same respective cohort. Same-day deaths were excluded from analyses since these individuals may not represent a population that can be treated postoperatively following a fracture event. To improve readability when reporting data, the term "1-year postfracture mortality" has been used herein to describe those deaths that occurred from 1 day to 1 year postfracture.

The relative frequencies of each fracture were calculated by dividing the total number of incidences of the fracture or fracture grouping by the sum of the incidence for all fractures or fracture groupings and then converting it to a percentage for each respective sex and age cohort. There was a small possibility of counting a patient multiple times if they experienced 1 or more events that fell within multiple fracture groupings.

Since few individuals had unique simultaneous hip fracture combinations in a single event (specifically, combinatorial fractures of S72.0xS72.1, S72.0xS72.2, S72.1xS72.2, and S72.0xS72.1xS72.2), we focused our efforts on incidences and mortality rates for each separate fracture code, excluding the other hip fracture codes for each of these individual analyses. We also included a metric composed of all fracture codes/combinations in the hip. The percentage change in survival probability was determined by subtracting the hip fracture mortality rate from the mortality rate of the other fracture/fracture grouping of interest.

To examine the impact of dementia on fracture outcomes, we explored patients with a diagnosis of vascular dementia (F01), dementia due to Alzheimer disease (G30), dementia with Lewy bodies (G31.83), or any combination thereof; these diagnoses were chosen in order to better unravel potential mechanisms of action since they encompass a large proportion of individuals with at least 1 specified form of dementia while removing individuals with unspecified dementia and relatively rare forms of dementia [22]. Dementia diagnoses were allowed from any time before the fracture to 1 year postfracture (including exactly 1 year postfracture). For T2D diagnosis, the code E11 was used and was required to be present in a patient's record from 6 months prior to the fracture to 1 year postfracture in order to ensure that patients with reversal or remission of T2D were excluded [23].

General queries determined the sizes of the male and female populations with a dementia or T2D diagnosis from 60 to 90 years of age from January 1, 2010, to December 31, 2019. Unlike the fractures, where we only allowed ICD-10 codes through 89 years of age, these diagnoses were allowed through 90 years of age since we were focused on mortality outcomes and this made them comparable to our mortality measures in our fracture cohorts that had allowed diagnoses of dementia and T2D through the 1-year follow-up. These were plotted using BioVenn [24]. Analyses were run on these subpopulations identically to the overall fractured populations, with the exception that cohorts were not propensity-score-matched because the cohort size was limited by requiring a fracture event in combination with a dementia or a T2D diagnosis.

Statistics

Propensity score matching was performed across different fracture groupings within the TriNetX system for the root category of each demographic, diagnosis, medication, procedure, and common lab variable (a maximum of 191 broad categories of characteristics outlined in Table S1 of Multimedia Appendix 1) recorded in both cohorts through 1 day before the fracture event. The day of the fracture was not included, since some patients may have received more immediate, or different, care than others. Not all cohort combinations had data for every characteristic. Propensity-score-matching methods can be found in Multimedia Appendix 2. Kaplan-Meier (KM) and hazard ratio (HR) analyses were performed using the matched cohorts of patients, excluding those that died the same day as the fracture. Log-rank tests established the statistical significance of the KM survival curves 1 day to 1 year postfracture. HRs, the CIs for the HRs, and tests for proportionality were calculated within the TriNetX system, which uses the R Survival package (v3.2-13) [25,26] and validates these results by comparing to them to those of SAS (v9.4; SAS Institute). The proportionality test was based on the scaled Schoenfeld residual [27].

Results

Fracture Incidences, Relative Frequencies, and 1-Year Mortality Rates

A total of 1,100,871 patients (758,995 [68.94%] female, 341,876 [31.06%] male) from 60 to 89 years of age with hip fracture codes of S72.0, S72.1, or S72.2 (Figure 1A), combinations thereof, or repeated fractures were retrieved from the past 10 years. Notably, narrowing the database query to only 1 fracture event of any fracture type or combination identified a substantially smaller pool of 408,922 patients (279,131 [68.26%] female, 129,791 [31.74%] male; Table 1) but reduced the confounding variables for the examination of individuals deceased within 1 year postfracture. Because simultaneous fracture combinations were allowed in the queries for 1 fracture event but repeated fracture events of the same type were not allowed, this suggests that more than 60% of elderly patients with hip fracture sustain multiple, temporally separated hip fractures of the same type or in the same region, ipsilaterally or contralaterally, or that the same fracture is repeatedly charted.

The racial and ethnic profiles of the elderly individuals in the TriNetX database's Diamond Network that experienced a single hip fracture event were largely unreported, perhaps because the network is derived, at least in part, from insurance claims. However, patient mapping by zip code suggests that these patients were widely distributed throughout the United States (Figure S3 of Multimedia Appendix 3). The majority of these patients suffered a fracture of the femur head and neck. The second- and third-most common hip fracture types were pertrochanteric femur fracture and subtrochanteric femur fracture, respectively (Figure 1B). Importantly, less than 8% of elderly patients presented with multiple simultaneous fractures during a hip fracture injury.

Figure 1. An anatomical depiction of the hip fracture codes and the percentage of hip fractures in patients 60 to 89 years of age with only 1 hip fracture event categorized by single, and combinations of, ICD-10 codes. Each hip fracture type is visually represented (A). As evident in the pie charts (B), the majority of patients with a single event of hip fracture broke the head or neck of the femur (S72.0). ICD-10: *International Classification of Diseases, Tenth Revision.*.

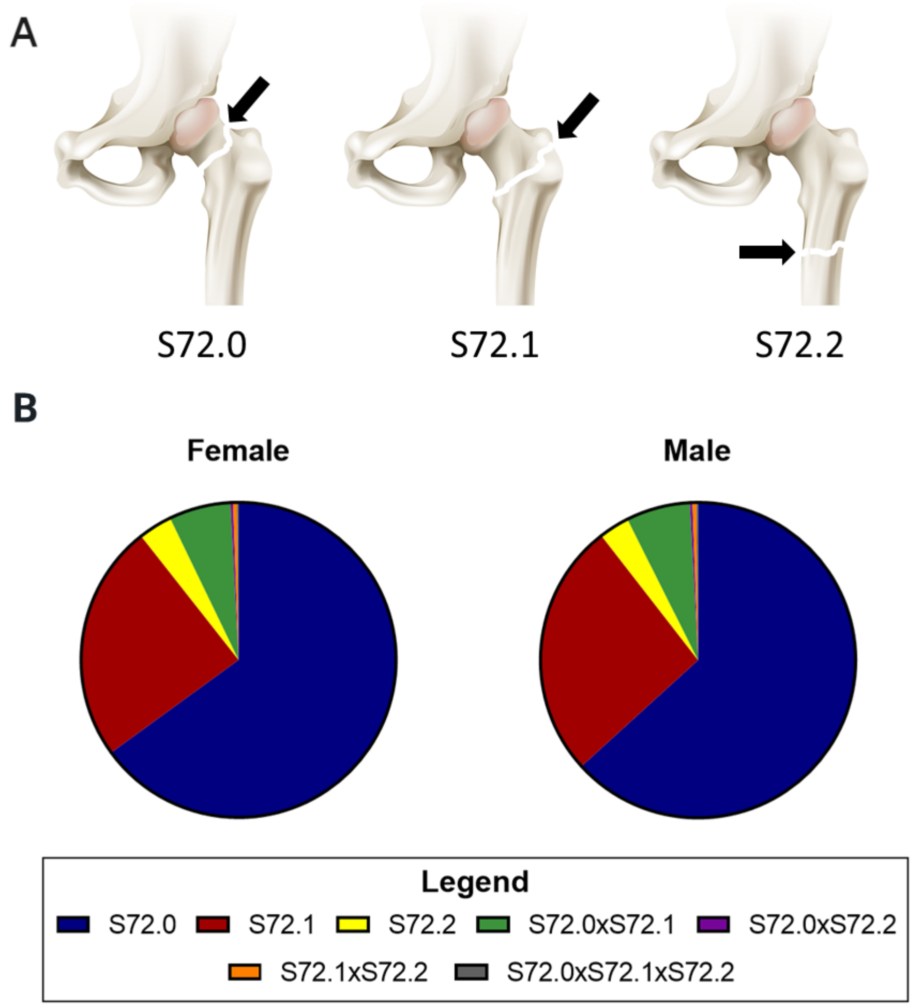


Table 1. Incidence and relative frequency of various fractures in the TriNetX Diamond Network separated by fracture code/code combinations in cohorts split by sex and age. Incidence entries include individuals deceased the same day as the fracture. Data on separated ICD-10[a] codes can be found in Table S2 of Multimedia Appendix 1; codes were aggregated, as described in the header for the table below, and individuals were only allowed 1 event with the ICD-10 code or pooled codes specified in each column from 60 to 89 years of age (instead of summing the codes of Table S2 of Multimedia Appendix 1 in order to avoid counting the same patient more than once). The relative frequency of each fracture/fracture grouping within a sex and age cohort is shown in parentheses and is specific to the fracture groupings studied herein, and there is a small possibility that patients were counted multiple times if they suffered fractures across the specified types/combinations.

Fracture site	Female			Male		
	60-69 years	70-79 years	80-89 years	60-69 years	70-79 years	80-89 years
Total counts of fracture events of the types/combinations queried, N	569,140	523,840	460,720	279,924	224,722	156,491
Hip (S72.0-2), n (%)	54,801 (9.6)	93,041 (17.8)	131,289 (28.5)	34,237 (12.2)	45,731 (20.4)	49,823 (31.8)
Humerus (S42.2), n (%)	74,332 (13.1)	72,525 (13.8)	54,692 (11.9)	30,484 (10.9)	23,277 (10.4)	14,242 (9.1)
Regions near the hip (S32.0-6), n (%)	100,347 (17.6)	131,154 (25.0)	149,943 (32.5)	66,584 (23.8)	65,507 (29.2)	52,597 (33.6)
Nonhip regions of the femur (S72.3-4), n (%)	19,796 (3.5)	23,556 (4.5)	24,608 (5.3)	11,186 (4.0)	9303 (4.1)	6928 (4.4)
Knee and lower leg (S82.0-4), n (%)	99,551 (17.5)	71,298 (13.6)	39,601 (8.6)	50,272 (18.0)	30,695 (13.7)	13,427 (8.6)
Talus, malleoli, and foot (S82.5-6, S92.1, S92.3-5), n (%)	220,313 (38.7)	132,266 (25.2)	60,587 (13.2)	87,161 (31.1)	50,209 (22.3)	19,474 (12.4)

[a] ICD-10: *International Classification of Diseases, Tenth Revision.*

The incidence and relative frequency of each skeletal region suffering a 1-time fracture changed as individuals aged (Table 1). For individuals 60-69 years of age, the most commonly affected skeletal region with a single fracture event (of those studied) was the talus, malleoli, and foot. In contrast, the hip and regions near the hip were the most commonly affected areas with a single fracture event in 80-89-year-olds. Importantly, the likelihood that a fracture event would occur at the hip increased nearly 3-fold in 80-89-year-olds compared to 60-69-year-olds, while the relative frequency of fracture types distal to the hip either decreased or remained largely unchanged during aging. The incidence of 1-time fractures of the portion of the femur distal to the lesser trochanter (nonhip regions of the femur) remained considerably lower than other fracture groupings regardless of age.

The largely increased incidence of hip fractures during aging likely reflects age-dependent changes, such as those of lifestyle, bone quality (eg, cortical porosity) [28], bone mineral density [29,30], or a combination of these factors. Table S2 of Multimedia Appendix 1 further segments each of the fracture groupings into unique ICD-10 codes; it includes more patients than Table 1 since individuals in a cohort with a specific ICD-10 code were allowed to have other fractures that were previously blocked via grouping. Consequently, Table 1 is more likely to eliminate confounding factors associated with fracture risk (eg, increased risk of fractures from osteoporosis [31]), while Table S2 of Multimedia Appendix 1 has greater statistical power.

Although the relative frequency of the various fracture groupings typically varied with increasing age (Table 1), the 1-year postfracture mortality rates across all fracture groupings increased with age and were consistently greater in males than in females (Table 2). The latter observation held for every ICD-10 code when analyzed individually (as demonstrated in Table S3 in Multimedia Appendix 1) and reflects the underlying greater general mortality rate associated with older age and being male [32,33]. Across all cohorts, patients with hip fracture consistently showed greater 1-year mortality rates compared to all other fractures, regardless of whether the comparison was to other fracture groupings (Table 2), to unique ICD-10 codes (as outlined in Table S3 of Multimedia Appendix 1), or to propensity-score-matched patients of fracture codes and groupings, as described more later (Tables 3 and 4, as well as Table S4 of Multimedia Appendix 1).

Table 2. One-year postfracture mortality rates separated by sex and age. ICD-10[a] codes were aggregated, and patients were only allowed 1 event with the ICD-10 code or pooled codes specified in each column from 60 to 89 years of age; same-day deaths were not included. One-year postfracture mortality rates for individual ICD-10 codes are summarized in Table S3 of Multimedia Appendix 1.

Fracture site	Female			Male		
	60-69 years	70-79 years	80-89 years	60-69 years	70-79 years	80-89 years
Hip (S72.0-2), n/N (%)	3573/54,775 (6.5)	8751/92,946 (9.4)	17,165/131,031 (13.1)	2859/34,213 (8.4)	6227/45,650 (13.6)	9743/49,673 (19.6)
Humerus (S42.2), n/N (%)	2089/74,308 (2.8)	3528/72,495 (4.9)	4908/54,640 (9.0)	1388/30,469 (4.6)	1910/23,259 (8.2)	2042/14,212 (14.4)
Regions near the hip (S32.0-6), n/N (%)	4664/100,310 (4.6)	9511/131,077 (7.3)	15,154/149,797 (10.1)	3961/66,555 (6.0)	6905/65,437 (10.6)	8385/52,495 (16.0)
Nonhip regions of the femur (S72.3-4), n/N (%)	985/19,785 (5.0)	1844/23,539 (7.8)	3146/24,562 (12.8)	653/11,183 (5.8)	921/9294 (9.9)	1164/6,909 (16.8)
Knee and lower leg (S82.0-4), n/N (%)	1907/99,535 (1.9)	2671/71,274 (3.7)	3216/39,571 (8.1)	1393/50,262 (2.8)	1528/30,680 (5.0)	1337/13,407 (10.0)
Talus, malleoli, and foot (S82.5-6, S92.1, S92.3-5), n/N (%)	2661/220,300 (1.2)	3307/132,242 (2.5)	3693/60,562 (6.1)	1839/87,149 (2.1)	2064/50,196 (4.1)	1692/19,464 (8.7)

[a] ICD-10: *International Classification of Diseases, Tenth Revision.*

Importantly, for each cohort, 1-year mortality rates following fractures of the talus, malleoli, and foot occurring in a single event (Table 2) closely aligned with recent reports of mortality rates in the general US population [32,33], suggesting that these fractures do not cause excess mortality in elderly patients. Consequently, we used these fractures as a baseline to estimate the general 1-year mortality risk, against which we assessed excess 1-year mortality risks resulting from the various fracture groupings. Overall, 1-year mortality rates following hip fracture ranged from 6.5% for 60-69-year-old females to 19.6% for 80-89-year-old males (Table 2). Relative to the estimated mortality rate in the general population, hip fractures increased 1-year mortality rates by 5%-7% for female patients and 6%-11% for male patients (Table 2), with the largest absolute increases in mortality rates paralleling increases in age. However, the largest relative change in 1-year mortality rates occurred among 60-69-year-old patients, with females and males at 5.4-fold and 4-fold greater mortality risk, respectively, following hip fracture compared to that estimated for the general population.

Rigorous KM and HR analyses of propensity-score-matched cohorts 1 year postfracture strongly supported the general population results (Tables 3 and 4, as well as Table S4 of Multimedia Appendix 1). Patients with hip fracture were propensity-score-matched to corresponding cohorts of patients with fractures of the upper humerus; regions near the hip; nonhip regions of the femur; knee and lower leg; or talus, malleoli, and foot. KM log-rank tests showed that hip fracture significantly decreased the 1-year postfracture survival probability relative to all other fracture groupings in each of the age and sex cohorts (Table 3). The percentage change in survival probability 1 year postfracture for each fracture grouping relative to the hip fracture grouping is shown in Figure 2A. The cohort with the largest absolute changes in 1-year survival rates across all fracture types was males 80-89 years of age (Figure 2B-F). Propensity-score-matched comparisons of the hip fracture group to each of the individual ICD-10 codes resulted in significantly lower survival probabilities for hip fracture relative to each other fracture type, with 3 exceptions: results were not significantly different for 60-69-year-old males with ischium or femur shaft fractures and for 80-89-year-old females with fractures of the lower end of the femur (Table S4 of Multimedia Appendix 1).

HRs calculated for hip fracture relative to all other fracture groupings exceeded 1 in all instances (Table 4). Importantly, the HRs for hip fractures relative to fractures of the talus, malleoli, and foot exceeded 3 in the 60-69- and 70-79-year-old female and male cohorts. Similarly, HRs established for hip fracture relative to each ICD-10 code exceeded 1 in all instances and exceeded 4.8 when hip fracture was compared to fracture(s) of the greater or lesser toe in 60-69-year-old females (Table S4 of Multimedia Appendix 1).

Table 3. Results from the KM[a] analysis performed on data from 1 day to 1 year following fracture for the propensity-score-matched sex and age cohorts of patients with a hip fracture (individually or in combination: S72.0, S72.1, and S72.2) relative to the other fractures/fracture combinations specified within the table. Individuals deceased the same day as the fracture were not included in the patient cohorts. Only 1 hip fracture or other respective fracture-type event specified for each row was allowed from 60 to 89 years of age. Analyses performed on separated ICD-10[b] codes can be found in Table S4 of Multimedia Appendix 1.

Age group (years)	Hip fracture cohort statistics		Other fracture cohort statistics		Log-rank test	
	Patients with outcome/patients in cohort, n/N (%)	Probability of 1-year survival (determined by KM curve), %	Patients with outcome/patients in cohort, n/N (%)	Probability of 1-year survival (determined by KM curve), %	χ^2 (*df*)	*P* value[c]
Upper humerus (S42.2)						
60-69, female	3234/50,849 (6.4)	92.9	1760/51,154 (3.4)	96.2	481.0 (1)	<.001
70-79, female	5773/63,408 (9.1)	89.8	3283/64,022 (5.1)	94.3	81.6 (1)	<.001
80-89, female	7027/52,099 (13.5)	84.7	4956/52,986 (9.4)	89.5	523.0 (1)	<.001
60-69, male	1986/24,947 (8.0)	91.1	1253/25,135 (5.0)	94.5	192.8 (1)	<.001
70-79, male	2945/21,583 (13.6)	84.7	1912/21,906 (8.7)	90.4	300.5 (1)	<.001
80-89, male	2809/13,227 (21.2)	75.7	2065/13,585 (15.2)	82.9	204.1 (1)	<.001
Regions near the hip (S32.0-6)						
60-69, female	3553/53,217 (6.7)	92.6	2793/53,489 (5.2)	94.2	111.9 (1)	<.001
70-79, female	8283/84,349 (9.8)	89.0	6514/85,097 (7.7)	91.5	293.5 (1)	<.001
80-89, female	14,975/107,520 (13.9)	84.1	12,176/109,465 (11.1)	87.5	511.1 (1)	<.001
60-69, male	2834/32,955 (8.6)	90.2	2205/33,177 (6.6)	92.5	100.0 (1)	<.001
70-79, male	5877/40,940 (14.4)	83.7	4653/41,515 (11.2)	87.4	226.7 (1)	<.001
80-89, male	8381/38,966 (21.5)	75.1	6829/40,065 (17.0)	80.7	358.6 (1)	<.001
Nonhip regions of the femur (S72.3-4)						
60-69, female	1326/19,457 (6.8)	92.5	990/19,485 (5.1)	94.4	56.5 (1)	<.001
70-79, female	2239/22,914 (9.8)	89.1	1860/22,973 (8.1)	91.1	46.6 (1)	<.001
80-89, female	3367/23,357 (14.4)	83.6	3171/23,481 (13.5)	84.9	12.0 (1)	<.001
60-69, male	890/10,866 (8.2)	90.7	656/10,924 (6.0)	93.3	43.1 (1)	<.001
70-79, male	1196/8879 (13.5)	84.9	927/8991 (10.3)	88.5	50.0 (1)	<.001
80-89, male	1397/6445 (21.7)	75.2	1170/6533 (17.9)	79.9	39.5 (1)	<.001
Knee and lower leg (S82.0-4)						
60-69, female	3423/52,623 (6.5)	92.8	1311/53,038 (2.5)	97.3	1051.7 (1)	<.001
70-79, female	5528/62,697 (8.8)	90.1	2570/63,403 (4.1)	95.5	1292.2 (1)	<.001
80-89, female	4973/37,797 (13.2)	85.1	3249/38,529 (8.4)	90.6	518.2 (1)	<.001
60-69, male	2517/31,105 (8.1)	90.8	1071/31,392 (3.4)	96.2	675.8 (1)	<.001
70-79, male	3475/26,988 (12.9)	85.4	1479/27,542 (5.4)	94.0	1032.7 (1)	<.001
80-89, male	2489/12,472 (19.9)	77.1	1357/12,934 (10.5)	88.3	538.7 (1)	<.001
Talus, malleoli, and foot (S82.5-6, S92.1, S92.3-5)						
60-69, female	3592/53,725 (6.7)	92.5	1082/54,228 (2.0)	97.8	1505.5 (1)	<.001
70-79, female	7258/78,836 (9.2)	89.7	2517/80,084 (3.1)	96.5	2741.9 (1)	<.001
80-89, female	7390/56,166 (13.2)	85.2	3669/57,850 (6.3)	93.0	1754.0 (1)	<.001
60-69, male	2754/32,621 (8.4)	90.4	988/33,094 (3.0)	96.7	976.0 (1)	<.001
70-79, male	4606/34,302 (13.4)	84.8	1655/35,247 (4.7)	94.8	1802.9 (1)	<.001
80-89, male	3687/17,652 (20.9)	76.1	1687/18,540 (9.1)	90.0	1201.9 (1)	<.001

[a] KM: Kaplan-Meier.

[b] ICD-10: *International Classification of Diseases, Tenth Revision.*

[c] Statistically significant (P<.05) results are italicized.

Table 4. Results from the HR[a] analysis performed on data from 1 day to 1 year following fracture for the propensity-score-matched sex and age cohorts of patients with a hip fracture (individually or in combination: S72.0, S72.1, and S72.2) relative to the other fractures/fracture combinations specified within the table. Individuals deceased the same day as the fracture were not included in the patient cohorts. Only 1 hip fracture or other respective fracture-type event specified for each row was allowed from 60 to 89 years of age. Analyses performed on separated ICD-10[b] codes can be found in Table S4 of Multimedia Appendix 1.

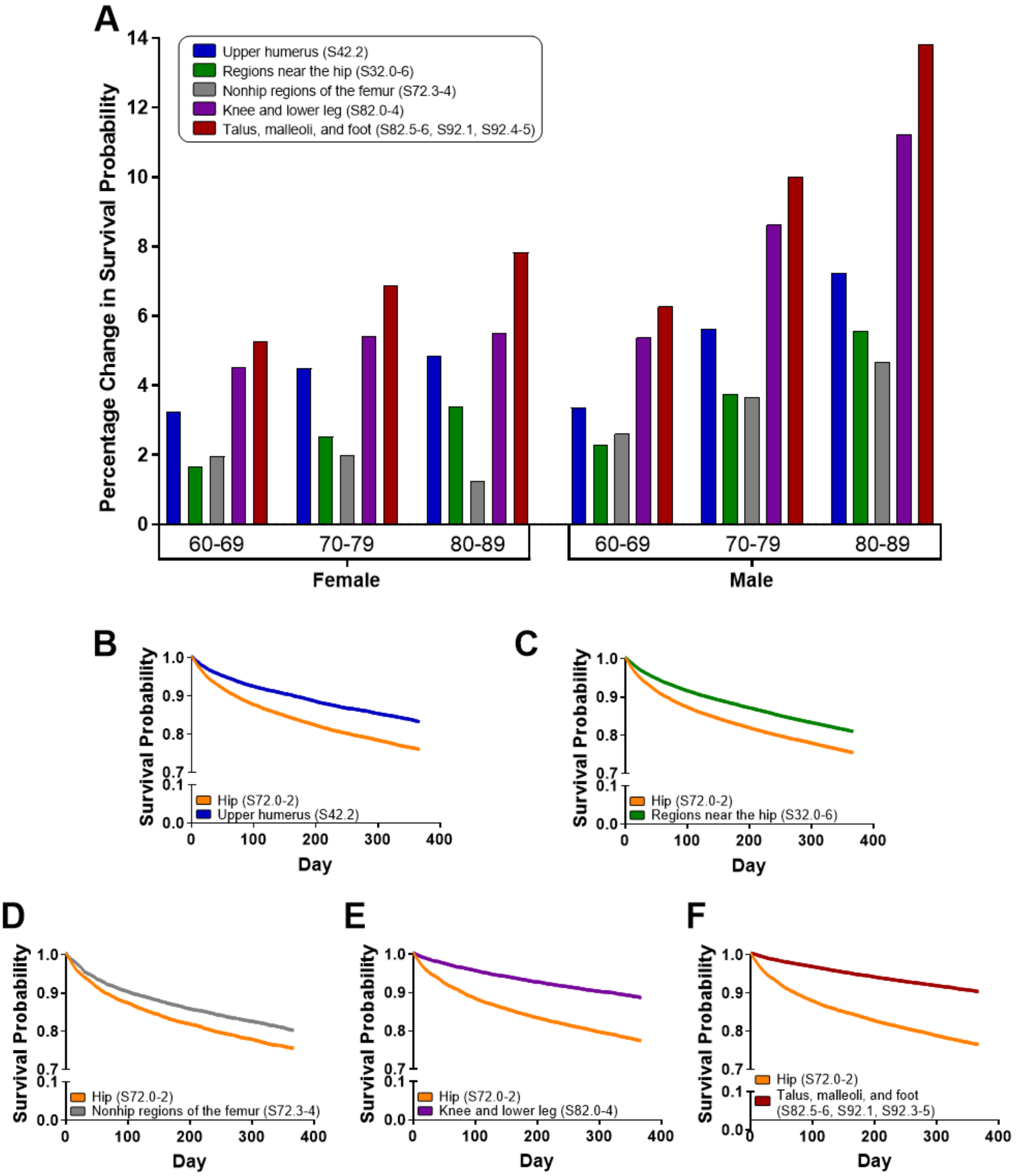
Age group (years)	HR (95% CI)	χ^2 (*df*)	*P* value[c]
Upper humerus (S42.2)			
60-69, female	1.89 (0.167-21.488)	23.7 (1)	*<.001*
70-79, female	1.85 (0.172-19.934)	24.4 (1)	*<.001*
80-89, female	1.52 (0.16-14.522)	51.6 (1)	*<.001*
60-69, male	1.64 (0.145-18.584)	0.9 (1)	.36
70-79, male	1.66 (0.164-16.752)	18.5 (1)	*<.001*
80-89, male	1.51 (0.181-12.564)	14.7 (1)	*<.001*
Regions near the hip (S32.0-6)			
60-69, female	1.31 (0.12-14.22)	2.4 (1)	.12
70-79, female	1.33 (0.13-13.493)	29.7 (1)	*<.001*
80-89, female	1.32 (0.144-12.017)	124.1 (1)	*<.001*
60-69, male	1.33 (0.129-13.651)	0.8 (1)	.36
70-79, male	1.34 (0.146-12.334)	22.7 (1)	*<.001*
80-89, male	1.36 (0.176-10.513)	57.3 (1)	*<.001*
Nonhip regions of the femur (S72.3-4)			
60-69, female	1.37 (0.127-14.732)	2.3 (1)	.13
70-79, female	1.24 (0.123-12.466)	1.5 (1)	.22
80-89, female	1.09 (0.123-9.64)	0.04 (1)	.85
60-69, male	1.40 (0.134-14.564)	2.0 (1)	.16
70-79, male	1.36 (0.146-12.682)	6.8 (1)	*<.01*
80-89, male	1.28 (0.163-10.105)	3.9 (1)	*.049*
Knee and lower leg (S82.0-4)			
60-69, female	2.75 (0.243-31.034)	37.1 (1)	*<.001*
70-79, female	2.30 (0.214-24.769)	56.8 (1)	*<.001*
80-89, female	1.66 (0.172-16.08)	47.7 (1)	*<.001*
60-69, male	2.50 (0.23-27.213)	12.4 (1)	*<.001*
70-79, male	2.61 (0.261-26.143)	41.7 (1)	*<.001*
80-89, male	2.15 (0.247-18.681)	35.9 (1)	*<.001*
Talus, malleoli, and foot (S82.5-6, S92.1, S92.3-5)			
60-69, female	3.53 (0.311-39.961)	51.4 (1)	*<.001*
70-79, female	3.15 (0.291-34.06)	116.8 (1)	*<.001*
80-89, female	2.28 (0.23-22.52)	210.4 (1)	*<.001*
60-69, male	3.01 (0.279-32.493)	18.7 (1)	*<.001*
70-79, male	3.17 (0.315-31.767)	126.0 (1)	*<.001*
80-89, male	2.66 (0.3-23.659)	94.1 (1)	*<.001*

[a] HR: hazard ratio.

[b] ICD-10: *International Classification of Diseases, Tenth Revision*.

[c] Statistically significant (*P*<.05) results are italicized.

Figure 2. The changes to survival probability 1 year after several fracture types relative to propensity-score-matched hip fracture patients. Men from 80 to 89 years of age showed the largest absolute percentage change in survival rates across all fracture types relative to their propensity-score-matched patient cohorts with hip fracture. KM survival curves for men from 80 to 89 years of age with fractures of the hip compared to fractures of the upper humerus (B), regions near the hip (C), nonhip regions of the femur (D), knee and lower leg (E), and talus, malleoli, and foot (F). Hip fracture survival probability curves were not identical in each figure since each independent propensity score matching analysis for each comparison selected different groups of hip fracture patients. KM: Kaplan-Meier.



Dementia and Type 2 Diabetes Comorbidities

The codes used to identify elderly patients in the TriNetX database diagnosed with either dementia, T2D, or both comorbidities identified approximately 1.6 million, 16.8 million, or 0.66 million individuals, respectively (Figure S2 of Multimedia Appendix 3). Subsequently, we explored general incidence of the fracture groupings in combination with the comorbidities in our age range of interest (Table 5) and the relative frequency of the various fracture groupings in patients with dementia (Figure S3A of Multimedia Appendix 3) or T2D (Figure S3B of Multimedia Appendix 3) across the sex and age cohorts of interest. A dementia diagnosis clearly shifted the fracture type away from talus, malleoli, and foot fracture toward hip fracture in all cohorts and toward fracture of regions near the hip in some cohorts (Figure S3A of Multimedia Appendix

3). In contrast, a T2D diagnosis had a much smaller impact, shifting the fracture type slightly away from hip fracture toward talus, malleoli, and foot fracture in some cohorts, although these effects were minimal (Figure S3B of Multimedia Appendix 3).

Similar to the general population cohorts, patients with hip fracture and dementia displayed greater mortality rates compared to other fracture groupings (Table 6) and all other ICD-10 codes studied (Table S5 of Multimedia Appendix 1).

Table 5. General incidence and relative frequency of various fracture types/combinations with dementia/T2D[a] in patients 60-89 years of age. Dementia diagnosis was allowed from any time before fracture to 1 year postfracture and was specified as any of the following ICD-10[b] codes or a combination thereof: vascular dementia, F01; dementia due to Alzheimer disease, G30; or dementia with Lewy bodies, G31.83. T2D was required to be recorded within 6 months prior to fracture to 1 year postfracture and was specified with ICD-10 code E11. ICD-10 codes were aggregated as described in the header for this table, and patients were only allowed 1 event with the code or pooled codes specified in each column from 60 to 89 years of age. Incidence entries include individuals deceased the same day as the fracture. The relative frequency of each fracture/fracture grouping is shown in parentheses and is specific to the fracture groupings studied herein and, as with Table 1, there is a small possibility that patients were counted multiple times if they suffered fractures across the specified types/combinations.

Total counts of fracture events of the types/combinations queried in combination with dementia/T2D	Hip (S72.0-2), n (%)	Humerus (S42.2), n (%)	Regions near the hip (S32.0-6), n (%)	Nonhip regions of the femur (S72.3-4), n (%)	Knee and lower leg (S82.0-4), n (%)	Talus, malleoli, and foot (S82.5-6, S92.1, S92.3-5), n (%)
With dementia (N=112,113)	37,084 (33.1)	12,625 (11.3)	34,211 (30.5)	6425 (5.7)	9070 (8.1)	12,698 (11.3)
With T2D (N=594,711)	100,804 (17.0)	72,748 (12.2)	146,301 (24.6)	28,353 (4.8)	91,376 (15.4)	155,129 (26.1)

[a] T2D: type 2 diabetes.

[b] ICD-10: *International Classification of Diseases, Tenth Revision*.

Table 6. One-year postfracture mortality rates in patients with dementia (specifically, any of the following ICD-10[a] codes or a combination thereof: vascular dementia, F01; dementia due to Alzheimer disease, G30; or dementia with Lewy bodies, G31.83) or T2D[b] (E11). A dementia diagnosis was allowed from any time before fracture to 1 year postfracture, while a T2D diagnosis was required to be recorded within 6 months prior to fracture to 1 year postfracture. Data on separated ICD-10 codes can be found in Table S5 of Multimedia Appendix 1; ICD-10 codes were aggregated as described in the header for this table, and patients were only allowed 1 event with the ICD-10 code or pooled codes specified in each column from 60 to 89 years of age. Same-day deaths were not included for this analysis.

Age group (years)	Hip (S72.0-2), n/N (%)	Humerus (S42.2), n/N (%)	Regions near the hip (S32.0-6), n/N (%)	Nonhip regions of the femur (S72.3-4), n/N (%)	Knee and lower leg (S82.0-4), n/N (%)	Talus, malleoli, and foot (S82.5-6, S92.1, S92.3-5), n/N (%)
With dementia						
60-69, female	180/1117 (16.1)	69/741 (9.3)	177/1391 (12.7)	42/307 (13.7)	76/804 (9.5)	85/1236 (6.9)
70-79, female	1213/6512 (18.6)	390/3009 (13.0)	945/6590 (14.3)	210/1270 (16.5)	240/2237 (10.7)	298/3280 (9.1)
80-89, female	3955/18,452 (21.4)	983/6031 (16.3)	2787/16,301 (17.1)	668/3383 (19.7)	591/3741 (15.8)	701/4877 (14.4)
60-69, male	140/854 (16.4)	47/385 (12.2)	119/922 (12.9)	23/151 (15.2)	46/401 (11.5)	45/598 (7.5)
70-79, male	813/3388 (24.0)	206/1015 (20.3)	673/3349 (20.1)	87/463 (18.8)	124/863 (14.4)	153/1264 (12.1)
80-89, male	1916/6647 (28.8)	337/1429 (23.6)	1355/5608 (24.2)	206/838 (24.6)	194/1016 (19.1)	286/1431 (20.0)
With T2D						
60-69, female	1217/13,972 (8.7)	840/18,279 (4.6)	1640/24,610 (6.7)	460/5881 (7.8)	856/23,717 (3.6)	1246/49,752 (2.5)
70-79, female	2728/23,917 (11.4)	1337/20,425 (6.5)	3234/34,770 (9.3)	756/7425 (10.2)	1751/25,936 (6.8)	1594/36,892 (4.3)
80-89, female	3695/26,451 (14.0)	1295/12,935 (10.0)	3786/31,507 (12.0)	882/6351 (13.9)	10,83/10,225 (10.6)	1315/16,585 (7.9)
60-69, male	1033/9552 (10.8)	604/8635 (7.0)	1400/18,454 (7.6)	255/3213 (7.9)	608/13,575 (4.5)	941/26,241 (3.6)
70-79, male	2146/14,099 (15.2)	868/8087 (10.7)	2698/21,630 (12.5)	398/3264 (12.2)	1039/13,445 (7.7)	1116/18,562 (6.0)
80-89, male	2570/12,659 (20.3)	668/4323 (15.5)	2618/15,195 (17.2)	385/2186 (17.6)	552/4428 (12.5)	745/7055 (10.6)

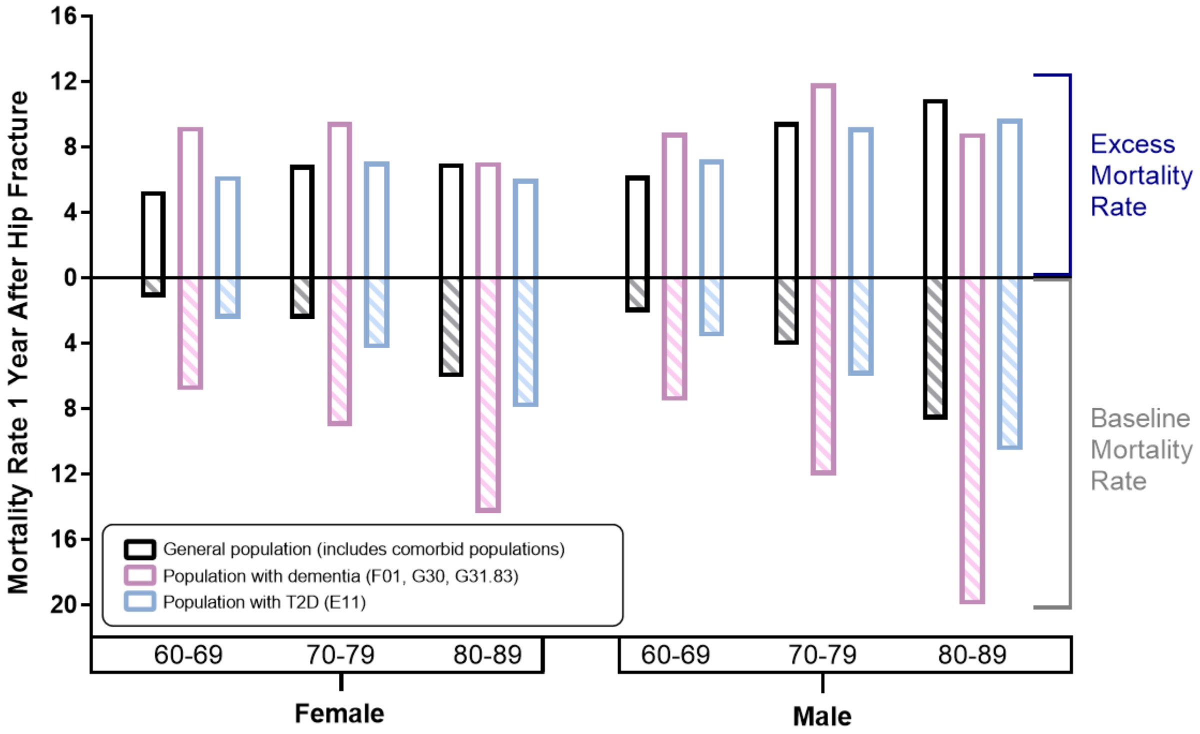
[a] ICD-10: *International Classification of Diseases, Tenth Revision*.

[b] T2D: type 2 diabetes.

For individuals with T2D and fracture, 1-year mortality results were similar to those of the general population. All cohorts with a T2D diagnosis exhibited a greater 1-year mortality rate after hip fracture relative to the other fracture groupings (Table 6) and other individual ICD-10 codes, with the exception of females with fracture of the lower end of the femur from 80 to 89 years of age (Table S5 of Multimedia Appendix 1).

Collectively, these data determined the extent that dementia or T2D as comorbidities exacerbate 1-year postfracture mortality rates. The comorbidities of hip fracture and dementia in the 60-69- and 70-79-year-old cohorts resulted in greater excess 1-year mortality rates compared to hip fracture in the general population (Figure 3). However, T2D combined with hip fracture did not show a similar exacerbation, and 1-year mortality rates for hip fracture with a T2D comorbidity were typically additive (equal to the combination of the baseline mortality rate and the mortality rate due to hip fracture) or less than additive. Instances of less-than-additive effects suggest the possibility of a mutual cause of mortality or that the care of the comorbidity may reduce the hip fracture–related mortality risk.

Figure 3. The effects of dementia and T2D in combination with hip fracture on mortality. To establish whether these comorbidities combined with hip fracture exacerbate the mortality rate beyond simply additive effects, the percentage of individuals with the comorbidity of interest deceased 1 year postfracture of the talus, malleoli, and foot was superimposed onto the 1-year mortality rate following hip fracture with the respective comorbidity (this was used as a representation of the baseline mortality rate; for the general population no comorbidities were specified, and it included individuals with the comorbidities of the other populations). Results showed that hip fracture was synergistic with dementia in younger cohorts but was either additive or less than additive for older cohorts with dementia and nearly all cohorts with T2D. T2D: type 2 diabetes.



Discussion

Potential Interpretations and Implications

Hip fractures confer a uniquely increased mortality risk relative to all other studied fracture groupings. From the upper humerus data, we inferred that the increased mortality is not the result of the fracture occurring at an appendage-torso juncture, and the remainder of comparisons exhibited generally increasing differences in mortality rates as the fracture site became more distal to the hip. Because more peripheral fractures are expected to have less of an impact on mobility, perhaps requiring a boot or a scooter instead of a wheelchair, these data suggest that mobility may play a critical role in mortality risk.

Given that the differences in mortality rates remained when patients were propensity-score-matched across cohorts, this suggests that there is likely 1 or more underlying hip-specific mechanisms. The comorbidity of dementia that was identified herein as acting synergistically with hip fracture to exacerbate mortality rates could not have been the sole driving force behind these increased mortality rates, since it was not synergistic at older ages where the percentage change in survival probability between hip fracture and talus, malleoli, and foot fracture was the greatest. As mentioned previously, 1 factor that might influence these observed differences in 1-year postfracture mortality rates is mobility, as it is common to not regain prefracture mobility following hip fracture [34-37]. This greater mortality risk associated with impaired mobility may stem from changes to self-care factors, such as the ability to acquire help immediately following a fall, or changes to the blood flow dynamics, since circulatory system disease has been identified as a leading cause of death in patients after hip fracture [38]. Additionally, greater proportions of daily sitting time have been associated with increased all-cause mortality risk [39]. Consequently, restoring mobility should be a treatment priority to reduce the mortality risk associated with hip fracture and other mobility-impairing fractures. Additionally, the differences in mortality rate between hip fracture and other types of fracture might result from differences in tensile strength [40], bone density [41], or bone quality; for instance, the femoral head is less isotropic but has consistently greater trabecular bone volume than the humeral head [42]. Together, this strongly supports future investigations to identify unique behavioral and cellular mechanisms occurring following hip fracture.

Exploration of dementia as a comorbidity revealed that fracture combined with dementia substantially exacerbates the mortality rate in younger elderly cohorts. This suggests that the increased 1-year mortality rates observed in patients with dementia and fracture may arise from synergistic mechanisms, whether cellular or behavioral in nature. The apparent lack of excess mortality associated with T2D as a comorbidity to fracture aligns with studies that reported no differences in 1-year mortality rates in populations of individuals that included those with type 1 diabetes (T1D) and T2D [43,44].

This work extends previous studies that have attempted to distinguish comorbidity-related deaths from those brought about directly by hip fracture. Previous studies have attributed 17%-32% of all hip fracture–associated deaths directly to the fracture event after subtracting out the comorbidities [45]. In contrast, this work indicates that hip fracture increases the 1-year mortality risk in the general elderly population by approximately 2- to 5-fold. In elderly patients with dementia, hip fracture approximately doubles the 1-year mortality risk for all but the oldest cohorts of patients. Our study further established that this excess mortality is not a consequence of any fracture type but is instead directly related to fracture location, with fractures of the hip associated with the greatest increases in the 1-year mortality rate.

Limitations

Despite the rigor of this work, several confounding variables remain. The TriNetX database, and analogous databases developed from EMRs, has difficulty accounting for patients that leave the health care system, as well as patients that are inaccurately diagnosed or whose diagnosis is later changed. Patients may move into a health care system with incomplete records or transfer between health care systems that both import data to TriNetX's Diamond Network, the latter of which could lead to counting a patient more than once. Moreover, in TriNetX, propensity score matching can only be performed through the day of an event, because testing statistics on survival requires the event to be the fracture event, and we could not propensity-score-match based on how individuals were treated or diagnosed postfracture.

Although same-day deaths, which accounted for less than 2% of the deaths that occurred within 1 year of hip fracture, were removed, we did not explore whether the trauma event(s) inciting or associated with hip fracture resulted in more extensive damage to the surrounding area that might acutely increase the risk of mortality. Low preoperative hemoglobin concentration and excessive blood loss during surgery are both linked to increased mortality rates [46], and patients with hip fracture and delayed surgical intervention present with significant blood loss over the days following hospital admission but before surgery [47]. Finally, a statistical limitation was the lack of corrections for multiple comparisons in the propensity-score-matched results, which were left out because this was an exploratory analysis and should be followed up with a prospective observational trial.

Conclusion

Hip fracture results in a greater 1-year mortality rate relative to the upper humerus and other fracture types/groupings of regions near and below the hip. This increased risk remains when cohorts are propensity-score-matched across a large number of characteristics, suggesting that this vulnerability is specific to this particular fracture type. Furthermore, the data herein established that dementia acts synergistically with hip fracture to exacerbate mortality rates in younger populations, but T2D does not appear to impact the mortality rate beyond an additive effect of the risks conferred by T2D and hip fracture independently. The data strongly suggest the necessity of future studies to explore unique elements of hip fracture events and therapeutic options targeting this fracture type specifically.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
The Excel file containing Tables S1-S5 referenced in the manuscript.
[XLSX File (Microsoft Excel File), 52 KB - aging_v5i1e32683_app1.xlsx]

Multimedia Appendix 2
Additional details on propensity score matching methods.
[DOCX File , 14 KB - aging_v5i1e32683_app2.docx]

Multimedia Appendix 3

The PDF containing Figures S1-S3 referenced in the manuscript.
[PDF File (Adobe PDF File), 329 KB - aging_v5i1e32683_app3.pdf]

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Abbreviations

EMR: electronic medical record
HR: hazard ratio
ICD-10: *International Classification of Diseases, Tenth Revision*
KM: Kaplan-Meier
T1D: type 1 diabetes
T2D: type 2 diabetes

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Original Paper

Identification of Digital Health Priorities for Palliative Care Research: Modified Delphi Study

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Abstract

Background: Developments in digital health have the potential to transform the delivery of health and social care to help citizens manage their health. Currently, there is a lack of consensus about digital health research priorities in palliative care and a lack of theories about how these technologies might improve care outcomes. Therefore, it is important for health care leaders to identify innovations to ensure that an increasingly frail population has appropriate access to palliative care services. Consequently, it is important to articulate research priorities as the first step in determining how finite resources should be allocated to a field saturated with rapidly developing innovation.

Objective: The aim of this study is to identify research priority areas for digital health in palliative care.

Methods: We selected digital health trends, most relevant to palliative care, from a list of emerging trends reported by a leading institute of quantitative futurists. We conducted 2 rounds of the Delphi questionnaire, followed by a consensus meeting and public engagement workshop to establish a final consensus on research priorities for digital technology in palliative care. We used the views of public representatives to gain their perspectives on the agreed priorities.

Results: A total of 103 experts (representing 11 countries) participated in the first Delphi round. Of the 103 experts, 55 (53.3%) participated in the second round. The final consensus meetings were attended by 10.7% (11/103) of the experts. We identified 16 priority areas, which involved many applications of technologies, including care for patients and caregivers, self-management and reporting of diseases, education and training, communication, care coordination, and research methodology. We summarized the priority areas into eight topics: big data, mobile devices, telehealth and telemedicine, virtual reality, artificial intelligence, smart home, biotechnology, and digital legacy.

Conclusions: The priorities identified in this study represent a wide range of important emerging areas in the fields of digital health, personalized medicine, and data science. Human-centered design and robust governance systems should be considered in future research. It is important that the risks of using these technologies in palliative care are properly addressed to ensure that these tools are used meaningfully, wisely, and safely and do not cause unintentional harm.

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KEYWORDS

palliative care; terminal care; supportive care; quality of life; symptom management; digital health; technology

Introduction

Background

Developments in digital health (describing technologies that use computing platforms, connectivity, software, and sensors for health care and related purposes) have the potential to transform the delivery of health and social care to help citizens manage their own health [1-3]. Currently, there is a lack of consensus about digital health research priorities in palliative care and theories about how these technologies might improve care outcomes. Therefore, it is important to articulate research priorities as the first step in determining how finite resources should be allocated to a field saturated with rapidly developing innovation. Global palliative care needs are expected to increase because of the consequences of an aging population; therefore, it is important for health care leaders to identify innovations to ensure that an increasingly frail population has appropriate access to palliative care services [4]. Research demonstrates that, when used well, digital health initiatives improve health care delivery and access [5-15], and the World Health Organization suggests that digital health should be an integral part of health priorities as a means to improve health on a global scale [16,17]. To date, many barriers have prevented the meaningful use of digital health in palliative care [18], including expenses, interoperability issues, data privacy and security concerns, lack of effectiveness and equity, and the concern that technology will reduce face-to-face consultations between patients and clinicians [19,20].

Strategic forethought (futurism) can help palliative care leaders recognize emerging trends and test, plan, and use these innovations in practice [21]. Consequently, this study aims to identify digital health research priorities and to theorize how innovations in emerging technologies can improve palliative care.

Aim

The aim of this study is to identify research priority areas for technology in palliative care.

Methods

Study Design

We used a Delphi process, informed by the Guidance on Conducting and Reporting Delphi Studies [22] in palliative care, to establish the opinions of palliative care experts. A Delphi process can be used as a consensus-based, forecasting process, enabling anonymous expert contributions to predict phenomena [23,24]. We chose to use the Delphi method because of its potential to achieve consensus in areas of uncertainty [25-28]. We conducted 2 rounds of the Delphi questionnaire, followed by a consensus meeting and public engagement workshop to establish a final consensus on research priorities for digital technology in palliative care. Data were collected between November 2018 and September 2019.

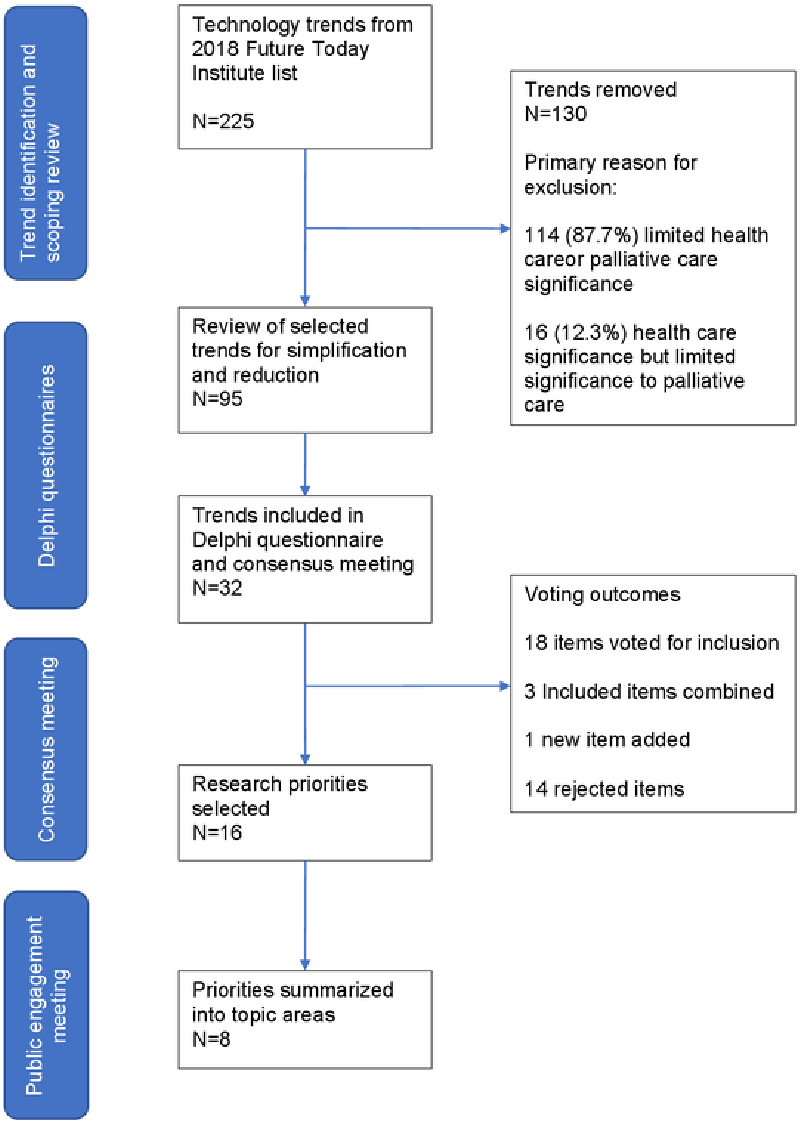
Identification of Technology Trends From the Future Today Institute

We selected technology trends most relevant to palliative care from a list of emerging technology trends reported by the Future Today Institute (FTI) [29]. The FTI is a multi-professional organization that uses data-driven applied research to develop models that forecast risks and opportunities across several disciplines, which are mapped into technology trends. The 2018 trend list included 225 emerging trends, which were stratified by FTI authors into 19 categories (Multimedia Appendix 1).

Selection of Technology Trends for Palliative Care

We developed criteria to select the FTI trends based on recommendations from a UK-based policy report, which reported public and professional views on new types of health care data [30]. We developed the following statement to select FTI trends for inclusion: “Trends should involve analysis or use data generated by a patient, caregiver or healthcare professional with potential use in palliative care.” A total of two authors (ACN and TMcG) reviewed all 225 FTI trends. We chose to review all FTI trends (despite their previous categorization) to ensure that no suitable trends, from categories deemed less relevant to palliative care (eg, agricultural technologies, space, and government and technology policy), were overlooked. We included 42.2.% (95/225) of the trends. We then combined and simplified similar trends to reduce the number to 32 (32/225, 14.2%; Figure 1). To confirm the validity of the trends in palliative care, we conducted a focused literature review to identify examples in which these technologies had been used in health care. An Excel (Microsoft Inc) spreadsheet was used to collate the data for reference.

Figure 1. Flow diagram to outline study process for identifying research priority areas.



Delphi Questionnaire Development

We developed 32 items for inclusion in the Delphi questionnaire, which reflected the 32 trends identified in the FTI Report (Figure 1). We used Google Forms (Google Inc) [31] to develop the survey. We designed a questionnaire to collect demographic information (geographic location, age, and occupation) and individuals' rating of importance for each item using a 5-point Likert scale (1=low priority to 5=high priority). To ensure that the survey questions were appropriate, we conducted a local prestudy pilot of the questionnaire and supporting materials (Multimedia Appendices 2 and 3).

Participant Recruitment and Consent

We solicited a convenience sample of professionals working in palliative care (including physicians, nurses, social workers, therapists, pharmacists, spiritual care staff, and managers) who were interested in technological innovation. We used professional networks, social media, and email to contact individuals (Multimedia Appendix 4). Consenting participants accessed the study material on the internet to complete an electronic consent form and a first-round Delphi questionnaire. Participants who completed the first round of the questionnaire were invited to participate in the second round.

Ethical Approval

This study was approved by the University of Liverpool Ethics Committee (approval number 3564).

Data Collection and Analysis

Quantitative statistical analyses of participant ratings were performed using the statistical software package SPSS (version 22.0; IBM Corp). We used the IQR to determine the level of agreement on the 5-point scales for each *area* on the questionnaire. The justification for the levels of agreement was based on thresholds previously used in palliative care Delphi studies, which used a 5-point Likert scale to determine agreement (Multimedia Appendix 5) [22,32]. We emailed a summary of the first-round Delphi results to each participant. The email included the following information: (1) a summary of how the participant rated each item in the first Delphi round and (2) a summary of all participants' responses for each item (pooled level of agreement). We provided this information so that participants could consider whether they wished to rank items differently in the second Delphi round, based on the ranking data generated by other participants.

Round 2 Delphi Questionnaire

We provided the participants with an electronic link to access the second-round Delphi questionnaire. We asked the participants to answer the same questions that were included in the first-round questionnaire. Participants were required to complete the questionnaire within 4 weeks. We analyzed the responses from the second questionnaire by IQR to provide a final list of items according to their level of agreement.

Final Consensus Meeting and Voting

We organized a consensus meeting to agree with the trend list as the final stage of the Delphi process [22]. All participants were invited to attend a meeting at the University of Liverpool, United Kingdom. The participants were divided into 2 groups. We attempted to ensure the groups were similar by allocating individuals according to gender, experience, and occupation. We provided participants with the Delphi results via (1) an oral presentation and (2) a written summary. ACN and TMcG acted as group facilitators, and ACN chaired the meeting. We facilitated the group discussions and voting. Each item was discussed and debated, and a *raised-hand* vote was undertaken within each group to determine whether each item was included or excluded from the final list.

After voting, we compared the outcomes between the 2 groups. Items were included if both groups voted for inclusion. Similarly, items were excluded if both groups voted for exclusion. When the groups disagreed (ie, one group voting for inclusion and the other voting for exclusion), we facilitated debate with both groups together, which was followed by rounds of voting until consensus was achieved.

Public Engagement Workshop

Following the consensus meeting, we conducted a public engagement workshop with lay representatives to determine their views on agreed priorities. Volunteer coordinators from the Marie Curie Hospice Liverpool and Liverpool University Hospitals National Health Service Foundation Trust invited palliative care volunteers (by telephone and email).

Results

Round 1 Delphi Questionnaire

Round 1 included 103 participants (Table 1). The median age of participants was 45 (SD 11.2) years. Most participants were women (65/103, 63.1%) and had a clinical background (74/103, 71.9%). The participants represented 11 countries, most commonly the United Kingdom (88/103, 85.4%). Most trend items (25/32, 78%) achieved a median priority rating of 4 or 5 (Multimedia Appendix 6), which suggested that participants considered most items to be important.

Table 1. Demographics of study participants (N=103).

Characteristics	First round (n=103)	Second round (n=55)	Consensus meeting (n=11)
Age (years), median (SD; range)	45 (11.2; 22-74)	44 (11.6; 22-74)	47 (11.5; 29-62)
Gender, n (%)			
Male	38 (36.9)	23 (41.8)	4 (36.3)
Female	65 (63.1)	32 (58.2)	7 (63.7)
Location, n (%)			
United Kingdom	88 (85.4)	47 (85.5)	11 (100)
United States	4 (3.9)	1 (1.8)	0 (0)
Germany	2 (1.9)	2 (3.6)	0 (0)
The Netherlands	2 (1.9)	1 (1.8)	0 (0)
Saudi Arabia	1 (1)	0 (0)	0 (0)
Canada	1 (1)	1 (1.8)	0 (0)
Brazil	1 (1)	1 (1.8)	0 (0)
Italy	1 (1)	0 (0)	0 (0)
Sweden	1 (1)	0 (0)	0 (0)
Argentina	1 (1)	1 (1.8)	0 (0)
Austria	1 (1)	1 (1.8)	0 (0)
Occupation, n (%)			
Clinical (nurse or physician)	74 (71.9)	38 (69.1)	6 (54.5)
Academic	16 (15.6)	11 (20)	4 (36.4)
Health care manager	4 (3.9)	2 (3.6)	1 (9.1)
Layperson	3 (2.9)	3 (5.5)	0 (0)
Allied health professional	2 (1.9)	1 (1.8)	0 (0)
Chaplain	2 (1.9)	0 (0)	0 (0)
Information technology	2 (1.9)	0 (0)	0 (0)

Round 2 Delphi

Of the 103 participants in round 1, a total of 55 (53.3%) of the participants completed the round 2 questionnaire. The median age was 44 (SD 11.6) years, which was similar to that in round 1. More women than men completed the questionnaire (32/55, 58%). The distribution of occupations was similar across both the rounds. Fewer countries (8/11, 73%) were included in the final sample. The final IQR analysis (Multimedia Appendix 6) demonstrated that most items (21/32, 66%) had *low* levels of agreement, with 6% (2/32) and 28% (9/32) of the items achieving *moderate* and *high* levels of agreement, respectively.

Consensus Meeting and Final List of Priorities

A total of 11 people participated in the consensus meeting (11/103, 10.7% of the total participants and 11/55, 20% of the second-round participants). The median age of the participants was 47 (SD 11.5) years, and most of them (7/11, 64%) were women. All participants were based in the United Kingdom and were mostly from clinical (6/11, 55%) or academic backgrounds (4/11, 36%). The debate resulted in agreement, rejection, modification (rewording and combination) of trends, and the addition of a new item, digital legacy (Multimedia Appendix 7). We classified the priorities into eight topic areas: big data, mobile devices, telehealth and telemedicine, virtual reality (VR), artificial intelligence (AI), smart home, biotechnology, and digital legacy (Multimedia Appendix 8).

Public Engagement Event

We conducted a public engagement event at the Marie Curie Hospice Liverpool, United Kingdom, attended by 6 lay representatives, 2 staff members (nurse and physician), and a medical student. We began the meeting with a presentation discussing the importance of studying technology in palliative care. We then presented an overview of the Delphi outcomes, research topic areas, and identified priorities. We allocated attendees into 2 groups, and we (ACN and SS) facilitated 2 separate discussions (each lasting 45 minutes) with each group. Discussion 1 involved a discussion about the priorities from the big data, AI, and biotechnology topic areas. Discussion 2 involved discussion of priorities from telehealth and telemedicine, mobile devices and wearables, smart homes, VR, and digital legacy topic areas. We asked attendees for their views on priorities to determine their opinions on appropriateness and to identify areas that they believed warranted further study or clarification. Further information about the public engagement meeting is presented in Multimedia Appendix 9.

Our public representatives recommended that future research should (1) ensure a human-centered co-design approach to ensure that technologies are designed according to the needs of individuals and (2) appropriate governance processes should be in place to evaluate the efficacy, effectiveness, and ethical issues of current and future digital health tools and systems.

Discussion

Summary of Main Findings

This is the first study to identify digital health research priorities for palliative care and provide guidance for researchers, funders, and policy makers to consider areas for future research and development. We identified 16 priority areas, which involved many applications of technologies, including care for patients and caregivers, self-management and reporting of diseases, education and training, communication, care coordination, and research methodology. We summarized the priority areas into eight topics: big data, mobile devices, telehealth and telemedicine, VR, AI, smart home, biotechnology, and digital legacy.

Contribution and Strengths of This Paper

Overview

The outcomes of our detailed analysis (involving a modified Delphi process and patient engagement workshop) indicate further digital health research is needed to study how technology can be best used to support palliative care. Our paper is the first priority-setting paper on palliative care digital health and provides a foundation for digital health–focused palliative care research.

Telehealth and Telemedicine

Before the COVID-19 pandemic, researchers highlighted the potential of using telehealth (ie, technology to support remote clinical access) and telemedicine (ie, technology to support remote clinical care delivery) in palliative care. These technologies are increasingly used in palliative care [33,34]; however, many have not been evaluated for use in real-world settings [19,35]. Beyond the pandemic, researchers can consider how these technologies can improve palliative care access (eg, for remote communities and hard-to-reach groups) to support new models of care (eg, telepalliative care clinics). It is also important to consider barriers (eg, equity of access, privacy, and security considerations), facilitators (ease of use and incentives), and use cases (eg, reasons for use) for the adoption of telehealth and telemedicine in palliative care.

Exploring AI

AI is often used as an umbrella term to describe several processes (eg, machine learning, natural language processing, deep learning, and neural networks) [36]. Clinicians and researchers are increasingly using AI to predict survival [37-40], classify pain severity [41,42], identify quality indicators [43,44], and identify serious illness conversations from electronic health care records [45]. However, most of these studies are exploratory and do not provide recommendations for clinical practice [18]. Therefore, researchers should explore how different AI techniques can support palliative care research and practice considering the ethical issues associated with these methods.

Big Data

Big data describes large amounts of (previously unmanageable) data that can now be processed by modern computer analysis techniques. The opportunities to use routine data to support palliative care decisions for populations and individuals have been reported previously [18,46]. Currently, there is no consensus on how nontraditional sources of big data can be meaningfully used in palliative care. For example, there is the potential to use patient-generated data (eg, wearables) for quality-of-life assessments. Furthermore, open-source genomic databases may provide opportunities to study the relationships between genetics and health to inform how data can be used for disease management. Social media and other forms of web-based data are increasingly used to support public and professional communication and to gain insight into public attitudes toward palliative care [47-50]. Consequently, researchers should identify which data to collect and how both traditional and nontraditional sources of palliative care big data can be best used [18,51,52].

Mobile Devices and Wearables

Many studies have described how mobile devices and wearables can support palliative care (eg, remote monitoring of physical activity and symptoms, delivery of well-being activities, documentation of advance care planning, education access or delivery, and guideline access) [53-57]. The capability of these devices to collect and store data is increasing; therefore, it is important to determine how meaningfully these data can be used [58,59]. Researchers have previously described how patient-reported outcomes can benefit palliative care patients [60-62]; however, further work is needed to explore how this technology can best support patient-reported outcomes collection (and use) in real-world settings [63,64]. It is important to examine how mobile devices are designed to meet the requirements of palliative care users [65]. Furthermore, studies should provide more information on how mobile devices can help patients record their care preferences (eg, advance care planning) [66,67].

VR Shows Great Potential for Palliative Care

VR is a human-computer interface technology that uses visual graphics, sounds, and other sensory inputs to create a web-based computer world [68]. Previous studies have described the potential of using VR to support psychosocial symptoms and well-being; however, most studies are unevaluated, so further research is needed [69-72]. We recognize the potential of VR to support palliative care education [73,74]; however, the consensus group did not identify this as a current priority. Following our study, we recognized that the COVID-19 pandemic has accelerated the use of web-based learning environments for medical education [75], particularly with the potential to use VR for communication skills training [73]. Consequently, it is possible that VR for education would be rated higher as a priority if this study were repeated.

The Smart Home

A smart home describes a living environment in which sensor-based systems and internet-connected devices (the internet of things) are used for remote monitoring and automation of appliances, such as lighting and heating [76]. Previous studies have illustrated how various technologies can support care for people experiencing a decline in their physical function (eg, web-based assistants and supportive robotics), which highlights the wider role these technologies may have in practice [77]. Consequently, future work should explore the usefulness of smart home technologies in supporting physical functions and the legal, privacy, and ethical issues associated with these developments [3,52,66,76-78].

Biotechnology

Biotechnology involves the combination of technologies with living things [79]. Palliative care–related developments include the use of biomarkers to predict survival [80,81], constipation, [82] and delirium [83,84], and the personalization of cancer pain according to genetics [85-87]. Consequently, it is possible to imagine future scenarios where technologies are used for early identification (and prediction) of clinical issues, facilitating personalized treatment for the individual (eg, early identification and management of pathological fractures).

Digital Legacy

A digital legacy is the digital information available about someone after death, such as social media, photos, videos, and gaming profiles [88]. The volume of digital information generated by citizens is increasing, creating new challenges after death [89]. The increasing use of cloud storage and social media contributes to uncertainty in data ownership, which creates difficulties for caregivers in managing the digital legacy of the deceased. Studies have demonstrated that health care professionals can positively support their patients in managing their digital legacy [88,90,91]. However, digital legacy is not routinely discussed in clinical practice, which means that we generally do not know how individuals want their data to be managed after death [92]. Therefore, we believe that researchers should explore how patients and caregivers can be supported to manage their digital legacy after death, with an exploration of the different methods and materials that can be used.

Relation to Previous Work in This Area and Areas of Interest Following the Novel COVID-19 Pandemic

Our study is synergistic with previous work, which has been conducted across topic areas [19,35]. We acknowledge that our study predates the pandemic and it is possible that the priorities we identified may now have shifted. However, we believe that our research findings are valid, as the digital health innovations adopted during the pandemic are in sync with our priority list. (Multimedia Appendix 10 [47,50,93-113]) [34,35]. For example, telehealth was commonly used during the pandemic, with many palliative care services using it to provide remote clinical support [93-105], communication [106], and education [107]. Technologies have been used to maintain connections and to develop communities of palliative care practice [108,109]. VR is used to provide psychological care and symptom management [110,111]. In general, the findings of these studies describe the potential benefits of digital health; however, the rapid implementation of these technologies has created a number of challenges (eg, technical issues, data security, and well-being considerations) that require further evaluation [106]. We are encouraged that these palliative care digital health studies, conducted during the pandemic, are within the scope of our identified priorities. Evidence suggests that the pandemic has accelerated the adoption of digital health in palliative care practice (and related research in these areas), rather than shifted to different priorities to the ones we identified. We expect the development and evolution of digital health research areas, which may be new *priorities* or linked to existing areas; for example, AI-driven data analysis of data from *internet of things* devices. Consequently, we believe that the COVID-19 pandemic has elevated the importance of digital health, as health organizations use technology to support palliative care after the pandemic.

Palliative Care Digital Health Priorities in Regions Unrepresented in This Study

Although geographic regions are unrepresented in our study (eg, Asia Pacific and Australasian or African regions), studies from these countries are consistent with our outcomes as they describe the emerging importance of palliative care digital health. Australian palliative care providers report digital health priorities that are similar to those identified in our study, with providers wanting innovations in the areas of client health records, telehealth, and personal health tracking [114]. However, digital health priorities are likely to differ between countries owing to geopolitical and socioeconomic drivers. For example, in Sub-Saharan African, digital health is not as established as in other high-income regions [115]. Consequently, Sub-Saharan African stakeholders describe digital health as part of a wider vision in this region to potentially improve data development and support the development of health care services [116,117]. Palliative care is a growing discipline in the Asia Pacific region, and current research describing digital priorities is limited, although it is acknowledged that digital health can play an important role in supporting education and training [118].

Limitations

It is possible that recent developments were not reflected in the priority list owing to the ongoing advancement of health care technologies. For example, the FTI trends list is now in its 2021 version and includes new trends, such as home medical laboratory tests and remote metabolic monitoring. Therefore, it is possible that relevant areas were absent from this analysis. Moreover, a weakness of digital health research is the rapid change associated with technology, which may cause the findings of this study to lose relevance over time.

Our decision to reduce the number of trends from 95 to 32 items has broadened the focus of the list, which means that it is possible that more specific and technical areas were not explored in greater depths (eg, faceprints, voiceprints, and chatbots). It is also possible that our Delphi participants will have different views on the priority of some areas post COVID-19, owing to the observed increase in digital health in practice. It is possible that because of the novel nature of some areas, participants gave more priority to familiar areas and therefore, less priority to unfamiliar areas. Questionnaires were mostly completed by participants from English-speaking countries, meaning that the experience of non-English–speaking populations may not be reflected. Specifically, our outcomes may not represent the Asia Pacific and Australasian or African regions, as we had no responses from these areas. Furthermore, the final priority list may not represent non-UK health care systems, as the consensus meeting was only attended by UK residents. We acknowledge that people from different professional backgrounds (including cultures and settings) may assign different levels of priority to trends because of their experiences, work requirements, and personal beliefs. As most participants were clinically focused, it is possible that the priorities were oriented to clinical utility rather than methodology.

Relevance to Research, Practice, and Policy

Decision makers should ensure that technology is relevant to the needs of palliative care users, as these requirements will influence the design, use, and function of systems [119,120]. For example, health care professionals may generally use technology to access patient data and communicate with other professionals, whereas patients may wish to access their own health data and contact health care services. Further research is needed to develop specific use cases for these scenarios to ensure that the technology can be used meaningfully to achieve the intended outcomes. Furthermore, as the user requirements of people with palliative care needs may differ from those of the general population [121] and because we currently lack resources for widespread implementation of all technologies, it is important that digital health studies provide the data needed to determine best practices and to help identify the barriers and facilitators for adoption.

Researchers should use appropriate methodologies to explore these questions and study associated areas, such as ethical issues, data security, and design. It is important that researchers work with the public, as the comments of the lay representatives in our study (from both the consensus meeting and public engagement workshop) described concerns about the use of personal data. Policy makers should consider issues related to the governance and ethics of current and future digital systems. From a design perspective, we suggest that palliative care professionals collaborate with creative industries (eg, designers, developers, and engineers) to ensure that the designed technologies fulfill the user requirements for specific palliative care use cases.

Conclusions

The priorities identified in this study represent a wide range of important emerging areas in the fields of digital health, personalized medicine, and data science. Human-centered design and robust governance systems should be considered in future research. Transdisciplinary studies using appropriate methodologies are required to further investigate this priority list. It is important that the risks of using these technologies in palliative care are properly addressed to ensure that these tools are used meaningfully, wisely, and safely and do not cause unintentional harm.

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Authors' Contributions

Study design was handled by ACN and TMc. ACN and TMc were involved with data collection. ACN, TMc, JS, JP, LC, and SS helped write the paper. Critiquing and reviewing of the final manuscript were conducted by ACN, TMc, SS, LC, JP, AF, PL, JS, and SM.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Future Today Institute 2018 Trends List.
[PDF File (Adobe PDF File), 48 KB - aging_v5i1e32075_app1.pdf]

Multimedia Appendix 2
Delphi questionnaire (Google forms).
[PDF File (Adobe PDF File), 865 KB - aging_v5i1e32075_app2.pdf]

Multimedia Appendix 3
Technology in Palliative Care study scoping review.
[PDF File (Adobe PDF File), 664 KB - aging_v5i1e32075_app3.pdf]

Multimedia Appendix 4
Summary of the networks used to invite palliative care professionals to participate.
[PDF File (Adobe PDF File), 80 KB - aging_v5i1e32075_app4.pdf]

Multimedia Appendix 5
IQR to be used to guide the level of agreement for Delphi responses.
[PDF File (Adobe PDF File), 75 KB - aging_v5i1e32075_app5.pdf]

Multimedia Appendix 6
Level of agreement for each *priority area* following both Delphi rounds.
[PDF File (Adobe PDF File), 162 KB - aging_v5i1e32075_app6.pdf]

Multimedia Appendix 7
Voting outcomes for consensus meeting.
[PDF File (Adobe PDF File), 106 KB - aging_v5i1e32075_app7.pdf]

Multimedia Appendix 8
Final list of priorities.
[PDF File (Adobe PDF File), 120 KB - aging_v5i1e32075_app8.pdf]

Multimedia Appendix 9
Technology in Palliative Care Public Engagement Event information.
[PDF File (Adobe PDF File), 183 KB - aging_v5i1e32075_app9.pdf]

Multimedia Appendix 10
Examples of technologies used in palliative care during the COVID-19 pandemic.
[PDF File (Adobe PDF File), 44 KB - aging_v5i1e32075_app10.pdf]

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Abbreviations

AI: artificial Intelligence
FTI: Future Today Institute
VR: virtual reality

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Original Paper

Predicting Working Memory in Healthy Older Adults Using Real-Life Language and Social Context Information: A Machine Learning Approach

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Abstract

Background: Language use and social interactions have demonstrated a close relationship with cognitive measures. It is important to improve the understanding of language use and behavioral indicators from social context to study the early prediction of cognitive decline among healthy populations of older adults.

Objective: This study aimed at predicting an important cognitive ability, working memory, of 98 healthy older adults participating in a 4-day-long naturalistic observation study. We used linguistic measures, part-of-speech (POS) tags, and social context information extracted from 7450 real-life audio recordings of their everyday conversations.

Methods: The methods in this study comprise (1) the generation of linguistic measures, representing idea density, vocabulary richness, and grammatical complexity, as well as POS tags with natural language processing (NLP) from the transcripts of real-life conversations and (2) the training of machine learning models to predict working memory using linguistic measures, POS tags, and social context information. We measured working memory using (1) the Keep Track test, (2) the Consonant Updating test, and (3) a composite score based on the Keep Track and Consonant Updating tests. We trained machine learning models using random forest, extreme gradient boosting, and light gradient boosting machine algorithms, implementing repeated cross-validation with different numbers of folds and repeats and recursive feature elimination to avoid overfitting.

Results: For all three prediction routines, models comprising linguistic measures, POS tags, and social context information improved the baseline performance on the validation folds. The best model for the Keep Track prediction routine comprised linguistic measures, POS tags, and social context variables. The best models for prediction of the Consonant Updating score and the composite working memory score comprised POS tags only.

Conclusions: The results suggest that machine learning and NLP may support the prediction of working memory using, in particular, linguistic measures and social context information extracted from the everyday conversations of healthy older adults. Our findings may support the design of an early warning system to be used in longitudinal studies that collects cognitive ability scores and records real-life conversations unobtrusively. This system may support the timely detection of early cognitive decline.

In particular, the use of a privacy-sensitive passive monitoring technology would allow for the design of a program of interventions to enable strategies and treatments to decrease or avoid early cognitive decline.

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KEYWORDS

cognitive aging; language complexity; social context; machine learning; natural language processing; Electronically Activated Recorder (EAR); behavioral indicators

Introduction

Cognitive Ability, Its Decline, and Older Adults' Behaviors

Cognitive abilities play a crucial role in the daily functioning of older adults [1]. Although decline in certain cognitive abilities is expected in the course of normal aging, some individuals may go on to experience decline to an extent that is pathological, namely mild cognitive impairment (MCI) or dementia [2,3]. It is argued that subtle changes in older adults' everyday behaviors may occur in the preclinical stage [4]. As such, behavioral indicators may provide an important avenue for detecting cognitive decline in this population. Some studies have started to quantify differences in the everyday activities (eg, medication intake and telephone use) of older adults experiencing normal aging versus those in pathological aging by observing participants and using manual reporting [5,6].

These methods could aid in detecting behavioral changes; however, they are also prone to human error, including recall bias [7]. Thus, the approach of visiting a health care professional for an examination may end up preventing older adults and their caregivers from continuously monitoring and proactively reacting to cognitive decline [8]. In fact, older adults visit health care professionals to receive cognitive examinations, such as cognitive assessment tests, blood tests, and structural imaging [9]. However, this may happen when the cognitive decline has become severe enough to disrupt daily functioning. In these cases, it is often too late for them to receive effective treatments and to make preventive plans with their families [10,11].

The Use of Technology to Predict Early Cognitive Decline in Real Life

To detect cognitive decline at an early stage, some recent studies have considered using technology to collect behavioral data from real-life settings, focusing on cognitively healthy older adults and those who have MCI [8,12].

For example, comparing the behaviors of healthy older adults with those with MCI, Seelye et al [13] collected 1 week of computer mouse movements. Their results showed that older adults with MCI had fewer total mouse moves and longer pauses between movements. In another study, Seelye et al [14] examined driving behaviors observed from a driving sensor and showed that older adults with MCI drove fewer miles and spent less time on the highway per day than those without MCI. To try understanding behavioral variability in normal aging, Austin et al [15] focused on word use in the internet searches of healthy older adults in a 6-month-long study with home-based unobtrusive technology. Their results showed that older adults with higher cognitive abilities used more unique words than older adults with lower cognitive abilities. Therefore, they argued that collecting the terms people use in internet searches may aid in detection of early cognitive decline [15].

The use of technology to collect objective behavioral indicators in real-life settings shows a few advantages with respect to clinical settings. It allows for generating high-frequency data over extended periods of time, offering more data than the assessments performed during appointments with health care professionals. High-frequency data could provide an objective baseline to understand individuals' own norms of behaviors that could be used to detect early cognitive decline [16]. Moreover, collecting behavioral indicators in real-life settings by means of technology empowers older adults and caregivers to monitor and detect cognitive decline, freeing them from the exclusive reliance on examinations by health care professionals. It could also help patients and caregivers to predict early changes in cognitive abilities. This could help reduce stress in caregivers, allowing them to better manage time and perform advanced planning [10]. Low-cost and unobtrusive technology methods have the potential to be applied to large-scale community studies for identifying at-risk populations [17]. However, to leverage the advantages offered by technology in the early detection of cognitive decline it is necessary to identify reliable behavioral indicators of cognitive decline for different populations of older adults (ie, healthy older adults and those with MCI or dementia) that can be effectively and unobtrusively monitored over time.

Linguistic Measures as Behavioral Indicators of Cognitive Decline

Linguistic measures elicited from speech are one type of behavioral indicator that have proved to be useful in predicting cognitive abilities. To this end, studies have considered the use of linguistic measures from transcribed speeches of healthy subjects, or those with different degrees of cognitive impairment in structured clinical assessments [18]. In fact, it has been shown that language markers predict normal and pathological cognitive functioning [19]. Typically, these studies are conducted in the lab, with elicitation of speech through clinical interviews and the recording of cognitive function scores via batteries of validated tests. For example, Fraser et al [20] examined various linguistic features, such as part-of-speech (POS) tags, grammatical complexity, vocabulary richness, and repetitiveness, and showed them to be useful in predicting dementia cases. Furthermore, more and more studies have focused on differences in language use between healthy older adults and those with MCI [19,21], with the aim of facilitating the detection of cognitive decline at an early stage [22].

Although linguistic markers captured from lab-based speech samples have shown promise in detecting cognitive decline, the limitations of these speech samples must be considered. For example, studying language in clinical settings through its elicitation may result in the generation of utterances that are not representative of daily language use. This may lead to a biased understanding of the cognitive abilities of the aging population [23]. Moreover, in clinical settings it is not possible to study the participants' social contexts. These contexts offer opportunities for older adults to engage in cognitively stimulating activities and they are protective of their cognitive abilities [24-26].Therefore, we argue that research focusing on the early decline of cognitive abilities would benefit from (1) considering everyday life settings where cognitive abilities are expressed and (2) collecting everyday language use and information on the social contexts of healthy older adults by means of unobtrusive monitoring technology.

As a first step in this direction, Polsinelli et al [27] recently tested whether healthy older adults' language in their everyday lives provides information about cognitive processes. In their study, Polsinelli et al assessed the cognitive abilities of healthy older adults with a battery of tests, including the testing of working memory. Working memory refers to the cognitive ability of maintaining input information while simultaneously performing complex tasks with this information, such as reasoning, communication, and learning [28]. It is an important aspect of fluid intelligence for the production of complex language [29].

They sampled real-life ambient audio data from participants' naturally occurring daily lives, transcribed the conversations captured in the ambient audio sound bites, and applied natural language processing (NLP); in their case, they used Linguistic Inquiry and Word Count [30], a very widely used and extensively validated closed vocabulary–based text analysis approach. With respect to protecting the privacy of participants and their bystanders, they followed a set of established procedures that included providing participants an opportunity to censor (ie, delete) selected recordings and alerting conversation partners about the possibility of their conversations being recorded, thereby ensuring passive consent [31,32]. Their results show that higher working memory was associated "with analytic, complex, and specific language" [27].

On the other hand, in examining age effects in language use using verbatim transcripts derived from real-life ambient audio recordings, Luo and colleagues [33,34] recently showed that healthy older adults produced more complex language with familiar conversational partners (eg, spouse, friends, and family) than with strangers, and more complex language in substantive conversations than in small talk. These findings support the assumption that some social contexts offer opportunities for cognitively stimulating activities. Thus, healthy older adults' social contexts may provide useful information for predicting their cognitive abilities over time.

Using Machine Learning and NLP to Predict Healthy Older Adults' Working Memory

Polsinelli et al's [27] and Luo et al's [33,34] studies suggest that the language use and social contexts encoded in everyday life ambient audio data may support the understanding of healthy older adults' cognitive abilities. This is seen as a first step toward an improved understanding of cognitive decline by means of information collected in everyday life. Therefore, in this paper we explore the possibility of predicting cognitive ability, namely working memory, by combining linguistic measures, including POS tags, and social context information computed from the verbatim transcripts of the sampled everyday conversations of healthy older adults using machine learning and NLP. In this study, the term "healthy older adults" is meant as "cognitively healthy older adults." The conversations were transcribed from the real-life ambient audio data that were recorded unobtrusively using a smartphone app [35]. We consider the data from Polsinelli et al's original study [27], where working memory was measured using two separate tests, namely Keep Track and Consonant Updating [27,36]. Therefore, in this study, we predicted working memory using Keep Track, Consonant Updating, and a combined score (ie, the mean score from Keep Track and Consonant Updating) [27,36]. To the best of our knowledge, this is the first study where machine learning and NLP are used to predict selected cognitive abilities of healthy older adults combining different sources of information, such as linguistic measures and social context, extracted from data collected in a naturalistic observation setting.

In future studies, the methods described in this paper could support the design of passive monitoring systems to detect early cognitive decline by recording, ultimately in a privacy-sensitive way (ie, protecting the content and context of the actual "raw" conversations), real-life ambient audio data and using information extracted from the everyday conversations of older adults. Systems with reliable performance may allow for designing intervention programs aimed at coping with early signs of cognitive decline in normal aging as well as at the preclinical stage of Alzheimer disease. This technology and intervention programs would, therefore, empower older adults and caregivers to monitor and detect cognitive decline autonomously. Low-cost and unobtrusive technologies have the potential to be applied to large-scale community studies for identifying at-risk populations [17]. This is in line with the recommendations of the World Health Organization's 2020 report on the global action of "Decade of Healthy Ageing 2020-2030," which states that technologies can empower older people to monitor and understand their own health, enabling greater decision-making about their own lives by tracking their trajectories of healthy aging [37].

Methods

Data Collection

Data used in this study originated within Moseley's [36] and Polsinelli's [38] dissertations and were studied by Polsinelli et al [27]. All participants from the original studies were community-dwelling individuals recruited from the greater Tucson, Arizona, community in the United States. Participants were recruited via community events and via research databases from prior and ongoing studies in the Department of Psychology and the Department of Speech, Language, and Hearing Sciences at the University of Arizona. Participants' living situations included retirement communities; mobile home communities; single-family homes, with and without a live-in partner; and residences in family members' homes, usually children.

All participants were cognitively healthy older adults, with no reported history of neurologic or psychiatric disorders. Polsinelli et al's [27] sample consisted of 102 participants (mean age 75.8 years, SD 5.8; mean years of education 16.5, SD 2.3; 54.9% [n=56] female; 62.7% [n=64] married). During the study, participants underwent cognitive testing in the lab and wore the Electronically Activated Recorder (EAR) app [31,35] that was installed on provided smartphones for 4.5 days of their daily lives. The EAR enables frequent, passive, and unobtrusive sampling of participants' language use in their natural environments via ambient recording [35,39,40]. The EAR was set to record 30-second audio files every 12 minutes (ie, five times per hour), except for a 6-hour overnight period. At the end of the study, after returning the EAR, all participants completed a standard EAR evaluation measure [27,39]. Polsinelli et al [27] collected 31,683 valid (ie, adherent and codable) and waking (ie, nonsleeping) sound files.

Recording raw ambient sounds raises important questions around privacy. Polsinelli et al's study implemented several safeguards to protect the privacy of participants and conversation partners. First, the audio sampling limited the net recording to a small fraction of the day (<5%), keeping the vast majority of conversations private in the first place. Second, the short recordings (ie, 30 seconds) ensured that minimal personal information was captured beyond what was necessary for reliable coding. Third, participants could review their recordings and censor (ie, delete) any they wished to remain private. Fourth, a "warning triangle" was placed visibly on the recording device to alert conversation partners of the possibility of being recorded, in order to ensure passive consent. Finally, the study was covered by a National Institutes of Health Certificate of Confidentiality, which protects the data against forced third-party disclosure. In implementing these procedures, the study followed the established guidelines for passive ambient audio sampling [31,32].

Data Generation: Measuring Working Memory

In this study, we considered working memory as measured by the Keep Track and Consonant Updating tests [36,38]. These are select subtests from Miyake et al [41] that served as the guiding model of working memory and executive functioning more broadly. During the Keep Track test [27,41,42], participants view a list of 15 serially presented words, that is, presented one at a time (eg, banana, golf, uncle, and so on). They are instructed to hold in mind the last word that is presented in predefined categories (eg, fruits, sports, and relatives). Initially, participants keep track of one category, but over duration of the test, they increase to keeping track of four categories, with three trials for each number of categories (eg, three trials of one category, three trials of two categories, and so on) [27]. Participants write down the last word they remembered from each predefined category, before moving on to the next trial.

In the Consonant Updating test [27,36,41], participants are required to say aloud the last four letters in a string of consonants appearing on the screen [27]. Each trial in the Consonant Updating test consists of five, seven, nine, or 11 letters in random order, for a total of 108 participant responses. In Polsinelli et al's study [27], 4 participants only completed the Keep Track test; in this work, we include only the 98 participants who completed both tests.

Data Generation: Transcribing and Coding Audio Files

In Polsinelli et al's study [27], a team of research assistants were trained to listen to each 30-second audio file, identify the participant's voice, and transcribe verbatim the spoken utterances only of the participants (ie, they did not transcribe speech from nonparticipants). Out of 31,683 audio files, 7450 contained snippets of conversations. Concurrently, research assistants coded for multiple behavioral and contextual variables. Codes were binary, indicating either presence ("1") or absence ("0") of a variable within the entire 30-second audio file. While audio files were coded for multiple variables, only the 19 variables relevant to this investigation are described here. These 19 variables, called "social context variables" in what follows, fall into the following overarching categories: environment (ie, in public or on the phone), presence or absence of social partners (ie, alone, with one person, or with multiple people), conversation partner (ie, self, pet, significant other, close friend or family member, acquaintance, or stranger), conversation type (ie, small talk, substantive conversation, or gossip), and activity (ie, socializing or entertaining, watching TV, eating or drinking, doing housework, or in transit).

For more detailed information on how EAR sound files are coded for daily behavior, we refer to Kaplan et al's work [43].

NLP of Transcripts: Linguistic Measures and Part-of-Speech Tags

In this study, we included three domains of linguistic measures that have been commonly examined in the cognitive aging literature. The first domain is idea density, also known as proposition density, representing the number of ideas that are expressed [44]. Studies show that idea density declines over age in both normal and pathological aging [44]. We computed idea density with the CPIDR (Computerized Propositional Idea Density Rater) software (version 5) [45]. The second domain is vocabulary richness, indicating usage of unique words. In this study, it was represented by the measure of entropy with the Chao-Shen estimator [46]. We computed vocabulary richness using the "entropy" package from R (The R Foundation) [47]. The third domain is grammatical complexity, indicating how complex the grammatical structures are [34,44]. We computed the scores with the syntactic complexity analyzer [48,49] in R. We focused on the measures of clauses and dependent clauses (ie, number of clauses, number of dependent clauses, mean length clause, and dependent clause ratio).

In this study, the measures computed from the aforementioned domains of linguistic measures are referred to as "linguistic measures." In addition to the linguistic measures, we also considered POS tags of written transcripts. POS tagging is the procedure that assigns a POS tag to each word in a corpus of textual data [50,51]. The POS tag encodes information on the role of the word and its context. In this study, we used the spaCy library in Python (Python Software Foundation) [52] to retrieve the POS tags for each word in all of the 7450 transcripts. The data set comprises 15 distinct POS tags.

Machine Learning

Feature Generation and Data Aggregation

To perform machine learning modeling and predict individual working memory scores, we aggregated the data set of 7450 transcripts at the participant level, arriving at 98 data points. We proceeded with the aggregation of the features as follows. Sociodemographic features (ie, age, sex, marital status, and education) were not aggregated, as they are constant for each participant. Linguistic measures were aggregated by computing the mean and SD of the distribution of the language measures of all transcripts for each participant. In addition, we concatenated the POS tags extracted from all transcripts of each participant. Finally, social context features (eg, “alone”) were aggregated by computing the percentage of transcripts in which the social context was detected (eg, “alone = 1”) for each participant. We collected all features resulting from data aggregation in Multimedia Appendix 1.

Target Variables

In this study, we aimed at gathering a foundational understanding of the problem of predicting working memory with information extracted from real-life audio data. Therefore, we considered three distinct machine learning regression problems. First, we predicted the standard scores of the Keep Track test for each participant. Second, we predicted the standard scores of the Consonant Updating test for each participant. Finally, we standardized the mean score of the Keep Track and Consonant Updating tests for each participant. This latter score measured working memory for each participant. The use of standard scores (ie, z scores) for cognitive ability tests is in line with previous studies in the literature [15,27]. However, we remark that we computed standard scores inside the repeated cross-validation routine on each training fold (see Experimental Setting section) to avoid “data leakage,” as recommended by Hastie et al [53].

Machine Learning Models

We considered random forest (RF), extreme gradient boosting (XGBoost), and light gradient boosting machine (LightGBM) algorithms [54-57] for this study, using their Python implementations. We chose them due to the possibility to consider different hyperparameter combinations and to explain results using feature importance scores. The RF feature importance score computes the mean (across all trees in the forest) Gini impurity decrease for the feature at hand: the higher the decrease, the higher the feature importance. The XGBoost and LightGBM feature importance scores compute the number of times (in percentages) each feature is used to split the data across all trees of the ensemble. Moreover, different authors considered RF and XGBoost algorithms for the detection of reminiscence from transcripts of conversations of older adults [58,59]. Similarly, Yordanova et al [60] used RF algorithms to detect social behavior from transcripts of daily conversations.

Experimental Setting

Overview

We provide information on the experimental setting by describing the (1) machine learning runs (R, when reported with run number), (2) repeated cross-validation routine, (3) recursive feature elimination (RFE) algorithm, (4) hyperparameters in the cross-validation, and (5) the evaluation metrics of the machine learning models.

Machine Learning Runs

We considered eight different runs of machine learning modeling, each corresponding to a different combination of features. We present them in Table 1, together with the total number of features per run. R0 was considered the baseline for all machine learning runs, as it contained only sociodemographic variables (ie, age, education, marital status, and sex; Multimedia Appendix 1). We also note that sociodemographic variables were considered in all runs of this study as control variables.

Table 1. All runs considered in this study.

Run	Feature combination	Features, n
R0	Sociodemographic	4
R1	Sociodemographic + linguistic measures	18
R2	Sociodemographic + social context	23
R3	Sociodemographic + POS[a] tags	19
R4	Sociodemographic + linguistic measures + social context	37
R5	Sociodemographic + social context + POS tags	38
R6	Sociodemographic + linguistic measures + POS tags	33
R7	Sociodemographic + linguistic measures + social context + POS tags	52

[a] POS: part of speech.

As our study dealt with a limited number of data points (ie, n=98), machine learning modeling needed to avoid the use of too many noisy variables and incur overfitting. This would lower reproducibility of results and their applicability to unseen data [61]. Moreover, in the presence of a small number of data points, resampling techniques, such as cross-validation, may show high variance. Therefore, we needed to introduce a routine to select the best-performing machine learning model by doing the following: (1) using resampling techniques such as cross-validation, (2) reducing the variance of cross-validation, and (3) performing feature selection on all runs to prevent overfitting.

Repeated Cross-validation

Standard k-fold cross-validation divides a data set into k nonoverlapping subsets. Each model is trained on k–1 folds and evaluated on the k-th fold, for a total of k models. Model performance (eg, the mean squared error; see Evaluation Metrics section) is the mean of the performance on all k folds used for the evaluation. With a fixed training data set, k-fold cross-validation depends on the randomness of partitioning the training data set into k-folds [62]. This variance is also called internal variance [63,64]. In particular, in the context of small data sets, Braga-Neto and Dougherty [64] stated that cross-validation error estimation shows high variance, with the effect of making “individual estimates unreliable for small samples.”

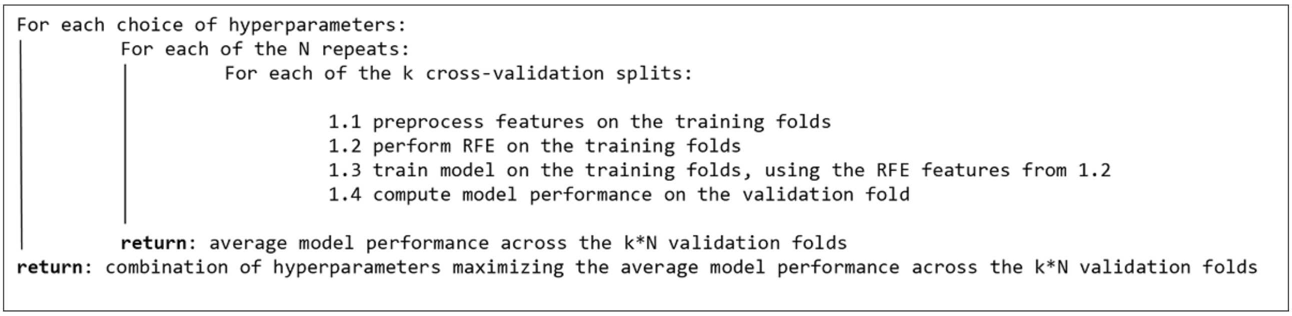
Repeated k-fold cross-validation is a procedure introduced to reduce the internal variance of k-fold cross-validation routines. The procedure called “repeated k-fold cross-validation with n-repeats” simply repeats k-fold cross-validation N times, with different splits, and averages the model performances across all folds from all runs. It provides a performance evaluation of the model that is more robust than the one computed from a single run of k-fold cross-validation. It has been suggested due to its performance, but at the price of a steep computational cost [65]. We refer to the work by Krstajic et al [66], in particular Algorithm 1, for more details on repeated cross-validation.

Our strategy is to apply repeated cross-validation with 2, 5, and 10 folds, and a number of repeats equal to 50, 20, and 10, respectively. For each k, the number of repeats, N, is chosen to have a total of 2 × 50 = 5 × 20 = 10 × 10 = 100 validation folds for the evaluation of model performance. These fold values have been considered by Molinaro et al [61] in their comparison of resampling methods. A small number of folds increases the bias of the cross-validation estimator, but it is computationally efficient [67]. A higher number of folds decreases the bias but increases the variance, as the validation sets become smaller.

Recursive Feature Elimination

To avoid overfitting, we performed feature selection by implementing the RFE algorithm [68] embedded in the repeated cross-validation routine. We used it for all runs to select the machine learning model with the best performance on the 100 validation folds, choosing different numbers of features to select. We summarize the algorithm performing repeated cross-validation with RFE in Figure 1.

Figure 1. Repeated cross-validation with the recursive feature elimination (RFE) algorithm.



```
For each choice of hyperparameters:
|        For each of the N repeats:
|        |        For each of the k cross-validation splits:
|        |
|        |                 1.1 preprocess features on the training folds
|        |                 1.2 perform RFE on the training folds
|        |                 1.3 train model on the training folds, using the RFE features from 1.2
|        |                 1.4 compute model performance on the validation fold
|        |
|        return: average model performance across the k*N validation folds
return: combination of hyperparameters maximizing the average model performance across the k*N validation folds
```

Hyperparameters in the Repeated Cross-validation

Table 2 summarizes all the hyperparameters tuned in the algorithm in Figure 1.

In particular, we preprocessed POS tags with term frequency–inverse document frequency (TF-IDF) normalization to use them as features in the machine learning modeling routines. We performed no hyperparameter tuning, by considering only 1-grams. The number of hyperparameter combinations depends on the machine learning run. For example, the best RF model for the R0 run emerged from fitting 4500 models. On the other hand, to select the best RF model for the R7 run, we fitted 220,000 models, following the algorithm in Figure 1. We then fit the model corresponding to the combination of hyperparameters from Figure 1 to the whole data set, following Algorithm 1 in Krstajic et al [66].

Table 2. Summary of all hyperparameters tuned in the repeated cross-validation with the RFE algorithm.

Algorithm or model	Hyperparameters
RFE[a] algorithm	• Number of features to select • Number of features to reduce at each step
Machine learning model (RF[b])	• Number of trees • Maximum tree depth
Machine learning model (XGBoost[c] and LightGBM[d])	• Number of trees • Maximum tree depth • Learning rate

[a] RFE: recursive feature elimination.

[b] RF: random forest.

[c] XGBoost: extreme gradient boosting.

[d] LightGBM: light gradient boosting machine.

Evaluation Metrics

The performance of each model in the repeated cross-validation with the RFE algorithm in Figure 1 was evaluated by computing the mean and SD of the distribution of the mean squared errors (MSEs) on each of the 100 validation folds. The MSE was computed as follows (q denotes the number of data points in the validation fold):

We used the MSE as the scoring method for the cross-validation. As we implemented the standardization of scores inside the repeated cross-validation routine, it follows that the MSE on the validation folds was computed using unstandardized scores.

Ethics Consideration

Participants whose data were studied by Polsinelli et al [27] gave permission for their data to be used in future research studies (Institutional Review Board No. 1300000709).

Results

Predicting Keep Track

In Table 3, we present the best models resulting from the repeated cross-validation with the RFE algorithm in Figure 1 for the Keep Track target variable. All results are obtained for 10 folds and 10 repeats. By definition of Polsinelli et al's experimental setting [27], the total number of recalled words during the test was 30. In this study, the mean of the Keep Track scores in the data set was 19 (SD 3.6); the minimum and maximum Keep Track scores were 10 and 27.

Table 3. Performance of the best models for the prediction of the Keep Track target variable. All results were obtained for 10 folds and 10 repeats.

Run	Model	MSE[a], mean (SD)	Features, n
R0	LightGBM[b]	13.26 (5.33)	4
R1	LightGBM	12.80 (5.43)	10
R2	LightGBM	12.46 (4.85)	5
R3	LightGBM	12.95 (4.98)	10
R4[c]	LightGBM	11.81 (4.92)	10
R5	LightGBM	12.12 (4.43)	20
R6	LightGBM	12.65 (4.92)	15
R7	LightGBM	12.02 (4.66)	25

[a] MSE: mean squared error.

[b] LightGBM: light gradient boosting machine.

[c] The best run was R4.

All runs improved performance with respect to the baseline (ie, R0). The best run was R4, which delivered an improvement of 11% in mean MSE on the validation folds with respect to R0. The resulting LightGBM model was an ensemble of 70 trees, with a maximum depth equal to 1. Moreover, the RFE algorithm selected 10 features for this model out of 37 (27%), as per Table 1, deleting 50% of features at each step. As seen at the end of the Results section, the model improved the mean MSE by 13% on the validation folds with respect to the constant model that predicted the Keep Track scores on the validation fold using the mean on the training fold, for each of the 100 splits.

Table 4 shows all of the 8 features out of 10 (80%) in the best LightGBM model for R4 with nonzero importance and their type. All three feature types (ie, sociodemographic, linguistic measure, and social context) were represented in the model. More than half of the features were of the social context type. The mean feature importance was 0.13. The most important features were the percentage of transcripts for which each participant was alone (ie, “alone_prc”), the age of the participant (ie, “age at EAR testing”), the mean of the distribution of the idea density of the transcripts per participant (ie, “mean_Density”), and the SD of the distribution of Chao-Shen–corrected entropies of transcript per participant (ie, “std_ChaoShen”).

Table 4. Features, their importance, and type for the best light gradient boosting machine model of R4 for prediction of Keep Track scores.

Rank	Feature[a]	Importance of feature	Type of feature
1	alone_prc	0.34	Social context
2	age at EAR[b] testing	0.16	Sociodemographic
3	mean_Density	0.13	Linguistic measure
4	std_ChaoShen	0.13	Linguistic measure
5	TV_prc	0.10	Social context
6	in_transit_prc	0.07	Social context
7	partner_sign_other_prc	0.04	Social context
8	small_talk_prc	0.03	social context

[a] Descriptions of features are listed in Multimedia Appendix 1.

[b] EAR: Electronically Activated Recorder.

Predicting Consonant Updating

In Table 5, we present the best models resulting from the repeated cross-validation with the RFE algorithm in Figure 1 for the Consonant Updating prediction task. As opposed to the best RF models in Table 3, in the case of Consonant Updating, the best models in different runs were obtained in the presence of different k values of cross-validation folds.

The mean Consonant Updating score in the data set was 24 (SD 10.6), and the minimum and maximum Consonant Updating scores were 0 and 45, respectively.

All runs, with the exception of R1, R2, and R4, improved performance with respect to the baseline (ie, R0). The best run was R3, where the LightGBM model delivered an improvement of 14% in mean MSE on the validation folds with respect to R0. The LightGBM model was an ensemble of 30 shallow trees with a depth equal to 1. The RFE algorithm selected only 5 out of the 19 (26%) available features for R3 (Table 1), deleting 10% of the features at each step.

Table 5. Performance of the best models for the prediction of the Consonant Updating target variable.

Run	k	Model	MSE[a], mean (SD)	Features, n
R0	10	LightGBM[b]	113.50 (45.55)	4
R1	5	LightGBM	114.85 (25.64)	18
R2	5	LightGBM	114.00 (26.04)	5
R3[c]	5	LightGBM	97.26 (21.38)	5
R4	10	LightGBM	114.30 (45.50)	10
R5	5	LightGBM	100.73 (22.93)	5
R6	5	LightGBM	100.07 (22.74)	5
R7	10	XGBoost[d]	101.38 (41.32)	5

[a] MSE: mean squared error.

[b] LightGBM: light gradient boosting machine.

[c] The best run was R3.

[d] XGBoost: extreme gradient boosting.

As seen at the end of the Results section, the best model improved the mean MSE by 15% on the validation folds with respect to the constant model that predicted the Consonant Updating scores on the validation fold using the mean of the scores on the training fold, for each of the 100 splits. Table 6 shows the nonzero feature importance for R3 of the LightGBM model (ie, the best model). All features were POS tags, namely “NUM” (ie, numeral), “INTJ” (ie, interjection), “NOUN,” (ie, noun), and “ADP” (ie, adposition).

Table 6. Features, their importance, and type for the best light gradient boosting machine model of R3 for prediction of Consonant Updating scores.

Rank	Feature	Importance of feature	Type of feature
1	NUM	0.37	Part of speech
2	INTJ	0.23	Part of speech
3	NOUN	0.23	Part of speech
4	ADP	0.17	Part of speech

Predicting Working Memory

In Table 7, we present the best models resulting from the repeated cross-validation with the RFE algorithm in Figure 1 for the prediction task of Working Memory. As in the case of Consonant Updating, the best models in different runs were obtained in the presence of different k values of cross-validation folds.

Similar to the prediction of the Consonant Updating scores, all runs, with the exception of R2 and R4, improved performance with respect to the baseline (ie, R0). The best run was R3, where the best XGBoost model delivered an improvement of 20% in mean MSE on the validation folds with respect to R0. The XGBoost model was an ensemble of 30 trees with a depth equal to 1. The RFE algorithm selected only 10 out of the 19 (53%) available features for R3 (Table 1), deleting 50% of the features at each step. The R5 and R6 best models showed almost equal performance and the same number of features.

As seen at the end of the Results section, the best model improved the mean MSE by 20% on the validation folds with respect to the constant model that predicted the Working Memory scores on the validation fold using the mean scores on the training fold, for each of the 100 splits. In Table 8, we show the 6 features with nonzero feature importance; they are the same as those for the best model predicting Consonant Updating, with the addition of the “PRON” (ie, pronoun) and “PROPN” (ie, proper noun) POS tags. In Table 9, the best models from Tables 3, 5, and 7 are benchmarked with the constant model predicting the mean value of the target variable for all three predictions.

Table 7. Performance of the best models for the prediction of the Working Memory target variable.

Run	k	Model	MSE[a], mean (SD)	Features, n
R0	5	LightGBM[b]	37.75 (7.94)	4
R1	10	LightGBM	37.70 (14.07)	10
R2	5	LightGBM	37.75 (7.93)	5
R3[c]	5	XGBoost[d]	30.23 (6.63)	10
R4	5	LightGBM	37.75 (7.93)	5
R5	10	XGBoost	31.49 (13.03)	5
R6	10	LightGBM	31.25 (12.24)	5
R7	5	XGBoost	32.22 (6.77)	5

[a] MSE: mean squared error.

[b] LightGBM: light gradient boosting machine.

[c] The best run was R3.

[d] XGBoost: extreme gradient boosting.

Table 8. Features, their importance, and type for the best extreme gradient boosting model of R3 for the prediction of Working Memory scores.

Rank	Feature	Importance of feature	Type of feature
1	NUM	0.30	Part of speech
2	INTJ	0.20	Part of speech
3	NOUN	0.20	Part of speech
4	PRON	0.13	Part of speech
5	ADP	0.10	Part of speech
6	PROPN	0.07	Part of speech

Table 9. Benchmarking the best models from Tables 3, 5, and 7 with the constant model predicting the mean value of the target variable for all three predictions.

Prediction	MSE[a] of constant model, mean (SD)	MSE of best model, mean (SD)
Keep Track	13.57 (5.37)	11.81 (4.92)
Consonant Updating	114.77 (45.71)	97.26 (21.38)
Working Memory	37.81 (14.05)	30.23 (6.63)

[a] MSE: mean squared error.

Discussion

Summary of the Prediction Tasks

We applied machine learning methodologies to Polsinelli et al's study [27] to predict cognitive ability, namely working memory, by means of the scores on the Keep Track and Consonant Updating tasks and a composite of both (ie, Working Memory). The best model for the Keep Track prediction exercise comprised sociodemographic, linguistic measure, and social context variables. Those for Consonant Updating and Working Memory comprised POS tags only. Our methodologies delivered an improvement of performance with respect to two baseline models (ie, the models using only sociodemographic variables and the models predicting the mean value of the target variable) for all three prediction tasks. All of the best models were gradient boosting ensembles: LightGBM for Keep Track and Consonant Updating, and XGBoost for Working Memory. All ensembles comprised "tree stumps" (ie, trees with only one split), and they made use of a limited number of features.

Feature Analysis for All Prediction Tasks

Considering the prediction of Keep Track scores, the high importance of social context variables in the model was in line with previous studies on the effects of social context on cognitive aging. Specifically, Luo [34] reported that older adults produce more complex language with their significant others than with strangers. Familiarity with significant others may have enabled more diverse conversation topics than talking with strangers. More diverse conversation topics may have offered more opportunities to engage in cognitively stimulating conversations and, thus, protect against cognitive decline. By contrast, a higher occurrence of nonsocial contexts, such as watching TV and being alone, indicated deprived opportunities for engaging in cognitively stimulating activities. Fancourt and Steptoe's [69] study showed that watching TV for more than 3.5 hours per day is related to cognitive decline in older adults. Moreover, social isolation has been shown to be associated with memory decline in old age [70]. The best model for predicting Keep Track scores indicated that the corresponding social context variables are important, in an ensemble of regression trees, in machine learning problems aimed at predicting working memory.

We note that "mean_Density" was the only linguistic measure with high feature importance, together with the SD of the distribution of the Chao-Shen–corrected entropies of transcript per participant (ie, "std_ChaoShen"). This finding is in line with previous literature, where idea density has been commonly used to predict cognitive decline in older adults [18,22].

Considering sociodemographic variables, only the age of the participants (ie, "age at EAR testing") was retrieved by the RFE algorithm for the best model in the Keep Track prediction. It showed a feature importance (ie, 0.16) that was higher than the mean of the distribution. We note that age was a significant variable in the models by Austin et al [15]. Interestingly, neither the sex, the marital status, nor the number of years of education of each of the participants appeared as features in the best models for all three prediction tasks. This is a point of difference with respect to Austin et al's results [15].

Finally, POS tags—via the generation of bag-of-words features using TF-IDF normalization—featured prominently in the prediction of Consonant Updating and Working Memory. This finding may suggest that how older adults structure their sentences (eg, encoded in the use of prepositions, which expresses relations between different concepts [27]) in their daily conversations reveals the integrity of aspects of their working memory. This is different than the prediction of Keep Track scores, where features, such as the counts of different social contexts coded from the transcripts, were also predictive. In particular, in both of the best models for Consonant Updating and Working Memory, the most important POS tag was "NUM" (ie, "numerals"). The POS tags "INTJ," "NOUN," "PRON," "ADP," and "PROPN" (ie, "interjection," "noun," "pronoun," "adposition," and "proper noun," respectively) also appeared in the models. We argue that their presence may indicate that recorded conversations showed a certain degree of variability, as recently detected in studies with the EAR device [25]. We also note that, in particular, interjections (eg, "oh," "uh," "yeah," and "uhm") are commonly used in the spoken language to shift the attention to the speaker or as a back-channel response in conversations.

The original Polsinelli et al study [27] also found that selected POS tags correlated with working memory, using a partial Spearman correlation analysis. Some of these POS tags were also important predictors in this study, including numbers, which featured prominently in two of our three models, and prepositions. In particular, in the case of numerals, the authors found statistically significant Spearman partial correlation (r=0.32, range 0.13-0.48) between working memory measures and the use of numbers in everyday conversations [27]. The replication is encouraging and warrants further investigation. As highlighted in the original Polsinelli et al study, prepositions are a component of more complex language, and it is possible that this complexity is associated with working memory. However, at this time, without clear theoretical reasons for the predictive power of specific POS tags, we are cautious about overspeculating and overinterpreting these data. It will be important for future work to replicate these findings in an unrelated sample to assist in better understanding these POS markers of working memory. It may be especially interesting to examine the broader context in which certain POS are used; for example, numbers may be used in the context of someone paying bills or doing taxes, which are behaviors likely associated with aspects of cognition, including working memory.

Results from this study provide preliminary evidence to support the prediction of an important cognitive ability, working memory, by (1) collecting behavior from everyday conversations of healthy older adults in a naturalistic setting using the EAR app, (2) generating different families of behavioral features, and (3) using machine learning methodologies, with automated feature selection routines and combining families of behavioral features. In particular, the machine learning methodologies went beyond the correlations between working memory and POS tags from Polsinelli et al's study [27] and showed how different sets of features generated from the transcripts of conversations predict cognition. The approach in this study can be used in everyday settings to collect linguistic measures and social context information using unobtrusive technology.

Using this methodology, it may be possible to design an early warning system for cognitive decline in older adults that uses samples of conversations in daily life. In fact, one of the largest challenges in the current cognitive aging field is early detection for early intervention. This methodology may be one potential tool for addressing this problem through early and continuous monitoring over months or even years.

Continuous monitoring could result in near-immediate notification—to the individual, to the individual's family, or to a health care provider—when there is a suggestion of decline. In this way, an individual would be identified much earlier on in the process of potential decline and could seek a full professional evaluation in a much timelier manner, thereby increasing access to care and intervention. It is also possible that these "alerts" from continuous monitoring could reduce help-seeking delays caused by fear or anxiety of diagnosis [10]. The results could supplement a comprehensive clinical assessment, offering reliable and ecologically valid objective information to support formal diagnosis [12]. The continuous collection of high-frequency data could also serve as useful baseline information for clinicians to understand the rate of cognitive decline or to determine effectiveness of treatments [16].

However, we highlight that older adults and their caregivers may express concern about threats that are potentially posed by sensing technologies and opaque machine learning methodologies in digital health, such as threats on autonomy, privacy, and freedom [71] and their effects on the trustworthiness of these systems [71,72]. Yet, research has shown that it is possible to gain understanding from the users when they are provided with sufficient knowledge about technologies and the possibility of knowledgeable participations [73]. In particular, the EAR method has established protocols to inform participants about study procedures and to enable participants to review their own recordings, providing ethical safeguard measures and a low level of obtrusiveness [31]. The EAR method has been used to collect data from older adults, and they rated the method with a low level of obtrusiveness [39]. Taken together, we argue that the EAR method, in combination with machine learning techniques, could be developed as a promising tool for monitoring and detecting cognitive change in older age.

Comparison With Previous Work

Previous research has investigated the relationship between natural speech, language, and cognitive functions in the context of preclinical Alzheimer disease, or other forms of dementia, by means of speech, NLP, and machine learning. The literature abounds in examples of different speech and language measures that intercept different phonetic, syntactic, and semantic aspects of natural speech to predict for different levels of MCI with machine learning classifiers. However, these studies are typically conducted in clinical settings [19,73,74]. While assessment in a clinical setting has clear benefits (eg, increased control and standardization), it is limited in its ability to capture the full ecology of a person's rich social life, including behaviors, language, and interactions in different social contexts and with different social partners.

On the other hand, naturalistic observation studies and the use of passive, mobile monitoring technology may assist in capturing "reliable contextual observations, made in more ecologically valid environments than purely the consulting room" [75] and generate high volumes of data. Polsinelli et al [27] have examined the "association between spontaneous, conversational language use in daily life and higher-order cognitive functioning in older adults without known cognitive impairment." In particular, they found that working memory "was associated with analytic (e.g., more articles and prepositions), complex (e.g., more longer words), and specific (e.g., more numbers) language" [27]. Therefore, one may argue that changes in language (ie, increasing use of more general words such as "thing" instead of a specific object name) could be potential behavioral markers of cognitive decline. Should an individual or his family members observe such changes in language or other changes in cognition (ie, memory decline), this may be the impetus for discussion with a doctor who may decide to refer them for a formal neuropsychological evaluation to determine the presence of cognitive impairment.

In the vein of naturalistic observation, but not interpersonal interactions, others have sought to use at-home technology device usage to monitor cognitive performance in older adults. Austin et al [15] investigated the relationship between internet searches and cognitive ability in older adults in a cross-sectional study. They continuously monitored the terms that 42 cognitively healthy older adults entered in internet search engines over a 6-month period by means of "an unobtrusive home-based assessment platform" [15]. The authors reported a total of 2915 searches and a median of 22 searches per participant over the 6-month period [15]. Their study showed the applicability of continuous unobtrusive home-based monitoring technology to possibly detect cognitive decline in older adults. In fact, their results showed that higher cognitive ability scores were associated with more unique search terms entered per search and that higher cognitive abilities were associated with the use of more obscure words, as measured with word obscurity, during searches [15]. To compare the behaviors of older adults with and without MCI, Lyons et al [8] examined computer mouse movements and showed that older adults with MCI had fewer total mouse moves and longer pauses between movements. Moreover, Seelye et al [14] examined driving behaviors observed from a driving sensor and showed that older adults with MCI drove fewer miles and spent less time on the highway per day than those without MCI. Finally, Piau et al [17] conducted a literature review of digital biomarker technologies for MCI or early-stage Alzheimer disease detection in home-based settings. Their review showed that technology using embedded passive sensors may support research on early decline of cognitive abilities among large populations.

The use of naturalistic settings allows for the planning of longitudinal studies to detect early symptoms of cognitive decline using machine learning and unobtrusive technology. However, we note that coding is a resource-intensive process, in terms of both the time and cost of human labor, that necessitates trained resources to generate high-quality codes. It becomes infeasible in the presence of high volumes of data. An alternative explored by Yordanova et al [60] is to automate the coding of social behaviors from the transcripts of everyday conversations using machine learning and NLP. However, a fully automated analysis of recorded conversations of older adults would also necessitate of a system to automatically detect speech and generate transcriptions that may also incur errors.

Limitations

This study has several limitations. The data set of transcripts had a limited number of records, as the naturalistic observation study [27] comprised 4 days of data collection and only 98 participants. We argue that the limited sample size affected the variability of contexts that were encoded in the transcripts and, ultimately, the performance of the machine learning models.

This said, we implemented a single cross-validation protocol for model selection and assessment due to the high number of runs, algorithms, and prediction exercises under consideration. However, this procedure may incur bias in reporting performance results [66]. Therefore, in future studies, we will consider using procedures, such as repeated stratified nested cross-validation [66], together with RFE to improve reporting of model performance.

Moreover, our work was based on a single naturalistic observation study. Therefore, future studies are planned to investigate the generalizability of its results.

Additionally, we did not aim at detecting *changes* in cognitive ability, as Polsinelli et al [27] performed cognitive ability tests once, for all participants. In this study, we focused on computing different families of features and combining them in multiple runs of machine learning modeling. Therefore, we considered three algorithms only (ie, RF, XGBoost, and LightGBM) to predict working memory. In future studies, we plan to use more advanced models (eg, neural networks) and to collect higher volumes of data. Finally, as in Polsinelli et al [27], we computed the cognitive ability of working memory using Keep Track and Consonant Updating scores, as well as their composite, called Working Memory. Therefore, in future studies we will consider predicting scores of other tests [76] and focus on other aspects of executive functioning [41].

Conclusions

Results from this study support the use of linguistic measure and social context information from the transcripts of everyday conversations to predict cognitive ability, namely working memory, in healthy older adults. Several studies have assessed the relationship between cognitive abilities and linguistic measures. However this research is somewhat limited by data collection in clinical interview settings. Alternatively, the approach in this study allows us to use everyday settings to collect and process linguistic measures and social context information using unobtrusive technology. This provides preliminary evidence for the design and deployment of early warning systems that use everyday samples of conversations to predict cognitive decline in older adults. The detection of early cognitive decline may allow for the design of intervention programs to assist older adults, their families, and the health care system in coping with cognitive decline.

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Authors' Contributions

AF is the corresponding author for this work; he designed and evaluated the machine learning pipelines for this study. ML computed the linguistic measures. BD originally proposed the line of research. AF and ML produced the first draft of the manuscript. AJP, SAM, and MRM were responsible for the original EAR study design and data collection. AJP, SAM, MRM, BD, ML, and MM provided important intellectual inputs on cognitive functions and naturalistic observation studies, which helped refine the machine learning pipelines. KY provided important intellectual inputs on the machine learning pipelines and revised them as well. All authors contributed substantially to revisions of the paper and its finalization.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Descriptions of all study variables.
[DOCX File , 18 KB - aging_v5i1e28333_app1.docx]

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Abbreviations

CPIDR: Computerized Propositional Idea Density Rater
EAR: Electronically Activated Recorder
LightGBM: light gradient boosting machine
MCI: mild cognitive impairment
MSE: mean squared error
NLP: natural language processing
POS: part of speech
R: run (when reported with run number)
RF: random forest
RFE: recursive feature elimination
TF-IDF: term frequency–inverse document frequency
XGBoost: extreme gradient boosting

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Review

Exploring Barriers to and Enablers of the Adoption of Information and Communication Technology for the Care of Older Adults With Chronic Diseases: Scoping Review

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Abstract

Background: Information and communication technology (ICT) offers considerable potential for supporting older adults in managing their health, including chronic diseases. However, there are mixed opinions about the benefits and effectiveness of ICT interventions for older adults with chronic diseases.

Objective: We aim to map the use of ICT interventions in health care and identified barriers to and enablers of its use among older adults with chronic disease.

Methods: A scoping review was conducted using 5 databases (Ovid MEDLINE, Embase, Scopus, PsycINFO, and ProQuest) to identify eligible articles from January 2000 to July 2020. Publications incorporating the use of ICT interventions, otherwise known as eHealth, such as mobile health, telehealth and telemedicine, decision support systems, electronic health records, and remote monitoring in people aged ≥55 years with chronic diseases were included. We conducted a *strengths, weaknesses, opportunities, and threats* framework analysis to explore the implied enablers of and barriers to the use of ICT interventions.

Results: Of the 1149 identified articles, 31 (2.7%; n=4185 participants) met the inclusion criteria. Of the 31 articles, 5 (16%) mentioned the use of various eHealth interventions. A range of technologies was reported, including mobile health (8/31, 26%), telehealth (7/31, 23%), electronic health record (2/31, 6%), and mixed ICT interventions (14/31, 45%). Various chronic diseases affecting older adults were identified, including congestive heart failure (9/31, 29%), diabetes (7/31, 23%), chronic respiratory disease (6/31, 19%), and mental health disorders (8/31, 26%). ICT interventions were all designed to help people self-manage chronic diseases and demonstrated positive effects. However, patient-related and health care provider–related challenges, in integrating ICT interventions in routine practice, were identified. Barriers to using ICT interventions in older adults included knowledge gaps, a lack of willingness to adopt new skills, and reluctance to use technologies. Implementation challenges related to ICT interventions such as slow internet connectivity and lack of an appropriate reimbursement policy were reported. Advantages of using ICT interventions include their nonpharmacological nature, provision of health education, encouragement for continued physical activity, and maintenance of a healthy diet. Participants reported that the use of ICT was a fun and effective way of increasing their motivation and supporting self-management tasks. It gave them reassurance and peace of mind by promoting a sense of security and reducing anxiety.

Conclusions: ICT interventions have the potential to support the care of older adults with chronic diseases. However, they have not been effectively integrated with routine health care. There is a need to improve awareness and education about ICT interventions among those who could benefit from them, including older adults, caregivers, and health care providers. More sustainable funding is required to promote the adoption of ICT interventions. We recommend involving clinicians and caregivers at the time of designing ICT interventions.

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KEYWORDS

older adults; gerontechnology; usability challenges; chronic disease; information technology; mobile phone

Introduction

Background

Chronic diseases represent a significant public health challenge worldwide and are the predominant cause of death among older adults [1]. Older adults are also vulnerable to occupational injuries arising from the effects of chemical, physical, and biological exposure in the workplace. In 2016, approximately 70% of deaths and 40% of disability-adjusted life years because of occupational injuries occurred in persons aged ≥55 years [2]. The burden of chronic diseases such as cardiovascular diseases (CVDs), diabetes, neurological disorders, and musculoskeletal disorders falls heavily on older adults [3]. The population aged ≥60 years is expected to increase to 2 billion by 2050 worldwide [4]. Consequently, the global burden of chronic diseases among older adults is anticipated to rise [5,6]. Given the increasing prevalence of aging and chronic diseases, it is essential to focus on health care innovation to improve personal health services such as self-management. Self-management is based on the concept that people can learn to manage their health using their skills and resources and thus become less dependent on external agents [7].

Information and communication technology (ICT) has been used in several settings to help individuals diagnose, treat, and manage chronic diseases better [8]. ICT interventions in health care, which we define herein as eHealth, have been shown to be cost-effective for monitoring and controlling congestive heart failure, stroke, chronic obstructive pulmonary disorder (COPD), diabetes, hypertension, asthma, dementia, and depression [9-13]. ICT interventions have also been used to support caregivers [14]. For example, mobile health (mHealth) has the potential to reduce the caregiver's work burden by supporting the monitoring of medication use and providing significant interaction with older adults, thus minimizing the need for hospitalization [15]. Hence, ICT interventions may provide a solution to some of the challenges of aging and chronic diseases. However, there is conflicting evidence regarding the effectiveness of using ICT interventions among older adults with chronic diseases. Some positive outcomes have been identified for simple telephone interventions [16], which in some cases generated similar outcomes to more complex technologies [17-19]. As per suggestions made by other authors, there are opportunities to explore and compare perceptions among direct service providers, older adults living with chronic diseases, and caregivers about the challenges of various types of ICT interventions in both high- and low-income countries [20-22]. Therefore, there is a strong impetus for exploring the efficacy of ICT interventions and how this effectiveness differs in various settings.

The current high use of ICT among young people shows that ICT could be a future intervention model in health care, enhancing the number of people in need who are reached [23]. However, the approach of older adults to internet and health technology differs from that of younger people. Older adults may have lower rates of computer use and health-related internet use than younger adults [24]. Indeed, Heart et al [25] found that older adults require some skills to adopt the use of ICT interventions. Older adults with chronic diseases have also been reported to face numerous challenges such as altered cognition, visual and hearing difficulties, lack of trust, and privacy concerns as they encounter technology [26,27]. Without adopting these skills and addressing barriers, older adults might not receive the optimal benefits of ICT interventions in routine care. Hence, there is a critical need to better understand and map the barriers associated with the use of ICT interventions among older adults with chronic diseases to maximize the future uptake of ICT interventions and support personalized health care [28]. It is also essential to identify enablers of the use of ICT interventions so as to facilitate the design of mitigating strategies to overcome the barriers to use. Most ICT interventions described in the literature have targeted children, adolescents, or younger adults. We are not aware of any previous systematic or scoping review of the enablers of and barriers to the adoption of ICT interventions for supporting older adults with chronic diseases.

Objective

In this review, we aim to identify (1) the available ICT interventions that have been used for managing older adults with chronic diseases and (2) the barriers to and enablers of using ICT interventions among older adults with chronic diseases.

Methods

Design

This scoping review was conducted using the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews) guidelines [29] and adopting the Arksey and O'Malley [30] framework. This framework outlines five stages for completing a scoping review: (1) identifying the research question; (2) identifying relevant published reports; (3) publication selection; (4) charting the data; and (5) collating, summarizing, and reporting the results

[30], all of which have been followed in the conduct of this review.

Database Selection and Search Strategy

A literature search was performed using 4 databases: Ovid MEDLINE, Embase, Scopus, and PsycINFO. We also used the ProQuest database to include eligible papers and proceedings published in association with computer science and technology conferences. We included articles and conference papers published from January 2000 to July 2020, which had full text in English and were peer reviewed. We selected the time frame of the past 2 decades to identify recent work undertaken on ICT interventions among older adults with chronic diseases. The population of older adults with chronic diseases could benefit from targeted health education interventions. We defined older adults as those ≥aged 55 years [31], so only studies with this definition were included. The search strategies were drafted through team discussions and checked and revised by an experienced librarian. We used the following search terms: *information and communication technology* or *mHealth* or *mobile health* or *telehealth* or *eHealth* or *remote monitoring* or *clinical decision support system* or *mobile phone technology* or *electronic health record* and *arthritis* or *asthma* or *back pain* or *carcinoma* or *cardiovascular disease* or *chronic obstructive pulmonary disease* or *diabetes* or *mental health* or *non-communicable diseases* or *chronic diseases* and *ageing* or *elderly* or *older adults* or *55+ age group* and *barriers* or *enablers* or *challenges* or *opportunities* or *benefits* or *threats*. We included eight major groups of chronic diseases in the review: arthritis, asthma, back pain, cancer, CVDs, COPD, diabetes, and mental health conditions. Multimedia Appendix 1 contains the search strategies and Boolean expressions for each database.

A total of 2 reviewers (SBZ and RKK) screened the titles and abstracts of the selected articles and identified duplicates. In cases of conflicting opinions regarding the eligibility of specific articles, the reviewers discussed their views with a third reviewer (SMSI) to reach a consensus. If inclusion was unclear from the title, the abstract was screened. Similarly, if inclusion was unclear from the abstract, the reviewer read the full text. We included original articles, all types of reviews, and conference papers (Table 1) for this scoping review. Once we identified suitable articles, we also looked for qualitative data included in the analysis. Here, we particularly looked for specific information related to barriers, enablers, and uses of ICT for supporting the care of older adults with chronic disease.

ICT Types and End Users

Our definition of ICT interventions in health care, otherwise known as eHealth, includes the following: mHealth, electronic health records (EHRs), clinical decision support systems (CDSSs), telehealth and telemedicine, virtual reality in health care, and information technology systems used in health care settings. mHealth includes the use of mobile phones, mobile apps, PDAs, and PDA phones (eg, smartphones and handheld and ultraportable computers such as tablet devices) [11]. Telemedicine and telehealth are considered subdomains of eHealth and comprise communication networks to deliver health care interventions from one geographical location to another [32]. A remote monitoring system is defined as a subset of mHealth and telemedicine, which uses sensors to generate patient data.

We use the following ICT terminology in this paper:

- ICT device: refers to hardware only
- ICT intervention: refers to a specific program of research or implementation of ICT (eg, computer, mobile phone or tablet apps, and telehealth)

We considered older adults living with chronic diseases, their caregivers or family members, and health care providers as end users of ICT interventions.

Data Extraction and Synthesis

SBZ, RK, and SMSI developed a data extraction form based on the aims of this review. SBZ and RK extracted data on the article title, names of first authors, publication year, study types or methods, setting, sample size, findings or recommendations, and expected or experienced barriers for all selected articles. Outcomes related to the use of ICT interventions were presented as *positive*, *no difference* or *negative* based on the conclusion reported in the included articles. No negative or neutral (no difference) outcomes were identified. In the case of qualitative data, factors related to barriers and enablers were coded in the data extraction form according to themes that emerged from the studies.

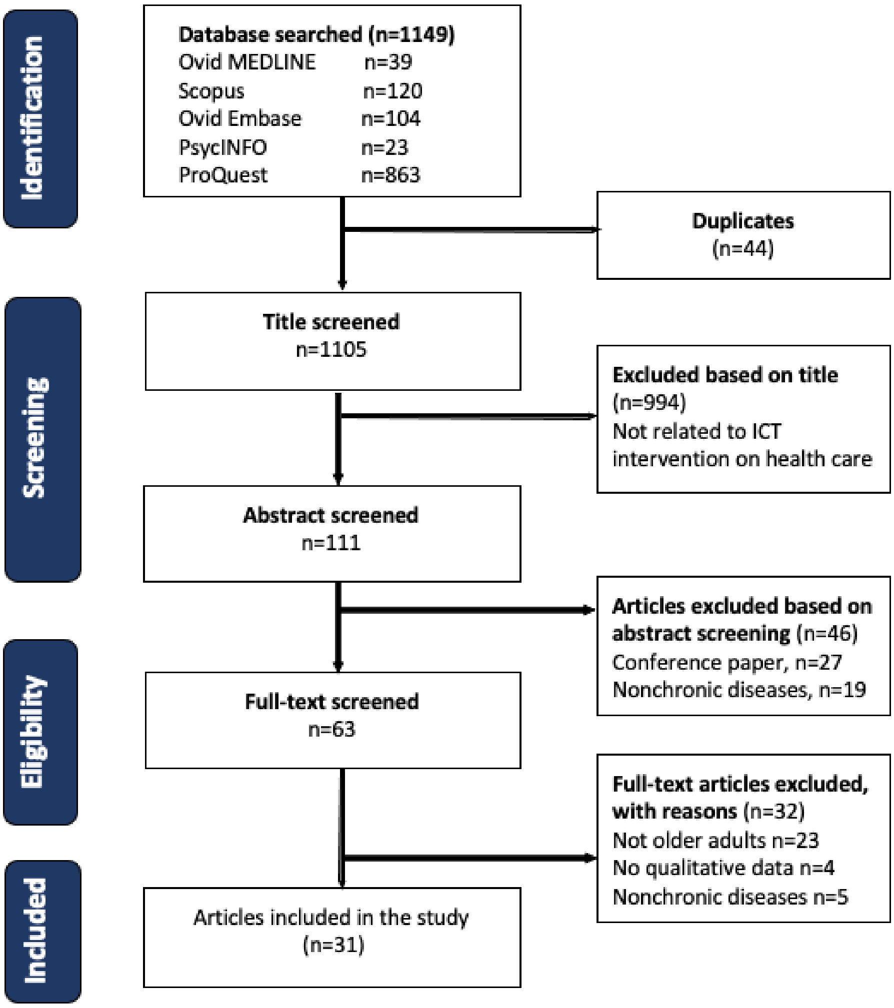
Second, we described and identified various ICT interventions—mHealth, EHR and CDSS, telemedicine, and remote monitoring—that were used for older adults with chronic diseases. Third, we reviewed articles to identify challenges in using ICT interventions among older adults with chronic diseases. For example, factors such as lack of motivation, comorbidities, poor adherence to treatment following ICT interventions, and absence of prior experience in the operation of ICT devices for older adults were considered as challenges. Issues related to costs of implementation, infrastructure, data security, and delays in making a decision were considered in the implementation category. Finally, we conducted a strengths, weaknesses, opportunities, and threats (SWOT) [33] analysis to explore the enablers of and barriers to the use of ICT interventions among older adults with chronic diseases. We used a codebook for the domains of *strength*, *weakness*, *opportunity*, and *threat* to report a descriptive analysis. Before this qualitative analysis, strategies for data coding were identified. SBZ and RK independently read and coded the articles. Each of the domains of SWOT was grouped into two categories: *patient-related factors (operational)* or *health care provider–related factors*. The patient-related category included factors associated with ICT interventions, which we define as *operational* here. We then applied this conceptual framework to identify emerging themes in each of these categories from the selected articles. Codes were then grouped into categories and eventually aggregated into 4 domains. After the initial round of coding, the 2 coders met with a senior researcher (SMSI) to cross-check the coding; thus, a final set of codes was agreed upon. The reviewers used Microsoft Excel 2014 to sort the articles.

Results

Overview

A total of 1149 articles, including conference papers (863/1149, 75.12%), were identified. Of the 1149 articles, 44 (3.83%) were duplicates (Figure 1). We excluded 86.51% (994/1149) of articles that were either not related to ICT interventions for older adults with chronic diseases or studies already reported in the systematic reviews that we included. Of the 1149 articles, after screening the titles and abstracts, 46 (4%) additional articles were excluded, leaving 63 (5.48%) articles for full-text screening. Of the 63 articles, there were 4 (6%) conference papers that were mostly based on formative research (design and development). As these papers lacked both quantitative and qualitative data (patient recruitment and barriers to and enablers of using ICT), we did not include them in the final selection. Finally, of the 63 articles, 26 (41%) were excluded following a full-text review, with 31 (49%) articles remaining (Figure 1).

Figure 1. Flowchart of the literature search used for the selection of articles. This flowchart provides information regarding the various phases of the investigation, including the number of articles identified and the number included and excluded following the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews) guidelines. ICT: information and communication technology.



Characteristics of Articles Included in the Review

The characteristics of the included articles are presented in Table 1. Of the 31 included papers (total number of participants, n=4185), 2 (6%) were randomized controlled trials (RCTs) [34,35], 10 (32%) described non-RCT design intervention studies [36-45], and 13 (42%) were review articles [46-58]. These 13 review articles comprised 4 (31%) systematic reviews [46,48,53,56] and 2 (15%) scoping reviews [50,58]. In addition, 19% (6/31) were conference papers that described cross-sectional studies [59-64] (Figure 2).

Table 1. Characteristics of included articles.

Study	Country	Study design or type of article	ICT[a] interventions	Instrument	Sample or articles	Target condition	Findings or recommendations	Limitations or challenges of ICT interventions
Miguel et al, 2013 [34]	Australia	RCT[b] (6-month study period)	Telehealth intervention	Face-to-face interviews	80	COPD[c]	• The telehealth group had comparatively fewer hospital admissions and a reduced length of stay than the control group.	• Maintenance cost (high)
Barbera et al, 2018 [35]	Finland, France, and the Netherlands	RCT	Internet-based approaches	N/A[d]	2725	Dementia, CHF[e], DM[f], and dyslipidemia	• Participants in the intervention arm were motivated to access information, advice, and motivational support throughout the intervention.	• High cost and country-specific adaptation were major limitations
Barron et al, 2014 [36]	United States	Qualitative	Patient portal (EHR[g])	Cognitive walk-through	14	COPD and CHF	• Patients with chronic diseases and caregivers were satisfied using the patient portal.	• Assistance required for portal use • Medical terms (unfamiliar)
Bhattarai et al, 2020 [37]	Australia	Qualitative	App for self-management of pain	Semistructured interviews	6	Arthritic pain	• Apps for self-management of pain were potentially valuable for older patients • App's content and usability features should be relevant to the users	• Apps were required to meet the user's needs • Pain self-management app might not be helpful if not designed to be used friendly
Chang et al, 2017 [38]	Taiwan	Qualitative	Telehealth	Semistructured (technology acceptance model)	18	DM	• Participants with diabetes self-managed their disease with the help of telehealth	• Mixed feelings regarding dependence on others for telehealth related problem solving
Coley et al, 2019 [39]	Finland, France, and the Netherlands	Mixed	eHealth intervention or internet counseling	Web-based questionnaire and semistructured interviews	343	CVDs[h] and diabetes	• Altruism and personal benefits were motivations for older adults' use of telehealth • Prevention of functional dependency on caregivers was a main underlying motivation	• Internet-based health information perceived as unreliable by older adults • Specific practical advice and encouragement was required for making lifestyle changes
Kim et al, 2019 [40]	United States	Mixed	Telehealth	Web-based surveys and in-depth interviews	20	Depression care	• Telehealth was perceived as useful for managing symptoms and reducing costs.	• Reimbursement and cost-related factors • Patient home environment (not suitable) • Agency-related characteristic (not well equipped)
Zettel-Watson et al, 2016 [41]	United States	Cross-sectional-exploratory study	Web-based health management tools	Web-based survey	169	Chronic diseases	• Most users (89%) were satisfied with web-based health management tools • Users were more likely to be younger, female, and married	• Privacy or security was a concern among participants • Users were not adequately aware of the exact benefits of web-based health management tools

Study	Country	Study design or type of article	ICT[a] interventions	Instrument	Sample or articles	Target condition	Findings or recommendations	Limitations or challenges of ICT interventions
Lee et al, 2016 [42]	United States	Pilot study	Android tablet with an installed app	A mobile-based health technology intervention	18	CVDs and CHF	• Knowledge of self-management (anticoagulation) significantly improved from baseline to follow-up • Participants were satisfied with the simplicity of the app	• Some health care providers were not receptive to their patients using mHealth[i] apps • Privacy and security of information was a concerned
Mirza et al, 2008 [43]	New Zealand	Pilot study (qualitative nature)	mHealth initiative (through SMS text messaging)	Semistructured interviews	18	Diabetes and heart disease	• High acceptability and recognition of the advantages of mHealth • Issues affecting mHealth adoption, such as social issues, technical issues, economic issues, clinical or organizational issues	• Patients' access to their EHR was recommended by the health care providers • Impaired abilities to cope with technology
Radhakrishnan et al, 2016 [44]	United States	Qualitative	Telehealth	Semistructured interviews	23	Cardiac disease, pulmonary disease, and DM	• Positive impact on cost-effectiveness and patient-centered outcomes • Home health management culture was important • Establishment of patient–clinician and interprofessional communication was required	• Factors negatively affected the telehealth program: • Financial challenges • Technical issues • Management and communication-related issues
Nymberg et al, 2019 [45]	Sweden	Qualitative	eHealth (EMR[j], telehealth, and mHealth)	Focus group interviews	15	Hypertension, diabetes, and COPD	• Mixed feelings toward eHealth by the older adults • Participants reported dissatisfaction in accessing health care	• Lack of will, skills, self-trust, or mistrust in the new technology • Organizational barriers (poor IT[k] systems)
Rocha et al, 2019 [46]	N/A	Systematic review	mHealth	A systematic review of reviews and meta-analyses	66 reviews	DM, mental illness, cancer, COPD, and CVDs	• mHealth interventions had positive effects on various health-related outcomes, including medication adherence • No adverse impact of mHealth was identified	• More research-based evidence was recommended for the incorporation of mHealth in clinical practices
Searcy et al, 2019 [47]	N/A	Narrative review	mHealth technologies	—[l]	—	CVDs	• mHealth interventions for older adults with cardiovascular disease yielded mixed results	• Physical limitations and cognitive challenges were identified as limitations
Peek ST et al, 2014 [48]	N/A	Systematic review	Electronic technologies	—	16 articles	Chronic diseases	• Apparent benefits of using mHealth were recommended for widespread acceptance	• Lack of security in using mHealth was a concern
Vollenbroek-Hutten et al, 2017 [49]	N/A	Narrative review	Various ICT platforms	—	673	Chronic pain, COPD	• Patients were satisfied with ICT-supported services	• Real-time contact and safe monitoring of patients in an emergency was challenging

Study	Country	Study design or type of article	ICT[a] interventions	Instrument	Sample or articles	Target condition	Findings or recommendations	Limitations or challenges of ICT interventions
Wildenbos et al, 2018 [50]	N/A	Scoping review	mHealth	Framework analysis	—	Chronic diseases	• A total of 4 critical categories of aging barriers influencing usability of mHealth were cognition, motivation, physical ability, and perception	• Obstacles related to cognitive and physical ability to use mHealth was difficult for older adults to overcome
Blass et al, 2006 [51]	United States	Narrative	Telehealth	Ethics and public policy (ethical challenges)	—	Physical or psychiatric illness	• Ethical challenges with homebound older patients were unique because of patient characteristics and features of the treatment environment.	• Protecting the confidentiality of personal information of users could be challenging
Bostrom et al, 2020 [52]	N/A	Narrative review	Various mHealth technology	mHealth cardiac rehabilitation	—	CVD, hypertension, arrhythmia, and CHF	• mHealth: cardiac rehabilitation represented a particularly attractive area compared with traditional barriers to facility-based cardiac rehabilitation • Improved accessibility to patients unable to attend traditional cardiac rehabilitation	• Safety of mHealth-based cardiac rehabilitation • Physical limitations (eyesight and fine motor skills) might limit use in older adults • Hesitance from older adults to adopt technology
Christensen et al, 2020 [53]	N/A	Systematic review	Video consultations	Different survey instruments	21 studies	Mental health practice (unipolar depression)	• Video consultations were found to be a viable option for delivering mental health care • Video consultations allowed patients to receive treatment at their home	• Incorrect diagnosis • Required trained health care providers
Gilbert et al, 2015 [54]	United States	Narrative	Gerontechnology: mHealth	Applications of gerontechnology by stakeholders	—	Chronic diseases	• A digital divide was developed between older adults and younger adults • Gerontechnology was found to be an essential limb of mHealth unique to older adults	• Without focusing on user-centered design, it would be difficult to widen the accessibility and engagement of older adults in the long run
Henriquez-Camacho et al, 2014 [55]	N/A	Narrative review	eHealth technologies	Problems related to age and technology	—	Chronic diseases	• eHealth technologies were found to have the potential to improve access to health care by empowering patients	• Difficulty in accessing eHealth care because of limited resources, lack of literacy, large geographical areas, and physical, cognitive, and visual impairment
Harerimana et al, 2019 [56]	N/A	Systematic review	Telehealth interventions	Users' perceptions of a telehealth intervention	13 articles	Chronic diseases	• Use of telehealth reduced emergency visits, hospital admissions, and depressive symptoms and improved cognitive functioning of the patients	• Obstacles for using telehealth were levels of education, cognitive function, living arrangement, and negative experience with the clinics
	N/A		Health IT					

Study	Country	Study design or type of article	ICT[a] interventions	Instrument	Sample or articles	Target condition	Findings or recommendations	Limitations or challenges of ICT interventions
Jimison et al, 2008 [57]		Narrative review		Barriers and drivers to the use of health IT	129 articles	Chronic diseases	• Rapid and frequent interactions from a clinician improved use and user satisfaction	• It was critical that data entry does not feel cumbersome and that the intervention fit into the user's daily routine.
Matthew-Maich et al, 2016 [58]	N/A	Scoping review	mHealth	Designing, implementing, and evaluating mHealth technologies	42 articles	Chronic diseases	• The implementation of mHealth technologies in home-based care for older adults and self-management of chronic conditions are important areas for further research.	• A user-centered and interdisciplinary approach is imperative to enhance the feasibility and acceptability of mHealth innovations
D'Haeseleer et al, 2019 [59]	Italy	Conference paper	Various ICT platforms for self-monitoring services	Focus group interview	12	Chronic diseases	• The skills to use computers were heterogeneous among the older adults • They perceived the use of health technologies as a threat to social interaction	• Health technologies are not ready for adoption by older adults yet, and further research on making them more accessible is required
Hosseinpour et al, 2019 [60]	Iran	Conference paper	Telecare	Medical records	38	Acute coronary syndrome	• An innovative telecare system based on artificial intelligence is presented for the early diagnosis of acute cardiac syndrome	• Improving the accuracy of the telecare system by using real-time information of users was challenging
Lorenz et al, 2007 [61]	Germany	Conference paper	mHealth	Semistructured interviews	8	Chronic diseases	• Older adults prefer the advanced interface, characterized by displays of graphical symbols and animations, of devices • They also preferred the basic interface with simple navigation over 2 different screens	• Participants preferred a device like the shape of a wristwatch, equipped with an unobtrusive system • It was challenging to develop a tool for all such older versus younger patients and persons with computer experience versus no computer experience instances
Pikna et al, 2018 [62]	Slovakia	Conference paper	ICT	Semistructured interviews	5	Chronic diseases	• Older adults usually use a mobile phone or a computer to share their experiences with others on different social networks	• The use of ICT can be a difficult challenge for seniors.
Termeh et al, 2015 [63]	Iran	Conference paper	Smart-watches and sensors	Implementation of a U-Health[m] system	—	Heart failure and arterial fibrillation	• U-Health approach is relatively low cost, can be implemented using simple equipment, and does not limit the movement of the patient.	• To get the notification patient has to have the watch on his or her wrist.
			ICT		12			

Study	Country	Study design or type of article	ICT[a] interventions	Instrument	Sample or articles	Target condition	Findings or recommendations	Limitations or challenges of ICT interventions
Wang et al, 2018 [64]	United States	Conference paper		Semistructured interviews		Chronic diseases	- Older adults were positively influenced for using new technologies	- Difficulty in accessing ICT care due to limited resources and lack of literacy

[a] ICT: information and communication technology.

[b] RCT: randomized controlled trial.

[c] COPD: chronic obstructive pulmonary disorder.

[d] N/A: not applicable.

[e] CHF: chronic heart failure.

[f] DM: diabetes mellitus.

[g] EHR: electronic health record.

[h] CVD: cardiovascular disease.

[i] mHealth: mobile health.

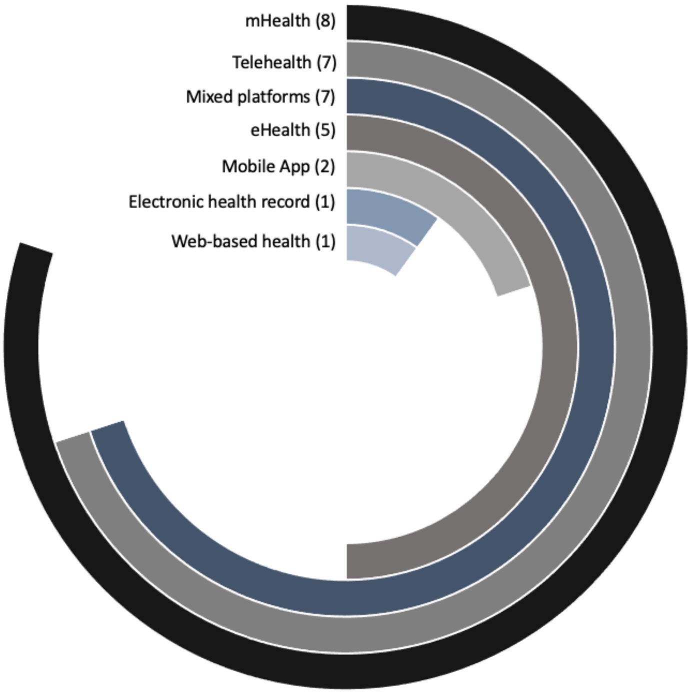
[j] EMR: electronic medical record.

[k] IT: information technology.

[l] Not available.

[m] U-Health: ubiquitous health.

Figure 2. Multilayered donut chart shows the distribution of information and communication technology interventions used in health care. This figure shows various information and communication technology interventions that have been primarily described in the included studies or reviews in our scoping review. The total number of studies or reviews that mentioned various information and communication technology interventions is included in the bracket. mHealth: mobile health.



In total, the systematic reviews used in the current synthesis included 122 independent studies. We did not include studies already reported in the systematic reviews as individual studies to avoid duplication. Clinical trial intervention studies (RCTs and non-RCTs) were conducted in Finland, France, the Netherlands [35,39], Taiwan [38], the United States [36,40-42,44,64], Australia [34,37], New Zealand [43], Germany [61], Slovakia [62], Italy [59], and Sweden [45]. Except for Iran [60,63], no studies were conducted in low- to middle-income countries (LMICs). Most of the studies, except 1 [41], were pilot studies or short-term interventions. Original articles were either qualitative [36-38] or used mixed methods [39,40]. Various methods were used to measure the outcome of interest, including cognitive walk-throughs [44], semistructured interviews [37,39,42-44,61,62,64], in-depth interviews [40], focus groups [45,59], and web-based surveys [39-41]. The Technology Acceptance Model [38] and the Unified Theory of

Acceptance and Use of Technology Model [48] were also used to assess the feasibility of ICT interventions in 2 studies.

ICT Interventions Used in Health Care

All articles provided evidence that ICT interventions are beneficial for health care among older adults with chronic diseases (Table 1). We identified various ICT platforms used for supporting health care providers as they manage chronic diseases in older adults. A total of 3 studies and 2 reviews mentioned the use of ≥1 mixed eHealth intervention such as electronic technologies, internet counseling, video consultation, EHR, and telehealth [39,45,46,48,55]. A total of 3 studies and 5 reviews, including 2 scoping reviews, focused particularly on mHealth [43,46,47,50,52,54,58], including mobile apps [37,42]. A total of 4 studies and 2 reviews focused on telehealth [34,38,40,44,51,56]. One study specifically focused on the use of a patient portal or EHR [36]. One study was on a web-based health management tool [40] for chronic care. Finally, 7 further reviews incorporated the use of a combination of ICT interventions [49,53,57], including EHR, mHealth, and video consultation, in providing care for older adults with chronic diseases. Figure 2 shows the distribution of ICT interventions that have been primarily used or described in the included original articles or reviews.

All the included articles reported a positive outcome for supporting the management of chronic diseases such as CVDs (eg, chronic heart failure, atrial fibrillation, and hypertension) [36,39,42-47,52,57], diabetes [35,38,39,43-46], COPD [34,36,44-46,49], dyslipidemia [35], arthritic pain [37,49], mental illness including depression and dementia [35,40,46,51,53], and cancer [46]. Thus, there were no reports of neutral or negative effects that might underdetermine the use of ICT interventions.

Challenges to and Enablers of Implementing ICT Interventions in Health Care

Multimedia Appendix 2 [34-54,56-64] describes the primary SWOT assessment outcomes.

Strengths

Patient-Related Factors

In many cases, identified in 48% (15/31) of articles, participants reported that the use of an ICT intervention was a fun or effective way for improving health [37,39,43,46-48,52-56,59,61,62,64] by increasing their motivation and supporting self-management tasks [38,42-45,47,50-52,54-57,59,61-63]. Approximately 48% (15/31) of articles identified that patients were frequently satisfied with using 1 or a combination of ICT interventions [34,41-44,46-49,52,55-57,62-64]. They encountered fewer face-to-face interactions with clinical staff and with other patients [34,35,37,39,41-45,48,52-55,57-62,64], thus mitigating their functional dependency [34,35,38,39,43,44,46-48,50,51,54,55,57-59,61-63] on clinical or hospital services. The use of ICT interventions gave them reassurance and peace of mind [34,35,43-45,47,48,50-52,57-59,61-64] by improving a sense of security and reducing anxiety [34,43,44,47,48,51,52,54,57,59-64]. Older adults with chronic diseases who participated in studies reported getting direct access to treatment and benefited from additional medical monitoring when they felt unwell. The use of ICT interventions also encouraged them to continue physical activity, maintain a healthy diet, and stop smoking [37,43-47,49,52,57,58,60-62,64].

Health Care Provider–Related Factors

One of the biggest advantages of ICT interventions that was identified was their nonpharmacological nature [35,39,42-46,48,51,52,54-57,61-64]. This point was made in 58% (18/31) of articles, with a particular focus on the value, for managing older adults with chronic disease, of providing health education and regular follow up. Health care providers reported the use of interactive push-notification features [38,43,46-50,54-57,59,60,62], larger screens [34,36,48,52,57,61] and written instructions [36,48,50] for ICT devices as helpful. Health care providers also expressed a desire to get more available functions, such as voice demonstration and video chatting, for integrating ICT interventions into routine systems (mentioned in 9/31, 29% articles) [41,46-48,50,52,54,55,61].

Weaknesses

Patient-Related Factors

The most common limiting factor, identified in 35% (11/31) of articles, was the lack of confidence in computer skills [40,45,47,48,50,54-56,59,61,64]. In addition, inconvenience arising from the need to have a continuous internet connection was identified in 48% (15/31) of articles [35,39,43-45,48,50,53-57,62-64]. Approximately 39% (9/23) of articles identified that participants felt embarrassed when they failed to correctly operate ICT devices [38,43-45,48,50,53,55-57,59,61,62,64]. As a result, they were sometimes dependent on other family members to operate the devices. This dependency made some people feel uncomfortable and concerned about bothering their family members for assistance with ICT devices [37,38,48,50-52,54,55,59]. Approximately 32% (10/31) of articles identified instances when participants did not voluntarily learn to use the ICT devices if their family members could operate it for them [38,42,47,48,50,52,54-56,61]. Participants also required support (supervision) for adhering to disease management behaviors [34,38,42,48,50,53,58,59,61-64] and maintaining their ICT devices. Some people were concerned regarding the potential loss of data or lack of protection of their privacy [41,44,45,48,51,52,54,55,61] when using ICT interventions. Approximately 39% (12/31) of articles identified that older adults lacked confidence in the use of an internet-based intervention, even if they had the necessary computer skills [40,42,48-50,53-56,59,61,64]. Some participants reported inconveniences associated with the ICT device itself, such as small screens or cramped keyboards [43,46-49,52-55,62] or inadequate battery life lasting 4 to 5 hours [43,46-48,58,61-64]. Approximately 39% (12/31) of articles reported that participants found the ICT devices hard to use because of a lack of familiarity with the medical terms used in the instructions of these devices [36,41,48,52-55,57,59,61,62,64].

Health Care Provider–Related Factors

Only a few weaknesses were reported for health care provider–related factors. Health care providers reported that some older adults with chronic diseases were dependent on family members or friends for using their ICT devices [38,47,50,52,61]. Hence, these participants, who were dependent on others, were sometimes not interested in learning how to operate the technology independently. In such cases, health care providers sometimes found it difficult to directly interact with patients using ICT interventions. An additional list of barriers to and challenges for the use of ICT interventions synthesized from current evidence is provided in Multimedia Appendix 3.

Opportunities

Patient-Related Factors

The authors of 58% (18/31) of articles reported that ICT interventions supported older adults in maintaining regular medical checkups [34,35,39,43-46,48,50,55-59,61-64] and attaining benefits from lifestyle changes [34,35,39,43-45,48,50,52,53,55-60,62-64]. The authors (19/31, 61% articles) also reported that most participants received encouragement from physicians and nurses to use ICT interventions [34,35,39,43-45,48,50,52,53,55-59,61-64] and develop their self-care disease management skills [34,40-42,45-50,53-55,58-64]. Most participants were partially willing to pay for taking up the ICT interventions [48,50,53-61,63,64] if they were affordable. Most of the participants, identified in 35% (11/31) of articles, were also keen to recommend the ICT interventions to others [43,44,48,50,52,54,55,57,59,61,62].

A range of operational factors was identified in relation to the use of hardware and software related to ICT interventions. Most of the investigators reported that the local context should be considered during the development of an ICT intervention [34,37,44,48,52-55,57,59-61]. For example, a mobile app should have personalization features to suit the user's preferences in their language [34,37,46-50,55,56,59-62,64]. Furthermore, participants wanted the ICT devices to be portable, rechargeable [38,43,46-49,53,56,59-63], simple, and easy to use [38,43-49,52-58,61-63].

Health Care Provider–Related Factors

In 48% (15/31) of articles, providers reported that they were satisfied that the ICT interventions allowed them to give special care to older adults with cognitive or sensory dysfunction [38,43,45-47,49,52-56,58,59,61,62,64]. There was consensus that clinicians' active involvement is crucial for the integration of an ICT intervention into a self-management strategy [34,37,41-45,50-52,55-58,61-63].

Threats

Patient-Related Factors

The authors of 32% (10/31) of articles reported that some older adults had hearing and sight impairment and that these disabilities restricted communication with health care providers [35,38,46,50,52,53,56,62]. Cost was another factor, which was identified in 39% (12/31) of articles, that influenced the uptake of ICT interventions. Despite significant improvement in the self-care ability of patients, participants were unwilling to continue ICT interventions that attracted a fee [36,38,43,44,50,53-57,61,62]. For example, a home telehealth program could not be sustained because of financial challenges, technical complexities, and communication-related issues, even after operating for 12 years [44]. When the participants perceived a new ICT intervention as expensive and complex [38,45,46,50,53-55,58,59,62], they lost interest in using that intervention [38,47,48,50,52,59]. Some participants reported that a breach of confidentiality [37,51,53,56] occurred while using an ICT intervention.

Health Care Provider–Related Factors

The authors of 23% (7/31) of the articles reported that providers were influential in motivating their patients to use or stop the use of ICT interventions [41,43,44,50,53,55-57,59,62]. For example, patients were found to stop using an ICT intervention if their physicians did not encourage them to use the respective intervention [41,43,53-55,57-59,61,62,64]. Most health care providers believed that ICT interventions should only be deemed as an adjunct to the medical management of chronic diseases. However, some providers expressed concerns regarding the widespread use of ICT interventions replacing traditional health care delivery models (mentioned in 10/31, 32% articles), which could result in job loss [35,40,45,51,54,55,58,60,61,63].

Discussion

Principal Findings

Overall, findings from this scoping review highlight the potential benefit of ICT interventions or eHealth (eg, mHealth and mobile apps, EHR, remote monitoring, CDSS, and telemedicine) for supporting older adults in self-managing chronic diseases. The review highlighted a range of operational and technical barriers to using these ICT interventions for older adults. Our review highlighted age-related barriers to using ICT interventions, including cognition, motivation, physical limitations (eyesight and fine motor skills), and perception, which limited the use of ICT interventions among older adults with chronic diseases. In this case, personalized learning may meet the unique needs, interests, and capacities of individual users to mitigate these limitations [65]. Some of these limitations could be resolved via design optimization of ICT interventions, such as increasing the screen contrast to mitigate the loss of visual acuity or simplifying task movements to facilitate ICT use in patients with arthritis or physical disability [41]. A number of challenges and enablers in integrating ICT interventions into routine practice were also identified. Most of the included studies were pilot or short-term interventions conducted in a controlled environment. Hence, longitudinal studies aimed at assessing the long-term effectiveness of ICT interventions should be a priority.

Our results indicate that some older adults with chronic diseases might have reservations when it comes to engaging with ICT interventions. We found operational and technical challenges, including a lack of willingness to adopt new skills, poor confidence, and the lack of necessary skills to operate ICT devices. These findings are consistent with the results of other studies where older people expressed no interest in using novel technology and struggled to think of the need for such an application in their own lives [66,67]. Acceptance of these electronic or digital technologies may be more difficult for the current generation of older adults who did not grow up with these technologies [68,69]. Mitigating strategies to increase ICT literacy using short e-learning courses (eg, 2 weeks with 10-minute sessions each day) have been shown to be suitable for older adults [70,71].

We found strong motivation and desire to use ICT interventions among older adults with chronic diseases because of the nonpharmacological nature of the intervention. Self-management of chronic diseases includes the maintenance of a healthy lifestyle and adherence to medication. However, older adults seem to require specific motivation to make practical changes, such as eating a healthy diet and being physically active, even if they are already aware of their value [36]. Nilsen et al [72] reported that the traditional approach of episodic care provided in the clinic or through hospital support systems might not be sufficient to prevent chronic diseases without incorporating ICT interventions in health care. Therefore, health care providers are motivated to use ICT interventions to communicate with their patients to know whether they follow their advice.

It is imperative to understand the duration that people require to achieve a cost-effective outcome from ICT interventions. Findings from this scoping review suggest that older adults living with chronic diseases and caregivers were unwilling to pay for the use of ICT interventions, although they were happy with the service. Most participants only offered to pay partially. An explanation for this result is that all participants in the studies we reviewed were from high-income countries and frequently reported the lack of an appropriate insurance scheme and reimbursement for procuring devices required for ICT interventions. Without addressing the payment model, it will be challenging to ensure the proper use of ICT interventions in health care, even if older adults desire to use them. Chen and Chan [73] also reported that implementation costs were not adequately highlighted in designing specific ICT interventions in many countries. Therefore, the high cost seems to be a critical factor in determining the ability of an older adult to accept these interventions. Similarly, we also reported a home telehealth program's failure after more than a decade of use because of financial challenges [44]. Hence, more sustainable funding and reimbursement are essential for promoting the adoption of ICT interventions.

In addition to the financial factors discussed above, this review highlights workload as an additional determinant of the adoption of ICT interventions. Managing life-threatening events, such as arrhythmia or heart attack, requires an immediate response from health care providers, and such a rapid response can be challenging to execute in many places, particularly in hard-to-reach areas. Failure to react to patients immediately may exacerbate the health risks of older adults with chronic diseases and render health care providers susceptible to accusations of negligence [74]. There is also the risk of generating false-positive alarms from these ICT interventions, which may require physical verification. Thus, such alarms could increase the workload of clinicians if they are required to personally evaluate every call. This may partly explain why not all clinicians were receptive to their patients using ICT interventions. Training can be a significant factor that influences health professionals' eagerness to use or refer their patients for using ICT interventions at home [75-77].

Future app developers should consider involving end users in the design and development process for ICT interventions. We reported that clinicians' involvement in the recruitment process appeared to influence the decision of participants to take part in the trials or studies. Hence, their involvement will be crucial for motivating patients to use ICT interventions. The authors also point out the necessity of ensuring that health care providers are encouraged and committed to recommending ICT interventions for their patients [13,78]. Otherwise, the willingness to use ICT interventions will never develop among patients, despite their ability to operate these devices. The general assumption that education is a relevant factor in adopting the use of ICT may not always be accurate, with the authors of an article reporting that level of education was not positively associated with the uptake of ICT interventions in the sample of patients they studied [79]. Health care providers can be an additional barrier to the adoption of ICT interventions by older patients. For example, Smelcer et al [80] reported that 30% of EHR system implementations worldwide failed because of their underutilization or inappropriate use by the clinician. They identify the concept of *medical authority*, where clinicians or health care providers affect medical practices such as diagnosis and management of chronic diseases for their patients, as critical for the implementation of EHR [81]. It seems likely that medical authority is also an essential factor in the implementation of other forms of ICT interventions.

Management of chronic diseases may require the engagement of multiple health care service providers [82]. This arrangement could be too complex for older adults with chronic diseases who are disabled or living in rural areas, particularly in hard-to-reach areas. Here, ICT interventions can play a significant role by offering interconnectedness among multiple providers. For example, some ICT interventions (CDSS and EHR) provide valuable features such as sharing data with other providers (interoperability) and providing patient-specific information such as drug adherence [83]. In doing so, we also report that some participants raised ethical and legal concerns related to sharing data (eg, privacy and security) with several providers. These barriers can be overcome if clinicians, health care workers, and service providers are obliged to maintain confidentiality and report all harmful events associated with the use of ICT interventions [10,13,78,84].

There are opportunities for implementing ICT interventions in LMICs to support the care of older adults with chronic diseases. Approximately 6.5 billion people reside in LMICs, and the proportion of older adults within this population will increase in the near future in these countries [85]. Most intervention studies that we included were from high-income countries. However, very few were from LMICs. Most developing countries lack the necessary financial strength to fund and implement ICT interventions properly. The good news is that the governments of many LMICs are also interested in investing in deploying eHealth to enhance health services, particularly in remote areas [86]. Finally, ICT interventions should help patients self-manage chronic diseases with minimal support from health care providers or clinics. Hence, clinicians and health care providers are required to convince patients to use ICT interventions in addition to routine clinic visits. None of the included reviews on ICT interventions reported harm. However, there are challenges to the implementation of these ICT interventions, particularly for older adults with chronic diseases. The provision of ICT literacy by health care providers and user-centered design by app developers may help older adults widen their engagement with ICT interventions [54]. Hence, longitudinal studies aimed at assessing the long-term effectiveness of ICT interventions should be a priority. Another priority should be to determine whether ICT interventions are clinically effective and cost-effective when used by rural health care providers. Hence, we recommend conducting a systematic review of existing studies on ICT interventions to evaluate their efficacy.

Limitations

To the best of our knowledge, this is the first review of its type to use the SWOT framework to identify strengths, weaknesses, opportunities, and threats for the use of ICT interventions to support the care of older adults with chronic diseases. A potential limitation of our approach is that we did not consult external experts during the review process. Nevertheless, by conducting a scoping review on this topic, we have defined the nature, extent, and range of research activities on ICT interventions for older adults with chronic diseases. Although we searched the literature exhaustively using 4 academic databases, in addition to ProQuest, there is a possibility that we missed some important studies. In this scoping review, we focused on providing an overview of the available research evidence on the use of ICT interventions in older adults with chronic diseases. Therefore, we included a good range of original studies, systematic reviews, and conference papers to help answer our research question. Importantly, none of the studies included in these reviews overlapped. We did not perform a critical appraisal of the literature, which was beyond the scope of our objectives (PRISMA-ScR checklist is given in Multimedia Appendix 4 [29]).

Conclusions

ICT interventions might help support the care of older adults with chronic diseases by increasing adherence to treatment and healthy lifestyles. However, the incorporation of ICT interventions into medical practice is still challenging. The involvement of clinicians is crucial for motivating people with chronic diseases to adopt ICT interventions to support self-management. There is a need to improve awareness and training in the available and effective ICT interventions among older adults and health care providers. Widespread implementation of ICT interventions will also require more sustainable approaches to funding and reimbursement. We recommend involving clinicians and caregivers when designing ICT interventions and integrating them into routine medical care.

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Authors' Contributions

SBZ, RGE, and SMSI conceived and designed the review. SBZ, RKK, and SMSI performed the literature searches and analyzed the data. SBZ, AGT, RGE, RKK, RM, and SMSI wrote the paper.

Conflicts of Interest

RGE reports grants from the National Health and Medical Research Council (Australia) and the National Heart Foundation of Australia outside the submitted work. RGE has also received consulting fees from Medtronic Australasia in relation to work other than that described in this manuscript. AGT reports grants from Monash University during the conduct of the study and grants from the National Health and Medical Research Council (Australia) outside the submitted work.

Multimedia Appendix 1
Search strategies for Ovid MEDLINE, Embase, Scopus, and PsycInfo databases.
[DOCX File , 31 KB - aging_v5i1e25251_app1.docx]

Multimedia Appendix 2
Framework analysis of strengths, weaknesses, opportunities, and threats on the use of information and communication technology in health care among older adults.
[DOCX File , 46 KB - aging_v5i1e25251_app2.docx]

Multimedia Appendix 3
List of barriers to and challenges for the use of information and communication technology.

[DOCX File , 23 KB - aging_v5i1e25251_app3.docx]

Multimedia Appendix 4
PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) checklist.
[PDF File (Adobe PDF File), 204 KB - aging_v5i1e25251_app4.pdf]

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Abbreviations

CDSS: clinical decision support system
COPD: chronic obstructive pulmonary disorder
CVD: cardiovascular disease
EHR: electronic health record
ICT: information and communication technology
LMIC: low- to middle-income country
mHealth: mobile health
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analysis
RCT: randomized controlled trial
SWOT: strengths, weaknesses, opportunities, and threats

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