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Feasibility and Acceptability of Technology-Based Exercise and Posture Training in Older Adults With Age-Related Hyperkyphosis: Pre-Post Study

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Abstract

Background: Hyperkyphosis is common among older adults and is associated with multiple adverse health outcomes. Kyphosis-specific exercise and posture training programs improve hyperkyphosis, but in-person programs are expensive to implement and maintain over long periods. It is unclear if a technology-based posture training program disseminated through a mobile phone is a feasible or acceptable alternative to in-person training among older adults with hyperkyphosis.

Objective: The primary purpose was to assess the feasibility of subject recruitment, short-term retention and adherence, and acceptability of a technology-based exercise and posture training program disseminated as video clip links and text messaging prompts via a mobile phone. The secondary purpose was to explore the potential efficacy of this program for kyphosis, physical function, and health-related quality of life in older adults with hyperkyphosis.

Methods: In this 6-week pre-post design pilot trial, we recruited community-dwelling adults aged ≥65 years with hyperkyphosis ≥40° (±5°) and access to a mobile phone. The intervention had two parts: (1) exercise and posture training via video clips sent to participants daily via text messaging, including 6 weekly video clip links to be viewed on the participant's mobile phone, and (2) text messaging prompts to practice good posture. We analyzed the subject recruitment, adherence, retention, and acceptability of the intervention. Outcomes included change in kyphometer-measured kyphosis, occiput-to-wall (OTW) distance, Short Physical Performance Battery score, Scoliosis Research Society (SRS-30) score, Center for Epidemiological Studies Depression score, and Physical Activity Scale for the Elderly (PASE) score.

Results: A total of 64 potential participants were recruited, 17 were enrolled, and 12 completed postintervention testing at 6 weeks. The average age was 71.6 (SD 4.9) years, and 50% were women. The median adherence to daily video viewing was 100% (range, 14%-100%) and to practicing good posture at least three times per day was 71% (range, 0%-100%). Qualitative evaluation of intervention acceptability revealed that the mobile phone screen was too small for participants to view the videos well and daily prompts to practice posture were too frequent. Kyphosis, OTW distance, and physical activity significantly improved after the 6-week intervention. Kyphosis decreased by 8° (95% CI –12 to –5; *P*<.001), OTW decreased by 1.9 cm (95% CI –3.3 to –0.7; *P*=.007), and physical activity measured by PASE increased by 29 points (95% CI 3 to 54; *P*=.03). The health-related quality of life SRS-30 score increased by 0.11 point (SD 0.19), but this increase was not statistically significant (*P*=.09).

Conclusions: Technology-based exercise and posture training using video clip viewing and text messaging reminders is feasible and acceptable for a small cohort of older adults with hyperkyphosis. Technology-based exercise and posture training warrants further study as a potential self-management program for age-related hyperkyphosis, which may be more easily disseminated than in-person training.

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KEYWORDS

acceptability; exercise; feasibility; hyperkyphosis; kyphosis; posture; spine; technology-based

Introduction

Interventions that reduce or slow the progression of age-related hyperkyphosis could have a positive impact on the health status among aging populations. A thoracic spine curvature greater than 40° is commonly defined as hyperkyphosis [1,2] and is prevalent among up to 40% of older adults [3,4]. Kyphosis progresses with age [3,2,5,6], and age-related hyperkyphosis is associated with reduced health-related quality of life (HRQoL), impaired physical function, falls, and elevated fracture risk, particularly when kyphosis progresses to ≥53° [7-13,4]. Recent randomized controlled trials demonstrated improvement in kyphosis and HRQoL after in-person physical therapist-guided kyphosis-specific spine-strengthening exercise and postural training programs over 3-6 months conducted in small groups of older adults with hyperkyphosis [14,15]. However, these labor-intensive programs are expensive to implement and maintain over longer periods of time in clinical and community settings.

One way to reduce the costs of such programs is to utilize digital technologies such as mobile phones, mobile apps, and text messages [16], which are becoming popular communication channels for older adults [17]. However, it is not known whether a technology-based kyphosis exercise and posture training program could provide an alternative self-management intervention that is acceptable and more easily disseminated than in-person training. According to a recent systematic review [18], several factors influence acceptance of technological devices that enhance aging in place for community-dwelling older adults. Older community-dwelling adults have concerns about the high cost, privacy issues, and usability of technological devices. They often question the perceived usefulness and need for technology over more traditional alternatives such as joining a local fitness center for an individual or a group-led exercise program. Older adults are concerned about the social influence of technology use and often look to friends or family for approval or recommendations of new technology. Nevertheless, there has been a rapid rise in mobile phone use among older populations over the past decade and in internet-based self-management programs [19] aimed at increasing physical activity and improving other chronic medical conditions in older adults. Studies suggest that older participants could easily handle the technology after initial training [16,20,21] and, in fact, are more likely to adhere to technology-based interventions [20,22,23]. A technology-based kyphosis exercise and posture training program, disseminated through a mobile phone, may be an acceptable alternative to in-person training for older adults with hyperkyphosis, but the feasibility and acceptability of this type of technology-based program have not been tested thus far.

The primary purpose of this study was to assess the feasibility of subject recruitment, retention and adherence, and acceptability of a technology-based exercise and posture training program disseminated as video clip links and text messaging prompts via a mobile phone. The secondary purpose was to explore the potential efficacy of this program on kyphosis, HRQoL, and physical function in older adults with hyperkyphosis.

Methods

Study Design and Participants

This study was a 6-week pre-post pilot trial. The study protocol was approved by the University of California, San Francisco (UCSF), Institutional Review Board prior to participant recruitment and enrollment, and all participants signed an informed consent. Participants were recruited from community talks, university research databases of older adults who had previously agreed to be contacted for future studies, and dental and physical therapy clinics at the UCSF Medical Center. Eligibility criteria were age ≥65 years, kyphometer-derived kyphosis measurement ≥40° (±5°), ability to walk ≥1 block independently without an assistive device, and access to a mobile phone. Participants were excluded for cognitive impairment (inability to draw a normal clock or recall any words on the Mini-Cog [24]). We recruited a small sample to determine feasibility and acceptability and provide preliminary estimates of the effects and SD in clinical measures of kyphosis, HRQoL, and physical function in older community-dwelling adults with hyperkyphosis.

Screening/Baseline Visit

Interested participants were initially screened by telephone, and those who met the preliminary inclusion criteria were scheduled for a face-to-face screening/baseline visit where baseline kyphosis was measured. Participants meeting all eligibility criteria were enrolled in the study and later attended a 30-minute face-to-face session (intervention) with the study coordinator who provided an overview of the 6-week program and a study manual that coincided with the study video clips including pictures and instructions for exercise and good posture during activities of daily living. This session included two components: instructions and practice in the technical aspect of logging in to the university and library websites to view the video clips and instructions and practice in responding to the text messaging prompts. Each participant was given a unique password and log-in instructions to the university and library websites.

Intervention

Design

The intervention was a 6-week exercise and posture training program comprising two parts: (1) exercise and posture training sent to participants on a daily basis via text messaging, which included a weekly video clip link to be viewed on the participant's mobile phone, and (2) text messaging prompts to practice good posture. Participants were instructed to view the weekly video clip once per day and practice good posture at least three times per day. The content of the intervention was tested in our previous randomized controlled trials [25,15]. The length of the intervention was chosen because it takes a minimum of 2 weeks to master learning, and a minimum of 6 weeks to adapt to exercise [26].

Exercise and Posture Training via Video Clips

The video clips were 45- to 60-second demonstrations of 6 lessons in exercise and posture training that taught participants good postural alignment and movement during activities of daily living (Table 1). Participants received daily text messages with a link to the specific weekly video lesson. The person in the video clip demonstrated ideal spinal alignment during activities of daily living, serving as a role model for good posture (Figure 1), and the pictures in the training manual reinforced the weekly lesson. We established a link to the study on the university library website, where participants could view the 6 video clips. Once the study coordinator enrolled participants in the study, they were able to view the study videos after successfully logging in to the study site on the library website. The log-in process involved 2 steps: log in to the university website with a unique password and then log in to the library website using the same password. The library website collected analytics that quantified viewing time for each participant for each video.

Text Messaging Prompts

Participants received daily reminders to practice good posture at least three times a day during their daily activities. At the onset of the study, participants could choose the frequency of text messaging reminders and whether they wanted to receive one, two, or three daily reminders. All participants were texted at the end of the day and instructed to reply to the question, "Did you practice at least 3 times today?" Participants were prompted to reply by text with 1 (yes) or 0 (no) every day during the 6-week program.

Text messages were sent automatically via the company, Twilio [27], a cloud communications platform service specifically programmed for this study. This tool allowed the research team to schedule the text messages for every participant and monitor and confirm delivery and individual responses.

Table 1. Exercise and posture training intervention: Weekly video lessons and training activities.

Week	Video lessons and training activity
1	Practice good standing posture
2	Practice good sitting posture
3	Bend from the hips and knees, and keep the spine straight
4	Neutral pelvic alignment supports good posture
5	Build spine strength with exercise
6	Improve balance

Figure 1. Screenshot of the exercise video on neutral pelvic alignment.

Postintervention Visit

After completing the 6-week pilot study, all outcome measures were repeated, and participants were interviewed by the study coordinator using a semistructured interview guide designed to explore participants' experiences and perspectives on acceptability of using the mobile phone and video-clip technology.

Measurements

Feasibility of Recruitment, Retention, and Adherence

We determined the number of participants who completed the telephone screening, how they heard about the study recruitment, the number of participants who met the eligibility criteria, and the number who completed the 6-week study visit. At baseline, we assessed self-efficacy of adherence to the intervention and asked participants how confident they were that they would practice good posture at least three times a day, watch the video daily, and reply to a text daily during the 6-week intervention.

Adherence to Video Viewing

The duration of viewing time for each video was recorded for every participant using the university library website analytics. Weekly adherence to video viewing was calculated as a percentage of the actual duration of viewing time/the expected duration of daily viewing time each week × 100. Maximum possible adherence was 100%, even if participants exceeded the expected viewing time.

Adherence to Practicing Good Posture at Least Three Times a Day

A text message question was sent to each participant at the end of each day, which asked them whether they practiced the exercise at least three times that day, and their responses were recorded in the study database. Weekly adherence to practice was calculated as a percentage of the number of actual days of practice at least three times divided by the expected days of practice at least three times × 100.

Qualitative Exploration of the Pilot Study

The study coordinator asked participants the following 7 questions at the postintervention visit: (1) Looking back over the last 6 weeks, what did you learn the most from the study? (2) What did you like the most about the study? (3) What did you like the least about the study? (4) What would you change about the study? (5) What do you feel would have motivated you more to improve your posture? (6) What advice would you give to other older adults to help improve their posture? (7) Is there anything else you would like to add? The responses were recorded and summarized.

Kyphosis, Physical Function, and Other Outcomes

Kyphosis and physical function measurements were performed at a university-based physical performance laboratory by a trained exercise physiologist before and after the 6-week intervention. The remaining questionnaires were administered by the study coordinator, and participants completed the questionnaires on a study iPad (Apple Inc, Cupertino, CA).

Kyphosis

Kyphosis was measured in degrees using a standardized protocol for clinically measured kyphosis (T3-T12) [28] and the Debrunner kyphometer while the participant stood in his/her usual posture (Figure 2). A higher degree of kyphosis indicated worse kyphosis [29-31]. The intraclass correlation coefficient for repeated observer analysis of kyphosis measurements using the Debrunner kyphometer is 0.95 [32]. Occiput-to-wall (OTW) distance, a surrogate clinical measure of kyphosis [33,34], was acquired with two rulers placed perpendicular, one vertically behind the head at the occiput and one horizontally measuring the distance from the wall to the vertically placed ruler, while the participant stood with both heels and the sacrum against the wall with the head positioned in the Frankfort horizontal plane (Figure 3). OTW distance >5 cm predicts a risk of hyperkyphosis [33,35]. Reproducibility of the OTW distance among older adults aged >60 years with excessive kyphosis was 0.99 for intrarater reliability and 0.93 for interrater reliability [36].

Figure 2. Kyphometer measurement of kyphosis.

Figure 3. Measurement of occiput-to-wall distance.

Physical Function

The Short Physical Performance Battery (SPPB) consists of three areas of lower-extremity function including static balance, gait speed, and getting in and out of a chair. Each area is scored individually (0-4 points) with a composite SPPB score of 0-12 points; higher scores indicate better physical performance [37].

Physical Activity

The Physical Activity Scale for the Elderly (PASE) questionnaire is a brief survey designed specifically to assess frequency, duration, and intensity level of physical activity over the previous week in persons aged ≥65 years. Scores range from 0 to 793 points, with higher scores indicating greater physical activity [38].

Depression Symptoms

The Center for Epidemiological Studies Depression (CESD) is a self-reported depression symptom scale. The possible range of scores is 0-60 points, with higher scores indicating more symptomatology and scores ≥16 indicating the presence of depression [39,40].

Health-Related Quality of Life

The modified Scoliosis Research Society (SRS-30) is a self-reported spine-specific quality-of-life instrument that includes four domains scored separately, with an overall mean composite score of 1-5 points (1=worst, 5=best). Domains include function/activity, pain, mental health, and self-image/appearance and an additional score for satisfaction with management [41].

Statistical Analyses

Baseline demographic characteristics of the enrolled participants were summarized using mean, SD, and range for continuous measures. Tabulations and percentages were used to summarize categorical variables. We used descriptive statistics of mean with SD and median to characterize process measures required to demonstrate adherence to the intervention. Kyphosis, physical function, and HRQoL scores at baseline and 6 weeks postintervention were summarized with means and SDs. Paired *t* tests were used to assess the effects of the intervention on changes in the scores from baseline to the end of the 6-week intervention period. The results were also reported with confidence intervals and *P* values. All analyses were conducted using SAS software, version 9.4 (SAS Institute Inc, Cary, NC).

Results

Feasibility of Recruitment, Retention, and Adherence

A total of 64 potential participants were recruited between January and May 2018, of which 29 met the preliminary eligibility criteria by telephone and were scheduled for an in-person clinic/baseline visit. Twelve potential participants did not meet the kyphosis eligibility criteria (kyphosis ≤40° ± 5°), and 17 (58.6%) met all eligibility criteria and were enrolled in the study (Figure 4). The 12 participants who completed the intervention and follow-up visit had a mean age of 71.6 (SD 4.9) years, and 92% had college, professional, or graduate degrees (Table 2). As per the baseline self-efficacy scales, participants were 97% confident they would practice good posture at least three times a day, 97% were confident that they would watch a daily video, and 98% were confident that they would reply to a daily text. Five participants did not complete the study. One dropped out for medical reasons, two dropped out during the first 2 weeks due to frustration with the two-step log-in process, one lost interest after 2 weeks, and one completed all aspects of the intervention but did not return for the 6-week postintervention testing. The mean age of the 5 participants (two male, three female) who did not complete the 6-week follow-up visit was 71.5 years, and 80% had college, professional, or graduate degrees (one unknown). The one participant who completed the intervention but did not return for the 6-week follow-up visit reported 50% confidence on the self-efficacy scales at baseline.

Adherence to Video Viewing

The mean adherence to video viewing over the 6-week study (n=12) ranged from 76% to 87% among those who completed the 6-week testing visit (Table 3). The median adherence to video viewing was 100% (range, 14%-100%).

Adherence to Practicing Good Posture at Least Three Times a Day

The mean adherence to practicing at least three times a day over the 6-week study ranged from 62% to 77% among those who completed the 6-week testing visit (n=12) (Table 3). The median adherence to practice was 71% (range, 0-100).

Preliminary Estimates of Change in Outcome Measures

Kyphosis, OTW distance, and physical activity measured by the PASE questionnaire significantly improved after the 6-week intervention (Table 4). Kyphosis decreased by 8° (95% CI –12 to –5; *P*<.001), the OTW distance decreased by 1.9 cm (95% CI –3.3 to –0.7; *P*=.007), and the physical activity score increased by 29 points (95% CI 3 to 54; *P*=.03). The SRS-30 quality-of-life composite score increased by 0.11 point (SD 0.19; *P*=.09), and individual self-image/appearance, pain, and function/activity domain scores were higher after the intervention, but not statistically significant (*P*>.05; data not shown).

Qualitative Exploration of the Pilot Study

Results from the semistructured interviews completed at the 6-week postintervention visit are summarized in Table 5. Participants had difficulty with the video technology interface, difficulty watching the videos on their phones, and questions about dosing of the posture instructions received in the videos and found the daily texts bothersome. Participants reported preferences for less frequent text messaging, ability to view the videos on a larger screen, more clarity regarding time spent practicing, and an easily accessible platform for viewing the videos.

Figure 4. Participant recruitment and retention.

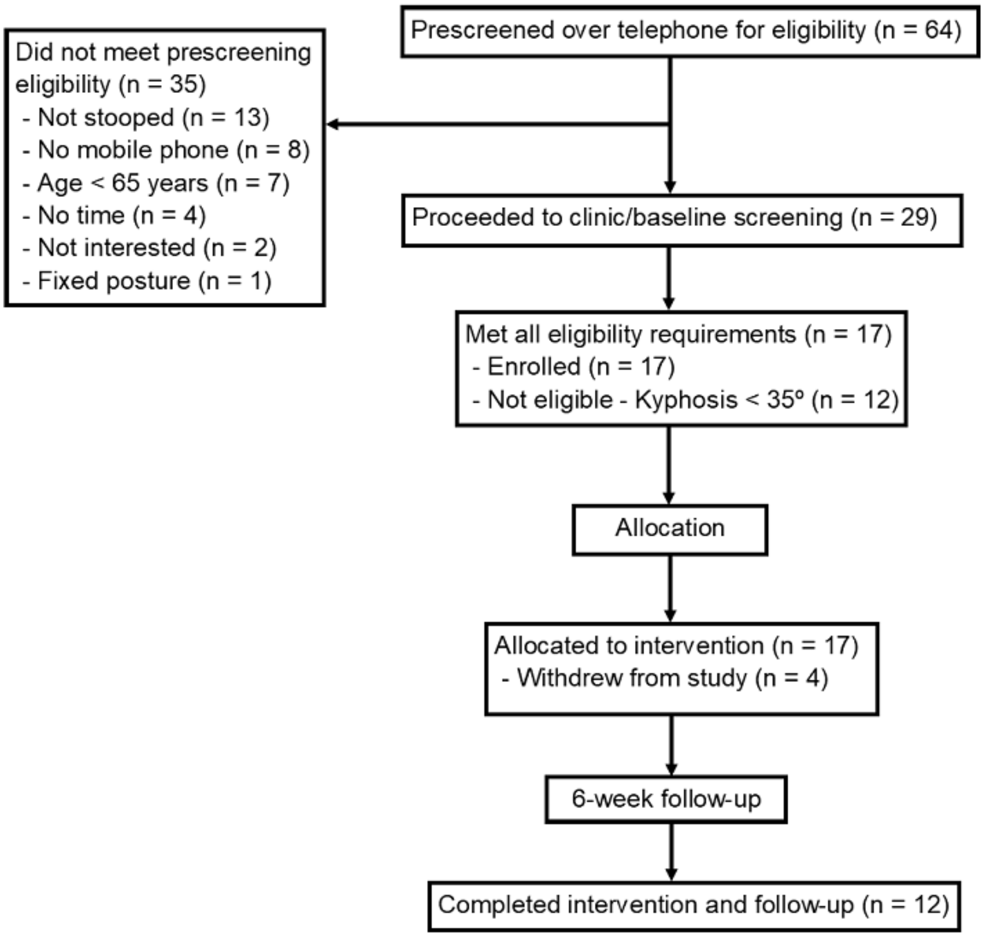

Table 2. Demographic characteristics of enrolled participants at baseline (N=12).

Variable	All participants
Age (years), mean (SD), range	71.6 (4.9), 65-81
Self-efficacy scale[a], mean (SD), range	
Practice good posture at least three times a day	9.7 (0.65), 8-10
Watch a daily video	9.7 (0.65), 8-10
Reply to a daily text	9.8 (0.45), 9-10
Sex (female), n (%)	6 (50)
Race/ethnicity (Caucasian), n (%)	11 (92)
Education, n (%)	
Some college, vocational, or high school	1 (8)
College graduate	5 (42)
Professional or graduate degree	6 (50)
Paid part-time or full-time job (yes), n (%)	4 (33)
Co-morbidities, n (%)	
0-1	7 (58)
≥2	5 (42)
Type of mobile phone, n (%)	
Android	3 (25)
iPhone	9 (75)

[a] Score ranges from 0 to 10 points and a higher score indicates a higher self-efficacy.

Table 3. Adherence to daily video viewing and practicing over the 6-week pilot study.

Activity	Adherence, mean (SD)						Adherence, median (range)
	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Weeks 1-6
Watched video daily[a]	76 (29)	87 (28)	84 (25)	79 (33)	76 (32)	76 (29)	100 (14-100)
Practiced at least three times daily[b]	62 (36)	75 (24)	77 (13)	77 (21)	64 (27)	70 (26)	71 (0-100)

[a] Adherence to video viewing calculated as actual viewing time divided by the total possible viewing time × 100 (maximum adherence was reported as 100%).

[b] Adherence to practice calculated as the number of actual days of practice at least three times divided by total possible number of days practiced at least 3 times × 100. Missing data on one participant who practiced the exercise, but failed to reply to daily texts.

Table 4. Baseline, postintervention, and preliminary estimates of change in outcome measures for participants who completed the 6-week testing visit.

Outcome measure	Baseline, mean (SD)	Postintervention, mean (SD)	Change[a], mean (SD)	*P* value for change	95% CI for change
Kyphosis degree derived using kyphometer[b] (degrees)	51 (10)	43 (12)	-8 (5)	<0.001	–12 to –5
Occiput-to-wall distance[b] (cm)	7.8 (4.1)	5.9 (3.2)	–1.9 (2.1)	0.007	–3.3 to –0.7
Short Physical Performance Battery (0-12 points)	11.1 (1.0)	10.9 (1.3)	–0.2 (1.0)	0.59	–0.8 to 0.5
Scoliosis Research Society (0-5 points)	3.94 (0.23)	4.05 (0.25)	0.11 (0.19)	0.09	–0.02 to 0.23
Physical Activity Scale for the Elderly (0-793 points)	109 (68)	138 (55)	29 (40)	0.03	3 to 54
Center for Epidemiological Studies Depression score[b] (0-60 points)	6.6 (4.9)	6.1 (3.7)	–0.4 (3.8)	0.71	–3 to 2

[a] Change reported for participants with baseline and 6-week post-intervention scores (n=12).

[b] Higher scores indicate worse kyphosis, occiput-to-wall distance, and CESD; negative change indicates improvement.

Table 5. Content of intervention, results, and lessons learned from the 6-week pilot study.

Content of intervention	Results	Lessons learned
Text messaging reminders sent to participants to practice good posture one, two, or three times a day every day for 6 weeks (no response requested)	Participant requests for text messaging reminders varied from one to three times a day	Daily text reminders too frequent for most participants (n=5)
Instructions to reply to the question, “Did you practice at least 3 times today”? (yes/no) every day for 6 weeks	Adherence to practicing at least three times a day: median (range)=71% (0%-100%)	Good adherence to practice at least three times a day
Instructions to watch video clips daily on a UCSF[a] library site (remote intervention)	Adherence to watching the videos declined after the second week from 87% to 76%; median (range) adherence=100% (14%-100%)	Cell phone screen too small to view videos (n=3); two-step log-in process was cumbersome (n=8)

[a] UCSF: University of California, San Francisco.

Discussion

Principal Results

We explored the feasibility of subject recruitment, retention, and acceptability of an exercise and posture training program sent as video clip links and text messaging prompts via a mobile phone to older adults with hyperkyphosis. Only 8 (12.5%) participants who were screened for the study did not qualify due to no access to a mobile phone, highlighting prior reports that technology use is rapidly increasing in older populations [17]. Of those who did not complete the 6-week postintervention visit, two dropped out during the first 2 weeks because of frustration with the two-step log-in procedures; we learned that a two-step process is too cumbersome, even for those who completed the study. Overall, participant acceptance and satisfaction with the intervention was positive. Adherence to the intervention was high among those who completed the 6-week intervention. Based on participant feedback, we learned that daily text messaging reminders were too frequent and participant preference for frequency of text messaging reminders is an important consideration for future studies. Furthermore, the mobile phone screen was too small for easy viewing, and future modifications should include access to the video for viewing on a larger computer screen and an accessible log-in without the two-step process. To investigate the effects of a technology-based intervention on kyphosis and kyphosis progression in the future, we plan to conduct a longer intervention with regular interactive video webinars to keep participants engaged, and provide online demonstrations and feedback to participants. These webinars could be accessed from individual personal computers that provide a larger screen and avoid the cumbersome two-step log-in process that our participants found difficult.

Kyphosis decreased by 8° (95% CI –12 to –5), OTW distance decreased by 1.9 cm (95% CI –3.3 to –0.7), and PASE score increased by 29 points (95% CI 3 to 54), which indicates improvement in clinical measures of kyphosis and physical activity, although we did not have a large enough sample to assess the potential efficacy of this program on progression of kyphosis, OTW distance, and physical activity in older adults with hyperkyphosis. Results of this study suggest that delivering an exercise and posture self-management program via technology is promising and deserves further investigation.

Comparison with Prior Work

Our results are consistent with studies showing that self-management programs that focus on day-to-day management of chronic diseases significantly improve heath behaviors and health status [42,43]. At baseline, our participants reported a high likelihood of adherence to the proposed self-management intervention, an indication of high self-efficacy that has been associated with a significantly higher likelihood of good outcomes among older adults with knee osteoarthritis [44,45]. High self-efficacy has also been shown to predict successful integration of other healthy behaviors and enhance sustainability of high levels of self-care [46,47].

Results of our study are also consistent with those of a previous systematic review that reported that text messaging reminders enhanced participants' abilities to self-manage their chronic condition (asthma, diabetes, or hypertension) [48]. Text messaging reminders have demonstrated efficacy in improving adherence to a variety of health behaviors across multiple domains [49-51]. Moreover, participants who perceived improvements in self-management preferred reminders via mobile phone messaging over email reminders, highlighting the acceptance and usability of mobile phone technology in older populations [48]. Another systematic review of smart technology interventions aimed at facilitating, supporting, and sustaining self-management through behavioral change in people with chronic obstructive pulmonary disease, concluded that the use of technology improved HRQoL and physical activity compared to face-to-face or digital/written support [52] and continued use of a smart technology intervention improves sustainability of behavior change over time.

The improvement in kyphosis in our study exceeds that reported in previous randomized controlled trials that tested the efficacy of in-person exercise and posture training interventions in older adults with hyperkyphosis over longer periods of time [14,15]. We used trained testers at the University's Clinical and Translational Science Institute's physical performance laboratory, provided additional training for our outcome measurements, and ensured high within- and between-tester reliability prior to the study. Although there were large SDs in the kyphosis measurements and a very small sample size, the change in kyphosis exceeded the standard error of the measurement. It is possible that our technology-based educational intervention improved motor control and provided participants self-management tools and greater autonomy for improving posture as compared to prior in-person interventions.

There are no prior studies that specifically target OTW distance; however, the 1.9-cm change in OTW distance observed in our study did not exceed the smallest detectable difference of 3.2 cm according to Bland-Altman criteria previously reported among adults with ankylosing spondylitis [34]. In contrast, the PASE scores of physical activity improved by 29 (SD 40) points, which is a robust 27% improvement from the baseline mean score of 107 (SD 61) points to 138 (SD 55) points at the 6-week visit. The mean score for older adults aged ≥65 years was 102.9 (SD 64.1) points, suggesting that educating participants about their posture may also increase their participation in physical activities compared to their age-matched peers [38]. Participants reported greater frequency and duration of walking and performing more yard work and home repair after the intervention. It is possible, although unlikely, that this additional physical activity contributed to a change in kyphosis, but we cannot discount the possibility that the skills learned from the intervention are responsible for both the increase in physical activity and improved kyphosis.

Limitations

This pilot study may be the first of its kind to investigate the feasibility of delivering a technology-based kyphosis-specific exercise and posture-training program by mobile phone over 6 weeks in older community-dwelling adults with hyperkyphosis. These programs have previously required in-person training for 3-6 months. However, there are several limitations. First, this was a pilot study without a control group, and the results may be larger than a between-group comparison in a controlled trial. Second, we excluded participants who were not English speakers and did not have access to a mobile phone, tablet, or computer. In addition, most of our participants were white and had college degrees or graduate degrees, which limits our ability to generalize the preliminary results to the overall older adult population with hyperkyphosis. Third, our sample size was small with large SDs in the effects; however, these data will be helpful in designing a future randomized controlled trial in a large sample. Fourth, failure to complete all aspects of the study was high, although one participant dropped out for medical reasons unrelated to the study, three dropped out within the first 2 weeks, and one completed all aspects of the study except the 6-week testing. This drop-out rate is within the range of 6% to 34% reported in exercise interventions in older persons. In addition, the early drop-out rate observed in our study is consistent with that in previous studies reporting the highest number of dropouts in the first 3 months of longer-term studies [53]. Fifth, our sample was highly educated and implementing this study in a lower-educated population may be challenging. However, a systematic review that described characteristics of community-dwelling older adults that influence acceptance of technology listed the familiarity of older adults with modern technology, the fit between the housing type and technology, and the compatibility of the technology with adults' cultural background, rather than educational level, as limiting factors [18]. Future randomized studies to determine the efficacy of this technology among larger and more diverse populations are needed.

Conclusions

Technology-based exercise and posture training using video clip viewing and text messaging reminders is feasible and acceptable in a small cohort of older adults with hyperkyphosis. Adherence to video viewing is excellent and adherence to practicing exercise at least three times a day warrants further study to optimize adherence and the optimal dose. Future trials should assess the benefits of more individualized feedback with posture training videos and customize daily text reminder prompts according to participant preference. Technology-based exercise and posture training in older adults with hyperkyphosis warrants further study as a potential self-management program for age-related hyperkyphosis that may be more easily disseminated than in-person training.

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Authors' Contributions

WK, YF, AG, and NL were responsible for designing this study and analyzing and interpreting the quantitative and qualitative data. SW was responsible for collecting the quantitative and qualitative data. FL was responsible for collecting the quantitative data. AG, SW, and CJ participated in analyzing the data. WK was a major contributor to writing the manuscript, and all authors edited, reviewed, and approved the final manuscript. FL programmed the cloud communications platform for our study.

Conflicts of Interest

None declared.

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Abbreviations

CESD: Center for Epidemiological Studies Depression
HRQoL: health-related quality of life
OTW: occiput to wall
PASE: Physical Activity Scale for the Elderly
SPPB: The Short Physical Performance Battery
SRS-30: Scoliosis Research Society
UCSF: University of California, San Francisco

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Original Paper

Relevance of Activity Tracking With Mobile Devices in the Relationship Between Physical Activity Levels and Satisfaction With Physical Fitness in Older Adults: Representative Survey

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Abstract

Background: Physical activity has been shown to positively affect many aspects of life, and the positive relationship between physical activity levels and health is well established. Recently, research on the interrelationship between physical activity levels and subjective experiences has gained attention. However, the underlying mechanisms that link physical activity levels with subjective experiences of physical fitness have not been sufficiently explained.

Objective: This study aimed to explore the role of physical activity tracking (PAT) in the relationship between physical activity levels and satisfaction with physical fitness in older adults. It is hypothesized that higher levels of physical activity are associated with a higher satisfaction with physical fitness in older adults and that this positive association is stronger for older people who use mobile devices for PAT.

Methods: As part of this study, 1013 participants aged 50 years or older and living in Switzerland were interviewed via computer-assisted telephone interviews. Bivariate and multivariate analyses were applied. The interaction effects between physical activity levels and PAT were evaluated using multiple linear regression analysis.

Results: Descriptive analyses showed that 719 participants used at least 1 mobile device and that 136 out of 719 mobile device users (18.9%) used mobile devices for PAT. In the multivariate regression analysis, frequent physical activity was found to have a positive effect on satisfaction with physical fitness (beta=.24, P<.001). A significant interaction effect between physical activity levels and PAT (beta=.30, P=.03) provides some first evidence that the positive effects of physical activity on satisfaction with physical fitness can be enhanced by PAT.

Conclusions: The results indicate the potential of PAT to enhance the physical fitness of older adults. However, the results also raise new issues in this context. Recommendations for further research and practice include the acquisition of longitudinal data, a more detailed observation of durations of use, and the development of devices for PAT considering health psychology and gerontology theories.

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KEYWORDS

physical fitness; wearable electronic devices; smartphone; mobile phone; aged; satisfaction; fitness trackers

Introduction

Background

Physical inactivity is a major health risk facing people worldwide, especially older adults [1]. Many people are not adequately physically active, and physical activity level decreases with age [2]. Various organizations, including the World Health Organization [3] and the US Department of Health and Human Services [4], have discussed the negative effects of insufficient physical activity at the public health policy level. Both these organizations have developed guidelines for the appropriate physical activity levels of each age group: for adults, at least 150 min a week of moderate-intensity or 75 min of vigorous-intensity physical activity is recommended [4]. The positive relationship between physical activity levels and health across all age groups is well established and widely documented [5,6]. An appropriate level of physical activity can also contribute to healthier aging processes [7] and prevent age-related cognitive decline [8]. Furthermore, it was demonstrated that physical activity not only positively affected health but also feelings of well-being such as happiness [9]. Self-reported fitness has also been shown to be a good predictor of mortality [10]. However, research also shows that general guidelines for physical activity do not appeal to everyone: women, for example, were more motivated by the 10,000 steps message than men [11], and general recommendations for physical activity levels that are not adapted to individual capabilities might even lead to feelings of overexertion in older adults [12].

Against this background, it is important not only to look at absolute levels of physical activity but also to consider their subjective evaluation. This includes the question of how satisfied an individual is with his or her physical activity levels and how this satisfaction is achieved. Recommendations for physical activity levels only provide a general framework. A good measure of individual satisfaction is not a global goal of, for example, 10,000 steps or 150 min, rather, it is the subjective estimation of the positive effects of physical activity on health and well-being.

Effects of Physical Activity on Subjective Experiences

Research on the interrelationship between physical activity levels and subjective experiences has gained attention in recent years. Empirical research has shown the positive effects of physical activity on health-related quality of life [13], subjective well-being, and life satisfaction [14-18]. Further research showed that walking and other types of physical activity significantly contributed to individual happiness in ordinary least squares (OLS) regression analyses [9]. However, the underlying mechanisms that link subjective satisfaction with physical fitness and actual physical activity levels have not yet been sufficiently explored in empirical research [19]. Ehlers et al [20] summarized current findings on the effects of physical activity on well-being in older adults, and the positive effects of physical activity on both negative and positive psychological states have been demonstrated. Nevertheless, the authors conclude that further research is needed to explain the specific effects of dose, mode, and underlying mechanisms on the positive effects of physical activity [20].

There has been some work on the age-specific effects of physical activity on subjective well-being. Pawlowski et al [17] showed that, although the effects are generally low, the positive effects of physical activity on subjective well-being increase with age. In another study, well-being was positively related to physical activity and physical function in older adults [15]. Qualitative research showed that older adults perceive physical activity as a behavior related to health and well-being [21]. Building on these findings, we focus in more detail on satisfaction with physical fitness levels as one example of subjective well-being and its relationship with physical activity levels.

Relevance of Mobile Physical Activity Tracking for the Effects of Physical Activity

Mobile tracking technologies such as activity trackers and other wristband sensors that track physical activity (eg, activity monitors, activity wristbands, and smartwatches), as well as apps on smartphones and tablets (eg, ActivityTracker, Runkeeper, and MyFitnessPal), are growing in popularity [22-24] and might be of relevance in this context. It has been shown that an individual’s level of physical activity can actually increase through the use of physical activity tracking (PAT) with mobile devices [25,26]. This has also been shown for the group of older people in a small experimental study [27]. The apps make use of gamification elements such as badges or rank lists that facilitate goal setting and increase self-efficacy [28-30]. Furthermore, the use of mobile devices for PAT can help users and health care professionals understand users’ health and symptoms, owing to the possibility of drawing correlations between user behavior and health outcomes [31]. As described by Morgan [32], “many of these technologies allow individuals to self-track, make records of and respond to a range of previously invisible biomedical and behavioral data.” In this sense, using mobile technologies for PAT increases access to relevant health-related data [32].

Despite a growing number of studies on PAT, the relevance of PAT in terms of the relationship between physical activity levels and subjective experiences of satisfaction with physical fitness has not been studied in detail yet. In addition, research on PAT has traditionally focused on young or middle-aged individuals [33-35] or individuals who are already physically active [36]. However, health-related issues and disease management gain importance as individuals age [37]. Qualitative research provided indications that PAT generally influences feelings of well-being, emotions, and awareness for physical activity [38]. Furthermore, a scoping review showed that older adults are generally interested in the use of technologies for health purposes and disease prevention [39]. In a randomized controlled trial, it was shown that an internet-based physical activity intervention that included accelerometry improved older adults’ quality of life [40], which is a further indicator of the relevance of PAT in this context.

Research Questions and Hypotheses

The objective of this study was to contribute to the literature on the positive effects of physical activity levels by examining the importance of PAT in this context. More precisely, we are interested in whether the relationship between physical activity levels and older adults' satisfaction with physical fitness is influenced by PAT with mobile devices (ie, activity trackers, smartwatches, smartphones, and tablets). Given the empirical evidence on the interrelation between physical activity levels and satisfaction with physical fitness in general [9,17,20], we generally assume a positive relationship between physical activity levels and satisfaction with physical fitness. Therefore, our first hypothesis (H1) is as follows:

> *Higher levels of physical activity are associated with a higher satisfaction with physical fitness.*

Mobile technologies for PAT allow for the quantification of the levels of physical activity, enable goal setting, and make achievements more visible [22,23]. Therefore, their use adds to the positive effect of physical activity levels on satisfaction with physical fitness. Our second hypothesis (H2) is as follows:

> *The positive association between physical activity levels and satisfaction with physical fitness is stronger for people who use mobile devices for PAT.*

Methods

Sample and Data

This secondary analysis is based on a survey performed in Switzerland [41]. In November 2016, 1013 adults, aged 50 years and older, were interviewed from the German- and French-speaking regions of Switzerland (representing approximately 92% of the entire Swiss population in that age group) using computer-assisted telephone interview. The response rate of the survey was 17.71% (1013/5719). Participation in the telephone interview was voluntary, and participants were asked for approval at the beginning of the interview. We consulted the Ethics Committee of the Faculty of Arts and Social Sciences of the University of Zurich to assess the ethics requirements for the study. The authors were required to complete a checklist to self-assess the ethical safety during the study [42]. On the basis of the outcomes of this self-assessment, no further application for approval to the ethics committee was necessary. In the first publication of study results, the authors [41] described the use of mobile devices among older adults in Switzerland and analyzed the ownership of smartphones, tablets, smartwatches, and physical activity trackers in more detail. The authors found that men, younger individuals, and people with a strong interest in new technology had a higher likelihood of using mobile devices. The secondary analysis in this paper focuses on the relationship of use with psychological variables.

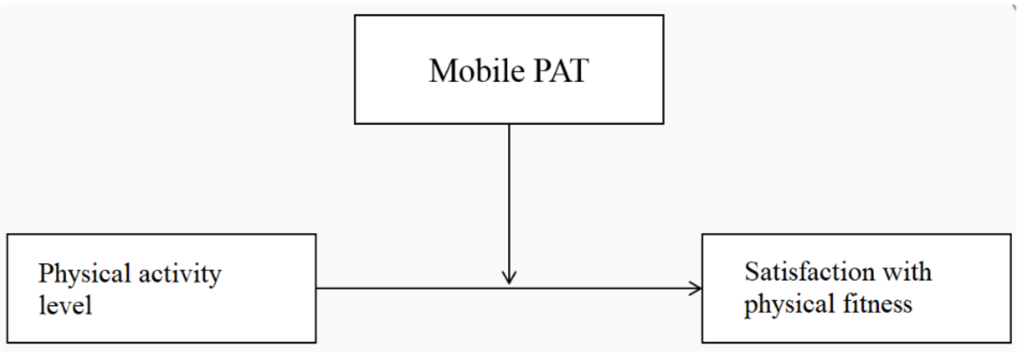
A standardized questionnaire with 24 questions about users' sociodemographic information and mobile device use for PAT was administered. A random sample of the permanent resident population of Switzerland aged 50 years and older was chosen from the commercial AZ-Direct database (based on the public phone book). No restrictions were imposed on upper age, current mobile device use, or type of housing. This study included a representative sample of all age groups examined across gender, education, and language region. Within the whole sample, 70.98% (719/1013) used at least 1 mobile device—such as a smartphone, tablet, and/or smartwatch—in their everyday life, whereas 29.02% (294/1013) reported that they did not use any of these devices. For the purpose of this paper, only the sample group of individuals who used any of the aforementioned mobile devices (n=719) was considered in the analyses. Participants' age in this group ranged from 50 to 88 years, with a mean age of 62.7 years (SD 9.45); 50.5% (363/719) were female; and 49.5% (356/719) were male.

Measures

Mobile PAT comprises activity trackers (ie, wristbands with accelerometer technology for monitoring and tracking fitness-related behavior, mostly based on counting steps and time periods of physical activity), smartwatches (ie, computerized wristbands with various functionalities and apps similar to those of smartphones, which run on their own operating systems), and smartphone or tablet apps; all of these can be used for tracking physical activity. We generally asked whether the respondents used apps or devices for the purpose of tracking physical activity; however, we do not have information regarding whether the respondents used the devices or apps actively or passively (eg, active measurement or automatic recording of steps). The use of these devices and apps was measured by self-report (1=never, 2=seldom, 3=once a week, and 4=daily). Individuals who used any of these devices or apps for PAT at least once a week are referred to hereafter as the *physical activity tracking group* (PAT group). Individuals who did not track their physical activity with any of these devices or apps or reported to use them less than once a week are referred to as the *no physical activity tracking group* (noPAT group). This formation of groups allows us to focus the analyses on regular users of PAT. All individuals belonging to the noPAT group do use at least 1 mobile device (ie, smartphone, tablet, and/or smartwatch) for purposes other than tracking their physical activity. This computed group variable was used as a dummy variable in the analyses (PAT group=1, noPAT group=0). Individuals who did not use any mobile device (n=294) were not considered in the analyses. This was done both to focus the analyses on the relationship of using PAT with satisfaction with physical activity and to include only those people with a comparable use behavior of technology into the analyses.

To test the research hypotheses, a set of variables that allowed the exploration of the use of mobile devices for PAT in more detail was taken into account. One central construct in the analyses was satisfaction with physical fitness. Satisfaction is an individual's mental state and a subjective measurement of his or her self-evaluated contentment. In the context of physical activity, this means that an individual is at ease with his or her physical activity levels (eg, he or she is satisfied with current fitness levels and the frequency and the intensity of exercise). Similar to previous research [16], an individual's satisfaction with his or her physical fitness was measured with the question *How satisfied are you currently with your physical fitness?* on 5-point Likert scales (0=not at all satisfied to 4=fully satisfied).

Figure 1. Research model of moderation analysis to show the effect of physical activity level on satisfaction with physical fitness moderated by physical activity tracking (PAT).



The level of physical activity was also measured using a self-reported question, as in previous studies [43]. Participants were asked, *How often do you exercise normally?* and evaluated on a 6-point scale (0=never to 5=daily). Age (*continuous*, in years), gender (*female* or *male*), and income (1≤CHF 4000, 2=between CHF 4000-9000, and 3≥CHF 9000 per month) were included as control variables because previous research has shown that a person's assessment of satisfaction is affected by these sociodemographic variables [44].

Statistical Analyses

SPSS version 24 (IBM Statistics) was used for statistical analyses. Missing data were excluded listwise. As a first step, we distinguished between the PAT and noPAT groups. To compare the characteristics of the 2 groups, we calculated *t* tests for independent samples, the chi-square statistics, and Cramér V. Furthermore, we evaluated Cohen *d* to estimate the practical relevance of the differences.

To test the research hypotheses, we performed multiple linear regression analyses (OLS). The dependent variable in these analyses was satisfaction with physical fitness (on a 5-point Likert scale). The independent variables included age (in years, mean centered), gender (reference female), income (reference more than CHF 9000), level of physical activity (on a 6-point scale), and PAT group (reference noPAT). In the first model (main-effect model), the main effects of the independent variables are reported. In a second model (interaction-effect model), we additionally included an interaction term between PAT and physical activity level. The interaction was calculated by multiplying the variables level of physical activity and PAT. Including the interaction term between physical activity level and PAT allowed us to model the effect of physical activity level on satisfaction with physical fitness depending on whether individuals tracked their physical activity with mobile devices or apps. This process is an example of moderation analysis (simple moderation analysis). As described by Hayes [45], a moderation analysis allows researchers "to determine whether a certain variable influences or is related to the size of one variable's effect on another." In this study, we expect the effect of physical activity level on satisfaction with physical fitness to depend on PAT, rendering PAT as the moderator variable. The conceptual model of moderation analysis according to Hayes [45] is illustrated in Figure 1.

Results

Characteristics of Physical Activity Tracking and No Physical Activity Tracking Groups

Altogether, 18.9% (136/719) participants used a device to track their physical activity and were therefore considered as members of the PAT group. Participants in the PAT group used an activity tracker (59.6%, 81/136), smartwatch (12.5%, 17/136), and/or smartphone or tablet app (57.4%, 78/136) to track their physical activity. Most members of the PAT group (74.3%, 101/136) used a single device to track their physical activity, whereas only a minority used 2 (22.0%, 30/136) or 3 (3.7%, 5/136) devices.

The remaining 81.1% (583/719) of participants used at least 1 mobile device but for purposes other than tracking their physical activity, and they were considered as members of the noPAT group.

On comparing participants in the PAT and noPAT groups (see Table 1), it was observed that there was no significant difference in age (t_{717}=0.96, *P*=.34, Cohen *d*=0.010). The mean age of the members of the PAT group was 61.95 (SD 9.43) years. Participants in this group ranged in age from 50 to 86 years. The members of the noPAT group had a mean age of 62.81 (SD 9.43) years and ranged in age from 50 to 88 years. Group membership differed significantly according to gender (χ^2_1=5.8, *P*=.02); 58.8% (80/136) of the individuals in the PAT group were male, whereas males comprised 47.3% (276/583) of the noPAT group. There was no significant relationship between group membership and income (*V*=.05, *P*=.47). In both groups, the majority of individuals had an income between CHF 4000 and 9000. Specifically, 50.4% (60/119) of the individuals in the PAT group fell into this income category, and 56.5% (277/490) of the individuals in the noPAT group fell into this same category as well. No significant difference was observed in members' satisfaction with physical fitness for the 2 groups (t_{716}=1.00; *P*=.32; Cohen *d*=0.187); this was also true for the frequency of physical activity (t_{245}=1.27; *P*=.21; Cohen *d*=0.112). Within the PAT group, there was no significant correlation between the number of devices that were used for mobile PAT and satisfaction with physical fitness (*r*=.07; *P*=.45).

Table 1. Characteristics of the physical activity tracking and no physical activity tracking groups (only respondents who own a mobile device, n=719).

Characteristics	User group		Significance	*P* value	Cohen *d*
	PAT[a]	noPAT			
Age (years), mean (SD)	61.95 (9.43)	62.81 (9.43)	t_{717}=0.96	0.34	0.01
Gender, n (%)					
Men	80 (58.8)	276 (47.3)	χ^2_1=5.8	0.02	—[b]
Women	56 (41.2)	307 (52.7)	χ^2_1=5.8	0.02	—
Income, n (%)					
<CHF 4000	17 (14.3)	65 (13.3)	*V*=.05	0.47	—
Between CHF 4000-9000	60 (50.4)	277 (56.5)	*V*=.05	0.47	—
>CHF 9000	42 (35.3)	148 (30.2)	*V*=.05	0.47	—
Satisfaction with physical fitness[c], mean (SD)	2.81 (1.00)	2.90 (0.92)	t_{716}=1.00	0.32	0.187
Mean frequency of physical activity[d], mean (SD)	3.72 (1.13)	3.58 (1.42)	t_{245}=1.27	0.21	0.112

[a] PAT: physical activity tracking.

[b] Not applicable.

[c] Measured on a 5-point Likert scale.

[d] Measured on a 6-point scale.

Predictors of Satisfaction With Physical Fitness

To analyze the effects of physical activity levels and PAT on satisfaction with physical fitness, a multiple linear regression (based on a simple moderation analysis) was performed. The level of physical activity, PAT, and interaction term between both variables were included as independent variables in the full model (model 2). The findings were compared with a model including only the main effects (model 1). In addition, we considered age, gender, and income as control variables in both regression models. All persons who used a mobile device in general were included in the analysis.

The main-effect model (model 1) has an adjusted R^2 of .08 and explains a significant amount of variance in terms of satisfaction with physical fitness ($F_{6,601}$=10.39, *P*<.001). Frequent physical activity was a significant predictor (*P*<.001), whereas inclusion in the PAT group showed no significance (*P*=.46). Likewise, age, gender, and income were not significant predictors (see Table 2).

Overall, the interaction-effect model (model 2) demonstrates a significant amount of variance within people's satisfaction with physical fitness ($F_{7,600}$=9.65, *P*<.001), with an adjusted R^2 of .09. The model revealed that frequent physical activity (*P*<.001) and inclusion in the PAT group (*P*=.02) were significant predictors of satisfaction with physical fitness. The interaction term given by *PAT * physical activity* also showed significance (*P*=.03). Again, age, gender, and income were no significant predictors for individual satisfaction with physical fitness (see Table 2).

In both models, higher levels of physical activity had a positive effect on satisfaction with physical fitness (main-effect model: beta=.27, *P*<.001; interaction-effect model: beta=.24, *P*<.001). People who were more physically active were more satisfied with their physical fitness status. Only within the interaction-effect model was there a significant effect of PAT group (beta=−.31, *P*=.02), indicating a significant difference in satisfaction with physical fitness between members of the PAT group and the noPAT group, when individuals are *never* physically active. Furthermore, within this model, the interaction term *PAT * physical activity* modeled the conditional effect of physical activity level on satisfaction with physical fitness depending on group membership (PAT or noPAT). The positive interaction effect (beta=.30, *P*=.03) indicated that the effect of physical activity on satisfaction was stronger for people in the PAT group, meaning that, when using mobile devices for PAT, the positive effect of physical activity level on satisfaction with physical fitness was stronger (see Figure 2). As shown in Figure 2, no differences in the level of satisfaction with physical fitness were observed between members of the PAT and the noPAT group when individuals were physically active on a daily basis.

Table 2. Multiple linear regression analysis of the predictors of satisfaction (measured using a 5-point Likert scale) with physical fitness (simple moderation analysis on only respondents who own a mobile device, n=719).

Predictor	Model 1: main-effect model[a]			Model 2: interaction-effect model[b]		
	b (SE)	Beta	*P* value	b (SE)	Beta	*P* value
Constant	2.18 (0.14)	—[c]	<.001	2.26 (0.14)	—	<.001
Age[d]	0.01 (0)	.06	.12	0.01 (0)	.06	.12
Gender: male (reference female)	0.01 (0.07)	.01	.84	0.01 (0.07)	.01	.89
Income: <CHF 4000 (reference >CHF 9000)	−0.22 (0.12)	−.08	.07	−0.22 (0.12)	−.08	.07
Income: between CHF 4000-9000 (reference >CHF 9000)	0.08 (0.08)	.04	.33	0.08 (0.08)	.04	.34
Physical activity[e]	0.19 (0.03)	.27	<.001	0.17 (0.03)	.24	<.001
PAT[f] group (reference noPAT)	−0.07 (0.09)	−.03	.46	−0.73 (0.31)	−.31	.02
Interaction: PAT * physical activity	—	—	—	0.18 (0.08)	.30	.03

[a] Adjusted R^2=.08, $F_{6,601}$=10.39, *P*<.001.

[b] Adjusted R^2=.09, $F_{7,600}$=9.65, *P*<.001.

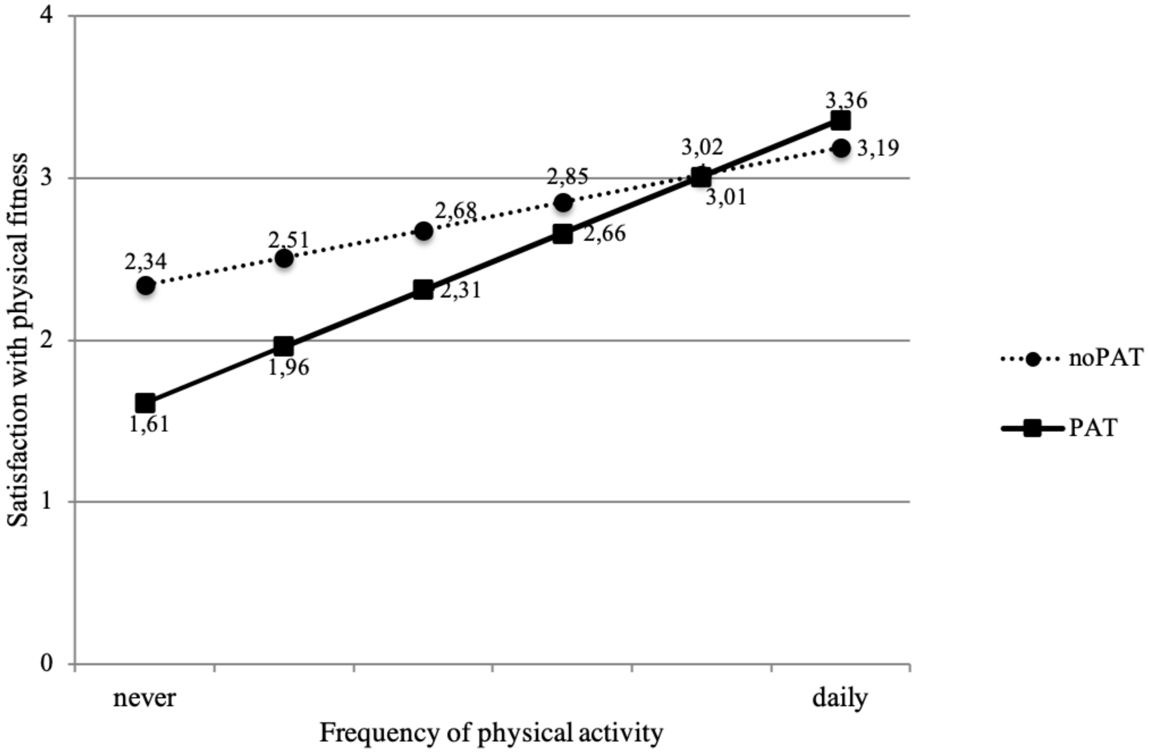
[c] Not applicable.

[d] Mean centered.

[e] Measured on a 6-point scale (*never* to *daily*).

[f] PAT: physical activity tracking.

Figure 2. Interaction diagram of the effects of physical activity level and physical activity tracking (PAT) on satisfaction with physical fitness. Graphic representation of unstandardized regression estimates for different groups depending on physical activity level and PAT. Values displayed for a female with mean age and medium income (between CHF 4000-9000). Frequency of physical activity was measured using a 6-point scale from never to daily and satisfaction with physical fitness was measured using a 5-point Likert scale.



Discussion

Principal Findings

This study was the first conducted in Switzerland—and to our best knowledge, among the first internationally—to examine the relevance of PAT in the relationship between physical activity level and satisfaction with physical fitness in a representative sample of individuals aged 50 years and older. Our analyses were based on 719 older individuals who use mobile devices in their everyday life.

Bivariate results showed that people who tracked their physical activity using a mobile device were more likely to be male. In the multivariate analysis, we addressed the relationship between physical activity level and satisfaction with physical fitness and mobile PAT in more detail. Examining the relevance of PAT for the positive effects of physical activity on satisfaction with physical fitness is an important research topic, as this might contribute to the well-being of older persons.

The multiple regression models revealed that physical activity level was a positive and significant predictor of satisfaction with physical fitness in both the main-effect model and the interaction-effect model. Individuals who were physically active more often were more satisfied with their physical fitness. These findings are in line with our research hypothesis (H1). Furthermore, we tested whether this relationship was influenced by the use of mobile devices for PAT. We found a significant positive interaction effect between physical activity level and PAT on satisfaction with physical activity; the positive effect of physical activity levels on satisfaction was stronger for people using PAT (H2). Results also showed that PAT had no positive effects on satisfaction with physical fitness in the main-effect model and for individuals who were not physically active on a regular basis (see Figure 2). These findings need to be discussed on several levels.

Comparison With Previous Work

In general, people who track their physical activity with a mobile device are more aware of how active they actually are, as compared with individuals who do not track their physical activity [32]. Research showed that they can better understand correlations between their behavior and possible health outcomes [46]. Therefore, when they indulge in frequent physical activity, it has a more positive effect on their level of satisfaction. This relationship was also identified in this study: PAT could add to the positive effects of physical activity on satisfaction with physical fitness. In contrast, it is reasonable to assume that individuals who are less physically active and use mobile devices for PAT do not overestimate their activity level, as often happens in subjective measurements of physical activity [47], especially for older persons [48]. As they are likely more aware of not meeting physical activity guidelines—such as the World Health Organization’s goal of reaching 10,000 steps per day [3]—they are consequently less satisfied with their physical fitness. Moreover, our results support this assumption as shown by the negative effect of PAT on satisfaction with physical fitness for individuals who were not physically active.

This negative effect of PAT on satisfaction with physical fitness is an important finding in the evaluation of possible impacts of PAT on well-being and motivation for physical activity. The positive effects of PAT cannot be assumed for everyone. Our results show that in the case of less frequent (not daily) physical activity, PAT might have negative consequences for the users. On the other hand, the use of PAT supports satisfaction with physical fitness for older adults who are physically active on a daily basis. This is an interesting result because this relationship among physical activity, PAT, and satisfaction might also influence the long-term use of PAT and the motivation for physical activity. Further research is needed to investigate these findings in more detail.

To analyze these mechanisms in greater detail, future studies should try to objectively measure the frequency and level of physical activity with tracking technology and electronic momentary assessments to get a more reliable measurement. A further point of interest might be whether the results would differ if activity had been measured using time instead of frequency. Some older people may be active frequently but have a short overall duration, and others may be active infrequently with a long weekly duration.

Furthermore, it can be assumed that activity trackers, or other devices and apps for PAT, are often purchased because individuals are unsatisfied with their current situation, such as their fitness level. In this case, there might be a reverse causality: negative satisfaction has an effect on using PAT and not vice versa. A recent study [43] provides some arguments for this assumption and shows that the health apps people have installed on their smartphone do not represent their actual behaviors but rather the behaviors they would like to change. In this way, PAT might be used for self-optimization. This will not happen in the short term, and positive effects might only be observable after longer periods of use. This study does not consider the duration of use. However, previous studies have shown that activity trackers are often not used for longer than half a year [49]. Individuals probably stop using devices for tracking physical activity before positive effects can be observed. To understand this issue, it is also important to know why individuals originally get the devices. Different motivations and intended uses can be assumed depending on whether the device is bought as a lifestyle device or prescribed by a physician and integrated into programs offered by health insurance providers.

On the basis of the empirical data in this study, it is not possible to reach a concrete conclusion, and the above assumptions need to be examined in greater detail. Future work could extend this research by using longitudinal data. This would allow for the examination of intraindividual change processes and objective tracking data, as it would be possible to study the relevant motivational mechanisms and relationships over time.

Practical Implications

With regard to the devices used for PAT, it should be noted that most current devices and apps have been developed without considering health psychology or gerontology theories. It is therefore unlikely that the devices used for PAT have been customized for long-term use or sustainable success among older users. A qualitative study with activity trackers showed that older adults might feel overstrained by predetermined goals that are not individualized [12]. The general guidelines for physical activity might exceed older adults' abilities, resulting in certain injuries or health problems. Therefore, defining appropriate goals is difficult for the group of older people. One recommendation could be to use official institutional guideline values as a starting reference point (eg, [3,4]) and then adapt these to the individual. Such an adaptation should be based on subjectively and objectively measured user performance, with the goal of avoiding feelings of being overstrained. A review of free coaching apps even showed that almost none of these apps were evidence-based or suitable for beginners [50]. Structured physical activity interventions with systematic training progression are important for older adults who want to lead healthier lives [51]. Therefore, scientists should assume responsibility for integrating evidence-based theories into the development of new technologies and mobile apps. One possibility might be to add dynamic concepts that allow for customization for different users as well as for individual development over time. In addition, physical activity–tracking products (ie, activity trackers as well as smartwatches, smartphones, and tablets) must target the specific needs, especially in terms of usability and usefulness of older users [52,53].

Limitations

As this study had a specific regional focus, the generalization of our findings is limited. The data provide only a cross-sectional view of the phenomena, but it is likely that there will be a further increase in mobile activity and health tracking among older individuals in general. Further research, possibly including longitudinal data, is required to examine the potential increase and to make inferences related to mobile activity tracking and subjective well-being and health over time and across individuals. Furthermore, it is possible that participants understand questions on subjective measurements (eg, the frequency of physical activity and their satisfaction with physical fitness) differently, which can affect the results. Furthermore, we did not have any information on the intensity of using PAT. We could only distinguish the PAT and noPAT groups. However, a more active use of PAT in everyday life might have greater effects. A qualitative study showed that older people often passively use devices for PAT in their everyday lives [21]. The effects of more irregular use of PAT (eg, tracking less frequent hiking tours) also could not be analyzed within this study, as the regular use of PAT was the focus of analysis. In future research, these aspects need to be clarified; they could also be the focus of future quantitative studies.

We only studied satisfaction with physical fitness. This key outcome of the study was only measured using a single item, which might be subject to bias. It should be noted that an overall evaluation of physical activity and its effects on subjective experiences should ideally be realized in a more differentiated matter. A 1-item measure is problematic, as the different dimensions of the phenomenon cannot be distinguished. However, the available variables used in our secondary data enabled us to analyze the relevance of mobile PAT in terms of the relationship between physical activity and subjective fitness in an exploratory way. Future studies should therefore operationalize this concept through a multidimensional approach and extend this view by both including other measures of satisfaction and quality of life and by using validated questionnaires to confirm the findings.

In addition, in this first study, data on important background factors (eg, technology knowledge, attitudes toward technology, and objective health status), fitness status (eg, objective measures of exercise, fitness status, and activity levels), everyday life factors (eg, coping with activities of daily life and social contact), and psychological factors (eg, attitudes toward health prevention and one's own life and aging, personality, and well-being) were unavailable. Further studies with a wider range of variables and a longitudinal design are therefore required to examine the study topic in greater detail.

Conclusions

This study provides some evidence that PAT can enhance the positive effect of physical activity levels on satisfaction with physical fitness. The results indicate the potential of mobile PAT to improve the well-being of older adults. Especially for older individuals, mobile devices can allow for the easy longitudinal monitoring and documentation of their health status. However, the results also raise new issues concerning the relationship between PAT and satisfaction with physical fitness. PAT showed a negative effect on satisfaction with physical fitness for individuals who were not physically active on a regular basis. We discussed this finding in the context of self-optimization through PAT, long-term use of the devices, and older adults' specific requirements in terms of usability and usefulness. Further research is required in this fast-moving field to understand relevant processes and causalities in greater detail.

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Conflicts of Interest

None declared.

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Abbreviations

noPAT group: no physical activity tracking group
OLS: ordinary least squares
PAT: physical activity tracking
PAT group: physical activity tracking group

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Viewpoint

Mobilizing mHealth Data Collection in Older Adults: Challenges and Opportunities

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Abstract

Worldwide, there is an unprecedented and ongoing expansion of both the proportion of older adults in society and innovations in digital technology. This rapidly increasing number of older adults is placing unprecedented demands on health care systems, warranting the development of new solutions. Although advancements in smart devices and wearables present novel methods for monitoring and improving the health of aging populations, older adults are currently the least likely age group to engage with such technologies. In this commentary, we critically examine the potential for technology-driven data collection and analysis mechanisms to improve our capacity to research, understand, and address the implications of an aging population. Alongside unprecedented opportunities to harness these technologies, there are equally unprecedented challenges. Notably, older adults may experience the first-level digital divide, that is, lack of access to technologies, and/or the second-level digital divide, that is, lack of use/skill, alongside issues with data input and analysis. To harness the benefits of these innovative approaches, we must first engage older adults in a meaningful manner and adjust the framework of smart devices to accommodate the unique physiological and psychological characteristics of the aging populace. Through an informed approach to the development of technologies with older adults, the field can leverage innovation to increase the quality and quantity of life for the expanding population of older adults.

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KEYWORDS

mHealth; older adults; data collection; digital divide

Introduction

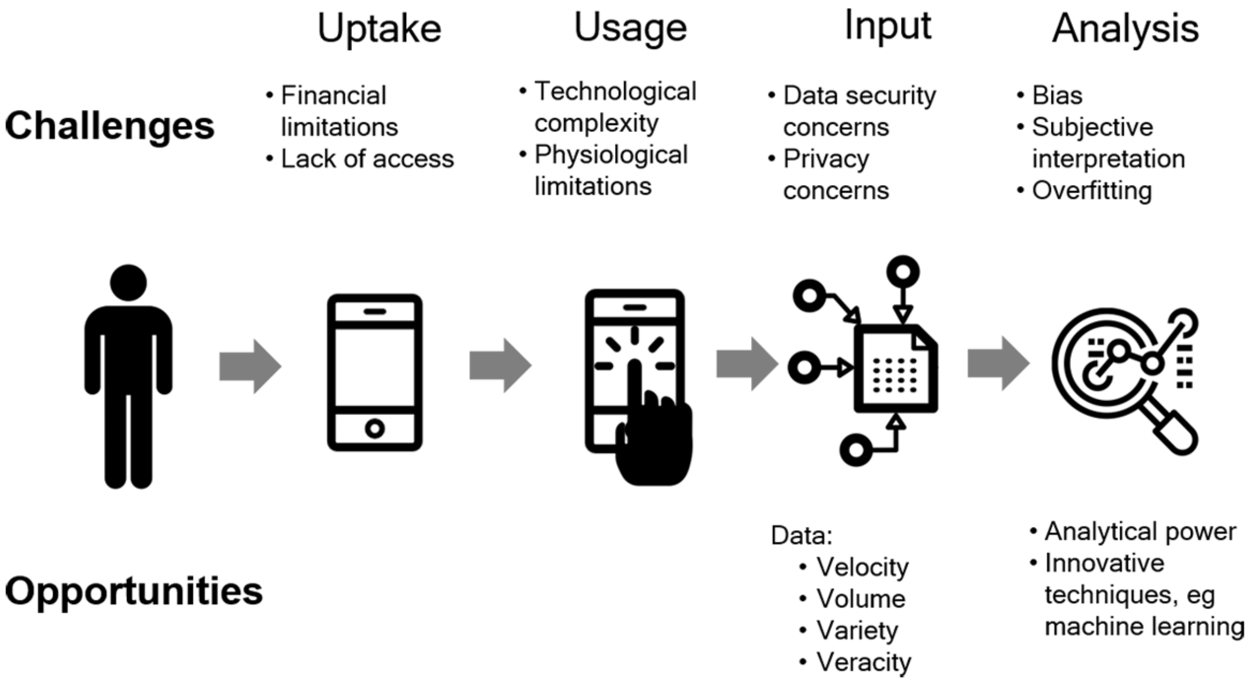
Exponential growth in technological innovations, alongside improvements in the accessibility and usability of these devices, has made technology a ubiquitous feature in daily life. Consequently, older adults now have increasing access to information and communication technology (ICT) devices, such as smartphones and wearables [1]. Globally, there is increasing interest in ICT for older adults, highlighted by numerous research and development initiatives, with 2 notable ones including (1) Aging Gracefully across Environments using technology to Support Wellness, Engagement, and Long Life, a Canadian Network of Centres of Excellence [2], and (2) the Active Assisted Living Joint Program [3], a European initiative that has invested over 700 million Euros in improving ICT access to groups such as older adults. As the proportion of older adults increases at an unprecedented rate, greater demands are being placed on already heavily burdened health care systems [4]. Therefore, it is imperative to address the needs of this expanding population and ensure that care provision meets the evolving needs of older adults.

However, new projects and national investments belie the fact that the role of technology in geriatric health is not new. Beginning in the late 1990s, the field of *gerontechnology* began as a convening point for gerontologists, geriatricians, and ICT experts to discuss the potential for integrating technologies that supported older adults [5]. During the formation of the field of gerontechnology, older adults were generally not the targets of technological innovation; however, the intersection of demography and technology seemed inevitable given the growth in both areas [5]. Since these early years, there has been considerable expansion in the depth and breadth of research and development in the areas of older adults and technology, from early investigations into aging in place (c. 1990 onward), to experimental houses (c. 2000 onward), to biorobotics (c. 2005 onward), and beyond [5]. This innovation and collaboration continues today as the field of gerontechnology expands to accommodate a burgeoning population of older adults and an influx of new technologies.

A more recent trend in gerontechnology is to collect multiple streams of data from users to capture self-reported survey data alongside capturing functional outcomes, such as physical activity. Complementing innovations in the capacity to collect data are mobile health (mHealth) technologies that have lowered the barrier to entry for more complex means of analysis. Although there is no consensus definition of mHealth, the World Health Organization has defined mHealth as mobile devices used in the health service and/or provisions such as smartphones, smartwatches, and other wearable technologies [6]. Data can now be analyzed in real time at a level of sophistication that has not been previously possible and using platforms that are increasingly user-friendly and often open-sourced. Even in 2012, gerontechnology was leading health care with the use of personal sensors in smartphones for fall detection and prevention, and now in 2019, gerontechnology is leading health care by using a myriad of sensors to help understand how everyday social and physical environments can be used to promote well-being [7,8].

Although rates of technology use among older adults are rising, these levels fall short of younger demographic groups [9]. Contributing to this discrepancy are access issues, that is, uptake, representing a first-level digital divide, as well as lack of skills, that is, usage, representing a second-level digital divide [10]. For example, in a study of cognitively intact older adults using a tablet device to report symptoms in an emergency department, only 56% correctly reported their age to the tablet [11]. However, digital technology use and literacy is not strictly age dependent, and innovative efforts to teach older adults, even those with memory impairments, to use smartphones will only increase rates of engagement [12]. Once these digital divides have been overcome, issues concerning the input and analysis of these data must be addressed. In this commentary, we highlight some of the challenges involved in uptake, usage, input, and analysis of mHealth and mHealth data alongside the opportunities provided by these innovations and suggestions as to where the field may be headed next (Figure 1).

Figure 1. Challenges and opportunities in mhealth–driven data collection.



Uptake (First-Level Digital Divide)

Older adults may encounter challenges that are not common to younger age groups, such as financial and physiological limitations, inhibiting access to innovations in technology [13]. For older adults living on a fixed pension or who are otherwise financially restricted, the prospect of investing in a device that they are unfamiliar with, do not necessarily see the value of, and that may seem dauntingly complex is not an appealing one. Similarly, physiological limitations faced by older adults, such as a decline in visual acuity and manual dexterity, may preclude the use of certain devices such as tablets or smartphones. Individuals with greater physical limitations, for example, frailty, have been observed to have lower technology uptake than prefrail or nonfrail peers [14]. Consequently, there is a movement toward simplified devices that accommodate these limitations of older adults as well as the desire for simplified interfaces and functionality. For example, apps designed to decrease the number of functions and increase the simplicity of use have been developed for the newest iPhones. This does not, however, necessarily indicate that older adults will be more motivated to purchase and use these devices [15]. Moving forward, highlighting the value of technological innovations and the potential benefits of their uptake may persuade even greater engagement with ICT among older adults.

Usage (Second-Level Digital Divide)

The level of skill required to actively engage with newer technologies also contributes to the reduction in the use of smart devices when compared with younger cohorts [1]. For older adults, integrating these devices into lifestyles may be difficult or simply unwanted, particularly for those who have functional deficits or who are not as technologically savvy. For example, a primary application of many sensor-based technologies among older adults is to quantify behavior among persons with dementia. These persons are unlikely to reliably interact with or carry smart devices, and the often-overlooked burden of regular charging may pose an additional use challenge. As such, there are unique physiological and psychological barriers inhibiting both individuals’ access to and use of these technologies.

Input

For older adults who may be unfamiliar with the ways in which their data are collected, stored, and used, apprehension about the collection of these data may be a significant barrier. Studies examining older adults’ perspectives on the use of technology as data collection mechanisms indicate that they are much more amenable to releasing their data if they believe that these data are going to be used to improve their health and well-being [16].

Although, in principle, the collection of data via paper and pen is the same as using a passive data collection device, for example, a pedometer, in practice, older adults may perceive this differently. For example, in a study of unobtrusive home monitoring technology, such as motion sensors, 60% of the participants reported concerns related to privacy or security after 1 year [17]. Addressing the complex issues surrounding the ethical implications of mHealth data collection, with respect to data privacy, security, and ownership, will be imperative to the successful integration of these technologies into older adult populations [18]. To ensure data anonymity, deidentification of users’ information will be required. Furthermore, third-party access to these data will need to be tightly regulated in conjunction with the deidentification processes [18]. Consequently, it will be imperative for researchers to provide—in addition to traditional informed consent—a comprehensive explanation of how the devices used in the study function, what types of data they do (and do not) collect, and how these data will be used.

Technology does not remain static, and the recent popularity of conversational agents, often referred to as chatbots, offers the potential of a new generation of devices where the input is through voice instead of touch. The implications of this new user interface for digital health devices could remove one of the chief barriers for geriatric patients today and usher an era of easier digital engagement for older adults.

Of course, technology alone will never be useful unless it is paired with the right clinical use cases. This raises the important issue of considering what the newest wave and future iterations of smart technologies can offer clinical research and care. Below, we explore details of mHealth data collection for the field and how to help reduce the two digital divides outlined above.

The primary advantages of mHealth data collection mechanisms stem from the four big data V's: velocity, volume, variety, and veracity [19]. The velocity of data refers to the capability of devices to collect and analyze data on a continuous basis. Smart devices can collect active and/or passive information throughout the day for as many days as required, providing a near-constant stream of information [20]. As a result of the velocity of these data collection mechanisms, the volume of data that is collected is immense. Alongside the expansion of the volume of data, the variety of variables captured has, similarly, expanded. Modern smart devices and wearables have a range of hardware suited for objective data collection, for example, global positioning system (GPS) and accelerometer, that enable a breadth of data collection that expands beyond the scope of what can be accomplished in a face-to-face interview.

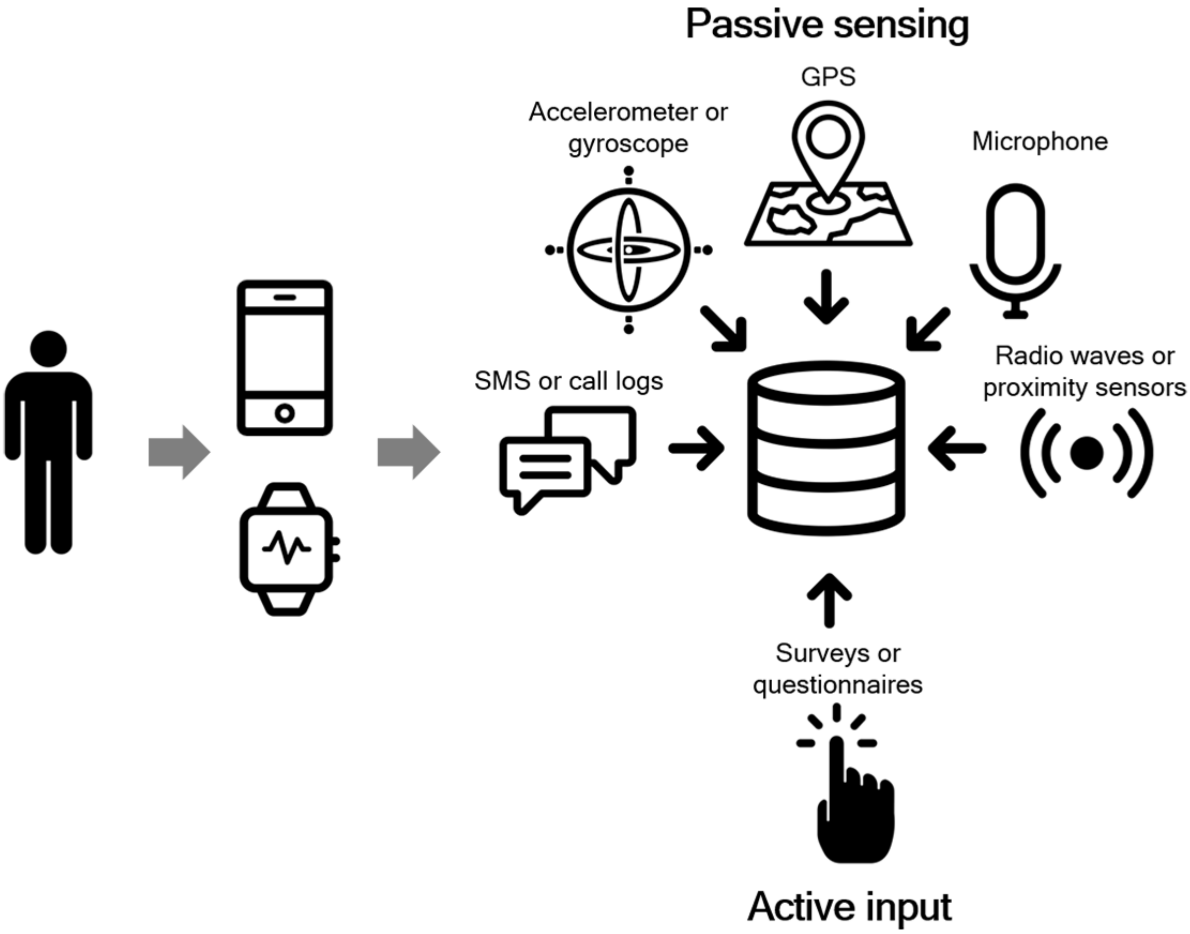
For researchers, the most important component of data collection is the final big data *V*—Veracity. The veracity of a data source refers to the quality (or validity) of the data in capturing the phenomena intended to be captured. Within the context of mental health data collection, the veracity of data collection via traditional methods may be compromised by external factors that may bias these results, for example, social desirability or recall bias. Study participants may demonstrate conscious (or unconscious) bias in what they are willing to reveal based on the characteristics of the survey administrator [21]. Recall bias in trying to recount symptoms and past experiences, especially for those who may have even mild memory impairments, creates yet another methodological concern [22]. In addition, survey administrators may record what they expect to hear rather than what is actually reported by the participant [23]. As a result, these data may not accurately reflect what an individual is actually feeling. Similarly, the subjective retrospective recall may not be completely accurate; for example, physical activity is generally over-reported [24].

An active method of data collection that demonstrates many of the advantages afforded by mHealth data collection mechanisms is ecological momentary assessment (EMA). EMA involves the collection of data, for example, thoughts, behaviors, and experiences, in the participant's natural setting and in real time [25]. Study designs can utilize event- or time-based designs, that is, having a data collection triggered by an event, for example, panic attack; or at a set time interval, every morning; or using a combination of these designs, for example, every morning and in the event of a panic attack. Some of the issues faced by traditional data collection methods alongside more novel techniques, such as EMA, include reactivity, that is, influence on behavior caused by assessing that behavior, and compliance, that is, the degree to which a participant complies with the data collection schedule. Studies employing EMA capturing a variety of outcomes, for example, chronic pain [26], problem drinking [27], and coping [28], have demonstrated low levels of reactivity [25]. Issues of compliance, however, are a limitation of EMA. As with traditional methods, such as paper-and-pen diaries, if participants do not complete the data collection activity, particularly in a nonrandom manner, this can heavily skew the results. Another consideration is whether reports are being completed on time or being pushed aside until they are due, at which point they are completed in bulk, effectively invalidating the data. Although EMA may not be able to foster greater compliance, it is possible to avoid the invalidation of data due to participants who *hoard and backfill* surveys and it is possible to time-stamp data collection to flag a potential instance in which this has occurred [25]. Although EMA is not a perfect method, it highlights some of the advantages afforded by mHealth data collection.

Passive sensing permits data collection without a study participant having to exert extra effort to input data. A major advantage of this type of data collection method is that there is little to no effort required, increasing compliance. Primary tools for passive data collection methods include smartphones and wearables. A recent systematic review of the use of smartphones employing passive data collection in health research contexts found 35 studies published using these data [29] on topics ranging from bipolar disorder [30] to sleep [31] to addiction [32]. The review reports multiple benefits of passive data collection demonstrated in these studies, notably regarding the precision of measures, such as predicting bipolar state change with 94% accuracy [33], ease of use [34], and the objectivity of the measurements [35]. The potential of passive data collection for older adults is clear, particularly given the absence of needing to directly interact with smart technology.

However, passive data can only be a proxy of behavior when the device is nearby the older adult, which as outlined above is not always true. Thus, recent work into passive sensing has moved beyond smartphones and smartwatches and explored an approach relying on radio waves. This approach may represent *true* passive sensing, in that it requires almost no engagement with the device on the part of the research subject, whereas smartphones or wearables must be carried by the user to collect data. Such an approach effectively facilitates *watching* but without requiring cameras. Thus, it may be less intrusive, and by mapping motion, it may shed light on several behavior patterns. Preliminary research has demonstrated how this technology may be used to map behavioral symptoms in dementia [36]. A growing body of literature describes how the ability to map motion using an array of sensor approaches including GPS and accelerometry in mobile and wearable devices as well as more passive sensors can impact the care of older adults with a range of psychiatric diagnoses [36,37]. Thus, new and evolving technological innovations will continue to reduce digital divides and may offer a new approach to the field, as outlined below in Figure 2.

Figure 2. mhealth data collection inputs. GPS: global positioning system; SMS: short message service.



Analysis

The ways in which data are being processed include increasingly sophisticated techniques. Advanced computational strategies, such as machine learning, go beyond the a priori testing of hypotheses generally performed by humans to have a computer *learn* from the data in an exploratory manner to identify relationships [38]. Although these approaches are largely data-driven, many of these analytic technologies involve the use of algorithms that may introduce bias. For example, feature selection can involve interpretation and input from analysts, which have the potential to be biased and/or misdirected [39]. This can also introduce issues where a computer *learns* on a training dataset but cannot generalize these findings to other studies, that is, overfitting [20]. Despite these limitations, when appropriately used as a supplement (rather than as a crutch) in clinical and research settings, the potential for exploiting these techniques for the betterment of older adults’ lives is immense. As new methods are developed to handle the increasingly complex data new sensors can generate, it will be imperative for the geriatrics field to work closely with data scientists.

Conclusions and Next Steps

With population aging placing unprecedented demands on various aspects of health care, it is becoming increasingly important to capitalize on new technologies to meet these demands, and thus, there is an urgent need to address these physiological and psychological barriers currently faced by older individuals with respect to the uptake of smart devices. Given the considerable opportunities and challenges of this integration and rather than waiting until the demographic shift is fully upon us, getting ahead of the curve will enable a smoother transition and increased potential for harnessing the advantages of these data collection mechanisms. If the proliferation and innovation in smart devices, wearables, and sensing devices is any indication of the increasingly sophisticated ways in which we will be able to collect data, the need to mobilize mHealth data collection strategies toward integration of older adults has never been greater. Traditional data collection methods remain invaluable resources in the study of aging, establishing the vast majority of existing literature. We do not suggest that these methods be replaced by mHealth technologies but rather to be used to expand the breadth of questions that can be asked and the depth of evidence that can be extracted from these questions. By supplementing traditional approaches to research with nontraditional methods, it is hoped that we can make greater strides toward the improvement of older adults’ lives.

In the context of increasing technological complexity, we will need to address both first- and second-level digital divides. Failure to simultaneously mitigate challenges in both digital divides could inhibit or prevent the capacity to harness emerging technologies. The progression of the field of gerontechnology in the last several decades suggests that there will be continued integration of technology into older adults' lives. This integration will, however, need to be conducted in a manner that addresses the limitations of emerging technologies and the acceptability and utility of these innovations in the lives of older adults. In particular, new devices must be developed with input directly from older adults, using user-driven principles, for example, human-centered design [40], and methods, for example, codesign and cocreation [41]. These approaches allow stakeholder perspectives to inform the relationship between a device and the user. Through an informed approach to the development of technologies with older adults in mind, the hope is that we can leverage these innovations to increase the quality and quantity of life experienced by the growing population of older adults.

Conflicts of Interest

None declared.

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Abbreviations

EMA: ecological momentary assessment
GPS: global positioning system
ICT: information and communication technology
mHealth: mobile health

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Protocol

Understanding Social Network and Support for Older Immigrants in Ontario, Canada: Protocol for a Mixed-Methods Study

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Abstract

Background: Older adults are the fastest growing age group worldwide and in Canada. Immigrants represent a significant proportion of older Canadians. Social isolation is common among older adults and has many negative consequences, including limited community and civic participation, increased income insecurity, and increased risk of elder abuse. Additional factors such as the social, cultural, and economic changes that accompany migration, language differences, racism, and ageism heighten older immigrants' vulnerability to social isolation.

Objective: This mixed-methods sequential (qualitative-quantitative) study seeks to clarify older immigrants' social needs, networks, and support and how these shape their capacity, resilience, and independence in aging well in Ontario.

Methods: Theoretically, our research is informed by an intersectionality perspective and an ecological model, allowing us to critically examine the complexity surrounding multiple dimensions of social identity (eg, gender and immigration) and how these interrelate at the micro (individual and family), meso (community), and macro (societal) levels in diverse geographical settings. Methodologically, the project is guided by a collaborative, community-based, mixed-methods approach to engaging a range of stakeholders in Toronto, Ottawa, Waterloo, and London in generating knowledge. The 4 settings were strategically chosen for their diversity in the level of urbanization, size of community, and the number of immigrants and immigrant-serving organizations. Interviews will be conducted in Arabic, Mandarin, and Spanish with older women, older men, family members, community leaders, and service providers. The study protocol has received ethics approval from the 4 participating universities.

Results: Quantitative and qualitative data collection is ongoing. The project is funded by the Social Sciences and Humanities Council of Canada.

Conclusions: Comparative analyses of qualitative and quantitative data within and across sites will provide insights about common and unique factors that contribute to the well-being of older immigrants in different regions of Ontario. Given the comprehensive approach to incorporating local knowledge and expert contributions from multilevel stakeholders, the empirical and theoretical findings will be highly relevant to our community partners, help facilitate practice change, and improve the well-being of older men and women in immigrant communities.

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KEYWORDS

geographic information system; immigrants; social network; social support

Introduction

Background

Older adults (aged 65 years or older) are the fastest growing age group worldwide, and in Canada, they are projected to comprise 25% of the population by 2050 [1]; thus, maintaining their well-being is a priority in Ontario, Canada [2]. Older immigrants form a large proportion of the older adult population in Canada, with the highest percentage of older immigrants residing in Ontario [3]. Older immigrants contribute to society through paid work and unpaid labor (childcare, cooking, and cleaning) that reinforces the overall economic well-being of the family and supports the educational pursuits and labor market activities of children and grandchildren. In addition, they often participate in volunteerism that promotes community cohesion and the development of social capital [4].

Multiple factors (eg, death of family or friends, retirement, and health or mobility problems) can negatively affect their active family and community engagement, which can potentially lead to their social isolation [5-8]. Social isolation, in turn, can negatively affect their income security, vulnerability and ability to respond to elder abuse, access to services and supports, and overall quality of life and ability to age well, independently and with dignity. Evidence suggests that social isolation is a risk to mental health [9-11].

Social support, “the interactive process in which emotional, instrumental, or financial aid is obtained from one’s social network” [12], is key to promoting well-being among older adults [13,14]. Social networks can be understood as “the web of identified social relationships that surround an individual and the characteristics of those linkages... It is the set of people with whom one maintains contact and has some form of social bond” [12]. Informal social networks can include family, friends, neighbors, and coworkers [15]. Newcomers (<10 years in Canada) often experience a significant loss in the quantity and quality of social networks and support [16-21]. The quantity and the quality of social networks and support can affect access to employment, transportation, food, and accommodation. Social support can ease the settlement and integration process [10,22] and promote resilience and capacity in the postmigration context by enhancing a sense of belonging, reducing exposure to and the effects of racism, and improving access to information and services [22-32]. Support from people within a shared ethnic community is often associated with better settlement and integration outcomes [22]. Ethnic communities can provide opportunities for religious participation, economic activity, and engaging in familiar roles and statuses, which can encourage political mobilization and material opportunities and reduce the effects of discrimination and racism [33]. However, there is also research that suggests living in too close proximity to ethnic neighborhoods may have adverse effects. Ethnic density in large urban settings can be the result of discriminatory housing policy, economic restructuring, and other external constraints on individuals, families, and communities and may not always have a positive impact on individuals [34-36]. Smaller ethnic communities, especially in smaller cities, may permit stronger social bonds that promote well-being [37]; they may also be perceived as less of a *threat* by the dominant group and, therefore, treated more positively.

Informal social networks can also be sources of conflict and abuse [9,22,38] or lead to pressure for reciprocity [39], with negative effects on the well-being of older immigrants [40]. For example, abuse of older immigrant women by family members has significant negative effects on their well-being, which can be exacerbated by ethnic community control of the older adults’ decisions about leaving the abuser, living alone, or engaging in paid employment [16]. As the sizes of the informal social networks vary across situations and contexts, formal sources of support may play an important role in helping older immigrants. Formal social support may be provided, for example, by social service or settlement agencies, health clinics, legal clinics, or police officers [15]. Successful settlement and integration are dependent on the quantity and quality of services that meet the needs of immigrants [41-43]. Funding cuts over the last 10 years, especially for new and sustainable programs, have reduced the quality and availability of services for immigrants [44,45]. In addition, immigrants, especially some subgroups (eg, older men and older women), underutilize shelters; hotlines; and social, health, and legal services [46-54] because of multiple intersecting factors such as lack of familiarity with services; lack of linguistically appropriate services; lack of accessible, portable, and coordinated services; confidentiality concerns; as well as discriminatory and racist practices embedded within services and service delivery [49,55].

Currently, programs and initiatives supporting older adults are often separate from those supporting immigrants and involve different ministries, organizations, and levels of government, which has resulted in a lack of cohesion among formal supports and a lack of awareness about what is available to older adults across organizations and sectors. Older immigrants are often more socially isolated than their nonimmigrant peers and face additional challenges, including language barriers and lack of familiarity with the new postmigration spaces and places [26,38]. Little is known about how older immigrants access local social networks or how these differ by their sociodemographic characteristics and by the size of the city in which they reside. Furthermore, access to and use of social (formal and informal) networks have not been compared and contrasted across large, medium, and small cities.

Study Objectives

The study objectives are to (1) understand the social needs, the nature and composition of networks, and the availability of social supports for older immigrants in Ontario as perceived by older men and women, family members, and leaders belonging to long-term and established (Chinese) and relatively newcomer and less-established (Middle Eastern and Latin American) immigrant communities and service providers and (2) identify the factors affecting older immigrants’ access to and use of informal and formal social supports, geographic inequalities, and the gaps between service needs and provision and how these shape older immigrants’ capacity, resilience, and independence.

Methods

Design

The study consists of a mixed-methods, sequential (qualitative-quantitative) design, conducted in 2 phases. Consistent with the collaborative, community-based approach to research, stakeholders representing the different immigrant communities and potential participants (eg, older adults, family members, and community leaders) have been involved in the development of the study proposal and in the formation of an advisory committee. The latter committee will provide recommendations on the recruitment of participants, data collection, and interpretation of the findings to ensure that our research process is culturally responsive and that the outcomes and outputs are relevant to stakeholders.

Phase 1 uses a qualitative approach to explore older immigrants' actual or preferred size and composition of informal and formal networks, type, model of delivery (eg, use of technology) and frequency of support used or preferred or accessed, and perceptions of reciprocity and conflict within such networks. Phase 2 is primarily quantitative and aims to clarify the gaps between older immigrants' needs and available services.

Setting

This study will be conducted in 4 cities in Ontario: Toronto, Ottawa, Waterloo, and London. These sites have been chosen to compare across large, medium, and small cities. Three language groups (Arabic, Mandarin, and Spanish) were selected for the size of the particular language-speaking population in these cities and based on the advice and feedback from our community advisory committees at each of the 4 sites.

Participant Recruitment

The inclusion criteria for older women and men are as follows: aged 60 years or older; have been living in Canada for less than 20 years; currently residing in 1 of the 4 cities (London, Ottawa, Toronto, or Waterloo); and speak Arabic (if in London, Ottawa, or Toronto), Mandarin (if in Toronto or Waterloo), or Spanish (in any of the 4 cities) as a first or primary language. Family members will be selected if they are aged 18 years or older and have 1 or more parents or grandparents who meet the study inclusion criteria.

We will recruit community leaders and service providers using our existing networks and contacts. The inclusion criteria for community leaders are as follows: aged 18 years or older and self-identify as a member of the selected immigrant communities and a leader (eg, educator, religious leader, legal advisor, politician, or advocate) in the community who works with older women and men living in the respective city. Service providers will be selected if they are aged 18 years or older and, in a paid (employment) capacity, provide services (such as educational, health, legal, or social services) to older immigrants belonging to the selected communities.

Phase 1 will involve data collection with 5 stakeholder groups: older women, older men, family members, community leaders, and service providers. We will explore the social support needs of older immigrants as well as the nature and composition of actual or preferred informal and formal networks. Given the diversity of older immigrant population with respect to location, size, and the availability of community-specific networks and resources, (as mentioned earlier) we will focus on Spanish, Mandarin, and Arabic in Toronto; Spanish and Arabic in Ottawa; Spanish and Arabic in London; and Spanish and Mandarin in Waterloo. Recruitment of participants will take place primarily via referral through the connections we have with the respective immigrant communities. We found this recruitment method to be effective in our previous research involving immigrant communities [15,56].

Data collection will be done through focus group sessions. These discussions allow participants to respond to each other's comments; to question, clarify, and elaborate on ideas; and to reach consensus about collective knowledge [57] within a short period. Focus group sessions will (1) follow a comparable protocol (combination of open-ended and standardized questions) that allows flexibility and evolution over the course of the study in response to emerging findings, (2) be held at participants' convenience and in the language of their choice and audio-recorded (with consent), (3) be cofacilitated by trained research assistants who speak the primary language of the community and/or have experience working with the particular community, and (4) be offered (as much as possible) at different locations in each city to make it convenient for participants to attend. Data collection sessions will be held separately with each of the 5 stakeholder groups at each city. For older women and older men, we will conduct separate sessions by gender to maximize comfort and encourage dialogue. Our previous work on sensitive topics (eg, abuse and violence) has shown that this type of group setting can create a safe environment in which self-selected women and men from immigrant communities discuss topics of importance to the participants quite openly. The group discussion will focus on exploring the social needs of older immigrant women and men, describing the nature and composition of their actual and preferred social networks, and identifying factors that contribute to their access to formal and informal supports within their community and area of residence.

Purposive sampling will be used to recruit a comparable number of participants in terms of age, gender, length of stay in Canada, and sponsorship status. We will include 6 to 8 participants per group session and hold 2 to 4 group sessions with each category of participants within each immigrant community. The resulting sample (size) will be adequate for subgroup analyses, while ensuring feasibility. The subgroup analysis will compare participants' responses by gender (32 women and 32 men per immigrant community), immigrant community (128 older adults per community), and city (64 per city). These subgroups' sizes exceed the number recommended to reach information saturation in qualitative data analysis (which is usually 20 to 25 participants) [58] and provide statistical power to detect medium-sized differences, setting power at .80 and *P* at .05 [59]. For family members' stakeholder group, separate sessions will be held for daughters or daughters-in-law (1-2 sessions per city), sons or sons-in-law (1-2 sessions per city), and grandchildren (1-2 sessions per city; 48 family members in total). We will attempt to represent diversity in terms of length of stay in Canada, income, employment, having (or not) children who live at home, having (or not) an older adult living with them, and extended family coresidence. Informal and formal community leaders will include leaders working with, providing support for, and/or advocating on behalf of older adults in their community (eg, faith leaders, media figures, and community advocates) and social, settlement, and health care workers from each community. One focus group session will be held with (6 to 8) community leaders in each city. One focus group session will be held in each city with (6 to 8) service providers (ie, social, settlement, and health), who work with older immigrants but do not belong to the selected immigrant communities.

Before data analysis, the audio recordings of the focus groups conducted in the 3 languages will be transcribed and then translated into English by the research assistants who conducted the sessions. Translations will be verified by our community partners fluent in the respective language. Researchers will independently code transcripts and reach consensus on these at regular meetings; they will also compare the codes to generate subcategories that reflect commonalities and differences in perceptions of social support and services within and across subgroups and communities. Gaps in emerging subcategories will be addressed in subsequent focus groups. The analysis will explore social dimensions (eg, gender, culture, language, length of stay in the country, and extended family coresidence); actual or preferred size and composition (gender, culture, age, and location) of informal networks; and types and frequency of support, reciprocity, conflict, and formal social support services (eg, police, legal, employment, continuing education classes, housing, and transportation). The data will be analyzed at different levels, beginning with the group session and then integrated across subgroups, communities, and the 4 cities to reveal common and unique issues. Member checks, peer debriefing, gathering diverse perspectives, careful documentation of the analysis procedures, identification and verification of themes, and interpretation of the findings will ensure the trustworthiness of the results [57].

Phase 2 will involve examining gaps between the need for age-friendly formal social support services and the availability of these services in each community and city, especially spatial equity in service provision and utilization. A geographical or spatial analysis approach using a geographic information system (GIS) will clarify individual travel behavior in accessing services among older immigrants and identify location gaps. This analysis will include 2 stages. The first stage (stage 1) will use qualitative GIS findings [59,60] to visualize and analyze patterns in using and accessing senior services, such as housing, transportation, employment, and continuing education classes, based on information collected from focus groups in phase 1. The second stage (stage 2) will apply various accessibility models to systematically examine the spatial relationship between residential patterns of older immigrants and the distribution of services for older adults, in terms of service capacity, service language, types of service offered, etc at each site.

A combination of qualitative and quantitative datasets will be utilized in both stages: information from focus groups (eg, location of participants and services used, frequency of visits, perception of service providers, and quality of social networks), 2016 Census data about neighborhood sociodemographic characteristics (eg, proportion of older adults), and data about services for older adults (eg, service provider locations and attributes) gathered from various sources such as Ontario 211 and municipal websites (eg, settlement.org).

Specifically, stage 1 will use GIS data to explore travel patterns in accessing services and how social networks, individual characteristics, and service availability affect activity space [61]. Residential locations of focus group participants will be geocoded, and a simple frame of activity space will be created for each individual, including the locations of the service provider(s) they visit and the locations and durations of other activities they engage in immediately before or after (eg, grocery shopping and visiting a friend) these visits. We will calculate the distance each participant travels to access services and compare travel patterns and extent of activity space with the participant's quality of social network, their perceptions about service provider(s) for older immigrants, and other basic demographic characteristics. Finally, we will compare the constructed activity space with the distribution of all service providers using the master dataset of senior services. This will help reveal some of the complex spatial relationships between residential location, neighborhood resource distribution, personal characteristics, and social network. For example, the results will help clarify whether participants would choose to bypass the closest service location in favor of an inconveniently located one that has language and culturally appropriate services or whether clustering services for older immigrants and other coethnic resources (eg, church and grocery stores) might encourage utilization.

Stage 2 will involve a systematic evaluation of service gaps for older adults. Census data have some limitations, preventing comparison between older adults' places of birth, age, location, and country of origin. Therefore, we will clarify service gaps for the older adult population in each study area as a whole using 3 different spatial analysis techniques and models. First, we will analyze service areas (the catchment area of each provider) considering 3 modes of transportation: walking, public transit, and private vehicle. Each service area will be decided empirically based on the travel behavior reported by focus group participants and insights generated from focus groups with service providers. Second, we will use the cumulative accessibility model as simple measures of accessibility from each census tract to service locations for older adults. This model can calculate the number of services included within the travel threshold from each census tract centroid. Finally, we will use an advanced accessibility model (2-step floating catchment area model) to compute spatial accessibility to service providers by considering the spatial distribution of services and competition among service users in census tracts [62,63].

Together, the results of these analyses will provide important insights about areas of underservice for older adults and possibly misdistribution of existing service providers. We will assign access scores to each census tract, which will have important policy implications for accessing the efficiency of existing services and programs for older adults. Although these spatial analyses will be performed based on census data containing the entire older adult population, by overlaying the accessibility maps on the distribution of study populations, we will provide rich data about the relationships between group-specific residential patterns and service accessibility. The data collected during focus groups about individual travel behavior will be critically important to determine the travel threshold parameters. Most previous research has used hypothetical threshold and catchment size [64,65]. Therefore, the integration of qualitative (focus groups) and quantitative (spatial accessibility models) data in Stages 1 and 2 is particularly innovative and advantageous.

Ethics Approval and Consent to Participate

This study has received approval from the Research Ethics Boards of Ryerson University in Toronto, Ontario; King's University College at Western University in London, Ontario; the University of Ottawa in Ottawa, Ontario; and Wilfred Laurier University in Waterloo, Ontario. Participants will be informed that their participation in the study is completely voluntary, and they can choose whether to be in the study or not. Participants will review and sign informed consent, in English or their own language (based on their preference), before participating. If any participant appears to be needing help, the moderator will provide supportive listening and information on how to access suitable agencies or services as needed. Participants will have the option to leave the group discussion at any time for any reason. If, after participation in a group discussion, participants decide they no longer want to be part of the study, they can choose to exclude data collected from them. For this to occur, the participant must inform the research team at the end of the interview or within 8 weeks after joining the study. Withdrawal within this time will result in removal and destruction of data contributed.

Results

Quantitative and qualitative data collection is ongoing. To date, focus groups with older women and men, and family members for each community at each site have been completed. In addition, the datasets for the GIS analysis have been secured and are currently being cleaned.

Discussion

Overview

Over the last 20 years, more immigrants have settled in suburban areas [66] instead of downtown cores. However, this change has not been reflected in funding, service, and resource allocation, resulting in extensive unmet social support needs [67]. Considerable research has focused on how place affects well-being [60-62,68-74] and the need for community locations where newcomers can build social networks and participate in cultural and political life [75,76]. However, little is known from a comparative perspective about how older immigrants access and use such social networks in small, midsized, and large cities. This study will compare less-established immigrant communities (with little or no support within their own community) with better-established communities (with more internal support) in large, medium, and small cities to help clarify key settlement and integration outcomes in the context of aging well. Specifically, there is limited knowledge on the extent to which older immigrants access and engage in formal and informal social activities as well as on their social needs, nature and composition of their actual and preferred social networks, and use of formal and informal supports. This research has also generally involved a single disciplinary perspective. Our multidisciplinary study will examine social needs, networks, and supports among older immigrants in a variety of geographical settings to identify factors that affect their access to and use of informal and formal social supports and the gaps between service needs and provision. The findings will advance scholarship in social work, immigration studies, nursing, and geography and will inform policy debates and practice change at local, national, and possibly international levels.

Strengths and Limitations

Recruitment of older adults from different immigrant communities is a potential challenge that will be mitigated by our collaborative and participatory approach to research. In addition, to fully clarify the factors (social, cultural, economic, and geographic) that affect the ability of older immigrants to access social networks and support, we have also brought together community partners from a range of sectors. We plan to develop evidence-based ways to promote social connection, reduce social isolation, and improve well-being among older immigrants living in large, medium, and small cities. We have already confirmed the participation of community partner organizations in the 4 cities: each will facilitate the research activity with the shared goal of advocating for and supporting the needs of older immigrants. Each has proven capacity in offering services to immigrants. These organizations rely on evidence-based results to inform their ongoing programs and the design, implementation, and evaluation of tools.

Conclusions

The findings will benefit the organizations serving older immigrants greatly and will also lead to social and cultural benefits for the communities represented by the organizations and older immigrants, in particular. The proposed partnership will develop evidence-based ways to promote social connections and reduce social isolation to make communities and cities more supportive of older immigrants.

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Authors' Contributions

SG, the principal investigator of the project, is leading the project upon which this protocol paper is based and has drafted the paper. SS provides methodological expertise to the project, has drafted the Methods section of the project application upon which this paper is based, and provided critical revisions on an earlier version of this paper. LW provides expertise in the area of Geographic Information System methods and has reviewed and provided critical feedback on this paper. BS is the co-investigator, provides expertise in the area of immigration, and has reviewed and provided critical feedback on this paper. DS is the co-investigator, provides expertise in the area of immigration, and has provided feedback on the project application upon which this paper is based. MWR is the co-investigator, provides expertise on international migration, and has provided feedback on the project application upon which this paper is based. IH provided feedback on the project application upon which this paper is based and reviewed and provided critical feedback on this paper. All authors revised and edited the manuscript critically for important intellectual content of the material. All authors approved the final version of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

GIS: Geographic Information System

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Original Paper

A Web-Based Mobile App With a Smartwatch to Support Social Engagement in Persons With Memory Loss: Pilot Randomized Controlled Trial

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Abstract

Background: It is estimated that the number of individuals living with dementia worldwide will increase from 50 million in 2017 to 152 million by 2050. Assistive technology has been recognized as a promising tool to improve the lives of persons living with memory loss and their caregivers. The use of assistive technology in dementia care is expanding, although it is most often intended to manage care and promote safety. There is a lack of assistive technology designed to aid persons with memory loss in participating in meaningful activities. The Social Support Aid (SSA) is a mobile phone-based app that employs facial recognition software. It was designed to assist persons with memory loss remember the names and relationships of the people they interact with to promote social engagement.

Objective: This study uses a pilot randomized controlled trial (RCT) design to evaluate the SSA. The objectives were to ascertain (1) the feasibility and utility of the SSA, (2) whether the outcomes of SSA use suggest potential benefits for persons living with memory loss and their care partners, and (3) how study design components could inform subsequent RCTs.

Methods: Persons with memory loss were randomized to the SSA (n=20) or the usual care control group (n=28). Quantitative data were collected at three timepoints (baseline, 3 months, and 6 months). Participants in the intervention group participated in qualitative interviews following completion of their 6-month survey.

Results: Participant eligibility, willingness to be randomized, and retention were not barriers to conducting a full-scale RCT; however, recruitment strategies should be addressed before doing so. Feasibility and utility scores indicated that participants felt neutral about the technology. Use of the SSA was not significantly associated with changes in quality of social interactions or quality of life measures over the 6 months of follow-up ($P>.05$). The qualitative analysis revealed three themes that described how and why the SSA worked or not: (1) outcomes, (2) reasons why it was or was not useful, and (3) recommendations.

Conclusions: There is a need to develop effective assistive technology that improves the quality of life of persons with memory loss. Assistive technology that allows persons living with memory loss to maintain some level of autonomy should be a priority for future research. This study suggests reasons why the SSA facial recognition software did not appear to improve the quality of social interaction and quality of life of people with memory loss. Results also provide recommendations for future assistive technology development and evaluation.

Trial Registration: ClinicalTrials.gov NCT03645694; https://clinicaltrials.gov/ct2/show/NCT03645694 (Archived by WebCite at http://www.webcitation.org/78dcVZIqq)

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KEYWORDS

Alzheimer disease; dementia; social support; quality of life; well-being; technology; social engagement; facial recognition; smartwatch

Introduction

Globally, the number of older persons aged 60 years and older is projected to more than double by 2050 and triple by 2100, increasing from 962 million in 2017 to 2.1 billion in 2050 and 3.1 billion in 2100 [1]. As the number of older adults increases throughout the world, so too will the prevalence of dementia [2,3]. The percentage of persons living with Alzheimer disease increases dramatically with age: 3% of people ages 65 to 74 years, 17% of people ages 75 to 85 years, and 32% of people ages 85 years or older have Alzheimer disease. In the absence of a medical breakthrough to prevent, slow, or cure Alzheimer disease and other dementias, it is estimated that the number of individuals worldwide living with the disease will increase from 50 million in 2017 to 152 million by 2050 [2,4,5].

As there is no cure for Alzheimer disease and other dementias, efforts to develop interventions and resources that improve the lives of persons living with dementia and their caregivers are a public health priority [6]. Assistive technology has been recognized as a promising avenue for such improvements and holds potential as a tool to promote the autonomy of persons with dementia by enabling their daily activities [7-11]. Assistive technology in dementia care can be defined as an item, piece of equipment, product or system driven by electronics that is used to help individuals or their caregivers manage the consequences of dementia [12]. Assistive technology has been shown to improve independence, behavior symptoms, and quality of life as well as reduce caregiver stress in randomized controlled trials (RCTs). Further, studies suggest persons with dementia generally have positive feelings about using assistive technology to promote their independence [6,12,13].

Although the use of assistive technology in dementia care is rapidly growing, such devices are often intended to assist caregivers rather than the person with dementia [12-15]. Most assistive technology in the context of dementia care is used for delivering assessments, assisting with activities of daily living (ADLs), safety, or in managing care. Few evaluations of assistive technology designed to enhance social well-being exist. This is particularly problematic given that one of the most pressing challenges for persons living with dementia and their caregivers is finding meaningful activities to engage in [8,12,14,16]. Further, it is essential that persons living with dementia have some level of autonomy for as long as possible when participating in meaningful activities, such as socializing, to maintain good quality of life [10]. Assistive technology may provide an opportunity for persons living with dementia to participate in meaningful and engaging activities, but the benefits of assistive technology in these domains remains unclear [10,12,14].

This study is a pilot RCT (NCT03645694) evaluating the potential of an assistive technology device, the Social Support Aid (SSA). The principal objective of this pilot randomized controlled evaluation was to ascertain (1) how participants perceived the feasibility and utility of the SSA, (2) whether the outcomes of SSA use suggest potential benefits for persons living with memory loss and their care partners, and (3) how the various study design components could inform subsequent larger-scale RCTs. This study fills a gap in the literature by evaluating the potential for an assistive technology device designed to aid persons with memory loss engage in meaningful social interactions.

Methods

Design

A pilot RCT design was used. A pilot RCT is generally employed to determine whether the elements required for conducting a successful, full-scale RCT are present. Specifically, a pilot RCT determines whether screening eligibility procedures operate effectively, recruitment targets are met, randomization is carried out appropriately and selection bias is mitigated, whether the intervention is carried out as intended, and if the intervention is sufficiently intense to result in the anticipated benefits [17]. An important objective of a pilot RCT is also to highlight challenges when conducting the intervention.

An underpowered RCT is not a pilot RCT [17]. It is important to note that this study was not designed as a pilot RCT a priori. However, the extent of qualitative and feasibility/utility data that were collected over the 6-month evaluation of the SSA allowed us to address many of the core objectives that are often posited in pilot RCTs. For this reason, we chose to label this project as a “pilot” RCT.

The Social Support Aid Technology

The SSA is a mobile phone-based app that employs facial recognition software. The SSA technology was developed by Advanced Medical Electronics, a research and development company specializing in medical devices. The SSA was designed to assist persons with memory loss remember the names and relationships of the people they interact with to promote social engagement. The technology consists of a mobile phone equipped with a facial recognition software app and a smartwatch. Up to 1000 individuals can be “enrolled” in the facial recognition app database. Enrollment includes typing an individual’s name and relationship to the person with memory loss into the app and taking pictures of the individual’s face from multiple angles. Once enrolled and in view of the mobile phone’s camera, the SSA app recognizes the individual’s face and alerts the smartwatch. The watch then vibrates and displays the individual’s image and text with their name and relationship to the person with memory loss. For pictures of the device, see Figure 1-4.

Figure 1. The Social Support Aid app home screen.

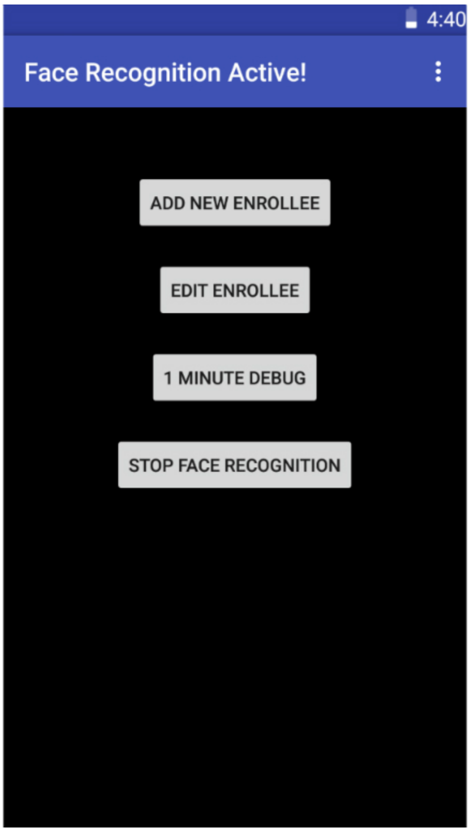


Figure 2. The Social Support Aid app enrollment instruction video.

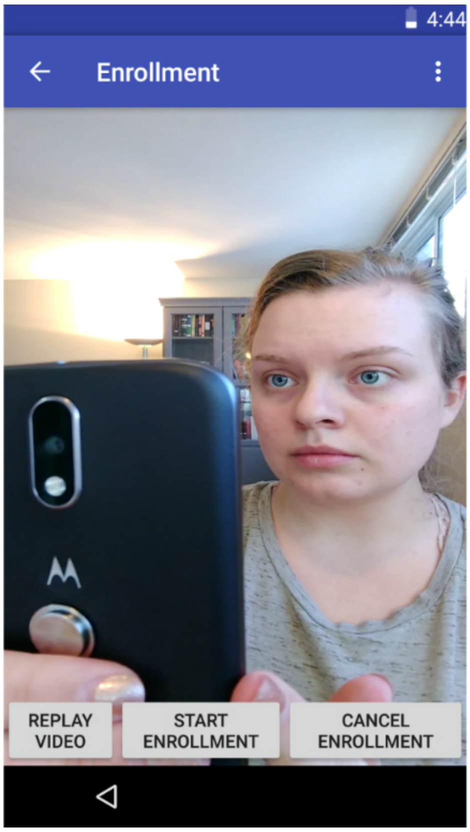
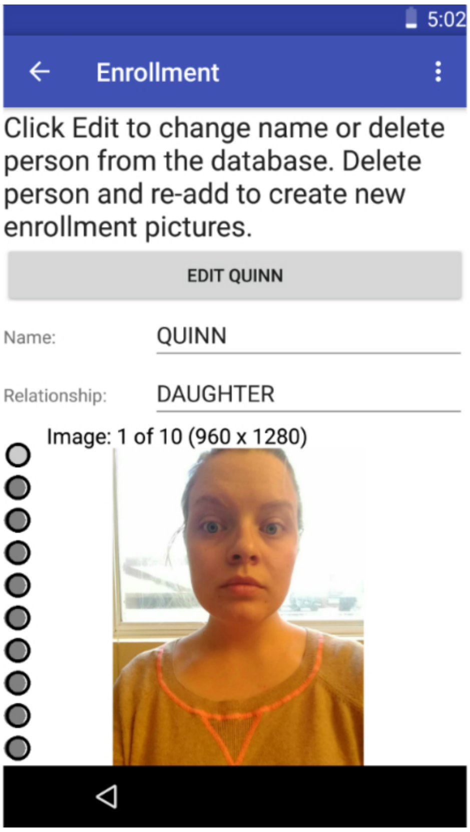


Figure 3. The Social Support Aid app enrollment screen.



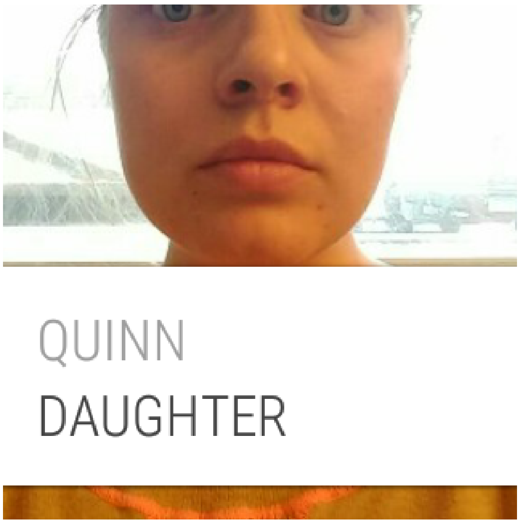
Click Edit to change name or delete person from the database. Delete person and re-add to create new enrollment pictures.

Name: QUINN

Relationship: DAUGHTER

Image: 1 of 10 (960 x 1280)

Figure 4. The Social Support Aid watch face after the app has recognized the face.



QUINN

DAUGHTER

During phase 1 testing of the SSA, 14 participants (seven dyads of persons with dementia or mild cognitive impairment and their caregivers) provided feedback on the SSA. Participants were given a demonstration of the SSA and were trained to use it. Participants were then walked through the SSA again and were asked a series of guided questions to elicit their opinions of the SSA. Qualitative data collected from the initial testing indicated that participants thought the technology would be useful in social situations and that they understood how to operate the SSA. Given the initial positive results, a more rigorous review was warranted. Results presented in this study are from the second phase of testing.

Recruitment

Individuals with dementia, memory loss, or memory concerns, as well as their caregivers, were recruited from the University of Minnesota Caregiver Registry (a registry of caregivers who gave permission to be contacted about opportunities to participate in research), the Minnesota State Fair, and through statewide newspaper advertisements from February to October 2017. Participants included caregivers and persons with memory loss. The following inclusion criteria were applied: (1) ability to fill out a survey in English or Spanish; (2) 21 years or older; (3) diagnosis of dementia or mild cognitive impairment, or has a self-identified memory concern (or a caregiver of such an individual); and (4) person with memory loss has sufficient cognitive capacity to provide verbal informed consent (measured by score of 20 or higher on St Louis University Mental Status examination).

Caregivers provided Health Insurance Portability and Accountability Act (HIPAA) authorization and written informed consent, and persons with memory loss provided assent. In instances where there was no caregiver available, persons with memory loss provided HIPAA authorization and written informed consent to participate. Participants were given US $100 following their completion of the study. The University of Minnesota's Institutional Review Board approved this study. This study was registered with ClinicalTrials.gov following clarification of the trial status and design (NCT03645694).

Data Collection

Data were collected at three time points: baseline, 3 months, and 6 months. Caregivers completed all surveys on behalf of the person with memory loss. Participants were asked for their opinion of their relative with memory loss (eg "How often *does your relative* feel confident?"). At baseline, surveys for participants caring for a person with memory loss measured ADLs, memory impairment, memory and problem behaviors, social interaction, and quality of life as well as demographic questions asking about themselves and the person with memory loss. Participants with memory loss who did not have a caregiver completed surveys on their own behalf. They received a slightly different version of the survey with questions being asked in reference to themselves (eg, "How often *do you* feel confident?"). Their baseline survey measured ADLs, memory impairment, social interaction, and quality of life as well as demographic questions about themselves. Surveys administered at 3 and 6 months were identical to the baseline surveys except that they did not include demographic questions. At 3 and 6 months, participants in the intervention group completed an additional feasibility and utility checklist. Participants were given the option to complete an online or paper version of the surveys.

Following completion of the baseline survey, participants were randomly assigned to either receive the technology or to continue with usual care. Participants were randomized at a ratio of 1:1 using a random number generator. Neither the participants nor researchers were blinded to randomization group. Research assistants met with participants in the intervention group in-person to provide the mobile phone and smartwatch and demonstrate how to use the SSA technology. Participants were given the technology to use at their discretion, and there was no requirement for how many times they had to use the SSA. Throughout the study, research assistants and the SSA developer provided technical support and answered questions regarding the technology. Participants in the control group were given the technology free of charge after completing the study.

Analysis

Recruitment, Randomization, and Retention

Chi-square and *t* tests were used to determine if participant demographics in the intervention and control groups were significantly different (*P*<.05). Chi-square and *t* tests were also used to compare participants who were lost to follow-up with those who were not.

Feasibility and Utility

Participants in the intervention group were asked to complete an additional survey at 3 and 6 months to assess their perceptions of feasibility and utility. This checklist included 15 Likert scale items asking participants to rate their level of agreement with statements such as "the technology works well," "SSA was easy to use," and "my relative felt lost using SSA" (=.89).

Assessment of Intervention Effect

Descriptive statistics were calculated for measures of quality of social interaction and quality of life. Social interaction quality was measured by asking participants to rate their satisfaction with the following types of communication: visits, phone calls, mail correspondence, and computer correspondence. Quality of life was measured using the Pleasant Events Schedule-Alzheimer's Disease (PES-AD; frequency =.84; enjoyment =.76) and Dementia Quality of Life (DQoL; =.92). The PES-AD asks with what frequency and level of enjoyment the person with memory loss experiences a list of pleasant activities (eg, being outside, listening to music, laughing). The DQoL asks participants to use a Likert scale to rate how often the person with memory loss feels a certain way (eg, satisfied, cheerful, angry, worried).

We imputed missing data using a Markov chain Monte Carlo method to conduct a five-fold multiple imputation. Analyses were conducted as intention to treat. Change scores were calculated to determine differences between outcomes at baseline and 6 months. To determine whether changes in satisfaction and quality of life in the intervention group were significantly different than changes in the control group, *t* tests were used. Statistical significance was assessed using two-tailed tests with a significance level of *P*=.05.

Qualitative Analysis

Following completion of the 6-month survey, participants in the intervention group were asked to participate in a semistructured interview; 13 individuals agreed to participate. The interviews took place over the phone and lasted between 10 and 30 minutes each. Interviews were transcribed by a professional service and organized into NVivo. Qualitative data were coded using Braun and Clarke's [18] six steps of thematic analysis. HM first read through all transcripts and then generated initial themes. HM and JG discussed and compiled codes into an initial coding framework. Next, HM coded all material and revised the coding framework as needed. The qualitative analysis was guided by the research question: How and why did the SSA work or not work for caregivers and persons with memory loss?

Results

Recruitment, Randomization, and Retention

Recruitment was a challenge despite the use of newspaper advertisements and community outreach. A total of 58 potential participants were assessed for eligibility; of these, all but one met the inclusion criteria. Six of the 58 potential participants were unwilling to provide informed consent and were not included in the study. None of the participants expressed unwillingness to be randomized. There were no statistically significant differences in participant demographics between the intervention and control groups (Tables 1 and 2), suggesting successful randomization. Of the 48 participants that were randomized, 44 finished the study (92% retention rate). Two participants with memory loss refused participation after undergoing randomization to the intervention group. Two participants who were caregivers were lost to follow-up, both in the intervention group (Figure 5). Participants lost to follow-up were significantly different with regards to randomization group and income, with participants in the intervention group and caregivers with an income of US $10,000 to US $14,999 and US $80,000 and over being more likely to be lost to follow-up.

Thirty-five participants were caregivers and 13 were persons with memory loss who had no caregiver available. Persons with memory loss were an average age of 74.90 (SD 6.98) years. The majority of persons with memory loss were non-Hispanic white (40/47, 85%), married or living with their partner (32/47, 68%), and had been diagnosed with dementia (29/48, 60%; see Table 1). Caregivers were an average age of 67.83 (SD 10.08) years. The majority were female (25/35, 71%), non-Hispanic white (30/34, 88%), and were caring for their spouse or partner (28/35, 80%; Table 2).

Feasibility and Utility

Mean feasibility and utility scores were calculated at 3- and 6-month follow-ups. The mean score at 3 months was 3.11 (SD 0.57) and at 6 months was 3.10 (SD 0.63), which suggested moderate feasibility and utility (items were scored one through five, with lower scores indicating less favorable perceptions of SSA's utility and higher scores more favorable). The item receiving the highest score was "the information provided on how to use SSA was clear to me" (3 months: mean 4.07, SD 0.62; 6 months: mean 4.06, SD 0.68). The item receiving the lowest score was "after using SSA, I feel like my relative is more at ease in social situations" (3 months: mean 2.71, SD 0.73; 6 months: mean 2.5, SD 0.97).

Assessment of Intervention Effect

A total of 48 participants were included in the analytic sample. The use of SSA was not associated with significant changes in PES-AD, DQoL, or measures of social interaction satisfaction (Table 3).

Qualitative Results

The qualitative analysis resulted in three themes that described how and why the SSA worked or did not: (1) outcomes, (2) reasons why it was or was not useful, and (3) recommendations. Participant names were replaced with pseudonyms when reporting results.

Outcomes

This theme describes the impact using the SSA had on caregivers and persons with memory loss. The majority of participants did not think their use of the SSA had any effect, although some mentioned positive and negative aspects of using the SSA.

Positive Outcomes

Most participants who thought their use of the SSA had an influence perceived the SSA in a positive fashion. Some participants stated that the SSA gave their relative confidence and independence, such as Marsha (caregiver, age 83), who said:

> *I wasn't always providing backup and that gave him more confidence...So he didn't have to rely on me giving cues or asking me any questions because he was able to use it and found an answer himself. I think that's important.*

For others, such as Kelley (caregiver, age 72), using the SSA was beneficial in that it provided a topic of conversation:

> *One of the really neat things about it is those people who we had successfully enrolled in it, they just got such a kick out of it when the phone would recognize them. That was just a delight to them and it was a good conversation opener. It was something that really enhanced our conversations with people.*

For some participants the technology was a novelty they enjoyed "tinkering around with" and demonstrating for friends and family.

Negative Outcomes

Although the majority of participants felt the SSA had a positive impact or no impact at all, some participants felt that the SSA resulted in negative outcomes. For example, Marge (caregiver, age 67) said that the SSA was an additional distraction, hindering her husband as he attempted to have conversations. Doris (caregiver, age 72) said that her husband's anxiety "went through the roof" while using the technology. The technology, she said, was too overwhelming and caused him to become agitated. Others reported that using the SSA was a source of frustration and in one case became a point of tension between the caregiver and person with memory loss. Rebekah (caregiver, age 69) explained:

> *I think it was frustrating and then it got that way for me, too, because I couldn't keep explaining it and explaining it and demonstrating. Because then it would just get to be a fight, arguing about what it was doing. He just could not quite comprehend [the SSA].*

Other caregivers said that the SSA was an additional burden, contributing to an already long list of caregiving duties. For them, the technology was "just one more thing" they had to keep track of.

Table 1. Persons with memory loss demographics.[a]

Demographic	Total (N=48)	Intervention (n=20)	Control (n=28)	*P* value
Age (years), mean (SD)	74.90 (6.98)	74.15 (5.22)	75.43 (8.06)	.54[b]
Number of living children, mean (SD)	2.77 (1.94)	2.53 (1.58)	2.96 (2.19)	.47[b]
Gender, n (%)				.73
Female	25 (52)	11 (55)	14 (50)	
Male	23 (48)	9 (45)	14 (50)	
Ethnicity, n (%)				.99
Non-Hispanic	40 (85)	17 (85)	23 (85)	
Hispanic	7 (15)	3 (15)	4 (15)	
Race, n (%)				.37
White, non-Hispanic	36 (84)	16 (84)	20 (83)	
White, Hispanic	2 (5)	2 (11)	0	
Asian	1 (2)	0	1 (4)	
≥2 races	3 (7)	1 (5)	2 (8)	
Marital status, n (%)				.53
Married/living with partner	32 (68)	13 (68)	19 (68)	
Divorced	3 (6)	1 (5)	2 (7)	
Widowed	8 (17)	2 (11)	6 (21)	
Separated	3 (6)	2 (11)	1 (4)	
Never married	1 (2)	1 (5)	0	
Education, n (%)				.88
Less than high school degree	6 (13)	2 (10)	4 (14)	
High school degree	5 (10)	2 (10)	3 (11)	
Some college	5 (10)	1 (5)	4 (14)	
Associate’s degree	4 (8)	2 (10)	2 (7)	
Bachelor’s degree	9 (19)	5 (25)	4 (14)	
Graduate degree	18 (38)	8 (40)	10 (36)	
Annual household income, n (%)				.33
<$25,000	11 (25)	6 (32)	5 (20)	
$25,000-$29,000	4 (9)	0	4 (16)	
$30,000-$39,000	4 (9)	1 (5)	3 (12)	
$40,000-$59,000	7 (16)	2 (11)	5 (20)	
$60,000-$79,000	7 (16)	4 (21)	3 (12)	
>$79,000	11 (25)	6 (32)	5 (20)	
Lives with caregiver, n (%)	31 (65)	14 (70)	17 (61)	.46
Diagnosed with dementia, n (%)	29 (60)	13 (65)	16 (57)	.58

[a] From nonimputed dataset.

[b] *P* values were computed with *t* test assuming equal variance; otherwise, chi-square test was used.

Table 2. Caregiver demographics.[a]

Demographic	Total (N=35)	Intervention (n=15)	Control (n=20)	*P* value
Age (years), mean (SD)	67.83 (10.08)	67.47 (13.33)	68.10 (7.14)	.86[b]
Number of living children, mean (SD)	2.39 (1.69)	2.57 (1.87)	2.26 (1.59)	.61[b]
Gender, n (%)				.83
Female	25 (71)	11 (73)	14 (70)	
Male	10 (29)	4 (27)	6 (30)	
Ethnicity, n (%)				
Non-Hispanic	34 (100)	15 (100)	19 (100)	
Hispanic	0	0	0	
Race, n (%)				.64
White, non-Hispanic	30 (88)	14 (93)	16 (84)	
White, Hispanic	1 (3)	0	1 (5)	
Asian	1 (3)	0	1 (5)	
≥2 races	2 (6)	1 (7)	1 (5)	
Marital status, n (%)				.16
Married/living with partner	30 (88)	14 (93)	16 (84)	
Divorced	3 (9)	0	3 (16)	
Never married	1 (3)	1 (7)	0	
Education, n (%)				.35
Less than high school degree	2 (6)	1 (7)	1 (5)	
High school degree	4 (11)	0	4 (20)	
Some college	4 (11)	3 (20)	1 (5)	
Associate’s degree	2 (6)	1 (7)	1 (5)	
Bachelor’s degree	7 (20)	4 (27)	3 (15)	
Graduate degree	16 (46)	6 (40)	10 (50)	
Annual household income, n (%)				.27
<$25,000	4 (13)	2 (14)	2 (11)	
$25,000-$29,000	2 (6)	0	2 (11)	
$30,000-$39,000	2 (6)	1 (7)	1 (6)	
$40,000-$59,000	4 (13)	0	4 (22)	
$60,000-$79,000	8 (25)	4 (29)	4 (22)	
>$79,000	12 (38)	7 (50)	5 (28)	
Work status, n (%)				.05
Working full or part-time	9 (26)	5 (33)	4 (20)	
Retired	24 (69)	10 (67)	14 (70)	
Relationship to PWML[c], n (%)				.57
Spouse or partner	28 (80)	13 (87)	15 (75)	
Child	6 (17)	2 (13)	4 (20)	

[a] From nonimputed dataset.

[b] *P* values were computed with *t* test assuming equal variance; otherwise, chi-square test was used.

[c] PWML: person with memory loss.

Figure 5. Participant flow diagram.

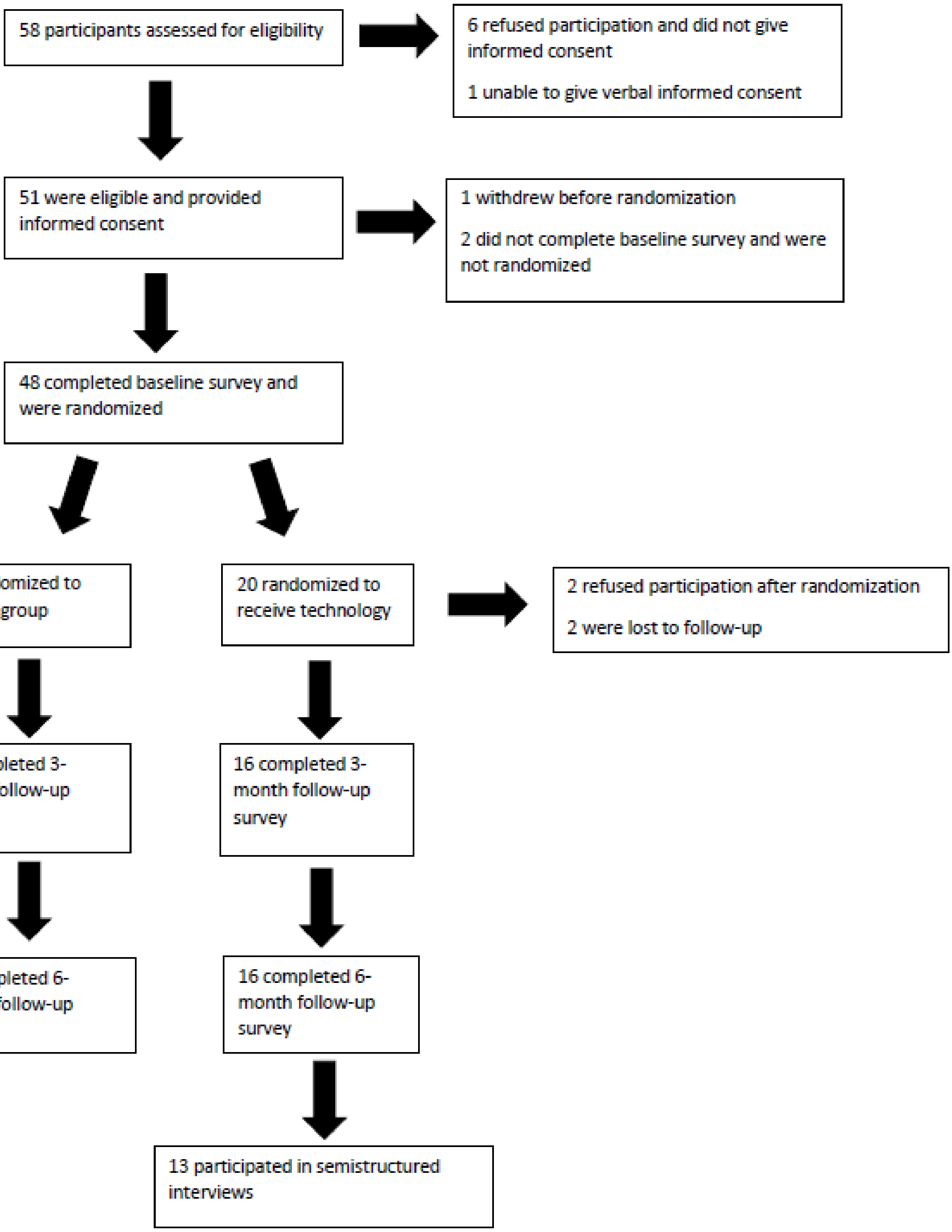


Table 3. Primary outcomes for persons with memory loss at baseline, 3 months, and 6 months.[a]

Outcome measure	Baseline, mean (SD)		3 months, mean (SD)		6 months, mean (SD)		*P* value
	Intervention (n=20)	Control (n=28)	Intervention (n=16)	Control (n=28)	Intervention (n=16)	Control (n=28)	
PES-AD[b] (frequency)[c,d]	2.28 (0.29)	2.38 (0.31)	2.19 (0.49)	2.23 (0.33)	2.3 (0.32)	2.24 (0.35)	.92
PES-AD (enjoyment)[c,e]	2.5 (0.26)	2.48 (0.29)	2.43 (0.47)	2.38 (0.34)	2.39 (0.32)	2.34 (0.33)	.88
DQoL[f,g]	3.47 (0.67)	3.58 (0.61)	3.4 (0.63)	3.29 (0.73)	3.38 (0.67)	3.38 (0.57)	.63
Satisfaction with quality of visits[h]	1.84 (0.96)	1.85 (1.13)	1.73 (0.80)	1.85 (0.99)	2.4 (1.19)	1.89 (1.09)	.18
Satisfaction with quality of phone calls[h]	2.05 (1.00)	2.24 (1.13)	2.2 (1.15)	2.44 (1.04)	2.53 (1.3)	2.52 (1.12)	.36
Satisfaction with quality of mail correspondence[h]	2.79 (1.25)	2.62 (0.87)	2.77 (1.30)	3.09 (0.73)	3 (0.88)	2.87 (1.22)	.57
Satisfaction with quality of computer correspondence[h]	2.5 (1.25)	2.18 (1.05)	2.31 (0.95)	2.36 (0.95)	2.72 (1.14)	2.56 (0.96)	.95

[a] For mean (SD), means were calculated from nonimputed dataset; *P* values were calculated from imputed dataset.

[b] PES-AD: Pleasant Events Schedule-Alzheimer’s Disease.

[c] Excluded by error from baseline survey for participants with no caregivers.

[d] 1=not at all, 2=1-6 times in the last week, 3=7 or more times in the last week.

[e] 1=not at all, 2=somewhat, 3=a great deal.

[f] DQoL: Dementia Quality of Life.

[g] 1=never, 2=seldom, 3=sometimes, 4=often, 5=very often.

[h] 1=very satisfied, 2=somewhat satisfied, 3=feel neutral, 4=somewhat dissatisfied, 5=very dissatisfied.

Reasons Why it Was or Was Not Useful

The majority of participants interviewed did not find the technology useful. Caregivers and persons with memory loss offered a variety of reasons why the SSA was not useful to them. These reasons could be divided into the following subthemes: (1) complexity of the SSA, (2) enrollment process, (3) impracticality, (4) stigma, and (5) functionality of the SSA.

Complexity of the Social Support Aid

Several participants felt that the SSA was too complicated and difficult for someone with memory loss to use. Many said that because of memory loss, they had difficulty using technology and learning new things. For example, Kent (person with memory loss, age 73) said:

> *My ability to use technology, it turns out, is much more diminished than I kind of expected it was. I just had trouble giving people instructions well enough to effectively get them enrolled in the system. I was not a very good guide.*

Often, the diminished ability to use technology was compounded by a general discomfort with technology. Doris (caregiver, age 72) explained:

> *But most [people with memory loss] may not have had very much experience at all with technology and have never had a cell phone, still have their landlines. And so, introducing something that’s so foreign to them, and that they’re intimidated by, at least initially presents an additional challenge.*

The concept of the technology posed a problem for some. Doris went on to explain how difficult the concept of the SSA was for her husband, Nathan (age 77), saying:

> *And in a way it assumes that the person [with memory loss] can make the connection between the name that’s on the watch and the person that’s looking at you...And so just seeing one little row of print on the watch, assuming they remember that that’s where it is, it didn’t connect with Nathan at all. I mean he was like “ok, so now what do I do?”...You know, conceptually it was hard for me to help Nathan understand what was going on, how the two pieces of technology interacted.*

Others would forget what the phone and watch were there for, resulting in confusion and agitation.

Enrollment Process

The enrollment process was frequently mentioned as a reason why the SSA was not useful. Enrollment consisted of entering an individual’s picture, name, and relationship to the person with memory loss in the SSA facial recognition database. Many said the enrollment process was time-consuming and cumbersome. Kelley (caregiver, 72) described the enrollment process, saying:

> *When it didn’t work well in capturing their photos, that made it get cumbersome...When they faced the camera at their face and they turned it one way and turned it the other way and all that, if that had accepted their photos it would not have gotten cumbersome. When it started to get cumbersome is when you had to do it and do it again and do it again.*

> *There’s only so many times that I felt comfortable trying to ask one person to do that.*

Others, such as Doris, felt uncomfortable asking people to enroll in the first place:

> *The concept of asking people that you want to have in the system to spend a few minutes, you know, getting into the system through that facial recognition process was really awkward...And so there was hesitation on our part who we would ask because it seemed like we were being a little bit intrusive to them.*

For these reasons, many said they only felt comfortable asking individuals they knew well to enroll. Consequently, the individuals they enrolled were often people that the person with memory loss did not have trouble remembering. Kelley explained:

> *If it had been a little bit easier getting them enrolled, then I think it would have been more useful...We were reluctant to reach out to anybody who wasn’t pretty close to us, to get them to put up with that process. There were a number of them who gave it a good try and just never made it [into the database]. We were not able to get them enrolled...The only people we had enter themselves into it were people that we were already reasonably close to and that we really weren’t having any problem remembering. If the circle were a little wider and if we had been able to get some people who were a little more distant from us enrolled, I could see there where it would really help with social interactions.*

Others said that the process was not conducive to enrolling others with memory loss or young grandchildren who had a hard time sitting still and following instructions.

Impractical

Some participants felt that the SSA was not practical for use in their everyday lives. For example, Marge (caregiver, age 67) said:

> *It’s like I’ve become this helicopter wife making sure I’m right there...We didn’t use it in a situation where it did anything for me. Like I said, I still had to be right there...I don’t leave him and most of the other caregivers don’t generally leave their significant other either.*

For many, their social interactions were not conducive to using the SSA. For example, Marge mentioned that the adult day service and a community chorus group for people with dementia were the only social settings that the SSA could be useful to her husband with memory loss. In both settings, name tags were already worn, limiting the usefulness of the SSA. Others mentioned that it was not practical to use during everyday interactions such as going to the movies, shopping, or going to the gym.

Stigmatizing

A few caregivers were concerned that the SSA was too conspicuous. For example, Maria (caregiver, age 34) said,

> *Well, it didn’t help because [my mother] wouldn’t wear it...She felt having that big phone around her neck just drew a lot of attention to her, which she does not like.*

For such participants, the technology was stigmatizing.

Functionality of the Social Support Aid

The functionality of the technology includes how well the SSA worked, the physical appearance of the technology, and characteristics of the phone and watch. Several participants reported that the SSA only worked in certain lighting. Some had trouble getting it to work outdoors and in dimly lit settings. Others reported that the SSA only worked when the camera was at particular angles. Marge (caregiver, age 67) mentioned that the software could not distinguish her son from her son-in-law, both of whom were bald and had beards but otherwise had little physical resemblance. Rebekah (caregiver, age 69) thought the SSA took too long to recognize a face. She said that by the time the SSA recognized the face, her husband had already asked her who the person was. Several participants thought the phone was too heavy to have hanging around the neck. Many thought the phone was uncomfortable and not practical for everyday activities. Doris explained:

> *[My husband goes] to a senior exercise facility. And that’s the most likely place where he’s going to see more than just family. But [the phone] kind of bounces around...He didn’t like that thing on his chest. It was just really awkward...Cause it’s not very secure in that position. It doesn’t stay down. If you stand up it just-or bend over it drops forward, right?...I think it’s kind of dangerous to have it flopping around.*

Feedback on the watch was mixed. Some felt it was too bulky, whereas others thought it fit nicely and was esthetically pleasing. Similarly, some felt the watch face was too small to read the text, whereas others thought it was sufficiently large.

Recommendations

Although most participants did not find the technology useful in its current state, most felt it had the potential to be beneficial. Many offered recommendations for how the SSA technology could be improved to maximize its usefulness for persons with memory loss and their caregivers. A number of participants recommended improving the enrollment process by allowing users to upload photos of the enrollee’s face instead of taking their picture. Several participants suggested replacing the phone and watch with something less obtrusive and conspicuous. Participants suggested replacing the watch with an earpiece. Arnie (caregiver, 75) recommended:

> *I have a Bluetooth interface between my hearing aids. Being able to, for instance, have some way of recognizing a face the way this system is designed, and to be able to speak—rather than look at my watch—to be able to hear the name of the person in my ears without even anything more than that would be extremely helpful. Even to someone who has no hearing aids. But being able to put something as inconspicuous [as an] earphone, to be able to connect*

> *wirelessly to a system that would recognize a face and put a name to it would be extremely helpful.*

Many also felt the phone was too obtrusive. Instead of the phone, they recommended a lapel pin, brooch, pendant, or necklace with a camera.

Discussion

Principal Findings

Results indicate that issues of participant eligibility, willingness to be randomized, and retention are not major barriers to conducting a full-scale RCT to evaluate the SSA. However, it is noteworthy that all participants who withdrew from the study or who were lost to follow-up were in the intervention group. There were no significant differences between baseline demographic measures of the groups, suggesting that randomization was successful despite the small sample size.

Feasibility and utility scores for both 3- and 6-month time points were 3.11 and 3.10, respectively, indicating participants felt neutral about the SSA. Our findings also suggest that the SSA may not have significant effects. Due to the small sample size, these results should be interpreted with caution and are subject to further investigation in a larger sample. The absence of empirical intervention effects is supported by the qualitative analysis, which revealed that the majority of participants did not find the SSA useful. Anecdotally, many participants mentioned they were not using the SSA, and a number of participants in the intervention group have contacted the study staff wishing to return the technology since the study ended. The qualitative analysis provides insight into why the SSA had few significant effects and provides recommendations for improving the technology. The majority of the participants interviewed did not feel their use of the SSA had any impact on the person with memory loss’s social interactions or quality of life. A few did note positive outcomes such as increased confidence and independence. Conversely, others mentioned negative outcomes such as increased frustration, agitation, tension between the caregiver and person with memory loss, and caregiver burden.

The qualitative analysis indicates five primary reasons explaining why the SSA was not useful to participants: complexity, the enrollment process, impracticality, stigma, and functionality. Concerns about the complexity, enrollment process, and functionality of the SSA are consistent with similar evaluations of assistive technology reporting usability and technical reliability as barriers to use among persons with memory loss. Assistive technology that requires wearing any form of equipment has been found to be stigmatizing in other studies (particularly for persons with memory loss); however, increased attention to esthetics may reduce the stigmatization of wearable assistive technology [12,19,20].

Future Research

Based on the findings of this pilot study, a full-scale RCT should invest significant time and resources in recruitment. In this study, recruitment was a challenge despite the use of newspaper advertisements and community outreach. Future assistive technology research in this population may consider partnering with community-based organizations to recruit participants. Subsequent research on assistive technology should also measure time spent using the technology and participants’ level of comfort with technology.

Although most participants reported having limited use for the SSA, almost all were enthusiastic about its potential benefit to persons with memory loss. Several offered suggestions for modifications to make it more useful. Before a full-scale RCT is conducted on the SSA, modifications recommended by participants should be addressed. Specifically, the process of enrolling users in the SSA database should be made less cumbersome and the SSA equipment should be replaced with less obtrusive and conspicuous options.

Findings from this pilot study highlight the importance of user-centered design and testing for future development of assistive technology in dementia and memory loss care. It is imperative that future assistive technology development goes beyond understanding theoretical causes and implications for cognitive impairment to understand what the person with memory loss wants from the technology [8]. Persons with memory loss and their care partners should be involved early in the process of assistive technology development [12]. As is evident in this pilot RCT, their insights should be incorporated in any future adaptation, full-scale evaluation, and dissemination of the SSA or similar technologies.

Strengths and Limitations

Assistive technology can give persons living with memory loss the ability to participate in meaningful and engaging activities; however, scientific evaluation of such assistive technology use remains limited [10,12,14]. This study fills a gap in the literature by evaluating the potential for an assistive technology device designed to improve the social interactions of individuals with memory loss. A strength of this study is the inclusion of both caregivers and persons with memory loss, incorporating the perspectives of all intended users. The study also included Spanish-speaking participants, allowing for a more ethnically diverse sample.

This study also has a number of limitations. As noted previously, this study was not considered a pilot RCT a priori, and it could be considered an underpowered RCT due to the challenges reported here (eg, small sample size, recruitment/enrollment issues, little evidence that the SSA exerts meaningful effects on key outcomes). Another limitation is that potentially important feasibility/utility outcomes such as time spent using the SSA and prior technology use were not collected because the study was not designated as a pilot a priori. However, the robust qualitative data available allowed us to reach a key conclusion more aligned with a pilot RCT design: that the SSA may require significant modification before it could proceed to a full-scale RCT and as an intervention that could exert both statistically and clinically significant benefits for persons living with memory loss and their care partners.

Another potential limitation is the inclusion of individuals with mild cognitive impairment and subjective memory loss in addition to those with a diagnosis of dementia. Although individuals with subjective memory loss may experience the intervention differently than individuals with dementia, we felt it was important to include individuals without a formal diagnosis. According to the Alzheimer's Association, a substantial proportion of those who would meet the diagnostic criteria for dementia are not given a diagnosis by a physician. Further, fewer than half of Medicare beneficiaries in the United States who have a diagnosis of dementia in their health records report being told of the diagnosis. As such, a large number of individuals living with dementia and their caregivers may not know they have dementia (at least in the United States) [2].

The accidental exclusion of the PES-AD from the baseline survey of participants with memory loss is another limitation. This error resulted in no baseline measure of PES-AD for the 13 participants with memory loss; however, all other measures of quality of life and social interaction were not impacted by this omission. Another limitation is that neither participants nor researchers were blinded; however, in a study such as this it would not have been feasible to render the intervention blind. Additionally, qualitative data were collected via telephone interview, which may not allow for the exploration of the user's experience of the SSA as an in-person interview would. Finally, the study has limited racial and ethnic diversity despite the translation of materials into Spanish and the inclusion of a Spanish-speaking research assistant.

Conclusions

Many effective assistive technologies have been developed to improve the management of care and quality of life for caregivers of persons with memory loss [21-23]; however, there is a need to develop effective assistive technology that improves the quality of life of persons with memory loss. This study indicates that randomization procedures were sound but that retention and recruitment procedures should be addressed before scaling up to an RCT. The assessment of intervention effects suggests that the SSA may not exert significant effects on quality of life and social interactions. Feasibility and utility data reveal that participants had generally neutral feelings toward the SSA. Qualitative findings suggest reasons why the facial recognition software did not improve outcomes and provide recommendations for future assistive technology development and evaluation.

One of the most prominent challenges for caregivers and persons living with memory loss is finding meaningful activities to engage in. Assistive technology that allows persons living with memory loss to maintain some level of autonomy when socializing or participating in desired activities harbors potential to maintain quality of life and remains a priority for future experimental research efforts.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
CONSORT EHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 406KB - aging_v2i1e13378_app1.pdf]

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Abbreviations

DQoL: Dementia Quality of Life
HIPAA: Health Insurance Portability and Accountability Act
PES-AD: Pleasant Events Schedule-Alzheimer’s Disease
RCT: randomized controlled trial
SSA: Social Support Aid

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Original Paper

Evaluating the Impact of Music & Memory's Personalized Music and Tablet Engagement Program in Wisconsin Assisted Living Communities: Pilot Study

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Abstract

Background: Individuals with Alzheimer disease or related dementia represent a significant and growing segment of the older adult (aged 65 years and above) population. In addition to physical health concerns, including comorbid medical conditions, these individuals often exhibit behavioral and psychological symptoms of dementia (BPSD). The presence of BPSD in long-term care residential facilities can disrupt resident's care and impact staff. Nonpharmacological interventions such as personalized music and tablet engagement maintain cognitive function, improve quality of life (QOL), and mitigate BPSD for older adults with dementia. Evidence of the impact of such interventions in assisted living communities (ALCs) is needed for widespread adoption and sustainment of these technologies.

Objective: The aim of this study was to assess the impact of Music & Memory's personalized music and tablet engagement (PMATE) program on QOL, agitation, and medication use for residents living in 6 Wisconsin ALCs.

Methods: The data collected were on the utilization of iPods and iPads by the residents. Residents' outcomes were assessed using the Pittsburgh Agitation Scale, the Quality of Life in Late Stage Dementia scale, and self-reported medication use. A mixed-methods approach was utilized to examine the impact of the PMATE program on these outcomes. Descriptive statistics were calculated. A paired *t* test explored changes in residents' QOL. A 1-way analysis of variance was utilized to examine changes in resident's agitation and QOL based on the resident's utilization of the PMATE program. Qualitative interviews were conducted with the individuals responsible for PMATE implementation in the ALC. Residents excluded from the analysis were those who passed away, were discharged, or refused to participate.

Results: A total of 5 apps, based on average times used by residents, were identified. In all, 4 of the 5 apps were rated as being useful to promote residents' engagement. PMATE utilization was not associated with changes in the residents' agitation levels or antipsychotic medication use over time. Over a 3-month period, the change in residents' QOL was significant (P=.047), and the differences across ALCs were also significant (F_{25}=3.76, P=.02). High utilizers of the PMATE program (>2500 min over 3 months) showed greater improvements in QOL as compared with low utilizers (a change of −5.90 points vs an increase of 0.43 points). The difference was significant (P=.03). Similar significant findings were found between the high- and midutilizers.

Conclusions: The study is one of the first to explore the impact of Music & Memory's PMATE program on residents living in ALCs. Findings suggest that higher utilization over time improves residents' QOL. However, a more comprehensive study with improved data collection efforts across multiple ALCs is needed to confirm these preliminary findings.

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KEYWORDS

Music & Memory; assisted living facilities; quality of life; agitation; medication adherance; iPod; iPad; implementation science; patient participation

Introduction

Background

Individuals with Alzheimer's disease or related dementia (ADRD) represent a significant and growing segment of the older adult (aged 65 years and above) population. In 2013, approximately 5 million older adults were diagnosed with ADRD with an estimated US $214 billion spent on medical office visits, medications, or formal/informal caregiving [1,2]. Long-range forecasts project that the number of older adults aged 65 years and above with ADRD will almost triple to 14 million by 2050 and health care expenditures will more than double to US $511 billion by 2040 [1,3,4]. This dramatic rise will place a major burden on long-term care facilities such as nursing homes (NHs) and assisted living communities (ALCs). Studies suggest that between 42% and 67% of residents living in ALCs have some form of moderate-to-severe cognitive impairment [5-7]. The state of Wisconsin is experiencing similar trends. In 2010, Wisconsin had almost 120,000 residents with ADRD. With a capacity for approximately 55,000 residents to reside in Wisconsin ALCs, national trends [1] would suggest that at least 15,500 of these individuals, or 28% of ALC residents, have some form of dementia. In addition, 48.7% of licensed Wisconsin ALCs provide care to individuals with ADRD [8].

Dementia Complications

Aggression, agitation, anxiety, or sundown syndrome are examples of behavioral and psychological symptoms of dementia (BPSD). These symptoms are frequently exhibited by individuals with moderate-to-severe dementia [5,9-12], can disrupt residents' care, and negatively impact staff and residents' quality of life (QOL). Although medications can control the physical aspects of BPSD, the medications may impact residents' health, diminish a resident's ability to participate in life events, and accelerate the disease [13-15]. However, there is currently an emphasis on person-centered care [16] or care that accounts for individual preferences. Some person-centered interventions for dementia include cognitive or motion-oriented (eg, reminiscence therapy), sensory stimulation (eg, visual or music therapy), and behavior management techniques [17]. These nonpharmacological interventions maintain cognitive function, mitigate individual behavior issues for older adults with dementia, improve residents' agitation levels, improve QOL, and reduce medication use for nursing home residents with dementia [18-21].

Music Interventions

Music therapy is a type of nonpharmacological intervention involving individual engagement through active or passive listening [22,23]. The impact on residents' outcomes is mixed. For example, a group music therapy intervention (ie, listening to music) has been shown to have no effect on changes in aggressive behaviors such as agitation and anxiety [24-28]. Other studies suggest that music therapy, depending on its focus (active vs passive), delivery mechanism (individual vs group session), and frequency (weekly vs biweekly), improves residents' BPSD including aggression, agitation, anxiety, and sundown symptoms, as well as QOL [27-36]. Individual music therapy sessions reduce agitation, disruptiveness, combativeness, and elopement, as well as the use of restraints and medications in individuals with dementia [37-39]. However, these studies were conducted in NHs or hospitals. Therefore, it is unclear if a personalized music intervention would improve BPSD or QOL for individuals with dementia living in ALCs. This study evaluated personalized music and tablet engagement (PMATE) programs in Wisconsin ALCs.

Objectives

Music & Memory Overview

The Wisconsin Department of Health Services (DHS) introduced Music & Memory to Wisconsin NHs in 2013 after the staff attended a conference where they viewed a video clip featuring Henry coming alive while listening to his personalized music [40]. Henry, the star of the 2014 Sundance Award—winning documentary film *Alive Inside, A Story of Music & Memory*—was among the first individuals Dan Cohen, MSW, Executive Director of Music & Memory [41], assisted in reconnecting with his personhood. The film highlights the power of individualized music to unlock the minds of those living with ADRD. The film follows Cohen in his efforts to "demonstrate music's ability to combat memory loss and restore a deep sense of self to those suffering from it" [42,43]. The mission of Music & Memory is to bring "personalized music into the lives of the elderly or infirm through digital music technology, vastly improving quality of life."

Music & Memory is a personalized music program, not music therapy. Individual care professionals or a team of caregivers is trained to create powerful personalized music playlists for each individual participant. The personalized music is provided to the participant through the use of iPods and other related digital audio devices. The personalized music enables individuals living with ADRD, as well as those with other cognitive and physical challenges, to reconnect with the world through music-triggered memories.

Wisconsin DHS was the first to adopt Music & Memory as a statewide initiative, with 25 states following suit. At the time of adoption, Music & Memory was in less than 700 NHs worldwide. As of 2018, more than 5000 organizations have adopted Music & Memory, with more than 400 organizations in Wisconsin [41]. Expansion is not just measured by the number of organizations who have adopted the program but also by the adoption in a wide variety of environments including ALCs and NHs as well as in the community [41].

In addition to the use of iPods, Music & Memory has introduced the use of iPads or tablets to further personalize the engagement of individuals with dementia. For this study, the term *engage* or *engagement* with regard to iPads or tablets refers to residents choosing to participate or not participate in iPad or tablet activities. These software app–driven activities include playing familiar games, reminiscing about life stories with music, viewing Web-based images or using Google Earth, dabbling in art, and reactivating lifelong learning interests.

iPads or tablets enhance residents' emotions through the use of multisensory activities. The availability of a wide range of software and apps, and internet access, allows for tailoring to residents' interests or hobbies, resulting in more meaningful, pleasurable activities for the residents. YouTube, entertainment, family photographs, games, Alzheimer's apps, music videos, and Skype, for example, help reduce residents' boredom and isolation while enabling greater independence, productivity, connection, and socialization [44]. Also, one study found that iPads increase caregiver confidence and their ability to engage socially and improve their personal life and health [45].

Music & Memory Impact

Further studies indicate that Music & Memory's personalized music program can reduce disruptive behaviors, major depressive episodes, residents' behavioral disturbances, and the use of antipsychotic or anxiolytic medications; improve residents' moods and reduce disruptive behaviors; or enhance swallowing in individuals with advanced dementia [46-48]. For example, an implementation in 2 memory care units within NYC Health + Hospitals, involving more than 100 patients, showed a reduction in the use of antipsychotic medications, physical altercations, and falls for residents who participated in the Music & Memory program [46]. However, results were mixed from several Wisconsin NH Music & Memory pilot projects targeting residents (eg, agitation and medication use) or caregivers (eg, job satisfaction and distress) [49-51]. These early implementations of Music & Memory lacked the robust support and training systems of today, including an online care community that promotes collaboration, continuous Web-based training for staff turnover and program expansion, and webinars to help NHs with implementation for specific populations.

Despite these findings, a more effective evaluation of nonpharmacological interventions, such as PMATE in ALCs, is needed [52]. Furthermore, it has been suggested that the intervention focuses not only on the personalization of the music (eg, linkage to personal history) but research should also explore the impact of music on individual resident and facility outcomes [53]. This study addresses this gap and reports on the implementation of Music & Memory's PMATE program in 6 Wisconsin ALCs and its impact on individual residents' outcomes.

Methods

Study Setting

This pilot study evaluated the impact of the PMATE program on residents' agitation and QOL in a convenient sample of ALCs in Wisconsin. Eligibility criteria included being an ALC in good standing with the Wisconsin Coalition for Collaborative Excellence in Assisted Living (WCCEAL) [54], having a primary population of individuals with ADRD, 25 beds or less, and a minimum of 4 residents on antipsychotic or antianxiety medication. An application (see Multimedia Appendix 1) was developed to assist with recruitment, which described the study including eligibility criteria. Upon completion of the application, interested ALCs agreed to implement Music & Memory as trained and to participate in the study evaluation. The 4 Wisconsin assisted living associations helped in recruiting ALCs that were also WCCEAL members. The association staff selected 6 ALCs (see Multimedia Appendix 2 for attributes) from the 14 applications received to participate in this initiative. After completing Music & Memory's PMATE training (see the training section for details), each ALC was provided with the equipment needed to implement the program. The equipment included a US $100 iTunes gift card, 1 external speaker, 1 headphone splitter, an average of 6 iPod Shuffles, headphones, and alternating current adapters for resident or tenant use. In addition, each ALC received an iPad Mini and iPad Pro. The iPad Pro, with a 12.9-inch retina screen, was provided for ease of residents' viewing. The iPad Mini was intended for staff training and familiarity and was not intended for use with residents. To help provide focus for the tablet sessions and to help promote positive outcomes, the apps selected and loaded on the iPads were centered on traditional activity-based subjects, such as reminiscing, that are both beneficial and engaging for people with cognitive impairment. The process of choosing the apps for this study was largely based on the research for, and results of, two community memory loss iPad programs [55,56], created by author DD.

These initial iPad memory loss programs used apps from 4 basic types of engagement activities—reminiscing, music, images, and games—which have been conceptualized differently for this study. Music & Memory added the app categories of lifelong learning and relaxation, and music was not considered as an app category owing to the study's use of personalized music with iPods. The final tablet engagement categories included apps from relaxation, lifelong learning, life stories, and games, as defined in the Data Collection section.

All apps loaded onto the iPad were available in the public domain. The most important requirement for successful app selection within the categories was deemed to be simplicity. However, simplicity is not the goal of most app developers. Bells and whistles, such as timers on games, pop-up ads, flashy elements to entice use, and gamification in general, are not helpful for people with memory loss and can, in fact, detract from the apps' effectiveness. In addition, the childish nature of simple apps can often infantilize the older users. For example, while looking for an easy crossword puzzle, it was discovered that the majority of simple puzzles were made for children with character sounds and rewards; see Multimedia Appendix 3 for a description of the apps included on the iPad.

Music & Memory Staff Training

Participating ALCs designated one person from the staff to serve as the project lead and another to serve as an alternate. The staff received training (three 90-min live webinars) on how to implement Music & Memory's personalized music program within their facility as well as 3 60-min live webinar trainings on how to use the iPad and the associated apps. Communities were encouraged to have all interested staff attend the training, as greater success is evident in organizations when multiple staff members receive training and are involved in the day-to-day operations of the program. Communities became certified as a Music & Memory organization upon completion of the training. The value of the training and equipment, provided at no cost to each ALC, was over US $1500. Intervention checks were not completed outside of the initial Music & Memory training or the evaluation. Due to high staff turnover, one ALC received an in-person visit from Music & Memory's dedicated staff member in the state. The ALC staff was encouraged to request additional support, as needed, which included access to Music & Memory's dedicated staff members.

Data Collection

The data collection in the study included residents' outcomes related to agitation, QOL and medication use, utilization of iPods to listen to music (frequency and length of time), app utilization on the iPad (frequency, time, and impact on the resident), and information on antipsychotic medications. In addition, phone interviews were conducted with the project lead from each participating ALC to understand how integrating PMATE into daily care impacted staff interactions with residents. Each data collection item is described below.

The Pittsburgh Agitation Scale (PAS) allows an observer to rate the severity of agitation related to dementia within individuals [57]. The PAS examines 4 general behavior groups: (1) aberrant vocalizations; (2) motor agitation; (3) aggressiveness; and (4) resisting care related to washing, dressing, eating, and medications. Raters used a 4-point scale when assessing residents' behaviors over a 7-day period. Application of the PAS in a geropsychiatric unit (ICC=.82) and NH (ICC=.93) showed high inter-rater reliability [57]. The PAS also inquires about hours of sleep for the residents during the observation period. In this study, the ALC staff were asked to conduct a weekly assessment (Monday to Friday) on each resident, and based on their observations, the residents' level of daily agitation was rated. In addition, the staff recorded hours of sleep during the rating period and whether physical restraints, PRN medications, Music & Memory, or other interventions were utilized to control a resident's agitation. PAS data were collected at 4 time periods in 2016: April 4 to April 8, May 2 to May 6, June 6 to June 10, and July 4 to July 8.

The Quality of Life in Late Stage Dementia (QUALID) is an 11-item scale that measures the QOL for an individual with late-stage dementia [58]. A professional caregiver who had regular resident contact and was familiar with the resident's general behavior completed the QUALID scale. The QUALID scale has high internal consistency reliability (alpha=.77), test-retest reliability (ICC=.81), and inter-rater reliability (ICC=.83) [58]. The individual completing the QUALID scale must have spent a significant portion of 3 of the last 7 days with the resident to accurately rate the items on the scale. To calculate a QUALID scale score, each item is scored on a 1 to 5 scale with the sum of the scores ranging from 11 to 55 points to represent the residents' overall QOL. Lower scores represent a better QOL. For this study, the ALC staff assessed residents' QOL at baseline on or around April 11 or 12, 2016, reflecting the residents' behavior during the week of April 3 to April 8, 2016, and again post intervention on or around July 12 or 13, 2016, related to residents' behavior during the week of June 4 to July 8, 2016.

For each participating resident, the ALC staff was asked to track residents' use including dose and frequency of antipsychotic medications from March through June 2016. The ALC staff also recorded iPod and iPad app utilization (date and time) and ranked the usefulness of the app in promoting residents' engagement using a 4-point scale (4=Very Useful, 3=Somewhat Useful, 2=Not Very Useful, and 1=Not at all useful). As a condition of study participation, residents' demographic information was not collected; therefore, a resident's profile could not be established.

The research team trained the staff from the participating ALCs on how to collect and report the data and provided a project binder to record the outcomes for each resident who participated in the pilot. The pilot timeline is shown in Multimedia Appendix 4. An overview of the data collection process is shown in Multimedia Appendix 5.

Data Analysis

Descriptive statistics related to residents' agitation, QOL, and change over time were calculated. No resident characteristics were collected as a part of this pilot study per the agreement with the assisted living associations.

In addition, iPod and iPad utilization (time and count) were calculated across the sample and by participating ALCs. The iPad app use statistics assessed the total number of times an app was used; the total number of residents using an app as well as the maximum number of times a specific resident used an app; the average number of times an app was used across all residents; and the percent of residents utilizing a given app. Quartiles based on total iPod and combined iPod and iPad use in minutes were determined. Statistics on the average usefulness of each iPad app were also determined.

A one-way ANOVA was utilized to examine changes in residents' agitation as well as the 4 behavior groups, scored by month when the intervention was the PMATE (0=No, 1=Yes) and if changes in the overall agitation score was related to total iPod or iPod and iPad utilization by quartile. A stepwise regression explored if the residents' agitation score from the previous day, hours of sleep during the observation period, and the use of the PMATE program could predict the current agitation score.

A paired sample *t* test determined if residents' QOL scores changed significantly over time. Residents were grouped based on their total PMATE utilization into 3 categories: <1000 min; between 1000 and 2500 min; and >2500 min of total use. A one-way ANOVA was utilized to determine if pre- and post-QOL scores differed by ALC and to explore changes in QOL scores by ALC and total PMATE utilization in minutes. Missing values for the pre-QOL scores were imputed, and a sensitivity analysis based on a sample of 29 matched pairs was performed to verify results.

Residents who passed away, were discharged, or refused to participate (n=6) were excluded from the analysis. Interviews were conducted with all 6 participating ALCs about their experiences with the PMATE program in their community. The analysis focused on the impact of the intervention on ALC residents and its impact on staff interactions. The study has been approved by the Health Sciences Minimal Risk Institutional Review Board at the University of Wisconsin–Madison (2016-0835).

Results

Data collection notebooks were returned by 5 of the 6 ALCs and contained data from 35 residents. Table 1 shows the utilization of the iPod and iPad by residents within an ALC and the total across all residents in the ALC.

The frequency of iPad app utilization and usefulness in promoting residents' engagement was determined for all residents and for all residents excluding those who passed away, were discharged, or refused to participate. The resulting information is shown in Multimedia Appendix 6. The top 5 apps (based on average times used by resident) in both groups were (1) Puzzable, (2) Colorfy, (3) Ted Talks, (4) Image Search, and (5) Words-Osmo. Across the 2 groups, 4 of the top 5 apps in terms of usefulness to promote residents' engagement were also the most frequently utilized (Image Search, Garage Band, Take a Break, and Ted Talks). Across all residents, Adobe Voice was rated more useful as compared with Puzzable for the exclusionary sample of residents. Figure 1 shows the average number of apps used per session versus the average minutes of iPad usage by residents within the ALC. Across the sample, residents utilized an average of 1.8 apps per session for approximately 23 min. Of the other apps utilized, 57 were not identified in the workbook. Of those identified, 26 uses were for Baby Bath, 2 for Music (unidentified), and 1 each for a Nature app, Talking Ben, YouTube songs, and YouTube and Photo.

Residents' agitation scores (total and by individual behavior group) decreased over time. However, no significant differences in PMATE utilization to address residents' agitation were found (results not shown). Similar nonsignificant findings were found from the regression analysis as well as the comparison with the change in overall agitation score by total utilization, measured in minutes, of the iPod as well as the iPod and iPad combined.

The QOL analysis was limited to 26 matched resident pairs with both a pre- and post-QOL score. Table 2 shows no significant differences across the ALCs in the pre- or post-QOL scores. At baseline, the average QOL score per ALC ranged from 19.2 (ALC 1) to 27.0 (ALC 4) indicating more positive resident QOL. Over a 3-month period, the change in residents' QOL was significant (P=.047), and the differences across ALCs were also significant (F_{25}=3.76, P=.02). Changes in QOL for individual residents are shown in Multimedia Appendix 7. Figure 2 shows the changes in QOL by total PMATE utilization over the 3-month period (April to June 2016). The difference between the groups is significant (F_{25}=5.09, P=.02), with the differences between the high utilizers as compared with the low (P=.032) and medium (P=.035) utilizers of the PMATE program being significant. Results from the sensitivity analysis (not shown) confirmed these findings.

Residents' use of medications by classification included antipsychotic (n=12), antidepressant (n=18), antianxiety (n=10), Alzheimer or dementia (n=9), or mood stabilizer (n=7). A total of 11 residents were on pro re nata (PRN) behavioral medications, and 2 residents went from scheduled to PRN medications. Although PRN medication use appeared to have decreased, the sample size was too small to draw conclusive evidence. However, the staff in 1 ALC was able to describe the impact of the PMATE program on 1 resident's medication use, stating the following:

> *We had a lady here that was declining, pretty steadily cognitively, with her speech; she was just not talking much anymore. Her gait was declining. She was part of our program. She has become very alert and interactive again, talking again, more mobile again. I have been able to get her off all her behavioral meds. Her family just could not believe the huge turnaround that she had*

Table 1. Total self-reported iPod and iPad use and minutes by residents within an assisted living community (ALC).

ALC and resident	iPod			iPad		
	Times utilized	Minutes utilized	Average minutes per use	Times utilized	Minutes utilized	Average minutes per use
ALC 1 (total)	**270**[a]	**7481**	**27.71**	**190**	**4462**	**23.48**
1	63	1732	27.49	43	870	20.23
2	52	1370	26.35	48	1610	33.54
3	27	249	9.22	48	1302	27.13
4	64	2000	31.25	33	465	14.09
5	64	2130	33.28	18	215	11.94
ALC 2 (total)	**45**	**3280**	**72.89**	**55**	**1287**	**23.40**
1	8	185	23.13	10	104	10.40
2	1	30	30.00	13	128	9.85
3	6	175	29.17	11	285	25.91
4	7	95	13.57	6	150	25.00
5[b]	5	2070	414.00	1	10	10.00
6	7	395	56.43	6	415	69.17
7	10	300	30.00	8	195	24.38
8[b]	1	30	30.00	N/A[c]	N/A	N/A
ALC 3 (total)	**133**	**10,812**	**81.29**	**47**	**735**	**15.64**
1	26	2272	87.38	8	170	21.25
2	19	1505	79.21	8	135	16.88
3	14	1740	124.29	N/A	N/A	N/A
4	8	870	108.75	3	45	15.00
5[b]	6	710	118.33	2	20	10.00
6	14	750	53.57	11	170	15.45
7	19	1225	64.47	8	115	14.38
8	14	945	67.50	6	75	12.50
9	13	795	61.15	1	5	5.00
ALC 4 (total)	**203**	**17,858**	**87.97**	**70**	**2405**	**34.36**
1	33	2390	72.42	18	645	35.83
2[b]	52	4388	84.38	11	375	34.09
3	32	2910	90.94	15	520	34.67
4	27	2155	79.81	14	495	35.36
5[b]	57	5990	105.09	12	370	30.83
6[b]	2	25	12.50	N/A	N/A	N/A
ALC 5 (total)	**233**	**24255**	**104.10**	**44**	**1035**	**23.52**
1	41	5230	127.56	6	135	22.50
2	42	5195	123.69	8	210	26.25
3	26	2245	86.35	6	105	17.50
4	32	2505	78.28	6	135	22.50
5	29	2560	88.28	5	90	18.00
6	37	4345	117.43	7	210	30.00

ALC and resident	iPod			iPad		
	Times utilized	Minutes utilized	Average minutes per use	Times utilized	Minutes utilized	Average minutes per use
7	26	2175	83.65	6	150	25.00
Grand total	**884**	**63,686**	**72.04**	**406**	**9924**	**24.44**

[a] Bolded values signify the total utilization (times and minutes) as well as the average time across all residents in the ALC.

[b] Data from 6 residents who passed away, were discharged, or refused to participate were excluded from subsequent analysis.

[c] N/A: not applicable.

Figure 1. Assisted living community resident iPad app use by average apps used per session versus self-reported iPad use in minutes.

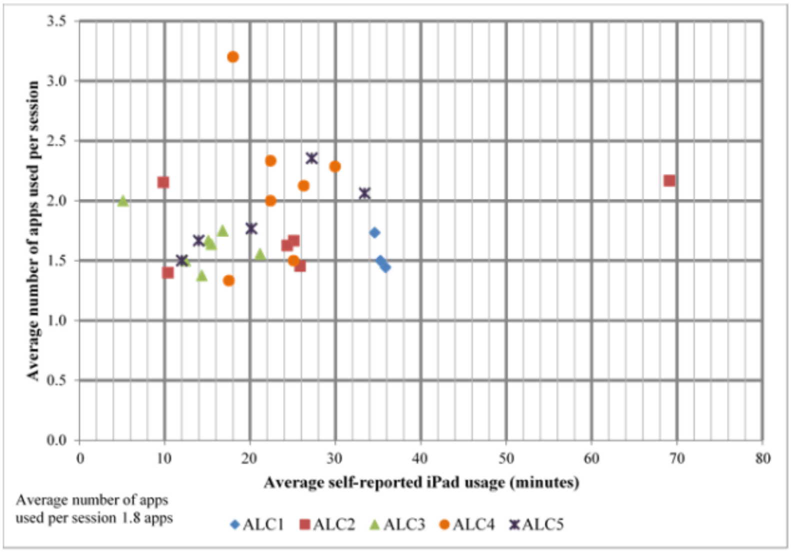


Table 2. Residents' quality of life (QOL)—pre, post, and changes over time by assisted living communities.

ALC[a]	Number of residents	Pre-QOL[b], mean (95% CI)	Post-QOL[c], mean (95% CI)	Change in QOL[d], mean (95% CI)
ALC 1	5	19.20 (14.36 to 24.04)	16.00 (9.26 to 22.74)	−3.20 (−6.41 to 0.01)
ALC 2	6	21.00 (14.23 to 27.77)	21.67 (15.85 to 27.49)	0.67 (−3.87 to 5.20)
ALC 3	5	22.80 (17.73 to 27.87)	21.90 (17.73 to 26.07)	−0.90 (−2.57 to 0.77)
ALC 4	3	27.00 (6.67 to 47.33)	16.00 (7.04 to 24.96)	−11.00 (−23.91 to 1.91)
ALC 5	7	26.43 (20.99 to 31.87)	25.29 (16.31 to 34.26)	−1.14 (−7.03 to 4.72)
Total[e]	26	23.15 (20.84 to 25.46)	20.94 (18.23 to 23.65)	−2.21 (−4.28 to −0.14)

[a] ALC: assisted living community.

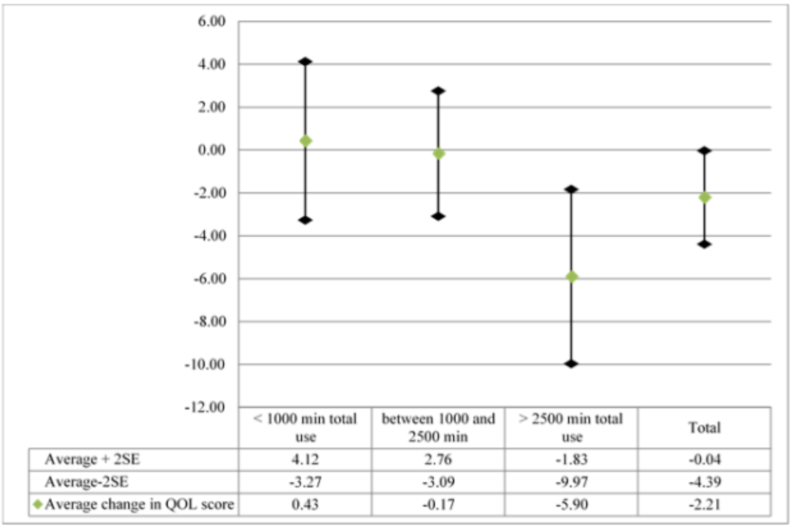
[b] No significant differences in pre-QOL across ALC (*P*=.18).

[c] No significant differences in post-QOL across ALC (*P*=.11).

[d] Change in QOL differs significantly by ALC (*P*=.02).

[e] Overall residents' QOL decreased significantly by 2.21 points (*P*=.047).

Figure 2. Changes in Quality of Life by Total Minutes using Music & Memory (iPod and iPad).



	< 1000 min total use	between 1000 and 2500 min	> 2500 min total use	Total
Average + 2SE	4.12	2.76	-1.83	-0.04
Average-2SE	-3.27	-3.09	-9.97	-4.39
◆ Average change in QOL score	0.43	-0.17	-5.90	-2.21

Discussion

Principal Findings

The study is one of the first to explore the impact of the Music & Memory PMATE program on residents living in ALCs. Findings suggest that higher utilization over time improves residents' QOL and that use of the PMATE program might be related to changes in agitation. The QOL for individuals with dementia in ALCs is similar to other individuals living with dementia who reside in NHs or other long-term care settings [58-62]. Our results found significant positive changes in QOL were influenced by PMATE exposure. Earlier studies suggested no or worsening change in QOL for individuals with dementia post pharmaceutical and nonpharmaceutical intervention implementation [61-65]. Application of the comfort versus discomfort subscales in our sample [66] showed a greater reduction, on average, of discomfort (−1.96) versus comfort (−0.36) in residents' QOL. Residents with the highest PMATE exposure (>2500 min) showed similar results.

Elements of discomfort observed in the study included emotional expressions such as appears sad, cries, has facial expression of discomfort, appears physically uncomfortable, verbalizes discomfort, irritable, or aggressive. Residents displaying these negative emotions exhibited improvements after utilization of the PMATE program, more so than residents who were already enjoying elements of comfort. Elements of comfort include the following: appears calm and comfortable, smiles, enjoys eating, enjoys touching or being touched, and enjoys interacting with others. In this subscale, the technological and nonpharmacologic PMATE intervention contributes to positive mood management through person-centered care for residents. Our study results provide promising evidence that PMATE exposure positively impacts residents' QOL; however, further research is needed in a larger sample of residents to confirm these findings.

In our study population, PMATE exposure had no significant impact on changes in residents' agitation. Although residents' agitation across the sample decreased over time, these changes appear to be a resident-specific phenomenon. The true impact of the PMATE program on residents' agitation levels may be masked by the small sample size and the inadequate reporting of the intervention used. For individual residents, PMATE use may result in a decrease in antipsychotic medication dependence. Despite these findings, staff reported that residents' PMATE participation did impact the residents as well as their interactions with them. As the staff in one ALC stated:

> *You could just see immediately, the resident would light up and it would even calm the staff somewhat because if the resident is very tense, and you do everything you can think of to help this resident, and then you put the music on, and if it relaxes them, I think it in turn helps the staff*

Another ALC expressed the positive impact on staff saying that "it gets them more involved with the residents and getting to know how they interact, what changes mood." However, a more comprehensive study across multiple ALCs is needed to confirm these preliminary findings.

Limitations

The study has several limitations. The small resident sample size (n=26) and a missing workbook from one ALC, which could have provided data for 6 additional residents, are a couple of the limitations. Self-reporting of resident outcomes and PMATE utilization, especially iPod use, represented another study limitation. Future studies should explore automated data collection for iPod and iPad utilization, which would decrease staff burden and increase accuracy. Missing data, especially for medication use, was another limitation. Depending on the sample size, chart reviews of medication use, or electronic health record extractions should increase the accuracy of changes in medication use over time for ALC residents. Finally, the study was limited to a 3-month period, which was not an adequate time period to assess antipsychotic medication use and implement changes based on the residents' PMATE interactions.

Conclusions

The use of nonpharmacological interventions, such as personalized music, is intended to maintain cognitive function, improve QOL, and help mitigate individual behavioral issues for older adults with ADRD. This pilot study represents a foundational step, providing researchers and practitioners with evidence that offering access to Music & Memory's PMATE program may be effective in improving outcomes associated with behavioral and psychological symptoms of dementia for residents living with ADRD in ALCs. These benefits, by virtue of their interactions with residents, are transferred to ALC staff through an enhanced sense of trust and improved relationships. Future research across a larger sample of ALC residents is needed to evaluate the impact of intervention dose levels on residents' outcomes and to identify effective approaches to implementing and sustaining the PMATE program in ALCs.

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Conflicts of Interest

MP is the cofounder of Generation Connect, which is a team of aging experts and technologists that work together with forward-thinking care organizations to build engagement solutions that promote person-centered care through technology innovation. DD joined Generation Connect after this pilot was completed. All other authors report no conflict of interest.

Multimedia Appendix 1
Assisted living community application.
[PDF File (Adobe PDF File), 113KB - aging_v2i1e11599_app1.pdf]

Multimedia Appendix 2
Attributes of participating assisted living communities.
[PDF File (Adobe PDF File), 120KB - aging_v2i1e11599_app2.pdf]

Multimedia Appendix 3
Tablet engagement apps.
[PDF File (Adobe PDF File), 185KB - aging_v2i1e11599_app3.pdf]

Multimedia Appendix 4
Park Family Foundation project timeline.
[PDF File (Adobe PDF File), 264KB - aging_v2i1e11599_app4.pdf]

Multimedia Appendix 5
Project evaluation binder.
[PDF File (Adobe PDF File), 254KB - aging_v2i1e11599_app5.pdf]

Multimedia Appendix 6
iPad app utilization and average usefulness of the app in promoting resident engagement.
[PDF File (Adobe PDF File), 116KB - aging_v2i1e11599_app6.pdf]

Multimedia Appendix 7
Changes in resident level quality of life.
[PDF File (Adobe PDF File), 90KB - aging_v2i1e11599_app7.pdf]

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Abbreviations

ADRD: Alzheimer disease or related dementia
ALC: assisted living community
ANOVA: analysis of variance
BPSD: behavioral and psychological symptoms of dementia
DHS: Department of Health Services
NH: nursing home
PAS: Pittsburgh Agitation Scale
PMATE: personalized music and tablet engagement
PRN: pro re nata
QOL: quality of life
QUALID: Quality of Life in Late Stage Dementia
WCCEAL: Wisconsin Coalition for Collaborative Excellence in Assisted Living

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Original Paper

Information and Communications Technology as a Health Promotion Method for Older Adults in Assisted-Living Facilities: Three-Arm Group-Randomized Trial

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Abstract

Background: The application of technology is an important and growing aspect in the field of long-term care. Growing evidence shows the positive impact of technology aids in helping the lives of the elderly. However, it is not known which aspects of information and communications technology (ICT) are preferred by older adults living in long-term care facilities.

Objective: The goal of the research was to compare the impact of ICT-communication, ICT-entertainment, and conventional care on older adults' health and psychological change after interventions among older adults in assisted-living facilities.

Methods: A three-arm group-randomized trial design was used to evaluate participants who resided in three different but comparable assisted-living facilities and received different aspects of the ICT interventions. A total of 54 older adults with disabilities received one of the three interventions over 12 weeks and completed pre- and postevaluations on quality of life, social support, and psychological well-being.

Results: Participants completing this study had a mean age of 73 (SD 11.4) years, and 50% (27/54) were male. Both the ICT-communication and ICT-entertainment groups showed significant improvement in the mental component of quality of life (4.11, *P*=.012 and 37.32, *P*<.001, respectively), family/friend–related social support (0.05, *P*=.001 and 0.04, *P*<.001, respectively), happiness (0.79, *P*=.038 and 3.72, *P*=.001, respectively), and depressive symptoms (–2.74, *P*=.001 and –7.33, *P*<.001, respectively). Importantly, participants in the ICT-entertainment group improved significantly more than the other two groups. The ICT-entertainment group also showed improvement in the physical component of quality of life (20.49, *P*<.001) and health care worker–related social support (0.1, *P*=.008).

Conclusions: Results suggest that the entertainment but not the communication part of ICT is the most effective health promotion method for improving the health and psychological well-being of older adults in assisted-living facilities.

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KEYWORDS

information and computer technology; quality of life; social support; psychological well-being; long-term care facilities; disabled; elderly; disability; assisted living; seniors; geriatrics

Introduction

Information and communications technology (ICT) apps have become foundational in aging communities worldwide. The internet is transforming the way older adults communicate and socialize with family and friends [1]. Particularly in older adults, social networking is becoming a general contributor to this communication, reflecting better overall health [2], and new possibilities are opening up through the concept of social capital and its potential relevance as a theoretical tool for investigating aging [3]. However, disabilities can affect psychological health along with the subjective sense of well-being [4], particularly among institutional care residents who are facing social barriers [5]. Social barriers are related to the social determinants of health, the conditions in which people are born, grow, live, learn, work, and age [6], causing people with these barriers to be less likely to mingle with or get support from family and friends, increasing disassociation with society. These barriers can result in a sense of negative well-being that may include feelings of abandonment or being left behind, affecting older people's outlook on life and in turn their quality of life [7].

Interventions involving the use of assistive technology may help overcome social barriers for older adults who live in long-term care facilities and thus improve their quality of life and sense of well-being [8,9]. However, there have been limited studies evaluating the efficacy of the use of touch screen devices in older adults who live in long-term care facilities, and research comparing communication and entertainment apps and their impact on the health and well-being of this population is lacking.

The objective of this study was to evaluate the impact of ICT on psychological well-being, quality of life, and physical and cognitive functioning in older adults living in long-term care facilities. In addition, we compared the effectiveness of ICT between those receiving the entertainment aspect versus those receiving the communication aspect of ICT learning to ascertain which aspect of the ICT was more welcomed by the population.

Methods

Research Design and Participants

A group-randomized trial design was employed in the study, for which three comparable community-based long-term care facilities in Southern Taiwan were selected. This study was approved by the institutional review board of National Cheng Kung University Hospital in Taiwan (number A-ER-102-425). No changes were made to the trial design after pretrial approval from the review board.

A total of 286 adults were living in the three facilities. After excluding those aged younger than 50 years, those unable to comply, and those who exhibited confusion or agitation, the remaining 86 adults, including 28 in site A, 32 in site B, and 26 in site C, were invited to participate. Each site was randomized to receive one of the three intervention methods: the ICT-communication (using Line, a freeware app for instant communications on electronic devices) group, ICT-entertainment (using YouTube, a video sharing website) group, and usual care group.

Only 66% (57/86) of participants signed informed consents, consisting of 19 in each group. Among them, 3 participants dropped out during the intervention (one moved to another city and the other two passed away), which resulted in a total of 54 participants (retention rate 95%) comprising the ICT-communication group (19/54, 35%), ICT-entertainment group (18/54, 33%), and usual care group (17/56, 30%). The research period from commencement to completion was May to September 2015.

Intervention Process

The usual care group included observation participants with routine daily activities. Participants allocated to the ICT-communication and ICT-entertainment groups received ICT training once a week for 12 weeks (see Table 1). The author and a research assistant led each ICT session and worked with no more than 10 participants in a group. Each session lasted about 90 minutes, with visual demonstrations using an overhead projector and hands-on exercises on all the contents. Touch screen tablets with individualized assistance devices attached, such as tablet holders and sensor pens especially designed for a specific disability, were used as the technology devices. Each class included a demonstration of the new skill and a repetition drill for learning. Each class also included a review and practice of the skill learned in the previous class.

In addition to training on general knowledge related to the tablet functions and inputting of data, the ICT-communication group participants learned how to invite friends to join in using the Line app, make a video call, download a sticker, send a photo card, send a text message, and attach a file through Line and send it to friends. Participants in the ICT-entertainment group learned how to search on YouTube for their favorite songs, TV shows, and videos.

Measures

All participants were interviewed in person and completed questionnaires at pre- and postintervention. The questionnaires include questions on sociodemographic variables, health-related quality of life (12-Item Short Form Health Survey [SF-12]), Taiwanese Inventory of Social Supportive Behavior (TISSB), Chinese Person's Happiness Inventory (CHI), and Center for Epidemiologic Studies Depression Scale (CES-D).

Cognitive Function

Cognitive ability assessments were conducted using a structured measure of cognitive performance, the Short Portable Mental Status Questionnaire (SPMSQ), a mechanism with high validity and test-retest reliability [10]. This 10-item structured survey is a widely used questionnaire designed to measure several intellectual areas including orientation, short- and long-term memory, general knowledge, and deciphering issues. The Chinese version of the SPMSQ has been authenticated in earlier studies [11], and a higher rating indicates a better cognitive intellectual capacity score. Cronbach alpha in our sample was .60 [12].

Table 1. Comparison of the curricula for the two intervention groups.

Class	Syllabus	
	ICT[a]-communication group	ICT-entertainment group
1	General knowledge about tablet functions: turn tablet on and off; keyboard functions	General knowledge about tablet functions: turn tablet on and off; keyboard functions
2	Input data using handwriting, typing, and voice commands for searching	Input data using handwriting, typing, and voice commands for searching
3	Invite friends to join; take and attach photos; add friends by shaking or using Quick Response feature	Search on YouTube for a movie, news, TV program, or favorite song
4	Make a video phone call using Line	Search on YouTube for a song and sing along (Karaoke)
5	Download a sticker using Line to make a photo card	Search on YouTube for a song or video to express your feelings
6	Make and send a photo card using Line; add sticker graphics	Search on YouTube for a popular song or video about your favorite reminiscence
7	Send a text message using Line and add a sticker	Search on YouTube for a movie, news, TV program, or favorite song and share with your friends
8	Attach a file	Search on YouTube for a song or video that gives you strength when you are having a difficult time
9	Search for a city or street using Google Maps; sightsee using Google Satellite	Search for a city or street using Google Maps; sightsee using Google Satellite
10	Experience YouTube by learning how to search for a favorite song	Experience Line by learning how to make a video or phone call
11	Make a video phone call using Line; send a text message and a sticker	Search on YouTube for a favorite song and sing it with a friend
12	Graduation	Graduation

[a] ICT: information and communications technology.

Physical Functional Status

Functional status was defined as the capacity to perform the activities of daily living (ADL) and the instrumental activities of daily living (IADL). ADL limitations refer to the requirements for accomplishing these 10 basic activities: bathing, dressing, transferring (3 items), going to the lavatory (3 items), and feeding oneself (2 items). Each item ranges from 0 to 5 or 0 to 15, ranging from no difficulty to being totally dependent on others. Total ADL score ranged from 0 to 100, with higher value indicating more disabilities. The IADL assessment included 8 items rating difficulties with participants' ability to go outside, use a telephone, shop, cook, engage in household cleaning, do laundry, take medication, and manage household finances, where each item ranged from 0 to 2 or 0 to 4, representing no difficulty to being totally dependent. Total IADL ranged from 0 to 24, with a higher value indicating a greater degree of disability. Significantly elevated correlations (tau=.83, r=.89, P<.001) were found between this measurement and the assessment of functional status by quality professionals, suggesting good criterion validity. In addition, good interrater reliability has previously been reported for the IADL [13] and the ADL [14].

Depressive Symptoms Scale

The CES-D, developed by Radloff [15], has been widely used in many community-based studies on the elderly with good reliability and validity [16]. The Chinese version of the CES-D scale is a reliable screening instrument for symptoms of depression in the elderly [17] and had good internal consistency (Cronbach alpha=.89) [18]. A total of 11 items were used to ask the participants their feelings over the previous week addressing appetite, level of depression, or degree to which they felt happy or lonely or found people to be unfriendly or to dislike them, were enjoying life, were feeling sad or that life was an effort, were unable to get going, and were experiencing restless sleep (positive items were reverse-scored). The questions had ratings from not at all (0) to always (2). The maximum score was 22, with a higher value indicating more depressive symptoms.

Health-Related Quality of Life

The SF-12, Taiwan version [19], was used in the study to assess health-related quality of life. Its internal consistency and test-retest reliabilities have been shown to be good (ranging from .67 to .82) [20]. There are two factors, interpreted as physical and mental components of health status, in this scale [21]. Each component ranges from 0 to 100. A greater score implies better health-related quality of life.

Social Support Scale

The inventory of the TISSB was used to evaluate participants' social health status [22]. The TISSB version was adapted from the original ISSB scale [23], which included 10 items evaluating emotional support; social integration; informational support; instrumental support from families, friends, and health care workers; and the overall satisfaction with these listed support objects. Each domain of the TISSB was rated from not at all (1) to always (3), with total score ranging from 10 to 30. Scores from 10 to 16 were considered low, 17 to 23 were considered to be moderate, and those 24 and higher were considered to be a high indicator of social support or satisfaction. The TISSB has been determined to have significant reliability (Cronbach alpha=.89) and validity in older adults in community dwellings [24].

Happiness

Well-being rankings were measured by means of the 10-item CHI [25]. Psychometric analyses revealed good validity and reliability (Cronbach alpha=.95). This project included the happiness measurement scale assessing the well-being of the respondents, including a positive effect, negative effect, and overall satisfaction toward life in the past three months, with each item ranging from 0 to 3. Total scores ranged from 0 to 30, with a greater score representing a higher well-being status.

Statistical Analyses

Data analysis included descriptive and inferential statistical analyses. Changes in the means and standard deviations of the variables at pre- and postinterventions were examined using the Wilcoxon signed-rank test. Intergroup comparisons of changes in the means and standard deviations in the three groups were conducted using the Kruskal-Wallis test and Dunn nonparametric comparison for post hoc Kruskal-Wallis testing. To adjust for multiple comparisons, significance was discerned after the Bonferroni adjustment by setting the alpha levels at <.005 and <.001.

Results

Participant Characteristics

The baseline sociodemographic and health status of the participants is shown in Table 2. Participants had a mean age of 73 (SD 11.4) years; 50% (27/54) were male; 70% (38/54) had less than an elementary school education; 54% (29/54) had an average financial status; average length of stay in long-term care was 36.2 months; average ADL score was 40.2 (higher level of dependence); average IADL score was 6.6 (subtle disabilities); average cognitive score was 9.6 (intact); the majority of the residents (47/54, 87%) had not had previous computer learning experience; and chronic disease count average was 2.3. Participants in the three intervention groups were not statistically significantly different in regard to any of the sociodemographic variables nor were they different in terms of disease, functional status, and variables related to quality of life, depressive symptoms, happiness, social support, and computer learning experience.

Comparison of the Intervention Effect Across the Three Groups

As shown in Multimedia Appendix 1, participants in both the ICT-communication and ICT-entertainment groups statistically significantly increased their quality of life mental component, family and friend social support, satisfaction with support, and happiness and experienced decreases in their depressive symptoms after the 12-week ICT intervention. In addition, participants in the ICT-entertainment group also statistically significantly increased their quality of life physical component and their health care worker–related social support scores after the 12-week intervention.

The results of the Kruskal-Wallis tests comparing changes in the three groups further indicated that the effects of ICT-entertainment and ICT-communication on improving the degree of social support from family and friends and the happiness of older adults living in long-term care facilities did not differ between the ICT-entertainment and ICT-communication groups. The ICT-entertainment group had a significantly greater increase compared to the ICT-communication group in physical and mental component for health-related quality of life and health care worker–related social support and had a greater decrease in depressive symptoms.

Table 2. Baseline characteristics of participants in the ICT-communication group, ICT-entertainment group, and usual care groups.

Characteristics	Total (N=54)	ICT[a]-communication group (n=19)	ICT-entertainment group (n=18)	Usual care group (n=17)	*P* value
Sociodemography					
Age (years), mean (SD)	73.0 (11.4)	72.9 (12.3)	72.9 (10.6)	73.2 (11.8)	>.99
Sex (male), n (%)	27 (50)	11 (58)	9 (50)	7 (41)	.61
Education, n (%)					.05
Illiterate (yes)	15 (28)	6 (32)	3 (17)	6 (35)	
Elementary school	23 (43)	5 (26)	10 (56)	8 (47)	
High school and above	16 (30)	8 (42)	5 (28)	3 (18)	
Financial status, n (%)					.85
Poor	24 (44)	9 (47)	8 (44)	7 (41)	
Average	29 (54)	10 (53)	10 (56)	9 (53)	
Rich	1 (2)	0 (0)	0 (0)	1 (6)	
Computer learning experience, n (%)					.39
No	47 (87)	15 (79)	16 (90)	16 (94)	
Yes	7 (13)	4 (21)	2 (11)	1 (6)	
Health status, mean (SD)					
LOR[b] (months)	36.2 (37.4)	28.5 (16.9)	50.3 (51.6)	29.3 (33.9)	.39
ADL[c] (0-100)	40.2 (31.5)	31.8 (31.2)	39.2 (29.6)	51.6 (32.5)	.12
IADL[d] (0-24)	6.6 (2.0)	5.8 (2.1)	7.2 (1.9)	6.7 (1.9)	.05
SPMSQ[e] (0-10)	9.6 (0.8)	9.5 (0.8)	9.4 (0.9)	9.7 (0.6)	.56
Disease[f] (count)	2.3 (1.1)	2.2 (1.0)	2.5 (1.3)	2.2 (1.1)	.61
HRQoL[g]–physical component, mean (SD)	26.5 (19.2)	27.7 (18.5)	25.8 (17.1)	25.9 (23.0)	.83
HRQoL–mental component, mean (SD)	33.8 (20.7)	33.9 (18.1)	31.6 (16.5)	36.0 (27.3)	.97
Social support–family/friends, mean (SD)	1.4 (0.3)	1.3 (0.2)	1.3 (0.3)	1.5 (0.3)	.10
Social support–health care workers, mean (SD)	1.6 (0.2)	1.5 (0.2)	1.7 (0.2)	1.6 (0.2)	.06
Satisfaction with social support, mean (SD)	2.3 (0.3)	2.2 (0.3)	2.3 (0.3)	2.3 (0.2)	.09
Happiness, mean (SD)	3.6 (4.0)	3.2 (3.2)	4.2 (4.4)	3.5 (3.9)	.88
Depressive symptom scale, mean (SD)	12.7 (4.4)	13.7 (4.6)	13.1 (4.6)	11.1 (4.1)	.15

[a] ICT: information and communications technology.

[b] LOR: length of residency.

[c] ADL: activities of daily living.

[d] IADL: instrumental activities of daily living.

[e] SPMSQ: Short Portable Mental Status Questionnaire.

[f] Disease count includes diabetes, hypertension, heart disease, cerebral vascular incidents, and others.

[g] HRQoL: health-related quality of life.

Discussion

Principal Findings

The objective of this study was to evaluate the extent to which social support, psychological well-being, and quality of life changed for participants receiving the communication aspect of ICT learning and for participants who received the entertainment aspect of the ICT learning versus the control group with usual care. This study indicates that the entertainment group of ICT learning had the highest change in terms of improving both the physical and mental components of health-related quality of life and happiness and decreasing depressive symptoms as compared with those who were in the communication group of ICT intervention and the usual care group. The ICT-entertainment group also exhibited a significant increase in social support related to health care workers and overall satisfaction with social support.

Previous studies have shown a trend in the communication aspects of ICT using email indicating decreased loneliness and isolation with the potential of improving psychological well-being [8,9,26,27]. Significant differences were found between the pre- and postintervention communication aspects of ICT-communicatiom in terms of the levels of health care worker–related social support and satisfaction with social support. In a prior study by Tsai et al [28], video conferencing with MSN/Skype was used as an intervention for nursing home residents and their families in which the outcome revealed significant changes in levels of social support and loneliness along with decreases in the level of social isolation. However, in our study, typing and texting were both challenging for most of the long-term care facility residents due to physical stiffness, arthritis, and shaky hands, causing an issue with trying to hold a computer tablet or use a touch screen. Residents were given tailored technology accessories such as tablet holders and touch screen pens that helped them overcome these barriers. The software app used in this study was Line; the features of this app involve video phone calling along with texting and the ability to produce and send video and picture files. Additionally, the Line app adds some variety, such as daily free cartoons or emojis that can be attached to messages or videos to communicate with their families or friends.

Interestingly, we found the entertainment aspect of ICT using YouTube was more welcomed by older adults living in long-term care facilities than the communication aspect of ICT using Line. Although participants in both the ICT-communication and ICT-entertainment groups statistically significantly improved in terms of their mental component of quality of life; family and friend social support; satisfaction with the degree of support, happiness, and depressive symptoms; participants in the ICT-entertainment group revealed a statistically significantly greater mental component score improvement and a unique improvement on the physical component of the health-related quality of life score. Specifically, while participants in the ICT-communication group improved the mental component of the health-related quality of life score by 4.11 points, the ICT-entertainment group increased by 37.32 points, which is more than two standard deviation increments. Similarly, while there was no significant improvement on the physical component of the health-related quality of life score for participants who received the ICT-communication intervention, participants in the ICT-entertainment group reported statistically significant improvement on the physical component of the health-related quality of life score by increasing 20.49 points, a more than one standard deviation improvement. Post hoc tests reveal statistically significant differences between the two groups, but we believe there is also clinical significance by using ICT-entertainment to improve both the physical and mental components of quality of life than by using the ICT-communication approach for older adults living in long-term care facilities.

ICT-entertainment has greater diversity as an app in terms of meeting the needs of the residents compared with ICT-communication, especially during the ICT learning classes. In addition, YouTube makes it easier to search for songs, movies, news, geography, on-line classes, or something to their interest. This app is a very useful, convenient tool for groups or for use as an individualized entertainment feature to stimulate and motivate the interest of elderly residents, and in addition, makes it possible for them to reminisce about past memories. For example, the YouTube music library options help trigger memories of the past through songs from their youth and family years, helping them to reminisce with family and friends. The residents sang along with music clips and read the text on the screen aloud. Nonverbal communications included clapping their hands and nodding their heads along with the music, dancing, waving their arms in the air, maintaining observation of the screen, observing persons speaking, and maintaining eye contact [29]. Using today's interactive touch screen computer devices is wonderful for older adults. Positive results from multimedia technology increased interaction particularly in the case of songs from their earlier years because it provided a greater depth and variety of materials from their past [30].

It was found that in contrast to the communication aspect of the ICT, which did not show significant improvement in participants' physical quality of life component, the recreation aspects of ICT using YouTube significantly improved participants' physical component of health-related quality of life. This finding echoes those of previous studies indicating that the YouTube app is a feasible means by which to conduct computer-based interactions intended to increase the sense of well-being and improve mood in viewers in order to generate greater communicative participation and engagement in a group [29]. In our study, old songs were found through YouTube for remembrance, comfort, and encouragement that caused the residents to talk and tell stories of their younger years with big smiles on their faces, helping them overcome their negative emotions and frustration. Psychologically, music has been shown to play an important role in emotional self-regulation, communication, and social interaction throughout life and also during the aging process [31]. Both singing and listening to music improve mood, orientation, and remote episodic memory and, to a lesser extent, attention, executive functions, and general cognition. Singing also enhances short-term and working memory, whereas music listening has a positive effect on quality of life. Because of advancements in technology, the modern vision for reminiscence has expanded beyond the tangible and traditional [32]. Findings on the effects of YouTube included improved well-being and mood; improved communication, interaction, and engagement; improved quality of life in an institutional care setting; and connection with YouTube reminiscence mediums.

Limitations

This study has some limitations. The sample size was a small convenience sampling of three long-term care facilities. The average participant reported low educational attainment, frailty, and physical disabilities that might have influenced their ability and willingness to achieve training on internet operational procedures or the writing requirements for computer information technology such as text messaging, email, and blogging, among others. We also excluded those who were bedridden or aged younger than 50 years.

Conclusion

Despite these limitations, this study provided evidence that touch screens, lightweight smart computer tablets, and easy-to-use software apps may be a promising form of health promotion activity for older adults living in long-term care facilities even when they are very frail. These leading technologies enable health care workers to assist residents so they can interact with families and friends, including repeat visitors hosting activities or social activities with other residents. In addition, ICT-entertainment has a greater impact in terms of meeting the needs of the residents compared with ICT-communication: it could be used as a sophisticated icebreaker tool to interact with residents, providing excitement and opening up a new means of communication for those who cannot express themselves in the way they desire.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Test of mean changes in quality of life, social support, happiness, and depressive symptoms after a 12-week intervention across the three groups.

[PDF File (Adobe PDF File), 181KB - aging_v2i1e12633_app1.pdf]

Multimedia Appendix 2

CONSORT EHEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 263KB - aging_v2i1e12633_fig.pdf]

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Abbreviations

ADL: activities of daily living
CES-D: Center for Epidemiologic Studies Depression Scale
CHI: Chinese Person’s Happiness Inventory
IADL: instrumental activities of daily living
ICT: information and communications technology
TISSB: Taiwanese Inventory of Social Supportive Behavior
SF-12: 12-Item Short Form Health Survey
SPMSQ: Short Portable Mental Status Questionnaire

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Original Paper

Mobile Support for Older Adults and Their Caregivers: Dyad Usability Study

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Abstract

Background: Evaluation of digital health applications to support older adults' independence and family caregiving is needed. Digital health is increasingly providing opportunities for older adults and their family caregivers to educate, engage, and share health information across digital platforms. Few apps have documented evidence of usability by older adults and their caregivers.

Objective: The objective of this study was to determine the usability of a mobile app in a community-based older adult population aged ≥65 years. The app was designed to improve engagement of the patient-informal caregiver team.

Methods: This observational usability study was conducted in participants' homes and independent living facilities in Baltimore, Maryland. Community-dwelling older adults aged ≥65 years and their caregivers enrolled as a dyad (n=24, 12 dyads). The usability evaluation was a mobile and Web-based app that allowed older adult users to record social and health information and share this information with their caregivers. The older adult-caregiver dyad downloaded the app to a smart phone or accessed the Web version, participated in training and onboarding, and used the app for a 1-month period. Participants responded to weekly surveys sent by app push notifications and to the usability and satisfaction surveys at the end of the study. Participant satisfaction and usability were assessed using the Modified Mobile Application Rating Scale (M-MARS) and the System Usability Scale (SUS).

Results: The final sample comprised 16 people (8 dyads). Responses to the M-MARS were comparable between older adults and caregiver respondents in terms of engagement and functionality. Caregivers rated aesthetics slightly higher (mean 3.7) than older adult participants did (mean 3.3). Although most responses to the SUS were around the mean (2.3-3.4), older adults and their caregivers differed with regard to integration of app features (mean 3.7 vs 2.8) and the need to learn more before using the app (mean 2.3 vs 3.1).

Conclusions: Technology ownership and use among older adults and caregivers was high. Usability and engagement of the mobile app was average. Additional training is recommended for older adults and their caregivers, including that on targeted behaviors for digital health record keeping.

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KEYWORDS

older adult; caregiver; mobile health; patient engagement

Introduction

The majority of older adults are cared for at home, and most care is provided by informal caregivers including unpaid family members. According to the Institute of Medicine, at least 17.7 million family caregivers provide assistance to persons aged ≥65 years [1,2]. Family caregivers not living close to aging family members require reliance on additional forms of communication. Studies provide evidence that almost half of the older adults report either needing help or receiving help with routine daily (instrumental) activities of daily living: shopping (90%), making medical appointments (61%), speaking to a doctor (55%), ordering medicine (48%), and keeping track of medicine (49%) [3]. Unmet needs can lead to falls, hospitalizations, emergency department visits, mobility issues, and medication errors [3,4].

Evaluation of the potential of mobile technology is needed to support older adults' independence and the family's role in caregiving. Older adults and their identified informal caregivers, together as a dyad, have not been included in technology evaluations. A wide range of new technologies marketed as support for older adults (electronic reminders, motion detectors, and wearable sensors) have promise, but only a few are supported by scientific evidence. Experts in the technology and aging field recommend that research on the safety and effectiveness of mobile technology or devices include input from older users and their caregivers [5-9]. Furthermore, there is a myth that older adults do not use technology [10].

Mobile health (mHealth) is a promising tool for delivering interventions designed to promote self-management but is not well understood in older adults, nor are there well-designed studies on its efficacy and effectiveness. Studies investigating Web-based usability evaluations to promote self-management are inconclusive or demonstrate only moderate effects [11-14]. Few studies demonstrating moderate effect are randomized; include usability evaluations maintaining behavior longer than 6 months; include older adults or minorities; or assess quality of life, which may be more important to older adults than disease control [15-17]. Research demonstrates that current self-management mHealth (apps or internet Web portals) support is associated with dropout within 1-3 months and fails to provide ongoing support or communication with providers when decision making is required outside office visits [18,19]. Exclusion of older adults from large clinical trials evaluating mHealth usability evaluations further underserves this population because of the *myth that older adults do not use technology*. A total of 67% of older adults, including minorities, use the internet (75% use it daily), and smart phone ownership is rapidly growing (42% in 2017) [20,21].

As individuals with technology experience continue to age, mobile technologies will become more accepted or automatic forms of communication [22-26]. However, acceptance and use among older adults are less than those among their counterparts owing to the design, cost, and expected usefulness. Even among current older adult users, differences in technology use and skills are observed for new retirees with workplace technology experience, the young-old (65-74 years old) and old-old (≥75 years old) [27]. The purpose of this research study was to conduct Phase I of a usability evaluation of a new mobile app used by older adults and their caregivers for health, by using a private social network (family or nonfamily informal caregivers) [24]. The Phase II study will evaluate the impact of individual app user information managed through an enterprise dashboard in provider practice settings.

Methods

Study Population

Participants (n=24, 12 dyads) were recruited at two independent living facilities in Maryland with community outreach programs, which the participants attended. All older adults lived in their own homes in the community and participated in independent living–sponsored activities (ie, classes in Spanish, falls prevention, and Tai Chi). One dyad (older adult and spouse) lived at the independent living facility. Trained facility site champions identified and obtained permission to contact potential eligible participants who were able to self-identify a caregiver to enroll as a dyad. The study sample was a convenience sample for a usability study. We estimated the sample based on potential for recruitment at the study sites and within the budget limits. A caregiver was broadly defined as a family or nonfamily informal caregiver, identified by the older adult as the primary unpaid person who assisted the older adult, if needed. Eligibility criteria for inclusion of the older adults were age≥65 years, living in the community, ownership of a mobile phone or access to the internet, and ability to pass cognitive screening. Participants were excluded if they had history of substance abuse; had a terminal diagnosis; were undergoing active chemotherapy; had significant vision or hearing impairment; were mute or aphasic; or received a physician's diagnosis of severe dementia, Alzheimer disease, schizophrenia, bipolar disorder, or major psychosis. There were no inclusion or exclusion criteria for caregivers, except that they were identified by the older adult participant and had access to a mobile phone or the internet in order to use the app. Research staff used an Evaluation to Sign Consent and the Modified Mini-Mental State (3MS) to assess the ability of the potential participant to provide informed consent [25]. The 3MS was used in our Evaluation to Sign Consent method, but not for determining or reporting cognitive status. Four dyads were lost to follow-up. Specific reasons for dropouts were not given to the researchers. Respondents who did not return repeated calls from study staff were excluded from the study.

The Institutional Review Board of the University of Maryland, Baltimore, approved the study protocol (HP-00076904), and written informed consent was obtained from all participants.

Approach

Usability Evaluation

Baseline assessments were conducted face-to-face at the community facility or participant's home. Participants residing out of the area were mailed study materials and provided consent remotely. Members of the dyad participated in group or individual training on the mobile app and Web portal. For convenience of the older adults and caregivers, participants were offered participation in a group training session or individual training. Training materials were the same for the two educational approaches. The pilot demonstration evaluation was a commercially available mobile app or internet-based portal provided by ICmed, which the Maryland Industrial Partnerships program funded [24]. At the time of this study, the app was newly commercially available but had not been specifically evaluated in an older adult population. The app allows users to create a personal profile and family health history tree; input health information into their profile; receive personalized, evidence-based advice based on the user's unique health profile; and track and collaborate with designated family members or caregivers [26]. The software is designed to connect individual users and caregivers to care providers, including health systems or care managers, but the study evaluated usability at the individual level. The software is designed for users of varying degrees of health status or frailty: Technically savvy and physically capable users can manage their own profile and collaborate freely with caregivers they select; users with limited technical or physical capabilities can participate where they are capable but can rely on the app design to provide the designated caregiver identical information and notification of every alert or message received by the user; and incapacitated users can delegate themselves to a caregiver's managed account, in which case the caregiver will be the primary coordinator and communicator using the app. For example, a user may include a future provider appointment in the calendar, which all designated caregivers would be able to view.

The participant was guided through the process of creating a new app account and entering basic demographic information. The dyad individuals were linked using the Family Sharing feature, enabling communication within the app. Participant training concluded by sending a test message to the app team, ensuring the dyad was properly connected. Participants were provided an app-onboarding guide and encouraged to add more information, including health information, using the app at home. Participants completing the 1-month usability evaluation and all surveys were given a US $20 gift card to compensate for their time.

Study Measures

Demographic data collected from the older adults and caregivers included a self-reported assessment of ownership and use of technology questions developed by the research team because no standardized survey instruments exist.

Participant engagement was measured by weekly surveys sent via an app push notification developed by providers at the independent living facilities. A push notification is an automated message sent by an app to a user when the app is not open. The purpose of such a notification in this study was to notify users when they were asked to respond to a set of questions. These questions were not standardized tools or measures but questions the independent living communities previously used in printed forms for the community outreach program, and were used to assess whether participants would use the app to respond to the same questions. Two types of weekly surveys were sent to participants. One set of push messages asked if the message was received, with options for "yes" or "no" response. The second set of push messages was developed with study sites to assess how engaged participants are in managing their health. Examples of these survey questions included, "I am fully aware of my current health condition," "I feel more motivated to take care of my health," and "I learned how to better monitor my health." Response categories ranged from strongly agree to strongly disagree. The number of responses to questions were tracked for each of three surveys. At the end of the 1 month of use, participants were mailed two surveys—the Modified Mobile Application Rating Scale (M-MARS) and System Usability Scale (SUS) [28,29]. The M-MARS instrument was modified for this study to assess app quality in three dimensions—engagement, functionality, and aesthetics. All items were rated on a 5-point scale from 1, inadequate to 5, excellent. The original MARS was designed as an app quality–rating tool to be used during the process of app development. In this study, commercial app development was complete; however, the three dimensions of app evaluation were relevant to our understanding of usability. As stated by the MARS developers, "the MARS is an easy-to-use, simple, objective, reliable, and widely applicable measure of app quality, developed by an expert multidisciplinary team. Although the generalizability of the MARS is yet to be tested, the scale can be modified to measure the quality of nonhealth related apps" [16]. Examples of the three dimensions of the M-MARS are as follows: (1) Engagement: fun, interesting, customizable, interactive (eg, sends alerts, messages, reminders, and feedback and enables sharing), and well-targeted to audience. (2) Interest: Is the app interesting to use? For example, did the participant use the education tab? (3) Functionality: app functioning, easy to learn, navigation, flow logic, and design of app. The SUS is a validated (*P*=.92) and calibrated instrument that measures a user's assessments of usability on multiple dimensions, including effectiveness, efficiency, and satisfaction [30]. Responses are measured on a 5-point scale from 1, strongly disagree to 5, strongly agree [31]. SUS questions are listed in Table 1.

Table 1. Evaluation of app usability and engagement among participants at 1 month using the System Usability Scale (1=strongly disagree to 5=strongly agree; n=17). Values are presented as scores.

Characteristic	Older adult (n=9), mean (SD)	Caregiver (n=8), mean (SD)	Total, mean (SD)	*P* value (*t* test)
I think that I would like to use the app frequently	3.2 (1.1)	2.7 (1.3)	2.9 (1.2)	.32
I found the app unnecessarily complex	2.6 (1.2)	3.1 (1.4)	2.8 (1.3)	.38
I thought the app was easy to use	3.4 (1.0)	3.4 (1.6)	3.4 (1.3)	.92
I think that I would need the support of a technical person to use the app	3.1 (1.8)	2.4 (1.7)	2.8 (1.7)	.39
I found the various functions in the app were well integrated	3.7 (0.9)	2.8 (1.3)	3.2 (1.1)	.10
I thought there was too much inconsistency in the app	2.1 (1.1)	2.5 (1.5)	2.3 (1.3)	.54
I would imagine that most people would learn to use the app very quickly	3.6 (1.1)	3.0 (1.5)	3.3 (1.3)	.40
I found the app very cumbersome to use	2.4 (1.3)	2.6 (1.5)	2.5 (1.4)	.80
I felt very confident using the app	3.3 (1.4)	2.9 (1.6)	3.1 (1.5)	.53
I needed to learn a lot of things before I could get going with the app	2.3 (1.1)	3.1 (1.6)	2.7 (1.4)	.24
MARS[a] (1=inadequate to 5=excellent)				
Engagement component	2.8 (0.8)	2.8 (0.9)	2.8 (0.8)	.94
Functionality component	2.6 (1.0)	3.0 (1.4)	2.8 (1.2)	.45
Aesthetics component	3.3 (2.7)	3.7 (0.9)	3.5 (0.8)	.08

[a] MARS: Mobile Application Rating Scale.

Statistical Analysis

Descriptive statistics (mean and proportions) are presented for the total sample and according to the type of respondent (adult participant and caregiver). Differences between types of respondents were assessed using *t* tests.

Results

In this usability study, 20 older adult participants provided permission to be contacted. A total of 24 older adult and caregiver subjects were deemed eligible, and 12 dyads were enrolled (n=24). All participants provided their age, and the mean age was 66.3 (SD 15.2) years overall, 77.8 (SD 4.0) years among the older adults, and 54.8 (SD13.3) years among the caregivers. One older adult participant was ineligible due to inappropriate age (<65 years old), and one older adult participant was ineligible due to a diagnosis of dementia. One additional caregiver and one older adult (from different dyads) did not respond to the researchers' contact attempts and were considered to be lost to follow-up. In total, four dyads were lost to follow-up. Finally, eight dyads (n=16) completed the study.

More women (n=19) than men (n=5) were enrolled (Table 2). Caregivers were predominantly female (n=11, 91.7%). The relationship between the dyads was parent-child in 75% of the participants. There was an equal number of black (n=12) and white (n=12) participants. Over half of the study population reported having at least a college degree or higher education (75%). Income for the majority of older adults enrolled in the study ranged from US $20,000-29,999 (33.3%), whereas the majority of caregivers enrolled had incomes of ≥US $100,000 (data not shown).

Technology skill and use reported by older adults and caregivers at baseline was high (Table 3). All participants used technology for various social and home activities (ie, paying bills) and all, except one, had internet or Wi-Fi at home. Two participants did not own a smart phone and, instead, accessed the internet and app through a Wi-Fi–enabled tablet device. In addition, 75% of older adults reported that they are at least somewhat skillful with technology and electronics, and all 12 caregivers rated themselves at least somewhat skillful; four caregivers considered themselves very skillful (Table 3).

Activities completed by older adults on the phone daily included making calls (75%) and reading emails (58.3%), whereas caregivers reported making calls (91.7%), sending and receiving text messages (91.7%), connecting to the internet (91.7%), and reading emails (91.7%) daily. Older adults in the study preferred to access the internet via a desktop or laptop computer (33.3%) and caregivers accessed the internet on their phone (75%). Common internet activities for both older adult and caregiver participants included connecting with family and friends, keeping up with current events, looking up information, and reading emails. Caregivers reported using the internet for paying bills, making reservations, sending or receiving photos, and purchasing products and services more often per month than older adults.

Table 2. Baseline characteristics of the participants and caregivers (n=24).

Characteristic	Older adults, n (%)	Caregivers, n (%)	Total, n (%)
Sex			
Female	8 (67)	11 (92)	19 (79)
Male	4 (33)	1 (8)	5 (21)
Race			
Black	6 (50)	6 (50)	12 (50)
White	6 (50)	6 (50)	12 (50)
Ethnicity			
Hispanic or Latino	1 (8)	1 (8)	2 (8)
Not Hispanic/Latino	11 (92)	11 (92)	22 (92)
Education			
Business/some college/graduate	8 (67)	6 (50)	14 (58)
Graduate school	4 (33)	6 (50)	10 (42)
Marital status			
Married	6 (50)	8 (67)	14 (58)
Widowed	3 (25)	0 (0)	3 (13)
Divorced	2 (17)	3 (25)	5 (21)
Never married	0 (0)	1 (8)	1 (4)
Missing	1 (8)	0 (0)	1 (4)
Relationship to the other (caregiver or older adult participant)			
Spouse	2 (17)	2 (17)	4 (17)
Child	0 (0)	9 (75)	9 (38)
Parent	9 (75)	0 (0)	9 (38)
Friend	1 (8)	1 (8)	2 (8)
Distance to relative who can provide assistance			
<25 miles	6 (50)	6 (50)	12 (50)
25-50 miles	2 (17)	2 (17)	4 (17)
>50 miles	2 (17)	2 (17)	4 (17)
Would need an airplane	2 (17)	2 (17)	4 (17)
Currently living with the other (caregiver or older adult participant)			
No	10 (83)	10 (83)	20 (83)
Yes	2 (17)	2 (17)	4 (17)

Table 3. Baseline technology ownership and use (n=24).

Component	Older adults (N=12), n (%)	Caregivers (N=12), n (%)
Level of skillfulness with technology and electronics		
Not skillful at all/not very skillful	3 (25)	0 (0)
Somewhat skillful	6 (50)	2 (17)
Pretty skillful	3 (25)	6 (50)
Internet or Wi-Fi at home		
No	1 (8)	1 (8)
Yes	11 (92)	11 (92)
Use of internet for the following activities		
Connecting with family or friends		
Never	1 (8)	1 (8)
<Once per month	1 (8)	1 (8)
1-5 times per week	1 (8)	3 (25)
Every day or almost every day	8 (67)	7 (58)
Keeping up with current events		
Never	1 (8)	1 (8)
<Once per month	1 (8)	0 (0)
1-5 times per week	0 (0)	1 (8)
Every day or almost every day	9 (75)	10 (83)
Looking for information		
Never	1 (8)	0 (0)
<Once per month	0 (0)	0 (0)
1-5 times per week	2 (17)	2 (7)
Every day or almost every day	8 (67)	10 (83)
Paying bills		
Never	4 (33)	0 (0)
<Once per month	6 (50)	5 (42)
1-5 times per week	1 (8)	5 (42)
Every day or almost every day	0 (0)	2 (17)
Reading emails		
Never	2 (17)	0 (0)
<Once per month	1 (8)	0 (0)
1-5 times per week	0 (0)	1 (8)
Every day or almost every day	7 (58)	11 (92)
Devices used most to access internet		
Desktop computer	2 (17)	2 (17)
Laptop computer	2 (17)	1 (8)
Computer tablet	3 (25)	0 (0)
Phone	5 (42)	9 (75)

The push survey messages received an average of 52%-57% responses from the participants. Response rates from older adult participants decreased from 56% to 46%, whereas those from caregivers remained at 58% over the 1-month period (data not shown in table). In the first push survey (week 1), participants strongly agreed that they were fully aware of their health conditions (66.7%), wanted to learn how to take care of their health (50%), and felt motivated to take care of their health

(66.7%). In week 4 of the intervention, among participants responding, "strongly agree," 60% were aware of their health conditions, 40% wanted to learn how to take care of their health, and 40% felt motivated to take care of their health. Fifty percent of caregivers indicated they wanted to use the app to "manage my or my loved one's health appointments or records" and "use the information to discuss or share health information" and 67% wanted to become "more engaged in their love one's health and have access to information in one place."

The SUS was administered to assess the usability of the mobile app, and specific SUS questions are included in Table 1. Although most responses fell along the scale midpoint (response of 3), older adults and caregivers differed with regard to several responses. Older adults more likely considered the app functions to be well integrated compared to caregivers (mean 3.7 vs 2.8; *P*=.10). Fewer older adults felt they needed to learn a lot of things before they could use the mobile app as compared to the caregivers who responded (mean 2.3 vs 3.1; *P*=.24). Responses to the M-MARS were comparable between older adult and caregiver respondents on engagement and functionality measures. Caregivers rated the aesthetic component slightly higher (mean 3.7) than older adult participants did (mean 3.3; *P*=.08).

Discussion

Principal Findings

Smartphone ownership and use among older adults has increased with nearly four in ten owners, doubling in number since 2013 [21]. This usability study revealed that while technology use was common in the cohort among well-educated older adults, engagement with the mobile app was average. Studies have reported older adults and caregivers may benefit from additional technical device training given either as a group or one-on-one [32-35]. In this study, participants were guided through onboarding training and provided an onboarding guide for self-use at home; participants would have probably demonstrated prolonged engagement if they were given weekly training sessions or reminders for engagement. Smartphone ownership was high among study participants, and the low rating for "needing to learn a lot of things before could get going with the app" indicates that participants could use the app (Table 1).

Older adult study participants were asked to change their behavior about how they store and manage health records by entering basic health information into the app. Previous research has demonstrated that older adults experience significant difficulties in using personal health record systems to complete simple health management tasks and are significantly less likely to use patient portals [36-38]. The research reported here identifies several areas where technology may be beneficial for older adult users. Communication technology (electronic health or mHealth) like the app evaluated in this study may be used for older adults to improve participation in health care decisions made by informal caregivers and providers [39], to self-manage health and social needs [40], and to improve engagement and social connections [41,42]. The study results are consistent with those of our previous research documenting that older adults will use mHealth to monitor or self-manage a specific disease like diabetes, because there is a perceived need for monitoring [43,44]. App use for this study may have been affected by the perceived lack of need for such an app. Caregiving experts stress the importance of creating a centralized health-related communication hub, given the complexity of medical conditions and volume of documentation that accumulates in the care of older adults [45]. In our study, we approached older adults first and asked them to enlist their caregiver to participate in the study. One possible approach to engaging older adults is to first establish the commitment of their caregiver. Studies demonstrate that caregivers recognize the need for digital information sharing and want to be informed of their loved one's medical care [7,8]. Caregivers are more likely to recognize the need for health record management and may be motivated to recruit and engage older adults to use mobile apps while also serving as the app account manager. App developers may alternatively consider targeting the "enterprise"—service providers such as long-term care facilities, assisted living facilities, or physicians' offices—rather than community members directly. The enterprise connection may be more appropriate because the app could be designed to link into electronic records, alleviating user burden. Although in our study, the independent living community champions assisted in study recruitment, the independent living facilities were not directly communicating with potential older adults as an enterprise approach, including assistance with onboarding and maintaining community members' records.

The pilot study design provided researchers and app developers with valuable information to improve usability of the app. Participants needed a dedicated and responsive support line for technical issues or user-attributed problems with the app. Technical issues, including, but not limited to, log in and connectivity issues, discouraged participants and delayed or limited use, likely leading to loss to follow-up. Links to education sites embedded within the app need to be specific to the health issues of older adults. Additionally, users may remain better engaged with customization, such as greeting users by showing their name on the welcome screen and as they navigate through the app's features.

The results of this evaluation are limited to the target study population. Participants were willing to enroll in a research project and participate in the study had to own a mobile phone, tablet, or device to access the internet. The cohort may not be representative of the current population of older adults who do not use digital resources. As younger generations age, technology experience and use will be ubiquitous. Additionally, older adult participants in the study had to identify a caregiver to participate in the study, which posed a recurrent issue: Not all older adults have an immediate caregiver or are willing to define a person's role as "caregiver." Researchers attempted to address this concern by using alternate phrases such as "loved one" or "care partner."

Conclusions

This usability study of a mobile and Web-based app in community-dwelling older adults and their caregivers demonstrated that technology use is high among this population; however, data indicated low participant usability and engagement. Mobile app companies would benefit from including older adults and caregivers in the development of technologies aimed at behavior change, including changes in behavior to maintain health records. This study provides information on the usability of a mobile app to support older people and their caregivers. The study further demonstrates the importance of education and training on technology use for older adults and their caregivers. Caregivers with technology experience may play an important role in demonstrating the use and benefits of technology to support care of older adults.

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Conflicts of Interest

None declared.

Authors' Contributions

CQ: study design, implementation, and evaluation; data analyses and interpretation; and manuscript writing. SS: study coordination, data reporting, and drafting manuscript sections. EB: data file creation, analyses, and interpretation and review of the manuscript. AGB: data analyses and interpretation and review of the manuscript.

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Abbreviations

mHealth: mobile health
M-MARS: Modified Mobile Application Rating Scale
SUS: System Usability Scale
3MS: Modified Mini-Mental State

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Original Paper

Older Adults' Attitudes Toward Ambulatory Technology to Support Monitoring and Coaching of Healthy Behaviors: Qualitative Study

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Abstract

Background: Prevention of functional decline demands a holistic perspective of health management. Older adults are becoming avid users of technology; however, technology is not yet largely used in supporting self-management of health in daily life. Previous research suggests that the low adherence to these technologies is likely to be associated with the fact that opinions and wishes of the older population are not always taken into consideration when designing new technology.

Objective: The aim of this study was to investigate the attitudes of older adults living independently regarding technology to support healthy behaviors, addressing nutrition, physical and cognitive function, and well-being.

Methods: In-depth semistructured interviews were performed with 12 older adults addressing 4 themes: (1) current practices in health management, (2) attitudes toward using technology to support health management, (3) wishes from technology, and (4) change in attitudes after actual use of technology. The fourth theme was investigated with a follow-up interview after participants had used a step counter, a smart scale, and a mobile app for 1 month. Data collected were analyzed using inductive thematic analysis.

Results: Participants were active in self-managing their health and foresaw an added value on using technology to support them in adopting healthier behaviors in everyday life. Attitudes and wishes differed considerably per health domain, with cognitive function being the most sensitive topic. Fears from technology mentioned were attention theft, replacement of human touch, and disuse of existing abilities. Poststudy interviews suggest that attitudes toward technology improve after a short period of use.

Conclusions: Technology to support aging in place must target health literacy, allow personalization in the design but also in the use of the technology, and tackle existing fears concerning technology. Further research should investigate the effect of these strategies on the adherence to technology to be used in daily life. We outline a set of recommendations of interest to those involved in developing and implementing technology to support aging in place, focusing on acceptance, barriers, and ethical concerns.

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KEYWORDS

wearable technology; telemedicine; independent living; healthy aging; nutritional status; cognitive function; physical activity

Introduction

The increase of life expectancy is one of the factors contributing to the growing proportion of the population aged above 60 years in developed countries. However, these extra years are not always perceived as *healthy years* with the World Health Organization stressing the need to *add health to years* [1]. One possible solution is by empowering older adults to self-manage their health and consequently prevent functional decline. Technology can play a crucial role here. In fact, in the last decade, we have experienced a growing interest in the research and development of technology for the use of older people. Ambulatory technology, that is, technology that is used to assess or intervene during daily life experiences, in particular, can provide continuous real-time information on the health status of the older individual, detect changes over time, and promote healthy behaviors to prevent or early detect functional decline.

Functional decline can result from a sudden event (eg, a fall resulting in hip fracture) or from a complex interaction between multiple factors combining, among others, lifestyle and presence of chronic diseases. Functional decline can also be a slow process that develops in daily life. In other words, prevention of functional decline requires a holistic approach to health, rather than focusing on one specific health domain. Hence, technology to prevent, detect, or even reverse functional decline should take a multidimensional perspective of health and should be integrated into the daily life of the users, in this case, older adults.

The adoption rates of such information technologies by older adults are growing [2], and contrary to popular belief, this age group is in general open-minded toward electronic health [3]. However, there are still well-known barriers constraining the adoption and acceptance of technology. Among the critical barriers to the adoption of technologies by older adults are privacy concerns, ease of usability for daily use, and the belief that the technology is not necessary, that is, the perception of no need [4].

One way to prevent these barriers is to include older adults in all phases of development of the new product or service, that is, participatory design. In fact, a review from Piau et al reveals that inadequate comprehension of user needs is a major issue compromising acceptance of technology [5]. Prioritization of needs and wishes of older adults to improve adherence to and acceptance of technology is mentioned not only by the older adults themselves [6] but also by several stakeholders involved in the development and deployment of technologies, such as care professionals, technologists, and policy makers [7,8]. However, despite the current knowledge on the importance of involving older adults in all phases of research and development, studies investigating the wishes of older adults with regard to technology to prevent functional decline are scarce. Furthermore, most user-centered design studies are performed envisioning the development of a product targeting 1 or 2 health domains [9,10], instead of the holistic approach required by the definition of functioning. In this work, we investigate, through semistructured interviews, the current practices in self-management and the attitudes as well as the wishes of older adults concerning technology to be used in daily life supporting their health management and preventing functional decline. Given the multidimensional definition of functioning, we take a holistic perspective of health, considering each one of the following domains in particular: nutrition, cognitive function, physical function, and well-being.

The literature has shown that the expected effort from using technology can decrease after a short period of use [11,12]. In addition, older adults perceive that sometimes they need a small nudge to use technology [13]. Consequently, we deployed a case study in which participants are provided with an example of ambulatory technology, and we investigated whether their attitudes toward monitoring health with technology change after the actual use. Thus, our study addresses 4 main points:

1. Current practices in health management
2. Attitudes toward using technology in health management
3. Wishes and expectations from technology
4. Attitudes toward using technology in health management after actual use.

This study extends the existent work on understanding the barriers and motivators to use technology among community-dwelling older adults [4,13] by looking at technology to support empowerment of older adults in managing their health, from the perspective of older adults. With this study, we aim to provide insights to researchers, clinicians, and all those interested in developing technology contributing to the improvement of acceptance and adherence to technology-based interventions to be implemented in the daily life of older adults.

Methods

Participants

A total of 23 older adults were recruited in local information markets to promote healthy behaviors in the region of Overijssel, the Netherlands, as well as in information sessions given to participants in the European Project FP7-Personalised ICT Supported Service for Independent Living and Healthy Ageing (PERSSILAA) [14] between December 2015 and January 2016. Within the PERSSILAA project, a multidisciplinary and international consortium developed, implemented, and evaluated a novel service model to screen for and prevent frailty among community-dwelling older adults [15]. This new service model was implemented in Italy (Campania) and the Netherlands (Overijssel), counting for involvement of more than 7000 older adults between 2013 and 2016.

All those interested in participating in this study received a letter explaining the research in more detail via post or email. Overall, 12 older adults confirmed interest in participating in the research and were invited for an interview at Roessingh Research and Development. The research was explained by the interviewers; the potential participants were given time to ask questions and afterward provided written informed consent. The ethical review board of the University of Twente approved the study. This study did not require approval of the medical ethical review board, according to European regulations, as all respondents were competent individuals and this study did not involve any interventions or treatments.

Semistructured Interview

An individual interview scheme was chosen as this method provides freedom and openness to explore the opinion of the participants. Each individual interview started with an introductory session in which 2 interviewers informed the participant that the interview would be audio recorded and that it would take approximately 1 hour. One of the interviewees was mostly engaged in the conversation and the other was responsible for taking notes and to intervene whenever necessary. The interview was divided into 5 main topics: general health management, nutrition, cognition, physical function, and well-being.

The general health management questions served the purpose to create a context to go further with the other topics by opening the interview. Current practices in health management, attitudes toward monitoring health with technology, and wishes from technology were assessed with the following open questions for each one of the health domains addressed: (1) *What are you currently doing to manage your physical function, cognitive function, nutrition, and well-being?* (2) *What is your attitude toward monitoring physical function, cognitive function, nutrition, and well-being?* and (3) *What are your wishes and expectations from technology to monitor physical function, cognitive function, nutrition, and well-being?* The well-being scale did not have a question regarding current self-management practices.

General Health Assessment

A general health assessment was performed to obtain an overview of the health status of the participants. Participants were given the choice to answer the questionnaire right after the end of the interview or to take it home and answer at a time of their convenience and send it to the research facilities via standard post. General frailty was assessed with the Groningen Frailty Indicator [16], a 15-point yes-no questionnaire exploring physical, cognitive, social, and psychological components of frailty, with a score equal to or above 4 being regarded as moderate to severely frail (referred to as *decline* in Table 1). Physical limitations were assessed using the physical functioning scale of the Short Form-36 Health Survey [17], a questionnaire with a range between 0 (limited) and 100 (not limited) and with a value higher than 61 being an indication of physical decline. Cognitive function was assessed with the AD8 Dementia Screening scale [18], with a score higher than 2 being an indicator of cognitive decline. Finally, the nutritional status was assessed with the Mini Nutritional Assessment Scale [19], with a total score in the questionnaire between 7 and 23.5 being an indicator of malnutrition (referred to as *decline* in Table 1). This frailty screening method was used with more than 10,000 people in Italy and the Netherlands during and after the European project PERSSILAA [15].

Actual Use of Technology

At the end of the interview, participants were lent a mobile phone, a Fitbit Zip step counter, and a smart scale Withings 30. The purpose was to let the older adults experience simple technology to monitor parameters from 3 health domains using technology.

Regarding the physical activity domain, the participants received instructions to wear the step counter in the pocket to assess the number of steps throughout the day. Feedback on physical activity was provided on the step counter and also on the screen of the mobile phone, using the Activity Coach app. This app has been used in interventions to promote physical activity among several clinical populations, such as cancer survivors [20,21] and patients suffering from chronic pulmonary obstructive disease [22]. In the mobile phone, participants received feedback on the number of steps they took in the current day and the distribution of steps in the current day per hour and during the last week per day. Participants could also see a representation of how far they were from reaching the daily goal. The daily step goal was set to 7500 steps, following recent research [23]. Participants were told that this goal could be changed upon request.

On the nutrition domain, a smart scale was used to monitor weight. The measurements on the smart scale were made available in real time on the Activity Coach app, with an indication of variation of weight and body mass index since the last measurement and also how (un)healthy the values measured were.

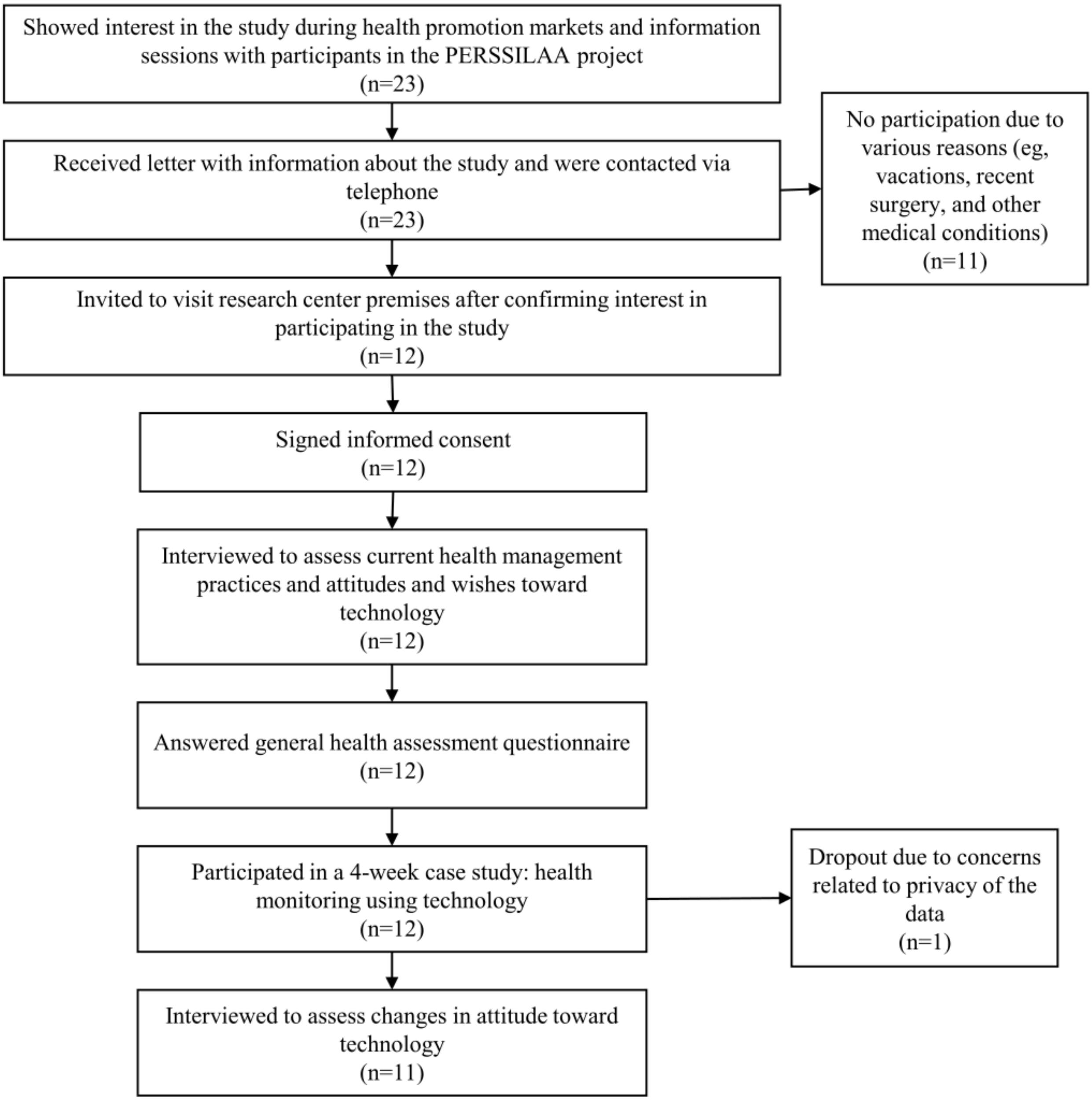
Well-being was assessed in de mobile app. Participants were asked at the end of every day (at 8.30 pm) to which extent they experienced 6 discrete positive emotions (*joy, amusement, awe, love or friendliness, interest, and serenity*) and to rate it on a Likert scale ranging from 1 (*not at all*) to 7 (*very intense*). The selection of positive emotions was based on the modified Differential Emotions Scale [24] and covered the full arousal or activation dimension.

The technology was carefully explained to the participants. The researchers encouraged the participants to contact the research team in case of any question or doubt. Participants were asked to use the technology at their own pace during 4 weeks. At the end of this period, a new interview was performed to assess the experience of the participants and evaluate whether their attitude toward using technology to monitor their health in daily life had changed.

Study Setting

This study took place between March and June 2016. The flow diagram in Figure 1 illustrates the several steps of the study and the total number of participants at each stage. Of the 23 older adults approached, 12 showed interest in participating in the study when contacted to schedule the interview. Reasons to not participate were being abroad for the duration of the study or health-related (eg, recent surgery). Both interviews were conducted face-to-face, at the premises of the research center, and with 2 researchers and 1 participant at a time. One participant dropped out of the study during the case study because of concerns regarding the privacy of the data collected. The researchers assured the participant that the data collected were treated following international guidelines, but nevertheless, the participant felt overwhelmed with the amount of data being collected on a daily basis. At the end, the concerns were not related to the study per se. This participant did not answer the questionnaire regarding current health status but gave permission to analyze the data collected until the moment of dropout in the analysis of the results.

Figure 1. Flow diagram with all phases of the study and number of participants at each phase. PERSSILAA: Personalised ICT Supported Service for Independent Living and Healthy Ageing.



Data Analysis

The interviews were audio recorded and transcribed verbatim. The transcripts were first categorized using a concept-driven approach by 2 researchers, considering the categories: *current practice*, *attitudes toward health management*, and *wishes from technology*. A more detailed categorization in subthemes was performed using inductive thematic analysis [25]. An iterative process was taken until eliciting the final codes. The data analysis was supported by the use of the qualitative data analysis software Atlas.ti 7.0 (Scientific Software Development GmbH).

Results

Participants

A total of 12 community-dwelling older adults (aged 65-78 years) participated in the interviews and 11 concluded the case study. Table 1 provides a summary of the demographic characteristics and health status of the participants at the moment of the interview. Overall, 7 out of the 12 participants were women and 8 lived with someone else (in most cases with the partner or spouse). Most of the participants were robust on the frailty scale, and the highest percentage of limitations was found on the physical functioning scale (only 2 out of 11 participants had limitations). Regarding previous experience with ambulatory technology, 8 of the 12 participants had a smartphone and 5 of them considered themselves advanced users, as they used the device for Web browsing and emailing. None of the participants had previous experience with ambulatory monitoring of physical activity or smart scale devices.

Current Practices in Health Management

Overall, 11 out of 12 interviewees mentioned general health practices from the physical domain (eg, sports), and half of the interviewees mentioned paying attention to eating habits on a daily basis (eg, avoiding candies). One interviewee mentioned sleep hygiene (eg, always sleep for 8 hours per night) and another mentioned mental well-being (eg, by performing pleasurable activities).

When asked about the reasons why it is important to keep track of their health, 9 participants mentioned their current medical situation, often suffering from at least one chronic condition. In addition, 4 interviewees mentioned that they want to keep doing their daily activities independently. Participants showed to be concerned about the fact that if they stop living normal life, they might not come back to current activity (eg, “Because if you start sitting still, you will rust.” [a 66-year-old female]).

Table 1. Demographic characteristics of the participants (age, gender, living situation, and education) and other parameters regarding lifestyle (smoking status) and current health status (general frailty, nutrition, cognitive function, and physical function).

Characteristic	Statistics
Age (years), mean (range)	69 (65-78)
Gender, n (%)	
Female	7 (58)
Male	5 (42)
Living situation, n (%)	
Alone	3 (25)
With someone else	8 (67)
Missing	1 (8)
Education, n (%)	
Elementary school	1 (8)
High school	3 (25)
Vocational school	6 (50)
University	1 (8)
Missing	1 (8)
Smoking, n (%)	
Smoker	2 (17)
Nonsmoker	9 (75)
Missing	1 (8)
General frailty, n (%)	
Decline	3 (25)
Robust	7 (58)
Missing	2 (17)
Nutrition, n (%)	
Decline	0
Robust	11 (91)
Missing	1 (8)
Cognitive function, n (%)	
Decline	1 (8)
Robust	9 (75)
Missing	2 (17)
Physical function, n (%)	
Decline	2 (17)
Robust	9 (75)
Missing	1 (8)
Body mass index, mean (range)	25.3 (17.4-36.1)

Another factor often mentioned was the fast decline or even sudden death of beloved ones in the surroundings of the interviewees and how that affects the self-perception of health. Finally, 1 interviewee mentioned that, with the amount of information available nowadays, it is imprudent (*silly*) if one does not take care of his own health.

When asked about the motivation to keep track of their health, none of the participants referred *to avoid disease*. Instead, the functional perspective of health was very present as participants said they wanted to be healthy to keep doing their daily activities independently.

In general, interviewees were aware that their health status is changing as they get older and wanted to adopt measures to slow down this process, such as monitoring their current health status and training to improve their general functioning (eg, “Health is your biggest treasure!” [a 68-year-old female]).

Nutrition

Overall, 11 out of 12 interviewees stated the adoption of healthy practices in their daily diet, such as cooking with low salt/sugar/fat/carbohydrates, taking small portions, and including vegetables in all warm meals. Only 1 interviewee mentioned not paying attention to the daily eating and added that he or she only cooks warm meals when accompanied, otherwise breakfast, lunch, and dinner would consist of bread. From the analysis of the interviews, it is clear that the eating habits are influenced not only by the medical background of the interviewee but also by the medical background of the spouse, as a couple is likely to cook and eat together. It is also noteworthy that the interviewee who would need to take care of daily diet the most (because of being overweight) was the only one who refers not paying attention to eating habits.

Cognitive Function

When asked about the current practices to self-manage cognitive function, most of the interviewees did not understand the concept. After hints from the interviewers, the interviewees mentioned that, in fact, although unaware, they were regularly training their cognition. Examples of activities mentioned were *puzzles* (n=6), *read books and newspapers* (n=6), and *play computer games* (n=2). Interviewees were aware that their memory was declining with age and showed to be concerned about that fact. For those who had relatives or friends who suffer, or have suffered, from conditions as Alzheimer disease, or similar, cognitive decline was perceived as a very sensitive topic to talk about.

Physical Function

Interviewees showed to be more aware of healthy behaviors concerning prevention of physical function decline than of any other health domain. A total of 7 out of the 12 interviewees practiced sports at least twice a week. Sports mentioned included tennis, golf, swimming, and fitness. In addition, 5 participants mentioned that continuing to do the household chores by themselves helped them to feel active. Other physical activities mentioned were dancing, volunteer work, and recreational biking or walking. Furthermore, 7 participants mentioned to use the bike for everyday commuting and only preferring the car or bus when the weather is bad. Noteworthy is that one of the interviewees mentioned that most of the daily physical activity comes from his or her role as an informal caregiver, considering that he or she needs to take care of everything for the spouse, whenever needed. In addition, 2 interviewees mentioned to be goal-oriented persons, and therefore, they could not think of biking, walking, or exercising without a meaningful activity. Participants reported that they felt more energetic when they are more active on a daily basis.

The medical background had a strong influence in the 3 health domains investigated. For example, in the physical function domain, for some participants, the medical condition was a motivation to be more active as, for example, diabetic patients knew that an active lifestyle would help in controlling insulin levels. For other participants, the medical background represented a constraint on becoming active, as for patients with chronic obstructive pulmonary disease or with cardiovascular diseases.

Compensation strategies were mentioned related to daily diet (nutrition domain) and physical function. For example, 1 participant said:

> *[My wife] cooks some special kind of bacon, it’s very nice and spicy, a good feeling; when I eat it, I don’t touch the sweets.* [78-year-old male]

Attitudes Toward Using Technology in Health Management

Nutrition

All interviewees recognized that it is important to keep track of the daily diet. However, 6 out of 12 participants claimed that they would not use a website or app to monitor their eating habits. Some participants said that they monitor their food intake by themselves and do not need technology to help with it; others believed that it would be too time-consuming to log everything they eat throughout the day in an app or website. One participant said he or she would prefer to talk to someone about the topic rather than to use technology. In addition, 2 participants kept a food diary log for a couple of years because of their diabetic condition.

Cognitive Function

All participants recognized the importance of keeping good cognitive functioning for performing daily activities independently. None of the participants stated clearly that they would not like to use an app or website to train their cognitive function. Moreover, 3 interviewees stated that they were afraid to get an overview of their cognitive function over time as they would not want to be confronted with a decline:

> *Well, I’m actually a bit afraid. [...] I’m doing everything to prevent it, but when I get it, I prefer not to be confronted with it.* [69-year-old female]

Reasons for this fear are close cases of dementia (eg, Alzheimer disease) or their own medical history.

Physical Function

When first asked, most of the interviewees were not open to the idea of monitoring physical activity. After explanation, 5 out of the 12 participants continued saying that they did not find it important to monitor physical activity with technology, as, according to them, they felt when they were active enough or when they were not. Due to that, participants perceive that they do not need to see the physical activity level in any technology:

> *Look, when I'm fit and active, I feel good. Well, and I can feel that myself, I don't need to see that on one of the computers, "you did this and that..."* [72-year-old female]

One participant mentioned that monitoring physical activity with technology would likely make him or her less attentive to the own body. At the end, 6 participants mentioned that they would maybe use an app or website to monitor their physical activity.

Well-Being

Participants were asked to think specifically of daily well-being, as in how they feel on a daily basis. Overall, 8 participants found it important to keep track of their well-being on a daily basis; 4 participants did not see any added value in monitoring well-being. One participant mentioned that she does not ever reflect on their own well-being:

> *No, no, no, but that's something like, I have never, you notice that, today I feel a bit better than yesterday. I have never thought about that, because the day starts with fixed routines, and you will see how it ends.* [72-year-old female]

Overall, 1 participant perceived emotional information too personal and would only share it with a specialist. In addition, 6 participants mentioned that they would at least try the app to monitor well-being and 2 interviewees totally rejected the idea of it.

Wishes and Expectations From Technology

Nutrition

In general, interviewees were not aware of the possibilities provided by technology. In this way, most of the suggestions came from the interviewers to which the participants provided vague answers, such as "Maybe that could be interesting." After suggestions from the interviewers, 3 participants said it could be good to obtain an overview of the daily food intake. The opinions of participants diverged regarding the possibility to monitor caloric and nutritional intake and obtain recommendation of healthy recipes. Reasons for not wanting such services were related to the reluctance to break old routines of eating.

Nevertheless, some participants themselves expressed the wish to have access to a website or app to monitor the nutritional or caloric intake. Moreover, 4 interviewees said they would wish to receive recommendation on healthy recipes tailored to their medical background and needs. In addition, 1 participant said he or she would like to share his or her own knowledge on nutrition with other people. Furthermore, 1 participant said he or she would rather talk to someone or follow a course than use technology.

Participants with a positive attitude toward the use of technology in daily life said that they would likely adapt their behavior to the recommendations or the overview provided by an eventual system.

Cognitive Function

The wishes from technology to monitor and train cognitive function were very conflicting. Although 7 interviewees stated that they would like to train cognitive function in a fun way, 3 interviewees clearly stated that they did not like games and would not want to play. In addition, 1 participant mentioned that, when existing, exercises should be short and vary over time to remain engaging. Another interviewee mentioned that the exercises should be tailored to the current cognitive level of the individual. Moreover, 3 participants said that they would like to be able to train their cognitive functioning with technology but would not want to see an overview:

> *I'm just afraid of it, you know? [...] Well, because it appeared that, with diabetic people, dementia occurs much more often. And then I think, oh boy...and I'm just hiding that. I am telling you now, but yes, that is a fear that I have.* [68-year-old female]

On the contrary, 3 interviewees mentioned that they would like to receive feedback on their progress over time. In general, participants recognized the importance of preserving cognitive function at old age:

> *Well, I think you should train it one way or the other, and whether that's done with some puzzles, with an app or through something else, I don't care, but it has to happen.* [66-year-old male]

Physical Activity

Participants expressed stronger wishes related to monitoring physical activity with technology than to any other health domain. Interviewees would like to see the distribution of physical activity throughout the day in terms of intensity of activity and number of steps (n=6), the distance walked and biked at the end of the day (n=2), as well as the quantity of calories burnt (n=2). Participants would also like to receive personalized coaching in terms of daily physical activity goals and functional physical exercises tailored to their health, age, and gender (n=3). In addition, 1 interviewee would like to be able to set his or her own activity goals. Another participant mentioned that he or she would likely be motivated by a gamified coaching system in which he or she could receive points every time the goals were reached. One participant would like to have a distinction between activities performed indoors and outdoors. Finally, 1 participant would not like to see the amount of time spent inactive as it would probably be too confronting.

Most participants mentioned that such technology would be very important to make them aware about their actual activity level in comparison with their peers—"am I really more or less active than other people of the same age or medical condition?"—and that they would adapt their behavior to the feedback received. A recurrent worry from 1 participant was the fact that technology could cause attention theft.

Well-Being

It was very difficult for interviewees to imagine how it would be to use an app to monitor well-being in daily life. After some hints from the interviewers, 1 participant said he or she would like to compare the well-being of different days. In addition, 4 participants said that they would like to obtain an overview over time to help understand what influences their well-being from day to day. One participant would like to see a figure comparing physical activity and well-being, and another participant would like to receive advice on how to improve well-being. One participant said that to talk about well-being, he or she had to feel sympathy and empathy from the app, *as if it cares*. One participant would like to have this app available on a mobile device instead of a computer.

Attitudes Toward Using Technology in Health Management After Actual Use

Participants were given technology to monitor their weight (parameter from nutritional domain), physical activity (physical function domain), and daily positive emotions (well-being domain) for a period of 4 weeks. The individual interviews performed after this period revealed that all participants were satisfied with using technology to monitor at least one health domain.

Weight monitoring was the favorite feature for 3 out of 11 participants. These participants said that the fact that the app stored the weight measurements automatically and provided an overview over time was very positive, as it saved time when compared with the conventional procedure of registering the weight with pen and paper. These 3 participants were those who showed a more positive attitude regarding monitoring of nutrition on a daily basis, as they had already been doing it upon request from their therapists.

Despite the moderate interest shown regarding the use of technology to monitor physical activity in daily life during the first interviews (only 6 participants said they would like to use an app in daily life), after the 4 weeks of the study, all participants reported a positive experience. Overall, 9 participants mentioned experiencing an added value with this feature and would like to keep using it, whereas the 2 other participants said that, although the idea was interesting, they would not use the monitoring system in daily life as they know they are more active than the general population of the same age. In addition, 8 participants mentioned that they became more active during the 4-week period, and 5 interviewees mentioned that they became more aware of their daily physical activity:

> *I find it a piece of art, in fact, that this is possible [...] Because it does make you aware of things that you don't really think about.* [67-year-old female]

The attitudes toward monitoring well-being on a daily basis changed less than in the physical function domain. After using the technology for 4 weeks, only 4 participants perceived an added value for monitoring well-being in their daily life. Nevertheless, 6 participants reported becoming more aware of their own well-being after using the technology. The most important reason was that they were invited to reflect on questions that they would not do by themselves. However, as the questions were the same every day, after a short period, the reflective effect vanished and most participants reported answering the question almost automatically. Furthermore, the low interest in monitoring well-being after using the technology for 4 weeks was influenced by the fact that, contrarily to what happened with weight and physical activity, older adults were not provided any feedback or overview on their answers.

Discussion

Principal Findings

This study explored current practices in health management, attitudes toward monitoring health in daily life supported by technology, and wishes of technology from the perspective of community-dwelling older adults. Moreover, we investigated whether the attitudes toward technology supporting health management changed after actual use of monitoring technology in daily life. The older adults in our study were in general engaged in their health management, particularly on the physical domain. Furthermore, the older adults were willing to use technology in daily life to monitor their health and to help them in the adoption of healthier behaviors, as long as they perceived the technology was tailored to their needs. However, the wishes of technology differed per health domain. In the nutritional and physical domains, older adults search for technology that creates awareness about current behaviors and coaches them in the adoption of healthier behaviors. Contrarily, for the cognitive function, older adults look for a training system but do not want to receive feedback on current status or an overview of changes over time. Furthermore, when developing technology to be used in daily life, not only the wishes should be considered but also the fears that the older adults state concerning technology, such as the replacement of human contact. In the next paragraphs, based on the results of our study, we provide a set of recommendations for those interested in the development and implementation of technology-based interventions to prevent functional decline in the daily lives of older adults.

Current Practices in Health Management

Although actively engaged in their health management, the older adults participating in our study were not always confident, or even right, about what they believed as being healthy or not. Moreover, older adults wish to obtain meaningful information about how and why they should change a current behavior. For example, when openly asked about general practices in health management, older adults primarily thought about the physical domain. Contrarily, none of the interviewees mentioned cognitive function, as also reported in the study by Menichetti and Graffigna [26]. This means that older adults are themselves not aware of the holistic dimension of functioning. Moreover, in our study, cognitive function was the most difficult health domain to talk about. Older adults did not understand what cognitive function was or their knowledge was limited to memory-related issues. Despite the fact that older adults have shown a better understanding about the physical domain, there are still misconceptions. For instance, it is not clear that being active goes beyond the practice of structured exercise. Interventions should make individuals aware that all daily movements count by promoting an active lifestyle beyond the motivation for physical exercise, as in the studies by Tabak et al and Fanning et al [22,27]. In the nutritional domain, beliefs on what is (un)healthy are affected by cultural traditions (eg, bread as the core element of all meals in a day in the Netherlands). *All-in-all, improvement of health literacy must be prioritized when aiming to prevent functional decline.*

In our study, older adults tend to adopt a functional perspective of health. This is in line with previous research suggesting that, as people grow old, the conceptualization of being healthy changes from *disease avoidance* to *being able to do daily activities independently* [1,28]. Further research should investigate the effectiveness of interventions in which technology supports the individual in reaching personalized goals related to daily activities. As an example, one can think about the goal: "I want to be able to pick up my grandchildren from school." Technology could then support in maintaining or achieving the skills needed from the different health domains to keep doing this activity independently. Therefore, *technology to support prevention of functional decline must go beyond the disease-oriented perspective and focus, instead, on strategies to maintain independence on daily activities.*

Attitudes Toward Using Technology in Health Management

Older adults were in general positive toward using technology in health management on a daily basis. However, technology should provide this support without interfering with the daily activities and without consuming too much time. This can be achieved with unobtrusive sensing and easy communication between individual and technology. Another general concern mentioned was the fear that, through the use of technology, older adults would listen less to the signals of their own bodies. In fact, technology can support and increase functioning, but it can also diminish capabilities through disuse [6,29]. Technology must then keep challenging older adults to use and improve their abilities instead of being a simple facilitator. Finally, the interviewees shared the fear that technology would replace human contact, as also reported by Peek et al [13]. In this case, technology can support communication between older adults in both real and virtual worlds. *Fears related to technology that deserve attention are (1) technology as attention thief in daily life, (2) technology leading to diminish abilities through disuse, and (3) technology as replacement for human contact.*

Older adults wish to perceive the technology as tailored to their own wishes, disabilities, and preferences. The World Health Organization identified *diversity in older age* as a challenge when developing policies targeting the promotion of healthy aging [1]. The same challenges serve for technology. Designers and technology developers should take that into consideration and design modular apps that allow older adults to enable or disable functionalities according to their personal needs and wishes. In this way, older adults also perceive as being in control over the technology, instead of feeling that they are being controlled by technology. For example, older adults must be given the possibility to decide whether they want to share their information with other people or not. Interventions to support prevention of functional decline should also be tailored in terms of the motivational messages generated (eg, based on current stage of change from the transtheoretical model [30]) or in terms of the strategy how the training is provided to the individuals (eg, gamified training of cognitive function vs reading challenging texts, based on individual's preference). Another possibility is suggested by Menichetti and Graffigna who define 3 experiential positions regarding health management: locked position, awakening position, and climbing position [26]. Technology might play different roles in each one of the experiential positions. In the first, it can go more in the health literacy direction; in the awakening position, technology might help setting up plans as daily tasks; and finally in the climbing position, technology can support the maintenance of good practices. In conclusion, *a one-size-fits-all approach is not possible in the use of technology to support prevention of functional decline.*

To talk about their health and, in particular, about cognitive function and well-being, older adults wish to feel that *the technology cares for them*. In fact, exploring wishes of technology to monitor well-being in daily life became extremely difficult as most of the older adults participating in this study did not see well-being as a component of their health or as something that can be monitored and trained over time. *Technology should show empathy and sympathy.*

Older adults would like to be given the opportunity to share their knowledge and experience with peers. Other social interactions of interest would be sharing experiences and nudging and congratulating each other. The need of a moderator could be avoided by creating closed groups where information is only accessible by friends. In this way, older adults would like to have an active role not only in the development of the app but also during its use. *Technology should provide the opportunity for older adults to share their own knowledge and experiences with peers.*

After using technology to monitor physical activity for a period of 1 month, all participants recognized the value of it, supporting the hypothesis that attitudes toward technology might change after a short period of use, as suggested previously [11-13]. Weight tracking in daily life is a procedure that people are already familiar with, as most people already do it on a regular basis. The advantage of technology is that it stores the results automatically and provides an overview over time. Well-being was from the beginning the health domain that participants were more skeptical about. This attitude barely changed after the study period. We strongly encourage researchers to perform similar studies but start with health literacy aimed to break the prejudice against well-being, as there is growing evidence that higher experience of positive emotions is not only associated with better physiological markers of health [31-33] but also with better functioning [34].

Strengths and Limitations

This study extends the work of Yusif et al, de Veer et al, and Peek et al [4,13] by taking a holistic perspective of health, without a design of a specific product in mind. The approach taken was "Imagine everything is possible, what would you like to see." This is strength of our study compared with existing literature as it does not limit the mindset of the participants.

The aim of this qualitative study was to develop a deep understanding of the health management practices in daily life and how these relate to wishes with respect to technology among older adults. To reach this aim, in-depth individual interviews (taking approximately 1 hour 30 min to 2 hours per participant) were conducted to get a deep understanding of the principles and values of each participant. In line with the prevailing view on qualitative research sample sizes in seminal papers on this point, we believe that the sample size is in line with the objectives of this study [1-3]. Through in-depth conversations with 12 older adults, we obtained a richness and depth of explorations and descriptions that would likely not be possible with shorter interviews with a larger population.

The interviews were part of a larger study regarding monitoring of health with mobile technology. The participants in this study were aware that they would receive ambulatory technology to monitor physical activity, weight, and daily well-being on a daily basis. Therefore, they were intrinsically motivated to use technology; otherwise, they would have not participated in the study. In this way, the data collected regarding attitudes toward monitoring physical activity might be biased as the participants were a priori interested in monitoring their physical activity; otherwise, they would not participate in the study. However, as we are thinking about technology for a population with no or mild limitations, we are exactly targeting people that have some sort of intrinsic motivations, instead of being told to use technology by a health care professional.

Most of the interviewees were not aware of the possibilities provided by technology and in general needed several hints to come up with suggestions, also reported in other studies [13,35]. The hints provided might have biased the results on the wishes from technology; however, not giving hints would make it impossible to have a conversation on the topic.

Conclusions

In this study, we explored (1) current practices in health management, (2) attitudes toward using technology in health management, (3) wishes of technology, and (4) changes in attitudes toward technology after actual use in daily life. On the basis of interviews with community-dwelling older adults before and after using technology, we conclude that older adults do wish to use technology in daily life to support them in managing their health in the prevention of functional decline, particularly in the nutritional, cognitive, and physical domains. Contrarily, well-being was not perceived as a health domain or it was not clear how technology can be of any support. Attitudes toward using technology in daily life only changed in the physical domain, but noticeably, with all participants perceiving an added value after use. We summarize the results of our study in a set of recommendations to researchers, clinicians, and all those interested in developing and implementing technology-based interventions in the daily life of older adults to support prevention of functional decline. Further research should investigate whether the proposed strategies improve adherence to interventions deployed in the daily life of older adults.

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Conflicts of Interest

None declared.

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Abbreviations

PERSSILAA: Personalised ICT Supported Service for Independent Living and Healthy Ageing

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Original Paper

Engaging Aging Individuals in the Design of Technologies and Services to Support Health and Well-Being: Constructivist Grounded Theory Study

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Abstract

Background: Changes noted within the aging population are physical, cognitive, as well as emotional. Social isolation and loneliness are also serious problems that the aging population may encounter. As technology and apps become more accessible, many basic services, such as those offered by social services, well-being organizations, and health care institutions, have invested in the development of supportive devices, services, and Web-based interactions. Despite the perceived benefits that these devices and services offer, many aging individuals choose not to engage, or engage in a limited manner. To explore this phenomenon, we developed a theory to describe the condition for engagement.

Objective: The main objective of this study was to understand the perceptions of an aging South African population regarding Web-based services and technologies that could support aging in place (AiP). Although the concept of AiP speaks to a great number of everyday activities, this paper explores aspects of health and well-being as being central to AiP.

Methods: The study used a grounded theory (GT) methodology, relying on an iterative and simultaneous process of data collection, coding, category development, and data comparisons. Data were collected through qualitative methods, including interviews (13 participants aged between 64 and 85 years), 2 participatory workshops (15 participants), and observations. The study focused on Charmaz's approach to constructivist GT, which puts forward the premise that theory or knowledge cannot take shape in a purely objective manner. Instead, theory is constructed through the interaction of the researcher and research participant. Coding and data analysis were supported with ATLAS.ti (ATLAS.ti Scientific Software Development GmbH).

Results: The study resulted in a substantive theory exploring the process of interaction and engaging factors through user insights and experiences. The emerging design theory, *Ageing User Decision-Driven Engagement* (AUDDE), explored the elements that support engagement with technology and supportive apps, which could offer access to required health and wellness services.

Conclusions: In AUDDE, the perceived value of the interaction is a crucial catalyst for engagement. Aging users continuously make meaning of their experiences, which affects their current and future actions.

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KEYWORDS

technology; healthy aging; grounded theory; qualitative research

Introduction

Background

Globally, health care systems have to deal with the exponential growth of the aging population, adding strain to health care service provision while still having to commit to achieving the sustainable development goal of the right to good health for all ages [1]. There is a general shift of the population toward older age being referred to as population aging [2], who not only live longer but also deal with complex interrelated factors related to their quality of life (QoL) [1-3]. At the same time, fast technology advances add pressure to the development of relevant technology-enabled health care services and the potential mediating role that technology could play toward the QoL of the older person [1]. The exponential growth of both the aging population with the complexity of health states and fast technology advances results in health care services struggling to deliver quality health services to maintain the human dignity of the aging population [4-6]. The needs and preferences of older people to enhance their intrinsic capacity to negotiate their own changing world toward new ways of functioning as part of healthy aging are complex [2,7]. Design thinking offers an approach that deals with complexity with a focus on empathy, context, ideation, and iteration as part of designing human-centered services [3].

The danger of fast technology advances is that they could potentially widen the gap between younger and older population groups, especially considering the diversity and multitude of cognitive and physical abilities and health status associated with aging groups, which may make adoption of technology more difficult [3]. Efforts should be made to include the older users in the service design and implementation processes, owing to their emergence as important consumers of services rather than merely regarding them as passive recipients of technology [1,8]. The design of fit for purpose service should focus on integrated care that is person-centered and empowers the care recipient for the older user to continue to contribute to society [7]. As a recipient of care services, it is important to understand the older users' experience in their own situated context [9]. *Gerontechnology* is a concept for considering the impact of technology on the QoL of the aging population, where technology has the ability to enable services [6]. When considering the relationship between technology and aging, it is important to regard older persons as active consumers of technology-enabled services and active cocreators of technology during the design process [8].

Many gerontechnology research studies deal with the design processes and methodologies [8]. Both participatory design and codesign approaches speak to the need to include participants in the exploration of a design challenge and the subsequent design process. One of the challenges older individuals face is that technology has not always been designed with their specific wants or needs in mind [10]. A participatory design approach can bridge this challenge by including older persons in the design process of health and well-being technologies and services [11-13]. Studies on the implication of Internet of Things for future health care services and devices for older individuals position a participatory approach as critical [14,15]. As technology develops, there remains a need to explore the complexities of technology use in health care services intersecting with the older user [3,16], as well as the role of the older user in the design process [6]. It is also necessary to unpack the inherent tension among design research that allows for iterations, ambiguity, rapid prototyping, and health research that is hypothesis-driven and where evidence-based research is the norm [3]. This paper attempts to contribute toward the understanding of the design of technology-enabled services for the older user.

The aim of this study was to propose a theory that can be used when designing health and well-being services with the aging population as a target group. Findings from the study contribute a substantive theory to the service design body of knowledge, which explains the engagement of older individuals with Web-based services (including services that support health and well-being). The study adds value to Web-based health care service design practice by developing a deeper understanding of user perceptions and experiences within a sociotechnical context.

Designing for an Aging Individual

Decreased physical mobility, eyesight, and cognitive processing may impact the QoL of older individuals. These individuals require support from family, friends, or the community to complete basic daily tasks and activities relating to their health and well-being. Technology and devices that support health care could offer alternative solutions to these challenges. These technologies can range from services that enable increased socialization (social media and communication applications) to health monitoring devices and emergency notification services.

The Web-based market for an aging population has been an area of research interest for a long period, but it has not yielded many insights into user-driven design in collaboration with older users [17]. This may be influenced by how aging users are viewed by both the service and goods providers, as well as the developers of health care and well-being technologies and services. A number of recent software solutions, apps and devices reflect the spectrum of interaction with aging individuals during the conceptualization and development of interventions and supportive solutions. These range from including aging individuals as end-user testers instead of cocreators [18] to collaborating with those close to the aging person (family and caregivers) [19]; finally, these also span to projects that include aging individuals in the process as cocreators [20].

The influence of age on the likelihood of engaging with technology is less extreme than once imagined [6,21], but the nature of, and influences on, the engagement of an older individual has been noted. Before the potential impact of health care technologies and services on the lives of aging individuals can be understood, the usage and perceptions of the aging population must be explored to identify possible barriers to participation.

From an economical perspective, it is crucial to consider the global growing aging community within our technological society [1,22]. If not considered during the conceptualization and design of products and services, it can be hypothesized that aging users who do not feel confident on use of the Web would cease to use the services that could possibly improve the support for their everyday activities and offer them greater independence [8,23].

Technology to Support Aging in Place

Gerontechnologies offer technologies and innovations specifically designed for an aging community [6,24,25]. Another definition offered by Iffländer [26] is *age-based innovations*, which are defined as products and services specifically designed to acknowledge the needs of older users. Irrespective of the assigned title, these products and services focus on enabling an aging community to remain autonomous and contribute to a greater sense of well-being (including increased social engagement). A possible contribution of supportive technology and access to Web-based services is facilitating aging in place (AiP) of aging individuals.

A lack of understanding specific user needs can have a major impact on the innovation of various technologies that can support AiP [27]. This understanding must include a review of human factors that consider an individual's limitations, his or her capabilities, as well as personal and cultural contexts [28]:

> *Only when the real needs of the elderly are correctly understood by innovators, fully specified in AiP digitalization, together with stakeholders' inclusion in the innovation process and proper consideration of human factors and other contextual factors…can then ensure the success of AiP implementation [26].*

To encourage continued engagement among aging users who can benefit from technology that facilitates AiP, the nature of their Web-based interaction, as well as the process of learning how to engage, must be considered. Aging individuals and those who care for them will embrace technological products and services that support AiP [20].

Methods

Grounded Theory Method

Grounded theory (GT) emerged from the research and practice of Glaser and Strauss in 1967 [29]. Since then, 3 main streams of GT have developed. The first represents the original ideals of Glaser (often referred to as Glaserian GT), the second variation of the method was conceptualized by Strauss and Corbin (in response to the earlier Glaserian variation), and finally, Charmaz's constructivist GT [30]. At the heart of each GT stream is the exploration of real-world situations through rigid analysis and documentation to gain insights, and it is not based on preconceived ideas or assumptions [31]. The types of data collection tools vary, but qualitative methods, such as in-depth interviews, are prominent. The information gained is analyzed through coding processes, followed by making sense of the complex data and finally coming to a cohesive theory grounded in the data. The process aims to conceptually explain how participants respond to a certain concept, phenomenon, or challenge [32]. The development of the theory is based on 3 foundations: constant data analysis (where data collection can happen simultaneously), theoretical saturation (data are collected and analyzed until nothing new is discovered), and theoretical sampling, which facilitates the emergence of theory [33].

Recruitment and Participants

Participants were recruited through a gatekeeper organization, which has a broad reach throughout the Western Cape and South Africa and attracts individuals from varying ethnic and socioeconomic backgrounds. Presentations were made to members to introduce the project and highlight the parameters of participation. The parameters were that the participants had to be over 65 years and have access to Web-based services through a personal or shared device. The study did not explore problems with connectivity or internet penetration within South Africa. Following the presentations, 23 individuals requested to collaborate on the study, out of which 13 were interviewed (Table 1). The 2 workshops were hosted with 15 participants, out of which 5 participated in the interviews before the workshop. Not all of the interviewed participants joined the workshops. This study thus featured a convenience sampling with regard to the open call for participation; however, all participants met the defined project parameters. For this reason, the sampling method aligns itself with the traditional theoretical sampling one would expect in a GT study.

Ethical considerations were a primary focus in the study, and recruitment was dependent on the participants' ability to give informed consent. Furthermore, 3 aspects contributed to the concept of informed consent practiced in the project: (1) participation was voluntary, (2) the nature of the project (including all benefits and risks) was explained before commencement of the research activities, and (3) participants' consent was *valid*. The validity of consent was defined through the work of Ratzan [34], which proposes that, "…the elderly research subject's actual understanding of the experiment be accurate and complete…" Ethical considerations in the project aimed to establish an empathetic grounding for interaction and placing the participant at the center of any consideration or project decision.

The research process was initiated with an open discussion with participants, during which the goals of the project were introduced along with research activities. Participants had the opportunity to discuss their concerns or excitement, from which comments were noted down on the *participant coding and information form*. The form was part of a research process map and toolkit document, which supported the gathering of informed consent and first stage research observations (Multimedia Appendix 1). To quote interviewed participants directly, in an anonymous manner, they were asked to select their own pseudonym. This allowed participants to select the name they wanted to be known by and shifted participant identification protocols associated with anonymity and research ethics into a more human-centered realm.

Table 1. Participant group and research activity participation.

Participant code (PC)	Pseudonym selected by participant (only for interviewed participants)	Age (years)	Gender	Device type	Participation in research
PC1	Victoria	76	Female	Mobile phone, tablet, desktop	Interview and workshop
PC2	Marie	72	Female	Mobile phone, desktop	Interview
PC3	Convict1	85	Male	Mobile phone, tablet, laptop	Interview
PC4	Cordelia	82	Female	Mobile phone, desktop	Interview
PC5	Susan	74	Female	Mobile phone, desktop	Interview and workshop
PC6	Ina	82	Female	Mobile phone, laptop	Interview
PC7	Doll	65	Female	Mobile phone, tablet, desktop	Interview
PC8	Hellet	78	Female	Mobile phone	Interview and workshop
PC9	Cody	76	Female	Mobile phone, desktop	Interview
PC10	Diana	69	Female	Mobile phone, desktop	Interview
PC11	Leonie	71	Female	Mobile phone, tablet, desktop, laptop	Interview
PC12	Dick	69	Male	Mobile phone, desktop	Interview and workshop
PC13	Taffy	74	Female	Mobile phone, desktop	Interview and workshop
PC14	N/A[a]	68	Female	Mobile phone, tablet	Workshop
PC15	N/A	66	Female	Mobile phone, desktop	Workshop
PC16	N/A	83	Female	Mobile phone	Workshop
PC17	N/A	65	Female	Mobile phone, laptop	Workshop
PC18	N/A	67	Female	Mobile phone	Workshop
PC19	N/A	71	Female	Mobile phone, desktop	Workshop
PC20	N/A	77	Female	Mobile phone, laptop	Workshop
PC21	N/A	70	Female	Mobile phone, desktop	Workshop
PC22	N/A	77	Male	Mobile phone, tablet, desktop	Workshop
PC23	N/A	79	Female	Mobile phone, desktop	Workshop

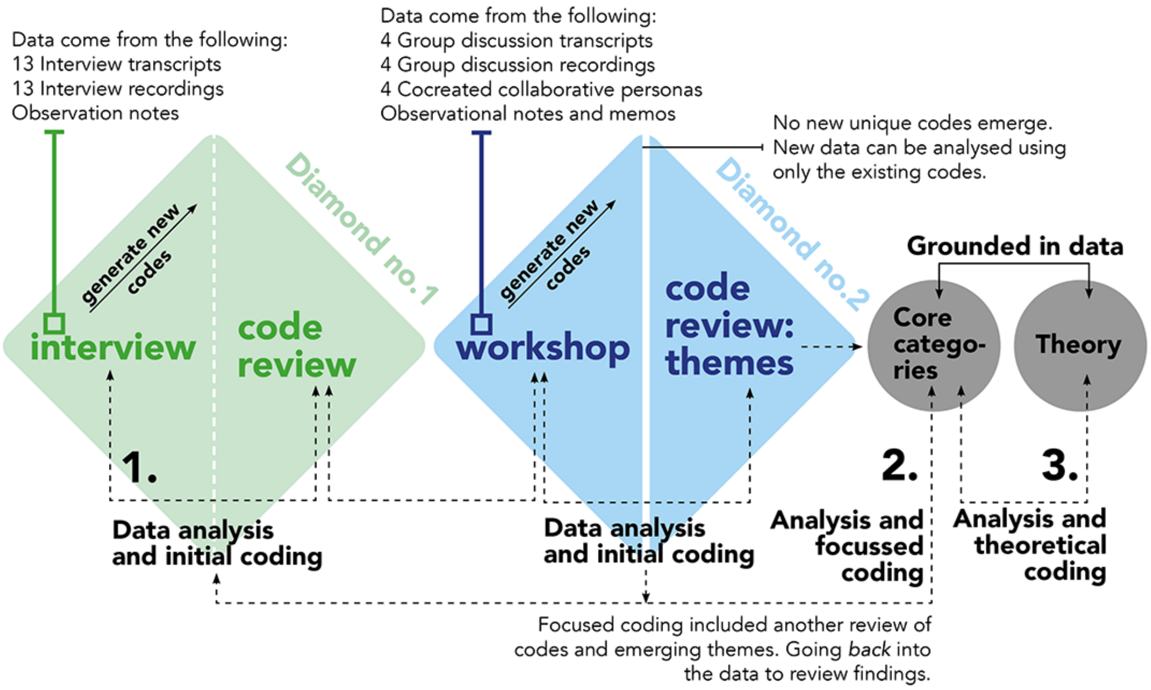
[a] N/A: not applicable.

Data Collection and Initial Analysis and Coding

The project followed a systematic process with regard to the collection and analysis of data in-line with GT. Data collection and analysis happen simultaneously in GT. The process of data analysis progressed through 3 main analysis cycles: initial coding, focused coding, and finally, theoretical coding. The initial coding cycle is rooted in iterative data collection and analysis. Once no new codes emerge as new data are analyzed, the focused coding and theoretical coding processes are completed. Data analysis was completed through line-by-line review and coding. ATLAS.ti, a Computer Assisted Qualitative Data Analysis software, was used to collate and analyze the data gathered. A key aspect of the software that assisted in the analysis of the data was its ability to code both abstractly, as well as in vivo. Using in vivo codes helps preserve participants' reactions and the meanings of their views and comments.

The data collection and analysis process mirrored the *double diamond* [35] design process (Figure 1). In the first diamond, 2 phases were completed: (1) the gathering and analysis of interview data and observational notes, followed by (2) the reflection and code review phase. Interviews were a critical method in this study as they allowed the researcher the opportunity to listen and reflect on experiences of older individuals. Participants could decide on where it was most convenient for them to meet, resulting in a number of interviews being conducted in participants' homes (10 in total); however, the remaining 3 interviews were conducted in a café. Participants were interviewed by a single researcher, who recorded the whole interview for transcription. To encourage a more open approach to interviews, participants were given contact details (email and phone number) to allow them to stay in contact with the researchers. If they wanted to share more information at a later stage, or ask a question, they could engage directly with the researcher.

Figure 1. Data collection and analysis process.



At the interviews, participants were asked to respond to the following questions:

- How do you use Web-based services in your everyday life?
- How do you feel about technology and Web-based services?
- What, if any, are the challenges you have noted when engaging with Web-based services?
- Would you want to engage with technology and Web-based services? If yes, what would you like to see and how would you want to engage with devices and Web-based services?

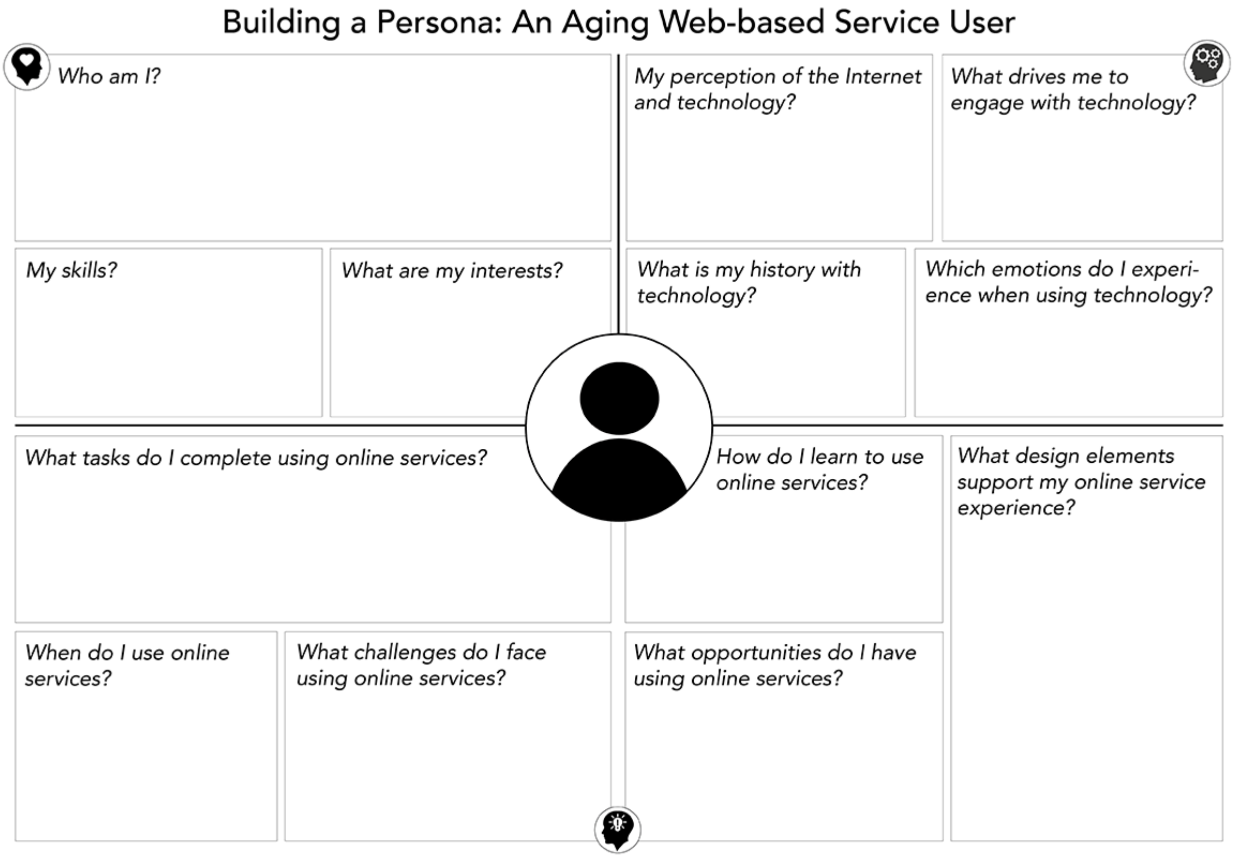
The driver of each interview was to develop a narrative around the participants' perceptions and experiences, and thus the questions were not considered as fixed. The interviewer remained open to conversational shifts as participants shared relevant stories. The process of *initial* coding during the analysis of 13 interview transcripts and observational notes was iterative, in that new data were compared with reviewed and previously coded data. Interviews ranged from 65 min to 93 min in length.

The emerging codes from the interview data analysis were seen as *provisional*, as they changed and evolved as more data were coded and compared. In the initial coding phase, the emphasis was on extracting data from interviews, comments, and observations captured during interactions with participants. The open process of initial coding yielded 155 individual codes. Following the code review, the number of codes decreased to 130 codes. This was the result of code-to-code analysis and the merging of conceptually similar codes. The second diamond also comprised 2 phases: (1) the gathering and analysis of workshop data (transcripts, observational notes, and workshop materials), followed by (2) the reflection and code review phase. In total, 2 workshops were completed, one with 7 and another with 8 participants. The workshops included 3 activities. The first activity was an introduction to a range of Web-based services, demonstrated on different devices and operating systems (Apple, Windows, and Android). At the interactive demonstration session, participants shared their own experiences. The second set of activities focused on the creation of a collaborative persona. The collaborative persona template (Figure 2) served as a discussion catalyst, probing the groups of participants to respond collaboratively.

Several key factors were highlighted through the activity. The discussions were recorded for transcription and analysis. The template and group discussion recording allowed for the gathering of experiences and perceptions from 3 distinct perspectives: the person, the person and technology, as well as the person and Web-based services (Figure 3). Each workshop group was facilitated by a design researcher who observed interactions and posed probing questions during group discussions and cocreation of personas. The paper-based personas were digitized following the workshops (Multimedia Appendix 2) and shared with workshop participants. The final workshop activity focused purely on the participants' needs. All facilitators and technical support worked with individual participants to answer questions regarding Web-based experiences, set up access where needed, or offered device support where possible.

Following the workshops, *initial* coding continued. Workshop materials (in the form of 4 cocreated personas), discussion transcripts for each of the 4 working groups, and observational notes were analyzed and coded. During the analysis and coding of data from the second workshop, no new codes emerged. The analysis and coding of workshop data were followed by a review of the captured initial codes. As part of the review, each code was assigned an introductory word or phrase, which identified the larger focus area and the theme of which the code was a part (Table 2).

Figure 2. Collaborative persona template.



Building a Persona: An Aging Web-based Service User

Who am I?

My perception of the Internet and technology?

What drives me to engage with technology?

My skills?

What are my interests?

What is my history with technology?

Which emotions do I experience when using technology?

What tasks do I complete using online services?

How do I learn to use online services?

What design elements support my online service experience?

When do I use online services?

What challenges do I face using online services?

What opportunities do I have using online services?

Figure 3. Participants and worksheets to support discussion and collaboration (workshop materials).

Table 2. Code groups resulting from code review.

Introductory word or phrase	Code group description
Cognitive impact	Codes relating to the positive and negative impact of using technology and Web-based services on cognitive functions.
Design	Codes relating to the impact of design and interface on the user experience of technologies and services.
Emotive response	Codes relating to both positive and negative emotions experienced by participants when engaging with technologies and services.
Infrastructure and affordability	Codes relating to the affordability of Web-based access and the infrastructure that supports it in South Africa.
Learning facilitation	Codes relating to the method, nature, and process of learning as experienced by the users.
Nature of the internet	Codes relating to the scope and nature of the internet.
Perception	Codes relating to how users perceive technologies and services: the benefit, value, challenges, and expectations.
Physical and digital	Codes relating to the intersection of the physical and digital space and when participants identified comparisons between the two.
Privacy and security	Codes relating to concepts of safety on the Web, Web-based threats, and privacy.
Reason for adoption	Codes relating to reasons for adoption of technologies and services.
Using services	Codes relating to actual technologies and services being used and the experience of specific service elements.
Interaction	Codes relating to all aspects of user interaction with technologies and services from both a positive and negative perspective.

Subsequent to the code review, a final list of 135 codes was defined. The code review process informed the next data analysis phase within the grounded study. The focused coding process critically reviewed each code and the emerging code groups, in relation to the theme identified throughout the data gathering process. The focused coding process resulted in a set of core categories.

Focused and Theoretical Analysis and Coding

Through a systematic review and analysis of codes (in relation to original data, initial codes, and identified themes), the focused coding process resulted in a set of core categories. All initial 135 codes were absorbed within the emerging core categories, and they reflected a more conceptual connection and relationship of themes noted during the code review. The core categories descriptions are grounded in the original comments and perceptions shared by participants. Through the coding process, the data gathered were deconstructed into essential elements, reviewed for patterns and relationships, and then constructed into more complex concepts. The core categories are *digital context*, *cognition and learning*, *emotive response to Web-based interaction*, *user context*, *perceived benefits*, *nature of user interaction*, and *design to support use*.

Digital Context

Aging users viewed technology as products and services that allow access to both convenience and information. Participants felt that products, apps, and services were not designed specifically with aging users in mind. Factors noted in this study that impact user engagement and willingness to interact relate to personal perception, emotional responses, and how each individual views his or her own ability to learn and master new technology.

Cognition and Learning

Diverse learning networks were noted in the study. When new skills, ways of working, and ways of learning are introduced, users must adapt their cognitive understanding to engage with the process. Cognitive ability plays a role not only in an aging user's willingness to engage but also in the long-term usage. Olphert and Damodaran [23] hypothesize that the difficulties that aging users face on the Web may be because of the complexity of technology combined with the cognitive load required to engage actively. In this study, participants mentioned 3 other main learning scenarios: learning from peers, learning from family members, and exchanges with external individuals (such as technical assistants at shops). The engagement with others resulted in mutual learning, during which the aging individuals expanded their knowledge and skill base, whereas those they interacted with developed a keener understanding of the challenges and opportunities that aging presents.

Emotive Response to Web-Based Interaction

Both positive and negative emotions were observed when participants discussed engaging with new technologies. One of the key emotional triggers noted by participants was that they often felt *forced* to engage with new technologies and services. The sense of frustration that they felt was heightened if their immediate network either could not or chose not to offer support and tutelage. Hellet (a pseudonym selected by the participant) noted the following:

> *I really think I need to go for lessons. My daughter always says "what lessons? Just sit and try" like I'm not trying in the first place.*

These early reactions to the use of a Web-based service can influence the way that older users experience the technology as a whole.

User Context

The requirements of aging users are often overlooked by developers and vendors as they do not play an active role in the conceptualization or design of Web-based services and other technologies [36]. Participants in this study acknowledged that they should play a greater role in becoming computer and device literate, to enable them to engage with new technologies and services with more confidence. Cordelia (a pseudonym selected by the participant) noted the following:

> *Programs are often designed by people who are too clever. Sometimes, I don't know what's going on, then what do you do? Explain to people. As we work, we learn...I need to learn by doing it myself.*

Acknowledging the unique personal context of an aging user is a key factor in facilitating Web-based engagement. The impetus to engage, the perceived value of Web-based engagement, and the design characteristics of an enabling environment must all be considered.

Perceived Benefits

The rise of Web-based activity among aging users is linked to their perception of services, technologies, and apps as tools to support everyday activities. One participant (with the pseudonym Victoria) noted the following:

> *So the value is when you have limited mobility, when you're housebound…You could have your Skype, which you can use to check in with your neighbors. If you are housebound and you can contact your friends or family. You can phone your neighbor. So the access is absolutely brilliant. You have unlimited access, you can access anybody, your children, anybody and let them know your situation.*

In the context of an everyday tool, supportive devices and services can offer users clear value propositions. Digital technologies and Web-based services play a major role in addressing the so-called *burden of care* often associated with an aging population [23]. Participants stated that Web-based access could benefit an individual by allowing access to emergency services, lessen feelings of loneliness and isolation, and benefit individuals with limited mobility. Access and support provided through technology could extend aging individuals' ability to age in place, allowing them to age in their own home even though various physical, cognitive, or social capacities may decline with age [26].

Nature of User Interaction

Once the perceived value of the interaction is high enough for an aging user to engage, even though he or she may have negative perceptions, the nature of the interaction space and platform may still impact continued engagement. In many cases the emotions noted included frustration at one's own inability to understand and successfully navigate a Web-based service and supportive devices, the fear of the unknown, and feelings of frustration when forced by family or community members to engage with digital technologies. These emotional reactions form part of the human experience of a technological interaction. Digital interaction and the design of this interaction may influence the user experience, as well as the process through which the user learns to navigate the interaction. If not considered during the conceptualization and design of Web-based services, it can be hypothesized that aging users who do not feel confident would cease to use the services that could possibly improve support for their everyday activities [23]. This result has led researchers to define a *fourth digital divide*, which is not characterized by a lack of access or skill but rather by a lack of clear motivation or interest [23].

Design to Support Use

Using devices and services does pose a number of challenges to aging users, including limited experience with devices, limited experience with Web-based services, or a lack of interest [37]. It is not only the design of the system that needs to support interaction and learning but also the design of interfaces and interactions. The applied practice of designing for aging users and creating more accessible design have received much attention from various projects and researchers over the past decades [37-42]. In addition to individual researchers, various projects have investigated accessibility from an aging perspective, including the *Web Accessibility Initiative: Ageing Education and Harmonisation* [43]—a European Commission Specific Support Action project (Information Society Technology 035015). Overwhelmingly, participants stressed the need for design elements that favor simplicity; however, this may not be an easily generalizable standard. One of the primary reasons for ending one's use of Web-based services has been described as *excessive complexity of the technology* [23]. Participants said that they preferred clear action buttons and a simple style of communication.

During the focused coding process, memos allowed the researcher to keep track of considerations and decisions. The writing up of memos also provides for a structured moment to pause and reflect on the process, encouraging a holistic reflective practice. Finally, the process of theoretical coding responded to the 2 coding aims stated by Flick [44]. First, the process aims to clearly understand and explore the research context or question. Second, it identifies the relationships among categories or components extracted from what was found.

During the theoretical coding process, the emergent core categories were reviewed from a structural perspective to understand the relationships between categories and the nuances at play when considering core categories as part of a whole and not individual sectors. The result of the theoretical coding process was the substantive theory, which explored the process and factors that impacted an aging individual's willingness to engage with technology and services. Saturation was explored at data level (when no new codes emerged through constant comparative data analysis) and again at theoretical level (when the emerging theoretical constructs, literature, and memos were compared and yielded no new variations). Through the process of theoretical coding, these categories formed the foundation for the emerging theory of *Ageing User Decision-Driven Engagement* (AUDDE).

Results

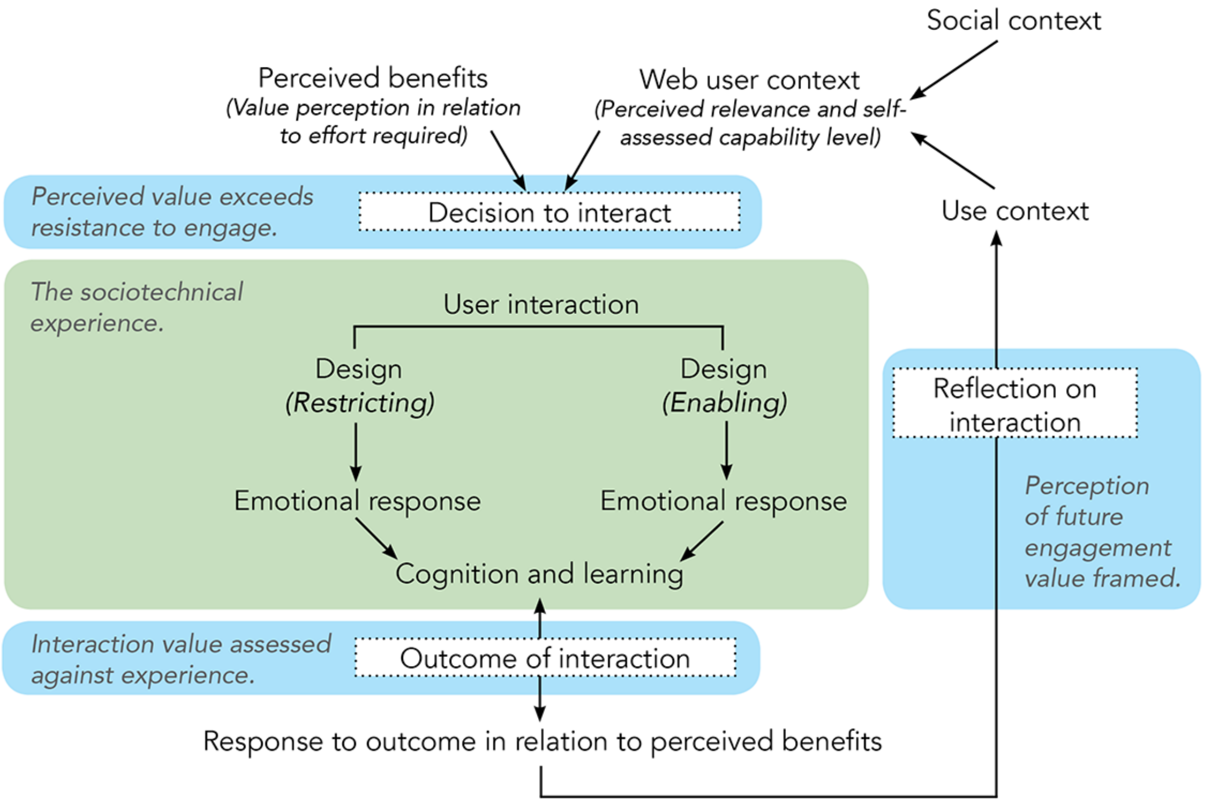
The result of the study was a grounded, substantive theory that explores the factors, and process, of aging individuals engaging with services on the Web. The term *cyber-seniors* refers to 2 emerging groups of aging users, the first is that of the *technology lovers* (who engage willingly and are fascinated by technology) and the second is that of the *technology users* [45]. Technology users see technology as a tool to achieve a specific goal. Participants who took part in this study were overwhelmingly *technology users*. Only 1 participant in the study could be defined as a technology lover; all other participants commented on the *tool* nature of Web-based services or their ability to *help you do something*. AUDDE (Figure 4) highlights the decision-determined engagement that characterized the aging technology users within this study.

The theory proposes an iterative process in the decision-making cycle. When aging users decide to engage with a supportive device, app or service, or decide not to engage, 2 main factors form the basis for their ultimate decision. These factors are defined as *perceived benefits* and *Web-based user context*. For a user to engage, the perceived benefits must outweigh any hesitation that forms part of the Web-based user context. The perceived benefits must be made clear through a value statement. This value statement could be found in the form of an advertisement, but among the aging, it will more likely be word of mouth or the suggestion of a trusted medical professional or a similar individual. Family members and peers are the most likely candidates to share a value statement with an aging individual. Once the individual is aware of the perceived benefit and value that an engagement may have, the decision to interact is dependent on the level of resistance within the user context. The Web-based user context is shaped by 2 spheres of influence, the *social context* and the *use context.*

The first sphere of influence that impacts the decision to engage is the user’s *social context*. Here, the social context refers to the perceptions of the aging individual’s social group, communities of interest, and communities of practice with regard to the technology. Within these social constructs, the aging individual may feel pressured to share the communal peer point of view of his or her social groups. The view of individual family members or friends has a similar ability to shape the perspective of an aging individual. The emotional and social influences on the willingness of an individual to interact with a supportive technology or service are crucial to potential engagement. Equally crucial is the emerging and constantly evolving *context of use*.

The use context of aging individuals is informed by every interaction they have had with the device or service in question, and it may even include a broader range of technological interactions. Every interaction contributes to an individual’s perception of ease of use, cognitive demand, convenience, and overall advantage. In this way, the use context is constantly evolving. The context of use is formed through a process that occurs when the user has decided to interact and revolves around 2 process points, the *outcome of the interaction* and *reflection on interaction.*

Figure 4. The theory of AUDDE: Ageing User Decision-Driven Engagement.



The outcome of the interaction is a process of evaluation that the user completes at the end of a task. The task does not have to be completed successfully, or even completed at all, for the outcome of the interaction to be evaluated. The design of technologies, devices, and services plays a pivotal role in user interaction. Services that take into account different levels of physical ability and focus on enabling simple and specific tasks are of greater value to aging users. Design choices that create an enabling experience elicit a positive emotional response from users. These emotions include pride in one's ability to complete the task unaided, a heightened sense of accomplishment, and joy. Given the nature of the activity, the completion of the task may also elicit a sense of relief. A design that restricts task completion elicits feelings of frustration and confusion. The emotional reaction to a task can often permeate the entire interaction. If aging users, for example, struggle to switch on the device or use it as intended, their initial feeling of minor annoyance can be aggravated by subsequent challenges. The emotional reactions experienced throughout the interaction affirm or challenge perceptions which the user had before. A positive experience may challenge a personal resistance to engage or strengthen previous beliefs that engagement has value. A negative experience may call into question previous perceptions relating to the value of engaging or reinforce previous resistance to engagement.

Linked to the emotional experience of aging users, while interacting with a Web-based service, is the cognitive experience and the potential for learning. Both physical and cognitive decline are key markers of the aging process; however, both manifest in varying degrees and escalate differently among the aging community. Products and services, which offer guidance in the case of possible lapses in user memory or provide a step-by-step task guide, support the unpredictable nature of cognitive ability among this user group.

The learning process for aging users is mediated by either an external stakeholder (a friend, a family member, or a professional encountered when seeking help) or self-exploration. These learning experiences may happen before engagement or may take the form of coached support while using a device or service. How an aging user interacts, the cognitive experience of the interaction, and the emotional consequences and resulting learning process are all interwoven elements of an iterative cycle. A user may go through multiple cycles within this sociotechnical experience before reaching the end of the interaction. The outcome of the interaction could be a successful task completion, an unsuccessful task completion, or an interrupted task (ended before either a successful or unsuccessful task completion). Irrespective of the nature of the outcome, the experience of the interaction will result in the user's reflection on the perceived value expectation in relation to the interaction experience. This process will inform the future *use context*.

Discussion

Involving Users in the Design Process

When reflecting on the emerging AUDDE theory, the complex nature of the networked society becomes clear. Knowledge and experience within the Web-based and digital service realm transcend single disciplines to create service systems:

> *Actual service systems can be described as complex sociotechnical systems, being approached in an interdisciplinary vision that integrates business functions, technology, and human resources, with the final aim of creating value and benefit through the generated services.* [46]

Acknowledging this complexity is crucial when conceptualizing and designing devices, technologies, app, and Web-based services, which aim to support the health and wellness of aging individuals. Researchers and designers must systematically review both the technical and social systems that are at play during an interaction [47]. The technical systems contribute engineered interaction spaces that are designed to be anticipatable and reliable. The social systems are in many ways dependent on the technical systems and evolve throughout interaction encounters. The fast pace of technological development today requires that we endeavor to gain a greater understanding of social systems, to navigate new sociotechnical interactions as they emerge [48].

End users are social beings, who evolve and grow. As such, it is impossible to define social value as a constant, and the social impact on interactions must be considered within the *more institutionalized traditions or regulations inside various user communities* [49]. To understand sociotechnical interactions, it is important to understand that the technology and social context develop reciprocally [50], as well as know the value system that these relationships represent. In AUDDE, the perceived value of the interaction is a crucial catalyst for engagement. Aging users continuously make meanings of their experiences, which affect their current and future actions.

Limitations

It must be emphasized that AUDDE is firmly grounded in the perceptions and shared stories of a specific group of aging users living in Cape Town, South Africa. The relevance of this theory to aging users' experiences outside this geographic area must be verified. The regularity of participants' use of supportive technologies was not a consideration within the delimitations of the study. AUDDE is a substantive theoretical contribution to the body of knowledge of design, but it has the potential to be explored within the context of other studies. To ensure that the emerging theory represented the views and shared experiences of participants, an interactive discussion session was conducted with a participant who took part in the interview and workshop. The session was discussion driven and presented the research process and emerging theory before requesting feedback and comments from the participant. The feedback supported the emerging theory, but feedback from a larger audience will be beneficial.

Conclusions

As the global health care systems become strained with growing aging populations [1], technology may facilitate alternative ways of engaging with and supporting older individuals. Health and well-being products and services draw on the potential of Web-based interaction and technology to support independence and AiP. Product and service design projects and initiatives encourage contributions from aging users to varying degrees. Some projects position older individuals as final validators of a product or service. In this case, input and feedback from the older individuals are gathered subsequent to the development of the artifact or service. Projects that focus on a human-centered approach position older individuals as central to the design and conceptualization process [3]. This approach allows for continuous feedback and interaction between the design team and the envisaged end users. AUDDE contributes to the theoretical body of knowledge in design and aims to explain how and why aging users engage with technology. The theory proposes an iterative cycle of evaluation during which users decide to engage when the perceived value of the interaction is greater than the perceived challenge of interacting. If health care products and services are to be contextually relevant and thus viable, aging individuals must be included in the design process.

Authors' Contributions

VDP recruited the participants, collected the data, conducted the analysis, and formulated the theory. RDLH supervised the study. VDP and RDLH drafted the manuscript and approved the final version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Research process map and toolkit.
[PDF File (Adobe PDF File), 759KB - aging_v2i1e12393_app1.pdf]

Multimedia Appendix 2
Digitized collaborative personas.
[PDF File (Adobe PDF File), 361KB - aging_v2i1e12393_app2.pdf]

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Abbreviations

AiP: aging in place
AUDDE: Ageing User Decision-Driven Engagement
GT: grounded theory
QoL: quality of life

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Original Paper

Mobile and Connected Health Technology Needs for Older Adults Aging in Place: Cross-Sectional Survey Study

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Abstract

Background: An increasing number of mobile and wearable devices are available in the market. However, the extent to which these devices can be used to assist older adults to age in place remains unclear.

Objective: This study aimed to assess older adults' perceptions of using mobile and connected health technologies.

Methods: Using a cross-sectional design, a total of 51 participants were recruited from a senior community center. Demographics and usage of mobile or wearable devices and online health communities were collected using a survey questionnaire. Descriptive statistics assessed usage of devices and online health communities. The Fisher exact test was used to examine the relationship between technology usage and having access to a smartphone.

Results: The sample was primarily comprised non-Hispanic white (35/51, 69%), educated (39/51, 76% any college), and female (36/51, 71%) participants, with an average age of 70 (SD 8) years. All participants were insured and nearly all lived at home (49/51, 94%). A total of 86% (44/51) of the participants had heard of wearable health devices, but only 18 out of 51 (35%) had ever used them. Over 80% (42/51) expressed interest in using such devices and were interested in tracking exercise and physical activity (46/51, 90%), sleep (38/51, 75%), blood pressure (34/51, 67%), diet (31/51, 61%), blood sugar (28/51, 55%), weight (26/51, 51%), and fall risk (23/51, 45%). The greatest concerns about using wearable devices were cost (31/51, 61%), safety (14/51, 28%), and privacy (13/51, 26%); one-fourth (12/51) reported having no concerns. They were mostly interested in sharing data from mobile and connected devices with their health care providers followed by family, online communities, friends, and no one. About 41% (21/51) of the older adults surveyed reported having ever heard of an online health community, and roughly 40% (20/51) of the participants reported being interested in joining such a community. Most participants reported having access to a smartphone (38/51, 74%), and those with such access were significantly more likely to show interest in using a wearable health device ($P<.001$) and joining an online health community ($P=.05$).

Conclusions: Our findings suggest that, although few older adults are currently using mobile and wearable devices and connected health technologies for managing health, they are open to this idea and are mostly interested in sharing such data with their health care providers. Further studies are warranted to explore strategies to balance the data sharing preference of older adults and how to best integrate mobile and wearable device data with clinical workflow for health care providers to promote healthy aging in place.

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KEYWORDS

mobile health; connected health; wearable technology; remote monitoring; independent living; aging in place

Introduction

Background

Aging in place is referred as being able to continue living in one’s own residence as they age [1]. According to the American Association of Retired Persons [2], nearly 90% of older adults would like to remain in their home for as long as possible [2]. However, aging is accompanied with a variety of chronic conditions, and aging in place is challenged by physical and cognitive function decline and consequently the lack of independence [3]. An increasing number of mobile, wearable, and remote monitoring devices, as well as online health communities, have shed light on aging in place and are making it increasingly viable for older adults to age at home.

In today’s market, there are numerous available and emerging tech products which can help older adults age in place, including but not limited to smart-home sensors, smartphone applications, wearable trackers, remote monitoring devices, online health communities, and telehealth platforms [4]. Wearable trackers and telehealth platforms can help the elderly monitor and manage their chronic diseases and improve health outcomes. There is evidence in the literature that wearable trackers and telehealth platforms can help the elderly engage in a healthy lifestyle [5,6], adhere to medication regimens [5,7], and monitor biomarkers and health indicators from home [8,9]. All these data can be shared with their health providers electronically and help them to manage chronic diseases and improve health outcomes.

In addition, the tremendous function of these technologies provides opportunities for older adults to safely and effectively perform activities of daily living, as well as instrumental activities of daily living. For instance, smart-home sensors embedded in walls, ceilings, beds, and floors can detect motion, gait, and fall risk and can help prevent injures [10]; mobile apps can track an older adult’s location, sending a signal to their own or their children’s smartphone app [11,12]. Digital memory aids can help the elderly remember chores or errands and remind them to pay bills [13].

Furthermore, smartphone and online health communities enable older adults get connected and interact with others [14,15]. Social interaction and social engagement are important factors for aging in place [16,17] and have been widely reported to be positively associated with healthy behaviors, self-reported health, physical function, cognitive function, psychological well-being, and longevity, even for the oldest old [14,18-21]. There are several possible underlying mechanisms for the positive effects of smartphones and online health communities on older adults’ overall well-being. For instance, online health communities provide older adults a platform to seek health information [22]. Also, the leisure activity and expanded social network available through online communities may provide social support, contribute to self-preservation, and serve as an opportunity for self-discovery and growth [14].

Mobile and connected health technologies can help older adults improve health conditions, slow down functional decline, ensure safety, stay connected, and maintain the ability and capacity to live independently. However, studies have documented that the usage of technology is low in older adults [23], especially compared with younger age groups [24], and the major reasons for using technology in the elderly are email communication, search engines, text processing, and Web-based shopping [25]. The acceptance and usage of mobile and connected technology in the elderly are determined by a variety of factors, including but not limited to person-related, technology-related, and contextual barriers [26,27].

Objectives

However, the extent to which mobile and connected health technologies can be used to assist older adults to age in place has not been well defined. Therefore, we aimed to study the older adults’ perspectives of using mobile, wearable, and remote monitoring devices, as well as online health communities for aging in place.

Methods

Study Design and Study Population

Using a cross-sectional design, a total of 51 participants were recruited from a senior community center in Harris County, Texas, in 2016 to assess older adults’ perceptions of using mobile, wearable, or remote monitoring technology, as well as online health communities. After completing a community assessment which included conducting a windshield survey, interviewing stakeholders within the senior community center, and interviewing older adult residents, along with a systematic review of currently available mobile apps, wearable trackers, and personal health devices, we developed a survey to examine if older adults would be interested in using mobile and wearable health devices as a means of tracking their health, as well as using online health communities.

The eligibility criteria for enrolling in the senior center included (1) residing in Harris County, Texas, (2) being aged 55 years or older, and (3) signing a participant agreement that includes a release of liability and acceptance of precinct and county rules concerning the operation of the center [28]. All seniors who registered in the senior center were invited to participate in the study. Those who agreed to participate in the study were recruited. Consent forms were obtained from each participant before conducting any study activities. The Institutional Review Board of the University of Texas Health Science Center at Houston approved this study.

Data Collection

All data were collected using survey questionnaires. Demographic characteristics included age in years, gender, race/ethnicity, education (college and higher vs other), marital status, insurance status, and living arrangement. A brief introduction and description of wearable devices were included in the questionnaire. Pictures demonstrating a set of wearable devices were also included in the questionnaire to help older adults recognize different types of health technology devices. Similarly, a statement describing online health communities was provided in the questionnaire. Questions were asked to assess older adults’ usage of home health monitoring devices, wearable health devices, and online health communities. For example, “Have you ever used a wearable health device?” was asked to assess the usage of wearable health devices. Available options for this question were “Yes” and “No.” We further explored their access to technological devices, their concerns of using health technologies, future interest in using wearable health devices and online health communities, the preference of health information they would like to track and share, and with whom they would prefer to share health information. For instance, “Who would you like to connect with in an online community? (Select ALL that apply)” was asked to assess their using of online health community. Available answers for the question included *family*, *friends*, *caregiver*, *health care provider*, *people in similar situations as me whom I don’t know*, *other (please specify)*, and *none of the above*.

Data Analysis

Descriptive analysis was used to examine the demographics of the sample. The same analytic approach was conducted to assess the accessibility, usage, data sharing preference, and concerns when using wearable devices or online health communities. Mean (SD) and number (percentage), wherever appropriate, were used to describe the results. Given the small sample size, the Fisher exact test [29] was adopted to assess the relationship between accessibility and the usage of wearable devices/online health communities. We examined this relationship as smartphones can be used as both a mobile device and as a means to access online health communities [30], which can better help us understand the feasibility of promoting health technologies in older adults.

Results

Sample Characteristics

The sample was primarily comprised non-Hispanic white (35/51, 69%), educated (39/51, 76% of any college), and female (36/51, 71%) participants, with an average age of 70 (SD 8) years (Table 1). All participants were insured, and 47% (24/51) reported having private insurance. Nearly all participants lived at home (41/51, 94%) and none lived in an assisted living facility or nursing home. About 27% (11/51) lived alone, and the rest were living with a family or another person.

Mobile, Wearable, and Remote Technology Use in This Sample

About 43 out of 51 (84%) of the study participants used a health monitoring device at home (Table 2) and 47% (24/51) of them used paper to write down the results, 29% (15/51) did not keep a record, only 10% (5/51) used a computer or phone to type the results, 6% (3/51) downloaded results, 6% (3/51) had results automatically transferred to a smartphone, and 6% (3/51) let health care providers download results when visiting doctors’ offices.

A total of 86% (44/51) of the participants had heard of wearable health devices but only 35% (18/51) had never used them. Over 80% (42/51) expressed interest in using such devices (Table 2) and were interested in tracking exercise/physical activity (46/51, 90%), sleep (38/51, 75%), blood pressure (34/51, 67%), diet (31/51, 61%), blood sugar (28/51, 55%), weight (26/51, 51%), and fall risk (23/51, 45%). The greatest concern about using wearable devices was cost (31/51, 61%), followed by safety (14/51, 28%) and privacy (13/51, 26%); approximately one-fourth of the sample (12/51, 24%) reported having no concerns.

Older adults reported feeling comfortable sharing exercise/physical activity, diet, sleep, heart rate, breathing, body posture, blood pressure, blood sugar, weight, mood, and fall risk data captured by mobile and wearable devices. They are mostly interested in sharing these data with their health care provider (30/51, 59% heart rate; 29/51, 57% blood pressure; 29/51, 57% exercise/physical activity; 28/51, 55% blood sugar; 27/51, 53% sleep; 27/51, 53% weight; 25/51, 49% diet) followed by family, online communities, friends, and no one (Table 3).

Table 1. Demographic characteristics of the sample (N=51).

Variables	Statistics
Age (years), mean (SD)	70 (8)
Gender (female), n (%)	36 (71)
Race/ethnicity, n (%)	
Hispanics	4 (8)
Non-Hispanic white	35 (69)
Non-Hispanic black	7 (14)
Non-Hispanic Asian	4 (8)
Education (college and higher), n (%)	39 (76)
Married (yes)[a], n (%)	31 (61)
Private insurance (yes), n (%)	24 (47)
Live at home/retired home (yes), n (%)	49 (94)
Live alone (yes), n (%)	14 (28)

[a] Never married, widowed, and divorced were considered as not married.

Table 2. Summary for mobile, wearable, remote technology use in this sample (N=51).

Health technology usage	Statistics, n (%)
Ever used an HMD[a] at home (yes)	43 (84)
Ever heard of WHD[b] (yes)	44 (86)
Ever used a WHD[b] (yes)	18 (35)
Currently using a WHD[b] (yes)	13 (26)
Be interested in using a WHD[b] (yes)	42 (82)
Ever heard of OHC[c] (yes)	21 (41)
Be interested in joining an OHC[c] (yes)	20 (39)

[a] HMD: health-monitoring device.

[b] WHD: wearable health device.

[c] OHC: online health community.

Table 3. Preference of sharing data captured by mobile and wearable devices in this sample (N=51).

Health data	Health care providers, n (%)	Family, n (%)	Friends, n (%)	Online health communities, n (%)	No one, n (%)	Other groups, n (%)
Exercise/physical activity	29 (57)	23 (45)	14 (28)	14 (28)	4 (8)	1 (2)
Diet	25 (49)	17 (33)	9 (18)	11 (22)	7 (14)	0 (0)
Sleep	27 (53)	19 (37)	9 (18)	10 (20)	6 (12)	0 (0)
Heart rate	30 (59)	18 (35)	6 (12)	8 (16)	3 (6)	0 (0)
Breathing	21 (41)	14 (28)	5 (10)	5 (10)	5 (10)	0 (0)
Body posture	18 (35)	12 (24)	3 (6)	5 (10)	7 (14)	0 (0)
Blood pressure	29 (57)	18 (35)	6 (12)	9 (18)	3 (6)	0 (0)
Blood sugar	28 (55)	15 (29)	5 (10)	8 (16)	3 (6)	0 (0)
Weight	27 (53)	14 (28)	6 (12)	8 (16)	5 (10)	0 (0)
Mood	18 (35)	12 (24)	5 (10)	6 (12)	11 (22)	0 (0)
Fall risk	20 (39)	11 (22)	3 (6)	6 (12)	8 (16)	0 (0)
Other	3 (6)	1 (2)	1 (2)	1 (2)	0 (0)	0 (0)

Online Health Communities

About 41% (21/51) of the older adults surveyed reported having ever heard of an online health community (Table 2). In addition, roughly 40% (20/51) of the participants reported that they would be interested in joining such a community, and the same percentage reported not being sure if they would join; 47% (24/51) of the participants surveyed reported that they would like to use the online community to connect to other people in similar situations who they do not know or to their health care provider (21/51, 41%). The data that older adults were mostly interested in sharing with other people in the online health communities were exercise/physical activity data (14/51, 28%), diet (11/51, 22%), and sleep (10/51, 20%). Finally, the most common concerns about joining an online health community was privacy (28/51, 55%) and fraud (20/51, 39%). However, about 20% (10/51) of all the participants surveyed reported having no concerns about joining online health communities.

Smartphone Access and Usage of Mobile/Connected Health Technology

Most participants reported having access to a smartphone (38/51, 74%; Table 4) and those with such access were significantly more likely to show interest in using a wearable health device ($P<.001$), despite the fact that they were not more likely to be currently using a wearable health device ($P=.14$) or to have previously used a wearable health device ($P=.33$) or a remote monitoring device at home ($P=.18$). In addition, those having access to a smartphone were more likely to report interest in joining an online health community ($P=.05$).

Table 4. The Relationship between health technology usage and having access to a smartphone in this sample (N=51).

Health technology usage	Having access to a smartphone		*P* value
	Yes (n=38)	No (n=13)	
Ever used an HMD[a] at home (yes)	34 (90)	9 (69)	.18
Ever heard of WHD[b] (yes)	32 (87)	12 (92)	>.99
Ever used a WHD (yes)	15 (41)	3 (23)	.33
Currently using a WHD (yes)	12 (32)	1 (8)	.14
Be interested in using a WHD (yes)	36 (97)	6 (50)	<.001
Ever heard of OHC[c] (yes)	18 (47)	3 (27)	.31
Be interested in joining an OHC (yes)	18 (48)	2 (15)	.05

[a] HMD: health-monitoring device.

[b] WHD: wearable health device.

[c] OHC: online health community.

Discussion

Principal Findings

This study explored to what extent mobile and connected health technologies can be utilized by older adults for aging in place. Overall, our findings revealed that there is a potential to promote mobile and connected health technologies in the elderly to improve health, extend independent life span, and age at home. However, some top concerns of using health technologies need to be addressed, such as the high cost for wearable health devices and privacy and fraud issues for using online health communities. One of our key findings was that a majority of older adults were interested in tracking health information and most were interested in sharing tracked health information with their health care providers, which imply the potential for connecting data from mobile and wearable devices to clinicians to promote aging in place.

Our study found that health technology use in older adults was low, and the top concerns for using wearable health devices and online health communities were different. Previous studies have reported that general technology use in older adults is relatively low (eg, 40.0% for email and texting and 42.7% for internet use), especially compared with younger groups [31]. We found that usage of wearable health devices was even lower in older adults (18/51, 35% for ever used; 13/51, 26% for currently using). The study shows that the top concern of using wearable health devices among older adults was the cost. This is partially consistent with Peek et al’s study, who reviewed 16 articles and reported that one of the major concerns of using technology for aging in place in community-dwelling older adults is the high cost [32]. However, a majority of the studies included in the review were qualitative studies, and they only examined the overall technology usage or focused solely on one specific health technology tool (eg, memory aids). Our study has quantified the concerns and provided a more practical implication. For example, for wearable health devices, the top concern was cost, whereas for online health communities, the top concerns were privacy and fraud. Therefore, we suggest that researchers, manufacturers/marketers, and policy makers work together and address one of the top concerns of using wearable health devices in the elderly. For instance, free wearable devices might promote wearable health device usage in the older population, and a free wearable health device intervention might affect health outcomes and promote healthier aging in place. Furthermore, studies are needed to assess whether this line of interventions would be cost-effective and reduce medical costs in the long term. Meanwhile, the usage of online health communities in older adults is increasing, but older adults are less knowledgeable about internet security than younger adults, and they are more susceptible to internet fraud [33]. However, effective and feasible strategies to increase safe internet usage in older adults, considering their knowledge and cognitive function, are still limited [34]. We call for the development of technologies and training materials to educate older adults in Web-based safety.

Importantly, this study found that a majority of older adults were interested in using wearable health devices, over one-third were interested in joining an online health community, and those having access to a smartphone showed higher interest in using wearable health devices and joining in an online health community. The findings reveal that there is a potential to promote use of health technologies in older adults to help them age in place. First, our findings are in line with the technology acceptance model (TAM). The major components of TAM consist of external variables, perceived usefulness, perceived ease of use, attitude, behavioral intention, and actual use [35,36]. External variables would refer to factors such as cost and fraud [37], which have been discussed above. Those who have access to a smartphone might perceive greater ease of use and usefulness of health technologies [38]; and consequently, as being found in our study, having access to a smartphone was positively related to the interest of using wearable health devices and joining in an online health community. Our findings provide critical implications for promoting health technology use in older adults. Specifically, the intervention strategies for those who have access to a smartphone might be different than for those who do not have such access. Further studies might be indicated to explore the specific needs of older adults using health technologies based on their previous experience of using a smartphone. However, a previous study has reported that those who have access to a smartphone tend to be younger, with higher education and income [24], all of which are highly related to the usage of technology [31]. Given the small sample size of our study, we were unable to determine whether the positive associations between having access to a smartphone and interest in using wearable devices or online health communities were confounded by demographic factors. Future studies with a larger sample size are needed to clarify the real underlying reasons of this positive association and provide further implications for intervention.

Notably, our findings contribute to understanding preferences for health information sharing in older adults. We found that if wearable health devices were available for older adults, a majority of them would be interested in tracking physical activity, sleep, diet, blood pressure, blood sugar, and weight, and they felt more comfortable sharing this information with their health providers than with their families, friends, or others. Even for online health communities, they would want to connect with their providers. This has significant implications for our future intervention strategies. Given the advantages of using mobile and connected health technologies for tracking health information and facilitating chronic condition monitoring and management [8], older adults' interest in tracking health information and sharing it with health providers shows promise for the promotion of aging in place. To our knowledge, this is the first study to explore preferences for sharing health information in older adults comprehensively. Overall, studies examining the sharing preference of tracked health information are scarce. Available literature has documented older adults' preference of sharing health information with researchers and families [39,40]. For data sharing preference with health providers in older adults, previous studies have not achieved a conclusion. One study found that a majority of older adults were willing to share monitored health information with the family or one's doctor, but it did not differentiate sharing preference between family and health providers and only focused on those aged 80 and over [41]. Another study reported that compared with those aged 18 to 24 years, older adults aged 65 and over were less comfortable sharing mobile health information with health care providers; however, that study did not examine older adults' willingness to share mobile tracked health information with providers [42]. Our findings indicate that connecting older adults with health care providers to help them age in place is possible. However, it should be noted that previous study shows that formal caregivers and health care providers would like their older clients to track health information for self-care and they would also be interested in providing feedback and individualized care to older adults based on data recorded by wearable health devices, while they were actually less interested in reviewing such massive data [43]. Therefore, studies are warranted to explore strategies to balance the data sharing preference of older adults and the availability of health care providers and effectively use monitored data to improve health and promote aging in place. For example, it would be beneficial to explore how to use informatics technologies to generate health implications from tracked data, so that health providers can use tracked data and provide health care recommendations, without the need to manually review massive amounts of data.

This study may be limited by the small sample size. Even though we did cover a variety of racial/ethnic populations, most of the study participants were non-Hispanic white. Notably, this study was conducted in Harris County, Texas [44], with approximately 43% Hispanic population, whereas in our study, only 8% were Hispanic. Therefore, the findings of the study may not be generalizable to the general population in Harris County. Future studies with a larger sample size and a focus on greater recruitment of minority groups are warranted. The literature has extensively documented the facilitators and challenges of using technology in the elderly; future translational research studies should consider a comprehensive approach to promote mobile and connected health technology in older adults, combining technical, informational, and social support [45].

Conclusions

The study results show that while many older adults were not currently using mobile and wearable devices, or online health communities, they were open to this idea, especially among those who had access to a smartphone. Older adults were most interested in sharing data captured by mobile and wearable devices with their health care providers. Similarly, health care providers were the preferred recipients of health care information sharing in online health communities. These findings confirm previous studies on technology acceptance and adoption by older adults. Furthermore, this study reveals the possibility of promoting mobile and connected health engagement in older adults. Researchers, technology manufacturers/marketers, policymakers, and health providers need to make efforts to increase accessibility and safety of using mobile and connected health technology. Further studies are warranted to explore strategies to balance the data sharing preference of older adults and how to best integrate mobile and wearable device data within the clinical workflow for health care providers to promote healthy aging in place.

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Conflicts of Interest

None declared.

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Abbreviations

TAM: technology acceptance model

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Original Paper

Care Team Perspectives and Acceptance of Telehealth in Scaling a Home-Based Primary Care Program: Qualitative Study

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Abstract

Background: Novel and sustainable approaches to optimizing home-based primary care (HBPC) programs are needed to meet the medical needs of a growing number of homebound older adults in the United States. Telehealth may be a viable option for scaling HBPC programs.

Objective: The purpose of this qualitative study was to gain insight into the perspectives of HBPC staff regarding adopting telehealth technology to increase the reach of HBPC to more homebound patients.

Methods: We collected qualitative data from HBPC staff (ie, physicians, registered nurses, nurse practitioners, care managers, social workers, and medical coordinators) at a practice in the New York metropolitan area through 16 semistructured interviews and three focus groups. Data were analyzed thematically using the template analysis approach with Self-Determination Theory concepts (ie, relatedness, competence, and autonomy) as an analytical lens.

Results: Four broad themes—pros and cons of scaling, technology impact on staff autonomy, technology impact on competence in providing care, and technology impact on the patient-caregiver-provider relationship—and multiple second-level themes emerged from the analysis. Staff acknowledged the need to scale the program without diminishing effective patient-centered care. Participants perceived alerts generated from patients and caregivers using telehealth as potentially increasing burden and necessitating a rapid response from an already busy staff while increasing ambiguity. However, they also noted that telehealth could increase efficiency and enable more informed care provision. Telehealth could enhance the patient-provider relationship by enabling caregivers to be an integral part of the patient's care team. Staff members raised the concern that patients or caregivers might unnecessarily overutilize the technology, and that some home visits are more appropriate in person rather than via telehealth.

Conclusions: These findings suggest the importance of considering the perspectives of medical professionals regarding telehealth adoption. A proactive approach exploring the benefits and concerns professionals perceive in the adoption of health technology within the HBPC program will hopefully facilitate the optimal integration of telehealth innovations.

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KEYWORDS

home-based primary care; homebound patients; telehealth technology

Introduction

Estimates show that there are between 1 and 4 million homebound US adults aged 65 and older [1-3]. As the senior population doubles over the next few decades, these estimates are likely to increase substantially. Homebound individuals often have complex chronic conditions and comorbidities, including heart failure, dementia, cancer, psychosocial issues, diminished functional status, and a higher risk of death [4-6]. There is increasing concern that older homebound adults are disadvantaged due to experiencing difficulties in attending traditional primary care office visits, which results in significantly decreased access to care. Instead, they rely heavily on costly emergency department visits and hospitalizations, which lead to further deterioration of health, diminished functional status, institutionalization, and a hastened death [7]. Ornstein et al found that the homebound are much more likely to have been hospitalized in the past year than their nonhomebound counterparts (52% vs 16%), and very few (12%) receive home-based primary care (HBPC) [3]. Given that long-term care and assisted-living facilities cannot accommodate the projected numbers of older patients with complex chronic conditions [8], the demand for HBPC programs will likely increase. To better address the increasing number of people needing care at home, more effective and less expensive care models are critically needed.

A recent systematic review of nine studies found that HBPC programs decrease emergency department visits, hospitalizations, and long-term care admissions while increasing patient and caregiver quality of life and satisfaction [9]. These programs improve performance of activities of daily living (eg, dressing and bathing) and instrumental activities of daily living (eg, managing medications) while reducing symptoms of depression and facilitating aging in place [10]. In one study, an HBPC program also demonstrated decreased monthly per-patient health care spending and hospital utilization [11]. However, the literature is mixed regarding the cost-effectiveness of HBPC, with some studies showing reduced costs and others demonstrating increased costs [12-16].

Telehealth, defined as the remote provision of health care through various telecommunication technologies, such as tablets, mobile phones, and other devices, is one modality that may assist in meeting these growing demands [17]. Whereas advances in medical technology in the previous century once threatened the survival of HBPC as a medical model, new mobile medical technology has facilitated the expansion of care in the home [18]. Telehealth is gaining broader acceptance and may improve the efficiency and capability of HBPC programs. Current efforts in telehealth include going beyond expanding access to care by also providing convenience to patients, expanding telehealth use from addressing acute conditions to addressing chronic conditions, and moving telehealth beyond hospitals to the home and mobile devices [17].

Care team acceptance of telehealth use is critically important, particularly in the early phases of initiating such programs [19]. It is essential to consider how telehealth is perceived by team members to influence service changes, patient-provider interactions, provider credibility, and autonomy, as well as technical issues resulting from adopting the technology [19]. Segar et al found that integrating telehealth technologies into community primary care involves adjusting provider roles and responsibilities [20]. Thus, considering the perspectives of medical professionals regarding telehealth before rather than after implementation is more likely to result in successful telehealth service integration [20].

Wade et al explored factors contributing to long-term success and sustainability of telehealth services [21]. Researchers found that clinician acceptance or willingness to either initiate or work with existing telehealth services explained the majority of the variance in telehealth uptake, enlargement, and sustainability. Clinician acceptance was a key factor for overcoming multiple barriers to success, including weak demand for telehealth, technical problems with the technology, and a paucity of funding resources. Studies of home-based telehealth for care of long-term chronic conditions have demonstrated positive outcomes, albeit many utilized poor methodological approaches and lacked theoretical frameworks [22,23]. Moreover, there is a dearth of research specifically investigating telehealth in HBPC for older adults with complex and advanced chronic conditions.

Self-Determination Theory (SDT) provides a useful theoretical framework for understanding motivations underlying the adoption of telehealth as well as, more generally, the acceptance of organizational change [24-26]. SDT proposes that people have three psychological needs: relatedness, competence, and autonomy [27-29]. Relatedness refers to the need for *belonging* and for caring relationships [27]. Competence is the need to experience mastery, and autonomy is the need to have control over choices and actions [27]. If satisfied, these needs can promote the growth of motivation. If the HBPC team perceives telehealth to foster these three psychological needs, they will be more motivated to accept and utilize it. Given that telehealth can substantially disrupt workflows, it is crucial to take into account how it may affect relatedness, competence, autonomy, and, in turn, motivation to adopt this technology to scale the HBPC program.

The primary objective of this study was to obtain greater insight into the perspectives and motivation of the HBPC team regarding the adoption of telehealth technology to scale the program to increase its capacity to reach more eligible patients in the community without adding additional care delivery team members.

Methods

Setting and Context

This study was conducted at a large integrated health system, which includes an HBPC program, also referred to as an Advanced Illness Management (AIM) program, consisting of interdisciplinary care teams with 11 primary care providers (ie, nurse practitioners and physicians), 9 care managers (ie, social workers and registered nurses), and 8 medical coordinators. The goal of the HBPC program is to provide longitudinal primary care to homebound, medically complex patients to meet their care needs in the home so they can remain living at home and avoid unnecessary hospital stays and emergency department visits. The care is patient centered, focusing on the patient’s goals of care, and much of the care is palliative rather than curative.

Annually, the program provides care to nearly 2000 unique individuals in Queens and Long Island, New York, NY. Those enrolled in the program are homebound; typically have multiple chronic conditions such as dementia, heart failure, and diabetes; and are in the last 1-3 years of life. The HBPC program partners with other programs within the health system along the continuum of care, such as emergency medical services, including a robust community paramedicine program [30]; home care nursing services; infusion therapy; and hospice. The HBPC program consists of interdisciplinary teams consisting of two providers, one nurse care manager, one social work care manager, and one medical coordinator.

Design

We conducted a qualitative study using in-depth, semistructured interviews and focus groups with a purposive sample of physicians, nurse practitioners, social workers, and medical coordinators from the HBPC program. We sought to understand the perspectives of the HBPC team on adopting telehealth technology. Practice care team members were invited to volunteer to participate in the interviews and focus groups as part of ongoing process improvement activities within the program. Participants were selected to provide a cross-section of different positions within the program. Semistructured interviews and focus groups were conducted using topic guides until data saturation was attained (ie, no new topics emerged with additional interviews). The topic guides are available in Multimedia Appendix 1. Focus groups were conducted after conducting the interviews. The focus groups served to review and revisit common issues that arose during the individual interviews. One member of the research team (AK) conducted the interviews. Two members of the research team (AK and RP) facilitated the focus groups. Institutional Review Board approval was attained before study initiation. Participants were informed of the study purpose, guaranteed confidentiality, and given the right to withdraw at any time.

Data Collection

Qualitative data were collected between February and August 2017. A total of 16 individual semistructured interviews were conducted with providers (5 physicians, 31%; 1 nurse practitioner, 6%), 4 registered nurses (25%), 3 social workers (19%), and 3 medical coordinators (19%). A total of 12 participants out of 16 were women (75%) and 4 were men (25%) (1 registered nurse, 25%; 3 physicians, 75%). Most interviews were between 15 and 30 minutes in length.

After all of the interviews were completed, three focus groups were conducted with 6-8 participants, which lasted 60-90 minutes. The first focus group included 6 administrative staff (5 female, 83%; 1 male, 17%), the second focus group included 8 care managers (4 registered nurses, 50%; 4 social workers, 50%—all female), and the third focus group consisted of 6 providers (4 physicians, 67%—2 female, 50%, 2 male, 50%; 2 female nurse practitioners, 33%). Of the 20 participants in the focus groups, half (2 administrative staff, 10%; 4 care managers, 20%; 4 providers, 20%) had also participated in the individual interviews. The moderator guides included a range of questions on perspectives regarding adopting telehealth as well as other ideas to scale the HBPC program.

Semistructured interviews and focus groups were digitally recorded, stored on an internal server to ensure security, and professionally transcribed. Transcripts were checked against the original recordings to ensure accuracy. NVivo 10 software (QSR International) was used to facilitate data storage, retrieval, and analysis.

Data Analysis

We used the template approach to analyze, in depth, the semistructured interview and focus group transcripts [31]. First, we constructed an initial coding template containing SDT concepts (ie, relatedness, competence, and autonomy) and codes representing preliminary themes identified in the data through careful reading and review of the text. Codes were organized hierarchically so that the highest-level codes represented broad themes in the data, with lower levels indexing more narrowly focused concepts within these themes. The initial list of codes was modified through successive readings of the transcripts until we achieved as full a description of the data as was feasible.

Results

Overview

The central focus of the interviews and focus groups was to explore ways to scale the HBPC program using health technology (ie, different types of telehealth such as messaging services, remote monitoring, and video visits) while still maintaining the "high-touch" nature of the program. Four broad themes—pros and cons of scaling, technology impact on autonomy, technology impact on competence in providing care, and technology impact on the patient-caregiver-provider relationship—and multiple second-level themes emerged from the analysis. We present quotes from the semistructured interviews that were representative of the themes.

Pros and Cons of Scaling

When participants were asked what the strengths of the HBPC program were, all indicated the vital service that it provides to homebound older adults and the need to expand and help more patients. The care team expressed concern and empathy for homebound patients waiting to be in the program and patients' health conditions, as described by a social worker:

> *Patients will say, "I've been waiting two years to be on the program." That's very sad. Or just to know that we can't help more people. Whenever you go out to a patient's home and you see that they've been homebound for some time with very limited support and resources, and it can be very difficult to observe and to think of the what-ifs. If only someone had gotten in sooner. So I think that's one of the biggest parts—tragedies for me, not being able to reach more people, because there's such a great need.* [Social worker #1]

Despite acknowledging that scaling the program is needed, concern and ambivalence was also expressed regarding increasing the patient census, as this might make it more difficult to provide the same level of personalized care. This conflict was exemplified by the same social worker who said the following:

> *But I think that as you grow, it takes something away...that intimacy. So it's hard. I think I'm struggling with that balance of getting bigger and*

> *having a larger census because...it'd be impossible to maintain the same type of relationship as I did when I had half the amount of people. I could see them more often. And now as we grow, we have to stretch it out more. Again, it's bittersweet for me because I like it small. But I know we have to grow...* [Social worker #1]

Technology Impact on Autonomy

Overview

Two second-level themes were identified within this main theme: increased burden and ambiguity. Different team members indicated being extremely busy and suggested that the addition of telehealth, the influx of data from the technology, and the need to respond to the alerts would be a burden limiting their autonomy in terms of controlling decisions and actions. Specifically, for providers, differentiating urgent clinical issues from nonurgent tasks or questions was considered vital when adopting telehealth. Having someone filter the telehealth alerts before they are sent to the provider for a response was perceived as needed for this technology to work correctly and to avoid physician burnout. In addition, some care team members indicated that adopting telehealth could lead to loss of control and increased ambiguity related to when and how to monitor and respond (ie, via telehealth or the phone) to patient and caregiver communications.

Increased Burden

When asked about incorporating telehealth to scale the program, the following comments were given by the participants:

> *It may be more of a burden if I'm bombarded with alerts.* [Social worker #1]

> *Yeah. There's a lot of—not documentation so much, but a lot of checklists, I guess that is—that are just kind of slow on the computer. But it's not a big deal. It exists everywhere, but it's a hassle. It'll just be one more checklist for people to fill out. I think it would add a layer of paperwork.* [Provider #1]

> *I know that the office provider, it's not like they ever have a free moment that they're not on the phone. If they're not getting a call, they're checking the prescription line to refill the prescriptions or they're calling a patient back that left a message. So now, they also have to check this?* [Social worker #2]

> *I think it would be a mistake to have push notifications that are unfiltered to a physician-level of care, personally. I think there has to be some kind of clinical judgment before it raises to the level of the physician or the physician's just going to get burned out. Because we're already getting so many tasks a day that the last thing we need is another ten tasks a day without it being filtered, at least.* [Provider #2]

> *I think the NP [nurse practitioner] in the office probably couldn't watch it [telehealth alerts] because we're already taking care of a million other things here, so I think it would be too much to add this to the NP's responsibility in the office.* [Provider #3]

> *Because then every time you get an alert, now you have to respond to that alert. And sometimes it might just be a nonclinical issue.* [Registered nurse #1]

Ambiguity

Regarding ambiguity, the following comments were given by the participants:

> *And I just think that if you give people too many options, it can get confusing in a lot of ways, you know? Well, do we call that person, do we go online and contact you that way?* [Social worker #2]

> *I think it's good, but who's watching it? You know what I mean? Who's—say if they—say all the sudden that the heart rate's up or their blood pressure is up. Who's getting the alert? You know what I mean? That's the big thing. Who's actually monitoring it?* [Provider #3]

> *What's the responsibility of the provider? Because basically, at any hour in the day, any caregiver can go onto this [platform] and ask a question, and it could be a nerve-wracking question to just let lie. So what's the responsibility?* [Social worker #2]

Technology Impact on Competence in Providing Care

Overview

Two second-order themes were identified within this central theme: increased efficiency and more informed care provision. The HBPC team perceived telehealth to increase efficiency by decreasing the need to travel to patient homes. The technology was reported to decrease the need for community paramedics. Instead of always sending a community paramedic to measure vital sign data, remote monitoring could be conducted first to assess how the patient is doing. Participants also reported that remote monitoring would enable them to make more informed decisions about patient care.

Increased Efficiency

Regarding increased efficiency, participants stated the following:

> *It allows you to touch more people without having to do that travel time. So I think it would be a great idea. Because a lot of the time wasted really is the packing up and saying goodbye and getting into the car and driving to the next house. So what you could see in two hours, you may see two patients in two hours, while you may see four patients by video in two hours. You could see double the amount of patients without even moving. So seems like it would be more efficient.* [Social worker #1]

> *And then not have to utilize the resources of sending a paramedic into the home to check a pulse ox [oximetry] in the middle of the night. So yes, things like that I think would be the most useful, like having the ability to take a snapshot of them and send a picture and to check his—just a quick pulse ox and heart rate and possibly blood pressure.* [Provider #2]

More Informed Care Provision

Regarding more informed care provision, a provider stated the following:

> *Sometimes I've decided, "oh, it would be nice if I had a pulse ox..." This is just someone who's anxious and is not someone who's really in extremis. And you have to talk them through it [anxiety]. And it would be much easier for me to feel comfortable doing that if I saw a pulse ox that's 99 percent when I'm talking to them.* [Provider #2]

Technology Impact on Patient-Caregiver-Provider Relationship

Overview

Three second-order themes were identified within this main theme: opportunity to make caregivers part of the team, overuse of technology by patients or caregivers, and some visits being more appropriate in person. Some participants felt that telehealth would enable caregivers to be part of the care team by increasing communication with the HBPC team about patient health status. However, there was also concern for caregivers and patients who might overuse the technology (eg, measure vital signs more often than needed), leading to unnecessary distress. Many team members felt that live visits should not be substituted entirely with video visits, as it is important to be present for difficult conversations physically, to convey empathy, and to perform physical exams.

Opportunity to Make Caregivers Part of the Team

Regarding the second-order theme, opportunity to make caregivers part of the team, a social worker stated the following:

> *Well, I'm trying to think what would be out of their scope. Like if they—well, let's say somebody had edema. And it was significant enough that it alarmed the HHA—the home health aide. What they are supposed to do is either call their family member and/or call their agency, right? What I'd like them to do is be able to call us, too, directly. As it stands now, my understanding is they really can't do that. But if there's a need, I want them to be able to be part of the team. Really, that's what I'm saying.* [Social worker #3]

Patients or Caregivers Might Overuse the Technology

Regarding the second-order theme, patients or caregivers might overuse the technology, a physician stated the following:

> *And it almost comes to the point where...they [caregiver] don't need to be checking something multiple times a day, where they're [patient] at a point in their life where they don't need to check a finger stick three times a day, they don't need to check a blood pressure three times a day. And it becomes problematic because it just creates more caregiver stress that's unnecessary.* [Physician #2]

Some Visits Better in Person

Regarding the second-order theme, some visits are better in person, participants stated the following:

> *I wouldn't love to do it for all my visits because a lot of my psychosocial needs or a lot of end-of-life visits or goals-of-care visits or stuff where there's a lot of emotion, I think is really effective in person where you can use body language, and you can touch a person, you know? So I think it all—there's a place for it, and there's a place where I think it would actually do more harm than good.* [Social worker #2]

> *I think it has to also be looked at, the satisfaction piece. It's very hard to have people who are used to—as a nurse, there's nothing better than touching and being with them. So having field people relegated to computer-based work is tricky. And there's a level of satisfaction. I don't think the pendulum should swing completely there. I think there could be a balance. So they still have that fieldwork, and that's work that for our patients needs to get done. That's [behind a computer] not really where we solely want to go. But I do think that there is room for that kind of work. Absolutely.* [Registered nurse #2]

> *And a lot of patients felt that that was definitely still impersonal. They would rather have someone there that's touching them and examining them and talking to them, and you know, just little things if you're—it's hard to convey empathy or sympathy to someone via the camera sometimes when you're giving them bad news. And that little simple holding of the hand really goes a long way kind of thing. So a lot of the elderly patients that I've come across, they didn't like that concept on video.* [Provider #4]

Discussion

The primary objective of our study was to obtain greater insight into the perspectives and motivation of the HBPC team regarding adopting telehealth to scale the program. The HBPC team acknowledged the need to scale the program to help more patients but was concerned about diminishing the personalized care they provide as the census increases. Using concepts of SDT as a framework, our results showed that adopting telehealth technology is perceived as having an unfavorable impact on autonomy, particularly remote monitoring; a favorable impact on competence in providing care; and a mixed impact on the patient-caregiver-provider relationship. Participants viewed telehealth favorably to the extent that it could increase efficiency, enable more informed care provision, and facilitate caregiver involvement. Abrashkin et al, in a study with HBPC patients and caregivers, found that caregivers were more likely to have access to and feel confident in using technology such as computers, Internet, tablets, and mobile phones when compared with patients [32]. An opportunity exists to involve caregivers in the use of telehealth technology to enable them to be part of the care team.

Incorporating telehealth into the daily workload was perceived as decreasing their autonomy, given the increased burden of remote monitoring, responding to alerts, and extra paperwork for an already busy care team. They expressed concern about the potential ambiguity and confusion around controlling choices in communicating with patients (eg, online, via a telehealth app), uncertainty regarding who will be responsible for responding to alerts, and which alerts need immediate responses. Regarding telehealth's impact on competence in providing care, participants believed that the technology could increase efficiency given the gained time not having to travel, decrease the number of community paramedic visits in which only an assessment is performed without treatments given, and increase informed care provision due to remote monitoring of patient health data. With regard to technology's impact on the patient-caregiver-provider relationship, the HBPC team believed that telehealth could facilitate increased caregiver involvement making them part of the care team. However, many participants indicated that some patients and caregivers might overuse the technology, which will increase patient and caregiver distress waiting to hear back on the technology platform.

Additionally, some visits would not be applicable via telehealth, especially those requiring seeing patients in their context, communicating bad news, and visits requiring an in-person presence to convey empathy. Replacing such visits with video visits was consistently mentioned to impersonalize the experience, limit empathy, and decrease patient satisfaction with the care they receive.

Adopting telehealth may be a potential best practice for improving efficiency and scalability, which, in turn, may address two significant challenges for HBPC programs: that community needs often exceed program capacity and the necessity of providing urgent visits [33]. Previous research conducted in non-HBPC settings has shown that provider acceptance of telehealth is a crucial determinant of successful adoption and sustainability [19,21]. Moreover, acceptance of telehealth is often a slow process impeded by negative perceptions of the technology [34]. In a recent study assessing nursing staff facilitators and barriers to telehealth use, Koivunen et al found that nurse attitudes toward telehealth remain somewhat negative and are thus a barrier to implementation [35]. Of note, there are no previously published studies exploring HBPC team perspectives on adopting telehealth; our findings are both consistent and differ from that previously reported in the literature in non-HBPC settings.

Given the slow adoption of technology in the health care sector [34,36], it is crucial to address care team perceptions regarding telehealth [20]. The SDT concepts of relatedness, competence, and autonomy are a useful framework to assess motivation to adopt telehealth technology in scaling HBPC programs [26]. Moreover, it is important to consider different functions of telehealth [17,22]. In our study, virtual visits were perceived more favorably when compared to remote monitoring. The HBPC team were concerned about remote monitoring due to loss of autonomy having to monitor patient data and respond to alerts but saw value in virtual visits for noncritical situations. This finding reflects the direction in which our HBPC program is going, where we have initiated a telehealth implementation for virtual visits but without remote monitoring. Future research should assess these perceptions through quantitative methodology across multiple HBPC practices.

A strength of our study was the use of two types of qualitative data: semistructured interviews and focus groups. An advantage of semistructured interviews is that this enables participants to voice their own opinions and perspectives without the influence of other viewpoints. The primary advantage of conducting focus groups is that the dynamic interaction among participants can increase the depth of inquiry, stimulating discussion of experiences and their meaning to each. A combination of semistructured interviews and focus groups can yield a richer, more complex, and insightful understanding of participant perspectives [28]. However, the study also had limitations that are important to consider. It is important to note that although participants were encouraged to express their perspectives freely at all the times, some may have felt inhibited from providing views that are more critical. Because data were collected at only one HBPC practice, the findings may have limited generalizability to other practices.

In conclusion, telehealth technologies that promote HBPC team motivation are more likely to be adopted and used over time. Our findings support the importance of considering the perspectives of medical professionals regarding telehealth adoption [21]. A proactive approach exploring the benefits and concerns professionals perceive in the adoption of health technology within the HBPC program is likely to facilitate the integration of telehealth innovations.

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Authors' Contributions

All authors contributed to the study conception and design. AK conducted the participant interviews. AK and RP facilitated the participant focus groups. AK, JS, and EW conducted the transcript coding work. AK, RP, JS, and JCS conducted the analysis and interpretation of the data. AK drafted the original manuscript. All authors contributed to critical review and editing of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Topic guides for semistructured interviews and focus groups.
[PDF File (Adobe PDF File), 69KB - aging_v2i1e12415_app1.pdf]

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Abbreviations

AIM: Advanced Illness Management
HBPC: home-based primary care
HHA: home health aide
NP: nurse practitioner
ox: oximetry
SDT: Self-Determination Theory

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Original Paper

Health Information–Seeking Behaviors of Family Caregivers: Analysis of the Health Information National Trends Survey

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Abstract

Background: The growing population of aging adults relies on informal caregivers to help meet their health care needs, get help with decision making, and gather health information.

Objective: The objective of this study was to examine health information–seeking behaviors among caregivers and to identify caregiver characteristics that contribute to difficulty in seeking health information.

Methods: Data from the Health Information National Trends Survey 5, Cycle 1 (N=3181) were used to compare health information seeking of caregivers (n=391) with noncaregivers (n=2790).

Results: Caregivers sought health information for themselves and others using computers, smartphones, or other electronic means more frequently than noncaregivers. Caregivers born outside of the United States reported greater difficulty seeking health information (beta=.42; *P*=.02). Nonwhite caregivers (beta =−.33; *P*=.03), those with less education (beta =−.35; *P*=.02), those with private insurance (beta =−.37; *P*=.01), and those without a regular health care provider (beta =−.35; *P*=.01) had less confidence seeking health information. Caregivers with higher income had more confidence (beta =.12; *P*≤.001) seeking health information.

Conclusions: This study highlights the prevalence of electronic means to find health information among caregivers. Notable differences in difficulty and confidence in health information seeking exist between caregivers, indicating the need for more attention to the socioeconomic status and caregivers born outside of the United States. Findings can guide efforts to optimize caregivers' health information–seeking experiences.

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KEYWORDS

disparities; family caregivers; Health Information National Trends Survey; internet use; mobile phone

Introduction

Family caregivers play a critical role in supporting the health, well-being, and quality of life for patients with chronic health conditions. Caregivers are defined as unpaid family members or friends who provide support and care to a loved one with a chronic health condition. Caregivers assist with activities of daily living, such as bathing, dressing, and toileting, provide emotional and social support, manage medications and finances, communicate with health care providers, and advocate on behalf of their loved one. Thus, caregivers are among the most engaged of health care stakeholders. Caregiving requires heightened awareness and knowledge of specific health information, medications, cost, insurance, health conditions, and the health care system. As such, family caregivers are often highly engaged in the pursuit of health information, support, and advice, both for themselves and others, more frequently than noncaregivers [1,2]. Caregivers rely on a range of informational sources, settings, and technologies, including referrals to other health care professionals, print material, community resources, and Web-based sources [3].

The availability and widespread use of the internet have increased the quantity of available health information and the speed at which caregivers can obtain resources and information.

Research has found that caregivers use the internet to seek general information on the medical, emotional, and financial aspects of caregiving, as well as seek assistance in interpreting symptoms, health conditions, and changes in patient behavior and relationships [4]. In addition, caregivers use internet-based peer support communities to seek information and emotional support, relying on the subjective opinions, experiences, and advice of fellow caregivers [5]. With the convergence of an aging population, rising health care costs, and the ubiquitous use of Web-based platforms to distribute health information, engagement of caregivers in health information technology has the potential to advance the clinical quality, caregiver well-being, and patient safety [6]. Furthermore, internet-based interventions are becoming increasingly prominent and provide accessible and affordable opportunities to remotely support caregivers [7]. Indeed, caregiver interventions once delivered in-person are now being successfully adapted into Web-based programs such as the web adaptation of the Savvy Caregiver Program and the FOCUS Program [8-10]. As more internet-based psychoeducational interventions are developed and adapted as Web-based programs, it is critical to continually assess how and why caregivers use the internet, so that interventions and Web-based services can be developed in ways that are congruent to the values, needs, preferences, and practices of caregivers.

To date, research has largely focused on barriers and facilitators of patients' use of the internet to seek health information, while far less is known about caregivers' appraisals of health information seeking [11]. As the shift of health information to Web-based platforms becomes more apparent, and the number of family caregivers' increases, it is critical to pay more attention to how caregivers use the internet to access health information and track disparities in information seeking among caregivers. In addition, studies have reported challenges surrounding health information seeking among patient populations, but caregivers' appraisal of health information seeking has received less attention [6]. Examining appraisals of health information seeking can yield valuable insight into caregivers who may need more tailored delivery of health information. Likewise, caregivers who are confident in health information seeking may be well positioned to assist in health communication campaigns.

Using a nationally representative sample drawn from the Health Information National Trends Survey (HINTS), this study aims to describe a variation in health information–seeking behaviors between caregivers and noncaregivers and their usage of the internet to find health information.

Methods

Sample

HINTS is a nationally representative survey administered by the National Cancer Institute since 2003. The HINTS target population is adults aged ≥18 years in the civilian noninstitutionalized population of the United States. HINTS 5 (Cycle 1) was conducted from January 25, 2017 to May 5, 2017. The questionnaire included a series of questions about caregiving. The sampling frame consisted of a database of addresses used by the Marketing Systems Group to provide random samples of addresses. The questionnaire was administered as a mailed survey; a total of 4 emails were sent out. All households in the sample received the first mailing and reminder postcard, while only nonresponding households received the subsequent survey mailings. Details on sampling strategies and survey design are available in the HINTS 5, Cycle 1 methodology report [12]. The final weighted response rate was 32.39% (3240/13,360).The final response rate was calculated using the RR2 formula of the American Association of Public Opinion Research.

Measures

Sociodemographic Variables

The following sociodemographic variables were included in analyses: sex (male, female), age (range 18-101 years), race (white, nonwhite) or ethnicity (Hispanic, non-Hispanic), annual household income (treated as a continuous variable; see Table 1 for categories), education (less than high school or high school graduate, some college, college or bachelor's degree), born in the United States (yes, no), employment status (employed for wages, not employed for wages), home ownership (own, rent, occupy without paying monetary rent), health insurance (yes, no), type of health insurance (employer-provided insurance, insurance purchased from an insurance company, Medicaid, Medicare, TRICARE or Veterans' Affairs insurance, other insurance), have a regular health care provider (yes, no), and marital status (married or living as married, not married).

Caregiver Status

To determine the caregiver status, participants were asked, "Are you currently caring for or making health care decisions for someone with a medical, behavioral, disability, or other condition?" Participants who responded "yes" also indicated whom they provided care to (child, spouse, parent, another family member, or friend). In this study, we excluded participants who indicated they provided care for a child because of the unique differences in responsibilities and experiences between this and other types of caregiving relationships. Participants who self-identified as caregivers were asked to indicate, "All conditions for which you have provided care for this person." Responses included cancer, Alzheimer's or confusion or dementia or forgetfulness, orthopedic or musculoskeletal issues, mental health or behavioral or substance issues, chronic conditions, neurological/ developmental issues, acute conditions, aging or aging-related issues, other, and do not know. Furthermore, participants were asked, "Thinking of all of the kinds of help you provide for this person or persons, about how many hours do you spend in an average week providing care?": (<5 hours/week, 5-14 hours/week, 15-20 hours/week, 21-34 hours/week, and ≥35 hours/week).

Health Information Seeking

Participants were asked a series of questions to assess their health information–seeking behavior. Participants were first asked, "Have you ever looked for information about health or medical topics from any source?" Those who answered "yes" were asked, "The most recent time you looked for health information, who was it for (myself, someone else, both)?" and

"The most recent time you looked for information about health or medical topics, where did you go first?" Responses were coded as books, brochures, pamphlets, cancer organization, family, friend or coworker, doctor or health care provider, internet, library, magazines, newspapers, telephone information number, and complementary, alternative, or unconventional practitioner.

To assess difficulty seeking health information, participants were asked the extent to which they agree (strongly agree to strongly disagree on a 4-point scale) with a series of statements based on the results of their most recent search for information about health or medical topics ("It took a lot of effort to get the information you needed"; "You felt frustrated during your search for the information"; "You were concerned about the quality of the information"; "The information you found was hard to understand"). Reliability statistics were calculated between these items, and good reliability was found (Cronbach alpha=.85), along with a singular factor structure. As such, a mean score was calculated among the items to create a singular difficulty in seeking health information measure. To assess confidence, all participants were asked "Overall, how confident are you that you could get advice or information about health or medical topics if you needed it?" on a scale ranging from 1 "not confident at all" to 5 "completely confident."

Using the Internet to Find Health Information

Participants were asked a series of yes or no questions to assess their use of the internet to find health information: "In the past 12 months, have you used a computer, smartphone, or other electronic means to do any of the following?" ("Look for health or medical information for yourself"; "Look for health or medical information for someone else"; "Buy medicine or vitamins online"; "Look for a health care provider"; "Use email or the internet to communicate with a doctor or a doctor's office"; "Made appointments with a health care provider"; "Track health care charges and costs"; "Fill out forms or paperwork related to your health care"; "Look up test results").

Data Analysis

Data analysis was performed using SAS/STAT software, Version 8 of the SAS System for Unix. Copyright (2018; SAS Institute Inc). First, univariate analyses were conducted for the sample, including the descriptive statistics only for participants who identified themselves as caregivers (Table 2). Next, bivariate analyses were conducted to examine the relationships between the variables of interest, including comparisons of the measures between caregivers and noncaregivers (Tables 1, 2, and 3). Finally, to understand the experience of caregivers seeking health information, 2 multivariate linear regression models were built using respondents who identified as caregivers—one with the measure of confidence in seeking health information as the dependent variable, and one with the difficulty seeking health information scale measure as the outcome (Table 4); all models were adjusted for. For all analyses, replicate weights were applied to account for the complex sampling design and derive representative estimates.

Results

Sociodemographic Characteristics of Caregivers

Table 1 summarizes the descriptive statistics for demographic and key caregiver variables. Caregivers (n=391) comprised 237 (58.4%) females and had an average age of 51.8 (SD 1.60) years. Among the 391 caregivers, 166 (51.4%) were employed, 266 (66.8%) were married, 251 (69.4%) were white, 313 (87.3%) were non-Hispanic, and 327 (84.7%) were born in the United States. The education level of the 391 caregivers was as follows: 98 (31.0%) had a high school education or less, 131 (33.9%) had some post-high school education, and 162 (35.1%) had a college degree or more.

Table 2 summarizes descriptive information on caregiver relationship and activities. Of the 391 caregivers, 148 (41.4%) reported that they provide care for a parent or parents, 92 (20.5%) provided care for a spouse, 50 (10.4%) provided care to another family member, and 24 (4.1%) provided care to a friend or nonrelative. In addition, 239 (63.6%) provided care to a person with multiple conditions and 136 (32.8%) reported providing <5 hours of care per week.

Caregivers' Health Information Seeking

Caregivers reported looking for health information (from any source) more than noncaregivers (Table 3). The internet was the most frequently used source of health information. More noncaregivers (1401/1932, 72.52%) reported using the internet in their most recent search for health information compared with caregivers (181/278, 65.1%). Caregivers more frequently reported that the last time they looked for health information was for both themselves and someone else, while most noncaregivers reported looking for health information for themselves only. Caregivers and noncaregivers reported low difficulty in seeking health information and moderate levels of confidence in obtaining information on medical topics.

Caregivers' Internet Experience

Among respondents who reported using the internet, caregivers used a computer, smartphone, or electronic means for health information–seeking activities more often than noncaregivers (Table 3). Compared with noncaregivers, caregivers more frequently use the internet to find health information for others (264/391, 71.1%), and make appointments with a health care provider (166/391, 46.8%).

In multivariable models predicting difficulty in health information seeking, we found that caregivers who were born outside of the United States reported greater difficulty seeking health information (beta=.42; P=.02; Table 4). In multivariable models predicting caregivers' confidence in health information seeking, we found that nonwhite caregivers (beta=−.33; P=.03), those with less education (beta=−.35; P=.02), those with private insurance compared with public insurance (beta=−.37; P=.01), and those without a regular health care provider (beta=−.35; P=.01) had lower confidence in seeking health information. Caregivers with higher income had greater confidence (beta=.12; $P \leq .001$) in seeking health information (Table 4).

Table 1. Descriptive statistics for demographic variables.

Variables	Caregiver (n=391), n (%)	Noncaregiver (n=2790), n (%)	χ^2 (*df*)	*P* value
Sex			3.8 (1)	.05
Female	237 (58.42)	1507 (49.85)	—[a]	—
Male	128 (41.58)	1097 (50.15)	—	—
Age in years	51.8 (13.93)[b]	46.63 (16.39)[b]	−3.03 (3180)[c]	.003
Employment status			4.3 (1)	.04
Employed	166 (48.64)	1396 (59.76)	—	—
Not employed	202 (51.36)	1276 (40.24)	—	—
Marital status			7.6 (1)	.006
Married or living as married	266 (66.79)	1547 (54.85)	—	—
Not married	125 (33.21)	1243 (45.150	—	—
Education level			0.2 (2)	.89
High school graduate or less	98 (31.00)	770 (32.14)	—	—
Some post-high school education	131(33.93)	789 (32.18)	—	—
College graduate or more	162 (35.07)	1231 (35.68)	—	—
Born in the United States			0.1 (1)	.72
Yes	327 (84.70)	2364 (85.66)	—	—
No	58 (15.29)	369 (14.34)	—	—
Ethnicity			1.2 (1)	.27
Hispanic	48 (12.72)	365 (15.82)	—	—
Non-Hispanic	313 (87.27)	2196 (84.18)	—	—
Race			5.1 (1)	.02
White	251 (69.35)	1924 (77.55)	—	—
Nonwhite	121 (30.64)	686 (22.45)	—	—
Home ownership			5.7 (2)	.06
Own	286 (73.01)	1915 (62.42)	—	—
Rent	87 (23.00)	729 (33.58)	—	—
Occupy without paying monetary rent	7 (3.98)	57 (4.00)	—	—
Household income (US $)			7.1 (8)	.52
0-9999	20 (5.264)	179 (6.84)	—	—
10,000-14,999	16 (4.76)	157 (4.59)	—	—
15,000-19,999	31 (8.54)	128 (5.58)	—	—
20,000-34,999	50 (10.86)	358 (12.46)	—	—
35,000-49,999	56 (17.24)	321 (14.52)	—	—
50,000-74,999	71 (18.03)	447 (18.98)	—	—
75,000-99,999	41 (11.82)	318 (12.33)	—	—
100,000-199,999	60 (19.94)	456 (17.89)	—	—
≥200,000	15 (3.50)	157 (6.82)	—	—
Has a regular health care provider			1.9 (1)	.17
No	100 (29.37)	792 (34.94)	—	—
Yes	289 (70.63)	1968 (65.06)	—	—
Has health insurance			0.1 (1)	.76

Variables	Caregiver (n=391), n (%)	Noncaregiver (n=2790), n (%)	χ^2 (*df*)	*P* value
No	19 (7.19)	130 (8.16)	—	—
Yes	370 (92.81)	2630 (91.83)	—	—
Health insurance type			14.7 (3)	.002
Private[d]	159 (40.87)	1227 (44.46)	—	—
Public[e]	122 (31.36)	980 (35.51)	—	—
Other[f]	89 (22.88)	423 (15.32)	—	—
None	19 (4.88)	130 (4.71)	—	—

[a] A dash indicates that no value was calculated.

[b] Values are mean (SD) rather than n (%).

[c] A 2-tailed *t* test was performed.

[d] Employer provided and insurance purchased directly from an insurance company.

[e] Medicare and Medicaid.

[f] TRICARE, Veterans' Affairs, and other insurance.

Table 2. Descriptive statistics for key variables.

Variables	Caregiver (n=391), n (%)
Whom caregiver provides care for	
A spouse or partner	92 (20.5)
A parent or parents	148 (41.4)
A close family member	50 (10.4)
A friend or other nonrelative	24 (4.1)
A child or children	0 (0.00)
Multiple caregiving relationships selected	77 (23.6)
Condition caregiver provides care for	
Cancer	17 (5.8)
Alzheimer's, confusion, dementia, forgetfulness	24 (4.8)
Orthopedic or musculoskeletal issues	15 (3.7)
Mental health or behavioral or substance abuse issues	9 (2.0)
Chronic conditions	19 (3.4)
Neurological or developmental issues	8 (1.3)
Acute conditions	2 (0.2)
Aging or aging-related health issues	18 (5.3)
Not sure or don't know	9 (1.7)
Multiple caregiving conditions selected	239 (63.6)
Other	13 (4.0)
Hours of care provides per week	
<5	136 (32.8)
5-14	87 (20.3)
15-20	39 (14.5)
21-34	20 (4.5)
≥35	82 (21.8)

Table 3. Caregiver and noncaregiver comparisons in the internet use for health care information seeking.

Item	Caregivers (yes), n (%)	Noncaregivers (yes), n (%)	χ^2 (*df*)	*P* value
Has respondent ever looked for information about health or medical topics from any source	324 (84.80)	2199 (80.03)	2.3 (1)	.13
The most recent time respondent looked for health information, where they went first				
Print sources (newspapers, magazines, etc)	27 (9.71)	139 (7.19)	12.2 (3)	.02
Friend or family member	8 (2.88)	74 (3.83)	—[a]	—
Doctor or health care provider	55 (19.78)	299 (15.48)	—	—
Internet	181 (65.11)	1401 (72.52)	—	—
Other (telephone number, complementary practitioner, or cancer organization)	7 (0.98)	19 (2.52)	—	—
The most recent time respondent looked for health information, who it was for				
Myself	106 (26.29)	1328 (59.30)	66.9 (2)	<.001
Someone else	92 (31.03)	377 (19.22)	—	—
Both myself and someone else	124 (42.68)	483 (21.48)	—	—
In the past 12 months, respondent used a computer, smartphone, or other electronic means to				
Look for health or medical information for yourself	286 (74.30)	1884 (71.13)	0.7 (1)	.40
Look for health or medical information for someone else	264 (71.09)	1480 (57.69)	12.0 (1)	<.001
Buy medicine or vitamins online	90 (22.80)	597 (20.60)	0.4 (1)	.53
Look for a health care provider	164 (44.67)	1058 (42.62)	0.3 (1)	.61
Communicate with a doctor or a doctor's office	148 (39.70)	983 (34.65)	1.7 (1)	.20
Make appointments with a health care provider	166 (46.85)	1075 (38.74)	4.2 (1)	.04
Track health care charges and costs	141 (36.58)	846 (33.95)	0.5 (1)	.49
Fill out forms or paperwork related to your health care	176 (47.63)	1051 (40.64)	3.1 (1)	.08
Look up test results	140 (33.24)	956 (33.31)	0.0 (1)	.98
Respondent has difficulty seeking health information	2.19 (1-4)[b]	2.12 (1-4)[b]	−1.1 (2494)[c]	.26
Respondent has Confidence seeking health information	3.56 (1-5)[b]	3.76 (1-5)[b]	2.67 (3180)[c]	.007

[a] A dash indicates that no value was calculated.

[b] Reported as mean (range).

[c] A 2-tailed *t* test was performed.

Table 4. The multivariate regression model predicting confidence and difficulty in seeking health information.

Variable	Confidence		Difficulty	
	Beta	*P* value	Beta	*P* value
Sex				
Female	.16	.14	−.20	.06
Male	Ref[a]	—[b]	Ref	—
Age in years	−.002	.41	−.004	.15
Race				
Nonwhite	−.33	.03	.09	.51
White	Ref	—	Ref	—
Ethnicity				
Hispanic or Latino	−.04	.84	−.29	.08
Non-Hispanic or Latino	Ref	—	Ref	—
Education				
High school graduate or less	−.35	.02	−.01	.97
Some post-high school education	−.17	.21	.07	.61
College graduate or more	Ref	—	Ref	—
Income	.12	<.001	−.02	.58
Marital status				
Married or living as married	−.16	.22	−.004	.98
Not married	Ref	—	Ref	—
Born in the United States				
No	−.29	.11	.42	.02
Yes	Ref	—	Ref	—
Occupation status				
Employed	.24	.09	.01	.91
Not employed	Ref	—	Ref	—
Health insurance				
Private[c]	−.37	.01	−.26	.09
Public[d]	Ref	—	Ref	—
Other[e]	.15	.35	−.05	.74
No insurance	.23	.45	.40	.19
Has a regular health care provider				
No	−.35	.01	−.07	.61
Yes	Ref	—	Ref	—

[a] Ref: reference group.

[b] A dash indicates that no value was calculated.

[c] Employer provided and insurance purchased directly from an insurance company.

[d] Medicare and Medicaid.

[e] TRICARE, Veterans’ Affairs, and other insurance.

Discussion

Principal Findings

Caregivers sought health information for themselves and used computers, smartphones, or other electronic means to find health information more frequently than noncaregivers. Caregivers born outside of the United States reported greater difficulty seeking health information, whereas caregivers that were nonwhite, less educated, privately insured, and without a regular health care provider reported lower confidence seeking health information. Caregivers with higher income reported more confidence seeking health information.

This study supports the notion that family caregivers are among the most engaged stakeholders of the health care system, and avid health information seekers. The internet has shifted how caregivers can find information and engage in the care of their loved one. Within our sample, more noncaregivers reported using the internet in their most recent search for health information compared with caregivers. This finding is likely attributed to the fact that caregivers are highly engaged in information seeking through a variety of resources (eg, doctors, books, and clinic brochures) of which the internet is but one important resource. Compared with noncaregivers, caregivers in this study more often used a computer, smartphone, or another internet device to find health information for others and make appointments with a health care provider. Our results parallel research that indicated caregivers are more likely than patients to report using the internet to perform health management activities [13]. These results support a growing number of Web-based caregiver interventions, which have found some positive response in reducing depressive symptoms, anxiety, and stress or distress among caregivers of adults with chronic health conditions [14]. Given the high rates of Web-based health information seeking, our findings suggest that caregiver interventions and services delivered on Web-based platforms are likely to be acceptable to caregivers who regularly use smartphones and electronic devices. Though the format of Web-based interventions may be acceptable, high-quality studies are required to identify their effectiveness. Consistent with previous research, caregivers in this study reported seeking information for themselves and others, indicating a dual purpose behind health information–seeking behavior [6]; this differs from noncaregivers, who mostly sought health information for themselves. A logical application of this finding is in the development of caregiver education tools and resources.

Despite high rates of health information seeking, this study highlights important differences in how caregivers appraise the experience of seeking health information and what characteristics account for these differences. As more caregiver support services are adapted and delivered using a Web-based format, these disparities are critical to understanding what subgroups of caregivers may be more or less likely to accept Web-based services and interventions. We found that nonwhite caregivers were less confident in seeking health information. Likewise, previous research has found racial differences in health information seeking among patient populations. Latino patients, for example, have been markedly less likely than white patients to seek health information and less likely to use it when they talked with their doctors [15].

While we found no differences in difficulty with health information seeking based on caregiver race or ethnicity, we did find that caregivers born outside of the United States experienced greater difficulty seeking health information. It may be that caregivers born outside of the United States have different cultural views on health, and that generic health information does not adapt to these beliefs [16,17]. Moreover, caregivers born outside of the United States may be unfamiliar with the complexities of the US health care system. It is possible that these findings reflect larger issues around immigration, especially access to resources for immigrants entering the United States. Caregivers are a particularly vulnerable subgroup of the immigrant population who experience barriers to accessing resources and services [18]. With an influx of recent national and state policies that target family caregivers (eg, RAISE Caregiver Act and the CARE Act), our results suggest that there may be a policy-level need to address the intracultural variations in information gathering among family caregivers [19]. Moreover, internet-based caregiver services, advocacy groups, and health care providers should ensure that health information is presented in ways that do not exclusively embrace US ideals. Furthermore, ethnic differences in caregiving occur at multiple levels (intrapersonal, interpersonal, and environmental); therefore, it is critical that resources for health information acknowledge these differences [20].

We found that caregivers with private insurance were less confident in seeking health information compared with public insurance. These findings align with a conceptual model of caregiving that positions health insurance coverage as an external variable that can facilitate or inhibit the caregiving, enhancing, or hindering the chances of success [21]. Likewise, caregivers without a regular health care provider were less confident in seeking health information. Caregivers who have an established relationship with their health care provider may benefit from these interactions, and the engagement with providers. While caregivers' interactions with providers can range from collaborative to disconnected, regular contact with a provider appears to play an important role in confidence seeking health information [22]. In addition, we found that caregivers with less education were less confident in seeking health information. This pattern is congruent with previous findings that showed individuals with lower education were less likely to seek health information and had lower confidence in their ability to obtain health information [23]. Our results support the notion that it is critical to assess the role of socioeconomic status in caregivers' health information–seeking confidence and improve the delivery of health information for vulnerable caregivers. As caregivers are highly engaged in seeking information for their loved ones, these findings support initiatives, such as shared access to medical records, patient information, and Web-based patient portals, which could engage and educate caregivers [24]. It is critical to not only give caregivers access to systems but also ensure that these systems are easy to access and that caregivers are confident in navigating these systems. Moreover, it is critical to developing systems with continuous input from caregivers as stakeholders [25].

Limitations

This work should be viewed within the context of several limitations. First, our data are cross-sectional. Therefore, our results are not intended to infer causality. Second, the survey obtained a relatively low response rate, which may have introduced some nonresponse bias. Finally, there are limitations to evaluating the caregiver status and experience through a population-based survey, which was unable to go into depth about caregiving experiences.

Conclusions

This study provides important insight into how caregivers seek information. It also identifies caregiver characteristics that contribute to differential appraisals of health information seeking. Caregivers actively seek health information for themselves and others and primarily use the internet to find health information. However, important disparities exist among caregivers in how they appraise health information seeking. Notable differences in the difficulty and confidence around health information seeking exist between caregivers, indicating the need for more attention to the socioeconomic status, gender, and immigration status. These findings may serve to guide efforts to optimize caregivers' health information–seeking experiences.

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Conflicts of Interest

None declared.

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Abbreviations

HINTS: Health Information National Trends Survey

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Original Paper

Mentalizing Imagery Therapy Mobile App to Enhance the Mood of Family Dementia Caregivers: Feasibility and Limited Efficacy Testing

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Abstract

Background: Family caregivers of patients with Alzheimer disease and related dementias (AD and ADRD) often experience high stress and are at high risk for depression. Technologically delivered therapy is attractive for AD and ADRD caregivers because of the time demands associated with in-person participation.

Objective: We aimed to study the feasibility and conduct limited efficacy testing of a mobile app intervention delivering mentalizing imagery therapy (MIT) for family caregivers.

Methods: A 4-week trial of the MIT app for family AD and ADRD caregivers was conducted to assess the feasibility of use and investigate changes in depression symptoms, mood, and caregiving experience. Semistructured interviews were conducted to characterize participants' perceived feasibility and benefits.

Results: A total of 17 of the 21 (80%) consented participants (mean age 67 years, range 54-79) utilized the app at least once and were further analyzed. Average usage of audio recordings was on 14 (SD 10) days out of 28 possible and comprised 29 (SD 28) individual sessions. There were improvements in depression with a large effect size for those who used the app at least moderately (P=.008), increases in positive mood postintervention (P<.05), and acute increases in mood following daily guided imagery practice (Stretching and Breathing, P<.001; Eye in the Center, P<.001; Nesting Doll, P=.002; Situation Solver, P=.003; and Life Globe, P=.006). Semistructured interviews revealed perceived benefits such as greater ability to remain "centered" despite caregiving challenges and positive reframing of the caregiver experience.

Conclusions: App delivery of MIT is feasible for family AD and ADRD caregivers, including aging seniors. Results showed moderate to high usage of the app for a majority of users. Limited efficacy testing provides justification for studying the MIT app for AD and ADRD caregivers to improve mood and reduce depression in larger, controlled trials.

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KEYWORDS

family caregivers; mindfulness; depression; mobile apps; psychotherapy

Introduction

Background

Despite frequently bearing significant physical, socioeconomic, and psychological burdens, millions of family members persist in providing informal care for a loved one with dementia [1]. In 2015 alone, it was estimated that informal caregivers of patients with Alzheimer disease and related disorders (AD and ADRD), the vast majority of whom are family members, provided 18.1 billion hours of unpaid assistance, saving the health care system more than US $200 billion a year [2]. The stresses of caregiving for a loved one with memory loss and behavioral changes frequently include sleep loss and other physically strenuous tasks such as assisting with bathing or dressing, role conflict with work and other interests, financial difficulties, and grief related to deterioration of the loved one and losses in the relationship [1-4]. Assuming the role of family AD and ADRD caregiver has been associated with a higher risk of depression and anxiety [5,6], compromised immune function [7], and increased mortality [8,9].

Several studies and systematic meta-analyses have found that mindfulness and related guided imagery interventions, which have salutary effects on depression and anxiety [10,11], hold promise for improving the health of family AD and ADRD caregivers by reducing negative psychological symptoms and increasing quality of life [12]. For example, caregivers undergoing mindfulness-based stress reduction reported lower depression and stress after the intervention [13,14]. A yogic meditation and imagery technique improved the mental and cognitive function of family dementia caregivers [15]. As the stressors that caregivers face are relational and not solely individual, treatments for caregivers that incorporate exercises that target reducing stress and address interpersonal challenges may be helpful. Our work with a relational guided imagery approach that incorporates principles of mentalization with mindfulness demonstrated benefit for insomnia, depression symptoms, and anxiety in an in-person pilot 8-week trial [16].

These promising data for alleviating symptoms of family AD and ADRD caregiver stress and depression required caregivers to come to the study site to receive in-person treatment and, thus, limited the pool of caregivers to those in local catchment areas who lived near academic medical centers. The dissemination of in-person interventions such as these is often limited by time to travel to the clinic and receive in-person care, transportation constraints, and, particularly in rural areas, a scarcity of trained professionals to provide high-quality specialty care [17,18]. The presence of these barriers means that, although mindfulness and guided imagery may help alleviate caregiver depression and anxiety, the interventions remain inaccessible for a sizeable number of caregivers.

Mobile apps are software programs residing on a portable device such as a smartphone, watch, or tablet. Advantages of app technology for therapy delivery include its ease of access to information, capability to deliver home practice exercises such as audio recordings, ability to send notifications and reminders, and potential to capture active and passive usage feedback. Apps may house information available for offline use, connect to websites, or both. Apps with information available offline may be ideally suited for delivery of therapies that provide regular home practice exercises so that caregivers do not need to connect to the internet each time they wish to use them.

Several apps have been targeted to ameliorate depression symptoms, by providing cognitive behavioral therapy [18,19] and behavioral activation [20], but none of which we are aware specifically promote a balanced understanding of the mental lives of oneself and others. We are aware of only 2 published studies using an app to deliver interventions to informal caregivers: a study of psychoeducation, in which the app platform was not reported to be a feasible delivery method [21], and a small open-label feasibility study to help share information among caregivers, case managers, and physicians [22]. Both of these studies used the app interface to connect to content hosted on the internet, thus maximizing connectivity but limiting accessibility to times when caregivers were online.

Objectives

To our knowledge, apps that deliver mindfulness or guided imagery practices to family dementia caregivers have not been studied. We investigated the feasibility for caregivers of a mobile technological app to deliver mentalizing imagery therapy (MIT), which incorporates guided imagery and mindfulness to facilitate self-regulation and increased perspective taking on the mental life of self and others [23]. Relative to other mindfulness techniques and apps of which we are aware, MIT occupies a niche in directly targeting the self and other understanding necessary to navigate challenging relationships when interpersonal understanding (mentalizing) breaks down [23]. Given prior preliminary successes of in-person groups using MIT techniques in reducing depressive symptoms of dementia caregivers [16,24] and the accessibility provided by smartphone apps, we hypothesized that this novel integration would be a feasible method of treatment for dementia caregivers. Consistent with the goals of a stage I feasibility study [25,26], we also aimed to conduct limited efficacy testing over the short term (4 weeks) and hypothesized that caregivers using the MIT app would experience an improvement in mood, reduction in depression, and benefits for the caregiving experience.

Methods

Overview

A 4-week open-label trial was conducted to test the feasibility of a remote MIT app in 21 family dementia caregivers. Participants were recruited with Facebook advertisements and flyers posted on the internet, provided at Alzheimer Association community meetings, and sent to the known dementia caregiver pool at the University of California, San Francisco (UCSF). The MIT app was approved by Apple and hosted on the app store [27] for participants to download onto a compatible iOS (version 9.3+) device such as iPhone, iPad, or iPod Touch. All procedures involving human participants were approved by the Committee for Human Research at UCSF.

Participants

Participants were eligible for the study if they were (1) English speakers, (2) 45 years or older, (3) had access to an iOS smartphone or compatible device, and (4) reported being the primary caregiver for a relative with dementia. Participants were excluded if they had active suicidal ideation or thoughts of violence toward others. The Consolidated Standards of Reporting Trials flow diagram for the study is presented in Figure 1.

Procedure

Participants underwent a 15-min telephone screening interview by a trained research assistant. If participants endorsed thoughts of suicide or violence, a comprehensive risk assessment was performed over the phone by a faculty psychiatrist. Written informed consent for participation was obtained by email. Following informed consent, participants completed online questionnaires measuring depression and mood using REDCap (Vanderbilt University). They were then directed to download the app from the Apple store and provided a personalized activation code. An optional conference call was offered for questions regarding download or activation. After 4 weeks of app usage, participants were sent the same set of online questionnaires, and a semistructured interview was performed with the first 8 completers by a fourth-year doctoral student in clinical psychology.

Intervention

MIT is a guided imagery and mindfulness intervention that incorporates principles of mentalization [23]. Mentalization refers to the process by which we consider and understand mental states along different dimensions: self and other, cognitive and affective, implicit automatic cognition and explicitly controlled, direct internal consideration of thoughts and feelings, and observation of external facial and behavioral cues [28]. MIT endeavors to help participants find balance among these different poles of mentalization. MIT also incorporates exercises to help participants mindfully observe themselves and understand the interconnectedness of self and other. The MIT app consisted of audio recordings of the MIT practices and 4 essays (1 for each week) explaining the concepts underlying each recording and supportive information, including specific stories of how family dementia caregivers used the techniques (Table 1). In addition, in the written instructions accompanying each week, participants were advised to listen to the audio recordings twice a day in the first week and once a day thereafter.

Measures

In-app data related to usage of specific audio recordings or reading material were obtained passively, and participant ratings were actively collected. These data were downloaded live from the device (or at the next online connection if the device was not connected to the internet during use) and saved to a Mixpanel database [29]. Depression and mood self-reports were obtained at baseline and after week 4 with REDCap-delivered assessments. In addition, they were obtained in the app after weeks 1, 2, and 3.

Depression was measured with the 16-item Quick Inventory of Depressive Symptoms–Self-Rated (QIDS), and severe depression was identified using a validated cutoff of 16 on the QIDS [30]. *Mood* was assessed with the Positive and Negative Affect Scale [31].

Acute Mood Change and Attention

During-meditation acute mood change and attention were obtained by self-report in the MIT app. After participants listened to an audio recording, they were prompted to rate their experience on a screen that included 3 Likert scales and a slider to select a numeric value. The first 2 scales measured “Overall feelings before practice” and “Overall feelings after practice” with a scale bounded by −5 to 5 and with intermediate integer values. Above −5 was a sad emoji, above 0 was a neutral emoji, and above 5 was a smiling emoji. The third app scale measured attention using the question: “How well did you focus,” with a similar scale of −5 to 5. Above −5 was *None*, above 0 was 50%, and above 5 was 100%.

Helpfulness of Reading

After visiting a page with reading material, the subject was prompted to rate the helpfulness of the material with a single item, “How helpful was this reading” on a scale of −5 to 5 with emojis identical to those for the immediate mood ratings.

Figure 1. Consolidated Standards of Reporting Trials flow diagram.

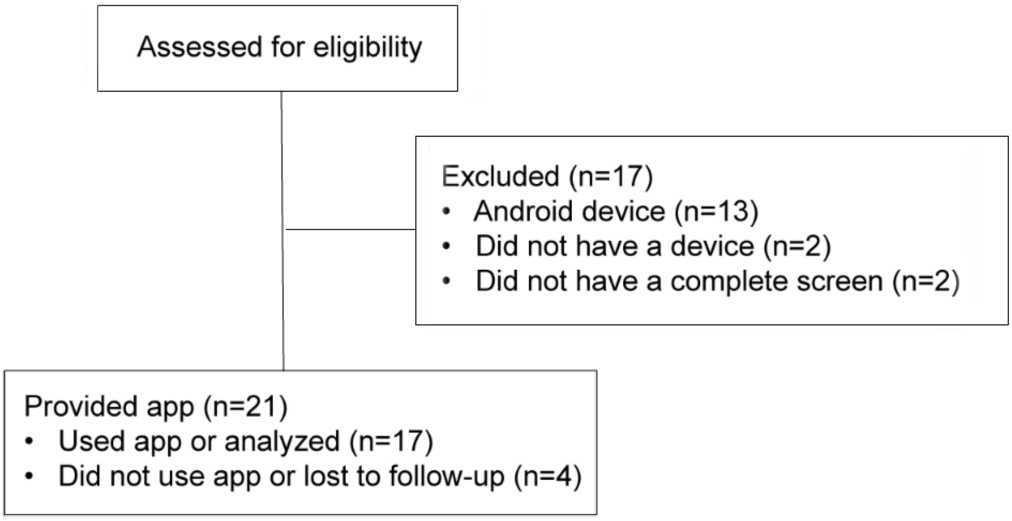

Table 1. Mentalizing imagery therapy experimental mobile app content and modules.

Module	Content
Imagery and mindfulness audio	
Stretching and Breathing	Guides the subject through a series of stretching exercises and a mindful breathing exercise.
Eye in the Center	Instructs users to focus on their sensations, thoughts, and feelings *mapped out* relative to their center (defined as a region in the lower chest midway between the base of the spine and the top of the head).
Nesting Doll	Instructs users to bring an image (visual or nonvisual) in the center region that includes a felt sense of their moment-by-moment internal thoughts, feelings, and sensations. The meditation progresses to imagine a nesting doll of a loved one (usually the dementia patient) along with the imagined loved ones' thoughts and feelings. Participants may send themselves and the loved one positive wishes "if they feel ready."
Situation Solver	Guided imagery that involves recalling a challenging experience from the perspective of self and loved one. Uses imagery rehearsal to reimagine the situation according to their values.
Life Globe	Meditation that involves becoming aware of one's connectedness with others, communities, the earth, and the larger universe. Takes perspective of the larger whole at each stage.
Additional features	
Mindfulness Tool	Mnemonic *BAM* (Breathing, Awareness, and Motivation) provided to help the subject quickly take steps to destress by focusing on breathing, awareness, and motivation (intention behind their actions).
Daily Reminders	Two daily notifications in the morning and at night were sent to remind the user to take time for themselves and meditate, practice an imagery technique, or use other features of the app. If the app was used in the morning, the night notification would not be triggered.

Exit Interview

Individual interviews based on a semistructured interview guide were conducted by videoconference with the first 8 participants who completed all 4 weeks of the intervention to understand the caregivers' perceived utility of the app in terms of their well-being, relationships, and sense of connectedness to others. Participants were asked questions such as "How did the app impact you?," "Do you think that the app changed your relationship or sense of connectedness with others?," and "Do you have any suggestions for improvement regarding the application?". Specific components (MIT exercises and readings) were reviewed, and subjects were asked whether each element was "helpful, and if so, how?". Broad suggestions were solicited regarding any improvements to the experience of using the app. Narratives were transcribed and responses were categorized into whether they indicated positive or negative experiences, difficulties, self-understanding, connectedness to others, mindfulness, and comments related to specific MIT components. Responses were then reviewed for perceived helpfulness, negative experiences or difficulties, types of benefits elicited by each MIT exercise, and suggestions for improvement of MIT app delivery.

Statistical Analyses

Outcome analyses were performed on the sample of users who downloaded and used the app at least once. Analysis of mood trajectory was performed with R 3.3.2 [32]. All data were tested with the Shapiro-Wilke test and found to not deviate from normality. Linear mixed models were used to assess depression and affect trajectory with time as the independent variable, adjusting for age and sex, and subject as a random factor using lmer in package lme4. *P* values were estimated using the Wald chi-square test (function analysis of variance in library car). Depression symptom trajectory was also assessed in the overall sample and in the subset of participants reporting severe depression symptoms. Usage was calculated as the total number of audio practice sessions the participants completed. Predictive analyses were performed to assess the impact of age, sex, or baseline mood on usage with linear models across all participants who completed the baseline screening assessments. Paired, 2-sided *t* tests were performed on (1) Likert mood ratings from before to after audio-guided practice sessions across participants and (2) QIDS ratings at baseline and last available QIDS completed. Cohen *d* for change in depression symptoms was calculated as the mean of the change in QIDS divided by SD of the change. The relationship between attention during a practice session and immediate mood change was evaluated by pooling data from across all participants and meditations and using a linear mixed-effects model with subject as a random factor, rating of focus as the independent variable, and immediate change in mood (mood after meditation−mood before meditation) as the dependent variable.

Results

Participants and Demographics

Figure 1 illustrates the flow of participants through the trial. Out of the 17 participants included in the analysis, 71% (or 12/17) were women and age was 66.52 (SD 8.61) years. All participants were white.

Feasibility

Imagery and Mindfulness Practice Data

Audio Recording Usage

Usage frequency was conservatively estimated in participants who listened to an audio recording at least once and also rated its effect (n=17 participants). Thus, if participants listened to part of a recording (or even the whole recording) but did not rate their mood change, this usage was not captured. Average usage across these 17 participants was on 14 (SD 10) days out of the 28 days possible, and 29 (SD 28) individual audio sessions were conducted. Examination of usage revealed that participants fell into 1 of the 3 distinct patterns that were almost equally split among the participants: low, or usage on less than 1/3 of days (n=6 participants); moderate, or usage on 1/3 to 2/3 of days (n=6 participants); and high, usage on more than 2/3 of days (n=5 participants). Most low users, 6 out of 17 participants (35%), tried the app a few times and then discontinued use; the average number of audio sessions was 5 (SD 6) over the 28 days. The moderate group contained a mix of participants whose use declined and also some users whose use increased; the average number of audio sessions was 25 (SD 6). The high-use group typically listened to an audio recording twice a day (and sometimes more); the average number of sessions was 64 (SD 24). Total usage among all 21 participants who were provided the app was not predicted by sex, age, or baseline depression symptoms, nor was usage among the 17 participants who used the app at least once *(P*>.3 for all comparisons).

Acute Mood Changes

Immediately after completing an exercise, participants rated their mood before and after the meditations. For each type of practice, average changes (on the 11-point Likert scale) in acute mood across participants were in the direction of improvement as follows: Stretching and Breathing 1.65 (SD 1.39) points, t_{15}=4.72, *P*<.001; Eye in the Center 2.17 (SD 1.67), t_{16}=5.36, *P*<.001; Nesting Doll 1.81 (SD 1.56), t_{11}=4.02, *P*=.002; Situation Solver 1.88 (SD 1.54), t_9=3.86, *P*=.003; and Life Globe 0.81 (SD 0.61), t_7=3.78, *P*=.006.

Stability of Focus

Across meditations, the average stability of focus was 2.14 (SD 1.81), corresponding to paying attention about 70% of the time. Greater focus during a meditation session was highly predictive of improvement in immediate mood (Wald χ^2_1=47.0; *P*<.001) across participants.

Knowledge Data Usage and Helpfulness

For the 4 informational documents in the app, subject’s reading usage was estimated based on the number of times they read the material and also rated its helpfulness. Out of the 17 users, 3 (18%) read all 4, 6 (35%) read 3, 3 (18%) read 2, and 5 (29%) read 1. Average *helpfulness* was 2.87 (SD 1.11) on the Likert scale (from −5 to + 5) or about 81% of the distance toward the upper bound.

Symptom Changes: Negative Affect, Positive Affect, and Depression

Linear mixed effects models in the 17 participants who used the app at least once were used to determine changes in affect over time, adjusting for sex and age. Negative affect decreased irrespective of age or sex: time χ^2_1=10.2, *P*=.001; age χ^2_1=0.2, *P*=.70; and sex χ^2_1=0.4, *P*=.53. In the model predicting positive affect, both time and age were significantly predictive of increased positive affect over the course of the study: time χ^2_1=4.5, *P*=.035; age χ^2_1=11.4, *P*<.001; and sex χ^2_1=0.1, *P*=.77. There was a trend toward improvement of depression symptoms across all participants: time χ^2_1=2.3, *P*=.13; age χ^2_1=3.4, *P*=.065; and sex χ^2_1=0.8, *P*=.38. Those subjects who used the app at least moderately (n=11) evinced a significant drop in average QIDS with a large effect size, from 9.72 (SD 4.38) to 7.82 (SD 3.68), t_{10}=3.30, *P*=.008, Cohen *d*=.99. Subjects not using the app regularly (n=5 completing QIDS) showed no change in average QIDS, 12.4 (SD 4.72) to 14.2 (SD 11.73), t_4=.33, *P*=.75, Cohen *d*=.15. In the 3 participants with severe depression (QIDS≥16 at baseline), depression significantly decreased over time: time χ^2_1=7.2, *P*=.007; age χ^2_1=0.3, *P*=.57; and sex χ^2_1=1.4, *P*=.24.

Exit Interview

Caregivers commonly described benefits of the app to their emotional and cognitive well-being, such as feeling more “centered,” “anchored,” “on an even keel,” and learning to “not get too overwhelmed” by their emotions. Caregivers found that these changes helped them to better care for their loved ones or accomplish what they needed to do, or with one caregiver feeling more like his or her “normal self.” About half of the caregivers also reported improvements in perspective taking with their care recipient and the disease process, for example, “realizing that when I’m mad at her it’s actually I’m mad at the disease she has.” Several caregivers reported that the app helped them shift their experience of caregiving, learning that “the person you’re caring for can be an inspiration and the light in you” and finding “a more positive way of focusing on the negative things that have happened.”

Overall, 7 of the 8 participants felt moved by at least one of the audio recordings and expressed preference for some recordings over others. Specific feedback on patient preferences supported that the individual techniques may have yielded intended effects. For instance, exercises focused on self-regulation (Breathing and Stretching and Eye in the Center) were experienced as soothing and centering, whereas the Nesting Doll and Situation Solver perspective-taking exercises that focused on mentalizing the loved one resulted in greater perspective taking. The Life Globe meditation, which taught connectedness with others and the world, was experienced as “really very comforting” or that it left the caregiver with an “expanded viewpoint.” In comparison, a minority of subjects found the mindfulness or internally focused attention exercises to be “disorienting” or found the imagery exercises to be too complex. Uniquely, 1 individual who reported that mindfulness had “always been a challenge” reported no benefit from the meditations but found the readings to be “phenomenally” helpful.

Participants also described some caregiver-specific challenges in engaging with the app, such as pulled away from the app by the care recipient and being asked to focus on a specific challenging caregiving experience, which for some was emotionally arousing. None of the caregivers reported technical difficulties with the app interface, and a few caregivers commented that it was “user friendly” and several mentioned that the notifications provided “a good reminder” to use the app. A few participants commented that they would have benefited from contact with an interventionist for support and guidance to ensure they were “on the right track.”

Discussion

Principal Findings

The MIT app demonstrated promise in 4 main areas: technical feasibility, usage, mood improvement, and relational understanding. The large majority of caregivers receiving the app downloaded it and listened to at least one audio recording. A few of the participants mentioned that the app was easy to use or improved convenience, whereas none mentioned technical difficulties as being a barrier to app use, suggesting that the design interface was accessible to this elderly cohort. This is the first demonstration that an entirely remote mobile app technology delivering MIT, without ongoing therapist guidance or content instruction, may be successfully delivered to an aging cohort of participants including seniors.

Download rates and usage of the MIT app were variable but overall higher than what we expected based on other reports of download and usage of psychotherapy apps in adults with low mood [18] or of mindfulness apps to reduce stress and improve mental health in general populations [33,34], in which participants downloaded or used the app at about a third to a half the frequency of what we observed. Reasons for this are unclear but could be because of our participants being caregivers, who overall are quite conscientious and highly motivated, or other differences in study design related to app content, participant selection, or the nonrandomized nature of our trial.

In our population, usage patterns varied by participant and appeared to fall into distinct groups. Two-thirds of participants fell into a moderate- or high-usage group, suggesting feasibility for these participants. Strikingly, about a third of participants used the app on average more than once a day, suggesting that for a sizable minority of caregivers, guided imagery and meditation exercises delivered via the app can become incorporated routinely at least over the 4-week period we studied. However, for one-third of the participants who tried the app, usage was low, suggesting a lack of feasibility for a subset of participants. Features at baseline such as depression symptoms, age, and gender did not predict this difference in usage; further research may be beneficial with qualitative methods to identify reasons for low usage.

There were acute effects on improving mood associated with practicing the guided imagery and mindfulness exercises, and there were significant findings at 4 weeks for improving overall positive mood and reducing negative mood. Complementing the quantitative findings were caregivers' perceived benefits that the app provided "calm," "lowered stress," and provided an "anchor" for their mood. These findings add to the body of evidence that mindfulness app use in adults [33,34] and technological therapy delivery for caregivers [35,36] improves symptoms. Reassuringly, for the most severely depressed participants in our population, there was no worsening over the 4 weeks, and on the contrary, there were promising signs for reducing depressive symptoms. The magnitude of depression symptom reduction was approximately 30%, indicating that the MIT app alone is not likely to be sufficient for fully resolving depression symptoms, but it might be beneficial to study for depression in combination with other treatments, as an augmentation therapy, or with the guidance of a therapist.

Caregivers' perceived benefits for relationships and connectedness took different forms. Participants found themselves better able to take the perspective on their loved one and recognize the role that the illness was playing in dementia. This suggests that the app helped to enhance mentalizing capacity in relation to their loved one. For some caregivers, a complex reframing of the caregiver experience resulted, such as being able to see their loved one as a "light and the inspiration" inside of them after the Nesting Doll. The Life Globe exercise particularly resulted in finding "comfort" in connectedness, and by recontextualizing themselves as part of a larger whole, discovering "a more positive way of looking at the negative." Remarkably, this higher-order reframing of themselves and their loved ones took place without therapist contact but merely by interacting with the app components. Further studies should address whether improved perspective taking and reframing may be mediators of effects on mood. The relational impact of the MIT app also provides support for studying it for other populations with high levels of interpersonal stress, who might specifically benefit from the balanced attention to self and others provided by the MIT exercises.

Regarding specific app components, individual caregivers clearly exhibited preferences for particular exercises. Most caregivers found the guided imagery and mindfulness exercises helpful. The subject who uniquely reported that none of the mindfulness or guided imagery exercises helped still found value in the reading material. Thus, providing a menu of options from which caregivers could choose increased the benefit of the app for a broader range of caregivers. Future studies targeted at identifying active components of the MIT exercises would thus need to account for moderating factors leading to individual preferences and also clearly specify which therapeutic goals of MIT were being examined (eg, affective self-regulation, mentalization of self, and mentalization of others).

Limitations

Limitations of the study include the small sample size for our statistical models, which could have predisposed to type II errors; lack of a control group to account for nonspecific effects of being in the trial; and low ethnic and racial diversity of participants. As other studies have found that minorities will engage in mobile app therapies [37] and have previously reported benefit with in-person MIT delivery [16,24], improving recruitment methods to target these populations online will be important in future studies. The interviews suggested that people having a history of feeling challenged by mindfulness practices may need more guidance. Regular contact with an instructor for encouragement, identification of experience, explanation of some of the more difficult exercises, and support might help. In addition, an interventionist might help participants engage in problem solving regarding a place and time to do the meditation without interruption by their loved ones. Moreover, prior familiarity with mindfulness and guided imagery techniques and with smartphone use was not assessed, and these would be helpful to study as potential moderators in future trials. Furthermore, information regarding concurrent depression treatments was not collected, and this would be helpful for determining the specificity of effects and how caregivers used the MIT app (ie, as a solo therapy or as augmentation of other mental health interventions). Although overall feedback was positive regarding the app design, research with quantitative, empirically based tools may help to more rigorously characterize usability.

Conclusions

Our findings demonstrate that using the MIT app was feasible for the majority of family caregivers who enrolled in the trial. The MIT app showed promising results in positive affect increase, decrease in negative affect, and depression improvements for participants reporting high depression symptoms. Moreover, reports were consistent with increased mentalizing of the care recipient and higher-level reappraisal of the caregiver experience. These findings provide justification for larger, randomized controlled trials that could address specificity of MIT app benefits for family AD and ADRD caregivers.

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Conflicts of Interest

None declared.

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Abbreviations

AD: Alzheimer disease
ADRD: Alzheimer disease and related dementias
BAM: breathing, awareness, and motivation
MIT: mentalizing imagery therapy
QIDS: Quick Inventory of Depressive Symptoms–Self-Rated

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Review

Factors Influencing the Adoption of Smart Health Technologies for People With Dementia and Their Informal Caregivers: Scoping Review and Design Framework

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Abstract

Background: Smart Health technologies (s-Health technologies) are being developed to support people with dementia (PwD) and their informal caregivers at home, to improve care and reduce the levels of burden and stress they experience. However, although s-Health technologies have the potential to facilitate this, the factors influencing a successful implementation in this population are still unknown.

Objective: The aim of this study was to review existing literature to explore the factors influencing PwD and their informal caregivers' adoption of s-Health technologies for home care.

Methods: Following the Arksey and O'Malley methodology, this study is a scoping review providing a narrative description of the scientific literature on factors influencing s-Health technology adoption for PwD and their informal caregivers. A search was conducted using PubMed, the Cochrane library, the IEEE library, and Scopus. Publications screening was conducted by 2 researchers based on inclusion criteria, and full-text analysis was then conducted by 1 researcher. The included articles were thematically analyzed by 2 researchers to gain an insight into factors influencing adoption that PwD and their informal caregivers have to encounter when using s-Health technologies. Relevant information was identified and coded. Codes were later discussed between the researchers for developing and modifying them and for achieving a consensus, and the researchers organized the codes into broader themes.

Results: Emerging themes were built in a way that said something specific and meaningful about the research question, creating a list of factors influencing the adoption of s-Health technologies for PwD and their informal caregivers, including attitudinal aspects, ethical issues, technology-related challenges, condition-related challenges, and identified gaps. A design framework was created as a guide for future research and innovation in the area of s-Health technologies for PwD and their informal caregivers: *DemDesCon for s-Health Technologies*. DemDesCon for s-Health Technologies addresses 4 domains to consider for the design and development of s-Health technologies for this population: cognitive decline domain, physical decline domain, social domain, and development domain.

Conclusions: Although s-Health technologies have been used in health care scenarios, more work is needed for them to fully achieve their potential for use in dementia care. Researchers, businesses, and public governments need to collaborate to design and implement effective technology solutions for PwD and their informal caregivers, but the lack of clear design guidelines seems to be slowing the process. We believe that the DemDesCon framework will provide them with the guidance and assistance needed for creating meaningful devices for PwD home care and informal caregivers, filling a much-needed space in the present knowledge gap.

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KEYWORDS

dementia; informal caregiver; smart health technologies; user-centered design; technology adoption

Introduction

Background

Dementia is a neurodegenerative chronic condition characterized by a progressive decline in a person's memory, thinking, learning skills, and ability to perform activities of daily life (ADLs). Currently, dementia affects 47 million people worldwide, and these numbers are expected to increase to 75 million in 2030 and 132 million by 2050 [1]. As a result, the World Health Organization has declared it a public health priority and launched a public health plan in 2017 [2]. A diagnosis of dementia also has a significant impact on family members of people with dementia (PwD), who often bear the responsibility of caring for them as their health deteriorates [3]. Individuals who provide unpaid and continuous assistance and have not been formally trained, such as spouses, children, or other family members, are referred to as *informal caregivers*, in contrast to *formal caregivers*, who offer paid professional services [3]. Furthermore, it is often the case that informal caregivers provide care to PwD in circumstances where formal health care does not reach because of health care systems infrastructure, socioeconomic status, or cultural preferences, among others [4].

Smart Health technologies (s-Health technologies) [5] *are the result of the natural synergy between m-Health and smart cities, from the Information and Communication Technologies (ICT) perspective, as well as that of individuals and society*. Nowadays, a wide variety of s-Health technologies are being developed to help the elderly, chronic patients, and their informal caregivers at home, showing promising results [6,7]. The use of s-Health technologies for dementia includes assisted living technology, ambient assisted living technologies, and smart homes. Cahill et al proposed [8] that s-Health technologies fall into 4 main categories, namely, (1) those used to promote safety, (2) those that foster communication and address memory loss problems, (3) those that provide multisensory stimulation, and (4) those that act as memory enhancers. The scientific literature points out that s-Health technologies may have a role in supporting informal caregivers of PwD for situations often associated with informal caregiving, such as symptoms of depression, stress and anxiety, or caring burden [9,10]. Recent research on the topic [11], however, has found that many of these systems fail to be effective in real-life cases because of their low acceptance and adoption, often relating this to usability issues.

Technology can facilitate the delivery of care, but there are certain factors that can diminish its effectiveness. Obstacles to adoption are many and can range from design choices to complex scenarios like potential ethical issues such as data ownership or privacy concerns derived from their use [12]. In terms of usability, challenges increase for dementia as we must also consider the cognitive and behavioral issues [13]. For PwD, even once familiar devices, such as washing machines, microwaves, kettles, or telephones, can be problematic, as the appearance and design of these have changed so much that they do not resemble the ones they had grown accustomed to [14].

Gaps in the Knowledge

Current trends in health information technologies suggest that solutions should be designed not only to be effective, acceptable, and nonharmful but also to be pleasant and engaging [15,16]. The use of user-centered design (UCD) principles generates systems that are easy to learn, have higher user acceptance and satisfaction, and lower user errors [17-19]. Design for PwD should consider dementia-related symptoms [13]. Furthermore, informal caregivers of PwD provide substantial care at home, at times with little assistance from paid professionals [3]. Informal caregivers of PwD spend large amounts of time caring for PwD and are very acquainted with the problems they face [20]. However, they are seldom included in the design process for s-Health technologies, which could prove beneficial.

To the best of our knowledge, there are no guidelines specifically created for designing s-Health technologies for PwD and their informal caregivers. There are sets of design recommendations such as the one created by Astell et al for *motor-based technologies for people with cognitive impairment* [21], Boman et al's work on using ICTs for persons with cognitive impairment [22], or Matthews et al's [23] summary of adoption factors for caregivers of dementia. However, these recommendations do not expand on the process of design, develop, and most of all, implementation of s-Health technologies [21].

The objective of this study was to examine the factors influencing PwD and their informal caregivers' adoption of s-Health technologies for home care and provide some recommendations for their design.

Methods

Study Design

Scoping review methodology aims to map the key concepts underpinning a research area, especially where an area has not been reviewed comprehensively before [24-26]. The Arksey and O'Malley methodology [24] was followed to produce a scoping review that provides a narrative description of the scientific literature on factors influencing s-Health technology adoption for PwD and their informal caregivers. A qualitative thematic analysis [27] was conducted on the results of the scoping review to generate a list of design recommendations that aim to help future s-Health technologies for PwD and their informal caregivers' researchers and designers.

Identifying the Research Question

The aim of this study was to review existing literature to explore the factors influencing PwD and their informal caregivers' adoption of s-Health technologies for home care.

Identifying Relevant Studies

We conducted a search on available literature on s-Health technologies for PwD and their informal caregivers following the selection criteria (see below). The search was conducted in the following databases: PubMed, Cochrane library, IEEE library, and Scopus. Initially, titles and abstracts of all publications retrieved from the initial search were screened by 2 researchers (EGF and LMM), and a full-text analysis of potentially suitable publications was then conducted by 1 researcher (EGF).

Inclusion criteria were as follows:

1. Publications in English language.
2. Literature that dealt with PwD and their informal caregivers.
3. s-Health technologies interventions that were designed, implemented, or evaluated for PwD and their informal caregivers in outpatient scenarios.
4. Publications that included primary or secondary outcome evaluations on usability and user experience, adoption barriers and enhancers, design, participant's level of satisfaction with the technology, and technology friendliness.

Exclusion criteria were as follows:

1. Studies that took place in nursing homes or care facilities.
2. Young-onset dementia studies.

The keywords and search terms used were organized into 3 main groups for clarity purposes: (1) dementia dementia-related keywords, (2) informal caregiver–related keywords, and (3) s-Health technologies–related keywords. A complete list of all keywords and the search string can be found in Multimedia Appendix 1.

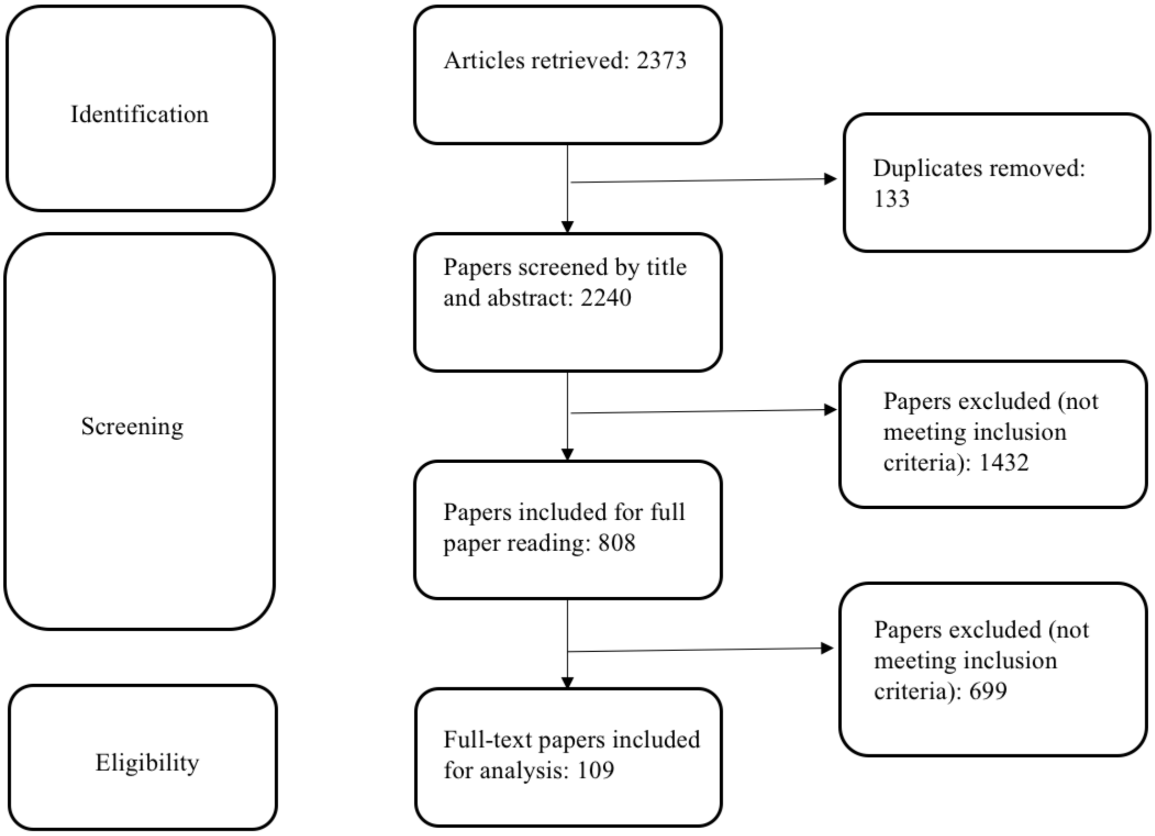
Results

Study Selection

In total, 2 researchers (EGF and LMM) completed the study selection process; disagreements were resolved by involving a third researcher (CB). The selection and analysis process was managed with EndNote X8 software for Mac (Clarivate Analytics, Philadelphia).

Our search strategy retrieved 2373 publications from the selected sources. After removing duplicates, publications were screened by title and then by abstract, which identified 808 papers to read by full text. A total of 109 publications met our inclusion criteria and were included for analysis. The study workflow selection can be seen in Figure 1.

Figure 1. Study selection workflow.



Charting the Data

Data extraction forms were created to obtain and organize information from the included studies, such as author(s), year and journal of publication, title, type of publication, study design and aim, target population, intervention, the type of technology included, outcomes, and potential technology adoption challenges described. A summary of the included publications can be seen in Table 1 and Figure 2.

Table 1. Publications summary table.

Characteristics	n
Type of publication	
Design studies	56
Book chapter	1
Review studies	8
Randomized controlled trials	6
Nonrandomized controlled trials	1
Qualitative studies	10
Case studies	3
Pilot studies	19
Longitudinal studies	2
Exploratory studies	2
Cross-sectional studies	1
Type of technology included	
Communication and Information Technologies (ie, electronic health, mobile health, telehealth, telecare, and home monitoring)	47
Assisted living technologies (ie, pervasive assistive technology, ambient assisted living technologies, and smart interactive artifacts)	56
Health smart home	7
Wearables and tracking devices	9

Figure 2. Numbers of papers identified per year.

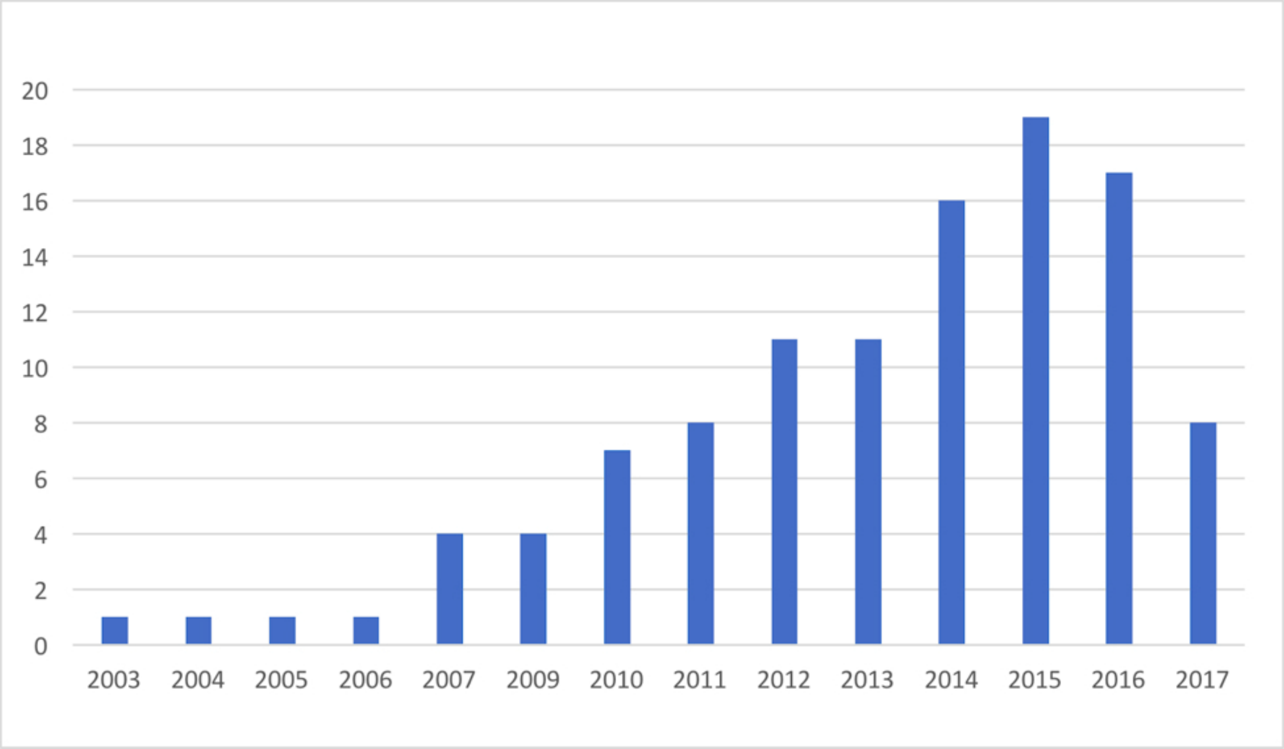


Table 2. Factors influencing the adoption of s-Health technologies for people with dementia and their informal caregivers.

Theme 1: Attitudinal aspects	Theme 2: Ethical issues	Theme 3: Technology-related challenges	Theme 4: Condition-related challenges	Theme 5: Gaps
Positive attitudes toward technology: improved quality of life; self-efficacy facilitator; and support tool. Negative attitudes toward technology: lack of technology acceptance; mismatched expectations and needs; and technology burden	Privacy concerns; autonomy concerns; and data ownership concerns	Design; digital literacy; and perceived usefulness	Cognitive decline; aging and physical capabilities; and condition acceptance	Market needs; research; and good practice guidelines

Collating, Summarizing, and Reporting the Results

Only qualitative and narrative data that could be obtained from the studies were included. The qualitative analysis was performed using NVivo software version 12 for Mac (QSR International, Melbourne, Australia). Data analysis was conducted independently by the 2 main researchers (EGF and LMM). Through the iterative process, relevant information was identified and coded. Codes were later discussed between the researchers for developing and modifying them, achieving a consensus. Researchers organized the codes into broader themes that said something specific and meaningful about the research question. Finally, a list of design considerations was created based on our findings, as a guide for future research and innovation in the area of s-Health technologies for PwD and their informal caregivers.

Emerging Themes

In this section, we provide a detailed description of the emerging themes and factors influencing the adoption of s-Health technologies for PwD and their informal caregivers that rose from our qualitative analysis of the included results. An overview is presented in Table 2.

Theme 1. Attitudinal Aspect

A user's attitude toward technology is crucial for its adoption. Having a positive attitude toward technology and having previous positive experiences are known to improve adoption [28,29]. Negative attitudes can act as barriers, resulting in nonadoption [8].

Positive Attitudes Toward Technology

Improved Quality of Life

Some informal caregivers see s-Health technologies as means to improve QoL through better care management, reducing their levels of anxiety, burden, and frustration, and also impacting positively on the QoL of PwD [30]. s-Health technologies are also seen to improve the ability to cope with challenging situations that arise from living with the condition [31]. There seems to be some empowerment happening as the costs and time saved by using the technology allow informal caregivers to gain more freedom [12,32,33]. For example, as shown in the study by Mitseva et al [32], being able to avoid the hassle of going over to the care centers or visiting the PwD's home was afforded by technology.

Self-Efficacy Facilitator

In some papers, using technologies is considered to promote PwD independent living, as it reassures both PwD and informal caregivers. s-Health technologies were able to provide entertainment and engage PwD [34,35], making it easier for PwD to stay out of hospice care while increasing informal caregivers' peace of mind [36-38].

Support Tool

Communication between PwD and informal caregivers can be greatly improved through s-Health technologies [8,30,34]. These technologies can enhance the user's social network and the support they provide [39]. Gradually introducing technologies to PwD's lives increased the chances for their adoption for ADLs, helping in their use for later stages of the disease. As mentioned in the study by Patterson et al [40], technologies even become invisible for the PwD maximizing its integration. A sudden introduction is recognized as a barrier, as it can make PwD reject technology [41,42].

Negative Attitudes Toward Technology

Lack of Technology Acceptance

The overall feeling from the literature seems to be that the elderly are reluctant users who do not engage with newer technology [43]. This may be so depending on the stage of the condition. Some studies presented the view that PwD do not see themselves as ideal users, either because they do not feel the technology is suitable for them or because they think that *they are not that bad* [39,44].

Mismatched Expectations and Needs

In the literature, it is common to find that PwD and informal caregivers have unrealistic expectations regarding what s-Health technologies can accomplish for them [31,45,46]. This is one of the most common perceptions as technologies are not considered sufficiently well suited to their needs [45] or they expect more than what technology can currently offer [31,46].

Technology Burden

Many negative feelings may arise from technology use, such as frustration, confusion, discomfort, embarrassment, or anxiety [14,37,47], which may have impacts on technology adoption. Some studies found that using reminder systems can be burdensome to informal caregivers, who continuously had to remind PwD to use the device [8,48,49]. Technology use also carries routine disturbance [43,50], fear of becoming dependent on technology, and fear of the informal caregivers being replaced by machines [51].

Theme 2. Ethical Issues

The use of s-Health technologies is not without ethical concerns as issues of autonomy, beneficence, and justice, among other moral issues, can be presented. Questions such as PwD's ability to provide truly informed consent, how is their privacy protected, or how confidential the information given is are present throughout the literature [52].

Privacy Concerns

Lack of privacy is described as a major issue for both PwD and informal caregivers, which is seen as a potential risk that could stigmatize them and take away their dignity [53,54]. Informal caregivers were usually putting PwD safety needs first over any other concern, believing that remote tracking could reassure them as caregivers [55], but they feared that it would be obtrusive to personal lives and wanted the option to turn it off [56,57].

Autonomy Concerns

Similar to the theme above, this concern is related to the fear that constant monitoring of PwD is restricting their freedom [53,54]. Preserving some semblance of autonomy was important as the loss of personal freedom can lead to the infantilization of PwD [58].

Data Ownership Concerns

Through the use of s-Health technologies, new and vast amounts of data are generated; who does it belong to seemed to be a frequent question. Preserving the confidentiality of sensitive data and preventing exposing it in any personally identifiable way was very important [59]. To avoid this, best practices in dementia research recommend the involvement of PwD [33].

Theme 3. Technology-Related Challenges

Technology is becoming part of PwD and informal caregivers' daily lives, but many devices require a number of different tasks to be performed for them to function properly. There are certain aspects that need to be addressed for the PwD and their informal caregivers to feel that s-Health technologies were not *dropped* into their lives with little to no information or guidance on how to use it [36].

Design

The design process plays an important role in its use, acting as a barrier or a facilitator. In terms of the devices' external aspect, overly bulky or too conspicuous gadgets can result in the technology being abandoned [8,60]. Smallness and discreteness for home-installed and body-worn devices were considered less stigmatizing in the literature [22,59,61,62]. Furthermore, it seems that PwD respond better to devices that have a familiar aspect [8,59], for example, televisions (TVs) with adapted interfaces to mimic older sets [41]. In regard to user interface design, the most frequent recommendation is that it should be user-friendly, simplified, and easy and clear to use [11,44,61,63-66]. This includes considerations such as appropriate colors, text font and sizes, and background styles and sounds, adapted to fit PwD's hearing and vision common problems [67,68]. Being able to tailor the technology to match PwD cognitive and health status is important as the disease progresses [36,69,70]. In addition, s-Health technologies that allow tailored content, such as pictures or components to make it *fun* to use, are considered less stigmatizing and hence more likely to be embraced [71]. Involving PwD and informal caregivers in the design process enhanced usability and technology acceptance [59,72].

Digital Literacy

The literature points out that PwD and informal caregivers are often unaware about what technology can do for them and what it can do to help in their daily activities [38,43,73]. The lack of information can act as a barrier, and proper supply can be a facilitator. Digital literacy [40,44] is so important that not being educated about it could increase the need for additional time and efforts to adopt a new device [40,74,75]. The lack of digital literacy was somehow mitigated when caregivers and PwD used technology together [76].

Perceived Usefulness

It is a recognized issue that target users of technology need to see it as valuable to adopt it [59,73,77]. This was true for both PwD and informal caregivers, who want to know this before even considering purchasing them [23,78]. These were some of the main issues associated with drop out from s-Health technologies studies [79]. Usefulness and cost are closely associated, as users tend to be surer about purchasing an s-Health technologies device when the price is low, as throwing them away will be less painful [73].

Theme 4. Condition-Related Challenges

There are a series of issues that PwD face as a result of living with the condition and the natural age-related changes. This gradual deterioration affects the performance of specific functional tasks as well as cognitive deficits that impair learning new systems and interfaces, impacting the interaction with new technologies [40].

Cognitive Decline

The nature of dementia can greatly result in active rejection of technology. There were several studies that were related in part to memory decline and aging-related problems such as hearing or vision [40]. PwD were more suspicious of new things [13]. In addition, condition denial is a factor for PwD as they generally do not wish to be reminded of their condition [30]. In the late stages of the condition, PwD have greater difficulties making decisions for themselves. This creates conflict for informal caregivers, who have to balance their own personal needs (eg, peace of mind) and the potential infringement of PwD's autonomy and independence [36,59]. There is literature that supports the involvement of PwD in decision making whether or not they have been legally or clinically deemed unfit [28]. Deciding early to what degree of decline PwD can continue participating in an intervention was a highlighted matter [43].

Aging and Physical Capabilities

Physical changes associated with aging, such as sight and hearing loss, health issues, or aging tremor, can impact the adoption of s-Health technologies. Using certain touch screens, keyboards, fonts, button sizes, colors, and design can be troublesome [8,40,79,80]. Considering issues with fine motor skills, flexible and intuitive technologies that require minimal physical effort [22] and minimize the need for interactions [76] are more appropriate. Optimizing the number of functions and features that can be integrated into each system makes it easier and simpler to use [71].

Condition Acceptance

As mentioned earlier, the lack of awareness and the disease denial attitude that this population usually has at the early stages imply a lack of recognition of their disabilities and needs, and therefore a rejection of any kind of help, including s-Health technologies [43]. However, in the case of the informal caregivers, they report that home care technology provides the PwD with a greater understanding and perception of the disease, enhancing the diagnosis acceptance [81].

Theme 5. Gaps

There is a common concern in the literature that there are many gaps in terms of the market availability of technological developments for PwD and informal caregivers, and lack of practical guidelines for the design and implementation of technologies [14].

Market Needs

In some aspects, market size may determine how much research is conducted. PwD and their informal caregivers are a relatively small percentage size compared with other health condition populations, and perhaps this explains the limited attention that the design and evaluation of technologies has received for this population [82].

Research

In general, technologies are designed by cognitively intact people, such as system developers, researchers, and their colleagues [82]. There is a noticeable lack of involvement of PwD and informal caregivers in research despite the fact that academic and industrial sectors claim how important this would be to avoid s-Health technology nonadoption or abandonment [33,63,72]. More research is needed to determine the appropriate level of interaction between the PwD and informal caregivers with the different technologies depending on the disease stage [59], and to determine whether successful outcomes are disease-related, age-related, or both [32].

Good Practice Guidelines

It is evident from the literature that there is a great need for guidelines on how to design and develop technological solutions for this population [31,83,84].

DemDesCon for s-Health Technologies: Dementia Design Considerations for Smart Health Technologies

The emerging themes obtained during our scoping review allowed the extraction of valuable insight that was grouped to create a series of design considerations for s-Health technologies for PwD and informal caregivers. We have called these Dementia Design Considerations for Smart Health Technologies or *DemDesCon for s-Health technologies*. Following the works of Astell et al [21], we have presented these design considerations as different domains to be taken into account. Each design consideration is detailed below. An overview of DemDesCon for s-Health technologies is presented in Figure 3.

Designers of s-Health technologies are encouraged to consider these different domains in their approach to the design process of solutions for PwD and informal caregivers and to reflect on the ramifications of their designs.

Cognitive Decline Domain

PwD undergo a series of cognitive decline issues that affect how they can relate to new technologies. The following sections reflect on design considerations regarding their cognitive capabilities.

Intuitiveness and Familiarity

PwD have a hard time acquiring new knowledge or developing new learning skills; hence, taking advantage of their preserved skills is considered that can facilitate this acquisition process [34,59]. In this case, the old saying of *less is more* seems to work better here. s-Health technologies interfaces have to be easy to use, clear, not complex, and as simple as possible [8,11,44,64,85,86]. s-Health technologies should encourage interaction [34] and have a uniform composition, paying attention to font type and size, colors, and shape of buttons [44,65,87]. As it is with hardware, the interface should emphasize *recognition rather than recall*, thus being easier, quicker, and better appreciated by the users [65].

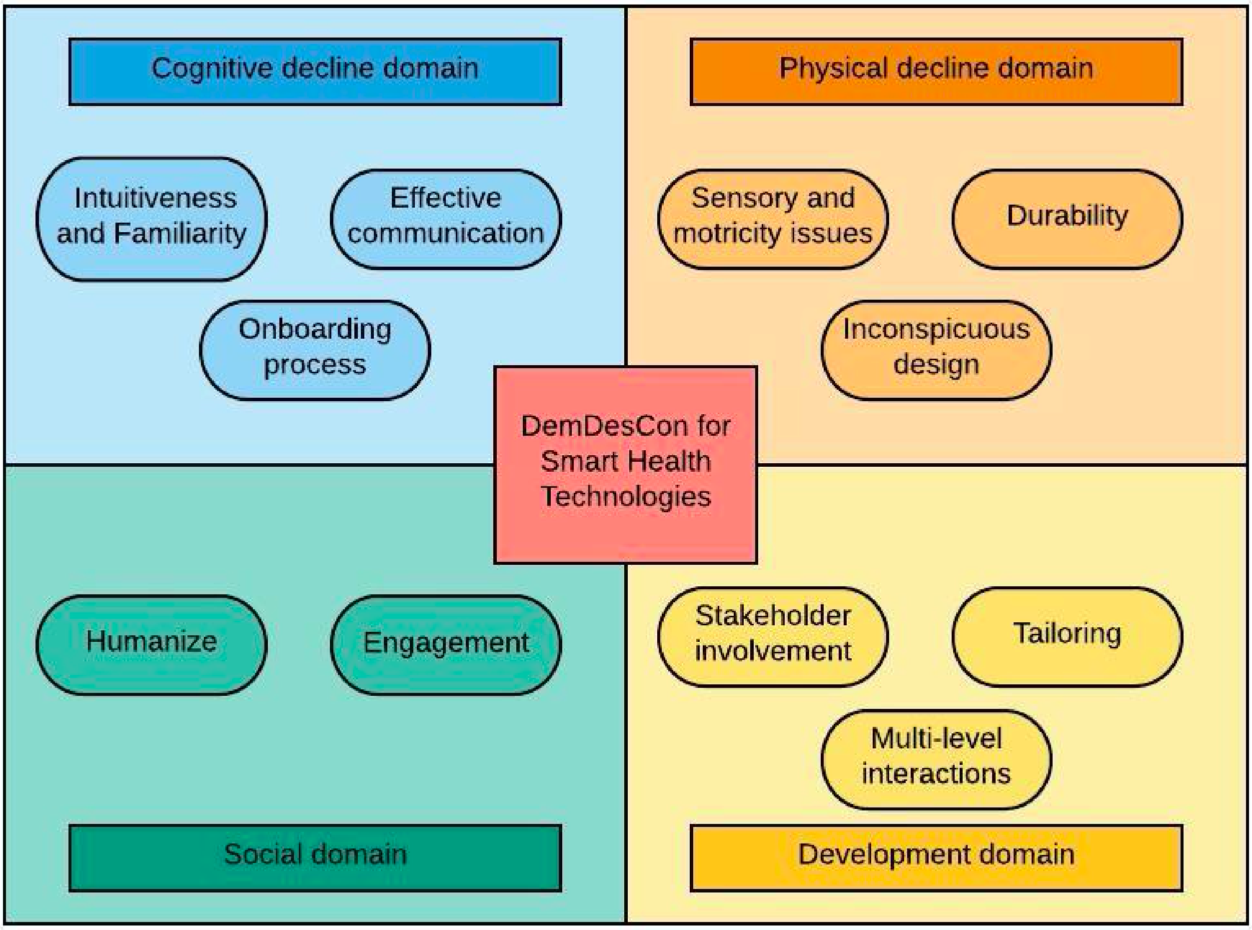
One approach that is recommended for s-Health technologies is to adopt a familiar look that mimics older devices. This is because learning new things is not a preserved skill for the PwD [13,88]. Using devices that mimic technology that PwD already use, such as old-fashioned TV screens, radios, or phones, have proved to have increase adoption [14]. s-Health technologies devices should aim to be comforting and nonthreatening to avoid them being rejected [89,90].

Effective Communication

Use of plain and common language is a must, to avoid PwD confusion [44] and to facilitate understanding and interaction. It is common in human nature that when we cannot understand something, we tend to abandon it or are reluctant to engage with it. The content provided should be tailored as well [44], providing well-distributed information and divided into different modules depending on each individual’s needs [87,88].

Setting simple and achievable goals or tasks with clear and appropriate instructions increases the chances that PwD’s cognitive impairment will not impede to carry them out [23]. To engage and retain PwD’s attention, a certain negotiation and interpretation needs to be done to present tasks in a way that seems attractive to the PwD [34].

Figure 3. Dementia Design Considerations for Smart Health Technologies (DemDesCon for s-Health technologies).



Onboarding Process

Introducing new technologies in the life of cognitively impaired people such as PwD should be done with careful consideration [91]. In early stages of the cognitive decline, cognitively impaired people are still able to provide consent about whether to use a piece of technology or not, and in later stages, it is recommended that their former wishes regarding having technology used for their care are taken into account [28].

Enough time should be given to PwD and informal caregivers to get used to using them, providing time to learn at their own pace and suiting preserved cognitive skills. Providers should provide guidance on how to use s-Health technologies [39] and allow sufficient time to practice [92]. In the event of system failures, home assistance should be provided, avoiding further disruptions of PwD or informal caregiver's life.

Physical Decline Domain

The gradual and progressive physical deterioration that PwD go through requires for potential s-Health technologies to take special notice to some particular condition-related aspects. Below are design considerations relevant to the physical decline of PwD.

Sensory and Motricity Issues

As PwD fine motor skills decline, using appliances or devices such as a computer mouse or TV remote control, can represent a struggle 34]. Adapting visual and audio signals to compensate these issues is recommended [23], for example, providing larger screens [34] or easily adjustable volume settings [8].

Durability

As PwD's condition deteriorates, they are more prone to destructive behaviors such as lashing out [90]. This is in part because of their lost motor skills and lack of cognitive processing as well as other disease-related problems such as their lost learning capabilities [59].

Taking these issues into account, the literature recommends that s-Health technologies for PwD be of robust materials or, in the event of wearable devices, not easy to be removed from clothes, belt, or body, to withstand these outbursts or potential neglect [38].

Inconspicuous Design

In line with the above mentioned information, portable and ergonomic devices are a good approach for the design of s-Health technologies for PwD [61,78]. It is also preferable that these devices be lightweight and comfortable to wear or carry and have reduced dimensions and discrete designs, as PwD are likely to have to carry them to frequent places such as a health care provider's office or family members' houses or even during vacations [23,91]. These recommendations facilitate and increase wearability and adoption [62,88]. Inconspicuous designs reduce feelings of stigmatization [49], unlike body-worn devices that are very noticeable, such as pendant alarms or Global Positioning Systems trackers.

The different locations and scenarios in which these s-Health technologies can be used present a challenge [71] as these devices may have charging requirements that can be bothersome, causing abandonment [8].

Social Domain

It is common for people and health care providers to, sometimes without noticing, infantilize PwD, thus taking their autonomy away from them. The following design considerations attempt to emphasize ways in which s-Health technologies can encourage PwD to stay active and offer them positive reinforcement.

Humanize

s-Health technologies in this field should try to support PwD, not seeing them as just mere objects or former humans that have lost their memory and abilities [93]. Technology should promote social interaction and avoid isolation [41]. Loneliness and sadness are very common in PwD and their informal caregivers; because of the disease progression, their social network keeps reducing, rendering them even more isolated.

s-Health technologies should aim to promote autonomy, making the PwD more independent and self-reliable in their ADLs [94]. A more independent PwD will give more free time to informal caregivers themselves, allowing them to engage in leisure and social activities as well as keeping physically and socially active.

Engagement

The content of the activity or intervention must be suited to meet PwD and informal caregivers' personal interest [76], for example, using audio-visual media such as photos, videos, or music that are appealing to them. In this case, the content should be customized for the PwD's own interests, hobbies, or preferences.

Development Domain

s-Health technologies are becoming more pervasive, but there is much room left for improvement in regard to creating solutions that are useful and meaningful for the intended audiences. The following design considerations aim to call for attention from researchers, developers, and designers as to what seems to be missing in the field of s-Health technologies for PwD.

Stakeholder Involvement

It is advisable to involve PwD and their informal caregivers in all phases of s-Health technologies design, as their input will enhance the suitability and acceptability of the solution as well as empower them [59,70,88]. Stakeholder involvement also helps to establish closer and more trustful relationships, to understand the needs and values of all stakeholders, and overall, adds value to the design [95].

Tailoring

Tailoring is a process for creating individualized communications by gathering and assessing personal data related to a given health outcome in order to determine the most appropriate strategy to meet patient's unique needs [96,97]. Compared to generic information, tailored information is more likely to be read, remembered and viewed as personally relevant [98]. Therefore, s-Health technologies have to reach the users in a way that is meaningful to them, being able to adapt to the different stages of the disease and the symptoms fluctuation, as well as to their physical and mobility decline, offering different solutions depending on the needs and assistance required, moving from an active user to a passive user when necessitated [74].

This tailoring is desired to be automatic, that is, the device works by itself with little or no direct human control, deciding the type and level of help required without the informal caregiver or the PwD intervention [39,74,99]. It has to allow to set up tasks and also make them adaptable to changes to patient's situation fluctuations and to not interfere with their daily routines [50,100]. This means that technology has to be as much flexible as possible and cannot be outdated as the disease progresses [50].

Multilevel Interactions

s-Health technologies for PwD should allow different levels of intervention, differentiating between health care professionals, other peers, family, and relatives [101]. The user has to be able, if desired, to personalize the support, information requested and shared, levels of assistance, and communication with different members of the support circle [81].

Discussion

Principal Findings

This scoping review is the first study of its kind to explore factors influencing the adoption of s-Health technologies for PwD and informal caregivers. A total of 109 papers were reviewed and thematically analyzed, providing insight into factors influencing s-Health technologies adoption when using these types of technologies for the home care environment. Emerging themes were divided and classified for better understanding. Furthermore, the insights that this review provides were used to produce a series of design considerations for future work in s-Health technologies for dementia home care. No other study has provided a similar list of design considerations for use in s-Health technologies for dementia before.

Comparison With Previous Work

A thorough review of the scientific literature highlights how previous works where technology has been used for dementia home care leave room for confusion with an ample array of terms and terminologies employed. The lack of a uniform nomenclature or taxonomy becomes apparent as a variety of concepts are frequently used together, even within the same publications, making it quite difficult to distinguish which type of technology is being referenced [102,103].

s-Health technologies for PwD and informal caregivers seem to be created nowadays with either the PwD [77] or the informal caregivers [44,81,104] in mind. It is less common in the cases where the services are being designed for both of them and integrated under the same tool [105,106]. This is in conflict with recommendations for designing technology in this population, as one of the essential points is the comprehensive creation and a participatory design [14,95]. Despite these issues and facing great difficulties, PwD and informal caregivers appear to be embracing dementia home care technologies slowly yet increasingly to facilitate and to assist them with their ADLs.

Another interesting finding in our scoping review is the significant emphasis that studies placed on feasibility, reliability, usability and user experience, and user engagement, regardless of overall goals of behavioral change. It would seem that the latter was not often accounted for or corroborated in the results. Furthermore, the methodology used in the studies varied even for assessing similar variables, making it difficult to extrapolate conclusions [107].

Working up from the gaps and themes that we discovered in our study, we turn our attention to the actual s-Health technologies design for PwD. Current trends in s-Health technologies design claim that UCD processes increase their adoption and use by the intended users [17]. In UCD, the needs and perspectives of users are placed in the highest of priorities and the product is designed to accommodate them [19]. Ideally, this should be an iterative design process, where the final users contribute with their knowledge and experience to develop a product that can be adapted to meet their own needs in a user-friendly manner. By following these design principles, systems that are easier to learn, have higher user acceptance and satisfaction, and have lower user errors are generated [17-19].

The design of s-Health technologies for PwD unfortunately does not follow the above approaches. In many cases, PwD and informal caregivers are not involved during the design process, so the value of their experiences and expertise is lost. It is more likely that they are involved in a user evaluation exercise that takes place after the design process has already reached an advanced stage. Thus, intended users have to make a great effort to understand and become familiar with the particularities of each device. In many cases, this is not successful, resulting in the device being abandoned for not being found useful or fit for its purpose [31]. There is a necessity to better understand the needs and perceptions of PwD and informal caregivers regarding technology, and to use this knowledge to address the deficits outlined above. Therefore, we believe that our work will provide light in those gray and diffuse areas where there are no guidelines at the moment.

As it stands, DemDesCon for s-Health technologies is aligned with current design models for technologies that advocate the need to consider condition-specific factors [108,109]. In addition, some frameworks also suggest involving stakeholders to ensure that the designed technology is more meaningful to end users [110]. We have included 28 publications [111-139] in Multimedia Appendix 1.

Limitations

One of the main limitations of this study relies on its research methodology, as scoping reviews do not explore the totality of all available studies; rather, it provides a descriptive view of the area of study. In addition, the scoping reviews do not seek for quality and weight of evidence or quality of the methodology of the primary research publications. It also has to be considered that the amount of information collected can lead into difficulties for the width and depth of the information to cover.

Furthermore, no quantitative or statistical analysis was performed on the included papers, but this is in line with the scoping review methodology. It is possible that the selection criteria may have left out studies that would be relevant to this research's goal, such as non-English publications that could hold relevant studies in other languages. Focusing on community-living PwD and their informal caregivers may have neglected other suitable studies conducted in caring homes or in other types of people with other chronic diseases that could also benefit from these types of interventions. In addition, young-onset dementia interventions have not been taken into account, and this could be a bias as we have mentioned in our paper; an early introduction is a key factor for technologies adoption.

Conclusions

Although s-Health technologies have been used in health care scenarios, more work is needed for them to fully achieve their potential for use in dementia care. As was present in the revised literature, s-Health technologies are seen by some as a complementary support tool that could improve the quality of life (QoL) of PwD and informal caregivers, who are willing to use these technologies if the conditions are right.

Our study found that the way of matching the appropriate technology to each individual, and at the right time, is not clear yet and more difficult than what it may seem. Researchers and companies are working toward developing valuable technologies for PwD and informal caregivers, but the lack of clear design guidelines seems to be slowing the process. This study offers a series of design recommendations under the shape of a framework: *DemDesCon for s-Health technologies*. We believe DemDesCon can provide guidance and assistance for creating meaningful devices for home care for PwD and informal caregivers, filling a much-needed space in the gap of knowledge. Nevertheless, more research needs to be conducted with longitudinal studies to appreciate how s-Health technologies work in the users' environment and how they interact with them.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Annexes.
[PDF File (Adobe PDF File), 293KB - aging_v2i1e12192_app1.pdf]

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Abbreviations

ADL: activity of daily life
s-Health technologies: Smart health technologies
PwD: People with Dementia
QoL: quality of life
TV: television
UCD: user-centered design

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Original Paper

Prioritizing the Needs of Caregivers of Older Adults to Support Their Help-Seeking Process as a First Step to Developing an eHealth Tool: The Technique for Research of Information by Animation of a Group of Experts (TRIAGE) Method

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Abstract

Background: Caregivers of functionally dependent older persons sometimes seek formal services to support their relatives. However, this process of help-seeking is complex.

Objective: The overall aim of the study was to use a co-design approach to develop an electronic health (eHealth) tool to support caregivers in their process of help-seeking. This study presents the first step of the design phase, which aimed to prioritize the user needs to be considered during the development of an eHealth tool.

Methods: A total of 3 groups of caregivers, community workers, and health and social service professionals participated in either a co-design session (1 or 2) or an advisory committee in 2 rural areas and 1 urban area. The needs identified in the academic literature and during a previous study were sorted (Technique for Research of Information by Animation of a Group of Experts [TRIAGE] method) by the participants (referred to in this study as co-designers) to obtain a consensus on those to be prioritized. Needs identified, grouped, and removed were ranked and compared.

Results: Of the initial list of 32 needs, 12 were modified or merged, 3 added, and 7 deleted as the co-designers felt that the needs were poorly formulated, redundant, irrelevant, or impossible to meet. In the end, 19 needs were identified for the design of the eHealth tool.

Conclusions: Many of the identified needs are informational (eg, having access to up-to-date information) and are probably met by existing tools. However, many others are emotional (eg, being encouraged to use the services) and offer an interesting challenge to eHealth tool development.

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KEYWORDS

caregivers; aged; help seeking behavior; community-based participatory research; eHealth; telemedicine

Introduction

Background

In Quebec, an estimated 296,000 men and 402,700 women are caring for their parents or in-laws, and approximately 80,200 men and as many women take care of their life partners [1]. About 8.1 millions of Canadians aged 15 years and above reported providing care to a family member or friend with a chronic condition, a disability, or age-related problems in the 12 months preceding a 2012 survey [2]. Care provision included transportation, meal preparation, bathing and clothing, and help with medical treatments. It can be assumed that this number has since increased. Quebec, like many other parts of the world, has an aging population [3]. The increase in the proportion of people aged 65 years or above will continue in Canada (including Quebec) in the coming years. This group will represent between 23% and 25% of the population in 2036 and between 24% and 28% in 2061 compared with 14% in 2009 [4]. The aging of the population is leading to an increase in the demand for support for older persons and, consequently, a rise in the number of caregivers [1].

Furthermore, one of the difficulties encountered by caregivers is the search for formal services to assist them in their role (services for themselves or for the elders they support) [5,6]. Increasingly, caregivers are turning to the internet to begin their search. Electronic health (eHealth) can support caregivers in this process [7-11]. Eysenbach defines eHealth as an emerging field at the intersection of medical information technology, public health and business, and referral to health services and information delivered or enhanced through the internet and related technologies [12]. It is from this perspective that this study emerged. Funded by the Quebec Ministry of the Family, this study aimed to develop an eHealth tool to support the process of help-seeking by caregivers of elderly people [13]. The development of this tool is intended to be inclusive, that is, the research team wanted all caregivers, regardless of their technological skills, level of education, or numerical literacy, to be able to use the tool efficiently. Furthermore, one of the promising interventions to achieve this is to develop the tool with future users; in this case, caregivers and potential health and social service professionals (HSSPs) and community workers [14]. Therefore, the chosen approach was co-design. Co-design refers to the creativity of designers and people not trained in design, working together in the design development process [15]. Thus, caregivers acting as designers can intervene directly in their future eHealth tool and draw upon their knowledge to develop technologies that respect their needs and their ways of doing things [13,16]. In this study, co-design started at the first step of the design phase to define the problem and understand the needs of caregivers [17]. This study specifically presents this phase of the study.

Needs of Caregivers

According to Amieva et al, caregivers' expectations and needs are principally twofold: first, the ready availability of information on the disease and, second, the acquisition of skills to optimize the help given to the patient on a daily basis [18]. Dunbrack, for his part, pointed out that the following needs are the most common: pain relief, grief support, respite, information about caregiving and illness, knowledge of how to deal with professionals and volunteers (knowing who does what), help with answering legal and financial questions, and emotional and spiritual support [19]. He also added that it is important to recognize changing information needs so that both the caregiver and the health care team can anticipate and plan for such changing needs [19]. Caregivers mentioned that they preferred oral communication with information in a form that they could refer to repeatedly to assimilate it more effectively (eg, a booklet, a book, a website, or a video) and return to over time to refresh their memory or fill in a blank [19]. The need for well-coordinated postdiagnostic support, greater continuity of care with regard to the personnel involved, and enhanced access to nonpharmacological interventions to support identity and social engagement was also found to be important for caregivers [20]. Another study found that family ties and affection make it difficult for those accompanying a loved one to identify themselves as caregivers. Lack of support or information about available supports, insufficient time and energy, a focus on the needs of the accompanied person, and inadequate cooperation with professionals are also obstacles preventing family caregivers from becoming aware of their own needs and expressing them [21]. It emerges from this study that isolation is both a key factor and the main consequence of this lack of awareness. Finally, on the basis of a systematic review of the literature, Plöthner and his team have identified needs that include work-life balance, respite, the importance of trusting service providers, low service costs, obtaining information on existing services, and pathologies and symptom management, among others [22].

Nevertheless, although the needs of caregivers are known and services to meet them exist, nonuse of services persists. Earlier studies have identified the reasons caregivers fail to use formal services, including service-related factors (knowledge of available services, multiplication of procedures, home care, transportation, cost, and reliance on organizations), relational factors (feelings of guilt, insecurity, rejection by the elder, and isolation), information factors (network knowledge, current and centralized information, and proactivity of stakeholders), experiential factors (previous experience with organizations and the extent of the burden), and personal factors (the caregiver's ability, denial, and self-identification) [23,24]. Bieber et al identified perceptions of useful services, misunderstood by health care professionals in terms of the level of burden experienced, the competence of the informal caregivers in providing care, little knowledge of available services, and difficulties in obtaining information about services owing to the complicated service system as all constituting barriers to the use of services [25]. On the basis of these earlier studies, this study aimed to prioritize the needs of caregivers of elderly people that can be met by an eHealth tool to support the process of help-seeking.

Methods

Research Design

This study was part of a broader participatory study using a 3-phase co-design approach: (1) identifying the needs of caregivers in terms of tools to support their help-seeking process, (2) developing a tool for caregivers corresponding to the needs expressed, and (3) testing the usability of the tool (see Latulippe et al [13] for more details). This study presents the first step of the design phase (box of Phase 2—Figure 1). Furthermore, 3 groups of caregivers, community workers, and HSSPs participated in either a co-design session (CoD1 or CoD2) or an advisory committee (AC).

The needs of caregivers have been examined in previous studies [22]. To avoid repeating these studies but rather build on them and deepen the reflection, we compiled a list of these needs. The needs identified in the academic literature and during a previous study [23] (see Multimedia Appendix 1) were sorted by the co-designers using a Technique for Research of Information by Animation of a Group of Experts (TRIAGE) method to obtain a consensus on those to be prioritized [26]. TRIAGE is a dynamic technique of information retrieval and, in some cases, decision making by a group of experts. First, 32 needs were presented, each written on a paper on the wall. By mutual agreement, co-designers had to choose, for each need, whether they place it in the basket (need to keep), in the trash (need rejected), or the refrigerator (need that did not reach consensus or that the co-designers could not choose). The co-designers could reformulate the needs, group them together if they considered them equivalent, or add some.

Next, by subgroup (caregivers together, community workers together, and HSSPs together), co-designers of the first CoD had to prioritize the needs identified in the basket, from most important to least important. We chose to make homogenous subgroups as we feared that caregivers would feel less comfortable taking a stand with workers. As the ways of prioritizing were very different from 1 group to another and made the analysis and choice of needs difficult, another technique was used for the second CoD. For the latter, after using the TRIAGE method (as for the first group), a comparison of the responses with group 1 was discussed in a plenary session, to understand the different reasoning underlying the choices. Then, each co-designer had to affix stickers (a maximum of 10) to the needs retained in the basket, which seemed a priority to him or her. Finally, the research team presented the results of Co-design 1 and 2 in a tabular form to the AC, highlighting points of convergence and divergence. The purpose of the AC was to decide on the needs to be retained for the development of the eHealth tool. A group discussion helped to achieve this goal.

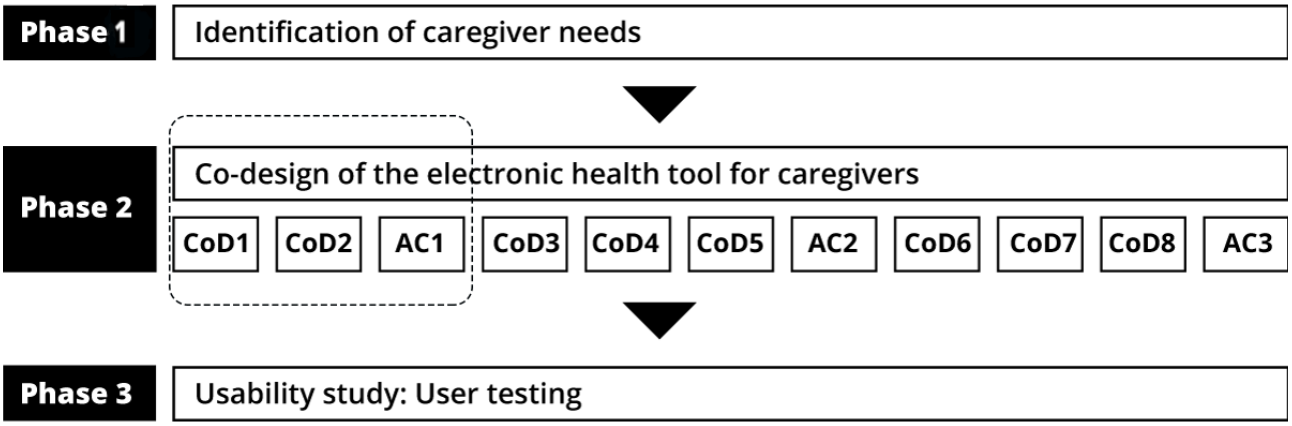
The Research Sites

The first 2 CoDs were held in cities in predominantly rural areas, namely Gaspésie (Grande-Vallée) and Côte-Nord (Baie-Comeau). The AC was held in Quebec City and included co-designers from the Capitale-Nationale and Chaudière-Appalache regions.

Recruitment

A purposive sampling strategy was employed. For the HSSPs, direct contact was made with management of senior services. For community workers, a direct approach was employed after researching community organizations for caregivers in the targeted territory on the Web. Community workers and HSSPs willing to recruit caregivers to participate in the study, through a direct approach, were solicited (see Latulippe et al [13] for more details).

Figure 1. Design phase of the entire project and steps involved in this publication (in a box). CoD: co-design session; eHealth: electronic health.



Analysis

After each CoD, the research team was debriefed to elicit their first impressions (eg, any surprising exchanges). Identified, regrouped, and withdrawn needs were classified with Excel (Microsoft) by 1 member of the research team and then validated with the rest of the team. The needs retained in the 2 groups, as well as the prioritization, were compared. The AC decided on the needs to be retained by group consensus.

Results

Sociodemographic Data

The group in the first CoD included 3 caregivers, 2 community workers, and 2 HSSPs (a total of 7 co-designers). The group consisted solely of women aged 37 to 66 years. The group in the second CoD included 4 caregivers, 1 community worker, and 1 health and social services worker (a total of 6 co-designers). This latter group comprised co-designers aged 41 to 77 years, one of whom was a man. The AC consisted of 1 caregiver, 2 community workers, 2 HSSPs, and 3 researchers who collaborated on the project (8 co-designers in all). Table 1 presents the sociodemographic data of all the co-designers (CoD1, CoD2, and AC) who contributed to the identification of the needs, with the exception of the researchers.

Table 1. Sociodemographic data of all co-designers.

Sociodemographic data	Caregivers (n=8)	Community workers (n=5)	Health and social service professional (n=5)
Sex (n)			
Women	7	4	5
Men	1	1	0
Age (years), range (mean)	42 to 77 (59.4)	25 to 66 (47.8)	33 to 53 (42.6)
Education level (n)			
Elementary school	1	0	0
High school	2	1	0
College	1	2	1
University	4	2	4
Age of the relative (years), range (mean)	61 to 94 (73.4)	—[a]	—
Diagnosis of the relative (n)			
Pick's disease	1	—	—
Autonomy loss	2	—	—
Intellectual disability	1	—	—
Muscular dystrophy	1	—	—
Stroke	1	—	—
Mental health disease	1	—	—
Cancer	1	—	—
Relationship to the person they provide care for (n)			
Children	3	—	—
Sibling	2	—	—
Spouse	2	—	—
Friend	1	—	—
Number of years to be a caregiver (years), range (mean)			
Between 1 and 60 years	20.3	—	—

[a] Not applicable as the notions of age, diagnosis, nature of the relationship with the relative and the number of years to be a caregiver do not apply to health and social service professional and community workers.

Technique for Research of Information by Animation of a Group of Experts and Prioritization of Co-Design Session

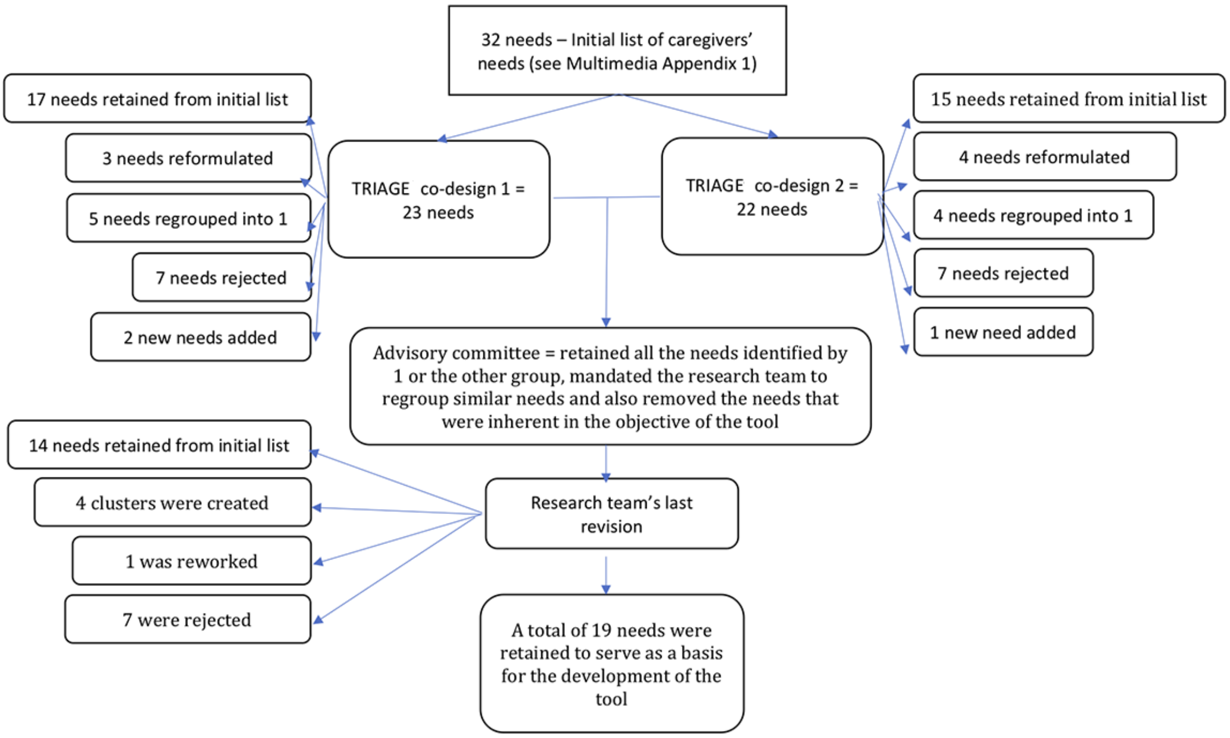
The entire process is shown in Figure 2, and the details of the choices made are shown in Multimedia Appendix 2. The first co-design group retained 17 initial needs. Co-designers reformulated 3 and regrouped 5 needs into one. They rejected 7 and added 2 for a total of 23 needs to consider for the prioritization exercise.

Caregivers retained all the needs in the prioritization exercise. They put them in order of importance. The HSSP retained the needs in the prioritization exercise and prioritized 2 needs that had been rejected in TRIAGE (having access to a network of people who know the resources and having access to a service suitable for older persons). The group of community workers chose all 23 needs in their prioritization exercise and put 1 need in their prioritization section that had been rejected in TRIAGE (having access to a service offer suitable for elders), which they classified into 12 subgroups.

The second co-design group selected 15 initial needs (without having seen the results of the first co-design), reformulated 4, grouped 4 into 1 and 2 into 1, rejected 7, and added 1 need. Co-designers from this second group proposed 22 needs to be considered in the tool. At our request, they then prioritized 10 needs.

Finally, the AC decided to retain all the needs identified by the groups as important (classified in the basket during the TRIAGE exercise). The committee mandated the research team to regroup similar needs and also remove those that were inherent to the objective of the tool (eg, finding resources) or beyond the limits of what the tool can do (eg, offering coordinated services). The result of the prioritization (10 more priority needs) at Co-design 2 was, therefore, not considered more than the prioritization of Co-design 1. From the initial needs, 14 were retained, 4 clusters were created, 1 was reworded, and 7 were rejected. Therefore, a total of 19 needs were retained to serve as the basis for the development of the tool (Textbox 1).

Figure 2. Diagram of the needs identification process used as the basis for the electronic health tool. TRIAGE: Technique for Research of Information by Animation of a Group of Experts.



Textbox 1. Needs retained to serve as the basis for the development of the tool.

1. Having access to up-to-date information, anytime, anywhere
2. Having access to educational interventions
3. Having access to a service offer suitable for elders
4. Having access to a keyword search
5. Being able to add training workshops, resources, and activities
6. Knowing the service offer (costs, transportation, home-based care, eligibility criteria, and proximity)
7. Asking questions
8. Receiving information regularly
9. Having access to concise and simple tools
10. Having a choice of language
11. Being reassured about resources
12. Being able to access and keep information easily
13. Recognizing the needs
14. Recognizing themselves as caregivers
15. Being comfortable using the service
16. Being able to connect with people experiencing the same situation
17. Being encouraged to request help before reaching a state of exhaustion
18. Being encouraged to use the services
19. Being guided in the help-seeking process

Discussion

Principal Findings

In summary, the results obtained are as follows: of the initial list of 32 needs, 12 were modified or added, as the needs were poorly formulated, redundant, irrelevant, or impossible to meet. In the end, 19 needs were identified for the design of the eHealth tool. There were no identified needs that surprised the research team as the initial list of needs came from previous studies and was, therefore, well justified. The 3 additions made by the co-designers (knowing about the proximity of services, being informed about staff stability, and being able to add training workshops, resources, and activities) are also consistent with the literature. Proximity or lack of proximity to services can be a barrier to using services as the extra time required to get to the resource signifies a greater expenditure of time and money [27]. Thus, it is important that the caregiver finds resources nearby or at least knows that transportation will be needed to get there. In addition, limited access to transportation, in rural areas among others, can make use of the service impossible [25]. The need to be informed about staff stability is not a surprise for people who have worked in the health or community network. A recent study by our team raised this issue as a factor in the nonuse of formal services [23]. However, this need, although considered significant, was not retained as organizations have little control over this aspect, which can vary greatly over time. The last need added, being able to add training workshops, of course, is a request from community stakeholders to promote their activity. Despite marketing efforts, some activities of community organizations do not attract enough participants. However, the need for information (eg, methods or strategies for managing physical and psychological care and access to care services) is well documented and could be met through conferences or workshops [28,29].

However, what surprised and even unsettled the research team was the rejection of the need being advised by a peer from the first group. The reasoning behind this rejection was that it is a need that should be met by the services and not via a Web tool. Several academic studies have documented the importance of support groups or the contribution that a peer may make in helping a caregiver [23,28,30]. This has led to the first epistemological issue: wanting co-designers to really share decision-making leads to a challenge in reaching agreement when experts have different perspectives (on the basis of theory, experience, and practice). This issue was faced by the Hendricks team, which also argued that this is inevitable when a real co-design approach is used [31]. When the second group chose to prioritize this need, this raised another issue related to the methodology: what should be done when there is a difference in the choices of co-design groups? Submitting the results of the first group to the second group at the end of the session and discussing the differences with them helped to further the discussion. The importance of the AC was highlighted in the face of these 2 issues. Here, the intervention of a third party (the AC comprised both caregivers and workers) made it possible to reach decisions and to continue the project without the research team having to take a stand in favor of one group or another.

Other Reflections on the Method Used

It is possible that basing reflection on an existing list of needs may influence the choice of co-designers. However, as this list comes from previous academic studies with caregivers, this appears to be useful data. In addition, the co-designer can completely modify the list (remove needs, add, or group them) and, thus, update this list. In our opinion, the fact that 3 different groups took part in this reflection and that, for each of the groups, there were caregivers, community workers, and HSSPs, also makes it possible to meet the scientific criteria of credibility. Finally, the fact that co-designers added 2 needs (to Co-design 1) and 1 need (to Co-design 2) demonstrates that co-designers were not passive in this reflection. We believe that this method makes it possible to meet the objective (identifying the needs of future users) efficiently, using a co-design approach, to allow more time for the development of functionalities and content of the eHealth tool.

Furthermore, the entire project covers several regions, including both rural and urban areas, to provide a variety of perspectives and includes a total of 74 co-designers. However, this study is about needs identification, the first part of the co-design phase of this project. This was carried out in 2 regions classified as rural (Co-design 1 and 2) and a city (AC) of the same province with a relatively small sample (21 co-designers in total). The identified needs of caregivers living in urban or rural areas may differ [25]. Thus, we can question the transferability of the data obtained. However, the choice of the method of TRIAGE from a list on the basis of the scientific literature (and consequently according to different perspectives) reassures us as to the transferability of the needs chosen for the continuation of the phase of co-design on one hand but also for the utility that this can represent for the academic and clinical community.

Although we believe that the needs identified can be applied to both rural and urban areas, this method does highlight the specific features of each of the regions. For example, consider the Aboriginal community on the Côte-Nord and the issue of confidentiality, given the small size of the community and the proximity of people in Grande-Vallée. To allow several regions to share their uniqueness, the rest of the project took place in different regions, and it was possible for co-designers to discuss the particularities of their region.

Limitations

Although this was not deliberate, the ethnicity of the co-designers was almost entirely Caucasian. Considering that culture greatly influences the perception of the role of a caregiver and the relationship with health services, it can be assumed that needs will be different for other communities [32]. Another limitation is that several caregivers had the dual role of being both community workers or HSSPs and caregivers. This may have influenced the choice of needs as knowledge of the health network before the role of a caregiver is a facilitator of resource use [23]. At the same time, it is also a reality. Caregivers necessarily take on several roles at once. Finally, the strategy for prioritizing needs was modified for the second group to limit the number of needs that would serve as the basis for developing the tool. To our knowledge, there are no recommendations as to the number of needs that can be used as the basis for a Web tool. At that moment, the fear was of not being able to meet all the stated needs. This change limited the ability to compare groups. Nonetheless, the AC decided to keep the initial needs that had been retained in the basket during the TRIAGE exercise, justifying their decision by the fact that if the need had been kept, it was considered important. In this sense, the prioritization exercise appears to be unnecessary.

Conclusions

Using a co-design approach and the TRIAGE method, caregivers of functionally dependent older persons, community workers, and HSSPs identified 19 needs serving as the basis for designing an eHealth tool to support the help-seeking process. The important objective of having access to up-to-date information at any time and in any place, educational and adapted interventions, a keyword search tool, information on the formal services offered, and the possibility of asking questions, receiving information regularly, and retrieving information effortlessly (needs expressed by co-designers) can be achieved quite easily with an eHealth tool, as long as it is simple and concise and in the future user’s language. Nevertheless, in this study, the innovative challenge offered by the co-designers is that of also responding to more emotional needs, such as being reassured about service providers, recognizing one’s own needs and those of the elder, recognizing oneself in the role of a caregiver, being comfortable using formal services, being in contact with peers, being encouraged to seek help before symptoms of fatigue appear, and, finally, being guided through the process of seeking help through an eHealth tool. The next step of the project involves co-designers (caregivers, community workers, and HSSPs) being asked to choose and develop functional and content requirements that meet the selected needs and, therefore, respond to this challenge. It is likely that several existing tools (Web and apps) for caregivers meet some of the needs identified in this study, especially those of an informational nature. As the eHealth tool targeted by this project is intended to complement what already exists, the next step of the study will be to analyze, with the co-designers, the tools available to identify the needs already met versus the needs yet to be met.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Initial list of caregivers' needs.
[PDF File (Adobe PDF File), 17KB - aging_v2i1e12271_app1.pdf]

Multimedia Appendix 2
Results of the Technique for Research of Information by Animation of a Group of Experts and decisions taken by the advisory committee.
[PDF File (Adobe PDF File), 89KB - aging_v2i1e12271_app2.pdf]

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Abbreviations

AC: advisory committee
CoD: co-design session
eHealth: electronic health
HSSP: health and social service professional
TRIAGE: Technique for Research of Information by Animation of a Group of Experts

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Short Paper

“Call a Teenager… That’s What I Do!” - Grandchildren Help Older Adults Use New Technologies: Qualitative Study

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Abstract

Background: Although family technical support seems intuitive, there is very little research exploring this topic.

Objective: The objective of this study was to conduct a subanalysis of data collected from a large-scale qualitative project regarding older adults’ experiences in using health information technology. Specifically, the subanalysis explored older adults’ experiences with technology support from family members to inform strategies for promoting older adults’ engagement with new health technologies. Although the primary analysis of the original study was theoretically driven, this paper reports results from an inductive, open-coding analysis.

Methods: This is a subanalysis of a major code identified unexpectedly from a qualitative study investigating older adults’ use experience of a widespread health technology, the patient portal. A total of 24 older patients (≥65 years) with multiple chronic conditions (Charlson Comorbidity Index >2) participated in focus groups conducted at the patients’ primary clinic. While conducting the primary theoretically driven analysis, coders utilized an open-coding approach to ensure important ideas not reflected in the theoretical code book were captured. Open coding resulted in 1 code: *family support*. This subanalysis further categorized *family support* by who provided tech support, how tech support was offered, and the opinions of older participants about receiving family tech support.

Results: The participants were not specifically asked about family support, yet themes around family assistance and encouragement for technology emerged from every focus group. Participants repeatedly mentioned that they called their grandchildren and adult children if they needed help with technology. Participants also reported that family members experienced difficulty when teaching technology use. Family members struggled to explain simple technology tasks and were frustrated by the slow teaching process.

Conclusions: The results suggest that older adults ask their family members, particularly grandchildren, to support them in the use of new technologies. However, family may experience difficulties in providing this support. Older adults will be increasingly expected to use health technologies, and family members may help with tech support. Providers and health systems should consider potential family support and engagement strategies to foster adoption and use among older patients.

(JMIR Aging 2019;2(1):e13713) doi:10.2196/13713

KEYWORDS

health technology; eHealth; family research; social support

Introduction

Background

Health care consumers are increasingly *going digital*, and older adults are the fastest growing users of the internet for health information [1]. Health technologies are positively associated with better medical outcomes [2] and have the potential to help older adults live independently, manage their health, and improve communication [3,4]. With increased access to and availability of technological tools, older adults are progressively expected to use emerging health technologies by health care providers and systems.

Older populations face barriers toward the adoption of health technology [4-6], and adoption rates of technology-based interventions remain low [7,8]. During health technology trials, many participants never use the technology available to them, and those who adopt the technology, commonly use the tool only a few times. However, once enrolled in a trial, older adults are more likely to complete a health technology intervention to manage their health than younger patients [9]. The initial adoption of health technologies is key to successful ongoing use.

Many factors contribute to older adults' adoption of new technologies, including cost, education, perceptions of the technology, human indicators, and health status [10]. The idea that family and friends may have an important role for technology adoption among older adults is fairly new [11]. There is evidence to suggest that older adults prefer learning technology skills from their informal networks, including children, grandchildren, and neighbors [12], and they particularly enjoy using technologies that improve communication with these networks [13]. However, little is known about the experience of the families providing technical support to their older adult loved ones.

Objectives

The purpose of this subanalysis was to explore older adults' experiences with technology support from family members to inform strategies for promoting adoption of new health technologies by older adults. Our primary study focused on assessing the user interface (UI) and user experience (UX) of a specific health technology linking patients to their electronic health record—patient portals. To support user-centered design of portal systems, the primary study employed a deductive theoretically driven data analysis strategy, and the results are reported elsewhere [14]. However, our inductive subanalysis of the primary data revealed the fundamental importance of family members in the adoption and use of technology. *Family support* was the only inductive code identified from the data. As the primary study focused on the UI/UX design of the patient portal and not technical support, the *family support* code was further analyzed separately in this subanalysis. The themes of the subanalysis are presented in this paper.

Methods

Summary of Primary Study Procedures

The larger study used a qualitative descriptive approach that resulted in the identification of the *family support* code further examined in this subanalysis. All research procedures were approved by the health systems' institutional review board.

Using the health system's electronic health record, we randomly identified (N=225) older patients (≥65 years) with multiple chronic conditions (Charlson Comorbidity Index >2). Patients who were non-English speakers, diagnosed with dementia, or residing in a skilled nursing facility were excluded from participation. Potential participants were mailed a letter inviting them to participate in a focus group that included an opt-out phone number. We called (N=210) patients who did not opt-out via phone to schedule. Of the 37 participants who were scheduled for focus groups, 24 participated in the study.

A total of 6 semistructured focus groups were conducted (by JDP). The focus group discussions lasted approximately 90 min and took place at the patient's primary health clinic. Questions were specific to the primary aim of the study and inquired about function, ease of use, and usefulness of the patient portal website and features. Focus groups were audio-recorded and professionally transcribed for accuracy.

Furthermore, 2 doctoral trained researchers conducted the analysis (JDP: primary investigator and KG: research assistant). The primary analysis used a theoretically driven code book founded in the technology acceptance model [15] related specifically to usability and use experience of the portal system. However, during initial coding, coders also used *open coding*, an inductive approach [16], to capture potentially meaningful information from responses.

Subanalysis of Family Support Code

After reviewing the first cycle codes, analysts identified that participants in every focus group referred to a family member helping with technology. The coding team labeled these responses *family support*. *Family support* was the only inductive code identified from the data. We then used a *heading and subheading* thematic approach [16] to further investigate the *family support* codes focused on who provided the tech support, how the tech support was offered, and participants' opinions about receiving *family support* technical assistance. This technique resulted in 3 subthemes reported below.

Results

Participants

Overall, 24 patients participated in focus groups (Table 1). Study participants were aged, on average, 78.4 (SD 5.4) years, and 50% were female. All participants were high school graduates, most attended college, and most participants' income was between US $30,000 and $50,000. All but 1 participant had a cell phone, primarily smartphones. Many participants regularly used email, the internet, computers, and social media.

Family Support for Using Technology

The subanalysis resulted in 3 subthemes: assistance from grandchildren and adult children, relationship building from technology, and potential challenges with family support. We did not specifically ask about family support, family members helping with the portal, or experiences working with family members to use technology. However, the inductive coding process revealed that family members were helping older adults to adopt and use new technologies, and grandchildren were the most commonly discussed. A few participants noted help from adult children as well. Participants were eager to share stories about their grandchildren and were impressed by their grandchildren's innate abilities to use technology. Responses suggested that participants experienced relationship building with their family members from learning new technological skills and using technologies to communicate. Although they were excited to seek help from grandchildren to use phones, televisions, or computers, the participants also identified challenges to obtaining help. Participants reported that grandchildren and adult children had a difficult time slowing down and explaining tasks to their parent or grandparent. Participants were also concerned that their grandchildren could break or further complicate the technology, that is, "mess up the remote-control settings." Participant quotes, representing participants from all focus groups, related to these findings are summarized in Table 2.

Table 1. Participant characteristics (N=24).

Participant characteristic	Value
Age, mean (SD)	78.4 (5.4)
Female, n	12
White, n	19
Hispanic, n	3
Education, n	
High school graduate	6
Some college	9
College graduate	9
Income, n	
<US $30,000	4
US $30,000-49,999	13
US $50,000-74,999	2
>US $75,000+	2
Choose not to answer	3
Own cell phone, n	
Smartphone	17
A regular or basic phone	6
Does not have a cell phone	1
Regular technology utilization, n	
Email	22
Look up information online	21
Use social media	13
Play computer games	15
Video chat	11
Instant messaging	8

Table 2. Family support quotations.

Subtheme	Quote
Assistance from grandchildren and adult children	• “My grandkids do that. I mean, like I said, if I have a problem, I call my grandkids. They're teenagers.” • “I give [Mia] the phone and she just zips right through it. Okay, thank you, I'm where I can work it now. Bye.”
Relationship building from technology	• “Well, my son's forty—let's see, my daughter's fifty. He'll be forty-eight this year, so he's always been a computer geek. So he builds [computers] and all that kind of crud. If I'm having a problem, I call him.” • “I think I still have my original flip phone, but my kids said, mom, you need this [smart phone].” • “It’s like whenever I don’t know something, I ask [my grandchildren], and they know. So it’s pretty cool. And then it’s kind of cool because I get to learn all the new lingo and that sort of thing.” • “Facebook, I got the app on there and my granddaughter helped me a little bit. She lives in California, so I don’t see her very often.” • “I use computer somewhat for email and stuff and then when I got my iPhone, I abandoned the computer. I may go on it once a month because I do Facebook and email. I Facetime with my granddaughter…I do!” • “I use Facebook. That's how I keep track of my daughter and grandson and granddaughter.”
Potential challenges with family support	• “She will sometimes slow down and have the patience to teach me. ‘Granny, you know.’ She just gets frustrated with me because it comes slow to me…She is just a wiz on that thing.” • “There are certain things that my son is going to teach me how to do something, and it’s so instinctive to him that he doesn’t even know how to explain it.” • “But you want to also be careful of 5- and 6-year-olds, because they could screw everything up, they really could. The reason they get something done is because they’re not afraid to try.”

Discussion

Principal Findings

Family support may have a key role in the successful adoption and use of emerging health technologies [17]. Our participants suggest that grandchildren and adult children are helping their (grand)parents learn to use new technology, troubleshoot issues, and adapt new technologies to older adults. This supports recent studies suggesting that children and grandchildren help older family members in the uptake of technology, purchasing devices, and installing equipment [18]. Grandchildren specifically were found to be the primary reason for older adults’ initial tablet use [19]. In a recent mobile health (mHealth) project, older adults specified children and grandchildren as their primary tech support contact and preferred using family over online manuals [20]. As older adults are seeking assistance from their informal network, providers and health systems should consider family support engagement as potential strategies to foster adoption and use of health technology among older patients.

Results from the focus groups also indicate that family members encounter some challenges in teaching new technology skills. This is contrary to previous research that suggests that grandchildren proudly teach their grandparents how to use electronic devices [21]. Another study also found that grandchildren were excited to teach their grandparents how to use Nintendo Wii, a gaming console, for exercise purposes [22]. Regardless, adult children and grandchildren may benefit from assistance or tips for how to navigate these frustrations while helping their older family members [17].

Additional research identifies that when children and grandchildren are involved with tech support, older adults are less likely to *play* or *figure out* how to use and fix technology, as they will wait for their family to solve the tech issue [18]. Peek et al [23] also found that older adults are sometimes afraid to burden their children and family with technology needs. Family members can only help to an extent with specific technologies. Manuals and tech support will likely remain important elements to support health technology adoption among older adults [24].

We did not elicit specific information about family support, yet the participants regularly documented the importance of their family members. The process of learning to use new technologies and using communication tools, such as Facetime and Facebook, connected our participants with their family. Currently, most health technologies are designed for an individual user, either a patient or caregiver, or to monitor an older adult providing specific information to a caregiver. Designing health technology systems with a creative family approach, rather than a single user, may improve adoption, use, and ultimately, health outcomes. For example, researchers recently examined a grandparent-grandchild mobile Health Buddies app to promote health knowledge, and it was found acceptable to use by participants [25].

Limitations

As a subanalysis, there are several limitations to our work. Our primary focus of the larger study was not to identify family support. We did not ask follow-up questions or inquire about family support experiences; therefore, we lack a full understanding of this type of technology assistance. We were able to conduct 6 focus groups with 24 participants, indicating saturation of our themes may not have been fully accomplished. We were unable to capture specific strategies used by grandchildren and adult children to help their older family members. Participants were mostly white and well educated with health coverage; thus, the experiences of family support are limited to this case study. Not all older adults have adult children or grandchildren, and the results did not capture other relevant forms of social support.

Conclusions

There is growing evidence to suggest that families assist older adults in the adoption of new health technologies. This study proposes that older adults are specifically reaching out to their adult children and grandchildren. Although family technology support appears beneficial, there may be some challenges for older adults and their family members. On the basis of our unexpected findings related to family technical assistance, it is important to consider the family context and include family members in the implementation of new health technology as they are likely helping older users.

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Conflicts of Interest

None declared.

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Abbreviations

mHealth: mobile health
UI: user interface
UX: user experience

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Original Paper

Requirements for an Electronic Health Tool to Support the Process of Help Seeking by Caregivers of Functionally Impaired Older Adults: Co-Design Approach

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Abstract

Background: In Quebec, Canada, many public, community, and private organizations provide resources to caregivers of functionally impaired older adults. Nevertheless, these resources may be difficult for caregivers to find. A co-design study was conducted to address the gap between caregivers and access to resources. The purpose of this study was to support the process of help seeking by caregivers of functionally impaired older adults through electronic health (eHealth).

Objective: The purpose of this study was to focus on the identification of functional and content requirements for an eHealth tool to support the help-seeking process of caregivers of functionally impaired older adults.

Methods: This study uses a co-design process based on qualitative action research approach to develop an eHealth tool with health and social service professionals (HSSPs), community workers, and caregivers. The participants acted as co-designers in identifying requirements for the tool. A total of 4 design workshops and 1 advisory committee session were held in different locations in Quebec, Canada. Activities were videotaped and analyzed with a conceptual framework of user experience.

Results: A total of 11 caregivers, 16 community workers, and 11 HSSPs participated in identifying the requirements for the eHealth tool. Several functional and content requirements were identified for each user need (19). Content requirements differed depending on the category of participant, corresponding to the concept of user segmentation in the design of information and communication technology. Nevertheless, there were disagreements among co-designers about specific functionalities, which included (1) functionalities related to the social Web, (2) functionalities related to the evaluation of resources for caregivers, and (3) functionalities related to the emerging technologies. Several co-design sessions were required to resolve disagreements.

Conclusions: Co-designers (participants) were able to identify functional and content requirements for each of the previously identified needs; however, several discussions were required to achieve consensus. Decision making was influenced by identity, social context, and participants’ knowledge, and it is a challenge to reconcile the different perspectives. The findings stressed the importance of allowing more time to deal with the iterative aspect of the design activity, especially during the identification of requirements of an eHealth tool.

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KEYWORDS

functionally-impaired elderly; caregivers; co-design; eHealth; telemedicine; help-seeking behavior

Introduction

Background

Statistics show that almost 50% of Canadians will provide care to a family member or a friend during their lifetime; age-related needs are the most common problem requiring caregiving (28%) [1]. Quebec is the province with the lowest number of caregivers, at 25% of the population. Nevertheless, this number will potentially increase as the population ages. Demographic projections show that, in 2036, seniors could comprise between 23% and 25% of the population. This will result in a significant increase in seniors requiring the support of caregivers.

In Quebec, caregivers have access to many resources offered by health and social service professionals (HSSPs) and community organizations. These resources are considered to be a source of services or support for caregivers and include (1) programs involving renovation credits; (2) respite-type services, practical advice, and emotional support; and (3) strategies to reduce stress and symptoms associated with depression [2]. Nevertheless, literature confirms that caregivers have difficulty in accessing resources and that the existing services are underutilized [3].

Electronic Health and Caregiving

According to a systematic meta-review, electronic health (eHealth) is a promising extension of the health care services currently available for caregivers, and evidence shows that interventions aimed at developing knowledge and providing information are efficient and effective [4]. eHealth, especially information and communication technology (ICT), can facilitate communication between caregivers and service providers [5]. The results specifically indicate an increased understanding of the illness [6]. Studies also confirm that eHealth can reduce caregivers’ depression and anxiety [7-9] as well as loneliness [9]. eHealth can allow caregivers to feel more confident about their caregiving skills [10]. It may bridge the gap between service providers and caregivers as it reduces distance obstacles, thus reaching underserved populations [11]. Nonetheless, caregivers’ needs are complex and vary depending on the diagnosis, changing caregiving roles, and family situations [12]. Therefore, for caregivers’ effective use of eHealth, the design of any eHealth tool targeting this population should involve a participatory approach [13-15].

Co-Design of Information and Communication Technology

Co-design was first known as participatory design, and it refers to “the creativity of designers and people not trained in design working together in the design development process” [16]. It can be defined as a “process of collaborative design thinking: a process of joint inquiry and imagination in which diverse people jointly explore and define a problem and jointly develop and evaluate solutions” [17]. The central principle of co-design is the involvement of end users and stakeholders in the design process [18]. It is generally considered as the concept of user involvement (or participation) in software development and system success [19].

Numerous studies have demonstrated positive correlations between user involvement and system success [20]. A systematic review revealed that of the 87 studies that were analyzed, 59 reported that user participation contributed to the success of the system developed [21]. This field of research is a promising method to discover the appropriate interactions between technologies and quality of life, especially in the health field [22,23]. The co-design approach has led to cultural change among staff and patients in hospital environments, with older patients benefitting specifically [22]. In another case, the co-design approach led to a better sense of security and reduced stress for caregivers as it provided for increased awareness of each family member’s personal schedule [23]. Examples of a co-design approach with the aging population can also be found in the studies by Ventura and Talamo [18] and Ho et al [24]. Although there is a growing body of research that uses a co-design approach, the lack of co-design studies of the specific populations of caregivers and functionally impaired older adults indicates that more work in this area is required.

In the participatory design approach, specifically co-design, users engage with designers and researchers to find creative solutions to poorly defined problems [16]. A diversity of approaches exists in co-design [25]; end users can contribute at specific steps or each step of the design process. Although there are many models for the process of technology design, typical steps of user-centered design include (1) understanding the context, (2) understanding user requirement specifications, (3) creating prototypes, and (4) testing [26]. For the design of the tool, we decided to use knowledge and constructs from user experience (UX) design theory.

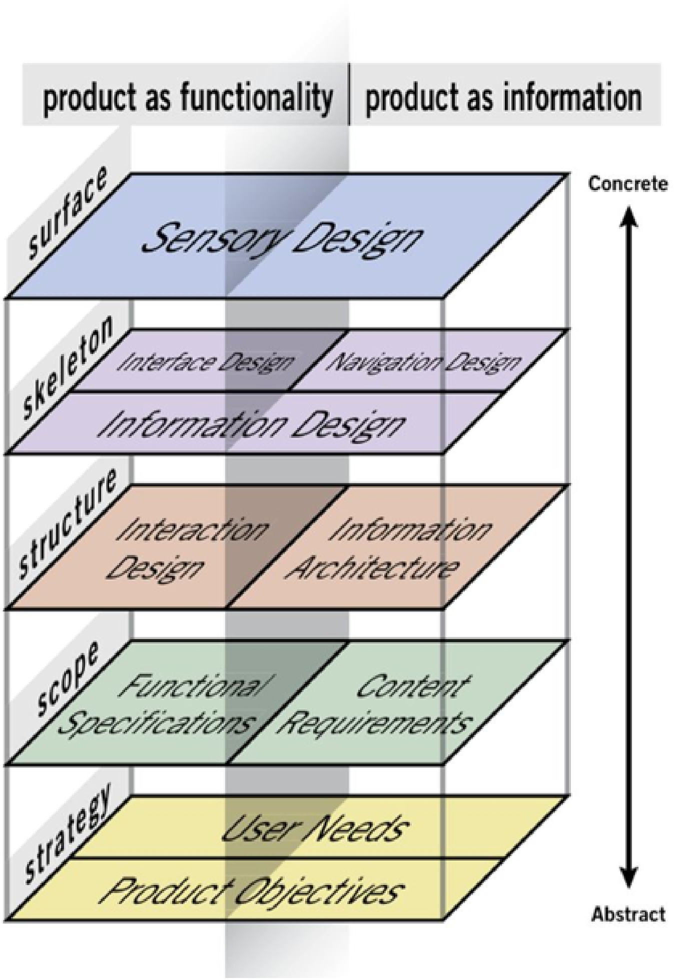
Conceptual Framework

To organize design sessions for the tool, we used the Conceptual Framework of User Experience proposed by Garrett [27]. The model (Figure 1) suggests a linear and iterative process for the design of Web-based technology. Garrett defines the different elements of UX in 5 dimensions: (1) strategy, (2) scope, (3) structure, (4) skeleton, and (5) surface. The elements are ordered with abstract-to-concrete considerations. Each dimension is considered in terms of the product as functionality on the one hand and the product as information on the other.

The scope step aims to identify the functionalities (functional specifications) and content required to meet the needs of users, based on the objectives of the product (strategy). Functional specifications (sometimes called *specs*) are the specific functionalities needed for the product and will guide the programmer's decision regarding the coding language to use. Content requirements identify what type of content is needed (text, video, etc), the expected size, the person responsible for each element of the content, and the frequency of update needed. Ideas about requirements then need to be prioritized to determine what should be included in the product. Other studies have also used Garrett's design constructs [28-30].

As part of a broad co-design study aiming to develop an eHealth tool to support the process of help seeking by caregivers of functionally impaired older adults, this paper reports on the scope dimension: the identification of content and functional requirements based on user needs. Traditionally, systems engineers write user requirement specifications; however, user input is crucial during this step. We must ensure that users are able to understand the specifications well enough to validate their accuracy [31]. According to El Emam and Madhavji [32], users should always participate in determining the requirements of system design, and different tactics can be used to promote participation. Mock-ups [33] and games [34] have shown impressive results. Notwithstanding the use of a UX conceptual framework, our approach (with user participation) involves a power-sharing creation model, whereas Sanders and Stappers [16] describe the research team as working in partnership with the participants.

Figure 1. Elements of user experience.



Methods

Co-Design Strategy

This paper is part of a broad project conducted in 3 phases (Figure 2). The objective of phase 1 was to identify the needs of caregivers of functionally impaired older adults. The objective of phase 2 was to co-design an eHealth tool to support the help-seeking process of caregivers based on the results from this phase. The methodology and results of phase 2 are reported in the following 4 papers:

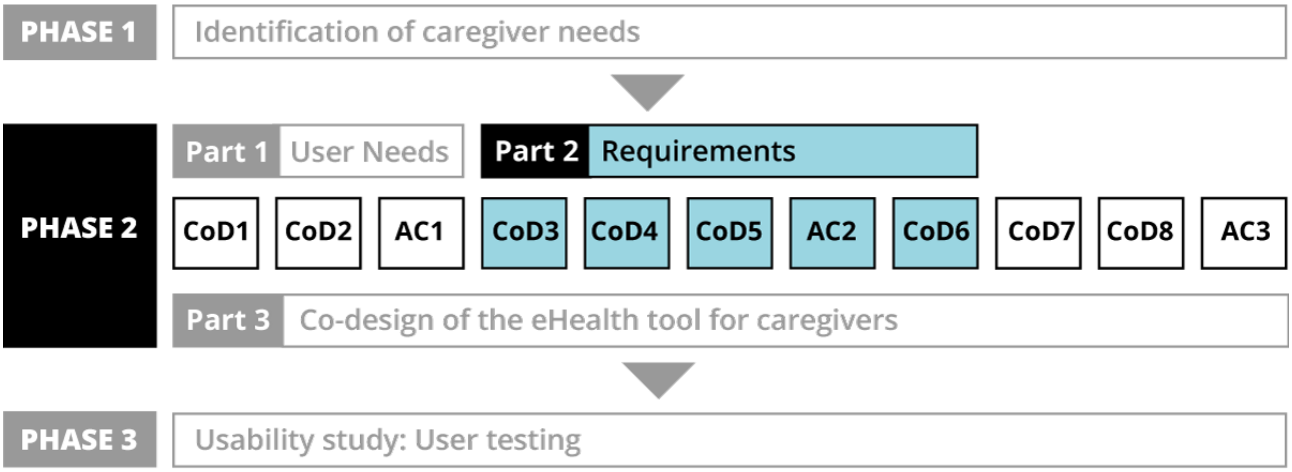
- The protocol of the global study [35]
- Part 1 focuses on the early stage of the design process: understanding the user needs [36].
- Part 2 focuses on the content and functional requirements based on user needs (this paper).
- Part 3 reports on the complete co-design process for the tool [37]

Finally, phase 3 is a usability study to verify the results obtained in the co-design process.

During phase 2, a total of 8 co-design sessions (CoDs) as well as 3 advisory committee sessions in 11 regions took place between May 2017 and June 2018.

The advisory committees guided the progression of the prototype, ensured continuity between CoDs, and made sure that the prototype conformed to the decisions made during the work sessions. The identification of requirements took place from CoD 3 to CoD 6 and during the second advisory committee session (AC 2; Figure 2).

Figure 2. Segment of the study concerned in this paper.



Participants (Co-Designers)

The participants recruited for this study were required to be potential users of an eHealth tool for caregivers of functionally impaired older adults in Quebec. Hence, we included 3 different categories of potential users: caregivers, workers from community settings, and HSSPs. For the purposes of this study, *caregivers* are defined as people who assist a functionally impaired older person on a sustained (weekly) basis. *Community workers* are defined as people from the community health network who offer services or interact directly with caregivers of functionally impaired older adults. *HSSPs* are defined as people from the public health care system who offer services or interact directly with caregivers of functionally impaired older adults. As part of their work, the latter categories of participants assist caregivers in their help-seeking process. They would be able to use the eHealth tool, which is designed for that purpose. For this study, they are considered to be potential end users.

Consistent with our methodological approach, the term co-designers (instead of participant) will be used to designate people who contributed to the identification of functional and content requirements.

We recruited co-designers from various regions of Quebec to meet the particularities of the people living in different regions. The sessions covered in this paper involved co-designers recruited from the following regions in Quebec: Saguenay-Lac-Saint-Jean (CoD 3), Bas-Saint-Laurent (CoD 4), Outaouais (CoD 5), and Montreal-Laval (CoD 6) for the CoDs and Capitale-Nationale and Chaudière-Appalache regions for the advisory committee sessions. Community workers were contacted directly (by phone or email). Direct contact was made with HSSP management of older adult services. The management used selection criteria to identify potential participants in their organization, and the HSSPs communicated with the research team. Caregivers received invitations to participate from either participating community organizations or the HSSPs. During the recruitment phase, the objective of the study was briefly explained to the co-designers: the design of an eHealth tool to support the help-seeking process for caregivers of functionally impaired older adults. All co-designers gave informed consent, and they received a nominal amount to cover travel and parking expenses. More details about the selection criteria and recruitment process are in the study protocol [35].

The co-design process also included the research team. Within the co-design spectrum, end users collaborate with designers and researchers to reach the design objective [16,18]. The research team interacts with participants during sessions and organized activities during the subsequent sessions. The research team included 3 researchers and 1 research assistant. The research director (DG) is a professor in occupational therapy, and the second researcher (KL) is a Doctor of Philosophy (PhD) student in educational technology and is specialized in occupational therapy. The other researcher (MT) is also a PhD student in educational technology and a specialist in the UX design field. The research assistant (MC) has an anthropology background. All members of the research team are currently working on other research projects with the aging population.

Data Collection

The sessions involved different types of activities with specific objectives (Table 1). The research team had initially set out an objective for each session based on Garrett’s UX framework [35]. As the sessions progressed, it became apparent that a review of these objectives was required and, at times, iterative changes were made to address specific issues. Researchers initially planned 2 sessions to identify the requirements of the tool. However, they added activities during the AC 2, CoD5 and CoD6, to address the remaining aspects of the identification of the requirements of this eHealth tool.

A total of 5 meetings were needed to complete the requirements, although CoD 5 and CoD 6 were not entirely devoted to the identification of requirements.

The activities were selected according to the objective of the session, were chosen based from previous work and literature [18,32,33,38], and were based on expertise of each research team members (Table 1). Some activities involved the entire group of co-designers and others involved subgroup workshops with a moderator. Each session ran for 3 hours and was videotaped by 1 camera (Canon), 2 iPads (Apple), and an audiotape with 3 audio recorders (Olympus), thus, ensuring that all data coming from subgroups were recorded. To ensure accessibility to the sites, sessions were held in rented meeting rooms in a central city of the region visited.

During CoD 3, laptop computers and iPads were used by co-designers to compare existing eHealth ICT tools. Participants were shown a total of 6 websites (English and French), 2 apps, and 1 video. Researchers selected these tools to obtain a wide variety of functionality proposals. After a short review, co-designers were invited to identify the user needs met by each tool and rate how they were met (good or needing improvement). Open Broadcast Studio was used to collect data for the website review as this software enables simultaneous recording of the screen and co-designers’ reaction (with the webcam).

During the paper prototype activity (CoD 5), the research team had prepared paper examples of functionalities and content requirements identified during CoDs 3 and 4. Participants had access to different sizes and colors of paper, scissors, pencils, and glue. They were asked to create paper website pages, decide on the functionalities and content for each page, and design how the pages were to be linked (Figure 3).

For the AC 2, paper prototypes were used to produce 3 interactive PDFs. Researchers presented these low-fidelity prototypes to the advisory committee participants as evidence of the progression of the work (Figure 4).

Data collected during sessions include audio and video recordings of co-design and advisory committee sessions, audio recording of preparation and after-action meetings, artefacts, paper documents used during sessions, and spreadsheets used by the research teams.

Table 1. Activities, objectives, and modalities for each session.

Session	Activity	Objectives	Modalities
CoD[a]3	Comparison of existing electronic health information and communication technology tools (websites and apps)	(1) Identification of the user needs that are already met by other tools and (2) identification of functionalities and content of existing tools related to those needs (what co-designers would keep, modify, or change).	Subgroup workshops
CoD 4	Brainstorming	(1) Identification of functional or content requirements for the needs not met by existing tools.	Group and subgroup workshops
CoD 5	Paper prototypes	(1) Prioritization of functional requirements and (2) structuring of content and design of information architecture.	Subgroup workshops
Second advisory committee session	Presentation of 3 prototypes and discussion	(1) Prioritization of functional requirements.	Group
CoD 6	Brainstorming	(1) Creation of content requirements and design of information.	Subgroup workshops

[a] CoD: co-design session.

Figure 3. Paper prototyping.

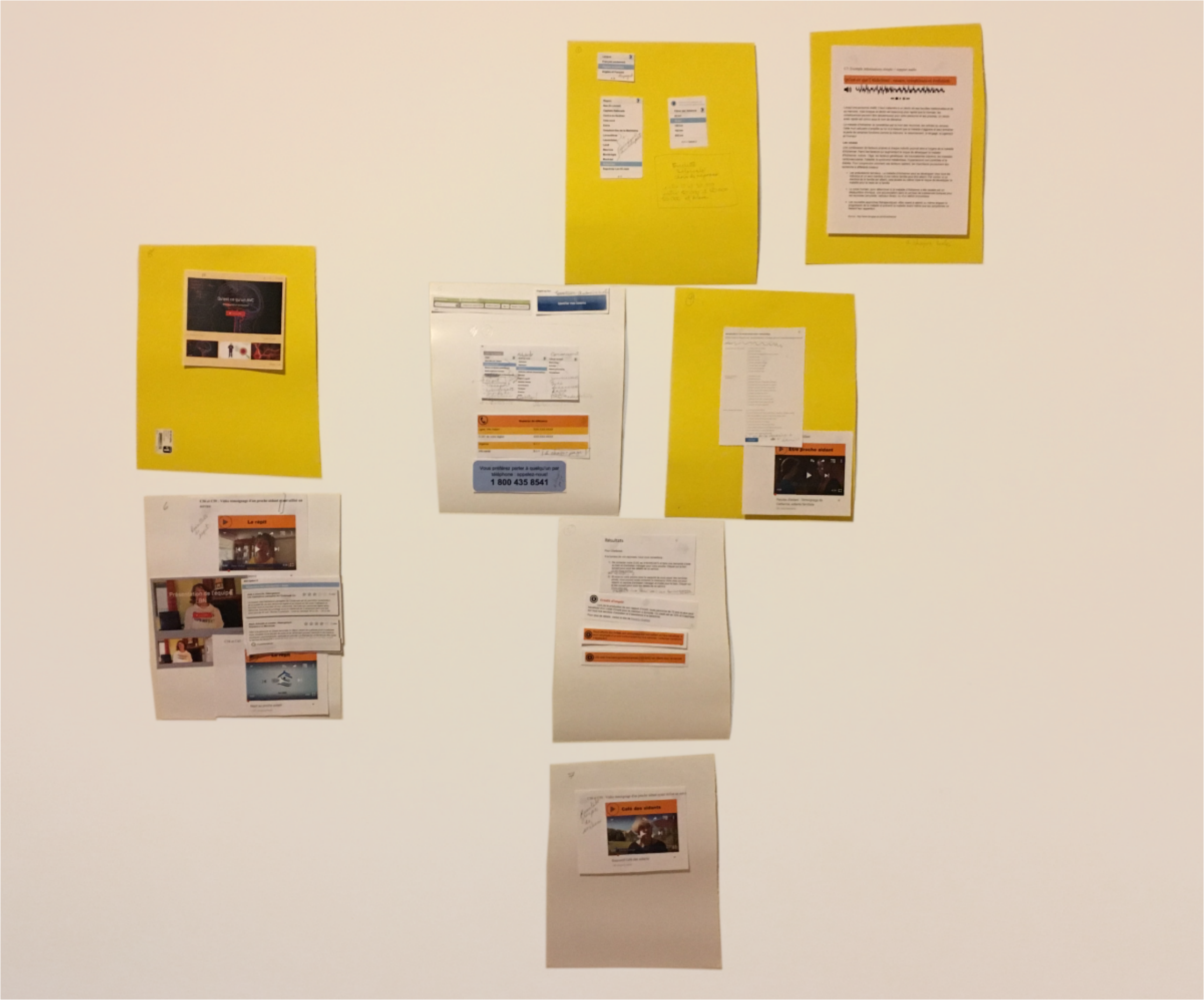
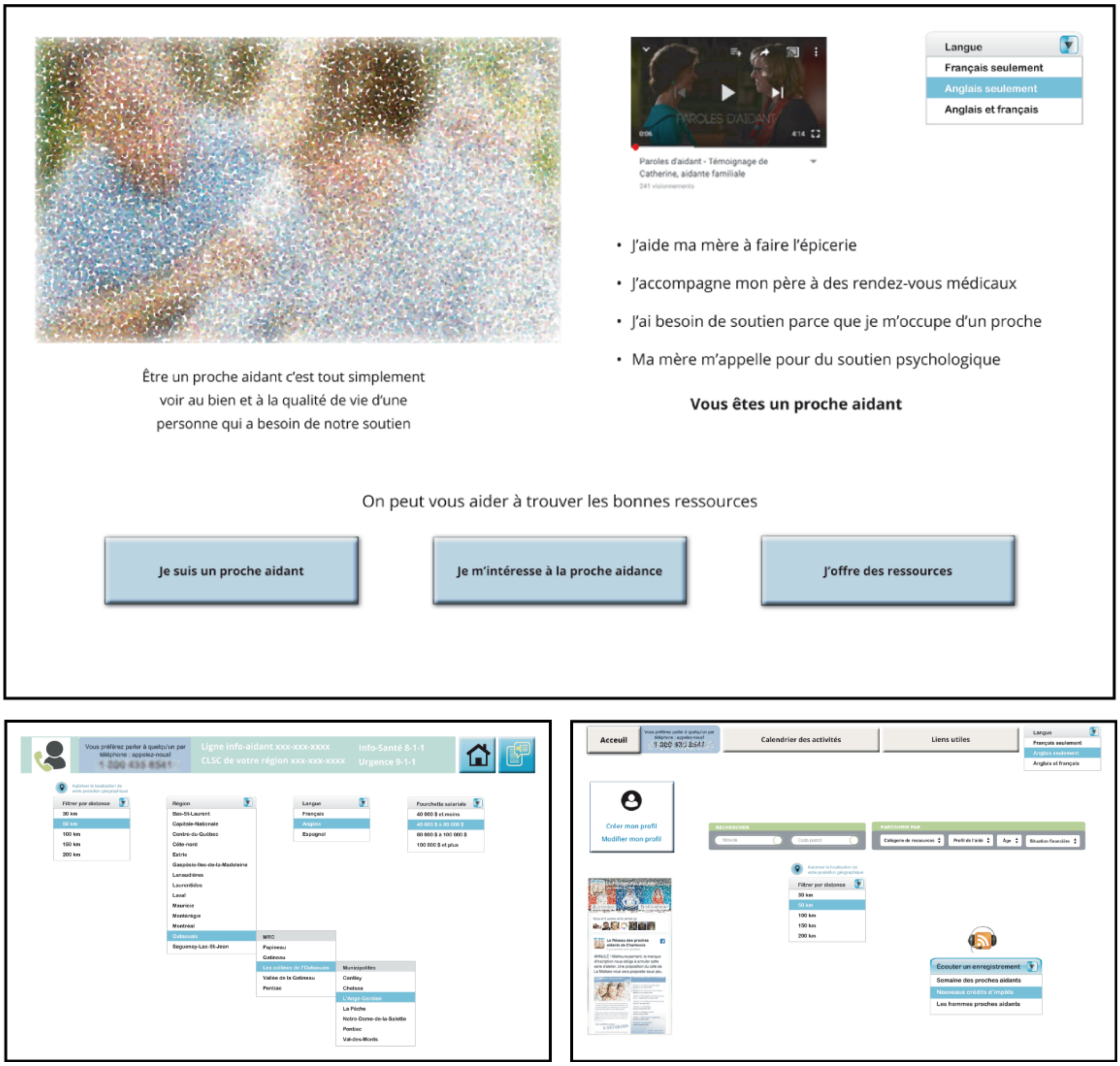


Figure 4. Interactive PDF (low-fidelity prototypes).



Être un proche aidant c'est tout simplement voir au bien et à la qualité de vie d'une personne qui a besoin de notre soutien

- J'aide ma mère à faire l'épicerie
- J'accompagne mon père à des rendez-vous médicaux
- J'ai besoin de soutien parce que je m'occupe d'un proche
- Ma mère m'appelle pour du soutien psychologique

Vous êtes un proche aidant

On peut vous aider à trouver les bonnes ressources

Data Analysis

For data analysis, we followed an analytic questioning method [39]. This method involves 3 major steps: (1) articulate operationalizing questions according to the research objective, (2) submit a relevant corpus to these questions to obtain a first draft of answers that will be used to generate more precise questions, and (3) answer the questions generated with direct answers (statements, observations, and propositions) or new questions if appropriate. In this case, the objectives of each session were articulated in a question form as a first step.

The principal objective of the scope dimension of Garrett's UX framework is to identify functional and content requirements based on user needs. Therefore, in the data analysis, we had to ensure that the requirements address each user need. After each session, the research team conducted a debriefing to underline significant results. We first analyzed data that were collected in response to the operationalizing questions (Table 2). The results were then recorded in a Microsoft Word or Excel document. When there were subgroup workshops, each member of the research team reported the results of the workshop where they acted as a moderator. In such cases, workshop results were then combined into a single document (Microsoft Word and Excel). Following the production of the reports, the research team met to review documents and to (1) confirm the validity of the interpretation of the information collected, (2) assess the degree to which the session's objectives were attained, and (3) design more precise questions to generate specific answers. It was sometimes necessary to refer to the audio and video recordings of the sessions to retrieve the negotiation of design decisions among co-designers. Often, more than 1 meeting (3-4 hours) was needed to get a complete picture of the results achieved and ensure their accuracy. Data were gathered in an Excel spreadsheet linking requirements and user needs.

Table 2. Data analysis.

Session	Operationalizing questions	Data analysis
CoD[a]3	Which needs from the user need list are addressed by the existing eHealth[b] tools? What are the requirements of existing tools addressing these needs? What changes would be required to better address the needs? Which needs are not addressed by existing tools?	(1) List of requirements related to user needs and (2) list of user needs not addressed by existing eHealth tool (N=8)
CoD 4	What are the potential content and functional requirements that could address the remaining needs?	List of requirement ideas to complete the list of requirements and address each user need
CoD 5	From all the requirements obtained in CoD 3 and CoD 4, which requirements should be prioritized? Based on a selection of requirements, what would be the appropriate information architecture?	Information architecture propositions (N=3) including prioritized requirements
Second advisory committee session	Based on the 3 architecture propositions, how must we prioritize conflicting functional requirements?	Decisions about conflicting functional requirements
CoD 6	What information should be included based on content requirements? How should the information be presented and formulated?	Prioritization of content requirements and content creation for functional requirements

[a] CoD: co-design session.

[b] eHealth: electronic Health.

Moreover, while conducting the analysis of the sessions, it became obvious to the research team that data differed depending on the category of users: (1) caregivers or (2) service providers. This resulted in the need for data to be separated into these 2 categories (segments of users).

Co-design can be considered as a type of action research, as a form of knowledge production (or cocreated) through an iterative process linking action and research [40]. Co-design shares many values and goals with action research, such as empowerment and democratization, and its rigor stems from trustworthiness [41] composed of 4 distinct properties: credibility, transferability, dependability, and confirmability [42]. Credibility was obtained with the review of documents to confirm the validity of the interpretation of the information. Transferability (or applicability) was obtained by visiting different regions of the province of Quebec, minimizing situational variations to the findings. Dependability was obtained with the Excel spreadsheet allowing trackable variance of the data from sessions. Finally, confirmability was obtained with the advisory committee editing the decision points throughout the process.

The study received ethical approval from the *Comité d'éthique de la recherche sectoriel santé des populations et première ligne* (2016-2017-10 MP).

Results

Participant Characteristics

A total of 11 caregivers, 16 community workers, and 11 HSSPs participated in the identification of requirements for the ICT eHealth tool (Table 3). Participants were executive officers (n=4), retired individuals (n=4), stakeholders (n=2), coordinators (n=2), nurses (n=2), public servants (n=2), mediators (n=1), homemakers (n=1), and researchers (n=1). This researcher participated as a caregiver.

Table 3. Sociodemographic data of co-designers.

Sociodemographic items	Caregivers	Community workers	Health and social service professionals
Gender, n			
Women	11	10	11
Men	0	6	0
Age (years)			
Range	44-82	25-62	28-49
Education level, n			
High school	4	0	2
College	3	1	4
University	4	15	5

Requirements Identified for User Needs

Functional and content requirements were identified for each user need (19 identified user needs; [35]). Most user needs were met by functional, content, or both categories of requirements. For example, only 1 content requirement was conserved for the need “Ask a question.” Content requirements are also sometimes directly related to functional requirements. This was the case with the user profile: it needed to be created or modified (functional), but we also needed to decide what was in it (content). Some requirements were identified for more than 1 need. Indeed, videos were a functional requirement (embedded video functionality) and a content requirement (the video itself) identified to meet the needs: "be reassured about resources," "recognize themselves as caregivers," and "be encouraged to use the services." In those cases, requirements were repeated as this allows the research team to track the needs that were met and to get a sense of the importance of each requirement.

Table 4 presents the final functional and content requirements for each need. Where functional and content requirements are related, they are presented next to each other. Sometimes the requirements that were suggested in the first sessions were then rejected during following session.

Nonretained Requirements

There were important differences between initial requirements identified during the third and fourth co-design activities and the final requirements. Almost half of the initially identified requirements during the brainstorming sessions (CoD 4) and with the paper prototypes (CoD 5) were not retained. It is important to note that when content and functional requirements were related, both were automatically rejected, thus increasing the number of nonretained requirements. For instance, "Embedded video functionality" was rejected when related to "Web documentary." However, the "Embedded video functionality" requirement was kept as it was also related to many other retained content requirements, as shown in Table 4. There were other requirements rejected as they were not related to design of an ICT technology but more to the nature of a service, that is, "Inducement from service providers" (invitation to their events).

There were disagreements among co-designers about specific functionalities: (1) functionalities related to the social Web, (2) functionalities related to the evaluation of resources for caregivers, and (3) functionalities related to emerging technologies. Although the functionalities related to the social Web were to meet significant caregivers' needs such as "Be encouraged to use the services," "Be encouraged to ask for help before reaching a state of exhaustion," and "Be able to connect with people experiencing the same situation," co-designers were concerned about advantages and safety issues for the community of users. Some HSSPs and community workers were especially concerned about the potential for caregivers to get misleading advice and receive discouraging comments from other caregivers. These participants even mentioned the risk of malicious people taking advantage of the situation as caregivers can become vulnerable at one point. HSSPs and community workers were concerned about the security of the information. Participants also mentioned there was already a social media tool connecting caregivers in Canada.

Debates over functionalities related to the evaluation of resources for caregivers as well as the social Web took place during AC 2 and the sixth co-design activity. Many co-designers, especially community workers, were uneasy with respect to the idea of evaluating resources. Another example of which is meeting caregivers' needs to "Be comfortable using the services" and "Be reassured about resources"; co-designers were worried about the possibility of misevaluations and the effect that a negative evaluation could have on service providers. Community organizations could be significantly affected by a negative evaluation as they rely on the financial support of the public. Moreover, co-designers reported concerns that caregivers would evaluate the person who provided the service and not the service itself. Therefore, "The assessing and ranking system (stars and vote)," "The Voting system (have you found this useful?)," "Suggestions for improvements," "Choice of comments to choose from," and "Add comments" were all rejected. Functionalities related to emerging technologies such as "Bots on Messenger," "Creation of a database to document the needs in relation to regions," and "Use of Big Data" were considered to be interesting but nonessential at this point. Participants suggested they could be retained for a second phase of development.

Table 4. Final functional and content requirements for user needs.

Needs and functional requirements	Content requirements
Ask questions	
—[a]	Phone numbers for the help line for caregivers
Be able to add training workshops, resources, and activities	
Add activities	Form to add activities
Add resources	Form to add resources
Be able to connect with people experiencing the same situation	
No requirements retained[b]	No requirements retained[b]
Be able to keep and retrieve information easily	
Add to favorites	My favorite page
Be comfortable using the services	
Enter preferences (ie, gender of the care assistant)	List of possible preferences
Embedded video functionality	Caregivers and users of resource testimonials
Twinning of caregivers	—
Embedded video functionality	Service provider testimonials explaining their resources
—	Details about services and resources
Be encouraged to ask for help before reaching a state of exhaustion	
No requirements retained[b]	No requirements retained[b]
Be encouraged to use the services	
Embedded video functionality	Virtual visits (presentation of the team, list of services)
Embedded video functionality	Video testimonial
—	Description of services: here are 5 places for respite services in your region, here you can visit, here are the services they offer, and here is the cost
Be guided in the help-seeking process	
Region repertory filter	Region repertory
Construction of the profile with questions	Resources repertory
—	Phone numbers for the help line for caregivers
Be reassured about resources	
Embedded video functionality	Video of a worker explaining the services
Embedded video functionality	User of resources testimonial
—	Details about services and resources
—	Explanation of how the resource meets the needs, even if indirectly.
Have a choice of language	
Language filter (one or more languages)	English and French version of the tool
—	English and French version of the tool
Have access to a keyword search	
Search engine (by keywords and postal codes)	Keyword list (suggestions)
Have access to services corresponding to the functionally impaired older person	
User profile creation/modification	Content of the user profile page
Information filter	Parameters of the filters
Have access to concise and simple tools	

Needs and functional requirements	Content requirements
Limit to only essential functionalities (avoid cognitive load)	Limit to only essential information (avoid cognitive load)
—	Use of simple, intelligible terms, accessible to different literacy levels
Have access to educational interventions	
No requirements retained[b]	No requirements retained[b]
Have access to up-to-date information, anytime, anywhere	
News feed	New publications
Add to favorites	Favorites page
Search engine for old publications	—
Know the service offer (costs, transport, home-based care, eligibility criteria, and proximity	
Editable profile to be filled by caregivers (ie, Zarit Scale, outil d'évaluation multiclientèle (OEMC), line 199 in the income taxes report)	Questions (ie, Zarit Scale, OEMC), line 199 in the income taxes report)
Access to resources with an algorithm	Algorithm rules and sequence of operations (the algorithm should specify its limits)
Form to add resources	Required information for resources in the form: cost (free or paid service), transport (or not), home-based care (or not), and eligibility criteria (list)
Region filter	Reliability of sources
Search by multiple criteria: keyword, age, financial situation)	—
Networking among service providers and caregivers	—
Geo-tracking	—
Central access point	—
Receive information regularly	
No requirements retained[b]	No requirements retained[b]
Recognize the needs	
Clickable list of needs	List of needs
Recognize themselves as caregivers	
Embedded video functionality	Video of caregivers
Assistant (algorithm) determining the needs	—
Requirements not directly related to a specific user need	
Add event to a calendar	Description of the event
Personal calendar	Personal calendar
Two profiles of users: caregivers and service providers	—
Audio description for visually impaired people	—

[a] No corresponding requirement was identified (functional or content).

[b] See explanations in the following section: *Impression of Unmet User Need*.

Requirements for Each Category of Users

As mentioned in the *Methods* section, it became obvious at one point that data regarding requirements were different depending on the user category (caregiver and service providers). Requirements identified for the caregiver category include (1) profile information requested, such as first and last name, email, password, region and sector, phone number, (2) consent to being notified when activities are offered in his or her region, (3) a personal calendar, and (4) the option of adding specific results to a Favorite page. The functional requirements for service providers are (1) a complex profile creation and (2) the option for adding activities and documents. This means that content requirements for each functionality must be related to an option (or word) in the search engine. For instance, when creating their profile, service providers must specify the services they offer and the customers' profile. As they are searching for resources, caregivers can specify the profile of the older person they assist. Furthermore, co-designers were especially concerned about the word choice. Service providers and caregivers do not always use the same term when referring to a profile or service. Therefore, the content requirement “Keyword list (suggestions)” had to be associated with the content requirements in the service provider profile “Add resources” to avoid a “no result found” message from the search engine.

Impression of Unmet User Needs

When requirements were first suggested and then not retained, the research teams tried to ensure that requirements for all the needs remained. Indeed, in some cases, requirements that had been rejected by co-designers left an impression of unmet user needs. Those needs are (1) having access to educational interventions, (2) receiving information regularly, (3) being able to connect with people experiencing the same situation, and (4) being encouraged to ask for help before reaching a state of exhaustion. Further analysis revealed that those needs had been met by requirements identified for other needs: “having access to educational interventions” and “being able to connect with people experiencing the same situation” were met by “Adding resources,” as resources could be an educational intervention or coffee break activities. “Receiving information regularly” was met by “Newsfeed,” and “being encouraged to ask for help before reaching a state of exhaustion” was met by “Assistant (algorithm) determining the needs” and testimonial videos of use of a service.

Discussion

Principal Findings

The participation of end users (or future users) during the specifications of requirements for eHealth tools is essential to ensure they are able to understand the requirements and confirm their correspondence with their needs [43,44]. Our results attest to the potential of their participation during this phase of the design process. The major findings of our study are the importance of (1) the iterative process of specifications of requirements for an eHealth tool and (2) the importance of user segmentation identification early in the process. Indeed, the diversity of potential users in this study (caregivers, HSSPs, and community workers) acting as co-designers resulted in a great diversity of views about requirements for the product. Merging co-designers’ perspectives was a major challenge and is also consistent with another study in which the requirements for an eHealth tool were developed with a co-design approach [45].

Iterative Aspect of the Process

Our results reveal major differences between the beginning of the identification of requirements and the final decisions. Work had begun in the direction of the decisions that had been made initially, only to eventually be reversed. Iteration is indeed a characteristic of design activities [46]. The iterative process of design decisions in this case is also consistent with other works using participatory approaches, such as co-design in the medical and health domains [15,47]. In our study, most iterations were incited by strong disagreements among co-designers about specific functional requirements. It was necessary to come back to these functionalities 2 or 3 times in different sessions to arrive at a consensus that made it possible to meet the respective needs.

Concerns About Functionalities Related to the Social Web

One problematic category of functionalities was functionalities related to the social Web. These are the ones commonly found in the Web 2.0. They are functionalities that allow users to communicate among themselves, thus creating a sense of community. Social networks have the potential to provide support and prevent feelings of loneliness [48], demonstrate benefits [49], and help caregivers deal with caregiving roles and responsibilities [50]. Even if evidence of the effectiveness of Health 2.0 technologies exists, our results indicate that there are still concerns about these technologies. Some caregivers mentioned that they did not have time to spend on social media as their role as caregivers was already time consuming. The safety and hazard concerns identified by HSSPs and community workers that may be misrepresented have also been discussed by Chou et al [51]. However, we question this perspective, which implies that the caregiver is a vulnerable person or is not able to judge the quality of the information provided. Would the benefits to be shared and encouraged by peers outweigh the perceived disadvantages? Is it possible to develop a system that would support both the quality of information and access to peer-to-peer exchanges? We decided to put this aspect aside considering the time and monetary constraints of the project, without eliminating it completely. This reflection will certainly be the subject of a project to further develop the tool.

Identification of requirements is a major step in the design process of ICT. It will define other steps, such as interaction design. Interaction design is part of the following design process structure according to Garrett’s framework. Interaction design involves the user behaviors and how the system will respond to this behavior. The choice of whether or not to include requirements related to eHealth 2.0 will impact how users interact with the product and how the system will respond. If, for example, co-designers had kept functional requirements such as “Live chat” and “Messaging between users,” we could expect that their interaction with the product would be more frequent and active. As of now, the tool interaction is mainly a search action. If caregivers were the only participants in the co-design of the tool, decisions could have been different. We asked the project’s coresearchers to explore the possibility of giving more weight to the caregivers acting as co-designers to include a social justice perspective. Given that the health and community stakeholders made serious arguments regarding the stakes involved, the researchers decided to find a consensus regarding the functionalities. This decision was also consistent with an implementation perspective. It is likely that community services and professionals will be recommending the tools to caregivers. Thus, if these groups did not accept the specific functionalities, they might block the implementation of the eHealth tool.

User Identity and User Segmentation

The profile requirement also raised many issues. Service providers and caregivers will not need to save the same type of data within the tool. These different categories of users correspond to the concept of user segmentation in the design of ICT [27]. Content requirements differed depending on the category of participant (segment of users). This means that the website must have a specific secure section for service providers and a specific secure section for caregivers. Some co-designers in the CoD 5 session suggested other types of user segments: one for relatives and another for the functionally impaired older adults themselves, allowing each to have a different profile on the website. As this would have been problematic in terms of the co-design approach, these profile suggestions were rejected. These user categories were not involved in the first 5 CoDs and 2 advisory committee sessions, thus they could not participate as co-designers. Moreover, there was considerable concern about the idea that the caregiver would need to be connected to a user's profile. Participants reported concerns about low–digital literacy users. They mentioned that older caregivers could be discouraged by having to create a user profile to gain access to the resource search engine. Therefore, it was decided that the user profile should be an option for caregivers and that the search engine should be accessible for unregistered users, thus adding a new user segmentation: the nonconnected (unregistered) user. User segmentation is an important design construct that must be considered early in the process. We found that our results demonstrate this and so are consistent with the results by Siek et al [15]. In our study, the requirements differed significantly for the 3 user segments (unconnected caregivers, connected caregivers, and service providers), resulting in difficulties in the discussions and negotiations regarding the requirements. The identification of user segments early in the process can facilitate the knowledge production regarding the specific requirements for each user segment.

The knowledge, social context, and identity of end users influence their design decision making. Future users may not be familiar with the design activity, and technical details of requirement specifications may be missing, thus increasing the time needed to complete the phase. Moreover, caregivers of functionally impaired older adults ranged in age from 44 to 82 years, which meant that some older adults themselves. Research shows that there is a second level of digital divide (skills and use of technology) related to age [52]: older people tend to have less digital literacy skills [53]. When acting as co-designers for the design of eHealth technology, older adults might have difficulty in understanding issues and implications related to the requirements identification of the technology being designed.

Limitations

To address the validity of our results and ensure they are transferable and applicable in other regions, we decided to sample in different regions of Quebec. Our assumptions were that we would address situational variations of user needs by visiting different regions. Notwithstanding its value in our methodology, this sampling process has certain limitations. As CoDs were held in different regions, participants were acting as co-designers during 1 session only. This resulted in participants working on content and functionality requirements that were based on the user need decisions of other participants. This could have influenced their motivation and engagement during the session, as they were not participating in the entire design process of the eHealth tool. Participant impressions about their participation can affect their motivation and have an impact on results [19,54]. To limit this impact, the research team worked to explain clearly why these choices were made and to highlight the importance of everyone's input in this product creation. To enhance co-designers' understanding of the results presented to them, we added a presentation to each session with more detailed explanations of previous decisions.

Conclusions

There is a growing body of research using a co-design approach for the design of eHealth technologies; however, most studies focus on the product developed and less on the design process. Moreover, there is a lack of common language to discuss the findings in the design of eHealth. This paper addresses these issues by using design theory in the discussion of the co-design of an eHealth ICT tool to assist caregivers of functionally impaired older adults in their help-seeking process. Results are discussed with design constructs such as the iterative nature of the process and user segmentation.

In this study, the iterative aspect appears to be even more important because the future users of the tool acted as co-designers. The number of iterations required increased, as it was sometimes a challenge to reconcile the different perspectives of co-designers coming from different regions of Quebec. Our findings stressed the importance of (1) allowing more time to deal with the iterative aspect of the design activity, especially during the identification of requirements and (2) identifying potential user segments early in the process, as user segmentation has implications on remaining design decisions. More research should be conducted to address the relationship between older people's digital literacy and their participation in co-design of eHealth for this population.

A usability study will be conducted next year. Usability refers to the "functional relationships between people and the products and systems they use" [55]. This usability study will help determine whether the product meets the usability criteria: usefulness, efficiency, effectiveness, satisfaction, and accessibility [56]. It will also contribute to the documentation regarding the potential for including users in the design process.

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Conflicts of Interest

None declared.

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Abbreviations

AC 2: second advisory committee session
CoD: co-design session
eHealth: electronic health
HSSP: health and social service professional
ICT: information and communication technology
PhD: Doctor of Philosophy
UX: user experience

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Original Paper

The Aachen Falls Prevention Scale: Multi-Study Evaluation and Comparison

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Abstract

Background: Fall risk assessment is a time-consuming and resource-intensive activity. Patient-driven self-assessment as a preventive measure might be a solution to reduce the number of patients undergoing a full clinical fall risk assessment.

Objective: The aim of this study was (1) to analyze test accuracy of the Aachen Falls Prevention Scale (AFPS) and (2) to compare these results with established fall risk assessment measures identified by a review of systematic reviews.

Methods: Sensitivity, specificity, and receiver operating curves (ROC) of the AFPS were calculated based on data retrieved from 2 independent studies using the AFPS. Comparison with established fall risk assessment measures was made by conducting a review of systematic reviews and corresponding meta-analysis. Electronic databases PubMed, Web of Science, and EMBASE were searched for systematic reviews and meta-analyses that reviewed fall risk assessment measures between the years 2000 and 2018. The review of systematic reviews was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis statement. The Revised Assessment of Multiple SysTemAtic Reviews (R-AMSTAR) was used to assess the methodological quality of reviews. Sensitivity, specificity, and ROC were extracted from each review and compared with the calculated values of the AFPS.

Results: Sensitivity, specificity, and ROC of the AFPS were evaluated based on 2 studies including a total of 259 older adults. Regarding the primary outcome of the AFPS *subjective risk of falling*, pooled sensitivity is 57.0% (95% CI 0.467-0.669) and specificity is 76.7% (95% CI 0.694-0.831). If 1 out of the 3 subscales of the AFPS is used to predict a fall risk, pooled sensitivity could be increased up to 90.0% (95% CI 0.824-0.951), whereas mean specificity thereby decreases to 50.0% (95% CI 0.42-0.58). A systematic review for fall risk assessment measures produced 1478 articles during the study period, with 771 coming from PubMed, 530 from Web of Science, and 177 from EMBASE. After eliminating doublets and assessing full text, 8 reviews met the inclusion criteria. All were of sufficient methodological quality (R-AMSTAR score ≥22). A total number of 9 functional or multifactorial fall risk assessment measures were extracted from identified reviews, including Timed Up and Go test, Berg Balance Scale, Performance-Oriented Mobility Assessment, St Thomas's Risk Assessment Tool in Falling Elderly, and Hendrich II Fall Risk Model. Comparison of these measures with pooled sensitivity and specificity of the AFPS revealed a sufficient quality of the AFPS in terms of a patient-driven self-assessment tool.

Conclusions: It could be shown that the AFPS reaches a test accuracy comparable with that of the established methods in this initial investigation. However, it offers the advantage that the users can perform the self-assessment independently at home without involving trained health care professionals.

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KEYWORDS

meta-analysis; elderly; self-assessment; hip injuries; leg injuries; sensitivity; specificity

Introduction

Background

Fall incidents are an increasing problem in aging societies [1]. Every third adult older than 65 years falls at least once a year [2]. Increased morbidity and mortality are typical consequences of this fall incidence or related injuries [3-5]. In addition, each individual's risk of falling is generally difficult to detect and is likely to be underestimated [2]. Thus, routinely assessing an individual's fall risk is recommended within the United States, United Kingdom, and Germany [6-8]. This assessment is mainly carried out by the family doctor and is based on the question about fall incidents or the subjective fear of falling. In the event that a potential risk is identified, further functional or multifactorial case risk assessment measures are applied. The National Institute for Health and Care Excellence (NICE, United Kingdom) recommends a multifactorial assessment for suspected cases of outpatients, which aims at different risk factors and does not only evaluate the pure mobility of the patients [7]. The United States Preventive Service Task Force (US PSTF, United States), on the other hand, recommends keeping the assessment as simple as possible and asking patients about their fall history as well as carrying out a functional assessment such as the Timed Up and Go Test [8]. The German College of General Practitioners and Family Physicians recommends a similar assessment as the US PSTF based on questioning patients' fall history and assessing their fall risk based on a functional test like the Timed Up and Go test [6]. A comparison of these guidelines shows that there is still no common best practice for assessing individual fall risks in different industrial nations. What all 3 approaches have in common, however, is that the initiative to carry out an assessment always emanates from the treating family doctor and, in addition, because of a multifactorial or functional assessment, is very resource-intensive and time-consuming [9-13]. Many of them are also problematic in terms of their interrater reliability [14-19]. Preventive measures are, thus, difficult and demand sufficient integration and implementation into aftercare and outpatient management [9,10,14,20,21]. Especially if patients' fall risk should be monitored over a long term, clinical assessment measures are oversized and unsuitable, particularly in terms of a low-threshold service. This leads to the inclusion of a high proportion of low-risk people and waste of resources in terms of clinical setting.

Patient-driven self-assessment as a preventive measure might be a solution [14,22,23]. A promising approach for patient-guided self-assessment of personal fall risk is the Aachen Falls Prevention Scale (AFPS) [11]. On the basis of a 3-step multifactorial and functional assessment, users can evaluate their personal risk of falling. The first step includes 10 yes/no questions (subscale 1) covering typical risk factors such as cognitive or visual impairment, continence problems, falls history, footwear that is unsuitable, health problems that may increase their risk of falling (osteoporosis, Parkinson, arthrosis, or rheumatic disease), or medication. The second step involves a 10-second free-standing test (subscale 2), enabling the users to identify certain balance problems by themselves. The third step is a self-evaluation on a 10-point Likert-type scale (third subscale and primary outcome of the AFPS). Users should rate their subjective risk of falling in regard to the results of the risk factor assessment and the balance test [11]. Thus, the AFPS incorporates a multifactorial fall risk assessment as recommended by NICE or the US PSTF [7,8]. The scale is designed to be used by older adults themselves. This is a benefit compared with most multifactorial fall risk assessments, as is mentioned before. In addition, older adults could perform this self-assessment on their own using a paper version of the AFPS or the corresponding Aachen Falls Prevention App (AFPA) [24]. Thus, older adults get empowered to assess their risk of falling on their own and to consult a physician in advance. In addition, it is also possible to reach groups of people who do not regularly take part in preventive examinations or checkups with their family doctor. For example, the corresponding self-assessment can be sent by the health insurance company. The advantage for the physicians treating the patients is that the self-assessment of the patient provides them with direct information about the existence of risk indicators. In addition, regular use of the AFPS will give an overview of these risk indicators, of balance problems, or of the self-perceived risk of falls changing over time. However, it is still open to what extent the AFPS is covered by clinical multifactorial assessments, which are carried out in a clinical environment with a high time and personnel expense.

Aim of This Study

The purpose of this study was (1) to analyze the test accuracy of the AFPS and (2) to compare these results with established fall risk assessment measures identified by a review of systematic reviews.

Methods

The objective of this study was to determine the sensitivity, specificity, and area under the curve (AUC) via receiver operating curves (ROCs) of the AFPS and to compare them with established measures. Accordingly, the methodological approach of this work is divided into 2 steps. In the first step, the corresponding characteristic values (sensitivity, specificity, and AUC) are calculated. In the second step, a systematic literature search was carried out with the aim of identifying relevant reviews of established case risk assessment measures so that the calculated AFPS characteristics can be compared with these.

Test Accuracy Analysis of the Aachen Falls Prevention Scale

The first objective of this study was to determine the test accuracy of the AFPS. The AFPS has 3 binary outcomes (positive/negative) associated with the 3 steps performed during self-assessment. Sensitivity and specificity were calculated regarding the primary outcome of the AFPS *subjective risk of falling*. Subsequently, sensitivity and specificity were calculated in the case that 1 out of the 3 outcomes of the AFPS identified a positive overall result. The same procedure was applied for the calculation of the ROC and thus the AUC values.

Sensitivity and Specificity

Sensitivity and specificity were calculated as described by Lalkhen and McCluskey, Lusardi et al, and Oliver et al [25-27]. Calculations were performed using Statistical Package of Social Science (SPSS) version 22 (IBM Corp). Pooled sensitivity and specificity were calculated using Meta-DiSc1.4 (Clinical Biostatistics team of the Ramón y Cajal Hospital in Madrid) [28].

Receiver Operating Curves and Area Under the Curve

Second, the reliability of the AFPS was analyzed by plotting ROCs. These curves plot the *sensitivity* against (*1-specificity*) for all possible parameter values. The ROC and the line of no discrimination (diagonal) differ from each other if the parameters analyzed are not randomly related. The AUC could be used to quantify this result. In case of a random relationship, the AUC value is 0.5. In the range between 0.5 and 0.7 for the AUC value, a test is considered less accurate, whereas in the range from greater than 0.7 to 0.9, it is considered moderately accurate. A perfect test would have an AUC value of 1 [29,30]. ROCs and AUCs were calculated using Bland-Altman analyses performed in SPSS separately for both studies.

Data Collection

Data from 2 studies by Knobe et al and Rasche et al, in which the AFPS was included, were used for test accuracy analysis [31,32]. In both studies, identification of fallers was performed according to the definition by Panzer et al [12,31,32]. Utilizing the fall risk screening criteria, participants reporting greater than or equal to 2 noninjury falls in the past year or greater than or equal to 1 injury fall were categorized as *fallers*; participants reporting no falls were categorized as *nonfallers* [31]. The test accuracy of the AFPS was calculated compared with this binary classification.

Comparison of the Aachen Falls Prevention Scale With Established Assessment Measures

The second aim of this study was to compare the sensitivity, specificity, and AUC values of the AFPS with established fall risk assessment measures. Hence, a review of systematic reviews was conducted to retrieve reliable sensitivity, specificity, and AUC values from literature. This review of systematic reviews was carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement [33].

Inclusion and Exclusion Criteria

Only reviews that fulfilled the following criteria were included: (1) published between the years 2000 and 2018, (2) stating specific values for sensitivity and specificity or AUC, (3) including fall risk assessment measures designed for outpatient application, (4) no specific investigation of a diseased subgroup of older adults, such as, for example, dementia patients.

Search Methods

Due to the aim of this study, only the electronic databases PubMed, EMBASE, and Web of Science were searched in July and November 2018. The search term was, because of the purpose of this study, defined as *fall risk assessment*. Reference lists from the identified publications were reviewed to identify additional research articles of interest.

Selection Process

Titles of records resulting from the literature search were independently screened by the first author and discussed with the coauthors. When further clarification was needed, the abstracts were consulted, and in a third step, the full text was retrieved. Disagreements were resolved by the senior author.

Data Extraction and Management

The authors extracted the following data and resolved any disagreements in consultation with the senior author: (1) authorship and publication-related information; (2) name of fall risk assessment measures reviewed; (3) overall sample size; (4) sensitivity and specificity values of the fall risk assessment measures; (5) and if available, AUC value for the fall risk assessment measures. Data were only extracted for the case risk assessment measures, which were examined in at least 2 of the 8 identified reviews. This procedure should ensure that the comparison was not based solely on the data from a single review. Furthermore, this procedure should ensure that scientifically relevant and correspondingly frequently discussed fall risk assessment measures were included in the comparison.

Methodological Quality Assessment

The Revised Assessment of Multiple SysTemAtic Reviews (R-AMSTAR) was used to quantitatively evaluate the methodological quality of identified systematic reviews regarding the inclusion in this study [34]. Reviews are evaluated by the presence of the following 11 domains: (1) an a priori design, (2) duplicate study selection and data extraction, (3) a comprehensive literature search, (4) the use of status of publication as an inclusion criteria, (5) a list of included/excluded studies, (6) characteristics of included studies, (7) documented assessment of the scientific quality of included studies, (8) appropriate use of the scientific quality in forming conclusions, (9) the appropriate use of methods to combine findings of studies, (10) assessment of the likelihood of publication bias, and (11) documentation of conflicts of interest [35]. Each domain is rated on a 4-point scale, whereas R-AMSTAR total scores range from 11 to 44 points. For inclusion of the evaluated review, a total score of 22 points was required [34]. The authors in charge of extracting data from the selected reviews also preliminarily and independently assessed the methodological quality of the contributions. The supervising author resolved any discrepancies.

Data Synthesis

Identified reviews were analyzed, and relevant data were extracted and recorded according to prior descriptions. Comparison of test accuracy data between established fall risk assessment measures and AFPS was performed descriptively.

Results

Test accuracy of the Aachen Fall Prevention Scale

Sensitivity and Specificity

Calculations were made based on 2 studies. The first sample retrieved from Knobe et al included 163 older adults (mean age 80.4 years, SD 6.4) [31]. The second one retrieved from Rasche et al contains 96 older adults with a mean age of 63.8 years (SD 7.02) [32]. Table 1 shows relevant data retrieved from the 2 studies.

Data from the study by Knobe et al [31] revealed a sensitivity of 56% (specificity of 64%) for the primary outcome parameter (self-assessment on 10-point Likert-scale) of the AFPS. If 1 out of the 3 outcome parameters of the AFPS is used to determine a positive result, then sensitivity could be increased up to 93%, whereas specificity thereby decreases to 11%. Calculations based on the data retrieved from the study by Rasche et al [32] showed a sensitivity of 66.7% (specificity 88.1%) for the primary outcome parameter of the AFPS. If just 1 out of the 3 parameters is used to determine a positive result, the sensitivity was again 66.7%, with a specificity of 84.5%.

Regarding the primary outcome of the AFPS (third subscale; 10-point Likert-type scale), pooled sensitivity is 57.0% (95% CI 0.467-0.669) and specificity is 76.7% (95% CI 0.694-0.831; see Figure 1).

If 1 out of the 3 subscales of the AFPS is used to determine a fall risk, pooled sensitivity is increases up to 90% (95% CI 0.824-0.951) and specificity decreases to 50% (95% CI 0.42-0.58; see Figure 2).

Receiver Operating Curves and Area Under the Curve

Following ROCs are described regarding the different outcome parameters of the AFPS. Calculations were made with SPSS. Figure 3 shows the test criteria of the primary outcome parameter of the AFPS using ROCs to discriminate between fallers and nonfallers. For the sample retrieved from the study by Knobe et al [31], the AUC for the primary outcome parameter of the AFPS was 0.692 (SE 0.043) and a 95% CI of 0.606-0.777. The AUC for the data retrieved from the study by Rasche et al [32] was 0.873 (SE 0.04) with a 95% CI of 0.796-0.980.

Figure 4 shows the test criteria of ROCs to discriminate between fallers and nonfallers for the AFPS if 1 out of the 3 subscales is used to determine a fall risk.

The AUC for 1 out of the 3 subscales was calculated to 0.629 (SE 0.044) and a 95% CI ranging from 0.543 to 0.716 for the data extracted from the study by Knobe et al [31]. The sample retrieved from the study by Rasche et al [32] revealed an AUC of 0.756 (SE 0.084) and a 95% CI ranging from 0.592 to 0.920.

Table 1. Data extracted for calculating sensitivity and specificity of the Aachen Falls Prevention Scale.

Variable	Faller (score)		Nonfaller (score)	
	Knobe et al (2018) [31]	Rasche et al (2018) [32]	Knobe et al (2018) [31]	Rasche et al (2018) [32]
Aachen Falls Prevention Scale (primary outcome)				
Subjective risk of falling ≥5[a]	49[b]	8[b]	27[c]	10[c]
Subjective risk of falling <5	39[d]	4[d]	48[e]	74[e]
Total	88	12	75	84
Aachen Falls Prevention Scale (1 out of the 3 criteria)				
Balance test or Self-test ≥5 or subjective risk of falling ≥5[f]	82[b]	8[b]	67[c]	13[c]
Balance test + or Self-test <5 or subjective risk of falling <5	6[d]	4[d]	8[e]	71[e]
Total	88	12	75	84

[a] Main outcome of the AFPS was positive (>5 points in the subjective fall risk assessment).

[b] Correct positive.

[c] False positive.

[d] False negative.

[e] Correct negative.

[f] At least 1 of the 3 criteria of the AFPS was positive and compared with the number of fall incidents (n≥2, or n ≥1 + 1 injury) within the last year.

Figure 1. Pooled sensitivity and specificity regarding the primary outcome parameter of the Aachen Falls Prevention Scale. circles: study samples sensitivity/specificity; blue bars: CI of sensitivity/specificity; diamond: pooled sensitivity/specificity; red lines: CI of pooled sensitivity/specificity.

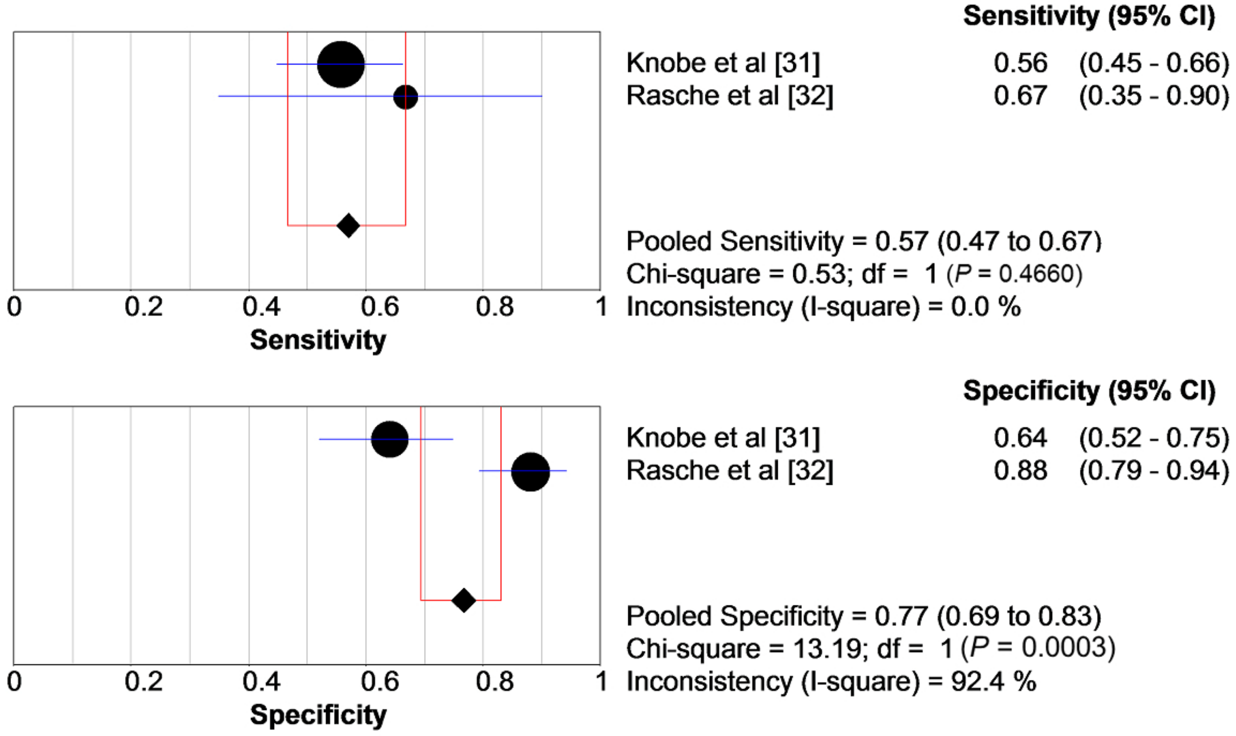


Figure 2. Pooled sensitivity and specificity regarding 1 out of the 3 steps of the Aachen Falls Prevention Scale. circles: study samples sensitivity/specificity; blue bars: CI of sensitivity/specificity; diamond: pooled sensitivity/specificity; red lines: CI of pooled sensitivity/specificity.

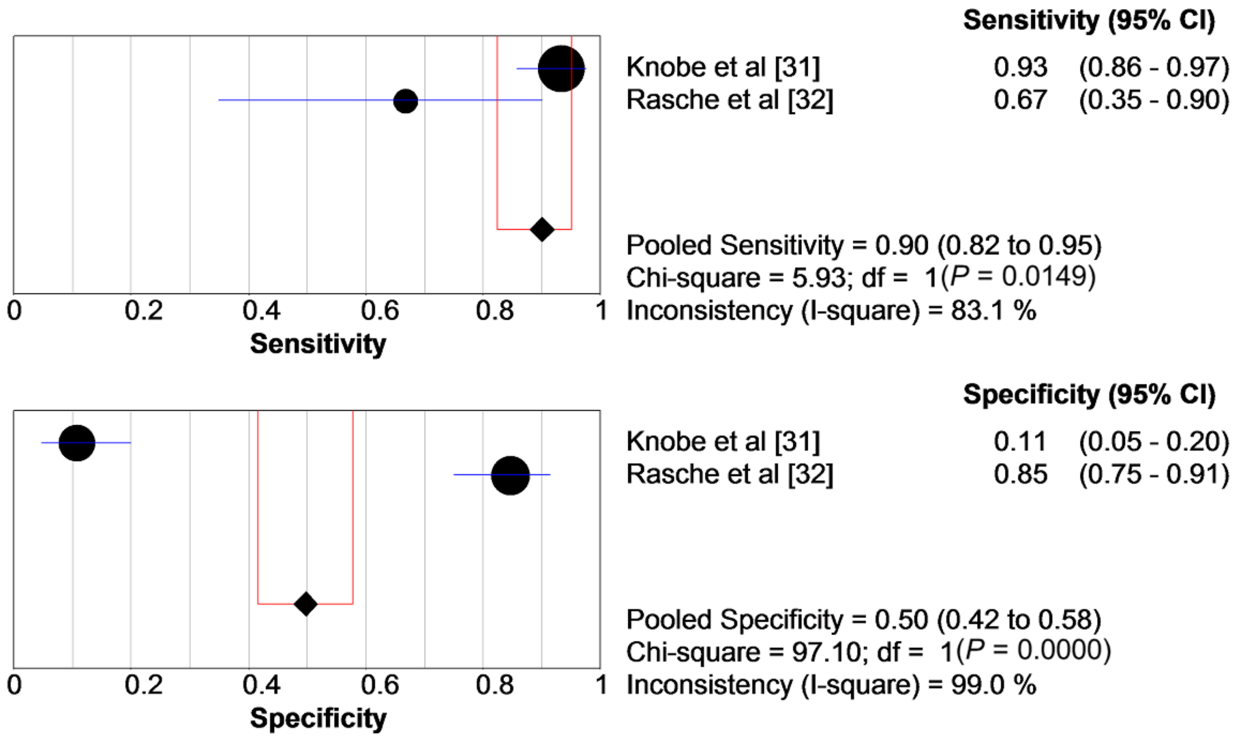


Figure 3. Receiver operating curves regarding primary outcome parameter (third subscale) of the Aachen Falls Prevention Scale to discriminate between fallers and nonfallers. Left side: Knobe et al [31] and right side: Rasche et al [32]; blue lines: receiver operating curves.

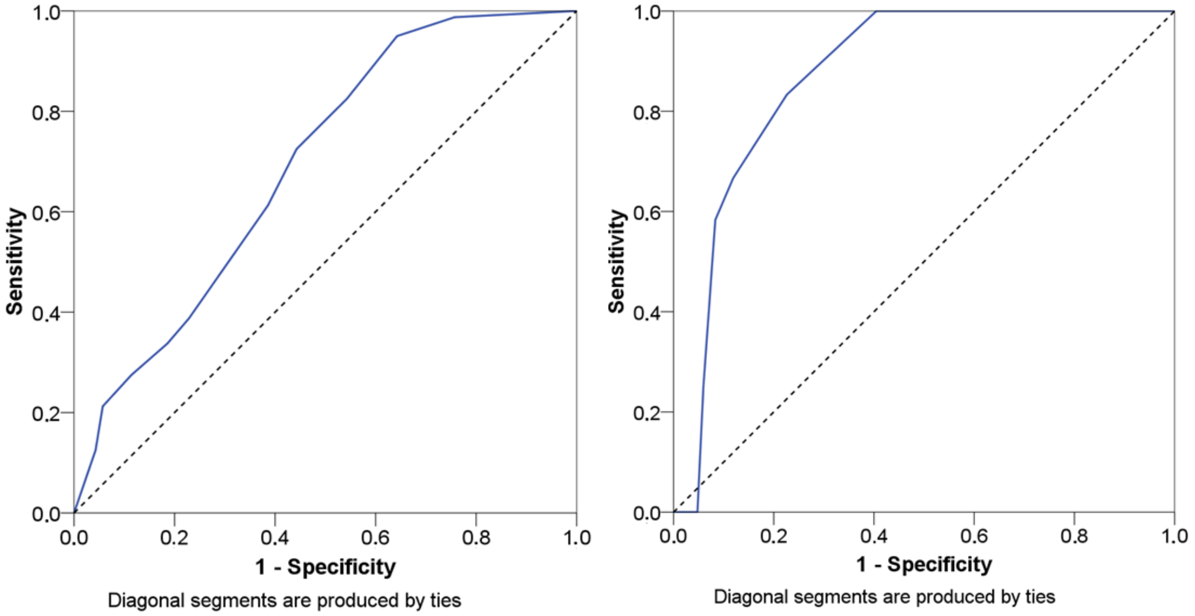
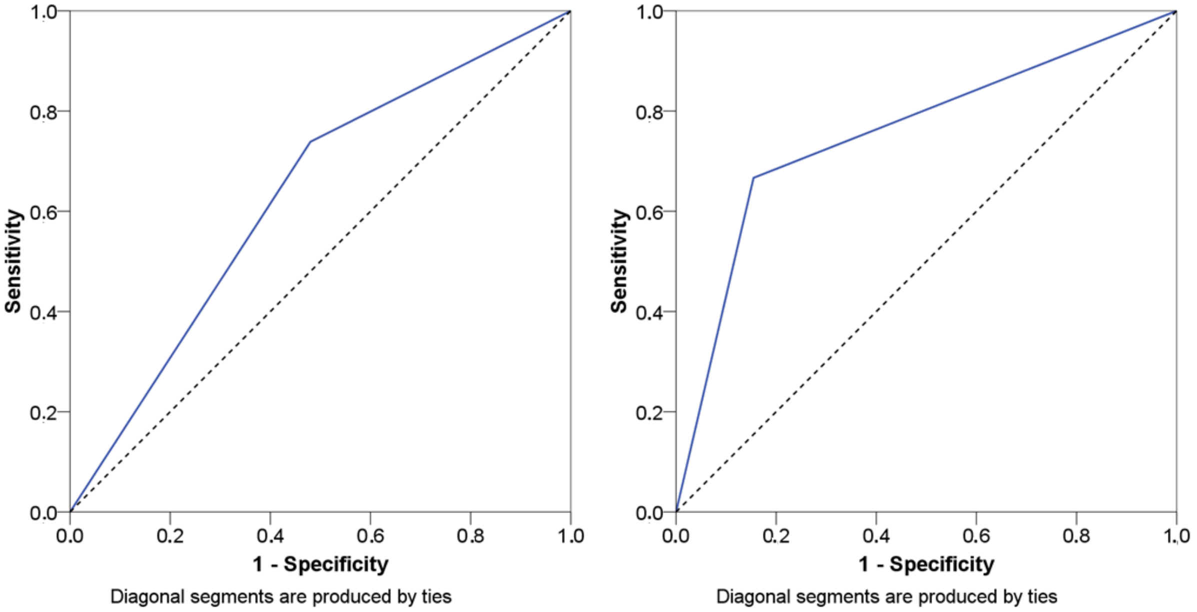


Figure 4. Receiver operating curves if 1 out of the 3 subscales of the Aachen Falls Prevention Scale is used to determine a fall risk. Left side: Knobe et al [31] and right side: Rasche et al [32]; blue lines: receiver operating curves.



Comparison of the AFPS with Established Assessment Measures

Figure 5 shows the article identification and selection process. In total, 948 articles were identified through keyword and reference search within PubMed and EMBASE databases. Of them, 937 articles were excluded after title and abstract screening. The remaining 11 articles were read full-text. Of them, 4 articles were excluded as these were unavailable to the authors. A further article was excluded as it did not fit the scope of this review. The remaining 6 articles were included in the review [25,26,36-41]. For all 6 reviews, the R-AMSTAR score was higher than 22 points (mean 40 points, range: 36-42 points).

Extracted Data

Table 2 gives an overview of the identified articles using the previously defined parameters: publication-related information, name of fall risk assessment measure, sample size, sensitivity, specificity, and AUC.

Data Aggregation and Comparison of Fall Risk Assessment Measures

Table 3 shows the extracted sensitivity and specificity values for the different fall risk assessment measures by means of mean value and range. Further corresponding values of the AFPS were included for comparison.

Figure 5. Results of the review of systematic reviews according to Preferred Reporting Items for Systematic Reviews and Meta-Analysis.

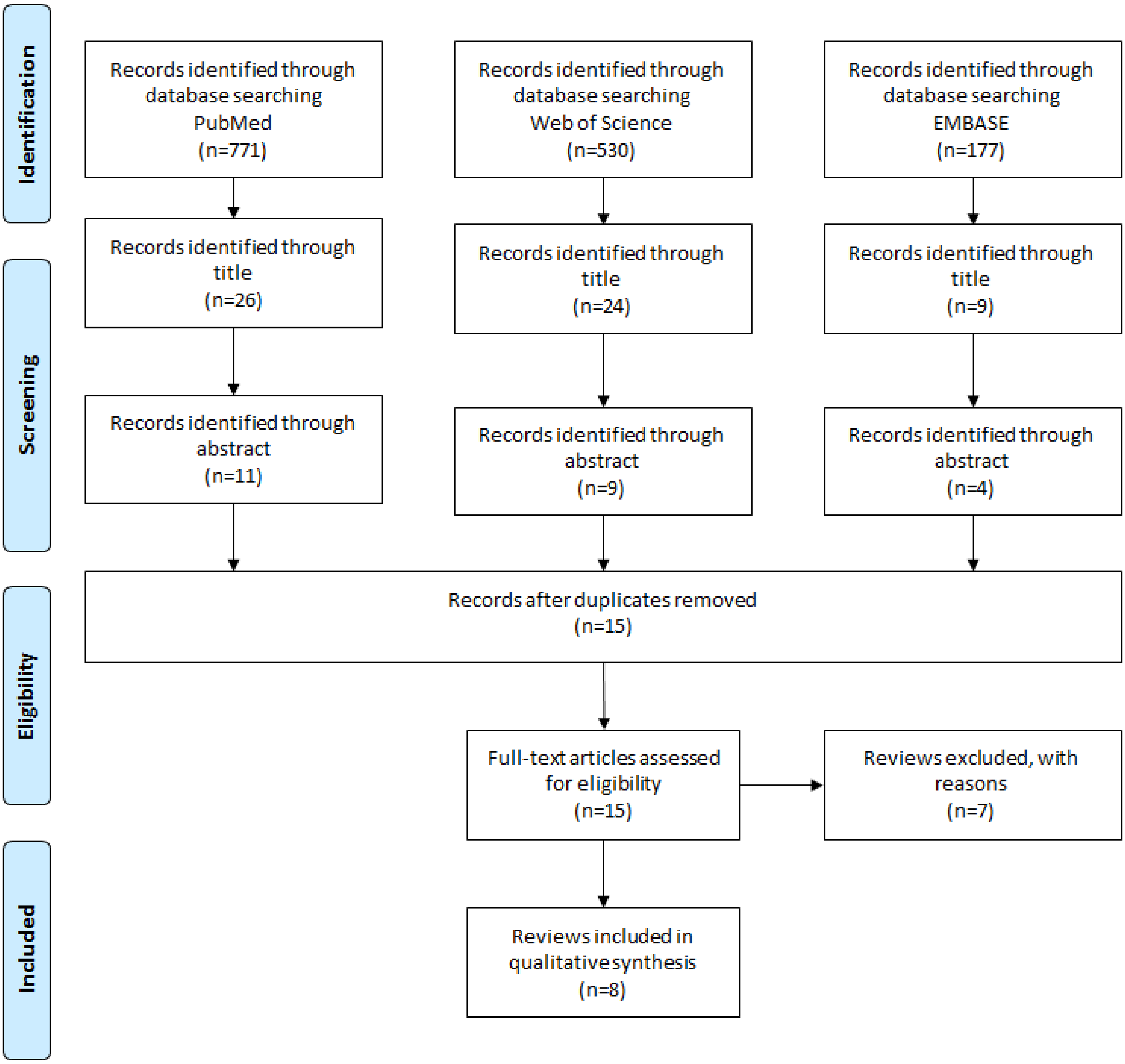


Table 2. Overview of identified reviews and extracted data for the meta-analysis.

Study and fall risk assessment measure	Sample size, N	Sensitivity, %	Specificity, %	Area under the curve (SE)
Perell (2001) [39]				
Berg Balance Scale	__[a]	77.0	86.0	—
Dynamic Gait Index	133	85.0	38.0	—
Elderly Fall Screening Test	361	93.0	78.0	—
Timed Up and Go	30	87.0	87.0	—
Performance-Oriented Mobility Assessment (Tinetti)	79	80.0	74.0	—
Oliver et al (2004) [26]				
Downton Fall Risk Index	135	90.6	26.8	—
Innes Score	2968	89.3	73.5	—
Morse Score	2689; 483	73.2; 95.7	75.1; 54.0	—
Schmid Score	2405	92.5	78.2	—
STRATIFY[b]	395; 446; 432	93; 54.4; 73.7	87.7; 87.6; 45.2	—
Aranda-Gallardo et al (2013) [36]				
Hendrich Fall Risk Model	—	62.8	64.0	—
Morse Fall Scale	—	75.5	67.7	—
STRATIFY	—	80.0	67.5	—
Matarese et al (2014) [40]				
Hendrich II Fall Risk Model	—	92	37	—
STRATIFY	—	63	71	—
Lusardi et al (2017) [25]				
Berg Balance Scale	1130	41	88	—
Five Times Sit-To-Stand test	3319	59	63	—
Timed Up and Go (cut off >0.74 s/≥12 s)	6410	56; 31	65; 85	—
Performance-Oriented Mobility Assessment (Tinetti)	1374	53	69	—
Single-Limb stance (cut off >6.5/>12.7)	3015	19; 90	63; 49	—
Park and Lee (2017) [41]				
Berg Balance Scale	1690	72	73	0.84 (0.02)
Nunan et al (2018) [37]				
Downton Fall Risk Index	—	91	39	—
Five Times Sit-To-Stand test	—	86	91	—
Timed Up and Go	—	49	72	—
Performance-Oriented Mobility Assessment (Tinetti)	—	64; 85	66; 56	—
STRATIFY	—	50	76	—
Park (2018) [38]				
Berg Balance Scale	570	73	90	0.97 (0.02)
Downton Fall Risk Index	231	84	26	—
Hendrich II Fall Risk Model	1754	76	60	0.75 (0.05)
Mobility Interaction chart	286	53	73	—
STRATIFY	2245	89	67	0.81 (0.30)
Timed Up and Go	427	76	49	0.80 (0.04)
Tinetti Balance scale	284	68	56	—

[a]Not applicable.

[b]STRATIFY: St Thomas's Risk Assessment Tool in Falling Elderly.

Table 3. Range of sensitivity and specificity of identified fall risk assessment measures compared with the Aachen Falls Prevention Scale.

Type of fall risk assessment measure and name	Mean sensitivity, % (range)	Mean specificity, % (range)	Area under the curve, mean (range)
Functional			
Berg Balance Scale	65.8 (41-77)	84.3 (73-90)	0.90 (0.84-0.97)
Timed Up and Go	59.8 (31-87)	71.6 (49-87)	0.80
Performance-Oriented Mobility Assessment (Tinetti)	70.5 (53-85)	66.3 (56-74)	—[a]
Five Times Sit-To-Stand test	72.5 (59-86)	77 (63-91)	—
Multifactorial			
Downton Fall Risk Index	88.5 (84-91)	30.6 (26-39)	—
Morse Score	81.5 (73.2-95.7)	65.6 (54.0-75.1)	—
STRATIFY[b]	71.9 (50-93)	71.7 (45.2-87.7)	0.81
Hendrich II Fall Risk Model	84 (76-92)	48.5 (37-60)	0.75
Aachen Falls Prevention Scale (primary outcome parameter)	57.0	76.7	0.724 (0.692-0.756)
Aachen Falls Prevention Scale (1 out of the 3 outcome parameters)	90.0	50.0	0.693 (0.629-0.756)

[a]Not applicable.

[b]STRATIFY: St Thomas's Risk Assessment Tool in Falling Elderly.

Discussion

Principal Findings

Sensitivity and Specificity of the Aachen Falls Prevention Scale

In this paper, the sensitivity and specificity of the AFPS were determined using a meta-analysis based on 2 independent studies. The results showed that by using the primary outcome parameter of the AFPS to discriminate between fallers and nonfallers, a pooled sensitivity of 57.0% and a pooled specificity of 76.7% can be achieved. If discrimination between fallers and nonfallers is based on a positive subscale (risk of falling present), the pooled sensitivity can be increased to 90.0%, whereas the pooled specificity thereby decreases to 50.0%. The AFPS, thus, exhibits an adequate combination of the necessary abilities that a patient-driven self-assessment tool should have. If all 3 outcomes are used, the fall risk is overestimated rather than underestimated, as sensitivity is about 90.0%. As a result, older adults may become more proactive and conduct a professional fall risk assessment at a clinic, even though it might just be a false alarm. Furthermore, the 2 studies investigated by Knobe et al [31] and by Rasche et al [32] showed that the AFPS can be used by users independently via a paper manual as part of a postal survey or via a digital manual as part of a Web-based survey. This indicates that, in addition to the specific test accuracy parameters, this instrument also fulfills the requirement of patient-driven fall risk assessment as stated in the Introduction. To what extent, however, this instrument has a positive effect on the work of family doctors within the guidelines of fall risk assessment of older adults remains unclear.

Comparison of the Aachen Falls Prevention Scale With Established Fall Risk Assessment Measures

The systematic literature research conducted in the second step identified 9 different fall risk assessment measures, which were examined in at least two independent reviews. Identified reviews revealed a variety of reported sensitivity and specificity values. Within the group of functional fall risk assessment measures, Timed Up and Go [25,37-39], Berg Balance Scale [25,38,39,41], and Performance-Oriented Mobility Assessment (POMA) [25,37,39] were most frequently discussed and analyzed within identified literature. The multifactorial fall risk assessment measures St Thomas's Risk Assessment Tool in Falling Elderly (STRATIFY) [26,36-38,40] and Downton Fall Risk Index [26,37,38] were most frequently investigated within identified reviews.

The lowest sensitivity in a single study, as well as on average, was identified for the Timed Up and Go test, followed by the mountain balance scale. It is noteworthy that the functional assessments show a lower sensitivity in comparison with the characteristic values of the multifactorial assessments. Functional assessments, on the other hand, have on average a higher specificity than multifactorial assessments. Compared with these instruments, the AFPS has the advantage that a high specificity of 76.6% or a high sensitivity of 90.0% can be achieved by selecting the considered outcome parameter (primary or 1 of the 3 subscales).

The AFPS, thus, offers an approach for mapping the advantages of both a highly sensitive and a highly specific test. Although the databases need to be strengthened by further studies, results show a promising approach. Compared with all the risk assessment measures examined in this review, the AFPS shows similar performance based on calculated sensitivity, specificity, and AUC. In addition, the AFPS has the advantage that it can be used by patients or caregivers themselves to monitor the risk of individual falls in the long term.

Limitations

The limitations of this study and the studies presented here are two-fold. On the one hand, limitations are to be discussed with regard to the investigation of the test accuracy of the AFPS, and on the other hand, limitations are to be discussed with regard to the systematic literature research conducted.

The study to examine the test accuracy is limited by the study size, which is small compared with the examination of established fall risk assessment measures. A total number of 259 persons were examined. The data were collected in a controlled telephone study and in an anonymous Web-based survey in the second study. For a more comprehensive investigation of the test accuracy, a stronger focus on controlled patient groups from the clinical context should be included in further studies to achieve a more detailed patient segmentation with regard to the risk of falls. Furthermore, the inclusion of only 2 studies did not allow for an in-depth analysis using the MetaDiSc1.4 software. The inclusion of further studies is necessary for the analysis using ROCs by MetaDiSc1.4. Thus, corresponding curves were analyzed using SPSS.

Regarding the literature review and comparison, further limitations need to be considered in the interpretation of the stated results. Correct data aggregation based on different identified reviews was challenging as different cut-off points were chosen but not reported comprehensibly. Furthermore, sensitivity and specificity values of established fall risk assessment measures are not drawn from results of primary studies but from reviews that have synthesized the results already. In this respect, the validity of the comparison must be limited. Furthermore, the parameters for the sensitivity and specificity of the individual fall risk assessment measures extracted from the reviews are based on a different number of studies and contain study populations of different sizes. Thus, the limitations of the identified reviews with regard to the significance of the parameters specified there are also relevant for this contribution. Given these limitations, the results should be interpreted with some caution, and further studies designed to investigate test accuracy by direct comparison with the same study population should be conducted.

Conclusions

This study investigated the test accuracy of the AFPS as a patient-driven self-assessment tool compared with established tools such as Timed Up and Go, POMA, STRATIFY, or Downton Fall Risk Index. This study showed that the AFPS is a promising tool for patient-driven fall risk assessment. It is quick and easy to use.

The AFPS showed suitable pooled sensitivity (57.0%; 95% CI 0.467-0.669) as well as a suitable specificity (76.7%; 95% CI 0.694-0.831) regarding discrimination between fallers and nonfallers by primary outcome. Sensitivity of the AFPS could be increased up to 90.0% (95% CI 0.824-0.951) and a specificity of 50.0% (95% CI 0.420-0.580) if 1 out of the 3 parameters of the AFPS is used to discriminate between fallers and nonfallers.

Thereby, the AFPS shows an adequate combination of the necessary abilities that a patient-driven self-assessment tool should have. If it is used as prescribed (all 3 subscales are used), the fall risk is rather overestimated than underestimated. Thereby, older adults might get sensitized and consult a physician for clinical fall risk assessment even in the case of a false alarm.

The systematic analysis of existing reviews of fall risk measures shows the multitude of available measures and the range of associated sensitivity and specificity values. No outstanding measure was identified in this study, which illustrates the difficulty of selecting these measures in a clinical context. Nevertheless, we were also able to show that the newly developed AFPS is a suitable instrument with which fall patients and elderly people can independently assess and monitor their individual fall risk in the long term. In particular, the approach of bringing this method to the smartphone of affected or interested older adults using an app constitutes a promising approach, as its sensitivity and specificity are comparable with established fall risk assessment measures.

Nevertheless, the multitude of methods reviewed in this study was developed with a focus on clinical use, as the methods are intended to support the assessment of the risk of falls by physicians or medical specialists. Instruments that are supposed to start one step sooner in the process and enable the patient to assess the individual risk of falling independently are not yet widespread. One instrument that can be used in this context is the AFPS. Other studies have already shown that this instrument, in form of a health app, can be and is used by older adults to assess their individual risk of falling [24].

All in all, according to the investigated data, the AFPS and thus the AFPA are suitable approaches for increasing patient autonomy and simplifying the process of individual fall risk assessment. Through the application of AFPS and the further spread of AFPA, older people can be made aware of the risk of falling and clinical resources can be saved through the initial self-assessment by the older adults themselves.

Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

AFPA: Aachen Falls Prevention App
AFPS: Aachen Falls Prevention Scale
AUC: area under the curve
POMA: Performance-Oriented Mobility Assessment
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analysis
R-AMSTAR: Revised Assessment of Multiple SysTemAtic Reviews
ROC: receiver operating curve
STRATIFY: St Thomas's Risk Assessment Tool in Falling Elderly

NICE: National Institute for Health and Care Excellence
US PSTF: United States Preventive Service Task Force

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Original Paper

Fall Risk Classification in Community-Dwelling Older Adults Using a Smart Wrist-Worn Device and the Resident Assessment Instrument-Home Care: Prospective Observational Study

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Abstract

Background: Little is known about whether off-the-shelf wearable sensor data can contribute to fall risk classification or complement clinical assessment tools such as the Resident Assessment Instrument-Home Care (RAI-HC).

Objective: This study aimed to (1) investigate the similarities and differences in physical activity (PA), heart rate, and night sleep in a sample of community-dwelling older adults with varying fall histories using a smart wrist-worn device and (2) create and evaluate fall risk classification models based on (i) wearable data, (ii) the RAI-HC, and (iii) the combination of wearable and RAI-HC data.

Methods: A prospective, observational study was conducted among 3 faller groups (G_0, G_1, G_{2+}) based on the number of previous falls (0, 1, ≥2 falls) in a sample of older community-dwelling adults. Each participant was requested to wear a smart wristband for 7 consecutive days while carrying out day-to-day activities in their normal lives. The wearable and RAI-HC assessment data were analyzed and utilized to create fall risk classification models, with 3 supervised machine learning algorithms: logistic regression, decision tree, and random forest (RF).

Results: Of 40 participants aged 65 to 93 years, 16 (40%) had no previous falls, whereas 8 (20%) and 16 (40%) had experienced 1 and multiple (≥2) falls, respectively. Level of PA as measured by average daily steps was significantly different between groups (*P*=.04). In the 3 faller group classification, RF achieved the best accuracy of 83.8% using both wearable and RAI-HC data, which is 13.5% higher than that of using the RAI-HC data only and 18.9% higher than that of using wearable data exclusively. In discriminating between $\{G_0+G_1\}$ and G_{2+}, RF achieved the best area under the receiver operating characteristic curve of 0.894 (overall accuracy of 89.2%) based on wearable and RAI-HC data. Discrimination between G_0 and $\{G_1+G_{2+}\}$ did not result in better classification performance than that between $\{G_0+G_1\}$ and G_{2+}.

Conclusions: Both wearable data and the RAI-HC assessment can contribute to fall risk classification. All the classification models revealed that RAI-HC outperforms wearable data, and the best performance was achieved with the combination of 2 datasets. Future studies in fall risk assessment should consider using wearable technologies to supplement resident assessment instruments.

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KEYWORDS

falls; elderly; wearable devices; machine learning; interRAI

Introduction

Background

By definition, a fall refers to "an event which results in a person coming to rest inadvertently on the ground or floor or other lower level" [1]. The high prevalence and negative impact of falls in older people have become a serious public health issue that affects the independence of older adults, distress in caregivers, and health service utilization [2]. Due to the multifactorial nature of risk factors for falls, current fall prevention strategies are comprehensive and multifaceted [3,4]. An important goal for geriatrics and public health agencies is to accurately identify fall risks and mitigate physical and psychological harm caused by falls. In fact, falls have been used as indicators of the quality of care in home care settings [5,6].

Heart rate (HR) and heart rate variability (HRV) are hypothesized biomarkers of frailty, which implies a growing susceptibility to stressors and functional decline [7,8]. These two parameters mirror the adaptability of the heart to stressors. The study by Ogliari et al (2015) [7] examined whether HR and HRV are correlated with functional status in the aging population. Participants with the highest resting HR had increased risk of decline in performing basic activities on the Activities of Daily Living (ADL) scale and Instrumental Activities of Daily Living (IADL) tasks, with a nearly 80% and a 35% increased risk, respectively [7]. Participants with the lowest HRV had approximately a 25% increased risk of decline in performing the ADL and IADL tasks [7]. The results have shown that a higher resting HR and lower HRV in the target population was associated with poorer functional performance in daily life, as well as higher risk of functional decline [7].

Frail older people expose to great risk for serious health problems, including falls, disability, hospitalization, and mortality [9]. A functional decline and a higher level of frailty caused by the muscular atrophy would escalate the risk for falls in older population [8,10,11]. The occurrence of falls increases with frailty level [4,11]. Frailty and HRV are not only indicators of the decline in health condition [7,8,10] but also served as independent predictors for incident falls in several studies [10,11].

Various studies have shown that loss of sleep implicates a decline in the sense of balance, associating with a number of cognitive impairments such as poor concentration, memory loss, low reaction, and impaired problem solving and cognition [12-14]. It has suggested that insufficient sleep may result in risk for falls [12-16]. Short sleep duration, which accounts for habitual night sleep difficulties, is significantly associated with falls [12-16].

Evidence-based fall risk assessment can lead to proper interventions for people who are at risk for falls. To categorize subjects into faller (high risk) and nonfaller (low risk) groups, the 3 main criteria identified in the literature [17] for such classification are as follows: (1) previous history of falls, (2) prediction of future falls, and (3) clinical assessments. Several studies have incorporated a variety of independent predictors into prediction models based on clinical tests. For example, the Berg Balance Test [18], clinical- and impairment-based tests [19], neuromuscular or cognitive tests [20], the blood pressure change on upright tilting [21], depressive symptoms [22], sleep problems or urinary incontinence [16], and frailty [10,11] have been utilized to predict falls in the aging population. These clinical assessments often use assessment scores to categorize older adults into a binary outcome, that is, fallers or nonfallers [23]. However, this type of assessment oversimplifies the risk of falling in older people, which is more accurately classified by continuous fuzzy boundaries between multiple risk categories rather than a hard boundary between only two groups [23].

Recent technological advances have incorporated wearable sensor-based systems into the protocols of fall risk assessment [17,23]. A wearable sensor system can continuously monitor body movement during day-to-day activities, carried out naturally in real-life environments [17,23]. In a review of fall risk assessment in older adults with sensor-based systems, Howcroft et al (2013) [17] evaluated inertial sensors, sensor location, assessed activity, variables, and prediction models of fall risk assessment [17]. The study revealed that variables measured by sensors have the potential to predict individuals who are at risk of falling and forecast the time-to-incident [17]. Marschollek et al (2011) [23] conducted a study to compare the predictive performance between the conventional fall risk assessment and sensor-based assessment in older adults [23]. The results demonstrated that accelerometer-based fall risk model has almost the same performance as a conventional assessment model [23]. Due to the multifactorial risk factors for falls, sensor-based prediction models may provide important information to conventional assessments and are possible to perform within real-life environments at low cost [17,23].

The interRAI suite of assessment instruments [24,25] are designed to provide standardized clinical data to support care planning in a variety of clinical domains. For example, fall assessments are used to guide care and service planning in a wide range of settings, from independent residences through nursing homes and palliative care [24,26]. The Resident Assessment Instrument for Home Care (RAI-HC) is a baseline geriatric assessment to evaluate older adults who utilize home care services by assessing their needs and ability levels [5,27]. With a variety of assessment information, the RAI-HC system is composed of two key components: the Minimum Data Set-Home Care, which is the basal portion of the RAI-HC, and the Clinical Assessment Protocols [27]. In addition, various clinical scales and indices within each interRAI instrument can also be used to evaluate each client's current health conditions (Scales: status and outcome measures). For instance, the measurement of ADL, cognition, communication, pain, behavior, and mood utilizes standardized scoring schema to generate summary indicators [26].

The interRAI assessment system is not only a suite of comprehensive and standardized assessment tools that are used in different care settings but has been utilized in several fall-related studies [18,27-44]. For example, Muir et al (2008) [18] conducted 1 prospective cohort study using the Berg Balance Scale to examine the predictive effectiveness for any fall (≥1 fall), recurrent falls (≥2 falls), and injury-related falls based on the interRAI Community Health Assessment (CHA)

[18]. The CHA and RAI-HC assessments have been widely used in studies investigating the risk factors for falls [18,27,32,33], fear of falling [28-31], and the comparative analyses of nonfallers versus fallers, nonfallers and one-time fallers versus recurrent fallers [18,27,32,33].

Objectives

To our knowledge, no prior research has combined off-the-shelf wearable sensor data with the RAI-HC assessment to examine the characteristics of different faller groups in older adults living in community, and, furthermore, to build classification models for fall risk assessment using these two data sources. This study aimed to (1) investigate the similarities and differences in physical activity (PA), HR, and night sleep patterns, which are risk factors associated with falls [7,12-14,45,46], among 3 independent older adult faller groups in community-based settings, with continuous measurements from a smart wrist-worn device and (2) create and evaluate fall risk classification models based on (i) wearable data (Wearable), (ii) the RAI-HC, and (iii) the combination of wearable and RAI-HC data (Wearable + RAI-HC). The number of previous falls was targeted as a proxy for fall risk throughout this study [18,27,32,33,47,48].

Methods

Study Design

Using a smart wearable device, a prospective, observational study was conducted to investigate the similarities and differences among 3 independent faller groups, that is, nonfaller (G_0, people who have zero (0) falls in the last 90 days), single faller (G_1, people who have 1 fall in the last 90 days), and recurrent faller (G_{2+}, people who have ≥2 falls in the last 90 days) in community-based settings, in a sample of older adults living in community settings, with continuous measurements of PA, HR, and night sleep. The nonfaller, single faller, or recurrent faller stratus is within 90 days to be consistent with the standard interval of the reassessment of RAI-HC [49].

Each participant was requested to wear the Xiaomi Mi Band Pulse 1S (hereinafter referred to as the *Mi Band*) on their wrist for 7 consecutive days while carrying out day-to-day activities in their normal lives. The Mi Band is a wearable activity tracker, monitoring the activity of movements, tracing quality of sleep, and HR. It is a low-cost band, weighted 5.5 g, and comes with power-efficient accelerometer and photoelectric HR sensor [50]. Xiaomi Corporation, a Chinese electronics company headquartered in Beijing, China is the manufacturer.

The battery capacity of the Mi Band is 45 mAh [50], with approximately 30 days standby time. We tested the battery life before data collection under normal wearing condition (ie, wearing the Mi Band while carrying out day-to-day activities naturally in real-life environments), which lasted more than 15 days. Before collecting data from each participant, the battery was fully charged. To ensure that no running-out-of-battery incident occurred during data collection, participants were given instructions and demonstration on when and how to recharge the battery by themselves before data collection commence. A printout copy of the instruction was given to each participant as part of the information kit during data collection period.

A Moto E mobile phone was paired with each Mi Band wirelessly via Bluetooth to collect data, synchronize, and provide health metrics to each individual. A total of two companion apps, Mi Fit and Mi Band Tools, were installed on each mobile phone to facilitate data collection. The wearable and RAI-HC data were further analyzed to create fall risk classification models and evaluate their classification performance.

Participant Recruitment

A sample of community-dwelling older people, who were active clients of the Waterloo Wellington Community Care Access Centre (WW CCAC) and were assessed with the RAI-HC instrument within a 1-year time window, was recruited in the Kitchener, Waterloo, Cambridge, and Guelph areas in Ontario, Canada between August and December 2016.

The inclusion criteria were that the participants must have been aged ≥65 years, living independently with or without family members at-home or community-based settings (eg, retirement home), and were able to walk without any assistive device. Individuals who have been diagnosed with end-stage disease or have been on medications of benzodiazepines, antidepressants, cardiac medications, narcotics, and anticonvulsants were excluded from participating in this study.

Informed written consent was obtained from all participants. This study was granted research ethics clearance by a University of Waterloo Research Ethics Committee. The study was also approved by the institutional review board at WW CCAC.

Measurements

Number of Previous Falls

To assess the fall frequency, participants responded to the following questions upon enrollment and at the end of the wearable data collection phase: (1) “Have you fallen in the last 90 days?” (2) “How many times have you fallen in the last 90 days?” As the reassessment of RAI-HC at a standard interval is 90 days [49], we complied with this time window for the measurement of falls. Participants were categorized into G_0, G_1, or G_{2+} based on their self-reported number of falls at the end of the wearable data collection phase.

There was a time gap between the RAI-HC assessment and wearable data collection (mean_{gap} 107.6 days, SD 18.1 days; range –67.5-431 days). Some participants had new falls since their last RAI-HC assessments, which resulted in discrepancies between the self-reported fall frequency at wearable data collection and the corresponding assessment on the RAI-HC system. To be consistent, self-reported falls frequency at the end of the wearable data collection phase was used when analyzing wearable data only. The fall frequency on the RAI-HC assessment was used for model-building based on the RAI-HC data only as well as Wearable + RAI-HC data. In case some participants self-reported fewer number of falls than what had been reported by their primary caregivers, the higher number of falls was used in this study.

Table 1. Variable description of wearable data.

Variable	Description	Unit
Daily distance	Daily average distance on walking, jogging, or running	Meter
Daily steps	Daily average steps on walking, jogging, or running	Number
Daily activity time	Daily average time people spend on walking, jogging, or running	Second
Daily resting heart rate (HR)	Daily average heart beats per minute (BPM) while at complete rest (sleeping)	BPM
Daily walking HR	Daily average heart beats per minute while at walk	BPM
Daily sleep duration	Daily average duration while at sleep at night	Minute
Daily deep sleep time	Daily average duration while at deep sleep at night	Minute
Daily light sleep time	Daily average duration while at light sleep at night	Minute
Daily awake time	Daily average duration while awake at night	Minute

Wearable Data

Wearable sensor data collected from the Mi Band included continuous monitoring of PA, HR, and night sleep. PA and night sleep data were collected every minute, whereas HR was monitored every 2 min. By default, the Mi Band and Mi Fit app present no built-in function to extract data. A third-party script allowed data extraction via Android backup [51]. Initial wearable data were aggregated as daily averages for the analyses in this study. A list of individual variables derived from the Mi Band is presented in Table 1.

Resident Assessment Instrument-Home Care Data

All participants with informed written consent contributed 1 assessment each, with the latest one being selected. In this study, we used 210 variables in the RAI-HC data for analyses, including demographic information, assessment information across all the screening domains (see Multimedia Appendix 1).

Statistical Data Analysis

Data analyses were performed using R (version 3.4.0), a free statistical software for data analysis by the R Foundation for Statistical Computing. Of the 38 variables, 40 cases and 1520 values in the wearable data, 55.3%, 65%, and 6.4% have at least 1 missing value, respectively, in terms of 1- (PA and sleep) and 2-min (HR) resolution. Of the 210 variables and 40 cases in the RAI-HC dataset, 19.8% and 100% had at least 1 missing value, respectively. Of the total of 8400 values corresponding to all combinations of the 210 variables and 40 cases, 16.3% were missing. The missing values in the RAI-HC dataset were replaced by referring to previous assessments. The missing values in the wearable data were imputed using the maximum likelihood estimates with the expectation-maximization algorithm (eg, [52]).

Descriptive statistics and simple statistical analyses were conducted to examine the similarities and differences in wearable data collected from the Mi Band from all participants. All wearable parameters (continuous variables) extracted from the Mi Band were tested for normality by using the Shapiro-Wilk test. The one-way analysis of variance (ANOVA) and Kruskal-Wallis H test were conducted to compare the means and medians of the 3 independent groups (G_0, G_1, and G_{2+}) for normally distributed and skewed data, respectively. A two-way repeated measures ANOVA test was performed to examine the differences between groups with repeated measurements of PA, HR, and night sleep, and hence, evaluate if there was an interaction between the 7 days of measurement and groups. In all statistical analyses, P values ≤.05 were considered significant. However, in case of any main effect statistical significance among all groups, pairwise comparisons between groups were investigated with Bonferroni correction.

Fall Risk Classification

To build the classification models and evaluate the classification performance of several models in classifying fall risks, a 2-step approach was employed. First, the ordinal attribute of falls (0, 1, and ≥2) within the last 90 days was used as the outcome variable, representing 3 faller groups (G_0, G_1, and $G_{2+,}$ respectively), for building proportional odds models (POM). Second, the 3-class fall risk was dichotomized in two different ways: (1) grouping $\{G_1+G_{2+}\}$ and comparing with G_0 and (2) grouping $\{G_0+G_1\}$ and comparing with G_{2+}. A total of 3 supervised machine learning algorithms were utilized: logistic regression, decision tree (DT), and random forest (RF).

Given the large number of features in both datasets, there was a good chance that many of them are collinear or redundant. The multicollinearity test was conducted, and the collinear variables with a high variance inflation factor (≥5) were omitted for further analyses [53]. To identify discriminative independent variables contributing to fall frequency and to create accurate classification models, the recursive feature elimination algorithm available in the Caret R package was employed to rank-order each predictor’s importance to classification. As both the wearable and RAI-HC datasets had many variables and relatively few cases, the objective of this feature selection process was to get a total number of best subset features of no more than 10% of the sample size for the final classification models.

Classification models were trained based on (1) Wearable, (2) RAI-HC, and (3) Wearable + RAI-HC. The growing method for DT models was Classification and Regression Trees algorithm, with pruning to avoid overfitting. Key parameters included pruned, minimum child size=3, minimum parent size=5, and Gini was applied as the impurity measure. Key parameters for RF models included the number of trees grown=100, minimum size of terminal nodes=5, and the number of variables sampled at each split randomly=3. Due to the small size of training data in this study, each final model was evaluated using leave-one-out cross-validation. For the 3-class outcome, the classification accuracy, recall, precision, and F_1 score were calculated for each final model, and the area under the receiver operating characteristic curve (AUC), accuracy, recall, precision, and F_1 score were calculated for the dichotomized fall risks. To minimize the impact of different fall assessment at two study elements on classification performance, individuals who had an additional fall each in between the RAI-HC and wearable sensor data collection within the last 90 days' time window were excluded for model building.

Results

Subject Characteristics

Of the 40 participants aged 65 to 93 years in this study, 22 (55%) were males, and 18 (45%) were females. Table 2 shows the basic characteristics of all participants in this study based on their latest RAI-HC assessments.

Statistical Analysis

The results of the Shapiro-Wilk tests of normality showed that only the daily activity time (G_0: P=.67, G_1: P=.30, G_{2+}: P=.09) was normally distributed in all 3 groups. Table 3 summarizes the PA, HR, and night sleep measurements collected by the Mi Band from different faller groups.

Table 2. Baseline characteristics of the participants.

Characteristics	G_0[a]	G_1[b]	G_{2+}[c]	Total
Partcipants, n (%)	16 (40.0)	8 (20.0)	16 (40.0)	40 (100)
Age (years), mean (SD)	75.2 (7.5)	74.0 (6.3)	77.8 (7.4)	76.0 (7.2)
Males	73.8 (9.8)	71.9 (2.1)	76.1 (6.5)	74.8 (7.2)
Females	76.2 (5.6)	75.3 (7.9)	82.9 (8.6)	77.3 (7.2)
Age group (years), n (%)				
65-74	8 (20.0)	7 (17.5)	6 (15.0)	21 (52.5)
75-84	6 (15.0)	0	7 (17.5)	13 (32.5)
85-94	2 (5.0)	1 (2.5)	3 (7.5)	6 (15.0)
Gender, n (%)				
Males	7 (17.5)	3 (7.5)	12 (30.0)	22 (55.0)
Females	9 (22.5)	5 (12.5)	4 (10.0)	18 (45.0)

[a] G_0 people who have zero (0) falls in the last 90 days.

[b] G_1 people who have one (1) fall in the last 90 days.

[c] G_{2+} people who have two or more (≥2) falls in the last 90 days.

Table 3. The measurements of wearable components by group.

Measurements	G_0[a]	G_1[b]	G_{2+}[c]
Daily distance (meters), median (IQR[d])	2040.7 (571.1-2643.2)	908.7 (163.4-1575.1)	490.8 (103.3-1551.2)
Daily steps, median (IQR)	3094.1 (889.4-4029.5)	1415.3 (238.1-2441.5)	768.1 (145.7-2408.6)
Daily activity time (seconds), mean (SD)	3160.2 (1725.2)	1921.4 (1264.1)	1732.4 (1670.7)
Daily resting heart rate, median (IQR)	69.6 (68.3-81.3)	78.7 (74.6-84.7)	77.7 (72.8-81.7)
Daily walking heart rate, median (IQR)	96.4 (93.4-101.1)	94.6 (91.6-105.3)	103.5 (92.2-130.0)
Daily sleep duration (min), median (IQR)	282.7 (247.8-368.3)	287.9 (144.8-428.0)	134.3 (112.8-234.8)
Daily deep sleep time (min), median (IQR)	67.7 (27.3-102.0)	69.1 (11.9-146.6)	27.1 (11.4-53.2)
Daily light sleep time (min), median (IQR)	231.4 (146.2-273.3)	200.0 (105.3-290.5)	116.0 (90.4-184.7)
Daily awake time (min), median (IQR)	21.0 (11.6-40.8)	11.9 (2.9-39.1)	6.1 (1.0-38.1)

[a] G_0 people who have zero (0) falls in the last 90 days.

[b] G_1 people who have one (1) fall in the last 90 days.

[c] G_{2+} people who have two or more (≥2) falls in the last 90 days.

[d] IQR: interquartile range.

Physical Activity Measurements

The one-way ANOVA test results showed that there was a significant difference in daily activity time (P=.04). However, the follow-up comparisons with the Games-Howell test indicated that the actual pairwise differences were not significant.

The Kruskal-Wallis H test results revealed that there was a significant difference in daily steps among the 3 faller groups (P=.04), with a mean rank daily steps of 26.53 for G_0, 18.00 for G_1, and 15.67 for G_{2+}. The posthoc Mann-Whitney test results showed that the daily steps were not significantly different between any two comparison groups, with a Bonferroni correction at a 0.05/3=0.0167 level of significance.

Similarly, a significant difference was found in daily distance among 3 faller groups (P=.04), with a mean rank daily distance of 26.53, 17.92, and 15.75 for G_0, $G_{1,}$ and G_{2+}, respectively. The posthoc Mann-Whitney tests with Bonferroni correction indicated that daily distance was not significantly different between any two comparison groups.

The two-way repeated measures ANOVA test results revealed that there was a significant main effect of steps by days between groups (P=.02). The posthoc tests with Bonferroni correction showed no significant pairwise differences among the 3 groups. The main effect of day of measurement was insignificant, indicating that there was no consistent difference in step counts across different days, if the groups being measured were ignored. No significant interaction effect between daily steps and the 3 faller groups was detected.

Heart Rate Measurements

The Kruskal-Wallis H test results indicated no significant difference in daily resting HR or daily walking HR between groups.

Furthermore, the mean, median, SD, and interquartile range (IQR) of each participant's daily average HR was examined for differences across the groups. The results of the normality test revealed that the SD of daily average HR was normally distributed across all 3 groups. The mean, median, and IQR of daily average HR were shown to be significantly non-normal (P<.001, P<.001, and P=.007, respectively).

The one-way ANOVA test results showed that there was no significant difference in the participants' SD of daily average HR. The Kruskal-Wallis H test results revealed no significant difference in the mean, median, or IQR of daily average HR between groups. The two-way repeated measures ANOVA test results revealed an insignificant main effect of HR by days between groups. The main effect of the days being measured was nonsignificant, indicating that there was no consistent difference in HR across different days, if the groups being measured were ignored. No significant interaction effect between daily average HR and the 3 faller groups was detected.

Night Sleep Measurements

The Kruskal-Wallis H test results revealed that there was no statistically significant difference in daily sleep duration, daily deep sleep time, daily light sleep time, or daily awake time among 3 faller groups.

The two-way repeated measures ANOVA test results showed an insignificant main effect of sleep duration by days between groups. The main effect of the days being measured was insignificant, indicating that there was no consistent difference in sleep duration across different days, if the groups being measured were ignored. No significant interaction effect between daily sleep duration and the 3 faller groups was detected.

Three-Class Classification Models

Table 4 shows the 3-class classification results for POM, DT, or RF on Wearable, RAI-HC, and Wearable+RAI-HC. In the 3 faller group classification, RF achieved the best accuracy of 0.838 (+/-0.199), recall of 0.775 (+/-0.233), precision of 0.730 (+/-0.259), and F_1 score of 0.748 (+/-0.248) using both wearable and RAI-HC data. The lowest accuracy occurred in POM using wearable data.

Table 4. Three-class classification results for proportional odds models, decision tree, and random forest on Wearable, Resident Assessment Instrument-Home Care, and Wearable+Resident Assessment Instrument-Home Care.

Dataset and classifier	Accuracy	Recall	Precision	F_1
Wearable				
POM[a]	0.378 (+/-0.198)	0.351 (+/-0.177)	0.267 (+/-0.147)	0.286 (+/-0.151)
DT[b]	0.595 (+/-0.184)	0.559 (+/-0.156)	0.389 (+/-0.186)	0.443 (+/-0.184)
RF[c]	0.649 (+/-0.166)	0.622 (+/-0.215)	0.550 (+/-0.242)	0.568 (+/-0.223)
RAI-HC[d]				
POM	0.568 (+/-0.211)	0.509 (+/-0.216)	0.417 (+/-0.238)	0.449 (+/-0.229)
DT	0.703 (+/-0.218)	0.649 (+/-0.232)	0.554 (+/-0.299)	0.581 (+/-0.270)
RF	0.703 (+/-0.288)	0.662 (+/-0.299)	0.649 (+/-0.321)	0.634 (+/-0.314)
Wearable + RAI-HC				
POM	0.676 (+/-0.170)	0.626 (+/-0.195)	0.593 (+/-0.195)	0.584 (+/-0.191)
DT	0.757 (+/-0.221)	0.703 (+/-0.254)	0.643 (+/-0.275)	0.662 (+/-0.266)
RF	0.838 (+/-0.199)	0.775 (+/-0.233)	0.730 (+/-0.259)	0.748 (+/-0.248)

[a] POM: proportional odds model.

[b] DT: decision tree.

[c] RF: random forest.

[d] RAI-HC: Resident Assessment Instrument-Home Care.

Binary Classification Models for G_0 Versus $\{G_1+G_2+\}$ and $\{G_0+G_1\}$ Versus G_{2+}

Table 5 tabulates the feature analysis results for all classification models, listing various features that have been selected in the 3 datasets with 3-class classification and dichotomization in two different ways. Table 6 and Table 7 list the binary classification results for the POM, DT, or RF on Wearable, RAI-HC, and Wearable+RAI-HC, utilizing two different ways of dichotomizing the 3-class outcome. In terms of binary classification models for $\{G_0+G_1\}$ versus G_{2+}, RF achieved the best AUC of 0.894 (+/-0.155), overall accuracy of 0.892 (+/-0.160), recall of 0.908 (+/-0.135), precision of 0.928 (+/-0.106), and F_1 score of 0.888 (+/-0.166) based on Wearable + RAI-HC. The AUCs of RF based on RAI-HC and Wearable data exclusively were 0.836 (+/-0.206) and 0.795 (+/-0.247), overall accuracies of 0.838 (+/-0.192) and 0.784 (+/-0.276), respectively; whereas for G_0 versus $\{G_1+G_{2+}\}$, RF achieved the best AUC of 0.865 (+/-0.125), overall accuracy of 0.865 (+/-0.132) based on Wearable + RAI-HC dataset. The AUCs of RF on RAI-HC and Wearable exclusively were 0.858 (+/-0.160) and 0.757 (+/-0.250), overall accuracies of 0.865 (+/-0.145) and 0.784 (+/-0.236), respectively.

Table 5. Feature analyses for all classification models.

Dataset	Three-class		G_0 versus $\{G_1+G_{2+}\}$		$\{G_0+G_1\}$ versus G_{2+}	
	Top 4 features	No. of times being selected in each LOOCV[a] iteration, n (%)	Top 4 features	No. of times being selected in each LOOCV iteration, n (%)	Top 4 features	No. of times being selected in each LOOCV iteration, n (%)
Wearable	Daily walking HR[b]	37 (100)	Daily steps	37 (100)	Daily walking HR	37 (100)
	Daily steps	36 (97.3)	Daily walking HR	37 (100)	Daily sleep duration	26 (70.3)
	Daily sleep duration	27 (73)	Median of daily avg. HR	36 (97.3)	Daily resting HR	23 (62.2)
	SD of daily avg. HR	14 (37.8)	Daily resting HR	17 (45.9)	Daily light sleep	23 (62.2)
RAI-HC[c]	MAPLe[d]	36 (97.3)	MAPLe	37 (100)	MAPLe	37 (100)
	No. of ER[e] Visits	31 (83.8)	IADL[f]-difficulty prep meal	34 (91.9)	No. of ER Visits	35 (94.6)
	IADL-difficulty prep meal	29 (80)	Psychiatric diagnosis	33 (89.2)	Short-term memory	27 (73.0)
	Psychiatric diagnosis	20 (57.5)	Overall change in care needs	27 (73.0)	Oral-problem chewing	10 (27.0)
Wearable + RAI-HC	MAPLe	34 (91.9)	MAPLe	36 (97.3)	MAPLe	35 (94.6)
	No. of ER visits	33 (89.2)	IADL-difficulty prep meal	32 (86.5)	No. of ER visits	32 (86.5)
	IADL-difficulty prep meal	33 (89.2)	Overall change in care needs	25 (67.6)	Daily walking HR	32 (86.5)
	Daily steps	33 (89.2)	Daily steps	24 (64.9)	Short-term memory	22 (59.5)

[a] LOOCV: leave-one-out cross-validation.

[b] HR: heart rate.

[c] RAI-HC: Resident Assessment Instrument-Home Care.

[d] MAPLe: The Method for Assigning Priority Levels.

[e] ER: emergency room.

[f] IADL: instrumental activities of daily living.

Table 6. Classification results for binary classification models G_0. versus $\{G_1+G_{2+}\}$.

Dataset and classifier	AUC[a]	Accuracy	Recall	Precision	F_1
Wearable					
LR[b]	0.680 (+/-0.323)	0.622 (+/-0.215)	0.604 (+/-0.222)	0.553 (+/-0.289)	0.552 (+/-0.250)
DT[c]	0.725 (+/-0.183)	0.757 (+/-0.139)	0.725 (+/-0.183)	0.676 (+/-0.278)	0.670 (+/-0.230)
RF[d]	0.757 (+/-0.250)	0.784 (+/-0.236)	0.757 (+/-0.250)	0.729 (+/-0.325)	0.720 (+/-0.294)
RAI-HC[e]					
LR	0.840 (+/-0.236)	0.730 (+/-0.213)	0.689 (+/-0.249)	0.644 (+/-0.304)	0.648 (+/-0.276)
DT	0.856 (+/-0.153)	0.865 (+/-0.132)	0.856 (+/-0.153)	0.868 (+/-0.181)	0.836 (+/-0.179)
RF	0.858 (+/-0.160)	0.865 (+/-0.145)	0.858 (+/-0.160)	0.870 (+/-0.186)	0.836 (+/-0.189)
Wearable + RAI-HC					
LR	0.743 (+/-0.251)	0.784 (+/-0.224)	0.766 (+/-0.232)	0.778 (+/-0.255)	0.755 (+/-0.246)
DT	0.842 (+/-0.229)	0.865 (+/-0.192)	0.851 (+/-0.213)	0.886 (+/-0.202)	0.849 (+/-0.214)
RF	0.865 (+/-0.125)	0.865 (+/-0.132)	0.865 (+/-0.125)	0.908 (+/-0.094)	0.853 (+/-0.139)

[a] AUC: area under the receiver operating characteristic curve.

[b] LR: logistic regression.

[c] DT: decision tree.

[d] RF: random forest.

[e] RAI-HC: Resident Assessment Instrument-Home Care.

Table 7. Classification results for binary classification models $\{G_0+G_1\}$ versus G_{2+}

Dataset and classifier	AUC[a]	Accuracy	Recall	Precision	F_1
Wearable					
LR[b]	0.599 (+/-0.306)	0.730 (+/-0.185)	0.599 (+/-0.252)	0.518 (+/-0.294)	0.551 (+/-0.275)
DT[c]	0.768 (+/-0.209)	0.730 (+/-0.184)	0.750 (+/-0.210)	0.682 (+/-0.262)	0.678 (+/-0.238)
RF[d]	0.795 (+/-0.247)	0.784 (+/-0.276)	0.795 (+/-0.247)	0.732 (+/-0.325)	0.742 (+/-0.307)
RAI-HC[e]					
LR	0.842 (+/-0.306)	0.649 (+/-0.156)	0.610 (+/-0.174)	0.514 (+/-0.264)	0.524 (+/-0.214)
DT	0.836 (+/-0.149)	0.811 (+/-0.187)	0.836 (+/-0.149)	0.836 (+/-0.217)	0.799 (+/-0.206)
RF	0.836 (+/-0.206)	0.838 (+/-0.192)	0.858 (+/-0.175)	0.869 (+/-0.165)	0.836 (+/-0.195)
Wearable + RAI-HC					
LR	0.838 (+/-0.234)	0.703 (+/-0.172)	0.676 (+/-0.200)	0.657 (+/-0.281)	0.626 (+/-0.231)
DT	0.858 (+/-0.160)	0.838 (+/-0.200)	0.869 (+/-0.154)	0.851 (+/-0.226)	0.829 (+/-0.218)
RF	0.894 (+/-0.155)	0.892 (+/-0.160)	0.908 (+/-0.135)	0.928 (+/-0.106)	0.888 (+/-0.166)

[a] AUC: area under the receiver operating characteristic curve.

[b] LR: logistic regression.

[c] DT: decision tree.

[d] RF: random forest.

[e] RAI-HC: Resident Assessment Instrument-Home Care.

Discussion

General Discussions

To the best of our knowledge, no prior study has combined off-the-shelf wearable sensor data with the interRAI assessment system to examine the characteristics of different faller groups in community-dwelling older people, or to build fall risk classification models with the combination of wearable and interRAI data. There was a gap in knowledge necessary to understand the associations between PA, HR, and night sleep and different fall frequencies in the target population. This pilot study aimed to fill this gap.

It was hypothesized that there were differences in PA, HR, and night sleep among the two faller groups in the target population. The statistical test results revealed a significant difference of PA, including daily steps, daily distance, and daily activity time between groups. The findings are consistent with the literature regarding PA and falls, that is, the decline in PA is associated with increased occurrences of falls [45,54]. However, the small sample size could have made it difficult to detect significant associations. Although there were group differences, the subsequent pairwise comparisons were not significant.

The findings in this study are in line with previous research that examined risk factors for falls in community-dwelling older adults [27,28,32,33,47,54]. For example, Gaßmann et al (2009) [47] examined predictors for single and recurrent fallers in older people living in community, and the results indicated poor health status, lower physical functioning, and mobility were risk factors for falls [47]. In our study, the top features (Table 5) incorporated into model-building were associated with poor health status, such as number of emergency room (ER) visits and IADL from the RAI-HC data, which are major risk factors for falls. As a baseline geriatric assessment to evaluate older adults who utilize home care services, the RAI-HC data represent a comprehensive assessment framework, which may serve well as a fall risk screening method. Similarly, wearable data contain discriminatory power in classifying fall risks. For instance, daily resting HR derived from the wearable device was associated with frailty, which was considered a risk factor for falls [7].

In the 3 faller group classification, RF achieved the best accuracy of using both wearable and RAI-HC data. It reveals that to achieve the best accuracy for classifying an individual into 1 of the 3 faller groups (G_0, G_1, or G_{2+}), applying the RF algorithm on both wearable and RAI-HC data outperforms all the other methods (Table 4). Considering dichotomization of the 3-class outcome, the combination of wearable and RAI-HC data led to the best classification results as well (Table 6 and Table 7). The 2 datasets represent distinct features associated with fall risk. For example, the wearable data provide objective information on motion, whereas the RAI-HC data represent a comprehensive geriatric assessment, measuring IADL, cognition, communication, pain, behavior, and mood utilizing standardized scoring schema to generate summary indicators [26]. The merging of these 2 datasets seems to bring in added value while conducting automatic feature selection with the recursive feature elimination algorithm.

Although dichotomizing to binary classification models, the RF algorithm with both wearable, and RAI-HC data led to a strong discrimination with the AUC of 0.894, whereas classifying an individual into nonfallers and single-fallers $\{G_0+G_1\}$ or recurrent fallers G_{2+}. It is recommended to use both datasets as Table 7 suggests, and the best features are the method for assigning priority levels (MAPLe), number of ER visits, daily walking HR, and short-term memory as tabulated in Table 5. Similarly, comparing with all the methods and models that classify an individual into nonfallers G_0 and fallers $\{G_1+G_{2+}\}$, the RF algorithm with both wearable, and RAI-HC data gave a strong discrimination with the AUC of 0.865 (Table 6). Again, it is recommended to use the combination of wearable and RAI-HC data; the best features are MAPLe, IADL-difficulty prep meal, overall change in care needs, and daily steps as tabulated in Table 5.

Comparing the two different ways of dichotomization, that is, G_0 versus $\{G_1+G_{2+}\}$ and $\{G_0+G_1\}$ versus G_{2+}, the classification models distinguishing $\{G_0+G_1\}$ and G_{2+} had better performance. However, the binary classification results of this study did not show any consistent trend as to whether G_1 is more similar to G_0 or G_{2+}. There seems to be no clear and hard boundary between any two adjacent groups. Intuitively, because of the multifactorial nature of risk factors for falls, the boundaries on both sides of G_1 are expected to be fuzzy.

Limitations

The main limitation of this study is the relatively small sample size, which is not robust to analyze the binary and accidental data of falls, especially in a machine learning context. The small number of participants compromise the accuracy and, therefore, the validity of this study findings. Although it may be difficult to generalize or draw conclusions relying on a small dataset, the leave-one-out cross validation method helps address the limitation of small dataset size. The gap between the wearable and RAI-HC data collection and the subsequent decision of using the fall frequency on the RAI-HC assessment for model-building on Wearable + RAI-HC data may have limited the true ability to compare various classifier performance between the groups. In particular, the wearable component may have been disadvantaged by correlating with outdated number of falls. Evidence suggested a response bias, in particular, social desirability bias may be introduced into this study, as some participants underreported their fall frequencies while compared with the responses from their primary caregivers. We used cross sectional data instead of longitudinal outcomes, which is another major limitation that has to be addressed in future work. The findings from this study suffer from limited generalizability because of the homogenous and small sample from community-based settings within a particular geographic area. Using retrospective fall occurrence and lack of follow-up observation accounts for another limitation. In addition, although the selected wearable device is capable of monitoring sleep patterns at night with auto sleep detection, it cannot reliably detect relatively short periods of sleep or fragmented sleep. As such, the Mi Band in this study did not properly identify daytime napping.

Conclusions

This study provides a knowledge base that future research in fall risk assessment can leverage. By obtaining a better and fuller understanding of fall risk and varying characteristics of older people with different fall histories, more suggestions that are informed can be made for individuals in this population. Both wearable data and the RAI-HC assessment can contribute to fall risk classification. All the classification models revealed that RAI-HC outperforms wearable data and the best performance was achieved with the combination of 2 datasets. Future studies in fall risk assessment should consider using wearable technologies to supplement resident assessment instruments. Future studies are needed to work around the limitations of this study. For instance, larger sample sizes, reduced gap between the RAI-HC and wearable sensor collection, longer study periods, and possibly fuller use of the collected longitudinal data may be helpful in better estimating fall risk classification performance. Studies on different older adult populations are warranted, including clinical inpatients, long-term care, or other institutional residents.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
List of the Resident Assessment Instrument-Home Care data variables used in this study.
[DOCX File, 22KB - aging_v2i1e12153_app1.docx]

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Abbreviations

ADL: Activities of Daily Living
ANOVA: analysis of variance
AUC: area under the receiver operating characteristic curve
CHA: Community Health Assessment
DT: decision tree
HR: heart rate
HRV: heart rate variability
IADL: Instrumental Activities of Daily Living
IQR: interquartile range
PA: physical activity
RAI-HC: Resident Assessment Instrument-Home Care
RF: random forest
WW CCAC: Waterloo Wellington Community Care Access Centre

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Original Paper

An Intervention to Promote Medication Understanding and Use Self-Efficacy: Design of Video Narratives for Aging Patients at Risk of Recurrent Stroke

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Abstract

Background: The debilitating effects of recurrent stroke among aging patients have urged researchers to explore medication adherence among these patients. Video narratives built upon Health Belief Model (HBM) constructs have displayed potential impact on medication adherence, adding an advantage to patient education efforts. However, its effect on medication understanding and use self-efficacy have not been tested.

Objective: The researchers believed that culturally sensitive video narratives, which catered to a specific niche, would reveal a personalized impact on medication adherence. Therefore, this study aimed to develop and validate video narratives for this purpose.

Methods: This study adapted the Delphi method to develop a consensus on the video scripts' contents based on learning outcomes and HBM constructs. The panel of experts comprised 8 members representing professional stroke disease experts and experienced poststroke patients in Malaysia. The Delphi method involved 3 rounds of discussions. Once the consensus among members was achieved, the researchers drafted the initial scripts in English, which were then back translated to the Malay language. A total of 10 bilingual patients, within the study's inclusion criteria, screened the scripts for comprehension. Subsequently, a neurologist and poststroke patient narrated the scripts in both languages as they were filmed, to add to the realism of the narratives. Then, the video narratives underwent a few cycles of editing after some feedback on video engagement by the bilingual patients. Few statistical analyses were applied to confirm the validity and reliability of the video narratives.

Results: Initially, the researchers proposed 8 learning outcomes and 9 questions based on HBM constructs for the video scripts' content. However, following Delphi rounds 1 to 3, a few statements were omitted and rephrased. The Kendall coefficient of concordance, W, was about 0.7 ($P<.001$) for both learning outcomes and questions which indicated good agreement between members. Each statement's Cronbach alpha was above .8 with SD values within a range below 1.5 that confirmed satisfactory content and construct validity. Approximately 75% (6/8) of members agreed that all chosen statements were relevant and suitable for video script content development. Similarly, more than 80% (8/10) of patients scored video engagement above average, intraclass correlation coefficient was above 0.7, whereas its Kendall W was about 0.7 with significance ($P<.001$), which indicated average agreement that the video narratives perceived realism.

Conclusions: The Delphi method was proven to be helpful in conducting discussions systematically and providing precise content for the development of video narratives, whereas the Video Engagement Scale was an appropriate measurement of video realism and emotions, which the researchers believed could positively impact medication understanding and use self-efficacy among patients with stroke. A feasibility and acceptability study in an actual stroke care center is needed.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12618000174280; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=373554&isReview=true

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KEYWORDS

Delphi technique; self-efficacy; stroke; personal narratives; video-audio media; beliefs

Introduction

Background

Medication nonadherence is prevalent at large especially in major chronic diseases, despite patient education and advanced knowledge and methods [1]. Regardless of a definite health economic impact, current endeavors of patient education interventions still appear to be inadequate [2]. Globally, stroke prevalence is not exempted from this cliché of medication nonadherence [3]. A similar situation and increasing aging population of poststroke patients in Asian countries, such as Malaysia, urge for robust and cost-effective patient education measures [4,5]. So far, insufficient patient education intervention reported the effects of video education in patients with chronic medical conditions such as stroke. It is also unknown if personal stories related to stroke medication management can enhance self-efficacy and promote adherence to stroke preventative medication or control stroke risk factors.

In educational strategy, 75% of information is engaged visually and about 13% of it is engaged using our hearing senses [6]. Hence, when a patient sees and hears a video, they have a higher probability of comprehending and reflecting the information. Videos delivered via television format allows viewers of any age group to grasp information at a continuous pace or in a relaxed and inducive environment [6].

The researchers proposed a patient education intervention at an outpatient stroke clinic as it may be a perfect venue for focused recurrent stroke education because it provides access to a common variation of people who are at high risk for recurrent stroke. In a quest for cost-effectiveness, the researchers utilized the prolonged waiting time in the clinic as an opportunity to deliver the intervention adjunct to the current medication therapy adherence clinic's (MTAC) effort that may benefit the patients with stroke. Time spent in the waiting area is a potential period for patients to gain knowledge and confidence in managing their medication [7]. This educational approach may be valuable to patients who were not inclined to electronic communication devices, lacking internet facility, or to those who depended on an external motivational environment such as peers.

The researchers believed that video narratives shown simultaneously with patient education modules are expected to have a positive impact on self-efficacy. Consequently, if the video is incorporated with theoretical behavioral constructs, it could induce self-reflection and simulation by a role model. In addition, if the video is repetitively seen, a *persuasive power* would be instilled whereby the individual's perception influenced by previous learning experience would have a change. The Social Learning Theory explains that an individual's behavior depends on the conditioning of the mind, influenced by his or her environment, which then controls the action of the doer [8]. The planned environment here was the video viewing activity in the waiting area of an outpatient stroke clinic. Besides, the role model impact would be more significant if the actual people who experienced the events delivered the video narratives [9]. It makes the content's objectives realizable and might induce the patient's confidence in justifying what was said, seen, or heard in the video.

Objectives

This study hypothesized that providing video narratives incorporated with theoretical behavioral constructs adjunct to the existing MTAC's patient education effort, informational brochures, counseling, and medication review would result in better stroke awareness, medication understanding, and use self-efficacy toward improved adherence. This study was the intervention development and validation phase of a randomized controlled trial (universal trial number: U1111-1201-3955) [10]. This study described the processes involved in the video narrative's development and validation.

Methods

The Delphi Method

The Delphi method originated from RAND Corporation studies from the 1950s and aimed to develop a reliable technique to obtain consensus from experts. Since then, many researchers have applied this organized method for expert problem-solving issues. They have also developed systematic guidelines of the process and analysis of the Delphi Method [11,12].

The researchers in this study applied a Delphi method to obtain anonymous consensus on learning outcomes, Health Belief Model (HBM) constructs, and content of video scripts which took place from October 2017 to December 2017 among experts experienced in stroke patient education. The consensus procedure incorporated 3 rounds of questionnaires via email to finalize expert panelists' viewpoints.

The process started with literature findings on the local need for stroke survivors. Most patients' crucial need encompassed feelings of being independent to have a good quality of life, reducing the severity and preventing recurrent stroke [13-16]. To be able to achieve these aims, the patient would require utmost confidence and self-efficacy. Moreover, the learning objectives must be able to reflect similar insights and align with the objectives of patient education of recurrent stroke preventative treatment and management guideline of Malaysia [14,15].

Fundamentally, the design of the content was based on the most widely used framework, HBM [17]. HBM has outlined few health behavior constructs that guide a patient's decision making ability such as perception of the risk of contracting the illness and how an adverse effect of illness affects their life, balancing the pros and cons of the actions if taken and prompts for the action. These HBM conditions led the researchers to develop an ideal set of questions as learning objectives to develop the video scripts. Other than scripts, presenting it as a video format was a valuable prompt for the patients with stroke *to take action* on their medication-taking habit.

The core of the Delphi method was the selection of a knowledgeable and experienced expert panel of members within the specific need of content development [18]. Therefore, the researchers invited members of the stroke community and health care professionals who then gave consent via email after provision of information and a brief explanation by the researchers.

The expert panel team of 8 comprised 2 neurologists, 2 pharmacists, 2 medical educationists, and 2 patients who had experienced a stroke. The neurologists were selected based on their 10 to 12 years of professional experience of diagnosing and prescribing medications to patients with stroke. The pharmacists were also selected based on their 10 to 12 years of professional experience of reviewing and dispensing prescribed medications to patients with stroke at the hospital and community level. Whereas, the medical educationists, who were also knowledgeable in developing curricular pedagogy, contributed to the suitability of learning outcomes for stroke according to local context and sensitivity. Finally, the patients with stroke for about 5 years had experiences and an awareness of the need for emotional support to enhance self-efficacy.

There is no specific sample size recommendation for the Delphi method in this area of study as different disciplines and purpose of discussion often result in dissimilar response rates and time [19,20]. However, the researchers ensured all members were homogenous of a specific niche for content development [18] as each of them were bilingual, had relevant knowledge about stroke, were well-versed in stroke preventative management and actively involved with the latest stroke research update and stroke community undertakings, and were willing to volunteer to respond to up to 3 rounds of discussions.

The Development of the Video Narrative Scripts

A fruitful discussion with the panel of experts led to the video narrative script development. The researchers developed the scripts in English and translated them into the Malay language with the help of a professional bilingual translator. Then, back translation was performed by another bilingual researcher who was not exposed to the initial scripts to verify the similarity of meanings. Both scripts (a neurologist's and a patient's version) addressed a brief summary of (1) the debilitating impact of stroke; (2) related risk factors of recurrent stroke, its prevention strategy, and benefit; (3) belief in self-confidence; and (4) real-life cues of successful recovery regardless of the severity of stroke. The Flesch-Kincaid reading level for the narrative scripts scored an average grade level of 6 [21]. Though each script was short (planned to be narrated within 2 min), it was precise with motivational aspects according to the behavioral constructs and was presented as a self-reflection story.

The Development of the Video Narratives

The researchers believed that it was ideal and realistic to have actual actors (ie, neurologist and a patient who had experienced a stroke) to narrate the scripts. Meanwhile, the video was taken at the Arts and Social Sciences School, Monash University, Malaysia, with the help of a technical officer. They narrated each video script, both in English and Malay language within 2 min, and the manner of speech was according to communication principles [22]. The narration and video footage were at a sensible pace with several pauses and facial expressions showcasing appropriate emotion. The researchers also highlighted the videos with written captions and subtitles with a readability level of 6 [21]. A freelance video designer edited the videos using Movavi Video Editor 14 (Version 10.0.0; Obscure Reference Generator (Version 2.1; Shareware, 2014). The videos were repeatedly edited after several rounds of comments on visuals, sound clarity, and presentation style.

Data Collection and Analysis

Delphi Method: Round 1

The researchers drafted the initial narrative script content guide from literature findings, which comprised 8 learning outcomes and 9 HBM-related questions linked to individual perceptions, cues to action, the likelihood of action, and self-efficacy. The panel of experts was given options (ie, yes: to agree to accept or no: do not agree to accept) and an open-ended question to add any other relevant information to the list or justify any redundancy. Hence, this round helped to establish the initial content and construct development of the list, clarification of meaning, and rephrasing or merging of a redundant statement. They were given 3 weeks' time to respond to the Delphi method coordinator.

It was accepted that, approximately, an 80% agreement from the panel (ie, 6 or 7 out of 8 experts) for response frequencies for each learning outcome and HBM question was to be accepted or omitted. This percentage cut off was an appropriate reference point to attain content and construct validity [23]. Hence, the researchers removed those statements that were not meeting about 80% agreement, whereas the rest of the statements and HBM construct questions were modified, rephrased, or merged based on the experts' feedback. Then the list was reedited in a survey questionnaire format and was emailed to the experts for Delphi method round 2.

Delphi Method: Round 2

The researchers repeated the same procedures and timeline as the previous discussion except that the panel of experts was asked to rank the level of relevance using a 7-point Likert scale (ie, 1: not at all relevant and 7: extremely relevant). They were asked to justify their choice of rank if it was 4 points and lower. Kendall W coefficient of concordance was used to measure the nonparametric rankings [24] for a better affirmation of content and construct validity. According to Kendall, the W value ranges from 0 to 1 (ie, 0: no consensus and 1: full consensus) with 0.7 and greater indicating strong agreement so that specific weaker agreement could be scrutinized and relooked to avoid bias and force agreement. Besides, an SD of below 1.5 was also considered to add value to the consensus compared with a percentile of agreement [25]. *P* values less than .05 are considered statistically significant.

The coordinator received comments and feedback to rephrase a few statements to illustrate appropriate meanings. The coordinator asked the expert panelists if they were willing to continue the rounds until the W value rises and all agreed. Hence, a final edition of learning outcomes and HBM questions were resent via an online survey questionnaire for the Delphi method round 3 discussion.

Delphi Method: Round 3

Round 2 discussion and analysis produced a summary of responses and clarification from the panel of experts, which gave an overall picture of final scoring and the current level of consensus of the *weaker strength* statements. The coordinator decided to run the final round of discussion, round 3, and the purpose was to hint the panel experts to confirm and justify revision of specific individual scores, which showed some discrepancies. Inter-rater reliability was determined with the ICC, whereby a 2-way mixed model (fixed raters) with absolute agreement was applied. An ICC value with 0.7 and greater indicated moderate to good reliability. W and SD values were then calculated, and subsequently, a full-detailed report of the discussion was sent to all expert members.

The Validity and Reliability of Video Narrative Scripts and Videos

A purposeful sample of 10 bilingual patients with stroke (within the inclusion and exclusion criteria of the trial) were requested to provide written feedback on the comprehension of the English and Malay video narratives scripts. The informed and consented patients were asked to reply either via email or via a prepaid postal service. Their responses contributed to face and content validity. They also viewed the video narratives in both languages and responded to the Video Engagement Scale (VES) that was presented to them face-to-face during their follow-up clinic visit. Test-retest was not appropriate as these patients were exposed to patient education materials, which could affect their follow-up responses. We expected occurrences of revision in every round of iteration. Therefore test-retest was not applicable to the Delphi method.

To the researchers' knowledge, there were no fixed guidelines to validate a video narrative for patient education; however, there has been a link between the construct of engagement and persuasive communication [26]. Therefore, the researchers adopted the VES to obtain feedback on the ecological validity of the video narratives [27]. The VES has been validated with right internal consistency, test-retest reliability, and content validity, and the authors suggested to use it to measure ecological validity and external validity of video vignettes [27]. VES was also developed based on videos with multiple cases and shots; therefore, this scale would be suitable to be related to emotion and motivation. The patients' ratings contributed to the ICC and Kendall W value, whereas Cronbach alpha above .7 indicated the accepted internal consistency of response ratings. All statistical analyses were done using IBM SPSS software version 22). Data preprocessing was done to maintain data quality such as normalization and double data entry to prevent errors, missing values, or inconsistent codes.

Ethics Approval

Approvals for this development and validation study have been obtained from the Malaysian Medical Research and Ethics Committee (NMRR ID-15-851-24737) and the Monash University Human Research Ethics Committee (ID 9640) whereas the MyStrokeStory trial was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12618000174280; universal trial number U1111-1201-3955).

Results

The Delphi Method

The researchers made no addition to the initial draft of the learning outcomes and HBM questions before the Delphi method round 1. We omitted statements that were redundant, had less than 80% agreement (ie, What is a stroke? How serious is having a stroke?), or were rephrased (ie, How common is a stroke? to Who is at high risk of stroke?). Whereas, few other statements or questions had only a minor correction. Therefore, 8 learning outcomes and 9 HBM questions were edited to 6 statements with 6 questions each for the Delphi method round 2.

In round 2, the W value was below 0.7. The mean ranking for learning outcomes and HBM questions also varied (ie, 2 experts were asked to justify their low score for learning outcomes and HBM construct questions 1 and 2).

However, in round 3, the list of learning outcomes and HBM questions was finalized (Table 1). Kendall coefficient of concordance, W, of approximately 0.7 indicated a firm agreement, and SD values below 1.5 confirmed satisfactory content and construct validity of learning outcomes and HBM questions. However, a reliability test was computed independently for round 3, whereby Cronbach alpha was above .7, which indicated good internal consistency; items on the finalized learning outcomes and HBM construct questions were developed on the similar idea or construct (Table 2).

The Validity and Reliability of Video Narrative Scripts and Videos

The researchers received positive feedback on the scripts (ie, good script, short and meaningful, and direct points), but there were not many comments on the structure of sentences or usage of words. Therefore, the researchers concluded that the scripts were suitable to the local context; hence, the narrative scripts were finally confirmed.

Table 1. The finalized video narrative scripts' learning outcomes and questions parallel with the Health Belief Model constructs.

Health Belief Model constructs	Learning outcomes	Questions
Individual perception: Perceived susceptibility; Perceived severity	1. To be able to recognize and understand stroke cause, symptoms, and effects 2. To understand the burden of stroke	1. What happens to you when you have a stroke? 2. Who is at high risk of stroke?
Likelihood of action: Perceived benefit; Perceived barrier	3. To understand lifestyle risk factors of stroke 4. To acquire information in medication understanding and use	3. How do you prevent another stroke? 4. How do medications reduce the risk of another stroke?
Self-efficacy	5. To understand and acquire skills of medication understanding and use self-efficacy after a stroke	5. How do you ensure your medication works for you?

Table 2. Final analysis of the Delphi method (n=8).

Raters	10 items, mean[a,b,c]
Member 1	4.4
Member 2	6.2
Member 3	4.6
Member 4	4.4
Member 5	5.5
Member 6	3.4
Member 7	5.4
Member 8	5.4

[a] Cronbach alpha: .908.

[b] Intraclass correlation coefficient (95% CI): 0.733 (0.384-0.919).

[c] *P*<.001.

Table 3. The Video Engagement Scale scores (n=10).

Raters	15 items, mean[a,b,c]
Patient 1	5.3333
Patient 2	5.6000
Patient 3	5.7333
Patient 4	5.9333
Patient 5	6.4000
Patient 6	6.5333
Patient 7	6.7333
Patient 8	6.8667
Patient 9	6.8667
Patient 10	6.6667

[a] Cronbach alpha: .925.

[b] Intraclass correlation coefficient (95% CI): 0.797 (0.572-0.921).

[c] *P*<.001.

The VES scores were above average, which exhibited a good link with perceived realism (Table 3). Out of 10 patients, more than 80% of them agreed on the validity of emotional and motivational aspects of the video narratives with a Kendall W value of 0.63 and SD average below 1.5. However, the Cronbach alpha above .7 indicated satisfactory reliability for all videos, which indicated good internal consistency; the emotional and motivational levels were on a similar agreement.

Discussion

Principal Findings

This study explicitly developed and validated video narratives to be used as intervention materials in a randomized controlled trial [10] whereby the researchers would be able to monitor the effect of narration from a doctor and patient with stroke on medication understanding and use self-efficacy of patients who have experienced stroke. The scripts were a general reflection of recurrent stroke and its underlying comorbidity management with a mix of motivation and advice, which hoped to trigger a sense of self-efficacy among patients with stroke to understand and use prescribed medication. The video narratives underwent rigorous processes (ie, development of script guidelines as in learning outcomes and HBM questions, bilingual script development, and video editing) and few phases of satisfactory validation: face validity, content and construct validity (Delphi method), reliability test, and ecological validity (video engagement with bilingual patients). Hence, these video narratives were considered valid and reliable to be presented to patients with stroke with a projected aim to avert stroke risk factors and, in the longer term, prevent recurrent stroke. Videos with patient narratives have the persuasive strength of behavior modification especially if culturally sensitive and embedded with a role model effect. Professional actors, good script constructs and content, appropriate language, and video presentation style play a part in delivering an impactful source in a behavioral intervention [28-30].

Strength and Limitations

There were some apparent limitations in this video narrative development. Face-to-face discussion was unable to be carried out in the Delphi method rounds owing to the lack of interval time and slow responses from the expert panel despite constant reminders. Hence, the Delphi method discussion ended in round 3 whereby force agreement would have occurred. The researchers were also aware that face validity and video engagement responses lacked the required number of participation from poststroke patients because of specific inclusion and exclusion criteria via purposive sampling method. Therefore, the video narratives' validation and study aim were skewed toward particular samples only, and hence, results could not be generalized to the whole population of patients with stroke. In addition, responses from nonbilingual patients were also not assessed owing to the delay during the purposive sampling period and having the VES available in the English version only.

Nevertheless, the Delphi method proved to be a versatile and helpful technique in conducting discussions systematically and reaching a consensus unanimously, eliciting precise ideas, and providing rich, in-depth data in defining an intervention strategy. In addition, the video narrative development processes were found to be useful as a guideline for other behavioral studies, which use video as their intervention, samples with chronic illness, and study sites other than health care centers.

The researchers believed that *no stone had been left unturned* in this development and validation process. The VES had helped to reveal the preliminary understanding of the patients' video engagement styles and emotions that were being affected (ie, realism, empathy, and awareness); however, we believed that bigger samples would produce far more significant data. The researchers recommend that the VES be summarized and translated in various languages in the future to test its effectiveness in distinguishing the video engagement style of multicultures. A future test of the video narratives' feasibility and acceptability in an actual stroke care center would undoubtedly add significance to its validation and effectiveness.

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Conflicts of Interest

None declared.

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Abbreviations

HBM: Health Belief Model
ICC: intraclass correlation coefficient
MTAC: medication therapy adherence clinic
VES: Video Engagement Scale

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Original Paper

Reading Level and Suitability of Congestive Heart Failure (CHF) Education in a Mobile App (CHF Info App): Descriptive Design Study

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Abstract

Background: Education at the time of diagnosis or at discharge after an index illness is a vital component of improving outcomes in congestive heart failure (CHF). About 90 million Americans have limited health literacy and have a readability level at or below a 5th-grade level, which could affect their understanding of education provided at the time of diagnosis or discharge from hospital.

Objective: The aim of this paper was to assess the suitability and readability level of a mobile phone app, the CHF Info App.

Methods: A descriptive design was used to assess the reading level and suitability of patient educational materials included in the CHF Info App. The suitability assessment of patient educational materials included in the CHF Info App was independently assessed by two of the authors using the 26-item Suitability Assessment of Materials (SAM) tool. The reading grade level for each of the 10 CHF educational modules included in the CHF Info App was assessed using the comprehensive online Text Readability Consensus Calculator based on the seven most-common readability formulas: the Flesch Reading Ease Formula, the Gunning Fog Index, the Flesch-Kincaid Grade Level Formula, the Coleman-Liau Index, the Simplified Measure of Gobbledygook Index, the Automated Readability Index, and the Linsear Write Formula. The reading level included the text-scale score, the ease-of-reading score, and the corresponding grade level.

Results: The educational materials included in the CHF Info App ranged from a 5th-grade to an 8th-grade reading level, with a mean of a 6th-grade level, which is recommended by the American Medical Association. The SAM tool result demonstrated adequate-to-superior levels in all four components assessed, including content, appearance, visuals, and layout and design, with a total score of 77%, indicating superior suitability.

Conclusions: The authors conclude that the CHF Info App will be suitable and meet the recommended health literacy level for American adult learners. Further testing of the CHF Info App in a longitudinal study is warranted to determine improvement in CHF knowledge.

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KEYWORDS

health literacy; reading level; patient education; heart failure; mobile app

Introduction

Heart Failure Education

Education is key to improve knowledge and persuade patients with congestive heart failure (CHF) to practice recommended daily self-management tasks of weight and symptom assessment, diet, exercise, and pharmacological therapy [1]. Evidence indicates that traditional patient education using printed materials does not support self-management skill development [1]. New patient-teaching strategies are needed for prolonged engagement of patients to support the development of tactical and situational skills [2]. The incidence of CHF is strongly dependent on age, with an estimated incidence of 1% at age 65 that approximately doubles with each decade thereafter, affecting 6.5 million Americans [3]. According to the Centers for Medicare and Medicaid Services, nearly 20% of all Medicare patients are readmitted to the hospital within 30 days and 34% are readmitted within 90 days of discharge [4]. As many as 79% of readmissions are considered preventable. The prospective EuroHeart Failure Survey (N=2331) from 24 countries followed patients with CHF for 12 weeks and reported that about half of the patients (49%) recalled receiving advice to weigh themselves at discharge [5]. American health care puts a great deal of emphasis on patient autonomy and patients' “right to know.” The American College of Cardiology/American Heart Association clinical guidelines include written educational instruction at the time of discharge as one of the core performance measures to improve CHF outcomes [6]. However, adequate communication skills and health literacy level is important for patients to understand the discharge instructions given, so they can follow them appropriately at home [7]. Inadequate communication skills may not mean resistance to the treatment plan or poor intellect, but rather a low literacy level. Thus, assessing and addressing health literacy levels of patients and reading levels of patient educational materials are warranted for patient safety and to improve outcomes among the elderly.

In recent years, patient-centered mobile health technologies have emerged as a way to actively engage patients in their health care decision-making process. Patients who are engaged as decision makers in their care tend to be healthier and have better outcomes. This is supported by the national survey of 1604 mobile phone users, where 76% of mobile phone users were constantly connected by technology [8]. African Americans and Latinos are reported to be 50% more dependent on mobile phones compared to the white population; about 80% of adults over the age of 65 use mobile phones and 42% are advanced-feature mobile phones [9]. Older adults aged 65 and over with no experience in technology are reportedly using mobile phones to manage daily self-management of chronic diseases [10,11]. Thus, embedding health education in a mobile platform is proposed to improve patient engagement, facilitate communication, help overcome health challenges, and improve disease management. However, health literacy could affect people's ability to navigate the health care system, including filling out complex health information forms and engaging in both self-care and chronic disease management [12]. This paper addresses the suitability and the reading-level assessment of patient educational materials included in the mobile app *CHF Info App*.

Health Literacy

Health literacy is the ability to understand health information and to use that information to make good decisions about one’s health and health care [13]. According to the US Department of Health and Human Services, over a third of US adults are reported to have difficulty with common health tasks, such as following directions on a prescription drug label, adhering to a childhood immunization schedule, or understanding the direction of a medication schedule from the instructions found in the medication container [13]. Health literacy also encompasses the educational, social, and cultural factors that influence the expectations and preferences of the individual [14]. According to the Centers for Medicare and Medicaid Services, about 70% of adults older than age 60 had difficulty using print materials and 80% had difficulty using documents such as forms or charts [15]. Limited health literacy affects adults in all racial and ethnic groups. The proportion of adults with basic or below basic health literacy ranges from 28% of white adults to 65% of Hispanic adults [13]. Approximately 90 million Americans have limited health literacy and have a readability level at or below the 5th-grade level [16]. Although half of adults without a high school education may have below basic health literacy skills, even high school and college graduates can also have limited health literacy [14]. The Joint Commission recommended that in order to self-manage their own health care, individuals must be able to locate health information, evaluate that information for relevance and credibility, and analyze risks and benefits. For those with limited literacy skills, self-management may be too much of a challenge to be overcome, especially if such challenges are undiscovered or ignored [7]. Suitability of educational materials (ie, ease of understanding and acceptance) and readability (ie, reading difficulty) at the level of patient education or understanding have been suggested as strategies to improve the knowledge of the CHF patient. Despite the American Medical Association (AMA) recommendation to provide all patient educational materials at a 6th-grade reading level, many educational materials do not abide by the rule [17].

With advances in medical science, health educational information can overwhelm people, even those with advanced literacy skills. Patient educational materials are potentially effective at improving patient comprehension and influencing health behaviors, especially if they are written at appropriate reading levels for patients. Currently, most institutions include links for patient education within electronic health records (EHRs). An assessment of reading levels of three commonly used patient education links in an EHR study reported varied reading levels: 11th-13th grade for EBSCO, 14th-17th grade for MedlinePlus, and 11th grade for Micromedex—grade levels above the 12th grade refer to the college or university level and beyond [18]. Similarly, an assessment of 339 online ophthalmic patient educational materials demonstrated a varied reading level ranging from the 10th to the 17th grade [19], which is higher than the AMA-recommended 8th-grade reading level. However, no reading levels are assessed on patient educational materials included in mobile apps. Recent reviews evaluated the quality of mobile apps regarding the ease of use, reliability, quality, scope of information, and aesthetics using the Mobile App Rating Scale, but not regarding the reading level of patient educational materials [20,21].

Therefore, the original theory-based development of the CHF Info App with 10 education modules was assessed for reading levels to meet those recommended by the AMA. The modules included in the app were based on educational materials from the Heart Failure Society of America (HFSA) with their approval; a link to detailed HFSA material is provided in the app for patients to navigate [22]. The CHF Info App was developed by educational technology and computer engineering students from the University of South Florida. The app was beta-tested on a small sample of patients and health care providers for usability [22] by the educational technology students. The content included was approved by cardiologists during beta-testing [22]. The educational material included in the CHF Info App evolved and additions were made based on input from patients and providers after beta-testing [22]. Given the influence of health literacy on understanding educational material, assessing for suitability and reading level of patient educational material was deemed a necessary next step before making the CHF Info App available for patient use. Therefore, the authors sought to determine the suitability and readability level of the materials included in the CHF Info App to meet the requirements of the AMA recommendations.

Methods

A descriptive design was used to assess the suitability and readability of the patient educational materials included in the CHF Info App. The Suitability Assessment of Materials (SAM) tool is composed of a 26-item Likert scale with four categories including message content, text appearance, visuals, and layout and design. The SAM instrument is a systematic tool that assesses printed health-related educational resources in a short amount of time. The validated SAM tool was used to assess the CHF Info App [23]. Two of the authors (PA and BR) independently assessed the suitability of the CHF Info App using the SAM instrument. These authors, both with doctoral-level education, objectively followed the SAM tool and coded each of the 10 modules according to content, appearance, visuals, and layout and design. Each item was scored as *superior* (2 points), *adequate* (1 point), or *not suitable* (0 points). The given score was divided by the total possible score to obtain a percentage; a score of 0%-39% is considered *not suitable*, 40%-69% is considered *adequate*, and 70%-100% is considered *superior*. Conflict between the coders was resolved by consensus and a workflow for improvement of the app was developed.

There are several predominant tools available online to measure the reading level of patient educational materials. The authors used the Text Readability Consensus Calculator, an online readability consensus assessment formula, which calculates reading level based on the seven most-common reading formulas to calculate the average reading grade level, reading age, and text difficulty of the text [24]. The prominent measures of readability documented in the literature are the Flesch Reading Ease Formula, which indicates that the best text should contain shorter sentences and words. A score between 60 and 70 is largely considered acceptable [25]. The Flesch-Kincaid Grade Level Formula presents a score as a US grade level, making it easier for teachers, parents, librarians, and others to judge the readability level of various books and texts [26]. The Simplified Measure of Gobbledygook Readability Formula estimates the years of education needed to understand a piece of writing, particularly for checking health messages [27]. The Gunning Fog Index estimates the years of formal education a person needs to understand a piece of text on the first reading. For instance, a Gunning Fog Index of 12 requires the reading level of a US high school senior [28]. The Fry Formula is calculated as the average number of sentences (y-axis) and syllables (x-axis) per 100 words. These averages are plotted onto a specific graph; the intersection of the average number of sentences and the average number of syllables determines the reading level of the content [29]. The Dale-Chall Formula is unique because, unlike other formulas that use word length to assess word difficulty, the Dale-Chall Formula uses sentence length and counts of “hard” words to calculate the US grade level [30]. In addition, the Linsear Write Formula is included to calculate the readability of technical manuals; also, the Automated Readability Index was designed to gauge the understandability of a text that produces an approximate representation of the US grade level needed to comprehend the text [24]. Therefore, the 10 education modules of the CHF Info App were assessed using the comprehensive Text Readability Consensus Calculator Formula to make sure the CHF Info App meets the AMA recommendations.

Results

A suitability assessment of patient educational materials from the CHF Info App was performed by two of the authors using the SAM tool. Both of the authors (PA and BR) with doctoral-level education were qualified to assess the quality of the material objectively using the SAM tool. Each item was scored as *superior* (2 points), *adequate* (1 point), or *not suitable* (0 points), as mentioned above. The result of the assessment demonstrated *adequate*-to-*superior* levels of agreement in all four components: content, appearance, visuals, and layout and design. The only item found to be inadequate or that was not specifically addressed in the CHF Info App was cultural difference. The authors agreed that the educational material provided in the CHF Info App was general and culturally neutral and did not address any one cultural preference. The CHF Info App was assessed as *superior* with a score of 77%. See Table 1 for detailed results.

The reading grade level for each of the 10 CHF educational modules included in the CHF Info App was assessed using the comprehensive online Text Readability Consensus Calculator formulas [24]. The reading level included the text-scale score, the ease-of-reading score, and the corresponding grade level. The materials included in the CHF Info App ranged from 5th-grade to 8th-grade reading levels with an average of a 6th-grade level, which meets the AMA recommendation (see Table 2).

Table 1. Suitability Assessment of Materials for patient education of the CHF[a] Info App.

Appraisal of components and related questions	Assessment based on score		
	Inadequate	Adequate	Superior
Appraisal of message content			
Does the material explain the purpose and benefits from the patient's view?		X	
Is the content limited to a few essential main points that the majority of the target population will benefit from?			X
Are behaviors and skills emphasized rather than just facts?			X
Are readers provided with opportunities for small successes?		X	
Are key points reviewed at the end of each section or page?		X	
Is the material sensitive to cultural differences?	N/A[b]	N/A	N/A
Is the new information placed in the context of the patients' lives?		X	
Are readers told what they should get from the material and what they can do to improve their health?			X
Is the organization of the paragraphs and sentences conducive to easy reading?			X
Are instructions broken down into easy-to-read parts?			X
Is the material interactive? Does it encourage the patient to write, answer questions, ask questions, cut out forms, etc?			X
Appraisal of text appearance criteria			
Is the font size no smaller than 12pt-14pt? Is zoom function available?			X
Is easy-to-read font used? Are there no fancy scripts or lettering?			X
Are bold and underline used instead of ALL CAPS and italics?			X
Are colors used to promote easy reading (ie, dark fonts on light backgrounds are best)?			X
Are overall sharp contrast and large font used?			X
Appraisal of visuals			
Do the visuals all help communicate your messages in a literal manner (ie, no abstract symbols)?		X	
Are the visuals culturally relevant and sensitive?		X	
Are the visuals easy for your readers to follow and understand? For example, if showing a sequence, are the steps numbered and labeled?		X	
Are internal body parts or small objects shown in context and in a realistic manner?		X	
Are the visuals professional and appropriate for an adult audience?			X
Are the visuals free of distracting details that take away from the main idea?			X
Do all of the graphics contribute to your message?		X	
Are examples given for any lists, charts, or diaries that readers are supposed to complete?		X	
Appraisal of layout and design			
Is the cover effectively designed?		X	
Are messages organized so they are easy to act on and recall (headings, subheadings, *chunking*, etc)?			X
Is there a lot of white space? Is there no dense text?		X	
Is the text easy for the eye to follow? For example, bullets, paragraph shape (40-50 characters wide is best), and text boxes.			X

[a] CHF: congestive heart failure.

[b] N/A: not applicable.

Table 2. Reading-level assessment of the CHF[a] Info App.

Scoring formula	Text-scale score	Ease-of-reading score	Grade level
Flesch Reading Ease Formula	84.8	Easy	N/A[b]
Gunning Fog Index	6.8	Fairly easy	N/A
Flesch-Kincaid Grade Level Formula	4.7	Easy	5th grade
Coleman-Liau Index	8.0	Fairly easy	8th grade
Simplified Measure of Gobbledygook Index	4.4	Easy	4th grade
Automated Readability Index	5.9	Easy	5th and 6th grade
Linsear Write Formula	6.1	Easy	6th grade

[a] CHF: congestive heart failure.

[b] N/A: not applicable.

Table 3. Comparison of words and text of standard US high school and adult readers and the CHF[a] Info App.

Measure	Average for US high school and adult readers	Average in the CHF Info App
Sentence length (number of words), mean (SD)	13-16 (1.3)	13 (0.7)
Reading level	7th and 8th grade	6th grade
Three-syllable text, %	12-14	4

[a] CHF: congestive heart failure.

In addition to the reading level, the online Text Readability Consensus Calculator provided a comparison of words and syllables, sentence length, and texts included in the CHF Info App corresponding with the standard of US high school and adult readers. The results showed appropriate sentence length, reading level at the 6th grade, and an average three-syllable text of 4%; the results also meet the AMA recommendation (see Table 3).

Discussion

Principal Findings

The findings of the assessment of the patient educational material included in the CHF Info App indicated a reading level of 5th-8th grade, with a mean of a 6th-grade level. This result is consistent with the recommendation from the AMA [17]. The ability to obtain and understand basic information about health in order to make informed decisions is vital and contributes to the complex area of health literacy. Although the use of medical terminology in patient educational material is often unavoidable, it has a profound impact on readability because of the use of polysyllabic medical terms, and the CHF Info App included fewer polysyllabic terms. The CHF Info App was made up of 4% of three-syllable text, which is much lower than the recommended average three-syllable text of 12%-14%; in addition, the average sentence length of 13 words met the standard for US high school and adult learners. A study by Chen et al showed that health literacy is associated with CHF knowledge, longitudinally (*P*<.001), among 51 patients with CHF with a mean age of 65 years [31]. Therefore, the authors conclude that the CHF Info App will be suitable and meet the health literacy level recommended for adult learners. Low health literacy was consistently associated with more hospitalizations; decreased ability to demonstrate taking medications appropriately; decreased ability to interpret labels and health messages; and, among elderly persons, poorer overall health status and higher mortality rates. Health literacy was independently associated with knowledge (*P*<.001), however, it was not related to self-care [32]. Therefore, our next step is to test the CHF Info App in a longitudinal study to measure improvement in CHF knowledge and self-care.

The reading-level assessment was complemented by the use of the SAM instrument, which assessed the content, appearance, visuals, and layout and design of the materials. The components were assessed as *adequate* to *superior* for all 26 items on the SAM instrument, with a total score of 77% indicating *superior*. Except for cultural difference, the other items were found to be *adequate* or *superior*. The authors concluded that the contents included in the CHF Info App are general, using common words, and are culturally neutral. However, further testing is needed among a diverse population to determine its usability and potential efficacy, since poor health literacy partially explains racial disparities in some outcomes [33]. Evidence supports the use of mobile phone-based telemonitoring and educational support for patients with CHF [11].

Limitations

One limitation is that this was a descriptive study that assessed the readability and suitability of a mobile phone-based CHF education app—the CHF Info App. The other major limitation is that the CHF Info App is available only in the English language. Further testing on a larger sample including elderly persons and a longitudinal follow-up are warranted to determine if the patient educational material included in the CHF Info App will improve CHF knowledge and self-care. Although the readability measures used in this study do address reading grade level and ease of reading, through assessment of word difficulty and sentence length, they do not consider other factors that may affect comprehension of health educational materials, such as cultural appropriateness, learning stimulation, and motivation. Although the suitability of educational material includes many factors, reading grade level is foundational to any patient educational material.

Clinical Implications

All patient educational material, whether in paper form or an app version, should identify reading level and how it was measured to provide further guidance for patients and health care providers to make sure that they meet the AMA recommendations. Future research should focus on continued assessment of health educational materials used for diverse populations and settings and investigation of readability measures among CHF patients.

Conflicts of Interest

None declared.

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Abbreviations

AMA: American Medical Association
CHF: congestive heart failure
EHR: electronic health record
HFSA: Heart Failure Society of America
SAM: Suitability Assessment of Materials

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Original Paper

A National Assessment of Access to Technology Among Nursing Home Residents: A Secondary Analysis

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Abstract

Background: According to the National Center for Health Statistics, there are over 1.7 million nursing home residents in the United States. Nursing home residents and their family members have unique needs and stand to benefit from using technology empowering them to be more informed and engaged health care consumers. Although there is growing evidence for benefits of patient-facing technologies like electronic patient portals on patient engagement in acute and outpatient settings, little is known about use of this technology in nursing homes.

Objective: The purpose of this study was to report findings from a secondary analysis of data from a national nursing home study of information technology (IT) adoption, called IT sophistication. We describe the extent to which nursing homes (n=815) allow residents or their representatives to access technology including electronic health records, patient portals, and health information-exchange systems as well as the ability of the residents or representatives to self-report data directly into the electronic health record.

Methods: We used descriptive statistics and regression techniques to explore relationships between information technology adoption (IT sophistication) and residents' or their representatives' access to technology. Covariates of location, bed size, and ownership were added to the model to understand their potential influence on the relationship between IT sophistication and resident access to technology.

Results: Findings revealed that resident access to technology was a significant predictor of the nursing home IT sophistication (*P*<.001). The inclusion of covariates—nursing home location, bed size, and ownership—with their interactions produced a nonsignificant effect in the model. Residents' or their representatives' use of electronic health records and personal health records were both significant predictors of overall IT sophistication (*P*<.001).

Conclusions: As nursing homes continue to progress in technological capabilities, it is important to understand how increasing IT sophistication can be leveraged to create opportunities to engage residents in their care. Understanding the impact of health information technology on outcomes and which technologies make a difference will help nursing home administrators make more informed decisions about adoption and implementation.

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KEYWORDS

nursing homes; health information technology; patient access; patient portals; personal health records; patient engagement; person-centered care

Introduction

Using health information technology (IT) to engage residents and promote person-centered care in nursing homes is a novel idea. Although there is growing evidence of the benefits of health IT on patient engagement in acute and outpatient settings, little is known about the use of this technology in postacute settings like nursing homes. Over 1.7 million nursing home residents in the United States [1] and their family members have unique needs and stand to benefit from using technology that will empower them to be more informed and engaged in their health care.

Nursing homes face unique challenges related to the adoption of IT. Over the last 9 years, the Centers for Medicare and Medicaid Services have spent over US $38 billion on incentivizing the adoption of IT in the United States through the “meaningful use” program [2]. Despite this substantial investment, not all providers were eligible to participate in the incentive program. Long-term acute care hospitals, inpatient psychiatric hospitals, home health agencies, and nursing homes (which provide rehabilitation and skilled nursing services) were excluded from the incentive program and now face substantial challenges in IT adoption. For example, prior to 2008, only 6% of long-term care hospitals had a basic electronic health record (EHR) in place, which is an adoption rate less than half of that among acute care hospitals [3]. In fact, between the years 2008 and 2015, acute care hospitals experienced a more than eight-fold increase in EHR adoption [4]. In 2017, more than 95% of all federal acute care hospitals in the United States had a certified EHR in place [5]. This gap in EHR adoption between acute and postacute providers continues to grow as more sophisticated EHRs are adopted, many of which include opportunities to improve patient engagement by giving patients digital access to their medical records.

Improving patient and family engagement has been identified as a priority for improving health care in the United States by organizations such as the National Academy of Medicine and National Quality Forum [6,7]. The role of patients and their caregivers in health care is changing, as more emphasis is being placed on person-centered care and shared decision making. Person-centered care is emerging as a targeted approach for improvement across diverse settings in health care including nursing homes. Many definitions of person-centered care have been developed; however, at the center of this concept is the importance of incorporating patient needs and perspectives into care delivery. In nursing homes and other postacute settings, person-centered care has been identified as a way to overcome institutionalization and dependency through enhanced autonomy and empowerment of residents and their family members [8]. Improvements in outcomes related to patient engagement such as patient activation and perceived quality of life are beginning to emerge as more emphasis is placed on patient access to their health data via technologies such as health information exchange (HIE) networks, patient portals, and personal health records.

Bidirectional HIE technology can be used to improve resident and family engagement in nursing homes. Electronic HIE networks allow providers, nurses, pharmacists, and patients to access and securely share medical information electronically, contributing to timely, safe, and cost-effective care. Despite the growing availability of secure electronic data exchange, most patients are still relying on paper-based records that they carry from one appointment to the next [9]. Improving the quality of care for nursing home residents requires HIE between a variety of stakeholders. In nursing homes, HIE is used frequently to monitor resident care tasks, coordinate and authorize care plans, communicate about resident care, and manage administrative and financial activities [10]. Without these exchange capabilities, nursing home providers face greater risk of breaks in vital communication about resident care, using incomplete clinical data, and experiencing limited capacity to make informed care decisions [10]. The potential benefit of HIE to nursing home residents includes improved communication among multiple providers, which may result in improved outcomes such as fewer medical errors, improved transitions in care, and reduced avoidable hospitalizations [11]. Although most HIE systems are used exclusively by providers, provision of access to these data to residents or residents’ representatives should be explored as an opportunity to promote engagement and person-centered care.

Promoting patient and family engagement using technological interfaces such as personal health records or patient portals has become a hot topic in health care. Patient portals are Web-based accounts that connect patients to their EHR. These “tethered” (ie, connected to the EHR) portals provide patients and family members with convenient and reliable access to information and offer resources to promote health by facilitating collaborative relationships between patients and providers, granting people access to and allowing them control over their personal health data, and promoting improved engagement in their health care [12]. Typical features of the patient portal include secure access to visit summaries, medication lists, test results, and appointment requests. More advanced functions such as secure messaging, access to educational resources, and the ability for the patient to enter data directly into the EHR are becoming more widely available. Recent empirical studies on patient portals have focused mainly on specific aspects of use (eg, use of specific functions such as secure messaging) and user characteristics, and almost all of these studies have been conducted in primary care and specialty clinics [13]. Although these studies hold promise for engaging patients in acute and outpatient settings, little is known about the use of patient-facing technologies, such as patient portals, by nursing home residents and their family members.

The purpose of this study was to assess resident access to technology in a nationally representative sample of US nursing homes and to explore the relationship between resident access to technology and overall IT adoption, called IT sophistication. The following research questions were used to guide the study:

1. What is the relationship between IT sophistication and nursing homes that have technology available to residents/residents’ representatives?
2. What is the relationship between IT sophistication and nursing homes that have technology available to residents/residents’ representatives after adjusting for type of ownership, bed size, and profit status?

3. How do specific resident-access components (ie, access to the EHR, personal health record, health information exchange, and self-reported data) impact total IT sophistication?

Methods

Design

We conducted a secondary analysis of data on the use of technology by residents and residents' representatives from a national survey of nursing home administrative leaders [14]. Nursing home administrators were chosen to complete the survey themselves or to identify a designee with oversight of IT systems. These administrators or designees were chosen because they had core knowledge of nursing home care processes and acted as managing officers in planning, organizing, directing, and controlling day-to-day operations in their facilities [15]. Nursing homes were randomly selected from each state using the Nursing Home Compare dataset. This publicly available dataset is maintained by the Centers for Medicare and Medicare Services [16]. The recruitment period used in this study was January 1, 2014, through July 31, 2015. This study was approved by the Institutional Review Board at the University of Missouri, Columbia (project number 1209004; exempt application number 116979).

Measures

We used a survey developed to measure nursing home IT adoption, called IT sophistication. A detailed description of the survey has been previously published elsewhere [14,17,18]. The survey contains a total of 50 questions related to three IT sophistication dimensions (IT capabilities, extent of IT use, and degree of internal and external IT integration) and three domains of care (resident care, clinical support, and administrative activities). The total IT sophistication score is calculated as the sum of responses in each of the three dimensions and three domains. The survey has been tested previously and determined to have good reliability and validity measures [17,19]. The Cronbach alpha values for the IT dimensions among the three clinical domains of resident care, clinical support, and administrative activities are 0.87-0.88, 0.86-0.91, and 0.69-0.80, respectively [14].

If a respondent indicated that they had the capability to offer residents or their representatives access to technology, they were asked to rate the extent to which residents or their representatives use that technology. If the respondent indicated no capability, they were not asked about the extent of IT use. The third dimension of IT sophistication (degree of IT integration) was not relevant to this secondary analysis.

To answer our research questions, we focused on four questions in the survey related to the dimension, extent of use, domain, and resident care. These questions specifically inquire about residents' or resident representatives' use of technology (Textbox 1).

Participants were asked to rate the extent of use of technology by residents or residents' representatives on a scale of 0-6 points, with 0 indicating "not at all" and 6 indicating "very much." We calculated a cumulative score using data from the questions in Textbox 1 for each home with a minimum score of 0 and maximum score of 24. For example, a nursing home with a total of 18 points could have reported a score of 6 for question 1 (use of EHR), 6 for question 2 (use of personal health record), 6 for question 3 (use of HIE), but 0 for question 4 (self-reported data).

Sample

The sampling strategy used in the primary study has been published elsewhere [14,18]. The final sample consisted of 815 nursing home leaders from every US state (except for Guam, Puerto Rico, and US Virgin Islands). Nursing homes were not stratified by the characteristics of location (eg, rural/urban), bed size (eg, <60 beds, 60-120 beds, >120 beds), and ownership (eg, for profit/not for profit) prior to random selection in case there was inadequate representation of these characteristics in some states. For example, Wyoming has a total of 38 nursing homes in the state, so there may not be any large homes in rural areas. This approach was used to ensure each facility had an equal opportunity to participate regardless of the characteristics of location, bed size, and ownership.

Data Analysis

Descriptive statistics were used to characterize the sample by using frequencies, means, and SDs. Simple linear regressions were conducted to examine the univariate relationships between IT sophistication and resident access to technology including access to EHR, patient portal, and HIE network and ability to self-enter data into the EHR. The dependent variable in the analysis was total IT sophistication (total_IT*), and the independent variable was resident access to technology (Res_Tech). Note that the Res_Tech variable makes a direct contribution to the total_IT*. Consequently, to assess the effect of Res_Tech on total_IT*, we decided to construct a new variable, which is total_IT* minus the contribution of Res_Tech. We performed the analysis first using the unadjusted total IT sophistication score and again using the new variable (total_IT*) to see if this changed the results. Ultimately, there was little difference when using the new variable in the analysis, so we decided to proceed with total_IT* as the dependent variable because we considered this to be a more statistically sound approach. We also calculated values of variance inflation factors to check for multicollinearity. In this case, the values were between 1 and 1.5, indicating multicollinearity, and the variance inflation factors were of little concern in the models presented.

Textbox 1. Survey questions related to the extent of use of technology by the residents or residents' representatives.

1. Resident or residents' representative use of electronic health records
2. Resident or residents' representative use of personal health records
3. Resident or residents' representative use of health information exchange
4. Resident or residents' representative use of self-reported data into an electronic health record

Next, covariates of location, bed size, and ownership were added to the model to understand their potential influence on the relationship between IT sophistication and resident access to technology. Lastly, we examined four components of Res_Tech—residents’ or their representatives’ use of EHRs, use of personal health records or the patient portal, use of health information exchange, and ability to enter self-reported data into the EHR—to understand their unique contribution to the overall IT sophistication score. SAS software, version 9 (SAS Institute Inc, Cary, NC) was used for all analyses.

Results

Of the 815 nursing homes included in this sample, 702 had a total Res_Tech score of 0, indicating no resident access to technology. Despite having a total Res_Tech score of 0, several of these homes had very high total_IT* sophistication (range 24.8-716.3; mean 282.6; SD 127.7). Sixteen homes in our sample had total Res_Tech scores of ≥12, indicating that these homes have a high extent of use of technology by residents or residents’ representatives. Demographic characteristics of the sample as well as those with a Res_Tech score of ≥12 are described in Table 1.

To address the first research question, we examined the contribution of Res_Tech to total_IT* sophistication (scored on a scale of 0 to 24 points). Table 2 shows the weighted means of total_IT* for each level of Res_Tech. The mean for each level was found using the Survey Means procedure with a Domain statement. Table 3 shows mean the Res_Tech scores according to nursing homes in the lower 20%, middle 20%, and upper 20% of total_IT* sophistication.

Figure 1 shows skeletal boxplots for the weighted means of total_IT* sophistication scores for each level of the scale. Overall, there appears to be an upward trend in the plot, indicating a positive correlation between total_IT* sophistication and the total Res_Tech score.

We used regression techniques to model the relationship between total_IT* sophistication and Res_Tech scores. We used the SurveyReg procedure to determine if the slope of the fitted regression line was significantly different from 0. It was different from 0, with an estimated slope of 17.7 (R^2=0.15; F=94.39; P<.001).

In order to address the second research question, we examined the model when the three covariates (nursing home characteristics) of location, bed size, and ownership with their interactions were included in the model. In this case, the estimated slope changed slightly to 17.3 (R^2=0.22; F=71.35; P<.001) indicating a small effect on including these characteristics in the model (Table 4).

Finally, to address the third research question, we assessed the contribution of each component (questions 1-4) of the Res_Tech score. Using the Total_IT* as the response variable, we fit a regression model using the four questions as predictors. Questions 3 and 4 were not statistically significant. Fitting a model with questions 1 and 2 showed that both were significant predictors (P<.001). The estimated coefficients were 29.7 and 29.0, respectively.

Table 1. Characteristics of nursing homes completing the survey and those with Res_Tech scores ≥12.

Characteristics	Sample (N=815)	Nursing homes with Res_Tech[a] scores ≥12
Ownership, n (%)		
For-profit corporation	448 (54.9)	11 (68.7)
Individual	25 (3.1)	0
Limited liability	6 (0.7)	0
Partnership	64 (7.9)	0
Government	6 (0.7)	0
Nonprofit	266 (32.7)	5 (45.4)
Location, n (%)		
Metro (population >50,000)	478 (58.7)	11 (68.7)
Micro (10,000-49,999)	126 (15.5)	3 (18.7)
Small town (2500-9999)	114 (14)	1 (6.2)
Rural (<2500)	97 (12)	1 (6.2)
Number of beds, n (%)		
>120 beds	191 (23.4)	5 (45.4)
60-120 beds	472 (57.9)	8 (56.2)
<60 beds	152 (18.6)	3 (18.7)
Total IT sophistication score (mean)	299.3	555.8

[a] Res_Tech: resident access to technology scores.

Table 2. Means of total IT sophistication for each level of resident access to technology.

Res_Tech[a] score	n	Mean	Standard error
0	702	282.6	5.7
1	16	300.0	23.3
2	13	417.6	39.1
3	16	312.5	28.1
4	22	460.6	27.5
5	5	283.3	42.0
6	11	491.4	39.0
7	3	352.3	10.6
8	7	479.2	62.1
9	2	439.1	66.7
10	2	526.6	97.8
12	5	467.2	49.3
16	1	613.9	0.0
18	4	493.6	24.4
20	1	646.9	0.0
24	5	665.7	74.4

[a] Res_Tech: Resident access to technology.

Table 3. Resident access to technology scores classified by lower 20% (total_IT*≤175.2), middle 20% (40th-60th percentile; total_IT* between 244.6 and 323.8), and upper 20% (total_IT*≥414.7) of total IT sophistication.

Total_IT*[a] group	Mean	Minimum	25th percentile	Median	75th percentile	Maximum
Lower 20%	0.05	0	0	0	0	5
Middle 20%	0.32	0	0	0	0	8
Upper 20%	2.79	0	0	0	4	24

[a] Total_IT*: total information technology sophistication.

Figure 1. Weighted means of total IT sophistication scores (total_IT*=total_IT–Res_Tech) for each level of resident or resident representative’s access to technology (Res_Tech). Total_IT*: total information technology sophistication; Res_Tech: resident access to technology.

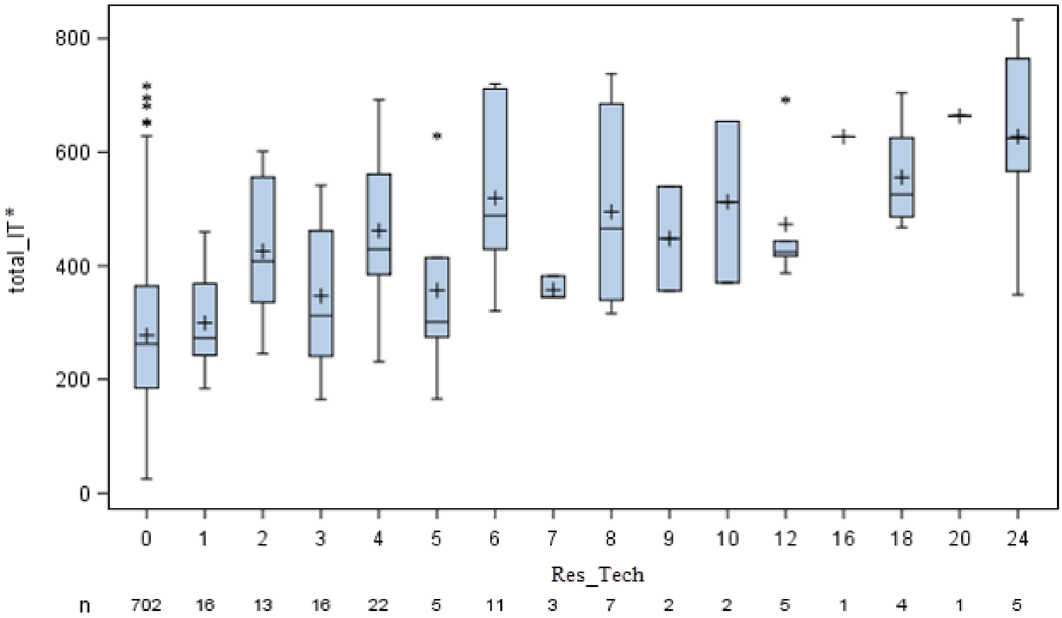

Table 4. Model total IT sophistication predicted by resident access to technology (covariates included).

Parameter	Estimate	Standard error	*P* value
Intercept	544.88	0.00	<.001
Res_Tech[a]	17.30	1.95	<.001
Location - metro	–215.89	20.23	<.001
Location - micro	–183.35	33.58	<.001
Location - rural	–166.98	78.86	.04
Location - small town	Reference	Reference	—[b]
Bed size 60-120	–304.47	35.03	<.001
Bed size <60	–275.61	52.60	<.001
Bed size >120	Reference	Reference	—

[a] Res_Tech: Resident access to technology.

[b] Not available.

Discussion

Principal Findings and Overview

Through this secondary analysis of national survey data, we examined the extent to which nursing homes allow residents and their representatives to access technology and compared these capabilities to overall IT sophistication. We found nursing homes with higher capabilities for resident access to technology have higher overall IT sophistication. As nursing homes continue to progress in technological capabilities, it is important to understand the impact of IT on outcomes and which technologies make a difference. This understanding will help nursing home administrators make informed decisions about adoption of technology and how it might be used to facilitate resident engagement and promote person-centered care.

The relationship we found between resident access to technology and overall IT sophistication in nursing homes is important for several reasons. First, it is clear that existing technological capabilities for nursing homes span a wide range. On one end, there are homes with highly sophisticated and integrated IT systems; however, they do not extend the use of these systems to residents and their family members. Of the 815 nursing homes included in this analysis, 702 (about 86%) homes had a total Res_Tech score of 0, indicating no resident access to technology. This implies that nursing homes are choosing to make IT investments in other areas rather than in patient-facing technologies. It is not known if this is due to limits in technical capabilities (ie, they do not have proper systems, infrastructure, or knowledgeable workforce to support resident access) or other reasons. In recent studies, providers have expressed concerns about patient-level access to health data, citing security, workflow, and regulatory concerns [20,21]. It is important to note, however, that none of these studies focused specifically on resident access to technology in nursing homes. Further research is needed to understand barriers to resident access that are unique to the nursing home setting and how they might be mitigated.

At the other end of the spectrum are nursing homes with high IT sophistication including some degree of resident access. There were 16 nursing homes in our study that had a Res_Tech score of ≥12. These nursing homes are early adopters of patient-facing technology and should be studied to understand how they are using this technology in the postacute setting. This was the first study of resident access to technology in nursing homes; thus, it establishes an important baseline upon which future work can be built. Future studies should explore the benefits and barriers as well as perceptions of patient-facing technologies in nursing homes and work to leverage these capabilities in a way that is most impactful for resident and family engagement.

In our study, resident access to the EHR and personal health record, or patient portal, was a significant contributor to predicting overall IT sophistication scores. Although nursing homes are ineligible for the Centers for Medicare and Medicaid Services incentive program, EHR adoption in nursing homes is growing. In 2016, the majority (64%) of US nursing homes had a fully implemented and operational EHR [22]. Having an EHR in place creates new opportunities for patient and family engagement, especially through the use of personal health records or patient portals. Although resident access to the EHR via a patient portal may be a new concept for nursing homes, patient-facing access is growing quickly in other sectors. As of 2015, 95% of hospitals in the United States provided patients with the ability to view their health information electronically and 69% allowed patients to view, download, and transmit their health information [23]. Patient portals are in their infancy, and evidence on their use remains largely limited to acute and ambulatory settings. Future research should explore the opportunities for enhanced portal use through training and development of features that residents and their families value and have the potential to improve care.

As EHRs become more mainstream in nursing homes, we can begin to explore their potential benefits such as connecting providers, patients, and other members of the interdisciplinary health care team via HIE to improve communication between stakeholders, transitions in care, and resident health outcomes. Although resident access to HIE systems was not a significant predictor of total IT sophistication in our study, we see value in resident access to these systems. In order to understand how

HIE systems could benefit nursing home staff, residents, and families, use cases have been developed to evaluate where HIE can have the most impact on communication and patient care [24]. Future studies should focus on the use of HIE by nursing home residents and resident representatives to better understand how these systems can be used to engage them in shared decision making, which is the cornerstone of person-centered care.

Limitations

This paper reports on a secondary analysis of a national survey, and thus, response bias for nursing homes that choose not to participate in the survey should be considered a limitation. Some nursing homes may have chosen not to participate because they had no technology that could report higher overall IT sophistication than what actually exists. Analyses were limited to data available from the national IT sophistication survey; therefore, no direct measurement of resident or provider perceptions of access to technology were available. This study did not include measurement of health care outcomes, so it is not known whether residents' access to technology facilitates self-management of health and health care. Finally, generalizability of findings is limited, and causality should not be implied as the result of this secondary analysis.

Conclusions

Patient-facing technologies have only recently been introduced in postacute health care settings like nursing homes. Analyzing the extent to which residents have access to technology in a nationally representative sample is the first step toward understanding the benefits of and barriers to implementation. Engaging nursing home residents and their families through the use of technology has the potential to improve outcomes and promote person-centered care. However, to realize these potential improvements, we must learn more about how residents' access to these technologies can be tailored for use in nursing homes and the perceived usefulness among various stakeholders including patients, family members, and their care teams.

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Conflicts of Interest

None declared.

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Abbreviations

IT: information technology
EHR: electronic health record
HIE: health information exchange
Total_IT*: total information technology sophistication
Res_Tech: resident access to technology

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Original Paper

Prevalence and Factors Influencing Use of Internet and Electronic Health Resources by Middle-Aged and Older Adults in a US Health Plan Population: Cross-Sectional Survey Study

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Abstract

Background: Health care organizations are increasingly using electronic health (eHealth) platforms to provide and exchange health information and advice (HIA). There is limited information about how factors beyond internet access affect use of eHealth resources by middle-aged and older adults.

Objective: We aimed to estimate prevalence of use of the internet, health plan patient portal, and Web-based HIA among middle-aged and older adults; investigate whether similar sociodemographic-related disparities in eHealth resource use are found among middle-aged and older adults; and examine how sociodemographic and internet access factors drive disparities in eHealth resource use among adults who use the internet.

Methods: We analyzed cross-sectional survey data for 10,920 Northern California health plan members aged 45 to 85 years who responded to a mailed and Web-based health survey (2014-2015). We used bivariate and multivariable analyses with weighted data to estimate prevalence of and identify factors associated with internet use and self-reported past year use of the health plan's patient portal and Web-based HIA resources by middle-aged adults (aged 45 to 65 years; n=5520), younger seniors (aged 65 to 75 years; n=3014), and older seniors (aged 76 to 85 years; n=2389).

Results: Although approximately 96% of middle-aged adults, 92% of younger seniors, and 76% of older seniors use the internet to obtain information, about 4%, 9%, and 16%, respectively, require someone's help to do so. The percentages who used the patient portal and Web-based HIA resources were similar for middle-aged adults and younger seniors but lower among older seniors (59.6%, 61.4%, and 45.0% and 47.9%, 48.4%, and 37.5%, respectively). Disparities in use of the internet, patient portal, and Web-based HIA across levels of education and between low and higher income were observed in all age groups, with wider disparities between low and high levels of education and income among seniors. Multivariable analyses showed that for all 3 age groups, educational attainment, ability to use the internet without help, and having 1 or more chronic condition were significant predictors of patient portal and Web-based HIA use after controlling for gender, race/ethnicity, and internet use.

Conclusions: Internet use, and especially use without help, significantly declines with age, even within a middle-aged group. Educational attainment is significantly associated with internet use, ability to use the internet without help, and use of patient portal and Web-based HIA resources by middle-aged and older adults. Even among middle-aged and older adult internet users, higher educational attainment and ability to use the internet without help are positively associated with patient portal and Web-based HIA use. Organizations serving middle-aged and older adults should take into account target population characteristics when developing and evaluating uptake of eHealth resources and should consider offering instruction and support services to boost patient engagement.

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KEYWORDS

digital divide; patient portal; information-seeking behavior; health education; patient preference; patient surveys

Introduction

The internet is often used as a source of health information by individuals interested in learning about new diagnoses, options, medications, or healthy behaviors [1-3]. Web-based patient portals provide individuals continuous access to test results and other information in their electronic health records and a convenient way to communicate with their health care providers, order medications, and arrange for appointments. Digital information technologies (DITs) can also connect patients and providers without a physical office visit, allowing providers to tailor care to patient-specific needs and preferences [4] and to conduct remote monitoring of health conditions [5,6]. Online support groups, chat rooms, and forums provide the opportunity for peer-to-peer sharing of health information and advice (HIA), as well as potentially serving as a source of support to adults who are socially isolated [7].

Because middle-aged and older adults are more likely to be managing chronic conditions than younger adults [8] or to be caregivers for family members with health problems, individuals in these age groups potentially have the most to gain from using the profusion of health resources available on the internet. It has been well-documented that in the United States, seniors (aged ≥ 65 years) are less likely than younger and middle-aged adults to use the internet, email, and patient portals and to trust the internet as a source of health information [9,10] and that within the senior age group, there are disparities by older age (>75 years), race/ethnicity, education, and income among older adults in use of DIT and specifically use for health-related purposes [9,11-18]. Less is known about the use of DIT and internet-based health information resources by middle-aged adults, who, like seniors, are not *digital natives* as they did not have the opportunity to learn to use computers, smartphones, the internet, and email during childhood [19-22].

In response to Meaningful Use requirements and recognized advantages of using a Web-based platform for secure communications and health information sharing, health care organizations have been investing substantial resources in developing user-friendly patient portals and health information websites, hoping that health plan members will transition to these Web-based resources for exchanging health information. Increasing adults' access to the internet and use of the internet and digital technologies for health-related purposes are also US governmental goals for the American public, stated in *Healthy People 2020* [23]. Although this transition is probably easy and welcomed by most younger adults, the same should not be assumed for middle-aged and older adults, many of whom did not have the opportunity to use computers, mobile devices, and the internet at school or on the job. Awareness of characteristics of middle-aged and older adult patients that may contribute to lower likelihood of engaging with patient portals and Web-based health information resources, combined with information about the sociodemographic characteristics of middle-aged and older adults in a target patient population, can help health care organizations plan and monitor this transition to electronic health (eHealth) platforms and identify segments of the patient population that may need a higher level of outreach and support to make this transition.

This study had several aims. First, we wanted to estimate and compare prevalence of use of the internet, patient portal, and Web-based health information resources among middle-aged, younger senior, and older senior adult members of a large Northern California, United States, health plan that had a well-established patient portal and health information website. Second, we wanted to examine the extent to which prevalence of the use of Web-based health resources was due to not being an internet user. Third, we wanted to learn whether sociodemographic factors known to be associated with disparities in use of the internet and Web-based health resources among older adults operated similarly among middle-aged adults. Fourth, we wanted to learn whether these sociodemographic factors remained significant predictors of use of Web-based health resources among those who were using the internet alone or with someone's help. Finally, we wanted to learn whether the ability to use the internet without assistance from another person, having easy access to a computer for using the internet, and having a chronic health condition influenced likelihood of using Web-based health resources beyond sociodemographic factors.

Methods

Setting

Kaiser Permanente in Northern California (KPNC) is a vertically integrated health care delivery system that serves over 2.5 million adult members who mostly reside in the San Francisco Bay Area, Silicon Valley, Sacramento area, or Central Valley, California, United States. The sociodemographically diverse KPNC adult membership is very similar to the insured population of Northern California with regard to demographic and health characteristics [24]. KPNC has a comprehensive website that provides information about health plan benefits and resources and health information (eg, about health conditions, medications, and healthy behaviors/lifestyle) that is accessible to both members and the general public and a secure patient portal that is only available to health plan members who register for and activate a patient portal account. For several years, the health plan has encouraged members to obtain HIA and communicate with health care providers using its website and patient portal.

Survey Sample

This study used data obtained from 5520 middle-aged adults (aged 45 to 65 years), 3014 younger seniors (aged 66 to 75 years), and 2389 older seniors (aged 76 to 85 years) who responded to the 2014/2015 cycle of the KPNC Member Health Survey (MHS). The MHS is a self-administered (mailed print and Web-based) survey that has been sent to independent stratified random samples of adults every 3 years beginning in 1993. The survey, which is only conducted in English, captures information about sociodemographic and health-related characteristics as well as access to different electronic modes of communication, sources used to obtain health information in the past year, and interest in using different modalities to obtain HIA. More information about the survey is available in an earlier publication [9] and on the survey website [25]. In the 2014/2015 cycle, the overall response rate was 49.3% for members aged between 45 and 85 years (40.9% for those aged between 45 and 65 years and 64.5% for those aged between 66 and 85 years).

Study Variables

Sociodemographic Characteristics

Age group (45 to 65, 66 to 75, and 76 to 85 years for age group comparisons; 45 to 55, 56 to 65, 66 to 70, 71 to 75, 76 to 80, and 81 to 85 years for regression models), gender (female and male), race/ethnicity (white, black, Latino, Filipino, East Asian, other Asian, Pacific Islander, and other), educational attainment (<high school graduate, high school graduate/GED/technical school, some college, and college graduate), and household income (US $35,000 to $50,000, $50,001 to $65,000, $65,001 to $80,000, $80,001 to $100,000, and >$100,000).

Health Characteristics

Self-rated health (excellent/very good, good, and fair/poor) and 1 or more chronic health condition in the past 12 months (diabetes, high blood pressure, heart condition, cancer, chronic obstructive pulmonary disease (COPD), chronic pain, severe musculoskeletal pain, severe headaches or migraines, depression, anxiety, and insomnia).

Use of Digital Technology

Uses the internet to get information from websites, uses the internet without help from another person, and has access to a computer or tablet if they want to use one.

Use of Web-Based Health Resources in Past 12 Months

Patient portal users were those who indicated having used the health plan's patient portal to email clinicians, view lab results, or refill prescriptions. Users of Web-based health information (HIA) resources were those who reported having obtained HIA from any website, using Web-based patient education programs (eg, preparing for a procedure, health calculator, or health lifestyle programs for nutrition, weight, stress, or exercise) or podcasts found on the health plan's website, or participating in an online chat room or community related to a health condition. Adults who had used Web-based HIA resources and/or the patient portal were considered to be eHealth or Web-based health resource users.

Data Analysis

All analyses were performed using SAS version 9.4 procedures for data from complex survey designs (SAS Institute, Cary, NC 2014) and data weighted to the age, gender, and geographic composition of the KPNC adult membership in 2014. Proc Surveyfreq was used to produce weighted percentages for our 4 outcomes of interest (use of the internet to obtain information, use of the internet without someone's help, use of the health plan's patient portal in the past year, and use of Web-based HIA resources in the past year) overall and by sociodemographic and health characteristics. We reported 95% margins of error around the estimated percentages that correspond to a 95% CI when added to or subtracted from the percentage estimate.

We examined the bivariate relationships of sociodemographic and health characteristics with these outcomes using bivariate Proc Surveylogistic models to test for statistically significant differences between subgroups as compared with a referent subgroup for each outcome. We then used multivariable logistic regression models to examine the independent association of these characteristics with each of the 4 outcomes after adjusting for the other characteristics. All logistic regression models included indicator variables for age group (reference group: aged 45 to 55 years for middle-aged, 66 to 70 years for young seniors, and 76 to 80 years for older seniors), gender (reference group: male), race/ethnicity (reference group: white non-Hispanic), education (reference group: college graduate), and income (reference group: ≤ $35,000). Models that predicted use of the health plan's patient portal and Web-based HIA resources during the previous year additionally used indicator variables for internet use status (reference group: uses internet by self, compared with no internet use to obtain information and use with someone's help), easy access to a computer (reference group: lacks easy computer access), and having 1 or more chronic condition (reference group: none of the chronic conditions) in addition to the sociodemographic factors. Indicator variables for unknown education and income were included in all models so that results would be based on the full age group. In supplemental files, we reported the results of multivariate logistic regression models of patient portal and Web-based HIA resource use that did not include the internet use of computer variables. All differences between subgroups mentioned in the text are statistically significant at $P<.05$ or greater; if differences are not mentioned, they did not reach that threshold. Although we did not adjust for multiple comparisons, we have reported results of all statistical comparisons.

Ethics

This study was approved by KPNC's Institutional Review Board.

Results

Characteristics of Survey Respondents

Table 1 provides a description of the characteristics of the middle-aged, younger senior, and older senior groups.

Table 1. Characteristics of middle-aged and older adult study groups.

Characteristics	45 to 65 years (n=5520), n (%)[a]	66 to 75 years (n=3014), n (%)	76 to 85 years (n=2389), n (%)
Age (years)			
45-55	2563 (54.9)	—[b]	—
56-65	2957 (45.1)	—	—
66-70	—	1521 (60.2)	—
71-75	—	1493 (39.8)	—
76-80	—	—	1956 (57.7)
81-85	—	—	433 (42.3)
Gender			
Male	2551 (47.7)	1482 (46.1)	1268 (45.0)
Female	2969 (52.3)	1532 (53.9)	1121 (55.0)
Race/ethnicity			
White non-Hispanic	3214 (58.4)	2109 (71.6)[c]	1695 (74.1)[c]
Black	429 (7.0)	195(6.0)	147 (6.0)
Hispanic	763 (13.6)	242 (7.2)[b]	238 (8.7)[b]
Filipino	312 (5.5)	160(4.8)	107 (3.7)
East Asian	509 (9.2)	176 (5.7)[c]	133 (4.9)[c]
Other Asian	143 (3.5)	59 (2.4)	27 (0.8)
Other	150 (2.8)	73 (2.3)	42 (1.8)
Education			
<12 years	143 (2.5)	117 (3.1)	188 (8.9)[c,d]
High school graduate/General Education Development	1025 (18.7)	596 (18.4)	654 (29.8)
Some college/AA degree	1878 (33.6)	1023 (35.1)	739 (29.9)
College graduate	2444 (45.2)	1250 (43.4)	781 (31.3)[c,d]
Household income (US $)			
<$25,000	389 (7.1)	355 (11.6)[c]	469 (24.5)[c,d]
$25,001-$35,000	273 (4.6)	300 (10.5)	292 (14.0)
$35,001-$50,000	547 (9.9)	413 (14.4)	402 (20.4)
$50,001-$65,000	527 (9.6)	328 (11.9)	278 (11.9)
$65,001-$80,000	639 (12.0)	365 (13.7)	233 (10.1)
$80,001-$100,000	800 (14.9)	360 (13.9)	192 (8.6)
>$100,000	2084 (41.9)	639 (23.9)[c]	254 (10.4)[c,d]
Health Status			
Excellent/very good	2932 (54.1)	1400 (48.3)[c]	815 (33.4)[c,d]
Good	1956 (35.6)	1152 (37.5)	1092 (45.7)
Fair/poor	627 (10.3)	454 (14.2)[c]	474 (20.8)[c,d]
More than one chronic condition[e]			
No	1909 (35.9)	621 (21.6)	369 (15.2)
Yes	3611 (64.1)	2393 (78.4)[c]	2020 (84.8)[c,d]
Uses the internet to get information from websites			

Characteristics	45 to 65 years (n=5520), n (%)[a]	66 to 75 years (n=3014), n (%)	76 to 85 years (n=2389), n (%)
Does not use	249 (3.9)	382 (10.6)[c]	651 (31.1)[c,d]
Uses with someone’s help or someone uses it for them	231 (4.0)	280 (8.6)	368 (15.7)
Uses by self	5038 (92.0)	2350 (80.8)[c]	1365 (53.2)[c,d]
Has easy access to a computer			
No	222 (3.6)	294 (8.2)	501 (24.2)
Yes	5276 (96.4)	2688 (91.8)[c]	1848 (75.8)[c,d]

[a] n: unweighted count; %: percentage of age group with this characteristic based on weighted survey data.

[b] Not applicable.

[c] Significantly different from the 45 to 65 age group at $P<.001$.

[d] Significantly different from the 66 to 75 age group at $P<.001$.

[e] Chronic condition: diabetes, high blood pressure, heart condition, cancer, COPD/chronic bronchitis, chronic pain, depression, anxiety, or insomnia, based on self-report.

Slightly over half of each age group is female. Compared with the middle-aged group, the 2 senior groups have higher percentages of non-Hispanic whites (approximately 70% vs 58%) and lower percentages of Hispanics (approximately 7% vs 14%) and East Asians (approximately 5% vs 9%), with no difference in percentages of blacks and Filipinos. Although the middle-aged and younger senior groups are similar with regard to educational attainment (>40% college graduates and approximately 20% high school graduates or less), the percentage of older seniors with a college degree is significantly lower (31%) and the percentage with no formal education beyond high school (39%) is significantly higher than the younger groups. The percentage considered lower income for the San Francisco Bay Area (≤$35,000) significantly increases with age (approximately 12%, 22%, and 39%, respectively), whereas the percentages with higher incomes (>$80,000) decreases with age (approximately 57%, 38%, and 19%). The percentage of adults who consider their health to be very good/excellent decreases with age, and the percentages with fair/poor health and 1 or more chronic health condition increase with age.

Table 1 also shows that easy access to a computer or tablet, use of the internet to obtain information from websites (by oneself or with someone’s help), and use of the internet without someone’s help declines with age group, with younger seniors significantly less likely than middle-aged adults, and older seniors significantly less likely than younger seniors to be using the internet (96%, 89%, and 69%, respectively) and have easy access to a computer (96%, 92%, and 76%, respectively). Figure 1 shows that in this health plan population, middle-aged adults are less likely than younger adults (aged between 20 and 44 years) to be using the internet to obtain information from websites, but also that there is a significant decline within the middle-aged and older adult age groups. Figure 1 also shows that there is an even steeper age-related decline in the ability to use the internet without the help of another person.

Use of the Internet to Obtain Information

Table 2 shows how internet use to obtain information varies by sociodemographic characteristics within and across the 3 age groups. For each age group, we presented the estimated percentage of internet users in different categories of sociodemographic factors, indicating whether categories of sociodemographic factors significantly differ from the referent group for that factor. We also report the adjusted odds ratios (AOR) for these characteristics after adjusting for the other sociodemographic factors. Within all 3 age groups, blacks, Hispanics, and Filipinos are less likely to be using the internet, whereas the percentages of East Asians who use the internet are similar to whites. In all 3 groups, prevalence of internet use increases with higher educational attainment. Internet use is lower among those with a household income ≤$35,000 compared with >$35,000 but, unlike with education, does not significantly increase at higher levels. In the multivariable models for all 3 age groups, educational attainment, low income, and younger age within that age group remain significant independent predictors of using the internet. In the 2 younger groups, blacks, Hispanics, and Filipinos remain significantly less likely to be internet users, whereas in the older senior group, only Hispanics remain significantly less likely to use the internet. Although the logistic regression models for all 3 age groups show similar AORs for sociodemographic characteristics, comparing percentages across age groups, for both sexes, all race/ethnicities and levels of education, and nearly all income levels, internet use is significantly ($P<.05$ or greater) higher among middle-aged adults than younger seniors and significantly higher among younger seniors than older seniors. In Table 3, the same patterns are observed for use of the internet without another person’s help. However, consistent with Figure 1, the percentages of adults who use the internet by themselves are substantially lower than internet use with or without help, especially among those at the lowest levels of education and income. In Multimedia Appendix 1, we show that significant disparities by race/ethnicity, education, and income persist in the percentages of internet users who use the internet without help.

Figure 1. Percentages of adult health plan members aged 20-85 who use the internet to get information from websites, by age group.

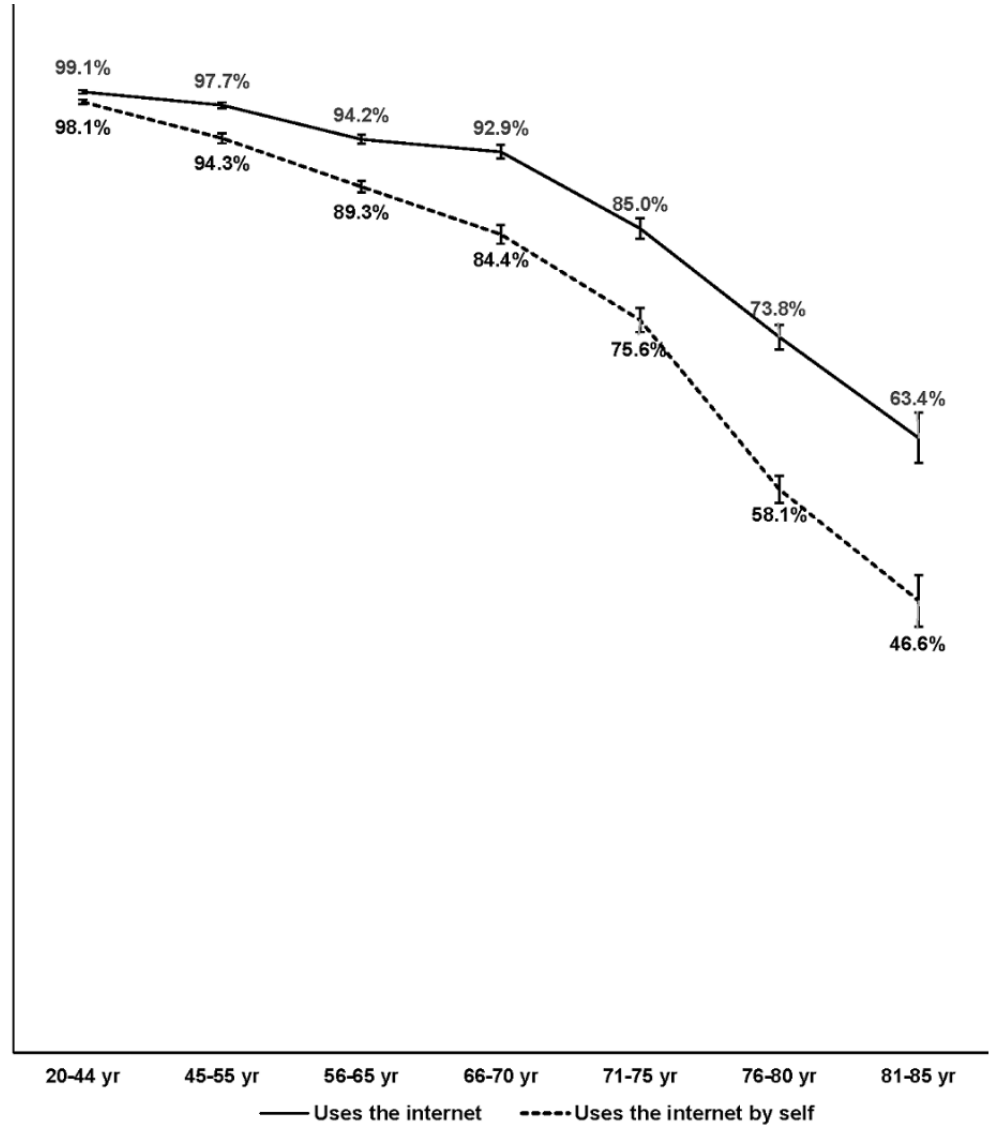

Figure 2 shows that for all age groups, internet use was higher among adults in excellent/very good health than adults in good health, whereas adults in fair/poor health were less likely to use the internet than those in good health. However, when we controlled for sociodemographic characteristics, health status was not significantly associated with internet use among middle-aged adults. In both senior groups, having excellent/very good health versus good health remained a significant independent predictor of internet use (AOR 1.60, 95% CI 1.17-2.18 for younger seniors and AOR 1.56, 95% CI 1.12-2.16 for older seniors), but fair/poor health was not independently significant. Adults with 1 or more chronic condition were not more likely to use the internet than those with none of the chronic conditions.

Use of Web-Based Health Resources in Prior Year

The percentages of adults in each age group who used Web-Based health resources during the previous year are shown in Table 4**.** In contrast to the age group differences observed regarding internet use to get information from websites, middle-aged adults and younger seniors had similar rates of use of Web-Based health resources, with approximately 60% having used the patient portal, 48% having obtained HIA from a Web-based source, and 68% having used at least one of these eHealth resources. The older seniors were significantly less likely than both younger groups to have used the patient portal (52%), Web-based HIA (45%), or either Web-based resource (52%). When we examined eHealth use restricted to internet users, the difference between older seniors and the middle-aged adults goes away, and the younger senior group has significantly higher percentages using these Web-based resources than the middle-aged and older senior groups.

Table 2. Sociodemographic characteristics differentiating middle-aged and older adults who report using the internet with or without someone's help to get information from websites.

Characteristic	45 to 65 years, weighted % (MoE[a])	66 to 75 years, weighted % (MoE)	76 to 85 years, weighted % (MoE)	45 to 65 years, AOR[b] (95% CI)	66 to 75 years, AOR (95% CI)	76 to 85 years, AOR (95% CI)
Age group						
Younger age[c] (ref[d])	97.7 (0.6)	92.9 (1.4)	73.8 (2.5)	(ref)	(ref)	(ref)
Older age[c]	94.2 (0.9)[e]	85.0 (2.0)[e]	63.4 (5.1)[e]	0.37 (0.26-0.52)[e]	0.51 (0.39-0.68)[e]	0.66 (0.50-0.88)[f]
Gender						
Male (ref)	95.7 (0.8)	89.9 (1.7)	75.6 (3.1)	(ref)	(ref)	(ref)
Female	96.6 (0.7)	89.7 (1.6	64.2 (3.9)[e]	1.69 (1.25-2.29)[e]	1.29 (0.97-1.73)	0.83 (0.64-1.07)
Race/Ethnicity						
White non-Hispanic (ref)	97.4 (0.6)	92.4 (1.2)	72.9 (3.0)	(ref)	(ref)	(ref)
Black	91.9 (2.6)[e]	78.8 (6.3)[e]	63.2 (11.2)	0.45 (0.29-0.70)[e]	0.42 (0.27-0.67)[e]	0.82 (0.45-1.49)
Hispanic	93.2 (1.9)[e]	81.2 (5.2)[e]	46.4 (8.0)[e]	0.58 (0.38-0.88)[f]	0.53 (0.35-0.81)[f]	0.52 (0.35-0.76)[e]
Filipino	93.8 (2.6)[e]	76.0 (7.4)[e]	62.0 (11.8)	0.35 (0.12-0.99)[f]	0.11 (0.03-0.38)[e]	0.99 (0.30-3.28)
East Asian	98.0 (1.2)	89.3 (4.8)	68.7 (10.2)	0.97 (0.31-3.05)	0.28 (0.08-0.95)[g]	0.98 (0.32-2.99)
Education						
<High school graduate	80.7 (6.3)[e]	57.4 (10.1)[e]	37.5 (8.8)[e]	0.09 (0.04-0.17)[e]	0.09 (0.05-0.17)[e]	0.13 (0.08-0.22)[e]
High school graduate	90.3 (1.9)[e]	77.4 (3.7)[e]	52.7 (5.3)[e]	0.15 (0.09-0.28)[e]	0.17 (0.11-0.26)[e]	0.18 (0.12-0.27)[e]
Some college/AA degree	96.5 (0.9)[e]	90.8 (1.9)[e]	75.4 (4.4)[e]	0.38 (0.21-0.68)[e]	0.39 (0.25-0.59)[e]	0.45 (0.29-0.67)[e]
College graduate (ref)	99.2 (0.4)	96.7 (1.0)	89.1 (3.0)	(ref)	(ref)	(ref)
Household income (US $)						
≤$35,000 (ref)	84.0 (2.9)	76.1 (3.6)	52.8 (4.8)	(ref)	(ref)	(ref)
$35,001-$50,000	91.2 (2.5)[e]	88.0 (3.4)[e]	73.2 (6.0)[e]	1.90 (1.27-2.86)[f]	2.04 (1.36-3.04)[e]	1.97 (1.36-2.85)[e]
$50,001-$65,000	97.0 (1.6)[e]	92.6 (2.9)[e]	82.4 (5.7)[e]	5.83 (3.22-10.54)[e]	3.09 (1.86-5.12)[e]	2.83 (1.73-4.64)[e]
$65,001-$80,000	97.6 (1.3)[e]	94.8 (2.4)[e]	80.5 (6.9)[e]	5.73 (3.18-10.32)[e]	4.20 (2.37-7.45)[e]	2.31 (1.37-3.92)[f]
$80,001-$100,000	98.7 (0.7)[e]	95.5 (2.1)[e]	85.6 (6.3)[e]	9.95 (5.34-18.56)[e]	3.57 (2.02-6.30)[e]	2.32 (1.30-4.12)[e]
>$100,000	99.4 (0.3)[e]	96.7 (1.6)[e]	90.0 (4.9)[e]	13.79 (7.44-25.56)[e]	3.81 (2.09-6.94)[e]	3.34 (1.79-6.25)[e]
Model c-statistic[h]	—[i]	—	—	.87	.82	.75

[a] MoE: 95% margin of error around estimated percentage (95% confidence intervals can be created from percentage ± MoE).

[b] AOR: adjusted odds ratio from logistic regression model that includes age group, gender, race/ethnicity (including *Other Asian* and *Other* race/ethnicity categories), education, and household income.

[c] Younger age: 45 to 55 years, 66 to 70 years, 76 to 80 years; Older age: 56 to 65 years, 71 to 75 years, 81 to 85 years.

[d] Ref: reference group for comparison of variable categories.

[e] Significantly differs from reference group at *P*<.001.

[f] Significantly differs from reference group at *P*<.01.

[g] Significantly differs from reference group at *P*<.05.

[h] The model c-statistic assesses how well the full logistic regression model predicts which individuals use the internet to obtain information with or without help from other people.

[i] Not applicable.

Table 3. Sociodemographic characteristics differentiating middle-aged and older adults who report using the internet by themselves to get information from websites.

Characteristic	45 to 65 years, weighted % (MoE[a])	66 to 75 year, weighted % (MoE)	76 to 85 years, weighted % (MoE)	45 to 65 years, AOR[b] (95% CI)	66 to 75 years, AOR (95% CI)	76 to 85 years, AOR (95% CI)
Age group						
Younger age[c]	94.3 (1.0)	84.4 (1.9)	58.1 (2.7)	(ref[d])	(ref)	(ref)
Older age[c]	89.3 (1.2)[e]	75.6 (2.4)[e]	46.6 (5.2)[e]	0.46 (0.36-0.59)[e]	0.68 (0.54-0.85)[e]	0.64 (0.49-0.85)[e]
Gender						
Male (ref)	90.8 (1.2)	81.4 (2.1)	58.6 (3.5)	(ref)	(ref)	(ref)
Female	93.2 (1.0)[f]	80.4 (2.1)	48.9 (4.0)[e]	1.86 (1.46-2.36)[e]	1.19 (0.94-1.49)	0.96 (0.74-1.23)
Race/Ethnicity						
White non-Hispanic (ref)	94.5 (0.8)	85.4 (1.6)	58.5 (±3.2)	(ref)	(ref)	(ref)
Black	86.1 (±3.5)[e]	70.2 (7.2)[e]	39.0 (±10.6)[e]	0.49 (0.34-0.71)[e]	0.57 (0.38-0.85)[f]	0.54 (0.32-0.89)[g]
Hispanic	85.9 (2.7)[e]	69.3 (6.3)[e]	29.1 (6.7)[e]	0.58 (0.42-0.79)[e]	0.59 (0.41-0.86)[f]	0.48 (0.33-0.70)[e]
Filipino	84.6 (4.4)[e]	51.4 (8.6)[e]	21.5 (9.3)[e]	0.29 (0.12-0.69)[f]	0.46 (0.21-1.00)[h]	0.18 (0.06-0.51)[f]
East Asian	95.3 (1.8)	81.8 (6.1)	57.3 (10.8	1.07 (0.44-2.56)	2.32 (1.02-5.27)[g]	0.85 (0.32-2.27)
Education						
<High school graduate	53.6 (9.3)[e]	29.0 (9.8)[e]	13.4 (5.5)[e]	0.04 (0.02-0.06)[e]	0.05 (0.29-0.10)[e]	0.08 (0.05-0.14)[e]
High school graduate	81.4 (2.6)[e]	61.8 (2.6)[e]	36.0 (4.1)[e]	0.12 (0.08-0.18)[e]	0.16 (0.11-0.22)[e]	0.22 (0.16-0.32)[e]
Some college/AA degree	92.3 (1.2)[e]	82.0 (1.2)[e]	60.9 (4.7)[e]	0.29 (0.20-0.43)[e]	0.39 (0.29-0.53)[e]	0.58 (0.42-0.81)[f]
College graduate (ref)	98.4 (0.5)	92.1 (1.6)	74.2 (4.2)	(ref)	(ref)	(ref)
Household income (US $)						
<$35,000 (ref)	73.0 (3.7)	62.8 (4.1)	35.7 (4.5)	1.00[i]	1.00[i]	1.00[i]
$35,001-$50,000	84.4 (3.3)[e]	77.2 (4.4)[e]	58.1 (6.5)[e]	2.03 (1.44-2.97)[e]	1.75 (1.26-2.55)[e]	2.01 (1.40-2.91)[e]
$50,001-$65,000	89.8 (2.9)[e]	85.3 (4.0)[e]	62.3 (7.8)[e]	3.31 (2.23-4.92)[e]	2.57 (1.72-3.86)[e]	1.92 (1.21-3.06)[f]
$65,001-$80,000	94.6 (1.9)[e]	84.7 (3.9)[e]	63.6 (8.4)[e]	5.02 (3.25-7.77)[e]	2.19 (1.49-3.22)[e]	1.89 (1.21-2.95)[f]
$80,001-$100,000	95.5 (1.6)[e]	90.4 (3.2)[e]	73.1 (±8.0)[e]	5.63 (3.60-8.80)[e]	2.91 (1.86-4.53)[e]	2.27 (1.39-3.70)[e]
>$100,000	98.0 (0.6)[e]	92.5 (2.2)[e]	75.1 (7.1)[e]	8.75 (5.85-13.09)[e]	3.01 (1.97-4.61)[e]	2.29 (1.44-3.66)[e]
Model c-statistic[j]	—[k]	—	—	0.86	0.80	0.76

[a] MoE: 95% margin of error around estimated percentage (95% confidence intervals can be created from percentage ± MoE).

[b] AOR: adjusted odds ratio from logistic regression model that includes older age within age group, gender, race/ethnicity (including *Other Asian* and *Other* race/ethnicity categories), education, and household income.

[c] Younger age: 45-55 year, 66-70 year, 76-80 year; older age: 56-65 year, 71-75 year, 81-85 year.

[d] Ref: reference group for comparison of variable categories.

[e] Significantly differs from reference group at *P*<.001.

[f] Significantly differs from reference group at *P*<.01.

[g] Significantly differs from reference group at *P*<.05.

[h] Significantly differs from reference group at *P*<.051.

[i] 95% CI not applicable.

[j] The model c-statistic assesses how well the full logistic regression model predicts which individuals use the internet to obtain information without help from other people.

[k] Not applicable.

Figure 2. Percentages of middle-aged and older adults who use the internet to get information from websites, by self-rated health.

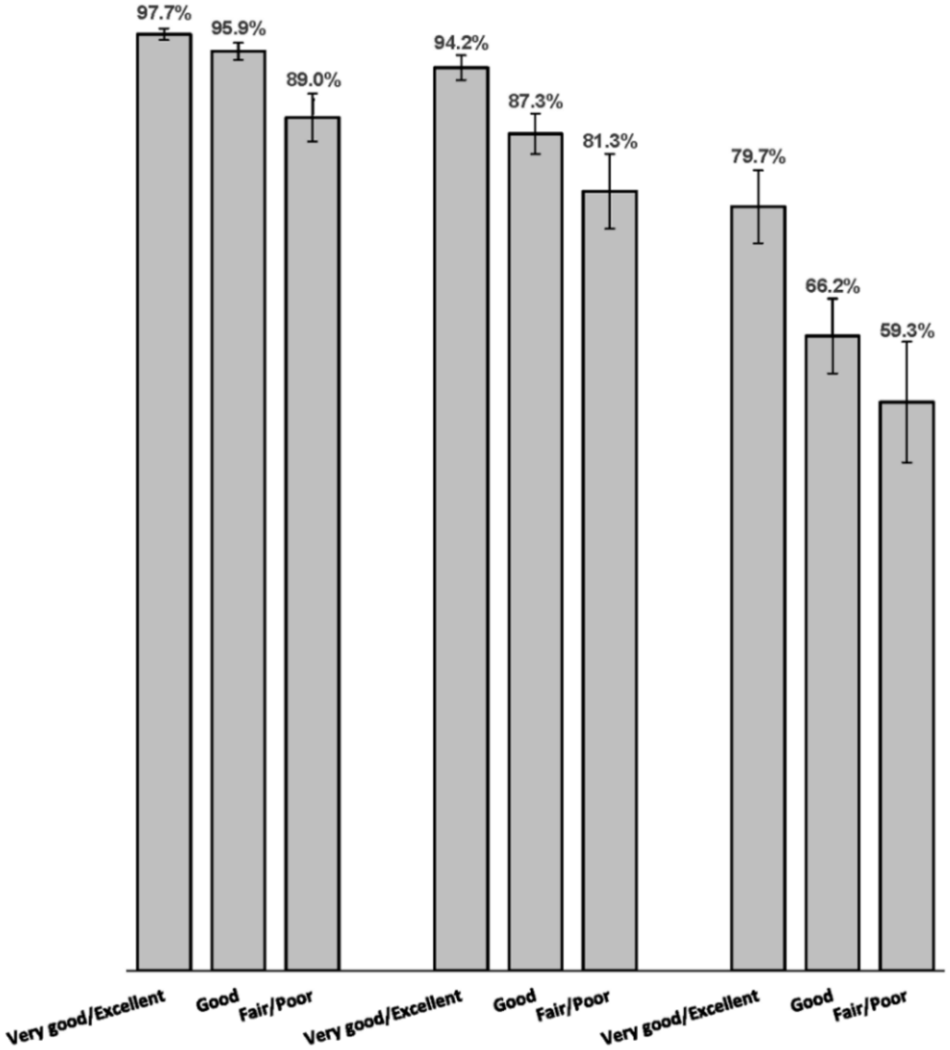

Table 4. Use of Web-based health resources by middle-aged and older adults in the past year, all and internet users.

Web-based health resource	45 to 65 years, % (95% CI)	66 to 75 years, % (95% CI)	76 to 85 years, % (95% CI)
Used health plan patient portal or Web-based HIA[a] resource			
All	69.0 (67.8-70.2)	68.1 (66.5-69.8)	52.2 (50.2-54.2)[b,c]
Internet users[d]	72.1 (70.9-73.3)	77.4 (75.8-78.9)[b]	70.5 (68.3-72.6)[c]
Used health plan's patient portal to send email, check lab results, or order a prescription refill			
All	59.6 (58.3-60.9)	61.4 (59.7-63.1)	45.0 (43.0-47.0)[b,c]
Internet users	62.3 (61.0-63.6)	69.7 (67.9-71.4)[b]	60.8 (58.5-63.0)[c]
Obtained HIA from a Web-based source			
All	47.9 (46.6-49.2)	48.4 (46.6-50.2)	37.5 (35.6-39.5)[b,c]
Internet users	50.1 (48.8-51.4)	55.2 (53.3-57.1)[e]	51.3 (48.9-53.6)

[a] HIA: health information or advice; includes having obtained health information in the past 12 months from any website or chat room/health community or having used a Web-based patient education program or podcast on the health plan's website.

[b] Significantly (*P*<.001) higher or lower than the 45 to 65 years age group after controlling for gender and race/ethnicity.

[c] Significantly (*P*<.001) higher or lower than the 66 to 75 years age group after controlling for gender and race/ethnicity.

[d] Uses the internet by self or with someone else's help.

[e] Significantly (*P*=.002) higher or lower than the 45 to 65 years age group after controlling for gender and race/ethnicity.

Table 5. Sociodemographic, health, and internet access characteristics differentiating self-reported users and nonusers of the health plan patient portal during the prior year, by age group.

Characteristic	45 to 65 years, weighted % (MoE[a])	66 to 75 years, weighted % (MoE)	76 to 85 years, weighted % (MoE)	45 to 65 years, AOR[b] (95% CI)	66 to 75 years, AOR (95% CI)	76 to 85 years, AOR (95% CI)
Age group						
Younger age[c] (ref[d])	59.3 (2.1)	66.2 (2.5)	46.9 (2.7)	(ref)	(ref)	(ref)
Older age[c]	57.4 (1.9)[e]	59.3 (2.9)[f]	37.7 (5.1)[e]	1.19 (1.05-1.36)[e]	0.94 (0.78-1.15)	0.83 (0.61-1.13)
Gender						
Male (ref)	52.5 (2.2)	61.9 (2.7)	45.5 (3.5)	(ref)	(ref)	(ref)
Female	65.4 (1.9)[f]	64.8 (2.6)	40.9 (3.9)	1.83 (1.61-2.09)[f]	1.27 (1.04-1.54)[e]	1.17 (0.90-1.53)
Race/Ethnicity						
White non-Hispanic (ref)	64.7 (1.8)	67.9 (2.2)	48.1 (3.2)	(ref)	(ref)	(ref)
Black	49.9 (5.1)[f]	47.7 (8.0)[f]	26.2 (9.7)[f]	0.59 (0.47-0.75)[f]	0.59 (0.40-0.87)[e]	0.40 (0.22-0.75)[e]
Hispanic	52.1 (4.0)[f]	49.8 (7.0)[f]	19.5 (5.4)[f]	0.74 (0.60-.0.90)[e]	0.68 (0.48-0.96)[g]	0.41 (0.26-0.63)[f]
Filipino	47.0 (6.2)[f]	37.4 (8.3)[f]	23.7 (10.1)[f]	0.85 (0.53-1.37)	0.42 (0.24-1.14)	0.85 (0.25-2.91)
East Asian	54.4 (4.9)[f]	68.4 (7.4)	40.2 (10.9)	1.17 (0.76-1.82)	1.49 (0.69-3.21)	1.31 (0.42-4.06)
Education						
<High school graduate	30.4 (8.7)[f]	23.7 (8.8)[f]	19.5 (7.1)[f]	0.48 (0.30-0.76)[e]	0.48 (0.24-0.95)[g]	1.16 (0.62-2.20)
High school graduate	50.2 (3.4)[f]	48.2 (4.6)[f]	33.1 (5.2)[f]	0.70 (0.58-0.85)[f]	0.71 (0.53-0.96)[g]	1.11 (0.77-1.62)
Some college/AA degree	58.7 (2.5)[f]	64.7 (3.2)[g]	47.7 (4.8)[g]	0.77 (0.66-0.90)[f]	0.88 (0.70-1.11)	1.02 (0.74-1.41)
College graduate (ref)	64.9 (2.1)	72.3 (2.7)	55.3 (4.7)	(ref)	(ref)	(ref)
Household income (US $)						
≤$35,000 (ref)	44.1 (4.2)	48.7 (4.3)	29.6 (4.4)	(ref)	(ref)	(ref)
$35,001-$50,000	54.7 (4.6)[f]	61.0 (5.3)[f]	47.4 (6.5)[f]	1.31 (0.99-1.72)	1.16 (0.73-1.64)	1.33 (0.88-2.02)
$50,001-$65,000	58.2 (4.7)[f]	64.7 (5.7)[f]	52.8 (8.0)[f]	1.42 (1.07-1.88)[g]	1.15 (0.81-1.64)	1.40 (0.91-2.17)
$65,001-$80,000	56.7 (4.2)[f]	65.7 (5.4)[f]	51.1 (8.6)[f]	1.16 (0.89-1.51)	1.16 (0.82-1.64)	1.24 (0.73-2.09)
$80,001-$100,000	65.0 (3.7)[f]	67.7 (5.3)[f]	52.8 (9.4)[f]	1.67 (1.29-2.17)[f]	1.10 (0.77-1.57)	1.20 (0.72-2.01)
>$100,000	63.7 (2.3)[f]	75.5 (3.7)[f]	58.1 (8.0)[f]	1.54 (1.23-1.93)[f]	1.60 (1.47-2.30)[e]	1.39 (0.86-2.24)
Uses the internet to obtain information						
Does not use	2.2 (2.0)[f]	3.0 (2.2)[f]	2.9 (2.4)[f]	0.03 (0.01-0.06)[f]	0.02 (0.01-0.05)[f]	0.02 (0.01-0.04)[f]
Uses with someone's help	33.4 (6.7)[f]	43.1 (6.3)[f]	41.6 (6.4)[f]	0.43 (0.31-0.60)[f]	0.35 (0.26-0.48)[f]	0.40 (0.29-0.56)[f]
Uses by self (ref)	62.8 (1.4)	73.4 (2.0)	66.4 (3.4)	(ref)	(ref)	(ref)
Has access to a computer						
No (ref)	13.3 (5.5)	8.0 (3.8)	7.0 (3.5)	(ref)	(ref)	(ref)
Yes	61.2 (1.5)[f]	68.6 (1.9)[f]	55.1 (3.0)[f]	2.33 (1.28-4.24)[e]	1.95 (0.97-3.95)	1.06 (0.52-2.14)
1 or more chronic condition						
No (ref)	49.3 (2.5)	58.1 (4.3)	35.7 (6.6)	(ref)	(ref)	(ref)
Yes	64.9 (1.7)[f]	64.9 (2.1)[e]	44.3 (2.9)[g]	2.22 (1.94-2.55)[f]	1.84 (1.47-2.30)[f]	1.76 (1.25-2.47)[e]
Model c-statistic[h]	—[i]	—	—	0.71	0.77	0.82

[a] MoE: 95% margin of error around estimated percentage (95% confidence intervals can be created from percentage ± MoE).

[b] AOR: adjusted odds ratio from logistic regression model that includes older age within age group, gender, race/ethnicity (including other Asian and other race/ethnicity categories), education, household income, internet use, computer access, and 1 or more chronic condition.

[c] Younger age: 45 to 55 years, 66 to 70 years, 76 to 80 years; older age: 56 to 65 years, 71 to 75 years, 81 to 85 years.

[d] Ref: reference group for variable categories.

[e] Significantly differs from reference group at *P*<.01.

[f] Significantly differs from reference group at *P*<.001.

[g] Significantly differs from reference group at *P*<.05.

[h] The model c-statistic assesses how well the full logistic regression model predicts which individuals used the patient portal.

[i] Not applicable.

Factors Associated with Patient Portal Use

Table 5 shows the relationship of sociodemographic, health, and internet access characteristics with use of the patient portal during the previous year. Within all age groups, there was no difference in patient portal use by self-rated health status (not shown) but having 1 or more chronic condition significantly increased portal use. Age, race/ethnicity, education, income, ability to use the internet without help, and having easy access to a computer were all significantly associated with patient portal use within all age groups. In the multivariable models, for all age groups, having 1 or more chronic condition and being able to use the internet without help significantly increased likelihood of having used the patient portal and having easy access to a computer increased likelihood of portal use among middle-aged adults and younger seniors. Educational attainment remained a significant factor for middle-aged adults and younger seniors, but not for older seniors. Within all age groups, blacks and Hispanics remained less likely than whites to have used the patient portal. A table showing AORs for age group– specific models that include only the sociodemographic and chronic condition variables alongside AORs in Table 5 is found in Multimedia Appendix 2. Comparing across age groups, older seniors of all race/ethnicities were significantly (*P*<.05 or greater) less likely than middle-aged adults and younger seniors of the same race/ethnicity to have used the patient portal. Older seniors also had significantly lower rates of patient portal usage than the younger 2 groups at the high school graduate, some college, and college graduate levels; younger seniors with some college and college degrees had significantly higher usage than similarly educated middle-aged adults.

Factors Associated with Use of Web-Based Health Information and Advice

Table 6 shows the associations of sociodemographic, health, and internet access factors with having used the internet to obtain HIA in the previous year. The overall percentages of adults who used Web-based HIA were lower than the percentages of those who used the patient portal, and disparities by race/ethnicity and levels of education and income were also not as large as found for patient portal use. In all age groups, Hispanics and Filipinos, adults with lower levels of education, and adults who needed help from another person to use the internet were less likely to have sought Web-based HIA. Among middle-aged adults, women were more likely to have sought HIA from a Web-based source than men, but the opposite was true among older seniors, with no gender difference observed among younger seniors. Similar to patient portal use, adults in all age groups who had 1 or more chronic condition were more likely to have sought Web-based HIA, but the rates of use did not differ by self-rated health status (not shown). In the multivariable models, lower educational attainment and requiring someone's help to use the internet all significantly decreased likelihood of having sought Web-based HIA, whereas having 1 or more chronic condition increased likelihood. A table comparing AORs for models that include only the sociodemographic and chronic condition variables with AORs in Table 6 is available in Multimedia Appendix 3. Comparing across age groups, older seniors were significantly (*P*<.05 or greater) less likely than middle-aged adults and younger seniors of all race/ethnicities (with the exception of blacks for older vs younger seniors, where *P*<.08) to have sought Web-based HIA. Older seniors at lower levels of income were also significantly less likely than middle-aged and younger seniors.

Age Group Differences in Internet, Patient Portal, and Web-Based Health Information and Advice Use Explained by Sociodemographic and Internet Access Factors

We examined whether the differences between middle-aged and senior age groups in internet use, patient portal use, and use of the internet to obtain health information shown in Tables 1 and 4 could be explained by differences in the characteristics of these groups using 3 sets of logistic regression models that compared the younger seniors to middle-aged adults, older seniors to younger seniors, and older seniors to middle-aged adults. Model 1 produced AORs adjusted for gender and race/ethnicity, and for patient portal and Web-based HIA use, having 1 or more chronic condition; Model 2 additionally adjusted for educational attainment and income; and Model 3 (for patient portal and Web-based HIA use only) added easy access to a computer and whether the person did not use the internet or required help from someone to use it. As is seen in Table 7, although differences in AORs between age groups for internet use substantially decrease after adjusting for education and income (Model 2) compared with adjusting for gender and race/ethnicity alone (Model 1), younger seniors remain significantly less likely than middle-aged adults, and older seniors significantly less likely than younger seniors, to be using the internet for purposes other than just email. The models for patient portal use show that additional adjustment for education, income, and 1 or more chronic health condition (Model 2) results in younger seniors being significantly more likely than middle-aged adults to have used the patient portal, whereas older seniors remain significantly less likely than younger seniors and middle-aged adults to have used the patient portal.

Table 6. Sociodemographic, health, and internet access characteristics differentiating self-reported users and nonusers of Web-based health information and advice resources during the prior year, by age group.

Characteristic	45 to 65 years, weighted % (MoE[a])	66 to 75 years, weighted % (MoE)	76 to 85 years, weighted % (MoE)	45 to 65 years, AOR[b] (95% CI)	66 to 75 years, AOR (95% CI)	76 to 85 years, AOR (95% CI)
Age group						
Younger age[c] (ref[d])	47.0 (2.1)	51.5 (2.7)	38.8 (2.6)	(ref)	(ref)	(ref)
Older age[c]	49.4 (1.9)	47.6 (2.9)	33.5 (5.0)	1.10 (0.97-1.25)	1.04 (0.87-1.24)	1.00 (0.75-1.35)
Gender						
Male (ref)	43.3 (2.2)	49.9 (2.8)	41.7 (3.5)	(ref)	(ref)	(ref)
Female	52.5 (2.0)[e]	49.9 (2.8)	32.3 (3.7)[e]	1.45 (1.28-1.64)[e]	1.06 (0.89-1.27)	0.85 (0.66-1.11)
Race/Ethnicity						
White non-Hispanic (ref)	51.9 (1.9)	52.7 (2.4)	40.0 (3.2)	(ref)	(ref)	(ref)
Black	48.6 (5.1)	41.7 (7.9)[f]	29.9 (10.0)	0.99 (0.78-1.25)	0.91 (0.61-1.35)	0.76 (0.42-1.38)
Hispanic	39.6 (3.9)[e]	41.0 (6.9)[g]	19.3 (5.4)[e]	0.74 (0.71-0.89)[g]	0.85 (0.61-1.20)	0.60 (0.39-0.94)[f]
Filipino	43.6 (6.1)[f]	32.8 (8.0)[e]	26.2 (10.6)[f]	0.70 (0.44-1.11)	0.71 (0.33-1.51)	1.95 (0.52-7.31)
East Asian	38.2 (2.4)[f]	53.0 (8.1)	30.2 (10.0)	0.53 (0.34-0.82)[g]	1.30 (0.62-2.72)	1.70 (0.49-5.85)
Education						
<High school graduate	21.1 (7.7)[e]	26.4 (9.3)[e]	20.2 (7.3)[e]	0.43 (0.26-0.72)[g]	0.74 (0.39-1.40)	1.46 (0.75-2.83)
High school graduate	40.1 (3.3)[e]	32.6 (4.3)[e]	26.5 (5.0)[e]	0.76 (0.63-0.92)[g]	0.52 (0.40-0.68)[g]	0.92 (0.64-1.33)
Some college/AA degree	49.1 (2.5)	51.5 (3.4)[e]	37.6 (4.6)[e]	0.91 (0.79-1.05)	0.88 (0.71-1.08)	0.81 (0.59-1.11)
College graduate (ref)	52.2 (2.2)	58.0 (3.0)	50.1 (4.6)	(ref)	(ref)	(ref)
Household income (US $)						
≤$35,000 (ref)	37.9 (4.1)	36.8 (4.2)	25.8 (2.2)	(ref)	(ref)	(ref)
$35,001-$50,000	45.5 (4.6)[f]	48.5 (5.4)[e]	36.8 (3.2)[g]	1.15 (0.87-1.51)	1.24 (0.90-1.69)	1.04 (0.70-1.56)
$50,001-$65,000	46.7 (4.7)[g]	51.6 (6.0)[e]	46.3 (4.2)[e]	1.15 (0.87-1.51)	1.34 (0.88-1.71)	1.34 (0.86-2.09)
$65,001-$80,000	44.0 (4.2)[f]	54.9 (5.7)[e]	43.8 (4.3)[e]	0.91 (0.70-1.19)	1.38 (0.99-1.90)	1.24 (0.78-1.97)
$80,001-$100,000	51.4 (3.8)[e]	54.6 (5.7)[e]	51.4 (4.8)[e]	1.23 (0.95-1.59)	1.19 (0.86-1.64)	1.55 (0.95-2.53)
>$100,000	52.2 (2.4)[e]	57.1 (4.3)[e]	50.4 (4.1)[e]	1.28 (1.02-1.60)[f]	1.24 (0.92-1.66)	1.35 (0.84-2.17)
Uses the internet to obtain information						
Does not use	0.0[h]	0.0[h]	0.2[h]	<0.01[h]	<0.01[h]	<0.01[h]
Uses with someone's help	28.0 (6.3)[e]	40.9 (6.3)[e]	40.2 (6.4)[e]	0.49 (0.35-0.68)[e]	0.59 (0.44-0.80)[e]	0.48 (0.34-0.67)[e]
Uses by self (ref)	51.0 (1.5)	57.2 (2.2)	56.2 (3.5)	(ref)	(ref)	(ref)
Has access to a computer						
No (ref)	10.6 (4.9)	9.7 (4.1)	6.8 (2.6)	(ref)	(ref)	(ref)
Yes	49.6 (1.5)[e]	53.8 (2.1)[e]	46.5 (3.1)[e]	1.91 (0.99-3.68)	0.65 (0.31-1.36)	0.49 (0.25-0.97)[f]
1 or more chronic condition						
No (ref)	39.2 (2.4)	45.4 (2.2)	27.7 (6.1)	(ref)	(ref)	(ref)
Yes	53.1 (1.8)[e]	51.2 (1.1)[f]	38.1 (2.8)[g]	1.91 (1.67-2.18)[e]	1.47 (1.19-1.82)[e]	1.96 (1.38-2.78)[e]
Model c-statistics[i]	—[j]	—	—	0.66	0.7	0.79

[a] MoE: 95% margin of error around estimated percentage (95% confidence intervals can be created from percentage ± MoE).

[b] AOR: adjusted odds ratio from logistic regression model that includes older age within age group, gender, race/ethnicity (including other Asian and other race/ethnicity categories), education, household income, internet use, computer access, and 1 or more chronic condition.

[c] Younger age: 45 to 55 years, 66 to 70 years, 76 to 80 years; Older age: 56 to 65 years, 71 to 75 years, 81 to 85 years.

[d] Ref: reference group for comparison of variable categories.

[e] Significantly differs from reference group at *P*<.001.

[f] Significantly differs from reference group at *P*<.05.

[g] Significantly differs from reference group at *P*<.01.

[h] 95% CI not applicable.

[i] The model c-statistic assesses how well the full logistic regression model predicts which individuals used a Web-based resource for health information or advice during the past year.

[j] Not applicable.

Table 7. Pairwise comparisons of middle-aged, younger senior, and older senior adult age groups' use of the internet, patient portal, and Web-based health information resources after adjusting for sociodemographic and other characteristics (Model 1 includes gender, race/ethnicity, and 1 or more chronic condition for patient portal and Web-based health information and advice use only; Model 2 includes gender, race/ethnicity, education, income, and 1 or more chronic condition for patient portal and Web-based health information and advice use only; and Model 3, for patient portal and Web-based health information use only, includes gender, race/ethnicity, education, income, 1 or more chronic condition, whether uses internet with help or does not use the internet, and whether has easy access to a computer. The age group listed after the "vs" is the referent group for the age group comparisons).

Internet resource and age group comparisons	Model 1, AOR[a] (95% CI)	Model 2, AOR (95% CI)	Model 3, AOR (95% CI)
Internet user (with or without help)[b]			
66-75 years vs 45-65 years	0.31 (0.25-0.37)[c]	0.40 (0.33-0.50)[c]	—[d]
76-85 years vs 66-75 years	0.25 (0.21-0.30)[c]	0.34 (0.28-0.42)[c]	—
76-85 years vs 45-65 years	0.08 (0.06-0.10)[c]	0.15 (0.12-0.18)[c]	—
Used patient portal in the past 12 months			
66-75 years vs 45-65 years	1.02 (0.91-1.13)	1.14 (1.02-1.27)	1.42 (1.26-1.61)[c]
76-85 years vs 66-75 years	0.41 (0.35-0.47)[c]	0.50 (0.43-0.58)[c]	0.75 (0.63-0.89)[c]
76-85 years vs 45-65 years	0.40 (0.35-0.45)[c]	0.54 (0.46-0.62)[c]	1.01 (0.86-1.20)
Obtained health information from a Web-based source in the past 12 months			
66-75 years vs 45-65 years	0.95 (0.85-1.05)	1.02 (0.92-1.10)	1.18 (1.05-1.32)[e]
76-85 years vs 66-75 years	0.56 (0.49-0.64)[c]	0.68 (0.59-0.78)[c]	0.95 (0.81-1.12)
76-85 years vs 45-65 years	0.51 (0.45-0.59)[c]	0.66 (0.58-0.76)[c]	1.15 (0.98-1.35)

[a] AOR: adjusted odds ratio; 95% CI: 95% confidence interval around AOR.

[b] AORs for internet use without help were virtually the same as those shown for internet use with or without help.

[c] Significantly different from referent age group at *P*<.001.

[d] Not applicable.

[e] Significantly different from referent age group at *P*<.05.

Additional adjustment for internet user status and computer access (Model 3) increases likelihood of patient portal use in the prior year by younger seniors compared with middle-aged adults, significantly reduces differences between older and younger seniors, and removes differences between older seniors and middle-aged adults. Similar results are seen for use of Web-based health information resources.

Discussion

Principal Findings

To our knowledge, ours is the first study to examine prevalence and factors influencing use of Web-based resources for health information and patient portals separately for middle-aged adults, younger seniors, and older seniors. Previous studies have shown that age, race/ethnicity, educational attainment, and low income are social determinants of being an internet user [11] and patient portal user [26-28] in adult and older adult populations. Our study showed that these factors operate similarly within middle-aged, younger senior, and older senior age groups to create disparities in use of the internet, use of the internet without help, and use of patient portals and Web-based health information resources. Furthermore, we showed that these same social determinants were associated with disparities in use of the internet without help from another person and use of Web-based health resources even among adults who used the internet. Our study also showed that differences between middle-aged and older age groups in prevalence of use of Web-based health resources were not fully explained by group level differences in sociodemographic, health, and internet access characteristics. By including information about the percentages of adults in different race/ethnic groups and at different levels of education and income who used the internet and 2 Web-based health resources alongside the results of the multivariable logistic regression models showing the independent relationship of these factors to use of these resources, we provide context for interpretation of the bivariate and multivariable associations of these factors with use of Web-based resources that is not generally been found in previous publications on this topic.

In our study, we found significant differences in prevalence of internet use and use of Web-based health resources across and within our middle-aged and older adult age groups. We found that the percentage of internet users aged between 45 and 55 years approximated that of younger adults and, similar to other studies [29], that the percentage of baby boomers (aged between 66 and 70 years) who use the internet did not significantly differ from that of older middle-aged adults (aged between 56 and 65 years). However, above the age of 70 years, we found steep declines in internet use, such that although over 90% of the youngest seniors were using the internet, less than two-thirds of those aged 81 to 85 years were doing so. We also showed that in contrast to younger adults, starting at middle age, there is an increasingly wide gap between the percentages of adults who use internet resources and the percentages who are able to do so without help from another person. This gap in how the internet is accessed has implications for how national and population-based surveys should consider measuring internet access, as well as for assessing progress toward meeting Healthy People 2020 goals for use of health information technologies.

Across all age groups, adults who used the internet but needed help from another person to do so were significantly less likely to report using the patient portal and Web-based health information resources than those who used the internet without someone's help. This disparity persisted even after controlling for education and presence of a chronic health condition, a factor that significantly increased likelihood of individuals using the patient portal and seeking HIA from a Web-based source in our multivariable analyses. The gap in skills and comfort in using the internet, which has been termed e-literacy or *digital readiness*, can potentially be remedied by motivational interviewing and demonstration of the advantages of using Web-based health resources to increase patient engagement, offering training (in-person, Web-based, and print materials) in how to use patient portal features and search for health information using the internet, and providing ongoing encouragement for use of Web-based resources.

In addition to e-literacy issues, access to high-speed internet and digital tools that make it possible for middle-aged and older adults to comfortably navigate the internet can also be a barrier to the use of Web-based health resources. In our study population, we found that one-third of middle-aged and older adults who do not use the internet at all and 42% of adults who need help from another person to use the internet do not have easy access to a computer. Although a growing percentage of adults own internet-enabled smartphones, in the short term, smartphones are unlikely to be used to interact with patient portals and to search for Web-based health information by middle-aged and older adults who lack easy access to an internet-enabled computer or tablet. A national survey of US adults found that in 2018, the use of internet-enabled smartphones remained significantly lower among middle-aged adults (73%) and seniors (49%) than younger adults (>90%), with less than one-third of adults ≥75 years and owning a smartphone [30]. Middle-aged and older adult smartphone owners primarily use their devices for phone calls, text messaging, and emailing [31]. In addition to the lack of experience and confidence, many older adults find it difficult to read information on small smartphone screens, use small virtual keyboards and touch screens to navigate the internet, and interact with apps [31]. Thus, increasing engagement with Web-based health resources may require helping those who do not have a computer or high-speed internet at home identify affordable laptop computers that they can take to venues offering free Wi-Fi, low-cost home internet plans, or other locations such as public libraries or friends' homes where they can use these tools with sufficient privacy. In situations requiring home internet, such as telemonitoring, it may be necessary to provide a computer and cover internet fees as a durable medical equipment benefit.

Consistent with previous research [29,32-34], we found that middle-aged and older adults with lower incomes and lower educational attainment were significantly less likely to be using the internet and using the internet for health-related purposes than those with higher incomes and higher educational attainment. Both low educational attainment and low income remained significant independent predictors of lower use of the internet and Web-based health resources in our multivariable models. Middle-aged and older adults who did not attend college are more likely to be *digitally unprepared* [35] than those with higher education as they are less likely to have had the opportunity to learn how to use computers and the internet while in school or at work. In addition, lower income adults, and especially older adults on fixed incomes, may not be able to afford high-speed home internet and a computer with sufficient memory and speed to interact with graphic-rich websites and streamed video content [31] or consider these digital technologies to be priority expenses. In our health plan survey, we found that adults with incomes of ≤$35,000 were not only less likely to be internet users than those at higher income levels, but also that the percentages who had easy access to a computer in this income group (86% of middle-aged adults, 78% of younger seniors, and 57% of older seniors) were significantly lower than those of similarly aged adults in the next higher income level. Similarly, computer access was significantly lower among those who had not graduated from high school (76% of middle-aged adults, 56% of younger seniors, and 42% of older seniors) than among those at higher levels of education. These findings suggest that the transition of health plans and government agencies to the use of secure portals and websites for dissemination of health information could potentially limit, rather than improve, the ability of less educated and lower income middle-aged and older adults to get health information and patient education and communicate with their health care providers in a way that feels comfortable.

Finally, we found that although having 1 or more chronic health condition was not significantly associated with being an internet user, this factor did significantly increase likelihood of middle-aged and older adults using the patient portal and obtaining health information from a Web-based source. This finding is unsurprising, given that adults with chronic health conditions would have more reason to use the patient portal to communicate with their health care providers, look up test results, and order prescription refills, and to obtain information and advice to manage their health conditions and health care. However, it does suggest that when possible, future studies should examine patient portal and Web-based health information use for the subpopulation of adults with a chronic health condition in addition to use in the broader population, especially when comparing use of these Web-based health resources across different demographic groups or over time.

Strengths

This study has several strengths. We used a large sociodemographically diverse dataset to examine the association of several social determinants with being an internet user and using 2 different types of internet-based health resources, a health plan patient portal and Web-based health information, separately for middle-aged, younger senior, and older senior adults. We showed how prevalence of internet use and use of Web-based health resources varied by race/ethnicity, educational attainment, income, and health status within and across these age groups in addition to evaluating the independent effects of these factors within age groups using multivariable models. Our ability to differentiate adults who were able to use the internet on their own from those who required help from another person and adults who had and did not have easy access to a computer enabled us to examine how these factors varied across age groups and affected use of Web-based health resources independent of sociodemographic factors.

Limitations

The survey was conducted with adults from 1 Northern California health plan membership that, although fairly representative of Northern California adults, is not representative of the US adult population with regard to educational attainment, income, broadband internet access, and access to a comprehensive health plan website. For over a decade, Kaiser Permanente has extensively promoted the use of its kp.org website to members as a resource to obtain HIA and the use of its patient portal to communicate with clinicians, view lab test results, order prescriptions refills, and access other health care–related information in the member's electronic health record. In addition, the health plan membership surveyed for this study was better educated (higher percentages of college graduates in each age group) and better off financially (lower percentages with household income <$35,000) than the overall US adult population around the time of the survey [36], had English as a primary language, and resided primarily in communities with good broadband coverage. The confluence of these factors would be expected to inflate the percentages of adults in all 3 age groups who used DITs and obtained health information from a Web-based source. In fact, compared with estimates for ages 45 to 65, 66 to 75, and 76 to 85 years in the US population from the 2015 Current Population Survey Computer and Internet Use Supplement, health plan adults in the same age groups were significantly more likely to be using the internet (approximately 96% vs 76%, 89% vs 64%, and 69% vs 42%, respectively), using the internet to obtain health information (48% vs 40%, 48% vs 31%, and 37% vs 20%, respectively), and using the internet to communicate or obtain health information from a health care provider (60% vs 22%, 61% vs 18%, and 45% vs 10%, respectively) [36]. Our patient portal use and Web-based health information resource use variables were based on self-report, which may have led to over- or under-reporting of use of these resources. However, most population surveys and studies of internet use for health purposes have similarly relied on self-reported data to study this topic. Survey response bias may also have resulted in overestimation of Web-based health resource use if adults who were better-educated, nonminority, and had 1 or more chronic condition were more likely to participate in the survey. Unfortunately, the post-stratification survey weighting factor did not adjust for these factors. Finally, although we were able to examine for race/ethnic disparities in use of the internet, patient portal, and Web-based health information resources, the survey dataset limited our ability to examine how gender, educational attainment, income, and internet use factors may differentially influence use of Web-based health resources by middle-aged and older adults of different racial/ethnic groups. Future research is needed on how these and other sociocultural factors influence uptake of DITs for health purposes within specific race/ethnic groups.

Conclusions

The internet offers a low-cost and effective method to access personal health information from secure patient portals and general health information from nonsecure websites. Web-based health information seeking behavior has been shown to help patients with chronic conditions become more knowledgeable and engaged with their health care, as well as better connected with resources to help them manage and cope with health-related concerns. Yet for many middle-aged and older adults, lack of education, financial strain, lack of computer and high-speed internet access, and inadequate skills and experience with regard to DITs will be barriers to their benefiting from eHealth information resources. As health plans begin to rely more heavily on patient portals and websites to communicate health-related information, digital divides between adults with lower levels of education and income and those with higher levels of education and income may negatively impact easy access to health information and patient education and make health care communications more difficult for middle-aged and older adults in vulnerable sociodemographic groups. This in turn may exacerbate disparities in health and health care use.

Health plans and other health organizations that want to serve the health information needs of all segments of a diverse population should take into consideration that middle-aged and older adults, especially those who are less educated and less affluent, are less likely than younger adults to engage with Web-based resources unless these resources are perceived to have demonstrable benefits over more traditional methods, to be convenient and easy to use, and to add to, not diminish, opportunities for social interaction with their health care team when this is a valued part of health care and the patient-provider relationship. Increasing use of patient portals and Web-based health information resources by these adults will require government agencies and health plans to make sure that their websites are easy to navigate and the content easy to view by aging adults, many of whom will have less visual acuity, motor coordination, digital experience, and access to sophisticated digital technology than the younger adults who often are responsible for developing these websites. Furthermore, middle-aged and older adults, especially those who are not already digitally engaged, will need active encouragement and support from health care providers to use Web-based health resources. Finally, health plans and government agencies offering patient portals and websites must continue to offer traditional patient counseling and information services to accommodate all patient preferences and needs.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Sociodemographic factors differentiating middle-aged and older internet-using adults who use the internet by themselves to get information from websites.
[PDF File (Adobe PDF File), 130KB - aging_v2i1e11451_app1.pdf]

Multimedia Appendix 2
Comparison of logistic regression models of factors predicting self-reported use of the health plan patient portal during the 12 months prior to the survey, by age group.
[PDF File (Adobe PDF File), 138KB - aging_v2i1e11451_app2.pdf]

Multimedia Appendix 3
Comparison of logistic regression models of factors predicting self-report of having obtained health information or advice from a Web-based resource during the 12 months prior to the survey, by age group.
[PDF File (Adobe PDF File), 137KB - aging_v2i1e11451_app3.pdf]

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Abbreviations

AOR: adjusted odds ratio
COPD: chronic obstructive pulmonary disease
DIT: digital information technology
eHealth: electronic health
HIA: health information and advice
KPNC: Kaiser Permanente in Northern California
MHS: Member Health Survey
MoE: margin of error

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Original Paper

Digital Information Technology Use and Patient Preferences for Internet-Based Health Education Modalities: Cross-Sectional Survey Study of Middle-Aged and Older Adults With Chronic Health Conditions

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Abstract

Background: Health information, patient education, and self-management (health information and advice, HIA) tools are increasingly being made available to adults with chronic health conditions through internet-based health and mobile health (mHealth) digital information technologies. However, there is limited information about patient preferences for using specific types of health information and advice resources and how preferences and usage differ by age group and education.

Objective: The objective of this study was to examine how use of digital information technologies and preferred methods for obtaining health information and advice varies by age group and education among middle-aged and older adults with chronic health conditions.

Methods: The study used cross-sectional survey data for 9005 Kaiser Permanente Northern California members aged 45 to 85 years who responded to a mailed and Web-based health survey conducted during 2014 and 2015 and indicated having at least 1 chronic health condition. Bivariate analyses and logistic regression models with weighted data were used to estimate and compare the prevalence of digital information technology use, past-year use of internet-based health information and advice resources, and preferences for using internet-based, mHealth, and traditional health information and advice modalities for adults aged 45 to 65 years, 66 to 75 years, and 76 to 85 years.

Results: The percentages of adults who used digital information technologies (computers, smartphones, internet, email, and apps), had obtained health information and advice from an internet-based resource in the past year, and who were interested in using internet-based and mHealth modalities for obtaining health information and advice declined with age. Within age group, prevalence of digital information technologies use and interest in internet-based and mHealth modalities was lower among adults with no college education versus college graduates. Differences in preferences for internet-based health information and advice modalities between the oldest and younger groups and those with lower versus higher education were substantially diminished when we restricted analyses to internet users.

Conclusions: Health care providers and organizations serving middle-aged and older adults with chronic health conditions should not assume that patients, especially those who are older and less educated, want to engage with internet-based and mHealth resources. In addition, increasing the engagement of nonutilizers of digital devices and the internet with internet-based health information and advice and mHealth apps might require both instrumental (eg, providing digital information technology devices, internet, and skills training) and social support. As part of patient-centered care, it is important for providers to ascertain their patients' use of digital information technologies and preferences for obtaining health information and patient education rather than routinely referring them to internet-based resources. It is also important for health care providers and consumer health organizations to user test their Web-based resources to make sure they are easy for older and less educated adults to use and to make sure that it remains easy for adults with chronic conditions to obtain health information and patient education using offline resources.

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KEYWORDS

internet; health status disparities; aged; health informatics; information technology; health education

Introduction

The prevalence of internet use among US seniors (ages ≥65 years) has been increasing, partly because of the aging of *Baby Boomers* into the older adult group [1]. However, surveys of US adults have consistently found that seniors are significantly less likely than middle-aged adults to be using the internet [2-4]. Data from the 2017 US Current Population Survey Computer and Internet Use Supplement (CPS-CIUS) suggest that in 2017, approximately 79% of middle-aged adults and 62% of seniors were using the internet, up from 77% and 56%, respectively, in 2015 [5,6]. Although the overall rate of senior usage was higher, there was a large disparity in internet use between younger seniors (aged 65 to 74 years, 70%) and older seniors (52% of those aged 75 to 84 years and 38% of those aged ≥85 years). Other surveys have confirmed this finding of lower prevalence of internet use among older versus younger seniors [2,4,6-11], those with higher levels of educational attainment versus those with lower levels of educational attainment [4,7-14], and among blacks and Hispanics as compared with non-Hispanic whites [4,7-10,14-17]. There is also some evidence that most seniors who are not already using the internet are unlikely to start doing so in the future [2].

Many middle-aged and older adults are using the internet to obtain information about health conditions and treatments, to get social support and advice from others with similar health-related experiences and to access apps to help them manage their health [15,18-21]. The CPS-CIUS 2015 survey showed that slightly over half of the middle-aged and older adult internet users in the United States had searched for health information online in the past year, which translates into approximately 39% of all middle-aged adults, 31% of all younger seniors (aged 65 to 74 years), and 23% of all older seniors (aged 75 to 84 years) [5]. These latter estimates are only slightly higher than Choi's estimates of 32% of adults aged 65 to 74 years and 14% of adults aged 75 to 84 years, on the basis of the 2009 National Health Interview Survey [7]. In addition to age, studies have shown racial/ethnic and educational disparities in the use of the internet to obtain health information [3,8,22,23].

There has been a burgeoning of health information websites, online interactive health programs, health-related forums, podcasts, and health apps on the internet since the early 2000s [18,19,24]. For many reasons, including marketing [25], consumer demand [26], federal regulations and incentive programs [27], and a growing body of evidence about improvement in patient engagement and health outcomes [28,29], health care providers and health organizations have begun to use the internet as a primary platform for providing information and advice on health and medical topics [30]. Approximately 60% of US adults have at least one chronic health condition, and this percentage is expected to increase as the population ages [31]. Internet users with chronic health conditions are more likely than other internet users to access health information online [32,33], and internet-based resources will become increasingly important tools for chronic conditions management (CCM) [34-38]. However, this shift to greater reliance on digital platforms for patient education and monitoring and patient-provider communication will potentially make it more difficult for older and less educated adults with chronic health conditions to obtain health information as they are less likely to have the digital technology (eg, Web-enabled devices, high speed internet) and skills and confidence to use the internet [4,37]. There is also some evidence that suggests many adults who use the internet might still prefer to obtain health information and advice (HIA) using more traditional methods, including print materials and oral communication with health care professionals [8,23,32,39-41].

Although there has been extensive research on patient portal use by middle-aged and older adults [38,42-48], there is less information about the use of internet-based health information and patient education resources by these age groups [7,23,49-52]. Given the trend of health information and patient education programs migrating to websites and other digital platforms, it is important for health care providers and organizations to have an awareness of digital information technology (DIT) use and preferred modalities for obtaining HIA among middle-aged and older adults with chronic health conditions as patient-centered care services for chronic conditions, including CCM programs and patient-facing health education resources, are being developed and implemented. In an earlier paper, we described the prevalence and factors influencing the use of the internet, patient portal, and online health information resources by middle-aged and older adult members of a large Northern California health plan [53]. In this paper, we describe DIT use and HIA modality preferences of middle-aged and older adult members of the same health plan who reported having at least one chronic health condition. We show how in this insured population, the use of DIT and interest in using internet-based HIA resources and apps differs by age group (45 to 65 years, 66 to 75 years, and 76 to 85 years), and within age groups, by level of education.

Methods

Setting

The Kaiser Permanente Medical Care Program in Northern California (KPNC) provides primary and specialty health care to a sociodemographically diverse membership that includes over 2.8 million adults who mostly reside in the San Francisco Bay Area, Sacramento area, Silicon Valley, and Central Valley. The KPNC adult membership is very similar to the insured population of Northern California with regard to sociodemographic and health characteristics [54]. For several years, the health plan has had a comprehensive website accessible to members and the general public, which provides information and advice about health conditions, medical procedures, medications and dietary supplements, and health and lifestyle risks and behavior change using online text, video, and podcasts, as well as online health behavior change programs available to members who register to use the patient portal.

Survey Sample

Data for this study come from middle-aged and older adults who participated in the 2014 to 2015 cycle of the KPNC Member Health Survey (MHS). The MHS is a self-administered (mailed print questionnaire and online) survey that has been conducted with independent stratified random samples of English-speaking adults every 3 years since 1993. The survey covers sociodemographic and health-related characteristics, digital technology use, use of the patient portal and different types of health information resources during the previous 12 months, and preferred methods for obtaining information and advice about managing health conditions and making changes in health-related behaviors and lifestyle. Information about the survey is found in an earlier publication [55] and on the survey website [56]. The overall response rate for this age group in the 2014 to 2015 survey cycle was 49.3% (40.9% for those aged 45 to 65 years and 64.5% for those aged 66 to 85 years).

The sample used for these analyses was restricted to the 9005 respondents (4163 aged 45 to 65 years, 2656 aged 66 to 75 years, and 2186 aged 76 to 85 years) who were not missing data on internet use status and who indicated having at least 1 of the following chronic health conditions during the previous year: diabetes, prediabetes, high blood pressure, heart condition, high cholesterol, cancer, Parkinson’s disease, urinary incontinence, chronic obstructive pulmonary disease/chronic bronchitis, asthma, allergies, musculoskeletal pain, osteoarthritis, frequent migraines or other types of headache, chronic pain, frequent insomnia, depression, anxiety, frequent memory problems, or frequent problems with balance or walking. This subsample includes 81.1% of all respondents aged 45-85 years, with 93% of exclusions because of not meeting the chronic health condition criterion.

Study Variables

Sociodemographic Characteristics

These included age group (45 to 65 years, 66 to 75 years, and 76 to 85 years for age group comparisons), sex (female, male), race/ethnicity (white, black, Latino, Filipino, East Asian, other Asian, Pacific Islander, other), educational attainment (no college, some college or community college degree, bachelor’s or postgraduate degree), and household income (HHI in US ≤$25,000, $25,001-$35,000, $35,001-$50,000, $50,001-$65,000, $65,001-$80,000, $80,001-$100,000, >$100,000).

Digital Information Technology Access and Use

The digital information technologies studied included having a mobile phone, smartphone, easy access to a computer or tablet, uses the internet (with, without help from another person) to get information from websites, uses email (with, without help from another person), able to send and receive text messages, able to use apps on a smartphone.

Use of Internet-Based and Noninternet-Based Health Information and Advice Resources in the Past 12 Months

Web-based HIA users were those individuals who reported obtaining HIA from the kp.org or another website, using a kp.org Web-based patient education program (eg, preparing for a procedure, health calculator, or health lifestyle programs for nutrition, weight, stress, or exercise) or podcast, or participating in any online chat room or community related to a health condition. Noninternet-based HIA users were those who indicated participating in any KPNC group or individual health education program/service or used KPNC print health education materials. Individuals who reported using any of the 2 categories of HIA resources were considered to have used any HIA resource.

Interest in Using Internet-Based Health Information and Advice Modalities, Health Apps, and Noninternet-Based Health Information and Advice Modalities

Individuals were asked to indicate whether they would like to get information and advice about how to manage health conditions and to make changes in health behaviors (diet, exercise, etc) using 1 or more internet-based and more traditional health education modalities. The checklist included 9 internet-based modalities (getting information from websites and/or doctor’s home page on the kp.org website, watching Web-based videos, watching live webinars or Web-based talks, listening to a podcast or online audio program, using a Web-based interactive program, emailed newsletters, getting HIA through a secure patient portal message, having a video visit with a patient educator, or joining an online chat room or online support community), health apps, and 7 more traditional/noninternet-based HIA modalities (telephone and in-person counseling sessions with a patient educator, in-person workshops and multi-session classes, DVDs, interactive computer programs, print materials, mailed health newsletters, and text messages).

Data Analysis

All analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC 2013) procedures for data from complex survey designs [57] and data weighted to the age, sex, and geographic composition of the KPNC adult membership in 2014. Proc Surveyfreq was used to produce weighted percentages with 95% confidence levels and Proc Surveylogistic was used to test whether differences between age groups and levels of educational attainment in access to digital devices and use of and interest in different HIA modalities were statistically significant after adjusting for race/ethnicity and sex. Analyses of patient-preferred HIA modalities were restricted to individuals who indicated interest in at least one modality in the HIA checklist. All differences between subgroups mentioned in the text are statistically significant at *P*<.05 or greater; if differences are not mentioned, they did not reach that threshold. Although we did not adjust for multiple comparisons, we have reported results of all statistical comparisons.

Ethics

Use of MHS data for this study was approved by KPNC's Institutional Review Board.

Results

Characteristics of Survey Respondents

The sociodemographic characteristics of the middle-aged (45 to 65 years), younger senior (66 to 75 years), and older senior (76 to 85 years) study groups are shown in Table 1. Slightly over half of all 3 age groups are female. Compared with middle-aged adults, the 2 senior groups are significantly (*P*<.001) more likely to be non-Hispanic white, and by San Francisco Bay Area standards, more likely (*P*<.001) to be lower income (HHI≤US $35,000) and less likely to have an HHI>US $80,000, with older seniors being less financially well-off than the younger seniors. Older seniors are significantly (*P*<.001) more likely than the middle-aged and younger senior groups to have no college (a high school diploma or less education) and less likely to be college graduates (bachelor's or postgraduate degree).

Digital Information Technology Use

Table 2 provides data on access to digital technology by age group and level of education. Compared with middle-aged adults, after controlling for sex and race/ethnicity, both senior groups are significantly (*P*<.001) less likely to have easy access to a computer (desktop or laptop), to own a smartphone, and to be using the internet, email, text messaging, and health apps, and older seniors are significantly (*P*<.001) less likely than younger seniors to be engaging with these digital technologies.

Table 1. Study sample characteristics.

Characteristics	45 to 65 years, n (%)[a]	66 to 75 years, n (%)	76 to 85 years, n (%)
Sex			
Male	1905 (46.9)	1286 (45.7)	1161 (45)
Female	2258 (53.1)	1370 (54.3)	1025 (55)
Race/ethnicity			
White non-Hispanic	2419 (58.6)	1867 (71.9)[b]	1541 (73.4)[b]
Black	359 (7.7)	175 (6.1)	141 (6.4)
Hispanic	584 (13.8)	206 (6.9)	219 (8.8)
Filipino	250 (5.9)	148 (5.2)	99 (3.9)
East Asian	349 (8.4)	148 (5.4)	121 (4.9)
Other Asian	91 (2.8)	49 (2.2)	24 (0.7)
Other	111 (2.7)	63 (2.2)	41 (1.9)
Education			
No college	921 (22.2)	633 (21.5)	765 (38.4)[b,c]
< High school graduate	112 (2.5)	106 (3.2)	174 (9.1)
High school graduate	809 (19.7)	527 (18.3)	591 (29.3)
Some college/AA degree	1481 (35.2)	910 (35.3)	675 (29.5)
College graduate (Bachelor's degree or higher)	1739 (42.6)	1087 (43.2)	724 (32.1)[b,c]
Household income (US$)			
≤$25,000	336 (8.1)	325 (12.0)[b]	428 (24.5)[b,c]
$25,000-$35,000	216 (4.9)	269 (10.7)	275 (14.4)
$35,001-$50,000	434 (10.2)	368 (14.6)	368 (19.8)
$50,001-$65,000	406 (9.9)	281 (11.6)	263 (12.5)
$65,001-$80,000	482 (12.2)	323 (13.6)	216 (10.2)
$80,0001-$100,000	601 (14.9)	312 (13.9)	172 (8.5)
>$100,000	1499 (39.9)	548 (23.6)[b]	225 (10.1)[b,c]

[a] n: unweighted count; %: percentage of age group with this characteristic based on weighted survey data.

[b] Significantly (*P*<.001) different from ages 45 to 65 years.

[c] Significantly (*P*<.001) different from ages 66 to 75 years.

Table 2. Use of digital information technologies by age group and level of education.

Digital technology use	45 to 65 years (n=3671)		66 to 75 years (n=2196)		76 to 85 years (n=1707)	
	%[a]	95% CI	%	95% CI	%	95% CI
All						
Uses the internet to obtain information						
Uses by self or with help	95.4	94.8-96.1	88.3[b]	87.0-89.6	67.5[b]	64.7-70.2
Uses by self	91.3	90.4-92.2	79.9[b]	78.2-81.5	53.6[b,c]	50.8-56.4
Uses email						
Uses by self or with help	94.9	94.2-95.6	87.7[b]	86.3-89.0	68.9[b,c]	66.2-71.6
Uses by self	91.5	90.6-92.4	81.2[b]	79.6-82.8	56.1[b,c]	53.3-59.0
Has access to a computer or laptop	95.8	95.2-96.5	91.3[b]	90.1-92.4	75.7[b,c]	73.2-78.3
Has a mobile phone	95.9	95.3-96.5	92.3[b]	91.2-93.4	81.1[b,c]	78.8-83.4
Has a smartphone	70.3	68.8-71.8	45.0[b]	42.9-47.1	18.2[b,c]	16.1-20.3
Able to send/receive text messages	76.1	74.7-77.6	52.8[b]	50.6-54.9	31.8[b,c]	29.1-34.4
If has a mobile phone	79.4	78.0-80.8	57.2[b]	55.0-59.4	39.2[b,c]	36.1-42.2
Able to use apps on a smartphone	54.5	52.8-56.1	28.3[b]	26.3-30.2	9.8[b,c]	8.2-11.3
If has a smartphone	77.5	75.9-79.2	62.8[b]	59.7-66.0	53.8[b,d]	47.4-60.1
No college (high school or less)						
Uses the internet to obtain information						
Uses by self or with help	88.0[e]	85.9-90.2	70.3[b,e]	66.4-74.3	45.9[b,c,e]	41.0-50.7
Uses by self	77.2[e]	74.3-80.2	55.4[b,e]	51.0-59.8	31.1[b,c,e]	26.6-35.6
Uses email						
Uses by self or with help	87.2[e]	85.0-89.5	69.2[b,e]	65.1-73.2	49.4[b,c,e]	44.5-54.4
Uses by self	78.1[e]	75.2-81.0	57.7[b]	53.3-62.0	32.7[b,c,e]	28.2-37.2
Has access to a computer or laptop	88.5[e]	86.2-90.7	77.3[b,e]	73.7-80.9	57.5[b,c,e]	52.6-62.4
Has a mobile phone	95.0[f]	93.5-96.4	90.1[b,g]	87.7-92.6	73.9[b,c,f]	69.4-78.4
Has a smartphone	56.9[e]	53.4-60.5	25.1[b,e]	21.1-29.0	11.1[b,c,e]	7.9-14.4
Able to send/receive text messages	67.9[e]	64.5-71.3	44.0[b,e]	39.5-48.4	26.6[b,c,g]	22.4-30.9
If has a mobile phone	71.5[e]	68.1-74.9	48.8[b,e]	44.1-53.5	36.1[b,c]	30.7-41.4
Able to use apps on a smartphone	41.4[e]	37.9-45.0	14.7[b,e]	11.4-17.9	5.0[b,c,e]	2.7-7.3
If has a smartphone	72.8[g]	68.5-77.1	58.6[h]	49.6-67.5	45.1[b,e]	29.6-60.6
Some college/AA degree						
Uses the internet to obtain information						
Uses by self or with help	95.8[e]	94.8-96.9	89.4[b,e]	87.2-91.6	75.4[b,c,e]	71.1-79.8
Uses by self	91.8[e]	90.3-93.2	80.9[b,e]	78.1-83.8	61.3[b,c,e]	56.5-66.1
Uses email						
Uses by self or with help	95.0[e]	93.8-96.1	88.3[b,e]	86.0-90.6	74.8[b,c,e]	70.3-79.3
Uses by self	92.2[e]	90.8-93.6	82.5[b,e]	79.8-85.2	64.6[b,c,e]	59.8-69.4
Has access to a computer or laptop	96.0[e]	94.9-97.0	91.6[b,e]	89.6-93.7	82.3[b,c,e]	78.4-86.2

Digital technology use	45 to 65 years (n=3671)		66 to 75 years (n=2196)		76 to 85 years (n=1707)	
	%[a]	95% CI	%	95% CI	%	95% CI
Has a mobile phone	95.7	94.6-96.8	91.9[i]	90.0-93.9	85.5[b,c]	82.1-89.0
Has a smartphone	70.3[e]	67.8-72.8	44.5[b,e]	40.8-48.2	20.1[b,c]	16.3-23.9
Able to send/receive text messages	75.2[e]	72.8-77.6	53.0[b,h]	49.4-56.7	34.9[b,c]	30.2-39.6
If has a mobile phone	78.6[e]	76.2-80.9	57.7[b]	53.9-61.4	40.8[b,c]	35.5-46.1
Able to use apps on a smartphone	53.6[e]	50.8-56.4	27.8[b,e]	24.5-31.2	10.3[b,c,i]	7.5-13.1
If has a smartphone	76.2[f]	73.4-79.1	62.5[b]	57.1-67.9	51.3[b]	40.8-61.8
College graduate (Bachelor's degree or higher)						
Uses the internet to obtain information						
Uses by self or with help	99.1	98.7-99.6	96.3[b]	95.2-97.5	86.7[b,c]	83.3-90.1
Uses by self	98.4	97.8-99.0	91.4[b]	89.6-93.2	73.9[b,c]	69.6-78.3
Uses email						
Uses by self or with help	98.8	98.3-99.4	96.4[b]	95.2-97.5	86.8[b,c]	83.5-90.2
Uses by self	97.9	97.2-98.6	91.9[b]	90.2-93.7	76.1[b,c]	71.9-80.3
Has access to a computer or laptop	99.5	99.2-99.8	97.9[b]	97.1-98.7	91.3[b,c]	88.5-94.1
Has a mobile phone	96.7	95.8-97.6	93.6[b]	92.1-95.2	85.6[b,c]	82.3-88.8
Has a smartphone	77.3	75.2-79.4	55.6[b]	52.3-58.8	25.0[b,c]	21.0-29.0
Able to send/receive text messages	81.2	79.3-83.2	57.0[b]	53.7-60.2	35.5[b,c]	30.9-40.2
If has a mobile phone	84	82.1-85.8	60.8[b]	57.5-64.2	41.5[b,c]	36.3-46.7
Able to use apps on a smartphone	62.1	59.6-64.5	35.3[b]	32.2-38.5	15.0[b,c]	11.9-18.1
If has a smartphone	80.3	78.0-82.5	63.6[b]	59.3-67.9	60.0[b]	50.9-69.0

[a] N: unweighted count; %: percentage of age group with this characteristic based on weighted survey data.

[b] Significantly (*P*<.001) lower than ages 45 to 65 years after controlling for sex and race/ethnicity.

[c] Significantly (*P*<.001) lower than ages 66 to 75 years after controlling for sex and race/ethnicity.

[d] Significantly (*P*<.01) lower than ages 66 to 75 years after controlling for sex and race/ethnicity.

[e] Significantly (*P*<.001) lower than college graduates in this age group after controlling for sex and race/ethnicity.

[f] Significantly (*P*<.05) lower than college graduates in this age group after controlling for sex and race/ethnicity.

[g] Significantly (*P*<.01) lower than college graduates in this age group after controlling for sex and race/ethnicity.

[h] Significantly (*P*<.01) lower than ages 45 to 65 years after controlling for sex and race/ethnicity.

[i] Significantly (*P*<.05) lower than college graduates in this age group after controlling for sex and race/ethnicity.

Table 2 also shows that across all age groups, noncollege graduates are significantly (*P*<.001) less likely than college graduates to be using these technologies. In addition, the same age group differences are seen at each level of education, with the exception of being able to use apps on a smartphone, which was extremely low prevalence across all groups.

Approximately 62.5% (95% CI 61.2%-63.8%) of adults aged 45 to 75 years and 53.5% (95% CI 50.7%-56.4%) of adults aged 76 to 85 years had in the past 12 months used at least one of the HIA resources asked about in the survey. After controlling for age group, sex, and race/ethnicity, past-year HIA users with no college education were significantly (*P*<.001) less likely than college graduates to have used an internet-based HIA resource—odds ratio (OR) 0.60 (95% CI 0.48-0.74)—whereas those with some college did not significantly differ from college graduates.

Use of Internet-Based HIA Resources in Past Year

Table 3 provides statistics on use of specific kinds of internet-based HIA resources in the past year by adults in these 3 age groups. Half of the adults aged 45 to 75 years and approximately one-third of those aged 76 to 85 years had obtained HIA from a website. However, no significant age group difference in accessing HIA from websites was observed among internet users. Approximately 10% of adults aged 45 to 75 years and 5% of adults aged 76 to 85 years had used a Web-based health education program, and the age group difference, although smaller, remained statistically significant among internet users. Health app use significantly declined with age (approximately 11% of those aged 45 to 65 years, 5% of those aged 66 to 75 years, and 3% of those aged 76 to 85 years, respectively), with prevalence of use among smartphone users approximately 3% points higher in each age group. Across all age groups, less than 3% of adults had listened to a podcast on the health plan's website and less than 1% had participated in an online chat room on any website. Figure 1 shows that across all 3 age groups, adults with no college education were significantly (*P*<.001) less likely than college graduates to have obtained HIA from a website, and in the 2 older groups, those with some college were also significantly less likely than college graduates to have obtained Web-based HIA. However, among internet users, education-related differences in obtaining internet-based HIA were greatly diminished in all age groups (see Multimedia Appendix 1 for results of age group-specific multivariable logistic regression models of past year use of HIA from a website). Use of health plan Web-based health education programs and podcasts did not significantly differ by level of education, but among middle-aged and older adults, those with no college education were significantly (*P*<.01) less likely than college graduates to have used health apps (ages 45 to 65 years: 7.8%, 95% CI 5.7%-5.9% vs 12.4%, 95% CI 10.6%-14.2%; ages 66 to 75 years: 2.4%, 95% CI 1.1%-3.6% vs 6.3%, 95% CI 4.7%-8.0%).

Interest in Using Internet- and Noninternet-Based HIA Modalities

Table 4 shows the percentages of all adults and internet users who indicated interest in obtaining HIA using specific internet- and noninternet-based modalities, restricted to the 86% of people who expressed interest in using at least one HIA modality asked about in the survey. Although 75% of all middle-aged and older adults expressed interest in using at least one of the internet-based HIA modalities, there were significant differences in interest among middle-aged, younger, and older seniors that persisted when restricted to internet users. Among all adults, after controlling for sex and race/ethnicity, 66 to 75 year olds and 76 to 85 year olds were less likely than 45 to 65 year olds to be interested in watching Web-based videos and webinars, using an interactive Web-based program, listening to podcasts, having a video visit with a patient educator, receiving HIA text messages, receiving emailed health newsletters, and using health apps. Adults aged 76 to 85 years were less likely than 45 to 65 year olds to be interested in obtaining HIA in messages sent through the patient portal, reading about health topics on a website, and receiving emailed health newsletters, but 66 to 75 year olds did not differ significantly from the middle-aged group. No age group difference was observed for print materials or counseling over the phone, but 76 to 85 year olds were less interested in counseling or classes that involved coming into the medical facility.

Table 3. Use of selected internet-based health information and mobile health resources in the past year, by age group and education.

Modality used in past year	45 to 65 years		66 to 75 years		76 to 85 years	
	%[a]	95% CI	%	95% CI	%	95% CI
Any internet-based health resource[b]	51.9	50.3-53.6	51.1	49.0-53.2	38.1[c,d]	35.3-40.8
Internet users[e]	54.3	52.5-56.0	57.4	55.2-59.7	54.8	51.6-58.1
Information from a website	50.2	48.5-51.9	49.4	47.3-51.5	36.7[c,d]	34.0-39.5
Internet users[e]	52.4	50.7-54.1	55.5	53.2-57.7	53	49.7-56.3
Web-based health education program	10.4	9.4-11.5	9.7	8.4-11.0	4.9[c,d]	3.7-6.0
Internet users[e]	10.9	9.8-12.0	10.9	9.4-12.3	7.0[c,f]	5.4-8.6
Podcast from health plan website	2.2	1.7-2.7	1.8	1.1-2.4	1.0[g]	0.5-1.5
Any health app	10.7	9.6-11.8	5.2[c]	4.2-6.1	2.7[c,f]	1.8-3.7
Smartphone users	13.9	12.4-15.3	8.5[c]	6.7-10.3	7.3[h]	3.1-11.6
Health chat room/online community	0.9	0.6-1.2	0.5	0.2-0.8	0.5	0.1-0.9

[a] %: percentage of age group with this characteristic based on weighted survey data.

[b] Internet-based health resources included information from a website, online health education program, podcast, or health chat room/online community.

[c] Significantly (*P*<.001) lower than ages 45 to 65 years after controlling for sex and race/ethnicity.

[d] Significantly (*P*<.001) lower than ages 66 to 75 years after controlling for sex and race/ethnicity.

[e] Internet users are those who used the internet on their own or with help. Ns for internet users: ages 45 to 65 years: 1259; ages 66 to 75 years: 699; ages 76 to 85 years: 429.

[f] Significantly (*P*<.01) lower than ages 66 to 75 years after controlling for sex and race/ethnicity.

[g] Significantly (*P*<.01) lower than ages 45 to 65 years after controlling for sex and race/ethnicity.

[h] Significantly (*P*<.05) lower than ages 45 to 65 years after controlling for sex and race/ethnicity.

Figure 1. Percentages of middle-aged and older adults who obtained health information from a website in the past 12 months, by level of education, all adults and internet users.

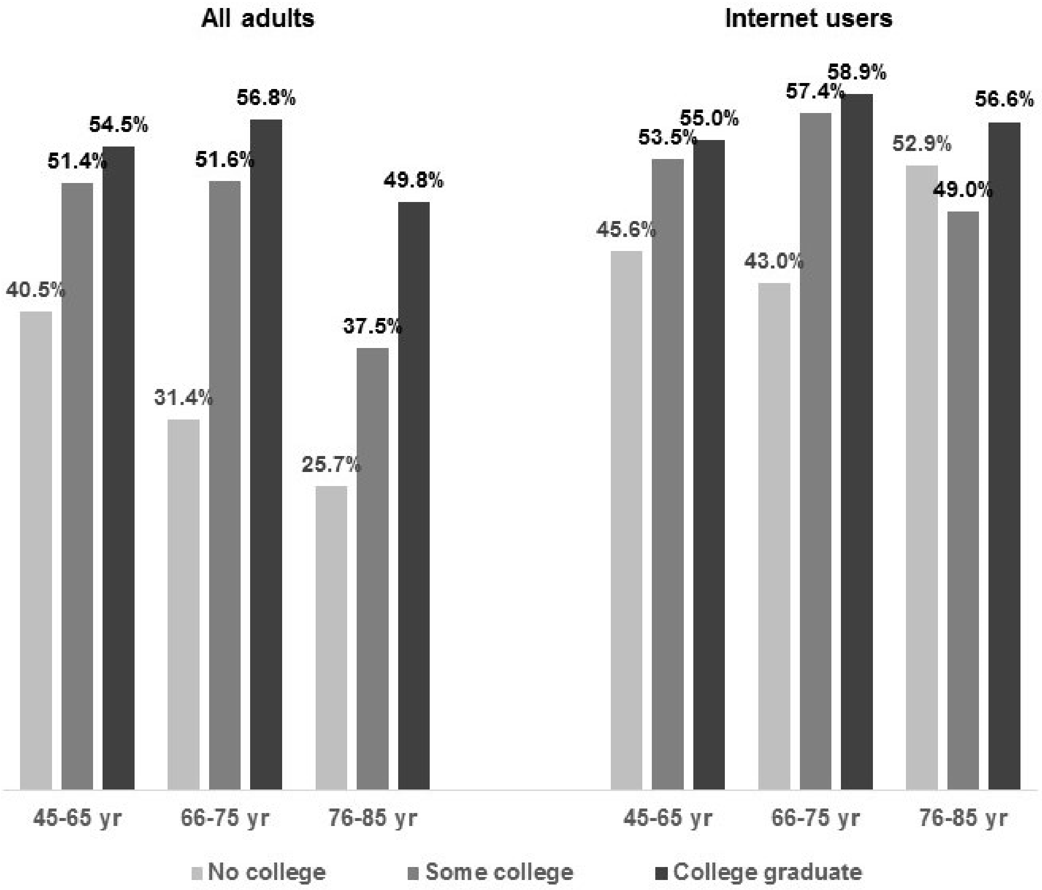


Figure 2 shows that across all age groups, adults with no college education were significantly (*P*<.001) less likely than college graduates to be interested in using at least one internet-based HIA modality, and among middle-aged and younger seniors, those with some college were also significantly less likely than college graduates to be interested in using any internet-based HIA modality. In Multimedia Appendix 2, we show that at all age levels, adults with no college education are significantly less likely than college graduates to prefer online HIA modalities.

As 97% of 45 to 65 year olds and 91% of 66 to 75 year olds interested in at least one HIA modality were internet users, prevalence of interest in using internet-based HIA modalities did not significantly differ between internet users and nonusers in those age groups. However, as only 73% of 76 to 85 year olds were internet users, interest in obtaining HIA from websites, patient portal messages, and emailed newsletters was significantly higher among online adults. Across all age groups, prevalence of interest in using health apps was significantly higher among smartphone users than all adults, but prevalence of interest in HIA text messages was not significantly higher among adults who currently use text messaging than all adults.

Figure 3 shows how the preference for obtaining textual HIA and health newsletters varies by age among those interested in textual HIA and health newsletters. Among those interested in textual information, preference for obtaining it only from print materials significantly increased with age (ages 66 to 75 vs 45 to 65: OR 1.44, 95% CI 1.22-1.69; ages 76 to 85 vs 45 to 65: OR 2.81; 95% CI 2.32-3.41 after adjusting for sex and race/ethnicity), whereas preference for obtaining information only from websites significantly declined with age (ages 66 to 75 vs 45 to 65: OR 0.77, 95% CI 0.66-0.89; ages 76 to 85 vs 45 to 65: OR 0.48; 95% CI 0.39-0.57). Similarly, among those who were interested in receiving health newsletters, preference for getting them only by mail significantly increased with age (ages 66 to 75 vs 45 to 65: OR 1.75, 95% CI 1.48-2.07; ages 76 to 85 vs 45 to 65: OR 4.05; 95% CI 3.31-4.95), whereas preference for getting them only by email declined with age (ages 66 to 75 vs 45 to 65: OR 0.60, 95% CI 0.51-0.70; ages 76 to 85 vs 45-65: OR 0.27; 95% CI 0.22-0.33). Compared with college graduates, after adjusting for age, sex, and race/ethnicity, adults with no college education or some college were significantly more likely to want print materials only (OR 2.11, 95% CI 1.72 to 2.58; OR 1.44, 95% CI 1.21-1.71, respectively) and mailed newsletters only (OR 2.83, 95% CI 2.30-3.48; OR 1.84, 95% CI 1.53-2.22, respectively), and significantly less likely to want emailed newsletters only (OR 0.41; 95% CI 0.33-0.51; OR 0.61, 95% CI 0.51-0.72, respectively); preference for internet-based materials only was not significantly associated with education.

Table 4. Preferred methods of obtaining health information and advice, by age group.

HIA[a,b] modality	45 to 65 years (n=3671)[c]		66 to 75 years (n=2196)		76 to 85 years (n=1707)	
	%[c]	95% CI	%	95% CI	%	95% CI
Any internet-based HIA modality[d]	79.3	77.9-80.8	72.5[e]	70.4-74.6	55.2[e,f]	52.1-58.4
Internet users[g]	81.3	79.9-82.8	78.6	76.6-80.6	69.8[e,f]	66.5-73.0
HIA from a website	50.5	48.7-2.2	49.2	46.9-1.6	35.1[e,f]	32.1-38.1
Internet users[g]	52.0	50.2-53.9	53.6	51.2-56.1	46.3[e,f]	42.7-49.9
Web-based video[h]	24.2	22.7-25.8	15.3[e]	13.6-17.0	7.1[e,f]	5.7-8.5
Web-based interactive program[h]	12.1	11.0-13.3	7.3[e]	6.0-8.5	2.9[e,f]	2.0-3.8
Video visit with a patient educator[h]	8.0	7.0−8.9	4.6[e]	3.6−5.5	2.7[e,i]	1.7-3.7
Message sent through the patient portal	38.1	36.3-39.8	38.5	36.3-40.8	23.9[e,f]	21.2-26.5
Internet users[g]	39.4	37.6-41.2	42.3	39.8-44.7	31.7[e,f]	28.4-35.0
Emailed newsletter	37.3	35.5-39.0	38.7	36.4-41.0	27.2[e,f]	24.4-30.1
Email users	38.6	36.8-40.4	42.7[j]	40.2-45.2	34.5[f,j]	31.0-37.9
Podcast/audio download[h]	7.3	6.4-8.2	4.4[e]	3.4-5.4	2.6[e,i]	1.6-3.7
Webinar or Web-based talk[h]	9.6	8.6-10.7	6.1[e]	5.0-7.2	2.8[e,f]	1.7-3.8
Chat room/online health community[h]	3.4	2.7-4.0	1.1[e]	0.7-1.5	0.9[e]	0.4-1.5
Health app	22.5	21.0-24.0	10.9[e]	9.4-12.4	4.3[e,f]	3.2-5.5
If has a smartphone	29.5	27.5-31.5	20.5[e]	17.6-23.3	14.9[e]	10.1-19.6
Any noninternet HIA modality[k]	71.0	69.3-72.6	76.6[e]	74.6-78.6	82.4[e,f]	80.0-84.7
Internet users[g]	70.1	68.4-71.8	74.7[e]	72.6-76.9	78.3[e,i]	75.5-81.1
Print materials	33.1	31.4-34.7	39.1[e]	36.8-41.3	42.2[e]	39.1-45.4
In-person workshop or multi-session class	25.8	24.2-27.3	25.3	23.3-27.3	21.2[i,l]	18.7-23.8
Counseling/coaching over the phone	16.3	15.0-17.6	17.2	15.5-19.0	18.2	15.7-20.7
In-person individual counseling	32.1	30.4-33.7	29.9	27.8-32.0	29.4	26.6-32.3
Mailed newsletter	24.2	22.7-25.7	35.9[e]	33.6-38.1	48.4[e,f]	45.3-51.6
Text message[m]	18.7	16.7-20.6	15.7[j]	13.2-18.2	8.9[e,f]	6.7-11.1
If has a mobile phone	19.1	17.1-21.1	16.5	13.9-19.1	10.6[e,n]	7.9-13.2

[a] HIA: health information or advice.

[b] Prevalence of interest in using an HIA modality is estimated from weighted data for the 86% of the sample that indicated interest in using any HIA modality in the survey checklist.

[c] %: percentage of age group with this characteristic based on weighted survey data.

[d] Internet-based HIA: information from a webpage, Web-based video, Web-based interactive program, video visit, patient portal message, podcast, webinar/Web-based talk, or online community or chat room.

[e] Significantly (*P*<.001) lower than ages 45 to 65 years after controlling for sex and race/ethnicity.

[f] Significantly (*P*<.001) lower than ages 66 to 75 years after controlling for sex and race/ethnicity.

[g] Internet users are those who use the internet on their own or with help. Ns for internet users: ages 45 to 65 years: 1259; ages 66 to 75 years: 699; ages 76 to 85 years: 429.

[h] Prevalence of interest among internet users is not reported but differs from prevalence for all adults in the 76 to 85 year age group by less than 5% and by less than 2% points for all adults in the 2 younger age groups.

[i] Significantly (*P*<.05) lower than ages 66 to 75 years after controlling for sex and race/ethnicity.

[j] Significantly (*P*<.05) lower than ages 45 to 65 years after controlling for sex and race/ethnicity.

[k] Noninternet HIA: information from print materials, workshop/class, in-person or phone coaching, text message, or mailed newsletter.

[l] Significantly ($P<.01$) lower than ages 45 to 65 years after controlling for sex and race/ethnicity.

[m] Only asked about in the 2015 survey questionnaire. Subgroup Ns are approximately half as large as above.

[n] Significantly ($P<.01$) lower than ages 66 to 75 years after controlling for sex and race/ethnicity.

Figure 2. Percentages of middle-aged and older adults interested in using Web-based resources to obtain health information and advice, by level of education, all adults and internet users.

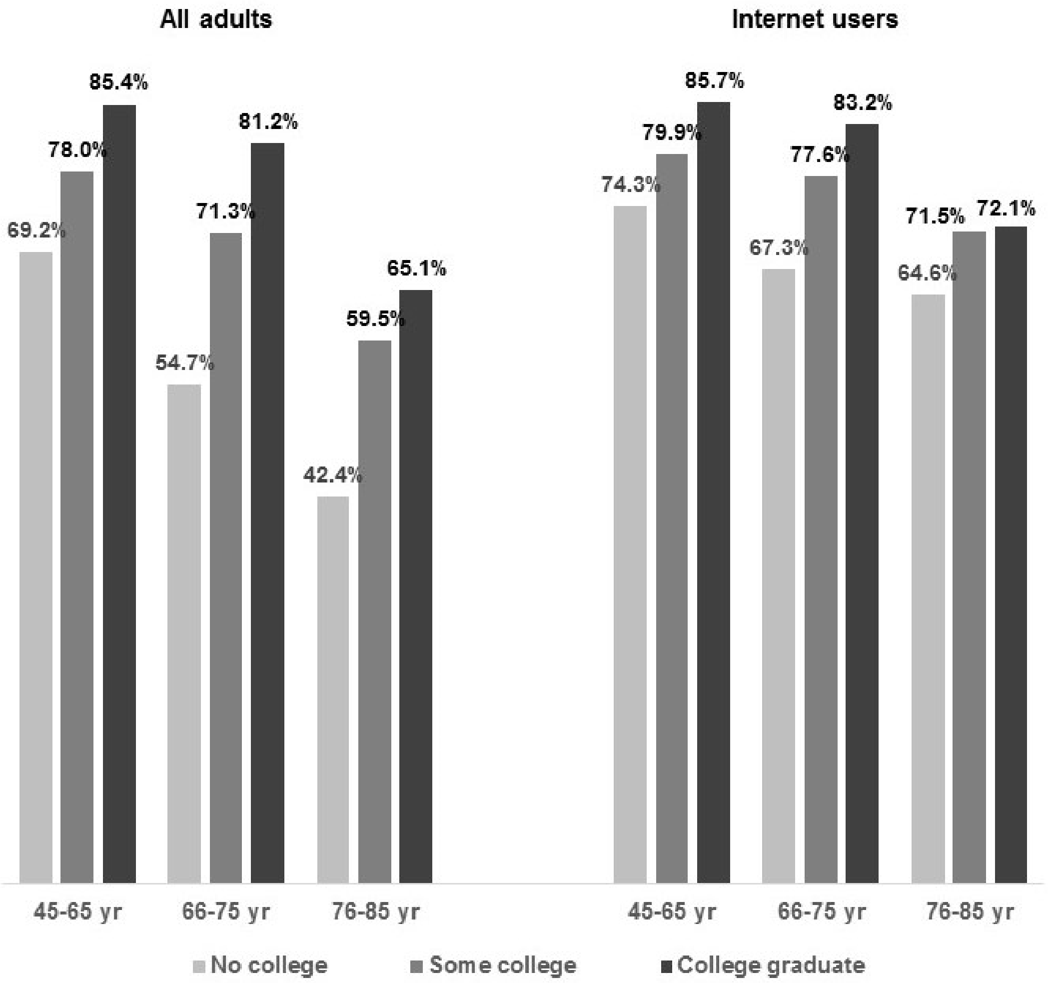
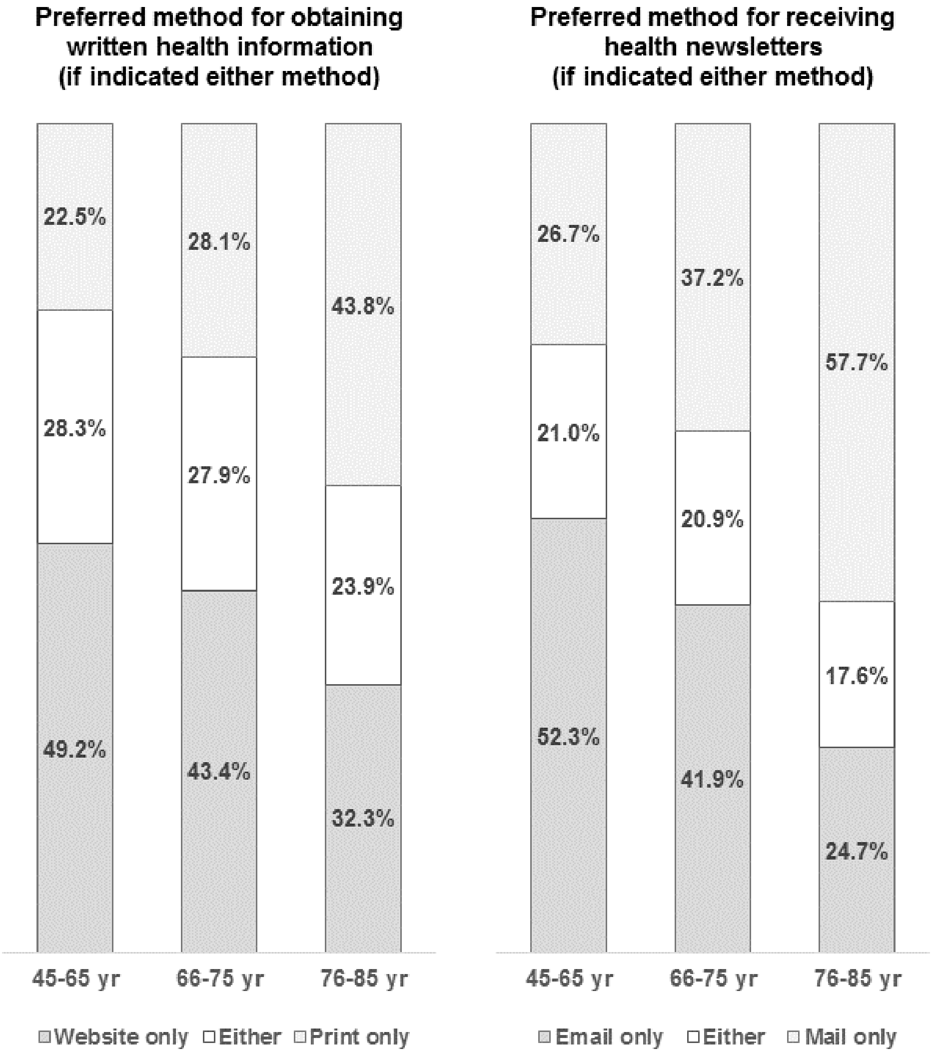


Figure 3. Differences by age group in preferred methods for receiving written health information and health newsletters.



Discussion

Principal Findings

Although we have previously reported on disparities in use of digital technologies and interest in using internet-based health information resources by seniors in this health plan population [23], in this study, which used data from a more recent survey, we extend the comparison to middle-aged adults and focus on adults who are managing chronic health conditions. In this study, we showed that there are significant age-group and educational disparities in access to or use of digital technologies used to access internet-based HIA, including computers, smartphones, email, text messaging, and apps. Specifically, younger (aged 66 to 75 years) and older (aged 76 to 85 years) seniors were significantly less likely than middle-aged adults (aged 45 to 65 years) to be using these digital technologies, and older seniors were significantly less likely than younger seniors to be doing so. Within each age group, we showed that use of these digital technologies was significantly lower among adults who have no formal education beyond high school or some college as compared with college graduates. Similar disparities by age group, and education within age group, in access to and use of digital technologies were also observed in the 2017 CPS-CIUS [6].

Across all age groups, only about half of adults had sought health information from Web-based sources during the past year or were interested in doing so in the future. Although younger seniors were less likely than middle-aged adults to use the internet alone or with help, we did not observe similar age group differences with regard to having used the internet to obtain health information in the past year or interest in using an internet-based modality in the future. Older seniors were less likely than the younger 2 groups to be using the internet and also less likely to have used or be interested in using internet-based health information resources. When we restricted our analyses to internet users, the difference between the older senior group and younger 2 groups in seeking health information from the internet in the past year substantially diminished, but the older group remained less interested in using an internet-based health information resource in the future. We found significant disparities by education in past year use and interest in future use of internet-based health information resources, although within age groups, the differences between college graduates and those with some college were much smaller than differences between college graduates and those with no college education, and the latter differences were still smaller among internet users.

With regard to interest in using specific health information and health education modalities, we found that interest in using Web-based health information resources (webpage information, Web-based videos, interactive patient education programs, webinars, podcasts/online audio programs, online chat rooms/communities, emailed newsletters, messages sent through the patient portal, text messages, and video visits with a patient educator) was substantially lower among older seniors than among the middle-aged and younger senior groups. For example, among those who were interested in textual health information and health newsletters, some of the differences (eg, interest in information from a website, emailed newsletters, and patient portal messages) were associated with not being an internet user or email user. This was not the case for most of the online modalities, where there was very little difference in percentages of all adults and online adults who were interested in using the modalities. Within all 3 age groups, interest in the online modalities was significantly lower among those with no college education than among college graduates.

Across all age groups, the percentages of adults who expressed interest in using health apps and podcasts in the future were about twice as high as the percentages of adults who had reported using these modalities in the previous year. Prevalence of interest in using health apps was also twice as high between younger and older seniors who owned a smartphone compared with all adults in those age groups, suggesting that as smartphone ownership increases in these older age groups, there is potential for greater uptake of health apps. Interest in listening to health podcasts was very low and was not substantially higher among smartphone owners than all adults for any age group.

The percentages of middle-aged, younger senior, and older senior adults in our study population who in 2014 used the internet to obtain health information were comparable with those observed in national samples for middle-aged and older adults [58] but substantially higher than estimates for all US adults in these age groups on the basis of the 2015 CPS-CIUS population (51.9% vs 39.2%, 51.1% vs 31.5%, and 38.1% vs 23.3%, respectively) [5]. This difference in internet-based health information seeking can be partially explained by differences in population demographics. Across all 3 age groups, compared with the US population, this study's population had higher percentages of adults who had attended some college or were college graduates and lower percentages with lower household incomes (>US $35,000) [5]. As numerous studies have shown that use of the internet increases as educational attainment and HHI increase, it is not surprising that this study's population had a higher proportion of internet users in all 3 age groups than the US population (approximately 95% vs 76%, 88% vs 64%, and 68% vs 42%, respectively) and thus had greater capability to search for health information online. When we restricted our comparison of these age groups to internet users, we found that the percentages in this study's population who had sought health information from the internet were only slightly higher than among these same age groups in the US population (52.4% vs 51.1%, 55.5% vs 50.2%, and 53.0% vs 45.1%, respectively) [5].

Another potential reason for the higher prevalence of internet-based health information seeking in our health plan population is that this study's population was restricted to adults who had at least one chronic health condition, and previous research has found that adults with chronic conditions are more likely to use patient portals and Web-based patient education resources [8,9,32,33,59,60]. The percentages of middle-aged and older adults who used the internet to obtain health information in the past year estimated from our survey and the 2015 CPS supplement are much lower than those reported in a 2012 Pew survey (71% of middle-aged and 58% of adults aged ≥65 years, who used the internet and 54% and 30%, respectively, of all adults in those age groups) [3].

The results of this study and other research suggest that when planning delivery of health information and patient education for adults with chronic health conditions, it is important to take into account the population's age group composition and educational attainment to gauge the likely uptake of internet-based and mobile health (mHealth; mobile technology-based) resources. Although more middle-aged and older adults are using the internet now than in the past [61], they are still less likely than younger adults to be using the internet and using the internet for functions other than email [7,9,14]. Many noninternet users lack easy access to digital technology (internet-enabled devices, high speed internet connections) that could connect them to the internet [8,12], and many older adults with chronic health conditions have physical or cognitive impairments that make it difficult to use internet-based resources [11,16,62]. In addition, even those currently using the internet might lack internet-based health skills (ability to access and use DITs for health purposes), experience, comfort, and trust in accessing internet-based health information resources [4,8,63]. For various reasons, they might also just prefer to get health information through print materials or directly from a person rather than from an internet-based source [23,32,39-41]. As adults with lower levels of educational attainment are less likely to seek health information in general, let alone use the internet to do so [64], it is important to make sure that HIA remains easily available through modalities that noninternet using adults will be more likely to use.

Without encouragement and support from health care professionals, family, and friends, middle-aged and older adults with chronic conditions who are not currently using internet-based health resources and health apps are unlikely to make the transition to electronic health and Web 2.0 [37]. However, even with encouragement, these adults are likely going to need assistance in gaining access to Web-enabled computers and other digital devices that they can comfortably use to connect with, navigate, and read information on the internet, as well as use high-speed internet or Wi-Fi if they have their own devices. Although younger adults find smartphones and tablets work well for performing online functions, aging adults with poorer vision and less manual dexterity might need to use a desktop or laptop computer with a larger screen and manual keyboard. They will also likely need training and support in how to use these digital tools, navigate the internet, conduct Web searches, and download materials [4]. Most public libraries offer access to computers and printers, Wi-Fi for people who bring their own Web-enabled devices, and librarians or volunteers to assist those who need help with online tasks [65]. Many libraries and community centers also offer classes for adults in how to use different types of digital devices and interact with the internet [66].

Developers of Web-based health information resources and health apps must also test their products with a wide range of potential end-users to make sure that these programs and tools are both effective in what they aim to achieve and easy for older and less educated adults to use [37]. In addition, health care providers and patient educators should not assume that even patients who are using a patient portal or are college-educated will follow up on recommendations to access Web-based health resources. Some patients, who might be willing to use Web-based and mHealth patient education and self-management tools but lack the equipment to do so, might also need financial assistance to purchase digital technology or to be given access to loaner equipment.

Strengths

This study has a number of strengths. First, the survey dataset enabled us to estimate the prevalence of use of multiple DITs and interest in using several different internet-based and mHealth modalities to obtain HIA in a population of insured patients with chronic health conditions. Second, because of the large sample size and sociodemographic diversity of the study cohort, we were able to show significant disparities in use of DITs and health information modality preferences across 3 age groups (middle-aged, younger seniors, and older seniors) and by education within age groups using directly observed weighted percentages, not just ORs from logistic regression models. Third, we were able to show how prevalence of previous use of and future interest in using different types of internet-based health information resources differed by age group and education among the segment of this patient population that was using the internet.

Limitations

The survey was conducted with adults from 1 Northern California health plan membership that, while fairly representative of Northern California adults, is not representative of the US middle-aged and older adult population with regard to educational attainment, income, broadband internet access, and health care coverage. The health plan membership is better educated and has a lesser percentage of low-income adults than the general US adult population and primarily resides in urban and suburban communities with widespread access to home and workplace broadband internet and free Wi-Fi in commercial and community settings. Moreover, members of this health plan are encouraged by the health care staff to use the comprehensive health information and health education resources available on the health plan's website. The confluence of these sociodemographic and internet-related factors might have increased the percentages of adults in all 3 age groups who used DITs and are interested in going online for health information. The survey did not include adults with a primary language other than English and with no health care coverage, and it did not include groups whose ability to access and preferences for using internet-based health information resources might differ from thus study's population and thus limit generalizability to the entire US population. This study's sample excluded adults who were missing data on internet use status. However, the percentages of respondents with missing data for this variable were so small (0.8%, 1.8%, and 3.7% of middle-aged, younger senior, and older senior adults, respectively, after weighting) that we do not believe this introduced much bias in the results. Finally, although we used logistic regression models to control for race/ethnicity and sex when we tested for age group and educational disparities in DIT use and health information modality preferences, we did not examine whether the same patterns of disparity were found across all race/ethnic groups. An earlier survey of seniors in this health plan membership found that within level of education, black and Latino seniors were less likely than non-Hispanic white and Asian seniors to be using the health plan's patient portal [8,23]. Future research is needed to identify whether sociodemographic and sociocultural factors differentially influence use of DITs and preferences for using specific internet-based and mHealth information modalities among adults in different racial/ethnic groups. Such information would improve the evidence base for development and implementation of patient-centered resources at the population level to prevent chronic health conditions and improve CCM, health outcomes, and quality of life.

Conclusions

DITs and internet-based health information resources provide a relatively inexpensive and effective way for adults with chronic health conditions to access information that can help them learn about and manage their health. However, this study found significant digital divides by age and educational attainment among middle-aged and older adults in ownership of digital devices and preferences for using internet-based resources to obtain HIA. These digital divides could potentially limit access to valuable health information and chronic disease self-management resources among vulnerable adult populations. Bridging digital divides in use of internet-based health resources will require ongoing personal encouragement from clinical staff for patients to try these new resources, including talking up the advantages of using these as an adjunct to and not replacement of aspects of the way they currently receive health care and obtain and share health information that they value. Patients reluctant to engage with digital information resources might also need to be provided with print materials and personal (nonvirtual) learning opportunities to become comfortable using these resources. Health care providers and consumer health organizations should also user test their internet-based resources before implementation to make sure that older and less educated adults will be able to use them easily and effectively. Finally, as part of providing patient-centered care, it will be important for health care providers and other consumer health organizations to continue to make it easy for patients to obtain health information and patient education from print materials, one-on-one patient counseling, and other more traditional modalities.

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Authors' Contributions

NPG conceived and designed the study, developed the survey questionnaire, directed the survey used for the study, performed all analyses reported in the paper, and wrote the paper. EC collaborated on the writing of the paper. Both authors read and approved the final paper.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Logistic regression models predicting use of Web-based health information and advice resources in past 12 months, aged 45 to 85 years and age groups 45 to 65 years, 66 to 75 years, and 75 to 85 years.

[PDF File (Adobe PDF File), 49KB - aging_v2i1e12243_app1.pdf]

Multimedia Appendix 2

Preferred methods of obtaining health information and advice by level of education, adults aged 45 to 65, 66 to 75, and 76 to 85 years.

[PDF File (Adobe PDF File), 224KB - aging_v2i1e12243_app2.pdf]

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Abbreviations

CCM: chronic conditions management
CPS-CIUS: US Current Population Survey Computer and Internet Use Supplement
DIT: digital information technology
DVD: digital versatile disc
HHI: household income
HIA: health information and advice
KPNC: Kaiser Permanente Medical Care Program in Northern California
mHealth: mobile health
MHS: Member Health Survey
OR: odds ratio

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Original Paper

A Rapid, Mobile Neurocognitive Screening Test to Aid in Identifying Cognitive Impairment and Dementia (BrainCheck): Cohort Study

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Abstract

Background: The US population over the age of 65 is expected to double by the year 2050. Concordantly, the incidence of dementia is projected to increase. The subclinical stage of dementia begins years before signs and symptoms appear. Early detection of cognitive impairment and/or cognitive decline may allow for interventions to slow its progression. Furthermore, early detection may allow for implementation of care plans that may affect the quality of life of those affected and their caregivers.

Objective: We sought to determine the accuracy and validity of BrainCheck Memory as a diagnostic aid for age-related cognitive impairment, as compared against physician diagnosis and other commonly used neurocognitive screening tests, including the Saint Louis University Mental Status (SLUMS) exam, the Mini-Mental State Examination (MMSE), and the Montreal Cognitive Assessment (MoCA).

Methods: We tested 583 volunteers over the age of 49 from various community centers and living facilities in Houston, Texas. The volunteers were divided into five cohorts: a normative population and four comparison groups for the SLUMS exam, the MMSE, the MoCA, and physician diagnosis. Each comparison group completed their respective assessment and BrainCheck Memory.

Results: A total of 398 subjects were included in the normative population. A total of 84 participants were in the SLUMS exam cohort, 51 in the MMSE cohort, 35 in the MoCA cohort, and 18 in the physician cohort. BrainCheck Memory assessments were significantly correlated to the SLUMS exam, with coefficients ranging from .5 to .7. Correlation coefficients for the MMSE and BrainCheck and the MoCA and BrainCheck were also significant. Of the 18 subjects evaluated by a physician, 9 (50%) were healthy, 6 (33%) were moderately impaired, and 3 (17%) were severely impaired. A significant difference was found between the severely and moderately impaired subjects and the healthy subjects (P=.02). We derived a BrainCheck Memory composite score that showed stronger correlations with the standard assessments as compared to the individual BrainCheck assessments. Receiver operating characteristic (ROC) curve analysis of this composite score found a sensitivity of 81% and a specificity of 94%.

Conclusions: BrainCheck Memory provides a sensitive and specific metric for age-related cognitive impairment in older adults, with the advantages of a mobile, digital, and easy-to-use test.

Trial Registration: ClinicalTrials.gov NCT03608722; https://clinicaltrials.gov/ct2/show/NCT03608722 (Archived by WebCite at http://www.webcitation.org/76JLoYUGf)

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KEYWORDS

dementia; neurocognitive tests; neurocognitive computerized assessment tools (NCAT); mild cognitive impairment (MCI); BrainCheck; digital testing; Alzheimer’s disease; electronic neurocognitive tools; computerized cognitive assessment; digital cognitive assessment

Introduction

As the baby boom generation grows older, the percentage of the US population over the age of 65 is expected to double by the year 2050 [1]. Concordantly, by 2030 the incidence of dementia is projected to increase from 35 million to 70 million [2]. Mild cognitive impairment (MCI) is considered an intermediate state between normal age-related decline and dementia. Data from the Mayo Clinic Study of Aging estimate the development of MCI in up to 29% of older individuals during the span of the 5-year longitudinal study [3]. MCI may progress to dementia or represent a potentially reversible condition related to a variety of conditions, including polypharmacy, depression, and sleep apnea [4].

The subclinical stage of dementia begins years before signs and symptoms appear [5]. Once clinically manifested, treatment for dementia is either palliative in nature or aimed at slowing progression, as no curative therapy currently exists [6]. Early detection of cognitive impairment, on the other hand, may identify treatable and reversible conditions. Although reversing disease expression of neurodegenerative conditions such as Alzheimer’s disease is not possible at this time, early detection of cognitive decline may allow for interventions to slow its progression or for implementation of care plans that may impact the quality of life of affected individuals and their caregivers [7].

The most commonly used neurocognitive screening tests include the Saint Louis University Mental Status (SLUMS) exam [8], the Mini-Mental State Examination (MMSE) [9], and the Montreal Cognitive Assessment (MoCA) [10]. These tools are able to distinguish impaired individuals from their healthy counterparts. Recent studies have reported the diagnostic sensitivity and specificity of the MMSE to be 81% and 89%, respectively [11], with similar performance for the SLUMS exam (82% and 86%, respectively), and the MoCA (91% and 81%, respectively) [11,12].

Although commonly used in clinical practice, none of the methods noted above are considered the “gold standard” for cognitive screening [13]. While the MMSE, SLUMS exam, and MoCA have relatively high sensitivities and specificities, each screener contains shortcomings. The MMSE relies heavily on memory and language, with little emphasis on other cognitive domains, such as executive function and visuospatial attention [14]. The SLUMS exam includes tests of executive function but is inferior to the MMSE when assessing activities of daily living and functionality [15]. The MoCA appears to be the most robust screener, however, it requires more research to establish its validity [16].

Furthermore, these screening tools are verbally administered by a physician or test administrator, with responses and scores recorded with pen and paper. When integrated into a physician assessment, the tools may be time-consuming, and the need for a test administrator may increase expenses but adds no additional physician reimbursement [17]. While the screening instruments are relatively simple to administer, it is uncertain whether the instruments are commonly administered and scored as intended in routine clinical practice. For example, a European study reported significant score discrepancies between MMSEs performed by general practitioners and neuropsychologists [18]. Digital neurocognitive testing has several advantages that include the following: (1) elimination of potential practice effects [19] and floor or ceiling effects [20] typically seen in pen-and-paper versions, (2) automated administration and scoring of the test items, and (3) automatic integration with electronic medical records [21]. In addition, digital testing can be readily delegated to a technician, thus focusing the clinician’s time on interpretation and decision making rather than test administration and scoring.

BrainCheck Sport is a computerized neurocognitive test available on iPad, iPhone, or a desktop browser and was previously validated for its diagnostic accuracy for the detection of concussion [22]. BrainCheck Memory is a modified version of this program that targets dementia-related cognitive decline. BrainCheck Memory functions as an app that can be downloaded from the Apple Store and accessed via password-protected log-in. The primary aim of this study was to assess the utility and accuracy of BrainCheck Memory—herein referred to as BrainCheck or BrainCheck Memory—as a computerized diagnostic tool for cognitive impairment among older adults.

Methods

This study of 583 subjects was subdivided into five cohorts for analyses: a normative population; SLUMS exam, MMSE, and MoCA comparison groups; and a physician-diagnosis comparison group. Additionally, a composite score was calculated to provide a sensitive metric for cognitive impairment.

Normative Population

Participants were volunteers from community centers, assisted living facilities, and a church in Houston, Texas. Inclusion criteria were as follows: age greater than or equal to 50 years, function in at least one hand, and normal or corrected vision. Exclusion criteria included a history of stroke or other neurological disability (eg, attention deficit hyperactivity disorder [ADHD] or epilepsy), inability to speak English or Spanish, and illiteracy, defined for study purposes as unable to read the written informed consent. All participants signed informed consent forms prior to participation in the study, as approved by the Solutions Institutional Review Board. No compensation was provided for study participation.

All testing was completed on iPads or iPhones. Tests were administered by trained, bilingual research staff and performed one-on-one in a quiet, well-lit space. Participants were provided with brief instructions prior to taking the battery of assessments, and clarification was provided during testing if needed. Additional instructions were not provided once testing began.

Comparison to Reference Screening Methods

Volunteers for the SLUMS exam and MMSE comparison groups were recruited via convenience sampling from community centers; volunteers for the MoCA and physician groups were recruited from two assisted-living facilities.

Diagnostic performance of BrainCheck was compared to that of an electronic version of the SLUMS exam created for this research. Prior to conducting BrainCheck's assessments, research staff administered the SLUMS exam via a Wi-Fi-connected iPad or iPhone. After completing the SLUMS exam, participants completed the BrainCheck assessment on the same device used during the SLUMS exam administration. Subjects with scores of 20 or lower on the SLUMS exam were included in the dementia group and those with scores of 21 or higher in the control group [8].

Screening performance of BrainCheck was also compared to both pen-and-paper versions of the MMSE and the MoCA. Pen-and-paper testing was performed before BrainCheck, which was administered on either an iPad or iPhone.

Finally, BrainCheck's effectiveness as a screening tool was compared to physician diagnosis. A licensed psychiatrist and medical adjudicator evaluated a sample of residents from two separate assisted-living facilities. Evaluations were performed one-on-one in a private space after the participant completed BrainCheck. While the psychiatrist and medical adjudicator provided evaluations following BrainCheck administration, BrainCheck results were not accessible to the practitioners during the course of the evaluation. Physician diagnosis was based on a personal and medical history followed by administration of the MoCA test. Volunteers were diagnosed as healthy, moderately impaired, or severely impaired.

Description of BrainCheck Battery

Identification of dementia requires impairment of at least two of the following domains: memory, language, praxis, gnosis, or executive functioning [23]. As such, BrainCheck Memory is a compilation of seven neurocognitive tests based on commonly included instruments in neuropsychological test batteries for detection of cognitive impairment. Six of BrainCheck Sport's assessments—Immediate and Delayed Recall, the Trail Making Test (TMT) A, the Trail Making Test B, the Stroop Test, and the Digit Symbol Substitution Task [22]—are included in BrainCheck Memory. Additionally, the Matrix Problems Task, adapted from the Raven Standard Matrices Test, was added to the battery of assessments to measure fluid intelligence (ie, the ability to reason and problem solve), a skill that commonly declines with age [24]. Participants were shown a pattern of three shapes and asked to select the next shape in the pattern series by choosing from six possibilities. Previous studies showed that dementia patients correctly identify a lesser proportion of matrices compared to elderly controls [25].

Results

Normative Data

We obtained normative data for 398 participants aged 50-91 years. Data were collected between November 19, 2015, and August 16, 2017. This population consisted of 318 (79.9%) female and 80 (20.1%) male participants. Gender distribution of subjects, while skewed compared to the general population, was determined by voluntary enrollment patterns in the study settings. The mean age was 70.2 years (SD 9.0). Distributions of scores for each assessment are shown in Figure 1, and basic statistics are shown in Table 1. All distributions were unimodal.

Comparison With the Saint Louis University Mental Status Exam

A total of 84 subjects were enrolled between November 22, 2016, and August 16, 2017. Of these, 19 (23%) were classified as demented—17 (89%) female; mean age 75 years (SD 9.5). These subjects were compared to 65 controls—55 (85%) female; mean age 62.9 years (SD 16.5). BrainCheck assessments correlated to SLUMS exam scores are shown in Figure 2. Analysis also revealed that BrainCheck batteries span a range of difficulties and domains that influence their correlation with the SLUMS test. For example, while most participants with a SLUMS exam score above 20 were able to perform equally well on the TMTs, the Digit Symbol Substitution Task effectively distinguished between participants in this range. Thus, the TMTs are easier than the Digit Symbol Substitution Task and may be better at detecting dementia while the Digit Symbol Substitution Task may be better at detecting milder cognitive impairments.

Figure 1. Normative distribution. Distributions of scores for individuals in the normative population are shown for each assessment. The number of normative data points in each distribution is indicated above each panel.

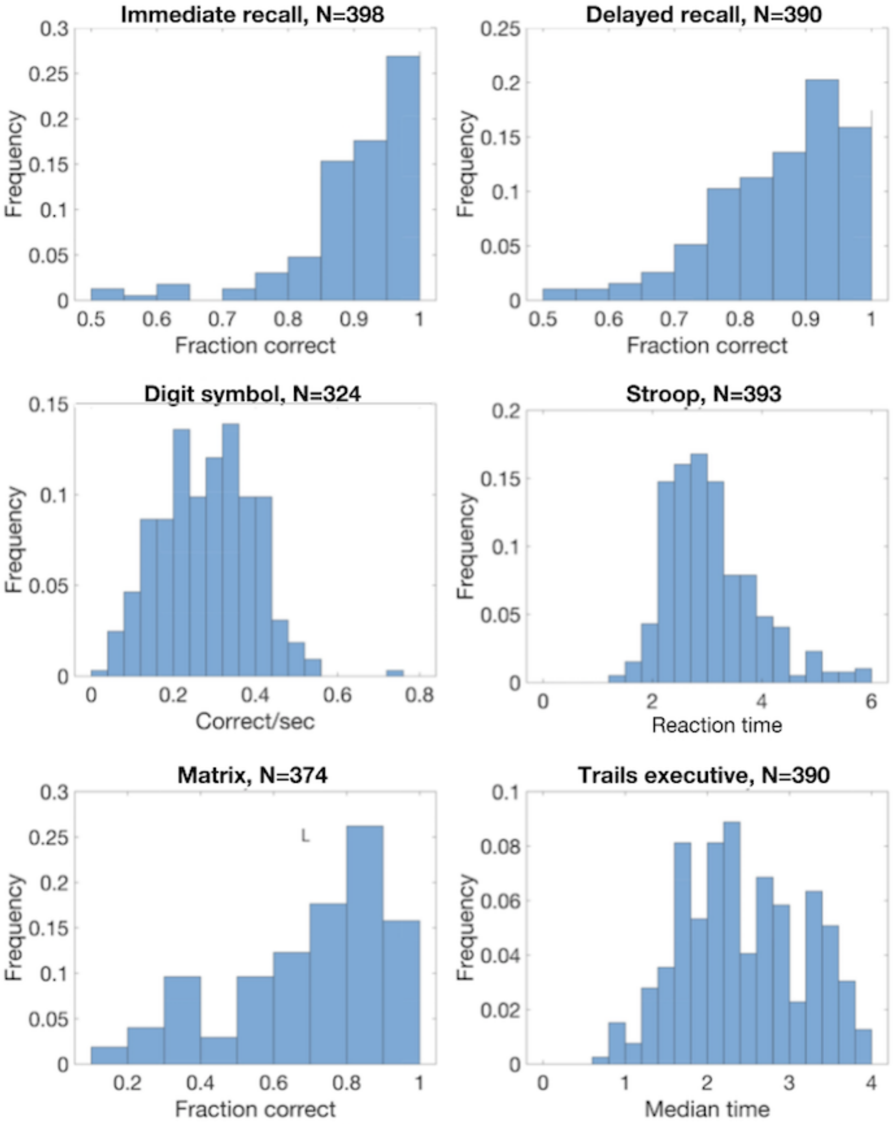
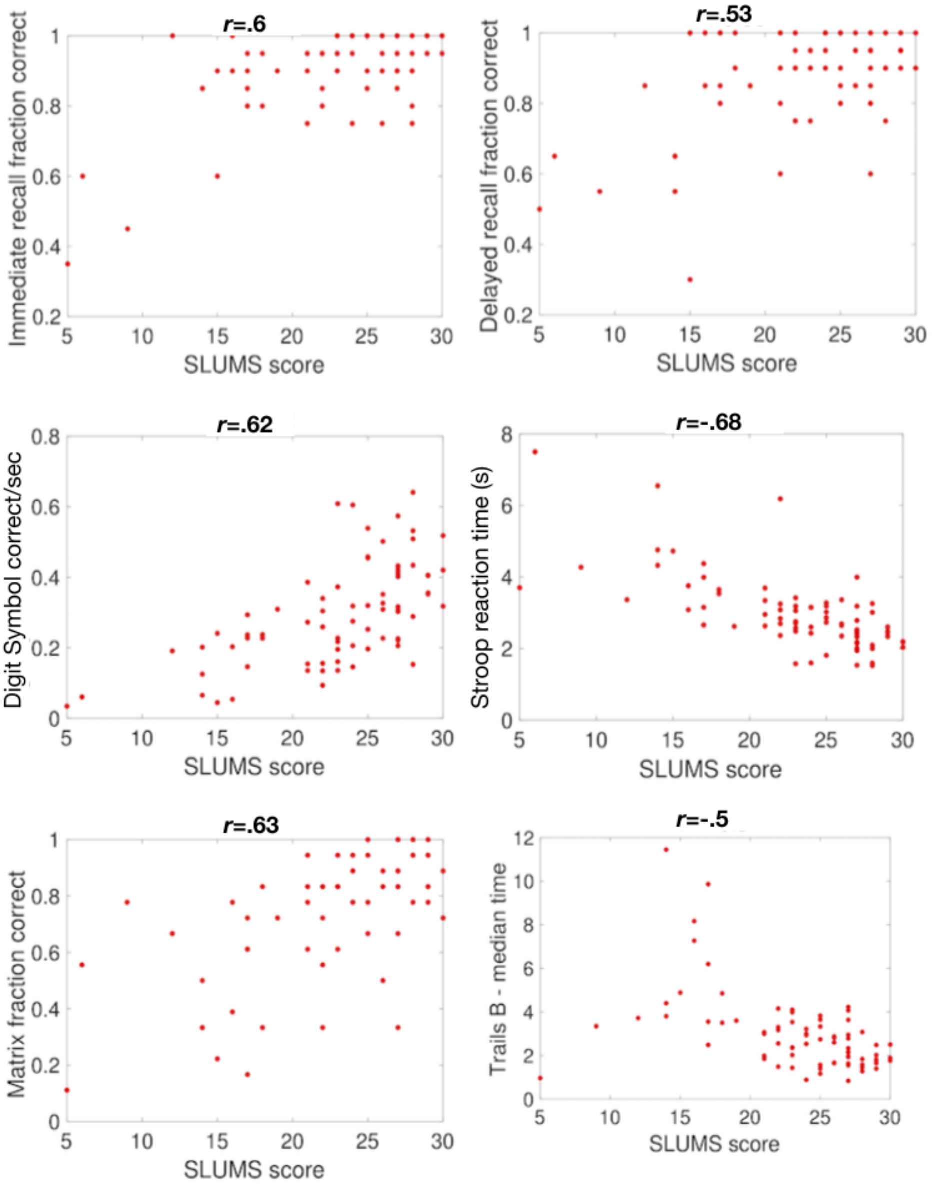


Table 1. Basic statistics of assessments used in the BrainCheck Memory battery.

Metric	Mean (SD)
Immediate recall fraction (%) correct	94 (7)
Delayed recall fraction (%) correct	91 (9)
Stroop mean reaction time in seconds	2.28 (0.74)
Trails A median reaction time in seconds	1.05 (0.44)
Trails B median reaction time in seconds	1.96 (0.98)
Matrix fraction (%) correct	83 (0.18)
Digit Symbol mean number correct per second	0.44 (0.14)

Figure 2. Comparison of BrainCheck assessments with the Saint Louis University Mental Status (SLUMS) exam. Shown are comparisons between SLUMS scores and the scores for each assessment. Each data point represents one participant who took both assessments. Pearson correlation coefficients are indicated above each panel.



Comparison With the Mini-Mental State Examination

Subjects who took the MMSE and BrainCheck (n=51) had a mean age of 73 years (SD 8.3), and 44 (86%) were female. Correlation coefficients between individual BrainCheck assessments and the MMSE were typically lower than with the SLUMS exam, but all were statistically significant and ranged in magnitude from .2 to .55 (see Figure 3).

Comparison With the Montreal Cognitive Assessment

Of subjects taking the MoCA and BrainCheck (n=35), the mean age was 85.2 (SD 6.3) and 30 (86%) were female. All BrainCheck assessments had correlation coefficients from .3 to .64 (see Figure 4).

Comparison With Physician Evaluation

A total of 18 subjects underwent physician evaluation: the mean age was 85.9 years (SD 7.3), 9 (50%) were healthy, 6 (33%) were judged to be moderately impaired, and 3 (17%) were judged to be severely impaired. Comparing the 9 moderately or severely impaired subjects to the controls, we found that 4 out of 6 (67%) BrainCheck assessments identified significant differences (*P*=.02) between the populations (see Figure 5), while the other two showed nonsignificant differences, possibly due to the small sample size.

Figure 3. Comparison of BrainCheck assessments with the Mini-Mental State Examination (MMSE). Shown are comparisons between MMSE scores and the scores for each assessment. Each data point represents one participant who took both assessments. Pearson correlation coefficients are indicated above each panel.

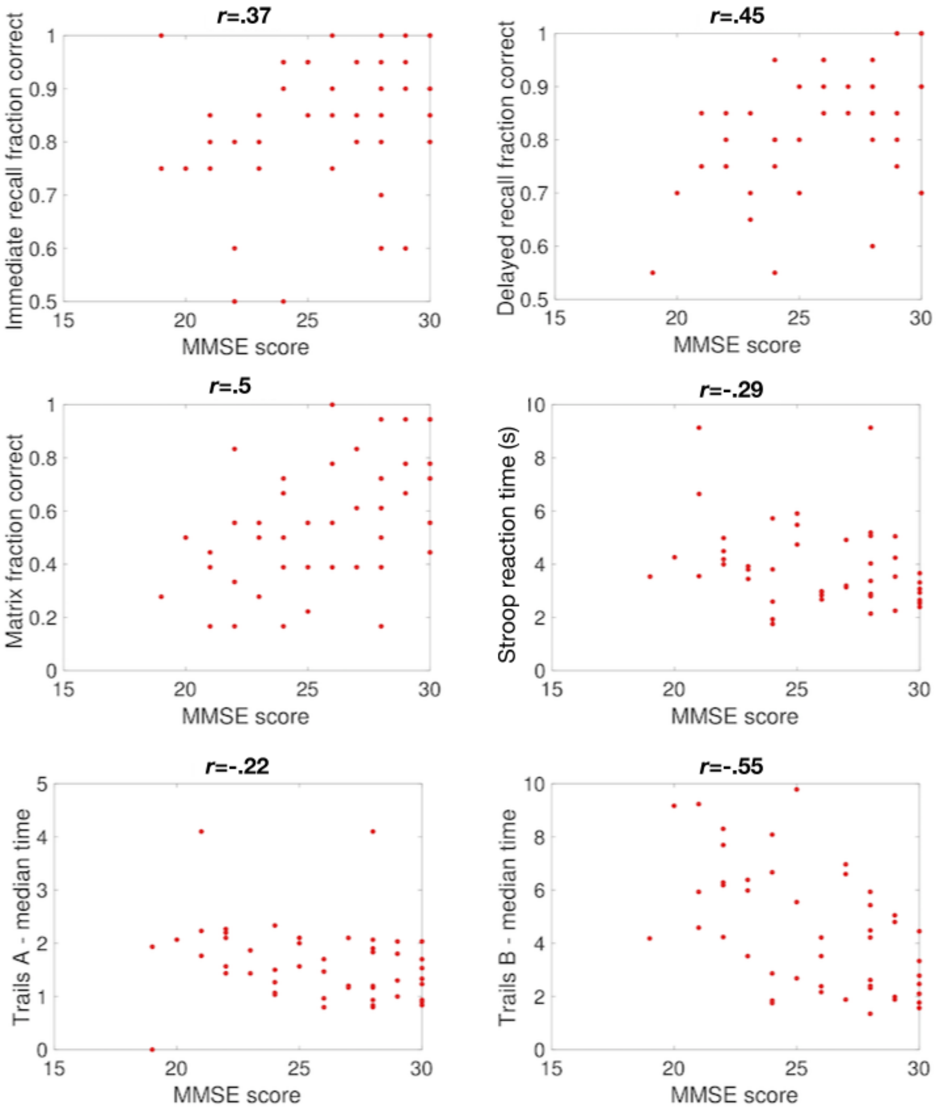


Figure 4. Comparison of BrainCheck assessments with the Montreal Cognitive Assessment (MoCA). Shown are comparisons between MoCA scores and the scores for each assessment. Each data point represents one participant who took both assessments. Pearson correlation coefficients are indicated above each panel.

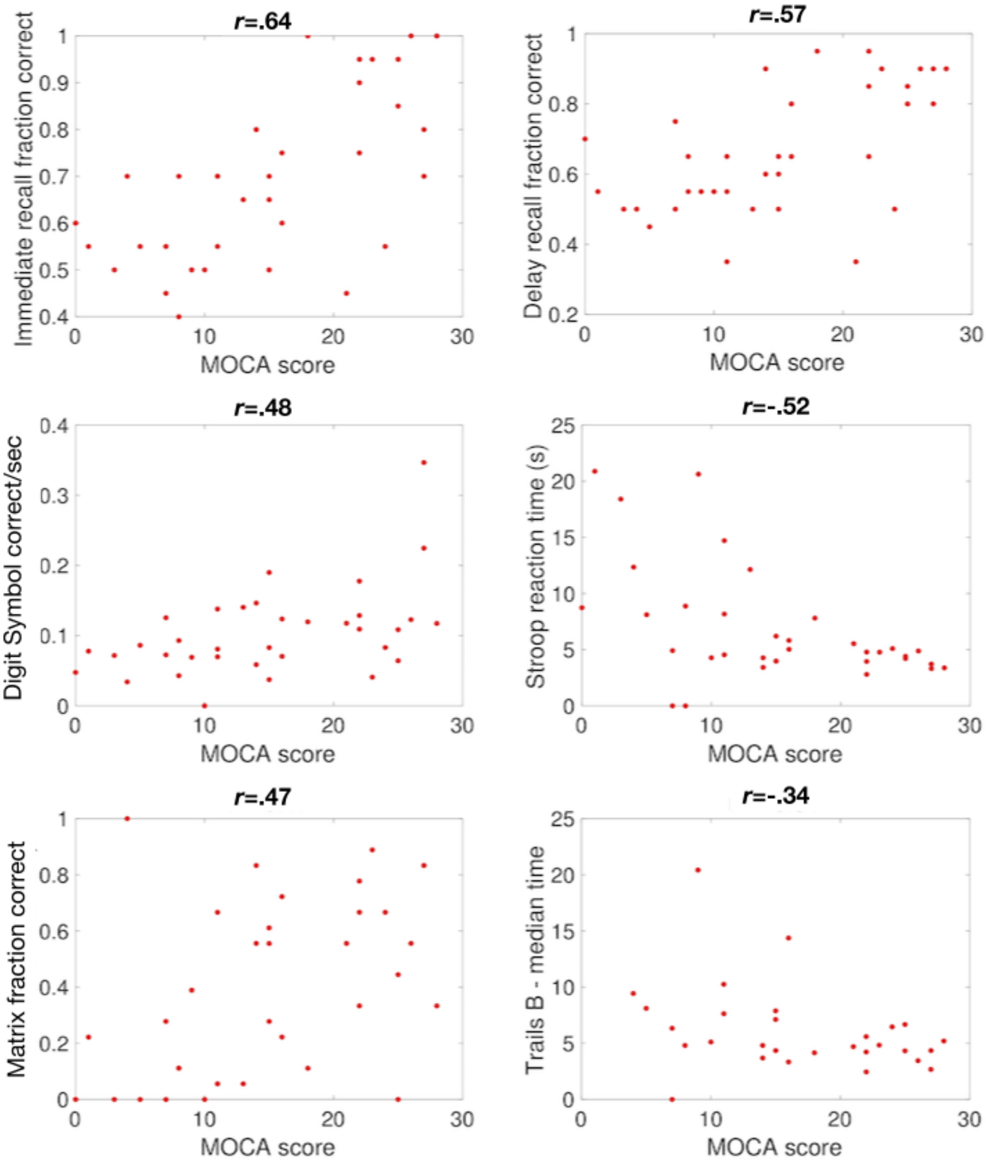
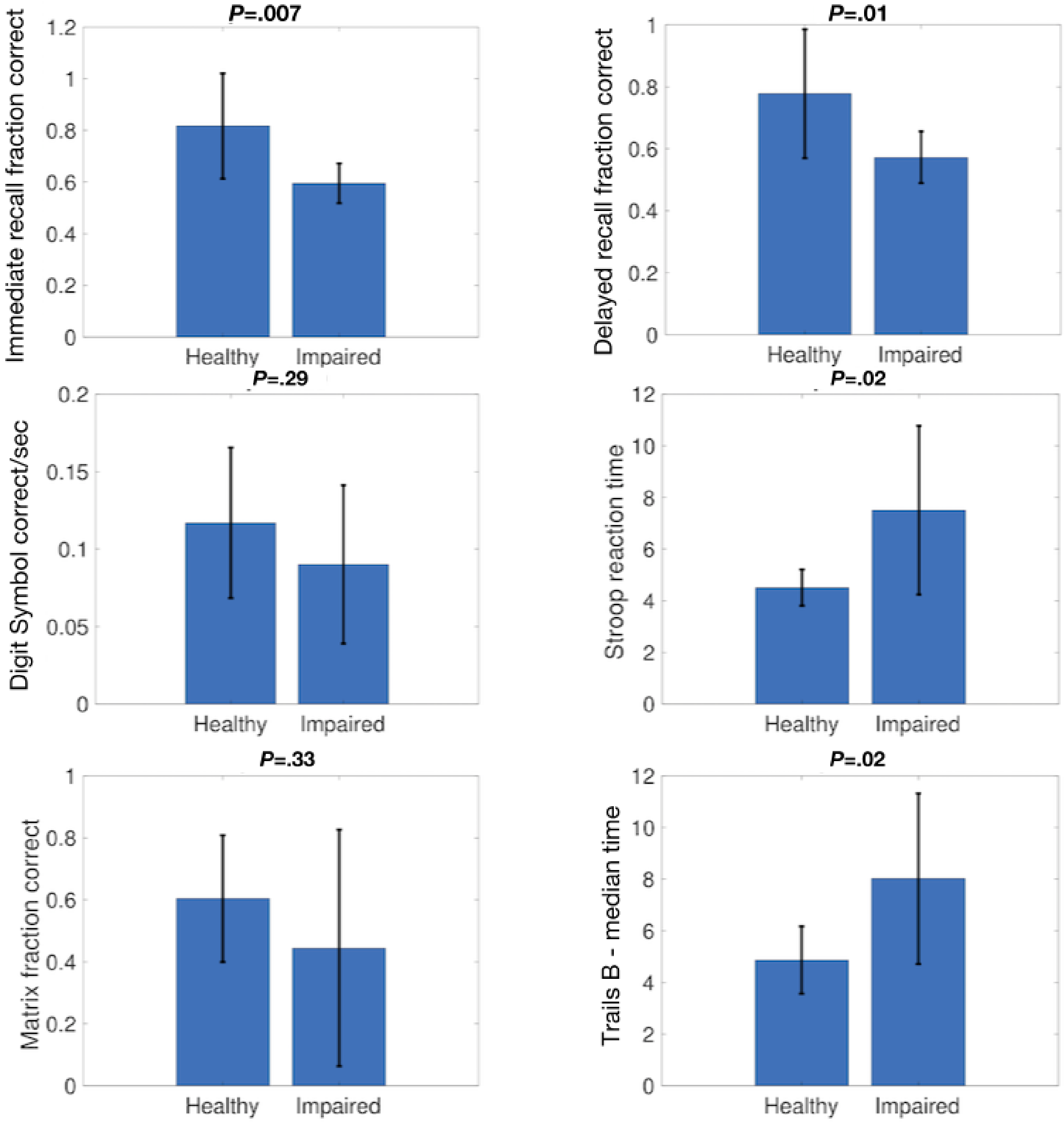


Figure 5. Comparison of BrainCheck assessments with physician diagnosis. Shown are mean scores on each assessment for patients classified as healthy or impaired by a physician. *P* values determined by a two-sided *t* test are given above each panel.



Defining a Composite Score for the BrainCheck Battery

We defined a scaled score for each assessment (s_a), such that it fell between 0 and 1. We then defined each assessment's contribution to the composite score (c_a) as $c_a= w_a s_a$ in assessments with metrics where higher scores indicated higher performance, such as the fraction of correct answers, and $c_a= w_a(1- s_a)$ in cases where higher scores indicated worse performance, such as in tests that measure a reaction time. The weights (w_a) were scaled such that their sum was 30, which ensures all composite scores fall between 0 and 30 per other established metrics, such as the SLUMS exam and MMSE. We then used an optimization algorithm to optimize the weights (w_a) to maximize the correlation between the composite BrainCheck score and the score on the SLUMS test. Once defined, we applied this optimized metric to our normative population and found a mean of 22.2 with a standard deviation of 2.9. With this optimized metric, we found excellent correlation between the BrainCheck score and the SLUMS exam score—Pearson correlation coefficient, *r*=.81 (see Figure 6).

To verify that this composite score performs well against other screening methods that were not used in the optimization, we evaluated the optimized composite score against the MMSE. We again found a strong correlation between the BrainCheck composite score and the MMSE score—Pearson correlation coefficient, *r*=.62 (see Figure 7)—which was stronger than both the correlations of the MMSE with any of the individual assessments and the correlation with the average of the BrainCheck assessments (*r*=.44). We further compared the composite score with the MoCA and found the composite score to outperform each of the individual assessments—Pearson correlation coefficient, *r*=.77 (see Figure 8).

We compared the BrainCheck composite scores in the groups of healthy and impaired individuals as measured by physician diagnosis. We found that impaired individuals had mean

BrainCheck composite scores of 14.4 (SD 3.8) as compared to 20.4 (SD 2.2) in the healthy individuals, a highly significant difference (*P*<.001). We noted that the mean score in the group diagnosed as healthy by the physician was still below the mean of our normative population, potentially indicating BrainCheck's ability to detect subtler cognitive deficits than a binary diagnosis.

Finally, we examined the sensitivity and specificity of the BrainCheck tests. Using the physician diagnosis, we found a sensitivity of 89% and a specificity of 78% (see Figure 9). Using a cutoff of 21 on the SLUMS test as the diagnostic criteria, we found a sensitivity of 81% and a specificity of 94% (see Figure 10) [8]. Taken together, these results show that the BrainCheck battery can function as a sensitive and specific screening tool for cognitive impairment.

Figure 6. Comparison between BrainCheck composite score and the Saint Louis University Mental Status (SLUMS) exam.

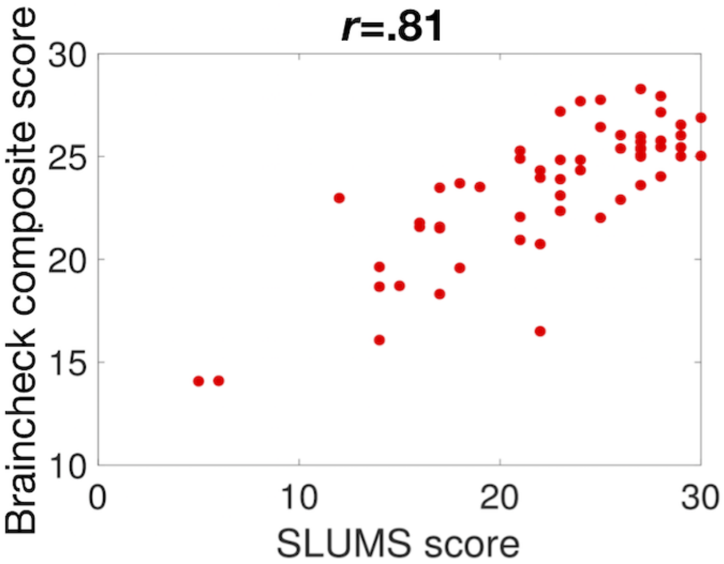


Figure 7. Comparison between BrainCheck composite score and the Mini-Mental State Examination (MMSE).

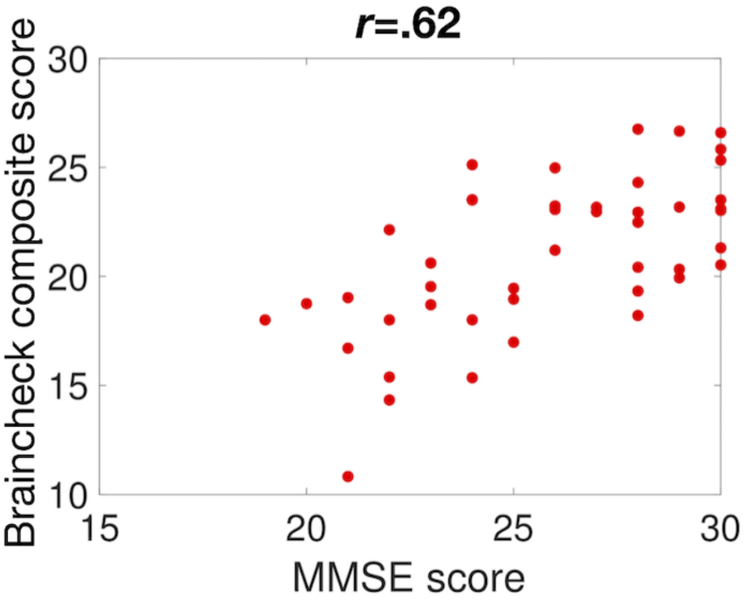


Figure 8. Comparison between BrainCheck composite score and the Montreal Cognitive Assessment (MoCA).

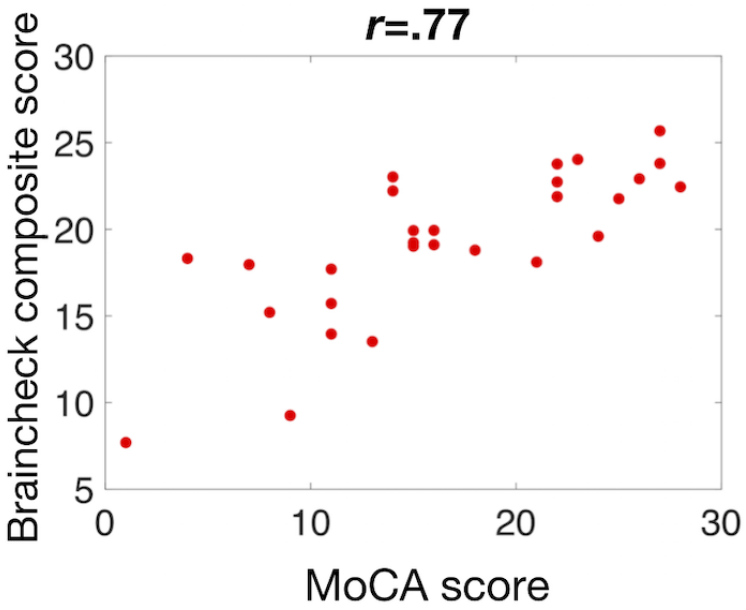


Figure 9. Receiver operating characteristic (ROC) curve for comparison between the physician diagnosis and the BrainCheck composite score.

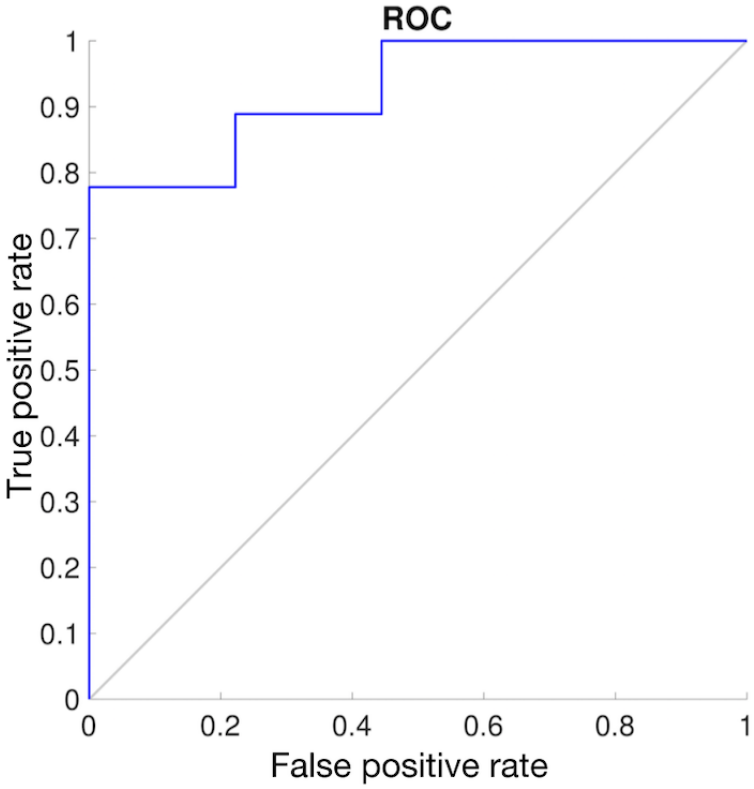
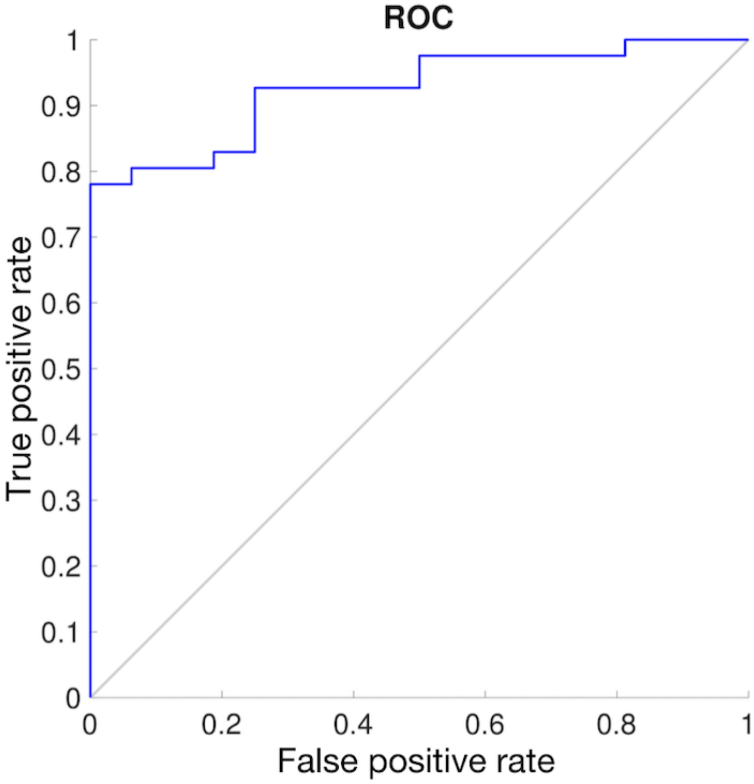


Figure 10. Receiver operating characteristic (ROC) curve for comparison between the Saint Louis University Mental Status (SLUMS) test (cutoff 21) and the BrainCheck composite score.



Discussion

Principal Findings

We found that BrainCheck's composite score is a valid screening tool for cognitive impairment in older adults, as it significantly correlates with scores on the SLUMS test, the MMSE, the MoCA, and physician diagnosis. Unlike the MoCA, the SLUMS exam, and the MMSE, which assess only a few cognitive domains across a series of 12, 11, and 12 items, respectively, BrainCheck's six assessments are able to measure multiple domains while remaining time-efficient [15], with completion times averaging approximately 21 minutes.

Although individual assessment correlations were only weak to moderate in strength, BrainCheck's strong composite score correlation, coupled with sensitivities and specificities comparable to those of the commonly used reference tests, demonstrate the value of utilizing the entire battery as a diagnostic aid. Automated scoring and the ability to take BrainCheck without a test administrator reduces potential interviewer bias and variances in physician provision of paper-based tools, which can be affected by training and time pressures in face-to-face assessment of patients. BrainCheck completion time indicates time spent by the subject, not the physician. While somewhat longer than the 10-15-minute estimate of MMSE administration time noted by the publisher of that screening tool, the BrainCheck protocol automates test administration and scoring, reserving physician time to interpretation of results and medical decision making.

Additionally, BrainCheck's portability, ease-of-use, cost-efficiency, and its ability to store information and connect to electronic medical records should make it a valuable clinical tool. Use of standardized cognitive tests additionally may provide additional physician reimbursement opportunities. Use of brief cognitive screening tools provided during the patient interview are often considered to be elements of the face-to-face visit and are not separately billed and reimbursed.

Limitations

Geographic and age-dependent convenience sampling was used to create our study sample. As such, availability of participants was limited, restricting sample size. Moreover, the four-to-one gender distribution of our sample exceeds the female-to-male ratios in the general population [26,27]. Lastly, some participants were unable to complete BrainCheck's entire battery of assessments. While this was accounted for during analysis, the missing data may have limited statistical power. In addition, other screening methods may be necessary for individuals with visual impairment, illiteracy, or movement disorders that preclude administration via a tablet.

Our exploratory physician diagnosis substudy revealed strong correlations between physician assessment and BrainCheck scores. However, due to our small sample size, more research is needed to compare and validate BrainCheck against physician diagnosis.

Conclusions

Future research should aim to investigate further the potential of BrainCheck to identify not only demented individuals, but those who might be categorized with MCI. A tool with the ability to detect MCI holds great relevance for the future of aging care, as MCI is a common precursor to further cognitive decline. Therefore, detecting MCI may aid primary prevention efforts [7], as well as aiding in the assessment and intervention of treatable or reversible cognitive impairment, potentially prolonging the quality of life of patients and their caregivers. Focus on screening for MCI may additionally reduce the proportion of test takers unable to use a self-administered tool, which can limit utility for individuals with more advanced dementias. Additional study of practice workflow and electronic health record integration will also evaluate factors that may facilitate or inhibit adoption of technology-based assessment tools such as BrainCheck, as physicians balance the need for comprehensive assessment of at-risk individuals with the time pressures of contemporary practice.

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Authors' Contributions

Conception and design of the study were performed by DME, YK, and BF. Data acquisition was performed by SG, WD, and IS. SG wrote the manuscript, which was revised and edited by BF, KMSR, WD, YK, and DME.

Conflicts of Interest

BrainCheck Inc provided personal fees in the form of annual salaries for the authors BF, WD, KMSR, YK, and DME; fees for consulting were provided to SG.

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Abbreviations

ADHD: attention deficit hyperactivity disorder
c_a: contribution to the composite score for each assessment
MCI: mild cognitive impairment
MMSE: Mini-Mental State Examination
MoCA: Montreal Cognitive Assessment
ROC: receiver operating characteristic
s_a: scaled score for each assessment
SLUMS: Saint Louis University Mental Status exam
TMT: Trail Making Test
w_a: weights

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Original Paper

Using Actigraphy to Predict the Ecological Momentary Assessment of Mood, Fatigue, and Cognition in Older Adulthood: Mixed-Methods Study

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Abstract

Background: Sleep quality has been associated with cognitive and mood outcomes in otherwise healthy older adults. However, most studies have evaluated sleep quality as aggregate and mean measures, rather than addressing the impact of previous night’s sleep on next-day functioning.

Objective: This study aims to evaluate the ability of previous night’s sleep parameters on self-reported mood, cognition, and fatigue to understand short-term impacts of sleep quality on next-day functioning.

Methods: In total, 73 cognitively healthy older adults (19 males, 54 females) completed 7 days of phone-based self-report questions, along with 24-hour actigraph data collection. We evaluated a model of previous night’s sleep parameters as predictors of mood, fatigue, and perceived thinking abilities the following day.

Results: Previous night’s sleep predicted fatigue in the morning and midday, as well as sleepiness or drowsiness in the morning; however, sleep measures did not predict subjective report of mood or perceived thinking abilities the following day.

Conclusions: This study suggests that objectively measured sleep quality from the previous night may not have a direct or substantial relationship with subjective reporting of cognition or mood the following day, despite frequent patient reports. Continued efforts to examine the relationship among cognition, sleep, and everyday functioning are encouraged.

(JMIR Aging 2019;2(1):e11331) doi:10.2196/11331

KEYWORDS

actigraphy; aging; ecological momentary assessment; mood; sleep

Introduction

Recent trends in behavioral health have demonstrated the importance of quality sleep in older age [1]. However, nighttime sleep disturbances are common in older adults [2] such as early waking, poorer sleep efficiency (SE), and trouble falling asleep [3-5]. Sleep difficulties in cognitively healthy older adults have been associated with self-reports of poorer physical and mental functioning [6,7], indicating the importance of sleep in successful aging (ie, the preservation of physical and cognitive functioning and avoidance of disease processes [8].

Sleep complaints in older adults are also associated with cognitive and functional difficulties [9,10]. For example, poor sleep quality has been associated with poorer global cognitive functioning [11-13], as well as with specific deficits in memory [14,15], attention, and executive functioning [16]. In addition, poorer overall health and increased daytime fatigue [17], as well as reduced participation in social and physical activities [18], have been attributed to poor sleep in the elderly. Although there is evidence that sleep problems increase in late-life, less is known about the specific sleep factors that contribute to both poorer cognitive and functional abilities. This study explored the impact of objectively measured sleep quality on self-reported measures of daily functioning (eg, mood, fatigue, and perceived cognitive functioning) in a community-dwelling older adult sample.

Ecological momentary assessment (EMA) allows the gathering of subjective measures multiple times per day [19,20]. EMA has been used extensively in research with physical activity monitoring [21,22] and to document affective changes [23,24]. A major advantage of EMA is capturing data in short timeframes, resulting in less bias from autobiographical memory strategies [25,26]. In addition, data collection occurs in the participants' natural environment without drastically changing or influencing their daily routine [27].

Given the variability in daily experiences, EMA approaches appear ideal for the assessment of fatigue, physical activity, and fluctuations in mood during the day. Furthermore, nightly comparisons may reveal more useful information relative to aggregated or averaged data, as night-to-night variability has been associated with greater sleep complaints in the elderly [28]. Lemola et al [29] found that greater variability in the total sleep time (TST) was associated with self-report of poorer sleep quality and subjective well-being; however, average sleep duration, sleep onset latency (SOL), and wake after sleep onset (WASO) were not related to self-reported well-being. McCrae et al [30] found that lower self-reported sleep quality was associated with more negative affect, but these relationships did not achieve significance for objective sleep measures. Russell et al [31] evaluated sleep measurements as predictors of next-day fatigue in patients with chronic fatigue syndrome and found that subjective, but not objective, sleep measures predict next-day fatigue. Furthermore, they found that negative mood in the morning mediated the effect between subjective sleep and fatigue.

This exploratory study tested a model of objective sleep measures as predictors of self-report measures of cognition, mood, and fatigue at 4 time blocks the following day (ie, morning, midday, afternoon, and evening). We hypothesized that greater SOL, poorer SE, and increased WASO from the previous night would predict EMA-based reports of more negative mood, greater daytime fatigue and sleepiness or drowsiness, and poorer perceived thinking abilities the following day. These relationships were expected to be strongest in the morning and midday time blocks because of their proximity to the previous night's sleep. In other words, if sleep quality impacts mood, cognition, or fatigue the following day, the influence would be greatest at times closest to the morning wake time (eg, feeling groggy or perception of less cognitive clarity in the morning) and prior to activities that could improve energy levels, mood, and cognition (eg, caffeine and exercise).

Methods

Participants

Participants aged ≥55 years were recruited from the community (eg, newspaper ads and health fairs) and completed phone interview screenings including a brief medical review, the telephone interview for cognitive status (TICS) [32], and the Modified Clinical Dementia Rating [33]. Participants were excluded from the study if they obtained a TICS score of ≤27 (the equivalent of a Mini-Mental State Examination of 24) [32] and a Modified Clinical Dementia Rating score >0, which would indicate cognitive impairment. Individuals with diagnosed sleep disorders (eg, chronic insomnia and sleep apnea) and current use of sleep medications or aids (eg, zolpidem and doxepin) were also excluded. Self-report of minor sleep complaints (eg, occasional difficulty falling asleep, staying asleep, or waking too early) were not considered exclusionary criteria, as these subthreshold sleep complaints are common in older adults and reflect normal sleep in a cognitively healthy population [3,4]. In addition, participants were screened for depression and excluded if they scored >10 on the Geriatric Depression Scale-Short Form [34], as well as other cognitive domains, including attention, verbal memory, language, and executive functioning (Table 1), to determine a cognitively healthy participant group.

In this study, 73 cognitively healthy older adults met the study criteria with, at least, 6 nights of actigraph data and <75% of EMA questions answered. The 73 participants (19 males, 54 females) had a mean age of 67.64 (SD 9.59) years. Table 1 provides the descriptive data of the sample. This study was part of a larger longitudinal study on cognition and aging; as such, all participants completed a 3-hour battery of cognitive tests and questionnaires; scores were compared with normative data, and participants whose scores fell ≥1.5 SDs below the mean were excluded from the sample (see Table 1 for average cognitive performances of the sample). After completing cognitive testing, participants wore an actigraph for 1 week while also completing EMA measures (ie, phone-based questions 4 times daily).

This study was approved for human subjects by the Washington State University Institutional Review Board under a study entitled "Activities of Daily Living, Executive Functioning and Aging" (Institutional Review Board Number 12606-011).

Sleep Measures

Actigraph

Mini-Motionlogger actigraphs (Ambulatory Monitoring Inc.) were worn on the nondominant wrist for 1 week of consecutive nights. Actigraph data were collected in Proportional Integration Mode, aggregated in 60-second epochs, and analyzed using the University of California, San Diego sleep scoring algorithm [35].

The following sleep variables were used for statistical analyses:

- SOL: Time elapsed from the start of the "down" interval of nighttime sleep until the first minute scored as sleep or inactive.
- SE: Percentage of minutes scored as "sleep" within the "down" interval.
- WASO: Total minutes scored as "wake" during the "down" interval after actigraphically determined sleep onset.

Table 1. Demographic data and mean summary data for older adult participants.

Variable or test	Mean[a] (SD)	Normative descriptor
Demographics		
Age	67.64 (9.59)	N/A[b]
Education (years)	16.41 (2.70)	N/A
Gender	N/A	19 male, 54 female
Verbal ability and global status		
Wechsler Test of Adult Reading total score	44.34 (3.61)	High average
Telephone Interview for Cognitive Status total score	35.30 (2.04)	Nonimpaired
Attention and speeded processing		
Symbol Digit Modalities Test Oral total	55.43 (11.84)	High average
Verbal memory		
Memory Assessment Scale List Delayed Recall	11.25 (1.18)	Average
Word finding and language		
Boston Naming Test total correct	57.23 (2.96)	High average
Executive functioning		
D-KEFS[c] Letter Fluency	41.90 (11.84)	Average
D-KEFS Design Fluency	26.62 (7.04)	Average
Frontal Assessment Battery total	16.83 (1.68)	Nonimpaired

[a] Unless otherwise indicated, mean scores are raw scores.

[b] N/A: not applicable.

[c] D-KEFS: Delis-Kaplan Executive Functioning System.

Textbox 1. Ecological momentary assessment phone questions and response options.

"Your general thinking abilities are currently...”

- Response options: Very Good, Good, Fair, Poor, Very Poor (1-5, respectively)

"Your general mood is currently...”

- Response options: Very Good, Good, Fair, Poor, Very Poor (1-5, respectively)

"How fatigued do you feel currently?"

- Response options: Not at all or none, A Little Bit, Somewhat, Quite a Bit, Very Much (1-5, respectively)

"In the past 2 hours, how sleepy or drowsy have you felt?"

- Response options: Not at all or none, A Little Bit, Somewhat, Quite a Bit, Very Much (1-5, respectively)

Ecological Momentary Assessment

EMA self-report measures of mood, fatigue, sleepiness or drowsiness, and perceived thinking were obtained using an automated phone system for 7 consecutive days (corresponding to actigraph data collection). Each day was divided into 4 time blocks as follows: morning (9:30-11:30 am); midday (12:30-2:30 pm); afternoon (3:30-5:30 pm); and evening (6:30-8:30 pm). Participants received an automated call at a random time during each time block. If they did not answer the phone, the system automatically redialed 10 minutes later (up to 2 redials within each block). The same 4 questions were asked at each time block, including the current assessment of mood, fatigue, drowsiness, and thinking abilities (Textbox 1). Questions included a 2-hour time window, “In the past 2 hours...,” to capture the time elapsed within the 2-hour time block. Participants used the numeric phone keypad to respond to questions using Likert-style continuums (eg, “For ‘Very Good’, press 1”).

The average TST for the sample was 413.69 (SD 76.60) minutes, which equates to roughly 6.89 hours of sleep per night. However, Spearman correlations revealed that the TST and the EMA question of daily activity completion did not demonstrate correlations with any other variable (ie, correlations >.200); thus, actigraphic TST and EMA completion of daily activities were not included in regression analyses. For comprehensiveness, when ordinal logistic regression (LR) models were run with and without TST, the presence of TST did not influence the outcome of the model. To increase the power of the ordinal logistic regression models, as well as eliminate predictor variables that did not demonstrate preexisting relationships with dependent variables, the TST was not included as a predictor of the EMA data in the regression models.

All variables were evaluated for normality prior to conducting statistical analyses. Although the EMA data were skewed, the transformation of the EMA data would make it difficult to interpret findings of the ordinal logistic regression models. Rather than using transformation techniques, and to preserve the ordinal nature of the EMA data, statistical procedures were selected depending on the data type. Spearman correlations (ρ) were conducted for rank-order correlations that did not assume a normal distribution (eg, EMA questions), while Pearson correlations (r) were conducted for actigraph data, which were normally distributed. Initial correlations were conducted to identify relationships between EMA and actigraph data. Then, a within-subjects ordinal logistic regression model was run using the variables that surfaced as having significant relationships with the dependent measure (per findings of Spearman correlations at P<.01); this model evaluated the influence of previous night's sleep measures on the EMA data the following day.

Ordinal logistic regression models were run individually for the prediction of the EMA data at each time block. Participants' age was held constant in all models. Measures of SOL, SE, and WASO from the previous night's sleep were entered simultaneously as predictors of EMA self-reports of mood, fatigue, sleepiness or drowsiness, and perceived thinking abilities at morning, midday, afternoon, and evening time blocks the following day. Significance values for model fit were set at P<.01.

Results

Actigraph Sleep Data

Participants wore actigraphs for an average of 7.47 nights (SD 0.40). Measures of SE (mean 91.93% [SD 5.02]), SOL (mean 20.30 [SD 16.23] minutes), and WASO (mean 38.10 [SD 28.34] minutes) were consistent with cognitively healthy older adult samples in other studies [36]. Longer SOL (r=−.361, P=.002), but not SE and WASO (r=−.096 to.020, P=.002), correlated with older age. Table 2 presents actigraph data for the participant sample.

Ecological Momentary Assessment Data

On average, participants completed EMA questions for 7.96 (SD 0.44) days and answered an average of 79.52% morning, 75.35% midday, 81.49% afternoon, and 83.03% evening phone calls. Older age exhibited small correlations with EMA reports of greater sleepiness or drowsiness at the morning time block (ρ=−.265, P=.03) and more negative mood at the morning time block (ρ=−.238, P=.04). Figure 1 shows the mean values of the EMA data.

Spearman Correlations

Correlations of evening EMA data (Day A, Time 4) with the EMA data the following day (Day B, Times 1-4) revealed that prior evening self-reports of mood, fatigue, sleepiness or drowsiness, and perceived thinking abilities generally correlated with EMA reports for identical questions the next morning, midday, afternoon, and evening (ρ=.389-.747, P=.002-.001; Table 3). All EMA questions generally correlated with each other at all time blocks (ρ=.335-.794, P=.001), except mood and perceived thinking abilities with fatigue and sleepiness or drowsiness at the evening time block (Table 3).

Model of Actigraphy and Ecological Momentary Assessment Data

Relationships Between Actigraph and Ecological Momentary Assessment Data

Spearman correlations (Table 4) revealed that greater WASO and poorer SE were related to EMA reports of greater fatigue (WASO: ρ=.395, P=.005; SE: ρ=−.402, P=.004) and greater sleepiness or drowsiness (WASO: ρ=.381, P=.01; SE: ρ=−.404, P=.004) at the morning EMA time block the following day. In addition, longer SOL from the previous night correlated significantly with greater fatigue at the afternoon time block (ρ=.372, P=.01). None of the other sleep variables from the previous night correlated significantly with any of the EMA questions at midday (ρ=−.358 to.347, P=.002-.003) or evening time blocks (ρ=−.292 to.239, P=.008-.009) the following day.

Ordinal Logistic Regression Analyses

Sleep Predicting Ecological Momentary Assessment Report of Mood

The model did not indicate adequate fit for the morning (LR χ^2_3=3.68, P=.30), midday (LR χ^2_3=2.37, P=.50), afternoon (LR χ^2_3=6.14, P=.11), or evening (LR χ^2_3=2.77, P=.43) time blocks when predicting mood. None of the sleep measures emerged as significant predictors of EMA reports of mood at any of the 4 time blocks the following day (z=0.24-0.74, P>.05).

Sleep Predicting Ecological Momentary Assessment Report of Fatigue

When predicting fatigue the next morning (Time 1), the model showed adequate fit (LR χ^2_3=8.05, P=.04). Regression coefficients for sleep predictors indicated that decreased SE (odds ratio, OR, 1.16, 95% CI 1.08-1.28) predicted an increase in fatigue in the morning time block, but WASO (OR 1.07, 95% CI 0.96-1.14) and SOL (OR 1.01, 95% CI 0.98-1.04) did not (Table 5).

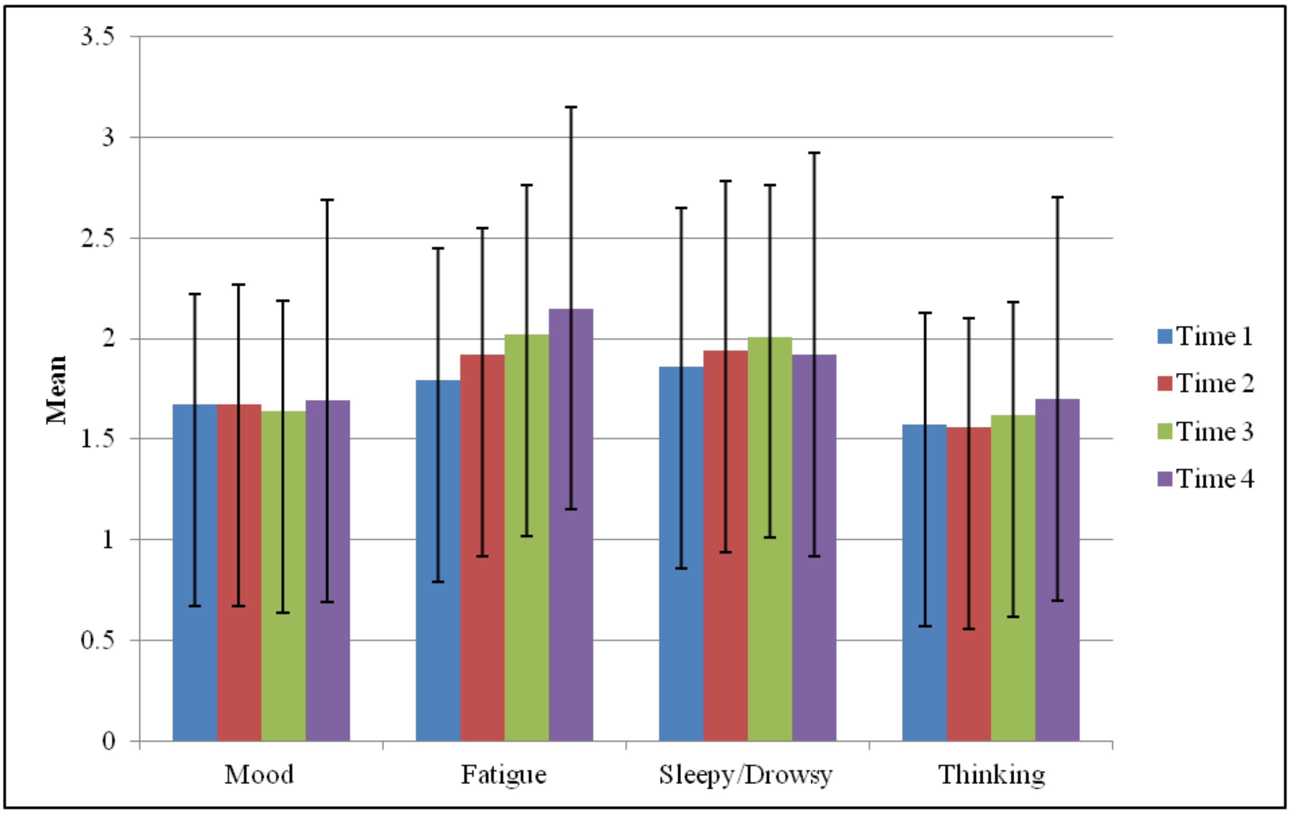
When previous night's sleep measures were used to predict fatigue at midday the following day, the model demonstrated adequate fit (LR χ^2_3=11.49, P=.004). Evaluation of regression coefficients indicated that an increase in SE (OR 1.12, 95% CI 0.73-1.20) predicted a decrease in the EMA-based report of fatigue. Furthermore, WASO (OR 1.05, 95% CI 0.97-1.11) and SOL (OR 1.00, 95% CI 0.97-1.03) did not predict significant changes in EMA-based report of fatigue.

Table 2. Participant averages of actigraph variables and correlations with participants' age.

Actigraph	Mean (SD)	Pearson's *r*	*P* value
Sleep onset latency (min)	20.33 (16.23)	−.361[a]	.002
Sleep efficiency (%)	91.93 (5.02)	.202	.08
Wake after sleep onset (min)	38.18 (28.34)	−.193	.10

[a] Significant at *P*<.01.

Figure 1. Mean values of ecological momentary assessment variables across times 1-4.



The models of actigraph sleep parameters did not indicate adequate fit for predicting EMA reports of fatigue in the afternoon (LR χ^2_3=5.85, *P*=.12) or evening (LR χ^2_3=2.28, *P*=.52). Sleep parameters from the previous night did not predict changes in EMA reports of fatigue the following afternoon or evening (*z*=−0.62 to 0.29, *P*>.05).

Sleep Predicting Ecological Momentary Assessment Report of Sleepiness or Drowsiness

When SOL, WASO, and SE from the previous night were used as predictors of EMA report of sleepiness or drowsiness the next morning, the ordinal logistic regression model showed adequate fit (LR χ^2_3=15.06, *P*=.002). Regression coefficients indicated that increased SE predicted a decrease in the EMA-based report of sleepiness or drowsiness the following morning (OR 0.87, 95% CI 0.63-1.06). However, WASO (OR 0.99, 95% CI 0.94-1.04) and SOL (OR 1.02, 95% CI 0.98-1.04) did not predict significant changes in EMA-based report of sleepiness or drowsiness.

Furthermore, models of sleep variables predicting EMA reports of sleepiness or drowsiness did not indicate adequate fit for midday (LR χ^2_3=6.59, *P*=.09), afternoon (LR χ^2_3=3.94, *P*=.27), or evening (LR χ^2_3=5.70, *P*=.13) time blocks. As such, sleep parameters from the previous night did not predict changes in EMA reports of sleepiness or drowsiness at midday, afternoon, or evening time blocks the following day (*z*=−1.22 to −0.09, *P*>.05).

Sleep Predicting Ecological Momentary Assessment Report of Perceived Thinking Abilities

When SOL, WASO, and SE from the previous night were used as predictors of EMA report of perceived thinking abilities the next morning, the ordinal logistic regression models did not demonstrate adequate fit for any of the EMA time blocks, including morning (LR χ^2_3=5.80, *P*=.12), midday (LR χ^2_3=1.70, *P*=.64), afternoon (LR χ^2_3=0.27, *P*=.96), or evening (LR χ^2_3=0.97, *P*=.81). As such, none of the sleep parameters emerged as significant predictors of EMA reports of perceived thinking abilities the following day (*z*=−1.73 to 0.26, *P*>.05).

Table 3. Spearman correlations between previous night and ecological momentary assessment questions the following morning, midday, afternoon, and evening.

Day B	Day A, Evening			
	Mood	Fatigue	Sleepy or drowsy	Perceived thinking abilities
Morning				
Mood	.747[a]	.541[a]	.419[a]	.794[a]
Fatigue	.535[a]	.579[a]	.335[a]	.465[a]
Sleepy or drowsy	.426[a]	.507[a]	.389[a]	.417[a]
Perceived thinking abilities	.610[a]	.479[a]	.386[a]	.674[a]
Midday				
Mood	.777[a]	.507[a]	.358[a]	.726[a]
Fatigue	.458[a]	.655[a]	.383[a]	.426[a]
Sleepy or drowsy	.374[a]	.529[a]	.478[a]	.393[a]
Perceived thinking abilities	.606[a]	.506[a]	.353[a]	.655[a]
Afternoon				
Mood	.675[a]	.591[a]	.451[a]	.675[a]
Fatigue	.636[a]	.720[a]	.453[a]	.571[a]
Sleepy or drowsy	.453[a]	.409[a]	.562[a]	.419[a]
Perceived thinking abilities	.711[a]	.554[a]	.437[a]	.771[a]
Evening				
Mood	.474[a]	.437[a]	.430[a]	.648[a]
Fatigue	.284	.531[a]	.571[a]	.305
Sleepy or drowsy	.197	.218	.560[a]	.194
Perceived thinking abilities	.383[a]	.420[a]	.359	.517[a]

[a] Significant correlation at *P*<.01.

Table 4. Spearman correlations of ecological momentary assessment variables with previous night’s sleep data.

Ecological momentary assessment (next day)	Sleep onset latency (min)	Sleep efficiency (%)	Wake after sleep onset (min)
Morning (Time 1)			
Mood	.208	−.287	.284
Fatigue	.258	−.402	.395[a]
Sleepy or drowsy	.273	−.404[a]	.381[a]
Perceived thinking abilities	.174	−.327	.304
Midday (Time 2)			
Mood	.262	−.144	.096
Fatigue	.328	−.358	.347
Sleepy or drowsy	.257	−.316	.267
Perceived thinking abilities	.312	−.232	.166
Afternoon (Time 3)			
Mood	.204	−.227	.192
Fatigue	.372[a]	−.329	.287
Sleepy or drowsy	.208	−.228	.163
Perceived thinking abilities	.255	−.153	.041
Evening (Time 4)			
Mood	.197	−.262	.165
Fatigue	.229	−.273	.225
Sleepy or drowsy	.145	−.292	.239
Perceived thinking abilities	.229	−.133	.054

[a] Significant correlation at *P*<.01.

Table 5. Ordinal logistic regression odds ratios for models predicting ecological momentary assessment self-reports based on sleep variables obtained the previous night.

Ecological momentary assessment (next day)	Actigraph data (Previous night)			χ^2	*P* value
	Sleep efficiency	Sleep onset latency	Wake after sleep onset		
Morning (Time 1)					
Mood	1.02	1.02	1.04	3.68	.30
Fatigue	1.16	1.01	1.07	8.05[a]	.04
Sleepy or drowsy	0.87	1.02	0.99	15.06[a]	.002
Perceived thinking abilities	0.87	1.03	0.99	2.80	.12
Midday (Time 2)					
Mood	1.11	1.00	1.05	2.37	.50
Fatigue	1.12	1.00	1.05	11.49[a]	.01
Sleepy or drowsy	1.00	1.01	1.02	6.59	.09
Perceived thinking abilities	0.99	1.01	1.02	1.70	.63
Afternoon (Time 3)					
Mood	1.05	0.99	1.04	6.14	.11
Fatigue	0.93	1.01	1.02	5.85	.12
Sleepy or drowsy	0.86	1.00	0.99	3.94	.27
Perceived thinking abilities	0.84	1.00	0.99	.27	.97
Evening (Time 4)					
Mood	1.01	1.00	1.02	2.77	.42
Fatigue	1.20	1.00	1.04	2.28	.52
Sleepy or drowsy	1.01	1.00	1.01	5.70	.13
Perceived thinking abilities	0.97	1.00	0.99	.97	.81

[a] Significant at $P<.05$. Confidence intervals are reported in-text.

Discussion

Principal Findings

This study was an exploratory approach to examine relationships between objectively measured sleep quality (eg, WASO, SOL, and SE) and self-report of mood, fatigue, sleepiness or drowsiness, and perceived thinking abilities in a cognitively healthy older adult sample using actigraphy and EMA phone-based self-reports.

Older age was related to EMA reports of greater sleepiness or drowsiness and negative mood in the morning. Relationships between participants' age and EMA questions of fatigue and perceived thinking abilities did not achieve significance. When the EMA data were compared between the previous night and the following day, reports of fatigue were markedly lower in the morning; however, EMA reports of sleepiness or drowsiness remained stable from the evening to morning and midday time blocks the following day. It is possible that the EMA questions of fatigue and sleepiness or drowsiness are not measuring identical constructs and that the wording of these 2 questions affected the reporting by participants (ie, “current” vs “past 2 hours”).

Consistent with the initial hypotheses, EMA reports of fatigue and sleepiness or drowsiness were related to previous night's sleep. Specifically, poorer SE was related to greater sleepiness or drowsiness the next morning. However, WASO and SOL were not significant predictors of EMA measures of sleepiness or drowsiness and fatigue the following morning. Furthermore, the TST was removed from the regression analyses owing to a limited relationship with any of the dependent measures, and no evidence of contributing to the overall model. Sleep measures were not strongly related to mood and perceived thinking abilities; this relationship was likely affected by the minimal variation in the EMA data for these questions (ie, mostly average reports).

Findings of predictive relationships between sleep the previous night and EMA measures the next morning were inconsistent. Poorer SE was associated with increased levels of sleepiness or drowsiness at the morning time block and levels of fatigue at the morning and midday time blocks. These findings support the research of McCrae et al [17] who found relationships between greater self-reported sleep problems with subjective complaints of daytime fatigue in older adults. This study expands these findings to include an objective assessment of sleep (actigraphy) as predictors of subjective daytime fatigue.

Previous night's sleep predicted only morning or midday EMA reports but did not predict EMA reports of fatigue and sleepiness or drowsiness at afternoon and evening time blocks. Other daytime factors (eg, naps and consumption of caffeine) may mitigate the impact of the previous night's sleep on energy levels later in the day. For example, one study found that greater variability in daytime naps was associated with poorer health status [37], and it is recommended that future research consider the implication of naps on cognitive and functional abilities.

Previous night's sleep did not predict EMA reports of mood and perceived thinking abilities the next day. Although the literature suggests that self-reported poor sleep is associated with depression and decreased functional status [38], this study found that objective sleep was not directly associated with mood. Our findings support the research of previous studies [30] that subjective, but not objective, sleep quality was associated with self-reported affect (eg, poorer sleep quality correlated with more negative affect). Of note, participants in this study were screened for depressive symptoms at the outset; thus, relationships with mood may be affected by the baseline levels of emotional symptoms for the participants. Interestingly, our results contrast the findings of Russell et al [31] who found that subjective but not objective sleep measures predicted self-reported fatigue the following morning, as our objective sleep measures did predict reports of next-morning fatigue; however, this study was in a generally healthy older adult sample, whereas others evaluated patients with chronic fatigue syndrome [31], suggesting differences in detections within clinical populations.

Limitations

The study sample was predominantly female, highly educated, and racially homogenous, which may limit the generalization of findings to other demographic groups. The number of participants excluded from the initial sample was substantial as a result of study requirements; larger sample sizes, as well as comparisons of healthy groups to those with sleep disorders or sleep medications, would be useful to assess the influence of medical and pharmaceutical impact on sleep and daily functioning. By nature of the EMA data, there were many individual variables and, as a result, a large number of analyses were conducted in this study, increasing the possibility of false-positive findings. To compensate for this, we used more stringent *P* values and reduced variables in the models to only those identified in initial correlation analyses (ie, removal of actigraphic TST and EMA daily activity performance). Regarding EMA limitations, the type of telephone number (eg, home vs cell phone) may have influenced the data collection, such that individuals who provided home phone numbers may not have been home to respond to the phone calls; the qualitative nature of missed response items is worthy of further investigation. In addition, the time blocks chosen for this study were based on focus-group information; however, this may not have accurately captured variation in wake-up time (ie, participants who would normally wake up sooner or later than the phone call period). Sensor-based assessment, such as using actigraphy or wrist-based fitness devices, could be a way to prompt EMA questions within a designated time of waking up, thus adjusting to the individual chronology of participants.

Future Directions

Future research should consider longitudinal effects of sleep and perceived functioning on actual cognitive and everyday performance. For example, if maintaining consistent sleep patterns is found to be more predictive of perceived functioning and, thus, contributing to actual cognitive performance, this could inform treatments for sleep disruption. Given the prevalence of naps as individuals age [39], it would be beneficial to include the influence of napping in models of sleep and daily functioning (eg, pre- and postnap EMA reports). Furthermore, research on sleep and neurodegenerative disease has explored the sleep profiles of those with mild cognitive impairment [40,41] and dementia [42], as well as neurological changes in poor sleepers with cognitive deficits [43]. Additional research efforts should investigate whether poor sleep is a robust contributor or risk factor for cognitive decline, as monitoring changes in sleep could be beneficial for the treatment of neurodegenerative disease.

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Conflicts of Interest

None declared.

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Abbreviations

D-KEFS: Delis-Kaplan Executive Functioning System
EMA: ecological momentary assessment
LR: logistic regression
SE: sleep efficiency
SOL: sleep onset latency
TICS: telephone interview for cognitive status
TST: total sleep time
WASO: wake after sleep onset

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Original Paper

Weekly, Seasonal, and Geographic Patterns in Health Contemplations About Sundown Syndrome: An Ecological Correlational Study

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Abstract

Background: Sundown syndrome (ie, agitation later in the day) is common in older adults with dementia. The underlying etiology for these behaviors is unclear. Possibilities include increased caregiver fatigue at the end of the day and disruption of circadian rhythms by both age and neurodegenerative illness.

Objective: This study sought to examine circumseptan (weekly) patterns in search volumes related to sundown syndrome, in order to determine if such searches peaked at the end of the weekend, a time when caregiver supports are least available. We also sought to examine both seasonal differences and associations of state-by-state search activity with both state latitude and yearly sun exposure.

Methods: Daily Internet search query data was obtained from Google Trends (2005-2017 inclusive). Circumseptan patterns were determined by wavelet analysis, and seasonality was determined by the difference in search volumes between winter (December, January, and February) and summer (June, July, and August) months. Geographic associations between percent sunny days and latitude were done on a state-by-state basis.

Results: “Sundowning” searches showed a significant increase at the end of the weekend with activity being 10.9% (SD 4.0) higher on Sunday as compared to the rest of the week. Search activity showed a seasonal pattern with search activity significantly highest in the winter months (36.6 [SD 0.6] vs 13.7 [SD 0.2], $P<.001$). State-by-state variations in “sundowning” searches showed a significant negative association with increasing mean daily sunlight ($R^2=.16$, $\beta=-.429$ [SD .149], $P=.006$) and showed a positive association with increasing latitude ($R^2=.38$, $\beta=.648$ [SD .122], $P<.001$).

Conclusions: Interest in “sundowning” is highest after a weekend, which is a time when external caregiver support is reduced. Searches related to sundown syndrome also were highest in winter, in states with less sun, and in states at more northerly latitudes, supporting disrupted circadian rhythms as another contributing factor to these behaviors.

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KEYWORDS

sundown syndrome; geriatric medicine; dementia; circadian rhythms; infodemiology; infoveillance; internet

Introduction

Agitation and aggression in older adults with dementia are accompanied by significant emotional costs for caregivers and accounts for approximately 30% of the total annual cost of caring for a person with Alzheimer’s disease in the community [1]. One of the most troublesome and common behavioral issues is the “sundown syndrome,” which is characterized by increasing agitation, confusion, and anxiety later in the day (late afternoon or evening) [2]. Sundown syndrome has shown to be present in 66% of community-dwelling older adults with dementia and greatly increases the risk of institutionalization [3].

The term “sundowning” was first used in the scientific literature by Cameron et al in 1941 when he described an increase in disorientation and agitation in a dementia patient placed in a darkened room [4]. The first systematic look at sundown syndrome found that 11 out of 89 facility patients exhibited these behaviors and that they were related to environmental factors such as the smell of urine, being awakened frequently, or being new to the facility as opposed to physiological ones [5]. Exum et al looked at the use of “as needed” (prn) medications in institutionalized older adults and found that medication use to control difficult behaviors occurred at institutionally defined times such as shift change (reflecting caregiver fatigue) as opposed to changes in ambient light [6].

Despite the large prevalence of caregiver reports of temporal changes in behavior, there is a lack of detail with respect to the underlying mechanisms [7]. Some work has suggested that there is no biological mechanism underlying behavioral issues in the late afternoon/early evening and is merely due to the effects of caregiver fatigue on subjective impressions [8]. Other work, however, has shown temporal increases in agitation and anxiety in animal models [7] and in human observational studies [9]. Due to the well-established impact of neurodegenerative dementias on circadian rhythms [10], some early studies have shown beneficial effects of both light therapy [11,12], increased natural light [13], and melatonin [14].

Traditionally, behavioral issues in dementia have been measured using clinical scales [15] and surveys [16]. One drawback to using these methods to determine temporal and geographic patterns is the long time lag between measurement and analysis [17] and the tendency of persons to answer in a socially desirable manner [18]. A newer technique, referred to as “infodemiology,” allows researchers to examine the hidden concerns and motivations of large populations using open access Internet search activity [19]. Open access Google search data have allowed us to find patterns in various populations’ hidden health concerns on a real-time basis. For example, recent work has determined which day of the week people contemplate smoking cessation [20] and which day of the week is the “healthiest day” [21]. Internet search data have also been used to find seasonal and geographic patterns in contemplations surrounding weight loss [22], exercise [22], restless legs syndrome [23], and mental health [24].

The current study uses United States Google search data to explore both caregiver fatigue and disrupted circadian rhythms as underlying mechanisms for sundowning behaviors. If caregiver fatigue is a factor in the interpretation of the behavior of older adults, we hypothesized that Internet search activity should peak at the end of each weekend, a time when caregiver supports are least available [25]. If alterations in circadian rhythms are a factor, search activity should be higher during winter months and state-by-state search activity should show positive associations with both increasing state latitude and decreasing sun exposure.

Methods

Internet Search Activity

The number of searches that have been performed for any given keyword can be computed using Google Trends, a Web-based tool. Since overall search activity often varies on different days of the week (eg, search activity is different on weekend vs non-weekend days), search is normalized for the overall number of searches and is reported as a score between 0 and 100 [26]. This normalization of search activity avoids biases due to changes in search activity (eg, during the winter vs summer months, or on weekend days) [26]. Search activity can also be narrowed to a specific country or state within a country. As per current standards for reporting Google Trends data in medical studies [27], daily search data were obtained from 2005-2017, and the database was downloaded as a .csv file accessed on September 7, 2018. The complete text for all queries was “sundowning.” All searches were limited to those classified by Google as in the “Health” subcategory in order to avoid non–health-related searches. As in previous studies of this type [21,27], this paper used only open access, publicly available aggregate data. A human subjects ethics board review was deemed unnecessary by our institution [28].

Circumseptan Temporal Pattern Analysis

The circumseptan (weekly) periodicity in “sundowning” searches for 2016 was determined using a continuous wavelet transformation [29], using the WaveletComp package in R version 3.4.2 [29]. Continuous wavelet transformations are similar to other methods of determining periodicity in time series analysis, such as cosinor or Fourier transformation analyses. The advantage of the wavelet transformation analysis is that there are no parametric assumptions required. Internet search data can often show long-term trending bias that can obscure short-term periodicities when other methods are used. Wavelet transformations are robust in the face of bias and allow us to detect more short-term patterns such as seasonal or circumseptan variations. It has also been used in previous studies to determine weekly patterns of health contemplations [20,21]. The time series was reconstructed with all periodic components less than 14 days after adding back the mean of the time series (wavelet transformations are centered about the mean), as in previous studies [20,21].

Seasonal Temporal Pattern Analysis

The magnitude of the seasonal shifts in search inquiries for “sundowning” was determined by the difference between the average volume of searches in winter months (December, January, and February) and summer months (June, July, and August) as done in previous studies [22,24]. Seasonal analysis was performed for all data from 2005-2017.

Latitude and Natural Light Exposure Data

Latitudes for the center of each state were obtained from the US Department of Commerce [30], and average percent daily hours of sunshine data for each state were obtained from the National Centers for Environmental Information [31] for 2016.

Statistical Analysis

In order to determine weekly patterns of search activity, we used our reconstructed time series to model the difference between Monday and the other days using day of the week as a factor variable ($\beta_{Tuesday} + \beta_{Wednesday} + \beta_{Thursday} + \beta_{Friday} + \beta_{Saturday} + \beta_{Sunday}$) as described in other studies [20,21]. This allows us to determine the percentage increase in "sundowning" searches for each day of the week relative to the search activity on Mondays by the formula $\beta_{Day\ of\ the\ week} / \beta_{Intercept\ (Monday)} * 100$ [20,21]. As established in previous studies, confidence intervals were determined through bootstrap sampling of the ratio's distribution (5000 simulations) [21,32].

The difference in search activity between winter (December, January, and February) and summer (June, July, and August) months was determined by a paired *t* test. The R core software package version 3.0.1 was used for statistical analysis with a significance level of $P<.05$ [30].

For our geographic pattern analysis, our primary response variable (Searches) was the normalized number of searches for the term "sundowning" on a state-by-state basis for 2016. Our predictor variables were the latitude of the center of each state (Latitude) and the percentage of time between sunrise and sunset that sunshine reaches the ground for each state (PercentSun), as used in previous investigations [24]. Density plots were visually inspected to identify data skewing. Any predictors that demonstrated skewing were logarithmically transformed (base 10) prior to the multivariable analyses [33]. Plots of residuals and a Q-Q (quantile-quantile) plot were examined for each model. For each simple linear regression, the coefficient of determination (R^2), and beta coefficients (β) are reported [33]. The R core software package version 3.4.2 was used for statistical analysis with a significance level of $P<.05$ [30].

Results

Circumseptan Temporal Patterns

None of our predictor or outcome variables demonstrated skewing on density plots. As shown in Figure 1, there was significant increase in search volume at the end of the weekend (Sunday) with searches being 9.5% (SD 4.2) higher. Sunday was the only significant factor variable, indicating that this was the only day of the week that showed a significant difference in search activity as compared to Monday. When all non-Sunday days were compared with Sunday searches, searches were 10.9% (SD 4.0) higher on Sunday as compared to the rest of the week. Google Trends normalizes search results for overall search activity to a score between 0 and 100.

Seasonal Temporal Patterns

Search activity showed a seasonal pattern with search activity significantly higher in the winter months while declining in the summer months (36.6 [SD 0.6] vs 13.7 [SD 0.2], $P<.001$) (Figure 2). Once again, Google Trends normalizes search results for overall search activity to a score between 0 and 100.

State-by-State Variations by Sunshine Exposure and Latitude

State-by-state variations in "sundowning" searches showed a significant negative association with increasing PercentSun (R^2=.16, β=-.429 [SD .149], P=.006), with states having a higher mean daily percent of number of sunny hours showing less search activity (Figure 3). Additionally, search activity was also higher in more northerly states, showing a positive association between sundowning searches and Latitude (R^2=.38, β=.648 [SD .122], $P<.001$).

Figure 1. Circumseptan patterns of search activity in the United States for "sundowning" for each day of the week as compared to Monday.

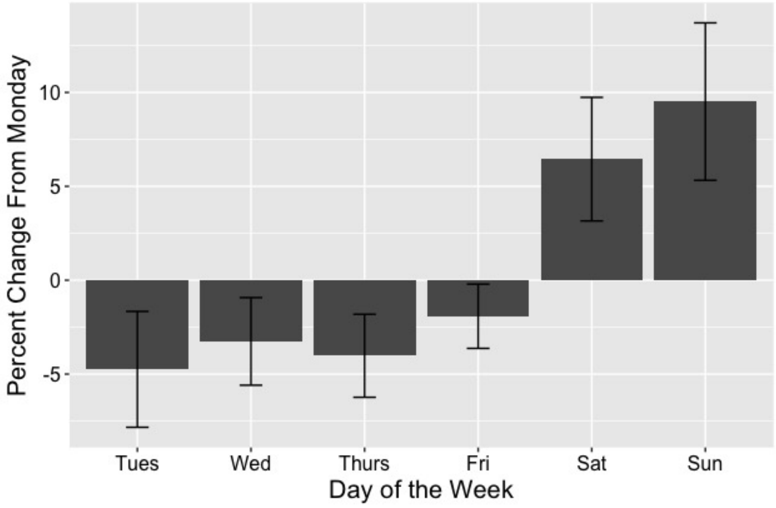


Figure 2. Seasonality of searches. Overall US search activity for "sundowning" for summer (June, July, and August) and winter (December, January, and February) months, showing much higher search activity during the winter.

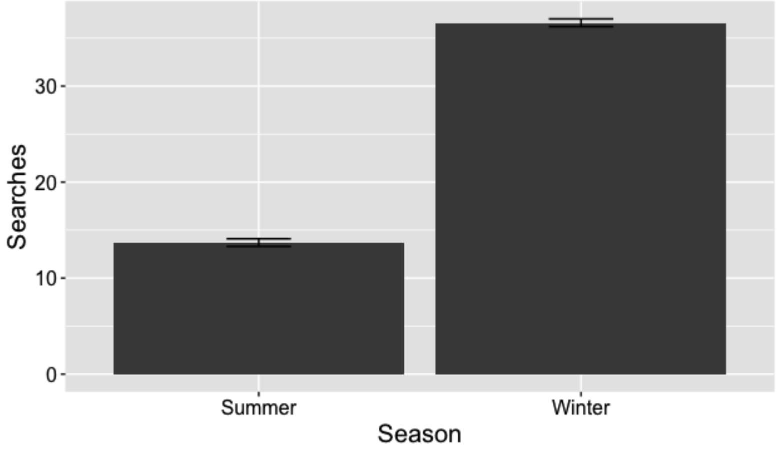
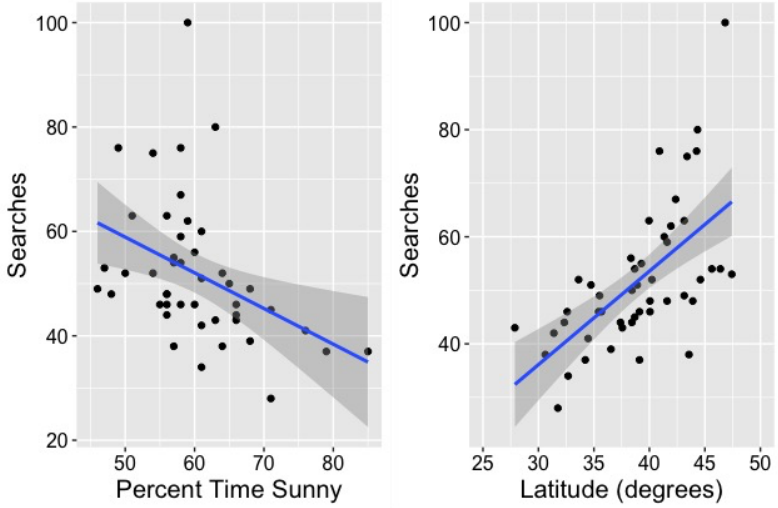


Figure 3. Search activity versus percent sunshine and latitude. Searches for "sundowning" showed a negative association with increasing percent daily sunshine and a positive association with increasing (more northerly) latitude.



Discussion

Principal Findings

Health contemplations surrounding sundown syndrome in the United States showed both geographic patterns and temporal periodicities, specifically, (1) interest in sundown syndrome increased at the end of the weekend by approximately 10%, (2) search inquiries were much higher in winter as opposed to summer months, and (3) state-by-state search inquires showed a negative association with the average percent of the day that was sunny and a positive association with more northerly (increasing) latitudes.

The current study demonstrates an increase in search activity as the weekend progresses (Figure 1), with searches for “sundowning” approximately 10% higher on Sunday. Given the fact that our dataset reflects billions of individual Google searches [34], an increase of 10% would represent an increase on the scale of millions of health contemplations. Since Google Trends normalizes all search activity for overall general search activity, this indicates an increase in contemplations about sundown syndrome, not merely an increase in Internet use during the weekend. The suggestion that sundown syndrome is at least partially associated with caregiver fatigue as opposed to being solely due to changes in environmental light is supported by our results. We demonstrated an increase in “sundowning” searches at the end of every weekend, a time when families typically perform caregiving duties without any outside assistance [25]. The end of the weekend is in some respects the “end of a shift” for family caregivers until outside caregiving assistance returns with the start of the weekday.

Like most species, humans have endogenous circadian rhythms. Like all mammals, humans have a biological clock located in the superchiasmatic nuclei (SCN) in the hypothalamus that has both body temperature and melatonin as outputs [35]. The natural period of this rhythm is longer than 24 hours and requires synchronization via light information delivered from the retina to the SCN through the retinohypothalamic tract [36]. Both aging and neurodegenerative disease reduce the neuronal activity of the SCN [37], providing a potential biological basis for sundown syndrome behaviors.

Our study demonstrated an increased interest in searches for “sundowning” during winter months as opposed to summer months, in states that had a smaller percent of sunny days, and in more northerly states. Since Google Trends data are normalized for overall underlying search activity, this is not merely due to an increase in search activity during colder, more inclement weather. Previous work in human subjects has shown an inverse relationship between natural light exposure and the regularity of circadian rhythms. In fact, the seasonal reduction in natural light exposure during the winter months has been linked with increased disruption of circadian rhythms [38]. Our results suggest that the reduction in natural light exposure during the winter months is one potential explanation for sundown syndrome behaviors. Caregiver stress cannot logically be the only explanation for this phenomenon. Amyloid precursor protein mice models show sundown syndrome behaviors similar to that described clinically [7] and there is certainly no "caregiver stress" in this scenario. As well, studies of light therapy [11], melatonin [14], and increased exposure to natural light [13] in cognitively impaired persons living in facilities all support disrupted circadian rhythms as a contributing factor to sundown syndrome behavior.

Clinical Implications

Our analysis of Google Trends data has demonstrated that health contemplations about sundown syndrome are higher at the end of the weekend, higher in winter months, and higher in states with less sunshine/more northerly latitudes. This ability to examine people's hidden contemplations could potentially allow us to target home supports more effectively. As an example, more resources for home supports could be deployed during the winter months or in portions of the country that get less natural light. The downsides of reduced person-power on weekends has been well demonstrated in the acute care setting [39], suggesting that these same issues may be increasing caregiver stress in the community setting as well. Our study provided correlational evidence for both the caregiver stress hypotheses and the circadian rhythm hypothesis for sundown syndrome.

Limitations

Although our study is suggestive with respect to the weekly, seasonal, and geographic patterns of healthy contemplations surrounding "sundowning," Google search activity does not indicate the underlying context for each search. Further research needs to be done to determine if targeting more home supports on the weekend, the winter months, and less sunny geographic locations would be a more efficient way to deploy health care resources.

In addition, Google Trends provides only normalized results of search data as opposed to absolute numbers of searches. Offsetting this, however, is the fact that the number of keyword searches are in the billions [40], so any observed seasonal, weekly, or geographic increase in normalized results likely represent millions of additional searches. For our search terms, we chose the colloquially used term "sundowning" as opposed to other more clinical search terms (eg, "sundown syndrome") in order to better target the layperson population, which is a potential limitation.

Our study also considered searches only in the United States. National differences due to differences in health care systems might have conceivably changed search behavior and is a potential future avenue of research. We also examined searches only in the "Health" section of Google trends, which might have omitted search queries related to caregiving and topics covered by the social science literature.

Conclusions

Health contemplations surrounding sundown syndrome behaviors are higher at the end of weekends, in less sunny states, in states at higher latitudes, and during winter months. These results provide support for both the caregiver stress and disrupted circadian rhythm hypotheses for sundown syndrome behaviors.

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Conflicts of Interest

None declared.

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Abbreviations

SCN: superchiasmatic nuclei

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Viewpoint

Design and Development of the Brain Training System for the Digital “Maintain Your Brain” Dementia Prevention Trial

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Abstract

Background: Dementia is the leading cause of disability worldwide, and interventions aimed at reducing the prevalence and burden of the disease are urgently needed. Maintain Your Brain (MYB) is a randomized controlled trial of a multimodal digital health intervention targeting modifiable dementia risk factors to combat cognitive decline and potentially prevent dementia. In addition to behavioral modules targeting mood, nutrition, and physical exercise, a new Brain Training System (BTS) will deliver computerized cognitive training (CCT) throughout the trial to provide systematic, challenging, and personally adaptive cognitive activity.

Objective: This paper aimed to describe the design and development of BTS.

Methods: BTS has been designed with a central focus on the end user. Raw training content is provided by our partner NeuroNation and delivered in several innovative ways. A baseline cognitive profile directs selection and sequencing of exercises within and between sessions and is updated during the 10-week 30-session module. Online trainers are available to provide supervision at different levels of engagement, including face-to-face share-screen coaching, a key implementation resource that is triaged by a “red flag” system for automatic tracking of user adherence and engagement, or through user-initiated help requests. Individualized and comparative feedback is provided to aid motivation and, for the first time, establish a social support network for the user based on their real-world circle of friends and family.

Results: The MYB pilot was performed from November 2017 to March 2018. We are currently analyzing data from this pilot trial (n=100), which will make up a separate research paper. The main trial was launched in June 2018. Process and implementation data from the first training module (September to November 2018) are expected to be reported in 2019 and final trial outcomes are anticipated in 2022.

Conclusions: The BTS implemented in MYB is focused on maximizing adherence and engagement with CCT over the short and long term in the setting of a fully digital trial, which, if successful, could be delivered economically at scale.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12618000851268; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=370631&isReview=true

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KEYWORDS

computerized cognitive training; dementia; clinical trial design; older adults

Introduction

Background

Late-life engagement in cognitively stimulating activities is associated with reduced risk for incident dementia [1]. Computerized cognitive training (CCT) is a specific type of structured cognitive activity that aims to enhance and maintain cognitive performance by means of repeated practice on controlled learning events, targeting specific cognitive processes [2,3]. CCT differs from other types of cognitive interventions by focusing on implicit practice rather than explicit teaching of strategies [4] and has several advantages over traditional pencil-and-paper approaches, chiefly, adaptivity, personalization, flexible administration, and engaging game-like environments [2,5]. Systematic reviews and meta-analyses of randomized controlled trials have established the efficacy of CCT for overall and domain-specific performance in healthy older adults [5], mild-to-moderate Parkinson disease [6], mild cognitive impairment [7], and major depressive disorder [8] in contrast to a lack of efficacy in people with established dementia [7].

There are no established standards for planning and delivering CCT [9]. Design factors such as the content of the training program, training schedules, delivery methods, and combinations with other interventions (eg, physical exercise) vary substantially within and across studies. Literature in this regard suggests that several key design factors may be important for treatment outcomes and fidelity and are briefly reviewed in this paper.

Targeted Domains

Cognitive effects of CCT tend to relate to the domains trained by the specific program [10,11]: Improvements in untrained tasks (mainly neuropsychological outcome measures) are more likely if the CCT program provided exercises in the same or related (proximal) cognitive domains. Thus, single-domain CCT programs such as those that train only working memory are less likely to lead to meaningful effects beyond the trained domain [5,12]. Since clinical endpoints in older adults comprise global cognitive outcomes, CCT programs typically include a variety of tasks targeting multiple cognitive domains, but the exact composition of domains within programs varies from one program to another [7].

Training Content

A key design consideration in multidomain CCT is the specific selection of targeted domains and related exercises. There are four major approaches to content design. The first and most common is a fixed schedule, whereby all participants receive the same content across all sessions [13,14]. This design is easy to replicate, but ignores individual differences and therefore may over- or undertarget cognitive strengths and weaknesses at the individual level. Second, the approach taken by most commercial CCT providers as well as in the Neuropsychological Educational Approach to Cognitive Remediation [15] is to allow participants to choose the exercises for each session. This approach may improve subjective outcomes and attitudes toward the program [16], but may limit overall improvement, as users tend to spend more training time on exercises they enjoy and perceive as strengths. Third, some studies use baseline cognitive profiles to guide individual training plans, so that areas of deficit will receive more training time [17]. This approach better addresses individual differences, but ignores domain-specific adaptation, which is the variability of training time required to induce change in the underlying ability [14]. Finally, the most custom-tailored option is to adapt content by setting an initial training plan founded on baseline performance and then changing the composition of exercises at set time points in response to within-training task performance [18].

Adaptivity

A specific advantage of CCT is the ability to adjust task difficulty and content to individual abilities and progress. Adapting training difficulty is assumed to increase engagement and build skills over time, and adaptive designs tend to be more efficacious than nonadaptive training [18,19,20]. Typical difficulty ("level") vectors include presentation length, response speed thresholds, number of stimuli, or problem complexity. One particularly useful adaptivity method is the "staircase" algorithm, whereby training difficulty is adjusted during a block, and the level will change after a certain number of consecutive correct or incorrect responses. Some programs change difficulty only between blocks, whereas others implement this within an exercise session.

Feedback

Feedback is crucial for any learning process and can be an important component that motivates people to engage with the CCT program over time, but its application to CCT is complex and a surprisingly understudied area of work [21]. Most CCT programs will provide feedback for each response within a block (right or wrong), which often assists individuals to develop skills in the specific task. Feedback after blocks may include a temporal (ie, reference to the past performance) or social comparison (ie, reference to others). Other common elements are cumulative scores (eg, “medals” or “brain points”) that convey a sense of progress and may support long-term adherence. Results from previous studies that tried to identify the most effective feedback mechanism report inconclusive results. For example, Burgers and colleagues [22] found that positive feedback was associated with greater motivation to train on the same task in the future, whereas negative feedback increased motivation to train immediately after feedback was given, arguably in order to compensate for performance in the previous attempt, while social comparison decreased motivation overall. Conversely, Katz and colleagues [21] examined the effects of gaming elements such as real-time scoring and scaffolding in children and found that these were distracting and did not lead to better performance compared to neutral training. However, the generalizability of such results to longer-lasting CCT programs in older adults is unknown.

Delivery Context, Support, and Settings

One of the major advantages of CCT over other cognition-oriented approaches may be the potential to deliver the intervention online inexpensively and at scale. This opportunity, however, has not yet shown sufficient efficacy in the literature. Large trials of home-based CCT reported substantial attrition [23] and frustration [24] as well as low compliance with the training program compared with laboratory-based, supervised training [25]. Furthermore, a comprehensive meta-analysis by Lampit and colleagues [5] found a statistically significant difference between training effects of home-based CCT compared to supervised settings, with the latter estimated to be about three times larger than the former. Novel uses of technology to assist the effective delivery of CT are required; see the paper by Ge et al [26] for a systematic review of this topic.

It has also been proposed that the repetitive nature of the training exercises, which often resemble cognitive tests, limits the potential for engagement and motivation of participants [27]. Gamification of CCT exercises has been proposed as a potential method of maximizing participants’ interest; however, this has not been extensively studied [28]. In the broader literature, it is known that individuals respond best and engage with learning and training when they are intrinsically motivated to do so [29]. Home-based training may be less sensitive to personal differences and thus unable to provide specific motivational cues. Supervision may therefore be important for maintaining adherence by adding a human element to training, motivational support to complete difficult challenges, and problem solving for information technology issues. However, supervision in the present scenario is labor intensive and not scalable to a public treatment at large.

Another potentially crucial aspect of CCT delivery that has not been explored systematically is the consideration of within-session sequencing of different CCT exercises. As described above, it is likely that motivation and engagement are fundamentally linked to an individuals’ desire to engage with training and thus maximize the potential for cognitive improvements [30,31]. Exploring novel methods of maximizing individuals’ ability to engage with exercises that target the most difficult exercises (ie, their weaknesses) is therefore important. To our knowledge, no study has assessed this fundamental design element.

Finally, one of the most important factors in long-term engagement with *any* behavioral intervention is building a community of practice [32], a concept co-opted from organizational theory [33,34]. Joint enterprise (improvement of brain health), mutual engagement (training attendance and adherence), and shared repertoire (learning and mastering the software and exercises) are the core self-sustaining features of a communal practice [35]. These factors are easier to address in center-based CCT, since trainees tend to meet with other trainees in the laboratory or facility, cross-validate each other’s reason for being there, and engage with and receive instructions from trainers or research staff. In contrast, with home-based CCT, individuals have a high risk of feeling isolated, lacking support, or not understanding the relevance of the activity to the “real world.” This is yet another potential reason for the high rate of attrition and low treatment fidelity reported in many home-based CCT studies.

The “Maintain Your Brain” Digital Health Trial

In the following section, we will outline how these design considerations have been addressed in the digital Brain Training System (BTS), which is one of four intervention “modules” within the Maintain Your Brain (MYB) trial (trial registration: Australian New Zealand Clinical Trials Registry, ACTRN12618000851268) [36]. MYB is the largest online cognitive decline-prevention trial to date and has recruited 6200 Australians aged 55-77 years with multiple dementia risk factors but no dementia diagnosis. Participants were recruited from the Sax Institute’s 45 and Up Study [37]. Up to four preventative lifestyle-based modules can be administered depending on the person’s individual risk factor profile: the BTS module for those with an inactive cognitive history or current lifestyle, a physical exercise module for participants who are physically inactive or have chronic diseases/risk factors for dementia known to benefit from exercise (eg, diabetes, hypertension, and frailty), a nutrition module for those reporting dietary intake that does not indicate adherence to a Mediterranean-type cuisine or those who have chronic diseases/risk factors for dementia known to benefit from this type of diet (eg, obesity, cardiovascular disease, and excess alcohol consumption), and a stress- and depression-management module for those with chronic stress or current anxiety/depression-based symptoms; see Heffernan et al [36] for more details on the criteria. Each module is administered sequentially as a 10-week high-intensity block (ie, the maximal 4-module intervention lasts 4 × 10 weeks, although there may be short breaks in between modules), transitioning to monthly booster sessions for the remainder of the 3-year follow-up. Participants allocated to the control group will complete basic tasks such as video quizzes on the MYB platform, instead of completing CCT.

Readers are directed to the trial protocol [36] for further details on all outcomes of the trial. Briefly, the primary outcome will be the change in cognition from baseline to 3 years, as assessed by the MYB cognitive test battery. A number of secondary outcomes will also be assessed to determine the real-world relevance of any improvements in cognitive testing. The following factors are most important to the above-described cognitive module: differences in the occurrence of incident dementia and changes to assess dementia risk [36].

Aims

Our primary focus is to describe how the novel BTS aims to maximize CCT efficacy in the context of a large-scale, population-based, publicly funded trial with necessary resource restrictions. Several innovations are introduced in this paper, including functionalities to enable online supervision and promotion of a social community as well as our novel "sandwich" algorithm that allows for the principled selection and scheduling of CCT exercises both within and between sessions. This information will be critical to informed interpretation of MYB findings, when available, and may prove useful to researchers conducting similar interventions in the future.

Methods

Overview of the Brain Training System Architecture

The implementation of CCT involves much more than simply providing a set or sequence of disembodied cognitive exercises. The process is illustrated in Figure 1, where the user is at the center of our system architecture. Exercises have been provided by our collaborating partner, NeuroNation (Berlin, Germany), as a set of 34 stand-alone exercises with their own internal logic and tunable parameters. Sequencing and streaming of these exercises in a user-customized way is a challenge because it requires filling out a matrix of 30 (sessions) × 17 (exercises/session) = 510 exercise slots.

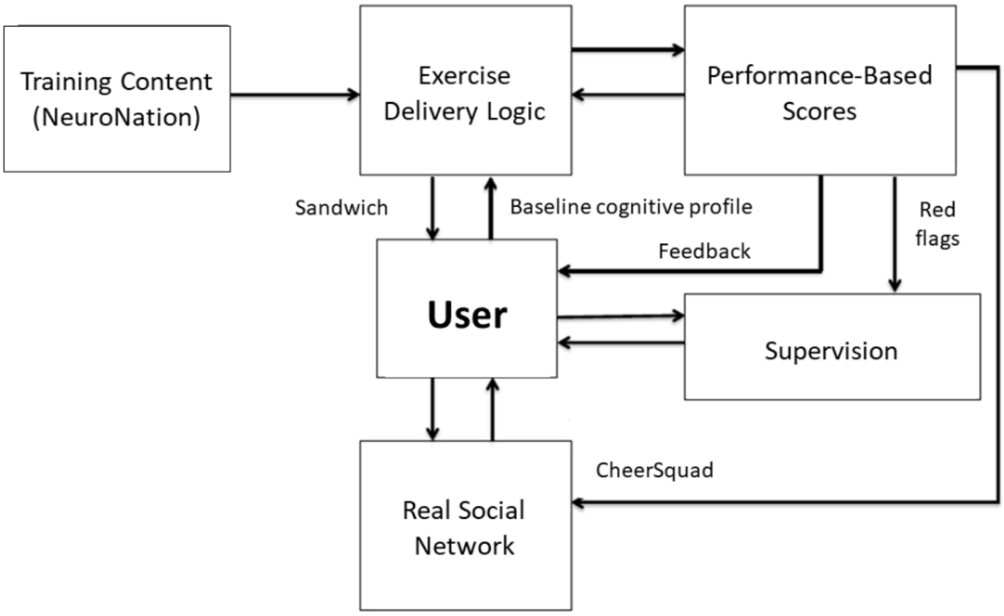
The BTS introduces a novel approach to CCT exercise delivery using logic built around the participant's initial cognitive profile, which is then updated during the evolution of their training process (detailed further below in terms of the "sandwich"). This logic therefore governs which exercises appear within a given session as well as the order of appearance in that session.

Next, a scoring system based on within-exercise performance was developed, which allows for comparable scores across exercises that are summated at the cognitive domain level. These scores were used for three main purposes: (1) to interact with the exercise logic algorithm to update the user's cognitive profile during the training process, (2) to provide performance feedback visually to the user, and (3) to automatically identify user engagement, compliance, or adherence issues for supervisory redress using the "red flag" system.

As mentioned above, the quality of supervision is a major determinant of the efficacy of CCT. Because MYB intended to recruit several thousand participants, individual one-on-one supervision, even online, was not feasible or desirable due to the intent of scalability. Our approach was therefore to triage our supervisor's interaction with users based on need, quantified by aggregation of red flags or user tickets. Supervision involved a combination of online chat messaging, emails, telephone calls, or Skype communication including screen sharing, if required, to provide live feedback on exercise engagement.

Finally, the fifth innovation in BTS was to enmesh the user's training experience with their real-world social network. This was accomplished with the Training with Friends functionality described below.

Figure 1. Functional architecture of the Brain Training System (BTS) where the participant is the central focus of activity. For any given session, BTS chooses the exercise based on the "sandwich" algorithm that responds to baseline cognitive profile and ongoing training performance and determines whether a particular exercise is delivered at the beginning, middle, or end of a session. Exercises were provided by our industry partner, NeuroNation. Performance-based scores are used to graphically feedback results to users, update their cognitive profile, and alert online trainers of users who most need support. Finally, real-world support is sought from the user's network of family or friends in order enhance training adherence, motivation, and experience.



Information Technology for the Brain Training System

The BTS depicted in Figure 1 is not a standalone system, but paired with the main MYB digital system that manages participant data and delivery of online modules. This loosely coupled architecture between MYB and BTS lends itself to ensuring seamless handover of information and that the load of one system does not adversely affect the other. To assist in scalability, BTS has been deployed with a horizontal scaling strategy, should the load on the system become too large for one server.

The PHP framework Laravel [38] was employed to implement BTS and utilizes the model–view–controller [39] architectural pattern. RESTful application programming interface Web Services [40] have been constructed to allow for third-party systems to interact with BTS. Content is consumed and structured such that logic can be applied to drive the participant's journey and exercise assignment through the system. MariaDB is utilized as the database for all data storage and retrieval.

A participant accessing BTS via MYB invokes a URL redirection (passing through obfuscated and encrypted identifiers) and is prompted to continue with their next available exercise. All exercises are delivered as Shockwave Flash Movie (.swf) files, and the system has embedded these exercises within the same web user interface to provide a seamless user experience. At the completion of each exercise, results are stored within BTS, and these data update the evolving cognitive profile of the participant. In addition, results are sent to the main MYB system via a RESTful application programming interface Web Service, so that the main MYB system aggregates all data across all modules. The BTS then assesses the session state and manages the next exercise or prompts the user that there are no further exercises to complete for that session.

Cognitive Domains and Content Delivery by the "Sandwich"

Measurement of baseline cognitive abilities and subsequent within-training improvement, along with classification of CCT exercises, correspond to seven cognitive domains: "Verbal Executive," "Verbal Memory," "Visual Executive," "Visual Memory," "Visual Attention," "Speed," and "Working Memory." A table of the MYB online cognitive tests and BTS exercises with corresponding cognitive domains is presented in Table 1.

Cognitive domains are used to build a cognitive profile, linking cognitive testing with CCT exercises. Classification was determined by consensus across the clinical authorship team. Note that many exercises share some cognitive elements, and classification was therefore based on the predominant and unique cognitive skills required for a given exercise. All exercises were provided by our collaborating commercial partner, NeuroNation. Cognitive testing was accomplished using a combination of an in-house developed LOGOS test and specific subtests from Cambridge Brain Sciences and CogState. CCT exercises are ideally completed across three sessions per week, translating to a module of 30 training sessions over 10 weeks. Each session lasts approximately 45 minutes and comprises 17 exercises. If participants miss a session, the allocated session remains available with no new sessions triggered (ie, sessions cannot be skipped) on the MYB platform until completed or the end of the 10-week intervention module (whichever is sooner). During postmodule follow-up that will last up to 3 years, booster exercises will be offered once a month.

The delivery of these exercises within BTS has been designed to maximize benefits to participants. The focus of this content delivery is the "sandwich" that is based on a novel insight around exercises anticipated to be "hard," "medium," or "easy" by participants. The first step in designing the sandwich (Figure 2) is to create a cognitive profile of the participant at baseline. Eight CCTs make up the cognitive profile (Table 1). This includes the MYB Cognitive Battery plus LOGOS (an in-house designed verbal memory measure that is completed over the phone via automated voice recognition). These eight tests have been selected to correspond to the seven cognitive domains described in Table 1. After completion of this battery, an estimate of the participant's strengths and weaknesses is possible. Standardized z-scores are created by comparing the individual's performance on each test to normative values collected during our pilot trial. Following this, cognitive domains can be ranked in order of strengths (highest comparative z-score) to weaknesses (lowest comparative z-score). Once this cognitive profile is created, the corresponding CCT exercises can be classified as "easy," "medium," or "hard" based on the domains they load upon (Table 1). For example, a CCT exercise tapping into a domain that is an individual's strength would be considered easy.

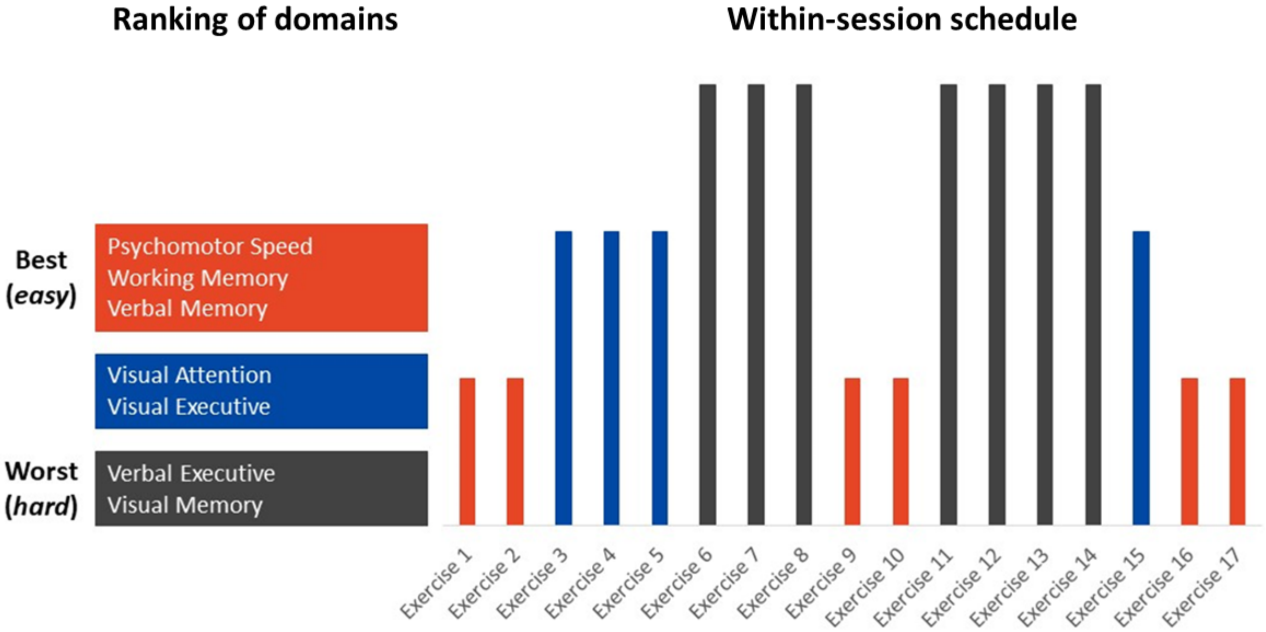
With this information, the initial sandwich is created and used for sessions 1-12. Each session will contain six easy, four medium, and seven hard exercises Subsequent sandwiches used in the sessions 13-18, 19-24, and 25-30 will adapt to reflect the participant's performance on the CCT exercises from the previous session range. Therefore, the cognitive profile originally based on baseline MYB Cognitive Battery will reflect performance on CCT exercises in comparison to the other participants in the trial. Subsequently, the cognitive profile will be adjusted based on the degree of improvement (or lack of) on specific exercises aggregated at the domain level. This therefore allows for adaptivity of content based on an individual's trajectories and responses to training. The sandwich will be refreshed at weeks 12, 18, and 24.

The training sessions consist of specially selected and integrated exercises from NeuroNation, a German brain-training software company. Each of the 34 training exercises were specifically chosen by the multidisciplinary MYB team to correspond to one of the seven cognitive domains of interest (Table 1). Although each of these exercises have been categorized as targeting a specific cognitive domain, as with most cognitive training exercises, they are inherently multidomain and may also target other domains to a degree. For example, regardless of the classification, many of the memory exercises may also train aspects of speed and attention. Although the domains chosen for training and exercise sequencing within a given session are responsive to the user's current cognitive profile, where multiple exercises that meet these specifications are available, the choice is pseudorandom.

Table 1. Cognitive domains and corresponding training exercises and tests.

Cognitive domain	Cognitive training exercise	Assessment of domain
Verbal Memory	Memory interrupted, Memo pair, Verbal learning	LOGOS
Visual Attention	Eagle eye, Clockwise, Memobox, Quick count, Quick switch	Cogstate - Identification
Visual Memory	Path finder, Path finder reverse, Restorer, Focus master, Polaroid picture, Symbolism, Turnabout, Reflector	Cogstate - One card learning test and Cambridge Brain Sciences - Paired associates
Verbal Executive	Word craft, Scrambled words, Domino word, Password	Cambridge Brain Sciences - Grammatical reasoning
Visual Executive	Plastic puzzle, Solitaria, Escalator, Color craze, Rotator, Form fusion, Missing link	Cambridge Brain Sciences - Spatial search
Working Memory	Parita speed, Form fever, Mixed memories	Cogstate - One-back test
Processing Speed	Split second, Flash glance, Form fever speed, Turning tables, Alphabet soup	Cogstate - Detection

Figure 2. Example of how an individual session of training is formalized using the “sandwich” algorithm. Red represents cognitive domains of strength, grey represents cognitive domains of weakness, and blue represents cognitive domains at the mid-level performance for the user. Cognitive training exercises that correspond to these domains will then be presented one by one. The first two exercises will be in a domain of strength (ie, easier to complete), the next three in the middle domain, the following three in an area of weakness (difficult to complete), and so on (ie, each session, an individual completes six easy, four medium, and seven hard exercises). Thus, the beginning, middle, and end of each session will feature the "easiest" exercises for that individual.



User Performance

User performance is critical for several reasons. First, these data are used to construct a feedback graph for users, which illustrates how they are performing relative to other users. Although there is no consistent empirical evidence on how to best provide feedback in CCT studies, our team’s clinical experience delivering CCT interventions across a number of populations suggests that some trainees are motivated to reach a minimum level or “standard,” while others are motivated to be the best. We have thus implemented a dynamic bar graph that visualizes how the participant is tracking in terms of performance on the seven cognitive domains, with a target zone representing the top performing 25%. It was our estimation that this graph will motivate those aiming to be at the top without demotivating those who are performing at lower levels. Second, participant performance data are also used to update the user’s cognitive profile and therefore sandwich algorithm. The third function is to automatically monitor compliance, adherence, and treatment fidelity as well as to identify participants who may be struggling to understand or appropriately complete the exercises. This is further described in the section “System-Initiated Flags” below.

Online Supervision

The Brain Training System

As discussed above, home-based CCT can be prone to participant attrition and frustration. In order to ensure participants are able to complete their allocated training with minimal frustration and dropout and to maximize potential benefit of the intervention, BTS was designed such that participants could interact with online trainers. The role of the trainer is to use online messaging, Skype video-conferencing, and phone calls to ensure participants have completed each task correctly and that queries or issues that arise are dealt with. BTS allows three ways in which trainers and trainees can interact.

System-Initiated Flags

In order for participants to stay on track and complete their allocated tasks correctly, BTS was designed to automatically create a "flag" if poor performance is detected. Poor performance was defined any of the following scenarios: (1) if the participant provides more incorrect than correct responses in an exercise, (2) if the participant scores zero correct answers in an exercise, and (3) if the participant fails to score above a predefined level or score on that task. These flags are expected to occur more frequently at the outset of training and are sensitive to users who have not understood the basic requirements of the task. In addition, a "decrease in performance" flag was created for a participant who, on two *consecutive* attempts of the same exercise (ie, across sessions), performs ≥10% worse on the second attempt than on the first attempt. This flag is sensitive to participants struggling with increasing difficulty. The aforementioned flags are grouped as "red flags." A separate group of flags are triggered to advise trainers and participants that adherence is not adequate. This "adherence flag" is created if participants take longer than 90 minutes to complete a training session or are absent for 72 hours between sessions. Adherence flags are visualized in BTS as "orange flags." Once three orange flags have been created, this system automatically produces an adherence red flag, notifying trainers of a more significant and persistent problem.

When a red flag occurs, it raises a "ticket" in BTS that must be responded to by a trainer. All trainers are alerted via email when a flag (or user-raised ticket, discussed below) is created. A trainer can take ownership of the ticket or assign it to another available trainer. This function allows escalation of tickets to different members and aids in managing rosters with multiple trainers. In addition, any red flag automatically triggers an email to the participants with a link on how to contact a trainer if they need help and tips for avoiding red flags in the future. Automatic emails are capped at 1 every 72 hours to prevent participant overload.

User-Initiated Tickets

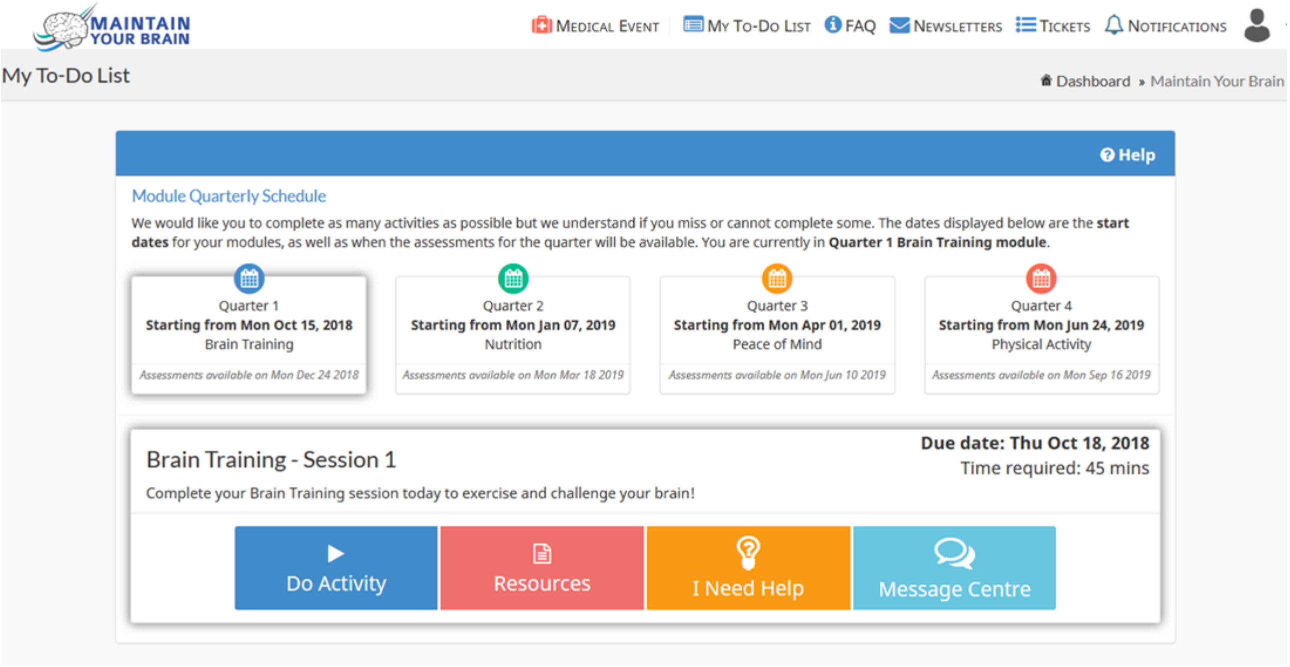
A user can create a ticket themselves by either clicking on the "I need help" button on their home screen or on the "message centre" button (Figures 3 and 4). This provides participants with a list of common issues or the participants can type in their own details. This form of message sends an email to all trainers, so that they can log in and assign the ticket. The assigned trainer will subsequently receive email notifications of any new related messages. The message center is open to all trainers for viewing general issues.

Online Trainers

Online trainers contact participants (either via the message center, Skype, or phone call) to resolve issues that are raised through the ticketing system. Trainers can drill down at the participant's specific performance history that triggered a flag and use their discretion to the level of help that the participant may require (eg, a message reminding them of instructions or a phone call to resolve a technical issue). A trainer can respond to each individual ticket (if the issue is task specific), a set of tickets via the message center (if the issue seems to be more general), or an individual help request (Figure 5).

In terms of trainer work flow, user-raised tickets are generally dealt with first. The second priority is participants with the most accumulated red flags. This may result in a phone call/Skype (eg, if a participant is failing to make any responses or any correct responses, it appears as a technical error or a lack of understanding) or a message (eg, if it is for one particular task and written instructions are deemed useful).

Figure 3. Screenshot of activity list from the participant's view. This centralized user area lists all required activities including outcome tests and training exercises.



My To-Do List

Module Quarterly Schedule

We would like you to complete as many activities as possible but we understand if you miss or cannot complete some. The dates displayed below are the **start dates** for your modules, as well as when the assessments for the quarter will be available. You are currently in **Quarter 1 Brain Training module**.

Quarter 1
Starting from Mon Oct 15, 2018
Brain Training
Assessments available on Mon Dec 24 2018

Quarter 2
Starting from Mon Jan 07, 2019
Nutrition
Assessments available on Mon Mar 18 2019

Quarter 3
Starting from Mon Apr 01, 2019
Peace of Mind
Assessments available on Mon Jun 10 2019

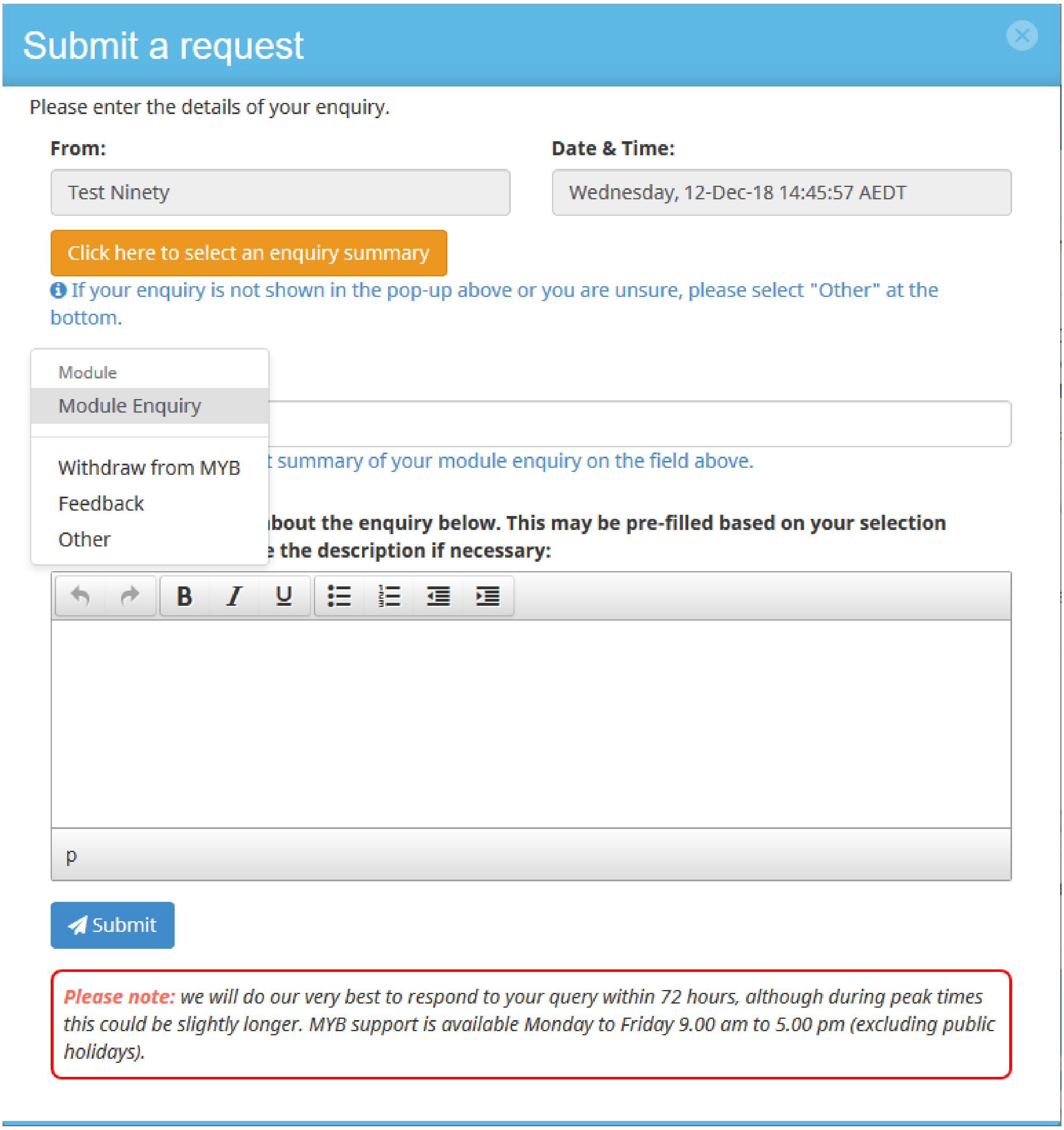
Quarter 4
Starting from Mon Jun 24, 2019
Physical Activity
Assessments available on Mon Sep 16 2019

Brain Training - Session 1

Due date: Thu Oct 18, 2018
Time required: 45 mins

Complete your Brain Training session today to exercise and challenge your brain!

Figure 4. Screenshot of the participant's view for submitting a help request. Participants can directly contact trainers for assistance at any time, by simply selecting "I need help" from their homescreen.



Submit a request

Please enter the details of your enquiry.

From: Test Ninety

Date & Time: Wednesday, 12-Dec-18 14:45:57 AEDT

If your enquiry is not shown in the pop-up above or you are unsure, please select "Other" at the bottom.

t summary of your module enquiry on the field above.

bout the enquiry below. This may be pre-filled based on your selection
e the description if necessary:

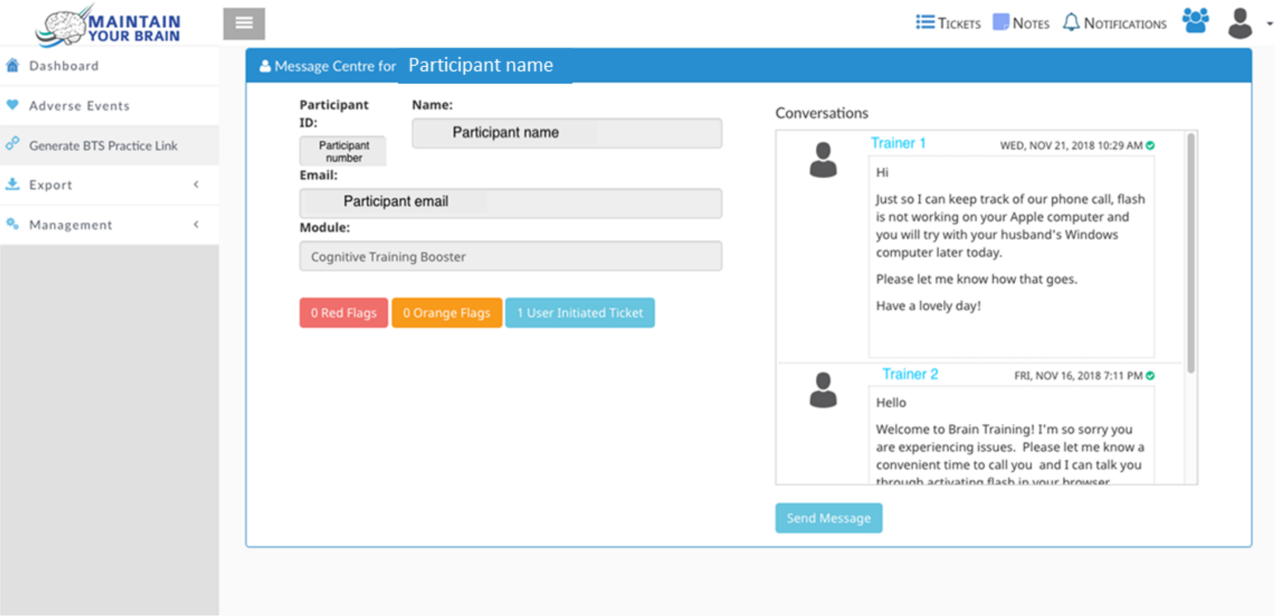
p

Please note: *we will do our very best to respond to your query within 72 hours, although during peak times this could be slightly longer. MYB support is available Monday to Friday 9.00 am to 5.00 pm (excluding public holidays).*

Trainers are allocated shifts on a roster with approximate 9 am to 5 pm coverage, 5 days a week. If a trainer is unable to resolve a ticket during his/her shift, he/she can pass on the ticket to the next scheduled trainer. This will give the new assigned trainer a notification when he/she logs into the system (as well as an email). Trainers can allocate a ticket to someone else to deal with (ie, the trainer, manager, or someone in a different area of the specialist MYB team, such as an information technology specialist).

Standard trainer strategies when working with participants includes coaching techniques such as encouraging phrases at the beginning and end of the interaction and dealing with the issue in the middle of the interaction. Trainers are able to generate practice links for participants in order to guide them through the exercise during the phone/Skype call. During our pilot trial, the most common issues have been participants not using the correct internet browser or software, not understanding of the task instructions, or not able to locate the instructional video, all of which were easily resolved by the trainers.

Figure 5. Screenshot of the message center from the trainer's view. Trainers receive messages from participants and can respond using a simple chat format as seen on the right or organize to communicate via email, Skype, or telephone.



Participant name

Participant ID: Participant number

Name: Participant name

Email: Participant email

Module: Cognitive Training Booster

Trainer 1 WED, NOV 21, 2018 10:29 AM

Hi

Just so I can keep track of our phone call, flash is not working on your Apple computer and you will try with your husband's Windows computer later today.

Please let me know how that goes.

Have a lovely day!

Trainer 2 FRI, NOV 16, 2018 7:11 PM

Hello

Welcome to Brain Training! I'm so sorry you are experiencing issues. Please let me know a convenient time to call you and I can talk you through activating flash in your browser

Real-World Community of Support

A key aim of CCT is to maximize engagement and motivation levels. Given that evidence suggests direct reimbursement for effort is less likely to boost engagement than intrinsic motivation [41], we developed a functionality whereby participants' family or friends can provide positive reinforcement and encouragement to increase a participants' sense of achievement, pride, and desire to continue. When participants start the 10-week module, they have the opportunity to list up to five friends/family members to create their "CheerSquad." These individuals are first emailed an invitation to take up their supporting role and then sent automatic emails when the participant reaches a training milestone. On these occasions, the friends/family members are asked to directly contact the participant and provide personal encouragement and support. Thus, through BTS, participants are designed to receive regular positive feedback from those they feel connected to in order to help maximize motivation and long-term program engagement.

Open-Access Research Platform

The BTS was created and developed specifically for the MYB trial based on public funding from the National Health and Medical Research Council of Australia. Our intent is therefore to make it as freely available as possible to the international research community. To facilitate this, BTS will be accessible on a cost-recovery basis to verified researchers who have public funding and where the research project does not have a commercial interest, funding, or purpose. Commercial enterprises or commercially funded research projects can also apply for access to the BTS on a non-exclusive fee-for-license basis. Note that users will need to come to their own arrangement with NeuroNation to utilize the company's CCT content for their particular research project; alternatively, they may substitute the BTS with alternate CCT content using their own information technology expertise and resources.

Results

The MYB pilot was performed from November 2017 to March 2018. We are currently analyzing data from this pilot trial (n=100), which will make up a separate research paper. The main trial was launched in June 2018. Process and implementation data from the first training module (September to November 2018) are expected to be reported in 2019 and final trial outcomes are anticipated in 2022.

Discussion

Development of the BTS module and wider MYB platform has been a complex process. It has been designed from the ground up by a multidisciplinary team of a system architects, platform design specialists, software engineers, and contract developers in collaboration with cognitive training and clinical researchers as well as third-party partners to meet the specific needs of MYB. The process of developing the design scope, technical specification, and final structure of BTS took about 1 year and delivery, debugging, and pilot testing the system took another year, including several iterations. The key challenges thus far included delivery of BTS within the budgetary constraints of this publicly funded research; algorithmically formalizing optimal processes for effective trainer-participant interactions, performance tracking, and content delivery; complexities associated with seamless integration with external information technology systems as well as the wider MYB platform; the variability of end user-computing environments including operating systems and internet browsers; use of FLASH video–based content that is increasingly unsupported by modern browsers; development of new CCT exercise content to target verbal memory; and the design, validation, and implementation of a novel automated test of verbal memory. The primary limitation of the platform design is that mapping of cognitive tests and exercises is based on consensus estimates of the most relevant cognitive domain and cannot account for the inherent multidomain nature of such tasks. Additionally, this platform introduces a number of novel factors (the sandwich, online trainers, feedback, and social support) that will not be independently assessed for efficacy.

In this paper, we have presented the design of a scalable system for delivery of CCT based on the best evidence to date. BTS is a key intervention module within the MYB trial that is anticipated to be the largest digital health intervention for cognitive decline and dementia prevention so far [36]. To the best of our knowledge, our CCT technology is unique and promises to increase our understanding of how to implement and facilitate effective training for older adults at home. This is a crucial unmet need, and we hope it will contribute to a reduction in the occurrence of dementia and cognitive decline in the community.

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Conflicts of Interest

HB receives Consulting Fees from Nutricia Australia Advisory Board; MV is a paid scientific advisory board member for the Barcelona Brain Health initiative and owns shares in a private company unrelated to the subject of this manuscript. He holds a provisional patent for IP unrelated to the subject of this manuscript and receives in-kind software support from NeuroNation. All other authors report no conflicts of interest.

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Abbreviations

CCT: computerized cognitive training
MYB: Maintain Your Brain
BTS: Brain Training System

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